

Demographic Factors and Perceived Social Support as Predictors of Burden of Care among Family Caregivers of Children Living With HIV in Akwa Ibom State



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ABSTRACT: The burden of care among caregivers has emerged as a significant public health concern. This study investigated demographic factors and perceived social support as predictors of the burden of care among family caregivers of children living with HIV (CLHIV) in Akwa Ibom State. Fifty-seven participants, comprising 6 males (10.53%) and 51 females (89.47%), were purposively selected from rural family caregivers receiving family support services from selected Non-Governmental Organisations (NGOs) in Akwa Ibom State. A cross-sectional survey design was employed, utilizing the Perceived Social Support Scale and the Burden of Care Scale for data collection. Descriptive statistics and multiple regression were used for data analysis. Results indicated that age significantly predicted the burden of care among family caregivers of CLHIV ($\beta = .322$; $t = 2.50$, $P < .05$). However, caregivers' education ($\beta = .031$; $t = .235$; $P > .05$) and relationship with the care recipient ($\beta = -.077$; $t = -0.58$; $P > .05$) did not predict the burden of care. Notably, perceived social support independently predicted the burden of care ($\beta = .292$; $t = 2.29$; $P < .05$). Furthermore, a significant joint prediction of demographic factors and perceived social support on the burden of care of family caregivers of CLHIV was found ($F = (6,56) = 2.82$; $P < .05$). The findings highlight the need for targeted interventions and support programs that address caregivers' needs, particularly in terms of social support networks, to alleviate the burden associated with caring for children living with HIV.

KEYWORDS: Burden of Care, Demographic Factors, Perceived Social Support, Children, HIV.

INTRODUCTION

Human immunodeficiency virus (HIV) in children necessitates the need for dedicated and appropriate adult care, considering the myriad challenges they face while living with the virus and striving to maintain their development and well-being (Asuquo, et al., 2017). Children living with HIV encounter obstacles in getting an inclusive education, establishing friends, and accessing healthcare (Asuquo, et al., 2013). The primary caregiver needs to make a significant financial, physical, and emotional commitment to caring for a child living with HIV, including providing nourishing food, administering antiretroviral therapy (ART) on time, accompanying the child to doctor appointments, and maintaining a watchful, nurturing home environment.

Daily stress from giving care and support drains family members' physical and mental resources, resulting in depletion and lethargy (Campbell & Foulis, 2004). There is a whole set of issues that create emotional strain, including worry, guilt, anxiety, anger, and uncertainty about the cause of the disease, the future, the needs of other family members, and whether enough assistance is being provided. Grieving over the loss of function of the person with the disease is experienced at the time of onset and often repeatedly at other stages in the person's life. Caregivers play a vital role in supporting family members who are sick, infirm, or disabled (Akintola, 2006).

In Africa, family life is centered on providing care. Parents look out for their children, spouses look out for one another, and family members support each other when disease or infirmity strikes (Asuquo et al., 2013). The family system faces additional pressures from disease, most of which persist for a long time. Many of these difficulties are independent of the person's condition, age, and household type they are part of. However, the burden of care is even more significant when caring for children living with HIV (Asuquo, et al., 2017).

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Infants, children, and teenagers with HIV should be able to live and thrive in communities of care that are based at home rather than in institutions. The difficulties faced by caregivers of children living with HIV are comparable to those faced by those caring for children with other life-threatening conditions. These difficulties include sadness, weariness, and exhaustion (Nath, 2017). Many caregivers lack sufficient time for self-care and therapy due to diminished energy and the physical demands of an HIV-positive child. Furthermore, the stressors associated with HIV, such as social isolation and stigma, may reduce the caregiver's willingness to reveal the virus and seek formal assistance for themselves or their families (Kalomo & Liao, 2018).

Families provide emotional support to children living with HIV in addition to personal care and practical assistance. As a result, the child relies on the caregiver, and their health is directly tied to the type and standard of care they receive (Kalomo & Liao, 2018). The physical, psychological, emotional, and financial effects of caring for a child living with HIV are referred to as the caregiver's burden of care.

Burden of care refers to the impact that care provided in physical, psychological, social, and financial terms has on the life of a caregiver of a sick individual unable to perform activities of daily life (Lora et al., 2012). The term "objective burden" describes demands that can be directly measured, such as the financial toll that an illness takes on families, the disruption of daily routines, and a patient's reliance on family members for both financial and practical care (Lora et al., 2012). The term "subjective burden" describes the caregiver's emotional reaction to the social and behavioral challenges faced by a child living with HIV. These caregivers are mostly family members in Nigeria, and many of them are mothers of the care recipients (Knapp, 2010). The majority of the care recipient's everyday needs are met by their caregivers. The burden of care increases as a result of this, and those who care for children living with HIV are more likely to experience psychological distress (Ilse et al., 2008).

Numerous factors have been identified as impacting the burden of care for family caregivers of CLHIV, but this study will investigate whether demographic factors and perceived social support may also play a role. Gender plays a significant role in the burden of care experienced by family caregivers, as evidenced by research conducted by Gadow et al (2010). Female caregivers, for instance, may encounter varying levels of emotional strain or physical exhaustion compared to male caregivers due to societal expectations and traditional gender roles. Moreover, the relationship type with the child also influences the burden of care. Tapscott (2016) highlighted that the caregiver's relationship with the care recipient significantly impacts the caregiving experience. Particularly, mothers and parents generally carry a heavier burden due to their emotional attachment and the daily responsibilities involved in caring for a child with HIV. Additionally, educational attainment is another factor affecting the burden of care among family caregivers of CLHIV. Joseph and Fineman (2011) established a link between caregivers' education levels and their caregiving burden. Higher educational levels equip caregivers with better access to information, resources, and coping mechanisms, potentially mitigating the burden associated with caregiving responsibilities.

Perceived social support describes how people view their friends, family members, and others as sources of practical, emotional, and all-around help when they are in need. In other words, it describes how individuals perceive the availability of practical, emotional, and overall help from their social network when they are in need. Studies have revealed that perceived social support predicts the burden of care for family caregivers (Skeen et al., 2016). Also, studies, such as those by Brisset (2010) and O'Reilly (2010), have demonstrated a significant relationship between perceived social support and the burden of care. Caregivers who perceive higher levels of support from their social networks tend to experience lower levels of burden and psychological distress. This study aimed to fill the gap in understanding the burden faced by caregivers of children living with HIV, helping healthcare practitioners create tailored programs and interventions to support affected families and address the needs of both the children and their caregivers. It was hypothesized that demographic factors would independently and jointly predict the burden of care of family caregivers of children living with HIV in Akwa Ibom State. It was also hypothesized that perceived social support would significantly predict the burden of care of family caregivers of children living with HIV in Akwa Ibom State

METHOD

Research Design

The study utilized a cross-sectional survey design due to its suitability for making single-time observations encompassing a wide array of naturally occurring variables essential for the study. This design facilitated the collection of data at a specific point in time, offering a snapshot of the variables under investigation without requiring longitudinal tracking. Additionally, the cross-sectional design allowed for the examination of relationships between variables at a particular moment, providing valuable insights into associations and patterns within the studied population.

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The Study Area/ Population of the Study

The research was carried out in Etinan and Ibesikpo Local Government Areas, situated in Akwa Ibom state, Nigeria, in the southeastern part of the country. These areas are positioned between latitudes 40321 and 50331 North and longitudes 70251 and 80251 East. Akwa Ibom State shares borders with Cross River State to the east, Rivers State and Abia State to the west, and the Atlantic Ocean to the south. Beneficiaries of donor-funded HIV intervention programs in selected rural communities of Akwa Ibom State were the target demographics of the study. The population consisted of approximately 100 caregivers of children who had benefited from HIV intervention projects by the Health and Development Foundation and the Women and Community Livelihood Foundation (WOCLIF) in rural communities of Akwa Ibom State.

Criteria for Inclusion and Exclusion

The study included caregivers who actively provided continuous care to children (aged 0–14) for the previous six months, as well as those between the ages of 18 and 80. Caregivers who fell into the following categories were not included: (1) passive secondary caregivers, (2) non-continuous caregivers for six months, (3) caregivers of newly diagnosed CLHIV for less than 6 months, and (4) caregivers under 18 years.

Sample Size/ Sampling Technique

The sample size consisted of fifty-seven (57) caregivers, comprising 6 males and 51 females, who were caring for children living with HIV. They were selected from beneficiaries of donor-funded HIV intervention projects in selected Non-Governmental Organizations (NGOs) in rural communities of Akwa Ibom State. Participants' ages ranged from 19 to 53 years, with a mean age of 37.4 years. A multi-stage sampling technique was adopted for the study. The Non-Governmental Organizations (NGOs) were selected using a convenience sampling technique. Only NGOs implementing projects in rural areas of the state were chosen because they are likely to serve the most vulnerable children living with HIV. The actual participants of the study were drawn using the purposive sampling technique. Since the HIV intervention sampled for this study had other beneficiary groups such as adults, adolescents, and pregnant women, only caregivers of children aged 0-14 living with HIV were purposively selected to participate in the study.

Materials

The major instrument used for data collection in this study was a questionnaire divided into three (3) sections. Section A contained information related to participants' demographic details such as age, gender, caregiver education, and relationship with the care recipient. Section B consisted of the Berlin Social Support Scale by Schulz and Schwarzer (2003), and Section C contained the Burden of Care Scale by Graessel, Berth, Lichte & Grau (2014).

The Berlin Perceived Social Support Scale (BSSS) is a 17-item scale designed to measure the level of support received by adolescents from family, friends, and others. The scale uses a five-point Likert format ranging from 1 to 5 (1= Strongly Agree, 2 = Agree, 3 = Undecided, 4 = Disagree, 5 = Strongly Disagree). The scale's norm is 48.25, where scores above 48.25 indicate low social support and scores below 48.25 indicate high social support. The social support scale demonstrated an internal consistency of .87. Okoro and Inyang (2022) reported a Cronbach alpha of .80 for the Nigerian sample.

The Burden of Care Scale is an 11-item scale designed to measure the level of care associated with caregiving as a family member. The scale uses a 4-point Likert format with options: Not So Much, A Little, Much, and Very Much, which are directly scored as 1, 2, 3, and 4, respectively. The scale's norm is 17, where scores of 17 and above indicate a high burden of care, while scores below the norm indicate a low burden of care. Graessel, Berth, Lichte & Grau (2014) reported a Cronbach alpha of .65, while Etim (2018) reported a Cronbach Alpha of .88 for the Nigerian sample.

Procedure

The selected NGOs were contacted, and their respective Executive Directors were met and briefed on the purpose of the study. They permitted for copies of the questionnaire to be administered to the desired participants during their Orphans and Vulnerable Children (OVC) meeting. A staff member of the NGOs was assigned to inform the researcher once the OVC meeting was scheduled. The staff members provided information on OVC and assisted in organizing the desired participants for the study. The participants were then briefed on the purpose and given copies of the questionnaire to complete.

Ethical Considerations

All participants were informed that collecting the research instrument implied consent, therefore only willing participants should collect it. The researcher recognized that participants could only give 'informed consent' to be involved in a study if they had a full understanding of the involvement requested of them. Therefore, adequate and honest information on the goals of the study, including the time commitment and the assurance of anonymity of their responses, was provided. Participation in the study was

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entirely voluntary, and participants were not in any way forced, pressured, deceived, or duped into participating. The nature of the study, affiliations, professional standing of the researcher, and intended use of the study findings were thoroughly and honestly explained to participants, and all questions and objections were satisfactorily addressed. Participants were informed that they had the right to refuse to answer any question they found unpleasant or offensive and that they were at liberty to discontinue participation at any point. Additionally, the questionnaire was designed in a way that makes it impossible to determine a participant's identity, as participants' responses were handled with utmost anonymity since they were not asked for their names or assigned numbers.

Statistics

The demographic data of respondents were analyzed using the simple percentage (%) method. Subsequently, the study's hypotheses were tested using a multiple regression statistical technique.

RESULTS

Descriptive statistics and multiple regressions were employed in the analyses.

Table 1: Summary of Caregivers' Demographic Characteristics

Variables	N	Percentage
Gender		
Male	6	55.5
Female	51	45.5
Relationship with Child		
Direct Parents	43	75.43
Grand Parents	7	12.28
Siblings	7	12.28
Highest Education		
Primary	5	8.77
SSCE	43	75.43
Tertiary	9	15.78
TOTAL	57	100

Table 1 above presents demographic information of participants. The table shows that 6 males (10.53%) and 51 females (89.47%) participated in the study. Table 1 also shows that 43 participants (75.43%) were direct parents of the children living with HIV, 7 (12.28%) were grandparents, and 7 (12.28%) were siblings. Among the participants, 5 (8.77%) had only primary school education, 43 (75.43%) had SSCE, while 9 (15.78%) had tertiary education.

Table 2: Summary Table of Multiple Regression Showing Relative Contributions of Demographic Variables and Perceived Social Support in Burden of Care among Family Caregivers of Children Living with HIV in Akwa Ibom State.

Predictors	B	t-value	Sig	R	R ²	F	P	df
Sex	.020	.1.56	>.05	.466	2.17	2.82	<.05	5
Age	-.322	-2.50	<.05					
Education	-.031	-.235	>.05					
Relationship with Child	-.077	-.587	>.05					
Perceived Social Support	.292	.2.294	<.05					

The findings in Table 2 above indicate that demographic factors (sex, age, caregiver's education, and relationship with the care recipient) yielded a coefficient of multiple correlations (R) of 0.466 and a multiple correlation square (R²) of 2.17. This demonstrates that the effects of demographic factors and perceived social support together account for 2.17 percent of the variation in the burden of care of family caregivers of CLHIV in Akwa Ibom State.

Specifically, Table 2 above indicates that participants' sex showed no significant independent prediction of the burden of care among family caregivers of CLHIV ($\beta = .020$; $t = .150$; $P > .05$). Age had a significant independent prediction of the burden of care

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among family caregivers of CLHIV ($\beta = .322$; $t = 2.50$; $P < .05$). The burden of care for family caregivers of CLHIV was not significantly predicted independently by the caregiver's education ($\beta = .031$; $t = .235$; $P > .05$). The relationship with the care recipient did not show a significant independent prediction of the burden of care for family caregivers of CLHIV ($\beta = -.077$; $t = -0.58$; $P > .05$). The burden of care for family caregivers of CLHIV was independently predicted by perceived social support ($\beta = .292$; $t = 2.29$; $P < .05$). Table 2 further indicates that there was a significant joint prediction of demographic factors and perceived social support on the burden of care of family caregivers of CLHIV ($F = (6,56) = 2.82$; $P < .05$). The results presented in Table 2 above demonstrate that only age as a demographic factor independently predicted the burden of care of family caregivers of CLHIV in Akwa Ibom State. The first hypothesis, which stated that demographic factors would independently and jointly predict the burden of care of family caregivers of children living with HIV in Akwa Ibom State, was rejected. However, findings presented in Table 2 confirm the hypothesis that perceived social support would significantly predict the burden of care of family caregivers of children living with HIV in Akwa Ibom State.

DISCUSSION OF FINDINGS

The burden of care affects the quality of care given to care recipients and the quality of life of the caregivers. The study's findings contradicted the hypothesis that demographic factors will independently and jointly predict the burden of care of family caregivers of children living with HIV in Akwa Ibom State. This result was consistent with the findings of Gadaw, Chernoff, Williams, Brouwers, Morse, and Heston (2010), which found that family caregivers' burden was influenced by the age of the caregivers. The finding also corroborated that of Ozer (2015), who discovered a strong correlation between the age of carers and the burden of care for children living with HIV. The results further refute Joseph and Fineman's (2010) conclusions that the burden of care and caregivers' education are significantly related. Additionally, the results were in direct opposition to Tapscott's (2016) findings, which indicated that the kind of relationship with care receivers was related to the burden of care experienced by family caregivers.

The findings of the study supported that perceived social support is an independent predictor of the burden of care of family caregivers. The finding corroborated Brisset's (2010) report that there is a significant relationship between quality of life, social support, and the burden of care of family caregivers of CLHIV. The finding also confirmed the findings of O'Reilly (2010), who found that individuals who received a high level of social support and low levels of loneliness experienced high levels of care-related burden. However, the study contradicted Lundberg, Thi, and Doan's (2016) report that social support did not predict the burden of care among family caregivers of children living with HIV.

CONCLUSION

Based on the findings of the study it was concluded that; (a) age is a significant predictor of the burden of care of family caregivers of children with HIV, (b) sex, caregivers' education, and relationship with care recipients do not predict the burden of care of family caregivers of children with HIV, (c) perceived social support is a significant predictor of the burden of care of family caregivers of children with HIV.

RECOMMENDATIONS

The following recommendations are made from the findings of the study;

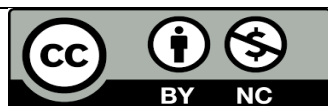
- I. There should be a massive media campaign to inform the public about the importance of assisting family caregivers of children living with HIV. This initiative will increase the degree of support provided to caregivers, reduce their workload, and improve their quality of life.
- II. Social workers should be hired by the government and other stakeholders to offer in-home care for CLHIV. This step will ease the strain on family caregivers, encourage the provision of high-quality care for the children, and enhance their overall well-being.
- III. As part of HIV healthcare services, healthcare professionals should provide special training to caregivers. This effort will make it easier for caregivers to manage CLHIV with high-quality care and less burden.

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