Health Workers in the Frontlines of the Aids Crisis

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Summary

The role of the health worker in AIDS education and in counselling of the AIDS victim in South Africa is discussed. A model of counselling intervention is proposed as well as the requirements for an effective counsellor.

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Curriculum vitae

Dr Betty Livingstone studied at Wits where she obtained an Honours degree in Social Work. She then obtained a MA from Ohio State University (USA) and a PhD from the University of the Witwatersrand, Johannesburg. Dr Livingstone has been a Health Worker in South Africa, Toronto and Atlanta (USA). She is currently a lecturer in the School of Social Work at the University of the Witwatersrand, and on the Editorial Collective of 'Critical Health'. She also co-ordinates an honours level and higher diploma course in Educational Social Work. During 1987/88 she was able to visit Britain to research Aids and the psychosocial implications of the disease.

With the steady growth in the number of AIDS victims and HIV carriers in South Africa, health workers – whether they like it or not – are becoming increasingly involved in the front lines of the crisis. Because of their specialized knowledge and skills, their commitment to the promotion of human welfare and their specific focus on people in transition with their environment, health workers are uniquely suited to respond to the personal and professional challenge of AIDS.

In order to respond to this challenge, the traditional roles of health workers may require modification. As well as being providers of medical intervention or emotional support, they will have to become educators and counsellors.

In South Africa we have a Third World situation, characterized by poverty and ignorance. Amongst our population there is little knowledge of what AIDS is, or of how it is transmitted. Often victims cannot afford treatment, since medical costs are exorbitant even for middle-class professionals. The Hudson Institute of America has pointed out that the incidence of AIDS relates to the socio-political environment, in that the poor are less likely to have access to education that would enable them to change their lifestyle and thus avoid the disease. "The disease may make certain ghetto areas ungovernable by the mid 1990s, with a corresponding upsurge in despair and anti-social behaviour and the refusal of health workers to risk their lives by entering these areas."[1]

In South Africa, it is necessary to be aware of the problems brought about by the migrant labour system. Some 4 000 migrant workers[2] have been identified as HIV carriers. The system of single-sex accommodation gives rise to prostitution and homosexuality. Van Vuuren[3] claims that promiscuous males and prostitues make up the majority of carriers. Jochelson and Leger[4] point out that partners of South African mineworkers who are left at home seek new sexual relationships, and so the vicious cycle continues.

Victims need very practical help on ways to change their lifestyles

In the more affluent sectors of our society, a considerable number of people, both heterosexual and homosexual, lead sophisticated international lifestyles, and are becoming part of the high-risk group because of their sexual patterns and use of drugs.

Unfortunately the AIDS crisis lends itself to the expression of prejudice and discrimination. Whites tend to think it is an African disease, while Blacks think it is spread by homosexual males. Indians tend to think that 'Coloureds' and Blacks are more likely to contract AIDS. The truth is that AIDS is not confined to any one group or class.[5]

Extensive AIDS education programmes and sound social management are imperative to help curb the spread of the HIV virus; to reduce ignorance, fear, panic and moral hysteria and to help combat prejudices and unjust practices.

1. AIDS and HIV counselling

Rogers[6] emphasises the need for counsellors to have a thorough **understanding** of the problems of those who seek their help, as well as the ability to empathize with their emotional states. This is particularly relevant when providing **support** for AIDS sufferers, who undergo severe psychological, emotional and social trauma. In addition, the health worker will be required to perform an **educative** function, both on an individual and a social level.

Education

Sexually active people must be assisted in understanding AIDS so that the spread of the disease can be prevented. It is vital that people have information on ways to change their behaviour in order to protect themselves and others. A recent article in the Morbidity and Mortality Weekly Report[7] points out that the virus is transmitted almost exclusively by behaviour that individuals can modify. As there is currently no cure for the disease, this is the best hope.

Suggested Educational Programmes

An appropriate education programme could aim at:

* providing basic medical information about AIDS and HIV – how it is transmitted, who is at risk, etc.
* promoting safe sex, thereby combatting ignorance and prejudice.[8]

Programmes should be designed for schools and workplaces. This would entail workshops, media campaigns, presentations at various institutions and the setting up and running of advice bureaux.

Effective Campaigns would need to

i) ensure that the scope and content of AIDS education is locally determined and consistent with community values;
ii) obtain a broad community participation;
iii) be consistent with the needs, age, educational background, etc of the target audience.

The US Department of Health and Human Services suggests[7] that the state departments of Health and Education should work together to accomplish effective school education about AIDS. They suggest that a team of representatives, including local boards, parent-teacher associations, school administrators, school physicians, nurses, teachers, educational support personnel, school counsellors and other relevant school personnel should receive general training

The virus is transmitted almost exclusively by behaviour that can be modified

about (a) the nature of the AIDS epidemic and means of controlling its spread; (b) the role of the school in providing education to prevent transmission of HIV; (c) the methods and materials to accomplish effective programmes of school health education about AIDS; and (d) school policies on children or staff who may be infected. There should be continued, up-to-date information about the most effective health education intervention strategies available.

Support

The other aim of counselling is, as Miller puts it, "To prevent and manage the psychological morbidity arising from the fear and knowledge of HIV infections"[5]. Individual counselling is vital in view of the high risk of psychological disturbance and suicide.

2. Stages of counselling intervention

Two stages of counselling intervention may be necessary: **pre-test** counselling of potentially HIV-infected people and **post-test** counselling of infected people and those close to them.

Pre-test counselling

At this point the nature and purpose of the test is explained. A sexual history is taken and the likely risk of infection is assessed. Most important, the person is prepared for the possibility of a positive test result.

Post-test counselling

The period immediately after the person has been diagnosed as seropositive is usually characterized by shock, anger, fear, depression, sexual dysfunction, despair and social trauma. It is a period of 'ventilation' when crying and hysteria are common. It is best for the person not to be left alone as suicidal impulses are likely.

It is also advisable that the person does not tell anyone of his or her condition at this stage, as the reactions of others could be even more damaging. Not only does the sufferer experience profound shock, guilt and despair, but he or she also has to face the possibility of the breakdown of important relationships, the loss of employment, exclusion from social networks and even from insurance policies and medical aid schemes. The staggering cost of medical care, if it is available, has to be confronted. The person may be victimized and ostracized, not only for having AIDS, but also for being gay. He or she becomes increasingly alienated as friends and family members begin to back off. Crisis upon crisis has to be faced while the person's physical condition deteriorates.

The worker who gives the test results will also be under considerable stress. Martha Winter Gross[9] gives an account.

'His birthdate was in 1963, making him 24,

not much older than my own son. He nervously sat down, then looked up at me expectantly and hopefully ... Why didn't my years as a psychologist and a professional counselor make this new role any easier? ... At moments like this, I can't help but feel like an executioner. How can I delay or soften the "bad news"? ... As I gathered my courage to tell him that his test had come back positive, he covered his head and began sobbing like a child ... I could only encourage him to let his feelings out as I felt my own tears of helplessness. Finally, he looked up with terror in his swollen eyes and just stared at me, numb from his fear and anger ... I was stung with the helplessness of not knowing how to take the pain away.' (p.14)

A great need for school personnel to be properly informed

After the initial crisis period, follow-up sessions are required in which various issues are discussed: safer sex, the domestic situation, occupational and recreational arrangements, infection control or 'health-boosting'[5] and the problem of who to tell and how to tell them. The sessions may involve a partner, but it must be remembered that these people often have a higher and more chronic level of psychological morbidity than that of the sufferer. Continued support is essential.

Long-term Issues

There are certain long-term issues that the AIDS victim has to address. The first of these is of an existential or spiritual nature.[10] The person may question why he or she, in particular, has been infected, and go on to question the purpose of his or her life. The person will try to bring meaning to the present situation and will often turn towards religion.

A high risk of psychological disturbance and suicide

The person may also have to face the break-up of a close relationship. If the person has not been in a monogamous relationship, there is the question of how to begin a new one or of how to approach the subject of safer sex. If there have been numerous or anonymous sexual partners, the person's lifestyle will have to alter radically.

Past issues may re-emerge. For example, an infected person may have been an 'in-the-closet' gay. Now he has to face the reality, not only of his infection, but of admitting to himself, his family and his friends that he is, in fact, gay.

Sometimes people may resort to drugs and alcohol. This obviously hinders the counselling process.

Possible Outcomes of Counselling

Grant and Anns[10] classify the possible results into three groups:

- The person takes control of his or her life. With potentially less time to live, the person makes the most of it and the quality of life improves. He or she may become extremely health-conscious or religious.
- The person lacks control over his or her health and behaviour and becomes increasingly obsessed with getting ill.
- The person fails to cope and may commit suicide. Intensive psychiatric and psychological intervention is necessary.

3. Model for effective AIDS and HIV counselling

Miller[5] makes the important point that AIDS and HIV counselling cannot succeed without active liaison with community support agencies. These agencies should provide practical help such as ongoing housing, as well as back-up counselling. The links must be kept open and flexible.

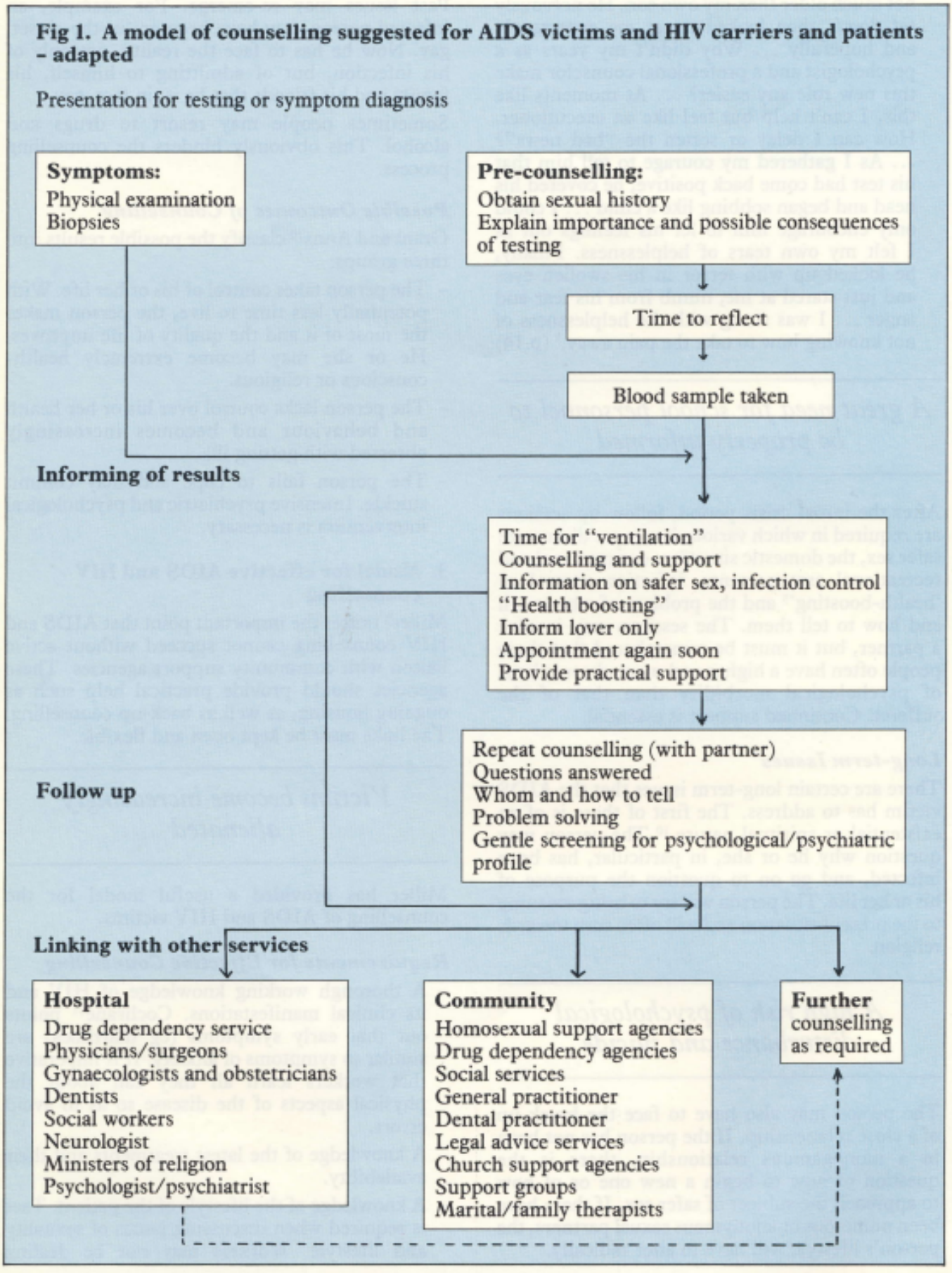
Victims become increasingly alienated

Miller has provided a useful model for the counselling of AIDS and HIV victims.

Requirements for Effective Counselling

- A thorough working knowledge of HIV and its clinical manifestations. Cochrane[11] points out that early symptoms (eg diarrhoea) are similar to symptoms of anxiety. It is imperative that workers learn all they can about the physical aspects of the disease so as to avoid errors.
- A knowledge of the latest treatments and their availability.
- A knowledge of the lifestyle of the patient. Tact is required when discussing issues of sexuality and lifestyle. Workers may not be dealing

Fig 1. A model of counselling suggested for AIDS victims and HIV carriers and patients – adapted



exclusively with AIDS and HIV infected people, but with a growing population of the worried well and the as yet unworried and still promiscuous. In such cases, the worker becomes a sex educator and therapist. It is vital to speak openly and frankly about sex.[12] Negotiating safer sex can often be difficult, and the workers may have to advocate complex behaviour changes in small steps.

- A thorough knowledge of back-up and referral services.
- An ability to recognize common psychosocial and clinical complications arising from the HIV infection, eg anxiety, depression, obsessive disorders, neurological indications and suicidal risk.

The worker must also have the counselling attributes of empathy and unconditional positive regard as well as being non-judgmental. Even more crucial is the possession of relevant information and genuine interest.

The Worker's Involvement

Many health workers feel frightened and vulnerable when working with AIDS victims. Their families may also be anxious and may put pressure on them not to be involved. However, with a clear knowledge of how AIDS is transmitted, the worker is not at risk. Even if a situation arises where the worker has to clean up body fluids, eg vomit or spilt blood, protective gloves may be used with ordinary household bleach which will kill the virus.

In the US, public health regulations prohibit care providers from refusing to treat AIDS victims. The worker should be aware that, through fear, hospital staff are reputed to ill-treat AIDS patients. If the patient is hospitalized, the worker should ensure that the patient's needs are being met.

. . . the break-up of a close relationship

Another vital issue is confidentiality. Owing to the tremendous stigma and victimization attached to having AIDS, it is imperative that the worker keeps his or her knowledge confidential. However, there is much controversy over a situation in which a client who is HIV positive is still having sex with a partner or partners who may be unaware of their infection. Does confidentiality take precedence? Does one have a duty to warn those who are unwittingly at risk? There are obviously no hard and fast rules concerning this but workers must be aware of the potential problem and as David Miller suggests,[5] it might be best to handle such an issue case by case.

Towards a Service Approach

The most widely accepted approach to counselling is non-directive and client-centred. With AIDS or HIV counselling, such an approach no longer seems relevant. Cochrane[11] states that, although asking about sexual practices and giving advice may be intrusive, the worker has a 'duty to warn'.

As the physical condition of the sufferers deteriorates, they become exhausted and may lose lucidity. Decision-making and problem-solving,

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. . . speak openly and frankly about sex to school children

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as advocated in a crisis model of intervention, become inappropriate. The worker has to take on more responsibility, make more decisions and be more directive – but not at the cost of the person's autonomy.

The crisis model fails to allow for the unique nature of AIDS. It is not a crisis that is insurmountable for a limited time because the person lacks coping and problem-solving capacities. Because death is inevitable, yet ironically unpredictable, there is no possibility for sustained problem-solving. Instead, the person's total defensive and coping strategies are progressively revealed and tested. Over time, AIDS comes to represent a 'challenge to survival, growth and mastery of self expression'.[13]

Health workers are often caught in a powerful dilemma. On the one hand they have to support the patient in overcoming the immediate crisis; this can usually be handled with some degree of problem-solving together with provision of support services. On the other hand, the worker has to prepare the patient for death, which may occur at any time. 'The balancing of these tasks, which connote both hope and hopelessness, within a tight frame, is the reciprocal burden for the patient and the worker.'[13]

Having shown that the crisis model of intervention is inadequate, Lopez and Getzel[13] propose a service approach to counselling. The worker first responds to the emotional and material needs of the AIDS victim and then arranges social supports, in collaboration with kin and friends.

A service approach has the following objectives:

- *providing material and supportive services* which permit AIDS sufferers maximum access to the community;
- *linking sufferers* to close family and friends;
- *maximizing sufferers' choices* about the type and provision of care available to them;
- *preventing and challenging* incidents of abuse, neglect, or prejudice from health care, social service, and other organizations;
- *preparing* sufferers practically for life-threatening events and for death;
- *supporting* sufferers during periods of guilt and self-doubt and helping them to come to terms with their lives and approaching deaths;
- *providing some degree of societal concern* (even when it may be missing in other areas of their lives) to counter social and existential loneliness.

The accomplishment of these objectives requires the systematic training of volunteers and professionals. Follow-up supervision and mutual support groups are used to pursue problems experienced by volunteers.

The service approach works in phases:

Phase 1 - Engagement and assessment

Initially, the worker engages the sufferer in a non-confrontational manner. He or she must allow for emotional expression on **the person's own terms**. The worker may assist with household tasks or management but the person's control and choices must be maximized.

Phase 2 - Supporting autonomy

The worker is concerned with the **person's problems as they arise** but never lets the person feel helpless as this will lead to further depression.

Phase 3 - Explaining the importance of a good relationship and the implications of AIDS

A **trust** develops between the worker and sufferer. The worker's motivation is likely to be questioned, because the sufferer doubts the worker's acceptance of him and his condition.

Phase 4 - Supporting the patient.

Indirect recognition of death

As the sufferer begins to 'reflect' on the past and talk of the future, the worker must be neither overly optimistic nor fatalistic. The person may be asking for **confirmation of life-decisions** made in the past and attempting to give meaning to the current situation.

Phase 5 - Monitoring and maintaining health needs

Health care becomes vital. If the person is hospitalized, the worker should see to it that their requirements are met.

Phase 6 - Supporting close relationships and group work

As death approaches, the sufferer may find it necessary to **reconnect with significant others**. The worker must assist, as well, in tasks such as will-writing.

Phase 7 - Caring and advocacy for the dying patient

Physical decline at this point may be rapid but the worker continues to support the patient, advocating dignified care. Finally, the worker may help organize funeral arrangements.

It is important to note that a person will benefit most if all providers of health care and social services work co-operatively.

4. Some support services in South Africa

- HIV Clinic, Johannesburg Hospital, Jubilee Road, Parktown (011) 488-4911
- GASA 6010 Counselling Service, Cape Town (Gay Association of SA) (021) 21-5420
- GAB Counselling Services (Gay Advice Bureau) (011) 643-2311; (031) 22-1788.
- AIDS Training and Information Centre (011) 725-0511.
- Centre for Applied Legal Studies (for legal advice) (011) 716-5678.
- AIDS Action Group (for information and education only) (011) 404-3600; (021) 21-5420.
- AIDSLINE, Department of National Health and Population Development:
  - Southern Transvaal: (011) 836-2232
  - Pretoria: (012) 325-5100;
  - Western Cape: (021) 97-8151;
  - Natal: (031) 305-6071;
  - Eastern Cape: (041) 22541;
  - OFS: (051) 472194;
  - Northern Cape: (0531) 29524;
  - Northern Transvaal: (01521) 6541.
- IHRG (Industrial Health Group), Department of Sociology, UCT, Private Bag, Rondebosch, 7700. (021) 650-3508; (021) 650-3720.

5. Further areas for AIDS counselling

Several areas have not been addressed in depth. These include the problem of women and children with AIDS or who are HIV infected. This has specific relevance for Child Welfare workers in adoption and foster care. Workers are faced with the dilemma of how and with whom to place such a child, how to counsel the parents and whom to tell of the child's condition.

Education programmes as primary prevention must begin in schools. Street children and runaways are also high-risk groups that must be dealt with.

So much in-depth research is being published almost daily, that it is beyond the scope of this paper to deal with all aspects of this dynamic area of concern.

Conclusion

This article has sought to cover the health worker's role in AIDS education and in the counselling of the AIDS victim in South Africa. The health worker, with his or her special clinical skills and knowledge of community services, can play a vital role in helping AIDS victims and those close to them. Support of the patient's family system, and community facilities can be networked and used to assist AIDS victims.

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