Fact Sheet 7 Counselling and HIV/AIDS

• Introduction:

Numerous studies suggest that good counselling assists people to make informed decisions, cope better with their health condition, lead more positive lives, and prevents further transmission of HIV. HIV/AIDS counselling is sometimes provided by trained counsellors, though nurses and caregivers are often in the ideal position to provide effective counselling, advice, and support.

A nurse in Ghana counsels a mother on the possibilities of mother-to-baby transmission of HIV/AIDS. (Credit: Cathy Sagui, JHU/CCP)

However, when nurses and caregivers are busy, emotional caring and support are often overlooked, despite evidence that providing emotional support does not take any longer than not providing such care. Frequently, nurses and others indicate that they do not know how to provide more subtle counselling and emotional

support, and therefore avoid this aspect of care. The following pages provide useful information about effective communication in the context of providing care to HIV/AIDS patients.

Effective communication and counselling require:

Fear of contacting HIV and becoming sick and dying from the disease.

self awareness of one's beliefs, values, and assumptions

a respectful, non-judgmental attitude

active listening, including accurate reflection of the issues or concerns

asking supportive questions that raise important issues, in caring, nonjudgmental ways

awareness of one's verbal and non-verbal behaviours

providing practical support, advice and information

discussing options for care, prevention, and support

encouraging patient and the family to make their own decisions

creating a quiet, private atmosphere

Remember that good counselling skills are best learned through practice.

Active listening

involves entering into the experience of the patient and trying to understand their circumstances. Accurate reflection means responding to the person, restating their concerns and highlighting the feelings expressed. Such practices lead to a deeper exploration by the person of his/her fears, misunderstandings and experiences. Active listening and reflection on the part of the nurse or caregiver can often be sufficient for the PLHA to feel cared for and supported, and can lead to improvements in their ability to cope, make informed decisions, and in their overall quality of life.

In conclusion, experiences of fear, stigma, isolation, discrimination and marginalization related to HIV/AIDS come from:

• Pre test counselling

The aim of pre test counselling is to provide information to the individual about the technical aspects of testing and the various implications of being diagnosed as either HIV positive or negative. Pre test counselling should focus on two main topics: (a) the person's personal history of risk

behaviours, or having been exposed to HIV , and (b) assessment of the person's understanding of HIV/AIDS (including methods of transmission) and the person's previous experiences in crisis situations. Information should be up to date and given in a manner that is easy to understand. Pre-marital testing of couples and testing of blood donors is different from testing of those suspected of having HIV/AIDS. However, both groups require sensitivity. Testing should be discussed as a positive act that is linked to changes in risk behaviour, coping and increasing the quality of life.

• Components of pre test counselling

Assessment of risk

Assessing the likelihood that the person has been exposed to HIV requires considering the following:

Frequency and type of sexual practices, in particular, high risk practices such as vaginal and anal intercourse without a condom, or unprotected sex with prostitutes;

Whether the person was/is part of a group with high risk prevalence for HIV infection (intravenous drug users, male and female prostitutes and their clients, prisoners, refugees, migrant workers, homosexual and bisexual men, and health care workers where the use of Universal Precautions (Fact Sheet 11) is erratic or incomplete.

Whether the individual has received a blood transfusion, organ transplant, or blood or body products. Note that in some developing countries, testing of blood for HIV might not occur.

Has the person been exposed to non-sterile invasive procedures, such as tattooing, scarification, female and male circumcision.

Assessment of understanding

The following questions should be asked in assessing the need for HIV testing:

Why is the test being requested?

What are the behaviour patterns or symptoms of concern?

What does the person know about the test and its uses?

What are the person's beliefs and knowledge about HIV transmission and its relationship to at risk behaviours?

Who could provide emotional and social support (e.g. family, friends, etc.)?

Has the person sought VCT before, if so, when, from whom, for what reason and what was the result?

Has the person considered what to do or how he/she would react if the result is positive, or if it is negative?

Preparation for pre test counselling

Effective pre test counselling will prepare the person for the test by:

Discussing confidentiality and informed consent for the HIV test including providing an understanding of the policies governing consent

Explaining the implications of knowing one is or is not infected.

Exploring the implications for marriage, pregnancy, finances, work, and stigma

Facilitating discussion about ways to cope with knowing one's HIV status (For example, has the person considered what to do or how she/he would react if the test is positive, or if the test is negative?).

Promoting discussion on sexuality and sexual practices.

Promoting discussion on relationships, with emphasis on the benefits of shared confidentiality between the person and his/her loved ones.

Promoting discussion on sexual and drug related risk behaviours, as appropriate.

Exploring emotional coping mechanisms and the availability of social support.

Explaining how to prevent HIV transmission.

correcting myths, misinformation and misunderstandings related to HIV/AIDS.

Benefits of pre test counselling

Pre test counselling helps people to make informed choices. However, it is important to note that people who do not want pre test counselling before taking the HIV test should not be required to have it. In addition, a decision to be tested should be an informed decision. Informed consent implies awareness of the possible implications of a test result (including the window period). In some countries, the law requires explicit informed consent; in others, implicit consent is assumed whenever people seek testing. The nurse/midwife must help the person understand the policy on

consent, and should explain the limits and consequences of testing. Therefore, it is important to be knowledgeable about the policies and guidelines governing your region. Access to pretest counselling is not always available, and some people might refuse this option. However, if the test is positive, there are considerable benefits to providing this service which include:

improved acceptance of HIV status and improved ability to cope

empowerment, including greater involvement of PLHA

facilitation of behavioural change

reducing the risk of mother-child transmission (Fact Sheet 10)

early management of opportunistic infections (Fact Sheets 4 and 5) and preventive therapy, (Fact Sheet 12)

contraceptive advice, and other information and education (Fact Sheet 8)

early social and peer support

normalizing HIV/AIDS

instilling hope and addressing the quality of life

planning for future care (Fact Sheet 3), making a will (Fact Sheet 8) and orphan care (Fact Sheet 5)

• Post test counselling

In post test counselling, it is important to put the person being counselled at ease. If possible, the room should be quiet, without the fear of being disturbed. Arrange the chairs so that bright light will not shine in anyone's eyes. The counsellor should then tell the person the test result. The result (either positive or negative) should then be discussed, including how the person feels about the result. Further information can be provided, though the person may be shocked, and may not fully understand all the information. In some circumstances, the post test setting might provide the only chance to counsel this person. Thus, asking them to repeat the information just presented, or to have some basic facts written down might be helpful. It is important for the person to have time to reflect on the result and understand the next course of action. Ideally, couple and/or family counselling should be started at this time and further counselling follow-up arranged.

• HIV-positive test result counselling

When the test result is positive, the nurse/midwife should tell the person as gently as possible, providing emotional support and discussing how best to cope with the results. This is not a time for

speculation, but rather a time to give clear, factual explanations of what the news means. Assess the emotional impact of the news, and validate the person's reactions as normal. Fear of dying, job loss, family acceptance, concern about the quality of life, the effects of treatment and response by society can be explored. If there is a concern that the person might not return for follow up counselling, then information about relevant health services should be mentioned. This would include available medical treatments such as antiretroviral therapy or treatment for opportunistic infections, and social services for financial and ongoing emotional support.

However, if follow up counselling is an option, then it would be advisable to leave this information to a later date when the person is better able to absorb the details and explore the available options. Assess the person's understanding and ability to use preventive methods. Free condoms can be given out during this session, together with advice on how to use them and where to get more.

How the news of HIV infection is accepted often depends on the following:

The person's physical health. People who are already ill often have a delayed response, and can only absorb information when they grow stronger.

How well the person has been prepared for the news.

How well supported the person is, both in the community and by family and friends.

The pre test psychological condition of the person. Where psychological distress existed before the result, learning the result could make the distress greater.

The cultural and spiritual values attached to AIDS, illness, and death. In some communities people might take a fatalistic attitude, whereas in other communities, AIDS is sometimes seen as evidence of antisocial or blasphemous behaviour.

Counselling and support activities need to address feelings of shock, fear, loss, grief, guilt, depression, anxiety, denial, anger, suicidal activity or thinking, reduced self esteem, and spiritual concerns. In addition, social issues such as loss of income, discrimination, social stigma, relationship changes, and changing requirements for sexual expression need to be explored.

• HIV-negative test result counselling

If the HIV test is negative, then counselling about at risk behaviours and methods of prevention are vitally important (see Fact Sheet 12). Also, the counsellor must explain about the "window period" (between 3-6 months) when a negative result may be a false negative. If there is concern about the HIV status of the person, counsel them to return for a repeat test in 3-6 months, and ensure that they take appropriate precautions in the meanwhile, explaining that they could become infected at any time. The counselling session is an ideal time to discuss sexual practices and preferences,

potential drug abuse (particularly intravenous drug use) and other at risk behaviours. Upon learning their HIV-negative status, the person may be more open to learning about safe sex practices and modifying risk behaviours. Free condoms can be given out during this session together with advice on how to use them and where to get more when needed.

• Continued counselling and support

The HIV-infected person and his/her family require further counselling and support following the initial meeting. Such support helps to improve their quality of life as well as to enhance their ability to cope and make informed decisions about ongoing care. Such counselling and support might include encouraging the PLHA to join a peer support group to learn where and how to access services, to find educational resources, and to obtain treatment. Spiritual and religious support might also be required, as well as support related to financial concerns and care for the family after the person's death. Where services exist, further individual counselling might also be beneficial. Such counselling might include discussions on safer sex practices, birth control counselling (Fact Sheet 12), and counselling and support during the ante natal, intra partum and post natal period (Fact Sheet 10) etc..

• Care for the caregiver

In many communities, there is little value placed on counselling. Consequently, counselling receives little if any financial support. As a result, counselling services are often fragmented, with no designated time or place for counselling sessions. In addition, health care professionals are expected to fit counselling activities into their already overburdened worklife, with little financial compensation. If counselling is not valued by policy makers and governments, it will be difficult for nurses, midwives and other health care professionals to value their roles as counselors. There is considerable evidence to suggest that nurses, midwives and other counsellors themselves need ongoing support and care, since caring for the sick and dying is very stressful. Unless there is adequate education, supervision, counselling and other support services available for caregivers, the result can be "caregiver burnout." What follows are some strategies to address these concerns.

Strategies to introduce and support counselling services

Convince the decision makers of the need and value of counselling services by quoting evidence of effective services in other communities, as evidenced by reports from a small evaluation project in your area.

Select counsellors and counselling trainees appropriately. These people should have warm and caring personalities, be good listeners, be respected by others, and be motivated and resilient.

Provide training workshops followed by supervised practice and ongoing training for the counsellors.

Provide instrumental and psychological support to the counsellors.

Be sensitive to the location and time of services. The time of services should address accessibility for women, men, youths, and couples. In addition, the sites where services are provided could be expanded to include maternal and child health clinics, hospital out patient clinics, community based programs, and STD and TB clinics. These locations could help reduce the stigma attached to an exclusive HIV or STD clinic.

Have adequate supply of condoms (with information on use)

Approach sex workers, street workers, intravenous drug users in the places where they live and work.

Introduce educational campaigns that increase awareness of counselling services.

Provide counsellors with adequate referral services. This includes referrals to other counsellors, support services, treatment management, laboratory testing, ante natal care/breast feeding /family planning services, and orphan care.

Set up clear counselling standards and protocols.

Questions for reflection and discussion

What are the essential elements in effective communication? Would you say that you are an effective communicator? If not, how might you strengthen this important role?

What are the important elements to consider in pre test counselling?

What are the benefits of pre test counselling?

What are the important elements of post test counselling? Why is this so important?

What role might you play in setting up relevant, accessible, and acceptable VCT?

How would you consider maintaining this service? What barriers might you encounter, and how would you consider

overcoming these barriers?

How do you care for yourself to prevent burnout? What else might you do to help you reduce some of the stress you might be feeling? Do you think that your workplace might do more to help you? If so, what would that be? How could you go about making this a reality?

References

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