

## Qualitative study on Perceived Social Support and Psychological Well-being of People living with HIV/AIDS

Nimona Shaka

School of psychology, College of Education and Behavioural Studies, Addis Ababa University, Addis Ababa, Oromia, Ethiopia

### Abstract

People living with HIV/AIDS (PLWHA) report feelings of self-doubt, self-consciousness, and negative interpersonal interactions, and feelings of hopelessness and despair related to their illness. Understanding about the social support available and received by PLWHA is important as it impacts their psychological well being. In-depth interviews were carried out with PLWHA receiving treatment and support from a Charity organisation at Fitchewereda. Fitchewereda is in Oromia region, Ethiopia. Participant recruitment was terminated when saturation of themes was obtained in qualitative interviews, totaling 12 participants. Acceptance of HIV status was difficult. A majority chose to seclude themselves and not face discrimination and a similar number were thinking others are discriminating them because of their HIV status. So self-stigma was also affecting psychological wellbeing more than experience of stigma. Being a member of the charity organisation and getting support from that organisation as well as interacting with others receiving treatment there were of assistance in their feelings of belongingness, coping among others. Members received assistance to learn new skills to earn a living and this boosted their self-confidence. Support from the charity organisation was an enabling factor. Participants valued this support, though they had felt that family support could have been better.

**Keywords:** HIV/AIDS, Psychological Well-being and Perceived Social Support.

### BACKGROUND

In response to the HIV epidemic, the Ethiopian government in collaboration with development partners has developed a five-year national HIV and AIDS strategic plan (2015) that adhere to global directions (Federal HIV/AIDS prevention and control office, 2014). However, impact is slow to pick up in certain areas. The HIV testing coverage remains unchanged between 2011 and 2016. The percentage of respondents who know that using condoms consistently and limiting sexual intercourse to one uninfected partner with no other partners can reduce the risk of HIV has increased from 32% in 2000 to 49% in 2016 among women and from 58% to 69% among men; not a substantial increase where knowledge is concerned (EDHS, 2016).

Discriminatory attitudes towards people living with HIV is an area of major concern. The 2016 Ethiopian Demographic and Health Survey (EDHS) found that discriminatory attitudes are higher in women than in men. For instance, 48% of women and 35% of men thought that children living with HIV should not be allowed to attend school with children. 55% of women and 47% of men would not buy fresh vegetables from a shopkeeper who has HIV. Considerable differences in discriminatory attitudes were observed between urban and rural areas: 28% of women and 27% of men from urban areas compared with 73% women and 60% men from rural areas held discriminatory attitudes. People including family members still have negative attitude and discriminatory behavior against PLWHA, at least implicitly (Thanh, Moland & Fylkesnes, 2012). Despite advances in clinical science, those infected with HIV continue to experience high levels of discrimination and stigmatization in the communities where they live (Vanable, Carey, Blair, & Littlewood, 2006), amongst other health-related stressors and challenges (Strine, Chapman, Balluz, & Mokdad, 2008). Stigmatization or the experience of discrimination to the extent that normal social life is disrupted, can have a profound impact on the lives of PLWHA, as the experience can affect their mental health (Wang, Li, Barnett, Zhao & Stanton 2012).

The above data is indicative that people go for testing late and are often unaware of the treatment for HIV infection. The fear of HIV/AIDS can lead to even family members being discriminating in behaviour and not providing the physical and emotional support that the sick person will need very badly. Stigma and discrimination of family, peers, friends and other stake holders will have impact on

**Correspondence to:** Nimona Shaka, College of Education and Behavioural Studies, Addis Ababa University, Addis Ababa, Oromia, Ethiopia. Email: nimona.shaka@aau.edu.et

**Received:** January 18, 2021; **Accepted:** January 22, 2021; **Published:** May 20, 2021

**Citation:** Nimona Shaka (2021) Qualitative study on Perceived Social Support and Psychological Well-being of People living with HIV/AIDS. In *J Sch Cogn Psychol*. DOI: 10.35248/2329-8901.19.7.215

**Copyright:** © 2021 Nimona Shaka, et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited

the mental state of the PLWHA and the psychological wellbeing of the person. Rates of current depression among persons living with HIV/AIDS have been estimated to be two to five times higher than rates of depression among persons who are HIV negative, and rates are as much as four times higher among women with HIV than women without HIV (Morrison, 2002; Asante, 2012).

Well-being is a dynamic concept that includes subjective, social, and psychological dimensions as well as health-related behaviors. People with HIV/AIDS report feelings of self-doubt, self-consciousness, and negative expectations about interpersonal interactions, and feelings of hopelessness and despair related to their illness (Kelly, 1993; Kylma, 2001). Studies have found that psychological well-being of people with HIV/AIDS can be affected by HIV/AIDS stigma through direct experiences of prejudice and discrimination (Scambler, 1998; Herek, Saha, & Burack, 2013; Chidrawi, Greeff, Temane & Doak, 2016). Symptoms of anxiety in young HIV positive individuals are positively correlated with perceived negative reactions of others to their HIV status. People with HIV/AIDS also reported more experiences of internalized shame and lower self-esteem than cancer patients did. In a study carried out in sub-Saharan Africa, people living with HIV/AIDS experience more mental distress than do HIV-negative individuals (Hsieh, 2013).

Strong social support has been associated with slower progression to AIDS, higher immune system functioning, and better medical treatment adherence (ref.....). PLWHA who have strong social support networks are more likely to have active coping strategies, and better psychological well-being and mental health than those with less robust social support network.. Social support also plays a major role in improving the quality of life of HIV-positive individuals (Zhang & Aleong, 2011). Perceived social support can influence coping in three ways. It can allow individuals to: structure situations so that stressful life events are less likely to occur, it can help in the development of effective personal coping skills, and it can allow individuals to seek and obtain assistance when needed (Nelson, 2004). Lack of social support and lower perceived adequacy of social support have been linked to poorer mental and physical health (Callaghan & Morrissey 1993; Carr & Gramling, 2004; Waddell & Messeri, 2006). This paper elaborated the findings from a study carried out to understand the relationship between perceived social support and psychological wellbeing of PLWHA.

## METHODS

Ethical Approval for the study was given by Fitcha Tesfa Birhan Association. The data were collected from the participants after obtaining informed consent. The benefits and risks of participating in the study and confidentiality conditions were elaborated in the informed consent. The researcher paid careful attention to respect the rights of the participants and confidentiality of the data. The only identifiable information mentioned in this paper is the Woreda where the study was carried out

### Study setting

The participants were HIV patients who were members of a Charity organisation at Fitcha Woereda. Fitcha is in Oromia region, North Shewa Zone. HIV testing in Oromia region is 2nd lowest in the country with only 15% each men and women reporting an HIV test in the 12 months prior to the survey. EDHS (2016) indicate that in Ethiopia, 69% of women and 84% of men know where to obtain an HIV test, and 40% women and 43% men have ever been tested for HIV and received the test results.

### Data collection and analysis

Using semi structured interview guide, 12 in-depth interviews were carried out among PLWHAs undergoing treatment at a clinic run by a non-government organisation. The study was conducted in 2015. Criteria for inclusion in the qualitative study were: (1) age above 18 years, (2) being HIV infected, (3) undergoing treatment for more than an year (4) was willing to participate in the study. Patients were purposively selected into the study. All of them were receiving ART from the NGO and in that capacity were also members of the organisation. This membership was also a source of support to the PLWHAs. Interviews were carried out confidentially at the NGO in private by two of the authors.

Participant recruitment was terminated when saturation of themes was obtained in qualitative interviews (Guest, Bunce, & Johnson, 2006). In non-probabilistic studies like this study, saturation is defined as the point at which no new themes or information emerges. In-depth semi-structured interviews were conducted in the local vernacular language: Afan Oromo. The semi-structured interview guides allowed for probing and clarification. The questions focused on psychological wellbeing, specifically self-acceptance, the establishment of quality ties to other, a sense of autonomy in thought and action, the ability to manage complex environments to suit personal needs and values, the pursuit of meaningful goals and a sense of purpose in life, continued growth and development as a person: the dimensions of Ryff's psychological wellbeing scale (Ryff, & Keyes 1995). Of special interest was the experience of social support by the participants like support from family, friends, community and others. The underlying assumption was that the current perception on the dimensions of the psychological wellbeing could be influenced by the social support and experiences of stigma and discrimination. The interview was completed in about 30 minutes.

A coding scheme of key concepts and themes were created by the authors initially (Bernard & Gery, 2010). The qualitative interviews were then analyzed focusing on identifying themes and relationship among themes. Data analysis was carried out concurrently with data collection using thematic approach. Codes and sub themes were identified and modified in the subsequent interviews. After thematic saturation, data collection was ended. The final analysis was carried out based on the modified and finalized codes and sub-themes.

## Result

Five males and seven females participated in the interview. Their ages ranged between 30-50 years.. Males were more likely to be educated.

### Self acceptance and self stigma

Self acceptance of the situation is the first step for happiness and psychological well-being. Learning that they are HIV positive led to different behaviors among the PLWHAs.

I was foolish .I did not know even what HIV/AIDS meant. I was not taking care of precautions because I feared nothing. I wish yesterday would be today and I would do things differently, but it could not be. Nothing can be changed now.”

[Male, 47 years]

A majority chose to seclude themselves and not face discrimination and a similar number are thinking others are discriminating them because of their HIV status and fighting with them. So self-stigma was also affecting psychological wellbeing more than experience of stigma and discrimination from the community.

“I prefer to pass through challenges by my own effort. I would never ask for help; I am strong enough”

[Male, 45 years]

“I can adapt myself to any kind of situation, persons and live peacefully with them; I have good neighborhood relation and there was no discrimination at all.”

[Male, 47 years]

Self-stigma also affected positive relation with others.

“I am always in conflict with my neighbors. Last time one of my neighbors wounded my head badly. They discriminate me and my children. And they spit when they pass by me.”

[Male, 30 years]

### Importance of network groups and their support

Having a space free from stigma and discrimination was particularly important for the participants. Even before, experiencing any stigma themselves they had developed fear based on stories they had heard about stigmatic experiences. The participants in the study were members of charity organisation that was part of the study, as well as received care and support form NGOs working for PLWHAs. Either because of this context or otherwise, the references to health workers or clinicians were positive.

“They (health workers) provided me with counseling services, love and good behavior. They follow our medicine adherence and encourage us not to stop it. There is no discrimination - I mean they treat us just like their family. Other respondents added another statement.”

[Female, 48 years]

Care and support were also provided by friends and neighbors.

“People were concerned much about me. My friends, relatives and neighbors are caring and supporting me.”

[Male, 43 years]

Participants felt cared for when the health care provider understood their fears and concerns and prompted them to discuss them. They felt relieved to learn their feeling of fear is normal and others too feel similar feelings. It helped them to discuss their feelings with fellow patients.

“The nurse made me sit down and explained to me that many people fear that others can understand they are HIV positive from the way they look. She said that my illness is only known to people I choose to disclose it. She also made me understand how sharing and communication will make me feel loved and belongingness.”

However, support from family did not meet with their expectations. Males often reported receiving support from family.

“My family does not support me. They discriminate and isolate me. I am disappointed and frustrated with it. Even if they isolate and deny supporting me, still I am happy with my friends’ support that has given me strength.”

[Female, 35 years]

“...I am getting support from my family, but it is not satisfactory...”

[Male, 40 years]

### Autonomy and independence issues faced by women

In the face of HIV infection and being widowed, women had difficulty earning a living and developing autonomy. Earlier they were dependent on their husband’s for everything. Other than caring for the husband when he was ill and going with him to the clinic, they

lacked skills like independent decision making and autonomy. As a result, widowhood made them feel lost and helpless.

“My husband was managing money. Now I have make money decisions myself”

[Female, 48 years]

“First I myself try to solve or change the situation; finally if I think it is beyond my capacity I seek help from others.”

[Female, 43 years]

“I leave what others say aside and continue in my way; I listen to my heart and choose what seems right to me.”

[Female, 33 years]

Trying for personal growth and development

Generally, large number of respondents reported that they try to solve the problem first and finally seek help. Others reported that they themselves have changed the situation where as few of them reported that they do nothing rather than praying, crying and patiently wait anticipating that the time or the God will change it. Women, more than men felt helpless in face of adversity. Both men and women, however tried to find a solution to the problem despite them first feeling overwhelmed by the situation. Money and livelihood was the most important stressor.

I am tensioned; I have no one to help me. I just pray and cry...”,

“When I face problem, I feel stressed and I have nothing to do. I leave it for God.”

The majority of respondents reported that they were engaged in different activities to improve their life. They have the sense of improvement and development. They were thankful to the volunteers and network members who shared knowledge and skills. Participants also narrated how the networks helped to increase their access to resources and equip them with skills to earn a living.

I am participating in income generating activities; I am consulting with others and micro finance organisations on how to improve my income further”

[Female, 33 years]

“I am working day and night; I do not consider myself as patient. If I stop working, then I will think too much and feel like a patient. Right now, work is helping me to cope as well as make money”

[Male, 47 years]

Coping and environmental mastery

Coping with life events emanating from their HIV status has made many respondents numb with life. They are living as long as they have life in them and are not focusing on happy events or on enjoying life.

“Life is meaningless for me; it is simply living.” “Life is nothing for me and I have no word to describe it.”

[Male, 45 years]

However, majority of the respondents tried to overcome their initial lack of interest in life. Sad as they were about their current quality of life, they tried to do as much as they can for their family. Children and their future continued to haunt them, though they find joy in the simplicity of the children’s world.

“Life is both good and bad; I said good because the availability of ART enabled me to survive. On the other hand, when I remember the time when I first knew that I am HIV/AIDS positive, I consider life as bad.”

[Male, 47 years]

“I am honest woman even I don’t know how I got HIV .Of course my husband has died of HIV/AIDS. But I am not sure whether I bring to him or he brought to me. No matter who brings it, I do not blame myself. I try to make the most of life or what is left of my life.”

[Female, 33 years]

“Despite HIV, I am a strong woman. I am ready to challenging all difficulties I face in my life. I am bringing up my children properly.”

[Female, 45 years]

## DISCUSSION

The investigation into psychological wellbeing and social support among people living with HIV was carried out using the factors of psychological wellbeing identified by Ryff. On the whole stigmatising experiences were minimal among the participants. All except one person mentioned being satisfied with the support from friends, neighbours and health care personnel. However, the respondents perceived the support from family as inadequate. Networks and membership in the study NGO enabled them to cope with their HIV status

with a positive attitude (Ghosh, Krishnan, Gibson et al., 2017; Latkin, Edwards, Davey-Rothwell, & Tobin, 2017).

PLHIV faced various stressors in handling their disease state and income generation. Women were at a disadvantage as by the time they are diagnosed with HIV, they are widowed. Interestingly, social network tended to evolve and change after their HIV diagnosis. Based on the extent to which patients were able to come to terms with their HIV status and overcome self-stigma, they were able to maintain their pre-existing social networks and relationships (Greeff, Uys, Wantland. et al., 2010; Mak, Cheung, Law, et al., 2010; Tran, Hwang, Nguyen, et al., 2016). Their illness made them members of the charity organisations and meet people going through similar anxiety and fears resultant of HIV status. So new friendships and networks evolved. Often, these friendships were crucial for new pathways to living and coping. Studies have found that support groups help reduce the stigma, reduce isolation, and build social networks (Fearon, Wiggins, Pettifor, et al, 2017).

More women than men felt helpless in the absence of their husbands. More often, husbands had died of HIV and widowhood coupled with HIV, left them with challenges of earning a living, making financial decisions and taking care of the family. While men were cared for by the wives, they were not satisfied by the support they received. For women, they felt that they were not receiving any support. Examination of social support from the wider community showed that more or less all were happy with the support from providers, friends and neighbours (Adedimeji, Alawode, & Odutolu, 2010). Dissatisfaction was closer to home because expectations were higher. It is possible that that additional burdens of earning a living and decision making made women incapable of caring for the husband as per his expectations. However, efforts at autonomy and environmental mastery went beyond any they felt was possible before HIV diagnosis. The impact of PLHIV networks and NGOs working for PLHIV for enhancing environmental mastery is well documented (Ghosh, Krishnan, Gibson et al., 2017; Latkin, Edwards, Davey-Rothwell, & Tobin, 2017). Despite PLHIV networks being in its infancy in Ethiopia, the small assistance from NGO is able to improve the psychological wellbeing of HIV patients.

Support from NGOs are enabling patients to learn a new skill and engage in income generation activities. Poverty is staring them in the face and quality of life is badly affected. This also brings with it, other psychological stressors. However, a positive attitude was present among most of the patients. They were ready to fight and face the challenges and not flee from the situation. Widowed women tried to not blame their husbands but rationalise about how they were infected. The patients' mental health needs were met to a great extent through the care and advice provided by nurses and other health care personnel (Borne, DeVries, 2009; Sayles, Wong, Kinsler, et al, 2009).

## References

1. Adedimeji, A.A., Alawode, O.O., Odutolu, O. (2010). Impact of care and social support on wellbeing among people living with HIV/AIDS in Nigeria. *Iran J Public Health*, 39(2):30-38
2. Asante, O.K. (2012). Social support and the psychological wellbeing of people living with HIV/AIDS in Ghana. *Afr J Psychiatry*, 15(5):340-5.
3. Bernard, H.R., Gery, W.R. (2010). *Analyzing qualitative data: systematic approaches*, 1st ed., New York: SAGE Publications.
4. Borne, B.V.D., DeVries, N. (2009). A model for understanding the relationship between stigma and healthcare-seeking behavior among people living with HIV/AIDS in sub-Saharan Africa. *AJAR*, 8: 201-212.
5. Central Statistical Agency (CSA) [Ethiopia] and ICF. (2016). *Ethiopia Demographic and Health Survey 2016*. Addis Ababa, Ethiopia, and Rockville, Maryland, USA: CSA and ICF.
6. Fearon, E., Wiggins, R.D., Pettifor, A.E., et al (2017). Associations between friendship characteristics and HIV and HSV-2 status amongst young South African women in HPTN-068. *J Int AIDS Soc*. 20, DOI: 10.1002/jia2.25029.
7. Federal HIV/AIDS prevention and control office, Ethiopia, (2014). *HIV/AIDS strategic plan, 2018-2020 in an investment case approach*. Addis Ababa: Ministry of Health and Family Welfare.
8. Ghosh, D., Krishnan, A., Gibson, B. et al. (2017). Social network strategies to address HIV prevention and treatment continuum of care among at risk and HIV infected substance users: A systematic scoping review. *AIDS Behav*, 21:1183-1207.
9. Greeff M., Uys L.R., Wantland D. et al. (2010). Perceived HIV stigma and life satisfaction among persons living with HIV infection in five African countries: A longitudinal study. *Int J Nurs stud* 47:475-486.
10. Guest, G., Bunce, A., Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18: 59-82.
11. Latkin, C.A., Edwards, C., Davey-Rothwell, M.A., Tobin, K.E. (2017). The relationship between social desirability bias and self-reports of health, substance use and social network factors among urban substance users in Baltimore, Maryland. *Addict Behav*, 73: 133-36.
12. Mak, W.W.S., Cheung, R.Y.M., Law, R.W. et al. (2010). Examining the attribution model of self-stigma on social support and psychological well-being among people with HIV+/AIDS, *Social Science and Medicine*, 64(8):1549-1559.
13. Ryff, C. & Keyes, C. (1995). The Structure of Psychological Well-Being Revisited. *Journal of Personality and Social Psychology*,

Vol. 69, No. 4, 719-727

14. Sayles, J.N., Wong, M.D., Kinsler, J.J., et al. (2009). The association of stigma with self-reported access to medical care and antiretroviral therapy adherence in persons living with HIV/AIDS. *J Gen Intern Med*, 24: 1101-08.
15. Strine, T.W., Chapman, D.P., Balluz, L., & Mokdad, A.H. (2008). Health-related quality of life and health behaviors by social and emotional support: Their relevance to psychiatry and medicine. *Social Psychiatry and Epidemiology*, 43, 151-159.
16. Thanh, C., Moland, M. & Fylkesnes, K. (2012). Persisting Stigma Reduces the Utilization of HIV-Related Care and Support Services in Viet Nam: *BMC Health Services Research*, 12(428).
17. Tran, B.X., Hwang, J., Nguyen, L.H., et al. (2016). Impact of socioeconomic inequality on access, adherence and outcomes of antiretroviral treatment services for people living with HIV/AIDS in Vietnam, *PLoS ONE*; doi:10.1371/journal.pone.0168687.
18. Venable, P.A., Carey, M.P., Blair, D.C., & Littlewood, R.A. (2006). Impact of HIV-related stigma on health behaviors and psychological adjustment among HIV-positive men and women. *AIDS & Behavior*, 10(5), 473-482.
19. Wang, B., Li, X., Barnett, D., Zhao, G., Zhao, J., & Stanton, B. (2012). Risk and protective factors for depression symptoms among children affected by HIV/AIDS in rural China: A structural equation modeling analysis. *Social Science and Medicine*, 74(9),