

Research Article

Challenges of Aging with the HIV Virus and Comorbidities

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Abstract

Since the introduction of antiretroviral therapy, the survival rate of infected HIV patients has been on the rise with a predicted increase by 2030. The longer a person lives with the virus, the more prone to HIV-associated chronic diseases he or she becomes, but it is not clear whether these diseases are solely from aging with the virus or from long-term use of antiretroviral therapy. Scientists, however, have failed to address the challenges of aging and living with HIV. The purpose of this study, driven by both social constructivism as well as the advocacy worldview, was to explore the lived experiences of participants older than 50, living with HIV for at least 20 years, to gain an understanding of how long-term use of antiretroviral therapy relates to the onset of comorbidities, which would lead to a new understanding of the challenges they face. The methodology of the study was a phenomenological approach; data were collected through participants' responses during recorded telephone interviews before being transcribed and analyzed using Nvivo software. Findings indicated that these participants live in daily survivorship filled with constant struggle between a series of comorbidities that develop overtime. Additionally, their journey is not only coupled with unmet needs of today but also with uncertainties of tomorrow. The findings can improve the current social conditions of the population in question by providing information to healthcare professionals so they can better address their needs, thus improving and maintaining their health

ABBREVIATIONS

ART: Antiretroviral Therapy; GDM: Gestational Diabetes

INTRODUCTION

HIV once a death sentence has become a chronic disease with infected individuals' life expectancy increasing, thus reducing their mortality from 2.2 to 1.8 million since the introduction of ART as its treatment [1]. Subsequently as of 2015, 50% of HIV individuals in the U.S. are 50 years or older [2]. However, such victory has been coupled with some new challenges, notably that of the onset of chronic diseases either from old age, aging with ART, or a combination of both [3]. Since their life expectancy is expected to ascend further by 2030, their challenges ought to be investigated to address the issues they face [2, 4, 5].

Rueda et al. (2014) and Negin et al. (2012) outlined that 65% of this population reported an onset of up to two chronic diseases since testing positive. This further shows that this aging population has a higher incidence of complications from comorbidities that arise from living with HIV [7]. As such, adequate treatment and proper monitoring are crucial for this growing group [7]. The literature showed evidence of limited access to health services as well as weak retention in care for HIV individuals 50+ [8; 4]. Additionally, Cahill et al. (2013) reported a lack of a proper system that would serve this group facing multi-morbidity issues [9]. The rationale behind this weak retention and whether or not 50+ HIV individuals are aware of the negative impact of being on ART, aging with the virus, and comorbidities that may arise from the combination are not addressed in the literature.

Lastly, although Brennen et al. (2011) did report that this population is affected by social issues such as depression, stigma and neglect thus suggesting a possible lack of support from their respective communities [10]; the literature does not outline any understanding of their experiences living and aging with HIV. Additionally, Brennen et al. (2011) also outlined the lack of adequate policies to address issues of this aging group mainly due to the lack of basic knowledge and understanding of their needs and the challenges they face [10]. To that effect, Rueda et al. (2014) recommended that studies focusing on exploring challenges of the aging population living with HIV and comorbidities be conducted to gain more insight [3]. As such, the purpose of this qualitative phenomenological study is to explore the lived experiences of participants 50 years or older living with HIV, to gain an understanding of the challenges they face as they age with the virus and comorbidities in order to improve their overall health and quality of life.

MATERIALS AND METHODS**Literature Search Strategy**

Peer-reviewed full text articles were searched in the Walden Library database using CINAHL and MEDLINE simultaneous search as well as Google Scholar and ProQuest Central from the years 2010-2015 to obtain a more current literature. The following keywords were used: elderly, HIV, comorbidities, challenges, psychosocial issues, depression, multi-morbidity, health services, health policies, and antiretroviral therapy. After identifying the five themes of my literature review, notably "increased life expectancy of people 50+ living with HIV", "onset

of comorbidities from aging with the HIV virus”, “limited access to tailored health services for people 50+ living with HIV”, “un-addressed psychosocial issues among 50+ HIV patients”, and “lack of policies and health care services for 50+ HIV patients”; I proceeded to finding articles that would outline each respective theme. Finally, I solely retained full peer reviewed articles before repeating the above steps when seeking articles for the remaining themes.

Research design

1. The study would answer the following questions via a qualitative research approach: What is the experience of people 50+ living with HIV?
2. How do people 50+ describe those experiences?
3. How do 50+ HIV+ patients describe the challenge of living with HIV and newly diagnosed comorbidities?

Setting and Participant Selection

This study was conducted via recorded telephone interviews. All participants had provided consent in accordance with IRB policies and were thus all-in agreement of participating and of being recorded. There were no personal or organizational conditions that appeared to influence the participants that could affect the interpretation of the study results.

Purposeful sampling was the sampling of choice. As such, participants were only selected if they had a connection to the phenomenon. Since my phenomenon is the experience of people 50+ living with HIV and comorbidities, I specifically selected those 50+ living with HIV. Participants were included in the study regardless of their race, gender, social economic status, and sexual orientation. As such, the inclusion factors were being 50+, living with HIV for at least 20 years, being on ART, and having at least one comorbidity since diagnosis. Newly diagnosed HIV patients were excluded from the study.

Patients fitting the inclusion criteria who were receiving treatments at the agency or members of online HIV support groups were provided with documentation offering them the opportunity to participate in the study; if retained for the study, they were contacted via telephone to schedule their interview. The latter took place wherever each participant saw fit as the study was via telephone.

Instrumentation and Procedure

Prior to starting any data collection, approval from the University Institutional Review Board (IRB) was obtained. Secondly, each participant was required to turn in their signed consent and give a verbal reiteration of their full understanding of the signed consent. More importantly they were reminded of their right to voluntarily refuse to participate or choose to exit at any given time. Once all of the above were completed, I started personally collecting all data directly from my participants through individual recorded telephone interview. Essentially, I asked 23 pre-determined open-ended questions, focusing on the participants’ experiences of living with HIV as well as all the drawbacks that arise from that. Once all interviews were completed, they were transcribed through a hired professional transcriptionist. Prior to doing so, I ensured that the transcriptionist submitted a signed confidentiality agreement attesting to the privacy of the participants and data.

After completion of each interview, participants received a \$5 gift card along with additional information pertaining to a phone line where, they could reach me directly, should they have further questions regarding the study. Additionally, information pertaining to their follow up interview, which would be scheduled at a later date, was provided as well. Also, an additional \$5 gift card was provided after the follow up interview. The follow up interview was critical to present participants with the core themes to attest for the accuracy and appropriate representation of their own experiences, while giving them an opportunity to comment on them [11]. Participants who dropped out of the study during the initial interview phase or the follow up interview still kept their incentive.

Data Collection

To complete this study, I recruited 10 participants. Once I obtained IRB approval, I began the recruiting process in early March 2017. I mailed a priority sealed and marked “confidential” envelope to the head of the AIDS resource agency, at which, participants received treatments. The agency, via their CEO, had approved and agreed to advertise the research; I had no part in the recruitment of participants at the facility, hence no access to their respective medical records. The mailed envelope contained all necessary documents pertaining to the study, specifically

Table 1: Characteristics of Participants.

Participants (P)	Gender	Age	Sexual orientation	Years since diagnosis	Number of comorbidities
P1	Female	62	Heterosexual	29	6
P2	Male	60	Homosexual	30	7
P3	Male	52	Homosexual	21	3
P4	Male	59	Homosexual	30	7
P5	Female	65	Bisexual	28	4
P6	Male	63	Homosexual	27	3
P7	Male	64	Homosexual	31	7
P8	Male	51	Homosexual	30	5
P9	Male	74	Heterosexual	21	1
P10	Male	55	Homosexual	25	9

fifteen approved IRB consent forms, pre-labeled and pre-stamped envelopes with my return address for them to return their signed consents form if they wished to participate in the study. Within a few weeks, I received two consents back from participants, which I reviewed carefully, to ensure they met the inclusion criteria before calling them to schedule their initial telephone interview. The initial interview was roughly an hour and fifteen minutes. At the end of the latter, participants were reminded that, as stated in the consent, they would be contacted in a few days to schedule the follow up interview to attest for accuracy of the collected data. Additionally, it would cover additional questions based on their responses in the initial interview to obtain clarifications in certain areas and/or additional details. The follow up interview was roughly thirty minutes.

The data collection process started on 4/24/17. Each participant was called on the day scheduled for the interview. While some were ready to proceed, some at times, had an obstacle that came into place and asked if they could reschedule, which I was able to accommodate without a problem. Each time I called a participant, I re-introduced myself to them, ensuring they knew whom they were talking to, before proceeding to confirming once more that they had consented to the study and that this would be recorded. They verbally voiced that they had consented on their own free will and were willing and ready to proceed. I recorded each interview session with a digital audio recorder and later transmitted the audio file for transcription to a transcription company bound to a confidentiality agreement. Upon obtaining the full transcript within 24hrs, I reviewed it and contacted the participants for a follow up interview based on their previous responses for accuracy of the data and to obtain clarifications and/or additional details in certain areas. The last interview was conducted on 8/27/17.

I was still awaiting eight prospective participants to show interest in my study and thus complete my population sample. Unfortunately, weeks and then months went by without any responses. With the guidance of my chair and after additional investigation, I found out that most of my population sample is extremely active in the online community where they find support from others fighting the same disease. As such, after successful IRB approval for a change in procedure in early July 2017, I was able to post an advertisement for my research on various Facebook groups for long-term HIV survivors. These groups which encompass people across states and outside the country, have one common factor, that of being HIV survivors. The advertisement posted contained my email address for prospective participants to email me with additional questions or to request the full consent that would enable them to make a better-informed decision. Twelve prospects initially submitted an email requesting the consent form for review but only eight emailed back their consent for possible inclusion. The remainder did not and after one email attempt without a response back, I assumed they had changed their mind and thus did not insist. As for the prospects, I carefully reviewed their forms to ensure they met the inclusion criteria; I later contacted them back to set up the initial interview. The latter lasted on average roughly an hour to an hour and fifteen minutes. As previously stated, they were also reminded at the end of the interview that they would be contacted in a few days to schedule their follow up interview. The latter lasted roughly thirty minutes.

I did not encounter any unusual circumstances. However, during the interview sessions, while answering one particular question, participants would at times unknowingly answer a question I was going to ask later in the interview. For that reason, I had to remind myself to be flexible and not repeat a question already answered just for the sake of being strict at following the interview format. Additionally, some participants that would go off on a tangent during the interviews and although I could have redirected them, I did not want to interrupt them because what they were sharing was still of value.

Issues of Trustworthiness

In order to assess credibility, also known as internal validity, scientists seek to outline a true picture of the studied phenomenon; this is an important factor as it shows how compatible the results are with actual reality [12]. To ensure genuine participation and shared experiences, each prospective participant was reminded of their right to decline participating in the study or withdraw at any given point without explanation.

Peer review is always important in scholarly work. As such, I welcomed any scrutiny and advice from my committee and peers throughout this process. In fact, their non-bias outlook on my project brought up fresh ideas that helped improve my methods and thus avoid jeopardizing the credibility of the entire study.

Lastly, Creswell (2009) recommended using member checking to assess the accuracy of the findings [11]. As such, during the follow up interview, I assessed for accuracy of their reported data to ensure an accurate representation of their interview.

Reliability outlines that most researchers use an approach similar to that of another so it can be replicated again [11]. As stated above, I provided a detailed methodology used in my study, so that it is easily replicable in a similar context, using the same methods, and the same type of participants. Although Shenton (2004) stressed that in phenomenology or qualitative research, aspiring to obtain similar results could be a challenge; one should at least be given the entire methodology so they can attempt to replicate the study [12]. Additionally, I kept a trail of all documentation used during the process so that one could easily trace it back if needed. The latter process is known as an "audit trail" [12]. Essentially, I kept a record of everything I did, whether it seemed important or not, from the notes I wrote, to interviews, and transcription. That way, other scientists could easily audit, retrace, and replicate if needed.

Confirmability is achieved when scientists successfully take steps to show the reader that the presented overall results in fact derive from the collected data and not from their own predispositions or interpretations [12]. As such, I remained as objective as possible to ensure that I presented information from the participants without adding my personal interpretation, thus avoiding researcher bias.

Data analysis

For proper data analysis, I opted for Nvivo software. The latter has proven adequate for scientists in both evaluating and interpreting qualitative texts [13]. This software allowed me to analyze 10 in depth interviews.

Before starting the interview process, I purchased a notebook that I used throughout the process as a research log. In the latter, I wrote down acronyms of the participants as well as interview dates. This notebook and everything pertaining to the research was kept in a locked cabinet in my home office and I was the only one with a key. Additionally, on the day of each interview, I wrote down the date, the start time, and overall length of the interview. At the end of each interview, I listened once more to the recorded audio then wrote down key elements and initial thoughts in the margin of the page addressed to the participant in question. Upon receiving back each transcribed document, I read it in depth multiple times, noting similarities in experiences among participants as well as any other shared experiences not necessarily related to the research questions. When I encountered the need for added details or clarifications on a specific thought shared by the participants, I wrote that down as well, and later generated questions to be asked in the follow up interview.

After multiple rounds of reading each transcript and adding key words and/or phrases pertaining to each interview in the margin of my notebook, I formatted the transcribed interviews in Nvivo style before importing the data into Nvivo software. After the latter, I ran a query in Nvivo to confirm at a glance major experiences shared by the participants. Following that, I began the process of coding. Coding is a process used by researchers to purposefully section out specific segments of the interview transcript whether it be small segments of a sentence, a whole sentence, or a full paragraph when deemed to be relevant enough to answer the interview questions, but more importantly the research questions [14]. While coding, I gradually and carefully organized each coded section under a specific category based on similarities. I once more read each coded category multiple times to ensure the containing segments were addressing the same idea and the responses were similar. The names that I chose for each category derived from the overall description of the participants' shared ideas or language. Once I completed naming all the various categories, I grouped them under a broader group called themes to encompass the main idea at hand.

Three main themes emerged from my analysis: "from fear of the unknown to ownership", "from ownership to survival", and "the constant struggle of surviving with HIV".

Theme 1: From fear of the unknown to ownership

- Category 1: Fear, anger, and rejection
- Category 2: Fear of rejection before acceptance
- Category 3: Ownership and self-advocacy

The first theme encompasses three categories and emerged from interview questions (IQ) 1, IQ 2, and IQ 4. This theme literally means that participants went from a state of fear to a state of ownership.

Theme 2: From ownership to survival

- Category 1: Knowledge and utilization of resources for survival
- Category 2: Societal support, another key to survival
- Category 3: Effective patient-clinician partnership

The second theme encompasses three categories and emerged from IQ 5 to IQ 10. In this theme, participants described moving from a state of ownership to a state of survival.

Theme 3: The constant struggle of surviving with HIV

- Category 1: Daily survivorship
- Category 2: Aging before your time
- Category 3: Existing despite the odds

This theme emerged from IQ 12 to IQ 20. In this theme, participants shared their constant struggle of living with the virus as well as living with the side effects and comorbidities that developed overtime.

RESULTS

Throughout my study, I sought to answer three main research questions labeled RQ1, RQ2, and RQ3. Based on the conducted analysis, three themes were substantiated from various interview questions to answer the above research questions. Theme 1, 2, and 3 respectively answered RQ1, RQ2, and RQ3.

RQ1: What are the experiences of people 50+ living with HIV?

Theme1: From fear of the unknown to ownership

Participants shared that their 20 to 30 years of experience from the time they received their diagnosis until today has been met with ups and downs. They all went from a state of fear, anger, or denial of the then, unknown virus to the medical body, to a state of acceptance and thus ownership. P3 had stated "with the initial stage when I was diagnosed, it was – I was scared". As such, in their own way, they embarked in a quest of knowledge to be better self-advocates and ultimately live a life as healthy and as long as possible with the treatments available to them at the time. However, the journey would not be without challenges. In fact, just as they had overcome fear of the virus and death that comes with it, they had to overcome fear of possibly being rejected by their loved ones and/or friends whom they would need for support and strength. To that effect, P7 reported "I just didn't want to discuss it with anybody, and because of the judgmental, that people would think worse of you because of it, or just the psychological thing that after they find out, it could be traumatic or destroy something". Additionally, they had to overcome the challenge of attempting to acquire the pricey HIV medication when uninsured or unemployed as well as tolerating and surviving the effects of the only medication available for those that were able to acquire them. P8 shared "I didn't have insurance at the time and I was probably in the hospital more than out, then I was basically granted emergency Medicaid". P1 on the other hand shared "I stopped taking the AZT because I had neuropathy within two to three weeks of taking the pill".

RQ2: How do people 50+ describe those experiences?

Theme 2: From ownership to survival

Once they passed the fear and denial stage, all participants had the desire to tackle the virus head on, one challenge at the time to survive as long as possible. As such, they dove deeper into self-educating on the virus, this time using various available HIV resources and programs.

P1 shared "I have gone to HIV 101 classes and attended HIV University". In the midst of all their numerous and frequent stays in the hospital, several participants pointed out the importance of having some kind of societal support whether from immediate family or partners, friends, or via social groups. P2 shared "when I was very sick it would have been very nice to have some familial support particularly after the time I left my ex because I had marginal income, but I didn't have that family of support to fall back on. So, I just had to make due with the best I could". Additionally, they shared tremendous stigma and injustice in the workplace in those times. For example, P10 stated "I was fired from a job for being positive".

Lastly, maintaining a healthy partnership with one's clinician was also addressed as important. Participants shared that regardless of the fact that their clinicians are mostly non-HIV specialized physicians, they are specialists in their own right and more importantly, they listen to them and are open to learning from them. In fact, P2 shared "sometimes I end up being the teacher if you will, to providers" and P5 added "I had to find a doctor who would trust me. I found a doctor that would listen to me".

RQ3: How do 50+ HIV+ patients describe the challenge of living with HIV and diagnosed comorbidities?

Theme 3: The constant struggle of surviving with HIV

Participants shared that their journey has not been without any challenges; in fact, it has been filled with side effects. The latter emerged from various HIV medications as well as from the long-term inflammatory process of HIV within their body. For example, P10 shared "There's a lot of fatigue. Every pill I take has a side effect, so we can't really tell what is really causing all the fatigue". They also shared constant struggle of keeping up with daily intake of their numerous pills to resenting them at times. P8 stated "I take five pills twice a day just for anti-virals. So, you know I'd say my biggest problem at this point is pill fatigue, but sometimes I resent every pill I take". Additionally, they shared that as years went on, some side effects became chronic affecting their daily lives. To that effect, P2 shared "Because of HIV I have lost the ability to work not once, but twice. And the first time was a direct causation from the HIV. The second time was from the side effects of at least one of the medications, we don't know which medication". Other side effects affected not only their physicality but also their self-esteem, aging them before their time. P7 stated "Fat distribution - one of the side effects is that you have light atrophy where the muscle patch in your face disappear, and so suddenly you're walking around looking like a human skeleton". However, the combination of multiple side effects coupled with numerous hospital stays forced the majority of participants into disability several times. Overall, they have come a long way; they are indeed survivors as P4 reported "Frankly, I feel as though I have walked through the valley of the shadow of death. I done come out the other end. You know what I mean?"

DISCUSSION

RQ1: What are the experiences of people living with the virus?

Based on the analysis, participants shared their experiences of living with the virus as one filled with ups and down, and

primarily with higher incidence of side effects in form of comorbidities. The latter confirms findings of Rueda et al. (2014) that the older population living with HIV is prone to comorbidities [3]. Additionally, some participants shared their frustration in attempting to acquire ART after their initial anger or denial phase, as well as the battle between their body and the medication; yet, their strong will to follow through with the treatment, thus living as long and as healthy as possible. To that effect, depending on participants' respective year of diagnosis, they reported surviving 20 to 30 years with a virus they were originally speculated to succumb to in at most 5 years if that. The latter confirms the findings of Samji et al. (2013) that if diagnosed and placed on ART early on, HIV patients are expected to live up to 70 years old, thus reducing the mortality rate [5].

RQ2: How do they describe those experiences?

Based on the analysis, participants described their experiences as multi-faceted from diving into self-educating, to struggling with fear of rejection from societal support, to isolation, and to developing somewhat of a partnership with their respective clinicians. In accepting their diagnosis, some participants decided to share that diagnosis with their societal "support" despite fearing rejection. This societal support varied from immediate family or partner, to friends/co-workers, to society via support groups. Unfortunately, some reported developing bouts of depression as well as stigma early on when diagnosed. The latter confirmed findings of Brennan et al. (2011) that this population may be affected by depression. Some of my participants in fact reported experiencing solitude which led to depression due to their moving into a newer community, one in which they were no longer surrounded by their peers. They described the latter as individuals sharing a similar sexual life choice and/or fighting the same virus; lacking that support, led to isolation. The latter confirms findings of Sankar et al. (2011) that while 25% of baby boomer HIV patients were moderately depressed due to overall poor physical health and lack of social support; 39% could be diagnosed with major depressive symptoms due to isolation [15].

Additionally, some participants did stress that they tend to isolate more as they age for various reasons confirming findings of Liu et al. (2014) that social interactions among older HIV patients were lower than their counterparts [16]. In fact, some reported isolation as a self-choice because most to all of their friends succumbed to the HIV infection. To that effect, P8 stated "in many ways my original circle of friends as an adult are probably three-quarters gone". Others are simply choosing solitude rather than experiencing rejection for being positive and not initially disclosing it or for simply being positive. To that effect P4 stated "it is isolating. HIV tends to isolate people. Not always, but it can. You just want to be with yourself. Because like if you meet somebody nice, you didn't tell them you were HIV positive from the get go, there is going to be a problem. But there is a problem. The problem is if you tell somebody you're HIV, they don't want anything to do with you. You are damned if you do. You're damned if you don't. Then, why bother? Why bother?"

On another note, most participants pointed out a good relationship that others even reported as partnership with their HIV clinician. However, the majority shared that the latter are mostly regular clinicians or infectious disease clinicians as

opposed to specialized HIV clinicians. As P2 stated “the doctors and it even sometimes applies to infectious disease docs, they don’t treat a tremendous number of HIV positive patients. So, they may not have a tremendous understanding of the processes by which the body reacts to your long-term HIV infection”. To that effect, P10 added “there’s a lot of worry about the side effects. Every pill I take has a side effect. I have to be very careful. I can’t take calcium with one of the HIV meds. I can’t take steroids with one of the HIV meds. I don’t think the hospital doctors knew enough, because they put me on steroids, and they weren’t supposed to put me on steroids. So, I’m suffering severe side effects the last two months with that. And I also have to educate some of the doctors in the ERs or in the hospital and say no to certain medications”. This confirms findings of Patel et al. (2015) that non-HIV specialists may not be as familiar with side effects and cross interactions of specific HIV medication with medication used to treat chronic diseases or side effects [17]. This could thus suggest that patients being initially treated and followed by HIV specialists are more likely to have a better prognosis than those being treated by generalists. Nonetheless, the latter stressed the importance of HIV healthcare services to meet the need of that growing HIV population [17]. Patel et al. (2015) also addressed a high incidence of HIV infected patients with multiple untreated comorbidities, which they attributed to the use of clinics not equipped with properly trained HIV personnel [17]. To that effect P2 stated “the doctors don’t treat a tremendous number of HIV positive patients. So, sometimes I end up being the teacher if you will, to providers”.

Moreover, Cahill et al. (2013) shared that there is a major lack of proper system to care for infected HIV patients 50+ [9]. In fact, some participants did report such lack to address for instance the side effects they develop or the battle with their respective insurers for various medications and/or procedures’ approval. To that effect, P8 stated “even having Medicare D and Medicaid in addition to that, having to appeal so many things that my Medicare D carrier has said, well, you can’t have that is a struggle. And having to go through an appeal process repeatedly to actually get medication that was appropriate to me is difficult. I was having muscle cramps. I still have a problem with that. And all of the medications that they kept insisting, no, take this instead, were directly counter indicated with my other medications. So that’s just a constant battle to keep the proper prescriptions flowing to the extent possible...”

Some findings did however contradict with my literature review. In fact, based on my analysis, all participants reported having access to basic HIV care as well as good follow up and retention; despite the fact that, because of their respective insurance carriers, some may run into difficulty in seeing specialists to treat their comorbidities. These findings contradict Mugavero et al. (2013) and Patel et al. (2015) who shared that half of baby boomers lack access to HIV care while others failed to be retained for follow up [18; 17].

RQ3: how do they describe the challenges of living with the virus and the comorbidities that develop?

Participants described their experience of living with the virus and the comorbidities that develop as a constant struggle in facing the various challenges that arose overtime, making it difficult for

them to for instance get around and thus enjoy a normal life. The latter confirms the findings of Rueda et al. (2014) that for older HIV patients, the multi-morbidity was coupled with decreased physical functioning [3]. In fact, my analysis showed that the longer participants had lived with the virus and the longer they had been on at least one ART, the more they experienced a major impact on their physical body such as fatigue or lack of stamina, making it challenging for them to get around. Oursler et al. (2011) did confirm the latter in reporting a significant decline of physical function among HIV patients older than 55 years ($p < 0.001$) as opposed to their counterparts who were not infected [19]. On the same note, Patel et al. (2015) showed that years living with the virus and use of ART were significant predictors of onset of comorbidities among older HIV patients [17].

Participants reported that being on ART for so many years did prolong their life, however it also increased their onset and incidence of comorbidities over the years. The latter is in line with findings of Vance et al. (2011) and Kim et al. (2012) that the longer this population was living with HIV, the longer their list of medications to treat their comorbidities [20; 21]. My analysis showed that early onset of comorbidities is not so much due to old age but more so to long-term usage of ART and living for a long time with the inflammatory process of HIV. Rueda et al. (2014) and Negin et al. (2012) did confirm that in fact, they noted a higher onset of comorbidities and its number among this aging population on ART as opposed to those not on ART [3; 6]. Rueda et al. (2014) added that at least 94% of HIV infected older patients on ART presented with at least one comorbidity, with the majority presenting with at least three; which is consistent with findings among my participants. Negin et al. (2012) and Deeks et al. (2013) also reported a similar increase. In other words, being on ART for an extended period of time is a major risk factor for early onset of chronic diseases as well as both multi-morbidity and the challenges that come with it.

Some findings did however contradict with my literature review. In fact, Liu et al. (2014) reported that the older the HIV patient was, the lower the level of well-being, the higher the level of depression, and the poorer the quality of life; which they attributed to low physical health and ongoing psychological challenges [16]. However, this contradicts with my findings because although some participants reported experiencing the above at one point or another, it was more so due to the number of years living with the virus, hence the effect of both longer-term inflammatory process of the virus and usage of ART on their body as opposed to their being or getting older.

In my study, I used the social constructivism framework by Berger and Luekmann [22]. Through this framework, the scientist seeks to understand one’s reality and daily experience as well as how it possibly affects their daily life [22]. Through my study, I was thus able to understand the phenomenon at hand, notably, the lived experiences and daily challenges of people 50+ living with HIV from their own perspectives as they age with the virus. Some challenges that were recurrent among most participants were the lack of sufficient specialized HIV providers despite getting good care from the self-proclaimed HIV clinicians. In fact, some like P2 stated “I go to the infectious disease clinic. In the VA system they have no HIV specialists and they don’t treat

a tremendous number of HIV positive patients. So, they may not have a tremendous understanding of the processes by which the body reacts to your long-term HIV infection. So, sometimes I end up being the teacher to providers, even occasionally to the infectious disease docs that I've had over the years. Because I've got specialized education that they haven't had, you know they were educated as generalized infectious disease docs, not HIV docs".

Additionally, other participants shared the shortage of gynecologists treating or specialized in HIV women care; hence, the struggle they face in finding someone qualified enough to address their concerns of aging with HIV while going through menopause. To that regard, P5 stated "None of the gynecologists know anything about women necessarily. That's the thing the women talk about in some of our groups. We don't know what is affecting us. Is it just menopause? Or, is it HIV that is affecting us?" The above clearly shows that despite their best effort to attempt at providing the best care possible for this population, they still lack the necessary knowledge. Furthermore, especially in dealing with this aging population prone to more comorbidities whether from aging alone or from aging with the virus and the poly-pharmacy; being knowledgeable on such poly-pharmacy and various interactions among such medications, and the process by which the body reacts to long-term infection is of extreme importance for the well-being of these patients. As such, this stresses the need for specialized HIV clinicians that could address the current and pressing concerns of this population.

Another aspect participant pointed out was in regards to isolation. In fact, some mentioned the need for more activities since they tend to isolate more as they age, and especially with HIV. For instance, P4 stated "it is isolating. HIV, it tends to isolate people. Not always, but it can. You just want to be with yourself". P1 added "we tend to isolate more as we age... I wish there were more social things like, you know, a lot of people, because they're living on such a fixed income, can't afford to go to like a show or even a movie. If they could take us to a movie or something, it would be nice". And finally, P10 stated "It's just easier to be by myself. I guess I have fallen into a routine the last few years of you know I have my dog and that's all I need. You know I really, I guess it's not easy making new friends".

I also used the advocacy worldview framework by Heron and Reason [23]. Heron & Reason (1997) stated that the latter uses knowledge gathered from experience to improve the quality of life of those involved in the phenomenon in question [23]. As such in my study, in order to understand and improve the health conditions of my participants, I listened to their shared experiences and more importantly their current needs, which could be used to contributing to policy changes and designing of appropriate programs. Brennen et al. (2011), Patel et al. (2015), and Cahill et al. (2013) reported the lack of policies addressing the "needs" and/or "issues" of the aging HIV patient, due to lack of knowledge surrounding their needs, stressing that such knowledge could improve their current quality of life [10; 17; 9]. As stated above, participants raised some concerns and needs of today. Specifically, they shared current needs for specialized HIV clinicians better equipped to grasp how their body react to the series of medication overtime or how their body ages on ART

while tackling menopause for instance. They also shared needs for more activities to reduce the isolation that they face more and more.

Finally, they shared their needs for policies that would enable them to obtain adequate medical coverage to treat the side effects of being on ART for so long and aging with the disease. For instance, they stressed the need for basic dental coverage, which really affect their appearance and thus self-esteem. To that effect, some participants did mention that such preventive coverage is not available. As such P8 stated "Medicare still does not offer preventive dental coverage, except for emergency extractions, and even that's very limited. So, at this point, after years of just not having access to anything, I had a bunch of teeth that rotted out and have now had to be extracted". And P7 stated "In treating people with HIV, we have to find a way to help people keep their teeth, and to keep their smile, and to not show the signs on your face. Because it's like if I'm walking down the street, most people don't think that's a gay guy. But, because of were the teeth were, and my face- the lipo-atrophy, I look sick. People would go, "He must be...," Do you know what I mean? But, there should be some level of preventative dentistry. Because you can't go through life- you're just already defeated before you even step out the door if you don't have a smile, if you don't have the teeth".

Additionally, they stressed the need for access or coverage to sculptr treatments for lipo-dystrophy and lipo-atrophy. In fact, some participants like P8 shared "it has gotten more difficult to get sculptural treatment as of a couple of years ago. At one point, you could get the facial filler material through the program on a sliding scale based on income. Now, the reimbursement rate is so low that there are no doctors who will accept Medicare for that. So, it's effectively not available. Also, if you have any insurance, they won't give you the material. You have to try to battle it out with your insurance company".

CONCLUSION

This study was conducted to assess the living experiences of HIV-positive participants 50 years and older living and aging with the virus. To gather data, I conducted recorded telephones interviews with ten participants, which I later transcribed, prior to analyzing the data using Nvivo 11 software. The latter analysis led to three themes, which enabled me to grasp a more detailed understanding of the daily life experiences of these participants as well as their true needs. For the most part, participants described that upon freshly being diagnosed, they went from fear, to anger or denial, to a state of acceptance. Additionally, the majority described a series of challenges to constant survivorship as they continued on their journey. The latter journey has been met with daily struggles and unmet needs. In fact, besides having to stay on top of their medication, they also have to adjust day by day to the series of side effects that develop. Moreover, some had to adjust to being forced into disability before their time because of their non-properly responding body, a body supposedly young enough to carry them yet too weakened by the virus and/or the medication treating it. The lives of these survivors today are described as merely existing; existing in a world where they have lost their appearance overtime, their self-esteem, and now slowly losing their memory yet, still fighting for better days ahead.

Other participants not only outlined their needs of today, but more importantly they also shared their uncertainties of tomorrow. To that effect, some participants, in the wake of their body weakening overtime from the long-term effect of both the virus and ART, shared their fear of losing their independence before their time whether it be through disability as a direct result of HIV for instance or as P5 stated through “aging and surviving with the virus in a society on low income”. On another note, some participants shared their fear of aging out with the virus in a society that does not yet have available assisted living facilities for their population group. For instance, P8 stated “looking forward I’m scared because you know I’m apprehensive about the availability of care, the availability of living arrangements and you know eventually, an assisted living facility or I suppose a nursing home. There are as yet no accommodations, there’s nothing that has been yet developed to address the needs of people living with HIV in those environments”.

It is imperative that additional research be conducted to ensure that this population does not age and face these challenges alone, as they felt when their journey began. On the contrary, the medical and scientific body in collaboration with stakeholders ought to work together to address their needs outlined in this study and to uncover additional ones they might have, to ensure that the challenges they once faced when HIV was a death sentence do not resurface, and that they do not become prisoners of the now chronic disease. As much as they can advocate for themselves, we can also be their voice, we have to work together in ensuring their time spent on Earth is memorable and enjoyable in the outdoors rather than in solitude, behind closed doors, in fear of today and worry of tomorrow. As these survivors are fighting and holding out hope, we must continue to fight with them and for them, we must continue the quest for a cure. Because as P8 stated “an HIV cure would be nice to improve my quality of life” and P2 added “if somebody had a magic wand and could take HIV away from me, yeah, I mean that would be great”.

HIGHLIGHTS

I recommend that positive social change in the lives of people 50+ living with HIV start with mutual trust and respect between this population and their health care associates, notably HIV clinicians, HIV nurses, and HIV case workers. Researchers who are the voice of these participants in providing their gathered information and stakeholders who could use the collected data to outline and implement specific policies could also contribute to effective social change. Through my study, I was able to uncover and get a better understanding of the challenges HIV+ participants face, as well as their daily experiences of living with HIV and comorbidities that develop. Using the reported data, other scientists could frame additional research questions for further studies, to expand even more the current body of knowledge in order to improve the quality of life of this population. Additionally, the healthcare associates, first in line in hearing the challenges and needs of the patients, should work closely with stakeholders and insurers to develop policies that would improve for instance their appearance and thus self-esteem, by ensuring they at least obtain basic preventive dental coverage under their insurance, which would enable them to access services not solely limited to emergency extractions. Moreover, healthcare associates and

stakeholders should work with manufacturers and insurance companies in developing a sliding scale that could enable them to afford sculptra treatment, both procedure and injection material, based on their income.

Moreover, community programs ought to develop appropriate social activities to keep this population as occupied and active as possible as they tend to isolate more as they age as this could possibly lead to depression. To that effect, P1 stated “I think a lot of people that are considered long-term survivors like twenty-plus years maybe or even ten plus years feel that they are being put on the back burner, they start isolating themselves. I mean I attend a support group even though sometimes they repeat the same presentations over and over I go for the emotional support and the socialization”. Healthcare associates should then work with HIV programs and stakeholders in developing more activities for this aging HIV population already living on a fixed income, to get them out of solitude and thus depression. Similar to the Meals on wheels system used for our elderly population, HIV programs could develop and implement a sort of *Friends on Wheels* program for those who are too weak to leave their house. The latter could be beneficial for them just to have on a weekly basis someone to talk to, play a game of checkers, or even take a walk to the park with when they physically feel somewhat better.

However, for those like P4 who stated “the older I get, the more I tend to dislike human beings. I tend to want to isolate and not be around people. That’s something I really struggle, because people can be jerks. I socialize on social media. I need to socialize more to have a better balance” or P10 who noted “I guess I spend a lot of time in bed. The exhaustion is a key piece, so that causes a lot of isolation”, developing a sort of *Friends on Line* program might be a better way for them to socialize. The latter, depending on the preference of the participant, could vary from a simple weekly telephone call, to an internet video call, to an internet chat conversation for those still reluctant to the face-to-face aspect or still working towards it. I think it could be more impactful to once in a while have a team of volunteers, for either program, that are themselves HIV survivors or even newly diagnosed. That way, because they have been through or are going through similar challenges, the recipient might be more receptive to opening up to someone that may have a better understanding of what they are currently experiencing. Additionally, if the volunteer is newly diagnosed, the recipient might even find meaning in sharing his/her experience thus impacting someone else while forgetting his/her own struggle for a moment. On the other hand, other participants might simply prefer a *Friend on Wheels* or a *Friend on Line* that is not living with the virus because as P1 stated “sometimes it gets old talking about HIV all the time”.

Despite them aging with HIV, which seem to take precedence over their overall health, the team of healthcare associates ought to stress the utmost importance of yearly physical exams with their regular physician, thus encouraging that follow through so that for instance women do not skip out on their mammogram and men on their prostate exams. To that effect, P1 shared “I very rarely—I mean, I should go for a PAP smear every couple of years, just you know, and I haven’t in a while. I recently just had my mammogram, which I hadn’t done in four years”.

In regards to being cared for by non-specialized HIV clinicians,

P5 stated “there is no gynecologist who sees an abundance of women with HIV. There are no specialty gynecologists for women. None of the gynecologists know anything about women, menopause, and HIV necessarily”. Lastly, P10 stated “I have to educate some of the doctors in the ERs or in the hospital”. Based on the above it is clear that participants are crying out for specialized HIV providers. As such, the team of healthcare associates should work with HIV programs and stakeholders in framing policies and providing funding so that, clinicians interested in caring for HIV patients, may acquire additional specialized HIV education, attend infectious disease Continued Medical Education (CME) conferences on current HIV topics; but also, take the time to follow the research and seek understanding of the side effects and interactions between various ART used to treat them.

Being that HIV clearly affects both males and females, pharmacists, emergency room clinicians or at least infectious disease clinicians seeing HIV patients in the emergency room settings, and gynecologists ought to also get current specialized HIV education if interested in treating that population. Moreover, guidelines could be developed to prevent clinicians not treating a designated amount of HIV patients on a yearly basis to take them on as patients. Specific guidelines should be developed by the team, stakeholders, and insurance companies to allow HIV patients to choose a specialized HIV clinician if the ones in their insurance network are not HIV specialized, and as such not equipped to treat them appropriately. Lastly, stakeholders and HIV programs should work with drug companies to offer periodic teachings on side effects and interactions of their approved HIV drugs not only to clinicians but also to insurance companies. The latter could be key in preventing the constant battle between insurers and patients attempting to avoid being forced to solely acquire a medication they know counteract severely with their current HIV regimen simply because it might be cheaper for the insurer.

In regard to follow up appointments for their HIV care, the team should work with HIV programs to implement a reminder phone call or text message especially for this aging group. In fact, some participants did report noticing memory loss as they are progressively aging with the virus. Although they understand how crucial their HIV follow up appointments are and are strongly against missing them, one cannot control the forgetful mind. For instance, P1 stated “I mean occasionally because of my memory loss I forget, I always ask them to give me a reminder call, but for the most part I am pretty much on it”. And P8 added “I am having issues with memory and concentration. I just feel like I’m inappropriate to my age”. Memory loss is clearly becoming an issue for long-term survivors; as such, reminder calls or texts could be essential in ensuring they do not miss these crucial appointments.

Overall and as stated above, these long-term survivors shared the impact of HIV on their daily lives, their feeling of being somewhat forgotten by this society, their need for activities that would create opportunities for them to socialize more, and their need for access to care to improve their physical appearance. Additionally, they shared their struggle to survive in this increasingly expensive society on low income, as P7 stated “physically I can’t work more, and the other situation is that if I

make one more dollar than I lose all my Medicare, I lose all my medication, and I can’t live like that. So, in that respect the biggest side effect is that we’re prisoners of our benefits and prisoners of what we need to survive”. Finally, they shared their fear of tomorrow in this same society still lacking accommodations for those on the verge of losing their independence or those without enough savings to retire. For example, P6 stated “I suppose that the challenge that’s playing on my mind quite a bit right now would be the vision and the thought process of losing my driver’s license, and that will just be horrifying. Not to be too dramatic, but that loss of independence at this age – I’m only 63”. And P8 stated “the impact of HIV and having been out of work for so long and been on disability and living barely above the poverty line is that at this point, while most of my friends have - own property and talk about retirement plans and 401ks and things like that, I have no savings, no property, no retirement plan other than eventually I will go back on Social Security, either by disability or by actually retiring. But with no assets and no pension, no retirement savings, I’m hoping to be able to at least save something now that I am returning to work at 51. We’ll see how long I can continue working, but it’s a rather scary proposition”.

Specifically, if implemented, the recommendations of my study could directly impact long term HIV survivors struggling in a world where they have outlived most of their friends and are somewhat rejected by a community of their own. For instance, if proper access to care and procedures is made available to them, this could allow them to continue living in lieu of simply existing, re-claiming their self-esteem while giving them a better incentive to step out of their secluded shell with confidence. Additionally, if suggested programs are put in place, this could enable them to create new bonds, socialize more, and eventually embrace the outside world thus reducing any possibility of falling into depression. Also, with the majority of people “forced” into disability because of the effects of the virus, or for those still struggling to maintain employment and thus adequate housing, framing proper guidelines that would ensure they obtain some sort of housing and nutrition assistance, could positively impact their lives. In fact, as P8 stated “when you’re not sure where your next meal is coming from, your doctor’s appointment two weeks from now might not be your first priority”.

Finally, the study could also have a positive impact on the next generation of newly diagnosed individuals. P8 stated “with the younger newly diagnosed folks, 18 to 25 or even 18 to 30, they generally have no experience of having to take medication on a regular basis. No experience of having to engage in healthcare on a regular basis. Plus, they have no memory of how devastating HIV was. They never went to funerals two and three times a week the way that folks my age or just a little bit older than me did. They never watched friends die around them. So, getting them to understand the seriousness of the diagnosis and getting them to - having to grasp, mentally, at the age of 21 that you’re gonna have to take medication for the whole rest of your life and you really can’t miss any dosages, is a pretty difficult thing to struggle with. And they frequently don’t have any kind of insurance coverage. If they do, it’s often under their parent’s insurance whom they don’t want to be receiving statements or bills from the insurance company for HIV medication”. Although this generation no longer has to face HIV as a death sentence, not only do they have to grasp

the seriousness of their diagnosis, they are currently living in a society where there is of yet no available facilities to care for those aging with the virus and not enough specialized providers to address their HIV associated chronic conditions to cite a few. Despite the plethora of shared experiences from long-term survivors, as stakeholders work on better aging days for those living with the virus, this newer generation could benefit from mentorship from these long-term survivors, as well as guidance towards a brighter future. As P4 stated “You go towards it. You embrace it. You deal with it. You don’t walk away from it. You have to run towards it, and deal with it in a proactive way versus just sitting back”. Lastly, key information obtained through these long-term survivors could be used to shape guidelines that could improve the current and future lives of newly diagnosed patients.

LIMITATIONS OF THE STUDY

In my study, I included participants who were 50 years and older, had lived with HIV for at least 20 years, were on at least one ART, and had at least one comorbidity so as to explore their experiences of living with HIV and the challenges that develop overtime. Being that I used a phenomenological approach, one limitation is that my findings cannot be generalized to a population group that does not share the phenomenon in question [12]. Additionally, I used 10 participants in my study and because of this adequate yet small sample size, the overall study results might not be generalizable to a larger population even sharing the same phenomenon in question [24]. In fact, the experiences and challenges gathered from the participants throughout the interview might not reflect that of the entire population living with the phenomenon even with similar backgrounds. Finally, the majority of my participants were male (80%) while only 20% were female, hence minority.

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