Original Article

OPEN ACCESS

Coping strategies and impact of disease among people living with HIV/AIDS: A qualitative study

Farooq Ahmed Noor[1], Zahida Qasim[2], Noor e Saba[3], Yasir Farhan[4], Muhammad Kaleem[5], Akhlaaq Wazeer[6]

[1,2,6] Department of Pathology, Divisional Headquarters Teaching Hospital, Mirpur [3] Regional Blood Centre, Department of Health, Peshawar [4] Tehsil Headquarters Hospital, Murree; [5] Department of Pathology, Mohtarma Benazir Bhutto Shaheed Medical College, Mirpur

Author`s Contribution

[1,2]study design and manuscript drafting, final approval of the version to be published, [3,4]data acquisition and analysis, [5,6]statistical analysis

Funding Source: None
Conflict of Interest: None

Received: February 27, 2020
Accepted: April 8, 2020

Address of Correspondent
Dr. Zahida Qasim,
Associate Professor of Pathology
DHQ Teaching Hospital, Mirpur,
Azad Jammu and Kashmir
Email:
dr_qasim2011@hotmail.com

ABSTRACT

Objective: The current study was undertaken to qualitatively investigate the coping strategies and impact of disease in HIV/AIDS patients.

Methodology: The study was conducted at the Divisional Headquarters Teaching Hospital, Mirpur, Azad Jammu and Kashmir from January to April 2019. The hospital is a divisional hospital for three districts namely Mirpur, Kotli, and Bhimber catering to a population of approximately 1.5 million. In-depth interviews and focus group discussions were conducted with twenty HIV/AIDS patients. For the analysis, the Interpretative Phenomenological Analysis technique was used. The major domain of the impact of HIV/AIDS was further divided into nine major themes. The other major domain was coping with HIV/AIDS which included themes of spiritual coping, problem-focused coping, and avoidance coping.

Results: Findings highlighted depression among people living with HIV/AIDS. The first sub-theme was the positive aspect which explains the family attitude towards illness as now they have become more caring and supportive towards the participant. The impact of disease is multifaceted including social, emotional, financial, and occupational. The participants were more inclined towards spiritual coping and problem-focused coping as compared to the avoidance coping.

Conclusion: The findings of the study highlighted the need of the assessment and management of the participants through a psychologist. HIV/AIDS patients need counseling and awareness on the disease and the things to consider while on treatment to cope with the stress. They must be provided the updated information on HIV/AIDS. The management of HIV/AIDS patients requires that issues of psychological stresses be coped with professionalism.

Keywords: HIV, AIDS, Pakistan, Coping, Discrimination

Cite this article as: *Noor FA, Qasim Z, Saba N, Farhan Y, Kaleem M, Wazeer A. Coping strategies and impact of disease among people living with HIV/AIDS: A qualitative study. Ann Pak Inst Med Sci. 2020; 16(1): 3-9.*

Introduction

HIV/AIDS and coping mechanisms have a critical relationship. The infection with HIV/AIDS may result in the adoption of coping strategies, which may have negative, adverse consequences. Acquired immunodeficiency syndrome (AIDS) has emerged as one of the major healthcare complications due to its pandemic status and severe disease features. Globally, 37.9 million [32.7–44 million] people were living with HIV at the end of 2018. Of these, 1.7 million were children (less than 15 years old).[1] AIDS is caused by human immunodeficiency

virus (HIV) resulting in serious, systemic dysfunction of the immune system. The global incidence rate of HIV/AIDS is declining[2] attributed to a combination of factors, including the significant scale-up of antiretroviral therapy over the past few years, the impact of HIV prevention efforts, and the natural course of HIV epidemics. However, the incidence of HIV infection is increasing in Pakistan, reaching approximately 165,000 cases in 2019.[3] Unfortunately, the cases reported so far, represent only the "tip of the iceberg". Poor awareness about HIV/AIDS with lack of information, persistent scarcity of financial resources, weak regulatory oversight and common misunderstanding that HIV only infects 'individuals with bad characters' are some aspects affecting the spread of HIV/AIDS.[4,5]

Epidemiological data from surveys of the general population indicate that women experience more symptoms than men[6,7] and this sex difference is also evident for disease-specific populations.[8] The clinical picture is usually divisible into four stages, i.e. an early, acute stage; middle, latent stage; and a late, immunodeficiency stage.

Living with a life-threatening syndrome-like HIV/AIDS is a stressful and emotionally challenging experience. In addition to the likelihood of premature death, HIV/AIDS is linked with a stigma which produces extraordinary personal and social complications.[9] Being a chronic and life-threatening disorder, HIV/AIDS is stressful to manage. HIV/AIDS comes under the same category of chronic illnesses which cause threats to human life resulting in physical and pathological changes and require long run observations to minimize the fatal effects of the illness. The disease results in psychological effects linked to the social, physical, sexual, and economic aspects of human life.[10] Thus, patients begin to view life in a different perspective as a consequence of these fatal changes. The neuropsychiatric effects of HIV can mimic idiopathic psychiatric disorders, resulting in a delay in diagnosis and treatment of the fundamental cause. Patients suffering from HIV/AIDS undergo severe forms of psychological stresses. The presence of substance abuse, anxiety, and mood swings are some of the many psychiatric predicaments faced by them.[11] These stresses have a link to the various aspects of the illness itself which may include a decline in mental capabilities and physical movements, increased hospitalizations, sexual disinterest and dysfunction, physical pains, various fatigues, and continuous stress related to death. The stigma is more common in women. This process fills women with feelings of shame and guilt, feelings that definitely do not help them maintain good self-esteem and a healthy mental state.[12] Anxiety is common in HIV/AIDS patients, and occur in 22 to 47% individuals.[13]

People with HIV and those close to them are subject to many things that may affect their mental health. Coping plays an important role in order to deal with chronic illness. Coping strategies consist of thoughts and behaviors that people use as a strategy to organize the internal and external demands of a particular stressing event or factor.[14] Coping strategies are influenced by factors such as socio-demographic, personal, socio-cultural and environmental aspects. Develop coping strategies is necessary to reduce the psychological suffering of people living with aids, arising from all the difficulties related to this disease.[15]

This qualitative study was carried out to understand the impact of HIV/AIDS on the life of the people living with HIV how they are coping with the disease.

Methodology

The data were collected from the Divisional Headquarters Teaching Hospital, Mirpur, from January to April 2019. The hospital is a divisional hospital for three districts namely Mirpur, Kotli, and Bhimber catering to a population of approximately 1.5 million. A sample of twenty diagnosed HIV/AIDS patients was taken and were selected through a purposive sampling technique. All these participants visit the hospital for routine checkups. Confidentiality of the study participants was maintained and the study was conducted after an informed consent from all participants.

For the analysis, the Interpretative Phenomenological Analysis (IPA) was used. The first theme was the impact of HIV/AIDS which was further divided into the nine further sub-themes. The first theme was the relationship issues experienced by the study participants after they were tested positive for HIV. It was further divided into sub-themes on the basis of the participant's responses.

In order to explore the phenomenology, open ended questionnaire was used. Questions were related to the demographic variables, diagnosed period, course of illness, mode of transmission, and changes in attitude after diagnosing, and their coping strategy which they use to fight with their disease, and what are the ways they use to cope with their ailment.

The data were collected in the Department of Pathology in a one-to-one setting. In-depth interviews (IDIs) and focus group discussions (FGDs) were conducted with study participants. The first stage semi-structured interview was used to collect the experience and expression of the participants about the phenomenon of their disease, its impact on their daily life, and how they cope with their illness. Then semi-structured interview was conducted by asking open-ended questions. Participants were asked to explain the impact of HIV/AIDS on their life and what coping patterns they adapt which they used to cope after they were diagnosed with HIV/AIDS. Every participant took 20-30 minutes to answer the questions.

After the in-depth interview and thorough review of the literature, list of 13 questions was identified through the open-ended questions which targeted and tap two main areas; (1) the impact of HIV/AIDS on the different dimensions of the life of the participants, and (2) the coping mechanism of diagnosed HIV/AIDS participants.

For the analysis purpose, the IPA analysis was used for the interpretation of the data. The analysis involved the first step of looking for the themes from the responses of the participants. The next step involved the building of the connection between the themes which involved the division of the themes into the subthemes.

The domain, impact of HIV/AIDS, was further divided into nine major themes elicited from the clusters of responses of the participants. These themes comprised of sub-themes which were relationship problems, emotional issues, health issues, financial issues, cognitive aspects, perception about the disease, change in life, and future apprehensions and concerns.

Results

A total of 20 participants were interviewed including 14 males and six females from the hospital settings. Table 1 shows the themes and the subthemes of the participants on the domains of relationship issues, emotional breakdown, health-a downhill journey, and cognitions dark and bleak. Table 2 deals with the themes and the subthemes of the participants on the domains of financial issues, perception about the disease, life a downward spiral, and future apprehensions and concerns. The table 3 is related to themes of the participants on the domains of spiritual coping, problem-focused coping and avoidance coping. A total of four participants responded to the positive aspect.

The first participant responded that:

"They have started taking care of me now as they think that I might die soon so they care about me more"

Participant number 11 responded that:

"My wife also has AIDS we are now living for children and our family is supporting and taking care of us in need"

The Participant number 10 responded that:

"My family takes care of me now they support me and take me to doctor for a regular checkup"

All of the above participants explained that family concerns and support are now helping them to overcome their illness as it's a positive aspect in their life which serves as a purpose of motivation towards life betterment and wellbeing.

"I have died for my family as they don't meet me anymore"

Participant number 7 responded that:

"My family and relatives are scared of my disease that's why they don't interact with me now anymore"

All of the above participants were experiencing rejection due to the illness and because of the negative perception of the people regarding illness.

Another theme of the relationship issue subtheme of the negative attitude was the interrogative attitude of the relative regarding illness. As participant number 1 responded that:

"*I am tired of the questions of relatives regarding my illness"*

Participant number 13 responded that:

"Family and relatives taunts me about my illness"

Participant number 6 responded that

"*My family and relatives think that I have this disease because of my family as they think immoral of my family because my whole family was infected with HIV/AIDS"*

The other theme of the participants on the domain of impact of illness was emotional breakdown which was further divided into 12 sub-themes elicited from the responses from the participants. The first sub-theme of emotional breakdown was experiencing anger which was experienced by the participants after the contraction of ill

Table 1: Themes and the subthemes of the participants on the domains of relationship issues, emotional breakdown, health- a downhill journey and cognitions dark and bleak (n=20)

Relationship issues		Emotional breakdown	Health- A downhill journey	Cognitions dark and bleak		
Positive aspect	**Negative aspect**			**Fear of death**	**Self- blame**	**Self-pity**
Family care and support (5)	Inhuman treatment (7, 10)	Anger (2,3,4,5,6,7,8,9,15)	Weakness (2,5,7,10,19)	I will die soon (4,6,7,9,12)	Ruined my life with my own hands (3,4)	What sin I have done (2,12,16)
	Interrogative attitude of relatives (1,4)	Crying spells (1,3,8,12)	Fatigue (11)	Thoughts about death (3,4,6,7,8,10, 19,20)	Being women is a curse (8, 11 12 19)	Question to GOD (3,17,20)
		Low mood (1,4,13,14)	Decline in health (1,6,7)	Tension about disease (5,8,12)	Punishment of sin (3,4)	Why me (2,9,12)
		Suicidal thoughts and attempts (4, 8, 12, 18)	Loss of appetite (8,11,17,20)			Spend rest of the life in same condition (2,12)
		Isolation (7,8,12,16,19)	Faint (2,10,11,16,20)			Life has ended (4,16,18,19)
		Shock (12)				Life is ruined (2,6,8,12,13,18)
		Helplessness(2,4,5,17)				
		Loneliness (6,9,12,18)				
		Guilt (1,3,4,6,9)				
		Self-hatred (1,2,4)				
		Patience (7)				

Table 2: Themes and the subthemes of the participants on the domains of financial issues, perception about disease, life a downward spiral and future apprehensions and concerns (n=20)

Financial issues		Perception about disease	Life-A downward spiral	Future apprehensions and concerns
Jobless (3,4,7,12,19, 20)	Increase in financial demands (1,7,10,12,15,19)	Incurable disease (1,2,3,4,6,9,11)	Dependent on others (3,4,8,10)	Fear of infecting others (6,8,10, 20)
		Disease leads to 100 more diseases (12)	Life has become miserable (6,9,12)	Desire to fulfill responsibilities (12,15)
		Disease finishes the man (7,8,12)	Home is empty and family is ruined (8,10)	What will happen to family, home who will take care (8,10,12)
		Dangerous disease (1,5,9,7,11)	Living for children (3,10)	Counting life days (4,9)
			Left alone (1)	Threat of divorce (18)
			Aimless life (4,9,12)	
			Fear of being perceived negative/bad character (1,7,8,14)	
			Can't get married (15,18)	

Table 3: Themes of the participants on the domains of spiritual coping, problem-focused coping and avoidance coping (n=20)

Spiritual coping	Problem-focused coping	Avoidance coping
Spiritual Treatment (2,7,8,12,13,18)	Will power to fight with disease (3,5,7,9,10,12)	Run away from home (4)
Seeking health strength from GOD (1)	Eat healthy food (11,12,15)	Nothing can be done now (3,4,7)
Seeking Forgiveness (6,11,13)	Avoid drugs/cigarettes (3,11,18)	Waiting to die (19)
Praying (1, 5, 6, 7,8,9,11,12)	Avoid illegal sex (4)	Time passing (5)
Fulfill GOD's test (15,19)	Help and care of others (3)	Keep self-busy in work (2)
Thankful to GOD for a every new morning (7,14)	Take long walks (2,6,8,12)	Nothing has changed (8,9,11)
Fate (11,12)	Take precautions (1,5,8)	
Disease is due to GOD's will (5,11)	Take care of health (1,3,6,8,12)	
	Don't hide information from doctor/consult Doctor (1,6,8,9)	

-ness and its impact on life. As participant number 1 responded that:

"*Now I am experiencing anger outbursts on every little thing that does not go into my favor"*

The other sub-theme of emotional breakdown was the crying spells experienced by the participants due to the HIV/AIDS. As participant number 1 responded that:

"At times I cry that why I have such dangerous disease"

Another participant number 14 responded that:

"I feel sad and cry on what has become of us as we are now dependent on others help and need"

Another participant number 2 responded that:

"*I feel angry and helpless about myself as nothing can be done now as I'm getting weak day by day and my life is no more the same*"

The other sub-theme emerged of emotional breakdown was the state of shock as experienced by the participant number 12 that:

"This news were shocking and unbearable for me as I was unable to digest it that how this can be possible as I have done nothing wrong"

Another participant number 15 responded that:

"Don't talk much to others and stay alone and depressed all the time due to this illness"

The last subtheme of coping with HIV/AIDS was the avoidance coping with was adopted by the participants in order to shun the thoughts about HIV/AIDS. The first subtheme emerged under the avoidance coping was the run away from home as reported by participant number 12 as he responded that:

"I feel like running away from home as I'm tired of the taunts of the family"

The other subtheme emerged under the avoidance coping was the nothing can be done now as responded by two participants 1 and 4 that: "*Now I have contracted the disease nothing can be done now suffering is written till the end of life"*

The other subtheme emerged under the avoidance coping was the nothing has changed denial of the illness and its impact on the life of the participant as reported by participant number 7:

"Nothing has changed in my life everything is the same"

The other subtheme which was seen under the avoidance coping was the waiting to die was reported by the participant number 19 was that:

"Now my life is over and I'm waiting to die now"

The other subtheme seen under the avoidance coping was the time passing as experienced by the participant number 7:

"There is no aim in my life is left now I'm waiting to die"

The last subtheme emerged under the avoidance coping was the keeping self-busy in work was experienced by participant number 10 as reported that:

"I keep myself busy at work so that I don't have to worry about my illness"

The above subthemes explained the coping mechanisms used by the participants in order to cope with their illness. It was based on spiritual coping, problem-focused coping, and avoidance coping and their further subthemes.

Discussion

The impact of depression, social support, and coping strategies on the development of HIV/AIDS and quality of life have been assessed by a number of researchers. Earlier studies have reported rapid development to AIDS and opportunistic infections and its association with increased stressful events, higher depression symptoms, and decreased social support.[16] The use of particular coping strategies was also found to affect the level of stress and adaptation differentially. Coping through denial was linked with a more advanced development to AIDS and increased levels of depression,[17] while coping via problem-focused was linked with a greater quality of life.[18]

Religious faith played an important role in their long-term coping strategies. Religious factors seemed dominant in order to cope with their illness.

HIV/AIDS-related stigma is regarded as a chronic challenge in any discussion about effective responses to the HIV/AIDS pandemic. Despite widespread recognition of the differential treatment of people living with HIV/AIDS (PLHA) by the society and its institutions, over the first 35 years of the epidemic, community, national, and global actors have only had limited success in lessening the damaging effects of this stigma.[19] Studies on stigma and discrimination and health-seeking behavior show that people living reluctant to delay enrolment in care until they are very ill.[20]

The main findings of our study were seen with reference to our culture that how people cope and what problems they face after acquiring HIV/AIDS. As there is a difference in western culture findings regarding the illness perception, stigma, coping mechanism and the impact on the life of the diagnosed person. The main themes emerged were the impact of illness and the coping mechanism which were further divided into the sub-themes elicited from the responses. The first domain was the domain of the impact of HIV/AIDS. This domain is further divided into nine major themes these themes comprised of sub-themes which were relationship problems, emotional issues, health issues, financial issues, cognitive aspect, perception about the disease, change in life, and future apprehensions and concerns. The subthemes highlighted the effect of the impact of HIV/AIDS on the life of the participants. It showed that almost all of the area's personal, emotional, social, and occupational factors are affected by this disease as there is a significant change in their lives after the contraction of HIV/AIDS. The other major domain was the domains of coping with HIV/AIDS. According to the findings, participants were more inclined towards the spiritual coping and problem-focused coping as compared to the avoidance coping. All these subthemes explained the cultural findings with respect to the study.

Conclusion

The findings of the study highlighted the need of the assessment and management of the participants through a psychologist. The counseling is necessary as the people are unaware of the disease and its adversity. The management of HIV/AIDS patients requires that issues of psychological stresses be coped with professionalism, and psychological counseling can both lessen morbidity and decrease its occurrence.

References

1. UNAIDS (2019). Global HIV and AIDS statistics - 2019 fact sheet. Available at https://www.unaids.org/en/resources/fact-sheet [Last accessed 27 Dec 2019].
2. Zhang S, Rust G, Cardarelli K, Felizzola J, Fransua M, Stringer HGJR. Adherence to highly active antiretroviral therapy impact on clinical and economic outcomes for medicaid enrollees with human immunodeficiency virus and hepatitis C coinfection. AIDS Care. 2015; 27(7):829-35.
3. National AIDS Control Programme, Pakistan. Available from https://nacp.gov.pk/ [last accessed 27 Nov, 2019].
4. Shaw GM, Hunter E. HIV transmission. Cold Spring Harb Perspect Med. 2012;2(11):a006965.
5. Hladik F, McElrath MJ 2008. Setting the stage: Host invasion by HIV. Nat Rev Immunol 8: 447–457
6. Podlekareva D, Mocroft A, Dragsted UB, Ledergerber B, Beniowski M, Lazzarin A, *et al*. Factors associated with the development of opportunistic infections in HIV-1-infected adults with high CD4+ cell counts: a EuroSIDA study. J Infect Dis. 2006;194(5):633-41.
7. Gallagher AM, Thomas JM, Hamilton WT, White PD. Incidence of fatigue symptoms and diagnoses presenting in UK primary care from 1990 to 2001. J Royal Soc Med. 2004;97:571–575.
8. Simren M, Svedlund J, Posserud I, Bjornsson ES. Predictors of subjective fatigue in chronic gastrointestinal disease. Alim. Pharm Ther. 2008;28:638–647.
9. Brion JM, Leary MR, Drabkin AS. Self-compassion and reactions to serious illness: the case of HIV. J Health Psychol. 2014;19(2):218–229.
10. Singer EJ, Thames AD. Neurobehavioral Manifestations of Human Immunodeficiency Virus/AIDS: Diagnosis and Treatment. Neurol Clin. 2016;34(1):33–53.
11. Logie C, James L, Tharao W, Loutfy M. Associations between HIV-related stigma, racial discrimination, gender discrimination, and depression among HIV-positive African, Caribbean, and Black women in Ontario, Canada. AIDS Patient Care STDS 2013;27:114–122.

12. Kontomanolis EN, Michalopoulos S, Gkasdaris G, Fasoulakis Z. The social stigma of HIV–AIDS: Society's role. HIV/AIDS 2017;9:111–118.
13. Celesia BM, Nigro L, Pinzone MR, Coco C, Rosa RL, Bisicchia F, *et al*. High prevalence of undiagnosed anxiety symptoms among HIV-positive individuals on cART: a cross-sectional study. Eur Rev Med Pharmacol Sci. 2013;17(15):2040–2046.
14. Silva LMS, Moura MAV, Pereira MLD. The daily life of women after HIV/AIDS infection: guidelines for nursing care. Texto Contexto Enferm. 2013; 22(2):335-342.
15. Pinho CM, Dâmaso BFR, Gomes ET, Trajano MFC, Andrade MS, Valença MP. Religious and spiritual coping in people living with HIV/Aids. Rev Bras Enferm. 2017; 70(2):410-417.
16. Fife BL, Scott LL, Fineberg NS, Zwickl BE. Promoting adaptive coping by persons with HIV disease: evaluation of a patient/partner intervention model. J Assoc Nurses AIDS Care. 2008;19(1):75–84.
17. Schwei RJ, Johnson T, Matthews AK, Jacobs EA. Perceptions of negative health-care experiences and self-reported health behavior change in three racial and ethnic groups. Ethnicity & Health .2017;22(2): 156-168.
18. Kohli R, Sane S, Ghate M, Paranjape R. Coping strategies of HIV-positive individuals and its correlation with quality of life in Pune, India. International Social Work. 2019;59(2):256–267.
19. Mahajan AP, Sayles JN, Patel VA, Remien RH, Ortiz D, Szekeres G, *et al*. Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward. AIDS 2008;22(Suppl 2):S67–S79.
20. Gesesew HA, Gebremedhin AT, Demissie TD, Kerie MW, Sudhakar M, Mwanri L. Significant association between perceived HIV related stigma and late presentation for HIV/AIDS care in low and middle-income countries: a systematic review and meta-analysis. PLoS One 2017;12(3):e0173928.