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Adaptive Challenges, Adaptive Work, and Adaptive Leadership Among Women Living With HIV in the Southern United States: Findings From a Qualitative Study

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Abstract

Women living with HIV have a higher burden of non-AIDS comorbidities and prevalence of chronic conditions. The Adaptive Leadership Framework for Chronic Illness clarifies living with complex health challenges by delineating the technical work of health care providers as well as the adaptive work and leadership behaviors of patients and their providers. We conducted a descriptive, qualitative study of women residing in the Southern United States who were participating in the Women's Interagency HIV Study in North Carolina. Twenty-two participants (mean age = 52.2 years; 90.9% self-identifying as Black or African American) completed semi-structured qualitative interviews. We identified adaptive challenges (e.g., affective and disclosure challenges) and adaptive work and leadership behaviors. Women learned skills to care for their health and support their families and to work with their providers to manage their care. Findings support the importance of identifying leadership behaviors for the purpose of developing person-centered interventions.

Keywords

Adaptive Leadership Framework for Chronic Illness; HIV; qualitative design; women living with HIV

In the United States, more than half (51%) of all people living with HIV (PLWH) are 50 years or older (Centers for Disease Control and Prevention [CDC], 2020b). Antiretroviral therapy (ART) has extended the life expectancy of PLWH across the globe (Teeraananchai et al., 2017). As persons live and age with HIV, ART adherence is critical because it prevents disease progression, contributing to the near normal life expectancy within this population and eliminates the risk of viral transmission to sexual partners (CDC, 2019; Collins et al., 2020, 2021). Despite these benefits, ART adherence alone does not fully reestablish health; even when PLWH achieve viral suppression, their risk for age-related non-AIDS comorbidities (NACMs) may be higher and occur earlier than in their counterparts not living with HIV (Collins et al., 2020, 2021).

The Women's Interagency HIV Study (WIHS) is the largest, prospective, U.S.-based cohort study of women who are living with or at risk for HIV ($N = 3{,}232$; Adimora et al., 2018). Recent findings from the WIHS have helped to characterize the specific age-related NACM burden among women living with HIV (WLWH; Collins et al., 2020, 2021). Findings indicate that WLWH have a higher NACM burden than those without HIV, as well as a higher prevalence of psychiatric illnesses; dyslipidemia; non–AIDS-related cancer; and kidney, liver, and bone disease(Collinsetal.,2020).Moreover, evidence suggests elevated NACMs in WLWH compared with men living with HIV (Chow et al., 2018; Palella et al., 2019).

Women living with HIV face distinct challenges and geographically specific determinants of health. For example, in the United States, women experience higher rates of poverty (Semega et al., 2020), a significant precipitating factor for HIV infection(CDC,2020a;Denning & DiNenno, 2019), as well as subsequent suboptimal treatment and care outcomes (Burch et al., 2016; Leddy et al., 2019). Despite having the second highest regional rate of HIV among women (228.1 per 100,000), women residing in the Southern United States have the lowest rates of engagement in HIV care and viral suppression compared with WLWH in all other regions of the country (Hoover et al., 2019). This disparity is attributable to social and structural barriers specific to the South, such as poverty (Leddy et al., 2019; Reif et al., 2017), high rural HIV burden (HIV.gov., n.d; Reif et al., 2016, 2017; Southern AIDS Coalition, 2018), lack of Medicaid expansion and low insurance coverage rates (Reif et al., 2017), high levels of stigma and racial and gender discrimination (Fletcher et al., 2016; McCoy et al., 2020; Relf et al., 2019; Rice et al., 2018), implicit biases in the clinical encounter (Harris et al., 2020), and the lowest federal funding levels for HIV prevention and care in the United States (Reifetal., 2017; Southern AIDS Coalition, 2018). Research findings show that negative experiences of HIV-related stigma are amplified for WLWH (Scofield & Moseholm, 2021); if internalized, they may adversely affect well-being, HIV care engagement, and ART adherence (Relf et al., 2019). The considerable effort required to adhere to a lifetime of ART, manage a higher age-related NACM burden, and address the social determinants of health that affect WLWH in the Southern United States present a unique and complex challenge for both WLWH and their health care providers.

Adaptive Leadership Framework for Chronic Illness

The Adaptive Leadership Framework for Chronic Illness (ALFCI;Andersonetal.,2015;Baileyetal.,2012)offersa useful person-centered approach to understanding complex health challenges and the technical and adaptive work that occurs over time (Figure 1). The ALFCI (Anderson et al., 2015; Bailey et al., 2012) is derived from the work of leadership expert Ronald Heifetz (Heifetz et al., 2009) and is based in complexity science (Thygeson, 2013). The ALFCI is a new approach to understanding chronic illness that clearly delineates technical challenges, adaptive challenges, and adaptive leadership behaviors essential for determining a plan of care to improve patient outcomes (Anderson et al., 2015).

In health care, technical challenges may be simple or complex, but they have known technical solutions that can be mediated by the expertise of a clinician (Anderson et al., 2015; Bailey et al., 2012). For example, combination ART is a technical approach to HIV management that requires the prescriptive authority of a clinician and extensive knowledge of ART treatment guidelines. Other examples of technical work by a provider includes ordering an HIV plasma RNA or genotype to evaluate combination ART effectiveness or screening a PLWH for depression.

Conversely, adaptive health challenges are always complex in nature, requiring adaptation, learning, and/ or some form of behavior change by the person experiencing the chronic illness; ultimately, the individual living with the chronic illness must do the adaptive work (Anderson et al., 2015; Bailey et al., 2012; Thygeson, 2013). As WLWH are living much longer, they must constantly adapt to the chronicity and often unpredictability of their health trajectories. Clinical approaches that acknowledge and facilitate adaptive processes are critical to helping WLWH achieve optimal health and wellness. An example of adaptive work required of the PLWH is learning how to self-manage the daily medication regimen and monitor and report symptoms they may experience, such as fatigue. Other examples of adaptive work include learning to navigate the AIDS Drug Assistant Program requirements, confront HIV-related stigma and discrimination, and develop healthy lifestyle behaviors, such as dietary and exercise changes, to improve their overall health. Their work is reinforced by the adaptive leadership behaviors of providers who acknowledge and support the processes undertaken by WLWH to achieve health and wellness.

Adaptive leadership facilitates adaptive work in two ways. First, it mobilizes providers and patients/families to collaborate, exchange information, and develop a shared meaning of complex health challenges, which is fundamental to adapting to a chronic illness. Second, it fosters provider/patient cocreation of approaches for the adaptive work needed to address those challenges (Anderson et al., 2015; Bailey et al., 2012). Through a better understanding of a WLWH’s specific technical and adaptive challenges, adaptive work and adaptive leadership strategies might enable health care providers to develop interventions to support them as they manage their chronic illness and strive for well-being (Anderson et al., 2015; Thygeson et al., 2010). Therefore, the ALFCI guided the exploration and description of the technical and adaptive challenges, adaptive work, and adaptive leadership behaviors among WLWH in the South in this study.

Method

Design and Data Collection

This study used a qualitative descriptive design (Sandelowski, 2000, 2010). The aim of this study was to explore and describe the technical and adaptive challenges, adaptive work, and adaptive leadership of WLWH residing in the Southern United States who were participants in the Women’s Interagency HIV Study (Adimora et al.,2018).Three stories of WLWH were developed by the senior author(M.V.R.), in consultation with the first author (D.E.B.), to serve as an elicitation device to facilitate the interviews. These pictorial stories depicted three Black or African American WLWH of different ages and explored experiences in several domains, including everyday discrimination, medical distrust, HIV-related stigma, disclosure, adherence, depression, ART adherence, and quality of life. (See Supplemental Digital Content 1, http://links.lww.com/JNC/A20.)

Each slide of the story included a picture of a women with a “thought cloud.” Within these “thought clouds” were statements related to the domains described above (i.e., everyday discrimination, medical distrust, and so forth). These embedded statements were associated with predeveloped probes intended to elicit reflections of the challenges of women living and aging with HIV and to guide the semistructured qualitative interviews (Cristancho & Helmich, 2019; King et al., 2013; Petty et al., 2018). The probes explored the technical and adaptive challenges associated with the domains and how a health care worker can help address challenges and foster new knowledge, skills, and abilities to support the self-management of WLWH in these domains. (Please refer to the Supplemental Digital Content 1, http://links.lww.com/JNC/A20 for an example of how the stories were presented, the elicitation statements, and the probes used to explore the domains from an adaptive leadership perspective.) In nearly all situations, the participants used their personal journeys and life experiences to respond to the “thought clouds” and related probes.

The semistructured interviews, conducted between July and October 2016, were recorded using two encrypted digital recorders. All interviews were transcribed by a doctoral nursing student under the guidance of the study’s principal investigator (PI), producing verbatim transcripts. The digital recordings were destroyed to protect the privacy and ensure the anonymity of the participant after confirmation of verbatim transcripts and data analysis. Each transcript was uploaded into NVivo 12.0 for data management and organization.

Sample and Participant Recruitment

A convenience sample of eligible participants was recruited from the North Carolina site of the WIHS, a longitudinal cohort study of women who are living either with or at risk for HIV. Adult WLWH who were 18 years or older, spoke English, and were able and willing to provide written informed consent were eligible to participate. To facilitate recruitment, a member of the WIHS study team introduced the study to eligible participants. Women who expressed interest in participating were asked by the WIHS team member if they would like to be contacted by the study’s clinical research coordinator. After receiving a referral, the clinical research coordinator contacted the interested woman to explain the study and answer any questions. Women who agreed to participate were scheduled for a one-time semistructured interview. The interviews were conducted in a private room at a WIHS study site by the PI of the study (M.V.R.) who had more than 30 years of clinical and research experience working with PLWH. Data saturation was identified at 17 interviews, but 5 additional interviews were conducted to ensure informational redundancy. Participants received a $75 gift card for participation ($25 for transportation costs and $50 for their involvement in the study).

Ethical Considerations

The study was approved by the Duke University Health System Institutional Review Board (IRB#Pro00067256). The consent form was read to all study participants, after which an opportunity was provided to have any questions addressed. Participation in this study was voluntary, and written informed consent was obtained from all study participants.

Strategies to Assure Trustworthiness

As described by Lincoln and Guba in the 1980s, the quantitative concepts of reliability and validity are replaced with the parallel concept of “trustworthiness” in qualitative research; this concept of “trustworthiness” comprised credibility, transferability, dependability, and confirmability (Guba & Lincoln, 1981, 1982; Lincoln & Guba, 1985). Comparatively, Whittemore et al. (2001) wrote about the concept of validity in qualitative studies and identified four primary criteria associated with validity: credibility, authenticity, criticality, and integrity.

Prior to and during data collection, the PI of the study (M.V.R.) reflected upon position and status (reflexivity) and how these related to the phenomena of interest and the population being interviewed. Furthermore, the PI met with the WIHS staff on several occasions to deepen his sensitivity in understanding the experiences of the population of interest—an essential component of trustworthiness. Through these discussions, the PI (a White male) and the WIHS staff explored the appropriateness of him conducting the interviews with a population that would most likely be composed of Black or African American women and a sample composed of all women, again addressing sensitivity; this critical appraisal is related to the integrity concept of validity as defined by Whittemore et al. (2001). Ultimately, these conversations helped to ensure reflexivity of the PI and added to the credibility (accurate interpretation of the participant’s statement) and integrity (self-criticality of the investigator). To support the validity concept of criticality, the critical appraisal of all aspects of the research benefited from having experts in the ALFCI; the experiences of WLWH; and issues of stigma, discrimination, adherence, and engagement in care involved in the study design and development of the interview guide and in the analysis and reporting of results.

As the analytical work unfolded, our focus was on seeking credibility (an accurate representation of the participant’s statement) of the findings through continued discussions and analyses of the collected data (Sandelowski et al., 1997). Additionally, during the writing phase associated with data analysis, we ensured authenticity by making certain that different voices were represented in the exemplar statements selected. To facilitate dependability of our findings, team members used an a priori developed code book and discussed emerging codes during regular team meetings. As part of the process of seeking credibility, only one person (the study’s PI, M.V.R.) conducted the 22 interviews. During the 4 months of conducting the interviews, the interviewer used constant comparison between interviews; this process allowed the interviewer to examine experiences unique and common to participants to increase depth of understanding. Finally, to assure transferability, we included rich details of our data as a means of comparison with the work of other scholars who have used the ALFCI (Bailey et al., 2019; Carthron et al., 2015; Stevenson et al., 2019).

Data Analysis

Each transcript was coded by two members of the study team. We used directed content analysis to code the data and began with a set of a priori codes related to the ALFCI

(Hsieh & Shannon, 2005). The code book was enhanced with a secondary set of codes specific to HIV and the phenomena of interest associated with the study's aim (everyday discrimination, medical distrust, adherence, engagement in care, depression, quality of life, stigma, and disclosure). New codes were added to the code book (resilience, well-being, coping, self-acceptance) in an iterative manner and were used to code all transcripts. Once initial coding had been completed, the team convened to discuss the emerging analytical lines in the context of the ALFCI. The three primary members of the team (D.E.B., C.C., and M.V.R.) responsible for developing this article reimmersed themselves in the data to explore the richness of the information related to technical and adaptive challenges, adaptive work, and adaptive leadership.

Results

Of the 22 WLWH who participated in the qualitative interviews, 19 self-identified as African American, 1 as African American and Hispanic, 1 as Native American, and 1 as White. The mean age of the participants was 52.2 years (range = 38–62 years); overall, 7 (31.8%) of the interviews were with WLWH younger than 50 years, and 15 interviews (68.2%) were with WLWH ages 50 years or older. The length of the interviews ranged from 40 minutes to 1 hour 40 minutes; the mean length of the interviews was 65.9 minutes, and only 2 interviews lasted less than 45 minutes. The interviews revealed technical challenges and adaptive challenges that include two themes: adaptive work, composed of three themes, and adaptive leadership behaviors.

Technical Challenges

Technical challenges were defined as "situations where both the problem and the potential solution can be clearly defined" (Thygeson et al., 2010). The challenge can be identified by the person experiencing it or their provider, and the work is done by the provider to address the issue. Two areas of technical challenges were identified by participants: obtaining and taking medication and receiving care. When asked where she would like to receive health care, one participant (#002) responded, "[blinded]Hospital. They are here to help you with your medicines." Another WLWH shared that she was unable to eat after her initial diagnosis and "they [health care provider] gave me some medicine to help me" (#001). When asked by the interviewer to reflect on the most important advice or assistance related to her medications that a health care provider might give a WLWH, a participant (#014) shared the following example that pertains to the work of the provider: "try this medication and see if that works for you. If that one doesn't work, then we'll find the right one that agrees with you." Each of these examples demonstrates technical challenges with known technical solutions requiring medication by an expert clinician.

Adaptive Challenges

We identified two themes related to adaptive challenges experienced by WLWH—affective challenges and disclosure challenges. Adaptive challenges were defined as the disparity between the demands of the present clinical circumstances and the capabilities of familiar methods, habits, or values. Adaptive challenges require the patient to adjust to a new situation and to adapt, learn, and change behavior (Anderson et al., 2015).

Affective challenges.—Women in our study described the emotional toll of living with HIV, such as depressed mood (Junkins et al., 2020). One woman (#018) talked about her denial on learning that she had AIDS: “I just shut down, isolated, got depressed. Went in and out of mental institutions. Tried to take my own life. I just didn’t want to know nothing. I was in denial….” When asked by the interviewer how she might respond if her health care provider did not treat her positively, another woman (#003) shared, “I would probably just go into a depressed mode. I really would. I probably would just lose it.” Several women expressed feelings that life was not worth living and that healing was made even more difficult when they were depressed; for example, participant #002 stated,

> I just want to be taught how to handle myself, and how to bring myself out of the depression… If I talk to somebody that understands it, that’s the only way I know I could bring myself out of it….

Another woman (#012) described her attempts to ensure that those close to her would not find out about her illness; she stated, “It made me plumb crazy. I had to be so careful about everything, and sneaky and devious about my own life. It was very exhausting, mind altering, and so depressing to be doing that….” These women described the challenges of living with a depressed mood.

Disclosure challenges.—The diagnosis of HIV presented women with numerous disclosure challenges. Some responded by hiding their illness and feelings from family and friends. For example, one participant (#002) stated, “I hide my medicine, any kind of medicine that you have to take, with concerns that they are in a different place than any other medication that I would have to take.” This same woman (#002), who identified as a mother and grandmother, shared the following:

> I don’t feel like I can be truthful with my grandchildren. Because I am afraid of what my son would do. You know, you don’t know what your kids gonna do. Will you be able to see your grandchildren or [are] you going to be able to play with them?

Another woman (#004) commented, “Well I do hide my feelings. My doctors’ appointments… I tell my daughter I am going to see my cancer doctor.” One woman (#018) described her attempts to hide her diagnosis while living in a prison, she stated, “Even though it was a secret, I felt like the words HIV was written across my forehead … I was in my own little prison. It was like everybody knew, so I was paranoid with it.” Some women reported having difficulty meeting new partners because they were reluctant to share their diagnosis. This is illustrated in the following statement by participant #010 who stated, “In the beginning I totally stayed away from the dating scene for probably 4 years.I was just too scared. I was just afraid of the reaction … afraid that their reaction might be a violent one.” Working to hide their diagnosis was challenging and left these women exhausted and fearful of potential violence from a partner.

Adaptive Work

Adaptive work with health care team.—Women worked with their health care team to manage and improve their health. Adaptive work, defined as specific adaptive changes (e.g., values/attitudes, skills, learning, and behaviors; Anderson et al., 2015) that women needed to make to achieve the clinical or lifestyle outcomes they desired, was identified in participant interviews. One woman (#001) told the interviewer that

> Patients should be able to trust the doctor to do what he knows is best. He is only human, and we have to know ourselves and our body before we even go into the doctor's office. I examine myself before I go in, so I know what to tell them.

Another woman (#003) stressed the importance of doing the right things to stay healthy: "I am going to see my primary care doctor as I should, and all my doctors as I should, [and] take my meds as I should, and do the right things … no drinking, no drugging."

Making a connection with a supportive care program allowed women access to an annual physical. One woman (#006) explained,

> [Care] Program, for example, was a good chance for me to get [a] pap smear annually. Made sure that my A1C was checked … so health care that I normally have access to, I was able to access through (Care) Program. They have where you go online and check your records and stuff like that so to make sure you are hooked up with that or if you have a Smart Phone. So, there are all kinds of things that happen in the office of the providers that [is]helpful.

Another woman (#007) shared the importance of advocacy: "I can ask for a second opinion …. You have to become educated with every illness …. You have to learn, and that way you are able to protect yourself …." These data exemplify the adaptive work undertaken by these women to maintain and improve their health.

Adaptive work and family.—The importance of educating family members about the disease was another component of adaptive work described by participants. Speaking of a friend who had AIDS, one participant (#001) said,

> She went to a family reunion, and they wouldn't let her use their bathroom. It's hurtful. I got a family that's not like that. Once they found out, they did research … My sister is a schoolteacher, and she encouraged them to do research.

The desire to see a grandchild led one woman (#002) to take optimal care of herself as illustrated by her statement, "I told my daughter I would just like to stay alive long enough to see my granddaughter. I knew my son wanted a baby at that time, [so] I started taking therapy and taking care of myself." She (#002) went on to say "Cause my sister, my daughter was kept telling me, 'You can do this' and I was just telling them no. I can't do this. I can't live like this, and in order to live a productive life you got to understand that you can do it." Another woman (#007) worked to support her daughter and other newly diagnosed women; she stated, "I did peer-to-peer education with people who were newly diagnosed, or [with] mothers that had children who were [HIV] positive. I worked with that 'cause I had a daughter that was [HIV] positive." Many women in this study prioritized their families and used adaptive work strategies not only to improve their own health but also to enhance the HIV-related knowledge of their family members.

Adaptive work and the HIV care continuum.—Women in our study who had lived with HIV for years expressed that they had worked to establish and maintain personal care practices to stay engaged in care and adhere to their ART. For example, one participant (#006) stated,

> I mean for me, little things are helpful … like reminders. They have reminders for appointments that remind you like a week in advance cause I'm notorious for getting the day or time mixed up … so you know reminders are good.

Another woman (#008) spoke to the importance of identifying a professional to talk with. "I also have a case manager, and we talk … I did see a psychiatrist. At the [clinic], I still see a [mental health professional] sometime." This same woman shared that she used codes to maintain her medication regimens stating "I got code[s], you got to use them … I use a little medicine thing …. You know that little thing that you put your pills in? I got 7 days' worth in here." Another woman (#014) shared that she used information from a focus group to adapt the timing of her medication to decrease side effects.

> The first time, I realize[d] I was a little light-headed … 'cause I was just taking it [the medication] when I thought about it. But then the more focus groups I went to, I learned that it was important to take it about the same time every day. I did that, and when I start doing that, I didn't have no side effects.

For some women, finding transportation to see their health care providers was a challenge. However, their determination to do the necessary work to live and obtain care was evident. For example, participant #004 stated,

> Well, I lived in (this town), and I had to go all the way to (that city).So, it was up to me to make a conscientious decision that I wanted to live, and that wherever I had to go to get the treatment …. I had to do what was necessary. I wasn't able to drive, so I found out the buses. I used to take 6 buses just one way to get to (that city) and 6 to get back.That's how much my health meant to me.

Having lived with HIV for a number of years, these women were positioned to care for their health by keeping up with their medication regimens and adapting to remain engaged in their care.

Adaptive Leadership

Behavioral characteristics of adaptive leadership, defined as the ability of the patient or the provider to address adaptive challenges (Bailey et al., 2012), were demonstrated by the women in our study and their providers. They described the emergence of successful new capacities as patients and their providers gained new values/attitudes, skills, and learning that enabled them to achieve their desired clinical or lifestyle outcomes. For example, one participant (#001) said, "My doctor would always ask, 'How does this medicine make you feel? What kind of effects did the medicine have and how could he fix it?'And then you work on it together." In this way, the described provider was demonstrating adaptive leadership by facilitating the cocreation of a solution to resolve the patient's medication concerns. Another woman (#002) shared the importance of working with her health care team: "It's a lot [of] pain, a lot of work, a lot of therapy… and knowledge and having people around me like [her health care team] that is there for me.” The importance of understanding how her disease had affected her body was shared by another woman (#006) when she stated,

> That’s a consequence… of not addressing the issue and thinking that’s normal and letting the high blood pressure wreak havoc on your organs…You can attempt to address it with that provider, and say “I know that’s not normal and I know that it has affected my organs, so if it’s ok with you, I would like to see that addressed and get back to what is considered normal range for everybody.” But everybody can’t do that.

Another woman (#002) shared, “When I started to look it up and realized what I am fighting… That’s when I stay with it and started getting it out of my head that I can’t do it. I said I can do this.” These women were demonstrating adaptive leadership by learning more about the consequences of their chronic illness and proactively working with a provider to address their health concerns.

Women learned from their providers the importance of safe sexual practices as described by this participant (#007) who stated, “… you know like that same social worker I was talking about… she talked to me about me being undetectable and about me passing the virus to someone else. And how it was less than such and such.” One woman (#017) described a difficult conversation with her boyfriend and having to use her skills as an adaptive leader to protect his health and well-being:

> He wanted to have sex and I was like “no.” I told him…“I have HIV,” and he said, “I don’t care” … I said, “I don’t have a condom,” and he said, “It don’t even matter. I love you,” so I called my sister crying, “I can’t do this.” I was worried about hurting somebody else.

The women in the study worked hard to engage and lead their care in partnership with their providers and significant others. Although this was not always easy, they demonstrated the importance of persistence in having difficult conversations when others’ health was at risk.

Discussion

Using the ALFCI (Anderson et al., 2015), we analyzed data derived from qualitative interviews and sought to describe the technical and adaptive challenges, adaptive work, and adaptive leadership behaviors among WLWH living in the South. The findings illustrate the familiar technical challenges conceptualized in the Adaptive Leadership Framework and frequently documented throughout the clinical HIV literature (Heifetz et al., 2009). Additionally, because of the contextual nature of this study (the South) and its focus on a specific chronicillness (HIV), the findings illuminate how illness-specific phenomena, such as affective and disclosure challenges, may act as adaptive challenges. The findings support that adaptive challenges may function to elicit behaviors that lead to poorer health outcomes for this population of women. Furthermore, the findings support the increasing recognition that more complex, adaptive approaches to health care, such as collaborative work identified in the model, likely possess the greatest potential for achieving health and well-being (Anderson et al., 2015).

We found examples of adaptive challenges that align with prior studies that have used the framework to guide their inquiry and organize the findings (Bailey et al.,2019; Carthron et al., 2015). Older African American women caring for their grandchildren have reported the challenges of self-silencing and self-sacrifice (Carthron et al., 2015) similar to those shared by the women in our study who hid their illness and feelings from family and friends. People with chronic hepatitis C experience affective symptom challenges related to depression and initiating new treatment similar to the affective challenges described by women in our study (Bailey et al., 2019).

We also identified the adaptive work and adaptive leadership behaviors among participants as they navigated the health care system, as well as the demands of chronic illness and relationships with family or partners. Specifically, our themes of adaptive work with the health care team, with family members, and across the HIV care continuum align with those of work done with providers by patients who are initiating treatment for chronic hepatitis C to cocreate strategies for medication adherence and resolution of issues with family members (Bailey et al., 2019). When patients or providers used adaptive leadership behaviors, they gained an opportunity to cocreate care with the potential to improve patient outcomes; these behaviors are also in alignment with a patient-centered approach in which providers consider the values of patients as they are planning care (Ebrahimi et al., 2021). Our findings, framed by the concepts within the Adaptive Leadership framework, contribute to a growing body of science that moves from addressing only the technical challenges experienced by WLWH to coproducing care that addresses their adaptive challenges in ways that recognize their life skills.

Our findings have important clinical and research implications. To our knowledge, no study has described the technical and adaptive challenges, adaptive work, and adaptive leadership behaviors of WLWH in the South. The findings from this study offer insights and guidance for health practitioners regarding the adaptive challenges operating within the lives of WLWH, the adaptive work that WLWH are doing to navigate those challenges, and the potential adaptive leadership strategies that can be used during the clinical encounter to develop a shared meaning of complex health challenges and cocreate potential solutions. The findings also support strength-based approaches to clinical management that acknowledge women’s knowledge and expertise about their own health and lived experiences, encourage information exchange, and prioritize collaboration. Guidelines released by an expert panel from the International Association of Providers in AIDS Care support the use of strength-based approaches, which have been shown to improve HIV care engagement and retention in high-resource settings (Okeke et al., 2014).

Further research is needed to explore and test the relationships among the adaptive challenges, adaptive work, and adaptive leadership strategies best suited to promote the health and well-being of WLWH in the South. Such exploration will likely require a robust combination of qualitative and quantitative methods, so that the relative contributions of these concepts can be determined to inform future adaptive leadership interventions.

Limitations

Because interviews were completed during a 4-month period, the experiences described by the participants are a point-in-time expression of experiences, feelings, and thoughts. As all participants were from the Southern United States, translating study findings to women in other geographic regions of the United States or other countries should be done cautiously. In this study, limited demographic information was collected. As such, we do not know the length of time participants had been living with HIV, making it difficult to appreciate the trajectory of the experiences the women described. Going forward, future research should be designed to prospectively follow newly diagnosed WLWH to better understand how the components of the ALFCI unfolds over time. This approach can help guide intervention development associated with common milestones that occur at certain points in time. We also need to acknowledge a potential power differential in the research process between the White male interviewer and the female participants who were primarily women of color. Even though we took multiple intentional methodological steps to reduce any power imbalances of the dominant culture, this may have influenced data collection.

Conclusion

This study identified technical and adaptive challenges, adaptive work, and adaptive leadership behaviors of WLWH in the South. Specifically, participants learned new skills to care for their health, support their families, advocate for a second opinion, and how to work with their health care team to manage their care as they lived with HIV. The adaptive leadership behaviors of WLWH and their providers reflected their willingness to work together to address adaptive challenges and achieve their desired clinical or lifestyle outcomes, including working together to address medication concerns and living with a chronic illness. Our findings contribute to an emerging body of findings that support the importance of identifying adaptive work and leadership behaviors for the purpose of developing person-centered interventions that might lead to improved health outcomes for WLWH.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Key Considerations

- Women living with HIV in the southern United States have complex health challenges exacted by the social determinants of health, stigma, and poverty.
- The Adaptive Leadership Framework for Chronic Illness is a useful, person-centered framework for understanding and addressing the technical and adaptive complex health challenges of women living with HIV.
- The Adaptive Leadership Framework for Chronic Illness is a shared governance approach to person-centered care.

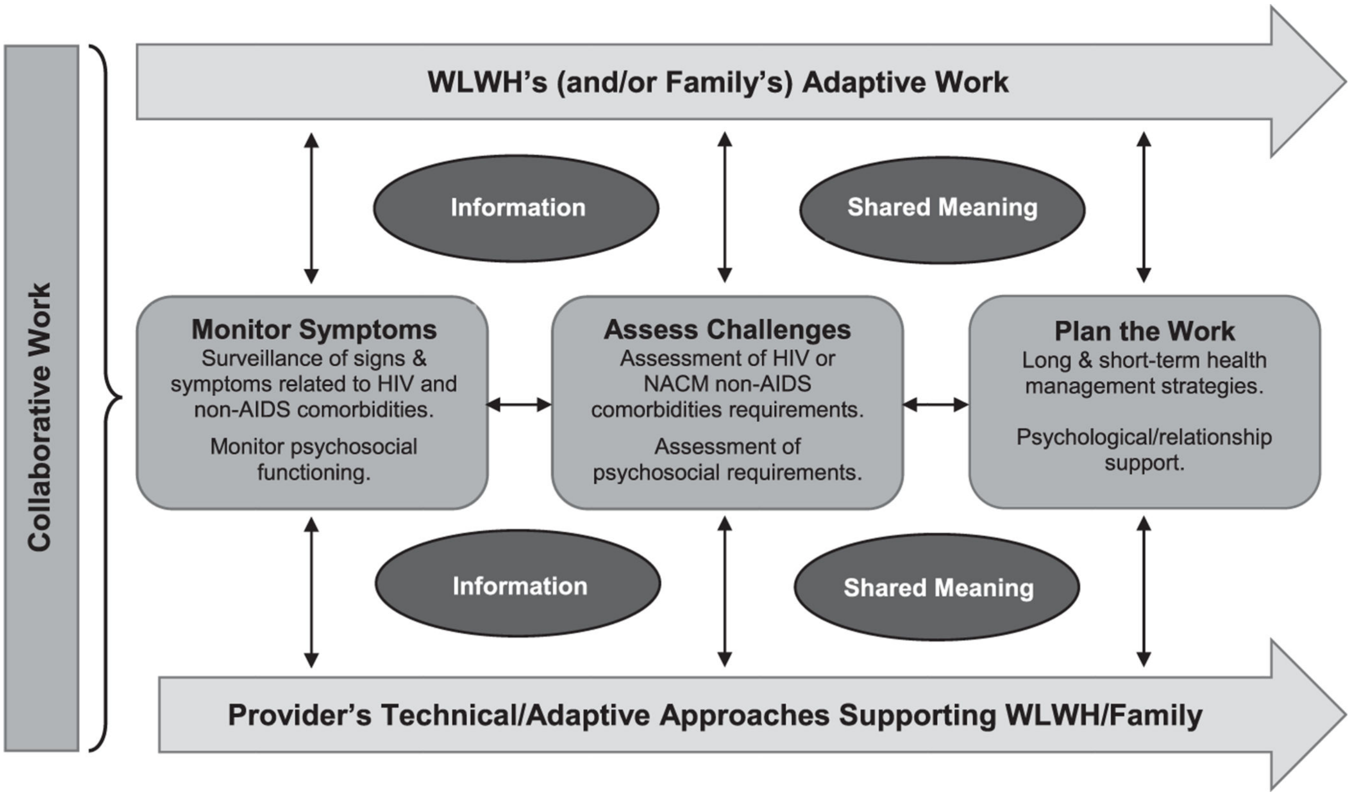

Figure 1.

Adaptive Leadership Framework for Chronic Illness and WLWH. NACM = non-AIDS comorbidities; WLWH = women living with HIV.