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Background

UNAIDS estimates that at the end of 2010, there were 34 Million people who were living with HIV and AIDS globally. It was also estimated that out of those, 68% (about 23 Million) were in Sub Saharan Africa. Although there is a decrease in the number of new infections, there were 2.7 Million people who became newly infected with HIV in 2010 out of which 70% (about 1.9 Million) were in Sub Saharan Africa.

Since the onset of the disease in the 1980s, most developing, countries, including those in which VSO works, groaned under the weight of weak and overburdened public health systems that were unable to cope with the increase in demand for services. One of the adopted coping mechanisms was task shifting; people who needed round-the-clock care and observation in hospitals were referred back to their homes and communities to be cared for by their families and volunteer community caregivers (VCCs). This led to the rise of Community and Home Based Care (C & HBC). The VCCs played a crucial role in nursing some of the people living with HIV and AIDS back to improved health and reintegrating them back to society, especially when antiretrovirals (ARVs) became more accessible.

A decade after the onset of freely available ARVs in the late 1990s, questions are being asked about whether C & HBC is important and whether VCCs are still relevant.

VSO is one of the founding partners of the Caregivers Action Network (CAN) and a member of the UK Consortium on AIDS and Development care and support working group. A number of VSO national programmes have C & HBC partners.¹ This paper seeks to outline VSO's position on C & HBC.

VSO's Programming

VSO has been implementing HIV and AIDS and health programmes in Africa, Asia and Latin America since 2000. The majority of these programmes have been in Africa. VSO's goal is to combat stigma, support prevention and increase the availability of treatment and care and support for those infected and affected by HIV and AIDS. In 2010, VSO operated dedicated HIV and AIDS programmes in 17 countries and there was also HIV and AIDS work being carried out in health and secure livelihoods programmes. VSO operates through placing volunteers to work with partners at different levels to strengthen their delivery capacity as well as advocating for policy change and/or implementation at national, regional and international levels. In 2010, VSO globally reached a total of 5,414,675 people through prevention, treatment and care and support interventions.

Definition

In HIV and AIDS, care and support may be defined as a comprehensive package of interventions aimed at assisting positive living and improving the quality of life for people living with and affected by HIV and AIDS.² These interventions include psychosocial, physical, socio-economic, nutritional and legal care and support.³ Community care refers to the care that sick patients receive from community health workers, neighbours or volunteers and care providers connected to programmes supported by

government, NGOs, churches or other civil society organisations; while Home care refers to the care that these patients receive in their homes from relatives, friends and other members of the household. In both cases, such care includes physical, psychological, palliative and spiritual welfare.⁴



A HIV Positive man with his Mother

Despite its importance, care and support remains the forgotten pillar of the Universal Access framework; it is rarely recognised in formal national AIDS responses or policies.⁵ At the global level, HIV care and support is not listed as a priority for many international institutions and donors.

Some of the reasons for this include:

- It happens out of sight, in the home.
- The belief that 'care and support is just part of treatment' thus ignoring its social and gender aspects.
- The attitude 'it is only for dying people' thus ignores the critical role in supporting adherence to ART.
- The majority of those who shoulder the burden of caring for the sick at homes and in the community are women, older people and girls who easily fall off the development agenda unless there is a conscious effort to include them.

The Burden of Care

According to UNAIDS up to 90% of care for the sick is provided at home.⁶ This includes care for PLHIVs and those with AIDS. There is now overwhelming evidence that women disproportionately carry the burden of care at home and in the community for adults and children living with and affected by HIV.⁷ VSO RAISA and WHO conducted a study in 2008/9 across six African countries, which showed that up to 80% of all volunteer secondary carers, are women.⁸ Likewise, 76% of children who dropped out of school to care for their parents and siblings were girls. It is women, girls and older people who provide care to PLHIVs because society views it as a continuation of roles of caring for their families. Duties that are related to home-based care are seen as domestic and are therefore considered to be women's work. This places an enormous burden on women, girls and older people, who are not recognized, valued or remunerated for the care work that they perform.⁹

Present Role of Volunteer Community Caregivers

Since the onset of free ARVs in the mid and late 1990s, HIV and AIDS have evolved and so have the roles of VCCs. The VSO RAISA/WHO research confirmed that the new roles of VCCs include promoting primary health care, education on prevention of common communicable diseases such as, dysentery, TB and HIV; adherence to ARVs and all other treatments; recuperation support including nutritional advice; caring for orphans and palliative care for patients with terminal illnesses.

Present Role of Caregivers in:

Prevention	Treatment	Care and Support
Condom distribution	Adherence Support	Providing Psychosocial Support to clients and their families
Family Planning education	Refilling Prescriptions	Provision of transport to clients
Counselling for HIV Testing	Treatment Education and Follow-up	Physical and Nursing Care
Infant Feeding Guidance	Treatment of Minor Ailments	Training household members in Care and Support
Education on Infection Prevention and Control	Training household members in Treatment Literacy and Adherence	Assisting with household chores
Education on ART	Facilitating referrals of clients to health centres / professionals	Nutrition Support
Community Education on STIs	Nutrition support	Referring clients and their families to social services and other agencies
Community Education on HIV Testing		Resource Mobilisation
Resource Mobilization		Palliative Care
Home Testing		Caring for orphaned and vulnerable children

Source: VSO RAISA and WHO, (2008-9), Consultations in Malawi, Mozambique, Namibia, South Africa, Zambia and Zimbabwe

VSO's Position on Caregivers

VSO strongly believes that Volunteer Community Caregivers should be supported if the gains made by the introduction of ARVs are to be sustained. VSO believes caregivers are crucial in the HIV and AIDS continuum i.e. prevention, treatment and care and support as well as mitigating the impact of the disease on the society, including caring for orphaned and vulnerable children (OVCs), who are estimated to be 14.8M in Sub Saharan Africa.¹⁰ VCCs are still very important in ensuring adherence to the treatment regime; treatment education, nutritional support and counselling, and thus reducing chances of defaulting in treatment. By supporting VCCs, stakeholders will also be supporting women, girls and older people who shoulder most of the care giving burden.



Income generating Projects in Southern Africa

VSO is calling for:

Remuneration and Social Protection

The service that caregivers provide to PLHIVs and OVCs should be governments' responsibility. Therefore, caregivers have a right to be financially rewarded or reimbursed in some way. They should be supported to reward them for their commitment as this directly impacts on the quality of care they provide. If there were to be remuneration, more men would potentially undertake care giving roles and this would ease the burden on women and girls.

Logistic and Material Support

Home Based Care (HBC) Kits are crucial for service delivery. Caregivers need to be provided with kits whose contents are replenished regularly. Home Based Care (HBC) kits contain eg. disinfectant and gloves thus protecting them from infection.

Income Generation

Supporting caregivers to access appropriate income generating projects to ensure their own livelihoods is essential. No caregiver should be impoverished as a result of the care she or he provides.

Training and Professional Recognition

There is need to standardise and regulate training provided to caregivers so as to improve and maintain the quality of care provided. Gaps in quality control and supervision put both patient and client at risk. Protocols of training and accreditation should be developed.

Psychosocial Support

Care work results in a lot of stress that can easily result in burnout. Care Providers should have access to counselling services as well as other psychosocial support mechanisms. This will have a direct impact on the quality of care they will be able to provide.

Gender Equity

Society expects women to be caregivers. This sometimes happens at the expense of women's livelihood and progress. Governments should empower women and encourage greater participation of men in care work.

Public Private Partnerships

There is need to advocate for stronger Public Private Partnerships since HIV and AIDS affects both sectors and thus require concerted effort by all stakeholders. Community and home based care and care work in general should be linked with broader national social protection programmes to ensure sustainability.

Conclusion

VSO strongly supports comprehensive strategies of preventing HIV and supporting the infected and the affected. We believe the rights of both PLHIVs and the affected including, those of VCCs should be respected in all interventions if the gains made in HIV and AIDS in the past decade are to be sustained and even scaled up.

Reference

1. CAN is a global network of organizations and individuals committed to realising a global health agenda that fully recognizes, integrates and supports caregivers and community-based care and support (including home-based care) as a fully recognized and resourced part of the health and care system. CAN focuses on strengthening caregivers in order to achieve improved access to quality care and support for the most vulnerable. The network is currently co-facilitated by Cordaid, HelpAge International, Huairou Commission, the International HIV/AIDS Alliance, and VSO. www.caregiversactionnetwor.org
2. Walking the Talk, VSO & Action Aid, pg32 2007
3. UNAIDS 2011-2015 strategy *Getting to Zero*
4. Scaling Up HIV and AIDS Prevention, Treatment, Care and Support in Community and Home-Based Care Programmes by Reducing the Burden of HIV and AIDS Care on Women, Girls and Older Carers in SADC- Published in 2011: pg 7
5. In 2010, the UK Consortium on AIDS and International Development held consultations on 'Care and Support,' which resulted in the publication of 'Care and Support,' the forgotten pillar of the HIV response.
6. UNAIDS Report 2004,pg 118.
7. UNDP and Huairou Commission Research; Compensation for Contributions 2009.
8. Secondary Care Provider A trained care provider who provides health services at community and home level, and is usually linked to C&HBC programmes supported by NGOs, faith-based organisations (FBOs), CBOs and other organizations at community level. In some cases, these cadres receive stipends and incentives, and are meant to support primary care providers. In this report, unless otherwise stated, care provider refers to secondary care provider: *Scaling Up HIV and AIDS Prevention, Treatment, Care and Support in Community and Home-Based Care Programmes by Reducing the Burden of HIV and AIDS Care on Women, Girls and Older Carers in SADC- Published in 2011*
9. Integrating gender into HIV/AIDS programmes in the health sector; Tool to improve responsiveness to women's needs –WHO, 2009 pg 30
10. <http://www.avert.org/aids-orphans.htm> as accessed on 16th February 2012



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