

Counselling people affected by HIV and AIDS

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Abstract

AIDS has challenged several aspects of contemporary social life and conventional approaches to health care. The social and medical responses to diseases have probably not been challenged so intensely for a long time. One social response to HIV/AIDS that has received much attention is the counselling of people affected by the disease. This paper reviews pertinent issues that must be considered when counselling people who are affected. These are discussed from the point of view of goals of counselling derived from two different counselling situations: counselling for the prevention of transmission that addresses both infected and non-infected people and counselling for the provision of psychological support for those who are affected. Counselling in HIV/AIDS care is unique but there are similarities and differences between counselling in HIV/AIDS care and counselling for general health promotion. Some of the problems associated with HIV/AIDS counselling in Nigeria are presented and some ways of dealing with them are suggested.

The meaning of counselling

To counsel means 'to advise, to recommend, to advocate, to exhort, to suggest, to urge' (*Oxford Dictionary* 1996:131). However, counselling as a concept, as observed by Miller and Bor (1991), has many interpretations. Whatever its goals, counselling is directed towards assisting people to take decisions, to effect a change, to prevent problems or crises or to manage them when they arise. Hopson (1981) thus, from a problem-solving perspective, saw counselling as helping people to explore problems and clarify conflicting issues, and to discover alternative ways of dealing with the problems by taking appropriate decisions and action.

Counselling for health promotion

Interpretations of the term 'health promotion' may vary, but in general, the function of health promotion is to help people take responsibility for their health and adopt a lifestyle conducive to good health, to promote behaviour which leads to quick recovery from illness, and to enable them to cope with dying.

Counselling for general health promotion, the avoidance of diseases, is both individualistic and group-oriented and usually considered an essential component of public health. The emphasis is on adopting what are considered good 'health habits'. Issues considered include good personal and environmental hygiene, good nutrition and safe drinking water, adequate exercise, relaxation and rest, and avoiding high levels of stress and health-risk behaviours such as smoking and excess alcohol consumption. These issues can be discussed openly and without fear of isolation or stigmatization.

Counselling to help a client attain quick recovery during an acute illness, however, usually incorporates more focused information about meeting needs specific to the particular

illness. This is often rewarding for the counsellor as the time during which the client is intensely dependent is shorter than that required to manage a chronic illness. When the disease is not life-threatening, stigmatizing and expensive to manage, although it may be chronic, there are fewer demands and less stress on the clients, their significant others and the counsellor.

Counselling for general health promotion is consistent with efforts to promote ideals of the infinite self through actions that are not too probing to the self. It is generally amenable to open discussion and to the adoption of actions which others in the society consider will equally promote their own health. Emphasis is on helping clients adopt actions that are consistent not only with enhancing the quality of life but also with increasing life expectancy. With counselling for socially accepted, non-stigmatizing illnesses, the emphasis for the client, the family and the health care workers must be on the whole person. Counselling for general health promotion emphasizes those things controlled by the clients and their social group, with assistance from the state, which enhance self-preservation and thus reduce morbidity and postpone mortality. Counselling for HIV and AIDS, however, is more complicated since HIV-positive people face difficulties arising from the nature of the disease, the way it progressively affects and consumes the biological self, and the difficulties that arise from the social perception of the illness and the people affected by it. As well, it causes strains in social relationships. Probably the biggest problem in meeting the needs of people with AIDS is that they must accept impending death while the health care model makes consistent and rigorous efforts to increase life expectancy. This is why AIDS counselling is different from other forms of counselling in general health and disease management. What then is AIDS counselling?

AIDS counselling

According to the World Health Organization, AIDS counselling is a confidential dialogue between a patient and the counsellor or care provider aimed at enabling the patient to cope with the stress and to take personal decisions relating to HIV infection and AIDS morbidity and mortality (WHO 1995a). Counselling in HIV/AIDS care is an interaction of information exchange, skill acquisition and emotional support between the counsellor, the person infected with HIV and others significant to the client who include family members, friends, health practitioners, employers and people who give spiritual support. The interaction is directed at meeting the physical, psychological and socio-economic needs of the client to enable him or her to attain optimal physical, mental and social health and functioning: to provide continuous support and to prevent HIV transmission to others. Counselling not only assists people who already have the infection to cope with the consequent problems, but also evaluates the risks of HIV transmission and facilitates behaviour to prevent further infection. Counselling in HIV/AIDS means giving information, facilitating risk reduction behaviour, and providing unconditional emotional support to the people affected.

Reasons for specialized counselling

AIDS counselling is different from other forms of care. The disease is not only a health problem with diverse consequences for an individual, but equally a problem for the family and society; it is also associated with intense and progressive human suffering which arouses diverse emotional reactions. Such reactions include fear, denial, loss, grief, anxiety, anger, rejection, isolation, annoyance, blame apportioning, pity, self-condemnation, depression and suicidal thoughts (Moynihan 1991; WHO 1995b). It is not only the clients who go through the grieving process but every person in their social network. Managing the disease involves

personal issues and often requires talking about things that are dreaded and aspects of life ordinarily considered very private. The uncertainty about several aspects of life was noted by Miller and Bor (1991). These are concerns about whether AIDS will develop and whether family and friends will reject the person infected. There will be doubts about their willingness to give support and about the availability and usefulness of treatment and the course of the illness. Other concerns are related to myths and lack of complete knowledge about the disease. The clients may be very fearful of the social attitudes that question their self worth and may bring scorn on the family. HIV also brings anxiety about possible family conflicts and problems concerning work and finance as the disease progresses. There may also be problems with friends, problems about meeting basic life needs, problems derived from sexuality and sexual relationships, changes in body image and anxiety about dying and death. AIDS counselling is different because the disease is accompanied by concerns that are not associated with other diseases, however severe; it is still a highly controversial disease with many facets: personal, social, political, legal and religious. Human rights, public health and many more aspects are involved in coping with it. Miller and Bor (1991) summarized the uniqueness of the particular counselling needs of people with HIV/AIDS. They noted that the disease has no cure, it is infectious and the most at risk are the young in the prime of their productive, active sexual and reproductive lives. The disease is almost always fatal, there are periods of acute illness and the end-stage is one of chronic illness which results in bodily changes, including changes in appearance. The terminal nature of AIDS challenges the illusion of immortality of the young. Associated with this are the practical, psychological and economic adjustments that have to be made by everyone affected. Again, there is the fear of so many uncertainties. HIV/AIDS is associated with incomplete knowledge and often with conflicting information. Significantly, definitive co-ordination of care is needed because of the many persons who are involved. Service provision as effective patient management can prevent many problems and enhance the quality of the patient's life.

Looking at the process of AIDS counselling, WHO affirms that it is a confidential, personalized process, until the client decides otherwise. The process involves reacting to the client's needs through conversation, without being didactic. It must be empowering and should help the client take decisions that will affect not only his or her life but those of the significant persons, especially the members of the family.

Counselling in HIV/AIDS is not only to protect and help clients, it is also meant to protect the other members of the family and community as clients are shown their role in preventing infection and in contributing to the general control of the disease.

The factors that make HIV infection and AIDS unique make necessary specialized counselling which according to Miller and Bor (1991) should provide personalized information and give social and psychological support focused on strengthening the client's sense of responsibility. The client needs this help to accept and benefit from new information which can enable the adoption of changes in lifestyle. Counselling should help the patient to define the problems that accompany the disease, and enable the persons concerned to make realistic decisions on how to reduce the impact of the disease on the patient and significant others. It should help people to acquire knowledge, skills and attitudes as well as the confidence to make the necessary lifestyle changes that facilitate preventive and therapeutic behaviour. This becomes particularly useful in resolving anxiety about relationships, intimacy and sexuality. Counselling should also help clients to accept the uncertainty of their future and objectively analyse such feared issues as illness and treatment, pain and separation from loved ones by death. Clients can also be helped to understand beliefs, religion and views about self as well as legal, ethical and human rights issues, as these are important to the clients and their significant others.

An understanding of this need for specialized counselling gives the counsellor a good base from which to adopt the most appropriate theoretical approach which will most help those who are infected and those close to them. The appreciation of HIV/AIDS as a chronic disease that has social implications and makes demands on everyone related to the person affected raises the question of who should be counselled.

People who should be counselled

Everyone needs counselling, although from different perspectives, as everyone has a role to play in care and in controlling the spread of HIV. Importantly, every sexually active person exposed to risks of contracting HIV needs individual counselling, focused on the behaviour that puts the person at risk. Counselling should be for men and women irrespective of sexual orientation; heterosexual, homosexual or bisexual. This is important for people with multiple sexual partners practising unprotected penetrative sex (now or in the past), sexual partners of these people, drug users who share injecting equipment, and recipients of unscreened blood products and donated organs, especially before the introduction of routine screening of donated blood. Others needing counselling are people who may have been exposed to infection through previous invasive medical and surgical procedures from traditional or orthodox practitioners. As well, people seeking help because of past or current sexual behaviour which has put them at risk should be given priority. Others seeking help include pregnant women who are HIV-positive, health practitioners with occupational exposure, and people who have been sexually abused, assaulted or raped. Others include people considered to be special high risk groups, such as sexually active teenagers and commercial sex workers, and people at different stages of illness from HIV infection. When traditional care-giving within the family becomes inadequate, it is time to seek the help of professionals to supplement the efforts of the family. Informal caregivers of people with AIDS are often lovers, spouses and other family members. These people stand to benefit significantly from counselling as they are prone to experience what DeCarlo and Folkman (1996) call 'compassion fatigue' or burnout from caring for a sick person for a long time or losing loved ones after a period of physically and emotionally demanding caregiving. Additionally, sexual partners who are also caregivers need counselling to encourage the adoption of safer sex practices. The fact that different types of people require counselling to achieve specific but diversified goals points to the variation required in counselling procedures.

Timing and method of counselling

Guidelines for counselling are derived from the need for primary, secondary and tertiary prevention of the spread of HIV and the need for care which will enhance the quality of life of people already infected. These guidelines also indicate when and how people affected by HIV or AIDS should be counselled. Three main times for guidance and counselling are before testing or screening; in the post-screening period; and when the client has been confirmed as having the infection. Pre-test counselling must take place before the client is screened. This provides education as well as guidance to the client. It is important that the client be properly informed before giving consent to the test so that he or she can understand the result of the test and not see it simply as a test for AIDS. This saves the health practitioner the problem of disclosing a positive result where the consent of the client had not been sought before sample collection. The client's last exposure to risk needs to be discussed in a way that will help the client understand the possible results. Also, the social consequences of the result need to be explored, bearing in mind the practical realities (McCreaner 1989; Miller and Bor 1991; Perakyla 1995). Confidentiality would be a concern to anyone contemplating having the HIV

test. The pre-test counselling session should handle this adequately, addressing the issue of who can and who cannot gain access to the results of the test. This is usually a very sensitive area, especially when the question arises of informing sexual partners or referring them for tests. These problems are discussed later in this paper. The immediate post-test face-to-face counselling session (usually very emotional when the result is positive) is not only to give the result but to address the implications to the client and the significant others. The client must be helped to understand the difference between being HIV-positive and having AIDS. His or her immediate concerns should be analysed with the purpose of advising a short-term plan of action. This requires the counsellor to discuss concerns, to ask questions and to review available care and support facilities. The post-test counselling period is a real challenge and is often emotionally demanding even for the practitioner when the client's result is positive. Other times when people affected by HIV or AIDS need counselling are when the HIV positive client is becoming ill, when the client is showing signs of AIDS-related conditions, when medical management is being considered, and when neurological impairment is manifesting. Counselling becomes indispensable whenever any form of crisis for the client or other close contacts arises. The terminal phase of the illness when the client and significant others have to contend with imminent death and all the issues involved calls for intensive emotional support by the counsellor. Bereavement counselling of persons significant to the client is also an essential component of AIDS care.

The needs assessment schedule is a good framework for the content and nature of the counselling sessions at different periods and stages of the illness. The major aims of the counselling process are information giving, promotion of risk reduction strategies and provision of emotional support. The counsellor should be able to determine which of the areas should receive the most attention depending upon the stage of the disease. Counselling sessions must give information to the person infected about the following:

1. Taking care of self: the client must get to know more about the infection and should be assisted in adopting attitudes, beliefs and actions which will protect the body's immune system (Lindsay, Fevens and Gee 1996).
2. Enhancing, improving and modifying nutrition as necessary.
3. Promoting physical fitness and rest.
4. Avoiding substances, events and actions that threaten the body.
5. Reducing stress and strain that compromise the physical, mental and psychological welfare of the body.
6. Seeking and giving support for self care.

The caregivers, as well as sharing knowledge from the identified areas listed, need guidance on caring for people with the disease, coping with changes and managing resources. They also need help to manage the stress that may arise in their caring for persons with HIV/AIDS. The caregivers should at all times direct their counselling towards enhancing positive living, meeting the medical, social and emotional needs of the client and supporting the family. Several factors affect how the counsellor should approach issues to be handled during the counselling sessions. One is the gender of the client and the implications of this on the ability to negotiate safer sex especially within the Nigerian socio-cultural context. Other factors include access to care and caregivers, socio-economic status, the occupation, social position and roles in the social network (at work, at home, and in other social gatherings), and financial status. Factors that also seem to be important include age, personality, philosophy of life, beliefs and practice of religion; cultural values about life and death; satisfaction with life achievements; and the perception of economic self. How some of

these factors could influence the levels of success in the Nigerian context may be understood from the case studies which follow.

Client presentation 1

Mr F.A. is a 38-year-old bank executive who agreed to have the HIV test after two pre-test counselling sessions following a series of treatments for what appeared to be non-specific illnesses. He is married with two children. His wife is a teacher in a private secondary school. They live in one of the big towns. Mr F.A.'s position in his place of work gives him access to quality health care. This was one of the things that had facilitated the diagnosis of HIV infection. From the comprehensive history taken, Mr F.A. was suspected of having contracted the infection from a blood transfusion he had received some five and a half years before when he was involved in a road accident. He acknowledged that he had had occasional 'sexual flings' with three women in the last five years. At the time of counselling, he affirmed having regular sexual relations with his wife to fulfil the marital obligation and with an undergraduate in the university who according to him 'gets him fulfilled'. Mr F.A. was very disturbed upon learning about his HIV-positive status. His concerns were how confidentiality would be ensured, the likely reaction of his wife and children, fears of losing his job and the consequences of that for the future of his children. He also expressed fear of rejection by his friends and family members and guilt about possibly infecting the women in his life who may have infected others. He was also fearful that, as his illness progressed, he would not be able to handle the tasks involved in daily life. He expressed distress and fear of the stigma he and his family would have to live with. According to him, he was not afraid of death. He expressed satisfaction with his professional achievement and his spiritual life.

Some of the factors that are pertinent to counselling this client are his marital status, his sexual orientation and practices as they affect the lives of his significant others, the job environment and his future on the job. His perception of himself and his achievements, access to resources to care for himself, his attitude to life, dying and death were complementary to the counselling process. He has adjusted to life with the disease and he has been able to change his work schedule to give him more time to rest. He has informed his wife who also tested HIV-positive. According to him, he informed his girlfriend (the one current at the time of diagnosis) indirectly but had not been able to persuade her to come for testing. He does not want this woman to be part of the counselling process yet. He said that he wanted to marry this woman but could not because of the crisis that this would have caused to his life. He has not been able to trace the other women with whom he had sex but he continues to make the effort. Access to health care resources through his work has been very useful in assisting him and his wife to manage infections and provide a good diet for the family.

Client presentation 2

Miss M.A. is a 24-year-old unemployed NCE graduate. She was advised to have an HIV test because of a recurrent vaginal yeast infection that was distressing her ; she tested positive. She is the only surviving daughter of her parents but has two brothers who are much younger. Her parents had to try hard to have their three children as they have a history of infertility. The parents are farmers and they had spent the bulk of their resources sending Miss M.A. to school. She has a fiancé who is from the same village. She would have married him but for the economic crises and the problem of unemployment. Her fiancé is a doctor scheduled to complete his National Youth Service a few months after the time of Miss M.A.'s presentation for counselling. Her first sexual experience was seven years previously when she was forced to have sex by a teacher in her secondary school. She had not had sex with any other man apart from her fiancé whom she had met about three years previously. She is very religious

and claims to be a 'born again Christian'. Her plan is to be married at the end of the year and to have a child, after which she hopes to start her degree program.

This client presents a typical situation where most factors are not conducive to easy counselling. Here is a young woman, just leaving school, with high hopes and plans of marriage and motherhood with a young man in a health profession. There are several issues that arise in this circumstance. These include her position in the family and the Nigerian cultural expectations of her ageing parents and her much younger brothers. The consideration of the strain that her parents had to go through while she was going to school weighed very heavily on the client. Her plan about her future family *vis-à-vis* marriage and motherhood was a difficult issue to resolve. Importantly, her gender does not help her to negotiate safer sex with her partner. The issue of condom use and negotiation for safe sex is something that she could not manage to discuss with her partner, particularly if he is also infected. Access to resources to manage her health is neither within her reach through the familial care protocol nor within the current health care and social service provision by government.

The persons affected by HIV/AIDS and the counsellors usually go through the stress of managing the crises of HIV/AIDS in our social system where the social or welfare services from the state for young and old alike are almost non-existent. This major constraint calls for constructive responses from the counsellor before he or she can have any effect on the life of the people involved. How does the counsellor achieve this?

Evolving constructive responses and supportive environment for HIV/AIDS counselling

I have found a blend of several conceptual or theoretical frameworks quite useful in attempting to arrive at constructive responses and provide supportive counselling for people affected by HIV or AIDS. These include doing everything possible to preserve the dignity of the infected person as well as to respect the individuality of each client. A supportive environment is achieved by genuinely accepting people with HIV/AIDS with no reservations and emphasizing positive living at all times. No one knows when they will die and what will be the direct cause of death. This makes it important to live every day in the best possible way. These are some of the philosophical or humanistic views that are useful along with some theoretical frameworks guiding counselling in HIV/AIDS care. The theoretical frameworks found very useful are the life cycle, the developmental approach to crisis management and the family systems theory. Applying Miller and Bor's (1991) summary of three subdivisions of the developmental framework, consideration is given to the stage of HIV infection or AIDS, the individual's stage of development and the family's stage of development.

This framework helps the counsellor to determine specific issues that will be of concern to the client at their age of contact. It also helps to review issues about HIV/AIDS that have a bearing on the relationship of the client with his or her family. It encourages seeking facts about the stage of the client's illness that could help the counsellor address the effect on the client's significant others. The framework also helps in hypothesizing anticipated responses of significant others when the client's health deteriorates. It assists in determining other factors that add to the stress of living with the infection. These might include the availability or otherwise of human and material resources and existing problems that could worsen the client's status. Difficulties for carers in the treatment environment, home-based or in hospital, are also analysed within the framework.

The Family Systems Theory of the Milan Center for Family Therapy is the other framework that has been useful in AIDS counselling. While discussing this theory is beyond

the scope of this paper, three identified aspects of the theory that are useful in AIDS counselling are presented here. These are the systemic view, the technique of counselling, and the use of hypothetical questioning. These are future-oriented through encouraging clients to describe their lives and relationships in hypothetical future situations. The systemic view looks at the problems and postulates what can be done about helping the clients function within the system of which they are a part. The technique makes use of 'circular questioning' in highlighting the clients' different feelings about the problems. This is done by one counsellor with direct contributions from other counsellors who stay in the background. Essentially, the ability of the counsellor to provide a supportive environment is dependent on certain qualities. The counsellor must be without prejudice and fear, and must be well informed but not ashamed to acknowledge limitations or seek more information when unsure. He or she must personally have come to terms with the disease and should not be judgemental, should not make assumptions and should be capable of respecting the clients' ways of coping with the infection. The counsellor must be willing to share responsibilities with other people in the team caring for the clients. It may be useful from experiences in the field to illustrate how responses could become supportive.

Client presentation 3

Mr O., about 38 years of age, was an old patient of one of my senior colleagues who had managed him since he was diagnosed HIV-positive about six years ago. He has accepted and adjusted to living with HIV as a result of the accessibility of health care and because of the level of acceptance that he received from the group. He was referred for counselling on a particular occasion following his expression of feelings of depression, dejection and hopelessness. He was ill but this was complicated by his wife leaving their home. He claimed that his wife had fought with him because he did not agree to spending some money they had in savings to settle her dowry. Mr O. appeared withdrawn and sad and he did not welcome the counsellor with his usual smile and comment about doing well. The strategies that were used in the counselling session that followed were as follows.

1. Sitting next to the patient after shaking his hand and exchanging pleasantries as the counsellor always does.
2. Acknowledging that the client's feelings and reactions may not be unusual.
3. Identifying specific areas of concern to the client and exploring what the client had done.
4. Commending the client for all that he had done to continue to take care of himself and to make appropriate contacts with his and his wife's relatives who were to resolve the crisis related to the dowry.
5. Inquiring whether he wanted the counsellor to talk to other members of the family as she is well known to all of them.
6. Conveying to the client that attention had been paid to his feelings and concerns. At the end of the session the client was again encouraged to get in touch with the counsellor whenever necessary.

It is important to stress that the use of all identified frameworks as well as others that may become more useful in the future has not solved all the problems of HIV/AIDS counselling, and may not do so, especially in Nigeria. There are problems, constraints and limitations to counselling for HIV/AIDS in Nigeria.

Problems of HIV/AIDS counselling in Nigeria

The three problems related to clients above are examples of the realities of HIV/AIDS in Nigeria today. There are several factors that may limit what the counsellor can do. There are ethical, legal, psychological and social issues that are challenging and at times frustrating to the counsellor involved in HIV/AIDS counselling. There are fundamental problems in ensuring privacy and confidentiality. Nigerian culture accepts that everyone in the neighbourhood takes an interest in what is happening in the lives of their neighbours. As positive as this may be at other times, it has been a hindrance in counselling patients with HIV/AIDS. The problem is that the counsellor may be inhibited in visiting clients at home to avoid bringing upon them suspicion and the associated stigma, possible ridicule and even possible homicide by non-supportive family members who may see the client as a disgrace. The inadequacy of the telephone system in Nigeria contributes in no small measure to making life uneasy even for people who ordinarily would have been willing to talk to the counsellors anonymously. While the few people working in this area may still be able to help through anonymous counselling, they lack facilities and resources to do this most of the time. It is uncertain whether appropriate and adequate counselling is provided through screening facilities provided by the government. Some people go without counselling before and after screening, except for the general health information that health practitioners give. Many health practitioners are as ignorant and as afraid as members of the general public, if not more so. The general pretence that anyone can do counselling and the poor attention given to the need to train people for this job may prove to be expensive for the country in the long run. There is an acute problem of non-availability of trained counsellors to handle most of the sensitive issues that often arise, to help the untrained persons who are forced to take responsibility and to give the time required to meet the needs of the people affected. Making use of any untrained available person to do HIV/AIDS counselling may be doing more harm than good.

An experience in the field to illustrate this is the case of a client who was counselled by a nurse in a state hospital in Osun state. The client was advised to seek to be discharged against medical advice from the hospital and 'get something done' as 'AIDS has no cure'. This client, who was not at the terminal phase of the illness, was reported to have left the hospital overnight after the discussion with the nurse. He was then reported to have committed suicide a few days later. Whatever strategies might have been used by the counsellor to reach other contacts for this client to help to prevent further infection could not be used. The nurse had prevented any useful intervention through her dismissive attitude. Yet from the society's point of view, her attitude would be respected as she was a trained health professional.

One other vital problem that is closely associated with the unavailability of trained persons is the inability of the persons trying to provide counselling to accept the realities of living with HIV/AIDS. An aspect which I am investigating is the extent to which people can realistically imagine their death as being possible in the next moment of their life, and how this can help them accept issues related to death and dying. Many people who are becoming involved in counselling for HIV/AIDS are as afraid of death as the person they have to counsel. Professional training in health care may not make any difference here. Therefore it is a false assumption that health practitioners can be relied upon to meet the crisis of counsellor shortages in HIV/AIDS.

Other problems arise from issues related to negotiating risk-reduction strategies in sexual relationships and tracing all the sexual partners of people with HIV who may require counselling. Three other problems usually arise here. The consent of the client is primary to any action to be taken by service providers. Tracing sexual partners of clients with HIV infection is contingent upon their giving information and consenting to the search.

Notification of partners is not a thing that the counsellor would want to do without the co-operation of the client. Talking about HIV/AIDS often requires talking about the sexual lives of people which in most Nigerian culture is not countenanced. Even where the counsellor may have got over the inhibitions on talking about sexual matters, it usually takes a long time to get all others involved uninhibited enough to discuss their sexual lives. The problem of who can negotiate to demand safer sex brings to the forefront perceived positions of the sexes, particularly when counselling female clients. Negotiating condom use had always been seen as a problem, not only for female clients but equally for males. This problem arises from the association by many people of condom use with promiscuity. Attempting to negotiate safer sex may imply an accusation of the partner or acknowledgement of personal promiscuity. Women are particularly disadvantaged in this regard as often the sexual behaviour and demands of the man take precedence over those of the woman, especially if the man is her husband. Unavailability of appropriate health care and social services to which clients can be referred for effective medical evaluation, and management for meeting other social needs, is a serious obstacle to effective counselling. Even where the client is willing to make all necessary changes in lifestyle to attain positive living with the support of the counsellor, both have to face the realities of lack of resources.

To procure essential drugs, to eat good food and even to have basic social amenities to enable appropriate changes in lifestyle and adoption of health care practices for people with HIV/AIDS require resources. The experience of the AIDS Support Group (now within the Nigerian Network for Ethics, Law and AIDS and the Network of AIDS Support Groups) provides another example. The AIDS Support Group, made up of a venereologist, a community physician, a clinical nurse, a specialist-counsellor, a dentist, and a priest was constituted in 1991 through the efforts of Professor Femi Soyinka in Ile-Ife, Nigeria. The team had to use resources raised by themselves to meet the needs of their clients. When the resources became so inadequate that the group were unable to function as they needed, the economic status of both the team and clients deteriorated in the face of the economic crisis in Nigeria, and the frustration of not being able to do anything gave way to despair. Despite the despair, an increasing number of people continued to be referred or personally contacted by the group for assistance. Up to the present the group still faces the problem of lack of resources to meet the increasing demand for counselling.

Ensuring confidentiality and giving a guarantee that information about the client is not revealed by members of staff continues to be a major problem. Stigmatization of people involved in caring for people affected by HIV/AIDS, and derogatory comments even from colleagues at work, often have to be endured. It must also be emphasized that most of the people involved in HIV/AIDS counselling in Nigeria today are engaged in other full-time jobs and usually have not enough time to meet the needs of the clients as well as their own needs as carers.

What should be done?

Health care delivery systems and the rights of clients within the system may be seen at various levels. To start with, counselling should be a fundamental right of the client in health care, irrespective of the nature of the disease or health needs that bring the client in contact with the system. This is not to say that every health practitioner should be made to undergo training as a counsellor for all terminal illnesses. It may be unrealistic to expect that present training of health professionals could be extended to include health counselling. However, there are signs of deficiencies in the training of almost all health practitioners; they lack skills to help clients manage sensitive issues related to their well-being. Major areas that require review are those of sex, dying and death.

There will always be demand for health counsellors. People die in Nigeria today with little or no support from trained counsellors. It may be felt that the family, especially the extended family system, provides some kind of support. However, the traditional social fabric continues to disintegrate as many people now live far away from their families. Many are becoming more individualistic and prefer the nuclear to the extended family system. There are problems with this as the familial support system continues to disintegrate without an appreciable increase in social services provided by the government, and the individual is left unsupported. The level of poverty of a majority of Nigerians continues to destroy the social network and directly contributes to the problems of HIV and AIDS. There is a need to look into the changing patterns of familial structures and interactions in Nigeria, and to how functional and supportive the extended family can be. Whatever problems the extended family system may have, there seems to be much to gain from it as a social collective. Many people dying of AIDS, even when abandoned by spouses, friends and employers, have been cared for by members of the extended family who may not have played an active part in their lives while they were in good health. After their death, it is usually the same family members who take responsibility for the nuclear family, or orphans left behind. There is a need to see how this old phenomenon of kinship can be improved upon to help the family cope with the crisis of AIDS in the absence of government social services.

Counselling is a time-consuming process that requires planning and devotion. Therefore, it should not be fitted into care regimes in which it is not highly regarded. However, it is becoming necessary for health practitioners to build scheduled counselling sessions into care regimes for all clients. It may take some time to incorporate trained health counsellors into the existing health team. However, it will suffice to have temporary service areas and give serial training without necessarily taking them away from their units.

As a matter of urgency, there is a need for anonymous counselling facilities. These for a start could be in the big cities and towns and possibly linked to all health units. It is also important to demand an improvement in the telecommunications system in Nigeria. Accessible phone booths are indispensable to people urgently seeking information.

Appeals must be made to the government, philanthropic organizations and individuals to help existing counselling groups to train more people. There is an urgent need to expand the scope of coverage to reach many more people affected, not only by HIV or AIDS, but by other terminal diseases.

Conclusion

AIDS counselling is the skill of helping people to take important decisions about life, relationships, dying and death. When the skill is well learnt it is adaptable to managing all health-related problems. The health and illness patterns of the world's population are changing, especially with the emergence of ageing populations and increasing life expectancy. There are changes in the patterns and forms of existing diseases as well as the emergence of new ones. The orientation to health and illness has gone beyond thinking of cure as the only major motive of caring. Life involves accepting limitations and living positively within them. Counselling is caring that goes beyond curing. The issues brought to light by the needs of people with HIV and AIDS, and the people affected by their relationship to those infected, go beyond the disease itself. We are all affected, otherwise the whole world would not be talking about it.

Some of the goals of counselling are to help young people understand their sexuality; to make people aware of their rights for sexual negotiation, especially where there are problems related to gender difference; to help find solutions to economic problems and to encourage an improved socio-economic status for women. As well, counsellors will aim to facilitate

premarital and intramarital communication, and to help in family crises which are part of HIV prevention and control.

Counselling can greatly help in the problems that accompany HIV and AIDS, especially in achieving the effective communication so greatly needed to attain reconciliation with the realities of living, dying and death.

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