

European Journal of Health Sciences (EJHS)




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*Ebobesem Margaret E.O, Dickson Shey Nsagha, Nicholas
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 Ebobesem Margaret E.O^{1*,2,4}, Dickson Shey Nsagha¹, Nicholas Tendongfor¹, Brenda Mbouamba Yankam^{4,5}, Claude Ngwayu Nkfusai⁶, Serge Ngekeng¹, Che Joseph Ngwa^{1,2} & Emmanuel Yenshu Vubo³

¹Department of Public Health and Hygiene, Faculty of Health Sciences, University of Buea, Buea, Cameroon

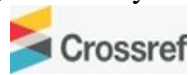
²Department of Nursing, Faculty of Health Sciences, University of Buea, Buea, Cameroon

³Faculty of Social and Management Science, University of Buea, Buea, Cameroon

⁴Malaria Consortium, Buea, Cameroon

⁵Department of Statistics, Faculty of Physical Sciences, University of Nigeria, Nsukka

⁶School of Nursing and Public Health, University of KwaZulu-Natal, Durban, South Africa



Article history

Submitted 16.05.2024 Revised Version Received 25.06.2024 Accepted 26.07.2024

Abstract

Purpose: Despite global efforts to prevent mother-to-child transmission (PMTCT) of Human Immunodeficiency Virus (HIV), challenges persist, particularly in low- and middle-income countries like Cameroon. This qualitative study explores the experiences of informal caregivers supporting HIV-positive pregnant and breastfeeding women in the PMTCT Option B+ program in Fako Division, South West Region, Cameroon.

Materials and Methods: Employing a sequential qualitative research design, the study involved fifty-one informal caregivers in focus group discussions and in-depth interviews. Thematic and interpretive phenomenological analysis, facilitated by Atlas.ti software, was utilized to explore caregiver challenges, coping mechanisms, and their impact on Antiretroviral Therapy (ART) adherence and overall well-being.

Findings: Caregivers face psychological, economic, and physical challenges, including emotional ambivalence, economic

constraints, and fear of infection. The study highlights caregiver burnout and identifies coping mechanisms such as emotional control, integrating HIV/AIDS into daily life, spirituality, feelings of hope, and seeking support from family and society. Despite challenges, caregivers find reward in witnessing care recipients' progress. The research also reveals gender role shifts and the importance of open discussions about HIV/AIDS.

Implications to Theory, Practice and Policy: Recognizing the crucial role of informal caregivers in PMTCT, addressing their well-being is essential. Training caregivers can enhance adherence, supporting UNAIDS goals, and alleviating health system burdens. This emphasizes the importance of caregiver involvement in achieving global HIV targets by 2030.

Keywords: *Antiretroviral Therapy, Global Health, HIV, Informal Caregivers, PMTCT*

1.0 INTRODUCTION

The Prevention of Mother-to-Child Transmission (PMTCT) of Human Immunodeficiency Virus (HIV) programs have been pivotal in global efforts to curb new HIV infections among children and reduce maternal AIDS-related deaths. Despite concerted global initiatives, achieving the set goals has proven challenging, particularly in low- and middle-income countries (LMICs) like Cameroon. The PMTCT cascade, which encompasses various steps from antenatal care to infant follow-up, plays a crucial role in ensuring successful outcomes. However, challenges such as high loss-to-follow-up rates and mortality following antiretroviral therapy (ART) initiation underscore the need for targeted interventions [1-3]. Nevertheless, the success of PMTCT programs depends on the enrollment in ART and the retention of mothers in the continuum of PMTCT care (20), which begins with the offer of antenatal HIV screening at the first antenatal care (ANC) visit, which is the gateway to PMTCT in health facilities (21, 22).

The global goals of the Joint United Nations Program on HIV/AIDS (UNAIDS) to reduce new HIV infections among children by 90% and AIDS-related maternal deaths by 50% were far from being met by the end of 2015. Option B+, an approach promoting immediate initiation of HIV-positive pregnant and breastfeeding women on ART, aimed to address barriers to ART access, yet its outcomes varied across programs [4-5]. With the increasing importance of identifying and implementing effective interventions, understanding the experiences of informal caregivers emerges as a crucial aspect to improve service uptake and retention for mothers and infants [6].

Cameroon, like many sub-Saharan African countries, has faced challenges in implementing PMTCT programs, starting from its pilot phase in 2000. The progression from single-dose Nevirapine to the introduction of Option B+ in 2015 marked significant milestones in the country's PMTCT journey. Despite these advancements, adherence and retention rates have remained below target levels. Informal caregivers, encompassing family, friends, acquaintances, or neighbors, represent a potential resource to enhance adherence and retention in the PMTCT cascade [7].

This work explores the experiences of informal caregivers of HIV-positive pregnant and breastfeeding women in Fako Division, South West Region, Cameroon, within the context of existing PMTCT services. The study aims to shed light on the impact of informal caregiver support on ART adherence and the quality of life of HIV-positive pregnant and breastfeeding women participating in the PMTCT Option B+ program. The research addresses critical gaps in understanding the role of informal caregivers and their potential contribution to achieving the ambitious PMTCT goals, providing valuable insights for policymakers, program implementers, and healthcare practitioners in LMICs.

Previous studies of HIV+ subjects on ART in Cameroon showed high rates of non-adherence, treatment interruption, and loss to follow-up [23, 25], and this was associated with drug resistance and virologic failure [24]. For ART treatment programs in Cameroon to be successful, it is critical to identify barriers to adherence, then determine and implement appropriate measures to promote and improve adherence. It is well known that a higher level of adherence is desirable for maximum viral load suppression hence prevention of mother-child transmission [26, 27]. Studies have shown that, pregnant women with good adherence to ART have a low risk (less than 5%) of transmitting of HIV infection to their children [28]. Despite of the increasing coverage of elimination of MTCT in Cameroon, there is limited information focusing on the level of adherence to antiretroviral drugs and its covariates among pregnant women and breastfeeding mothers.

Cameroon has been facing challenges putting in place an effective response for its HIV/AIDS epidemic, both in care and treatment as well as for PMTCT. A sentinel survey among pregnant women aged 15–49 years in 2011 indicated a seroprevalence of 7.8%, ranging from 4.3% in the Far

North Region to 11.9% in the Centre Region [31]. With this high HIV prevalence in pregnancy and the low coverage of ART (61%) for pregnant and breastfeeding HIV-positive women [29], the Cameroonian government followed the WHO programmatic updates [30], recognizing the potential advantages to pilot Option B+ in two health districts in the country.

Care services for people living with HIV/AIDS have shifted from hospital-based care to community-based and in-home care. Informal caregivers have helped make this shift possible unlike professional care providers, informal caregivers are often on call 24-hours a day and are not protected by a limited work day or professional distance [30]. Caregivers often provide front-line medical and mental assessment, being the first to note changes in health and to decide when to go for help [31]. In some communities there is still fear and stigma surrounding HIV disease. Caregivers may fear social rejection, loss of job and/or housing and may thus conceal their caregiving status from family, friends, and co-workers [32].

2.0 MATERIALS AND METHODS

Study Area

This qualitative study was conducted in Fako Division, South West Region, Cameroon, encompassing four health districts, including Buea. Fako Division, with a population of approximately 604,669, covers 2093 km², and Buea, the regional capital, hosts seven Health Areas with a population of 200,000 [8], providing a diverse setting to capture representative informal caregiver experiences in PMTCT services.

Study Design

A sequential qualitative research design was employed, focusing on informal caregivers of HIV-positive pregnant and breastfeeding women in the PMTCT Option B+ program.

Qualitative Study

A descriptive qualitative approach involved five focus group discussions (FGD) and twelve in-depth interviews (IDI) among fifty-one informal caregivers. Each FGD comprised 6 to 11 participants, ensuring diverse perspectives. The study was conducted for a period of six months (June 2018-November 2018).

Study Population

The study enrolled two participant sets: HIV-positive pregnant and breastfeeding women in the PMTCT Option B+ program and their primary informal caregivers.

Inclusion Criteria

This study included: HIV-positive pregnant and breastfeeding women on ART for at least four weeks; Breastfeeding mothers with infants ≤ 18 months; Primary informal caregivers providing care for over a month; Informal caregivers aged fifteen years or above; HIV-positive pregnant and breastfeeding women and caregivers residing in Fako Division's Health Districts; Willingness to be followed-up for the study, and Ability and willingness to provide informed consent.

Exclusion Criteria

The study excluded participants with a history of medical or psychiatric disorders impacting informed consent, and participants residing outside the Buea Health District area.

Sampling Technique

Purposive sampling recruited fifty-one informal caregivers, identified through recommendations from PMTCT clients and health providers. In-depth interviews continued until saturation, ensuring data richness.

Data Collection Technique

Focus Group Discussions: Five sessions explored caregiving experiences, challenges, and relationships. Sessions, conducted over six months, involved 6-11 participants, a facilitator, a recorder, and a note-taker.

In-Depth Interviews: Twelve interviews delved into challenges, psychological experiences, and coping strategies, ensuring a deeper understanding. Key informants also contributed.

Data Management and Analysis

Participants used nicknames, and discussions were recorded and summarized. Transcriptions were stored securely for analysis. Atlas.ti software facilitated thematic and interpretive phenomenological analysis. Thorough steps ensured reliability and validity, including triangulation, member checking, and prolonged engagement for data saturation. This robust methodology aimed to comprehensively explore informal caregiver experiences in PMTCT services, providing valuable insights for enhancing program effectiveness in LMICs.

3.0 FINDINGS

Demographic Data for Primary Informal Care-Givers

This study involved 51 primary informal caregivers in focus group discussions and in-depth interviews, using pseudo-names for confidentiality. The majority were female (38), with 10 adolescents. Most caregivers were aged 40-49, and 17 were married. Eleven were HIV positive, 22 negative, and 12 undisclosed. Thirty-one co-resided with care recipients. Education levels varied, with 14 having secondary education. Employment-wise, 15 were self-employed, nine permanently employed. Twenty-one cared for children, and most (31) had 1-5 years of caregiving experience as shown in Table 1.

Table 1: Demographic Data of Informal Primary Care-Givers

Variables	Categories	Participants No (%)
Gender	Male	13 (25.5 %)
	Female	38 (74.5 %)
Age	Below 20 years	10 (19.6 %)
	21-30 years	6 (11.7 %)
	31-40 years	19 (37.2 %)
	41-50 years	11 (21.5 %)
	Above50	5 (9.8 %)
Marital status	Married	17 (33.3 %)
	Not married	18(35.2 %)
	Widow	8 (15.6 %)
	Separated	8 (15.6 %)
HIV and AIDS Status	Positive	11 (21.5 %)
	Negative	22 (43.2 %)
	Not known	18 (35.2 %)
Co-resident with care recipient	Yes	31(60.7 %)
	No	20(39.2 %)
Level of Education	Primary	22 (43.2 %)
	Secondary	14 (27.4 %)
	Tertiary	6 (11.7 %)
	Other	9 (17.6 %)
Employment status	Self	15 (29.4 %)
	Not Employed	27 (52.9 %)
	Employed	9 (17.6 %)
Relationship with care recipient	Spouse	8 (15.6 %)
	Child	5 (9.8 %)
	Parent	21 (41.14 %)
	Friend	7 (13.7 %)
	Distant Relative	10 (19.6 %)

Experiences of Informal Caregivers

In this qualitative study on the experiences of informal caregivers for PMTCT Option B+ clients, several themes and subthemes were identified across the data generation processes. The dominant themes include challenges of caring, the caring experiences, burdens and rewards of caregiving, and coping with the role of caring.

Psychological Challenges

The informal caregivers' work involves many stressors, including personal and work-related factors. These stressors lead to emotional and physical responses, such as anxiety, hopelessness, irritation, and exhaustion. The death of the care recipient is highlighted as a major psychological challenge, leading to grief and, in some cases, prolonged grief with potential psychiatric consequences. Financial difficulties, strained relationships, and the emotional toll of caregiving contribute to the caregivers' psychological challenges.

"My daughter, it is disheartening to see that the effort of caring you put on the patient is not helping to improve their health..." (FGD; a 54-year-old Female).

Economic Challenges

Most caregivers, often not employed, rely on informal markets for income, leading to financial strain. Caring for a chronically ill individual incurs significant costs, including medical expenses and the need for nutritious food. Financial constraints result in stress, frustration, and feelings of helplessness, impacting the caregivers' ability to meet the care recipient's medical and physical needs, including regular medical check-ups.

"...Sometimes it's really difficult to care for the infected, the last time she fell seriously ill, I went to look for money to take her to the hospital for about 4hrs. If we had money, I could have taken her to the hospital on time. Early morning the next day, the baby passed away. This broke my heart because of my financial constraints; my daughter was taken to the hospital late resulting in her death..." (FGD; a 51-year-old female).

Physical Challenges

Caregivers also face physical challenges, including symptoms such as weight loss and sleep disturbances due to the emotional toll of dealing with an HIV diagnosis in their care recipient. Fear of infection, especially during activities like bathing the sufferer, is heightened when caregivers lack proper protective measures. Conflicting feelings, misconceptions about infection, and concerns about skin integrity contribute to the physical challenges of caregiving.

"I did not know how to deal with it. I even lost weight. ...This is not the way I used to be." (FGD; a 41-year-old Male).

The Caring Experience

Commonalities in caregivers' responses reveal emotional ambivalence, physical challenges, and economic constraints throughout the caring process. Issues such as emotional struggles, physical difficulties, and financial burdens are consistently expressed by caregivers.

Emotional Ambivalence

In exploring the emotional aspects of the caregiving experience, various dimensions of emotional ambivalence emerged from focus group discussions and in-depth interviews. These aspects included emotional roller coasters, emotional confusion, fear of death, and suffering multiple losses.

a) Emotional Roller Coaster: Participants described a turbulent emotional journey marked by uncontrollable and unstable feelings. Anticipation of a positive diagnosis and subsequent confirmation led to conflicting emotions. Carers expressed shock, sadness, and a sense of hurt upon learning about the HIV diagnosis of their close relatives. Emotional fluctuations were evident, as highlighted by a respondent who felt a mix of emotions depending on the health status of the care recipient.

"... as I was caring for my wife, I became aware of the signs and symptoms as I observed her, so I prepared myself to be emotionally ready for anything. When I was tested, I was also found to be positive..." (FGD; a 52-year-old male).

b) Emotional Confusion: Caregivers reported feeling grateful for knowing the care recipient's status but experienced confusion about their own status. Being intimately involved with the sufferer raised questions about the caregiver's own health, leading to emotional turmoil and confusion. This emotional state became a complex situation for caregivers as they navigated their roles both as caregivers and as individuals with potential health concerns.

"When my wife tested positive for TB, she was advised to be tested for HIV and AIDS of which she also tested positive. As husband and wife, we were intimate naturally all the time. Now I am so...so...confused, I don't know whether I have it too. If it comes out that I am also positive, then who will look after the other...?" (FGD; a 42-year-old Male).

c) Fear of Death: Knowing the HIV status of a loved one triggered fears of death, especially when previous family members had succumbed to the disease. Participants expressed anxieties about losing their loved ones and the perceived threat associated with being HIV positive. The fear of death was compounded by observations of multiple deaths in the family, intensifying the emotional distress.

"AIDS is a killer disease. We buried my son two years ago. Now I am scared for his wife who is heavily pregnant. ARVs have helped to sustain her life this far (shaking her head), it's scarring!"

d) Suffering Multiple Losses: Fear of the care recipient's death led to concerns about the impact on their children and the loss of cultural significance associated with having a child. Caregivers also experienced loss in terms of intimacy, support, and income. The fear of impending bereavement and the anticipation of future challenges created a sense of loss and grief among caregivers.

"When she is worse, I become very worried. My sister has four children and I have three, my main worry is these children should anything happen, I really do not know" (FGD, Young male, participant number 1).

Burdens and Rewards of Caregiving

Burdens of Caregiving

Psychologist term "caregiver burden" was used to describe the physical, emotional, financial, and social challenges associated with caregiving. Both objective and subjective burden were discussed, encompassing disruptions in daily routines, financial hardships, emotional strain, and social consequences.

"... When my sister got worse, I took leave from work so that I can care for her. My employer then said I will be paid half my salary and if I exceed two months, he will look for someone to replace me" (IDI; a 17-year-old female).

Caregivers faced objective burden through changes in household routines, missed workdays, family frictions, and loss of income. Subjective burden manifested in caregivers feeling trapped, nervous, and depressed about their relationship with the care recipient. Factors contributing to caregiver burden included unexpected role assumptions, physical demands, emotional issues, financial impact, and societal stigma.

"...the illness of my wife leaves me with no plan. It's difficult for me to bathe her, and, as such, I asked her mother to come and stay with us" (a 42-year-old male).

Rewards of Caregiving

Despite the challenges, informal caregivers highlighted positive aspects, considering caregiving as an opportunity to make the care recipient see the purpose of life, provide assistance, develop empathy, gain a sense of personal effectiveness, and experience positive feelings associated with love and care. Caregivers found joy in witnessing the care recipients' progress, such as improvements in eating, walking, and bathing independently.

"It brings joy to see the care recipients, who couldn't eat on their own, eating, walking and even bathing on their own" (FGD; a 36-year-old female).

Caregiver Burnout

The rewards in caregiving did not necessarily alleviate stress, as high levels of involvement, whether positive or negative, could lead to caregiver burnout. Emotional exhaustion, depersonalization, and reduced personal accomplishment were identified as components of burnout. Focus group discussions revealed that caregivers could become emotionally exhausted, leading to a withdrawal from social interactions.

"Caregivers get emotionally exhausted and will come to fear facing a new day of the same or even worse caregiving activities, as a result, the caregiver becomes cocooned in their own activities and avoids mixing with others in the social sphere" (a 46-year-old female of the old women focus group).

Coping with the Role of Caring

Responses to questions on this theme revealed commonalities among the caregivers, and these will be discussed based on the sub-themes of controlling emotions, integrating HIV and AIDS into their lives, turning to spirituality, acquiring feelings of hope and gathering support from family and society.

Controlling Emotions

Caregivers acknowledged the necessity of maintaining emotional resilience, especially in the presence of the care recipient. Many felt that revealing their distress could adversely impact the care recipient's well-being. Consequently, caregivers often prioritized the care recipient's welfare, suppressing their emotions to shield both themselves and the recipient from additional stress. This act of emotional control was a common coping strategy, as expressed by a 46-year-old female caregiver:

"I felt so bad, such that I used to cry, but hid myself so that she couldn't see me because she was going to be worse" (IDI, a 46-year-old female).

This practice aligns with findings by Michio [9], indicating that family caregivers often employ self-control as a coping mechanism. Caregivers believed that projecting strength and concealing their emotional distress helped instill hope and courage in the care recipient.

Integrating HIV and AIDS into their Lives

Caregivers have embraced the reality of the care recipient's illness as an integral part of their daily lives. Assisting the sufferer in effectively dealing with the diagnosis became a primary focus. Encouraging and supporting the care recipient in adhering to medication regimens brought a sense of fulfillment to caregivers. Despite challenges such as medication side effects, caregivers found reward in being the "treatment buddy" and witnessing improvements in the care recipient's condition. A 27-year-old male caregiver shared:

"To be in her company...I then encouraged her to take her treatment every day. At times it was difficult, I used to feel sorry for her....I then became strict to her...she is much better now" (ID; a 27-year-old Male).

Acknowledging the illness and learning to live with its challenges represented a pivotal aspect of the caregiving journey. Initial feelings of sadness, confusion, and helplessness evolved into acceptance as caregivers and recipients openly discussed the disease. This openness fostered a sense of relief and acceptance, as illustrated by a 43-year-old male caregiver: *"She is telling them about her sickness and that made me free to also talk about it to others. She has accepted it, so I also just have to accept it... She talks about it too"* (FGD, a 43-year-old Male).

Spirituality

Spirituality emerged as both a positive and negative coping mechanism among caregivers. Positively, caregivers expressed engaging in prayer and attending religious services as sources of spiritual support. Seeking solace in spirituality provided comfort and hope. A 49-year-old female caregiver described: *"When I worry a lot I go to church...sometimes I pray by myself"* (IDI, a 49-year-old female).

Conversely, some caregivers perceived the infection as a divine test of faith, leading to questions such as "Why me, God?" A 41-year-old female caregiver articulated: *"I wonder what is God doing or maybe He is testing my faith in him"* (FGD; a 41-year-old female).

Spirituality as a coping mechanism resonates with findings from studies by Nora [10]; Wrubel [11], identifying faith as a common element in the caregiving experiences of diverse populations.

Feelings of Hope

Caregivers, despite facing fear, helplessness, and confusion, experienced moments of hope for the recovery and well-being of care recipients. The introduction of Antiretroviral drugs (ARVs) brought relief, fostering optimism among caregivers. Primary caregivers, initially apprehensive about societal and familial reactions, found hope as care recipients openly acknowledged their diagnoses. In contrast to the findings of Bateganya et al. [12] highlighting helplessness and despair, this study revealed that caregivers initially faced such emotions, but openness about the disease and ARV treatment instilled hope. Observing successful HIV activists also contributed to caregivers' hopeful outlook.

"I am now feeling better; I told myself that she is going to be fine. She's going to have nothing now because she is getting treated and she is also talking about it now." A female caregiver (FGD; 34 years old):

Gathering Support

The process of "gathering support" involved caregivers seeking information and assistance related to HIV/AIDS. Caregivers disclosed HIV status to elicit assistance, sought practical help from friends and neighbors, and joined home-based care organizations for comprehensive support. Positive experiences with support were highlighted, although challenges, such as family interference causing stress, were acknowledged. The study noted a shift in gender roles, with men actively participating in caregiving tasks traditionally perceived as 'women's work.' Despite initial reluctance to openly discuss their challenges, caregivers, especially men, eventually sought social support and advice to cope effectively.

"In the beginning, I was afraid of how people would react... Since I am speaking about it, I'm feeling much better; they are supportive... They bring her medication and also advise me on what to do." A male caregiver (IDI; 37 years old).

"There is a girl in the house behind us whom I always ask to give me help like bathing, cleaning, or even cooking for us when I maybe have to take one of them to the doctor or hospital." A female caregiver (IDI; 42 years old).

"The home-based caregivers are very good people to get help from if they are trained in working with people like her..." A care provider (IDI).

"Some family members come to give you stress pretending to be helping the care recipient when they will actually try to look for faults in my caregiving work." An older female caregiver (FGD; 51 years old).

"Now that people are openly talking about HIV and AIDS, we can now join support groups free of stigmatization and discrimination and discuss how to overcome stress to improve our care for the care recipients." A female caregiver in the focus group (43 years old).

Discussions

The study utilized thematic content analysis to delve into the experiences and coping strategies of primary informal caregivers in the context of HIV and AIDS. The findings were organized into five main themes: challenges of caring, the caring experiences, burdens and rewards of caregiving, caregiver burnout, and coping with the role of caring. Caregivers depicted the caring process as both challenging and emotionally ambivalent, characterized by positive and negative experiences. Financial challenges were prevalent due to unemployment among caregivers, leading to physical symptoms and strains. This aligns with the findings of Zachariah [13] findings on caregivers experiencing health problems related to depression and the care recipient's illness symptoms.

The study highlighted the physical challenges faced by caregivers, supported by Uys [14], indicating symptoms of poor physical health associated with care-related demands and stressors. The fear of infection among caregivers, as discussed by Grimwood [15] and Ekaete [16], was not universal in the present study, with some caregivers not considering the risk even when dealing with blood. Family and societal responses to the diagnosis were complex, with emotional turmoil and stigma. Caregivers often faced rejection and hostility, leading to discrimination and isolation for both the caregiver and the care recipient. Limited emotional and cognitive support compounded the challenges, forcing caregivers to resort to poor coping mechanisms.

Managing their experiences and societal responses, caregivers mentioned controlling their emotions, attending to spirituality positively or negatively, and hoping for better outcomes with the introduction of antiretroviral therapy. The study suggested that caregiving in the HIV and AIDS context is emotionally challenging, and caregivers may still experience stigma, resulting in nondisclosure. The emotional experiences of caregivers were complex, including shock, hurt, sadness, and anticipatory grief. Emotional distress was heightened by the intimate relationship between the caregiver and the care recipient, affecting their ability to cope effectively.

Financial demands intensified feelings of helplessness. Ekaete et al. [16] also found in their study that poverty increased the worries of caregivers, as they could not reach their care recipients' health needs. The result of this study corroborated with these findings, as the participants expressed their financial challenges. Zachariah et al. [17] and Grimsrud [18] in their studies also noted that poverty increases the worries of caregivers, as they might not have enough money for a balanced diet and regular medical check-ups.

The study also revealed that most caregivers and care recipients were unemployed, lacked available social grants, and faced economic constraints. The care facilities were distant from caregivers' and care recipients' living areas, necessitating special hired transport, adding to their distress. Helplessness, due to emotional difficulties, is supported in the research of Wardlaw [19], who found that caregivers experience feelings of helplessness, denial, and despair. Emotional difficulty associated with knowing that an intimate relation is living with the virus was observed not to be experienced by the caregivers only. Participants in the study reported different emotional experiences of the family and the community when they knew about the care recipient's diagnosis.

The study found that support was mostly offered to the care-recipients and not so much to the caregivers. Coping mechanisms employed by caregivers included controlling emotions, self-control, integrating HIV and AIDS into their lives, spirituality, feelings of hope, and gathering support from others through discussions and support group facilitations. Poor coping mechanisms used by caregivers in the study included denial and inappropriate humor.

4.0 CONCLUSION AND RECOMMENDATIONS

The findings of this study have important clinical and public health implications in the context of reaching the 2030 UNAIDS 90-90-90 targets toward an AIDS-free generation. Informal caregivers, predominantly close relatives, played a crucial role in supporting HIV-positive pregnant and breastfeeding women, despite facing emotional and physical challenges. Primary caregivers developed coping mechanisms, including empathy and faith, but their own well-being was compromised. Notably, women with informal caregivers demonstrated higher adherence to antiretroviral therapy (ART) and better quality of life. Training informal caregivers in the care continuum could enhance adherence rates, contributing to meeting UNAIDS Super-Fast-Track Targets. Factors influencing adherence, such as partner support and education, should be addressed to prevent drug resistance and reduce the financial burden on health systems. The study underscores the importance of recognizing and supporting informal caregivers in achieving global HIV goals.

Competing interests: The authors declare that they have no conflict of interest.

Financial Disclosure: None.

Funding/Support: None.

Ethics approval: Ethical approval for the study was sought from the Ethics Committee of the Faculty of Health Sciences, University of Buea, Cameroon.

Acknowledgements: The authors are grateful to all who took part in this study.

Authors contribution: MEE0 designed the study. MEE0 and BMY developed the manuscript. MEE0, EY, NT, BMY, CNN, and DNS provided substantial comments for the writing of the manuscript. All authors read and approved the final manuscript.

REFERENCES

1. Mendelsohn J.B., Schilperoord M., Spiegel P., et al., Adherence to antiretroviral therapy and treatment outcomes among conflict-affected and forcibly displaced populations: a systematic review. *Confl Health* 6, 9 (2012).
2. John D, Christophe L, Willian B, Modeste K, Antoinette T, Robert C, Olivier k; Antiretroviral Treatment Program Retention among HIV-Infected Children in the Democratic Republic of Congo, 2014, Available from: [http:// pubmed central canada. Ca/pmc/articles/PMC4277274/](http://pubmedcentral.ca/pmc/articles/PMC4277274/)
3. A Gamell; Prevention of mother-to-child transmission (PMTCT) of HIV/AVERT 2017, Available from: <https://www.avert.org/professionals/hiv-programming/prevention/prevention-mother-child>
4. National PMTCT Protocol Guidelines.pdf, 2014. Available from: [https://www. k4 health. Org/sites/files/ National PMTCT/Protocol %20Guidelines.pdf](https://www.k4health.org/sites/files/NationalPMTCT/Protocol%20Guidelines.pdf)
5. Myer L, Phillips TK., Beyond “Option B+”: Understanding Antiretroviral Therapy: *JAIDS Journal of Acquired Immune Deficiency Syndromes*. Available from: [http://journals.lww.com/jaids/ Abstract/2017/06011/ Beyond Option B Understanding_ Antiretroviral.3.aspx](http://journals.lww.com/jaids/Abstract/2017/06011/BeyondOptionBUnderstandingAntiretroviral.3.aspx), 2017
6. Lethin C; Formal support for informal caregivers to older persons with dementia through the course of the disease: an exploratory, cross-sectional study | *BMC Geriatrics*, 2016, | Full Text. Available from: [https://bmcgeriatr.biomedcentral. com/articles/10.1186/s12877- 016-0210-9](https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-016-0210-9)
7. Rosenberg NE; Improving PMTCT Uptake and Retention Services Through Novel Approaches in Peer-Based Family-Supported Care in the Clinic and Community: A 3-Arm Cluster Randomized Trial (PURE Malawi), 2014; Available from: https://www.researchgate.net/publication/Improving_PMTCT
8. Cameroon Demographic and Health Survey and Multiple Indicators Cluster Survey (2011) (DHS-MICS). [https://dhsprogram.com/ pubs/pdf /FR260 /FR260.pdf](https://dhsprogram.com/pubs/pdf/FR260/FR260.pdf)
9. Michio Y, Jinkook L. Effects of Informal Caregivers’ Health on Care Recipients: SSRN; 2016. Available from: [https://papers.ssrn. com/sol3/papers. cfm?abstract_id =2789936](https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2789936)
10. Nora S; Who Will Be There to Care? The Growing Gap between Caregiver Supply and Demand-BP_Caregivers; 2002; .pdf. Available from: [http://www. nhpf. org/library/background-papers/BP_Caregivers_1-02.pdf](http://www.nhpf.org/library/background-papers/BP_Caregivers_1-02.pdf)
11. Wrubel J, Folkman S. What informal caregivers actually do: the caregiving skills of partners of men with AIDS. *AIDS Care*. 1997; 9(6):691–706.
12. Moses B, Ugo A, Uchechi R, Maxia D,; Impact of Support Groups for People Living With HIV on Clini... : *JAIDS Journal of Acquired Immune Deficiency Syndromes*; 2016. Available from: [http://journals. lww. com/jaids/ pages/articleviewer. asp?year =2015&issue= 04151&article= 00013&type=Fulltext](http://journals.lww.com/jaids/pages/articleviewer.aspx?year=2015&issue=04151&article=00013&type=Fulltext)
13. Zachariah R, Teck R, Buhendwa L, et al. Community support is associated with better antiretroviral treatment outcomes in a resource-limited rural district in Malawi. *Trans R Soc Trop Med Hyg*. 2007;101(1):79-84.

14. Uys LR. The practice of community caregivers in a home-based HIV/AIDS project in South Africa. *J Clin Nurs*. 2002;11(1):99-108.
15. Grimwood A, Fatti G, Mothibi E, Malahlela M, Shea J, Eley B. Community adherence support improves programme retention in children on antiretroviral treatment: a multicentre cohort study in South Africa. *J Int AIDS Soc*. 2012;15(2):17381
16. Ekaete FA, Etowa BJ, Adejumo P; Assessing the Relationship between Caregivers Burden and Availability of Support for Family Caregivers' of HIV/AIDS Patients in Calabar, South East Nigeria, 2013, [cited 2017 Jul 7]. Available from: http://file.scirp.org/pdf/WJA_
17. Zachariah R, Teck R, Buhendwa L, et al. Community support is associated with better antiretroviral treatment outcomes in a resource-limited rural district in Malawi. *Trans R Soc Trop Med Hyg*. 2007;101(1):79-84.
18. Grimsrud, A., Lesosky, M., Mothibi, E., Kalombo, C., Bekker, L. G., & Myer, L., Implementation and operational research: Community-based adherence clubs for the management of stable antiretroviral therapy patients in Cape Town, South Africa: A cohort study. *Journal of Acquired Immune Deficiency Syndromes*, (2016) 71(1), e16–e23.
19. Wardlaw LA. Sustaining informal caregivers for persons with AIDS. *Fam Soc*. 1994; 75(6):373– 384.
20. World Health Organization *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: recommendations for a public health approach*. Geneva, Switzerland: WHO (2013).
21. Tweya, H, Gugsu, S, Hosseinipour, M , Speight, C , Ng'ambi, W , Bokosi, M, et al. Understanding factors, outcomes and reasons for loss to follow-up among women in option B+ PMTCT programme in Lilongwe, Malawi. *Trop Med Int Health*. (2014) 19:1360–6. doi: 10.1111/tmi.12369
22. Vogt, F, Ferreyra, C, Bernasconi, A , Ncube, L , Taziwa, F , Marange, W, et al. Tracing defaulters in HIV prevention of mother-to-child transmission programmes through community health workers: results from a rural setting in Zimbabwe. *J Int AIDS Soc*. (2015) 18:20022. doi: 10.7448/IAS.18.1.20022
23. Rougemont M, Stoll BE, Elia N, Ngang P. Antiretroviral treatment adherence and its determinants in Sub-Saharan Africa: a prospective study at Yaounde Central Hospital, Cameroon. *AIDS Res Ther*. 2009;6:21.
24. Meresse M, Carrieri MP, Laurent C, Kouanfack C, Protopopescu C, Blanche J, et al. Time patterns of adherence and long-term virological response to non-nucleoside reverse transcriptase inhibitor regimens in the Stratall ANRS 12110/ESTHER trial in Cameroon. *Antivir Ther*. 2013;18(1):29–37.
25. Pefura-Yone EW, Soh E, Kengne AP, Balkissou AD, Kuaban C. Non-adherence to antiretroviral therapy in Yaounde: prevalence, determinants and the concordance of two screening criteria. *J Infect Public Health*. 2013;6(4):307–15.
26. Chagomerana MB, Miller WC, Tang JH, Hoffman IF, Mthiko BC, Phulusa J, et al. Optimizing prevention of HIV mother to child transmission: Duration of antiretroviral therapy and viral suppression at delivery among pregnant Malawian women. *PloS one*. 2018; 13(4):e0195033. <https://doi.org/10.1371/journal.pone.0195033> PMID: 29614083

27. Okonji JA, Zeh C, Weidle PJ, Williamson J, Akoth B, Masaba RO, et al. CD4, viral load response, and adherence among antiretroviral-naïve breast-feeding women receiving triple antiretroviral prophylaxis for prevention of mother-to-child transmission of HIV in Kisumu, Kenya. *JAIDS Journal of Acquired Immune Deficiency Syndromes*. 2012; 61(2):249–57. <https://doi.org/10.1097/QAI.0b013e318262514f> PMID: 22692094
28. Gamell A, Luwanda LB, Kalinjuma AV, Samson L, Ntamatungiro AJ, Weisser M, et al. Prevention of mother-to-child transmission of HIV Option B+ cascade in rural Tanzania: The One Stop Clinic model. *PloS one*. 2017; 12(7):e0181096. <https://doi.org/10.1371/journal.pone.0181096> PMID: 28704472
29. Billong S, Fokam J, Billong E et al. Distribution épidémiologique de l'infection à VIH chez les femmes enceintes dans les dix régions du Cameroun et implications stratégiques pour les programmes de prévention. *Pan Afr Med J* 2015;20:79.
30. WHO. WHO, Programatic Updates; Use of antiretroviral drugs for treating pregnant women and preventing HIV infection in infants. WHO, Geneva, April, 2012.
31. Ekaete Francis Asuquo, Josephine B. Etowa, Prisca Adejumo; Assessing the Relationship between Caregivers Burden and Availability of Support for Family Caregivers' of HIV/AIDS Patients in Calabar, South East Nigeria, 2013,. Available from: http://file.scirp.org/pdf/WJA_
32. OFFICE ON WOMEN'S HEALTH; Caregiver stress | [womenshealth.gov](https://www.womenshealth.gov), 2015, Available from: <https://www.womenshealth.gov/a-z-topics/caregiverstress>
33. Kohli R, Purohit V, Karve L, Bhalerao V, Karvande S, Rangan S, Reddy S, Paranjape R, Sahay S., Caring for Caregivers of People Living with HIV in the Family: A Response to the HIV Pandemic from Two Urban Slum Communities in Pune, Indi, 2012.

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