

PERCEIVED PSYCHOSOCIAL NEEDS, SOCIAL SUPPORT AND QUALITY OF LIFE IN SUBJECTS WITH HIV/AIDS

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ABSTRACT

The psychosocial needs, social support, quality life and adjustment of subjects with HIV/AIDS were assessed using a self-report instrument with 40 items and a Cronbach's alpha coefficient of 0.74. Eighteen patients at varying stages of HIV infection who knew their sero-status served as subjects. Results showed that the needs perceived as most important by HIV/AIDS patient were not met by their most valued sources of social support. Fifteen (83.3%) subjects expressed dissatisfaction with the quality and quantity of support received since the diagnosis of HIV/AIDS, 12 (66.7%) reported poor social adjustment to the diagnosis, 11 (61.2%) reported low quality of life/wellbeing and 8 (44.4%) reported severe lifestyle changes caused by the disease. Perceived social dysfunction was in four areas – fear of stigma in 15 (83.3%) subjects, lack of satisfying relationship with family in 15 (83.3%) subjects, lack of inner motivation in 12 (66.7%) subjects and social isolation in 12 (66.7%) subjects. Subjects with extrovert personality perceived significantly more lifestyle changes, reported a higher fear of rejection and a lower degree of adjustment to the disease than subjects with introvert personality. Subjects with late-stage HIV infection reported a lower social adjustment to the disease, a lower quality of life and more severe lifestyle changes. Satisfaction with social support correlated significantly with quality of life and social adjustment. It is therefore concluded that the higher the level of satisfaction with social support, the higher the quality of life and social adjustment to HIV/AIDS. The health worker should therefore harness and encourage the provision of qualitative social support for people living with HIV/AIDS.

Keywords – Psychosocial needs, Quality of life, Social support.

INTRODUCTION

The diagnosis and treatment of HIV/AIDS are associated with complex psychosocial effects like stigma, rejection, fear of the unknown, impaired quality of life and the need to make remarkable lifestyle changes (Sowell & Opava 1995). These psychosocial issues can be as devastating to the person living with HIV/AIDS as the physical symptoms. There is therefore the need to focus on the psychosocial aspects of HIV/AIDS care, as these are critical to the wellbeing of the HIV-infected person. Stigma impairs society's willingness to provide the needed social supports to sufferers (Herek & Capitano 1993). Yet, social support has been found to be vital in ensuring social adjustment in chronic diseases and an improved quality of life. According to Kaplan, Cassel & Gore (1977) and Hirsch (1980), coping with illness is facilitated through social support. Such support strengthens the individual's ability to realistically appraise stressful events and develop effective coping strategies. It also moderates the effect of stress (Cobb 1976), enhances wellbeing (Sowell & Opava 1995) and influences health outcomes and

recovery patterns (Zink 1996). Cohen & Willis (1985) have attributed these influences to the fact that socially supportive relationships provide emotional support, affection and companionship and therefore aid coping, adjustment and wellbeing.

The purpose of this study was to identify the perceived psychosocial needs, social support and quality of life in subjects with HIV/AIDS. Quality of life is the perceived physical, psychosocial and spiritual wellbeing of the individual.

MATERIAL AND METHODS

This descriptive study, lasting twelve months, was carried out in two hospitals in Calabar (General Hospital and Infectious Diseases Hospital). The total population of inpatients with HIV/AIDS who knew their diagnosis and were seen in the hospital during the period of study, served as subjects. This totalled eighteen patients (8 with early AIDS disease and 10 with late – stage disease with opportunistic infections). Permission to carry out the study was obtained from the co-ordinator of

the AIDS control programme in the State and the medical directors of both hospitals. Written informed consent was obtained from the subjects. Subjects' confidentiality was assured by using codes rather than subjects' hospital numbers during data collection.

A self-report instrument with 40 items on a five-point Likert type-scale, was developed by the investigators and used to interview subjects. The items were adapted from three standardized instruments (Quality of Life tool by Ferrell et al. 1992, with a reliability coefficient of 0.71 to 0.85; Sarason's social support questionnaire by Sarason et al. 1983 with a test-retest reliability coefficient of 0.83 to 0.90; Linn's social dysfunction rating scale by Linn et al. 1969 with Kendall's index of 0.91). The instrument was pre-tested on a convenience sample of six subjects at various stages of HIV infection, with a Cronbach's alpha coefficient of 0.74 (global) and 0.61 to 0.82 (subscales). Six items on the personal data section were adapted from Eysenck's personality inventory (1975) to identify subjects' personality trait.

Data were analyzed using descriptive statistics, t-test for significance of scores and Pearson correlation for relationship between variables. Data entry and analysis were made using EPI-INFO-6 programme. On the social support subscale, scores of 4-8 indicated low amount/satisfaction with social support, 9 to 15 (moderate) and 16 to 20 (high). On the quality of life scales, scores of 12 to 26 signified low wellbeing, 27 to 47 (moderate) 48 to 60 (high wellbeing). On the social dysfunction scale scores of 8 to 19 signified low social dysfunction (high social adjustment), 20 to 30 moderate on both indices and 31 to 40 signified high social dysfunction (low social adjustment).

RESULTS

The sample comprised 10 (55.6%) males and 8 (44.4%) females with age ranging from 26 to 58 years with a mean age of 31.7 years and standard deviation of 7.3. Two (11.1%) subjects knew their sero-status for less than three months, 6 (33.3%) for 3 to 6 months 5 (27.8%) for 7 to 12 months and another 5 (27.8%) for over 12 months (Table 1).

The needs perceived as most important by subjects for their adjustment to the disease were psychosocial (love, trust, acceptance, empathy, esteem, encouragement) for 10 (55.6%) subjects, and instrumental needs (finance, effective drugs, practical helping activities) for 6 (33.3%) subjects. Only 2 (11.1%) subjects identified information as the most important need. Only 3 (16.7%) subjects reported that their most

important needs were being met. Identified sources of social support included family (for emotional and financial support), friends and colleagues (for financial support) religious associates (for emotional and spiritual support) and healthcare workers (for informational support). The most valued sources of social support were spouse (44.4%), children (22.2%) and siblings (22.2%), while the most valued networks of support were family/friends (44.4%), family/religious associates (33.3%) and family/neighbours (22.2%). Fifteen (83.3%) subjects expressed dissatisfaction with the quantity and quality of support they received from these valued sources since the illness.

Table 2 shows the degree of psychosocial indices perceived by subjects. Twelve (66.7%) subjects reported low social adjustment to the illness, 5 (27.8%) reported moderate adjustment and 1 (5.6%) reported high social adjustment. Social dysfunction was perceived in four areas - fear of stigma (83.3%), lack of satisfying relationship with spouse/partner and family (83.3%), lack of inner motivation (66.7%) and social isolation (66.7%). Responses were not mutually exclusive. Three (16.7%) subjects reported a high amount of social support but only 1 (5.6%) reported satisfaction with such support. Perceived quality of life was low for 11 (61.1%) subjects, moderate for 5 (27.8%) and high quality for only 2 (11.1%). The two who reported high quality of life had known their sero-status for less than three months. Eight (44.4%) subjects reported severe lifestyle changes imposed by the disease, 7 (38.9%) reported moderate changes and 3 (16.7%) mild changes.

The type of life style changes perceived by subjects were social, in terms of altered relationships, lack of leisure and social activities for 13 (72.2%) subjects and physical - poor personal care and activities of daily living for 5 (27.8%). Subjects generally reported poor adjustments to these changes and expressed the need for more social contacts and social support.

The means, standard deviation and t-test values on the psychosocial indices presented on Table 3 show a mean of 32.8, S.D. of 8.0 and t-value of 2.51 significant at 0.02 level for the social dysfunction scale. These results indicate a significantly low social adjustment to the disease. Physical quality of life/wellbeing and lifestyle changes were also significant ($p=0.02$ and 0.001 respectively). Other values were not significant.

Other results indicate that the personality of the subjects correlated significantly with social adjustment ($\gamma = 0.44$, $\rho = 0.05$), with satisfaction with social support ($\gamma = 0.43$, $\rho = 0.05$) and with lifestyle changes ($\gamma = 0.61$, $\rho = 0.001$). Personality was not statistically correlated with

TABLE 1. SOCIO-DEMOGRAPHIC CHARACTERISTICS OF SUBJECTS (n= 18)

	CHARACTERISTICS	no	%
1	AGE: 26 to 36 years	4	22.2
	37 to 46 years	7	38.9
	47 to 58 years	7	38.9
2	MARITAL STATUS:		
	Single	3	16.7
	Married	9	50.0
	Divorced/separated	6	33.3
3	SEX: Male	10	55.6
	Female	8	44.4
4	WORK STATUS (current)		
	Unemployed	6	33.3
	Employed	10	55.6
	Student	2	11.1
5	DURATION OF KNOWLEDGE OF DIAGNOSIS		
	Less than 3 months	2	11.1
	3 to 6 months	6	33.3
	7 to 12 months	5	27.8
	over 12 months	5	27.8

TABLE 2. DEGREE OF PSYCHOSOCIAL INDICES IN SUBJECTS

PSYCHOSOCIAL INDICES	DEGREE OF INDICES			TOTAL	
	LOW	MODERATE	HIGH		
SOCIAL ADJUSTMENT	N	12	5	1	18
	%	66.7	27.8	5.6	100
SOCIAL SUPPORT (amount)	N	9	6	3	18
	%	50.0	33.3	16.7	100
SOCIAL SUPPORT (satisfaction)	N	15	2	1	18
	%	83.3	11.1	5.6	100
QUALITY OF LIFE	N	11	5	2	18
	%	61.1	27.8	11.1	100
LIFESTYLE CHANGES	N	3	7	8	18
	%	16.7	38.9	44.4	100

TABLE 3. MEAN AND STANDARD DEVIATION OF PSYCHOSOCIAL INDICES IN SUBJECTS

PSYCHOSOCIAL INDICES	\bar{X}	S.D.	t	P
SOCIAL ADJUSTMENT (Max. = 40)	32.8*	8.0	2.51	0.02
QUALITY OF LIFE (max = 60)				
- Physical (max. = 15)	13.1	4.1	2.43	0.02
- Psychological (max. = 25)	9.9	3.2	1.65	0.10
- Social (max. = 20)	8.1	2.4	1.62	0.10
SATISFACTION WITH SOCIAL SUPPORT (Max. = 20)	5.6	2.2	1.70	0.10
LIFESTYLE CHANGES (max. = 35)	23.4	7.3	3.83	0.001
ADJUSTMENT TO LIFESTYLE CHANGES (max. = 15)	3.8	1.6	1.17	0.20

* A high mean indicates high social dysfunction.

amount of social support received and with quality of life. Extroverts perceived more lifestyle changes ($\gamma = 0.54$, $\rho = 0.02$), reported a lower satisfaction with social support ($r = 0.46$, $\rho = 0.05$), lower social adjustment to the illness ($\gamma = 0.56$, $\rho = 0.01$) and a higher fear of rejection and stigma ($\gamma = 0.68$, $\rho = 0.001$) than introverts. Subjects with late - stage HIV infection expressed significantly lower social adjustment ($\gamma = 0.55$, $\rho = 0.01$), experienced a lower level of wellbeing ($\gamma = 0.45$, $\rho = 0.05$) and more severe lifestyle changes ($\gamma = 0.51$, $\rho = 0.02$) than those with early HIV infection. Satisfaction with social support correlated significantly with the quality of life ($\gamma = 0.48$, $\rho = 0.02$) and with social adjustment ($\gamma = 0.43$, $\rho = 0.05$). This implies that the higher the level of satisfaction with the social support received, the higher the perceived quality of life and social adjustment.

DISCUSSION

Subjects' need for love, acceptance and encouragement (psychosocial needs) were basically unmet, probably because of the stigma associated with HIV/AIDS. Various social support networks were available to meet subjects' physical needs. However, subjects' most valued source of social support did not give satisfactory support once the diagnosis was known. Subjects reported some degree of alienation by the family (identified as the most valued source of support). This may be because of the feeling of blame, distrust and fear of contagion by family members which probably hindered satisfying social relationships and caused poor adjustment to the disease. Social support is necessary for effective coping and adjustment to illness, but the quality of social support is more important than the quantity and the composition of the support network more vital than the number of people in the network (Keele-Card et al, 1993). Therefore the sick person must be satisfied with the amount, structure and duration of the social support received. However subjects in this study reported a general dissatisfaction with the quantity and quality of support received from their most valued source of support. This may have been responsible for the high level of social dysfunction, depression, loneliness and social isolation reported by the subjects. The healthcare provider and the social worker must therefore ensure that the most valued source of social support provides as much support as possible to the person living with HIV/AIDS. This can be achieved through counselling. The African culture encourages family cohesion and support,

but the stigma and fear of contagion associated with HIV/AIDS hinder strong family bonding with the infected person. This study has shown that HIV/AIDS affects wellbeing, imposes considerable lifestyle changes and hinders effective adjustment to the disease. Such lifestyle changes may have contributed to the poor psychosocial wellbeing especially in subjects with late - stage infection. Healthcare workers should therefore focus on the psychosocial aspects of HIV/AIDS care in order to reduce the stress of the diagnosis, enhance patients' wellbeing and promote adjustment to the disease. The family should also be supported and encouraged to give as much social support as possible both quantitatively and qualitatively.

The study was limited by the small number of subjects available. A study lasting longer, using a larger sample and involving many hospitals may be necessary to establish normative patterns.

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