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RESEARCH PAPER

Stigmatized Discrimination, Barriers to Care and Depression among people living with HIV (PLHIV): Role of Perceived availability of belonging Social Support

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ABSTRACT

Current study aims to assess the impact of perceived stigmatized discrimination (PD), perceived barriers to care (PBC) and Perceived belonging social support (PBS) on depression (DP) among PLHIV residing in rural areas. This research also investigates moderating role of PBS in the PD-DP as well as PBC-DP relationship. Using purposive convenient sampling technique, data for this quantitative study were collected through cross-sectional surveys from a rural sample (N = 278) of PLHIV. Participants of the study provided information on socio-demographic factors, PD, PBC , DP and PBS. Present study found PD, PBC and PBS significantly predicting Depression. PBS was found significantly mitigating the PD-DP link, however, moderating impacts of PBS could not be found in PBC-DP relationship. Current research highlights importance of providing acceptance to the PLHIV and reducing the barriers to care among PLHIV residing in rural areas of Pakistan. Further research is needed to investigate moderating role of spiritual support and engagement coping in the perceived stigmatization and depression relationship.

KEYWORDS Barriers to Care, Bio-Psychosocial Model, Social Stigma Theory, Stigmatized Discrimination, Transactional Model of Stress and Coping

Introduction

Prevalence of mental stress among PLHIV has been reported to be 2-4 times greater as compared to general population (Wang et al 2018; Duko et al 2019). Mental strain relates to adjustment issues, social relationships, adherence to medical treatment and even risk for one's life (Mayston et al 2012; Charlson 2016). According to empirical findings (Ahmed et al 2021; Grov et al 2010; Schuster 2012) the antecedents of psychological distress among PLHIV have been reported to be disease-stigma, discrimination, side effects of medical treatment and even neuropsychological changes. However, among PLHIV some groups are more vulnerable to psychological distress for instance, women (Kelly, et al, 1987), and those with visible symptoms (Heckman et al., 1998; Rounds, 1988). Prevalence of high degree of HIV-stigma in rural populations found in past studies (Georgas, 1989; Heckman et al., 1998; Katakis, 1984, Rounds, 1988; Zukoski & Thorburn, 2009) have been reported even in latest studies (Amare 2018; Pappin et al 2012; Thai et al 2018; Tesfaw et al 2016) that investigated higher level of stigma and distress among women, PLHIV residing in rural areas, advanced stage patients, lonely individuals, patients facing disease-stigma as well as limited social support, unemployed or from low-income group, low in education, involved in substance use especially those who inject drugs. Ahmed et al. (2021) reported depressive symptoms among PLHIV and attributed these symptoms to HIV-disease stigma. HIV-disease has been found attributed to moral deviations on the part of the patients. Khan et al (2019) and Khan et al (2017) also reported misconceptions and limited knowledge about HIV-disease related to HIV-disease stigma. Empirical findings have highlighted that due to the general public's lack of disease knowledge people try to avoid PLWHA out of fear of

contracting the disease (Ahmed et al. 2021; Khan et al 2019; Khan et al 2017; Steward et al 2008).

Stigma and Limited social support

On account of disease-status PLHIV reported limited social support (Vanlandingham, et al., 2005; Heckman et al., 2002; Galvan, 2008), or support inadequate to their needs (Peters-Golden, 1982) low in seeking support (Foreman, 2003; Ware, et al 2006). Vanable et al., (2006) also had similar findings. Luoma & Hakamies-Blomqvist, (2004) investigated that patients experiencing progression of their disease have reported discriminatory treatment from co-workers, neighborhood and even from their social network. Patients with visible symptoms express their apprehensions about prejudicial treatment, they also reported not having adequate support from others , they experience issues related to social relations and worries about issues related to death (Lethborg, et al 2006).

Prejudicial treatment towards PLHIV

Social rejection and discriminatory treatment after the diagnosis of HIV-disease is not uncommon among PLHIV (Heckman et al 2002; Kalichman et al., 2000; Vanable et al , 2006). Discriminatory treatment has been reported by the PLHIV in their social relationships as well as in the workplace (Herek, et al 1999). Prejudicial treatment results in isolation, loneliness , anxiety , and psychological issues (Bolmsjo, 2000), depression and anxiety (Dahab, et al., 2008; Folkman, et al 1992 ;Li**, 2**009) low esteem (Tesfaw et al, 2016). thinking of committing suicide and risk of committing suicide (Steward et al., 2008) and even perceiving that support is not available to them Galvan, et al., (2008) and they are burden on others (Rydahl-Hansen, 2005). These symptoms are followed by passive coping strategies (Ahmed et al 2021) e.g PLHIV were found isolating themselves and avoid seeking social support (Duko 2019).

Barriers to Care

According to Lubkin and Larsen, (2006) stigma follows inequitable and discriminatory treatment, however, severity of such treatment is conditional on the level of stigmatized condition Dahab et al., (2008) and Murray et al., (2009) found commonly reported barriers in the life of PLHIV as follows: disease stigma, disclosure and treatment related concerns, limited personal resources, limited information about their disease, disease and limited professional care . Heckman et al., (1998) highlighted that PLHIV report inaccessibility to caring health care professional for getting treatment.

Due to afore-mentioned barriers disease stressors are perceived as uncontrollable by the PLHIV, this perception leads them to depression (Heckman et al., 2002),non- adherence to medical treatment and resistance to their illness (Aguocha et al 2015; Chan et al 2017). HIV-disease stigma has been found affecting disease disclosure as well as treatment adherence (Maman et al 2009; Nhamo et al 2010). Non-adherence to medical treatment has also been found an outcome of psychological distress among PLHIV (Ahmed et al 2021).

Considering the prevalence of stigmatized discrimination and psychological distress among PLHIV in Pakistan (e.g., Ahmed et al 2021), and social rejection to PLHIV due to the fearof contracting disease (e.g., Khan et al., 2019; Khan et al 2017), it was required to investigate in the local context the barriers to care and stigmatization among PLHIV. As recommended by the researchers for instance Heckman, (2003) to study HIV-disease from bio-psychosocial model, and as highlighted by WHO (2016) to show caring and supportive attitude towards PLHIV , which facilitates handling of illness-related stressors (e.g National Board of Health, 2005; Saunders, 2006) and in adherence to treatment (Heckman, 2003; Kanyemba 2021;West 2019). Current study aimed to investigate the perception of

stigmatized discrimination, barriers to care, perceived availability of social support and depression among PLHIV. Moreover, this study also investigated the moderating role of perceived availability of belonging social support in the stress-distress link. As previous studies have suggested high degree of HIV-stigma among rural populations (e.g Heckman et al., 1998; Thai et al 2018; Tesfaw et al 2016),sample of this study has been drawn from rural population of Pakistan.

Considering the Lazarus and Folkman (1984) model of stress and coping , Goffman, (1963) social stigma theory and the past empirical findings, following hypotheses have been formulated

H1: PD predicts DP among PLHIV

H2: PBC predicts DP among PLHIV

H3: PBS predicts DP among PLHIV

H4: PBS moderates the PBC and DP link among PLHIV

H5. PBS moderates the PD and DP relationship among PLHIV

Material and Method

Population and Sample

Using purposive convenient sampling techniques data was collected from a rural sample of 278 PLHIV with an age range between 32-69 years (M = 44.6, SD = 1.20) with 62 % females and 38% female participants. Data for this study were gathered from 320 Advanced stage PLHIV, receiving medical treatment however, after the process of data cleaning valid responses were 278 (response rate was 87%). Sample of this study were predominantly from low to middle SES. Besides, obtaining information on study variables data were also collected about gender, age, employment, education, and marital status. Considering the limited education of rural sample, Urdu translated version of all scales were used in this study. Study sample was given information about the nature of this study. They were given assurance of confidentiality as well as anonymity. They were also informed about estimated time for providing the information and the that they could withdraw from this research any time. After obtaining the written informed consent they were given socio-demographic questionnaire sheet as well as questionnaires related to study variables. They were asked to provide honest answers following the response format.

Measures

Present study assessed stigmatized discrimination among PLHIV using 12-items disease-related stigma scale (Heckman et al. 1998) on a 4-point rating scale (1=Never, to 4=often). Alpha reliability coefficient of this measure was .85 in the present study. Barriers to Care scale (Heckman, et al. 1998) consisting of 13-items was used to assess the severity of problems faced while accessing services. PLHIV rated perceived barriers on a 4-point response format (1 = No problem at all and 4= major problem). Alpha reliability coefficient was .82 in this study. A sub-scale of Interpersonal Support Evaluation List (Cohen, et al 1985), namely 10 items of belonging social support (PBS) were rated on a 4-point ratio scale (0 =definitely false, 3=definitely true) by the PLHIV. The reliability of this measure was α =.94 in current study. 21-item-self report instrument BDI (Beck & Steer, 1993) was used for assessing Depression. Response format ranged from 0 to 3, 0= min whereas 3= max. The Alpha reliability coefficient of this measure was .92 in the current study.

Results and Discussion

Table 1
Descriptive Statistics, Correlation and Alpha Reliability coefficients among the study variables

		Mean	SD	1	2	3	4	5
1	PD	2.50	.45	**(.84)**	.09	-.19**	.38**	.-18
2	BC	2.51	.58		**(.81)**	-.22**	.23**	-.19
3	PBS	1.53	.64			**(.95)**	-. 51*	.69
4	DP	1.31	.59				**(.93)**	-.46
5	AS	1.21	.41					**(.86)**

Note: PD: Perceived discrimination, PBC; perceived barriers to care, PBS: perceived belonging support, DP: Depression, PAS perceived appraisal support,

**p<.001, *p<.01

Table 1 demonstrates descriptive statistics, mean, standard deviation, and correlation between the study variables. As reflected by the Alpha reliability coefficients (ranging from 0.81- .95) adequate internal consistency was found (Nunnally, 1978). Moreover, the results indicate that PD and PBC significantly correlate with DP. Moreover, significant negative correlation between PD and PBS as well as PBC and PBS can be seen in the above table. PD and PBC are significantly positively related to PD. PBS is significantly negatively related to DP.

PD and PBC are inversely related to PBS providing evidence for discriminant validity. PD and PBC significant positive correlation with outcome variable DP provides evidence for criterion validity, same holds true for the inverse correlation between PBS and DP. Furthermore, PBS and PAS are significantly positively related to each other hence providing evidence of convergent validity.

Table 2
Moderated Multiple Regression analysis of PD, PBS and PBC as predictors of DP

Model	*b*	*SE*	*t*	LLCI	*ULCI*
(Constant)	1.15	.03	48.01**	1.11	1.20
PBC (centered)	.06	.02	2.38**	.01	.15
PBS (centered)	-.21	.03	-8.11**	-.23	-.13
PBCx PBS	-.03	.02	1.09	-.16	-.01
(Constant)	1.13	.02	47.21**	1.07	1.18
PD (centered)	.10	.02	4.23**	.06	2.67
PBS(centered)	-.18	.03	-6.87**	-7.16	-4.99
PD x PBS	-.11	.03	-2.14*	-2.85	-.62

*PD: perceived discrimination, PBC: Perceived barriers to Care, PBS: Perceived belonging support, DP: depression, **p < 0.001 and *p < 0.01.*

Table 2 shows the results of the moderation analysis. Findings indicate significant impact of PBC on DP (b = 0.06, p < 0.001), and PD on DP (b = 0.10, p < 0.001). PBS also has a significant impact on DP (b = -.21, p < 0.001), thus supporting the H1, H2, and H3 that anticipated PD, PBC and PBS as significant predictors of DP. In this study moderating impact of PBS in the relationship between PBC and DP were not found, hence H4 was not supported. However, the moderating effect of PBS on PD (PD × PBS) had a significant impact on DP (b = -0.11, p < .01). Therefore, hypotheses H5 was supported that anticipated moderating impact of PBS in the PD-DP relationship.

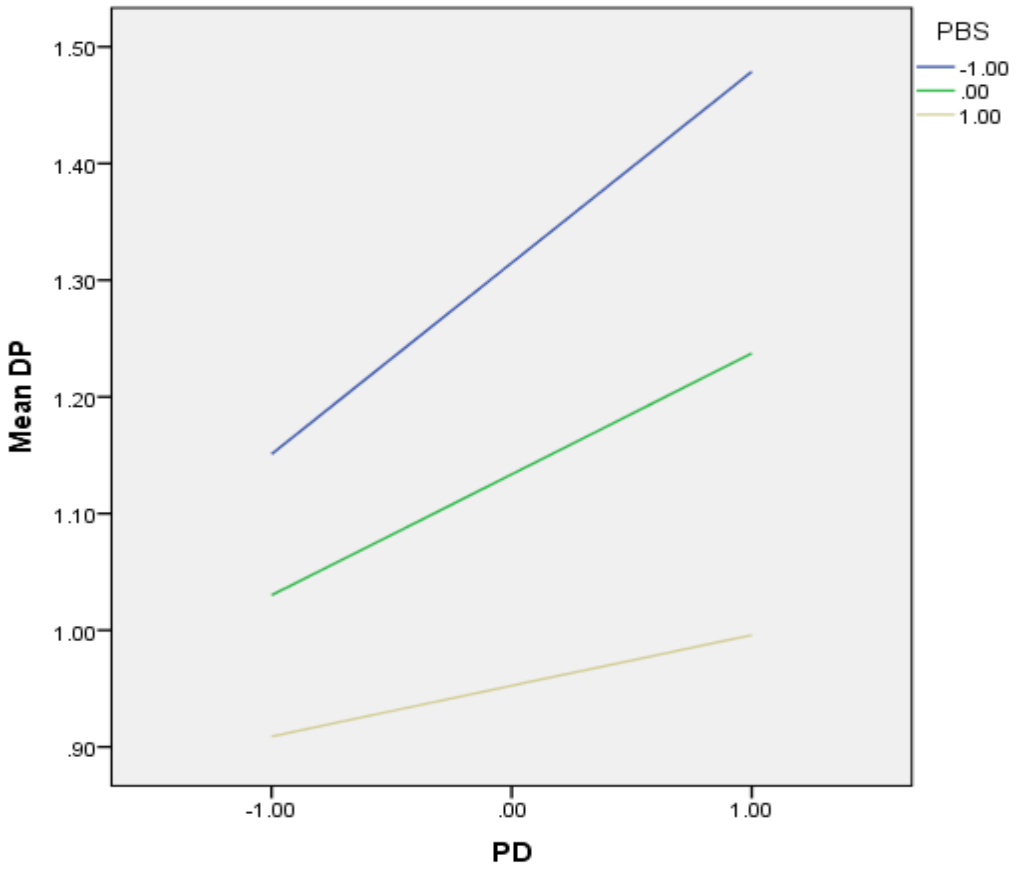

Figure 1 showing visual inspection of moderating relationship

Present study was conducted to investigate level of Perceived stigmatized discrimination (PD) Perceived Barriers to care (PBC) Perceived availability of belonging social support (PBS) and depression (DP) among PLHIV residing in rural areas of Pakistan. Moreover, the moderating role of PBS was also investigated in PD-DP and PBC-DP relationship. PD could significantly predict level of DP among PLHIV, thus supporting H1 of this study. This result is consistent with previous research findings that demonstrates stigmatization predicting depressive symptoms (Kalichman, 2000; Li et al. 2009) suicidal ideation (Carrico et al., 2007; Steward et al., 2008) isolation , loneliness , anxiety and psychological issues (Bolmsjo, 2000; Major & O'Brien, 2005) among PLHIV. Perceived barriers to care could significantly predict level of depression among PLHIV the result was consistent with previous research findings for instance by Heckman and Anderson, (2002) and Heckman et al., (2002) PLHIV disease stressors namely barriers are perceived as uncontrollable leading to depression. PLHIV in rural areas report relatively more barriers to care (Heckman et al., 1998). PBS significantly predicted DP thus supporting H3 that demonstrates PBC positively relates to DP. Perceived availability of belonging social support (PBS) could not moderate the PBC and DP relationship thus not supporting H4 that anticipated moderating role of PBS in PBC-DP relationship. Perceived availability of belonging social support (PBS) could mitigate the PD and DP relationship thus supporting (H5) that anticipated moderating role of PBS in the PD-DP link. These findings are consistent with previous study where patients perceiving availability of social reported reduced level of distress (Cohen & Wills, 1985) lesser psychological symptoms (Cohen & Leis, 2002; Noris & Kaniasty, 1996), improvement in QoL (Serovich, et al., 2001**)** and appraised barriers as less threatening (Heckman et al., 2002).

Conclusion

Findings of this study revealed PD and PBC predicts depression among PLHIV. PBS plays a moderating role in the relationship between PD and DP relationship among PLHIV. However, PBS could not mitigate the negative impact of PD on DP. Perceived availability of belonging support for PLHIV is believed to be a best social resource for making them feel valued thereby improving their level of depression. Our study adds to the literature in the field of perceived stigmatization discrimination, barriers to care and perceived availability of belonging social support by developing a study framework, that captures moderating impact of PBS in the PD -DP link.

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