

Services for care, treatment and support of people living with HIV

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SERVICES FOR CARE, TREATMENT AND SUPPORT FOR PEOPLE LIVING WITH HIV:

Why services for people living with HIV are different from other health services

Chronic care – a new paradigm for health care and treatment.

In low income countries, the care and support needs for people living with HIV are very different from tradition treatment at the health center or referral hospital. In the past, people came to hospitals and health centers for acute care for sudden illness or trauma. There was little or no need for continuity of care and maintenance of individual patient records. Health workers tabulated patient personal details, presenting complaints, diagnosis and treatment in the clinic register. Few patients returned for follow up treatment but for those who were seen again, it was a simple matter to look back in the clinic register to find details of the presenting complaints and treatment. However, people who are living with HIV need lifelong care, support and treatment from the time of diagnosis as being HIV positive. This requires keeping of individual patient records which must be kept confidentially. These medical records must be available to the health worker to review and update as required, and when the patient is referred for health care in other facilities and hospitals, the health worker must include information from the medical record in the referral letter. To ensure timely, coordinated care, health information systems are needed that track people who are diagnosed as HIV positive over time. Good clinical health care for people living with HIV is complex.

Clinical care needs of people living with HIV

Includes:

- screening for tuberculosis
- diagnosis and treatment of sexually transmitted infections
- family planning and other reproductive health services
- midwifery care and prevention of mother to child transmission services, for pregnant women
- prevention, timely diagnosis and treatment of opportunistic infections
- antiretroviral therapy commencing at the appropriate time, and
- nutritional support

The Big Picture First

The wider needs of people and families living with HIV

Social & spiritual needs

It is important to remember that people living with HIV have social and spiritual needs as well as biomedical needs. The needs may vary with time depending on how well the person is or what clinical treatment they need. Some will benefit from regular, long-term counseling or a support group; some will want spiritual support from a minister/imam of their faith, particularly in the latter stages of HIV related disease. Health centers should establish a local referral network that can offer these vital services. People living with HIV and their families often form local organizations that advocate for better access to

care and treatment, and more resources to be spent on addressing HIV. Some people living with HIV run local support groups and these can be very useful for referring people for psychosocial support. However, not everyone will want to disclose their HIV infection widely, and so these people might not want referral to an organization of people who are living openly with HIV.

Economic needs

People living with HIV and families affected by HIV are often amongst the poorest in a community. Poverty might have been a driver for risky behaviors that led to becoming HIV positive or, the economic providers in the home may have been ill and unable to work. Household resources may have been used up seeking treatment from formal and traditional health care providers before the diagnosis of HIV infection. Grandparent and child headed households may be economically very precarious. Such HIV-impacted households may have acute need for financial support as well as longer term needs for economic strengthening through livelihood skills building and access to microcredit and jobs. Most health centers are unable to directly meet patients' economic needs, but the social worker should gather information on local charitable organizations and religious societies that offer financial assistance. Links are needed with nongovernmental organizations, community organizations and development projects that offer livelihood support.

Food and nutrition needs

Some households affected by HIV are not nutritionally secure. That is they cannot guarantee that household members will receive the required food and nutrients for a healthy life. This is a particularly problem when people living with HIV are taking antiretroviral therapy. Some antiretroviral drugs have to be taken with food. Additionally, persons who begin to recover their health while taking antiretroviral therapy may develop large appetites as their bodies endeavor to increase calorific intake and put back on weight lost during illness. Long term, communities have to be assisted to become nutritionally secure. Both government poverty reduction plans and donor assisted development projects need to focus on nutritional security in communities that suffer periodic acute hunger or chronic food insufficiency. In the short term, antiretroviral services need to link with international food programs or local charitable organizations that can help individual families who need food assistance.

Legal needs

Many people living with HIV and their families need legal support. This may be connected with property ownership and inheritance rights, drawing up wills, and making provision for care of children in the future. Where customary practice is for the man's relatives to take charge of land and property after his death, it is particularly important that women and children have their legal rights protected. As it is often too late, when property is snatched after a funeral and women and children are left without, legal support is needed before a person living with HIV becomes terminally ill. Most health centers are unable to give legal guidance, but people living with HIV need to know from where they can receive legal guidance and support.

The need for chronic care management

When people first learn that they are HIV positive, they may react with anger or denial. They may not hear advice on keeping well, avoiding infections and seeking prompt

treatment for symptoms of sexually transmitted infections, tuberculosis and other infections. Many people are frightened to disclose that they are HIV positive to their spouse, other relatives and close friends. In all societies, AIDS stigma is common and discrimination occurs in the family, community and the workplace against persons who are thought to be HIV positive. A person who is newly diagnosed as HIV positive may therefore be reluctant to return to the health center for follow up, and may not be willing to join a support group. Yet the health center staff need to follow up HIV positive patients to ensure they receive optimum care and that they return to the health facility for care and treatment when needed. Care management is important for the continuous care of people who are HIV positive. It can be undertaken in the health center or in the community by lay people who have received training and are supervised by health care workers. Some models for care and treatment — for example in Rwanda¹ — use nongovernmental organization community volunteer care managers. Other models — for example Ethiopia² — use a new cadre of non-clinical health facility employee

The care manager's role

The role of the care manager is to know what services and resources are available for care, support and treatment of people who are living with HIV; to make the referrals to the services, and help people living with HIV access available services and resources. In hospital and health centers providing HIV clinical services, the HIV service clinical director works with staff to develop clinical care algorithms and patient flow plans specific to their situation. Care manager training and refresher training should include use of the local clinical care algorithms. The care managers' supervisors must ensure that the care manager understands the clinical care algorithms and patient flow plans. For community services and resources, the care manager must liaise with community health workers and others in the community who can help map the resources available locally [see box *Mapping of community assets*]. Although the counselor or social worker may need to follow up with his or her HIV positive clients until they are willing to be referred to support groups in the community, the counselor or social worker should introduce HIV positive clients to the care manager, in confidence, as soon as a positive diagnosis is made. The care manager should outline a care plan for each HIV positive client with the referrals that will be needed over time outlined and the resources and services available locally noted.

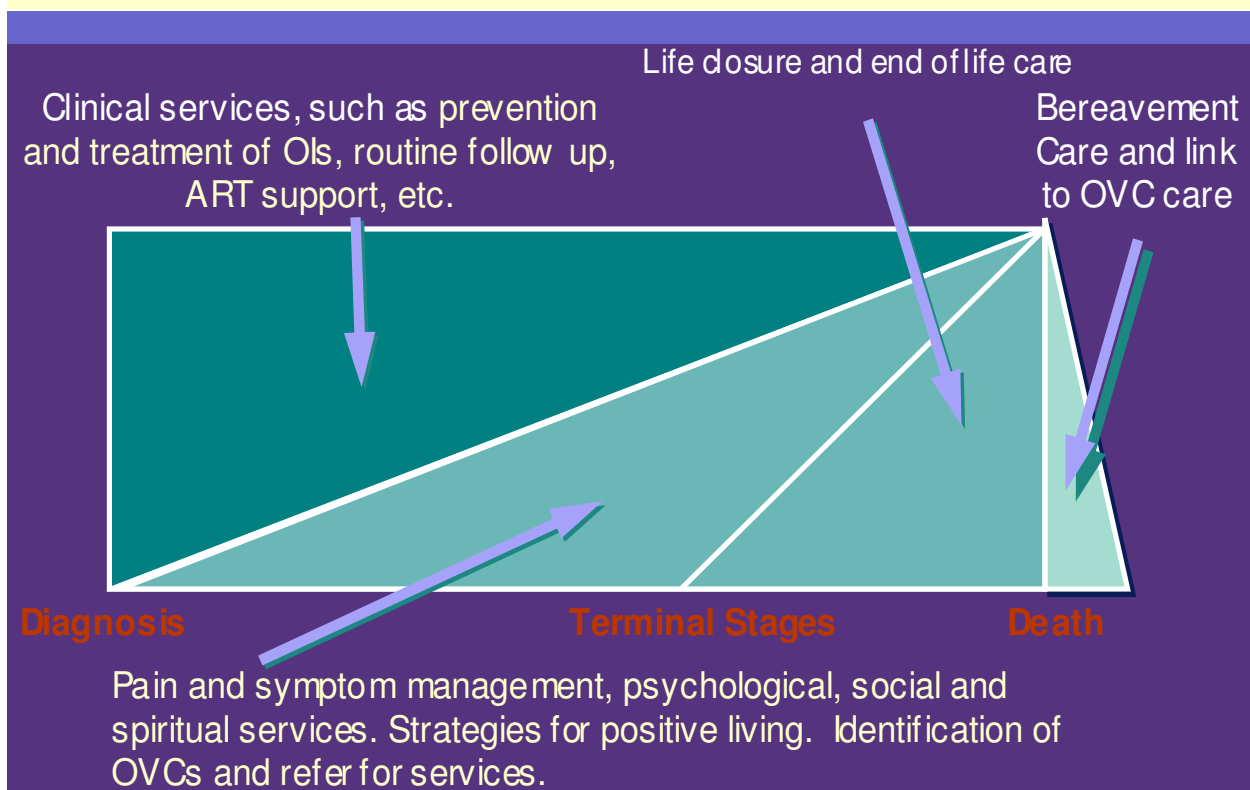
<p>Mapping of community assets A Practical Checklist</p> <ul style="list-style-type: none"> ➤ psycho-spiritual support ➤ legal advice ➤ economic and livelihood opportunities <p>offered by:</p> <ul style="list-style-type: none"> ➤ local faith-based organizations, and ➤ other nongovernmental organizations <p>and local resources, such as:</p> <ul style="list-style-type: none"> ➤ retired nurses living in the community ➤ ministers of religion/imams with particular interest in pastoral care ➤ associations of people living with HIV <p>Mapping of community assets needs to be undertaken when an antiretroviral service commences and to be periodically updated as the local situation changes.</p>

The care plan

People living with HIV have need for care and support, as well as clinical diagnostic and treatment services from the time of diagnosis that they are HIV positive before antiretroviral therapy is needed. The need for care and support and clinical diagnostic and treatment services continues after the person commences antiretroviral therapy. The

objective of the care plan, that includes holistic support and treatment needs, is to maximize the quality of life of people living with HIV and their families. The care plan is thus a holistic palliative care plan and includes vigorous prevention and treatment of opportunistic infections, nutrition support, spiritual, psycho-social and economic support. [See diagram *the continuum of palliative care*, below, for a representation of the complexity of palliative care over the course of HIV and AIDS.] As people living with HIV accept their diagnosis, the care manager ensures that each person is helped to disclose to their sexual partner, is screened for tuberculosis and sexually transmitted

The continuum of palliative care*



infections and receives cotrimoxazole and impregnated bednets, and preventative treatment for malaria (and tuberculosis and cryptococcal infection if required by local ministry of health protocols). The care manager makes the referral to the community health worker, and the experienced care manager advises clients on living positively and protecting their health, and protecting the health of sexual partners. Over time, the care

* Diagram adapted from O'Neil, J et al (2003) *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS*. Health Resources and Services Administration, U. S. Department of Health and Human Services, Washington DC, **and** The Center for Palliative Care Education (no date) *Palliative Care & HIV/AIDS: An Overview* (PowerPoint presentation) University of Washington, Seattle.

manager takes responsibility for ensuring the family receives guidance on succession planning for their children – drawing up wills that identify who should care for their children in the future, who will receive which property and land, and developing memory books or boxes for the children³. The care manager liaises with the community health worker or home care volunteer about ART support, managing treatment side effects, and treating common symptoms. If a patient defaults from clinic attendance, the care manager follows up with the patient in the community or seeks the assistance of the community health worker for community follow up.

Linking care and treatment with prevention to address stigma

People living with HIV can be powerful advocates for an effective response to the epidemic in the community. Once a person is comfortable disclosing that he or she is HIV infected – this may be once they are receiving psychosocial support from an association of people living with HIV or it may be once they begin to feel well on treatment – persons living with HIV can be an important resource in the community for effective prevention campaigns, for providing psychosocial support to the newly diagnosed, and educating families and communities on how they can support people to take antiretroviral therapy. Not all people who are diagnosed as HIV positive are able to become a resource in their community, but many do and they then contribute to reducing the stigma associated with HIV by their openness. The care manager or the community health worker should encourage those HIV persons who are able, to volunteer with local faith-based and community-based organizations, or to join local health office prevention campaigns, or just to raise awareness of prevention, living positively, and ART among their own friends and neighbors. People living with HIV should be accorded great respect by the local health office as local experts who know better than any health worker what they are the local drivers for risk behaviors, and the barriers to prevention and accessing care support and treatment.

About MIDEGO

MIDEGO works with partners to build capacity for developing gender sensitive policies and designing holistic programs and services that address HIV from a gender sensitive perspective. MIDEGO facilitates collaborative strategic planning and design processes, working with stakeholders including community representatives and ensuring a gender analysis of proposals and plans for HIV services and programs. MIDEGO trains program managers and implementers in community mobilization and empowerment, and coaches them in applying empowerment approaches and gender equitable practices in their work.

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References

¹ Rwanda—URC Project: *Quality Assurance Project (USAID)*

http://www.urc-chs.com/news/HIV_AIDS.htm#Rwanda (accessed March 5th, 2007)

² USAID (2006) HIV/AIDS Services at the Health Center and in the Community, RFP 663-P-06-003. USAID/Ethiopia: Addis Ababa

³ Smith, CL & R O'Brine (2000) *Memory book for Africa*. Kampala, Uganda: CLS Development Services/National Community of Women Living with HIV/AIDS in Uganda (NACWOLA). [Available from: Teaching Aids at Low Cost (TALC), PO Box 49, St Albans, Herts AL1 5TX, UK. Fax: +44 1727 846 852 Email: info@talcuk.org Web: www.talcuk.org]