



Impact of Mental Wellbeing and Spirituality on Quality of Life and Coping Among People Living With HIV/AIDS.

BhavnaMukund

Clinical Psychologist

Rejani T.G.

Assistant Professor in Clinical Psychology

ABSTRACT

People living with HIV/AIDS (PLWHA) require prolonged care with specific focus on coping strategies, positive mental health, and spiritual being. Recovery among people living with HIV/AIDS can be facilitated by adaptive coping, which can be influenced their mental health and spiritual well-being. The research examines the impact of the need and attitude of spirituality and mental well-being on the overall Quality of Life (QOL) and their coping mechanism to deal with HIV/AIDS infection. The study found that majority of the participants had used problem solving and cognitive restructuring strategies to cope but did not felt the need for spirituality in dealing with their illness and that mental well-being has a positive effect on the physiological & psychological and social relationships and on coping strategy. The study found a positive effect of spiritual attitude on QOL. PLWHA frequently used problem solving and cognitive restricting techniques to face and overcome the challenges associated with their illness and improved their QOL.

KEYWORDS : HIV/AIDS, Spirituality, Mental Well-Being, QOL, Coping,

Introduction & Review

With the recent advances in clinical tests and treatments for those suffering from HIV/AIDS, the survival of these patients has increased and their Quality of Life (QOL) has become an important focus for researchers and healthcare providers (Walker, Grassly, Garnett, Staneki, Ghys, 2004). WHO (1998) has defined QOL as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, standards, expectations and concerns".

PLWHA are more likely to experience a number of life stressors including loss of physical and social functioning, managing difficult and complex medical regimens and chronic pain which can affect their coping mechanisms in a varied manner (F Baingana et al, 2005). Many studies have brought out that spirituality can arm one with better ability to tackle stress and provide better coping ability. Spirituality is an important contributor to feelings of well-being (Cotton et al., 2006). Qualitative research indicates that PLWHA reflect on their spirituality in the wake of getting an HIV diagnosis (Tarakeshwar et al. 2006) and often see their life and ailment from a spiritual perspective (Guillory et al. 1997, Tarakeshwar et al. 2006). In addition, despite less involvement in any organized religion, individuals diagnosed with HIV/AIDS incorporate God (Jenkins 1996, Woodwell, and Sowell 2001) and previous experience with religiosity and spirituality (Jacobson et al. 2006) into the coping process. They likewise discover religious adapting methodologies to discover importance in their lives, and looming demise (Corless, 2002 and Hall, 1998; Kelly M. et al. 2010).

Mental well-being – which includes perceived positive relationships and a purpose in life, as well as environmental mastery – is important for older adults to age successfully. It can also have a positive impact on HIV prevention. (Golub S. et al. 2013). Well-being has five measurable elements under the acronym PERMA (Seligman, 2011). Positive emotions include peace, gratitude, satisfaction, pleasure, inspiration, hope, curiosity and love. Engagement – When we're truly engaged in a situation, task, or project, we experience a state of flow: time seems to stop, we lose our sense of self, and we concentrate intensely on the present. Relationship refers to having meaningful, positive relationships with others. Meaning comes from belonging to and serving a cause bigger than ourselves. Accomplishment/Achievement means striving to better ourselves in some way, whether we're seeking to master a skill, achieve a valuable goal, or win in some competitive event. Further research has confirmed that receiving social support from significant social network members can promote positive psychological adjustment in people living with HIV (Mavandadi, Zanzani, Ten, Oslin, 2009). Many studies have shown that HIV leads to a general decline in mental health and efficient and effective coping styles. Patients with HIV are faced with numerous psychological and biological problems which make them different from other people (Jonsson et al., 2013). Not many Indian studies were conducted on HIV/AIDS on these dimensions. Hence the present study attempted to explore the

impact of spirituality and mental well-being on the QOL of PLWHA.

Methodology

Cross sectional design was used in the study. A purposive sample of 60 people diagnosed with HIV/AIDS (30 males and 30 females) has been taken, and data was collected from a non-government organization (NGO) situated in Lucknow. PLWHA (with a confirmed medical diagnosis) above 18 years of age only were included in the study. The Exclusion Criteria included presence of any co-morbid psychiatric illness/ neurological trauma or brain disease/mental retardation.

Tools Used:

Demographic sheet. Demographic details (including period taken for confirmation of diagnosis) of PLWHA were noted with their mode of infection (sexual contact, blood transfusion and drug injection).

Coping Strategies Inventory (CSI -Short Form) (Tobin D.L., 1984). There are a total of 14 subscales on the CSI including eight primary scales. The items are scored on a Likert scale from 0 to 5 carrying equal weight. The scores range from 4 - 72, indicating higher the score better the coping efficiency of the individual. Cronbach's alpha coefficient ranges from 0.71 to 0.94 indicating that the test yields strong reliability. The scale has factorial validity assessed using Werry's hierarchical factor analysis program.

The Warwick-Edinburgh Mental Well-being Scale (WEMWBS) (Tennant et al. 2007). It is a 14-item scale; each answered on a 1 to 5 Likert scale. Items cover different aspects of eudemonic and hedonic mental well-being and are worded positively. Item scores are summed to produce a total score ranging from a minimum of 14 to a maximum of 70 with higher scores representing higher levels of mental well-being. Test retest reliability was found to be high (0.83) and WEMWBS showed good content validity.

WHO QOL HIV BREF (WHO Field Centre for the Study of QOL of Bath, 2008). WHOQOL-HIV comprising 31 items evaluates the QOL from six domains and 29 facets. Responses to the items were scored from 1 (least favourable condition) to 5 (most favourable condition), with the domain scores, ranging from 4 to 20, being calculated by multiplying the average scores for all items in the domain by 4. A higher score would indicate a better QOL on the corresponding domain. It is found to have internal consistency (Cronbach's alpha) ranging between 0.67 and 0.80 across the six domains.

Spiritual and Religious Attitudes in Dealing with Illness (SpREUK) scale (Büssing, 2005). The items of the SpREUK were scored on a 5-point scale from disagreement to agreement (0-does not apply at all; 1-does not truly apply; 2-don't know (neither yes no no); 3-applies quite a bit; 4- applies very much). Scores > 50% indicate higher agreement (positive attitude), while scores < 50 indicate disagreement (negative attitude). The internal consistency estimates of the

SpREUK-15 range from 0.86 to 0.91 (Cronbach's alpha).

Spiritual Needs Questionnaire (SpNQ) scale (Büssing, A. 2010) this scale has 4 core dimensions of spirituality needs, i.e., religious needs, inner peace needs, existential needs and giving generativity needs. The patients rate whether they currently have the respective needs (yes / no), and how strong they were to them. To measure the significance of spiritual needs for the individual, the instrument uses a 4-point scale from disagreement to agreement (0- not at all; 1-some-what; 2- strong; 3- very strong). When the mean score of each domain is greater than 1 then it indicates that the need has some relevance and a mean score less than 1 should be neglected. The internal consistency estimates of SpNQ range from 0.74 to 0.92.

Procedure:

After obtaining informed consent from the authorities of a NGO, participants and the ethical approval of the concerned bodies; participants were specifically informed about the study and the associated confidentiality. Data was entered on the SPSS version 20 and was analysed by using appropriate statistical procedures.

Results

The results were obtained by analysis on SPSS version 20. The techniques used were Multiple regression analysis, Mean and Standard deviation.

The demographic data (Table 1) shows that maximum participants were in their young adulthood, aged between 20-29 years, N= 31, (51.7%) and equal number of male and female participants (Male =30, female =30) were engaged for the study. Among the participants most of them were married (N=35, (58.3%), and had education up to secondary level, N= 29, (48.3%).Maximum number of participants are engaged in private jobs, N=22, (36.7%) and they belong to middle socio economic status, N= 26 (43.3%) with an annual income of Rs.20,041 to Rs.33,240 and were settled in urban areas as their domicile, N=30(50%). Most had contracted HIV/AIDS through sexual intercourse, N=35 (58.3%) with their partners (husband/ girlfriends) and had conceded to their illness within three to four years of contact, with the average onset in the year 2012 (N= 73.2%, M =2012 & SD= 2.250).

Table 1: Socio-demographic details of the sample.

Variables	Sub variables	Frequency	Percentage	Mean & Standard Deviation (SD)
Income/Socio economic status	Less than 10,032 p.a (BPL)	7	11.7%	-----
	10,033 to 20,040 p.a. (low middle class)	19	31.7%	
	33,241 to 33,240 p.a. (middle class)	26	43.3%	
	33,241 to 66,840 p.a. (upper middle class)	6	10.0%	
	Above 66,840 p.a. (upper class)	2	3.3%	
Domicile	Urban	30%	50%	-----
	Rural	6	100%	
	Semi-Urban	24	40%	
Onset	1-4	44	73.2%	M=2012 SD=2.250
	5-8	13	21.75%	
	9-11	3	5.1%	
Mode of infection	Sexual Partner	35	58.3%	-----
	Blood Transfusion	10	16.3%	
	Drug Injection	15	25%	

Table 2. Mean and Standard Deviation (SD) of variables undertaken in the study.

Variables	Mean	Standard deviation (SD)
Problem Solving	9.00	3.288
Cognitive Restructuring	8.98	2.937
Expressed Emotions	6.85	2.821
Social Contact	6.87	3.457
Problem Avoidance	6.32	2.873
Wishful Thinking	5.32	3.307
Self-Criticism	4.62	3.003
Social Withdrawal	4.03	3.210
Problem Focused Engagement	17.98	5.673
Emotion Focused Engagement	13.80	5.572
Problem Focused Disengagement	11.65	4.902
Emotion Focused Disengagement	8.65	5.075
Engagement	31.78	10.583
Disengagement	20.30	8.133
Coping Total	52.00	16.311
Mental Well-Being	45.10	8.889
Spiritual Attitude in Dealing with Illness	40.27	10.953
Religious Needs	10.88	4.235
Existential Needs	9.72	3.728
Inner Peace Needs	10.30	4.350
Giving Generativity Needs	6.42	2.540
Spiritual Needs Total	37.32	10.768
QOL Physical	7.40	1.532
QOL Psychological	7.78	2.051
QOL Social Relationships	12.40	4.537
QOL Environment	7.60	2.149

In total 26 variables were quantified (see Table2). Descriptive statistics are summarized in the table 1 for the same. On the tertiary sub scales of coping, the results indicates that majority of the participants had engagement type of coping (M =31.78 & SD=10.583) indicating that most participants were actively engaged to perceive and negotiate the stressful situation in an optimistic way. On the secondary sub scales of coping inventory, majority of the participants had used problem focused engagement style of coping. (M=17.98 & SD=5.673) which shows that participants have focused themselves on changing the meaning of the stressful situation to deal effectively and emphasis on the current situation at hand. On the primary sub scales of coping it is observed from the results that most of the participants had used problem solving (M= 9.00 & SD=3.288) and cognitive restructuring (M= 8.98 & SD=2.937) strategies to cope with the illness. Majority of the participants have positive mental well-being (M=45.10 & SD=8.889) which indicates that they are optimistic about overcoming their illness. Majority of participants have secured a mean score (M=40.27 & SD=10.953) on their spiritual attitude in dealing with illness, which means that they were disengaged in their spiritual attitude in dealing with illness. Whereas mean score higher than 50 indicates engagement in spiritual attitude in dealing with illness. Majority have felt the need for spirituality in dealing with their illness.

Most have scored high on all the four sub scales of spirituality needs, among them the religious needs ($M=10.88$ & $SD=4.235$) and finding inner peace needs ($M=10.30$ & $SD=4.350$) were the maximum. The mean analysis trend shows that the participants had enhanced QOL in terms of social relationships ($M=12.40$ & $SD=4.537$) indicating that the participants wished to strive for and maintained cordial social relationships with most others in their life.

Table 3. Summary of Multiple Regression Models Analysis

Independent Variables	Dependent Variables	Model Summary				
		Significant variables	F change	Sig value change	Adjusted R square value	Effect of significant variable/s
Mental wellbeing (MW), Spirituality (SI), Religious needs (RN), Existential needs (EN), Inner peace needs (IPN), Giving generative needs (GGN), S Needs (SN)	Problem Solving	MW	9.778	0.003	0.13	positive effect
	Cognitive Restructuring	MW and SI	9.196	0.004	0.242	MW - Positive, SI-negative
	Expressed Emotions	MW and SI	4.615	0.036	0.152	MW - Positive, SI-negative
	Social Contacts	None	-	-	-	-
	Problem Avoidance	MW	6.374	0.014	0.09	positive effect
	Wishful thinking	MW	7.388	0.009	0.113	positive effect
	Self-criticism	MW	8.965	0.004	0.119	positive effect
	Social withdrawal	None	-	-	-	-
	Problem focussed engagement	MW and SI	5.624	0.021	0.224	MW - Positive, SI-negative
	Emotion focussed engagement	MW and SI	4.105	0.047	0.114	MW - Positive, SI-negative
	Problem focussed disengagement	MW	11.804	0.001	0.115	positive effect
	Emotion Focussed Disengagement	MW	6.250	0.015	0.082	positive effect
	Physical quality	MW	4.549	0.037	0.057	positive effect
	Psychological quality	MW	6.794	0.012	0.089	positive effect
Social relation quality	MW and SI	11.14	0.001	0.301	MW - Positive, SI-negative	
Environment Quality	SI and GGN	7.129	0.010	0.279	SI-positive and GGN-Negative	

All the variables were enlisted and data was transferred in SPSS version 20. Variable were analyzed for descriptive statistics and correlations (Pearson's coefficient) (see Table 2). All the variables were also tested for the normal distribution using Shapiro-Wilk's test.

Multiple Stepwise Regression analysis was used to understand the cause effect relationship among coping, QOL (QOL), spirituality and mental wellbeing. F test was used to remove variables in stepwise regression ($p<0.05$). R square values were used in order to understand the importance of significant independent variable in selected regression models. Residual analysis was performed to validate the regression model. Variables under Coping and QOL were used as dependent variable and variables under mental wellbeing and spirituality were used as independent variables.

Effect of mental wellbeing and spirituality on coping

Table 3 provides a summary of several multiple regression model tested to explain the cause of coping. Mental wellbeing was found to be significant in most of the models explaining variance in different coping parameters (See table for variables used as dependent in the models). Such as Problem solving ($F=9.778$, $p=.003$) and Cognitive

Restructuring ($F=9.196$, $p=.004$). It is also seen that positive mental wellbeing has led PLWHA to use both problem focused engagement ($F=5.624$, $p=.024$) and Emotion focused coping when ever encountered with hardships and illness. Some of the dependent parameter also showed significant negative relationship with spirituality in dealing with illness.

Effect of mental wellbeing and spirituality on QOL

Table 3 gives the summary of multiple regression models tested. Mental wellbeing, spirituality and generative giving need were found to be significant in different QOL parameters. Physical ($f=4.549$, $p=0.037$) and psychological quality ($f=6.794$, $p=0.012$) were best explained by mental wellbeing. Social Relation quality was best explained by mental wellbeing and spirituality. Spirituality has negative effect and mental wellbeing has positive effect on social relationship quality ($f=11.14$, $p=0.001$).

Environmental quality was positively affected by spirituality while giving generative needs affected it negatively.

Overall it seems that mental wellbeing is the most important independent variable among the tested variable as the explanatory variable of models tested.

Discussion

Socio-Demographic Details

The study undertaken shows that majority PLWHA are in their young adulthood, aged between 20-29 years, $N=31$, (51.7%) This is consistent with the findings amongst Africans in South Africa (Nelson Mandela/HSRC Study of HIV/AIDS South African National HIV Prevalence, Behavioural Risks and Mass Media, Household Survey 2002).

From table 1, it is observed that majority of participants had education up to secondary level, $N=29$, (48.3%). Maximum were engaged in private jobs, $N=22$, (36.7%), and they belonged to middle socio economic status, $N=26$ (43.3%) with an annual income of Rs.20,041 to Rs.33,240. Domestically and internationally, HIV is a disease that is embedded in social and economic inequity (Perry, 1998), as it affects those of lower socioeconomic status at a disproportionately high rate. Research on SES and HIV/AIDS suggests that a person's socioeconomic standing may affect likelihood of contracting HIV and developing AIDS. Furthermore, SES is a key factor in determining the QOL for individuals after they are affected by the virus. Our study shows majority of the participants are not highly educated and with low income.

It is noticed that majority of people were settled in urban areas as their domicile, $N=30$ (50%) and had contracted HIV/AIDS through sexual intercourse, $N=35$ (58.3%) with their partners but most of them took almost three to four years to seek medical treatment and counselling, ($N=73.2\%$).

Effect of Mental Well-being on Coping among PLWHA

The study has found positive effect of mental well-being on problem solving ($f=9.196$, $p=.004$) and cognitive restructuring ($f=9.778$, $p=.003$) abilities as coping strategies in stressful situations. The findings state that higher mental well-being enables to think in the direction of managing stressful situations, find positivity and derive a sense of purpose even when faced with a threatening or challenging scenario. Recent research has found that practical and emotional coping mechanisms seem to have the greatest positive effect on psychosocial well-being (Harrison et al., 2013). Practical coping strategies, including seeking social support and solution-focused coping, are associated with lower reports of depression and loneliness (Hansen et al. 2013).

The study found among PLWHA that positive effect of mental well-being on problem focused engagement strategy has been used as effective coping in stressful environment. ($f=5.624$, $p=.021$). This finding indicates that participants having positive mental well-being have enhanced capacity for aiming on problem resolving and viewing day to day situations from a positive perspective and derive meaning from life. People living with HIV/AIDS who coped with the stigma of HIV/AIDS by engaging with the stressor using primary control engagement (e.g., problem solving) or secondary control engagement (e.g., cognitive restructuring) coping strategies would report fewer symptoms of depression and anxiety and more self-esteem than they

perceived more HIV/AIDS stigma (Susan, Miller, McCuin, and Solomon. 2012 Feb). Also, a positive relationship of mental well-being was found on the emotion focused engagement process of coping strategy, ($f=4.105$, $p=0.047$) which involves the participants to be socially active, positively involved with others, seek positivity in stressful environment and thrive and flourish in life

Effect of Mental wellbeing on QOL

This study has found a positive effect of mental well-being on the physiological aspects of QOL of the participants ($f=4.549$, $p=0.037$). This aspect indicates that enriched mental well-being leads to improved physical health, improving the quality of sleep, being more energetic and are relieved from feelings of pain and discomfort and vice versa. On the contrary Breitbart, McDonald, Rosenfeld, Monkman, Passik (1998) state that many PLWHA find it challenging to attend to daily tasks of living, participate in moderate to vigorous physical activities, or have sufficient energy or vitality to engage in an active social life while managing HIV/AIDS. Fatigue or low energy has been associated with both physical and psychological morbidity and poor QOL in persons with HIV/AIDS. However, a study by Penedo, Frank, Dahn, Jason (2005) state that participants engaging in regular physical activity display more desirable health outcomes across a variety of physical conditions. Further, the present study found a positive relationship of mental well-being on the psychological aspects of QOL of the participants ($f=6.794$, $p=.012$), indicating that improved mental well-being would not only lead to an improvement on the cognition for example thinking, memory, concentration and learning of the participants but also enhanced their self-esteem. The study also indicates that, the participants' positive mental well-being would improve their notions about self-image, bodily appearance and helps to eliminate negative emotions about oneself like those of self-blaming, criticising, feelings of worthlessness etc. The study conducted by Stinson et.al. (2008), on PLWHA too corroborated with the research findings that enhanced self-esteem may have played a role in the extent to participants could receive support of family and friends. Self-esteem has been shown to influence on interpersonal relationship because individual feeling of self-worth have a bearing on both their beliefs and social behaviours.

It is also noticed that a positive relationship of mental well-being on social relationship aspect of QOL, ($f=11.14$, $p=.001$), wherein the participants were found motivated to have substantial relationship with family, peers, and at work place. The research study indicates, improved mental well-being leads to increase interpersonal relationships and greater social support and vice versa. Study done by McDowell and Serovich (2007) upholds the same view i.e., greater amount of social support has been seen to be associated with less negative and more positive affect in PLWHA. Moreover, people with living with HIV and aids who are satisfied with the amount of social support available to them tend to experience less psychological distress, a higher QOL and more self-esteem (Li, Sung, Panithee, Chuleeporn, Borus, 2009) whereas, those who perceive low level of social support experience increased distress. (Catz, core, McClure, 2002)

Effect of Spiritual attitude and need on QOL and Coping among PLWHA

Consistent with prior results (Shields, 2004) the study found a positive effect of spiritual attitude on QOL (environment dimension) of people suffering from HIV/AIDS ($f=7.129$, $p=.010$). The results indicated that participants who possessed spiritual attitude towards their illness had enhanced capacity for adjustment to their physical environment. They felt financially secured and could invest their time and energy on pleasurable activities. Participants had better-quality adjustment in the family to deal with the illness.

The results shows that the study has found a positive effect of spiritual attitude among PLWHA in that, the more the participants cultivate spiritual attitude the less they tend to be negatively affected by expressed emotions of family, peers and other social groups (which is generally negative) and spirituality helps them to enrich their QOL. ($f = -.289$, $p=0.025$) Qualities such as awe, meaning of life, faith and connection to a spiritual being make significant contribution to the overall rating of QOL, above and beyond that of psychological well-being or social connection (Saxena, Connell & Underwood, 2002). In the development of a new WHO instrument to measure QOL in people living with HIV and AIDS it was concluded that it was crucial to include measures of the contribution of spiritual factors to life. "Many PLWHA reported experiencing a more intense spiritual life as a result of their HIV infections" (WHOQOL AIDS Group, 2003).

However the study also found the negative impact of spiritual attitude in dealing with illness in few coping dimensions, wherein being spiritual has not helped the PLWHA to cope well. Religion can also contribute negative features to a person's spirituality, such as guilt and inappropriate revenge-motivated behaviours. In general, though, the positive contribution of religion to spirituality is the dominant effect (Underwood, Gordon, 1999). People with HIV/AIDS also reported more experiences of internalized shame and lower self-esteem than cancer patients did (Fife & Wright, 2000).

CONCLUSION

The aim of the study was to study the impact of spirituality and mental well-being with QOL and coping among PLWHA. A positive effect of mental wellbeing has been found on the QOL of PLWHA and on the coping strategies. Majority of PLWHA, who had positive well-being, coped well with their illness. The study did not find any significant effect of Spirituality on various coping strategies used by PLWHA; however it had its positive impact on their QOL. But, being spiritual and having positive mental well-being helped the PLWHA to have better coping strategy and also helped them improve their QOL.

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