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Impact of Informal Care-Giving on Adherence to Antiretroviral Therapy among HIV Positive Pregnant and Breastfeeding Women in Fako Division

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ABSTRACT

Background: Adherence to antiretroviral treatment (ART) is vital to a successful implementation of Prevention of Mother to Child Transmission (PMTCT) program. A relationship exists between high prevalence of HIV among pregnant and breastfeeding women and the demand for health care services on both formal and informal caregivers. Hence HIV's burden transcends the health care system to families and friends who are without appropriate sensitization and educational preparation to take up the caregiving role to meet the health need of their family members. The study therefore aimed at investigating the impact of informal care-giving on adherence to antiretroviral treatment (ART) among HIV positive pregnant and lactating women in Fako Division, South West Region, and Cameroon.

Methodology: A cross-sectional descriptive study was conducted among 384 pregnant women and lactating mothers in the PMTCT program from twelve health facilities located in Fako Division in the South West Region of Cameroon. Data were collected using a structured questionnaire. Data analysis was performed using descriptive statistics, as well as bivariate and multivariate logistic regression.

Results: The mean (±SD) age of the participants was 28.15 (±7.70) years with the age group of 21 to 30 years constituting half (50.3%) of the study population. A high proportion (64.1%) of HIV positive pregnant women were receiving care related to their HIV infection and treatment from informal care-givers. Distant relatives were the highest category (50.0%) of informal care-givers. The husbands of the pregnant women provided the least (0.7%) informal cares to the women. Almost three quarter of the women had a low level of adherence to ART compared to a greater proportion of participants with poor level of adherence. no significant association was observed between informal care and clinic appointment ($\chi 2 = 0.551$, $p = 0.458$). There was statistical significant association between socio-demographic variables and informal care giving.

Conclusions: The health care provided by the patient's social network is important in low income settings. There is a significant contribution by the informal caregivers who form the backbone of health care system round the world. Informal caregivers operate as extensions of health care systems performing complex medical and therapeutic tasks and ensuring care recipient adherence to therapeutic regimens.

KEYWORDS: *Informal care givers, HIV positive pregnant women, Adherence, retention, Quality of life*

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INTRODUCTION

Prevention of mother -to-child transmission (PMTCT) services have been part and parcel of most national HIV control programs though their implementation has varied greatly across countries and over time [1]. In 2011 the Joint United Nations Program on HIV/AIDS (UNAIDS) launched an ambitious program to eliminate new HIV infections among children while keeping their mothers alive [2]. This was known as the global plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive, which covered all low - and middle-income countries but with special focus on 22 countries with the highest number of pregnant women living with HIV [3]. These countries which later on became known as the priority countries of the global plan are all found in sub-

Saharan Africa but for India. More global and national commitments are needed in sub-Saharan African countries with over 90% of pregnant women living with HIV in need of comprehensive PMTCT services [4]. The Global Plan over-arching goals states, "Global goal 1: Reduce the number of new HIV infections among children by 90% and Global goal 2: Reduce the number of AIDS -related maternal deaths by 50%" [5].

At the end of 2015, despite all the concerted efforts put in place by the World Health Organization (WHO) in consultation with partner organizations these goals were far from being met [6]. Unless the proportions of affected pregnant women and mothers identified, initiated, and retained in care are in excess of 90%, the UNAIDS Super-Fast-Track Target of reducing the number of children newly infected to less than 20,000 by 2020 is no more than a commendable aspiration [7]. This retention rate could be enhanced with the involvement of informal caregivers in the PMTCT cascade [8] . Informal care towards HIV positive pregnant and breastfeeding women can be provided by family, friends, acquaintances, or neighbors for which they do not have to be financially compensated [9]. The caregiver is considered informal because the relationship between the caregiver and the person in care is not established or regulated by any organization or employer [10]. Informal caregivers of people with HIV/AIDS provide practical help and nursing care at home and can be great sources of social support (11).

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 [13]. 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 [14]. 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 [15].

Prevention of mother to child transmission (PMTCT) is a pillar of reduction and elimination of HIV vertical transmission. Considerable efforts have been made with local and international community to design appropriate interventions to eliminate HIV transmission to children but still there are some challenges existing [16]. The use of antiretroviral drugs for PMTCT worldwide has resulted to a marked decrease of Mother to child transmission (MTCT) from over 370000 children in 2009 to as low as 160,000 children in 2014 [17, 18]. Cameroon also responded considerably well through introducing her elimination plan of mother to child transmission aiming at improving health of parents and their children by scaling up comprehensive PMTCT and pediatric HIV care through intensive treatment and supporting services [19]. Since the inception of Implementation of PMTCT services in Cameroon in 2014's, several milestones have been witnessed ranging from single dose niverapine (sdNVP) during perinatal to the current combination treatment, option B+ [20].

It is well known that a higher level of adherence is desirable for maximum viral load suppression hence prevention of mother-child transmission [21, 22]. 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 [22, 23]. 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. Therefore, this study aimed at providing an insight on the Impact of Informal Care-giving on Adherence to Antiretroviral Therapy among HIV Positive Pregnant and Breastfeeding Women in Fako Division, South West Region, Cameroon

Materials and methods

Study Design

This was a descriptive and analytical cross-sectional study which involved pregnant and lactating mothers on Option B+ enrolled in PMTCT programs in selected health facilities. The study was conducted from March 2019 to June 2019.

Study area

The study was conducted in twelve health facilities within the four Health Districts in the Fako Division of the South West Region. The Fako Division covers an area of 2093km2, and has a population of 534854 people. The selected health facilities were in the Buea health District with 29 health facilities, Limbe Health District with 34 health facilities, Tiko Health District with 20 health facilities and Muyuka Health District with 18 health facilities. From the Buea Health District, four health facilities were selected; the Buea regional Hospital, CMA Muea, St. Veronica Medical Center and the Seventh Day Adventist Health Center. From the Limbe Health District, three facilities were selected; the Limbe Regional Hospital, Bota District Hospital and the Mile 4 Intergrated Health Center. From the Tiko Health District, three health facilities were selected; the C.D.C. cottage hospital, Tiko District Hospital and CMA Mutengene, and from the Muyuka Health District, two health facilities were selected; Muyuka District Hospital and the Holy Trinity Hospital.

These facilities were selected based on high coverage, specifically receiving well over 90% of the pregnant women seeking ANC in their respective health districts and partly because they are the major accessible areas in which PMTCT is being implemented. These health facilities serve large number of antenatal attendees per year ranging from a minimum of 400 to a maximum of 1000 visits. These sites were among the health facilities that were selected to pilot Option B+ in this region with its staff being the first to be trained in Option B+ procedures and task shifting in the country.

Sample Size

It was estimated using the formula below:

Where n= sample size,
Z= = 1.96 (standard normal value at 95% confidence level)
p= prevalence of intestinal parasites among HIV positive patients = 50% [24].
e= precision of the event of interest = 0.05
= 384 participants

Thus the study recruited a minimum sample size of 384 participants.

Sampling technique

Cluster random sampling, purposive and convenient sampling was used to sample the participants. Firstly the health facilities in Fako Division were divided into natural subgroups called cluster based on their status as health districts with public, profit making or faith-based health facilities. Secondly, health facilities were randomly selected from each grouping. Lastly, the Participants were sampled using a non-probability sampling method known as the convenient sampling. Convenient sampling was applied among pregnant mothers and lactating women consulting for PMTCT services in the respective health facilities. Study participants were serially enrolled until sample size was reached. This was purposely done due to a small number of pregnant and lactating mothers on option B+ treatment. On the day of data collection, mothers were approached as they were arriving and asked to participate freely to the study until the sample size was reached. Patients visiting PMTCT clinic on their scheduled visits were informed about the study. Those patients who fulfilled inclusion criteria and agreed to participate in the study were provided with a consent form for signing.

Data collection tool and technique

Data were collected using questionnaire adopted from the tool to measure ART adherence in resource constrained settings developed and validated in South Africa [25]. The structured questionnaires administered by the principal researcher and through the help of trained assistant assistants. Questionnaires were delivered to the respondents by face-to-face contact, for them to fill and return within one week. The questionnaire was pretested with fifty HIV positive pregnant women around non-controlled area before the actual data collection in order to ensure the appropriateness of the content regarding the questions, language and organization. Questionnaires were then adapted based on any new changes found to ensure validity. The questionnaires were administered to participants who verbally consented and signed the consent form. At the end the exercise, the number of consent forms were counted to ensure it corresponded to the number of questionnaires. The questionnaires were then checked, validated and stored for subsequent use for data entering.

Measurement of variables

Measurement of good or poor adherence were based on pill count method as well as validated set of questions. Good adherence by pill count: This was considered when the study participant had an adherence of more than 95% of the prescribed pills while poor adherence was when one missed more than 5% of all doses in a month period. Pill count as a measure of adherence was ascertained by counting the number of remaining pills in relation to total number of prescribed doses during last visit.

Adherence by self-reporting method: The level of adherence was also measured using four measurement questions adapted from the experience in South Africa, which were designed to measure adherence in resource constrained settings [25]. A study participant was considered to have good adherence if she responded "no" to all four of the questions. However, if she responded "yes" to at least one question, she was considered to have poor adherence. Covariates of this study involved social demographics, HIV stigma, adherence counseling, disclosure status, and distance from health facility. Others were level of education, gestation age, and lactation status, and place of residence (rural or urban). Moreover, distance from home to nearby health facility, knowledge on option B+ PMTCT and male partners support were also included.

Data analysis

A pre-designed EpiData Version 3.1 was used to enter the data. Further consistency, data range and validation checks was performed in SPSS version 21.0 to identify invalid codes. Descriptive and inferential statistics was used. Descriptive statistics of frequencies and percentages was used to summarize the data. Inferential statistics utilized sample data to make estimates, decisions, predictions or other generalizations about a larger set of data. By the application of inferential statistics (chi-square test), the level of significance was determined at the p value of .05. Variables in the questionnaire was coded for easy entry and analysis of the data. Data was made essentially of categorical variables and they were analysed using frequency and proportions and Multiple Response Analysis to aggregate responses within conceptual components. Chi-Square test of equality of proportion was used to compare proportions for significant difference. Association or relationship between two variables was assessed using Chi-Square test and Spearman's Rho correlation test. Multivariate logistic regression was used to adjust for confounding, thereby analyze factors that were independently associated with retention and adherence. Also, two sample tests for Binomial proportion test were applied. Data was presented using frequency table, charts and code-grounding-quotation table. All statistics were presented at the 95% Confidence Level (CL), Alpha =0.05.

Ethical considerations

Ethical clearance to collect data from the participants was obtained from the Faculty of Health Sciences Institutional Review Board and also authorization from the Regional Delegation of Public Health of the South West Region to carry out research in the health district and health facilities within the region. Each participant gave their written consent before they could participate in the study while parental consent was gotten for participants less than 21 years. Women who could not read had the consent form read to them by a study staff and they could give their informed consent by using their thumb prints.

Participants only gave their consent after they have been informed on the study procedures, benefits, risks, voluntary participation and have been assured of their confidentiality For participants' confidentiality, names were not written on the questionnaires. Only codes were used to identify participants. Participants' information was also stored in password protected computers.

Results

Socio-demographic and baseline obstetric characteristics of the study participants

The sample size envisaged at the beginning of the study was attained evidence by the participation of Three hundred and eighty four (384) women enrolled in the PMTCT program in the selected health facilities in Fako Division.

The mean (±SD) age of the participants was 28.15 (±7.70) years with the age group of 21 to 30 years constituting half

(50.3%) of the study population. There were 123 (32.0%) singles and 119 (31.0%) married women. Women with informal level of education [21(5.5%)] occupied the least position whereas those with secondary level of education [117(30.5)] were among the highest. There were 112(29.2) women with a catholic religious background. Many [122(31.8)] of the women were unemployed followed by housewives [66(17.2)]. The socio-demographic characteristics of participants are summarized on table 1 below.

Table 1: Association of socio-demographic variables with Informal care among women in the PMTCT

Characteristic		Informal Care Giving		Chi square	p-value
		Absence No(%)	Presence No(%)		
Age group	<21 years	24(36.4)	42(63.6)	3.120	0.374
	21-30 years	76(39.4)	117(60.6)		
	31-40 years	31(32.0)	66(68.0)		
	41-50 years	7(25.0)	21(75.0)		
Marital status	Single	52(42.3)	71(57.7)	6.271	0.180
	Married	44(37.0)	75(63.0)		
	Widowed	9(22.5)	31(77.5)		
	Divorced,	9(28.1)	23(71.9)		
	Concubine	9(34.3)	46(65.7)		
Level of Education	Informal	7(33.3)	17(66.7)	8.611	0.072
	Completed Primary	28(29.5)	67(70.5)		
	Completed Secondary	48(41.0)	69(59.0)		
	Completed High School	26(28.9)	64(71.1)		
	University and Higher	29(47.5)	32(52.5)		
Religious affiliation	Catholic	50(44.6)	62(55.4)	7.641	0.177
	Presbyterian	36(37.1)	61(62.9)		
	Baptist	18(26.5)	50(73.5)		
	Pentecostal	23(29.9)	54(70.1)		
	Muslim	6(37.5)	10(62.5)		
	Others	5(35.7)	9(64.3)		
Occupatio n	Unemployed	43(35.2)	79(64.8)	4.979	0.546
	Housewife	22(33.3)	44(66.7)		
	Farmer	17(32.7)	35(67.3)		
	Business	20(33.9)	39(66.1)		
	Student	12(32.4)	25(67.6)		
	Staff employed in the civil sector	9(47.4)	10(52.6)		
	Staff employed in the private sector	15(51.7)	14(48.3)		

Obstetric and Antenatal History of participants

A majority [184(47.9%)] of the women were in the second trimester of their pregnancy with 6(1.6%) of them experiencing the post term period. There were 108(28.1%) and 130(33.9%) women with one and two numbers of previous deliveries respectively. About half (49.5%) of the participants were in their second trimester of pregnancy at the time of enrolment. Most [200(52.1%)] of the woman had attended one antenatal clinic at the time of interview. A majority [284(74.0%)] of the participants had attended all their schedule antenatal clinic visits. The obstetric and antenatal histories of the participants are presented in table 2.

Table 2: Obstetric and Antenatal Histories of HIV positive pregnant women in Fako Division

Variable		Frequency (%)
Obstetric History		
Gestational age	First trimester	40(10.4)
	Second trimester	184(47.9)
	Third trimester	154(40.1)
	Post term	6(1.6)
Number of deliveries	None	37(9.6)
	One	108(28.1)
	Two	130(33.9)
	Three	77(20.1)
	Four and more	32(8.3)
Antenatal History		
Gestational age at first ANC	First trimester	181(47.1)
	Second trimester	190(49.5)
	Third trimester	13(3.4)

ANCs attended	None	1(0.3)
	One	200(52.1)
	Two	142(37.0)
	Three	28(7.3)
	Four	13(3.4)
Missed ANC	None	284(74.0)
	One	79(20.6)
	Two	21(5.5)

Clinical Characteristics of Study Participants

The clinical characteristics of study participants are summarized on table 3. Majority [230(59.9%)] of the women had been diagnosed HIV positive within one year. The majority [331(86.2%) and 360(93.8%)] received pre- and post-test counseling respectively. Tenofovir containing regimen was the most [371(96.6%)] used ART among the women involved. Nine-tenth [346(90.1%)] of the partners of the women under the study had been tested for HIV with [112(29.2)] being positive and [189(49.2)] negative

Table 3: Clinical Characteristics of study participants

	Variable	Frequency (%)
Duration of HIV diagnosis	≤12 months	230(59.9)
	13-24 months	105(27.3)
	25-36 months	26(6.8)
	37-48 months	18(4.7)
	>48 months	5(1.3)
Pretest counseling	No	53(13.8)
	Yes	331(86.2)
Posttest counseling	No	24(6.3)
	Yes	360(93.8)
ARV regimen	AZT/3TC/NVP	8(2.1)
	AZT/3TC/EFV	5(1.3)
	TDF/3TC/EFV	371(96.6)
Duration on ARV	≤12 months	229(59.6)
	13-24 months	105(27.3)
	25-36 months	25(6.5)
	37-48 months	18(4.7)
	>48 months	7(1.8)
Partner tested	No	38(9.9)
	Yes	346(90.1)
Partner's HIV status	Negative	189(49.2)
	Positive	112(29.2)
	Unknown	83(21.6)

Proportion of pregnant women with informal care-givers

A high proportion (64.1%) of HIV positive pregnant women were receiving care related to their HIV infection and treatment from informal care-givers. This type of care was not recorded in 35.9% of the pregnant women (Figure 1).

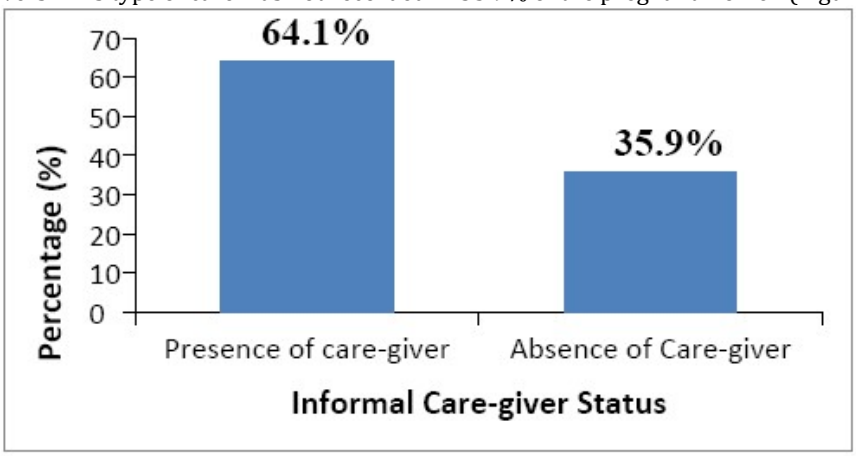

Figure 1: Proportion of women with informal care in the PMTCT program

Category of care-givers among HIV positive pregnant women

Close relatives were the highest category (50.0%) of informal care-givers. The husbands of the pregnant women provided the least (0.7%) informal cares to the women (figure 2).

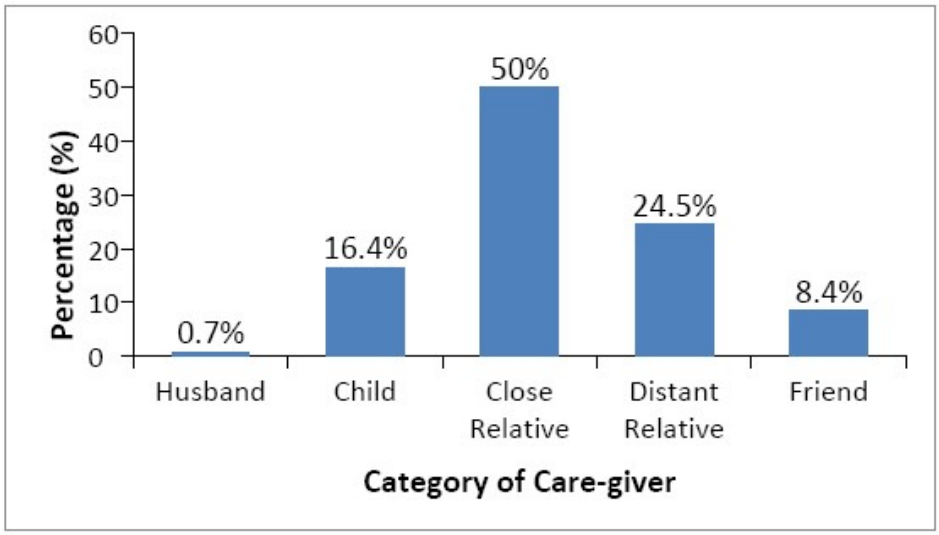

Figure 2: Category of Informal Care-givers among women enrolled in the PMTCT

Role of Informal care giver as a result of disclosing status

A high proportion (79.9%) of care-givers was reminding the participants of their treatment. A fraction (10.2%) of the supposed care-givers tends to stigmatize the women. (Figure 3)

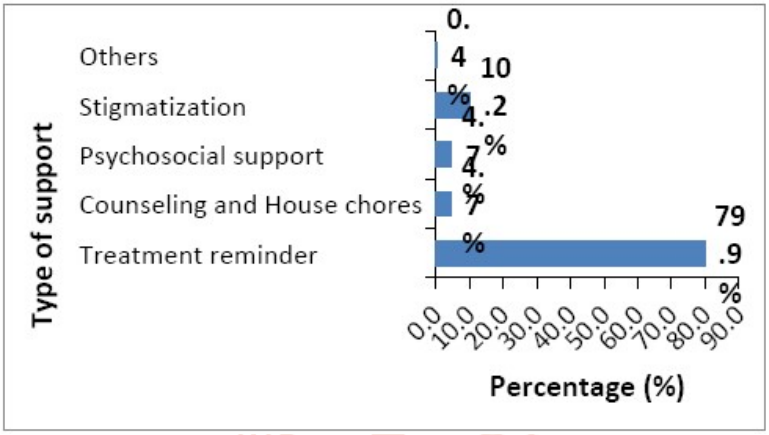

Figure 3: Role of Informal care giver as a result of disclosing status

Adherence to ART among study participants

Almost three quarter (75.8%) of the women had a proper level of adherence to ART compared to a lesser proportion (34.2 %) of participants with poor level of adherence.(Figure 4)

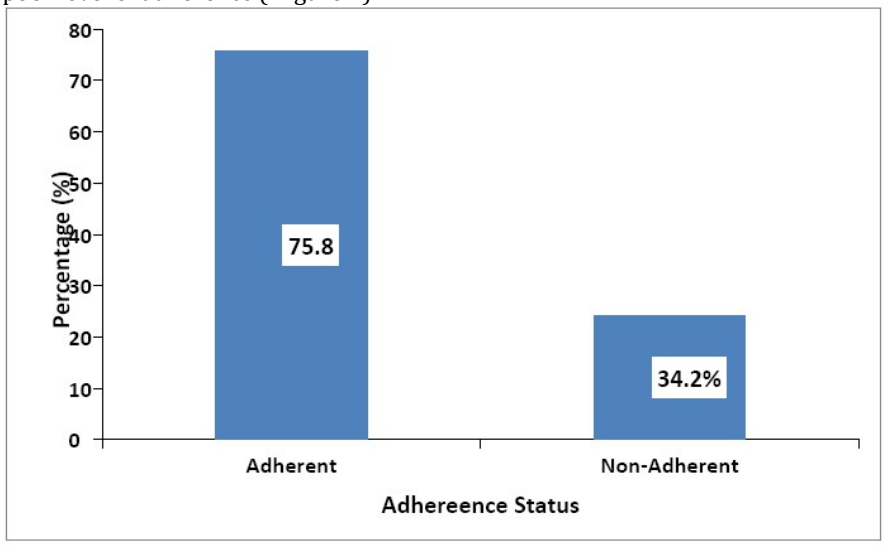

Figure 4: Level of Adherence to ART among women enrolled in the PMTCT

Association between adherence and Informal Care-giving among women in the PMTCT Out of the participants who had informal care-givers, 190(77.2%) were adherent to ART, however, a significant association was observed between informal care and adherence to ART ($\chi 2 = 0.789$, $p = 0.004$).

Association between adherence and Informal Care-giving among women in the PMTCT

			Informal Care Giving	
		Absence No (%)	Presence No (%)	Total No (%)
Adherence Status	Non-adherent	37(26.8)	56(22.8)	93(24.2)
	Adherent	101(73.2)	190(77.2)	291(75.8)
	Total	138(100.0)	246(100.0)	384(100.0)

3.1 Association between Missing Clinic Visits and Informal Care-giver

Among the participants with informal care-givers, 185(75.2%) attended all clinic appointments. A significant association was observed between informal care and clinic appointment ($\chi 2 = 0.551$, $p = 0.458$).

Table 4: Association between Missing Clinic Visits and Informal Care-giver

			Informal Care Giving	
		Absence No (%)	Presence No (%)	Total No (%)
Appointment Schedules	Attended	99(71.7)	185(75.2)	284(74.0)
	Missed	39(28.3)	61(24.8)	100(26.0)
	Total	138(100.0)	246(100.0)	384(100.0)

Association of socio-demographic variables and informal care giving

Table 5 summarizes the association between socio-demographic characteristics and informal care giving among study participants. There was a statistically significant association between socio-demographic variables and informal care giving.

Table 5: Association of socio-demographic variables with Informal care among women in the PMTCT

Characteristic		Informal Care Giving		Chi square	p-value
		Absence No (%)	Presence No (%)		
Age group	<21 years	24(36.4)	42(63.6)	3.120	0.374
	21-30 years	76(39.4)	117(60.6)		
	31-40 years	31(32.0)	66(68.0)		
	41-50 years	7(25.0)	21(75.0)		
Marital status	Single	52(42.3)	71(57.7)	6.271	0.180
	Married	44(37.0)	75(63.0)		
	Widowed	9(22.5)	31(77.5)		
	Divorced,	9(28.1)	23(71.9)		
	Concubine	9(34.3)	46(65.7)		
Level of Education	Informal	7(33.3)	17(66.7)	8.611	0.072
	Completed Primary	28(29.5)	67(70.5)		
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	Presbyterian	36(37.1)	61(62.9)		
	Baptist	18(26.5)	50(73.5)		
	Pentecostal	23(29.9)	54(70.1)		
	Muslim	6(37.5)	10(62.5)		
	Others	5(35.7)	9(64.3)		
Occupation	Unemployed	43(35.2)	79(64.8)	4.979	0.546
	Housewife	22(33.3)	44(66.7)		
	Farmer	17(32.7)	35(67.3)		
	Business	20(33.9)	39(66.1)		
	Student	12(32.4)	25(67.6)		
	Staff employed in the civil sector	9(47.4)	10(52.6)		
	Staff employed in the private sector	15(51.7)	14(48.3)		

Association of obstetric and antenatal history with informal care

No statistically significant association was observed between the obstetric and antenatal variables on the one hand and with informal care giving on the other hand. The associations between obstetric and antenatal variables with informal care giving are summarized on table 6.

Table 6: Association of obstetric and antenatal history with informal care among women in the PMTCT

Characteristic		Informal Care Giving		Chi square	p-value
		Absence No (%)	Presence No (%)		
Gestational age	First trimester	20(50.0)	20(50.0)	5.227	0.156
	Second trimester	67(36.4)	117(63.6)		
	Third trimester	50(32.5)	104(67.5)		
	Post term	1(16.7)	5(83.3)		
Number of deliveries	None	20(54.1)	17(45.9)	7.167	0.127
	One	41(38.0)	67(62.0)		
	Two	40(30.8)	90(69.2)		
	Three	26(33.8)	51(66.2)		
	Four and more	11(34.4)	21(65.6)		
Gestational age at first ANC	First trimester	73(40.3)	108(59.7)	2.881	0.237
	Second trimester	61(32.1)	129(67.9)		
	Third trimester	4(30.8)	9(69.2)		
ANCs attended	None	1(100.0)	0(0.0)	3.534	0.473
	One	73(36.5)	127(63.5)		
	Two	53(37.3)	89(62.7)		
	Three	7(25.0)	21(75.0)		
	Four	4(30.8)	9(69.2)		
Missed ANC	None	99(34.9)	185(65.1)	0.922	0.631
	One	32(440.5)	47(59.5)		
	Two	7(33.3)	14(66.7)		

Association of quality of life factors and informal care giving

Comparing quality of life and informal care giving among participants, it came out clear as can be seen on the table 7 below that respondents with informal care givers have a higher quality of life than respondents without informal care givers.

Table 7: Association of quality of life factors and informal care giving among study participants

Characteristic		Informal Care Giving		Chi square	p-value
		Absence No (%)	Presence No (%)		
Enough energy for daily living	No	122(35.9)			0.950
	Yes	16(36.4)			
Negative feelings	Always	134(36.4)	234(63.6)	0.868	0.352
	Rarely	4(25.0)	12(75.0)		
Satisfaction with ability to perform task	Satisfied	8(27.6)	21(72.4)	1.327	0.515
	Dissatisfied	121(36.2)	213(63.8)		
	Fairly	9(42.9)	12(57.1)		
Acceptance by acquaintance	No	121(37.5)	202(62.5)	2.061	0.152
	Yes	17(27.9)	44(72.1)		
Assistance to function	Necessary	133(36.1)	235(63.9)	0.159	0.690
	Not necessary	5(31.2)	11(68.8)		

Disclosure of HIV status

Out of the women (64.1%) who disclosed their HIV status to care givers, most of them (39.1%) indicated treatment reminder as a major reason for disclosure of status discontinued treatment while a small proportion (24.1%) said helping out with house chores was a reason why they needed informal care givers. (Figure8).

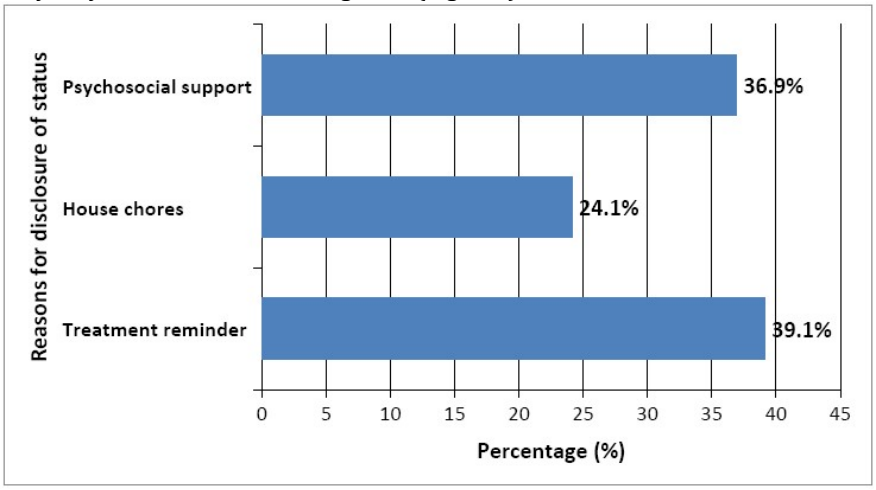

Figure 8: Reasons for Disclosure of HIV status Reasons for Regret about Disclosure of HIV Status

Among the women who were able to disclose the HIV status to their care givers, questions were raised if they regretted their decision of disclosure, 70.1% were highly disappointed with their decision of disclosure. persons who regretted disclosure status attributed this to stigmatization by their supposed care givers at home. Detailed findings are presented on the figure 9 below.

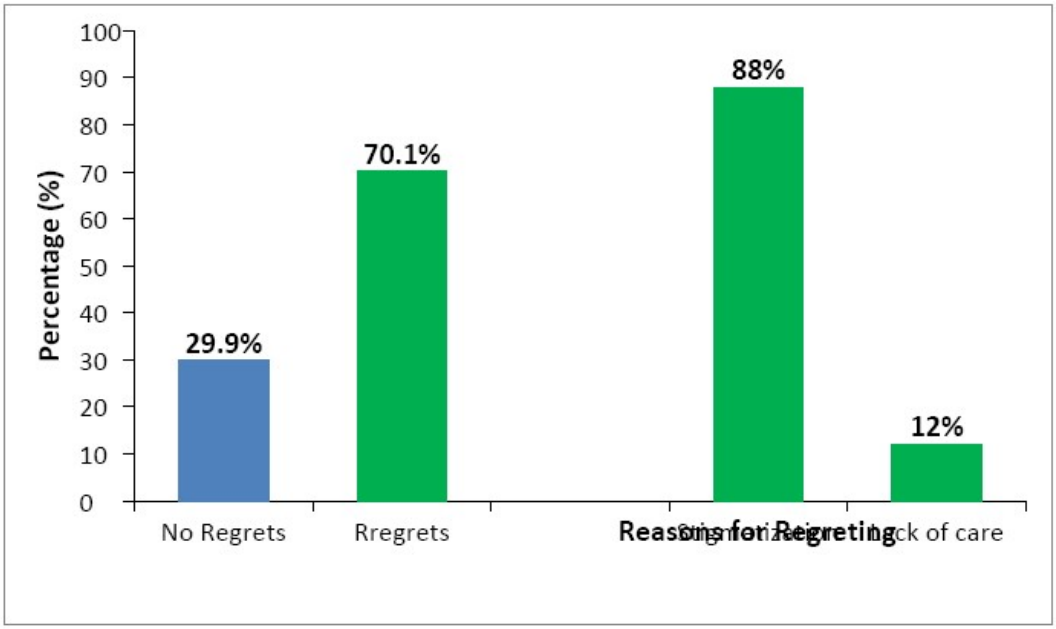

Figure 9: Reasons for Regretting about Disclosure of HIV status Reasons for Refusal to Disclose HIV Status

On the other hand, some of the study participants did not disclose their HIV status to anybody. The most frequently cited reason for non-disclosure was fear of abandonment (26.4%). This is followed by fear of rejection and abandonment (18.2%). Several other reasons were advanced as shown on the figure 10 below.

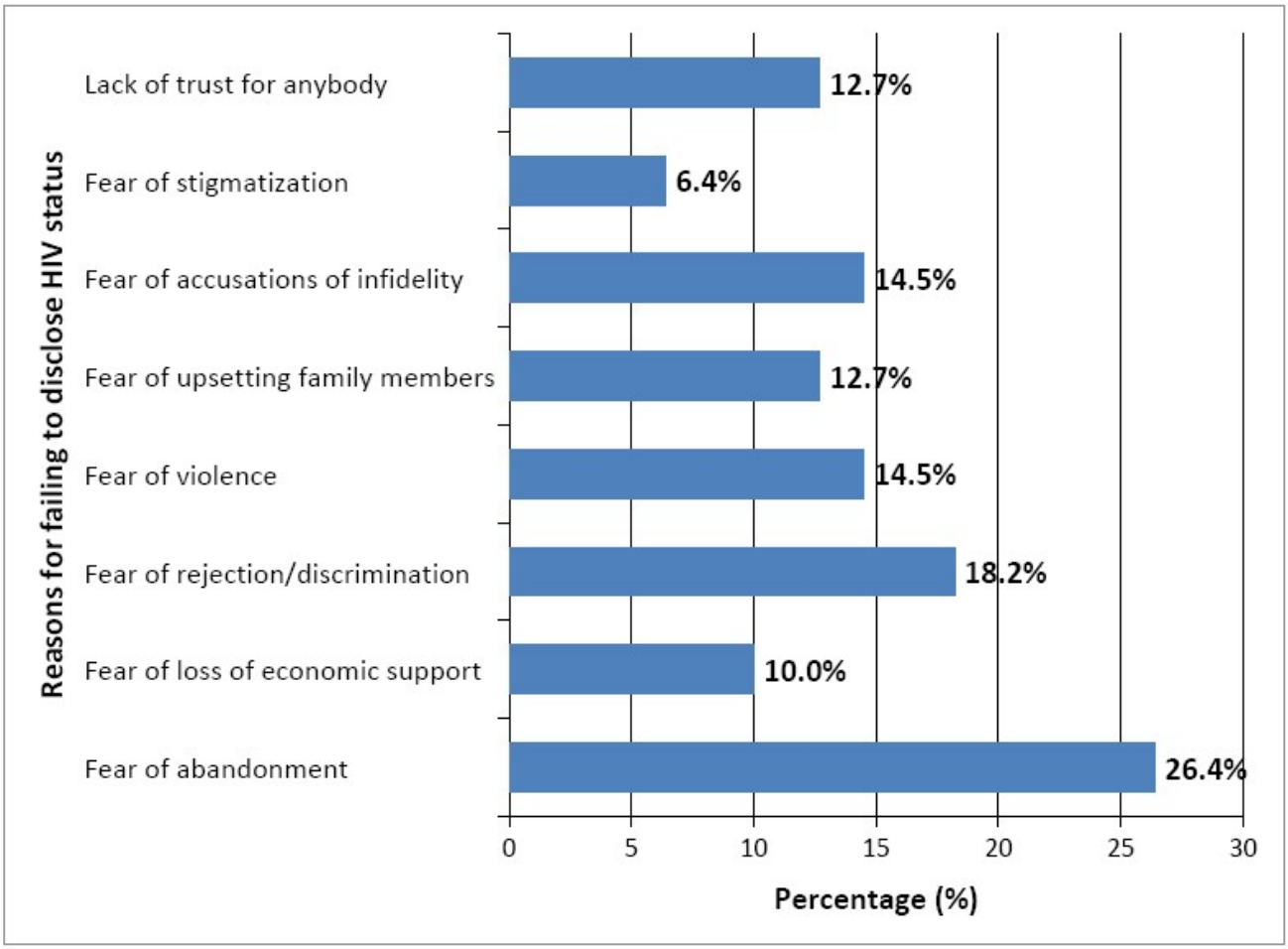

Figure 10: Reasons for Failure to Disclose HIV Status

Discussion

The present study examined the role of informal care givers on adherence in PMTCT. Initially, the study sought to determine the proportion of positive pregnant women with informal care givers. The sample size envisaged at the beginning of the study was attained evidence by the participation of Three hundred and eighty four (384) women enrolled in the PMTCT program in selected health facilities in Fako Division.

The predorminant age group in the study was 21- 30 representing 50.3% with a mean age of 28 years. This was the youngest age group and represents the reproductive age of the study participants. There were 123 (32.0%) singles and 119 (31.0%) married women. Women with informal level of education [21(5.5%)] occupied the least position whereas those with secondary level of education [117(30.5)] were among the highest. There were 112(29.2) women with a catholic religious background. Many of the women were unemployed followed by housewives.

A majority of the women were in the second trimester of their pregnancy with 6(1.6%) of them experiencing the post term period. There were 108(28.1%) and 130(33.9%) women with one and two numbers of previous deliveries respectively. About half (49.5%) of the participants were in their second trimester of pregnancy at the time of enrolment. Most [200(52.1%)] of the woman had attended one antenatal clinic at the time of interview. A majority [284(74.0%)] of the participants had attended all their schedule antenatal clinic visits.

Majority of the women had been diagnosed HIV positive with one year. Most received pre- and post-test counseling respectively. Tenofovir containing regimen was the mostly used ART among the women (10, 13). Many partners of the women had been tested for HIV with 112(29.2) being positive and 189(49.2) negative. 83(21.6) of the status of men were unknown (17).

A high proportion of HIV positive pregnant women were receiving care related to their HIV infection and treatment from informal care-givers (3.) This type of care was not recorded in 35.9% of the pregnant women. Close relatives were the highest category of informal care-givers (3,4.102). The husbands of the pregnant women provided the least informal cares to the women. This is contrary to the finding which stipulated that many of the informal care givers are women, who are unemployed, and come from the same community as the PLWHA. They are often poor, frequently lack empowerment and recognition among other features (2,3,27). A high proportion of care-givers was reminding the participants of their treatment (101). On the other hand some researchers stipulate that the most important roles of informal care givers are emotional support and helping with house chores (19). A fraction of the supposed care-givers tends to stigmatize the women (29). This is probably due to the fact that there is stigma surrounding HIV disease. Community rejection of HIV-positive individuals because of their disease or the mode of transmission often extends to the relatives and friends who provide care (29). Rather than face stigmatization, some caregivers try to conceal their caregiving activities by withdrawing from social relationships and also stigmatize the patient as a coping mechanism. Those who do acknowledge their caregiving status may find it difficult to obtain support from familial or social networks (103,104).

Almost three quarter of the women had a proper level of adherence to ART compared to a lesser proportion of participants with poor level of adherence. This finding correlates the finding that stipulates that if Professional clinicians can include the caregiver in the "triad of care"- doctor, patient, care giver-and train them in simple medical procedures, they will help to improve patient care and adherence to Antiretroviral therapy (29). In same lime light another researcher confirms this finding by reiterating that adherence and retention rate could be enhanced with the involvement of informal caregivers in the PMTCT cascade (23)

Out of the participants who had informal care-givers, were adherent to ART, however, no significant association was observed between informal care and adherence to ART ($\chi 2 = 0.789$, p

$= 0.374$). Among the participants with informal care-givers, attended all clinic appointments, however, no significant association was observed between informal care and clinic appointment ($\chi 2 = 0.551$, $p = 0.458$).

When the Association of socio-demographic variables and informal care giving was assessed, it was observed that there was statistical significant association between socio-demographic variables and informal care giving. The positive correlation between socio-demographic variables and informal care giving is consistent with the expectation informal care giving role is a vital aspect that enhances quality of life and retention in care.

Comparing quality of life and informal care giving among participants, it came out clear that the respondents with informal care givers have a higher quality of life than respondents without informal care givers.

Out Of the women who disclosed their HIV status to care givers, most of them indicated treatment reminder as a major reason for disclosure of status while a minority said helping out with house chores was a reason why they needed informal care givers. Among the women who were able to disclose the HIV status to their care givers, majority of them were highly disappointed with their decision of disclosure. Most of those who regretted disclosure status said so because they were being stigmatized by their supposed care givers at home**.** On the other hand, some of the study participants did not disclose their HIV status to anybody. The most frequently cited reason for non-disclosure was fear of abandonment. Secondly, most of the women said fear of rejection and abandonment was their main reason of non-disclosure.

Conclusively, as earlier hypothesized, a high proportion (64.1%) of HIV positive pregnant women were receiving care related to their HIV infection and treatment from informal care-givers and Close relatives were the highest category of informal care-givers. The basic care provided was treatment reminder while a few provided psychosocial support. Informal care giving is a package of activities that attempts to provide holistic care to HIV positive pregnant and breastfeeding women to enhance adherence, retention and quality of life.

Conclusion and Recommendations

A high proportion of HIV positive pregnant women were receiving care related to their HIV infection and treatment from informal care-givers. This type of care was not recorded in 35.9% of the pregnant women. Distant relatives were the highest category of informal care-givers. The husbands of the pregnant women provided the least informal cares to the women. Almost three quarter of the women had a low level of adherence to ART compared to a greater proportion of participants with poor level of adherence. The adherence to ART was lower among HIV positive pregnant women without informal care givers as compared to their counterparts with informal care givers. The low proportion of good adherence of option B+ therapy for PMTCT in Fako Division might be signalizing a regression of the PMTCT program in South West region, Cameroon. Arraying more efforts to enhance Informal care giver support and involvement on those on treatment for a longer duration in the PMTCT program may yield more significant outcome. Moreover more efforts to monitor option B+ adherence to ART should be made while implementing cohort monitoring and evaluation of role of informal care givers as well as regular viral load measurements.

Supporting information

Data collection tool. This is data tool of 384 pregnant women and breastfeeding mother on option B+ antiretroviral treatment in Fako Division, South West Region, Cameroon.

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