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Spirituality, social capital and service: Factors promoting resilience among Expert Patients living with HIV in Ethiopia

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Abstract

People living with HIV (PLHIV) in Ethiopia and other developing nations face numerous challenges to their health and well-being, including poverty, limited healthcare infrastructure, and high levels of societal stigma. Despite these challenges, resilient trajectories have been observed even within such resource-limited settings. In Ethiopia, such resilience is exemplified by the ‘Expert Patients’, HIV-positive lay health workers who function as adherence counsellors, health educators, outreach workers and community advocates. We conducted a multi-method qualitative study with 20 Expert Patients in Addis Ababa, Ethiopia in order to understand pathways to resilience in this select population. Participants described 3 key mechanisms of resilient coping: (1) The use of spirituality and faith-based practices to manage psychological difficulties associated with living with HIV; (2) Utilisation of social capital from family and community networks as a buffer against the psychological and economic consequences of societal stigma; and (3) Serving others as a mechanism for finding optimism and purpose in life. Interventions designed to facilitate and/or augment these social processes in the wider community may be promising strategies for improving health among PLHIV in Ethiopia and other resource-limited settings.

Keywords

Ethiopia; peer educators; HIV/AIDS; resilience; social capital

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Introduction

An estimated 1.2 million people are currently living with HIV/AIDS in Ethiopia (World Health Organization, 2013). In addition to the direct physiologic damage resulting from HIV infection, people living with HIV (PLHIV) in Ethiopia face multiple social challenges to their health and well-being, including poverty, limited healthcare infrastructure, and societal stigma and discrimination (Oxford Poverty and Human Development Initiative, 2013; Kloos, Converse, Mesfin, Hailemariam, & Assefa, 2010). These socioeconomic and cultural factors often act as barriers to engagement in HIV care, increase strain on the support networks of PLHIV, and ultimately have adverse impacts on mental and physical health (Maes, Shifferaw, Hadley, & Tesfaye, 2011; Lifson et al., 2013; Biadgilign, Deribew, Amberbir, & Deribe, 2009). In spite of these complex and potentially synergistic barriers to healthy living, however, many Ethiopian PLHIV are successfully maintaining adherence to antiretroviral therapy (ART), engaging regularly in HIV care, and enjoying an improved quality of life (Asfawesen et al., 2011; Okello, Stuer, Kidane, & Wube, 2013).

Research from Ethiopia and worldwide shows that barriers to the well-being of PLHIV have received comparatively more academic attention than facilitators of health. In contrast to traditional public health and biomedical paradigms that focus on disease and risk factors, research focused on resilience, defined as positive adaptation in the context of adversity, seeks instead to understand social processes that facilitate healthy coping (Almedom, 2005; Luthar, Cicchetti, & Becker, 2000). One practical application of resilience research is the positive deviance approach, which seeks to identify culturally grounded and sustainable solutions to health problems by identifying and observing the practices of ‘positive deviants’, outliers who achieve optimal outcomes in spite of significant challenges (Marsh, Schroeder, Dearden, Sternin, & Sternin, 2004). The goal of such work is to later disseminate these health-creating practices to wider populations and in so doing, improve outcomes at a community level.

Resilience in the context of the Ethiopian HIV epidemic is exemplified by the ‘Expert Patients’ (EPTs) working in clinics and hospitals around the country. The EPTs are HIV-positive lay health workers who function as adherence counsellors, health educators, outreach workers and often community advocates for other patients living with HIV (Gusdal et al., 2011). In order to serve these functions, the EPTs must maintain their own physical health, possess substantial understanding of the disease process, and disclose their HIV status many times daily during interactions with other patients and the community. The EPTs are selected through competitive processes based on their ability to fulfil these roles, and thus represent a unique and particularly well-adapted subset of PLHIV in Ethiopia, who can be viewed as a pre-selected group of positive deviants. Utilising positive deviance as our theoretical framework, the objective of this study was to gain an understanding of the social processes influencing resilience among a group of Ethiopian EPTs.

Methods

Study context

We conducted our study at the All-Africa Leprosy, Tuberculosis and Rehabilitation Training Centre (ALERT), a government hospital located in Addis Ababa, the capital city of Ethiopia. The outpatient HIV clinics and inpatient wards at ALERT provide care for over 13,000 HIV-infected men, women and children. Antiretroviral therapy (ART) and related medications are provided free of charge through government programmes.

Study design

This analysis is derived from a multi-method qualitative study designed to explore the lived experiences and resilience of the ALERT EPTs. Data collection took place over a month period in May-July 2012. The study involved in-depth interviews with each participant, Photovoice sessions and accompanying group discussions, and direct participant observations. We utilised multiple methodologies to provide additional context and confirmation of our findings (Morse & Field, 1995). Such multi-method triangulation has been described as a way to increase the internal validity of qualitative studies (Maxwell, 2013; Farmer, Robinson, Elliott, & Eyles, 2006).

In-depth interviews—The in-depth interviews comprised the core of the study and are the source of the majority of the qualitative data. The semi-structured interview guide included seven major domains as well as a list of optional probes to facilitate thoughtful discussion responses to the questions. Interview domains included: 1) Background and childhood; 2) HIV/AIDS Diagnosis; 3) Living with HIV/AIDS; 4) Stress and Coping; 5) Social Networks and Social Support; 6) Religion; and 7) Program ALERT. Two trained Ethiopian MPH-level interviewers (one male and one female) conducted and digitally recorded the interviews in Amharic. At least two additional study team members served as observers in each session. Interviews lasted between 40 minutes and 3 hours. After each interview, study team members debriefed to discuss emergent themes, which were incorporated into subsequent interviews in an iterative manner. Three participants were asked to return for a brief second interview to follow up on issues needing further clarification. All interviews were subsequently transcribed in Amharic and translated into English by a professional service.

Photovoice—Photovoice is a participatory action research methodology in which participants take pictures documenting strengths and needs in their communities, and later reflect on these photographs in group discussions (Wang & Burris, 1997). The Photovoice project took place over a three-week period after the individual interviews were completed. We provided digital cameras and instructed participants to take pictures representing their lives in the home, at work and in the community. Participants selected photos for group discussions, which were led by one of two co-authors (MT and MGA) who are Ethiopian physicians at ALERT, while another author (SAH) observed the group and recorded field notes. Although the photographs are not utilised in this particular analysis, themes and individual participant contributions were taken from field notes of the group discussions and included in our findings below.

Direct participant observations—Direct participant observations involve the presence of a researcher witnessing events and activities of interest, and systematically documenting behaviours, nonverbal cues and events in the form of field notes (Bogdewic, 1999). For this study, direct participant observations primarily took place at ALERT and served to enhance our understanding of the EPTs functions in the hospital setting. There were also several observations done in the community to observe EPTs in home and organisational settings. In each of these instances, SAH recorded field notes, which were incorporated into the final qualitative dataset.

Demographic questionnaire—All participants completed a brief written demographic survey to document: age, gender, hometown, ethnicity, religious affiliation, marital status, educational level, years since HIV diagnosis, and years working as an EPT.

Recruitment and informed consent

At the time of study initiation, 20 EPTs were employed at ALERT. All of the EPTs were invited to an informational meeting in which the entire research team was present to introduce themselves and describe their roles in the study. The details of study participation were explained fully in both English and Amharic (the official language of Ethiopia). The EPTs were informed that they had the option to participate in any part of the study, all parts, or none at all. Participants were compensated 150 Ethiopian *birr* per day of active study participation for a total of 1650 *birr*. This rate was comparable to compensation for other overtime work-related activities. Written informed consent was obtained from each of the participants. The Emory University Institutional Review Board and the ALERT/Armauer Hansen Research Institute (AHRI) Ethical Clearance Committee approved the protocol.

Thematic analysis

All transcripts and field notes were imported into MaxQDA (VERBI software, Berlin, Germany), a qualitative data management software package. The major steps of our thematic analysis involved data processing, code development, and elicitation and refinement of themes and thematic relationships that emerged through this process (Braun & Clarke, 2006). Two authors (SAH and DG) developed and refined a qualitative codebook using the following process. First, these two analysts read through two transcripts together and identified and defined salient concepts as preliminary codes. Subsequently, a subset ($n=6$, 30%) of the interview transcripts were coded in parallel and compared. Disagreements led to further discussion and refinement of the attributes and dimensions of the codes. Once code definitions were refined such that both analysts were able to apply the codes with little disagreement, each analyst independently coded all 20 interview transcripts to ensure reliability and sensitivity of coding. Field notes from Photovoice discussion sessions and direct observations were coded by SAH, who also wrote in-depth analytic memos comprising case summaries for each participant.

Results

Characteristics of study participants

All 20 EPTs agreed to participate and completed all phases of the study. The sample was predominantly female (95%) and Christian (60% Ethiopian Orthodox, 35% Protestant), and the majority (85%) was of Amhara ethnicity (see Table 1 for further demographic characteristics). Although the study was based in Addis Ababa, participants were born and raised in many different parts of Ethiopia. Only 30% described themselves as natives of Addis Ababa; others had migrated from rural areas in search of economic and/or educational opportunities.

Sources of resilience

All 20 participants described resilient life histories in which they overcame adversity and were now living more peaceful and stable lives than previously. Our analysis led to the identification of three key social processes that helped participants to cope successfully with the pervasive stressors associated with living with HIV in a resource-limited setting. First, they described the use of spirituality and faith-based practices to manage the psychological difficulties associated with living with HIV. Secondly, they described the utilisation of social capital from family and community networks as a buffer against the psychological and economic consequences of societal stigma. Lastly, participants described the ways in which service to others helped them to find new purpose and optimism in life.

Spirituality and faith-based practices—All of our participants, the majority of whom were Ethiopian Orthodox Christians, endorsed religion as an important component of their lives and worldviews. Prayer, personal faith in God, and relationships with spiritual leaders and fellow worshippers were cited as sources of hope and comfort, aiding psychological adjustment while living with HIV. Although participants cited religion as important in their lives more generally, religion appeared much more prominent in their life narratives after HIV diagnosis than before, and it seemed especially important in the period immediately following receipt of an HIV diagnosis.

One of the most frequently cited religious experiences was the pilgrimage to certain large Ethiopian Orthodox churches for *tsabel* (holy water) treatments. *Tsabel* is used in a variety of ways as prescribed by religious officials; it can either be drunk or used externally for washing or baptism. The use of *tsabel* predates HIV and is used for a variety of ailments; however, from our participants' narratives it appeared that the majority of pilgrims they encountered in the *tsabel* sites were HIV-positive. Over half of our participants detailed *tsabel* treatments as an integral part of their journey with HIV, as most of them sought these treatments almost immediately after receiving their HIV diagnosis. For many participants, the *tsabel* was a residential experience, in which they lived on church grounds for months to years. While living at these sites, they followed rigorous prescriptions of fasting and prayer, and drank copious amounts (up to five litres daily) of *tsabel* in hopes of curing HIV and/or related symptoms. Others travelled daily or weekly to be baptised with *tsabel*, but did not take up residence at the sites.

The experience of going to the church and taking the *tsabel* contributed to participants' lives by providing a sense of inner calm and hope for the future. Some of this hopefulness was derived from a belief that the *tsabel* experience led to physical cure. In fact, several participants in the group discussions related that they were continuing to receive *tsabel* on occasion, while also taking ART, in hopes that their HIV would be cured. Prayer and reflection that accompanied the *tsabel* were also described as being therapeutic and helping participants to feel more at peace. Additionally, social bonds formed with other PLHIV at the churches provided critical emotional support. These various benefits of the *tsabel* experience, and religion more generally, are illustrated in the passage below:

[Religion] has a very important place [in my life]. I think it was religion that helped me recover. I feel more comforted praying/talking and pouring my heart out to God than to people trying to counsel and advise me. When I tell God, I feel I get a response there and then. There is something behind me that tells me to be strong, saying that having the virus is not the end of life. That was what revived my hope. It is not only that you have drunk and gotten cured by the holy water. The fact that it relieves you from all the bad thoughts you have in your mind shows you that religion has a very important role. It gives you an adequate response to the questions you have in your mind, which people wouldn't be able to address. You get many friends at the holy water. Many people are capable of keeping your secrets and I also learned to keep their secrets they confided in me as well. Then I did everything I should to fulfil all religious matters and finally got much better. (Mahletⁱ, age 30)

Despite extolling the benefits of faith and spirituality in their own lives, many of the EPTs simultaneously cited religion in general, and *tsabel* more specifically, as being significant barriers to care for the patients they counselled. For some of these patients, faith-based and biomedical perspectives were irreconcilable, leading them to choose religion over medicine and ultimately become non-adherent to ART, as described below:

[Some patients] stop taking the medicine due to religion. Some religious institutions teach them not to take the medicine and instead to look for the blessings of God. I also know that this happens in different religious institutions. But currently, these people who are working in these religious institutions are getting education. They did not have knowledge. Therefore, due to fasting they don't take medicine regularly (Hiwot, age 35).

In contrast, the EPTs explicitly integrated their faith-based and biomedical health care practices into their own daily lives, as described here:

I think there is no problem if the holy water and medicine are used/taken simultaneously. I think there is nothing wrong if I keep my faith and at the same time take my medicine. I can even take my medicine while fasting. I can even take my medicine with little holy water and continue fasting until 3 o'clock or 4 o'clock in the afternoon (Meskerem, age 30).

ⁱIn the interest of protecting participant confidentiality, all names used here are pseudonyms.

For some, the experience of taking and adhering to ART was not only integrated into daily religious rituals, but also integrated into the conceptual orientation towards spirituality.

I used to believe science and faith are to be taken separately. But now I understand that they are one and the same. They are both medicines that help you a lot. My faith is in God ultimately. I take the holy water and take the medicine. I never want to miss the time I take my medicine. I believe it is God that allows the preparation of the medicine too. I have medicine and I don't interrupt the medicine to go to the church or to the holy water. I consider the medicine as something sacred (Mahlet, age 30).

The difference between the EPTs and their patients was therefore not the degree of religiosity, but the ability to integrate faith-based and biomedical practices as complementary treatments for their HIV.

Social capital—All of the EPTs described the importance of their social networks to their ability to cope with the challenges of living with HIV. These discussions evoked the idea of *social capital*, defined here as the sum of an individual's resource-containing, reciprocal, and trustworthy social network connections (Chen, Stanton, Gong, Fang, & Li, 2009). Approximately half of our sample drew primarily on social capital from pre-existing familial relationships to help them cope with HIV. Analysis of these participants' life histories showed that they were all well-embedded in a close network of immediate family members when they first received their HIV diagnosis. Upon hearing of their diagnoses, these participants' relatives were immediately supportive, providing a buffer against stigma and its sequelae via both emotional support and tangible aid. For the other half of our participants, however, family networks did not provide significant social capital. For some, stigma eroded pre-HIV social relationships when relatives discriminated against participants or even forced them to leave their familial homes after learning of their diagnoses. Others simply did not have strong family connections because their parents or siblings were living far away (as in the case of many who had migrated from rural areas) or were deceased. When family was absent, participants used social capital derived from new social networks that were largely based on their new HIV-positive identity. The following representative case histories from Tigist and Saba illustrate family-derived and community-derived social capital, respectively, as mediators of resilience and buffers against stigma and poverty.

Case 1: Tigist (Family-derived social capital): Tigist, age 30, was born and raised in Addis Ababa. She grew up in a “low economic situation”, with a loving and supportive nuclear family including both parents and several younger siblings. Her father passed away when she was in the eleventh grade—after which time she had to help her mother shoulder the responsibility of providing for her siblings. She dropped out of school to help her mother sell injera (a type of bread that is the staple of the Ethiopian diet) and soon entered into an arranged marriage, in part to help improve her family's finances. Her husband died several years later, leaving her again in the position of finding an income to help support her family. Like many participants, she tried to emigrate to the Middle East to work as a housemaid and send money back to her family. An HIV test was a requirement for her visa application, and she tested positive, becoming aware of her status for the first time. She became depressed

and isolated herself from friends and social gatherings over the next two years, fearing stigma that was known to be widespread in the community. However, she disclosed the results immediately to her family, all of whom were supportive throughout. She was particularly appreciative as she described one brother who repeatedly sought out HIV-related information and support services for her, even though he knew that these actions might cause others to suspect that he was HIV-positive himself. Armed with this information and her family's encouragement, she was eventually convinced to join an HIV service and advocacy organisation in their locality. She was subsequently linked to HIV care services at ALERT and started on ART, and she continues to be adherent to her medications with the support of her family.

Tigist's story illustrates several key points that also characterised other EPTs with predominantly family-derived social capital. Her familial relationships are close ties featuring reciprocity and mutual support; she sacrificed her education to provide for her family when she was younger, but her family provided care for her after her diagnosis. Her family members provided emotional support to help her cope with the psychological effects of HIV and the associated perceived stigma and social isolation. They also provided food and shelter, shielding her from the potential effects of discrimination on food and housing security and making her illness more manageable. Her family network supported her completely for two years and helped her to find the NGO, which provided a complementary support network. All of our participants were involved in NGOs in their community, but the centrality of these non-family networks in participants' lives varied depending on the availability of family support.

Case 2: Saba (Community-derived social capital): Saba, age 33, was born in a rural village in eastern Ethiopia. Her father died when she was an infant, and her mother did not have means to support her, so she was raised by her grandmother and later sent to Addis Ababa to live with an aunt while attending secondary school. Saba describes each of these homes as economically depressed settings in which she was required to do a lot of household labour, compromising her ability to study. When she did not pass the college entrance exams, she temporarily lived with some friends who encouraged her to get married for improved financial stability. She agreed to marry her first husband, an older man whom she did not know previously; he died nine months into their marriage. After his death, she became ill herself. In this period, she describes discrimination from her neighbours, who were suspicious that she might have HIV and often gossiped about her. Having no support, she made the pilgrimage to Entoto Mariam for tsabel treatments. While living there, she became friends with many PLHIV who encouraged her to get tested, leading her to learn her HIV-positive status. She described the situation at Entoto Mariam as follows:

[My house there] was very small like a chicken house and I paid 40 birr per month for rent, but I was very happy. I have never slept without food even though I had no one to bring me food everyday. We used to share what we have. It was good. Although I had nothing, I was happy.

She lived there for two years, then returned to Addis Ababa and eked out a living selling injera; most of her patrons were friends. She continued to get weaker, and a friend who

knew her status convinced her to go to ALERT, where physicians started her on ART. Several years later, she met an HIV-positive man at church; they are now married, and she describes her husband as a supportive partner. Both of them are very active in the community and especially in the community coffee ceremony programme. The traditional coffee ceremony is a classic feature of traditional Ethiopian home and community life. Saba described the HIV-related community coffee ceremony that she and her husband help to organise in their neighbourhood:

The coffee ceremony is a gathering given by village dwellers. We call both those who are HIV positive and negative people and teach them about HIV. We usually get some people who ask for forgiveness for their wrong discriminatory actions they committed, after they understand about the problem. I believe all these things happen due to low levels of understanding. That is what the coffee ceremony has brought for us. The community gathers and discusses it openly. The other benefit of coffee ceremony is it provides ways for us [PLHIV] to help each other. For example, if a person is in short of money even to come to ALERT, they will be given some money from the contributions we collect from the crowd at the coffee ceremony. When someone is found ill, all of us will go and visit him/her turn by turn. We also have a saving scheme and we save 10 birr per month in addition to the contribution to coffee ceremony group, which is 2 birr per month. Then we also give a credit service to the members to get a small loan, work with it and pay back with small interest.

Saba's story illustrates several sources of community-derived social capital that were described by many participants. She highlights multiple HIV-related social networks including her community at the *tsabel* site, the community coffee ceremony programme, and a large NGO. Unlike Tigist, Saba had relatively little familial support, but she formed important new connections including friendships at the *tsabel* site and her second marriage. Within these networks of PLHIV, she found a refuge from stigma and discrimination in the larger community. Additionally, the coffee ceremony programme provided a forum for educating the community and decreasing stigma in the neighbourhood, as well as providing economic and emotional support to members.

Service to others—The EPT job at ALERT naturally involves serving others, albeit with some financial compensation. Participants universally enjoyed their jobs working as EPTs, and gained great personal satisfaction, as below:

In the first place we are paid. Secondly, we have the chance to meet so many people with whom we can share our experience. But the most important thing is the interactions I have everyday with the patients. It is more than a good salary. It has changed my life positively. I am always happy when I can help at least one patient in a day. This helps me to sleep peacefully (Amina, age 34).

Of note, for most of our participants, the experience of service started before their employment at ALERT. Before becoming EPTs, the majority had volunteered as home-based care providers under the auspices of one of the NGOs. In addition to tangible benefits (e.g. food, rent assistance, educational opportunities) that participants directly received from

these organisations, many also reflected on the significant effect that these volunteer experiences had on their perspective about their own disease. One benefit was that doing this sort of work increased participants' knowledge of HIV, and perhaps more importantly, increased their knowledge about the efficacy and availability of ART.

I had the chance to see people who were suffering a lot while I was working as a door-to-door service provider. . . While we were taking the training, the trainer was a nurse and was teaching us some facts about HIV. I benefitted a lot from this training. It gave me good insight about HIV and related issues. (Yodit, age 30)

In addition to gaining knowledge about their own disease process, the feeling of helping others through these volunteer experiences was universally described as lending meaning to the EPTs' own lives. Such experiences made them grateful for their own relatively good health, while at the same time giving them a sense of purpose, and of pride in their unique expertise for this important work.

When I started to work as a home based care provider I started considering myself a professional. I was providing an important service to people. I was able to convince people who wanted to stay in their homes and die there to come to the health service instead. This was a great contribution for me. . . Initially I was thinking only of my life but then I started thinking of being useful for others too. I started thinking of saving other people too. I think that is what gave me strength. (Mahlet, age 30)

Discussion

Our qualitative data highlighted spirituality, social capital, and service to others as the primary resources facilitating resilience in our sample of Ethiopian EPTs. Religion and spirituality are consistently described as a central part of life in Ethiopia (Olsen, Jensen, Tesfaye, & Holm, 2013). Other work has similarly demonstrated the dual roles played by religion in the lives of PLHIV; as it can be a barrier to biomedical treatments in patients who prefer faith-based treatments such as *tsabel* to the exclusion of medications (Berhanu, 2010). Feelings of guilt and shame may also be associated with religiosity in dealing with HIV, and could impede psychosocial coping (Olsen et al., 2013). Additionally, religious institutions can increase stigma against PLHIV in some settings. Among our sample, however, participants were accepted within religious communities, and many actually gravitated towards religious institutions (the *tsabel* locations) that specifically catered to PLHIV. Our participants therefore found ways to reconcile biomedical and faith-based attitudes towards HIV. They used their faith to find optimism and hope in life, but did not perceive their faith as being in opposition to the biomedical treatments that they counselled others about and took themselves. Building on their success in integrating faith and medical approaches, future interventions in the Ethiopian setting should continue to include faith leaders and contexts in ways that highlight the compatibility of these seemingly disparate worldviews.

Social capital has previously been described as a critical resource for facilitating positive outcomes among PLHIV in Africa. Most notably, Ware and colleagues' ethnographic analysis found social capital to be the key to explaining ART adherence success in Nigeria,

Tanzania, and Uganda (Ware et al., 2009). Our findings confirm the importance of social capital for PLHIV in the Ethiopian setting, and detail specific sources of social capital and mechanisms of utilisation that led to successful coping with HIV for our participants. Other work has highlighted negative aspects of social capital in the HIV/AIDS context—referring primarily to the concern that greater social cohesion in a given community could exacerbate ingroup-outgroup distinctions and thus worsen stigma against PLHIV (Chiu et al., 2008). In our study, social capital functioned primarily as a buffer to the psychological and socioeconomic effects of stigma. Some of the discrepancy in these findings can be explained by definitional differences. Our conception of social capital focuses on personally accessible network resources as opposed to cohesive characteristics of the community as a whole; of note, both of these are established theoretical perspectives on social capital (Kawachi, Kim, Coutts, & Subramanian, 2004). From this study, we cannot answer the question of whether or not greater social cohesion in the community exacerbated stigma for participants, but we can demonstrate how our participants utilised their own network connections to cope with stigma and other stressors. In discussing stigma and its sequelae, participants described stigma that was self-imposed as well as external stigma manifested in discrimination from the larger community. As shown in our case examples, family support was especially helpful for participants who were struggling internally with self-imposed stigma. Over time, the close emotional bonds of a family network provided emotional support to help PLHIV accept their diagnosis. Formal organisations could also provide emotional support, but they were particularly useful for overcoming tangible discrimination at the community level; for example, difficulty obtaining housing or employment. The two different patterns (family-derived and community-derived) of successful social capital utilisation suggest that HIV support interventions would ideally incorporate a multi-pronged approach including family-based interventions, as well as scale-up of existing community-based programmes such as the coffee ceremony.

Service to others was the third strategy employed by our participants to improve their psychological well-being and engagement in care. Peer counsellors (both paid and volunteer) are a widely used resource in the African HIV epidemic in general, and in Ethiopia more specifically (Gusdal et al., 2009). The use of lay health workers is particularly critical in countries like Ethiopia that have catastrophic human resource crises in the health care professions. Prior research has also demonstrated the personal satisfaction that these individuals receive from engaging in such work (Gusdal et al., 2011). However, our study is among the first to demonstrate the ways in which EPTs translated these benefits into their own health. Investment in scale-up and/or supporting financial incentivisation for programmes such as the volunteer home-based care programme is likely to have dual benefits both for task-shifting in the healthcare workforce and also for improving health among EPTs themselves.

There are several limitations to our findings. Two co-authors were previously known to our participants, as they worked together at ALERT. This pre-existing relationship may have facilitated trust and rapport between the study team and the participants. At the same time, although all participants appeared to share their stories and opinions quite openly, there could be an increased social desirability bias as these co-authors were also physicians and therefore in a position of power at the workplace relative to the EPTs. Several demographic

characteristics of our sample could also be viewed as limitations. Our sample was overwhelmingly female. Although other studies have also reported female predominance in peer educator/volunteer populations in Ethiopia (Maes et al., 2011; Gusdal et al., 2011), we cannot report on gender differences based on these findings. Similarly, Muslims were underrepresented in our sample relative to the general Ethiopian population, and different spiritual practices and cultural norms within the Muslim population likely lead to distinct faith-based strategies for resilient coping for Muslim PLHIV that we were unable to uncover.

Our findings and limitations point to several future directions for intervention development and research. One might question the applicability of strategies utilised by these exceptional individuals to other Ethiopian PLHIV. However, consistent with the positive deviance approach described earlier, we believe that our findings are likely to be applicable to others. Our participants faced all of the barriers that are described for Ethiopian PLHIV more generally—poverty, gender inequity, and stigma—but they overcame these barriers by applying existing social structures to successful coping with HIV. Religious institutions, HIV-related NGOs, and accompanying volunteer opportunities should be accessible and culturally acceptable to most, if not all PLHIV in Addis Ababa. Future efforts should focus on strengthening the sustainability and capacity of these organisations to support PLHIV. In terms of research, future studies should aim to fill some of the gaps in our study population. For example, research should be conducted with the goal of understanding resilience among other populations including Ethiopian men living with HIV, who are likely to have different types of social networks and coping strategies than the predominantly female sample we interviewed here; and Muslim patients, to gain an understanding of Muslim-specific religious communities and rituals that might be used to enhance resilience.

Our study is among the first to utilise a positive deviance approach to understanding resilience among PLHIV in Ethiopia. While facing myriad stressors, the EPTs demonstrated the ability to improve their own health through effective utilisation of personal and community resources. The most prominent of these resources were spirituality, social capital and service to others. Interventions that augment these assets in the wider community have the potential to improve health outcomes and general well-being among Ethiopian PLHIV.

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Table 1

Demographic characteristics of participants.

Characteristic	Total Sample (n=20)
Age	
Age Range	30-43 years
Median Age	34 years
Gender	
Female	19 (95%)
Male	1 (5%)
Religion	
Ethiopian Orthodox Christian	12 (60%)
Protestant	7 (35%)
Muslim	1 (5%)
Ethnicity	
Amhara	17 (85%)
Oromo	3 (15%)
Education	
Less than 12 th grade	6 (30%)
12 th grade	8 (40%)
Some postsecondary training/education	6 (30%)
Years Since HIV Diagnosis	
Range	5-12 years
Mean	8.2 years