

Needs and Experiences of People Living with HIV/AIDS Regarding Implementation of Community Home-based Care Services in a Rural County in Western Kenya

Njororai Fletcher¹, Ganu Daniel² and Nyaranga K. Caleb³

Abstract

Community home-based care framework is an integral and integrated part of health care for people living with HIV/AIDS (PLWHA). This study aimed to report the needs and experiences of PLWHA receiving community home-based care in a rural population in Western Kenya. The sample size for the study was 373 PLWHA who were aged 18 and above, disclosed their HIV sero-status, and were receiving any of the CHBC services. The study was a cross-sectional exploratory and data was gathered over a period of four weeks. The findings revealed that needs were mainly what they lacked which include proper health care facilities; support from the government; drugs, counseling support; knowledge and education on the disease; home care equipment and tools; and adequate qualified healthcare professionals. Another major barrier to quality care is poor road network which impacts transportation for both the health workers and patients in provision and access of health care services and other resources respectively. The findings further revealed a strong relationship between influences of adequate care on the status of the illness. Receiving adequate

¹ The University of Texas at Tyler, Department of Health and Kinestology, USA

² Adventist University of Africa, Kenya, School of Postgraduate Studies, Department of Public Health, Kenya.

³ University of Eastern Africa Baraton, School of Health Sciences, Kenya.

clinical care $p=0.000$ ($X^2 = 159.650$, $df = 10$), receiving adequate psychological care $p=0.000$ ($X^2 = 107.197$, $df=4$), receiving adequate nursing care $p=0.000$ ($\chi^2 = 35.802$, $df=4$), and receiving adequate social support $p=0.000$ ($\chi^2 = 35.277$, $df=4$) significantly influenced health status of the patients. We recommend continued and timely monitoring and evaluation in implementation of CHBC for these rural populations as critical in understanding contextual factors and experiences of PLWHA for better health outcomes.

Keywords: HIV/AIDS, Community, Home-based Care, People living with HIV/AIDS.

1 Introduction

Community home-based care is an integral and integrated part of health care for people living with HIV/AIDS (WHO, 2002). According to the World Health Organization (WHO), CHBC encompasses provision of health services and support by formal and informal caregivers within the home in communities. The CHBC models in general adopt a holistic approach to care. The models span a continuum of care for the physical, social, nutritional, psychological, emotional, economic, and spiritual needs collaboratively with and within the community setting (Defilippi, 2005). The CHBC models are meant to be comprehensive and all-encompassing in terms of services (preventative, promotive, therapeutic, rehabilitative, and palliative), including education, staffing, supplies and equipment, sustainability, monitoring and evaluation (Pretoria Department of Health, 2001; UNAIDS, 2012; WHO, 2009). These models also involve basic and essential components of primary health care adhering to basic principles in health care and patient support.

The World Health Organization provides a systematic framework for establishing and maintaining CHBC services in resource-limited settings for People Living with HIV/AIDS (PLWHA) and those with other chronic or disabling conditions. The World Health Organization defines CHBC as:

Any form of care given to ill people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities. The goal of CHBC is to provide hope through high-quality and appropriate care that helps ill people and families to maintain their independence and achieve the best possible quality of life (WHO, 2002: pg. 6).

The CHBC evolved from Home based care frameworks (HBC) in the mid 1990's as WHO developed a care continuum as a response to mitigate the shortage of formal health care personnel and strain on the formal health care system in the face of increased needs for long-term care, introduction of antiretroviral therapies (ART) and chronic disease management in the face of the HIV/AIDS epidemic

(Lindsay, 2002; Ogden, 2004). A key component was diversification of services to support patient recruitment to ART programs, patient adherence to medicinal regimens, retention on treatment, and support to rebuild their lives and livelihoods (Aantjes, 2014; WHO, 2009). The participatory approach of this framework aims at community mobilization, empowering communities, promoting context specific responses to the needs of PLWHA, and increasing access to resources and care (Aantjes, 2014; Moetlo et al, 2011). Effectiveness of CHBC framework requires multi-sectoral and interdepartmental involvement. A systematically integrated approach to care and support is required with government, donor and community-based care organizations combining their respective skills and means to ensure that home-based care works to bring essential change to people's lives in communities. While many countries in Sub-Saharan Africa have integrated CHBC in their national strategy for HIV/AIDS, many variations exist across countries and within a country on how the guidelines are implemented, supported, monitored and evaluated (Aantjes, 2014; ILO, 2011). In their study, (Moetlo et al, 2011) found that community home-based care can be largely implemented but need more support and resources including training, financial support, structure of responsibilities, and linkage to formal health system.

In Kenya, integration of community and home-based care guidelines in the national HIV framework, the Kenya National AIDS Strategic Plan (KNASP), and their implementation has taken place widely over the last decade (ILO, 2011; Mohammed, 2005; USAID, 2005). The National AIDS and STIs Control Program (NAS COP) is the AIDS Control Unit in the Ministry of Health and the technical arm of the fight against the pandemic. NAS COP also has the overall mandate of providing technical guidance, standards, and direction to all health care services related to HIV. The NAS COP is therefore the supervisory body for these community-based programs. The most relevant to the immediate needs of Community care programs in Kenya are the Constituency AIDS Control Committees (CACCs), whose members are drawn from the same sectors as the district and provincial committees. The HBC programs train Community Health Workers (CHWs) for 11 days to become HBC caregivers. They are supervised by facility health workers who are trained nurses and are overseen by the district HBC coordinator (ILO, 2011). There is need to assess how these CHBC are providing these services as well as the experiences of PLWHA in different communities to capture the contextual differences and outcomes of the practices as a springboard on the important role these programs play. This study sought to assess the needs and experiences of PLWHA regarding implementation of the CHBC services in a rural county in Western Kenya.

2 Methodology

Research Design

The study was conducted using cross-sectional exploratory study design.

According to Sanchez (2012), the Kenya National Bureau of Statistics indicate that there is 49.1% rural poor population against 33.7% urban poor population of all the 45.9% poor population by 2006. The major indicator here is that more urban population is employed as compared to the rural unemployed. The state of the nation has led to higher unemployment level in the rural hence the country is being affected by the rural to urban population. The state of Kenya has a 48% poverty level by 2013, with a majority of the poor living in the rural areas (IMF, 2012).

Study Area

The study was conducted in Shaviringa and Shamakhokho Divisions of Hamisi Sub-County in Vihiga County, Kenya. The county has 4 Divisions, 8 locations, and 28 Sub-locations. Two divisions were randomly picked from the 4 divisions in Hamisi Sub-County in a rural county in western Kenya. Vihiga County is located around 80 kilometers north west of Eldoret, around 60Km North of Kisumu and approximately 350km west of Nairobi City. The county has a total population of 554,622 (2009 census). The climate in Vihiga is mild, generally warm and temperate with a rainfall ranging from 1200 mm to 2100mm annually and it rises to an altitude of 1800m above sea level. The main economic activity in the area is tea and dairy farming with minor horticulture practiced.

Study Population

The study population comprised of about 554,622 and a sample size for the study included 373 people living with HIV /AIDS (PLWHA), 18 years of age and above residing in the area, had disclosed their HIV sero-status, and were receiving any of the CHBC services.

Sampling Procedure

Purposive sampling method was used to obtain the number of respondents. The inclusion criteria included subjects who had cognitive capacity to understand what is needed from home-based care services and communicate these needs. The participants were identified by households and 187 participants were recruited from the Shaviringa Division and 186 were recruited from Shamakhokho Divisions. PLWHA who were less than 18 years of age were excluded because this is the age that marks transition between childhood and adulthood in most Africa countries including Kenya. In Kenya, the HIV prevalence rate among people aged 18 and above was 6.0% in 2013, with prevalence among young females aged 18-24 higher than that of males in the same age group at 2.7% and 1.7% respectively (KNBS, 2009). Adult HIV /AIDS prevalence in Vihiga among women was 6.2%, Men 3.9% giving an average of 5.1% (National AIDS and STI Control Program, 2014).

Data Collection tools

Standardized semi-structured questionnaire was used to gather the data. The

questionnaire comprised six items: the socio-demographic profile of the participants, health status and disease knowledge, disease management, needs, experience and challenges, components of home based care services in Vihiga and stigma towards PLWHA.

Data analysis and processing

Quantitative data was analyzed using Statistical Package for Social Sciences (SPSS) version 20 software (SPSS Inc., Chicago, Illinois, USA). Descriptive statistics was used to report the socio- demographic characteristics of the sampled participants while Pearson chi- square test was used to test the association of the professional help/care and stigma, socio-demographics and disclosure, professional help and self-rating on health status and disease management, needs and challenges, professional help and disease knowledge.

Data quality assurance, was done through appropriate recruitment and training of interviewers; where four research assistants/interviewers were picked from the health discipline and had been trained as community health workers using the Kenyan Government Community health worker's manual for 2006. They had worked for a period of six months and above in the community and knew the topography of the area to help reach sampled homes. The main objective of the training was to harmonize concepts on survey design and content of the tools that were to be used in the survey. There was a lead field researcher with an assistant who coordinated all the activities including field supervision of data collection by the interviewers and data entry as well. All questionnaires were examined for completeness and consistency during the interviews on a daily basis.

Ethical Considerations

Ethical clearance was obtained from the Institutional Research and Ethics Committee of the University of Eastern Africa, Baraton (UEAB with reference number REC: UEAB/13/10/2015). Permissions was obtained from the County AIDs Coordinator (CASCO) and Divisional AIDs Coordinator (DASCO). Participation of subjects was voluntary and written informed consent was obtained from all respondents; they were assured of privacy and confidentiality. Participation was voluntary and participants could leave the study at any point of the interview if they wished to withdraw. There were no consequences of any kind if they decided not to participate.

3 Results

Enrollment

Purposive sampling of 373 people living with HIV/AIDS aged 18 years and above were identified and consented to take part in the research study.

Population and Sample Characteristics

Among the HIV/AIDS population who enrolled to take part in the study, 51.7% (n = 185) were married and 15.4% (n = 55) were not married (see Table 1 below). A little more than half of the population (64.5%, n = 238) had completed primary education. Out of the total sample, 71.5% (n = 263) were female and 28.5% (n = 105) were male. The highest percentage 31.6% (n = 116) of the participants were within the 31-40 age bracket and a good portion 18.8% (n= 69) were above 50 years old and this has implications for aging with HIV/AIDS and targeted interventions. Unemployment in the area is high with 43.4% (n = 158) having no employment and a large portion 32.7% (n= 119) were self-employed. A bulk of the respondents 88.8% (n= 246) earned less than Ksh 5000 (approximately USD 50), which is below the national minimum wage per month, which is Ksh 10,954.70.

Table 1: Demographic Profile of Respondents

Characteristics	Category	N	%
Gender	Male	105	28.5
	Female	263	71.5
Age Group (in years)	31-40	116	31.6
	>50	69	18.8
Education	No Education	48	13.0
	Primary	238	64.5
Income (in KES)	<5000	246	88.8
	5000-9000	21	7.6
	10000-15000	6	2.2
	>15000	4	1.4
Marital Status	Married	185	51.7
	Unmarried	55	15.4
Work History	No employment	158	43.4
	Self-Employed	119	32.7

The study reveals that 17.9% (n = 38) of the PLWHA disclosed their status due to trust they had in their partners and 32.5% (n = 69) disclosed due to support they hope to get from their partners. More so, 9.4% (n = 20) and 4.7% (n = 10) were tested with their partners and were advised by healthcare providers respectively. Interestingly, 23.1% (n = 49) wanted to know their status and went in for test voluntarily. On the other hand, 76.9% did not disclose their status because of fear of stigma, shame, and gossip. In all, 18.8% of the respondents suffer other chronic illnesses such as diabetes and hypertension alongside the HIV/AIDS.

Needs and Experiences

The study revealed that the needs of the community were lack of proper health care facilities 40.2 % (n = 136); lack of support from the government 33.1% (n = 115), lack of income generating activities 44.5% (n=152). Also, lack of qualified health care professionals 6.3% (n= 22) and poor infrastructure or lack of proper road network 6.1% (n = 21) are noteworthy findings with implications for the health and care of PLWHA in the rural communities. Lack of income generating activities, lack of government support, and lack of proper health care facilities account for the highest priority that could make the PLWHA enjoy improved health and quality life (Table 2 below).

Table 2: Needs and Barriers to Quality HIV Care and Support

Barriers	Frequency	Percent
Lack of Qualified Health Care Professional	22	6.3
Lack of Proper Health Care Facilities	136	40.2
Lack of Proper Road Network	21	6.1
Lack of Support by the Government	147	33.1
Lack of Income Generating Activities	152	45.0
Lack of Agricultural Support	21	6.4
Food Aid	17	5.2
Education On HIV/AIDS	41	12.5
Others	112	32.3

Table 3 below shows results on the relationship between demographic factors and disclosure of HIV/AIDS Status. The results revealed that gender $p=0.974$ ($X^2=0.000$, $df=1$) and marital status $p=0.811$ ($X^2=2.268$, $df=4$) have no significant relationship with disclosure of HIV/AIDS status. On the other hand, personal rating of health status $p=0.003$ ($X^2=15.703$, $df=4$) and actual status of illness $p=0.03$ ($X^2=6.690$, $df=2$) showed positive relationship with disclosure of HIV/AIDS status. This suggests that those who disclosed their health status actually had the disease. A majority of those who disclosed their status rated themselves as being in good health status 57% (n = 205), while 17% (n=62) self-reported being in very good health status and 5.5% (n=20) reported being in poor or very poor health status. The results also revealed that a majority of those who disclosed their status reported they were getting better 56.9% (n = 204) while 3.35% (n = 12) reported their status getting worse.

Table 3: Socio-Demographic Factors and Disclosure of HIV Status

	<i>Category</i>	<i>Yes</i>	<i>No</i>	<i>Pearson Chi-Square Test</i>
Gender	Male	83	18	$\chi^2 = 0.000$ $df=1$ $p = 0.974$
	Female	214	45	
Marital Status	Married	150	32	$\chi^2 = 2.268$ $df=4$ $p = 0.811$
	Unmarried	43	11	
	Widow/widower	53	12	
	Separated	31	5	
	Divorced	9	4	
Rating on Health Status	Very Good	62	20	$\chi^2 = 15.703$ $df=4$ $p = 0.003^*$
	Good	205	32	
	Not Sure	6	6	
	Poor	17	5	
	Very Poor	3	2	
Status of Illness	Getting Better	204	51	$\chi^2 = 6.690$ $df=2$ $p = 0.03^*$
	Getting worse	12	6	
	Still the same	71	8	

*Significant at $p < 0.05$.

Table 4 below also shows the relationship between influences of professional help on status of illness. Receiving adequate clinical care $p=0.000$ ($X^2 = 159.650$, $df = 10$), receiving adequate psychological care $p=0.000$ ($X^2 = 107.197$, $df=4$), receiving adequate nursing care $p=0.000$ ($\chi^2 = 35.802$, $df=4$), and receiving adequate social support $p=0.000$ ($\chi^2 = 35.277$, $df=4$) significantly influenced health status of the patients. Regarding clinical care, about 94% ($n = 241$) were receiving continuous checkups and 98% ($n = 251$) were currently receiving clinical care. On the other hand, 13.3% ($n = 34$) were not put on medication on time. Relating to psychosocial, spiritual and counseling care, 92.6% ($n = 237$) received pre and post counseling care. On the other hand, about 32% ($n = 81$) did not receive family counseling and about 6% ($n = 14$) did not receive counseling on adopting positive living attitude. Also, 37.5% ($n = 96$) failed to receive spiritual counseling.

Table 4: Influence of Professional Help on Status of Illness

Factor	Category	Status of Illness			Pearson Chi-Square Test
		Getting better	Getting worse	Still the same	
Adequacy of clinical care	Adequate	45	3	68	$\chi^2 = 159.650$ df=10 p = 0.000*
	Average	169	8	6	
	Poor	45	7	6	
Adequacy of psychological care	Inadequate	74	3	66	$\chi^2 = 107.197a$ df=4 p = 0.000*
	Average	160	6	11	
	Adequate	25	9	3	
Adequacy of nursing care	Adequate	10	1	13	$\chi^2 = 35.802^a$ df=4 p = 0.000*
	Inadequate	145	8	59	
	No care	104	9	8	
Adequacy of social support	Adequate	96	5	25	$\chi^2 = 35.277a$ df=4 p = 0.000*
	Inadequate	74	4	48	
	No social support	89	9	7	

*Significant at $p < 0.05$.

On nursing care, 94.1% (n = 241) were educated on personal environmental hygiene but about 90% (n = 229) were not provided with home care kits. About 21% (n = 53) were not followed up by Nurses or Community Health Workers (CHWs). On Social Support, about 60% (n = 153) did not receive any counseling or education of income generation activities, only 43% (n = 110) were advised to join a 'SACCO', a cooperative organization, and only 57.9% (n = 148) received some kind of education on livelihood support.

Table 5: Correlations Between Status of Illness and Experience of Professional Help

	Status of illness	Clinical Care	Psychosocial/spiritual care and Counseling	Nursing Care	Social Support
Status of Illness	-				
Clinical Care	-.380**	-			
Psychosocial/spiritual care and Counseling	-.278**	.558**	-		
Nursing Care	-.199**	.274**	.453**	-	
Social Support	.044	.131	.181*	.206**	-

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2 tailed).

The result (Table 5 above) shows that those who are getting better tend to receive less professional help (clinical, psychosocial/spiritual, nursing). Pearson correlations analysis showed that status of illness correlates negatively ($r = -0.380$, $p < 0.01$) with clinical care and Psychosocial/spiritual and counseling care ($r = -0.278$, $p < 0.001$) Table 5. Another important finding is that nursing care correlates positively ($r = 0.206$, $p < 0.01$) with social support.

4 Discussion

The present study was conducted to identify needs and experiences of PLWHA in the rural setting of Western Kenya. The study has several important findings that have implications for future CHBC in Kenya. First, participants reported significant unmet needs in the following areas: economic opportunities, food aid or support, education, income generating activities, employment, spiritual counseling and social support. These findings are supported by findings from study conducted by Boryc et al (2010) who found that the most commonly community home-based care services received by PLWA in Guyana are prevention and hygiene education, emotional and social support, and counseling. Lemke (2005) also found that as HIV/AIDS disease progresses, the individual's ability to work and participate in income-generation opportunities decreases resulting in reduced household income. The study again identified economic needs among the respondents, which consistently identifies economic hardship as one of the main concerns expressed by them. This finding was also expressed in the study of Keogh, Allen, Almedal, & Temahagili (1994). This response addresses the issue of economic strengthening opportunities for PLWHA in Western Kenya.

There was also an identified need for social support. Kabore et al (2010) found that patients exposed to community-based supportive services experienced a more rapid and greater overall increase in CD4 cell counts than unexposed patients. Furthermore, they also had higher levels of adherence, attributed primarily to exposure to home-based care services. Their study also reported that patients receiving home-based care and/or food support services showed greater improvements in selected health-related quality of life indicators. They also found that social support helped patient's emotional well-being. These findings were supported by Bekele et al (2013) where social support was found to improve emotional and mental health and overall quality of life for PLWHA.

The survey also demonstrated that there is a great need of professional help in terms of clinical care, as 35.5% of pregnant women are not taking medication to prevent mother-to-child-transmission (PMTCT). We also observed that psychosocial and spiritual counseling were lacking. The PMTCT is the provision of treatment, care, counseling and psychological support to women infected with HIV, their infants, and their families and this initiative help mothers and safeguard their infants against the virus.

Community based evaluation of PMTCT utilization of mothers in Western Kenya

(Kohler et al, 2014) showed that 18% were not taking drugs to prevent the virus from infecting their children even though they were attending antenatal. Other studies (Chinkonde, 2009 & Kim, 2016) have identified several different levels at which barriers to adherence to PMTCT manifest. Thus, at the personal level barriers may be due to type and level of knowledge, attitudes, psychological state, and beliefs regarding HIV, PMTCT and ARTs, perceived benefits and constraints to HIV testing and services related to PMTCT. At the program and health facilities level are factors such as accessibility in terms of costs, distance to the facility, service hours, lack of counseling, quality of care including attitudes of health care providers and staff towards patients. At the community level are barriers such as stigma, discrimination, religious beliefs and lack of social and family support and networks. At the policy level are structural barrier such as level of implementation of relevant policies and guidelines on PMTCT, health education and mass awareness, and capacity of the health systems focusing on financing, structure, and workforce and handling patient data. Therefore, addressing gaps in PMTCT in this rural area requires a multi-level strategy.

The CHBC could be the best method to care for many people with HIV/AIDS and those suffering from chronic or terminal diseases outside the clinical care settings in developing countries where health systems are weak and/or inadequately prepared for these demands (WHO, 2002). The World Health Organization further stressed that home care draws on two strengths that exist throughout the world: families and communities^{1d}. First, families are the central focus of care and form the basis of the CHBC team, and second communities are places where people live and a source of support and care to individuals and families in need. Research evidence clearly demonstrates that most people with chronic illnesses especially in developing countries would rather be cared for at home and that effective home care improves the quality of life for ill people and their family caregivers. Masiye (2001) found that between 70% to 90% of illness care takes place within the home setting. At the local level CHBC is designed to provide physical, emotional and spiritual care and support; establish a continuum of care; develop mechanisms for educating the ill people, caregivers and CHBC teams; ensure adequate supplies and equipment for the CHBC program (Wesonga, 2015).

An intervention to address psychosocial development or support and coping ability of PLWHA is paramount in improving their health outcome. Findings from our study showed that this was an unmet need in our population and this could contribute to many other problems and negative health outcomes among PLWHA. In another study (Psychological Support for People Living with HIV, 2010) results showed that a range of psychological interventions can make a considerable difference to the long-term health and well-being of someone living with HIV, including how well they manage their condition, less likely to engage in unsafe sex and adhere to treatment. The study also showed that consistent, specific standards against which psychological support services for people living with HIV can be commissioned and planned at a local level are missing and are needed (Psychological Support for People Living with HIV, 2010). There have been

lower rates of depression among PLWHA who received psychosocial and spiritual counseling in Nepal (Amiya et al, 2014). Higher perceived family support relative to low perceived family support was inversely associated with depression and suicidal ideation. Family members and friends provide majority of home-based care for PLWHA. Support from family members will curb psychological distress and will offer protective effect in terms of depression and suicidal risks. In turn the family members also caregivers need support hence to be integrated in the services for support and counseling to empower them carry on this challenging tasks and be worked from an informed position. This study found that 64.5% have had only primary education and this has reflected in their income generation. Furthermore, 43.4% had no employment on their own and majority 70.3% were earning below national daily wage. The national minimum wage per month is Ksh 10,954.70. More than 50% of the respondents indicated the need for some assistance to generate income for their self-sustenance. With this situation, there is a need for proper income generating activities in this community for PLWHA to improve their livelihoods. Provision of support systems and opportunities for income generation and empowerment for better livelihoods is critical for quality of life, well-being and health outcomes in general of PLWHA (ILO, 2016). Policy planners at all levels should make this a priority consideration in the strategic plans and community initiatives. There is the need for proper income generating activities in the AIDS community.

Study limitations

The following are limitations of the study which could also be considered as potential areas for future research: first, the findings can only be generalized to people living with HIV receiving CHBC services in the rural western Kenya but could be replicated in other parts of the country; second, the study focused on a rural population hence may not include perspectives and situation of the PLWHA residing in the towns or urban-designated parts of this location; and third, this was a cross-sectional study which presents data only one- point- in- time therefore the findings do not reflect changes and trends over time.

5 Conclusion

Consistent with the framework that guided this study and supported by existing literature, this study revealed important findings on the experiences and needs of PLWHA receiving CHBC services living in the rural populations of Western Kenya. Based on the findings, while a substantial portion of CHBC needs are being addressed by the CHWs and family members, some outstanding needs and gaps include income generation opportunities, food support, psychosocial and spiritual counseling, and healthcare facilities and infrastructure that remain. Respondents reported that the existing CHBC provisions have improved their

quality of life and their thoughts about living with HIV however, more resources need to be directed toward ensuring quality of care in this sector in the county and across the country. We suggest that future studies in Western Kenya link CHBC service provision with specific health outcomes, and examine the effectiveness of providing services to people living with HIV through a community-based model in Kenya for policy planning.

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