

I. COMPREHENSIVE MANAGEMENT OF PERSONS WITH HIV INFECTION

THE NEEDS-BASED APPROACH TO PERSONS WITH HIV INFECTION

The moment that an adult or child is *suspected* of having HIV infection, the issue of his/her care and management is thrust into the spotlight. The responsibility for providing care is usually shared by the professional team, the community, and the patient; there are moments when the balance of responsibility lies solely in one quarter, but in other times, there is considerable overlap. Regarding the care of persons living with HIV/AIDS (PLWHA), the concept of a continuum of care is most useful and applies to that which starts at home or in the community and expands to the clinic, doctor's office, or hospital. As such, best practices in comprehensive care are achieved through a team approach; ideally, this team and its resources are carefully planned.¹

Most essential is good communication between the professional and nonprofessional team members, and mutual understanding of roles, responsibilities, and relationships are an integral part of this communication. Excellent communication between all parties becomes vital especially when the patient is receiving antiretroviral drugs (ARVs), for they must be continued without interruption. Change in rural Haiti is an example of a best practice in such a situation; there, patients choose trustworthy persons from the community to serve as *accompagnateurs* who complete regular, direct observation and documentation of the patients taking their medications.

The first meeting between the healthcare professional and the patient is often at the request of the patient, the family, or a concerned friend. From the first moment of meeting, the professional must focus on beginning a cooperative partnership with the patient, for what often begins is a process of negotiation between the professional caregiver and patient. From the caregiver's perspective, the primary objective of the partnership is adherence--not just to drug treatment, but to further clinical and laboratory investigations and to any necessary aspects of lifestyle change.

Building trust between these parties is paramount, because the validity and reliability of communication depends squarely on trust and trustworthiness. Furthermore, optimal care is based on optimal communication. Understanding the patient's mental and emotional status is vital to the success of communication and, by extension, to the success of treatment. The healthcare worker must also get a clear picture of the patient's circumstances, including employment, economic status, and social support network. For example, in some larger Caribbean countries, the cost of transportation to and from the health clinic or hospital is prohibitive,² absorbing monies usually devoted to investigations and therapy. Or, a patient living on the street may be less adherent to medications than someone who has a home. Hence, the best care plan for each patient must be formed from the clearest appreciation of the patient's circumstances.

¹This article assumes that family members, friends, front-line healthcare workers, and others in the support team (e.g. pharmacists, laboratory personnel, and administrators) have positive attitudes toward PLWHA. The care that the patient experiences is proportional to these individuals' knowledge, but it is also heavily dependent on their attitudes. Willingness to give care and the degree of interest and concern are usually evident by general deportment—therefore, it is imperative to maintain a helpful and caring attitude at all times.

²This problem is obviated if funds have been provided to cover these costs, as is true in some situations.

Many needs of PLWHA are identical to those of persons with other illnesses, but because of the aura and stigma that often surrounds HIV/AIDS, the patient and the family may have additional requirements as outlined in the following tables.

Table 1: Medical Needs of PLWHA*

Access to health team
Means of transport
Medical monitoring (e.g. interviews, examinations, laboratory tests)
Patient education
Nutritional plan of action
Dietary and/or nutritional supplements
ARVs and drugs for opportunistic infection (OI) prophylaxis and treatment
Provision of condoms, when necessary
Crisis care and terminal care
Education of significant others (e.g. knowledge, skills, attitudes)
Supervision and supplies for caregivers at home, hospice, or hospital
Response to special needs

*Adapted from a multidisciplinary focus group.

Table 2: Counselling[&] Needs of PLWHA[†]

Pre- and post-test counselling
Individual and group support for counselling concerning general life issues
Counselling regarding interpersonal relationships, sexuality, and sexual issues
Spiritual counselling
Discussion and clarification of issues related to personal and family confidentiality
Counselling and support in preparation for dying, and when necessary, including arrangements for children

[†]Adapted from a multidisciplinary focus group.

Table 3: Counselling[&] Needs of Family and Friends of PLWHA[°]

Education about HIV, including reassurance about personal safety in long-term social contact situations
Emotional and spiritual support
Bereavement counselling

[°]Adapted from a multidisciplinary focus group.

[&]A Special Note on Counselling

The purposes of counselling include: clarifying information related to the disease, helping the client manage new circumstances, expressing negative and positive emotions, adjusting lifestyles, setting realistic personal goals, and identifying and using available support systems. The client

may be a PLWHA; a contact of the primary case; someone who may suspect, rightly or wrongly, that he/she is infected; a healthcare worker; or a family member or friend of a PLWHA.

The type of counselling described here is not synonymous with giving advice. Talking to a person or talking at a person is often not enough to change his/her behaviour. Listening with empathy and discerning the facilitators and obstacles to behaviour change are a starting point to what is often a difficult process for the HIV-positive person. The changes that should occur in the person are often multiple and long-term, requiring external support. The doctor or nurse alone may not be able to bring about these changes.

Counselling may be carried out at many levels, sometimes by laypersons and at other times by professionals. Professional counsellors are few in most Caribbean countries and, at the time of this writing, there are even fewer of these persons in the region with training or experience in issues related to HIV/AIDS. For this reason, the best substitutes must be engaged in this area of counselling while the pool of professionals grows.

Table 4: Self-Care Needs of PLWHA*

Physical and mental: <ul style="list-style-type: none"> • Keeping physically fit • Maintaining the best possible nutrition • Living a balanced life including work, rest, recreation, and sleep • Good personal hygiene and sexual safety in order to avoid unnecessary contact with infection
Social
Economic and financial
Spiritual

* Adapted from a multidisciplinary focus group.

Table 5: Social Support Needs of PLWHA†

Companionship
Legal advice and services
Employment
Income-generating activities
Occupational therapy
Cash and kind for short-term support
Food and shelter
Means of transport
Child welfare
Involvement in community life

† Adapted from a multidisciplinary focus group.