Is there any Burden or Impaired Quality of Life of Caregivers of Patients with HIV/AIDS?

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Abstract

Introduction: HIV has become a chronic illness like Diabetes and Chronic Kidney disease. Chronic diseases not only affect the lives of those suffering from the illness but also affect the lives of family members who take care for them.

Objectives:

(iv) To assess burden of caregivers of patients with HIV/AIDS

(v) To assess quality of life of caregivers of patients with HIV/AIDS

(vi) To associate burden with quality of life of caregivers

Methodology: A sample of 100 caregivers was selected using convenient sampling method. Research variables under study were burden and quality of life of caregiver. The tool used for data collection consisted of semi-structured questionnaire for socio-demographic characteristics of patient and caregiver and standardized tools namely, Zarit Burden Interview and WHO Quality of Life – BREF scale.

Results: Majority (35%) of the caregivers reported to have mild to moderate burden. The mean burden score was 37.37$\pm$14.61SD. In quality of life, social domain showed a maximum score of 61.08$\pm$15.41SD and psychological domain a minimum score of 55.39$\pm$14.21SD.

There was significant strong negative correlation between mean burden score and the scores of four domains of quality of life. The result indicated that the caregivers who reported higher degree of burden had reduced quality of life.

Conclusion: The study revealed that there is significant strong negative correlation between burden and quality of life of the caregivers. Care giving role can be enhanced through formal education programme on HIV/AIDS care giving and home service.

Keywords: *HIV/AIDS, caregiver, burden, quality of life.*

Introduction

Health is a state of complete physical, mental and social well being and not merely the absence of disease or infirmity [WHO] [1]. Many factors combine together to affect the health of individuals and communities.

The appearance of a disease in a family member entails countless changes in the family structure. Chronic diseases not only affect the lives of those suffering from the illness but also affect the lives of family members who take care for them.[2] When the disease is HIV/AIDS, the situation gets worse, as this is a stigmatized illness the population fears, due to the suffering it causes to

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patients and relatives.

The caregivers of HIV/AIDS patients experience multiple physical, emotional, social and financial stresses and these factors can seriously affect their quality of life. Caregivers can get personal satisfaction by helping to reduce the suffering of their relatives. The negative aspects of care giving have been described as caregiver burden or stress.[3] So, more focus should be placed on providing moral and social support to improve the caregivers' quality of life.

Need for the Study

It is felt by the investigator that there is a need to conduct a study on the caregiver burden and related quality of life of the primary caregivers of patients with HIV/AIDS. This study aims to elicit the caregiver burden and quality of life of the primary caregivers of the HIV/AIDS patients undergoing treatment.

Family caregivers, especially those who share same house with an ailing family member, providing 24 hours care a day adding on to their own problems. Their leisure activities are also curtailed by the daily tasks and stressors of caring for loved ones. The family caregiver's identity, coping strategies, self-care efforts and social network may be disrupted. Decrease of pleasurable and meaningful activities also add to the perceived burden of the caregivers.

Aim

The aim of the study is to assess burden and quality of life of caregivers of patients with HIV/AIDS undergoing treatment in a selected tertiary care hospital."

Objectives of the Study

- To assess burden of caregivers of patients with HIV/AIDS undergoing treatment in a selected tertiary care hospital.
- To assess quality of life of caregivers of patients with HIV/AIDS undergoing treatment in a selected tertiary care hospital.
- To associate burden with quality of life of caregivers of patients with HIV/AIDS undergoing treatment in a selected tertiary care hospital.

Hypotheses

H0: There is no association between burden and quality of life of caregivers of patients with HIV/AIDS undergoing treatment in a selected tertiary care hospital.

H1: There is association between burden and quality of life of caregivers of patients with HIV/AIDS undergoing treatment in a selected tertiary care hospital.

Material and Method

Study design: Facility based cross-sectional study

Setting: Anti-retroviral Therapy (ART) centre of a tertiary care hospital of Pune.

Sample size: Calculated on prevalence rate as 62.2% based on previous study[5], considering absolute precision as 10% and 95% confidence interval. Sample size was calculated to be 91. The researcher chose sample size as 100.

Sampling technique:

Non probability convenient sampling.

Population:

Caregivers (spouse, parent, grandparent or children) in the age group of 18–65 years who provided care to the HIV/AIDS patient for least 6 months of duration were included.

Data collection:

Data was collected using a semi-structured questionnaire which included socio demographic and clinical details of the care givers and patients. Caregiver burden was assessed using the Zarit Burden scale and the WHOQOL-BREF Questionnaire was used to assess the QOL of caregivers. The scoring was done in accordance with the guidelines given in the respective instruments.

Zarit burden scale was used to score caregiver's burden. It consists of 22 questions. Items were answered on a 5-point likert scale (never, rarely, sometimes, quite frequently, or nearly always). Using these scores, the level of burden was categorized into little (0–20), mild to moderate (21–40), moderate to severe (41–60) or severe (61–88) burden.

WHO's QOL scale (WHOQOL-BREF) was used to assess quality of life in this study. The WHOQOL-BREF questionnaire contains 26 items including two items (global scores) i.e. overall QOL and general Health and 24 items of satisfaction that are divided into four domains: physical health, psychological health, social relationships and environmental health. Each item is rated on a 5-point Likert scale. The four domains have a score range of 4–20 that was transformed to 0–100 scale.

Statistical Analysis

Data collected was analysed using SPSS Version 17 statistical software. For socio demographic data and burden, frequency distribution and percentage were calculated, while for level of care burden and quality of life, we calculated the mean and standard deviation.

Correlation between caregivers' burden score and quality of life was established using Karl Pearson's Correlation Coefficient. The p-value <0.05 was considered to be significant.

Findings

Socio demographic characteristics of caregivers

A total of 100 caregivers participated in the study. The maximum number (39%) was of the age group ranging from 20 – 30 years. Majority (65%) of them were married and were female caregivers . Nearly half (44%) of the caregivers provided care for 1-5 years duration. More than half (67%) of the caregivers got support from their family members in providing care to the HIV/AIDS patients [Table 1].

Table 1: Socio demographic characteristics of caregivers n=100

Sample Characteristics	**Category**	**Frequency (f)**	**Percentage (%)**
Age (Yrs)	**20 – 30**	**39**	**39**
	31 – 40	23	23
	41 – 50	26	26
	51 – 60	12	12
Gender	Male	31	31
	Female	**69**	**69**
	Transgender	0	0
Marital status	**Married**	**65**	**65**
	Widowed	6	6
	Unmarried	27	27
	Divorced	2	2
	Separated	0	0
Educational status	Illiterate	6	6
	Primary	24	24
	Secondary	25	25
	Higher secondary	**27**	**27**
	Graduate & above	18	18
Relation with patient	**Husband/wife**	**45**	**45**
	Parent	17	17
	Grand parent	9	9
	Children	29	29
Type of family	**Nuclear**	**53**	**53**
	Joint	47	47
Occupation	Employed	28	28
	Unemployed	**43**	**43**
	Self employed	29	29
Monthly family income (Rs)	≤10000	26	26
	10001 – 25000	44	44
	25001 – 50000	30	30
	>50000	0	0

***Cont...* Table 1: Socio demographic characteristics of caregivers n=100**

Duration of care provided (Yrs)	6mth – 1	22	22
	1 – 5	44	44
	5 – 10	19	19
	>10	15	15
HIV status	Positive	42	42
	Negative	58	58
	Not known	0	0
Illness other than HIV/AIDS	Yes	23	23
	No	77	77
Get support from other family member in care giving	Yes	67	67
	No	33	33

Socio demographic characteristics of HIV/AIDS patients

More than half (64%) belonged to the age group of 26 – 50 years and around 55% of the subjects were female. Almost an equal number of subjects (46% and 44%) were in Stage II and Stage III. [Table 2].

Table 2: Socio demographic characteristics of HIV/AIDS patients

Characteristics	**Category**	**Frequency (f)**	**Percentage (%)**
Age (Yrs)	≤25	19	19
	26 – 50	**64**	**64**
	≥50	17	17
Gender	Male	45	45
	Female	**55**	**55**
	Transgender	0	0
Stages of HIV/AIDS	**Stage II**	**46**	**46**
	Stage III	44	44
	Stage IV	10	10

n=100

Caregiver Burden and Quality of Life

The mean Burden score was 37.37±14.61SD. Majority (35%) of caregivers reported mild to moderate burden. Only 9% subjects reported severe burden [Table 3].

Table 3: Distribution of caregivers as per burden score n= 100

Characteristic	**Category**	**Frequency (f)**	**Percentage (%)**
Burden	Little or No Burden (0-20)	25	25
	Mild to Moderate Burden (21-40)	35	35
	Moderate To Severe Burden (41-60)	31	31
	Severe Burden (61-88)	9	9

The social domain of quality of life showed a maximum score of 61.08+15.41SD and psychological domain showed the minimum score of 55.39+14.21SD.[Table 4]

Table 4: Mean scores of QOL domains **n= 100**

Characteristics	Category	QOL score	
		Mean	SD
Quality of life	Physical domain	56.49	13.68
	Psychological domain	55.39	14.21
	Social domain	61.08	15.41
	Environmental domain	55.84	14.03

The QOL scores among caregivers had a negative correlation with caregiver burden and the finding was statistically significant in all the four domains ($p< 0.0001$). [Table 5]

Table 5: Correlation between mean burden and domains of QOL of caregivers **n=100**

Correlation between burden score and domains of QOL	r Value	P Value
QOL (Physical domain)	-0.55	<0.0001
QOL (Psychological domain)	-0.60	<0.0001
QOL (Social domain)	-0.66	<0.0001
QOL (Environmental domain)	-0.59	<0.0001

Discussion

In a study done on 360 caregivers in Mangalore, 37.8% of study samples had little or no burden. Severe burden was reported by 10% of the caregivers.[3] Another study[4] on caregiver burden among 409 caregivers in Thailand using Zarit scale, 53% of caregivers experience moderate to severe burden and 13.4% had severe burden. Inverse association was observed between caregiver burden and quality of life ($p=0.004$) and depression and quality of life ($p<0.0001$). Social support had direct positive association with caregiver's quality of life ($r= 0.48$, $p<0.0001$).

In the Mangalore study done WHOQOL-BREF scale was used to assess the Quality of life. Physical domain of QOL showed maximum score of 60.28±13.08, while a minimum score of 51.88±14.20 was seen in social domain. This is in contrast to our finding. Caregiver burden was compared with each domain of QOL using ANOVA with $p<0.05$. It was found to be statistically significant with a p-value <0.001.

A similar study[6] on quality of life of caregivers in Taiwan revealed that they felt most stressful on disclosure and stigma issues and most worried about patients' interpersonal relationships and had poor quality of life.

Limitation

Our study had some limitations. Our study design was cross sectional; therefore, causal interpretations cannot be established. It was a single centre study so the results may not be generalized.

Recommendations

For future research work following recommendations are made:

- A qualitative study can be undertaken highlighting the experiences of the caregivers of HIV/AIDS patients.
- A study to assess the comparison of caregiver burden among HIV/AIDS and other chronic diseases can be conducted.

Conclusion

The present study adopted descriptive survey approach to assess the burden and quality of life among the caregivers of HIV/AIDS patients undergoing treatment in a tertiary care hospital. It revealed that there is significant strong negative correlation between the burden and quality of life among caregivers in all the four domains (p< 0.0001). The association of caregiver burden and stages of HIV/AIDS was found statistically significant (p = 0.037). The caregivers of HIV/AIDS patients experience severe burden of physical, psychological and social forms.

Conflict of Interest: Nil

Source of Funding; Self

Ethical Clearance: Permission was taken from Institutional Ethical Committee. Written informed consent was obtained from the study subjects.

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