

# Social Wellbeing Predictor of illness behavior among HIV seropositive individuals

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## ABSTRACT

**Objective:** The objective of the present study was to compare the social wellbeing of HIV seropositive individuals and individuals the normative population who are not HIV positive to find out how social support affects physical well-being.

**Design:** A multiple group design was used to assess the intensity and impact of social support on HIV seropositive individuals, and individuals from the normative population. The study utilized a cohort method which lasted a period of four years.

**Main outcome measure:** Social support and physical wellbeing

**Results:** Totals of 120 subjects- drawn from different organizations/ institutions in Zambia and India were enrolled into the study. The descriptive analysis of Indian participants shows that HIV seropositive who received inadequate social support obtained 65% on somatic symptoms while individuals from the normative population obtained 43.3% From Zambia 67% of the HIV seropositive individuals who received inadequate social support experienced somatic symptoms in the recent past as against 50% individuals from the normative population. Regarding social support from friends and family, the 'F' ratio for diagnosis and nationality was significant at 0.01 revealing that HIV+ individuals obtained the least social support. Correlation between the level of physical illness behavior [somatic symptoms] and social support from friends was found to be -0.389 while that for social support from family was - 0.307. This indicated that physical illness behavior is negatively and significantly correlated with perceived social support from friends and family.

**Conclusion:** When the level of social support is perceived to be high by an individual, then it's likely that physical illness behavior will be low because those who had adequate social support from either their friends or families had less illness behaviour. The results therefore illustrate that less levels of social support and physical illness behavior seem to co-exist. Therefore provision of adequate social support should be included in the management and treatment of HIV seropositive individuals in order to enhance their quality of life.

## INTRODUCTION

People living with the HIV should be mindfull of not just physical health care but also social support during the course of their illness. It is a well known fact that Anti Retroviral drugs [ARVs] can prolong life. But what's the use of just prolonging life or leading a miserable life for a long time? Is it not more ideal to prolong life using ARVs and also at the same time add life to years through improving their social support in order to enhance quality of life? When the prevalence of HIV is high it could mean more people are living with HIV and that the ART medicine is working. For some politicians when the HIV prevalence is high, they perceive the situation to be much better because then it means that more people are living for a long time. However, for some scholars, the situation might be perceived negatively because it means there would be many more people living who are probably spreading the HIV. To a lay person the two positions are somewhat confusing because much as they would want to live longer, which the ARV drugs have so far been able to do, most people do not know what it takes to lead a quality life or add life to years.

**Keywords:** Social support, somatic symptoms, HIV seropositive

A diagnosis of a life-threatening condition such as being infected with HIV is a major source of stress that is likely to affect both physical and emotional well-being because in addition to the stress of chronic illness, HIV seropositive individuals may also struggle to cope with other significant stressors such as the financial strain and unwelcome changes in lifestyle and close relationships<sup>1</sup>. In contrast, being in a supportive relationship with significant others may protect HIV+ individuals against depression which is directly related to physical illness behavior<sup>2</sup>. The perceived relationship between what one gives and what one receives [concept of social reciprocity] is related to the concept of being treated fairly, and that this is strongly linked to health and productive activities<sup>3</sup>. This therefore means that because social support from friends and family is an essential factor in healthy relationships, it is an important mark of social well-being<sup>4</sup>.

A constellation of factors that might foster an individual to receive social support from significant others include discharging negative thoughts, feelings and behaviors in an adaptive way, after hurtful experiences of contracting HIV. This kind of trait, also called dispositional forgiveness, may have significant consequences for self-perceptions, interpersonal relationships, as well as health and medical outcomes in the context of HIV/AIDS. Lack of dispositional forgiveness might thus lead to increased psychosomatic complications because an infected individual is unable to cope with stress and consequently lack resistance to physical illness.

Research has shown that the quality of interactions between HIV seropositive individuals with others has diverse influences on all aspects of their health and functioning (Elliott & Umberson, 2004)<sup>5</sup>. Social isolation is strongly associated with morbidity and mortality, and it has a strong positive relationship with physical and mental health and healthy lifestyle [House et al, 1988]<sup>6</sup>. In spite of that, sometimes, individuals who disclose their positive antibody status to others experience a loss of relationship and social support to an extent that even when they desire to maintain their social support systems, they may discover that others are now fearful and avoidant of them<sup>7</sup>. This means that to some people, the role of social support in improving

the quality of life through facilitating adherence and coping behavior among infected individuals still remains unclear. Therefore pertinent questions on the subject which requires answers from empirical research are as follows: How can one detect cases of inadequate social support going on among seropositive individuals in society? How can one predict such cases with maximum accuracy?

Thus, the above situation poses a problem for effective management of HIV because research shows that HIV infected individuals suffering significant stress, but receiving minimum social support to deal with it, will develop AIDS more quickly<sup>8</sup>.

The current study was conducted to compare the social wellbeing of HIV seropositive individuals and individuals from the normative population who are not HIV positive to find out how social support affects physical well-being in India and Zambia.

### **Hypotheses**

The foregoing theoretical analysis led to the formation of the following hypotheses.

- Being diagnosis HIV seropositive will influence social support received from family and friends.
- Illness behavior is positively correlated to inadequate social support.

### **METHODS**

#### **Study design and sampling**

A multiple group design was used to assess the intensity and impact of social support on HIV seropositive individuals, and individuals from the normative population. Data from Lusaka- Zambia and Bangalore-India conducted from 2001 to 2004 was used in the present study. A total of 120 respondents took part in the study. In Zambia participants (n=60) were recruited from University Teaching Hospital and Kara counseling centre while in India [60] they came from Snehadhan and Karnataka Network for people Living with HIV [KNP+]. HIV seropositive individuals and those from the normative population were selected from

the hospital setting or other health institutions to establish diagnosis of their HIV status. Individuals from the normative population were basically those individuals who had gone there for the purpose of voluntary counseling and testing in order to know their status. The criteria used to select these institutions depended on the availability of the required respondents in those institutions.

The sampling technique which was used in the research was stratified sampling because the population was categorized on the basis of nationality (Zambians and Indians) and on the basis of diagnosis (individuals from the normative population and HIV seropositive individuals). Randomized sampling was not used because of the nature of privacy in matters relating to HIV especially in India. Therefore only those individuals who met the inclusion and exclusion criteria and had consented to be available for the present study were selected. Exclusion criteria for HIV seropositive individuals selected included 1) being too ill to come to the assessment centre 2) being a current intravenous drug user 3) inability to speak English 4) previous history of psychiatric or neurological consultations and mental deficiencies 5) unwillingness to be part of the study 6) exposure to a similar study before.

All the participants were males between the ages of 18 and 50 years in order to come up with a more homogeneous population and cut down on the effects on extraneous variables such as sex. The ages between 18 and 50 was selected because the HIV prevalence in both India and Zambia is mostly within this range. The sample was ethnically diverse in the sense that it included two broad and different ethnicities; Indians and Zambians because with a more culturally diverse HIV+ population, we could better understand who is more likely to forgive and what factors specifically contribute to this important construct. In essence, what is called acculturation might be a significant extraneous variable that could affect HIV+ individuals, especially if they are unfamiliar with dominant cultural social norms, which could affect the quality of care or treatment they receive. Homogeneity in terms of sex and literacy levels was enhanced by ensuring that HIV seropositive individuals selected for the present

study were all diagnosed in the first one year and their educational background/status was at least grade ten.

The present study involved administering the social wellbeing questionnaire to determine levels of social wellbeing and somatic symptoms of the subjects.

### Instruments

- I. Consent form:** A consent form was developed for the present study. This is a written consent form which elicited information that the respondents have agreed to be part of the study. Prior to the administration of all parameters, the willingness of the subjects was ascertained and they were made to sign a consent form.
- II. Information schedule:** This information schedule, which was semi-structured, was specially developed to collect data relevant for the study and ascertain certain socio-demographic details.
- III. Social Support from friends (PSS-Fr and Family (PSS-FA) questionnaire:** This was developed by Murrell (1983). This scale was designed to measure the extent to which an individual perceives that his/her needs for support, information, and feedback are fulfilled by friends (PSS-Fr) and family (PSS-Fa).<sup>9</sup>
- IV. Markers of HIV Illness Stage: Symptoms questionnaire: (SQ)** The Symptoms Questionnaire was developed by Kellner in 1986. This instrument was developed from the Symptoms-Rating Test (SRT) with the aim of making the scales more sensitive for clinical research. The SQ consists of 92 items of which 68 items indicate symptoms (subscales) and 24 items are antonyms of some of the symptoms that indicate well-being (well-being subscales). These form the basis for the following Somatic Symptoms sub scale<sup>11</sup>

### Ethical consideration

Before the study commenced, the Ethics Committee approval was obtained. Full explanations about the purpose of the study were made to participants and

informed consent was obtained from those who agreed to participate in the study. Therefore, all necessary ethical guidelines were considered in this research.

### Data Analysis

The data were analyzed in SPSS 11.5 (Chicago, IL, United States of America). Chi-square analysis was used to compare the three groups to ensure that they were homogenous. When appropriate, Pearson correlations to assess the relationship among diagnoses, continuous anxiety measures and physical illness behavior. Repeated measures analysis of variance (Two way ANOVAs) assessed changes in continuous anxiety variables overtime. T tests were also carried out.

### RESULTS

**Table 1:** The sample distribution of the study.

	HIV seropositive Individuals	Individuals from the normative population	Total
Zambia	30	30	60
India	30	30	60
	60	60	120

The first stage consisted of classification of the respondents into groups based on their diagnosis. The sample size in this stage of study consisted of 120 subjects- drawn from different organizations/ institutions in Zambia and India.

**Table 2:** Distribution of HIV+, and Normal individuals from Zambian institutions.

Institution	HIV(+)		Normal	
	Freq	%	Freq	%
University Teaching Hospital (UTH)	0	0	0	0
KARA Counseling Centre	10	33.3	0	0
Network of Zambian people with HIV/AIDS (NZP+)	16	53.3	0	0
Miscellaneous	4	13.3	30	100
<b>Total</b>	<b>30</b>	<b>100</b>	<b>30</b>	<b>100</b>

Table 2 indicates the distribution of HIV seropositive individuals, and normal individuals from Zambian institutions. These included University Teaching Hospital, KARA Counseling center, and Network for people living with HIV.

**Table 3:** Distribution of HIV+ and Normals from Indian institutions.

Institution	HIV(+)		Normal	
	Frequency	%	Frequency	%
Snehadhan	8	26.6	0	0
KNP+	16	53.3	0	0
Miscellaneous	6	20	30	100
<b>Total</b>	<b>30</b>	<b>100</b>	<b>30</b>	<b>100</b>

#KNP+: Karnataka network for people living with HIV

Table 3 indicates the distribution of HIV seropositive individuals, and normal individuals from Indian institutions. These institutions are as follows Snehadhan, Karnataka Network for People Living with HIV.

**Table 4:** Age distribution of the respondents from Zambia and India.

Age	ZAMBIA				INDIA			
	HIV(+)		Normal		HIV(+)		Normal	
	Freq	%	Freq	%	Freq	%	Freq	%
20-29	13	43.3	14	46.6	6	20	20	66.7
30-39	11	36.6	12	40	19	63.3	8	26.6
40-50	6	20	4	13.3	5	16.6	2	6.6
<b>Mean</b>	<b>33.1</b>		<b>32.6</b>		<b>34.9</b>		<b>26.5</b>	
<b>S.D</b>	<b>7.1</b>		<b>7.27</b>		<b>6.19</b>		<b>7.12</b>	

Table 4 indicates the age distribution of the sample. The reason for selecting this age group is because it constitutes both the HIV prevalence [the percentage of persons ages 15 to 49 who are HIV infected] and HIV incidence [the percentage of uninfected 15 to 49 year olds who become newly infected each year]

**Table 6:** Family income of respondents from Zambia and India

To check whether the samples in terms of annual family income are comparable, chi square analysis was done and the table 6 gives the results.

Family annual income	India			Zambia		
	HIV(+)	Normal		HIV(+)	Normal	
Below 219 US Dollars	7	5	24	9	16	32
219 US Dollars to 879 US Dollars	13	14	40	13	7	33
879 US Dollars to 1,319 US Dollars	10	11	26	8	7	25
<b>Total</b>	30	30	90	30	30	90
	X <sup>2</sup> =3.200 Not significant DF=2			X <sup>2</sup> =1.867 Not significant DF=2		

Since all the above X<sup>2</sup> values are non-significant, we can therefore conclude that the groups are homogenous in terms of the significant demographic variables of education and annual family income. The rationale for selecting a homogeneous group in terms of social-economic status, [respondents who are above poverty line] is because, poverty has been reported to play a significant role in not only the spread of HIV but also in expediting the progression of HIV into AIDS<sup>8</sup>.

**Comparisons between Zambia and India**

**Social support**

Social support refers to availability and satisfaction of care one receives from friends or family. In India 81.65% of the individuals from the normative population received much social support as against 58.4% of the Indian HIV seropositive individuals. On the other hand, the descriptive analysis done on Zambia to compare HIV+, and individuals from the normative population, shows that 46.7% of the Zambian HIV seropositive individuals received social support as against 78% Zambian individuals from the normative population.

**Somatic symptoms**

Somatic symptoms in the present study are the indicators of physical illnesses such as head pains, cramps, muscle pains, upset bowels, nausea, weak arms and legs and not feeling healthy generally. The descriptive analysis of Indian participants also shows that HIV seropositive obtained 65% on somatic symptoms while individuals from the normative population obtained 43.3%. On the other hand the descriptive analysis done on Zambia to compare HIV+, and individuals from the normative population, shows 67% of the Zambian HIV seropositive individuals experienced somatic symptoms in the recent past as against 50% individuals from the normative population.

**Table 7:** Results of the Perceived Social Support from Friends and Family scale in and individuals from the normative population in India and Zambia

Variable	Diagnosis Nationality	HIV+		NORMAL		TOTAL	
		Mean	SD	Mean	SD	Mean	SD
Perceived Social Support from Friends[PSS-Fr]	Zambia	12.63	4.29	13.50	4.42	13.63	4.16
	India	7.93	4.03	12.67	2.06	10.87	4.09
<b>TOTAL</b>		10.28	4.76	13.08	4.10	12.25	4.34
	Main Effects			Df	F	Sig	
		Diagnosis		2	11.87	.000**	
		Nationality		1	23.31	.000**	
	2-way Interaction	Nationality x Diagnosis		2	3.795	.024*	
		HIV+		NORMAL		TOTAL	
		Mean	SD	Mean	SD	Mean	SD
Perceived Social Support from Family [PSS-Fa]	Zambia	9.07	5.11	13.70	3.64	12.03	4.36
	India	11.17	5.27	14.60	4.41	13.56	4.84
<b>TOTAL</b>		10.1	5.26	14.15	4.03	12.79	4.66
	Main Effects			Df	F	Sig	
		Diagnosis		2	17.99	.000**	
		Nationality		1	5.81	.017	
	2-way Interaction	Nationality x Diagnosis		2	.302	.739	

\*\* P<.01; \* P<.05, NS Not significant



**Table 8:** “t” scores comparing the different subgroups on Perceived Social Support from Friends and family.

Scale	Social support from friends			Social support from family		
	Zambia	India	Total	Zambia	India	Total
HIV & Normals individuals	-2.09*	-3.84**	3.82**	-2.74**	-4.04**	-4.72**

**Social support from friends [PSS-Fr]:** The 'F' ratio for diagnosis and nationality is significant at 0.01. The results reveal that in general, considering diagnosis, HIV+ individuals have the least social support from friends. The F ratio for the main effects and interaction effects to social support from friends are all significant. Looking at the table, it is clear that with regard to diagnosis that HIV+ persons received lower social support from anyone.

With reference to nationality, Zambians have higher social support from friends than Indians. This indicates that diagnosis and nationality interactively influence Social support from friends. So, the hypothesis is accepted.

**Social support from family:** The 'F' ratio for diagnosis alone is significant at 0.01 and the F ratio for interaction between nationality and diagnosis is not significant. This indicates that diagnosis alone has influenced social support from family. So, the hypothesis is partially accepted. However looking at the table we see that in general, Indians have greater social support from family compared to Zambians who revealed greater social support from friends.

**Correlations between physical illness behavior [Somatic symptoms] and social Support**

Hypothesis 2 stated that physical Illness behavior is negatively correlated to adequate social support. In order to carry out the investigation, the symptoms questionnaire was administered and the Pearson coefficient of correlation was computed. Physical illness behavior implies somatic symptoms which in the present study are indicators of physical illnesses such as head pains, cramps, muscle pains, upset bowels, nausea, weak arms and legs.

**Table 9:** Correlation between the level of physical illness behavior [somatic symptoms] and social support .

SI No	Factors correlated to Somatic symptoms	Correlation Coefficient
1.	Social support from friends	-0.389**
2.	Social support from family	-0.307**

Physical illness behavior is negatively and significantly correlated with perceived social support from friends and perceived social support from family. It implies that when the level of social support is perceived to be high by an individual, then it's likely that physical illness behavior will be low. It's therefore likely that a lower level of social support is a core factor that might be responsible for the quick progression of HIV infection into AIDS.

**DISCUSSION**

The present study reveals that in both Zambia and India, HIV+ individuals have less social support from friends and family compared to individuals from the normative population. It was also found that Indian HIV seropositive individuals who had less illness behavior obtained more social support from family while Zambian HIV seropositive individuals who had less illness behavior obtained more social support from friends. This variation can be explained in terms of the higher rate of disintegration of extended families in Zambia compared to India. The extended family system in Zambia used to serve us an effective channel of social support to individuals with deep-seated problems such as fatal infections and disabilities. The implication of this result is that Indians are bound to be more resilient than Zambians in the face of stressors associated with the HIV infection because families are culturally expected to give more social support than friends. Therefore, generally it can be argued that social support from friends and family is one of the felt needs of HIV seropositive individuals.

Although, the main barriers to social support include persistence of stigmatization and discrimination of HIV infected individuals, one other reason why some of them perceive less social support from friends and family is because of their avoidant reactions (not being open about their illness or infection). Avoidant

reactions can unconsciously heighten distress and leave an individual feel shunned, vulnerable, and isolated from the very people who are supposed to be dependable sources of social support. It is therefore important for HIV seropositive individuals to face the challenges of the HIV infection and the increasing stress to which they are subjected by dispelling inappropriate negative attitudes. Therefore it can be argued that one of the reasons some HIV seropositive individuals perceive less social support from friends and family is perhaps partly because of the by-products from their emotional upset when they became fearful and avoidant of others. However, there can no doubt be situations where the HIV seropositive individuals may respond to seropositivity in emotionally healthy ways, but feel isolated or rejected because of the reactions of significant others. The present study therefore recommends that soon after an HIV+ diagnosis, emotionally sustaining kinds of social support should be made more available to supplement the efforts of problem-solving types of social support.

Another reason why some HIV seropositive individuals perceive less social support is probably because they experience a less meaningful life. It can therefore be concluded that social support is essential for an individual infected with HIV to adjust. At the same time, religious institutions should be seen to emotionally support infected individuals rather than negatively judge them or reject them. This is important because to cope with their suffering, individuals infected with HIV need not only physical but also and psychological closeness. Lastly it was also found that those HIV seropositive individuals who had perceived less social support also reported increased feelings of loneliness even if they lived in communities surrounded by many people. The antagonism between the social support received and the loneliness experienced can be interpreted in line with the argument that there are many individuals who experience feelings of loneliness even when other people are around them. At other times they may be by themselves but feel no loneliness at all. This leads us to conclude that loneliness is primarily an inner feeling that does not always depend on whether or not others are present. The inner feeling of loneliness comes when an

individual perceives himself to be isolated from others, or lacks the social skills needed to relate to others. It is thus important to distinguish loneliness from solitude.

Against the above reasons why HIV seropositive individuals perceived less social support from friends and family than individuals from the normative population, social support can thus be said to be very important because it offers them opportunities to talk about their problems, fears, hopes, and experiences.

#### **Limitation of the present study**

1. Although HIV seropositive individuals and individuals from the normative population were matched on age, education, and economic status, their selection did not ensure complete random selection because of ethical obligations of seeking consent for them to participate in the study.
2. None availability of female HIV seropositive individuals from India due cultural reasons led the researcher to exclude female subjects from the sample.
3. Illiterate individuals were not included in the present study.

#### **CONCLUSION AND RECOMMENDATIONS**

In conclusion, the present study shows the significance of social support for infected individuals by friends and family. The prevalent dissatisfaction as well as negative attitudes towards self and others among HIV+ individuals is attributed to factors such as inadequate social support. It is evident that social support can help reduce illness behaviour and add quality to the longer life span due to the ARV drugs. Social support also enables HIV+ individuals to discover new resources within themselves and retain a positive outlook. Since the benefits of investing on care are manifold: suffering is reduced and improvement is seen in the quality of life; economic and social productive activity is likely to be prolonged, the provision of appropriate social support to each person infected with the HIV should be seen as a mandatory clear moral humanitarian obligation.

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