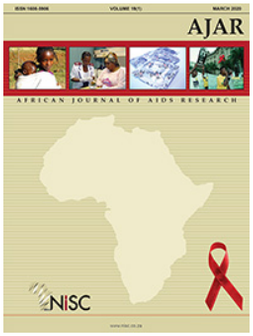

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Research Article

Resilience and pathways to wellness among HIV-positive patients in Ghana: a qualitative study

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Few African studies have focused on resilience factors related to engagement in HIV-related care among people living with HIV; instead, many studies have identified health risk factors and barriers within this population. Informed by the Disability-Stress-Coping Model of Adjustment, a qualitative study was conducted to develop a better understanding of psychosocial factors that can promote positive behaviours and subjective wellness for people living with HIV in Accra, Ghana. Thirty patients from the two largest HIV clinics in Accra participated in in-depth individual interviews. Using a thematic analysis approach, three individual-level factors related to resilience and subjective wellness were identified: (1) holding positive attitudes towards the pathway from HIV testing and diagnosis to healthy living with HIV; (2) placing appropriate (but not absolute) levels of trust in the clinical care environment; and (3) judicious disclosure of their HIV status to key individuals. Findings support a resilience framework that focuses on individual strengths and positive adaptations to HIV diagnosis in order to enhance understanding and promote the HIV care continuum for people living with HIV in this context. Development of resilience-focused approaches to public health intervention is particularly important in low-resource settings such as Ghana where research tends to focus on deficiencies and healthcare inadequacies for people living with HIV.

Keywords: female sex workers (FSW), key popilation, men who have sex with men (MSM), people living with HIV, qualitative

Introduction

HIV infection remains a global public health challenge. There are over 39.6 million people living with HIV in the world (Herrick, Stall, Goldhammer, Egan, & Mayer, 2014; Bariola et al., 2015; UNAIDS, 2018). Sub-Saharan Africa accounts for approximately 66% of those living with the disease; this region is the most severely affected by the HIV epidemic (WHO, 2019). According to epidemiological surveillance data, Ghana had an estimated 310 000 diagnosed people living with HIV as of 2017 (a general population prevalence of 1.6%), with some of the key populations most affected including men who have sex with men and female sex workers, in addition to non-female-sex-worker heterosexual women and heterosexual men (Ulasi et al., 2009; Nelson et al., 2015; Ali et al., 2019; UNAIDS, 2018). According to some estimates, 49% of people living with HIV in Ghana are unaware of their status (UNAIDS, 2013) and only 33% of people living with HIV receive HIV treatment (UNAIDS, 2018). Although the government of Ghana has invested significant resources in preventing new infections, barriers to retention in HIV care have been characterised (Ankomah et al., 2016; Reece, Norman, Kwara, Flanigan, & Rana, 2016; Ali et al., 2019; Kanyangarara, Sakyi, & Laar, 2019; Sakyi et al., 2019). Additional investments in systems of HIV care in Ghana are needed (Ayisi Addo et al., 2018). Ghana operates a decentralised health care services administrative structure, with services operating at primary, secondary and tertiary service levels. First-point primary health care including HIV-related services is typically provided at community-level clinics and health centres, staffed primarily by nurses and physician assistants. More complex HIV-related services are referred to higher levels of service care based on this hierarchical structure (Ayisi Addo et al., 2018).

Ghana's health officials have employed biomedical, harm reduction and structural-level strategies to promote linkage to care and improve health outcomes among people living with HIV (Atun, Pothapregada, Kwansah, Degbotse, & Lazarus, 2011) . Despite these strategies, Ghanaians living with HIV have had to contend with sociocultural, legal, political and economic challenges that have exacerbated pressures on the country's public health infrastructure and diminished coverage of HIV treatment (Djomand, Quaye, & Sullivan, 2014). Challenges to living with HIV and barriers to treatment adherence in Ghana and elsewhere in sub-Saharan Africa have been well documented (Croome, Ahluwalia, Hughes, & Abas, 2017). Many studies have demonstrated that the fear of obtaining HIV-positive status is a primary barrier to testing due

to concerns about abandonment, rejection and even violence from partners and significant others, as well as the perception that an HIV diagnosis is an immediate precursor to death (Mshana et al., 2006; Deblonde et al., 2010; Wagner et al., 2012; Kishamawe et al., 2015; Wagman et al., 2015; Gourlay et al., 2016). Even when individuals overcome the fear to test, attempts to avoid stigma can lead people living with HIV to hide their status from family and friends in order to avoid being blamed for bringing the virus into a family, or to avoid accusations of infidelity (Mshana et al., 2006; Muya et al., 2015; Emlet, Shiu, Kim, & Fredriksen-Goldsen, 2017). Fear of status disclosure and social stigma have also been shown to interfere with a patient's ability to both link with and adhere to care (Mshana et al., 2006). Poverty is another well-studied social factor that has hindered Ghanaians from engagement with HIV care. Low income is often associated with limited access to high-quality health care, housing, transportation and a plethora of other issues (Croome et al., 2017).

In the face of these systemic and individual-level barriers, many people living with HIV in Ghana have successfully linked with and adhered to HIV care recommendations and report overall wellness. These individuals can be characterised as exhibiting forms of resilience, which refers to the process or ability to persist and meet one's goals despite substantive challenge (Herrick et al., 2014). In the context of people living with HIV in Ghana, resilient individuals are of interest because their actions and psychosocial resources may provide insights into strategies to optimise HIV treatments and interventions in low-resource settings. Often, public health research and interventions are based on deficit models, which focus on risk factors and vulnerabilities that lead to negative outcomes. However, resilience-based approaches that are patient-centred and rooted in the realities of specific social contexts may prove to be more advantageous (Emlet et al., 2017; Guðmundsdóttir, Guðmundsdóttir, & Elklit, 2006). By understanding the processes that enhance resilience resources, rather than emphasising the determinants and consequences of disease, public health entities can develop interventions that correspond with motivations and preferences that promote strength and wellness.

The current study builds from Wallander and Varni's Disability-Stress-Coping Model of Adjustment (Wallander & Varni, 1992). The premise underpinning this model is that individual responses to long-term health conditions can range along a continuum of risk exacerbation to risk resistance. Factors that exacerbate risk include psychosocial stress, and factors that promote risk resistance include resilience-promoting intrapersonal and social ecological resources (Wallander & Varni, 1992). Risk-resistant or resilience factors influence the lived experience of long-term health conditions by enhancing the individual's coping abilities (von Weiss et al., 2002).

While this model has been traditionally applied to chronic illnesses, such as studies involving mothers of children with genetic disorders, it has relevance for HIV research in low-resource settings such as Ghana (Betancourt, Meyers-Ohki, Charrow, & Hansen, 2013). This model is useful in studying resilience among people living with HIV in Ghana because it offers a possible explanation for how resilience factors can positively disrupt the causal pathway between risk factors faced by people living with HIV and negative health outcomes observed among these individuals. Indeed, studies have demonstrated that resilience-promotive factors help to reduce harmful HIV-related risks and improve desired outcomes in people living with HIV (Chaudoir et al., 2012; Jamshed, 2014; Emlet et al., 2017). What is lacking in the current body of literature, however, is how feasible such a model will be in understanding and potentially promoting health and wellness among people living with HIV in a low-resource setting such as Ghana.

Given the potential utility of resilience-based approaches to health promotion and wellness among people living with HIV in Ghana, the aim of this paper was to explore resilience-related factors in a group of HIV-infected patients who have successfully linked to and remained engaged in care. Focusing on this sub-population allowed this study to identify factors that can promote a desirable outcome (i.e. linkage and engagement with care) rather than further identify health deficiencies in a vulnerable population.

Materials and methods

Given the exploratory nature of this study, we used qualitative methods to understand the phenomenology of resilience in order to develop understandings of subjective perceptions and experiences that can contribute to positive health outcomes, such as engagement with care, among people living with HIV in Accra, Ghana. The research questions were investigated through in-depth individual interviews. Due to the study's focus on resilience and positive health experiences, the study purposively aimed to interview patients identified as having high adherence with treatment and appointment recommendations (i.e. meeting all appointments during the past six months). Patients who met these criteria were identified by health providers and were then invited to screen for enrolment into the study.

The study took place at two HIV clinics in Accra, Ghana from June to July 2016. The research team consisted of a graduate-level researcher trained in qualitative methods, interviewing and protocol implementation, who was supported by two local, linguistically fluent staff members who were employed through the clinics to assist in recruitment and interviewing. The team was trained in protocol administration, interviewing techniques, data collection and management. Designated office space was used at both clinics for screening and conducting interviews.

The study's inclusion criteria consisted of: (1) being 18 years and older, (2) receiving a positive HIV diagnosis issued by a clinician at a health facility at least six months prior to the study's start date, (3) receiving care at one of the clinics, (4) having attended all medical appointments (e.g. medical follow-ups, pharmacy collections, blood work) during the past six months. Individuals who self-diagnosed their HIV status were excluded, and those who were recently diagnosed (within six months of the study's start date) were excluded due to the possibility that these individuals were still experiencing acute reactions to their diagnosis and had not had enough time to develop resilience or coping resources. These criteria were selected based on recommendations of Loutfy and colleagues concerning the most effective recruitment strategies for HIV-positive patients

(Loutfy et al., 2014). In addition to purposively recruiting patients who had linked and engaged with care, we used a quota-based sampling frame to maximize diversity in the sample, enrolling 30 participants total from three designated groups: men who have sex with men ($n = 10$), female sex workers ($n = 10$), non-female sex workers and non-men-who-have-sex-with-men heterosexuals ($n = 10$). Allocation to categories was based on self-identification.

Clinic staff facilitated the identification and selection of prospective participants. In order to reduce bias, all individuals approached for the study were informed that their participation or refusal to participate in the study would not affect their treatment at the clinic. Screening, consent and interviews were conducted in the patient's own language by the principal investigator or research assistants. Participants were reimbursed 20 Ghanaian Cedi (approximately US$5) at the end of the interview.

A semi-structured interview guided the conversations. Leading questions and probes were designed to elicit narratives that could support, disconfirm or add complexity to concepts of resilience and coping, while also allowing participants to lead the conversation (Saddiq, Tolhurst, Lalloo, & Theobald, 2010). A first-draft interview guide was developed in English and then translated into the three main local non-English languages in Accra: Twi, Ga and Dagomba. The interview guide was vetted through pre-testing interviews conducted using proxy participants; based on pre-testing, the guide was adapted and enhanced for cultural appropriateness. Participants were first asked about their general experience as an HIV-positive individual as well as the circumstances surrounding their diagnosis. Subsequent questions then elicited specific and contextual narrative data regarding participants' experiences, beliefs and behaviours concerning their experiences linking to and engaging with care. Questions were asked such as "What motivates you to attend all of your appointments?" and "Has knowing that you are HIV-positive changed your life goals? How?" to probe participants about risk-resistant or resilience factors. We asked participants "What is it like to go to this clinic? Can you tell me how it was helpful? Can you tell me how it was not?" to ask about clinic-based environmental factors (see Appendix 1). The semi-structured format allowed participants to partially determine the order and flow of required domains of interest based on their own narratives. Each interview lasted about 60 minutes and was audiotaped with the patient's explicit permission.

Data interpretation and analysis was conducted following principles of thematic analysis (Braun & Clarke, 2006). Notes and memos were written during and after each interview to capture details of each participant's impressions and gestures, as well as other general observations of the conversation. All recorded interviews conducted in the local language were transcribed verbatim and then translated into English by the research assistant. Interviews conducted in English were translated and transcribed verbatim by the lead author. To protect participants' confidentiality, transcribers omitted all personally identifying information.

The data were subjected to standard qualitative techniques of analysis, specifically open coding of the entire data corpus, axial coding of selected codes, marginal remarks that elaborated on specific codes or passages, comparisons across codes, and memo-writing. Analysis began with descriptions, initially based on interviewer notes and memos, and augmented by transcript data from the individual interviews. Analysis was both deductive based on the Disability-Stress-Coping Model, and inductive based on emerging themes or concepts.

Study procedures were approved by the Ethical and Protocol Review committee of the College of Health Sciences at the University of Ghana (CHS-Et/M.8–P 4.4/2015-2016).

Results

Table 1 organises the main themes and subthemes for this analysis. Three major themes were identified in the qualitative interviews that characterise dimensions of resilience in this sample: (1) Holding positive attitudes towards the pathway from HIV testing and diagnosis to living with HIV; (2) placing appropriate levels of trust in the clinical care environment; (3) judicious disclosure of their HIV status to key individuals. Below we will elaborate more on the three main themes drawn from this sample.

Theme 1

The first theme identified was the ability to view HIV testing and diagnosis as key steps on the pathway toward healthy living with HIV. A common view held in the general community, recounted by many participants, was to regard HIV testing with great fear and to perceive HIV diagnosis as a "death sentence". Moreover, HIV testing is highly stigmatised in the general community due to its normative association with sex work, same-sex behaviour and substance use, all of which represent stigmatised acts and subgroups that many community members perceive as culpable for HIV transmission. For example, one participant reflected on the stigma commonly associated with HIV testing and diagnosis:

> *If you have HIV it means you are sex worker, you have multiple sex partners or you have travelled to Abidjan. So wherever you are found with HIV there is stigmatization. So I did not want to be stigmatized and so I did not want to go to the clinic [to get tested].* (Female sex worker, age 49 years)

Participants' narratives, such as the excerpt reported above, revealed a commonly held deficit-based perception of HIV testing in the general community in which HIV testing is done reactively to confirm a person's presumptive disease state. By contrast, an alternative resilience-focused approach to encourage proactive testing can overcome stigma and fear by promoting more positive attitudes towards the act of testing. Narratives in this sample evinced a more adaptive view of HIV testing and diagnosis – i.e. as steps that individuals can take in the direction of seeking care in order to improve long-term health. Below is a quote from a woman who regularly sought opportunities for HIV testing. She emphasized that frequent testing afforded her the opportunity to identify health-related issues with her body and therefore be better equipped to address the issue. As such, she tested regularly and was motivated to do so. She contrasted her approach to testing with others in the community who feared obtaining an HIV diagnosis. This

Table 1: Summary themes identified from HIV-positive men who have sex with men, female sex workers and heterosexuals: themes and subthemes with illustrative quotes

Major theme	Sub-themes	Representative quote
Positive attitudes towards the pathway from HIV testing and diagnosis to living with HIV	Ability to view HIV testing and diagnosis as key steps on the pathway towards healthy living with HIV	*If you have HIV it means you are sex worker, you have multiple sex partners or you have travelled to Abidjan. So wherever you are found with HIV there is stigmatisation. So I did not want to be stigmatised and so I did not want to go to the clinic [to get tested].*
		They [nurses] came around, they asked everyone to come and check [their HIV status] so that in case of anything they would see it early. Some of the ladies were afraid and said they would not go and do the check up because they might find something with their blood, but I have been advising them not to be afraid. But for me, anytime they came I went to have [the HIV testing] done.
		I think if 100 people [are asked], 92 people are scared of testing of this sickness…. I got the chance to test because I was OK [with it]. I was weak and cannot do anything, doctor gave the opportunity to do the test … so out of this I can see for you to test your HIV, its good … it is good for you to check and if they say you are having HIV positive … we have medicine although it cannot cure it, it can maybe increase your age.
		When I went for the test, initially, I was shocked but when I was transferred here I saw people who are worse than me so if I have HIV, it's not a big deal. And then they [the doctors] talked to me that if I am taking my drugs, as far as I do, I will live better and long, so I just forget that HIV is really a big deal. Then I just take my mind off HIV. I do my things as if I haven't gotten the HIV. I don't think about it at all and if it's time for me to come to the clinic, I report. When it's time to take my drugs, either in the morning or evening, I don't miss them. That simple!
Appropriate levels of trust in the clinical environment	Trust in clinical environment: insufficiencies of the care environment	*Now the doctors are limited. One doctor, two doctors, when they are many three or four.*
		When you come on clinic days, you could even come here very early but you might be the last person to leave here.
		If anything is going wrong with my body, they can see it. Someone might be there and something might be going wrong with the person but the person might not know. I want to come for my appointment so that in case something is going on wrong with me, the doctors will see it since I do not want to get sick.
		My life is in my hands and so I can keep it now by coming to my appointments and taking my drugs… I said earlier that I hold my life in my hands and I have been made aware now that the medicine is my life and so I cannot miss my dose.
		I've even come over to meet a friend who is lying down, very sick … he wasn't taking the medication and led to his death. So, I think, and I can see the doctor saw that he was closer to death. So this always push me when it is time for my appointment.
	Trust in clinical environment: medical staff	*When I got here (Korle Bu clinic), Aunty Anita [an HIV counsellor] has been so good to me, she has been calling, when I forget, when I started taking my medication, she and Aunty Edith have been calling me, talking to me, encouraging me, and sometimes if I'm confused and I'm all alone, I do think about negative things and negative thoughts about me and if I feel it's more over me, I pick up a phone, call Aunty Anita, and tell her what I'm going through, and she'll be like give me some words, quote me through the Bible and those things….*
		[Coming to the appointments] is very good because if you are want to live a long life then you are supposed to make the appointment dates all the time. If the doctor gives you an appointment date and you fail to come, you are killing yourself, not the doctor.
		So that if anything is going wrong with my body, they can see it because I love my life. Someone might be there and something might be going wrong with the person but the person might not know. I have a friend who was fat but when he was down with the disease now he is slim. I want to come for my appointment so that in case something is going on wrong with me the doctors will see it since I do not want to get sick to the point that I would be disgraced and also it is because I love my love.

continued on next page

Major theme	Sub-themes	Representative quote
	Trust in clinical environment: medication	*No, no, no, [I have] not even [missed] one dose. At all. If you miss it, you are going to start from day one again…. I mean if you miss one tablet today, you see the tablets doesn't kill the viruses, but they cover it somewhere, but if you haven't taken your tablets today, the tablets work for 12 hours and then it is done, the viruses come out again to eat within you so every day you are supposed to take your drugs.*
		My thought is to take the medicine – my medication serious and live long I know the drugs is my life…. Without the drugs I can't live for long so that's why I'm saying that.
		When I miss my dose which means I am denying myself of living. When I take the medicine at 8 o'clock in the morning, by evening time 8 o'clock in the evening the previous morning dose would have performed its function and needs more fuel to continue functioning and so I have to take it.
		At first they said there was no prevention, they don't give any, there was not any medicine that can … so people were scared of it … if you check and they say you are having HIV-positive that means you're leading to death. But right now we are having, God being so good, we are having some medicine although it cannot cure it, it doesn't cure it but it … it can maybe increase your age, the day that you're supposed to die, it will increase your age, it leads you to some place that you don't even think you'll be there, [uhm] if only you are on your drugs [uhm], taking it according to the doctor's instruction [uhm], I think you are ok with that, I think….
		My life is in my hands and so I can keep it now by coming to my appointments and taking my drugs…. I said earlier that I hold my life in my hands and I have been made aware now that the medicine is my life and so I cannot miss my dose.
		I've even come over to meet a friend who is lying down, very sick … he wasn't taking the medication … something like alcohol and smoking and those things, [he was not] avoiding … [and led to his] death. So, I think, and I can see the doctor saw that he was closer to death. So [the death of my friend] always push me when it is time for my appointment
		When I came to the hospital, they told me to stop it (herbal medicines) and not take it. Yes, I was taking it before…. I was taking it because of how I felt when the illness started and so people asked me to go in (to see the herbalist) for that. I was having headache, boils all over and waist pains and I was becoming slim too…. I went [to the herbalists] on my own that day. He did nothing, I just bought the drug [he had] … the drug was a syrup…. I took it twice a day. [The syrup] helped me initially but it got worse that is why I came here [Korle Bu].
		I have a lot of things going on like with work, with business, something that I want to achieve in life. I realise that without taking my medication I couldn't be put to feel healthy to go through all this. So I'm in as much as I want to be healthy and to be able to achieve my dreams in life and live a fulfilled life, I have to take my medication to be able to lead a fulfilled life.
Resilience-promotive factors specific to stigmatised individuals	Disclosure and support: heterosexuals/potential resilience achieved through disclosure to significant others	*From the time that I got diagnosed with this disease, I really didn't have this serious stigmatization because my parents and my sisters were really really supportive and they really helped me through everything. They have been still helping me through everything, even buying my drugs and everything…I have many siblings like seven … each and every one of them knows [and] my cousins who are also having the same sickness they know about it.*
	Disclosure and support: men who have sex with men and female sex workers/Creation of support network	*When I first met [names of peers], I felt like crying and [they] advised me to stop crying because [they have] had this illness also for long. [They] told me that we should all come together and be one and look for medicine to help out.*
		Only my friends know my status. No one [in my family] knows, even my children are not aware…. [I keep it from them because] I do not know what would happen when I tell them … it might bring about maltreatment and also will not accord you the respect due you and even prevent you from coming to the crowd.
		As for my dad, he was mad because of one or two things, my behaviour [homosexuality] was, how my behaviour was doing there, once I got myself into … that's why my dad was mad at me and was not ready to [accept my homosexuality] … up to now he even says that [I am HIV-positive] because of the behaviour I'm in, he doesn't even want stand at a place and [declare] that I'm even his son.

woman emphasised to her peers the benefit of receiving an earlier HIV diagnosis:

> *They [nurses] came around, they asked everyone to come and check [their HIV status] so that in case of anything they would see it early. Some of the ladies were afraid and said they would not go and do the check-up because they might find something with their blood, but I have been advising them not to be afraid. But for me, anytime they came I went to have [the HIV testing] done.* (Female sex worker, age 32 years)

Another participant viewed testing as a way to optimise wellness and promote longevity. Although she conceptualised that individuals may fear testing, this participant viewed testing as "good" and an opportunity to check for illness. Furthermore, by shifting her focus from worrying about the consequences of being HIV-positive (that is, catastrophising the results) to identifying health issues and treatment methods to improve health, she appeared better equipped to carry out the necessary tasks for treatment:

> *I think if 100 people [are asked], 92 people are scared of testing of this sickness…. I got the chance to test, doctor gave the opportunity to do the test … so out of this I can see for you to test your HIV, its good … it is good for you to check and if they say you are having HIV positive … we have medicine although it cannot cure it, it can maybe increase your age* (Heterosexual female, age 23 years).

Theme 2

A second theme was related to resilience regarded placing appropriate (but not absolute) levels of trust in the clinical environment, including the health systems in general and relationships with health providers. Importantly, participants acknowledged and expressed criticism regarding aspects of the care environment – including crowding, waiting times and limited staff – but differentiated structural issues from their interactions with providers. Below, participants reflected on insufficiencies of the care environment:

> *Now the doctors are limited. One doctor, two doctors, when they are many three or four* (Heterosexual male, age 55 years).
>
> *When you come on clinic days, you could even come here very early but you might be the last person to leave here* (Heterosexual female, age 28 years).

Nonetheless, we observed that participants valued their interactions with medical staff, whom they held in high esteem. Having a strong relationship with providers, including clinic nurses and HIV doctors, was important to participants' wellness and adherence to treatment recommendations. Because of having adaptive interpersonal dynamics with providers, patients described being better able to adhere to treatment advice and recommendations. We observed positive motivations derived from personal contact with medical staff and trust in their capability to address clinical concerns:

> *When I got here [name of clinic], Aunty Anita [an HIV counsellor] has been so good to me. She has been calling when I forget, when I started taking my medication. She and Aunty Edith have been calling me, talking to me, encouraging me, and sometimes if I'm confused and I'm all alone, I do think about negative things and negative thoughts about me and if I feel it's more over me, I pick up a phone, call Aunty Anita, and tell her what I'm going through, and she'll be like give me some words, quote me through the Bible and those things….* (Man who has sex with men, age 33 years)
>
> *If anything is going wrong with my body, they can see it. Someone might be there and something might be going wrong with the person but the person might not know. I want to come for my appointment so that in case something is going on wrong with me, the doctors will see it since I do not want to get sick.* (Man who has sex with men, age 42 years)

In addition to having trust in their providers, participants expressed confidence in the effectiveness of their HIV medications, a factor that contributed to adherence. While all participants understood that there was no cure for HIV, participants acknowledged that taking their doses on time would help to combat the virus and reduce disease progression:

> *My thought is to take the medicine serious and live long. I know the drugs is my life. Without the drugs I can't live for long so that's why I'm saying that.* (Man who has sex with men, age 21 years)
>
> *When I miss my dose which means I am denying myself of living. When I take the medicine at 8 o'clock in the morning, by evening time 8 o'clock in the evening the previous morning dose would have performed its function and needs more fuel to continue functioning and so I have to take it.* (Heterosexual female, age 48 years)

Notably, participants reflected on the personally empowering value of HIV medications, which conferred on them the perception of having control over their health and quality of life. For example, participants noted the empowering nature of medication adherence:

> *My life is in my hands and so I can keep it now by coming to my appointments and taking my drugs…. I said earlier that I hold my life in my hands and I have been made aware now that the medicine is my life and so I cannot miss my dose.*
>
> *I have a lot of things going on like with work, with business, something that I want to achieve in life. I realise that without taking my medication I couldn't be put to feel healthy to go through all this. So I'm in as much as I want to be healthy and to be able to achieve my dreams in life and live a fulfilled life, I have to take my medication to be able to lead a fulfilled life.* (Heterosexual male, age 65 years)

Linked to this sense of trust in medication was knowledge concerning the consequences of not taking medications. Many participants recalled friends or loved ones who had experienced rapid disease progression or death due to limited access or medication non-adherence. Thus, the personal value for medications was based on first-hand awareness of the deleterious effects of treatment barriers:

> *I've even come over to meet a friend who is lying down, very sick … he wasn't taking the medication and led to his death. So, I think, and I can see the*

doctor saw that he was closer to death. So this always push me when it is time for my appointment. (Heterosexual female, age 43 years)

Theme 3

Disclosure of HIV serostatus is a very complicated process for HIV-positive patients. Due to the highly stigmatised nature of HIV infection, people living with HIV often choose not to disclose their status in order to protect themselves from prejudice and discrimination. Despite these deterrents, participants in the sample expressed the potential resilience achieved through disclosing their status to significant others. Through selective disclosure to family and peers, they were able to elicit external support and achieve improved psychosocial outcomes:

From the time that I got diagnosed with this disease, I really didn't have this serious stigmatisation because my parents and my sisters were really, really supportive and they really helped me through everything. They have been still helping me through everything, even buying my drugs and everything…. I have many siblings like seven … each and every one of them knows [and] my cousins who are also having the same sickness they know about it. (Heterosexual female, age 30 years)

However, disclosure challenges were more complicated among men who have sex with men and female sex workers due to stigmas related to sexual orientation and sex work – which are acts and identities that violate local norms and moral codes. Unlike their heterosexual counterparts, men who have sex with men and female sex workers expressed fear and anticipated abuse due to disclosing their HIV status. For example, one participant recounted the following:

As for my dad, he was mad because of one or two things, my behaviour [homosexuality] was, how my behaviour was doing there, once I got myself into … that's why my dad was mad at me and was not ready to [accept my homosexuality] … up to now he even says that [I am HIV-positive] because of the behaviour I'm in, he doesn't even want stand at a place and [declare] that I'm even his son. (Man who has sex with men, age 19 years)

Thus, narratives revealed that resilience was derived from selective and judicious disclosure to others who could provide non-judgemental support and affirmation, and discretion around those who would ascribe moral judgements and place blame on individuals for their HIV infection.

Discussion

Guided by the Disability-Stress-Coping Model of Adjustment framework, this article seeks to describe how stresses associated with living with HIV in a low-resource setting can be buffered through resilience-promoting factors. We found this proposition to have support among people living with HIV in Ghana, where a sample of highly adherent individuals described health-promotive factors that enabled them to adhere to the care continuum and experience positive health outcomes. Specifically, we found three individual-level resilience-promoting factors, which included (1) reframing HIV testing/diagnosis as a key step along the pathway to care and wellness, (2) placing appropriate levels of trust in health providers (while still acknowledging and criticising problems in the healthcare system), (3) exercising HIV status disclosure judiciously to others who can provide support and affirmation. Given these observations, it is important that studies further consider the role of resilience-promotive factors that support health engagement and clinical wellness among people living with HIV.

Findings from this qualitative study of people living with HIV in Ghana provided support for the application of Wallander and Varni's Disability-Stress-Coping (1992) model in general, as well as the use of a resilience framework in particular, for understanding strategies to bring about successful HIV treatment programmes in low-resource settings. Specifically, the three factors identified in this study corresponded with stress-processing factors identified by Wallander and Varni's model as predictors of coping/resilience abilities. As explained in the Wallander and Varni model, we found that for people living with HIV these stress-processing resilience factors can moderate or influence people's ability to remain resilient, as demonstrated through actions such as remaining in care and adhering to treatment. This study cannot provide specific details regarding the development, intersections and interactions between these resilience factors, or regarding the impact of these factors on health outcomes over time. Moreover, due to the study design, the study cannot differentiate health outcomes based on the presence or absence of specific resilience factors.

Our study suggests that, in addition to the individual-level resilience factors described by participants, the clinical environment plays an important factor in promoting resilience and wellness – in particular, the role of trust between the patient and the medical staff. Patients who remained in the care continuum did so, in part, due to their deep trust in providers, which included primary doctors, nurses and specialists providing HIV care. Patients tended to engage with and adhere to treatment out of a strong desire to maintain healthy outcomes and based on support from their providers. However, because participants were recruited from two specific clinics that had a reputation for providing competent care, it is unknown whether patient trust in health providers would be adaptive in less competent care environments.

While patients' trust in HIV medications was observed as being important to promoting resilience, there can be potential drawbacks. Over time, some patients might develop drug resistance, adverse side effects, or co-morbid infections, which can compromise trust in HIV medications and erode resilience-related outcomes. To safeguard against this possibility, it is important that resilience-based interventions educate participants regarding the potential inadequacies of the medication as the disease progresses.

As seen in previous work, our study highlights how disclosure and social support contribute to engagement in care and wellness (Betancourt et al., 2013; Earnshaw, Bogart, Dovidio, & Williams, 2013). As noted, disclosure must be exercised with caution – especially for men who have sex with men, female sex workers and other stigmatised populations that might be blamed or retaliated against for their HIV status. Also, specific types of social

support can have more instrumental consequences for HIV outcomes, such as encouragement to remain adherent, money for medication and transport to the clinic. Therefore, resilience-focused interventions that promote disclosure and social support must be grounded in the ecological resources and actual types of support that individuals can take advantage of.

There are practical implications of these findings. Resilience-focused interventions can take the form of one-on-one health education to help individuals reframe HIV testing, diagnosis and care as personally empowering opportunities to exercise agency, prolong life, and engage with family and peers. Resilience training may also be offered in peer-led group sessions, where highly adherent patients can support newly diagnosed peers with coping and navigating the healthcare system. For men who have sex with men and female sex workers, resilience training sessions should incorporate disclosure tips to help elicit support from trusted family and friends. Early resilience training can be crucial for newly diagnosed people living with HIV, as many default during the testing and linkage stage and are difficult to retain in the care continuum.

There are several limitations to this study. The study was conducted at two well-resourced infectious disease clinics and therefore findings cannot be generalised to other populations. Even though we sought to enhance diversity within the sample (including men who have sex with men, female sex workers, and non-female-sex-worker heterosexuals), a more varied and larger population could add further complexity to this subject. It is important to note that we selected for highly adherent patients in order to focus on relatively "successful" patients; this sampling strategy was purposive by design and prone to selection bias. Findings reported here might not be applicable to explain resilience among those who do not engage in care yet evince positive health outcomes, or to those who engage in care at less-resourced clinic environments. Although the main findings identified resilience-promotive factors at the individual level, resilience can also be derived from community, environmental and structural resources; more focused research is needed to clarify whether and what types of extra-individual resources promote resilience among people living with HIV. We also understand that there are multiple socioeconomic factors such as age, poverty level, relationship status or family environments that may have influenced the experiences of resilience in this population, which were not examined directly in this study. It is important that future research investigates how these factors affect resilience in low-resource settings such as Ghana.

In conclusion, resilience-focused research and interventions can provide important insights into promoting wellness and positive health outcomes among people living with HIV. Resilience-focused perspectives on HIV can be particularly relevant in Ghana and elsewhere in sub-Saharan Africa. Multiple study designs including further qualitative research, quantitative surveys and longitudinal designs may be useful in order to inform the development of resilience-based interventions for people living with HIV, which can be tested in clinical trials. Applications of a resilience framework to HIV prevention interventions (e.g. pre-exposure prophylaxis, microbicides and behavioural risk reduction) can also be relevant for Ghana. Samples that are used in future studies should also consider a wider breadth of diversity and should explore resilience factors that are common across groups as well as those that are specific to subgroups. These stratifications would allow public health officials to demarcate more specific resilience factors as they relate to stages of the HIV care continuum and population socio-demographic characteristics.

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Appendix 1: Interview question guide

Introduction

My name is Chantal Lewis and I am a student from Brown in the United States. I am meeting with you as a follow-up to a recruitment interview that you completed while you were in the waiting room. You said then you are willing to have more of a conversation about your experience as a HIV-positive patient.

Are you still willing to help us out?

(*If yes*) *Proceed with informed consent statement*

(*If no*) My team and I will be in town for the next couple of months. May I approach you after your appointment so we can talk?

If yes When will be a good time today?

If no Is that because:

[ ] you do not wish to participate in an interview?

[ ] another reason?

If unable to proceed, please go to closing statement.

Informed consent

Read informed consent

Do you have any questions or concerns?

Recruitment verification questions

To get started, I would like to verify that you have received a positive HIV-test result in the last 6 months. I would also like to confirm that you are a patient of the Korle Bu HIV clinic. Is that correct?

If yes: *Continue with next question*

If no: I tested more than 6 months ago.

I do not receive care here at the KBTH *[Continue to closing remarks]*

1) *Grand Tour*: Learning about your experiences as an HIV positive patient is important to us. Could you describe to me how you came to learn that you were HIV positive, and what happened after that?

If no Perhaps we can start with something that you feel comfortable sharing with me? Can you please describe to me the events that led up to your diagnosis? What made you decide to get tested for the disease?

Thinking back to the time you got diagnosed, what did you know about HIV? Can you share some of your thoughts once you heard the news and what you did in the week after that?

2) Outside of the doctors and nurses here does anyone else know about your status? Can you tell me the story of how they found out?

Can you tell me a time when you had good support from _____? Perhaps not so good support?

If went to church- You had mention that you had a church family. Do they know about your status? Have the church provided support? If so can you tell me about?

Thank you for sharing with me those memories. I will now like to talk about your current experience.

3) Please tell me how you manage your HIV-care?

What is it like to go to this clinic? Can you tell me how it was helpful? Can you tell me it was not?

Does (*person from general social support)* _____ help you with your HIV-care?

Was this always the case since your diagnosis?

How often do you come to the clinic?

What motivates you to attend all of your appointments?

You mentioned before that _____ was hard for you in the beginning. How you were able to get pass this?

Can you tell me a story how you managed to still make your appointment even though _____happened?

Why is making your appointment important to you?

Can you tell me about an example when you missed your appointment? Why did you miss it? Is that the only reason you miss it?

4) Looking back is there anything that the clinic could have done to help you to make your appointment?

5) Now, I would like to discuss the circumstances surrounding your HIV medication. Did the doctor prescribe any HIV-medication at the time you found out you were HIV positive?

[ ] No*: move on to next question*

Is there a reason you for you have not been prescribed medication?

[ ] Yes

Some HIV-positive patients tell me different reasons as to why they take their medication most of the time or all of the time. Why do you take your medication?
Can you think of a time when you almost missed a dose?
[ ] No: *move to next question*
[ ] Yes
What happened? Why did you change your mind?
Is there a reason why you miss some of the doses?
What do you think the doctors or clinic can do to make it easier for you stay committed to taking your medication?

6) Has knowing that you are HIV-positive changed your life goals? How?
Why did your goals changed since your diagnosis?
Can you tell me about your story? Have you experienced any significant life changes since your diagnosis? What went well and what could have gone better?
How as your life goals changed since your diagnosis? Stories such as what positive changes or negative changes that have occurred will help us to understand how improvements to HIV-care management can be made.
Was there a time where you felt as if you were not able to achieve your goals? Or were you even more motivated to accomplish them?

7) Some people think that one's attitude makes a big difference in living a good and happy life despite having HIV. Do you think that your attitude makes a difference?

8) Thinking back to when you were first diagnosed, how have your attitudes changed?

Thank you once again for providing me all those details. Now I would like to discuss your current health practices.

9) Can you give me some examples of things you do to stay healthy?
And why you do them?
Are these the same as before your diagnosis? Did they improve or worsen?
How has the clinic helped with this?
Can the clinic do anything better to encourage more healthy behavioral practices?

Thank you for your help so far. For this portion of our conversation I would like to talk a little more about you and how you perceive your future as a HIV-patient.

10) Are there many people in your community with HIV?
What are your thoughts on the spread of HIV in your community?
Knowing what you know now about the disease, what advice would you give to others about it?
How can they remain strong with HIV?

Demographics
To wrap up, there are a few questions that I have to ask everyone we interview.
In terms of sexual partners, do you prefer to be with a man or a woman or both?
[ ] Homosexual
[ ] Heterosexual
How old are you?
If offer valid age enter here _____
If not move to next question
Is the Korle Bu Teaching Hospital your primary care clinic?
If yes: move to next question.
If no: Where is your current primary care facilities? _____
Revisit this with question 1B

Conclusion
We are near the end; you have been very helpful
"Is there anything else you would like to tell me about your experience in the last few months?"
"Is there anything I should have asked that I didn't?"
What do health professionals most need to know about patients with HIV?
Closing statement: (*adjust for ineligible participants)* Thank you for taking the time to speak with me today. Your experiences will help us to educate health professionals and to improve care of persons at the end of life