Discussion Paper on Care and Support

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Introduction

As the number of infected and affected people with HIV/AIDS increase, the pressure on the support and care services increases to improve their quality of life. The burden of taking care of the HIV/AIDS infected and affected falls on families and communities, particularly the women, of these people. This has increased the necessity to investigate the difficulties in providing PLWHA with the necessary support and care services and to develop recommendations that can alleviate their situation.

Defining "Care and Support"

People living with and are affected by HIV/AIDS should not only be offered certain services, such as diagnosis and treatment, but a broader range of services that focuses on every aspect of their lives, therefore supportive and complementary services are needed. These should include psychosocial, spiritual, legal, clinical, nutrition and daily living need (FHI, 2004: 2; WHO, ©2004: 5). All of these services are packaged into the concept of the continuum of "HIV/AIDS care and support" and should be delivered to people from diagnosis until death, with support for the family after death (Russell & Schneider, 2000: 328).

Care and support programmes should ensure that all people have access to diagnosis, health care and support services. They should reduce the morbidity and morality rate and should promote opportunities for the prevention of HIV transmission in the delivery of health care services. Overall it should strive to improve the quality of life of both people infected and those affected by HIV/AIDS (WHO, ©2004: 5).

Components of care and support

The WHO (©2004: 5-6) and the FHI (2004: 2) have identified four components of HIV/AIDS support and care. The common components are clinical care, socio-economic impact, human rights & legal support and psychosocial support. The WHO (©2004: 5-6) also identified "involving PLWHA" as a component, generally known as the GIPA principle. The "Greater Involvement of People Living with HIV/AIDS" as an important component of care

and support was also highlighted at the 2006 International AIDS Conference in Toronto, Canada.

At a workshop held by the AIDS Consortium (AC) on HIV care and support in September 2006, most of these components were identified by workshop. The workshop identified the following components as the most crucial:

- Clinical care
- Psychosocial
- Economic (socio-economic)
- Family and Children

Human rights (encompassing stigma and discrimination) were also identified as an issue that cut across all four of these key components (AIDS Consortium, 2006).

Clinical care
Generally clinical care includes medical care and nursing, testing and counselling, preventative therapy, the management of STIs and other HIV/AIDS related diseases, palliative care, Voluntary Counselling and Testing (VCT) and Prevention of Mother to child transmission (PMTCT) and lastly supportive services such as laboratories, nutrition and health education / health promotion (FHI, 2004: 2; WHO, ©2004: 5-6).

At the AC Workshop in September 2006, clinical care was further developed to include areas that needed urgent attention in strategic and operational plans and policies.

- Home-based care
- The necessity for government leadership in ARV sites
- Education and encouragement on early diagnosis
- District health services including Home Based Care (HBC) and VCT with clear support programmes that links into communities.
- Human resources, such as health care workers, nurses and ALL medical personnel should receive standardised training, care and support, with their rights being addressed as well as conditions of employment and remuneration.
- Referrals from and between CBOs, as well as traditional healers should be formalised.

- The increased rollout of health services in prisons with the necessary health care workers (nurses and doctors) for adherence to best practice.

Clinical care should be provided to everyone regardless of his or her age or gender (AIDS Consortium, 2006).

Psychosocial support

Psychosocial support includes counselling that meets emotional and spiritual needs. This can be achieved through support groups, peer and volunteer outreach programmes, other community support services, orphan care and bereavement care (FHI, 2004: 2; WHO, ©2004: 5-6).

At the AC Workshop in September 2006, psychosocial support was further developed to include areas that needed attention in strategic plans and policies, these are:
- Support groups for families, PLWHA, child headed households, counsellors, caregivers and traditional healers.
- People should be encouraged to break the silence and talk about all issues within their support groups.
- Necessity for lay and professional counselling with adequate supervision and de-briefing
- Counselling for people on adherence to, and use of ARVs
- The reduction of stigma and discrimination
- Pay more attention to the needs of vulnerable groups, such as Orhpans and Vulnerable Children (OVCs), refugees, sex workers, truck drivers and migrant populations (AIDS Consortium, 2006).

Economic support

The field of economic support is identified by the WHO (©2004: 5-6) and the FHI (2004: 2) as the component "socio-economic impact". This component includes material and social support that ensures the daily living needs of HIV/AIDS infected and affected are met. These include housing, food security, helping hands in the household, insurance that includes HIV/AIDS treatment and general economic security (FHI, 2004: 2; WHO, ©2004: 5-6).

The September 2006 AC workshop identified the field of economic support together with more specific areas that should be attended to. These areas are:

- The HIV affected and infected should be supported to develop income generation skills
- Food security must be increased and the delivery of food parcels improved
- Education of the young and the old should be further developed
- More social workers and social auxiliary workers in order to decrease the pressure felt due to a shortage of skilled workers in social development
- Many services in the formal and informal sector suffer from a lack of resources including human resources and funding.
- Refugees should have access to social security and health services, economic participation and their existence should be normalised.
- Social security needs to be reviewed, child care grant expanded to 18 years and disability and other grants reviewed with possible development of a Chronic Illness Grant (AIDS Consortium, 2006).

Family and Children

The AC Workshop identified the following areas that should be developed within the national policies and strategic plans:

- Free essential services should be supplied, particularly to child headed homes
- Standardised health care system should be investigated
- General childcare and specifically care and support for OVCs should be further developed and enhanced.
- Grants that will enable the family to support itself as well as the children should be further developed (as noted in par.3.3)
- More should be done to improve care of mothers, including increased promotion of and access to PMTCT. (A child survival is highly dependant on the mortality of the mother)
- Refugees access treatment and care for adults and children, even if they do not have South Africa identity documents. Not providing these services violates the constitution.
- The inheritance rights of children and women should be protected (AIDS Consortium, 2006).

Difficulties in providing care & support services in South Africa

Community involvement

In South Africa any discussion on HIV/AIDS care and support automatically includes the question: "How can the community be involved?" This increases pressure on community organisations to respond to the need for home-based care. The increasing number of people infected and affected by HIV/AIDS has had a negative impact on the capacity of the formal health sector, highlighting their inability to satisfy the care and support needs of the people (Quinlan & Desmond, 2002: 35). The burden of care and support falls therefore on the family and the community of a person (Russell & Schneider, 2000: 327-328).

Community-based organisations are seen by the government as essential to ensure sustainable HIV/AIDS care and support, and not a replacement for governmental programmes. However, this is not so easily achieved (Zungu-Dirwayi, ©2004: 34). Communities are not homogenous; they have different people and different cultures with different traditions and beliefs. These diverse communities add to the difficulties of standardising care and support. CBOs, on the other hand, do know their communities and have a certain amount of influence. It is therefore necessary for the government and communities to work together. The government should play a developmental role and provide an integrated approach and should not rely on CBOs as an easy fix for a very difficult problem (Desmond & Quinlan, 2002: 36; Russell & Schneider, 2000: 328).

Many communities do not have food security. In many families the little income that they have is used for providing the sick with medical treatment and not on necessities. In many communities people used to share food, but because of drought and poverty many lack the resources and this is not possible any more. In some cases where there are CBO volunteers that help families they share their food with the family they are taking care of. Some volunteers supply food parcels to their clients, but in many places there are no food parcel programmes or school lunch packs and it is difficult to access government help, such as grants, without South African identity documents (AIDS Consortium, 2006; Zungu-Dirwayi, ©2004: 57).

Capacity and training programmes

The difficulties experienced with CBOs are not limited to their involvement in HIV/AIDS care and support but also include their capacity. The capacity of an organisation or an individual is the skills that that person has to successfully manage a programme and in the field of HIV/AIDS.

Many community organisations do not have the necessary capacity to implement programmes and lack the resources. Many are unable to successfully record and store documentation. This hampers the management programmes and projects (AIDS Consortium, 2006; Russell & Schneider, 2000: 332). It is also true that a great disparity exists between organisations in rural and urban areas. Organisations in urban areas are often better organised and have access to necessary resources, while this is not true for organisations in rural areas (Zungu-Dirwayi, ©2004: 68).

Although many community organisations do receive training there is no standardisation of training and service delivery. Training programmes have different contents and quality (Russell & Schneider, 2000: 333).

Human Resources are also a challenge. Many organisations depend on volunteers. Maintenance and retention of volunteers are often a challenge (Russell & Schneider, 2000: 332). The registration and support for CBOs and NGOs delivering services is inadequate and inconsistent (AIDS Consortium, 2006).

Implementation of policies and strategic plans

Many policies and strategic plans have been developed to guide the fight against the HIV epidemic, but many of these are partially implemented or not at all.

Active and clear distribution of guidelines and policies is lacking, meaning that people are often unaware of policies and plans. Many people that are responsible for the implementation of these guidelines do not have the necessary technical skills, knowledge to ensure implementation or the numbers are simply too few. Few support systems exist that can assist in implementation and many lack resources to implement the policies and plans,

such as in-service training and pharmaceuticals (Modiba, 2002: 3; Zungu-Dirwayi, ©2004: 37, 41, 68).

Effective monitoring and evaluation of policies and strategies is lacking and therefore the effectiveness of these policies cannot be determined (Zungu-Dirwayi, ©2004: 34).

Health care workers and services
Many health care workers face psychological and physical challenges in supporting HIV/AIDS infected and affected people. Problems such as burnout, fear of contracting the disease and compassion fatigue occur daily, which leads to a loss of personnel, thus stretching the services of the formal health sector even further (AIDS Consortium, 2006; Modiba…[et al.], 2002: 3). Many workers do not have access to support systems to help them to cope with the demand of providing support and care services to PLWHA. The availability of organisational support systems, even informal networks, can reduce stress and burnout under health care workers (Modiba…[et al.], 2002: 4).

Many health care workers still have difficulty in dealing with HIV infected people leading to discrimination against such patients. This negative attitude towards such patients leads to a decrease in the quality of care (Modiba…[et al.], 2002: 4; Zungu-Dirwayi, ©2004: 56).

In rural areas many people still do not have proper access to health care services. Clinics are not accessible, transport is not affordable or non-existent and distances to hospitals are far, hampering care and support of the chronically ill (Zungu-Dirwayi, ©2004: 34, 57).

Stigmatisation and discrimination
Many people infected with and affected by HIV/AIDS still fear stigmatisation and discrimination from their communities, family and others outside their inner circles. Some cultural and traditional norms that are practiced can have a negative effect on the delivery of support and care services. Other beliefs and practices increase the possibility of HIV transmission, for example breastfeeding. In some cultures it is believed that the mother should breastfed her baby as an illustration of her maternal role, negatively impacting on PMTCT. (It should not be forgotten that economic conditions also impact on this choice). Orphans sometimes suffer under cultural beliefs that cause them to get caught up in family

feuds and to suffer from neglect. This happens quite often when it is believed that the reason for the parents' death is a curse on the family (Zungu-Dirwayi, ©2004: 34, 37, 57).

Stigmatisation and discrimination also have a negative impact on accessing VCT services. Many VCT centres lack sufficient qualified or skilled counsellors causing delays and poor service (Zungu-Dirwayi, ©2004: 56). Expansion of VCT services is required, with consideration of supplementary opt-out testing in certain situations (AIDS Consortium, 2006).

Discrimination continues to keep people away from services leading to people dying undiagnosed, in fear and isolation and lacking psychological support (AIDS Consortium, 2006).

Recommendations for the future

An analysis of the components of "care and support" and the areas of importance identified by the AC Workshop of September 2006, as well as the variety of difficulties that exist with the delivery of care and support services, have highlighted the following areas of concern.

Capacity of CBOs

The need for CBO programmes in the fight against the HIV epidemic cannot be denied. CBOs must therefore be strengthened through further development and capacity building. Standards must be developed to guide skills development (or accessed in the national qualifications framework). Partnerships between organisations, government and other sectors require ongoing strengthening.

Training on standardised care and support models is required to elevate service delivery. Care and support of the carer (including all levels of health care workers) is formally required – an environment where they feel safe to share and discuss HIV/AIDS is required to address internal stigma. Health care workers struggle with the same issues as their clients.

Government should play a developmental role and provide clear and practical leadership and response on HIV/AIDS

Policy evaluation and monitoring

Policy development should be conducted through partnerships with the government, NGOs, CBOs and PLWHA. It is very important to have the input of PLWHA in policy development and standards, as well as all other aspects of the epidemic – "nothing for us without us".

Regular monitoring and evaluation of policies and plans must be implemented to ensure that targets are met. Monitoring and evaluating mechanisms are to be developed and updated, including care and support indicators. Existing mechanisms should be easier accessible and made known to all stakeholders. Monitoring and evaluating should be apart of the programme's resources and should therefore be factored into the total cost of a programme.

Guidelines on monitoring and evaluating should be developed in partnership with the government and NGOs to ensure that all the needs are met.

Referral system

A proper referral system should be in place between governmental organisations and non-governmental organisations that includes all of the organisations in between. All of the services within the country should be linked to provide an integrated, standardised service of quality to PLWHA. A referral system will ensure that anyone, anywhere in the chain will be able to receive help with specific needs and questions. It should also be remembered that people use both traditional and formal health services. It is therefore important that a referral system also include traditional healers and services. Western and traditional medicine practitioners must work together and the research on traditional medicine should be expanded.

Health care workers

Health care workers should receive standardised and formal training at all levels to provide the necessary care and support for HIV infected and affected people. Training health care

workers in ethics and rights will ensure that their attitudes improve toward PLWHAs. Training must be extended to include traditional healers. The AC September 2006 Workshop's suggested target of traditional healers trained is 600 a year, plus all health care workers.

It is, however, also necessary to ensure that services exist that can support the caregivers to guard against burnout and exhaustion and provide debriefing. Psychosocial support and debriefing will improve the quality of service provided.

The position of volunteers, such as community health and home based care workers, should be formalised and liveable remunerations standardised. An urgent plan of action that deals with the human resource crisis must be developed and implemented.

Economic

Minimum standards for social protection must be introduced and social security reviewed. Childcare grants should be expanded to the age of 18 and disability and other grants must be reviewed. The possibility of developing a Chronic Illness Grant must be explored.

HIV infected and affected people should be supported to develop income generation skills and the issue of food security must be addressed. Refugees should have access to social security and health services, economic participation and their existence should be normalised.

Family and Children

Free essential services should be supplied in certain circumstances, particularly to child headed homes, and general childcare, specifically care and support for OVCs, should be further developed and enhanced.

More should be done to improve care of mothers and an integrated package of service should be developed. The child survival depends on the mortality of the mother. Save the mother and you will save the child.

Rights of refugees and children should be upheld in terms of access to treatment and care.

Lack of South African documentation should not be a basis for the denial of service. The inheritance rights of children and women should be protected.

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