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Internalized HIV Stigma, Psychological Distress, and Quality of Life in a Collectivist Culture

Ayesha Noor[1], Valerie Earnshaw[2]

[1]Assistant Professor, Department of Management Sciences, Shaheed Zulfiqar Ali Bhutto Institute of Science & Technology, Islamabad
[2]Associate Professor, Department of Human Development and Family, University of Delaware, USA
Correspondence: ayeshanoor.2012@gmail.com[1]

ABSTRACT

Background: This study analyzes the impact of internalized HIV stigma on psychological distress and quality of life among the individuals infected with HIV in collectivistic culture.

Method: Questionnaires were distributed to 250 PLWHA and a total of 138 questionnaires were returned.

Results: The results shows that internalized HIV stigma negatively affect the quality life of HIV infected people with mediation of psychological distress. The results also depicted that collectivistic culture positively exacerbate the relationship between internalized HIV stigma and psychological distress.

Conclusion: Overall this study shows that internalized stigma affects the quality of life in collectivist culture. Implications are also given at the end.

Keywords: Internalized HIV Stigma, Psychological Distress, Quality of Life, Collectivist Culture, Psychosocial and Emotional Aspects, Discrimination, Help Seeking Behavior.

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Introduction

There are approximately 36.7 million PLWHA worldwide and 4 million infected people are living in Asia (WHO, 2013, 2016). It has been depicted in various studies that PLWHA experience stigma (Herek, 2002) from others in a range of settings, including familial, educational, employment, and healthcare (Busza, 2001; Thornicroft, Rose & Kassam, 2007; Yoshioka & Schustack, 2001) resulting in poor mental and physical health, greater social isolation, fewer educational and employment opportunities, and less healthcare access and treatment(Campbell et al., 2005; Leserman, 2008; Lichtenstein et al., 2002; Liu et al., 2006; Thornicroft et al., 2009) due to labeling, stereotyping and discrimination (Link & Phelan, 2001) that undermines the wellbeing of people living with HIV/AIDS (PLWHA) globally (Parker & Aggleton, 2002) due to which Quality of life is well thought-out of as a vital factor to study among the HIV infected individuals in any context (Mannheimer et al., 2005; Rongkavilit et al.,2010).

Collectivist culture are more attributed to accelerate the HIV stigma as compare to individualistic culture (Liamputtong,2013)because stigma varies across different cultures (Valdiserri, 2002) and disclosure of HIV widely depends upon the cultural factors (Körner, 2007).

Triands (1995) distinguished between collectivist and individualistic cultures due to the difference of beliefs, values and practices .Asian culture is more oriented towards collectivism (Hofstede, 1980; Turiel,2004) Pakistan has a collectivist culture and is one of 12 Asian countries wherein 90% of HIV cases are reported (Khalil et al., 2015), HIV stigma remains understudied in Pakistan. There has historically been limited understanding of HIV among people in Pakistan (Farid & Choudary, 2003; Irfan et al., 2002). A study conducted on HIV patients in organizational setting of Pakistan reported that the infected people face a lot stigmatization due to HIV (Bashir, 2011).Similarly another study shows that people encounter an elevated level of internalized stigma because of any infectious disease in Pakistan (Noor et al., 2016). Pakistan is therefore an ideal context in which to study associations between internalized stigma, collectivism, and quality of life.

Collectivist Culture

The norms and values of particular cultures shape the thoughts, feelings, and behavior of its people (Schwartz, 1994), including as they relate to internalized stigma. HIV internalized stigma affects more on the physical and emotional wellbeing of the infected individual in presence of certain inequalities in the society (Fekete et al., 2017) The extent to which cultures are collectivist vs. individualistic plays a critical role in the progression of stigma and how individuals within a culture experience stigma (Liu et al., 2006). Collectivist cultures are shaped around groups and importance is placed on following shared group values (Hall, 1976). In contrast, individualistic cultures are shaped around individuals and importance is placed on following individual values. Evidence suggests that this aspect of culture affects the wellbeing of individuals (Fulmer et al., 2010), and researchers have argued for the importance of studying associations between collectivism and individualism with wellbeing (Du et al., 2014).

Collectivist culture may strengthen the association between internalized HIV stigma and psychological distress. Although understudied, the influence of HIV stigma on individual wellbeing is theorized to fluctuate across cultures (Herek & Mitnick, 1998).In collectivist cultures, the entire family is viewed as accountable for individual family members' actions, and thus the entire family experiences HIV stigma when an individual family member is living with HIV (Liamputtong, 2013). Moreover, individuals in collectivist cultures display greater concern about the effects of their actions on others (Hui & Triandis, 1986). PLWHA in collectivist cultures may therefore experience greater psychological distress because they feel that they have brought shame on their entire family, rather than only on themselves (Yoshioka & Schustack, 2001). Individuals differ in the level to which they internalize the values of collectivist culture (Triandis et al., 1988). Therefore, within a collectivist culture such as Pakistan, individuals who internalize stigma and report greater collectivism may experience more psychological distress than individuals who report less collectivism.

Internalized Stigma, Psychological Distress and Quality of Life

HIV stigma is described as social devaluation and discrediting (Goffman, 1963) as different kinds of stigma are attached in disclosing the HIV condition (Mao et al., 2017).In addition to experiencing stigma from others, PLWHA may internalize stigma by endorsing negative stereotypes and prejudice associated with HIV and applying them to the self (Bennett et al., 2016; Earnshaw & Chaudoir, 2009; Grodensky et al., 2015; Lee et al., 2002). When compared to stigma experienced from others, internalized stigma appears to be particularly potent predictor of several indicators of wellbeing among PLWHA (Earnshaw et al., 2013).

Internalized stigma may undermine the quality of life of PLWHA in Pakistan. Quality of life is a multidimensional construct involving individuals' subjective assessments of their lives related to several domains, including physical, social relationships, psychological and environment (World Health Organization, 2004).Internalized stigma is connected with worse overall quality of life among PLWHA in China (Xianhong et al., 2011). Additionally, internalized stigma is allied with indicators of worse wellbeing related to specific domains of quality of life among PLWHA, including physical health, mental health, and social support (Ballester-Arnal et al., 2016; Earnshaw et al., 2015; Lee et al., 2002;Remor et

al., 2016;Yang & Mak, 2017).Some evidence suggests that internalized stigma is a stronger predictor of certain domains of quality of life, including psychological wellbeing, than stigma experienced from others (Earnshaw, et al. 2013).

H1: Internalized HIV stigma is negatively associated with quality of life among PLWHA in Pakistan.

Internalized HIV stigma may be related with lower quality of life via the mechanism of greater psychological distress among PLWHA in Pakistan. HIV/AIDS imposes a significant psychological burden or distress (Hudson et al., 2001; Liu et al., 2013; WHO, 2008), including due to experiences of HIV stigma. A number of studies have indicated that experiences of HIV stigma, including internalized stigma, are related to increased psychological distress (Charles et al., 2012; Deribew et al., 2010; Emlet, 2007; Lee et al., 2002; Pappin, Edwin, & Booysen, 2012). Additionally, meta-analytic evidence demonstrates that internalized stigma specifically is associated with worse mental health, including psychological distress among the people who are living with a array of stigmatized characteristics (Mak et al., 2007). Internalized stigma is theorized to be allied with increased psychological distress for several reasons. Internalized stigma has been conceptualized as a form of self-hatred, which leads to negative affect (Lee et al., 2002). Internalized stigma is also theorized to make individuals more sensitive to experiences of stigma from others, which are experienced as chronic stressors in the environment that may lead to distress (Williams et al., 2003). Moreover, internalized stigma may lead people to withdrawal from others, and ensuing diminished social support may result in psychological distress (Dew et al., 1997; Katz et al., 1996; Tesfaye & Bune, 2014). Emotional or psychological distress is considered as an important predictor in assessing the quality of life among the PLWHA (Sowell et al., 1997) as psychological distress has the major influence on QoL (Herrmann, 2013)

H2: Internalized HIV stigma is positively associated with psychological distress among PLWHA in Pakistan.

H3: Psychological distress is negatively associated with quality of life among PLWHA in Pakistan.

H4: Psychological distress mediates the relationship between internalized HIV stigma and quality of life among PLWHA.

Methodology

The HIV/AIDS patients in Pakistan were contacted. The participants were approach with the help of NGO'S who are working for the prevention of HIV and also through hospitals in which HIV infected patients were treated. Initially 281 PLHA were identified but most of them refused to participate in the study and it become quite challenging to collect the data .As a result only 138 infected individuals were convinced to participate. The participants were those who even after the diagnosis of the HIV continue their jobs and had some working experience

Data was collected through self-reported questionnaire to ensure the confidentiality of the respondents. For this an informed consent was obtained (Bhutta, 2002) and the participants were ensured that the data will be only for the research purpose and for this the details were not shared with the author for avoiding direct contact. The respondents filled the questionnaires by themselves and for illiterate people the questionnaire was read and responses were recorded on 5 point Likert scale with 1 indicating strongly disagree and 5 indicating strongly agree.

Questionnaires were distributed to 250 PLWHA and a total of 138 questionnaires were returned having the response rate of 55% .21.7% of respondents had an educational level of masters or above, 47 % had a bachelor's degree, and 31.2% percent had matriculation degree. There were more male (83.3%) than female (16.7%) respondents. The majority of respondents (67.4%) were married. 41% of respondents were between the ages of 20 and 30 years, 25.4% were between 30 and 40 years,11.6% were between40 and 50 years, and 21.7% were 50 years and above.

Measures

Internalized HIV Stigma. Six items were adopted from Kalichman et al.'s Internalized HIV Stigma scale (2009). Sample items include "*It is difficult to tell people about my HIV infection*", "*I feel guilty that I am HIV positive*", and "*I sometimes feel worthless because I am HIV positive*". The scale was reliable, with an alpha of 0.82.

Psychological Distress. Ten items are adopted from the K10 psychological distress scale developed by Kessleret al. (2002). Items asked respondents to reflect on the last 30 days, and sample items include "*About how often did you feel nervous?*", "*About how often did you feel hopeless?*", "*About how often did you feel so nervous that nothing could calm you down?*". The scale was reliable, with an alpha of 0.75.

Quality of Life. Twenty-six items for measuring quality of life were adopted from was the brief version of the World Health Organization's Quality of Life Scale (2004) Example items include "*How would you rate your quality of life?*", "*To what extent do you feel your life to be meaningful?*", "*How often do you have negative feelings such as blue mood, despair, anxiety, depression?*". The scale was reliable, with an alpha of 0.70.

Results

First, correlations between study variables were explored (see Table 1). Internalized HIV stigma and psychological distress were negatively correlated with quality of life, suggesting that respondents with greater internalized HIV stigma and psychological distress reported a lower quality of life. Internalized HIV stigma was positively correlated with psychological distress, suggesting that respondents with greater internalized HIV stigma also reported greater psychological distress. Next, the Process macro was used to examine hypotheses 1 and 2 (see Table 2).

Table 1: *Means, standard deviations, and correlations (N=138)*

	M	**SD**	**1**	**2**	**3**
1.Internalized HIV Stigma	3.25	.560	1		
2.Psychological Distress	3.14	.596	.614**	1	
3.Quality of Life	3.35	.338	-.256*	-.165*	1

*Note: * p< .05, **p<.01*

Table 2: *Mediation analysis*

	Coeff	**se**	**t**	**p**	**R-sq**	**F statistic**
Internalized HIV stigma- Psychological distress	.6284	.0656	9.5749	.0000	.6477	48.5432
Internalized stigma-Quality of life	-.1607	.0715	-2.2475	.0263		
Psychological distress-Quality of life	-.2311	.0702	-3.2928	.0013	.4201	15.8154
Total Effect						
Internalized HIV stigma- Quality of life	-.3321	.0547	-6.0670	.0000		
Direct Effect						
Internalized HIV stigma - Quality of life	-.2311	.0702	-3.2928	.0013		
In direct Effect						
Internalized HIV stigma - Quality of life						
	Effect	SE	LLCI	ULCI		
ISM	-.1010	.0434	-.1992	-.0255		

Internalized HIV stigma and psychological distress was negatively associated with quality of life (controlling variables were gender, marital status, age and qualification) supporting hypothesis 1 and 3 Additionally, internalized HIV stigma was positively associated with psychological distress, suggesting that individuals who internalized HIV stigma to a greater extent also experienced greater psychological distress supporting hypothesis 2. Once the effect of psychological distress was controlled for, the effect of

internalized HIV stigma on quality of life became statistically insignificant. This suggests that psychological distress mediated the association between internalized HIV stigma and quality of life, supporting hypothesis 4.

Discussion

This present study investigated links between internalized HIV stigma, collectivist culture, psychological distress, and quality of life among PLWHA in Pakistan, where HIV stigma is pronounced due to limited awareness regarding HIV (Farid & Choudary, 2003; Irfan, Ahmed & Iqbal, 2002). HIV stigma affects the quality of life severely (Liu et al., 2012), results suggested that internalized HIV stigma is linked with worse quality of life among PLWHA in Pakistan that are align with earlier studies that HIV stigma results in poor quality of life among PLWHAs (Aranda-Naranjo,2004; Deacon,2006;Holzemer,2009;Li etal.,2011 Logie & Gadalla, 2009) due to psychological distress as previous studies depicted that HIV stigma results in psychological distress among the HIV infected individuals (Griffin & Rabkin, 1997; Mak et al., 2007; Riggs, Vosvick & Stallings, 2007; Rinehart et al.,2018; Simbayi et al., 2007; Stutterheim et al.,2009 Wu et al., 2008).

Moreover, the study suggests that this association is strongest among PLWHA who endorse collectivism to a greater extent. Studies depicted that internalized stigma leads to rejection of HIV infected individual within the same culture (Derose et al., 2010).Little research to date has scrutinize the role of collectivism in associations between HIV stigma and wellbeing in Pakistan or other collectivist cultures. Yet, theory suggests that HIV stigma varies from culture to culture and stigma may manifest differently in collectivistic and individualistic cultures. Because Stigma progression is culture specific (Heatherton ,2003) and HIV stigma is determined by Individualism–Collectivism culture (Zang, Guida, Sun, & Liu ,2014) so it is crucial to study HIV stigma in a particular context (Corrigan & Watson ,2002; Murthy ,2002; Zang et al.,2014). These results suggest that the effects of internalized stigma may be stronger for people who live in a collectivist culture and these findings are in line with the previous studies that in collectivist culture HIV infected people experience higher level of stigma as compare to individualistic culture (Li et al.,2008; Liamputtong,2013; Zang et al.,2014). Because HIV is viewed as a shame and humiliation in collectivist culture for entire family or group due to one infected member (Li et al., 2008).

Limitations and Future Direction

This study gives the important insight into understudied associations between HIV stigma and wellbeing in collectivist cultures; there are certain limitations that should be considered when interpreting the results. Firstly, the response rate was low. A larger and more diverse sample is needed for greater confidence regarding the generalizability of results. Secondly, greater research is required to investigate why collectivism moderates associations between internalized HIV stigma and psychological distress.

Conclusions

This study furthers the understanding of links between internalized HIV stigma and wellbeing in developing countries with collectivist cultures such as Pakistan. Results support the importance of developing strategies to adapt HIV stigma interventions to collectivist vs. individualistic cultural contexts. For example, it may be important to address familial relationships when intervening on HIV stigma within collectivist cultures.

HIV condition not only affects the quality of life of the infected individual but also of their family and closed one's. (Smolak & El-Bassel, 2013; Yang & Kleinman, 2008) Greater work is needed to understand and intervene in HIV stigma in collectivist culture to improve the wellbeing of PLWHA. Studies including family members and others who are close to PLWHA may provide greater insight into these associations

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Conflict of Interest

Authors declared no conflict of interest.

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ORCID iDs

Ayesha Noor [1] https://orcid.org/0000-0003-2984-8438
Valerie Earnshaw [2] https://orcid.org/0000-0002-4147-3301

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