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## **RESEARCH REPORT 4**

### **Paid Care Workers in Tanzania:**

A general description of nurses and home base care givers

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## Introduction

Home Based Care services in Tanzania were officially initiated by the Ministry of Health (MoH) in 1996 as a pilot study in 8 districts in two regions that is Rukwa and Coast regions. The essence of the pilot was to train home based care providers who were to support HBC program. During this pilot period which lasted for two years, the MoH trained 51 HBC providers. After this initial period, the ministry instructed districts to 'mainstream' HBC services in their plans and programs (URT/MoH: 1999). Additionally, the MoH in collaboration with TACAIDS developed Home Based Care Guidelines which became operational in 1999 and further revised in 2005. These guidelines spelt out the rights of people living with the HI virus and described the responsibilities of various actors in the continuum of care. According to the HBC guidelines, PLWHA are entitled to: (i) referral facilities, care facilities services and provision of drugs and equipment, (ii) care by community health workers and (iii) support for primary care givers within the family.

In the continuum of care, the family is identified in the guidelines as the primary care giver. While each adult family member is expected to provide some kind of support to the PLWHA, the family is also expected to choose one primary health care giver, who will provide nursing care, emotional support and other services needed by the person suffering from HIV&AIDS-related illness. The centrality of the family in caring for the PLWHA, particularly those who are in their terminal stages, assumes that the family is best suited for emotional support, that public resources will trickle down to this level, and that there will be family members able and willing to support the person with PLWHA.

After the family the PLWHA is expected to be supported by care services which are to be provided through the existing hierarchical structures of the health services. In this hierarchy, the village health services are the lowest level of health care delivery in the country. Ideally, this level is supposed to offer preventive services which can be offered in homes. Each village is expected to have a health post managed by two health workers chosen by the village government among the villagers and be given training before providing services. There is no data to inform how many villages have village health posts in Tanzania. Each village government determines remuneration for the village health workers. The Home Base Community Care givers referred to in this paper are mainly recruited from the villages. In the Tanzanian context, the village is the lowest administrative structure composed of a Village Assembly, Village government, and various development/social committees. Actors in various structures of the village are not formally paid, but a village government has powers to remunerate some of the volunteers depending on the resource base of a village.

The second tier is the Dispensary Services. A dispensary cater for between 6000 to 10,000 people and supervise all the village posts in its ward. The rural dispensaries are staffed by a rural medical aid (RMA) with one or two assistants; in some cases a nurse/midwife is provided. The RMA receives a three year training course in anatomy, physiology and hygiene and is expected to have knowledge in diagnostic methods and treatment of common diseases. A nurse (grade A) receives three year training in a more broad range of knowledge/skills related to care, but not provided with competencies in diagnostic methods. A nurse is supposed to 'aid' the RMA and the RMA is considered to be superior to a nurse/midwife. This superiority is socially constructed and not related to the number of years one has been trained. Within the continuum of care, a nurse from a rural dispensary would supervise the Community care giver, through providing them with rudimentary knowledge on the 'ABCs' of the HIV&AIDS, how to care for PLWHA, as well as provide them with HBC kits when they are available. They also train them on how to keep progress record for the PLWHA.

Supporting the dispensaries are health centres. These are supposed to give priority to preventive measures and hygiene education but in reality they are extensively used for treatment of common diseases. Most of the health centres have room for minor surgery and provide 20-30 beds for in patients including maternity cases. A health centre is run by a Medical Assistance (M.A) with secondary education with more elaborate education in diagnosis and treatment as well as training in minor surgery. This is of higher grade than the rural medical aid. The medical assistant is normally assisted by one or two rural medical aids, a nurse/midwife with one or two maternal and child health aids and health assistant. In the continuum of care the Medical Assistant would provide treatment to the PLWHA who has been referred to by the RMA. The PLWHA might be admitted for treatment or for further diagnoses.

Above the health centre there is a district hospital. This is the base for staffing and supplying all rural units with equipment, and medicine. Generally, there is one district hospital per administrative unit and it is the district hospital that any difficult or serious case is referred to from the lower levels. The district hospitals are provided with medical doctors one or more depending on the size, stores for drugs and equipment, and a diagnostic laboratory, ex ray, operation facilities and beds for referred patients. Each district has a Health Management Team (DHMT). The DHMT is expected to mainstream HBC services in the health services.

Above the district is a regional hospital. Strictly the regional and district hospitals are similar except that the regional hospital has more facilities and more highly skilled health personnel that is 5-10 doctors including one specialist. The highest level is the national referral hospitals, endowed with more sophisticated equipment, more specialists, and more staffing across all cadres.

The HBC program is premised on the assumption that a functional referral system is in place, and that resources for HIV&AIDS will trickle down to the households with PLWHAs particularly the poorest households. Additionally, it is further assumed that there will be individuals within and outside the households who will be willing to volunteer to provide needed care for the bedridden patients in their households. Although the HIV&AIDS is supposed to be multi sectoral, the care services highly depend upon the health care facilities. This seems to have overstretched the human resource capacities of the health facilities which were already experiencing a human resource crisis.

One of the major challenges limiting the implementation of health policies and particularly the HIV&AIDS programmes including care and treatment is lack of qualified human resources in the health sector. While data on the size of health workers by category is not easily available in Tanzania, all existing literature and political pronouncements indicate a human resource crisis in the health sector. The CMI report (2006) asserts that Tanzania has the world's lowest coverage of physicians, with only 0.02 medical officers or specialist per 1,000 persons (CMI: 2006: 4). Additionally, at a Joint Health Sector Review in 2004, the Permanent Secretary of Ministry of Health declared that in .... "the area of human resources, I believe we have now reached a crisis point". At the Annual Review of 2005, Minister of Health asserted that the crisis now has reached emergency proportions. In his address to the Regional Medical Officers in 2005, the then President of the United Republic of Tanzania His Excellency Benjamin Mkapa is quoted to have said "the shortage of health personnel ... "is a serious problem, which requires urgent steps." (CMI report: 2006: 9).

According to the Human Resource Health (HRH) census in 2001/02, the size of active supply of health workers was 49,900 (MoH: 2004), which translates into staff per population ratio of 148 per 100,000. In 1994/95, active supply was approximately 67,600 health workers (census

1994/95). Hence active supply decreased by 19,300 health workers over the period between 1994/95 and 2001/02 ( Dommick and Karowski: 2005). The authors further claim that given the conservative assumption about increments and attrition, the size of the total workforce will continue to decline to approximately 37,900 by 2015 (ibid)

The human resource crisis notwithstanding, the HIV&AIDS pandemic and particularly the implementation of the Care and Treatment programmes has increased the demand for human resources for health sector across all categories of health workers. McKinsey study (2004) estimated that the Tanzanian HIV&AIDS care and treatment plan will require almost 10,000 full time health workers. Dominick A and Kurowski C (2004) study further claim that more than 25% of all the health services are provided to patients infected with the virus. These authors further asserted that further increase of this share was expected with the implementation of the NCTP for PLWHA. The Plan had set a target of treating 65,000 PLWHA with antiretroviral drugs (ARVs) by the end of 2005, and at least 400,000 by the year 2008. The WHO suggests an even more ambitious scaling up of care and treatment, aiming to treat 220,000 PLWHA with ARVs by the end of 2005 (MoH, 2003). If the NCTP was to be implemented fully, it was expected that the demand for health workers would have significantly grown. The provision of antiretroviral treatment to approximately 500,000 PLWHA in 2008 would require approximately 9,300 FTEs (URT 2003).

In disaggregating the shortage of health cadre by skill, the CMI report (2006) compares the actual staffing levels to the staffing norms, in which the greatest shortage was found among Assistant Medical Officers/clinical officers and lab technicians (60%) followed by nursing cadre (50%) and doctors (40%) (CMI report: 2006: 23).

To make matters worse, the distribution of the health workers is skewed in favour of the higher levels of health services which are not easily available to the majority of people in the rural communities. This is demonstrated in the following table.

#### **Health Facility FTEs Proportion of the total**

Health Facility	No of Staff	% of total
Hospitals	24554	55%
Health Centres	5917	13%
Dispensary	14284	32%
<b>Total</b>	<b>44755</b>	<b>100</b>

Source Census data 2001/02

In a nutshell, there is a serious shortage of human resource in health sector which has impacted all health workers generally. When there is a shortage of skilled human resource, the nursing cadre seem to shoulder a disproportionate burden of care This is the context within which health workers supporting the HIV&AIDS pandemic in treatment and care are expected to deliver quality services including the HBC which heavily rely on the health sector workers.. In the following section we discuss briefly the nursing cadre as it relates to the HBC programme.

#### **Nursing Cadre and HBC Services**

Data on the actual size of the nursing cadre is not systematically compiled and hence it is difficult to determine the actual gap in this category. But data compiled by the Tanzania Nurses and Midwives Council (TNMC) suggests that as of July 2007, the country had a total of 20,115 nurses out of whom 7,254 had diploma and higher levels and 12,861 were certificate holders (TNMC: 2008). These data contradict data provided by the shadow Minister of Health from the opposition camp during the 2007/08 budget. He claimed that

Tanzania had only 9,093 nurses out of the needed 14,743 hence generating a gap of 38.3% making Tanzania the 165<sup>th</sup> country in the world in terms of the ratio of nurses per population. ([www.parliament.go.tz/bung/doc/afya](http://www.parliament.go.tz/bung/doc/afya)). The WHO Country Health System Fact Sheet 2006 for Tanzania records that the nursing density per 1000 population was 0.37 (World health Statistics 2006 [www.who.int/whosis/en/](http://www.who.int/whosis/en/)). All in all, there is clearly a shortage of the nursing cadre.

There is also geographical variation in terms of nurse: population ratio. The 2005 report from one district council (Morogoro) revealed that the ratio of nurses to population was 1: 888, while for general physicians it was 1:290,316 and for Assistant Medical Officers (AMOs) it was 1:6,598. (URT: 2006: pg.5). In an interview with a retired nurse, we were informed that a maternity wing in the Kilimanjaro Christian Medical Centre (KCMC), a faith-based hospital which acts as a referral hospital, has not been opened for one year now since completion because of shortages of nursing staff (interview in 2008).

Despite the shortage of nursing cadre, the training of nurses for all levels lags behind the needs for this cadre. From 2002 to 2007 for instance, the number of nurses graduating annually from training institutions increased from 910 to 4,000 for diploma holders and from 469 to 13,791 for certificate holders. This increase has not bridged the resource gaps within the nursing cadre.

Services rendered by the health sector are hierarchically provided. In the health pyramid, a nurse is considered as a skilled worker occupying the lowest position in the skill hierarchy of the health workers. While the training of a nurse focuses more on patient care, due to human resource crisis in the health sector, nurses find themselves doing multiple tasks including those which they were not trained for. In an interview, a programme officer of the Reproductive Health Programme with UNFPA, who had previously worked as a nurse for nine years, said that “nurses are multi tasked, at one time they take the role of doctors, as they diagnose and prescribe medicine, they also act as cleaners as they are expected to join the semi-skilled staff in general cleanliness of the facility, while at other times, they act as messengers as they have to deliver health equipment and materials including HIV & AIDS kits, drugs, and other equipment to the lower level health facilities. Those who have not trained as midwives find themselves doing midwife tasks if posted in areas where there is no midwife or when faced with a neighbour who is delivering at home”.

In the continuum of care, the nurses offer skilled support to the community-based health workers who in turn support the primary care givers. Some of the nurses attend to the needs of HIV&AIDS patients in a health facility, others supervise the programme from a health facility, some of them are based in a primary health facility in which case they are expected to supervise the non-health staffs who are volunteers, and others are volunteers who have retired from their nursing career. As supervisors they also provide counseling, prescribe ARVs, follow up patients at home to ensure adherence to requirements, as well as compile reports for the program. The nursing cadre is hence critical in the continuum of care. They perform these tasks under very tough working conditions which are further elaborated in the following section of this paper.

The patient care tasks which include bathing a sick person, including cleaning of those who vomit or have diarrhea, caring for TB patients, as well as cleaning and dressing wounds subject nurses to the danger of infections. . The Service Provision Assessment (ORC Macro/NBS/TACAID: 2007) revealed that health workers in both government, private, faith based institutions were subjected to “*hospital acquired infection*” due to lack of infection control facilities. The Tanzania Service Provision Survey (2006) revealed that out of the

hospitals which were included in the survey, only 5% had all items for infection control, which included running water, soap, latex gloves, boxes for disposing sharp items as well as chlorine-related disinfectants. Of the hospitals covered, only 54 % had running water, 74% had soap, 20% had latex gloves, 23% had boxes for disposing sharp items, and 80% had chlorine related disinfectants. Similarly, of the health centres included in the survey, only 11% had all the mentioned infection control facilities, 45% had running water, 56% had soap, 51% had latex gloves, 32% had boxes for disposing sharp items, while 71% had chlorine related disinfectants. Of the dispensaries covered, only 12% had all items for disposal of waste, while 36% had running water, 59% had soap, 51% had latex gloves, 48% had boxes for disposing sharp wastes, and 84% had chlorine related disinfectants. All in all, less than one third of the sample covered had all the needed facilities for waste disposal. This means, most of the health workers are vulnerable to hospital-related infection, but nurses are even more vulnerable than some other cadres due to the nature of the work of patient care. Vulnerability increases with the care of PLWHAs (TSPAS : 2006 ).

During the celebrations of ‘Nurses’ Day’ in 2008 the chairperson of the Nurses Association called upon the government to support the nurses whom she claimed were working under very stressful conditions, with low salaries, without adequate working tools, and without any incentives ([www.habarileo.co.tz/biasharafedha](http://www.habarileo.co.tz/biasharafedha))

Like other professionals in the health sector, the nurses receive very low salaries given the level of their qualifications and the responsibilities they carry. A diploma holder in nursing take home salary that is after all taxes deductions is US\$230 per month. This nurse will use roughly \$ 80 per month for fair, another \$80 for a room; she will need a house keeper if she has a baby or children. At the end of the day, she hardly has a balance worth a decent meal ( Interview: 2009) Nurses as other health workers in the public sector are civil servants who receive benefits in the form of salaries, and pension contributions. Only a few additional benefits exist such as the travel allowances. Salaries of public sector health workers are set according to the Tanzanian Government Scale with few executive scales for senior/political positions and a different arrangement for government agencies/departments whose salaries are influenced by the market. An analysis of the wage scales for health workers revealed a highly compressed wage scale for health professionals. For instance, the basic salary of a trained nurse or clinical officer exceeds the salary of an unskilled worker who was trained on the job by TTS. 10,000 (\$7) per month (ibid).

According to information from the MoH, the compensation framework in the public sector lacks monetary incentives that are explicitly linked to performance attributes. For example, health workers do not receive any reward for serving in hardship areas, such as remote rural areas, like other professionals. In Tanzania, there are only two separate tools to enhance performance of health workers, one implemented at Muhimbili College of Health Science (MUCHS) in respect of teaching and administrative staff, and the other in the form of Selective Accelerated Salary Enhancement (SASE) The latter mainly applies to staff in various ministries. The nursing staff at the ‘coalface’ is not eligible for either of these.

Implementation of the SASE began in 2001. The scheme provides stop-gap enhancements of pay for those with critical skills and high performance in the public service. SASE targets senior administrative staff and a few non-senior staff who perform special tasks. Nurses are not considered for inclusion in this category. The McKinsey (2004) report claims that the impact of SASE has been far less than desired and potentially counter-productive. The program appears to have demoralized many front-line workers (which includes the nursing cadre), as the benefits were limited to higher-ranking officials.

Unclear terms of service further erode the morale and discourage trained nurses from continuing to render their services in public health facilities. In an interview with one of the daily papers, a graduate in BSc nursing expressed her frustrations which forced her to resign from her MoHSW post this year. She claimed that she graduated in BSc, nursing in 2005 and applied for a job in the ministry as a Nursing Officer Grade 3, carrying a salary of 260,000 Tshs a month (US\$230) per month. The MoHSW offered her a job but refused to offer her this scale on the grounds that those who had been offered this scale in the previous years had been treated as special cases filling in emergency gaps. After lengthy communications with high authorities of this ministry in vain, the nurse decided to resign from the job ([www.jambonetwork.com/blo.sept. 1st 2008](http://www.jambonetwork.com/blo.sept.1st.2008)).

Workload is another challenge which nursing cadre faces in Tanzania. In his alternate budget speech for 2007/08, the Shadow Minister of the MoHSW questioned government commitment in addressing the human resource crisis of the ministry. Making reference to the maternity ward of the Mhimbili hospital, the minister claimed that one nurse is serving 50 babies in the maternity ward, while one nurse in a general ward is serving up to 60 patients per day. ( It should be noted here that reports from various sources claim that at least 50% of hospital beds are occupied by patients suffering from HIV&AIDS-related illness (NMSF: 2008). Thus a large proportion of this large number of patients would be HIV-positive or have AIDS.) This is an unbearable workload according to the minister. He also questioned the rationale of paying an incredibly low ‘call allowance’ for nurses of Tshs 150, (\$ 15 cents). He further wondered as to why nurses were not paid a risk allowance considering the difficult conditions to which they are exposed during working hours ([www.parliament/go.tz/bunge/docs/afya](http://www.parliament.go.tz/bunge/docs/afya)).

In an interview with the head of a government-owned voluntary counseling and testing facility in Rangi Tatu dispensary in Ilala District in Dar es Salaam, we were informed that the workload for the nurses working in this centre was high, as the physical facility was too small to accommodate additional staff. Additionally, it has not been possible to conduct follow-up visits for patients under ART because of the workload. And yet there is a good number of patients who attend the clinic once, and after the prescription of ARVs, they do not turn up on prescribed dates. Under ideal circumstance, the nurses are expected to do follow up visit in their homes to check on progress. This is not happening due to shortage of staff.

The Baseline Study Report from Muhimbili National Hospital (Mwahonda 2004) indicated that the overall motivation level among staff is low. Roughly 50% of doctors and nurses were not satisfied with the working conditions. Dissatisfaction was attributed to a lack of clear job descriptions, lack of performance management, limited opportunities to participate in decision making, poor information flows between management and staff, poor supervision, low salaries and poor staff welfare. Additionally, an ILO study (2009) revealed that although 79% of the health personnel was satisfied with the security of their jobs, 79% were not satisfied with their pay, 60% were not satisfied with their training while 21% reported some discriminatory practices. The majority complained of long working hours to the tune of 75 hrs per week instead of the normal 45 hrs. per week. Resulting from this long working hours, the majority complained of ill health. Some of the common reported ailments included: Fatigue, backache, irritability, headache, stress, sleeping problems as well as anxiety.

Low motivation is also linked to staff shortages, low salaries, poor working conditions (equipment and housing), favouritism and lack of transparency in human resource management practices (e.g. transfers, selection for training and upgrading), limited supervision and monitoring; weak disciplinary procedures, limited and slow opportunities for promotion that are based on seniority rather than merit, rigid employment management



policies that discourage labour mobility, slow decision-making across the public service, and conflicting lines of accountability at district level ( Dominick A and Kurowski C: 2006).

All in all there is no motivation to support the HBC programmes from the nursing cadre or any other health worker due to the described working conditions in the health facilities. This raises issues of sustainability of the HBC programme in its current form. The condition for the non household home-based care givers is even worse as most of them are not remunerated for the services they render for the HBC programme. In the following section we discuss the non health HBC givers.

### **Non-household Home Based Care Givers**

There is a paucity of data on the number of non-household care givers involved in supporting HBC services in Tanzania for PLWHA. Because quantitative analysis is not possible due to lack of data, in this report we can only show some indicative data.

The Tanzania Commission For AIDs (TACAID) progress report of January 06-Dec. 07 2007, indicated that by the end of 2007, about 20 per cent of adults and children with advanced HIV infection were receiving ARVs, as illustrated in the following table x below

### **Antiretroviral (ART) Therapy Coverage (2006-2007)**

	January Dec.2006	– Jan.-Dec.2007
Number of all adults and children with advanced HIV infection	1,816,326	1,867,918
No. of all adults and children with advanced HIV infection receiving ARV	363,265	373,584
Percentage of adults and children with advanced HIV infection receiving ARV	20%	20%
No of children with advanced HIV infection receiving ARV	5,985	10,834
No. of adults with advanced HIV infection receiving ART	54,356	127,895

Source: TACAIDS: 2008. pg. 25.

If we are to assume that the majority of individuals with advanced HIV infection will in one way or another need some elements of HBC services, it means that as of December 2007, there were 1,867,918 Tanzanians in need of HBC services.

The Tanzania HIV&AIDS Indicator Survey ( THIS) (2003/4) further revealed that out of the 355 chronically ill persons aged between 18 – 59 who were very ill for 3 or more months during the 12 months preceding the survey, only 16.3% lived in households which had received medical support, 13.8% lived in households which had received emotional support, 11.6% lived in households which had received material or practical support, and only 3.8% lived in household which had received all the three components of support. The survey revealed further that support is more common for adults living in urban areas than rural areas, and provision of all the three types of support is more common for ill adults living in the poorest (among whom 5.4% access all three) and the wealthiest (5.1% of whom have access to all three) households. Furthermore the survey revealed that older people are more likely than younger ones to receive all three types of support. This is further illustrated in the table below:

## External Support for Chronically ill Adults, Tanzania 2003-04

Background characteristic	Medical Support	Emotional Support	Material or practical support	All three types of support	Number of chronically ill persons
Age					
18-29	15.6 %	14.1%	8.5%	3.5%	102
30-39	16.7%	18.7%	11.2%	2.2%	101
40-49	17.3%	9.1%	15.4%	4.7%	81
50-59	15.7%	11.9%	12.0	5.4%	70
Sex					
Male	21.4%	20.3%	12.2%	5.8%	153
Female	12.4%	8.9%	10.8%	2.2%	201
Residence					
Urban	29.7%	23.9%	16.7%	3.9%	82
Rural	12.3%	10.8%	10.0%	3.7%	273
Wealth Quintile					
lowest	14.3%	17.7%	12.2%	5.4%	91
Second	14.8%	10.8%	6.6%	3.3%	69
Middle	12.0%	2.8%	5.7%	2.8%	74
Fourth	12.8%	12.6%	14.3%	1.6%	58
Highest	29.2%	25.5%	20.5%	5.1%	63
Total	16.3%	13.8	11.6	3.8	355

Source: THIS: 2003/04. MoH/NBS: 2004 pg. 17).

The above table suggests that although the majority of Tanzanians are willing to support a PLWHA in their own households<sup>1</sup>, there is very little external support trickling down to these households with the PLWHAs.

The head of the counselling and social support Unit of the National Aids Control Program (NACP) ( in an interview) claimed that as of last year (2007), there were approximately 60,000 patients in need of home-based care. She further maintained that approximately 20% of the PLWHA need antiretroviral treatment and that all those under treatment require some elements of home-based care. The NACP (2007) estimated that 1,400,000 people were living with HIV as of 2007. , Out of the estimated about 400,000-500,000 were in need of ART, while some 1.2 million were in need of drugs for Opportunistic infections (OIs). This implies that about 400,000-500,000 Tanzanians who are living with the virus might be in need of some elements of HBC. In addition to care for the bedridden, a number of those under ART including those who are not bed ridden might need follow-up visit to ensure adherence to prescriptions. Home visits are normally conducted by non-household care givers.

The Mapping study by Pathfinder (2006) suggested that non-household care givers should carry a minimum of 6 patients load and a maximum of 21 beyond which it will overburden

<sup>1</sup> 9 in 10 Tanzanians would be willing to care for a relative who is sick with AIDS in their households, and that more men than women are likely to be willing to take care of a relative with AIDS (87.7% women and 89.5% men would be willing to care for a relative sick with AIDS) in their own households. This willingness suggests that the majority of Tanzanians would, if all other factors are taken care of, take care of PLWHA.

these care givers who are doing this on a voluntary basis. If we take the minimum load of 6 patients per care giver (volunteer) and assume that up to 500,000 PLWHA are in need of ART and hence in need of some element of HBC, it would imply that the HBC program would need at least 24,000 (for maximum load) or 83,000 (for the minimum load) non-household care givers.

The head of counselling and social support Unit of the National AIDS Control Program (NACP) however admitted that actual data on the need for HBC services are not yet available because the MoHSW had not developed tools for data reporting. She said that such tools were in the process of being developed. She also claimed that ideally each district should have at least two people supporting the Home Based Care Programmes whose main responsibility is to train the community volunteers. To date, only 80 districts out of 127 districts have officers dealing with HBC services in addition to other duties allocated to them. But in the majority of these districts, the HBC program is not comprehensive and not coordinated. There are also very few resources both human and financial allocated to the HBC program. (Interview: July 2008)

The head of the Information and Communication Unit of the NACP (in an interview) was of the view that the HBC was ill-conceived, and wrongly located in the MoHSW. The health sector, he further asserted, is currently working at 40% capacity of the needed human resources for the hospital-related problems. He further maintained that the MoHSW does not have enough resources, knowledge or capacity to handle the HBC program. He underscored the need for a multi-sectoral approach and the mainstreaming of HBC in district plans and budgets (Interview : July 2008)

The TACAID's civil society and Private Sector Response Officer was also of the view that the districts have not been able to mainstream HIV&AIDS in their plans and budgets generally, and hence the HBC program is not visible in district plans and budgets. According to him, the problem with districts and local government structures has been capacity to absorb the donor money. According to this officer, in the year 2006, the local government was only able to utilise just 32% of the funds allocated for HIV and AIDS activities, and yet very few resources are reaching HIV patients and their families at household level (Interview August 2008)

Lack of capacity to mainstream HIV&AIDS programs in district plans and expenditures was confirmed in a quick review of 11 District Medium Term Plans randomly selected from some of the Medium Term Plans and Budgets which were being reviewed by TACAID during the time of this study. Although all the plans indicated HIV&AIDS to be a top priority, it was not possible to establish how much of the districts planned budgets were going to be directed to HBC program activities. Additionally, all the reviewed plans indicated that prevention was going to take priority in HIV&AIDS. The HBC program activities were visibly missing as a priority area in both plans and budgets.

From these observations, it is difficult to establish the actual needs for the HBC program, in terms of human and financial resources. Nevertheless, in all the interviews, and from the documents reviewed, there is a claim that HBC services are not sufficiently resourced. In its annual report (2006-2007), TACAID acknowledges that HBC givers are very few and under capacitated. The report further notes that while civil society organizations (CSOs) provide HBC in a few areas, the government providers are not able to provide for the needs of the people living with the HI virus, which include food, transport, medicine, and economic support (ibid: pg. 19). In this same annual report, TACAID claims to have trained 6,800 community health workers, including 5,400 community-based and 1,400 HBC workers

(TACAID: 2008) this number is small compared to the crude estimated needs of those who are ill.

From the observations made from the plans and interviews, we can propose that the HBC program is not yet allocated visible public funds and that the majority of activities related to HBC are being carried out by the voluntary sector. Some of the organizations which are known to be conducting HBC include: faith-based organizations, TUMAINI, Care International, AMREF, World Vision, PASADA, WAMATA, FARAJA, Pathfinder, to mention but a few. In the following section we review some of the challenges which non home-based care givers face, as per a reviewed of existing literature and interviews conducted with care givers from some of the organizations

### **The Non-Household Care Givers (The voluntary cadre)**

The PASADA HBC program functions in a three-tier system. The first tier is made up of a supervisory cadre composed of paid staff working for PASADA. At the time of research, this team was made up of five officers, that is, one Assistant Medical Officer (AMO), who heads the HBC unit, and four nursing officers. The second tier is made up of 14 community-based nurses and one clinical officer, located in the PASADA-owned dispensaries. These are also paid staff working for PASADA. The final tier is made up of volunteers, and at the time of this research there were 300 volunteers. These are not paid, but they are given a token fee of 15,000 Tshs per month which is supposed to be a travelling allowance. The paid staff works five days in a week, and 8 hours in a day. The supervisors carry out home visits as well as train and supervise the community-based nurses who in turn train and supervise the volunteers (PASADA: 2006, and 2007)

During 2006, approximately 1,929 patients received home-based care services from PASADA, with a total of 15,371 home visits by the supervisors. This is a decline from 2,348 patients with a total of 14,416 home visits in 2005. The decline is attributed to a number of factors. First, there was a community-based nurse who resigned, and hence reports were not available. In addition, some of the PLWHAs who benefited from the HBC services recovered and hence graduated from HBC services, while a few might have died. (PASADA: 2006) From 2004 to 2007, PASADA had the following HBC patients.

#### **No of HBC patients attended by PASADA**

Year	No. of Patients.
2004	1,426
2005	2,348
2006	1,929
2007	2,310
2008 to July	856

Source: compiled by head of HBC Unit PASADA (2008)

The head of the PASADA HBC unit claims that they are reaching approximately sixty percent of the HBC patients needing their support. The main role of the supervisors is to support the volunteers through providing them with training, follow up new cases identified by volunteers, as well as visit those PLWHAs who do not have primary care givers. In addition to their monthly salaries, the supervisors receive a transport allowance of 30,000 Tshs. They also attend seminars, and two of the staff nurses are registered in distance learning. The head of the HBC unit is of the view that the nurses supporting the HBC programme are highly motivated, and are essentially driven by passion. After each home visit, they ease their tensions through group therapy, by sharing their day's experience, and for those few, who meet very challenging cases, including visiting the most deprived households some of which

are either child headed households or PLWHAs headed households, they attend special counseling

The bulk of HBC work for PASADA is conducted by volunteers. In 2006 the PASADA HBC program had 300 volunteers serving the 1,929 patients. Some of the volunteers are also PLWHAs. The volunteers are expected to engage in a number of activities. These include: identifying PLWHAs, carrying out home visits, providing nursing care to the PLWHAs, and providing special support to the most vulnerable. As noted above, each volunteer is paid approximately 15,000 Tshs, as a transport allowance.

Some of the challenges which the volunteers face include transport, in that most of them have to walk long distances on foot because they cannot afford the transport costs. Poverty affects both the patients and the volunteers. Most of the volunteers are retired or unemployed people who have to struggle to make ends meet. PASADA has attempted to motivate the volunteers through training, providing them with the transport allowance, and the most disadvantaged are also provided with food support. A few of them were also provided with bicycles and bags.

The PASADA HBC programme, like other similar programmes, is totally dependent on donor funding. PASADA has been receiving funds from the Princes Diana Memorial Fund, Steven Lewis Foundation, USAID and Global Fund. This creates problems of sustainability (PASADA: 2007). Donor dependency also threatens the sustainability of other HBC programmes as reported in a discussion with care givers of the Service Health Development Education for People Living with HIV&AIDS (SHIDFHPA).

When this research was being conducted the HBC programme for SHIDFHPA had come to an end due to lack of funding as donor funding had come to an end. And yet the HBC program was still being carried out by a few volunteers the majority of who were PLWHAs. In an interview with a few care providers from SHIDFHPA, it was revealed that the HBC givers were working under very stressful conditions with very little support from the organization. One care giver for instance revealed that she is a single mother with one child and three grandchildren and she is also herself living with the HI virus. When she started providing services she was given just 15,000 Tanzanian shillings per month for transport (equivalent to US\$ 14). But at the time of the interview, this allowance was no longer forthcoming. When she started, she used to have a kit with gloves, and some medicine, as well as food aid support for the patients, but as of now, she no longer has this basic kit. And yet she has continued with home visits and care services just to give the patients hope without material support. At times, when she has her own earned income, she buys a few things to take to her critically sick patients particularly those who have no primary care givers. Other problems mentioned by these care providers included lack of support for their own children, particularly those HBC givers who are also PLWHAs, lack of training, lack of emotional support, particularly those who are dealing with terminally sick patients, the workload and the expectations from the families and household which are receiving care ( interview)

The Pathfinder mapping study of HBC services in five regions of mainland Tanzania made the following observations with regards to the non-household care givers whom they referred to as Community Health Workers (CHWs). Community Health Workers are volunteers who provide care services to PLWHAs at household level. The CHWs normally get three weeks training on how to care for PLWHAs. In addition they also receive a transport allowance, and when available HIV kit which contains gloves and food supplement. In return, the CHWs are expected to provide nursing care to PLWHAs, provide training to primary health care givers (i.e. caregivers within the household), and provide material support like food, gloves, recruit

new PLWHAs for support as well as refer those who need specialized care service to the relevant health facility ( Pathfinder International : 2006)

In the first place the transport allowance is not sufficient to support the care givers in the execution of their voluntary services. Related to this is the expectation from the PLWHAs and family members that the CHWs have resources which they are expected to deliver, including food, medicine and protective gear for the primary health care givers. The CHWs are often forced to part with their own meagre resources to support the PLWHAs who are in a desperate condition.

Additionally, the CHWs are not sufficiently equipped to offer all the services required to the PLWHAs in a holistic manner. Making reference to the CHWs in Arusha, and Tanga for instance, the mapping study revealed that the care givers are unable to support the PLWHA on how to write a will and, worse still, was unable to refer them to legal clinics for such support.

Similar sentiments were expressed by the Faraja Care givers whose stories are summarized in the following boxes. The Faraja Trust Fund was founded in 1991 by a medical doctor (Dr. Lucy Nkya). It started with three volunteers, but currently (2008) it has 83 volunteers including peer educators, home care nurses, and credit advisers as well as life skill trainers. The Home Based Care programme is one of its core programme activities and is currently serving 671 PLWHAs among whom 94 are children. The HBC has 19 volunteers who among other activities do the following: home visits, providing counselling services, HIV&AIDS education, supporting income generating activities as well as support PLWHA in burial services (Faraja; [www.yci.org/pdfs/resources](http://www.yci.org/pdfs/resources)). The stories of the non-household care givers typically provide a rough picture of the conditions which are also experienced by the majority of care givers in similar programs. In the following section, we have extracted some of the stories of Faraja Care givers from their website (ibid.)

**Case study 1: Selma Kibwa**

Salma Kibwa is 49 years old, widowed and the mother of 5 children aged 12-20. In 1995, her husband passed away from AIDS-related illness and 6 years later, she discovered that she was infected as well. She was unsure on how she contracted HIV, but knows it could only be one of two ways. Previously she worked in a hospital as a delivery nurse, and thinks there is a possibility that during this time in her life she may have contracted HIV. Alternatively, she could have contracted it from her husband who she thinks was promiscuous and alcoholic. After informing her husband's family that she was positive, they abandoned her and her children. After her husband passed away, she joined Faraja as a volunteer with the HBC programme. The allowance is hardly sufficient to support her five children. Fortunately, her eldest daughter does some temporary jobs which supplement family income. She is of the view that if she and other volunteers were to be given start-up capital, it would enable them to start and run small business at the same time as they continue to render services to HBC. (Extract from Teresa \_Anne Martin) [www.yci.org/pdfs/resources](http://www.yci.org/pdfs/resources)

**Case Study 2: Hamis Ismail**

Hamis is one of the very few male non-home-based care givers with Faraja HBC programme. He is convinced that he contracted HIV from his wife who had multiple partners. When the wife died he suffered social exclusion from both family members and community surrounding him. He immediately contacted Faraja who assigned him a leadership role in the HBC programme. He gets involved in a number of their activities including: monthly support group meetings, income generating and loan facility group meetings, as well as home visits. In return he gets a stipend, access to herbal medicine through Faraja, and training on counseling. The stipend he receives is hardly enough to support his family, and he has kept on postponing an operation (in his genital area) because he knows this will keep him in bed for several weeks and hence he will not be able to get the stipend which is needed for the upkeep of his own family. Like other PLWHAs he worries about the future of his children as well as his health status. (ibid.)

**Case study 3: Sarafina Dalamis**

Sarafina Dalamis is a single mother raising a son and a daughter without support. Born of a Tanzanian Asian father whom she had never seen, she was raised by a hardworking mother who committed suicide in 1985 when Sarafina was 12 years old. Unable to get school fees, Sarafina was forced to drop out of school before she completed primary education. Later she co-habited with a man with whom she had two kids. Unfortunately, her partner had multiple partners from whom he got infected and infected her. As if this was not enough, her partner ran away taking with him most of their movable property, leaving her with the two kids to care for. As she also started suffering from OIs, and STIs, she decided to check her HIV status and was informed of her positive status. This is what landed her with Faraja who supported her with counseling and later she joined the team of volunteers with the HBC programme. She however, admits that although the Faraja team is supportive particularly when she falls sick, she does not get enough to eat well and hence falls sick frequently. The amount of stipend she gets from Faraja is hardly enough to meet the house rent, electricity bills as well as food for her family. (ibid)

Most of the care givers interviewed expressed their concerns over the quality of care services as well. There was concern that some of them lack the basic skills and knowledge on care services needed for PLWHAs. A study conducted by TGNP (2006) in two districts on the care burden revealed that HBC interventions did not significantly reduce the primary care givers' burden within the households. Most of the non-household care givers were volunteers and the majority of them were also women who did this work with very little or no support. Additionally the study found out that most of the household-based as well as non-household care givers were never exposed to basic training on the rudimentary skills of how to care for a PLWHA and how to take care of themselves when caring. Most of the volunteers were paid too little remuneration to afford transport cost, or were not paid at all. And yet home-based care is solely dependent on the volunteers as expressed by the coordinator of Tumaini Home-Based Care Program: *"Without volunteers, you can't do anything. The volunteer is the engine of this machine. They are working really hard"* (Interview: 2008).

The National Multi Sectoral Frameworks notes that the quality of HBC is low and that there has been insufficient human and financial resources directed to the program.

## **Conclusions**

The government has not facilitated financial and human resources to support the HBC program particularly the home-based care services of PLWHAs. This implies that the intention of ensuring access to health care for all as spelt out in the HBC guidelines is far from being realized. The extent of HBC needs for PLWHAS have not yet been determined because tools to assess such needs have not been put in place. The non-household care services for PLWHAs are essentially carried out by a few civil society organizations which rely heavily upon donor funding and the labour of volunteers who in the majority of cases are women. This dependency on external funding and volunteer labour threatens the sustainability of the HBC programme in its current form. The volunteers include retired nurses, PLWHAs and poor women and very few men, all of whom end up subsidizing the cost of care for PLWHAs. And yet, most district councils do not have capacity to utilise the AIDS money allocated to them.

The health facilities which have HBC programme components, both public and private including faith-based institutions, heavily rely upon the services of nurses as counsellors, supervisors of volunteers and trainers of non-health HBC providers. This implies putting additional stress on an already overworked nursing cadre. Within the health workforce, the nursing cadre (the majority of whom are women) seem to carry a disproportionate burden of care without adequate compensation. Those working in a health facility are for instance subjected to risk-related conditions as they are not provided with proper protective gear when attending PLWHAs including those who are terminally sick. . The monthly transport allowances for nurses who join the HBC as supervisors of home-based care is not sufficient to cover all the needed follow-up visits. They are also forced to part with their own money to pay for transport or to support the PLWHAs who are in desperate conditions. The bottom line is that the HBC programme is a burden to the households and to the few who are either working in HBC programmes as paid employees, or those who have volunteered to support these care services.



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