

“Ho uno stato di salute complicato... e l’infezione da HIV sta proprio lì in mezzo”: uno studio qualitative su come gli anziani gestiscono condizioni corniche multiple.

“I got complicated health... and HIV is right there in the middle”: A qualitative study of how older adults with HIV self-manage multiple chronic conditions.

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Riassunto

Condizioni corniche associate all'età sono in aumento tra gli adulti anziani con HIV. Le multimorbidità complicano la cura non solo dal punto di vista del paziente, sebbene si sappia poco su come gli adulti anziani con HIV e condizioni corniche multiple (MCC) diano priorità e gestiscano le proprie situazioni.

Questo studio affronta tale lacuna nella ricerca.

Uno studio qualitativo esplorativo è stato condotto tra gli anziani con HIV e MCC. Le linee guida per l'intervista sono state sviluppate usando una revisione della letteratura. Le interviste individuali, condotte da remoto da coordinatori della ricerca addestrati nei metodi qualitativi, sono state audioregistrate e trascritte. L'analisi tematica è stata disegnata usando il Framework Method. Un totale di 30 partecipanti è stato arruolato da due centri clinici accademici a Chicago, Illinois, e Chapel Hill, North Carolina, e da un centro clinico di comunità a Raleigh, Carolina. L'età media dei partecipanti era di 63 anni; metà si identificata come Black e due terzi come maschio.

L'analisi tematica mostrava: 1) misurarsi con le MCC è comune e complicato; 2) la priorità data alle diverse condizioni varia secondo l'importanza percepita e la difficoltà di gestione; 3) la gestione delle visite può essere complesso; 4) le MCC possono rendere difficile aderire ai trattamenti farmacologici; 5) l'insicurezza abitativa ha un impatto negativo sulle visite e sull'aderenza alle medicazioni, e 6) la preoccupazione per le interazioni avverse da farmaci e per le conseguenze indesiderate è comune. In conclusione, la cura centrata sulla persona e un supporto aggiuntivo sono necessari per gli adulti anziani con multimorbidità.

Abstract

Age-related chronic conditions are increasing among older adults with HIV. Multimorbidity complicates care from the patient perspective, though little is known about how older adults with HIV and multiple chronic conditions (MCC) prioritize and manage their conditions. This study addresses that research gap.

An exploratory, cross-sectional qualitative study was conducted among older adults with HIV and MCC. Interview guides were developed using a review of the literature. Individual interviews, conducted remotely by research coordinators trained in qualitative methods, were audio recorded and transcribed. Thematic analysis drew from the Framework Method.

A total of 30 participants were enrolled from two academic health centers in Chicago, Illinois and Chapel Hill, North Carolina, and one community health center in Raleigh, North Carolina. The average age of participants was 63; half identified as Black and two-thirds as male. Thematic analysis revealed: 1) contending with MCC is common and complicated; 2) prioritization of conditions varies by perceived importance and difficulty to manage; 3) visit management can be challenging; 4) MCC can make it difficult to adhere to medications; 5) housing insecurity negatively impacts visit and medication management, and 6) concern about adverse drug interactions and unintended consequences is common. Person-centered care and additional support are necessary for older adults with multimorbidity.

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Introduction

Adults with HIV are living longer, healthier lives (1). Yet older adults with HIV in the United States are also more likely to be diagnosed with multiple chronic health conditions compared to those without HIV (2, 3). Further, age-related comorbidities are expected to increase in prevalence in this population (4).

Multimorbidity, or the presence of multiple chronic health conditions, presents numerous challenges for health systems and patients (5). Health systems must ensure care coordination, monitor polypharmacy, and prevent adverse events, while patients must meet competing demands, including prioritizing conditions, attending clinic visits, and self-managing medication (6). Clinics and health centers providing care to individuals with HIV must also anticipate, screen, treat, and often coordinate care for comorbidities.

Despite these efforts, the ways in which older adults with HIV and multimorbidity prioritize and manage conditions, and the challenges they face, is not well understood. Therefore, we conducted a qualitative study among older adults with HIV and multiple chronic conditions. Our objectives were to identify challenges participants face in navigating clinical visits and medication-taking as part of their self-management routines.

Materials and methods

We conducted exploratory in-depth interviews with patient participants. Our research approach was applied qualitative research (7, 8) and we drew from the Framework Method for thematic analysis (9). Researchers involved in this study comprise research coordinators, PhD-level researchers, and HIV care clinicians, none of whom are aged 50 or older.

Ethical approval was obtained from the Northwestern University Institutional Review Board (STU00218516), and the Office of Human Research Ethics at the University of Carolina at Chapel Hill (23-0821); approval was also obtained from the Research Review Panel at the Wake County Health and Human Services – Division of Public Health.

Eligibility Criteria

English-speaking patients from participating health centers were eligible if they were: aged 50

or older, diagnosed with HIV, and living with 2 or more other chronic health conditions. For interviewing purposes, internet access, an active email address, and access to videoconferencing technology or a phone were required. Sites were determined based on existing relationships between the researcher team and health centers, and to ensure participation of individuals from areas with high HIV prevalence.

Recruitment Procedures

Recruitment procedures varied slightly by institution. At the academic site in Chicago, an electronic data warehouse (EDW) query was used to identify potentially eligible participants. At the other 2 sites, clinic staff approached potentially eligible participants in person to inform them of the study and gauge interest. Contact information of those interested was uploaded to a secure SharePoint site and accessed by Research Coordinators (RCs) at Northwestern University.

Following these procedures, potentially eligible participants were contacted by phone; an RC provided additional information about the study and confirmed eligibility. To ensure a diverse sample, quota sampling was employed with a goal of recruiting at least: 15 participants who identified as Black or African American, 5 who identified as Hispanic or Latinx, 10 who identified as women, 10 who identified as men, 10 with a viral load (VL) >1,000 copies/mL in the past 5 years or a lapse in HIV care (defined as having no appointments in a 12 month period within the past 5 years). Those interested and eligible were engaged in the informed consent process and enrolled in the study.

Data Collection

RCs trained in qualitative methods conducted remote interviews with participants between November 2023 and February 2024. Interview guides were exploratory, designed to elucidate ways in which participants prioritize and manage conditions. Topics drew from prior published literature (see Supplementary Materials for the guide) (10–12). Interviews lasted approximately 45 minutes and were audio recorded over secure web conferencing technology. At the conclusion of each interview, the RC administered a brief questionnaire comprised of demographic questions, validated measures of patient activation, (Consumer Health

Activation Index (13)) and health literacy (brief three-item screener (14)). These quantitative data were securely recorded in REDCap software (15, 16). After each interview, the RC took detailed field notes, creating initial memos of emerging themes (8).

Analysis

Audio files from completed interviews were professionally transcribed; de-identified transcripts were uploaded to NVivo Qualitative Software for analysis (17). Drawing from the Framework Method, transcripts were read for familiarity and content memos were written (9). A codebook was then drafted, comprised of *structured codes* pertaining to topics from the interview guide and *emergent codes* from transcript reading and memo writing. Three coders pilot tested the codebook on the initial six transcripts; these were double coded with all coding reconciled and the codebook clarified during regular meetings; remaining transcripts were independently coded, though all coding continued to be reviewed and agreed upon. Following the coding process, coding reports were reviewed; themes and sub-themes were iteratively identified. Finally, Excel matrices were created with rows representing individual participants and columns representing individual themes and illustrative quotes (9). Summaries were written across participants to highlight overall themes (8). To support trustworthiness, themes were compared to post-interview field notes (8).

Results

Participant Characteristics

A total of 30 participants were enrolled. A detailed description of their sociodemographic and health characteristics is provided in **Table 1**. In brief, approximately two thirds of participants were recruited from the academic site in Chicago. The average age was 63 years.

Half (50%) identified as Black or African American. Most identified as male (66%), reported some college education or less (63%), and less than \$50,000 in annual income (69%). Half (50%) had a chart indication of a VL >1,000 copies/mL in the past 5 years.

Most (77%) self-reported an overall health status of good to excellent, while less than half had low health literacy (37%) and low patient activation (47%).

Thematic Findings

Thematic findings corresponding to topics addressed in our interview guide included the following: 1) contending with MCC is common and complicated; 2) prioritization of conditions varies by perceived importance and difficulty; 3) visit management, particularly coordination of schedules, can be challenging; and 4) MCC can make it difficult to adhere to medications as prescribed. Two emergent themes were also identified: 5) housing insecurity negatively impacts both visit and medication management, and 6) concern about adverse drug interactions and unintended consequences is common.

Theme 1: Contending with MCC is common and complicated.

A majority of participants self-reported 3 or more chronic health conditions, in addition to HIV. The most often reported conditions included high blood pressure and high cholesterol, followed by diabetes, chronic kidney disease, heart conditions, mental health concerns, and obesity. In addition to HIV care providers, most participants reported receiving care from clinicians in specialty areas. A majority also reported taking medications to treat 3 or more of their conditions.

Theme 2: Prioritization of conditions varies by perceived importance and difficulty.

Participants were asked explicitly whether and how they prioritize their conditions. Most frequently, they described HIV as the most important condition to manage, with some explaining they worry about the potential for HIV to 'get out of control' or that they could encounter drug resistance. One participant explained:

"My HIV [is the most important for me to manage] ... I know that without the HIV medicine, it'll cause my viral load to go up, and I know that if you miss a lot of dosages, it's a possibility that the medicine may stop working for you. Then you'll have to try to find another medicine and try, and it may not be as effective as the medicine is right now... My HIV is truly important to me." (62-year-old non-Hispanic Black female).

When asked which condition was the most difficult to manage, responses varied.

Table 1. Sociodemographic and Clinical Characteristics of In-Depth Interview Participants.

Description	Overall N=30	Description	Overall N=30
Sex, n (%)		No insurance	1(3.57)
Male	20(66.67)	Marital status, n(%)	
Female	10(33.33)	Married	4(13.33)
Gender, n(%)		Widowed	2(6.67)
Male	19(63.33)	Separated	2(6.67)
Female	10(33.33)	Single	16(53.33)
Transfeminine	1(3.33)	Living with a partner	6(20)
Age		Income ^b , n (%)	
Mean (SD)	63(6.23)	Less than \$50,000	20(68.97)
Median (min-max)	62(55-85)	Between \$50,000 and \$99,999	7(24.14)
Hispanic, n(%)	5(16.67)	\$100,000 or more	2(6.9)
Race, n(%)		Site, n (%)	
Black or African American	15(50)	Academic Health Center in Chicago, IL	19(63.33)
White or Caucasian	14(46.67)	Academic Health Center in Chapel Hill, NC	8(26.67)
Asian	0(0)	Community Health Center in Raleigh, NC	3(10)
Multi-race	1(3.33)	Health Description	
Education, n (%)		Patient Activation Level (CHAI), n(%)	
Some college or less	19(63.33)	Low	14(46.67)
College graduate	5(16.67)	Moderate	12(40)
Graduate degree or more	6(20)	High	4(13.33)
Language, n (%)		Overall health status, n(%)	
English	30(100)	Excellent-Good	23(76.67)
Spanish	0(0)	Poor-Fair	7(23.33)
Insurance ^a , n (%)		Health literacy, n (%)	
Private	12(42.86)	Limited	11(36.67)
Medicaid	4(14.29)	Adequate	19(63.33)
Medicare	7(25)	Viral Load >1000 copies/mL, n (%)	15(50)
Multiple	4(14.29)	Past Year Lapse in HIV Care, n (%)	3(10)

a. 1 missing.

b. 2 missing.

Author Credit:

APP: Conceptualization; funding acquisition; methodology; supervision; writing- original draft

CS: Conceptualization; resources; supervision; writing- review and editing

CEF: Conceptualization; resources; supervision; writing- review and editing

CH: Formal analysis; investigation; writing- review and editing

ES: Formal analysis; investigation; writing- review and editing

KA: Formal analysis; writing- review and editing

GW: Formal analysis; project administration; writing- review and editing

TM: Investigation; resources; writing- review and editing

NV: Investigation; resources; writing- review and editing

MB: Conceptualization; supervision; writing- review and editing

SCB: Conceptualization; supervision; writing- review and editing

STATEMENTS AND DECLARATIONS:

Ethical Considerations:

Ethical approval was obtained from the Northwestern University Institutional Review Board (STU00218516), and the Office of Human Research Ethics at the University of Carolina at Chapel Hill (23-0821); approval was also obtained from the Research Review Panel at the Wake County Health and Human Services- Division of Public Health (no number provided).

Consent to Participate:

Participants provided electronic written consent to participate.

Consent for Publication:

Not applicable

Declaration of Conflicting Interest:

APP reports grants from Merck, Pfizer, RRF Foundation for Aging, Lundbeck, Gilead, and Eli Lilly through her institution; and personal fees from Gilead. SCB reports grants from the NIH, Merck, Pfizer,

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Data Availability:

Data from this qualitative study are not publicly available. However, de-identified transcripts may be available upon reasonable request from the corresponding author.

Some felt they had become accustomed to self-management strategies over time, claiming nothing was truly difficult:

"None of it. It's not difficult. How can I explain this? It's not a difficult thing. If you get into a-- I've been doing this, taking this stuff, different medications for over 10 years, and its routine now." (60-year-old non-Hispanic Black male).

However, several participants expressed HIV was the most challenging aspect of their health.

As one participant explained, the potential for drug resistance made HIV a particularly difficult condition to manage:

"HIV... After over 30 years of being on antiretrovirals, there aren't many options left for me because I have resistance... it is out of my hands. I'm compliant with the medication that's available to me, but there's very limited availability of medications after this one is found to be ineffective." (63-year-old Hispanic white male).

Additionally, several participants described how diabetes was the most difficult condition to manage, as it requires lifestyle modifications and more complex treatment regimes, including insulin injections for some.

One participant described how incorporating daily injections into established routines for oral medications required an adjustment period:

"I've recently switched to insulin about 6 months ago. It's taken me a little while to manage that one better from going from a pill form of medication to the insulin..." (58-year-old non-Hispanic white male).

Theme 3:

Visit management, particularly the coordination of schedules, can be challenging.

Participants were asked explicitly about two separate ways in which contending with multiple chronic health conditions could affect their abilities to fully participate in care. The first was regarding the need to attend multiple clinical care visits. Some participants reported limited difficulty managing and attending visits, either due to support from the patient portal, clinic staff, or because they have the time, due to retirement, to dedicate to visit management. Yet most of these participants also recognized that visit management - for appointments and for laboratory testing - was likely difficult for others. As one participant explained:

"If I was working, it'd be very difficult because it's a lot of appointments, but I'm like retired now. It's what I do... It's a lot of appointments and it just ain't doctors' appointments - it's testing." (63-year-old non-Hispanic white male).

Nevertheless, a similar number of participants reported they do encounter challenges managing visits for multiple conditions. Difficulty coordinating schedules was a common explanation. One participant explained challenges coordinating with other doctors:

"It's difficult to coordinate that at times. Sometimes my therapy provider's visits interfere with the availability of the specialists that I see. Sometimes you have to go with the specialist visit, because you can never reschedule that. That's not going to happen in the next year." (63-year-old Hispanic white male).

Another revealed challenge coordinating multiple visits while maintaining employment:

"When I was coming often, I would start missing appointments [on purpose]. I'm like, 'I can't keep taking these days off.' I don't care how important you say it is to come. I am tired of taking days off." (55-year-old non-Hispanic Black female).

A few participants attributed their challenges to mental health concerns, particularly depression, that impede their abilities to attend visits, while others noted a lack of reliable transportation. One participant noted:

"What helps me is having some friends or relatives that will come and pick me up or go with me. I live by myself and sometimes the challenge is just feeling lonely and getting depressed." (69-year-old non-Hispanic Black female).

Theme 4:
MCC can make it difficult to adhere to medications as prescribed.

Participants were also asked how the need to manage multiple conditions affects their abilities to take medications as prescribed. Half the sample expressed some challenges in medication taking, with most describing a general distaste for having to take an ‘overwhelming number’ of medications. As one participant reported:

"I hate taking all these pills. I don't want to be tethered to 15 medications a day." (65-year-old non-Hispanic Black male).

In addition to feeling overwhelmed about the number of prescribed medications they are required to take, some participants reported depression and anxiety negatively impact their abilities to take their medication as prescribed:

"[When] I'm in pain, I get depressed, I won't even take the pills. I no longer even care about the viral load. I don't care. I don't want to talk about it at that moment. I just need this pain to stop. I need not to feel depressed...." (55-year-old non-Hispanic Black female).

Contending with other conditions, such as addiction, kidney failure, or lung cancer, reportedly made it difficult for some participants to be adherent to their prescribed medications. For example, one participant explained how complications from kidney failure impacted his adherence to antiretroviral therapy (ART):

"Well, so far as HIV meds, that became really, really challenging especially as I started concentrating more on the kidney failure.... it became really difficult to take them [HIV medications] I developed nausea and sometimes even vomiting if I thought of even taking those medications." (60-year-old non-Hispanic Black male).

Theme 5:
Unstable housing negatively affects both visit and medication management.

A few participants described prior experiences with unstable housing. During those experiences, they noted health maintenance, in general, and “a homeless lifestyle - they don’t mix” (63-year-old non-Hispanic white male). Another participant further explained:

"At any moment, my housing could be interrupted, and if that's interrupted, I really won't be too

concerned about making appointments and trying to stay abreast on my HIV care because I'll be too concerned about where am I going to live, how am I going to live, how am I going to eat if I'm going to eat. That's always in the back of my mind." (60-year-old non-Hispanic Black male).

Theme 6:
Concern about adverse drug interactions and unintended consequences is common.

Although participants were not explicitly asked about drug interactions, many reported concerns and even frustration with how they perceived their ART was impacting their other conditions. Some worried treatment options for other conditions were limited due to their ART. For example:

"I got complicated health care, to say the least. It's just a lot of things going on and HIV is right in the middle of them. Like I said, those certain HIV drugs interact with so many other medications, and it just makes it difficult to be treated." (63-year-old non-Hispanic white male).

Still others attributed experiences with weight management, hypertension, or hyperlipidemia, to potential unintended consequences of ART. For example, one participant described how ART contributed to his hyperlipidemia, which he now manages with yet another medication:

"...the cholesterol pill I'm taking... I ended up with this apparently from taking medication [for HIV]". (58-year-old non-Hispanic Black male).

Despite these concerns and frustrations, participants did not report altering the dosing or dosing schedules they were prescribed; instead, they largely accepted the complicated health care situations in which they found themselves.

Discussion

Results from our 30 qualitative interviews with a diverse group of participants revealed many self-reported ‘good or excellent’ health despite contending with HIV and numerous chronic health conditions. Hypertension and hyperlipidemia, also prevalent in other studies conducted among adults with HIV (18-20), were the most frequently reported comorbidities in our study. HIV was mentioned by many as the most important condition for participants to manage, yet it was not necessarily the most difficult; participants found a variety of other conditions, such as diabetes, to be the more challenging. Relative importance often

depended on participants' perceptions of the necessary lifestyle modifications needed to manage conditions as well as the experience or threat of drug resistance. These results are consistent with prior studies conducted by members of our team and others, in which individuals with HIV report challenges incorporating lifestyle changes into established health self-management routines (11, 21).

Managing multiple visits was perceived to be difficult by many participants, with some reporting, as other studies have, that mental health challenges and/or a lack of reliable transportation impede attendance (10). Mental health challenges and competing needs of other conditions were also thought to negatively impacted medication adherence; however, these were largely referred to as challenges participants contended with while adjusting to new diagnoses and/or prescription regimens. Medication adherence reportedly improved with familiarity and support. In this and other studies, older adults with multiple chronic health conditions and HIV have reported reliance on others, whether for transportation, health care decision-making, or social support (12). Additional work may need to focus on caregivers and on the subpopulation of patients without sufficient support so as to better understand their needs, including those with unstable housing (22).

Participants in this study expressed concern about ART, particularly that their regimens may have caused or exacerbated other conditions. Similarly, concerns about drug interactions were raised. These perceptions are notable, as they likely pertain to a 'legacy of worry' about HIV medications, as historically, ART regimens were much more prone to interact or contraindicate other medications than they are today. Although few studies, to our knowledge, have examined these concerns from the patient perspective, calls have been made for in-depth research in this area (23).

Pharmacist-led educational and medication management programs have been successfully conducted among individuals with HIV, and should be expanded to support patients with comorbidities (24).

With modern ART regimens frequently involving lower pill burdens and fewer drug interactions, exposure to pharmacy expertise might not only reduce adverse consequences of medication but also offer an opportunity to allay patient worries formed during earlier ART eras.

Additionally, opportunities to streamline or consolidate ART (for example using once daily dosing, single table regimens, or long-acting injectable ART) could address some concerns related to polypharmacy and further support patient abilities to self-manage multiple chronic conditions and polypharmacy.

This study is not without limitations. Results are not generalizable. Nevertheless, we purposefully enrolled a diverse sample of older adults to identify common themes among those living with HIV and multiple chronic health conditions.

Furthermore, our sample was less activated overall; results could vary among more activated patients. Despite this, the comments participants raised during this study are relevant and, as noted above, similar to those raised in other published studies.

Conclusions

Older adults living with HIV and multimorbidity were recruited from clinics with robust linkage to subspecialty services; nevertheless, they reported a variety of challenges with health self-management. Improvements in person-centered care, including, but not limited to, support from clinical care teams and the patient portal, may be necessary to ensure individuals are able to fully participate in care for each of their complex health conditions.

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