Caregiver Burden, Quality of Life and Coping Mechanisms among Caregivers of Children Living with HIV in Lagos, Nigeria

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Summary

INTRODUCTION

Children living with HIV/AIDS (CLWHA) are significantly affected psychosocially and their caregivers may experience stress with negative effects. This study assessed the caregiver burden, quality of life and coping mechanisms.

MATERIALS AND METHODS

It was a descriptive cross-sectional study among 246 caregivers of CLWHA. Psychological distress and caregivers' burden was assessed using General Health Questionnaire-12 (GHQ-12) and Zarit Burden Interview-12 (ZBI-12) respectively. Data analysis was done using Epi info software version 7 and the level of significance was set at $p < 0.05$. Ethical approval and informed consent were duly obtained.

RESULTS

Of the sample (n=246), 93.1% were females and the mean age of the caregivers was 41.3±8.5 years. Only 9.4% of the respondents had a high caregiver burden while majority (72.0%) experienced 'no to mild' burden. Over half (54.9%) had mild to severe psychological distress. The physical domain aspect of quality of life scored highest (71.1±15.0), while the lowest was in the environment domain (57.6±15.6). Religious coping was the most adopted mechanism in this study.

CONCLUSION

Majority were categorized as having mild or no caregiver burden but experienced psychological distress while caring for CLWHA. Psychological wellbeing and the mental health of caregivers of CLWHA should be a focus of support.

Keywords: *Burden, Caregiver, Children, Coping, HIV*

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Introduction

Living with HIV significantly affects the psychosocial well-being of children.[1] Children living with HIV often have to confront several challenges as they get older such as internalized stigma and discrimination, disclosure challenges and difficulties understanding ART therapy and adherence.[2] It has been shown that there is a strong correlation between the negative effects of HIV, cognitive development and functioning among CLWHA, suggesting a need for early childhood intervention.[3]

According to UNAIDS, 26% of children living with HIV in Nigeria aged 0-14 years are on ART.[4] Children who were initially not expected to survive are now facing academic, emotional and social issues related to living with a chronic condition and the burden falls on the caregivers.[5] In cases where the caregiver is HIV positive, a new challenge emerges as a different approach to care is required.[6] Caregivers living with HIV in addition to taking care of the child also have to cope with their own physical health symptoms, complex drug regimens, stigma and fear of AIDS-related death.[7] Also, the reduced stamina and physical demands of a HIV positive child leave many caregivers without sufficient time for counseling and self-care.[8] All these affect their overall mental health and quality of life, and hence depression is common, especially among caregivers who struggle financially.[7,9]

Another source of burden for the caregivers is the stigma that surrounds HIV infection. Community rejection of children living with HIV often extends to their caregivers. Rather than face the stigmatization, some caregivers try to hide their caregiving status by disengaging themselves from social relationships and may, therefore find it challenging to obtain support.[8] Many caregivers go through psychological distress.[10] Expecting a negative outcome, feeling of disappointment, watching their children go through pain and inability to change the course of event all have an overwhelming impact on the caregiver's health.[11]

Several studies have examined care, stigma and disclosure among CLWHA but there is paucity of data on the caregiver burden in this setting. Therefore, this study was aimed at assessing the caregiver burden, psychosocial distress, quality of life and coping mechanisms among caregivers of CLWHA.

Materials and Methods

Study Design

This was a descriptive cross-sectional study among caregivers of children living with HIV/AIDS who attend ART clinics for children in Lagos State.

Study Participants and Sampling

Adult caregivers of children less than 18 years of age and living with HIV were included in this study. The minimum sample size of 246 was calculated using the Cochran's formula; n = (Z^2pq/d^2), where, n= Minimum sample size required, z= Standard normal deviate at 95% confidence interval= 1.96, p- Prevalence from previous study, q = (1-p), d- Acceptable margin of error (0.5%=0.05). The prevalence *p*, represents the prevalence (17.7%) of psychosocial disorders among the caregivers of people living with HIV/AIDS in Delta State, Nigeria[13]. A consecutive sampling method was used to recruit participants until the desired sample size of 246 was reached.

Study Instruments and Data Collection

The data was collected using interviewer-administered questionnaires. The questionnaire consisted of questions on socio-demographic and socio-economic characteristics of respondents; level of psychological distress; caregivers' burden; quality of life and coping mechanisms. The research assistants were trained successfully before the data collection which took place at an appropriate time during the caregivers' clinic appointment. Data analysis was performed using the Epi Info Statistical Package (version 7. 1.5.2).

Psychological distress was measured using General Health Questionnaire 12 (GHQ-12)[14.] Each question on the GHQ-12 had a score range of 0-3. The maximum score obtainable was 36, and the minimum score 0. Scores 0-11 was normal, scores 13-15 indicating mild stress, scores 16-20 indicating evidence of distress, and scores >20 indicating severe psychological problems.

Caregivers' burden was assessed by Zarit Burden Interview 12 tool (ZBI). ZBI is a 12-item instrument measured on a 5-point Likert Scale option as 0=never, 1=rarely, 2=sometimes, 3=quite frequently and 4=nearly always. The scores are categorized as follows: Scores 0-10 indicate 'no to mild burden', scores 10-20 indicate 'mild to moderate burden', and scores >20 indicate 'high burden'.[15]

Quality of life was measured with the WHOQOL-BREF tool. It comprises of 26 items; 24 of which were divided into four domains (physical, psychological, social and environment), with two individual items assessing the perception of overall quality of life and general health. Domain scores were scaled in a positive direction (i.e. higher scores indicative of 'higher quality of life'). The mean score of items in each domain was used to calculate the domain score. The raw domain scores were transformed to a 0-100 scale. Scores above 50 were good, and scores below 50 were poor.[16]

The BRIEF-COPE tool was used to compute coping mechanisms of the respondents. The respondents rated the degree to which they use each coping strategy to deal with particular stressful event on a 4-point Likert scale that ranges from "I haven't been doing this at all" to "I've been doing this a lot".[17]

Ethical Considerations

Ethical approval was obtained from the Health Research and Ethics Committee (HREC) of the Lagos University Teaching Hospital (LUTH). Permission to conduct the study was obtained from the chief medical directors of the institutions involved in the study. Informed written consent was obtained from each caregiver and participation was completely voluntary. Confidentiality and privacy were assured and maintained throughout the study

Data Analysis

The data was analyzed using the Epi Info Statistical Package (version 7. 1.5.2). The variables were presented as frequencies and Chi-square test was used to test the association between categorical variables. Mean and standard deviation was calculated for the variables in the quality of life domains and the psychological distress level where values assumed a normal distribution. The level of significance was set at $p< 0.05$.

Results

Socio-Demographic Characteristics

The mean age of respondents was 41.3±8.5 years, and almost all were females (93.1%). Majority were married (82.9%) and had secondary education as their highest level of education (61.0%). Approximately three-quarters of the caregivers were self-employed (72.2%). About 63.0% of the caregivers earned less than N18, 000 (~$50) monthly and only 1.2% earned more than N100,000 (~$277) monthly.

Caregiver and Index Child Characteristics

Majority (81.7%) of the caregivers were HIV positive themselves and were the biological parents (86.2%) to the CLWHA. Only 6.5% of them had more than one child living with HIV. The majority (88.2%) of the children were attending school.

Caregiver Burden and Quality of Life Scores

Less than half (45.1%) of the participants had a normal stress level while 12.2% of them had severe psychological distress. The mean psychological distress score and standard deviation was 12.4 ± 5.8. Over one-quarter (28.5%) of participants were in the category of mild stress. The caregiver burden was high in 9.4% of the caregivers while the majority (72.0%) of the participants had 'no to mild' burden. Among the quality of life domains, the participants scored highest (71.1±15.0) in the physical health domain and lowest (57.6±15.6) in the environment domain

Coping Mechanisms

The most commonly used approach oriented coping mechanism using the BRIEF-COPE scale was acceptance (38.2%) followed by positive reframing (14.2%) and the least was emotional support in 2.9%. Within the avoidant coping mechanisms, 'Religion' was highest (63.4%), closely followed by self-distraction (42.7%) while the least used were substance use (0.4%) and venting (0.4%).

Discussion

Psychological distress affected more than half of the caregivers in this study. This finding is consistent with a study conducted in Udupi, rural India on HIV-infected children where 50.3% of caregivers were distressed.[14] However; lower prevalence was observed in studies conducted in Enugu (39.0%) [13] and Niger Delta region (17.7%) [18] of Nigeria. These variations could be due to the difference in the location of these studies. The present study was carried out in Lagos which is the commercial nerve centre of the country associated with the high cost of living, heavy traffic on road networks and high cost of living.[19, 20] These factors may partly contribute to the high prevalence of psychological distress seen in this study. It could also be attributed to the burden of providing care in a low-income country like Nigeria as informal caregiving can be financially draining; pose substantial economic strains resulting from lost wages and the stigma may limit job opportunities.[21]

Generally, it has been shown that childhood chronic illnesses significantly affect family functioning. Caregivers may experience varying degrees of stress with the risk of psychosocial disorders and other health effects of stress. Moreover, psychological distress in caregivers can disrupt continuity of care and hence adherence to treatment for the CLWHA.[22] This stress is not limited to caregivers of children living with HIV but caregivers of children who are critically ill.[18] For example, in Enugu-Nigeria, Ijezie reported a prevalence of 84% for psychosocial disorders among parents whose children had cerebral palsy.[9] Another study in Enugu reported a prevalence of 34.4% among parents of children with epilepsy.[23]

Less than a tenth (9.4%) of the respondents experienced high burden. Most of the caregivers had no or mild burden (72.0%) and 18.7% had mild to moderate burden. This finding is parallel to the study conducted by Singh et al where only 11.4 % experienced moderate to severe burden.[24] However, the findings in this study vary significantly from that stated in the study in rural South Africa where 40% of the caregivers showed high burden.[25] While in our own study, biological parents were the majority caregivers, the children in the South African study were orphans, and even though they were being taken care of by extended family, the additional responsibility apart from their own children might have weighed heavily on the caregivers.[23]

Higher prevalence of caregiver burden were also reported in Thailand, Southern India and Calabar, Nigeria (66.5%, 53% and 35.8% respectively).[26,27,28] This could be because these studies recruited caregivers of people living with HIV and not only children.

This study found that the quality of life of the caregivers was generally good. The highest mean score was seen in physical domain (71.1±15.0), while the lowest score was in environment (57.6±15.6). This is comparable to the study conducted in India, where the quality of life was generally good, and the highest domain score was in physical health (60.28±13.08). In the study carried out in Thailand, the quality of life was also good with mean quality of life score of (89.9). Contrary to this study, studies conducted in China and Taiwan on the quality of life of caregivers of people living with HIV/AIDS revealed poor quality of life for both.[7, 29]

The findings of this study showed that religion/faith was a main coping mechanism among the respondents and the least used was substance abuse. Active coping, positive reframing and acceptance were also used as coping mechanisms by many caregivers, while venting and denial were the coping mechanisms least used after substance abuse. Active coping involved working, watching television etc. It is not unusual that many caregivers anchored on their faith as a coping mechanism. In a religious country like Nigeria, people resort to comfort in religious belief when they have problems. Substance abuse being the least used coping mechanism could be because majority of the caregivers in this study were females and it has been shown that women are less likely to abuse drugs as a stress coping mechanism, than men.

The finding in this study is similar to those conducted in Uganda, South Africa and America, where spiritual support was among the coping mechanisms used most often.[30,31,32] However, the findings in this study is at variance with a Kenyan study, where maladaptive coping mechanisms such as substance use, self-blame and behavioural disengagement were common.[17]

Conclusion

Majority of the respondents had mild or no caregiver burden but there was a high prevalence of psychological distress while caring for CLWHA. Despite the high prevalence of psychological distress, the quality of life of the majority of caregivers was good. The main coping mechanism used by caregivers was religion followed by acceptance. Very few of the caregivers in this study engaged in substance abuse and venting, as a coping mechanism.

Recommendations

It is recommended that psychological wellbeing and the mental health of caregivers of CLWHA should be a focus of support.

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Appendix

Table 1: Descriptive Statistics of the Study Participants (n = 246)

Socio-Demographic Characteristics	Frequency (n=246)	Percentage (%)
Age (years)		
18-44	181	73.6
≥45	65	26.4
Mean age 41.3±8.5		
Sex		
Male	17	6.9
Female	229	93.1
Marital status		
Married	204	82.9
Not married	42	17.1
Level of education		
No formal education	16	6.5
Primary	35	14.2
Secondary	150	61.0
Tertiary	45	18.3
Work status		
Employed	36	14.6
Self employed	178	72.4
Unemployed	28	11.4
Retired	4	1.6
Estimated income per month (n=217)		
< N18,000	155	63.0
N18,000 – N50,000	43	17.5
N50,000 – N100,000	16	6.5
>N100,000	3	1.2
No Income	29	11.8

Table 2: Caregiver's HIV Status and Childcare Characteristics

Caregiver Characteristics	Frequency (n=246)	Percentage (%)
Caregiver's HIV Status		
Positive	201	81.7
Negative	45	18.3
Caregiver's relationship to the index child		
Parents	212	86.1
Other relatives	24	9.8
Guardian	10	4.1
Number of CLWHA being cared for		
1	230	93.5
2 and above	16	6.5
Child schooling		
Yes	217	88.2
No	29	11.8

Table 3: Psychological Distress, Caregiver Burden and QOL Scores

Distress level	Overall (%) (n=246)
Normal	111(45.1)
Mild stress	70(28.5)
Evidence of psychological distress	35(14.2)
Severe distress	30(12.2)
Mean±SD 12.4±5.8	
Caregiver burden	Overall (%)
No to mild burden	177(72.0)
Mild to moderate burden	46(18.7)
High burden	23(9.4)
WHOQOL-BREF Domains	Mean±S.D
Physical Health	71.1±15.0
Psychological Health	65.0±16.1
Social Relationships	60.9±14.5
Environment	57.6±15.6

Table 4: Assessment of Coping Mechanisms among Respondents

Brief-COPE Scale	Not at all (%)	A little bit (%)	A medium amount (%)	A lot (%)
Approach Oriented Coping				
Active Coping	81(32.9)	40(16.3)	105(42.7)	20(8.1)
Positive Reframing	34(13.8)	25(22.4)	122(49.6)	35(14.2)
Acceptance	15(6.1)	19(7.7)	118(48.0)	94(38.2)
Emotional support	100(40.7)	53(21.5)	86(35.0)	7(2.9)
Avoidant Coping				
Religion	0(0.0)	7(2.9)	83(33.7)	156(63.4)
Self-distraction	81(32.9)	40(16.3)	105(42.7)	20(8.1)
Denial	213(86.6)	17(6.9)	11(4.5)	5(2.0)
Venting	221(89.8)	21(8.5)	3(1.2)	1(0.4)
Substance use	234(95.1)	8(3.3)	3(1.2)	1(0.4)
Self-blame	173(70.3)	46(18.7)	19(7.7)	8(3.3)