• Introduction: Comprehensive care across a continuum

Comprehensive care involves a network of resources and services which provide holistic, comprehensive, wide ranging support for people living with HIV/AIDS (PLHA) and their families. A continuum of care includes care between hospital and home over the course of the illness. There are many issues that need to be addressed before continuous can be provided. There need to be adequate resources (financial, supplies, services, staff, volunteers, government and community support), and connections between them. Care must incorporate clinical management, direct patient care, education, prevention, counselling, palliative care and social support.

• Components related to comprehensive care include:

  • Clinical Management and direct physical care to PLHA and his/her family (Fact Sheets 4 & 5)

  • Education (for health workers, family, neighbours, volunteers, etc.) (Fact Sheet 9)
• Involvement of the PLHA

• Counselling (social, spiritual and emotional support) (Fact Sheet 7)

• Voluntary testing and follow-up (Fact Sheet 7)

• Adequate resources (medicines, medical supplies, linen, food, clothing, shelter, money)

• Advocacy and legal aid (Fact Sheet 6)

• Prevention strategies (Fact Sheet 12)

• Care for the caregivers (Fact Sheet 7)

• Protection and infection control (Fact Sheet 11)

• Strategies to promote acceptance of PLHA, and reduce stigma and isolation in institutions and communities (Fact Sheet 6).

Although many countries will not have adequate resources to address all these components, each country can be working toward comprehensive care.

• Sites in the continuum of care

• Home care is care given to sick people in their homes. This might include people caring for themselves, or care given by family, friends, neighbours, health and social service workers and others. Such care can be physical, psychosocial, spiritual and palliative.

• Community care is care given by people within the community. This care might be given by nurses, midwives, trained volunteers, community health or TB workers, traditional healers, non-governmental organizations (NGO), local leaders, teachers, youth groups, lay or religious leaders etc. Health centre care is given to sick people in a community health centre by nurses, midwives, counsellors, social workers, traditional healers, volunteers and other staff.

• District hospital care is given to sick people by doctors, nurses, counsellors, social workers, education services, legal aid.
**Optimal professional service allocation for HIV/AIDS care**

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<th>Human resources</th>
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**Basic principles in a continuum of care**

1. Listen to the person with HIV/AIDS and his/her family, and enable them to plan for the future (Fact Sheet 7).

2. Care can, and should be integrated with prevention to provide for a comprehensive, holistic system of HIV management (Fact Sheet 12).

3. Care-givers/institutions must not be discriminatory or judgemental in order to provide accessible and acceptable programs of care and prevention based on respect for human dignity. (Fact Sheet 6).

4. Confidentiality must be respected and basic rights observed (Fact Sheets 1 & 7).

5. Providing and making referral to counselling and other support networks is important for to comprehensive, holistic care (Fact Sheet 7).

6. Preventing HIV-related infections is cost effective in preventing deterioration of the person’s overall health status resulting in heavy costs to the health care system (Fact Sheets 4 & 5).

7. Expensive in-patient care can be kept to a minimum with available, accessible and acceptable links and referral mechanisms in a comprehensive, holistic care continuum.

8. The more involvement of the local community and its resources, the more cost effective, comprehensive and holistic is the care. Local people are well suited to provide appropriate care.

9. Many people prefer to die at home, therefore, terminal care outside hospital should be a viable option. However, adequate support will be necessary (Fact Sheet 8).

10. Staff usually need, and benefit from education (Fact Sheet 9), supervision and support. Addressing the needs of the care givers helps reduce stress amongst the staff (Fact Sheet 7).

11. In many countries, people with HIV/AIDS and their families are good advocates and a useful resource in planning and providing comprehensive, holistic care.
Integrating HIV prevention and care

It is important to combine care with education and prevention strategies. Listening to and learning from the affected person/family is a vital component of care (Fact Sheet 7). Counselling services, sexually transmitted disease (STD) clinics, maternal child health clinics and other health and social services can play an important role. In this way, voluntary testing and counselling, education about risk behaviours, and the distribution of condoms is possible. Such activities should be combined with counselling, clinical management and physical care. It is important to build on the care that people already provide for themselves within their communities. Incorporating and strengthening existing programs such as cancer care or care for the chronically ill are important strategies.

The figure below provides a visual representation of a conceptual framework of comprehensive care across the continuum.

• **Steps in linking services across the continuum**

1. **Assess the level and type of need**
   What are the reported numbers PLHA with HIV related illnesses in your area? Refer to records in local hospitals, antenatal, STD or TB clinics where HIV testing has been carried out. If available, check the national HIV data base. If this information is not available, while maintaining the need to respect confidentiality, make an assessment yourself by observing and discussing these numbers with various community groups.

   What are the local attitudes towards AIDS? How are PLHA viewed by their families and communities? What do PLHA and their families need? Often their needs are financial and material support such as lack of jobs, money, food, clothing, shelter, water, transportation, and medicines. Other major needs might include medical care, emotional and spiritual support, and education about HIV.

   What care is already being provided? What is the impact on health services and staff? What are the trends for outpatient attendance, hospital admissions and bed occupancy rates? Are staff experiencing difficulty related specifically to HIV care?

   What referral problems exist between hospitals and community health facilities?

   Are appropriate medicines available at the relevant sites of care? What are the most commonly used medicines for treating HIV related infections? Who would pay for the medicines? Are their adequate supplies of condoms and other household and medical supplies?

   How are HIV related illnesses treated in the community? Who treats the PLHA, in what manner?

   How is contact maintained with people diagnosed with HIV and later discharged? To what extent are counselling and testing available and being used?

   What community services already exist? Could they be expanded or further utilized to include care for the PLHA?

   Could care for PLHA be incorporated into the care of people with other chronic illnesses?

   Could links be improved with STD, family planning, TB, maternal/child health services or other social services?

   What other services are there in the community? Are NGOs providing care, prevention, education or counselling?

   This list of assessment measures might be too much for the isolated nurse/midwife. However, it is important to consider as many of these questions as possible within your region.

2. **Developing strong referral systems**
   Setting up a workable structure will require co-ordination with the hospital, clinics, voluntary and confidential counselling and testing and other support agencies (government and non-government). A good referral system is important between hospital, home, clinic and other people and agencies (eg. traditional healers, community health workers).
3. Staff and training
It is important to train community health workers and others in the care and prevention of HIV. This training can include management of common illnesses such as skin rashes, diarrhoea, and how to train family carers in basic nursing and home care (Fact Sheets 4 & 5). It might also be important to provide them with the basic essential medicines and supplies. These community health workers can be important to the team as they have first hand knowledge of the community.

4. Wider involvement
Make strong community links by using established structures:
• organize meetings and workshops with local healers. These gatherings provide valuable opportunities for sharing knowledge and perceptions about HIV/AIDS, the roles for healers in prevention and care, infection control, and referrals to hospitals and clinics
• meet with local NGOs and community leaders including religious and traditional organizations to discuss their perceptions of the epidemic and possible ways to support families and provide community education
• develop and maintain close links with staff from other agencies, education and welfare departments, including social workers, counsellors, and others working with PLHA and their families.

5. Counselling
Emphasize the importance of ongoing counselling, not just before and after HIV testing. It is important to combine care with emotional support and education on HIV prevention and infection control. Ideally, all staff need training in basic counselling skills (Fact Sheet 7). Also, referral systems should be maintained with the hospital based counsellor.

6. Care at home
Visits by the home care team are valued by PLHAs and their families for medical care and advice. Transport to hospital (where available), emotional support, education and help with basic needs (food, shelter, supplies) are also important. One of the most important issues is money. Sources of income (eg. welfare departments, NGOs, starter grants for income generation) should be investigated and a list provided. It is also important that, when the family is unable to cope, PLHA who are critically ill, are referred to hospital if at all possible. However, many patients choose to die at home, so counselling (Fact Sheet 7), palliative care (Fact Sheet 8), and practical support for the PLHA and his/her caregivers is very important. Help might also be required after the PLHA has died, and could include emotional support, instructions on how to safely prepare the body, and funeral arrangements. (Fact Sheet 8).

7. Care costs
Sufficient resources need to be allocated in order that the continuum of care programme to be sustainable in the long term. Although training community volunteers can reduce some long term costs, consideration must be given to costs associated with on-going training and supervision (Fact Sheet 9). Direct costs to the family, such as payment for medical and traditional treatments, extra food and other items, should also be taken into account. Other costs, some of which are less easy to measure include: loss of earnings, loss of agricultural productivity, and the additional workloads put on women and girls.
8. Programme monitoring

Indicators for measuring the success of the continuum of care efforts need to be established at the start, and team members need to keep accurate records in order to assess the quality of care. A successful continuum of care involves using existing services appropriately so that the PLHA can use the site and service to best suited to their health and/or social service need. Team members may wish to monitor the following indicators of quality of care:

- number of PLHA accessing resources in the continuum of care
- number of referrals
- number of PLHA who use the appropriate site to fit their health/social service needs
- types of linkages between resources and services
- number of drugs, medical supplies and condoms distributed
- changes in hospital attendance
- changes in community attitudes
- the number of PLHA sharing news of their diagnosis with family/friends
- satisfaction with treatment
- support for the PLHA and his/her carers and health care workers
- volunteer training given

• Continuum of care checklist:

Does the district plan or the review consider:

- ✓ Comprehensive care policies and guidelines for (a) clinical management, (b) nursing care, (c) counselling and voluntary counselling and testing, and (d) social support?
- ✓ Resource mobilization across the continuum of care to provide (a) discharge planning, (b) referral networks, (c) government/NGO links, and (d) community support to PLHAs and caregivers?
- ✓ Integration of HIV/AIDS care with existing services such as (a) in- and out-patient care, (b) health centres and dispensaries, (c) tuberculosis, sexually transmitted disease and maternal/child and family planning clinics?
- ✓ Prevention intervention as part of care by (a) counselling partners of PLHAs, (b) supplying condoms, (c) educating family members, and (d) stimulating support groups among PLHAs?
• **Questions for reflection and discussion**

How can a continuum of care be implemented in such a way that services are provided for the PLHA and his/her family where they are most needed?

How can prevention and care be integrated across the continuum?

How can the PLHA, the family or caregivers be directly involved in planning care?

How can stigma and fear of HIV be addressed? What can you do to help change people’s attitudes?

What strategies do you consider to be necessary to sustain a continuum of care model?

How can you ensure that patients are linked with other services and referred to other care options when necessary?

If you are working in a situation where you have little support, how can you contribute to the continuum of care?

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**References**

Allocating Resources. AIDS ACTION Newsletter, (38), AHRTAG, 1997.


