BARRIERS IN SEEKING HIV CARE SERVICES: AN INVESTIGATION OF PEOPLE INFECTED WITH HIV IN PUNJAB-PAKISTAN

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Original Article

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ABSTRACT

This study examined the barriers in accessing health care and level of well-being among people living with HIV/AIDS. Survey with structured interview was conducted on 420 registered HIV patients with PACP who were selected through double stage cluster sampling and convenient sampling. The results showed that majority of respondents were male and between age of 18-37 years. Common barriers to care were long distance to care, stigma and personal financial resources. Most of respondents had moderate level of overall, physical and social well-being, moderate to high level of functional and cognitive well-being, while low to moderate level of emotional well-being. Among barriers to care, personal financial resources, and stigma significantly lowered well-being while long distance to care, and behaviour of medical staff reduced well-being very little. Personal financial resources was the strongest predictor of change in well-being.

Keywords: Barriers to Care, Well-being, Stigma, HIV/AIDS, Poverty, Discrimination

INTRODUCTION

Pakistan, a country with second largest Muslim population, is on the way to face and respond to HIV crisis (Rai et al., 2007). According to UNAIDS (2016), around 130,000 people were living with HIV in Pakistan while National AIDS control program estimated the number of people with HIV increased to 190,000 till end of 2020 (NACP, 2020). The first reports of HIV in 1987, implicated contaminated blood transfusions as one of major causes (Khanani et al., 1988). The additional route refers to emigrants or Pakistanis settled abroad. These were the more important risk factor of HIV transmission in early years, as established thoroughly by fact that about 70 percent of HIV patients from a sample of about 15,000 individuals over a period of 6 years (1986–1992) lie in this category (Kayani et al., 1994). Majority of the HIV infected people were deported workers from the Gulf States (Shah et al., 1999). Recently, other factors like low literacy rates and high levels of poverty have made Pakistan more at risk to HIV infection than other countries (UNAIDS, 2016). HIV is steadfastly entrenched in Pakistan. This is classified as a concentrated epidemic signifying that occurrence in known risk groups surpasses five percent (World Health Organization, 2018).

In developing countries like Pakistan, among general public, HIV is a disease which is still misunderstood. HIV/AIDS is not only an ailment that disturbs a person's physical health but is a social disorder as well. As a result, HIV and AIDS are intricately entwined in a variety of psychological and socio-economic processes. People infected with HIV/AIDS have to face numerous challenges throughout their lives which hinder them to access medical care including acceptance of HIV positive status, disclosure to others, stigma, social rejection, financial issues, lack of family support and social support. These encounters appear to have substantial effect on health (Li et al., 2009; Ullah & Naz, 2021), psychological well-being (Yi et al., 2015) and quality of life (Kaur & Kumar, 2018) in people living with HIV/AIDS. Further, strict antiretroviral therapy schedules mostly with adverse effects, lifestyle modifications, concern about future also have substantial effect on mental health of people living with HIV (Pinho et al., 2017).

In Pakistan, HIV positive people faced various forms of stigma and discrimination such as verbal abuse, negative self-perception, social isolation and fear of infection which had negative relation with social support and psychological well-being (Tufail, Rafique, & Kamran, 2017). Female patients faced more stigma and fear of disclosure when compared with male patients (Husain, Khalily, & Zulfiqar, 2021). Further, to ensure a better quality of life or well-being, a lot of emotional, psychological, social, medical and spiritual care is required (Paul & Premraj, 2017).

OBJECTIVES

This study focused on the following objectives:

1. To explore the social, psychological, medical, and economic problems of people living with HIV/AIDS.
2. To assess the level of physical, emotional, functional, social, and cognitive well-being as perceived by people living with HIV/AIDS.
3. To know how problems perceived as barriers to care related to their well-being.

METHODOLOGY

Survey with structured interview was done for data collection from HIV/AIDS patients registered with Punjab AIDS Control Program (PACP) and getting ART treatment. Total 44,000 HIV patients were registered and for survey, a sample of 420 outdoor patients (18 years & above) was selected through cluster and convenient sampling technique. Firstly, two districts (Dera Ghazi Khan & Rawalpindi) were selected and then patients were selected proportionately: 336 out of 3700 in Dera Ghazi Khan & 84 out of 950 in Rawalpindi. The inclusion criteria for study participants included HIV/AIDS patients who were (i) registered and taking medications from PACP treatment centers, (ii) showed willingness to participate in this study, and (iii) above the age of 18 years. The data were analyzed by various statistical analyses including frequencies, percentages, Chi-square, correlation coefficients, post-hoc test, simple and multiple linear regression models. The study examined gender and age as background variables; barriers to care, as independent variable; and well-being as dependent variable. The independent variable was measured through a 12-item Barrier to Care Scale (BACS) developed particularly for HIV/AIDS patients (Heckman et al., 1998). The dependent variable was measured by 46-item Functional Assessment of Human Immunodeficiency Virus Infection (FAHI) Quality of Life Instrument Version 4 (Cella et al., 1996).

RESULTS

The socio-economic characteristics of respondents included their gender and age. Table 1 shows that in gender, majority 61.0% of the respondents were male, 33.3% respondents were female and only 5.7% of them were transgenders. In age, most 36.7% of the respondents were from age category of 28-37 years, 26.4% were from age category of 38-47 years, 23.3% were from the age category of 18-27 years and 13.6% were from the age group of 48 years and above. Majority of participants were between age of 18-47 which means that they were active in their familial and occupational lives.

Table 1: Socio-economic Characteristics of the Respondents

Gender	**Frequency**	**Percentage**
Male	256	61.0
Female	140	33.3
Transgender	24	5.7
Total	***420***	***100.0***
Age		
18-27	98	23.3
28-37	154	36.7
38-47	111	26.4
48 & Above	57	13.6
Total	***420***	***100***

Table 2: Distribution of the Respondents Regarding Barrier to Care

Barriers to Care Scale	**No Problem at all f (%)**	**Very Slightly Problem f (%)**	**Somewhat a Problem f (%)**	**Major Problem f (%)**	**Total f (%)**
Long Distance to Care	3 (0.7)	26 (6.2)	91 (21.6)	300 (71.5)	420 (100)
Behavior of medical staff	44 (10.5)	154 (36.7)	191 (45.5)	31 (7.4)	420 (100)
Community Stigma	2 (0.5)	4 (1.0)	45 (10.7)	369 (87.8)	420 (100)
Personal Financial Resources	6 (1.4)	35 (8.3)	154 (36.6)	225 (53.7)	420 (100)

Table 2 represents the results about barriers to care measured as long distance to care, behaviour of medical staff, community stigma and personal financial resources. In long distance to care, majority 71.5% of respondents reported long distance as a major problem, for 21.6% it was a somewhat problem, for 6.2% it was a very slight problem, and only 0.7% said that long distance was not a problem for them. In behaviour of medical staff, 45.5% or respondents stated that it was somewhat problem for them, 36.7% described it as a very slight problem, 7.4% recognized it as a major problem and only for 10.5% behaviour of medical staff was not a problem at all. In community stigma, vast majority 87.8% of respondents reported it as a major problem, 10.7% said it was somewhat a problem, 1.0% stated that it was a very slight problem and only 0.5% of respondents described it was not a problem at all. In personal financial resources, 53.7% of respondents said it was a major problem, 36.6% stated it as somewhat a problem, only 8.3% reported it was a very slight problem and only 1.4% of respondents felt it as no problem at all.

Table 3: Distribution of the Respondents Regarding Overall Well-being and its Dimensions

Dimensions of Well-being	Low f (%)	Moderate f (%)	High f (%)	Total f (%)
Overall Well-being	16 (3.8)	368 (87.6)	36 (8.6)	420 (100)
Physical Well-being	33 (7.9)	345 (82.1)	42 (10.0)	420 (100)
Emotional Well-being	277 (66.0)	133 (31.7)	10 (2.4)	420 (100)
Functional Well-being	30 (7.1)	191 (45.5)	199 (47.4)	420 (100)
Social Well-being	28 (6.7)	262 (62.4)	130 (31.0)	420 (100)
Cognitive Well-being	63 (15.0)	219 (52.1)	138 (32.9)	420 (100)

Table 3 elaborates the self-reported score of people living with HIV/AIDS on overall well-being scale and its subscales. The results show that in terms of overall well-being, 87.6% of respondents had moderate level, 8.6% had high level and 3.8% had low level of well-being. In physical dimension, 82.1% of respondents had moderate level, 10.0% had high level and 7.9% had low level of well-being. In emotional dimension, 66.0% had low level, 31.7% had moderate level, and 2.4% had high level of well-being. In functional dimension, 47.4% had high level, 45.5% had moderate level, and only 7.1 % had low level of well-being. In social dimension, 62.4% had moderate level, 31.0% had high level and 6.7% had low level of well-being. In cognitive dimension, 52.1% had moderate level, 32.9% had high level and 15.0% had low level of well-being.

Table 4: Effects of Barriers to Care on Well-being: Simple Linear Regression Analysis

	Independent Variables	b.	SE	R^2	Beta	P
1	Barriers to Care	-0.100	0.035	0.019	-0.139	.004

Dependent variable: Well-being Significance level:<0.05

Table 4 shows the results of simple linear regression, the regression coefficient of the variable had a negative sign with value (b=-0.100), and it is highly significant at (P=.004) with (R^2=0.019). The values given depicts that barriers to care (independent variable) significantly predicted the well-being (dependent variable) as 13 percent of the variation in the well-being was explained by barriers to care. Further, one level increase in barriers to care made a 10.0 percent decrease in well-being.

Table 5: Effects of Sub-Scales of (Barriers to Care) Variables on Dependent Variable (Well Being): A Multiple Linear Regression Analysis

Model		Unstandardised Coefficients		Standardised Coefficients	
		b.	Std. Error	Beta	Sig.
01	**Constant**	2.649	0.256		0.000
	Long Distance to Care	-0.050	0.028	-0.029	0.856
	Behaviour of Medical Staff	-0.059	0.048	-0.061	0.218
	Community Stigma	-0.159	0.027	-0.198	0.031
	Personal Financial Resources	-0.192	0.043	-0.261	0.009

Significance level :<0.113 R^2=.108 SE=.348

Table 5 represents the results of multiple linear regression model, in which the quantitative measure of "well-being" was considered as a dependent variable, and the four barriers to care "long distance to care", "behaviour of medical staff", "community stigma" and "personal financial resources" were taken as independent variables. According to the results, the value of coefficient (b=2.649) was significant with the (P=0.000) and R Square value of (R^2=0.108). This model showed that two variables significantly affected the dependent variable "well-being", but "personal financial resources" was the strongest predictor for variance/change. The variable wise portrayal of the results drawn from the regression coefficient model is discussed below:

Long distance to care showed a negative relationship with well-being as regression coefficient value was (b=-0.050). It was nonsignificant at the value (P=0.856). It means that 2.9 percent of variation in well-being was explained by long distance to care. Further, one level increase in long distance to care caused a 5.0% decrease in well-being of people living with HIV/AIDS but that impact was not significant. Behaviour of medical staff showed a negative relationship with well-being as regression coefficient value was (b=-0.059). It was nonsignificant at the value (P=0.218). It means that 6.1 percent of variation in well-being was explained by behaviour of medical staff. Further, one level increase in behaviour of medical staff caused a 5.9% decrease in well-being of people living with HIV/AIDS but that impact was not significant.

Community stigma showed a negative relationship with well-being as regression coefficient value was (b=-0.159). It was significant at the value (P=0.031). It means that 19.8 percent of variation in well-being was explained by community stigma. Further, one level increase in community stigma caused a 15.9% decrease in well-being. So, it could be concluded that the increase in community stigma significantly decreased the well-being of people living with HIV/AIDS. Personal financial resources showed a negative relationship with well-being as regression coefficient value was (b=-0.192). It was significant at the value (P=0.009). It means that 26.1 percent of variation in well-being was explained by personal financial resources. Further, one level increase in personal financial resources caused a 19.2% decrease in well-being. So, it could be concluded that the increase in personal financial resources significantly decreased the well-being of people living with HIV/AIDS.

Table 6: Crosstab of Gender and Barriers to Care

Gender of the respondents	Barrier to Care				Total
	No problem at all	Very slight problem	Somewhat a problem	Major problem	
Male	3	27	198	28	256
Female	0	14	112	14	140
Transgender	0	1	21	2	24
Total	3	42	331	44	420

Chi-Square =3.328 df=6 Sig=0.776 Gamma=0.044 Sig=0.679

Table 7: Crosstab of Gender and Well-being

Gender of the respondents	Well Being			Total
	Low	Moderate	High	
Male	8	217	31	256
Female	8	131	1	140
Transgender	0	20	4	24
Total	16	368	36	420

Chi-Square =19.074** df=4 Sig=0.001 Gamma=-0.374 Sig=0.008

Table 8: Post-hoc Comparison in Groups of Gender by Well-being

Gender	Male		Female		Transgender	
	Mean	SD	Mean	SD	Mean	SD
Well-being	2.17	.381	1.95	.249	2.09	.381

Significance level:<0.05

The association of gender with barriers to care and well-being was examined by Chi-square test (Table 6 and 7) and results showed a nonsignificant (0.776) association between gender and barriers to care depicting that both variables were independent of each other. The results of association between gender and well-being showed significant association (0.001) between these variables. Gamma value (-0.374) showed moderate and inverse relation. Further, post hoc test for gender (Table 8) found that male respondents had higher level of well-being while female respondents had lowest level of well-being.

Table 9: Correlation Coefficient of Age with Barriers to Care and Well-being

Variables	Spearman's Correlations	Barriers to Care	Well-being
Age	Correlation Coefficient	.108*	.008
	Sig. (2-tailed)	.027	.869

Table 10: Post-hoc Comparison in Groups of age by Barriers to Care

Age	18-27		28-37		38-47		48 & above	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Barriers to care	2.91	.499	2.99	.443	3.02	.539	3.09	.434

Significance level: <0.05

Table 9 presents the relationship of age with barriers to care and well-being and results of correlation coefficient analysis showed a positive significant relation (r = .108*, P = .027) between age and barriers to care depicting that increase in age was related to more barriers to care. Further, post hoc test for age (Table 10) found that older respondents faced more barriers to care the younger ones. The respondents in age category (18-27) faced minimum barriers to care while respondents in age category (48 & above) faced maximum barriers to care. The results of correlation between age and well-being showed positive nonsignificant (r = .008, P = .869) relation between these variables depicting no difference between age categories regarding well-being.

DISCUSSION

The results showed that majority of respondents were male and between the ages of 18-37, the age crucial for career, familial and other social activities. The common major problems reported by majority of people living with HIV/AIDS in this sample were long distance to medical care, community resident’s stigma against HIV/AIDS, and less personal financial resources. On the other hand, resistance of medical staff to provide care was perceived as somewhat problem by nearly half of respondents as staff of PACP medical centre was cooperative but they faced resistance from medical staff of other medical centres. Due to fear of disclosure and refusal from medical staff, people living with HIV were unable to get medical care from nearby medical centre and had to travel far away for seeking medical care. Stigma and discrimination about HIV was prevalent in study area. So most of participants disclosed their HIV status to only close family members and concealed from community. They avoided social gatherings and public participation due to fear of disclosure and stigma, consequently, suffered from loneliness and isolation. Further, job loss, less employment opportunities and incapacity to work due to physical symptoms forced most of them to live hand to mouth. These results are consistent with previous studies as most of literature showed that community stigma was major problem faced by people living with HIV/AIDS (Mutumba et al., 2015; Yi et al., 2015; Tufail et al., 2017; Anima-Korang et al., 2018). Other major barriers were job loss and financial issues (Cloete et al., 2010; Abubakar et al., 2016; Paul & Premraj, 2017; Nyongesa et al., 2022), discrimination and rejection from family, relatives or community members (Kirloskar, 2013; Narang et al., 2015; Li et al., 2009).

According to results, majority of respondents had moderate level of physical and social well-being. As they were receiving ART, the physical symptoms of HIV were controlled and physical health of most participants was good. Due to traditional family system, social support and cooperation from family was also available to most of participants and their relationships with family members were strong. In functional and cognitive dimension, majority of respondents had moderate to high level of well-being as ART had restored their functional and cognitive capacities. While in emotional dimension, majority of respondents had low to moderate level of well-being as fear of disclosure, stigma, rejection, isolation and discrimination lead them to stress. However, in terms of overall well-being, majority of respondents had moderate level score. These findings are consistent with previous studies which reported that HIV patients had only a fair level of well-being

(Li et al., 2009; Kaur & Kumar, 2018). Further, depression, anxiety and stress were also found common among HIV patients (Tesfaw et al., 2016; Nanni et al., 2015).

The results of simple linear regression showed that barriers to care decreased the well-being of people living with HIV/AIDS. It can be said that people who faced more barriers to care were more likely to have poor well-being. Moreover, results of multiple linear regression also presented that barriers to care significantly reduced well-being of people living with HIV/AIDS. Personal financial resources and community stigma significantly lowered well-being while long distance to care, and behaviour of medical staff reduced well-being very little. Personal financial resources were the strongest predictor of change in well-being. The previous literature also evidenced that personal resources, job loss and monetary issues (Dejman et al., 2015; Nyongesa et al., 2022), community stigma (Li et al., 2009; Yi et al., 2015; Tufail et al., 2017; Anima-Korang et al., 2018), rejection from family and community (Tesfaw et al., 2016; Kirloskar, 2013) and resistant behaviour of health care staff (Kose et al., 2012) caused poor quality of life and wellbeing in people living with HIV/AIDS.

In terms of gender, no differences were found in barriers to care reflecting that male, female and transgenders faced barriers at same level also evidenced by (Rongkavilit et al., 2010) while other previous studies reported that females with HIV faced more barriers to care than males (Gordillo et al., 2009; Kose et al., 2012; Basha et al., 2019: Hussain et al., 2021). Further, a significant inverse association was found between gender and well-being depicting that males living with HIV/AIDS had better well-being than transgenders and females which were also consistent with previous literature (Gordillo, 2009; Yi et al., 2015). The reason might be that females were subordinate in patriarchy, so they faced more stigma, rejection and discrimination. They could not take decisions at their own about seeking medical care and treatment adherence. Regarding age, significant differences were found in barriers to care as older people with HIV faced more barriers to care than their younger counterparts. The reason might be fact that aging is linked with dependency and comorbidities. On the contrary, differences in well-being were not significant reflecting that all people had same level of well-being irrespective of their age.

CONCLUSION

The study found that common problems perceived as major barriers to care were long distance to care, community stigma and less personal financial resources. Majority of people with HIV had moderate level of overall, physical and social well-being, moderate to high level of functional and cognitive well-being, and low to moderate level of emotional well-being. The people who faced more barriers to care also had poor well-being. Less personal financial resources and community stigma caused significant decrease in well-being of people while effect of long distance to care and behaviour of medical staff was very little. Based on findings of study, it is suggested that comprehensive policy for job security, employment opportunities and financial assistance should be devised. Further, civil society and support groups are needed to engage regarding provision of enabling environment and logistic arrangements.

STRENGTHS AND LIMITATIONS

The study explored the barriers HIV patients faced in accessing HIV care and assessed physical, emotional, functional social and cognitive well-being. Furthermore, assessing well-being by using multidimensional approach highlighted the need of using a holistic model for better treatment, care and counselling of HIV/AIDS patients. The major limitation of study was to collect data through interview schedule and included 18 years and above outdoor patients.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

All procedures performed in study were in accordance with the ethical standards of Punjab AIDS Control Program (PACP), Punjab, Pakistan. Written informed consent with signature and/or thumb impression was taken from the study participants. However, the researcher read out consent from for illiterate participants and took thumb impression from them on consent form. The study participant understood the content of the consent form and gave consent to participate in the study before starting the interview.

ACKNOWLEDGEMENT

I am grateful to the Project Director, Punjab AIDS Control Program (PACP) as well as District Staff of PACP Dera Ghazi Khan and Rawalpindi for their permission and support in accessing the participants of study.

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