

A Palliative Care Training Manual:
Community based male
caregivers in Africa

The African Palliative Care
Association (APCA)
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Foreword:

This training manual for community based male care givers of PLWHA is a result of a collaborative project between the African Palliative Care Association (APCA), The Canadian Hospice Palliative Care Association (CHPCA), and the national palliative care associations in Uganda, Kenya, Zambia and Tanzania and their local member organisations.

The need for effective palliative care service provision across Africa has never had such a high priority. By December 2007 an estimated 22.5 million people in Sub-Saharan Africa were living with the human immunodeficiency virus / acquired immune deficiency syndrome (HIV / AIDS) (68 per cent of the global disease burden), with 1.6 million AIDS deaths (76% of global AIDS deaths) and 1.7 million new infections (68% of global new infections) reported in that year alone from this resource-constrained region.¹ For the overwhelming majority of Africans who currently endure these and other progressive, life-limiting illnesses, access to culturally appropriate holistic palliative care (that includes effective pain management) is at best limited, and at worst non-existent.

The African Palliative Care Association in partnership with international, regional and local advocates and promoters of palliative care is responding to t

his need through an approach that aims to promote and support the scale-up of palliative care development across Africa. In addition to extending the coverage, APCA and its partners strive to ensure those services attain an optimal quality that is cognisant of their resource-constrained operational environment. Increasing the number of effective care givers is an important strategy, among others for ensuring that PLWHA access quality and comprehensive palliative care services. Therefore APCA and its partners recognise and support the role of men in care giving. The development of a specially designed training manual for male care givers across Africa is an indication of APCA's commitment to the promotion of the participation of men in care giving.

According to a VSO-RAISA conference report of 2003², some success was noted in men's involvement in home based care, reversing the tradition that nursing the sick is a female domain. A study of the participation of men in home based care for PLWHA in Tanzania³ found that the majority of men lack motivation and skills to perform care work and the cultural issue of same sex caring is a factor for consideration. It further found that men who have received adequate training can be accepted by communities as care givers to both sexes. This study recommended that allocating resources to encouraging male participation within HBC programs is something that HBC programs have to prioritise based upon their knowledge of the communities they serve. Understanding the role of men in policies for HBC is important for implementing successful care to the millions of PLWHA in SSA.

¹ WHO/UNAIDS Joint United National Programme on HIV/AIDS, December 2007.

² Voluntary Services Overseas –Regional AIDS Initiative of Southern Africa (2003); Men, HIV & AIDS regional conference 2003 report back

³ Mark Christopher Winton (2007). Home Based Care for PLWHA in Sub-Saharan Africa: The participation of men

Reports from men who are currently involved in care giving indicate a positive change in their own homes and families as a result of the caring attitudes, knowledge and skills they gain from being part of care giving teams for the sick. Such attitudes and skills are acquired through on going training and access to education and experiences of caring for PLWHA and other life threatening illnesses.

Experiences of undertaking this project for empowering male care givers with palliative care knowledge and skills indicate that while men are increasingly taking on the caring role for PLWHA and more are acquiring a positive attitude about care giving, they generally lack the necessary skills for effective care provision. This therefore compromises the quality of care they provide to sick members in their own families, but also to those in the community. This lack of knowledge and skills also results in frustration of men as their minimal participation in care giving is widely interpreted as lack of willingness to care for the sick. Resulting from such circumstances, APCA and its key partners recognise the need to build the capacity of male care givers for PLWHA in order to increase access to holistic and quality care. It is upon this background that I recommend all individuals and organisations providing HIV/AIDS care and support to increasingly target the participation of men in care giving and utilise this resource to build their capacity to provide effective care.

Dr. FAITH Mwangi-Powell
Executive Director, African Palliative Care Association

Dedication

This work is dedicated to all men who are involved in care giving for People Living with HIV and AIDS and their families, as well as those living with other life threatening illnesses such as cancer.

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- Reach Out Mbuya

- Hospice Africa Uganda (HAU)
- The Aged Family Uganda (TAFU)
- Kitovu Mobile Home Care Programme
- Positive Mens Union (POMU)
- Association of Men Living with HIV/AIDS Uganda (MELIA)

Kenya:

- Coast People Living with HIV/AIDS (COPE)
- Kenya AIDS NGOs consortium (KANCO)
- Coast Hospice
- Portlitz HIV Support Organisation (PASO)
- Bangladesh Bamako Initiative
- Movement of Men Against AIDS in Kenya (MMAAK)
- KICOCHEP

Zambia:

- CRS – SUCCESS project
- Zambian People Living with HIV/AIDS (NZP+)
- Family Health Trust
- Salvation Army
- Prisons Care and Counselling Association.
- Network of People Living with HIV/AIDS
- Defence Force Medical Services
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- PASADA
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Acronyms:

HIV	Human Immuno Virus
AIDS	Acquired Immuno Deficiency Syndrome
APCA	African Palliative Care Association
CHPCA	Canadian Hospice Palliative Care Association
CRS	Catholic Relief Services
PCAU	Palliative Care Association of Uganda
TPCA	Tanzania Palliative Care Association
KEHPCA	Kenya Hospices and Palliative Care Association
KICOCHEP	
PCAZ	Palliative Care Association of Zambia
ART	Antiretroviral Treatment
OIs	Opportunistic Infections
STIs	Sexually Transmitted Infections
PASADA	
PLWHA	People Living With HIV/AIDS
MoH	Ministry of Health
WHO	World Health Organisation
MCGs	Male Care Givers

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INTRODUCTION AND BACKGROUND TO THE PROJECT AND THE DEVELOPMENT OF THIS DRAFT TRAINING MANUAL

This manual, and a unique resource for training male care givers in Africa was developed through a collaborative project between the African Palliative Care Association (APCA), the Canadian Hospice Palliative Care Association and four national palliative care associations in Africa namely:

1. Palliative Care Association of Uganda
2. Kenya Hospices and Palliative Care Association (KEHPCA)
3. Palliative Care Association of Zambia (PCAZ)
4. Tanzania Palliative Care Association (TPCA)

The project which resulted into the development of this manual aimed to empower men with knowledge and skills of palliative care as they take on the primary care givers role for people living with HIV/AIDS in the target countries of Kenya, Tanzania, Uganda and Zambia and thereafter be used across Africa. This would be undertaken through training and education using a specially designed training manual for male care givers in Africa. The key activities for the entire project included:

- i. A rapid needs assessment to provide baseline information and guide the project implementation process, more specifically the development of a suitable training manual for male care givers.
- ii. Development of a training manual and trainers guide
- iii. Pilot testing of the training manual and guide in project countries, and launching a final manual and trainers guide for use by project countries and other African countries.

The draft manual is comprised of a total of 17 modules each with a set of topics/sessions which were drawn from results of the rapid needs assessment for the capacity building needs of male care givers in palliative care. In the rapid assessment which was undertaken in Uganda, Kenya, Tanzania and Zambia, male care givers including men living with HIV/AIDS and professional carers working closely with them identified key areas where men required knowledge and skills for effective care giving. The content of this training manual is derived from the findings of this assessment, a report of which is available as a separate publication at APCA. A review of locally available training manuals in each project country and other relevant materials also informed the content and structure of this manual. The manual is strongly dominated by ideas and views of male care givers including PLWHA from project countries, most of whom have drafted or reviewed topics of the manual. Available professional and technical resources within project countries and elsewhere in Africa were identified and utilised in the manual development process.

Summary of manual development process:

Throughout out the manual development process, APCA provided overall coordination at the regional level. The four national palliative care associations identified relevant organisations in their countries which significantly contributed to the entire project and more specifically to this training manual by providing skilled authors and reviewers for various topics.

The manual development process comprised of a series of activities which were undertaken both at regional level with coordination from APCA and at country level

with coordination from the national palliative care associations. All project countries participated in project planning and implementation through the following activities.

- A regional project planning meeting which aimed at mapping out the project implementation framework.
- In-country project stakeholders meetings which aimed at introducing the project to the local stakeholders and identifying country project teams.
- A rapid needs assessment for capacity building needs of male care givers in each project country which explored the key areas relevant for the training of male care givers.
- Collection and review of available local materials in each country
- Regional material review and drafting workshop where the content and structure of the training manual, the trainers guide and the actual training were agreed.
- Drafting of a training manual and trainers guide by selected authors and reviewers under the coordination of APCA.
- Pilot testing of the training manual and guide in three project countries i.e. Uganda, Kenya and Zambia.

The content and structural framework of this manual was designed by a project working group composed of national palliative care coordinators and representatives from local organisations in project countries, including organisations for men living with HIV/AIDS.

Men are strongly respected members of communities in Africa. In most cases they are heads of families and occupy most of the local leadership positions in their communities. APCA and all stakeholders involved in this work believe that providing men with skills of care giving and advocating for their role at international, regional, national and local/community level will reduce the burden of care giving among their female counterparts but as well increase access to care and contribute to effective care and support for PLWHA.

We greatly hope that the adequate use of this manual in training male care givers will contribute to effective care giving for PLWHA in Africa.

Rationale of the manual and the training of male care givers:

In the African context, the role of care giving for the sick is predominantly for women. However, the overwhelming burden of care for PLWHA requires all members of society to contribute to care, including men who sometimes find themselves in situations where they must care for themselves or for their family members. Although some men have acquired knowledge and skills of care giving and are involved in care for PLWHA as volunteers, there is an on-going need to train many more men to participate in care giving. The existing gap in care giving knowledge and skills among men prompted the implementation of a project aimed at empowering male care givers for PLWHA to provide palliative care. Male care givers from Uganda, Kenya, Tanzania and Zambia were central in the implementation of this project, which resulted into the development of a training manual specifically for male care givers.

This draft manual that will be pilot tested in Uganda, Kenya and Zambia through this training is aimed at providing an opportunity for a comprehensive review of the manual and obtaining feedback from the participants to facilitate the development of a final version.

The training manual for male care givers is developed to facilitate the training of men in Africa to enhance the knowledge and skills in care giving for PLWHA, a role that traditionally belongs to women. The manual and accompanying training programme will raise the profile of men in care giving. It tries to identify the role of male care givers in various aspects of care giving.

Several training manuals do exist in Africa, which target varied care givers including health care workers and community volunteers. Additionally, varied training programmes are currently implemented to enhance care giving skills for PLWHA. However, there is no single training manual/resource or training for that matter targeting men to empower them with skills of effective care giving, despite a cultural environment in which they have not been mentored to care for the sick. This training manual for male care givers has been developed to meet this need therefore. It is envisaged that a training manual designed for empowering male care givers will enable them to completely appreciate, understand the magnitude of commitment and care expected of them, not only theoretically but practically too. A rapid needs assessment that was conducted prior to the development of this manual indicated a positive attitude among them to provide care, but with a challenge of lack of care giving knowledge and skills along with the continued perception among communities that care giving is a women's role.

The manual comprises a total of 17 modules, each with various sessions/topics which are to be covered in an 8 days pilot training programme. It is accompanied by a trainers guide to provide guidance to ant facilitators/trainers who will use this manual in the training of male care givers in Africa.

The manual provides the necessary information for male care givers to enable the provision of effective palliative care in the home and other settings. It covers a range of palliative care topics which are extremely relevant for care giving. Male care givers are advised to always seek the assistance of other health workers for further elaboration and clarification of aspects included in this manual which they don't understand.

Who is this manual targeting?

The manual and accompanying training is primarily targeting community based male care givers working closely with services/facilities providing care and support to PLWHA. However, training using this manual is not limited to men alone. It is important for men to be trained along with women as this promotes partnership in care giving. It is also important for women to understand the changing trends in care giving and to accept and be supportive to male care givers and advocate for their role in communities that perceive care giving as a role of women.

There are various training programmes in Africa for training community volunteers. Although these programmes vary slightly or greatly in content and structure, a review of existing materials undertaken during this manual development process

found that all these programmes are closely related in regard to their goals and objectives, and community approach?. It is therefore possible that male care givers already have some experience in some topics covered by this manual. Trainers/facilitators should take this as an opportunity to enrich the training and encourage the sharing of experiences with those who have never had any training before.

How to use this manual:

Manual users: This manual will be used by health care professionals, allied health care professionals, trained and experienced community based health workers/volunteers including trained male care givers to undertake the training of male care givers.

It is important indeed for community based volunteers and health care workers to support each other in the training of male care givers using this manual. Some of the topics in the manual are medical, although simplified for community based male care givers and will require clarifications from health care workers. Other topics are very much community oriented and will require the input and clarification of community based health workers or volunteers.

A trainer's guide has been developed alongside this manual to assist trainers and facilitators in conducting this course. Both the training manual and trainers guide will undergo regular review and update, given the dynamic and advancing nature of health care.

The trainers/facilitators for this pilot training have been drawn from the project working group, the country project teams, participating local organisations and from the list of authors for various topics in this manual.

Training duration: The training of male care givers using this manual will require a total of eight (8 days) although this may change following the pilot testing of this manual. The duration of each topic/session is outlined in the trainer's guide. However, parts of this manual can be used to train male care givers on a specific topic or topics depending on the needs of the target group and the scope the trainer wishes to cover.

Number of participants: The number of participants on this course will be between 20 and 25 at any one time.

Target countries: The countries targeted for pilot training include Kenya, Zambia and Uganda and once the final version of the manual is available, it will be used across Africa.

Teaching methods: The training methods to be adapted include theoretical and practical methods such as demonstrations, group work, role plays, facilitation, brainstorming, videos, case studies, personal stories and experiences, didactic, drama, patient testimonies etc. The methods applicable to each topic/session are outlined in the trainer's guide.

Trainers/facilitators are encouraged to read and understand this manual, along with its accompanying trainer's guide and to use it in preparation of sessions in a way that suits them.

Goals and objectives of the pilot training:

Unlike any other training you may be familiar with, the aim of this particular training is to pilot test the materials which have been developed for the training of male care givers across Africa. Your contribution and feedback is very essential in the review and finalising of this training manual and the accompanying trainers guide. To pilot is to test something for further improvement drawing on guidance and direction from those participating in the pilot.

Aim of the pilot-testing:

To pre-test the training manual and trainer's guide so that feedback is obtained and compiled to improve and finalise it for future use in Africa in the training of male care givers. Feedback will be required in the following areas:

- Aim and objectives of the training
- Content of each session
- Facilitation of sessions
- Duration of sessions and the entire course
- Suitability of content to the target group
- General training methodology

Goals and Objectives of the training for male care givers:

Goal of the training:

The goal of this training will be to provide male care givers with relevant knowledge, attitude and skills required for the provision of palliative care for PLWHA.

Objectives of the training:

1. To increase knowledge of participants in palliative care provision as they take on the primary care givers role for people living with HIV/AIDS in the target countries and other African countries. The training will orient men to the concept of palliative care and its practical applicability in communities.
2. To address attitudes of participants as they take on the care giving role in palliative care for PLWHA and other life threatening illnesses.
3. To equip participants with care giving skills in palliative care which would help them in addressing community specific care issues related to HIV/AIDS and other life threatening illnesses.
4. To promote the transfer of knowledge and skills from participants to PLWHA and their families in regard to important information, skills and practical knowledge required for HIV/AIDS care at community level.
5. To promote the role of male care givers in palliative care giving among participants and encourage the transfer of care giving knowledge and skills to more men so that care giving becomes a shared role in Africa.
6. To enhance confidence of participants as they increasingly take on the care giving role and to encourage them to normalise the care giving role among men in Africa

At the end of the course, participants should be able to:

1. Pass on appropriate knowledge to PLWHA and their families, as well as those living with other life threatening illness
2. Reflect on personal and community attitudes towards the male care giving role for PLWHA continue to demonstrate positive attitudes in care giving.
3. Demonstrate holistic care giving skills in palliative care provision and share similar skills with PLWHA and their family members as well as men and women in their communities.
4. Identify and provide basic care to patients in need of palliative care and their families
5. communicate and counsel patients in their care
6. Provide basic nursing care at home
7. Make appropriate referrals for patients to access holistic care
8. Work as members of a multidisciplinary team in the provision of care to PLWHA and their families, and to influence their communities especially men to participate in care giving.

Assessment and Evaluation of the pilot training:**Pre and post-test:**

Participants will complete a pre- course test which will be marked to assess their palliative care knowledge, skills and understanding before the course. They will complete a post- course test exactly the same as the pre-test to assess how much palliative care knowledge, skills and understanding they would have gained from the training. These tests will be used to show the immediate changes in knowledge (some effects/outputs of the training) in the target group.

General pre-course assessment:

Participants will also complete a pre-course assessment form to capture their current knowledge and skills in the various topics of palliative care and as well rank their interest in learning about the various topics in the manual. Their responses will guide facilitators on where to put more emphasis and allocate more time throughout the entire training.

Session and daily evaluation:

Since this is a pilot test of the entire manual and training, each session will be evaluated by the participants using a session evaluation form. Their feedback will be used to review each topic to input into the manual with regard to content & suitability, duration of topics, mode of delivery/facilitation, teaching aides, and any other relevant issues prior to producing the final manual.

To ensure that objectives of the training are met, a daily qualitative review of the training will be done. This will enable facilitators to check whether objectives of training as well as participants expectations are being met. Also gaps will be identified

on a daily basis and addressed. The most important aspects learnt from the daily presentations will also be identified.

End of course evaluation:

At the end of the course, a review of course objectives and participants expectations will be done to check whether these have been met. They will also fill an overall course evaluation form which will capture their general perceptions about the course. This feedback will guide the review and production of a final manual and trainer's guide.

Follow-up and mentorship suggestions:

- National palliative care associations need to provide ongoing support to participants through inviting them to participate in palliative care activities under their coordination.
- Participants can also be encouraged to become registered members of national palliative care associations. They could also encourage organisations for which they are working to become institutional members of national palliative care associations.
- The organisation/team undertaking this training could also organise support visits to places of work for the participants in 3 to 6 months of completion of training. A support supervision checklist will be developed to assist in the follow up and after-training mentorship efforts
- Participants could be encouraged to submit simple summary reports on how knowledge and skills of the training is enhancing their work i.e. at 3 months, 6 months and after a year.

Some of the key indicators for success of the training, also for focus during follow-up may include;

- No of men trained in palliative care by type of organisation
- No of men involved in teaching male care givers using this manual
- No of organisation by type involved in the training of male care givers

Participants would be encouraged to seek immediate support from the national palliative care associations in their country as well as to plan and attend regular education sessions at their places of work facilitated by themselves or other local palliative care providers. Follow up activities will be incorporated into work-plans of the national associations regular and this will be part of the project sustainability strategy.

Participants will receive certificates of attendance upon completion of all the course sessions.

MODULE 1.0: FUNDAMENTALS OF PALLIATIVE CARE

SESSION ONE: AN INTRODUCTION TO THE HOSPICE AND PALLIATIVE CARE CONCEPTS

Learning objectives:

- Define Hospice and Palliative Care concepts.
- Describe a brief history of Hospice and palliative care
- Discuss the approach to palliative care and identify its key components/elements and principles as described by the World Health Organisation.
- Differentiate palliative care from home based care.
- Discuss regional and national palliative care initiatives
- Discuss the role of male care givers in palliative care delivery and training.

1. History of Hospice and palliative care:

Palliative care is a recognised medical speciality and health discipline which evolved from the Hospice movement. Hospices are traced back to times before the 19th century as places which provided care for strangers, travellers, destitute, the sick and the dying most of whom were pilgrims.

In the early 19th century, Hospices were established in Ireland and France and UK for the dying. Later, the Hospice and palliative care concepts were fully researched by Dr. Dame Cicely Saunders and commenced in a modern sense in 1967 in Britain with the establishment of St. Christopher's Hospice in London. Her discoveries have since guided the modern Hospice and Palliative care concepts, including the current WHO definition of palliative care. Dame Cicely Saunders encouraged and motivated all palliative care providers in her words to any patient as below:

*'You matter because you are YOU
You matter up to the last moment of your life
And we will do all that we can to help you
To LIVE until you die'*

2. What is Hospice?

- From its historical background, Hospice is commonly understood as a building where sick people are taken to die.
- In the modern sense, Hospice is not a building, but a philosophy or spirit of care for the patient, the family and of ourselves as carers.
- The word Hospice originates from the Greek word "Hospes" and the Latin word "hospitium" which mean hospitality. In this regard the Hospice spirit of care offers hospitality to patients and their families in a relationship similar to that of a guest in our homes.
- From the hospice philosophy evolved the Palliative care Philosophy to meet the gaps in care for people with life-threatening illnesses
- Hospice care incorporates pain and symptom relief and focuses on peace and dignity for the patient and the family.

Reflection on experiences (2 minutes)

Reflect on and note the kind of relationships which exist in health care settings between the patient, family members and the health care providers.

3. What is palliative care?

In 1990, the World Health Organisation defined palliative care as the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families.

In 2002, WHO redefined palliative care as:

‘An approach which improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

WHO further elaborated palliative care by describing its *principles* below.

Principles of palliative care;

- Provides relief from pain and other distressing symptoms;
- Neither hastens nor postpones death;
- Affirms life and regards dying as a normal process;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Enhances quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as antiretroviral therapy (ART), chemotherapy, or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Palliative care for children is as important as palliative care for adults and is elaborated as representing a special, closely related field to adult palliative care.

Palliative care for children is the active total care of the child’s’ body, mind and spirit and also involves giving support to the family. (WHO, 1998)

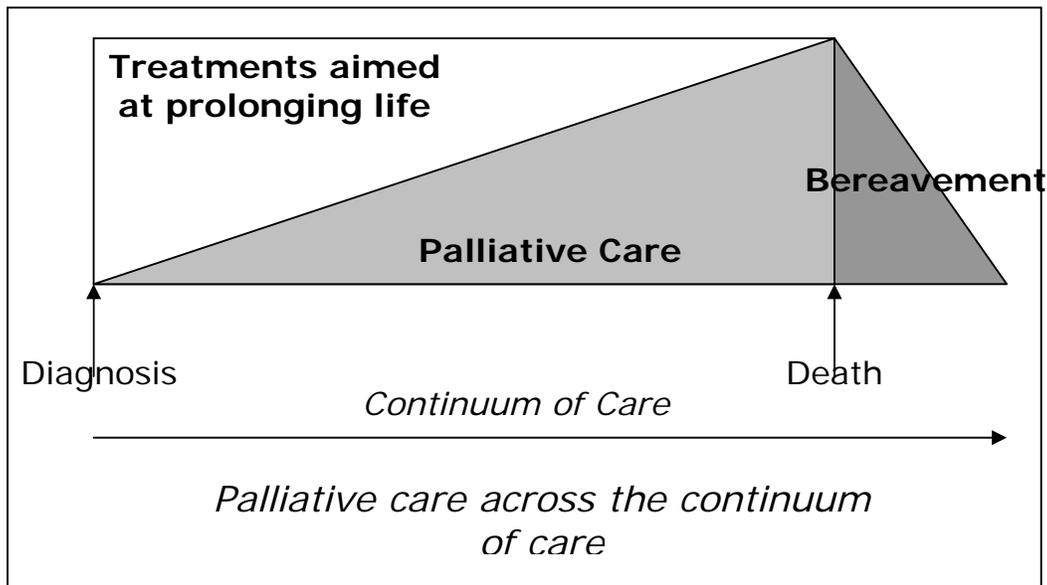
Nothing would have greater impact on the quality of life of children with cancer than the dissemination and implementation of the current principles of palliative care, including pain relief and symptom control. (WHO, 1998)

Although the above statement made reference to children with cancer, it is very applicable to children living with HIV and/AIDS.

Palliative care is often mistaken to be end of life care. However, palliative care begins much earlier at the point of diagnosis of a life threatening illness and progresses into end of life and beyond death where family members are supported through grief, loss and bereavement.

Palliative care is therefore delivered across a continuum of care as elaborated by the diagram below.

Palliative care across the continuum of care



The provision of comprehensive palliative care requires the input of many people, ranging from family members to health professionals, and from community members, including traditional healers, to non-governmental organizations (NGOs) or community-based organizations (CBOs), so as to create a continuum of services through all stages of illness: diagnosis to progression through end of life and bereavement. It is this provision of comprehensive care across the continuum from home care and community support to institutional services (primary, secondary, and tertiary), social services, and back that will ensure the needs of patients and their families are met.

According to Merriman (2005), palliative care has two essential elements:

- i) Pain and symptom control: where modern evidence-based methods are used, including the administration of oral morphine for severe pain.
- ii) Supportive care: which includes psychological, social, spiritual, and cultural needs of the patient and family, including bereavement care.

4. Approach to palliative care delivery and its key components/elements

The main approach for the delivery of palliative care is the *Holistic Approach to care*. This approach looks at the patient as a whole being and aims to meet all the needs of the patient and the family.

Palliative care through the holistic approach aims to meet the physical, psychological social and spiritual needs of patients and their families within their cultural context. Sensitivity and respect for the cultural, religious and spiritual beliefs and values of individuals and their families is very essential in palliative care. The key components of palliative care therefore include:

- *Physical care*
- *Psychological care*
- *Social care*
- *Spiritual care*

All which provided to patients and families within their cultural context, an approach referred to as the holistic approach.

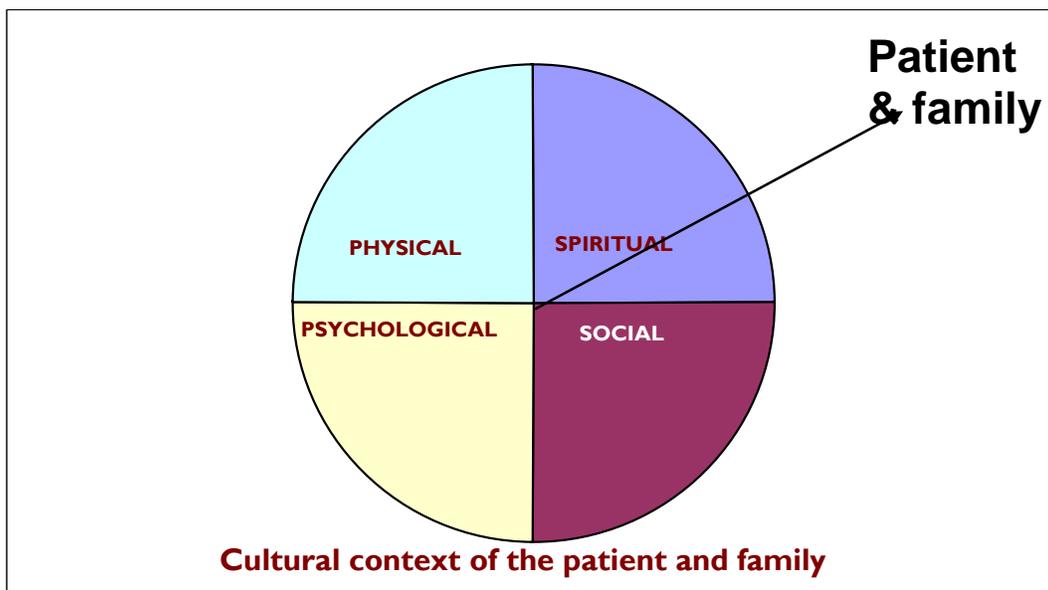
Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.

An organisation addressing only one of the components of palliative care is not providing palliative care by the modern definition. However, the needs are so wide that usually no one organisation or person can meet them all. In order to provide comprehensive palliative care, organisations and individuals must collaborate with each other e.g. through networking and appropriate referrals.

The holistic approach to palliative care delivery:

The approach encourages care for the patient as a whole person with physical, psychological, social and spiritual aspects but also as a person who is part of a family, a community, a culture, beliefs etc all of which do impact of the patient and the care given. This is illustrated in the figure below.

The holistic approach to care:



Key aspects for palliative care

- Quality of life for the patient and the family
- Holistic approach is used to provide care
- The patient and family are at centre of care
- Aims to achieve peace, comfort and dignity for the patient and family
- Aims to make a difference to the family resulting in this illness & death being a more positive experience for them

5. Palliative care and home based care.

There is a current confusion between palliative care and home based care. It is therefore important to obtain clarity of the two.

What is the difference between home based care and palliative care?

- Home-based or community-based care is not in itself palliative care but is a method of delivering palliative care
- Palliative care can be provided at the community as well as facility levels.
- A hospice is one way of providing palliative care but is not the only way

Some elements of home based care/Supportive care

- 'holding-hands' and kind words
- Elements of Psychosocial and spiritual care
- Basic hygiene within the home
- Practical help within the home
- May include some OVC care
- It might include basic patient care e.g. bathing

Key elements in palliative care

- Pain assessment and management
- Symptom assessment and management
- Psychosocial assessment and management of needs
- Assessment & management of Spiritual needs
- Bereavement care and support
- Good supervision of care providers

Palliative care is much more than holding hands or kind words as HIV/AIDS is characterised by life threatening infections and conditions that require much more action such as enabling PLWHA to access health care workers for medical care.

6. Hospice and palliative care in Africa

Palliative care was initially introduced into Africa for cancer patients in the 1980s in South Africa and Zimbabwe and in Kenya and Uganda in the 1990s. It has since spread to the rest of Africa.

Within each country, Hospice and palliative care has continued to grow. Country specific information on trends can be obtained from the African Palliative Care Association (APCA) or the national palliative care association in each country.

7. Palliative care and HIV/AIDS:

HIV/AIDS epidemic increased the number of people in Sub-Saharan Africa (SSA) needing palliative care to overwhelming numbers. The current HIV/AIDS statistics in SSA still justify this overwhelming need for palliative care.

Current HIV/AIDS statistics for Sub-Saharan Africa

Number of people living with HIV/AIDS	22.5m (68% of global disease burden)
AIDS deaths	1.6m (76% of global AIDS death)
New infections	1.7m (68% of global new infections)

WHO/UNAIDS, December 2007

Palliative care is a vital part of the continuum of care necessary for people living with HIV/AIDS and their families.

There is an assumption that with ART, HIV/AIDS will become a manageable illness and that palliative care will no longer be necessary or applicable. Although patient care has been enhanced by ART, it has also been complicated by changing uncertainties involving therapy, adherence, side effects etc. Palliative care is therefore essential in the era of ART as it encompasses modern medical management of HIV/AIDS including prevention and treatment of OIs, treatment of cancers, intensive nutrition, life style management and ART.

Important notes to always remember:

ART does not replace palliative care. Palliative care plays a significant role in the era of ART as elaborated in this table:

- AIDS remains an important cause of illness and death in Sub-Saharan Africa and the need for comprehensive care is huge.
- ART is not always attainable due to lack of access. There is a need to provide comprehensive care to those who have no access to ART
- There are people who fail to respond/adhere to ART where palliative care becomes the priority management option
- Adherence follow-up – palliative care teams are positioned in such a way that they on adherence to ART at home but also palliative care addresses social issues that are vital to adherence such as identifying a treatment companion.
- Pain and symptom control remains a priority in PLWHA to be addressed by palliative care
- The management of OIs and concurrent illness in PLWHA
- Late initiation of treatment leaves palliative care is a priority option
- Dealing with the reactions and side effects of ART, as well as resistance
- Management of HIV/AIDS related cancers
- Management of AIDS-related disabilities that occurred before ART was started

8. Some general challenges for the delivery of palliative care in Africa

- The big need for palliative care services in Africa due to HIV/AIDS, cancer etc
- Extending coverage *whilst* ensuring quality
- Further recognition of the importance of palliative care in the different sectors e.g. MoH, Universities, Donors, NGOs, community etc
- Limited number of people trained to deliver palliative care
- Inadequate logistics and resources
- Availability of drugs and other resources
- Ensuring that palliative care does not get ‘watered down’ but is provided in an affordable and culturally appropriate way.

Identify some challenges for delivering palliative care in your country

9. Challenges for palliative care within the context of HIV/AIDS

- Complex Disease Process
- Complex Treatments
- Stigmatisation and discrimination
- Complex family issues
- Role reversal on families

- Burden on health care workers and community care givers

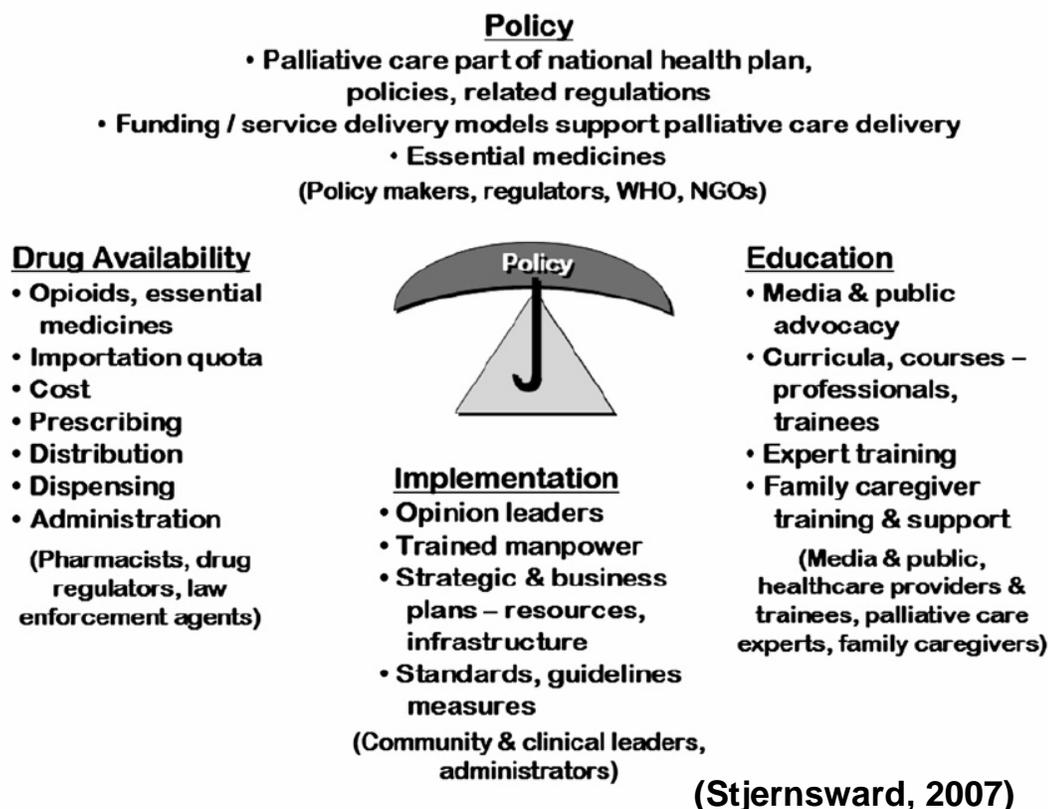
10. Some general suggestions for delivery of palliative care

- Palliative care should be integrated into all your existing services to patients and families
- Palliative care can be provided across a range of care settings and models including home, out reach, hospital etc
- Palliative care should be provided where possible by a multi-disciplinary team which includes community volunteers and traditional healers as well as nurses, doctors and other health care professionals.
- It is important for care givers to work closely with organizations delivering palliative care and to continue learning from them
- Co-ordination of activities through national associations and APCA is important for a greater impact in each country and the region.

11. What is needed for good Palliative Care?

- Attention to detail – this is obtained through a holistic assessment of the patient and family and understanding all the needs they have.
- A holistic tool should be used in assessment
- All service providers should be empowered with skills of delivering palliative care
- A multidisciplinary approach
- Use of the WHO public health model to palliative care. This is elaborated below.

WHO FOUNDATION MEASURES FOR PALLIATIVE CARE: THE PUBLIC HEALTH MODEL FOR PALLIATIVE CARE



12. The role of male care givers in palliative care delivery and training

- Provision of holistic care to the patient and the family or making appropriate referrals to ensure access to holistic care.
- Identification of resources available in the community that are relevant to patient care and making use of them e.g. religious leaders to support spiritual and religious needs, Community based organisations to provide support within their mandate e.g. Income generating activities etc
- Encourage and participate in training men to deliver palliative care in its true sense and to sensitise the community on the role of man in care giving.
- Act as role models for other men and the communities at large by providing good palliative care in an ethical manner.
- Linking patients and families to palliative care services and playing a key role in maintaining such links.
- Providing on-going education in palliative care to patients, their families and the communities.

13. Conclusion:

- Freedom from pain is a fundamental human right (WHO)
- The holistic approach can bring peace to those with terminal illnesses and their families even when approaching death

- Palliative care is affordable in if medicines are made available and health workers and other care providers are trained in Palliative Care
- Policy makers including the community local leaders are important in making palliative care available
- Implementing knowledge and skills obtained from any palliative care training is essential for ensuring its availability to those in need.

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SESSION TWO: MODELS FOR PALLIATIVE CARE DELIVERY

Learning objectives:

- Describe models of palliative care delivery available in Africa, and specifically in each country.
- Discuss the essential aspects for any effective palliative care delivery model/programme.
- Identify the role of male care givers in increasing access to services through the various palliative care delivery models.

I. Introduction:

Models simply mean ways or methods of delivering palliative care in this context. Palliative care can be delivered through:

- A specialist approach e.g. by a Hospice or
- A generalist approach as part of any existing health care services e.g. in hospitals, through existing home based care programmes for PLWHA etc

There are various ways in which palliative care can be delivered to the patient and the family. Some of those available in Africa are shared in this session. More specifically palliative care can be delivered through various creative ways and in different settings shared below:

- Home care
- Outreaches
- Roadside clinics
- District palliative care teams

- Hospital based palliative care teams/programmes
- Day care (facility based or community based)
- In-patient Hospices
- Links between community based volunteers and facilities/organisations
- NGOs, CBOs, FBOs

The whole package of palliative care i.e. physical including pain and symptom control, psychological/emotional, social and spiritual care can be delivered through the above methods/models in a culturally sensitive manner.

A single organisation or facility can use a combination of methods to deliver palliative care to PLWHA and their families and those with other life threatening illness e.g. Hospice Africa Uganda delivers palliative care through home based care, in combination with day care, out patient, outreaches and roadside clinics. Male care givers can link into all these approaches, working in collaboration with palliative care teams to ensure access to services.

2. Some models of palliative care delivery

i) Facility-Based Palliative Care



This includes palliative care delivery **at health centres, hospitals, outpatient clinics, inpatient units and hospices.** Facility based palliative care services can easily be extended to the community through home-based care, outreaches and day care programmes. PLWHA and their families should have ongoing access to medical care while at home, at

an outpatient clinic. This may be situated either within the hospital or at a location closer to where they live, such as a primary health care clinic.

Hospital-based palliative care teams are part of facility based palliative care. these see referrals in the hospital, commence on treatment, and then communicate with teams or care givers in the community to provide a continuum of care. they assess the patient whilst in hospital and advise on the continuum of suitable palliative care after discharge to the community. A number of hospitals have embarked on providing a

home care service themselves. However, hospices, FBOs and NGOs currently provide the bulk of home-based care.

Reflection:

1. Name hospitals you know in your setting which are providing palliative care services.
2. Which services do they provide?
3. How can you assist PLWHA and their families to access hospital based palliative care services

ii) Outreach services

- Outreach care is provided by specialist palliative care health workers who travel for a day from their health facilities to other centres beyond their catchment area to provide palliative care services closer to the community. Outreach teams usually see walk-in patients. However, bed ridden or too ill patients who cannot reach the centre may be visited at home.
- Outreach programmes give a chance to those who are ill or too far to reach the specialist palliative care provider to access care. They expand the geographic area a programme can cover.
- It allows palliative care providers to train, advise and support general health care providers and volunteers, attached to outreach sites in palliative care.
- A place of worship e.g. church or mosque can host an outreach clinic.

ii) Road side clinics

Roadside clinics happen when team members arrange to meet a patient or their relative at the side of the road to consult and give treatment. Such clinics can allow the team to see more patients in a day or to see patients outside the programme's catchment area. This method often leads to the development of more formalised outreach clinics.

As a palliative care team travels for the outreach clinic;

- Patients can be seen and provided with care at various locations along the way/road as agreed with their health workers. These locations may include; trading centres, schools, at a sign post, under the tree etc.
- Road side clinics allow for care at the community level, at a time and place convenient to the patient and his/her family.

iii) Day care

The aim is to provide the patient with some time out of home, and relieve the home carers by enabling them perform other duties rather than caring for the patient. Day care usually brings the patient and or carer from his/her home, to a facility or community environment. It usually happens once a week but frequency is dependant on the nature of setting or organization. Day can therefore be in two forms i.e. facility based or community based. In the community day car can be organised at a place of worship, a community centre etc.

- Services offered to patients include; entertainment, meals, medical care/nursing care, diversional therapy e.g. exercises, counselling, hand craft, etc
- Day care is usually organized by a team of volunteers and clinical staff
- Day care gives patients an opportunity to share experiences, coping mechanisms, challenges and benefits of palliative care, those related to their condition.
- Day care provides support for patients' psycho-social and spiritual needs.
- The patient chooses to be on the programme or not, based on the information provided and their physical ability to do so.
- Where possible, the patient is provided with transport
- Day care can be organized at a facility or in a community environment e.g. church or mosque. Day care may not be a stand-alone service, but it can be part of a comprehensive set of services.

Male care givers can have significant contributions in initiating day care services and mobilising community members to be part of such a programme, mobilising resources for the programme and ensuring its continued existence.

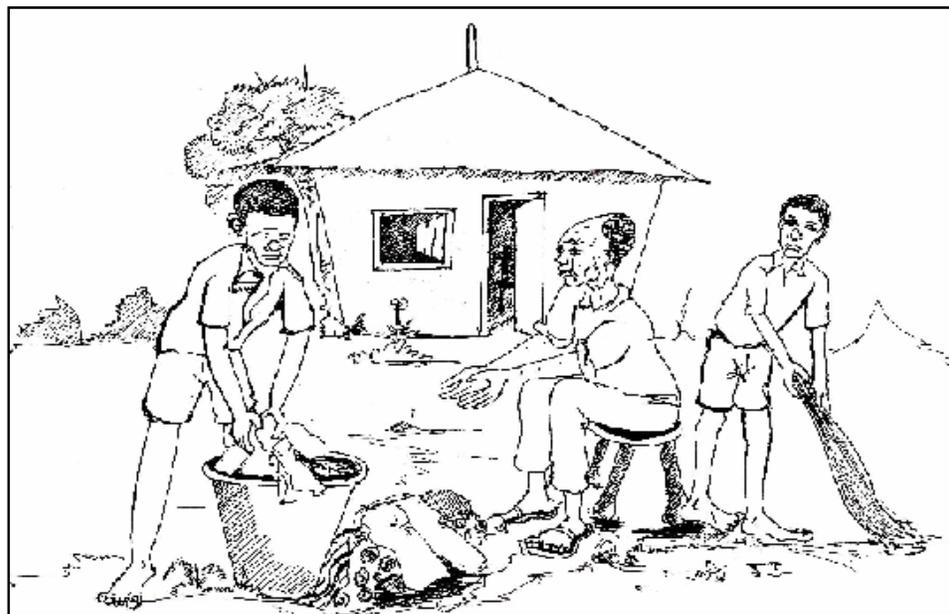


iv) Home Based Care (HBC)

All being equal, people with HIV/AIDS and their families prefer for care to be provided at home. (Kikule, 2003; Sepulveda, 2003). This statement derived from key palliative care studies in Africa emphasise the role of home based care in palliative care provision.

- Home- Based Palliative Care involves delivery of a comprehensive package of care to the patient and the family, at home.
- This package includes pain and symptom management, psycho-social care, spiritual care and other aspects of physical care including patient assessment and management and within their cultural context.

- It is important to be sensitive and respect the culture and beliefs of the patient and family.
- This form of care is provided by specialist palliative care teams, working in partnership with facility based health care workers, trained Community Volunteer Workers, spiritual carers and allied health professionals.
- Other stakeholders in provision of this care include; health professionals, the family and community members.
- Home based care may be provided by facility-based services like a hospice/hospital or by community-based services.
- Provision of home-based palliative care using an integrated approach of both facility based and community based services is a preferred model, since it allows the patients and their families to access comprehensive care, as well as utilizing all the available resources.



Two Community Volunteers assisting in the Patients' Home

v) Palliative Care for special populations

Children and the elderly are usually considered as special populations/groups in the provision of palliative care and are often mentioned in publications and programmes. However other groups such as the army, military and disabled persons are often forgotten. These groups have a right too to comprehensive services and should be reached with palliative care services. Palliative care to such groups may be provided through:

- Consultations from a palliative care team i.e. regular visits to their settings
- Training health care workers, allied health professionals and volunteers working with these groups to integrate palliative care in their services for PLWHA.
- Training these groups e.g. prisoners to participate in care provision for their colleagues.

Male care givers can advocate for the provision of palliative care services to special populations such as the prisoners with NGOs, CBOs, FBOs, public services and other programmes they link with, but also can participate in actual service provision to such groups.

3. What is important while determining the model to use in delivering palliative care?

The following questions are important in determining which model to use.

- What are the palliative care needs of the people you serve?
- Where are the people who need palliative care services?
- What are the current methods for delivering holistic care to PLWHA and their families within a particular setting?
- What resources are available i.e. financial, human, community etc?
- What model is suitable for your type of service?

For any effective palliative care programme/service the WHO Public Health Model/Foundation measures of ***education, drug availability, government policy/support*** and ***practical implementation of programmes*** using this model is important.

4. Role of male care givers:

- Have knowledge of all the models available in your setting and make appropriate referrals for PLWHA and their families
- Establish good relationships with teams providing services through these models and provide practical care with them in the communities.
- Share community palliative care needs with facilities/organisations providing care
- To be knowledgeable of and relationships about the continuum of care i.e. every point/setting where PLWHA and their families can access palliative care and be able to advise appropriately.
- Take a lead in the establishment and continued existence of community based day care programmes but also could provide services to patients attending facility based day care.

5. Summary and conclusion

- Current evidence indicates that using an integrated approach to delivering palliative care is effective. This includes the use of multiple models and ensuring a continuum of care for PLWHA and their families.
- It is important to deliver palliative care services using a method/model that is appropriate for those to benefit from the services. The best model is that one which suits the needs of the local people.

- Any effective palliative care programme should integrate services with ongoing education, and advocacy for palliative care including pain and symptom management and access for all PLWHA and their families.
- Recognition of a holistic and patient centred approach has opened many peoples' eyes to the need for good communication, a thorough assessment, a range of treatment options, and involvement of the patient and family in health decisions.
- Palliative care has helped people to see life as a journey in which death is a normal part of the process.
- Community involvement in care provision through all the models described above is essential and it contributes to the success and sustainability of services.
- Whatever model is used to provide services, it is important to aim to extend coverage for increased access while maintaining quality of services.
- Choosing an appropriate model for palliative care delivery requires a lot of creativity to ensure that even the furthest and poorest patient can be reached with services.

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MODULE 2.0: INTRODUCTION TO THE CONCEPT OF CARE GIVING

SESSION ONE: THE CONCEPT OF CARE GIVING:

Learning Objectives

- Define care giving and a care giver
- List the different types of care givers
- List the qualities of a care giver
- High light the challenges in care giving

1. Introduction

Concept of care giving is human and it is the humanness that makes us provide care. The magnitude of the HIV/AIDS has turned many people into carers. This is mainly because of the problems people have faced and also seen patients go through. The epidemic has increased the burden of caring. This burden can be minimized or made

easier if more male take on the caring role, which is thought to be a traditional role for women. Caring for HIV/AIDS patients calls for joint effort. Empowering male as care givers will provide skills and ease the heavy load of caring which women experience. Community care givers are a resource for effective delivery of palliative care.

2. Who is a care giver?

A care givers is some one who is available and willing to care for the sick person. Caring involves helping patients with their physical, emotional, spiritual, and social needs in culturally sensitive manner with human dignity and respect.

3. Types of care givers:

There are mainly two types of care givers; Primary and secondary care givers

3.1 Primary care givers include:

- Relatives
- Spouses/partners
- Friends
- Community volunteers
- Children
- People Living with HIV/AIDS

3.2 Secondary care givers include:

- Health professionals
- Counsellors
- Social workers
- Spiritual counsellors
- Psychologists

The two types of carers listed above can address the different aspects of holistic care of PLWHA. Holistic care involves supporting the physical, emotional, spiritual and social needs. Everyone listed above has a role to play in caring for patients living with life limiting illnesses.

4. Who needs Care?

All patients need care but more especially people living with life limiting illnesses i.e PLWHA, and or cancer. Caring for these people includes:

- Providing emotional and spiritual support to the patient and family.
- Providing HIV and AIDS care and support
- Providing education on nutrition, hygiene and preventive care
- Providing basic nursing care and helping with activities of daily living(feeding, bathing, dressing and toileting)
- Acting as advocates for PLWHA (link with community for resources, clinics and other health services, communicate with health professionals etc)
- Supervision of ART, TB, pain medications and other treatments
- Reducing stigma and discrimination by treating PLWHA with dignity and respect.
- Mobilising support for HIV and AIDS in the community
- Providing information on HIV, AIDS and ART
- Making appropriate referral for PLWHA

5. Qualities of a care giver

- Willingness to help
- Good listener
- Empathetic
- Tolerant
- Non Judgmental
- Trust worthy and maintains confidentiality
- Committed
- Gets along with others.
- Self respect and confident.
- Role model in the community

6. Why be involved in care giving:

People want to become community volunteers for different reasons. If you interview people you will get varied responses. In a rapid needs assessment for the capacity building needs of male care givers, men shared the following reasons which influence their decision and participation in care giving:

- Compassion for those suffering
- Recognition in the society
- Religious duty
- They want to pay back what they received when they themselves were sick.
- PLWHA feel a sense of commitment to others who are HIV positive
- They want experience in the caring role
- Volunteerism makes them responsible people in society
- It makes them popular in society
- Earns them leadership positions in society.
- It gives them a chance to develop self knowledge and skills in the caring role.

7. Challenges in care giving

The caring role poses a lot of challenges to caregivers and more especially to male care givers. These challenges can be discussed under three groups

7.1 Cultural Challenges

- In the African culture caring is seen as a feminine role
- Male care givers are seen to be taking a way the feminine role and are not easily accepted in the communities as care givers
- Men are not expected to undertake basic nursing care tasks

7.2 Caring related challenges

- Balancing between voluntary and personal time
- Heavy work load
- High expectations of clients
- Lack of clarity of what carers are expected to do.
- Lack of incentives
- Fear of infection
- Lack/inadequate support supervision from care giving organizations
- Lack of materials required to undertake the caring role

- Lack of recognition for their work
- Interpersonal problems with their clients
- Lack of space and privacy while caring
- Feeling of inability to make important decisions that affect for their clients and their work.
- Powerlessness to change some aspects of the clients problems
- Lack of transport to visit patents
- Hostile family members (i.e husbands, wives, relatives sometimes misinterpret male intentions related to care giving)

7.3 Challenges related to feelings or knowledge

- Facing death and dying and frustrations of others all the time
- Emotional attachment to PLWHA and their families
- Feeling bereaved and grieved all the time
- Not knowing what to do in some situations
- Spouses who don't want to disclose (Secrecy and fear of disclosure among PLWHA)
- The lack of knowledge and skills to provide effective care

7.4 Some ways to address challenges to care giving:

- Sensitizing communities so that they realize that the caring role is for both male and female
- Sensitize the community to accept male community care givers
- Train male care givers in basic nursing skill to engage in the caring role
- Realize and accept limits
- Always to share challenges encountered. This can be a learning experience for others as well.
- Communicate regularly with the health workers and consult regularly when in doubt
- Have a forum where male care givers can meet and share experience, learn and support each other.
- Have a support system in place

8. Conclusion

Men who have engaged in care giving have found it satisfying. Some say it has changed their lives positively, made them better husbands and fathers. However as you carry out this role you need to know your limits. Remember you don't have to do everything and you are not alone in this caring role. Always consult and communicate with the members involved in the caring role.

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MODULE 3.0: BASIC FACTS ON HIV and AIDS

SESSION ONE: FACTS ON HIV and AIDS

Purpose and objectives: The purpose of the session is to define HIV and AIDS and in order for the care givers to provide correct information to clients and community members who may require this information.

Learning objectives:

By the end of this session, the Male Care givers (MCG's) should be able to:

- Define HIV and AIDS
- Enumerate the mode of transmission of HIV
- Explain the risk factors for HIV transmission
- Explain in simple terms how HIV affects the body leading to AIDS
- Teach clients and community members on prevention of HIV infection

1. Defining a) HIV and b) AIDS

a) HIV: What is HIV? (Human Immunodeficiency Virus) HIV is found in human blood, breast milk, semen and vaginal fluids. HIV is a virus that attacks the body and makes it weak. When the body is weak, it is easier to get ill with cough, diarrhoea, fever and other health problems. HIV by itself is not an illness and does not instantly lead to AIDS. An HIV infected person can lead a healthy life for several years before s/he develops AIDS. It eventually causes AIDS (Acquired Immunodeficiency Syndrome), a condition in which a person is affected by a series of diseases because of poor immunity. You cannot tell by looking at someone whether he or she is infected with HIV or has AIDS. An infected person can appear completely healthy. However, anyone infected with HIV can infect other people, even if they have no symptoms.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) estimates that there are now 40 million people living with HIV or AIDS worldwide. Most of them do not know they carry HIV and may be spreading the virus to others.

2. Global summary of the AIDS epidemic December 2007 (UNAIDS)

Number of people living with HIV in 2007
Total 33.2 million [30.6–36.1 million]
Adults 30.8 million [28.2–33.6 million]
Women 15.4 million [13.9–16.6 million]
Children under 15 years 2.5 million [2.2–2.6 million]
People newly infected with HIV in 2007
Total 2.5 million [1.8–4.1 million]
Adults 2.1 million [1.4–3.6 million]
Children under 15 years 420 000 [350 000–540 000]

AIDS deaths in 2007 Total 2.1 million [1.9–2.4 million]
Adults 1.7 million [1.6–2.1 million]
Children under 15 years 330 000 [310 000–380 000]

The **immune system** is the body's defense system against diseases. White blood cells called **lymphocytes** play an important role in helping the body's immune system. **CD4** cells are a special type of lymphocyte. In HIV infection, the virus attacks the immune system. HIV destroys the special CD4 cells, and it is the loss of CD4 cells that leads to the weakening of the immune system. See Figure 1.

b) AIDS Definition: What is AIDS? As the name, Acquired Immunodeficiency Syndrome indicates, AIDS is a health condition that results from the deficiency in the body's immunity following HIV infection. HIV attacks the human body by breaking down its immune system that is meant to fight diseases. Over a period of time, the immune system weakens and the body loses its natural ability to fight diseases. At this stage, various diseases affect the infected person. There is no cure for AIDS. Treatment, care and support is, however, available for people living with HIV.

Understanding the Acronym:

- **Acquired** means a disease you get during life rather than one you are born with.
- **Immune Deficiency** means a weakness in the body's immune system.
- **Syndrome** means a group of particular health problems that make up a disease.

Common Myths and Misconceptions about HIV and AIDS

- Issues related to causes of AIDS
- Issues related to transmission e.g. by insects/mosquitoes and other sources
- Issues related to cure of AIDS by herbalists and other false products on the market
- Issues related to condom use. Effectiveness morality etc.
- Others

3. The Progression of HIV Infection to AIDS

The progression of HIV to AIDS refers to the time from HIV infection to the time when PLWHA develop AIDS. The progression of HIV to AIDS depends on individual circumstances and environment and is never the same in every person. The progression of HIV to AIDS consists of six major phases:

1. HIV Infection
2. Window Period
3. Sero-conversion
4. Asymptomatic Stage
5. HIV related illness
6. AIDS

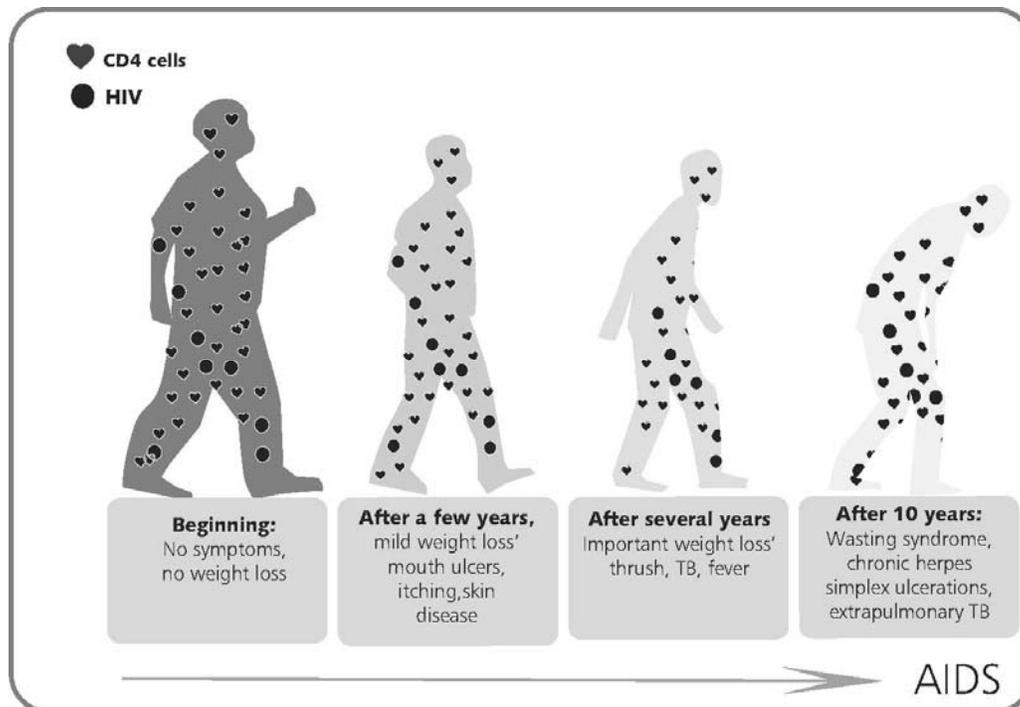


Figure 1. HIV progression. Source: HIV Prevention, Treatment, Care and Support- A training Package for Community Volunteers.

As time progresses, the hearts (CD4) decrease and the circles(HIV) increase. When the hearts go down and the number of circles go up, more problems arise. When more circles exist, infections become more serious and last long.

4. Mode of Transmission of HIV

- 1) Unprotected sex; vaginal oral or anal sex. This includes even people on Anti Retroviral Treatment (ART).
- 2) Direct contact with blood, or body fluids of an infected person. (Examples- Blood transfusion, intravenous drug injections, sharp instruments e.g. at the herbalist.)
- 3) From an infected mother to her child: During either i) pregnancy, ii) delivery or iii) breast feeding.

5. Factors Affecting Transmission

A. Factors that Increase Risk (Risk is any action or behaviour that increases the likelihood of exposure to disease/problems)

All sexually active individuals are at risk of contracting HIV, more so the presence of the following risk factors will definitely increase chances of infection.

5.1 Unprotected Sexual Contact

All unprotected sexual contact (oral, anal and vaginal sex) will enhance one's risk for HIV infection. The swelling or rupture of wounds on genitals caused by STIs increases

risk of infection during unprotected sexual contact

5.2 Drug Abuse and Alcohol Consumption

Drug use and alcohol consumption increases risky behaviors that can lead to HIV transmission

Sharing contaminated needles increases the risk of HIV transmission.

5.3 Multiple Sexual Partners and/or Casual Sex

Not knowing your HIV status or that of your partner places you at risk for HIV infection

Individuals who have multiple sexual partners or engage in casual sex frequently are at greater risk of HIV infection

When one or both partners are not faithful the risk of HIV infection increases for the individual and their sexual partners.

B. Factors that Increase Vulnerability

Due to their situation, some people may have limited choice about whether or not they can reduce behaviours that might put them at risk for HIV infection, thus they become vulnerable or have increased risk.

i. Social Mobility

HIV and AIDS often follow routes of trade and commerce (trucking routes, cross border trading).

Mobile populations can be at greater risk to HIV infection because they may not have a regular sexual partner. Sex work can also follow routes of trade and commerce, increasing risk of HIV infection among both sex workers and their clients.

ii. Stigma and Denial

Because of stigma and denial, people may not make use of HIV Testing and Counseling services to become aware of their status, or know the status of their partner.

iii. Conflict

- HIV spreads more easily in times of war or conflict
- Rape, use of sex workers and inadequate health care are situations worsened through war that contribute to the spread of HIV.

iv. Culture

- These are traditions, beliefs and practices that can influence the way people think and behave such as wife inheritance, polygamy, rites of passage and genital mutilation can increase risk if people are not well informed on how to reduce transmission of HIV through safe practices.
- Culture can promote denial or stigma of PLWHA.

v. Gender

- Gender inequalities increase the vulnerability of women to HIV infection (a

woman's ability to negotiate for safer sex or refuse sex, women forced to engage in transactional/ intergenerational/commercial sex).

- Abuse of young girls or boys.

vi. Poverty

- Poverty reduces people's ability to access accurate information on HIV/AIDS and how to protect themselves
- Poverty can force women into transactional sex to meet basic needs, increasing their vulnerability to HIV
- People living in poverty cannot always access medical care that reduces the risk of transmission (condoms, ARVs).

6. What Male Care Givers Can Do to Empower and Support People in Vulnerable Situations

Male care givers act as the first point of contact for many clients at the community level. They play a key role in assisting clients to problem solving by offering counseling and referral. MCGs can also educate the community on preventive methods and direct the communities to taking drugs.

7. Methods of Preventing HIV

The greatest tool is learning more facts about HIV and how to prevent or manage it.

7.1 Methods of Preventing HIV Transmission

The following are actions that decrease the risk of HIV transmission:

i) Safer Sex

- Abstinence (not having sex at all).
- Correct and consistent use of condoms - male and female condoms.
- Having sex in a **faithful** monogamous (one partner only) or polygamous relationship protects partners from contracting or transmitting HIV if they are not exposed to HIV through drugs or other activities
- Delaying sex is important in young people who may not be prepared or able to negotiate safer sex
- Avoid having multiple partners and/or casual sex
- Being aware of each other's HIV status and taking necessary precautions
- Non penetrative sex with no fluid exchange (mutual masturbation, kissing, cuddling)

ii) Prevention of Mother to Child Transmission (PMTCT)

PMTCT involves methods that help prevent a mother passing HIV on to her baby during pregnancy, child birth or breastfeeding

iii) Positive Prevention

Positive prevention aims to increase the self-esteem and confidence of

HIV positive individuals to protect their own health and avoid passing the infection to others.

Elements of Positive Prevention Include:

- Protection from HIV re-infection
- Disclosing HIV status to partners
- Engaging in safer sex
- Mothers preventing HIV from being passed to their children during pregnancy, child birth or breastfeeding
- Taking ARV medications consistently and properly
- Preventing other infections
- Taking Prophylaxis

vi) **Universal Precautions against Infections**

MCGs need to take steps to ensure no contact with blood and body fluids, for themselves and for the primary caregivers of clients. Keeping sterile medical equipment and taking all possible measures to avoid disease transmission and for self protection are called 'Universal Precautions' and should be used in every caring situation, whether you know your client's HIV status or not. Universal precautions not only help prevent the spread of HIV, but other infectious illness such as Hepatitis (Disease which causes jaundice or yellow eyes.)

- Do not share needles, toothbrushes, razor blades or other sharp objects.
- Cover any open cuts or sores on clients, partners or caregivers.
- Clean up any blood or body fluid with mild disinfectant (diluted bleach), and protect hands with gloves or plastic bags.
- Wash clothes or linen with blood or body fluid on them separately.
- Dispose of waste contaminated with body fluids safely.

If Caregivers Feel They Have Been Exposed to HIV Infection They Should:

Immediately wash skin or wound entry point with soap and water, then wash the area out with saline or mild disinfectant. Report to their local health facility immediately. Post exposure prophylaxis (PEP) maybe available or they will be referred.

Post Exposure Prophylaxis (PEP) are antiretroviral drugs (ARVs) that are taken after exposure to HIV transmission by blood or fluid contact with an HIV infected person. These drugs should be taken within 72 hours from the time of exposure to HIV infection.

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SESSION TWO:

VOLUNTARY COUNSELING AND TESTING (VCT) AND PREVENTION OF MOTHER TO CHILD TRANSMISSION (PMTCT): BASIC INFORMATION FOR MALE CARE GIVERS

Learning objectives:

The aim of this session is to provide MCGs with information about HIV Testing and Counseling that is important to provide to clients and for their own day to day work. Learning objectives include:

- Discuss the process of VCT
- Identify the forms of HIV counseling
- Describe how disclosure can be supported
- Discuss the importance of PMTCT and the role of male care givers

I. The Process of HIV Testing and Counseling

The most empowering aspect for people who use HIV Testing and Counseling services is that they will know their HIV status and will know more about HIV, AIDS, and their health. Whether they are HIV positive or negative, knowing their status will allow individuals to make important choices about their health and future (how to prevent contracting or transmitting HIV, health services available to them if they are HIV positive, important information on nutrition and health that will allow them to live positively for many years to come)

- Ongoing counseling and support is often made available to those who are HIV

Step-by-step of 'The HIV Testing and Counseling Experience':



Figure 2: The Testing and Counseling experience: Source IRC et al, 2006: HIV Prevention, Treatment Care and Support A training Package for Community Volunteers.

2. Client Initiated HIV Testing and Counseling

i) Pre-Test Counseling

Four main components that pre-test information should focus on include:

a) Explanation of HIV and AIDS: The counselor will discuss what HIV is, what will happen during the test and what the test results mean.

b) Explanation of confidentiality: It will be explained that it is the client's decisions whether or not they want to tell other people the results of their HIV test.

c) Confirmation of client's willingness to proceed with the test: HIV tests are never mandatory and clients have the right to refuse testing at any point.

d) Obtaining Informed Consent: To proceed with testing, **informed consent** must be reached between the individual and counselor. Informed consent means that the individual has been provided with important information about HIV and AIDS and HIV testing, has fully understood what has been discussed and based on this agrees to undergo an HIV test. If the person decides he or she does not want to take an HIV test after pre-test counseling, he or she is fully entitled to make that choice. Remember, HIV Testing and Counseling is voluntary and NOT mandatory testing.

Blood Sample

- If the individual chooses to have an HIV test, a small sample of blood will be taken safely and privately in a separate room
- In many tests used now, the person will be able to receive their results in a matter of minutes but this may take hours or days in other settings.

ii) Post-Test Counseling

After the test, the counselor will talk to the person alone about the results (it is

up to that person whether he or she wants to tell others his or her status)

a) If test result is positive and has been confirmed:

- Counselor explains that a positive result means the person has HIV.
- Provides information for ongoing care and arranging for follow-up visits.
- Provides advice on safer sex practices to avoid infecting others and avoid getting other sexually transmitted infections and/or harm reduction practices to avoid re-infection with another strain of HIV.
- Clients will be referred as needed to additional prevention and/or care services, including support groups and special services for vulnerable populations.

b) If test result is negative:

- Counselor explains that a negative result means the person has no HIV but also explains the window period and encourages the client to be re tested in 6-8 weeks if they feel they have been recently exposed within the same period.
- Client is counseled on the importance of staying HIV negative through safer sexual practices.
- Clients will also be referred to additional prevention and/or care services, including peer support groups and special services for vulnerable populations.

3. Supporting Disclosure

Disclosure is the process a person living with HIV goes through to tell others about their HIV status. This may include a partner, or other family members including children, friends, colleagues and members of the community. After an HIV positive test result, health professionals will discuss the advantages of disclosing their HIV status.

Disclosure of HIV status is important for the prevention of HIV transmission and for adherence to ART. If the client does not feel ready to disclose their status, the counselor will reassure them that their test results will remain confidential.

MCGs can play an important role in helping to support disclosure by clients e.g. providing practical support and guidance on how to go about it and sharing important information.

4. Prevention of Mother to Child Transmission (PMTCT)

PMTCT involves methods that help prevent a mother passing HIV on to her baby during pregnancy, child birth or breastfeeding. A mother undergoes VCT and then has the opportunity to receive additional care and support (including ART) during pregnancy and delivery and post delivery in order to minimize the risk of transmission to the unborn or newborn baby. For VCT the same facts as stated above apply.

4.1 The role of MCGs in PMTCT is:

- To **inform clients** (both men and women) that mother to child transmission of HIV can occur during: Pregnancy, At the time of delivery, After birth, through breastfeeding
- **Educate parents** about their options, and the implications for **the health of the mother and the baby.**
- **Prevent** unintended pregnancies among HIV-infected women, if family planning services are not available at your local clinic, refer the client so that s/he properly receives support and services to prevent unintended pregnancies.
- If only **one partner is HIV** positive (*These are commonly referred to as **discordant couples***), educate on how important it is to use **condoms** to prevent passing infection to the other partner.
- **For all people:** Remember that becoming infected with HIV during pregnancy and breast-feeding poses an increased threat to mother-to-child transmission. HIV prevention efforts must address pregnant and breastfeeding (lactating) women, especially in high prevalence areas.

An additional way that MCGs can help clients and family members to prevent mother-to-child transmission of HIV is to assist clients with family planning. This involves providing them with important information and referrals.

References

Helen Jackson (2002) AIDS Africa A Continent in Crisis. SAfAIDS

“Facts for Life: What you and the people **you care about need to know about HIV/AIDS”** http://www.amfar.org/binary-data/AMFAR_PUBLICATION/download_file/3.pdf

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SESSION THREE: POSITIVE LIVING

Learning objectives:

- Discuss the meaning of positive living
- Describe the important aspects of positive living and the general importance of positive living
- Identify the role of the male care givers in supporting positive living

1. What is Positive Living?

Positive Living is a concept, which stipulates that a person should have an optimistic attitude towards self and others. It involves having a positive outlook to living and life. It also means living responsibly with HIV. People with HIV infection can prolong their lives by making positive choices to care for their own mental and physical health. Positive living is also described as steps taken by PLWHA that enhance their lives and increase their health. The following are very important aspects of positive living:

- Nutrition
- Prevention of Other Infections
- Encouraging Physical Activity as appropriate

2. Important aspects of positive living

2.1 Physical care

i) Proper nourishment/nutrition

Educating PLWHA and their families about food safety is an important way for community based male care givers to assist in preventing other infections. Food safety is an important part of nutrition for PLWHA because:

- PLWHA are more likely to become seriously ill from food poisoning because their immune system is weakened and is less able to fight off infection.
- By causing diarrhea, food poisoning can lead to the loss of nutrients and fluids. It will be more difficult for PLWHA to recover from food poisoning due to their weakened immune system and it could put them at risk for malnutrition or opportunistic infections.

Having a balanced diet is an essential part of positive living. A person with HIV/AIDS needs to feed on foods with essential nutrients required by the body. These include:

- **Proteins:** both plant and animal proteins, which help repair cells of the body. Examples of animal proteins include meat, fish and chicken while examples of plant proteins include beans, peas and groundnuts.
- **Carbohydrates:** These are energy giving foods. They include maize, sugar, rice, millet, cassava and sorghum. The energy given strengthens the body and enables its systems to function well, adding to the body's capacity to fight infections including HIV.
- **Vitamins:** These are foods that give our body the ability to fight off infections. They repair our body cells and protect the body from infections/diseases. These are available from fruits and vegetables such as mangoes, jackfruit, cabbage, carrots, tomatoes etc.
- Water, Mineral salts and fats are important too.

Further details on nutrition in HIV/AIDS are included in module 10.0, topics 10.1 and 10.2.

ii) Prevention of Other Infections:

PLWHA already have a damaged immune system and it becomes more damaged if they pick up other infections. With a damaged immune system, they are more likely to pick up other infections and therefore should avoid environments/situations with such infections.

Avoiding STIs: It is very important for PLWHA to avoid STIs. This can be done in the same way as avoiding HIV infection, using condoms, reducing partners, abstinence, being tested and treated. STIs damage the immune system and so are not good news for someone with HIV. STIs increase the infectivity of someone with HIV. They also increase the vulnerability to HIV infection if negative.

Protection against malaria: Malaria is a life threatening condition and avoiding it helps PLWHA to remain well and healthy. Prevention of malaria is therefore a priority in positive living e.g. by use of treated bed-nets.

Other infections to prevent include water borne infections, chicken pox, measles, flu, colds etc.

iii) Encouraging Physical Activity As Appropriate

Doing light physical exercises:

Exercising the body regularly keeps the body strong and enables it to work well. This is so because exercises enable proper circulation of blood and oxygen to the different parts of the body, regulating body temperature and getting rid of unwanted waste products especially through sweating.

If the body is not exercised regularly, the muscles in the body tend to waste away and harden. This may lead to stiffness of joints with consequent aches and pains.

Exercise is important because:

- It can make the person feel better and maintain muscle tone.
- It stimulates appetite and prevents weight loss.
- It reduces nausea
- It improves functioning of the digestive system
- It strengthens muscles

Ways of increasing exercise: Walking, running, sporting, cycling, house work etc

Exercises PLWHA can do:

- They can do exercises they feel physically able to handle e.g. going for a walk with a friend, help with cleaning the house, collecting firewood or water etc.
- Relaxation exercises such as yoga and meditation are good choices for PLWHA at any stage of illness as they help a person mentally and physically, but do not place stress on the body.
- If the person is strong, exercises can be done 3 -5 times a week for approximately 30 minutes of continuous activity.

iv) Resting

PLWHA need to take enough rest or sleep. This helps to reduce the fatigue and stress on the already weakened body. It is healthy for a person to have at least 08 hours of sleep daily. People who find it uncomfortable to keep unoccupied can involve in handcraft work, listen to music, read, etc.

2.2 Medical Care:

A person with illnesses due to HIV infection needs to seek prompt medical attention. Most opportunistic infections that affect people with HIV/AIDS are treatable. Prompt treatment of these opportunistic infections reduces the severity of illness. Early diagnosis and treatment of infections retards the multiplication of HIV in the body. When a person's health is controlled he or she is in a better position to continue work, which will in turn help the person to plan better for the future for self and family. A person with HIV can get treatment from well-established government, mission and private clinics in and around the country.

Adherence to prescribed medications by the health care worker enhances the lives of PLWHA. It is important to stick to the instructions given by the health worker in relation to medications i.e. the time, the methods of taking it, respecting time for medical review etc

2.3 Avoid habits that endanger your health:

People with HIV infection should try as much as they can to avoid habits that endanger their health; such as smoking, drinking alcohol.

Taking alcohol and smoking cigarettes or intoxicating drugs such as spirits and marijuana weaken the body generally and can easily expose the person to various infections/health hazards that can affect the various organs/systems of the body like the respiratory system, liver and the brain.

Alcohol and drugs claim a substantial amount of a person's income and impairs his/her reasoning capacity, which hinders the his/her ability from making rational decisions thus exposing the person to accidents and renders him/her to reckless ways of life. They (alcohol and drugs) also reduce an individual's appetite for food, which denies the body the much-needed nutrition. This leads the person to complications such as peptic ulcers, diarrhea and vomiting.

2.4 Avoid having unprotected sex

Having sex without a condom leads to:

- Re-infection, which can increase the viral load, accelerates the reduction in immunity and subsequently precipitates illness
- Pregnancy, which weakens the health of the mother
- Increases the risk of Mother to Child Transmission on HIV
- Increases the risk of acquiring other STIs that tend to be aggressive in HIV infection
- Increases the risk of infecting others

Sex is tiring even to people whose immunity is not compromised, and if done frequently, it drains the already weakened body. Therefore it would be healthy to reduce the times that it is done.

2.5 Hygiene of the body and the environment

People with HIV should maintain the cleanliness of their environment and body.

i) The body

- Hair should be kept short and clean to avoid lice
- The mouth and teeth should be cleaned regularly with a soft toothbrush
- The skin should be washed and oiled regularly to avoid dryness and cracks
- Nails should be kept short and clean to avoid germs and bruising of the skin if scratched
- Clothes/beddings should be kept clean and free of fleas, lice and skin problems

ii) The Environment

The house, compound and households should be kept clean and free of disease carrying insects and animals. This means the house should be cleaned regularly to keep off flies, cockroaches, fleas, rats, ant, bedbugs, lice, etc.

Household utensils should be washed, dried and stored properly to keep them clean so as to avoid ailments as diarrhea.

The vegetation in and around the compound should be trimmed regularly and any places that encourage stagnation of water should be blocked/filled up with earth to keep off mosquitoes thus avoiding attacks of malaria

2.6 Psychological Care:

i) Counselling

It is important for the person to seek counseling in order to discuss any worries and problems that may arise. Counseling involves the person sharing out his/her problems with any other person they confide in. Usually a problem shared is a problem halved. Ventilating certain feelings e.g. anger and fears calms down a person and has a healing effect on them. Counseling services are offered almost at all AIDS service organizations in the country.

Psychological adjustment: *It is important for a person to accept the fact of being infected with HIV. This will help the person to have the will to live and look at the present and future with hope. Blaming oneself and others for your situation will not solve anything. Grieving over a situation renders the person helpless and lowers self-esteem. It is therefore good to maintain hope for the best in life.*

ii) Spiritual care

A person with HIV infection may at one time seek spiritual counseling. In such a case, the person should be given chance to have the counseling the way they wish. Spiritual counselors should take precautions not to use judgmental language. Prayers and praises should not relate to sorrow but instill hope. In addition the counselor should not force his/her religious beliefs and values on the client.

2.7 Socio-economic involvement:

i) Keeping busy

This involves the person to take on leisure activities like watching football, listening to music, visiting friends, relatives, watching films and reading newspapers. This makes the person occupied therefore keeping off unnecessary thoughts.

Apart from leisure activities it is important for the person to engage in income generating activities so as to be able to provide at least some basic needs to his/her family such as education to the children, food and shelter. This also helps the person to be self-reliant. Over depending on others for survival is problematic. So keep to your job until you are completely unable to continue with it.

ii) Fellowshiping/support groups

It is important for the person to get involved in constructive social gatherings such as churches, groups for People living with HIV/AIDS, sports/choir and other clubs. Apart from keeping the person active fellowshiping uplifts the person and increases their self-esteem. It also improves their self-image, which renews the confidence the person would have lost. During fellowshiping the person with HIV learns certain coping mechanisms from another one with HIV who could have gone through similar situations or experiences. This gives the person additional strengths to carry on with life. And this is commonly referred to as “peer support”.

2.8 Summary of the benefits of Positive Living

Physical and Medical care:

- Enables one to live longer and improve their quality of life
- Helps in prevention of HIV transmission to other people
- Helps transmission of opportunistic infections
- Protects individuals from getting re-infected with HIV
- Helps to improve adherence to programs such as ART and PMTC
- Enables one to have a strong immune system to fight disease
- Enables one to have energy to perform daily activities

Psychosocial

- Helps to effectively cope with HIV infection
- Helpful in confronting HIV/AIDS related stigma
- Helps to fight stigma and discrimination

2.9 Obstacles to Positive Living

- Stigma (People may not seek and use HIV/AIDS services because of stigma)
- Poverty (People may not afford good food for proper nutrition)
- Lack of information / awareness (people may not have access to information about positive living or whether they have HIV)
- Peer Influence (It may be difficult for some to adapt new lifestyles for fear of losing their friends)
- Workload (e.g. Others may be too busy to take their medication)
- Lack of access to services (People may have inadequate or no HIV/AIDS services in their communities, e.g in the islands of Uganda)

2.10 How can male care givers help PLWHA

- Encouraging positive living and sharing information on how it can be achieved e.g. prevention of other infections, good nutrition, exercises etc.

- Practical support to PLWHA to develop personal programmes for exercise i.e. what activity the person can do, how long, what else they need to facilitate exercise etc.
- Male care givers are well situated to influence positive living in the communities and should be role models for positive living, whether with a positive or negative status.
- Facilitating access to recommended foods e.g. through community networks.
- Making appropriate referrals for access to positive living services e.g. counseling.
- Identifying persons with difficulties in accepting their condition and helping them to adapt positive living strategies.

References:

1. IRC, SAfAIDS & WHO, (2006). "HIV Prevention, Care and Support. A Training Package for Community Volunteers"

SESSION FOUR: STIGMA AND DISCRIMINATION

Learning objectives

- To come to a common understanding of the meaning of stigma.
- To define self-stigmatization
- To come to a common understanding of the meaning of discrimination.
- Discuss the impact of stigma and discrimination on care and support for PLWHA and their families.
- Discuss the strategies for reducing stigma and discrimination at community level.

1. Introduction

HIV/AIDS is not only the greatest health challenge of our time, but it is also the greatest human rights challenge. Those aware they are HIV-infected shoulder the twin burdens of stigma and discrimination, which remain major impediments to preventing HIV transmission and providing treatment, care and support to people who are HIV-infected and their families.

HIV/AIDS related stigma is increasingly recognized as the single greatest challenge to slowing the spread of the disease at all levels including community/provider level.

The most effective responses to the HIV/AIDS epidemic are those that work to prevent the stigma and discrimination associated with HIV, and to protect the human rights of people living with HIV and those at risk of infection.

PMTCT Generic Training Package Participant Manual

2. What is Stigma?

Stigma refers to unfavourable attitudes and beliefs directed towards someone or something. HIV/AIDS related stigma refers to all unfavourable attitude and beliefs

directed towards PLWHA or those perceived to be infected and towards their significant others and loved ones, close associates, social groups, and communities.

Stigma is further described as a state of causing shame, disgrace, dishonor, humiliation, discredit, scandal discrimination neglect, embarrassment, isolation, rejection to PLWHA or affected with HIV/AIDS.

The process of stigmatization also includes the phase of ***self-stigmatization*** which, in the case of HIV and AIDS, leads to non disclosure and non access to care and treatment services.

Self-stigmatization is the shame that a person experiences on internalizing the negative responses and reactions of others.

Stigmatization is a ***process*** of devaluation i.e. the person stigmatized becomes unworthy, and that stigma in all its forms is a powerful tool of social control. By putting blame on certain individuals or groups, society can excuse itself from the responsibility of caring for and looking after such people.

2.1 Self stigmatization:

What are the consequences of self- stigmatization?

- It leads to depression, withdrawal and feelings of unworthiness.
- It weakens people's already depleted strength.
- It impedes openness about one's HIV+ status.
- It leads to isolation, even within the family context.
- It reduces a person's access to health care as he/she doesn't seek it.
- It impedes on prevention of HIV transmission and providing treatment, care and support to people who are HIV-infected and their families.

2.2. Examples of stigmatizing messages and attitudes:

- Believing that PLWHA indulge in immoral behaviors, deserve what they get or are being punished by God for their sins
- A person who refuses to buy food from a vendor who is HIV-infected or does not allow his family to use utensils used by a PLWHA
- Use of language e.g. "has that disease e.g. in Uganda referred it as *siliimu*", "walking corpse", "expected to die", etc
- Lack of knowledge and fear foster stigma e.g. lack of understanding between HIV and AIDS, equating HIV-positive test with imminent death etc
- Shame and blame are associated with HIV/AIDS – many people assume that individuals who are HIV-positive must have been infected through sexual activities deemed socially or religiously unacceptable i.e. relating to being promiscuous, careless, lack self control and therefore responsible for their infection

2.3 Stigma has made PLWHA be categorized as;

- People who deserve what they have become they are.
- Sinners
- Those people with loose morals
- Cursed people
- Disobedient group

2.4 Why are people with HIV and AIDS stigmatized?

- Due to lack of knowledge, information and understanding
- Ignorance
- Fear of becoming infected
- Because AIDS is a life-threatening condition
- Because it leads to lack of dignity
- Cultural beliefs because it is associated with behaviors that are already stigmatized i.e. specific sexual behavior
- Attitudes
- Social status
- Religious beliefs antiquated moral judgements
- Because HIV and AIDS is associated with some of the most elemental aspects of the human experience i.e. sex, blood, disease and death (in many cultures these are taboo subjects)

3. What is discrimination?

Discrimination is the treatment of an individual or group with partiality or prejudice. It is often defined in terms of human rights and entitlements in various spheres, including healthcare, employment, the legal system, social welfare, and reproductive and family life.

Discrimination occurs when a distinction is made against a person that results in him or her being treated unfairly or unjustly on the basis of their belonging, or being perceived as belonging, to a particular group.

Stigmatization reflects an attitude but **discrimination** is an act or behavior. Discrimination is a way of expressing, either on purpose or inadvertently, stigmatizing thoughts.

Stigma and discrimination are linked. Stigmatized individuals may suffer discrimination and human rights violations. Stigmatizing thoughts can lead a person to act or behave in a way that denies services or entitlements to another person.

3.1 Examples of discrimination:

- A person with HIV is denied services by a health care worker or any other care giver.
- The wife and children of a man who recently died of AIDS are ostracized from the husband's familial home or village after his death.
- An individual loses his job because it becomes known that he/she is HIV-infected.
- A person finds it difficult to get a job once it is revealed that he/she is HIV-infected.
- A woman who decides not to breastfeed is assumed to be HIV-infected and is ostracized by the community.
- In the work pace where job applicants have been forced to go for mandatory HIV/AIDS test before being considered for a job.
- In hospital where doctors would look for excuses not to see a client because of their HIV status.

- The insurance companies fear to give cover to people with HIV/AIDS because they are categorized as belonging to high -risk groups

Freedom from discrimination is a fundamental human right founded on principles of natural justice that should be universally applied to people everywhere. According to the United Nations Commission on Human Rights Resolutions, **“discrimination on the basis of HIV/AIDS status, actual or presumed, is prohibited by existing human rights standards.”**

Discrimination against PLWHA or people thought to be infected is a clear violation of human rights.

3.2 Areas where stigma and discrimination are practiced:

- Within families i.e. moral judgment and feelings of shame in having a family member infected.
- Within communities i.e. finger pointing, verbal abuse, refusing to rent accommodation to people infected, physical abuse etc.
- Within religious communities where PLWHA are seen as immoral people having behaved immorally.
- In schools and this is true even for children orphaned by AIDS (associated stigma)
- Towards women who are blamed for infecting others (double standards).
- In caring environments such as communities, health facilities etc - care givers who offer love and support to family members living with HIV/AIDS may also exhibit stigmatizing and discriminatory behaviour e.g. blaming and scolding although care givers do not recognize this behavior as stigmatizing.

Discuss in pairs examples of stigma and discrimination messages or attitudes you have heard or seen in your communities/settings:

- Through the media (newspaper, television, radio)
- Health services
- Workplace
- Religion
- Family
- Community

Examples of stigmatisation and discrimination

In the media

- Suggesting in the media that there are specific groups of people with HIV who are guilty (such as sex workers or injection drug users) whereas others (such as infants) are innocent.
- Depicting HIV/AIDS as a death sentence, which perpetuates fear and anxiety, and labels HIV as a disease that cannot be managed like any other chronic disease.
- Using stereotypical gender roles, which may perpetuates women’s vulnerability to sexual coercion and HIV infection.

In health Services

- Refusing to provide care, treatment and support to PLWHA
- Providing poor quality of care of PLWHA.
- Violating confidence.
- Providing care in stand-alone settings (such as clinics for sexually transmitted infections) that further stigmatise and segregate PLWHA.
- Using infection-control procedures (such as gloves) only with patients thought to be HIV-

positive, rather than with all patients.

- Advising or pressuring PLWHA to undergo procedures, such as abortion or sterilisation that would not be routinely suggested for others.

In the workplace.

- Requiring testing before employment.
- Refusing to hire people who are HIV-infected and HIV-affected.
- Mandating periodic HIV testing.
- Being dismissed because of HIV status.
- Violating confidence.
- Refusing to work with colleagues who are HIV-infected because of fear or contagion.

In the context of religion

- Denying participation in religious/spiritual traditions and rituals (such as funerals) for PLWHA.
- Restricting access to marriage for PLWHA.
- Restricting participation of PLWHA in religious activities.

In the family and local community

- Isolating people who are HIV-infected.
- Restricting participation of PLWHA in local events.
- Refusing to allow children who are HIV-infected or HIV-affected in local schools.
- Ostracising of partners and children of PLWHA.
- Using violence against a spouse or partner who has tested HIV-positive.
- Denying support for bereaved family members, including orphans.

4. Impact/effects of stigma and Discrimination on care and support:

Stigma is disruptive and harmful at every stage of HIV/AIDS continuum, from prevention and testing to treatment and support e.g. people who fear discrimination and stigmatization are less likely to seek HIV testing while person who have been diagnosed may be afraid to seek necessary care. PLWHA also may receive suboptimal care from workers who stigmatize them. Other effects of stigma and discrimination include:

- Reducing an individual's choices in healthcare and family/social life
- Limiting access to measures that can be taken to maintain health and quality of life (discourages positive living)
- Limits access to services – stigma and discrimination may discourage individuals from contact health and social services, thereby increasing the risk of transmission to partners or children. Even when services are available, people may not use them due to stigma and discrimination.
- Stigma can fuel new HIV infections e.g. by preventing people from getting tested, by making people less likely to acknowledge their risk of infection, discouraging HIV-infected people to discuss their HIV status with their sexual partners and with those with whom they share needles.
- Stigma may deter PLWHA from adopting risk-reduction practices that may label them as HIV-infected.
- Can lead to social isolation e.g. through such acts like rumours and gossip, ejection from the home, rejection by the community, and verbal abuse.
- Stigma and discrimination pose challenges to the delivery of PMTCT services where women may avoid replacement feeding because they will be labeled as HIV-infected if they are not breast feeding. Children of mothers who participate in PMTCT may experience secondary stigmatization because people assume that they are HIV-infected.
- Promotes violation of human rights e.g. the right to health care.
- Increases mortality rate
- Disintegration of families

- Increase number of street children and families
- Increase the burden on care givers and family careers
- Increase OVC and child headed families and people may not want to take over their care due to the association with HIV/AIDS
- Stigma and discrimination from others may result into self stigmatization

4.1 Secondary stigma (stigma by association)

This is a situation when stigma extends beyond the infected individual to stigma by association. An example is situations such as “if I sit near someone with AIDS, others will think I have AIDS too.” Employees of HIV/AIDS service organizations are sometimes seen as PLWHA. Male caregivers too come across such circumstances.

5. Dealing with stigma and discrimination in health care settings and communities: What male care givers can do:

5.1 At national level:

All HIV/AIDS programmes should address HIV/AIDS related stigma i.e. at national level, community, social and cultural level, PMTCT sites and at individual level.

- Stigmatization is a social process that can be addressed on the community level. It is therefore to involve the community in fighting stigma and discrimination.
- Support and advocate legislation that protects the rights of PLWHA as human beings and patients.
- Support and promote legislation that protects the legal rights of PLWHA e.g. health care, education, employment etc
- Advocate for laws supporting anti-discrimination policies or activities at local level.
- Support national efforts to scale-up treatment of HIV with ART for those in need and advocate for quality treatment programmes in the community.
- Encourage and bring on board PLWHA and their families to participate in national advocacy and in designing, developing and evaluating programmes and policies.
- Advocate for funding and the training and fellow male care givers, and for PLWHA to be included in education programmes.
- Invite local politicians and leaders to participate in care giving and to serve as role models to the rest of the community e.g. they can visit organizations providing care and acknowledge their good work, can test for HIV and encourage other community members to do the same.

5.2 At community level:

- Provide HIV/AIDS education and training to members of the community, especially key opinion leaders, traditional birth attendants, traditional leaders, religious leaders and family care givers.
- Increase community awareness of HIV/AIDS services available and support them to see their role and responsibilities.
- Mobilize social support for PLWHA i.e. community and family support.
- Build partnerships with social institutions in the community e.g. with churches, schools, CBOs etc as this will enhance sustainability and develop a broad base for services.

- Facilitate the exchange of ideas and information on HIV/AIDS by community members e.g. through social activities such as sports, drama etc.
- Encourage PLWHA to join together to challenge stigma and discrimination
- Support the establishment of PLWHA organizations and networks, including those that enable people to demand recognition and defend their rights.
- Sensitise PLWHA about their rights and support them in advocating for these rights.
- Help communities to reflect on the language used and attitudes which could result in stigma and support them to change this.
- Ensure patient confidentiality at community level and serve as role models to the rest of the community.
- Get to know the community well and ensure that misconceptions about HIV/AIDS are clarified.
- Facilitate peer and community support including support groups which are helpful in sharing experiences.
- Counseling and education for PLWHA about stigma and discrimination and why it should be fought.
- Training of community e.g. Church leaders, youth groups and women groups and men's groups.
- Bring all HIV and AIDS services into communities at community level, a good example of this is HBC and Home-Based Palliative care.
- Use PLWHA who are open about their status to work at community level in sensitization activities, as HBC volunteers, sharing their experiences.
- Work closely with religious leaders of all denominations. They are in positions of power as people listen to them and respect what they say. However, they are often the ones who actually increase stigma because of their misguided moral judgments.

6. Summary and conclusion:

- While stigmatization reflects an attitude, discrimination is an act or behaviour
- International and national human rights declarations affirm that all people have the right to be free from discrimination on the basis of HIV/AIDS status.
- HIV/AIDS –related stigmatization and discrimination may discourage PLWHA from accessing key HIV services and may also:
 - discourage disclosure of HIV status
 - reduce acceptance of safer infant-feeding practices
 - Limit access to education, counseling, and treatment even when services are available and affordable.
- Male care givers have a role in reducing stigma and discrimination in health care settings, in the community and at national level.
- Male care givers along with others in care giving should be role models in fighting stigma and discrimination at community level.
- It is important to involve PLWHA and community support in the fight against stigma and discrimination.

References:

1. PMTCT – Generic Training Package Participant Manual, 2006
2. National Community Women Living with HIV and AIDS (NACWOLA), Uganda (2007), Coping with Stigma. A Facilitators' Manual.

MODULE 4.0: BASIC NURSING SKILLS AND ACTIVITIES OF DAILY LIVING (ADL)

SESSION ONE: PRACTICAL ASPECTS

Learning objectives

- Identify practical care/nursing care aspects for PLWHA
- Demonstrate basic nursing skills relevant in providing care for PLWHA at home
- Discuss the importance of basic nursing care at home

1. Introduction

Nursing care is special attention given to a patient, with the aim of providing comfort and support, to improve his/her quality of life and the family within a facility setting BUT also within a home. All care givers, including male care givers can provide basic nursing care for PLWHA at home. It is therefore important for male care givers to have basic nursing skills as this enables the provision of practical care and passing on similar skills to the family members. PLWHA and with other life threatening illness, as well as their family members appreciate if basic nursing care is provided to them at home. Advantages of providing nursing care at home include:

- It facilitates the sharing of important skills with PLWHA and family carers
- Saves them the burden of going to the facility/health centre of hospital every time such care is required, some times there is no transport to do this or the patient is too weak to reach the facility.
- The patient and the family remain in a familiar environment, making it convenient for the patient and family.
- Providing nursing care to patients at home cuts down costs for the family

Please share examples of practical/nursing care which can be provided at home and share the advantages of providing such care at home.

2. Importance of Nursing Care

- Promotes hygiene thereby controlling other infections
- Minimizes further health deterioration
- Promotes better nutrition to the patient
- Enhances comfort
- Reduces pain and other distressing symptoms
- Improves the quality of life of the patient and family
- Creates awareness to a patient and the affected family members, about the patient's prevailing condition
- Creates interpersonal relationship between the care providers and the patient

PRACTICA/NURSING CARE ASPECTS:

I) WOUND AND STOMA CARE

Learning objectives

By the end of the topic, participants will be able to:

- Define a wound and a stoma
- Describe how to clean a wound and stoma
- Describe and demonstrate how to prepare the solution for cleaning wounds, and how to apply it

1. Definition of a wound

A wound is a tear or a break in the continuity of the skin or body tissue

Examples: Kaposi 's sarcoma wounds below



2. Causes of a wound

- Injury
- Operation
- Diseases

3. Types of Wounds

- Open
- Closed or inside

4. Characteristics of cancer wounds

- Usually don't heal
- Smelly if not treated
- They keep on growing bigger and bigger
- Bleed easily
- Irregular

5. STOMA

Is an opening into the abdominal surface e.g. of the bowel or Ureter and windpipe.

5.1 Causes of a Stoma

- Obstruction in the intestines
- Cancer of the large intestines
- Growth in the food pipe
- Obstruction in the air way

- Obstruction in the ureters
- 6. Dressing a wound or stoma**
- 6.1 Why dress a wound or stoma?**
- To kill germs and stop further multiplication of germs
 - To reduce bad smells and excessive discharge
 - To prevent pus formation
 - To aid healing
 - To make the patient feel comfortable
 - To protect the affected area from further injury
- 6.2 How to dress a wound**
- i) Preparing to clean a wound or stoma**
 A combination of the following can be used:
 Gauze, Cotton or piece of clean cotton cloth, Bandages, Rock salt/ savlon, Water, Paw paw/honey, Flaggy, Gloves/polythene bags, Colostomy bags
 Items for dressing should be kept as clean as possible. The solution for cleaning a wound should be locally prepared from rock salt if required.
- ii) Method for wound cleaning**
- Have a convenient place for cleaning the wound
 - Wash hands with water and soap
 - Prepare rock salt solution
 - Wear gloves if available or polythene bags on the hands
 - Have an extra bag ready for used dressings
 - Clean the wound from in outward movement and throw away the used pieces in another polythene bag.
 - Wipe off solution to dry the wound and area
 - Apply crushed paw paw / honey or crushed flaggy as required.
 - Leave the area open or cover with a light gauze to allow good air circulation
 Apply a thick dressing when necessary. i.e when the wound is bleeding or has a lot of pus.
 - Repeat it as required.
- iii) Care of the dressing materials:**
- Dirty dressings should be disposed off in the pit latrine or burned
 - Washable materials should be washed thoroughly in hot water with soap and boiled for five minutes, if possible.
 - They should then be dried in the sun and ironed before using again
- 7. Conclusion**
 It is important for individuals with wounds/stoma, to keep them clean to prevent bad effects and complications

With help of your facilitator, you can now practice how to clean and dress a wound or stoma including the preparing of the cleaning solution.

II) MOUTH CARE

Assisting with mouth care will help a patient to have clean mouth and this relieves discomfort, prevent mouth sores, bad smell from the mouth and make eating less painful. Mouth care should be done at least twice a day (morning and Night) and before and after meals.

a. How to care for the mouth

i. Brushing Teeth

If the patient is too ill or weak the male carer can help using the following steps:

- Help the person into sitting up position. Or if the person is not able to sit up help lift the head
- Place a towel under his/her chin
- Give a sip of water to moisten the inside of the mouth
- Use a tooth stick or soft bristled toothbrush. If this is painful use clean pieces of cloth from old cotton materials.
- Brush the teeth using gentle strokes starting at the gum line and moving to the edge of the teeth using toothpaste, toothpowder, or baking soda and water to clean the teeth
- Brush the cheeks, gums and tongue gently
- Try remove all food particles and crusted materials
- Rinse with cool water and spit into a bowl or basin placed under the chin
- If the person is Unconscious use a cotton pieces (put on the gloved finger and gently clean inside the mouth - rub along the teeth, gum and teeth). Let the person lie on the side to prevent choking.

ii. Denture Care

- If the person has dentures, remove them and clean using either a brush or cotton pieces
- Use cool water and toothpaste of his choice
- Do not soak dentures in a bleach use plain water to soak denture

iii. Lip Care

If the person's lips are dry, cracked, or sore

- Put a water soluble lubricant such as Vaseline, honey or Glycerin and borax on the lips
- Avoid oil based products such as Chap Stick and mineral oil on open sores as these may cause the sores worse

vi. Rinsing

- If the person is not able to get out of Bed, the mouth should be rinsed every two hours at the same time you do skin care. For unconscious person wipe the mouth with a piece of clean cloth.

b. Why mouth care?

- Mouth becomes dirty
- Mouth becomes smelly. This is unpleasant and affects the patient and carers
- Infections develop
- Patient has discomfort when eating
- Generally affects sense of well being
- Patient becomes more isolated / depressed

c. Causes of Smelling Unpleasant Breath and Mouth

- Poor/lack of proper oral hygiene
- Infection i.e. oral candidacies
- Dehydration
- Rotten tissue in the mouth (cancer, gum disease)
- Stomach problems
- Alcohol, Cigarettes,

d. Management

- Clean teeth with toothbrush and paste / or moistened cloth

- Mouth washes – salty water, bicarbonate (baking powder)
- Treat infections in the mouth i.e. oral Candidiasis
- Infection following cancer – give Metronidazole mouth washes
- Encourage fluids (if the person is able)
- Encourage well balanced diet
- Avoid spicy foods, Acidity fruit which will cause pain in the sores (can use straws to bypass sores in the mouth), Sodas, Avoid dry/hard foods (crisps, cassava bones etc)

III) BED MAKING AND BED BATH

Bed Making:

Normally a bedroom is a place where a person feels comfortable to rest and relax when tired, to sleep after a long day's work, cry when in distress and to have a quiet time when praying to God, etc. The room should be a pleasant environment, with good airflow, and enough light.

a. Useful items to keep in the room are:

- A chair
- A mat or small table to put the medicines, and other supplies on
- A small bucket or basin

b. Aim of Bed Making

- To make the patient feel comfortable and fresh
- To prevent pressure sores
- To make sure that the patient is in a tidy place

c. Equipment Required for Bed Making

If they are affordable, here are some items that are used in preparing a comfortable bed for the patient:

- A pair of bed sheets
- Blanket
- Pillows and pillow covers
- Bedcover (Not always)
- For patients with incontinence, plastic sheets and a smaller sheets to cover the plastic sheet are required
- Extra soft pillows for supporting aching or painful limbs
- Mosquito net

d. Bed Making

There are various ways of bed making. The condition of the patient will guide us to what type of bed to make.

For example:

- Patients with difficulty in breathing will need to be in a sitting-up position supported by two or more pillows.
- Patients who need to lie flat will need one or two pillows only.
- Patients with backache will need to lie on a hard surface.

e. The Act of Bed Making

This process may require;

- One or two people.
- Explaining to the patient what is to be done.
- Handling the patient gently, as he/she already has pain.

- Inquire where the worst pain is especially when turning the patient
- f. **Bed Making with the patient sitting up.**
 - Get extra pillows and then fold the sheet in three parts.
 - Change the bottom sheet from top to bottom.
 - If there are two carers making the bed, they should support the patient alternatively
 - The top bedding can also be folded in three parts, but remember to leave the patient covered at all times with a sheet or a piece of cloth.
- g. **Bed making with the patient lying flat.**
 - Roll the bottom sheet length-wise and then change the bottom sheet from side to side.
 - Rolling the patient onto one side and then the other, to improve accessibility without the patient leaving the bed
 - If the patient has a leaking wound, a plastic and small sheet is necessary

IV) BATHING AND TOILETING

BATHING:

Bathing is an important part of patient care and offers both physical and emotional comfort. For PLWAH losing the ability to bath and take self to the toilet can be very frustrating and stressful. Helping individuals to bath and to go to the toilet is an important aspect of practical care, although sensitive. While undertaking this form of support, care givers should respect the dignity of the patient at all times.

Please get into pairs and share some challenges male care givers may come across while providing practical care in a home such as bathing a patient or helping the to go to the toilet.

How can you maximize comfort and dignity for the patient in providing such care?

a. Helping some one who is strong enough - How you can offer care

Someone who is strong enough and able to move about can be helped to wash in a bathroom. Giving the person an opportunity to do it themselves, this promotes independence.

Preparation and bathing:

- The patient can be bathed while seated on a chair
- Ensure safety of the bathroom e.g. availability of bars for holding on
- Gather all the things which are required before helping the person into the bathroom e.g. clean clothes, soap, sponge/face towel, body towel, Vaseline/lotion etc
- Ensure warm water is available if required and check the temperature to make sure it is appropriate.
- Help the person get into the bathroom
- Allow the person to wash as much as possible. You may need to help with the back, legs, feet

- Allow the person to wash the genital area as most people fear to expose it. Assist if the person is unable
- Offer assistance out of the bathroom and help to dry
- Help the person into clean clothes

b. Bed Bath - How you can offer bed bath

Someone who must stay in bed will benefit from a bed bath every day. As well as providing cleanliness, it helps refresh the patient. Although a bed bath can be given at anytime, often people who are ill have more energy in the morning. Ask the person what time would be best. Raise the level of the bed if this is possible to lessen the strain on your back.

i) Important steps in bathing a bed bound patient

- Gather all equipment/requirements needed, for easy reach for yourself or the patient.
- Minimise the number of relatives in the room for privacy and comfort of the patient
- Prepare the patient by explaining the procedure
- Explain to other family members when starting the procedure and involve them where necessarily. Always wash your hands and put on gloves, when necessary.
- Close the windows/draw the curtains and close the door, to provide privacy.

ii) The actual bathing process

- Strip the bed and cover the patient with a sheet or a suitable cloth.
- Expose only the areas you want to wash at a time.(If the bedding is soiled follow the steps for handling soiled beddings)
- Help the patient into a suitable position
- Protect the bed with a plastic sheet
- Place a basin of warm water on the stool/table; try to ensure that the patient can reach toilet articles
- Permit the patient to bath self if the condition allows. Leaving the room for a short time is also encouraged especially when the patient is able to manage on his/her own.
- When the patient has finished bathing to the extent possible; return, change the water and complete the bath by:
 - Washing the patient's back
 - Attending to the patient's feet
 - Taking care of pressure areas
 - Cutting the finger and toe nails
 - Helping the patient to put on clean clothes
 - Making his/her bed
 - Helping with the combing or shaving, when required



- Encourage to cleaning the mouth, if unable to do it for him/herf
- Leave patient in comfortable position

iii) Other things to remember

- Remember shaving, make-up and brushing and styling hair are important parts of care and will help the person feel more comfortable. Often a rest before and after these activities will help prevent the person from becoming over-tired.
- Use a gentle soap on the skin, then rinse and dry.
- Start at the face and work down towards the feet.
- Wash the genital and anal areas last and remember to ask for the patient's permission before you clean these parts. It is important that these areas be cleaned well at least daily as bacteria tend to collect there. Wash between the persons legs from the front toward the back. Rinse well.
- Apply lotion if desired after drying an area.

iv) Clearing the materials/Items used

- Remove all things used during the bath
- Leave the area clean and neat
- Pour away the waste water
- Wash and hang to dry any piece of cloth, towel and containers used during the bath
- Keep soap and other items used for the next use
- Remove plastic gloves, then wash and dry your hands

Special issues to be handled in a sensitive manner:

Gender issues – there are sensitivities around male care givers helping female patients with bathing. You can train a family care giver to help with this practical aspect or invite a female care giver to help. If you are to do it, you must make sure it is fine with the patient and family and also that it will not be misinterpreted by the patient, family and the community.

Living conditions - Availability of clean water, crowded household or distance to facilities to make regular bathing and toileting in the community could affect the dignity of the patient and strategies need to be devised to simplify the process for the patient and family.

Conclusion

- Try to keep the bed dry
- Straighten out creases and remove crumbs
- Try to make the patient as comfortable as possible and ensure that pain is minimised.

TOILETING:

Elimination - Is a process by which the body removes waste products.

a. Types of waste products:

- Faeces
- Urine
- Sweat
- Body discharge
- Sputum
- Vomitus

b. Routes of elimination

- Defecation
- Passing urine
- Sweating
- Discharging
- Coughing
- Vomiting

Toileting -Defecation

This is the act of passing stool-faeces. The person may need help to use the toilet. A commode, a urinal or bedpan depending on their mobility can be used. Respect the dignity of the patient when helping with toileting and ensure privacy. If the patient is able to go to the toilet offer whatever help is needed and stay near by.

What you can do to help with toileting:

- Keep toilet floor dry for safety
- Place toilet paper or its equivalent within reach
- Give privacy if the person can be left alone
- Allow time as needed
- Help with wiping up as needs

You can also educate the family care giver on these steps.

Urinals - These are small collection bottles that men can use to collect urine.

Some men use the urinal while standing and the other prefer to use when sitting.
(In the absence of specially made urinals you can improvise with ordinary plastic bottles)

Bedpans - Most people find it difficult and awkward to use a bed pan, but if a person is not able to get out it may be necessary

Commodes - Commodes are portable toilets in a form of a chair .They can be positioned dose to a bed of the patient who is able to get up but too weak to walk up.

V) POSITIONING/TURNING/TRANSFERRING SOMEONE IN BED

If a person is completely bedridden, too weak to move, is paralyzed or is unconscious then this person is termed as a bedfast patient. Changing the position of a bedfast patient in bed is a most important task. Long periods without moving can lead to pressure sores which are a serious problem. Also changing the position in bed helps keep the person's lung free of mucus and can help to ease pain and breathlessness.

Who is a Bedfast Patient?

The bedfast patient is one who cannot move out of bed and everything is done for him/her. A bedfast patient is no longer upright and active. This affects the circulation of blood resulting into a number of problems.

Reasons to be a bedfast patient

- Severe weakness.
- Severe illness on and off
- Paralysis due to spread of cancer to the bones of the back.
- Damaged bones due to spread of cancer.
- Stroke

Transfer of a bed ridden patient:

If the person is unconscious or unable to weak to move, people can help with the moving (transferring).

When transferring from the bed to chair

- Roll the client on one side

- Move the client to the side of the bed
- Hold your hands on the persons pelvic or ask the person to rise his/her buttocks
- Stand in front of the person and hold both shoulders keep persons feet flat on the floor
- Transfer from bed to chair Hold client from shoulders and knee
- Remember that if you lose your balance it is better to keep person fall gently
- Move all obstacles from your path way
- Call for help when you are not able to help the patient alone

VI) PRESSURE AREA MANAGERMENT FOR THE BEDFAST PATIENT

Care of pressure areas includes care of the bed,

- Frequently changing of bed sheets and keeping them dry, smooth and free from crumbs.
- Lifting the patient carefully and positioning him/her well in bed, for comfort.
- If able, should sit for some time to relieve the pressure areas.
- Help to move and exercise the patient's limbs, to assist in good blood circulation

Management of incontinence

Incontinence is inability to control urine or stool

- If incontinence occurs, it is necessary to keep the patient clean and dry at all times by changing beddings frequently or using polythen papers to protect the bed or receive urine in case of a male patient. as
- If possible help the bedridden patient sit up in a chair from time to time

When changing position in bed lift the patient rather than dragging as it breaks the skin

Bed Sores

- Look for damaged skin on the pressure area points i.e. Back, Shoulders hips everyday
- Use soft materials available under the sick person.
- Change the position of the sick person in bed every 2 hours
- Bed sores are difficult to manage once they have developed

Who is at risk of getting bed sores:

- emaciation (wasted patients),
- Very weak patients who can not turn in bed by themselves
- Unconscious patients
- Incontinent patients (patients who can not hold urine of faeces)



VII) SKIN CARE:

Management of Itchy skin:

- Itching skin is very common. It can be due to infection or body reaction to any irritant
- You can help the sick person get relief by trying any of the following:
- Cool the skin or foment it
- Avoid heat or hot water on it
- Avoid scratching
- Cut finger nails short
- Use cool cloth soaked in water Apply aqueous cream or Vaseline on the itching part of the body and a bath before drying.
- Use table spoon of vegetable oil in 5 litres when washing the sick person
- Apply cucumber or wet tea bags in the itchy area

VIII) FEEDS AND FEEDING

Feeds - These are different types of food and drinks given to people in order to keep them healthy..

Reasons for feeding

- Feeding for pleasure
- Good nutrition
- Good body build up
- To replace used food in the body
- To prevent hunger
- To boost immunity

Reasons for failure to eat include:

- Loss of appetite, - occurs in most of the patients with advanced disease.
- Difficult in swallowing
- Mouth surgery or mouth sores
- General dislike for food-
- Constipation - makes the patient lose interest in eating more food
- Depression - A patient in low mood and loss of self esteem may find it difficult to eat
- Serving of the meal - Too much food on a plate affects patients' appetite

Important points to note:

- The patient's reducing intake of food/fluid, is usually disturbing to the carers/family.
- This is mainly because eating has a very special symbolism as well as meaning in the African culture.
- When a patient has good appetite and stable body weight, it is considered as a sign of good health.
- Failure to eat may be a bigger problem for the family because they might think that the patient is going to die of hunger
- Explanation to the patient and relatives plays a very big role
- Before feeding place patient in a comfortable position
- Show care, love and patience to the patient
- Food should be served in small portions at a time
- Encourage patients to ask for the food of their choice
- Relatives need to be advised to eat together with the patient

- In case there is vomiting, drugs can be given
- When the patient's condition deteriorates, give only what can be tolerated e.g. fluids

IX) BREATHLESSNESS

It is important for male care givers to know how to help a patient with breathlessness and to be able to support the family in managing this condition.

Breathlessness is an unpleasant sensation of being unable to breathe easily it comes as a result of disease to the lungs, Severe anxiety, obstruction to the main bronchus, or abdominal distension

Feeling breathless can:

- Increase the breathlessness
- Cause fear and lack of understanding
- Panic
- Increased anxiety and increased respiratory rate

How to help a breathless person

- Reassurance the person that you are there to help him/her
- Open windows to allow in fresh air

Encourage him/her to relaxation

If it is hot you may fan with news paper or a clean piece of cloth

Ask the person to breath with you

Consult a health worker if the condition persists

Safe handling and disposal of sputum

- Handle sputum with care to avoid spreading infection
- Use a tin with ash or sand in it for the sputum
- Keep it cover all the time
- Empty container in the pit latrine and wash with detergent such as Jik or Omo or with boiled water

X) MEDICATIONS

Most persons have many medicine prescribed and it is essential that these medicines are handled carefully and accurately. Educate the patient and the carers at home how to handle the mdications.

a. Role of the Male Care Giver:

- Teach the patient to take drugs on time
- Encourage the family members to support the as he takes the medications i.e give or remind him/her to take the medication on time.
- Count the drugs on every visit to make sure that the patient is taking them correctly
- Advice patient and family to keep drugs appropriately i.e stored in a cool dry place and out of the reach of children
- Check the Expiry date of the drug

SESSION 4.2 INFECTION CONTROL AND UNIVERSAL PRECAUTIONS (PEP)

Learning objectives

By the end of the session, participants will be able to:

- Define infection control and Universal precautions and identify the sources of infection in a home
- Explain the purpose of universal precaution and methods used.
- Demonstrate the ability to provide client and their families with accurate information on universal precaution
- Provide clients and family care provider with knowledge and skills to provide prevention care

What is infection?

It is a condition where there is presence of germs in the body causing illnesses.

Family members/carers are getting infected unknowingly because of lack of knowledge.

It is therefore important for Community volunteer Workers, to educate the family carers on how to handle their loved ones, without getting infection

Sources of infection in the home

- Body secretions i.e. vomit, stool, sputum, blood, urine or soiled dressings.
- Used unspecialized sharp instruments e.g. razor blades, safety pins, tooth brushes.
- Skin diseases e.g. open sores
- Shared clothes and beddings
- Shared utensils
- Contaminated food
- Air inhalation
- Pets e.g. cats, dogs, chicken

The person living with HIV/AIDS has a weak immune system and can acquire opportunistic infections easily; therefore universal precautions should be taken in a home to prevent infection from spreading from one person to another.

Precautions for infection control:

Hygiene

- Disinfection
- Safe handling of sharp/piercing instruments
- Waste disposal

UNIVERSAL PRECAUTIONS

What are universal precautions?

Are simple infection control procedures that reduce the risk of transmitting infectious agents through exposure to blood, body fluids and contaminated medical or other type of equipments among clients family member and health care workers. The community care worker should take precautions while caring for client whether you know if they are HIV positive or not

Prevention of infection

Home hygiene

- Keep patient/client's room dry and clean
- Minimize dust and air particle infection, by sprinkling water before sweeping
- Keep patient's beddings aired and clean regularly
- Use water proof material (mackintosh) in cases of incontinence of urine or stool
- Observe general cleanliness to the home
- Good ventilation in the room
- Drinking water should be boiled and stored in clean containers
- Avoid food poisoning
- Maintain proper disposal of waste products
- Disinfect equipment and materials in the home

Personal hygiene of the patient

- Brush teeth, bathing, cutting nails, shaving and washing the hair
- Wash hands before eating and after visiting the toilet
- Use clean clothes and beddings
- Avoid sharing skin piecing objects
- If diagnosed with T.B, avoid sharing utensils in the first few weeks of taking medicine

Care givers Hygiene

Wash hands with soap and water before and after caring for the patient/client

The nails should always be cut short

The hands should be washed after visiting the toilet and after attending to the patient/client

Important points:

Reassure the caregivers that there is an extremely low risk of getting HIV/AIDS through caring activities if the following universal precautions are taken:

- Wash hands with soap and water before and after caring
- Wear gloves when contacting blood or body fluid
- Keep wounds covered
- Clean up blood, urine, faeces with ordinary household bleach i.e jik
- Clean cutlery, linen, basins etc with ordinary washing products
- Keep clothing's and sheets stained with blood diarrhea or other body fluids separate from other household laundry
- Use a piece of plastic, paper, gloves or a big leave to handle soiled items
- Do not share toothbrushes razor, needles, or other sharp instruments that pierce the skin. properly disinfect tools that are used for caring

All care givers should observe universal precautions while maintaining the dignity of clients.

Universal precautions are not needed with casual household contact

Questions for reflection:

1. What is the purpose of universal precautions?
2. What are the methods for universal precautions?
3. When are universal precautions not required?

POST EXPOSURE PROPHYLAXIS (PEP)

Refers to a method of preventing the uptake of HIV after being exposed to transmission by blood or fluid contact with an HIV infected person. For PEP ARVs should be taken within 72 hours from the time of exposure to HIV infection.

What can caregivers do if they think they have been exposed to infection?

Questions for reflection:

1. Discuss the availability of PEP in your country
2. If PEP is available, discuss how male care givers can access it and the national protocols.
3. Discuss the importance of universal precautions in preventing exposure to HIV infection.

Precautions taken before PEP OR immediately after exposure

- Wash with soap and water any wound or skin site in contact with infected blood or fluid then wash out with saline or mild disinfectant
- Rinse eyes or exposed mucous membrane thoroughly with clean water or saline
- Report immediately to the hospital or clinic in charge of PEP and follow local PEP protocol.

Conclusion:

Male care givers have got an important role in the provision of basic nursing care to PLWHA in partnership with their family members. Additionally male care givers are well positioned to educate and pass on practical and basic nursing skills to the family care givers.

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MODULE5.0: PSYCHO-SOCIAL ISSUES IN ADULTS AND CHILDREN

SESSION ONE: COMMUNICATION AND COUNSELING IN ADULTS

Learning objectives:

By the end of the module, participants will be able to:

- Explain the counselling concept
- Describe the counseling process and demonstrate ability to apply it in real life situations.
- Explain positive attitudes and communication skills in counseling and general communication

1. Introduction

Counselling and Communication are integral part of every day life. In palliative care, effective counselling and communication play a vital role in caring and managing chronically ill patients. Therefore, male care givers need to be able to offer counselling and communicate effectively in order to deal with the needs of patients and their families. This module focuses on counselling and communication skills for male care givers while offering care and support to patients in chronic care.

2. What is counseling?

Counseling is a special form of interpersonal communication through which a patient is facilitated to make changes or adjustments in their attitudes and behavior by empowering them to make appropriate decisions and to act on them with the aim of helping them either to solve, reduce or to cope with their situation/problems.

- Counseling is a process but not a one time event
- Who should do counseling: someone with good communication skills, someone with the interest and time to help people with problems?
- Categories of people who need counseling - every one with chronic illness such as cancer, HIV and AIDS requires counseling including all his family members

Counselling is interpersonal communication through which a person is helped to assess hi/her current situation, explore more of his/her own feelings and be able to cope with appropriate interventions.

It is a dialogue between a person with a problem(client) aiming at enabling the client to cope with stress and take personal decisions related to HIV/AIDS

2.1 Importance of counselling

- Provide factual information on HIV infection and disease
- Provide social and psychological support to anyone with a chronic illness affected by HIV.
- HIV infection causes fear, loss of hope and helplessness that calls for psychological support

- Counselling leads to positive living.
- Reduces self-stigma and discrimination
- To prevent the spread of HIV infection
- Facilitate adherence to medication

2.2 Categories of people who need counselling:

- Children, adolescents, adults, married people, the engaged, HIV positive person persons who are terminally ill etc
- People who may be worried about their sero status
- Person who knows his/her sero status and wants partner to take an HIV test
- A couple with discordant results
- Person with many sexual partners
- Person who wants to disclose sero status to important other like partner, friend, parent, sibling
- Person diagnosed with HIV/AIDS
- Persons diagnosed with cancer
- Relatives and family of Cancer and AIDS patient
- Caretaker of cancer patients and PLWHAS
- Person who has lost the partner
- Children of the infected parents
- Client who wish to start ARVs
- Persons who are raped or sexually assaulted.

2.3 Qualities of a good counsellor

- Approachable
- Kind
- Good communication skills
- Presentable
- Compassionate
- Respect others
- Role model
- Honest

2.4 When and where should counselling be done

- Private, quiet place without interruptions
- When it is convenient to the client and they have consented to it
- When time is available for both the client and counsellor

3. THE COUNSELING PROCESS

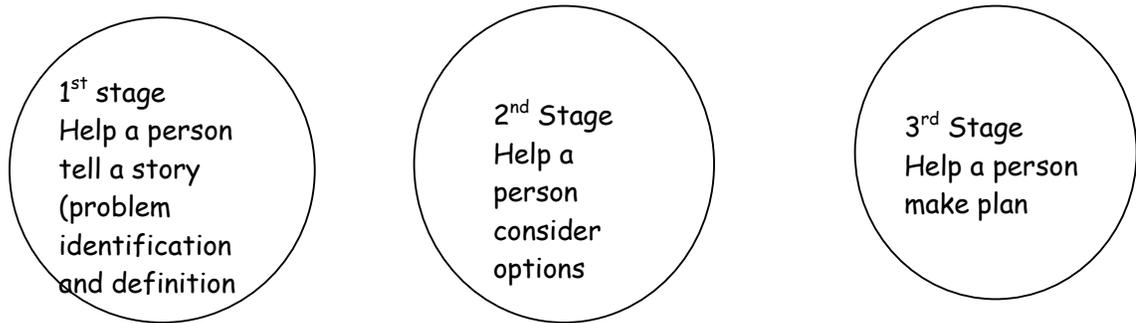
3.1 Learning points:

The Counseling process has three main stages based on positive attitudes and communication skills

Stages of counseling process:

- *Helping a person to tell the story*
- *Helping a person examine the possible options to deal with or solve the problem*
- *Helping a person make a plan*

3.2 Stages in counseling plus positive attitudes and communication skills



Positive attitudes	Knowledge area	Communication skills
<ul style="list-style-type: none"> ■ Empathy ■ Caring ■ Confidentiality ■ Non – judgmental ■ Acceptance 	<p>Knowledge area</p>	<ul style="list-style-type: none"> ■ Listening ■ Checking understanding ■ Asking question ■ Answering questions

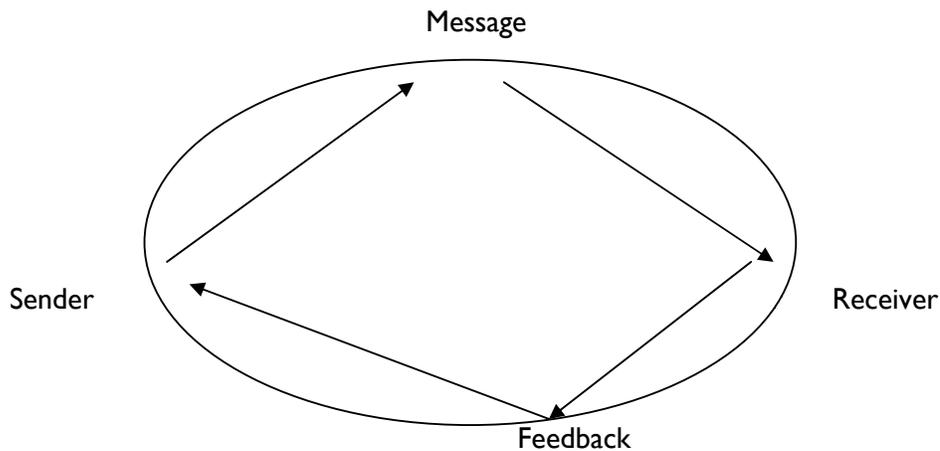
3.3 Characteristics of client centred counselling

- Client sets the priorities
- Counsellor provides option not solutions
- Involves having a dialogue. The counsellor does not lecture
- Counsellor shows respect for the client
- Counsellor is non-judgmental (does not moralize or preach)
- Shared authority and expertise. Counsellor does not always know the best
- Make joint plans based on individual or couple situation
- Empower the client other than letting them feel helpless

4. COMMUNICATION SKILLS AND POSITIVE ATTITUDES

Communication is a two way process between two or more persons in which ideas, feelings and information is shared with the ultimate aim of reducing uncertainties and clarifying issues. It is a two way street- only becoming complete when there is a feedback.

It is **a two Way Street** – only becoming complete when there is a feedback.



Palliative care requires use of good communication skills while counselling to facilitate healing and coping mechanisms. Both verbal and non-verbal communication is important while sending the message and receiving feedback. Communication in palliative care is seen as a therapy, which is used to help the patient to either cope or solve the problem.

4.1 Communication involves:

- Paying attention to the other person
- Being a good listener
- Being aware of non verbal communication
- Using clear and suitable language
- Asking appropriate questions
- Making sure that you have understood

4.2 Common ways of communication:

- Talking/Speech
- Body and hand movements-body language
- Writing
- Drawings and pictures
- Music, dance and drama

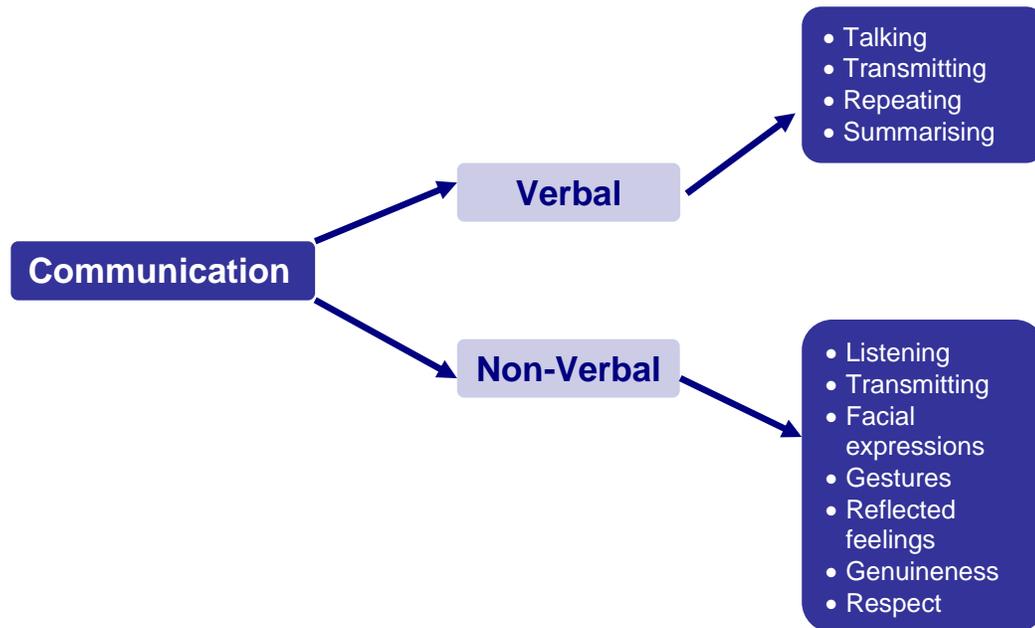
4.3 Types of communication

1. Verbal communication

This is the exchange of ideas through spoken or written expression (use of words)

2. Non-verbal communication

This involves the expression of ideas, thoughts or feelings without the spoken or written word. This generally expression in form of body language that includes gestures and facial expressions.



Both verbal and non-verbal form the basis of inter-personal communication.

Body Language

This is an extremely important part of communication and includes sitting at the same level as the patient (without any barriers), maintaining eye contact and having a suitable facial expression. It can include nodding and appropriate mannerisms. It is important that we observe the patients' body language as their facial expression and bodily position may reveal much more about how they are feeling than what they are saying.

4.4 Four major communication skills are,

- Active listening
- Checking understanding
- Asking questions
- Answering questions

i) Active Listening

- Active listening refers to the ability to hear and understand messages patients and families are communicating.
- It is an art, a skill, a discipline and therapy that is developed through practice. It is based on hearing with interest and understanding what others say to us.
- To listen one has to be very attentive to what others say to them.
- The patients' messages may be verbal or non-verbal.
- Listening involves empathy and understanding the content of both the verbal and the non-verbal messages.

- Active listening is an essential part of communication, and can considerably enhance the patient's quality of life.
- Through body language i.e. nodding, appropriate facial expressions and eye contact, techniques such as repeating and summarizing this will show that you are listening to the patient.
- These techniques can be summarized in one word '**ROLES**'- the indicators of attention:

R-elax
O-penness
L-ean forward
E-ye contact
S-it near (comfortably near)

- Using minimal responses, include short phrases like mm, then, uh huh, short actions like nodding, repeating a few key words or even silence. These show that the health professional is attentive and understands what the patient is communicating.

Reflection on Listening

You are not listening to me when.....	You are listening to me when
<ul style="list-style-type: none"> ▪ You do not care about me ▪ You say you understand before you know me well enough. ▪ You have an answer for my problem before I've finished telling you what my problem is ▪ You cut me off before I've finished speaking. ▪ You finish my sentence for me. ▪ You find me boring and don't tell me. ▪ You feel critical of my vocabulary, grammar, or accent. ▪ You are dying to tell me about something. ▪ You tell me about your experience, making mine seem unimportant. ▪ You are communicating to someone else in the room. ▪ You refuse my thanks by saying you haven't really done anything. 	<ul style="list-style-type: none"> ▪ You come quietly into my private world and let me be. ▪ You really try to understand me even if I'm not making much sense. ▪ You grasp my point of view even when it's against your own sincere convictions. ▪ You realize that the hour I took from you has left you a bit tired and drained. ▪ You allow me the dignity of making my own decisions, even though you think they might be wrong. ▪ You do not take my problem from me, but allow me to deal with it in my own way. ▪ You hold back your desire to give me good advice. ▪ You do not offer me religious solace when you sense I am not ready for it. ▪ You give me enough room to discover for myself what is really going on. ▪ You accept my gift of gratitude by telling me how good it makes you feel to know you have been helpful.

(Source: **Hospice Palliative Care Association of South Africa, 2005**)

ii) Paraphrasing (Checking understanding)

It is important to check whether you have understood. This lets the person know that you have been listening attentively while checking your own understanding.

The three basic ways of checking understanding are:

- Paraphrasing the patient's story
- Summarizing the patient's story
- Identifying and reflecting the person's feelings and emotions from patient's story.

iii) Asking questions

- The use of questions is an important and effective skill in communication.
- Questions need to be used purposefully both for the patients benefit and for the benefit of the helper.

iv) Questions should be asked with the aim of:

- Getting information
- Assessing knowledge
- Directing and focusing decisions
- Getting a deeper understanding of the person's problem
- Prioritizing issues
- Setting the pace of the dialogue with the person seeking assistance
- Showing that we are trying to understand the person and the problem better

v) Questions can be categorized in to three types and these include;

1. Open-ended questions

- These questions invite a person to talk and explain a situation.
- These questions offer a variety of possible responses and they normally begin with '**W**' plus one '**H**'. (**What, Why, When, Which, Where and How**).
- e.g. **What makes you feel bad?**
- Allow time for expression of feelings - **How did you feel when you were diagnosed with cancer?**
- They give control to the patient e.g. **What prompted you to come for an HIV test?**
- They are not restricting.
- It gives them chance to express their feelings and concerns.
- No assumptions are made in open-ended questions.
- Thought provoking and challenging
- Allow further exploration of the patient's feelings – **What worries you most**

2. Closed ended questions

- These are brief and restricting questions.
- They are used for obtaining factual information.
- These questions ask for confirmation or denial.
- They are answered with either Yes or No e.g. **“Are you in pain?” “Does this part of your body hurt?”**
- The control is with the care provider but not the patient.
NB. These questions are for obtaining facts, checking available information and not for knowledge of feelings.

3. Leading questions:

These types of questions imply the following;

- The preferred answer - suggest a desired response e.g. **“I know you must be feeling a lot of pain aren’t you?”**
- The patient has no control over response – e.g. **I bet you are using a condom aren’t you (only a brave one will disagree).**
- Assumptions are made– e.g. **“I guess you are worried about the operation and that’s why you cannot sleep isn’t it?”**

vi) **Answering questions**

When answering questions, it is very important to understand that behind every question there is a story therefore it is good to be honest and to give accurate answers:

A few things must be done as listed below:

- Give correct information
- Provide clear and simple information
- Check for understanding or misunderstanding
- Respect and reinforce important information

4.4 **Meaning of positive attitudes:**

Attitudes are the way a person perceives a particular situation or a person’s opinion towards something or someone.

There are four basic attitudes in communication and these also apply in counseling.

i) **Non Judgmental**

- This means treating people as they are and not condemning them.
- Treating them with respect, dignity, avoid criticizing and condemning them.
- While observing this positive attitude in communication, it is important that you avoid relating the patient’s problem to his/her own beliefs, values, norms and culture.

ii) **Confidentiality**

- The health professional should not reveal any information that he/she gets from his/her patient.
- The health professional can only reveal information after getting consent from the patient.
- Confidentiality for verbal and non- verbal information must be kept!
- Every patient has a right to confidentiality and it is important that they feel secure as they communicate with male care givers.
- This contributes to freedom of expression and ability to pour out their heart during the counseling and communication process..

iii) **Empathy,**

- Putting oneself in the patient’s “shoes” by understanding and accepting the patient’s situation.
- It involves listening and understanding the patient’s situation thus giving the male care giver deeper understanding patient’s problem and thereafter a better helping process.

iv) **Caring**

This means giving someone attention or being concerned about one's well-being. We show care by being approachable, welcoming, showing interest etc. It entails making the patient feel at home and showing interest in what they say.

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SESSION TWO: COMMUNICATION AND COUNSELING IN CHILDREN

Learning objectives:

- Define communication with children
- Explain basic communication with children
- Explain principles for effective communication with children
- Identify barriers to communication with children
- Explain different Tools & Media used in communication with children
- Demonstrate acquired skills and techniques

1. Introduction:

Although there are different types of counseling, each relies on **communication** as the basic tool for bringing about change in a person's feelings and behaviors. Children like adults need the therapeutic support to enable them with challenging circumstances that they face. **Counseling = communication**

What do you understand by communication with children?

Communication with children is the use of age appropriate language to facilitate both the passage of information to the child and expression of their feelings

2. What is so different about communication with children?

Children are unique... they are not small adults

They have physical, psychosocial and spiritual needs that are different and our responses need to be different than those we would give to adults

3. Communicating and counseling children requires building a therapeutic relationship and creating good rapport that involve the following:

- Trust- a trusting relationship between the care giver and the child leads to a successful therapeutic support

- Safe place-The counseling environment needs to safe and quiet to allow free sharing
- Confidentiality – Information shared with the child should kept confidential and only shared with their consent.
- Family focused- Because children live in families their families need to be involved in care.
- Child centered.
- Non-judgmental
- Culturally sensitive

Meeting the child at their level is very important while counseling and communicating with children and young adolescents.

Group discussion:

Group 1: Explain principles for effective communication with children

Group 2: Identify barriers to communication with children

Group 3: Explain different Tools & Media used in communicating and counseling children.

4. Principles in counseling and communicating with children

- **Family involvement** :Ensure family involvement or other significant adults in the care of the child; regular family meetings are important to bring about change

- **Patience**

Communicating well with sick children takes time; develop patience and make the time you have with the child COUNT.

- **Participatory approach** :Include children in their care, **Speak with the child and not to the child**, teach them about their illness, prepare them for the impending death in case their parents or important others are terminally ill

- **Freedom To Express**

Allow children to express their worries and anxieties through play, drawing, songs or other activities.

- **Honesty**

NEVER lie to a child! A child's trust in those who are caring for him can be destroyed, future care will be feared and their anxiety increased!

- **Respect:**

Respect children for who they are with an non-judgemental attitude. Do not ignore the child's viewpoint

5. Barriers to effective communication and counseling in children

- Language: inappropriate age level
- Adult's failure to come to a child's level

- Wrong message/wrong information
- Lack of active listening
- The assumption that the child is too small to understand

6. **Consequences of barriers Miscommunication**

- Misinformation
- Mistrust
- Anger and frustration
- Isolation
- Blame
- Denial

7. **Tools and media for counselling and communicating with children**

- Young children express themselves best with play
- Language is still very concrete
- Do not have words to express feelings easily, as these are more abstract qualities
- **Drawing and play** are best ways for young children to communicate thoughts and feelings

Play is a language for young children

- For children play is a child's natural medium of expression
- Adults talk
- Children play
- Adults use words
- Children use toys

8. **Therapeutic communication with the older child**

- Telling or writing stories
- Drawing
- Music and dance
- Drama

Case scenario:

Rose 10 years old stays with her mother; father past a way last year to AIDS. Rose's mother is currently bedridden; she has been diagnosed with cervical cancer and she is also living with HIV and AIDS. Rose looks depressed, she is refusing to eat and she does not want to go to school.

During home visiting Rose's mother expressed her concerns about her daughter's behavior.

As a male care giver offer counseling support to Rose

Reference

1. Tindyebwa D, Kayita J, Musoke P et al (2006) Handbook on pediatric AIDS in Africa. ANECCA.
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3. AIDS Relief & RCQHC (2008) : Psycho social care and counseling of HIV infected children and adolescents: Training manual – Un published

SESSION 5.3 GRIEF, LOSS AND BEREAVEMENT IN ADULTS

Learning objectives:

- Define basic concepts of grief, loss, mourning and bereavement
- Discuss the reactions after Loss/grief
- Describe the types of grief
- Describe how AIDS grief is unique.
- Discuss how to generally help the bereaved, and the role male care givers can play.

1. Introduction

There are key concepts that we need to understand so as to do better bereavement counselling to adults and children. These are: Loss, grief, mourning and bereavement.

Loss: It is a situation where some one is deprived of something or some one that is significant in his/ her life. The various types of Loss include: Loss of a person/ loved one, Loss of property, loss of sight, body part e.g. a limb, a run, sight, virginity, dreams or hope for the future, loss of a relationship.

Mourning: This refers to a state of showing sorrow or regret for the loss of some one or something. It is the social face of grief or external/public expression of a loss/grief e.g. crying or wailing. This expression does not necessarily relate to the significance of the loss; it is usually related to cultural and religious values and encourages social support for the mourner.

Bereavement: This is a state of being deprived of or loosing some one or something dear to you. It is a situation to anyone who has lost a person to whom they are attached. It is a state of having suffered a loss. This incorporates the period of adjustment in which the bereaved learns to live with the loss. The root of the word “bereaved” means to be robbed of something valuable.

A bereaved person is one who has lost someone or something dear to them.

Grief: it is a normal, dynamic process that occurs in response to any type of loss. The process encompasses physical, emotional, cognitive, spiritual and social reactions to loss. It is highly individualised, depending on the person’s perception of the loss and is influenced by its context and concurrent stressors.

It is a situation that contains thoughts, feelings and behaviors that are a result of bereavement and mourning. It is the psychological and emotional reactions to bereavement. Grief can be further described as:

- A painful emotional reaction to a loss/ intense sorrow. It is internal questioning and making sense of what has happened.
- It is a normal response to loss and is part of a healing process that helps a person to let go of the past and adjust to the present and the future.
- It is not a “form of weakness” or “lack of faith”
- Grief can be hard, stressful and tiring, but is not an illness

- The process of grieving begins as soon as a person is diagnosed with a life threatening illness such as HIV or cancer in anticipation of multiple losses. This type of grief is called anticipatory grief.

Anticipatory Grief - Grief that occurs in advance of an impending death. Both the patient and the family members and friends experience anticipatory grief.

2. Typical Reactions to normal grief:

Grief is normal when someone realizes that death has occurred and acknowledges this intellectually and emotionally. Normal grief lasts a few hours to days and at least two to 12 weeks.

2.1 Emotional and cognitive reactions

Emotions may change from time to time. This is normal and will settle with time.

The range of emotional and cognitive reactions may include:

- Shock, numbness, emptiness
- Withdrawn or explosive moods
- Anger, rage
- Denial, disbelief
- Frustration
- Guilt, regrets
- Yearning, searching
- Sadness, depression, despair
- Loneliness, isolation
- Forgetfulness
- Fear
- Feeling overwhelmed and worthless
- Anxiety
- Restlessness

2.2 Behavioral and mental Reactions

These might be feelings the person has never experienced before such as:

- Crying
- Feeling slowed down
- Loss of interest
- Increased use of alcohol, cigarettes drugs
- Making more mistakes than usual.
- Seeking memories of the deceased
- Loss of concentration
- Increase use of distraction such as TV, Radio
- Hostile Outburst
- Confusion, "this cant be real"
- Day dreaming
- Nightmares, dreams of loss

2.3 Interpersonal and social reactions

When someone is grieving, she/he can as if she/he is alone in understanding the importance of their loss. They may require the support of others, yet be unwilling to allow them to get close because of the belief that no one can appreciate what they are going through. Such feelings may include:

- Unrealistic expectations
- Lack of interest in other's activities
- Withdrawal from others
- Dependence on others
- Fear of being alone yet with isolation and loneliness
- Disorientation
- Loss of security and feeling out of place with previous friendships
- Feeling stigmatized/avoided
- Feeling presence of deceased
- Changes in social networks
- Family role changes
- Rushing into new relationships

2.4 Physical reactions

- Tight chest and palpitations
- Gastro intestinal disturbances
- Sleep disturbances – trouble to sleep or sleeping too much
- Loss of appetite, overacting
- Loss of energy, weakness
- Manifestation of symptoms experienced by the deceased
- Tightness in the throat
- Shortness of breath
- Dizziness
- Headache
- Diarrhea, constipation, vomiting
- Restlessness
- Decreased sexual drive
- Crying, sighing
- Dizziness, shivering, faintness

2.5 Spiritual reactions

Irrespective of their beliefs, PLWHA may go through a period of deep spiritual upheaval and reactions may include:

- Blaming life, self or others
- Lack of meaning or purpose in life
- Wanting to die
- Continuing to ask “why did this happen?”
- Blaming or feeling separation from own spiritual or religious power

3. Types of grief:

3.1 Normal grief – as discussed in previous sections

3.2 Anticipatory grief – defined in section one above

3.3 Abnormal grief/complicated grief:

Abnormal or Complicated grief: Complicated grief reactions last longer or are more severe than normal grief. For those grieving from AIDS-related death, there are many risk factors for complicated grief. This is common in both children and adults. It is always caused by or due to lack of psychological support structures,

which would enhance normal grieving process. The end results of complicated grief to the victim include: depression, aggression, petty crime, social withdraw/ isolation, harming oneself or suicide, anger, rage, etc

- Abnormal grieving occurs when painful emotional reaction is prolonged, delayed, unresolved over a long period of time.
- When the bereaved doesn't accept the loss.
- When there are prolonged emotional reactions for more than six months.

i. Symptoms of Abnormal/complicated Grieving

- Having signs and symptoms of the deceased person.
- Easily gets depressed and cry.
- Having strong feeling of guilt and blame.
- Feels angry and cuts off from family and friends.
- Frequent suicidal ideas
- Psychological disorders e.g. anxiety

ii. Who is at risk of abnormal/complicated grief and how is it manifested?

- A person who is not able to complete grieving the process may not be capable of showing love to others e.g. a parent who has lost a child and still has other children. The other children may be neglected.

iii. Types of abnormal/complicated grief:

Delayed grief: The individual makes a conscious and successful effort to avoid grieving as it is too painful or there are too many responsibilities or there is no time to grieve. This is very common to individuals who get caught up for example with funeral arrangements and other necessary logistics. This situation may make the survivors over occupied, and in so doing it ends up affecting the normal grieving process. In delayed grief, grieving starts after more than two weeks and it is more severe and more prolonged.

Blocked grief/Inhibited or Absent grief: there is no evidence of grieving despite the reality of death. The individual is either denying death or actively blocking the reality because it is too painful. This is always due to the survivor's failure to accept the death or loss. In most cases they are in a denial state. This blocks normal expression of feelings or thoughts in relation to the loss. This may happen in young children or the elderly and can lead to hyperactivity, irritability and depression.

This type of grief can be managed with guided mourning and grief work.

Aborted grief: This total failure to grieve for the loss of a loved one or something. This may be due to a situation where the care givers deliberately refuse to tell the children what happened to their loved ones. They instead always tell them that their parents live in a distant place or country yet they really died. Yet some people or neighbors could be telling them the fact of their parents' death. This puts the child in a dilemma because he/she fails to know which is right and wrong. This situation may make some children or people abort the grieving process.

Chronic grief: Usually develops normally and increases and there is no evidence of any reduction of grief over the months or years. Individuals show features of recent bereavement even years later. The nature of the relationship may have been over-dependant and could lead to anger and guilt.

Oscillating grief: the individual allows grief to emerge but realises that it is too painful and actively suppresses the grief and pushes it back. This succeeds only for a short while and the grief emerges again. It takes a huge amount of mental energy which eventually runs out causing anxiety and depression.

4. Why AIDS related grief is unique, complex and different

Discuss this in pairs

Some answers:

- The care giver might be HIV positive as well and the grief might spark off threats of personal loss
- The societal reaction to it, and the compound nature of the burden it brings to society.
- Stigmatisation
- Lack of social support
- Caregivers Stress
- Fear of being infected
- Mourners who are HIV+

5. Factors that influence the magnitude of grief/risk factors for abnormal or complicated grief

- **Relationship with the deceased:** The more the attachment the more the pain the survivor experiences e.g. loss of a spouse, adult child etc
- **Mode and type of death** especially when it is sudden/unexpected, for example: murder, suicide, accident, disaster, miscarriage, stigmatised e.g. AIDS death etc.
- People with depressive illness, **unsolved or exaggerated or inadequate grief** will often have more time of grieving for longer time than those with out such history.
- **Concurrent stresses** that result from the crises, which always rise following death of a loved one, for example in a situation where the deceased was the provider.
- **Vulnerabilities** – such as low self esteem, no close relationships, other life crises, inability to carry out important rituals etc

For complicated or abnormal grief, it is important to make appropriate referral to health care workers for further medical evaluation.

6. Markers of Normal AND Abnormal grief: Common signs of stress

Normal grief	Abnormal grief
<ul style="list-style-type: none"> ▪ Accept death emotionally ▪ Present at deathbed, funeral etc ▪ Able to get rid of belongings apart from momentos ▪ Able to visit grave at sensible intervals ▪ Express grief ▪ Able to connect with good memories 	<ul style="list-style-type: none"> ▪ Unable to accept death emotionally ▪ Avoid dying process, viewing body, funeral etc ▪ Unable to get rid of belongings ▪ Maintains a shrine, too few, too many photographs ▪ Avoid or over do visits to the grave ▪ Cannot connect with good memories, but occupied with unpleasant events ▪ Maintains contacts, conversations with the deceased ▪ Hallucinations, illusions ▪ Preoccupied with thoughts of the deceased

7. Important to remember

- Everyone grieves differently and there are no quick fixes or set of ways to grieve
- The pain of loss never goes away but lessens over time, patience through bereavement support is therefore essential for a care giver
- People may deny the fact of death to protect themselves from the pain of grief
- Grieving is a normal process in response to a loss
- Peoples response to loss varies according to cultures and situations Example in African cultures men are not expected to cry.
- Some may repress thoughts and feelings surrounding death.
- Some refuse to cry and suffer in silence and try to be strong.
- However Studies shows that people who are allowed to grieve tend to cope better than those who postpone.

8. What male care givers can do to support PLWHA through bereavement:

- Listen well and allow the person or family to go over events
- Give permission to grieve in ways that work for them
- Bear with the grieving
- Reassurance that the reactions are normal
- Provide information about the grief process, what to expect etc
- Attendance at bereavement groups; encourage the use of support groups
- Permission to take a break from grieving
- Remind them that there is no time frame for the grief journey
- Encourage good self care
- Encourage the use of rituals
- Pre bereavement support for families

- Assessment and identification of people at risk of complicated bereavement. people showing complicated grief should be referred to a health care worker or other professional such as a social worker for further management.
- Support of the family at the time of death
- Anticipatory guidance to patient and family
- Meeting the family after bereavement especially when they come to collect personal effects
- Follow up and visit at home
- Work with the family before and after bereavement.
- Provide emotional support and facilitate expression of grief

9. Ten ways to support the bereaved:

- By Being there
- By listening in an accepting and non judgmental way
- By showing that you are listening and that you understand something of what they are going through
- By tolerating silence
- By being familiar with your own feeling about loss and grief
- By offering reassurance
- By not taking anger personally.
- By recognizing that your feeling may reflect how they feel.
- By not talking too much.

To adopt to loss, a person must complete four tasks.

- Accept the reality of the loss.
- Work through the pain of the loss.
- Adjust to life following the loss.
- Move on with life.

10. 12 tips of Freedom Guidelines of healing in Grief (Alan Wolfelt)

1. Realize that their grief is Unique.
2. Talk about their Grief.
3. Expect to feel a multitude of emotions.
4. Allow themselves for numbness.
5. Be tolerant for their physical and emotional limits.
6. Experience grief attacks.
7. Develop support System.
8. Make use of rituals
9. Embrace spirituality.
10. Allow search for meaning.
11. Treasure memories e.g. anniversaries
12. Move toward Grief for Healing.

11. Supporting the bereaved- what you can say and what you can't say

What you can't say

- I know how you feel
- You will get over this
- Please don't cry
- It will be OK
- IT WAS God's will
- God knows best
- You can have another child
- You will find someone else
- You should be glad they are no longer suffering
- Call me if you need me – this puts effort on the bereaved who is unlikely to call

What you can say

- I am sorry
- I am sorry you are hurting
- I can't imagine what you are going through right now
- Go ahead and cry. It is OK
- I am here for you
- I don't know how you feel but I do care about you
- Refer to the deceased by name

12. The four tasks of mourning.

- **Accepting the reality of the loss.** When one dies, he/she goes forever and will not return. Some people, who refuse to believe that death is real, do not get stuck in the grieving process at the first task. Death is irreversible.
- **Working through the pain of grief.** The pain of grief is not physical and emotional. Avoiding reminders of the dead like using alcohol or drugs are unfortunately the common ways people happen to use in accomplishing this second task. Taking a walk for instance can help to reduce the pain. Endeavor to be busy.
- **Adjusting** to an environment in which the deceased is missing. Endeavor to learn to interact or work with other people. Through interactions with them, or doing things will help you wash off the grief pain.
- **Relocation.** This simply means re- entering life without the deceased. Find out your own ways of satisfying social, emotional or physical needs.

References

1. The Foundation for Professional Development (2005). Course in Palliative Care in HIV/AIDS. A study Material
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SESSION 5.4 GRIEF, LOSS AND BEREAVEMENT IN CHILDREN

Learning objectives:

- Identify the myths and misconceptions relating to grief, loss and bereavement in children
- Discuss children's understanding of death by age
- Discuss strategies for supporting children through loss, grief and bereavement

1. Introduction:

Historically it was thought that children did not grieve. This is not true. Children do grieve but not always like adults. Their understanding of death, the way they react to a loss and what helps them, often varies by age. Like adults each child is unique and reactions to death and expressions of grief vary widely based on their age, level of understanding and relationship with the deceased. Children don't grieve constantly, but periodically. Their grief seems to come and go. A child may cling and cry, at the same time wanting to be left alone. After a while, grief seems to fade away, then something triggers the memory of the deceased parent again. Many children do not get chance to mourn the death of parents. Children sometimes go through nightmares and outburst of anger. Some avoid thinking and talking about the deceased and sometimes experience concentration problems. Many are helpless, aggressive and depressed. Children think about their own infection, death, parents death etc and some also go through separation from siblings such as brother or sister.

2. Myths and misconceptions adults have towards grieving children:

- Children do not understand death at all
- Children are passive and ignorant about what happens around them and therefore there is no harm in excluding them in important family processes/rituals.
- Discussing about death with children is a taboo and harmful to them.
- Children only become real people when they are much older.
- Children should not participate in funeral proceedings nor should they view dead bodies as this brings bad luck to them.
- Children are incapable of making decisions or solving problems for themselves and therefore adults should do it for them.
- Children have no personal thoughts or feelings about their lives or the people around them.
- Children have no personal thoughts for feelings about their lives or the people around them.
- Children who display maladaptive behaviors are just naughty and stubborn. So deserve to be punished.

3. Children and grieving: Some facts:

- All ages sense the sadness, feel the loss and pain, fear death and being left alone.
- All ages may feel guilt for what has happened
- Children under three years of age cannot grasp that death is forever.
- Children under 10 years may fear getting sick or dying. If the deceased is a parent, a child may worry that the other parent will die too.
- Children over 10 understand better but may not be able to talk about death.

4. Why grieving or grief counselling is necessary for children and adults:

- To increase the reality of loss in the grieving person and letter accept it.
- To help the grieving person deal with both observable (expressed) and unobservable (latent) effects resulting from loss.
- To help the grieving person overcome various difficulties that could be a barrier to one's adjustment to a normal life.

- To encourage the grieving person say appropriate goodbye to the lost someone or something and to feel comfortable to reinvest back into life.

5. Why is grief counselling necessary for children?

- To enhance positive coping skills.
- To enhance resilience.
- To help them accept death or loss.
- To facilitate the normal grieving process.
- To provide a conducive environment for them to freely express their feelings.
- To facilitate readjustment to normal routine in the absence of the loved one or something.
- To help them say appropriate final bye-bye to the lost person or something.

6. Why do children always fail to grieve?

- Some children happen to have had a conflict or strained relationship with their lost loved ones or parents. So if death occurs, a child may instead feel relieved! This inhibits the normal grieving process.
- Some children lack reliable social support networks to help them through the grieving process. Care for them in most cases ends on the burial day for their parents/ loved ones. On going support is not available for them. This makes them vulnerable to complicated grief and its related consequences.
- In a situation where death of a loved one is uncertain. For example in a situation where parents died when the child was too young to understand death, most caregivers tend to have a belief that when they disclose the fact of death to the child (now the relatively grown up one) that it would affect him/ her. So they deliberately keep on deceiving the child. Incidentally. Much as there would be some “correct rumours” around that are accessible to the child, the child may be confused of the two which is right and which is wrong. The child may decide to abort the grieving process.
- Most children do not understand the need or the relevancy of grieving. This is in most cases due to the fact that the parents or guardians themselves are ignorant about the same. So since both are green, the children are very vulnerable to adapt to the abnormal grieving process. (This is a situation where a person may totally not grieve or delay grief, mask the grief or exaggerates the grief.)

7. Children’s reaction to loss.

Children’s reaction to loss varies depending on age factor. The following are various reactions grouped into psychological, social and physical categories.

7.1 Psychological reactions

- Some do not mind especially the very young.
- Disbelief especially when death was sudden
- Anxious/ worried especially for living on their own with out their gone provider/ caregiver.

- Visual and auditory hallucinations, these are frequent experiences about the bereaved: like images, sounds.
- Pre occupation with thoughts about the deceased for example: how can I recover the lost person
- Some lose hope
- Denial: Some children may think that the deceased is actually still present.
- This is always true shortly after death.
- Seeing no real meaning in life.
- Nightmares.

7.2 Social reactions.

- Crying
- Anger- some may think that the caretakers themselves killed their loved ones.
- Fatigue/ helplessness especially due to the pre occupation with thoughts of the deceased.
- Social withdrawal/ isolation.
- Loss of interest in social activities like play, domestic work...
- Concentration and attention problems due to absent mindedness.
- Avoiding the things that remind them deceased belongings like clothing, beddings, utensils,...
- Fearing to visit gravesites
- Clinging
- Restless
- Poor self-esteem

7.3 Physical reactions

- Fatigue
- General body weakness/ lack of energy
- Aches and pains
- Loss of appetite
- Hyperactivity
- Dryness of the mouth
- Regression to earlier stage of development.

8. Childrens' understanding of death by age and how they can be supported through grief and bereavement:

Helping grieving children will be most effective when you take into account their age and their understanding of death.

8.1 Children from birth - 2 years.

These do not understand the concept of death/ loss. You can not easily explain to them what death is.

- The child doesn't understand what has happened.
- They have no concept of death.
- But they still miss parent's touch, voice, smell and comfort.
- They display changes in sleeping, eating, cry more irritable or angry. (regression)

How to help:

- Infant should be kept in same home environment, with brothers or sisters, and an affectionate and close substitute caregiver who is reliable and consistent.
- Provide a lot of physical contact.
- Let not the child's routine/s be changed.
- The child's environment should stay/ be the same.
- Give a child time to play.

8.2 Children of 2- 5 years old

These are always self centred and care for only themselves not others. The following are their usual ways of understanding death.

- Death is not permanent; it is only a sleeping trip for example
- They always anticipate the return of the deceased.
- Some see death as abandonment thinking the deceased didn't want them any more
- In addition, their grief is shown through crying, regression, refusal to be touched and on- and off grief reactions.
- May have periods where they forget what has happened.
- Eating habits may change, signs of distress, sleeping disorders, bed wetting etc.

How to help:

All strategies for those in 0-2 years are applicable in addition to the following:

- Re-assure them they did not cause death.
- Share positive memories and stories about the deceased.
- Advocate for names that are not provocative over the deceased.
- Consistent substitute caregiver, comfort, encouragement, hugs, physical reassurance, child to stay with siblings and close family members.
- Listen to what child is saying, and understand what child is feeling.
- Pray with them, and share positive memories of deceased. Encourage child to play with other children.

8.3 Children from 6 - 9 years

These always mix fantasy with reality. They are always interested in knowing what caused what.

- Their concept of death is forever.
- Orphaned child longs for the parent, showing signs of sadness, grief and may cling to substitute caregivers.
- Some children become angry towards the deceased and the surviving adult too.
- They may ask the same questions many times, wanting to know 'how and why' a person died.
- Questions may be difficult, but its important to answer them as honestly as possible.
- They ask them selves about what really caused the death.
- They are fearful of the similar deaths to occur.
- They are always angry to those they perceive to have caused the deaths, from God to any one else.

- They have difficulty in expressing or articulating their feelings.
- They have repressive behaviors.
- Grief will include sadness, depression, anger, helplessness and deep emotional pain, and longing for parent - may suppress or have outbursts.
- Child sees surviving adults in distress, understands that death is beyond control, has ability to mourn, feels vulnerable, copies adult mourning behaviors.

How to help:

- Death should be openly discussed. Don't say mummy has gone to sleep, Reassure the child about his/her care.
- Tell the truth. Provide simple and honest answers/ explanations using simple language
- Child needs to know, that it was not his or her action that made a person die.
- Play therapy can process healing and coping.
- Let them ask questions and talk about death.
- Encourage them to pray for self and also for the deceased.
- School teachers may notice change in child after death of parent. Responses of school and teachers are critical to child's well being.
- Child can re enact and cope through play therapy.
- Encourage to take part in Sport, to release tension, or be part of a group e.g. community work
- Sense of belonging gives sense of security.
- Taking part in spiritual and cultural rituals can be consoling, where children feel they are not alone.

8.4 Children from 9- 12 years and over.

These can understand that death is final. They know the possible causes of death; this leaves them powerless.

- Children may deny what happened.
- Go through similar mourning process as adults
- Thinks about meaning of death and life after death
- They are anxious and experience sleep disturbances
- Poor school performance.
- Disrupted social relationships.
- Anger
- Regressive behaviors

How we can help?

- Encourage participation in rituals/visiting the grave after funeral.
- Knowing where the body is buried give a sense of control to child.
- Peer Group Support, teacher's support.
- Spiritual support e.g. religious explanations.
- Participation in sports.
- Even if a child has come to terms/he/she/may still miss parent for long time.
- Allow Grief to come and go.
- Lots of Patience, Compassion
- Be honest with them about what happened.

- Use simple and clear language
- Listen to what they are saying.
- Understand their feelings and encourage them to express them.
- Share positive memories about the deceased.
- Teach them life skills.
- Hand over small responsibilities and tasks to them.

9. General strategies on helping children to grieve:

How adults grieve affects the way children grieve. People who smile bravely when they are sad confuse children. Adults who admit their feelings and cry with children help them accept and understand death. You can help children grieve in the following ways:

- Include children in what is happening
- Listen carefully to the meaning behind what children are saying about their feelings
- Be honest and give answers in words they understand
- Reassure children that illness does not always lead to death
- Remind children that they are loved just as much as ever during the time of grief
- Tell children that their thoughts and feelings are normal and it is okay to cry
- Reassure children that others understand their grief
- Encourage them to express feelings by talking, painting, drawing, music etc
- Try to keep the children's routine as much the same as possible

10. Important to note while helping grieving children:

- The children's understanding of death/ loss always depends on their level of development and understanding. Normally, children understand death better from the age of nine.
- Their impact of loss of a loved one always depends on closeness / relationship, s/he had with the deceased, the care of others/ guardians around the child.
- Children assess themselves more negatively after the loss of their loved ones, especially the parent(s)
- Most children have these thoughts/questions in their minds although they may not articulate them:

Common thoughts/questions grieving children have:

- *Did I cause this to happen?*
- *What will happen to me?*
- *Who will take care of me?*
- *When will I stop feeling sad?*
- *How long will I like myself?*
- *Why do some people die when they are very young?*
- *Is being dead like sleeping?*
- *Does being dead hurt?*
- *Am I going to die next?*
- *Why has this happened to me?*

- Most children go through almost the same processes of grief just like adults do. However, the difficulties in coping could be due to their young defense mechanisms especially denial and regression.
- Counseling the grieving child can be done:
 - Soon after the death of a loved one.
 - When the child does not understand what is happening yet s/he is nine years and above old.
 - When the child is not adjusting to the current or normal routine.

Concluding remarks:

The following are not only important for the counselor to know but also any other caregiver(s) such as male care givers.

- Be honest to the children about what happened (the loss). Misinformation or denial of access to information could result into disastrous consequences.
- Always involve children in the funeral arrangements and rituals, for example writings (announcements), collecting gravels, flowers, etc
- Encourage them to express their feelings, as bottling them would lead to more problems in the future.
- Do not be overprotective especially to the teens/ adolescents. They need some privacy.
- Even though some may be nearing to adulthood, do not expect them to feel, think or act like an adult.
- Let the child know that s/he is still loved and special.
- Help them to understand that death occurrence was not their fault (many of them always feel the guilt of losing their loved ones.)
- Spend some time with them.
- Grief is tiring so help them to go early to bed/ rest
- Give soft foods since they are re- assuring and are reminders of earlier happier days with the deceased.
- Making a scrap book for pictures/ photographs and other mementoes can be helpful.
- Listen to them.
- Calm nurturing is important: holding, cuddling, stroking and assuring them that they are loved.
- Remind the children that they are not alone. You care about them.
- Do not hide the fact that you are also upset, express your feelings too.

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3. The Foundation for Professional Development (2005). Course in Palliative Care in HIV/AIDS. A study Material
4. Macmillan, Peden, Hopkinson and Hycha (2004). A Caregivers Guide: A hand book about end – of – life care. The Millitary and Hospitaller Order of St. Lazarus of Jerusalem and The Canadian Hospice Palliative Care Association

SESSION 5.5 STRESS MANAGEMENT/CARE FOR CARERS

Learning objectives:

By the end of this topic participants should be able to:

- Define stress and care giver burn out
- Discuss the importance of care giving
- Identify causes of stress in care giving
- Discuss strategies for stress management

1. Introduction:

It is important to know that HIV and AIDS care has an impact on the Lives of Caregivers. This impact must be explored and strategies to deal with the impact implemented. The impact may range from normal stress to burn out.

2. What is stress?

Stress is defined as feelings of being emotionally, physically or mentally overwhelmed and drained when faced with a certain situation, event or person.

Important things to understand about stress are that:

- Stress is something that can be managed
- Everyone feels stress sometimes
- Different people feel stress for different reasons
- No one responds to stress in the same way
- Stress combines in some people to produce burnout.

3. Causes of stress among male care givers:

3.1 Causes related to Caring giving Duties

- Heavy workloads
- Lack of incentives
- Fear of infection
- Inadequate support or supervision from their umbrella organisation
- Lacking the ability to refer clients to services they need
- Lack of medication such as ARVs and materials they need for caring (such as gloves or sanitation equipment)
- Lack of clarity about what they are expected to do
- Lack of recognition for their work
- Interpersonal problems with their client
- Lack of space and privacy while caring
- Feeling unable to make important decisions that affect their clients and their work
- Feeling powerless to change some aspect their clients' problems
- Not feeling as though they can input their own unique solutions for caring

3.2 Causes Related to care givers Feelings or Knowledge

- Being faced with death and dying

- Feeling bereavement and grief
- Stigma associated with HIV and AIDS
- Secrecy and fear of disclosure among PLWHA
- Emotional attachment to PLWHA and their families
- Fear from witnessing the impact of HIV and AIDS for Caregivers who are also PLWHA
- Knowledge that AIDS is incurable
- Lack of knowledge that results in Carers not know what to do to help
- Feeling powerless to change some aspect their clients' problems
- Not feeling as though they can input their own unique solutions for caring

3.3 Causes Related to Personal Lives

- Financial hardship
- Personal demands competing for attention with caring demands
- Dealing with illness within their own families

4. What is Caregiver Burnout?

Caregiver Burnout results from stress that is built up over time until a carer is no longer able to cope. Burnout is not something that happens in one moment or even in one day. It is the result of feeling stress over a period of time. If not dealt with, this stress can combine to impact negatively on a caregiver's mental or physical health; damage his/her relationships; and ultimately, his/her ability to care for PLWHA effectively.

4.1 Psychologists define Burnout using three separate emotional signs:

- Feeling emotionally overextended and feeling as though you lack the energy to face another day
- Feeling "used up" and not caring about work like you used to or treating others negatively
- Growing sense of inadequacy, not feeling as though you are "good enough" to care effectively.

4.2 Recognizing Burnout

Caregiver Burnout can take many forms, and it is important that male care givers recognize the signs of burnout in themselves and in fellow caregivers. Having one or more of the symptoms below does not necessarily mean that a person is burnt out. It does mean, however, that they are suffering from some form of stress that can become burnout if left unattended. Like most problems, coping with stress is best done by addressing it in the open and seeking out methods of helping you cope with stress. Session Three will offer some strategies for preventing and reducing burnout that male care givers can and should use.

4.3 Factors Contributing to Caregiver Burnout

There are many different reasons why caregivers feel stress. Stress can be felt as a result of the impact of caregiving on the personal life of male care givers, because of aspects of their job or special factors of dealing with HIV and AIDS in their homes and community.

4.4 Signs of Stress that could result in Burnout include:

Physical

Backaches
Change in eating
pattern
Diarrhoea
Elevated blood
pressure
Excessive
fatigue
Bowel
disturbance
s
Sleeplessne
ss
Muscle Tension
Weight
loss or gain
Constipatio
n
Headaches

Emotional

- Anger and frustration
- Depression
- Not feeling good enough, feeling guilty or helpless
- Loss of interest in and commitment to work
- Loss of confidence and self - esteem
- Feeling restless
- Mood swings
- Excessive worry about the future
- Feeling overwhelmed
- Afraid to grieve

Behavioural

- Always late
- Neglecting duties
- Tearfulness
- Emotional outbursts
- Withdrawal from family or friends
- Difficulty getting on with people
- Loss of quality in work performance
- Decreased ability to make good judgements
- Increased drug or alcohol Use
- Resisting change
- Resignation from caring activities

4.5 Assessing stress and burn out among male care givers:

- Loss of interest in and commitment to work
- Loss of punctuality and neglect of duties
- Feelings of inadequacy, helplessness and guilt
- Loss of confidence and self-esteem
- Tendency to withdraw from clients and colleagues
- Loss of sensitivity in dealing with clients
- Loss in quality of performance in work
- Irritability
- Difficulty getting along with people
- Tearfulness
- Loss of concentration
- Sleeplessness
- Excessive fatigue
- Depression
- Bowel disturbance.

4.6 Strategies for Preventing and Reducing Burnout through Self-Care

People deal with stress in many different ways. The ways in which people deal with stress are often called **Self-Care**. Self-Care can be described as thoughts and activities that people use to deal with stress. Coping can involve something as simple as going for a walk to clear your head, reading a good book or talking with friends or other male care givers about the stress you feel.

In addition to the personal coping methods each of us use, specific tools for coping with the stress of caregiving have been developed.

5. Five Strategies for Self-Care

5.1 Use Coping Strategies

Ways that male care givers can use coping strategies include:

- Educate yourself (patient's status, understanding HIV, AIDS and ART)
- Ask questions (its OK to say 'I don't understand, can you please explain')
- Keep a daily journal
- Discuss your problems and feelings with a friend
- If you are feeling very stressed and are unable to cope seek professional help
- Get rest, listen to what your body is telling you
- Debriefing by discussing care related problems with your supervisor or other care givers as they occur
- Make use of your spiritual support system
- Engage in recreational activities outside of work

- Encourage self-care by the patient and family

5.2 Change Your Approach to Caregiving

- Establish realistic goals of what you can and cannot do and talk to your supervisor about needing to make changes in your work
- Divide tasks into manageable parts (small acts of Care)
- Learn how to adjust the pace of Caregiving.
- Ask others to help
- Take time away-time off

5.3 Relaxation Techniques

- Visualization (pleasant images and feelings)
 - Take a "Worry Break" (take 10 min each day to put all worries into a box, close it and do not open it again until the next day)
 - Deep breathing (in through nose, out through mouth)
 - Do things YOU enjoy (socializing, listening to music, reading)
- Body Relaxation Exercise

5.4 Strive for Good Health

Ways in which male care givers can strive for good health and reduce stress are: • Stop or reduce unhealthy behaviours (smoking, drinking and drug abuse increase stress in the long run)

- Ensure your basic needs are met where possible (eat 3 meals a day, drink water, sleep 7-9 hours a day, exercise)
- Welcome all your emotions and express them appropriately

5.5 Build a Support Network

The Support Network of care givers can include:

- Family members, relatives and friends
- Other caregivers
- Faith communities
- Caregiver support groups
- Support groups for PLWHA.

Sharing Strategies for Self-Care

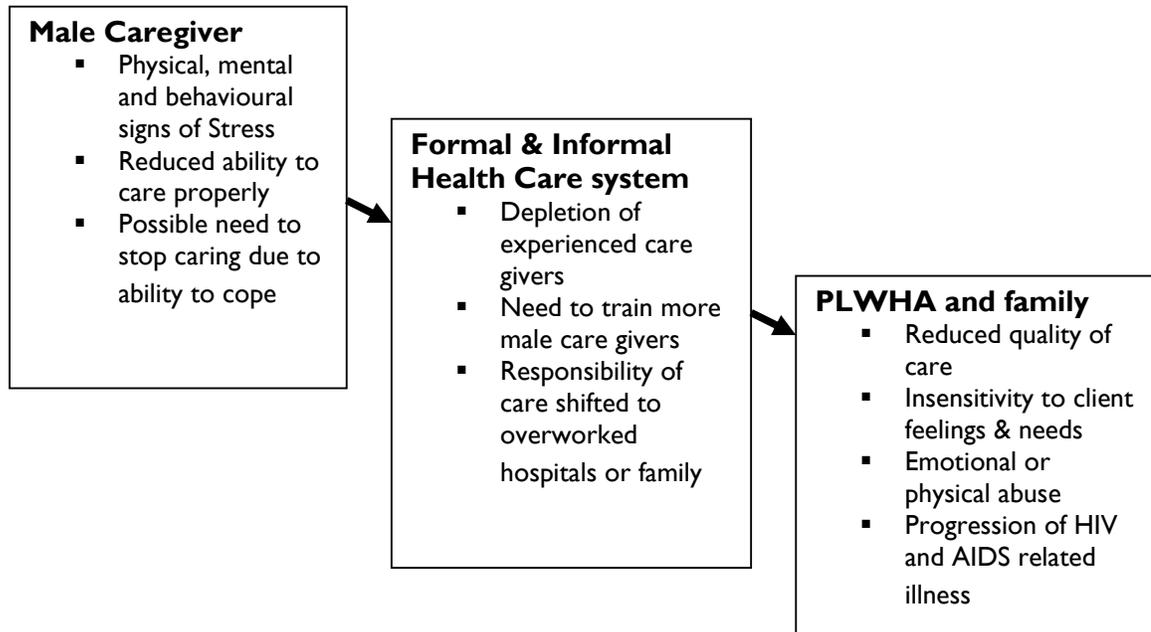
Now that you are equipped with strategies for self-care, it is important that you share these



Source IRC et al, 2006: *HIV Prevention, Treatment Care and Support A training Package for Community Volunteers.*

strategies with the primary caregivers of their clients and clients themselves. By assisting clients and families to reduce stress, male care givers may find that the level of stress they experience from caring activities also reduces.

6. How Caregiver Burnout can affect care for PLWHA



Source IRC et al, 2006: HIV Prevention, Treatment Care and Support A training Package for Community Volunteers.

7. Why should male care givers participate in care giving?

7.1 Rewards of Care giving

When people speak of caregiving, people often only speak of how and why it is difficult. The many rewards of caring that care givers experience are often left out.

Care giving for PLWHA and their families:

- Brings a sense of mission and purpose to the life of Carers
- Presents a chance to develop self-knowledge and new skills
- Builds a sense of personal effectiveness by demonstrating competence under difficult circumstances
- Creates positive feelings of loving, caring and feeling needed
- Makes people feel like they have made a difference and contributed to their Client's well being

Another reward of caring can be the recognition that caregivers receive in the community for the important service they provide. It is important that facilitators consider how are male care givers recognised for their work in the community and how or if this may need to be improved.

SPECIAL CONSIDERATIONS IN CARING FOR CARERS

I. Caring for child carers

a. The effects of caring on children

Children are often the least acknowledged, but most affected, carers in the home. It is important for male care givers to consider how child carers may be affected.

Possible effects of providing care on children:

- **Educational effects:** reduced time spent at school, school drop outs to meet demands of caring for sick parent or sibling
- **Social effects:** child carers often miss important social opportunities such as sports, play and socialising with peers
- **Emotional effects:** watching a parent or family member suffer with illness is difficult for children. As child carers have usually not received formal training they can be left wondering "Am I doing this right?", "Am I doing enough?"
- **Physical effects:** children face physical limitations in providing care (such as moving someone who is bedridden) which can impact their health and growth.
- **Financial effects:** children faced with the responsibility of caring are often also faced with the responsibility to care for the family's financial needs. Poverty and illness often lead children to engaging in risky behaviour in exchange for money (sex workers, child labour) that can put them at risk and increase their vulnerability to HIV infection.

b. The Needs of Child Carers

The first step in caring for child carers is recognising the needs of child carers in your area.

c. Developing Community Awareness About Caring for Child Carers

Part of the reason communities find it difficult to provide assistance for child-headed households, or households in which children are acting as caregivers is that they are often not 'visible' within community networks. A good way for you to encourage caring for child carers is to create community awareness about the challenges and needs of child carers.

2. Caring for Carers living with HIV

PLWHA are known to make excellent caregivers for other PLWHA as they have a good understanding of what it is like to live with HIV and the emotions experienced by clients in the same situation.

Male care givers who know their HIV status should be given special consideration for care if they are HIV positive. Those who do not know their HIV status should be supported to make use of HIV Testing and Counselling services.

PLWHA who are carers should be encouraged to adapt health-seeking behaviours through the timely treatment of OIs and access to ARVs when and if they are available.

Exercise: In pairs

1. ***Please share the rewards of care giving in your setting***
2. ***How do you tell that the people you are caring for are appreciating?***

8. Summary of key points

- To enable management within the very demanding area of Palliative Care, male care givers need to be aware of their own needs and feelings.
- They should be able to identify signs of stress and utilise effective coping strategies, to prevent burnout.
- It is therefore important that we are well supported, to enable us function well as human beings and to be able to give optimum care to our patients and their families.
- Know your own limitations
- Always explain what you can do to those you are providing care so that they know what to expect otherwise overwhelming expectations from them could cause you stress.

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SESSION 5.6 SEXUALITY IN HIV/AIDS PALLIATIVE CARE IN AFRICA

Learning objectives :

- Define Sexuality
- Appreciate the effect of gender and role perception on sexuality
- Identify sexuality needs and problems of patients
- Undertake a simple assessment of sexuality needs
- List some sexual practices

1. Introduction

Sexuality needs and problems of patients living with life limiting illnesses receive little attention and coping mechanisms are rarely discussed and addressed. This is mainly because culture strongly influences sexuality perspectives. Sexuality is seen as a culturally sensitive and private matter. However to provide holistic care to these patients, we need to understand that sexuality influences and is influenced by the biological, psychological, sociological and spiritual aspects of being (Kezier, 1998). Patients do not stop being sexual beings when they become sick, nor do they leave their sexuality behind when they are seeking for medical services.

2. Essentials of sexual counseling

2.1 Definitions

Sexuality includes all those things that contribute for one to be called a woman or a man. It includes body image, self-esteem and how we would like others to see us. It is more than sexual desires, activity and orientation. It involves touching, intimacy, and the physical closeness of others, and can be an expression of warmth and caring, relationships and gender roles.

2.2 How to address patient sexual needs

Patients need encouragement and support for them to discuss their positive and negative difficulties and experiences. To provide truly holistic care to patients with life limiting illnesses sexuality issues must be addressed. Community volunteers should be:

- Comfortable to discuss sexual issues non judgmentally in order to help patients
- able to encourage patients to discuss their sexuality concerns and address them together so that it can assist the return of intimacy and sexual functions
- able to accept that sexuality is an important area of health care intervention
- willing to allow patients to express their sexuality in their own way
- to use good communication skills and also demonstrate patience
- Should demonstrate knowledge of basic sexual problems, including how social problems and treatments may affect sexuality and sexual functions and which interventions facilitate sexual expressions and functions

Carers need to give patients the opportunity to express the physical and emotional pain of their sexuality. Good role models among men should be identified and encouraged to assist in raising awareness among other men. There is need to create openness around sexuality in life-limiting illness

2.3 Addressing the pain of sexuality includes:

- Encouraging patients to discuss sexuality issue with colleagues and spouse
- Sharing experiences of working with patients having such pain
- Identifying those colleagues who feel comfortable discussing sexuality
- Acknowledging that sexuality is a private matter and observing the cultural aspects involved.
- Arranging date of review and reflect on any new approach to sexuality regularly.

3. THE EFFECTS OF GENDER AND ROLE PERCEPTION ON SEXUALITY

While in western cultures children are raised knowing that men and women have equal roles in sexual decision making and relationships, it is not the case in Africa.

Women

- Are expected to be submissive to men from birth. Women/girls are expected to kneel before men—including their own older brothers.
- The male child sees his role as one of leadership and physical domination of the female.

- If a female is not submissive to the male's wishes and needs, they are physically force into submission.
- When a woman with HIV/AIDS admits to sexual problems, it is almost impossible to get the partner to come for counseling or to meet a health professional.
- If a woman suggests that they go for testing or medical check up such a thing may incite the husband to beat her or inflict such psychological pain or withdrawing financial support.
- Although more and more educated women are demanding sexual equality in the public arena, there is still a challenge around the traditional beliefs about the roles in their home and village.

Men

- Still feel they must dominate their female partner, both sexually and in their own lives. Hence more educated or successful woman often has a greater chance of marriage difficulties.
- African men base much of their self-esteem on their sexual ability
- Men are rarely prepared to discuss the woman's sexuality difficulties.
- Elderly men who are ill and need care are frequently concerned about not being able to get an erection and satisfy a young partner.

It is therefore important to counsel them so that they can overcome this feeling of having lost their dominance and physical ability, which could lead to depression. Keep this cultural issues in mind as we take care of patients and be aware of our own culture and the culture's approach to sexuality.

4. SEXUAL NEEDS AND PROBLEMS OF PATIENTS

Sexual issues in HIV/AIDS

Every human being has a sexual identity and sexual needs, although their importance may vary greatly from person to person and according to what else is happening in their lives. These needs and feelings may exist regardless of how old a person is or whether or not s/he has a partner at the time.

To maintain self-esteem and a healthy body image, patients with life limiting illness nearing need not only sexual activity but also touching, intimacy and the physical closeness of others. They also need to fulfill gender roles within families, effective communication with their partners, counseling, and privacy, pain control and to make their own decisions. Failure to address patients' sexuality needs may result in the loss of body image, self-esteem, libido as well as an inability to engage in sexual activity, forced and painful sexual intercourse, break up of relationships, abandonment, domestic violence and stress-related problems. Intervention should aim at achieving better communication between partners, providing adequate information, and offering practical support.

4.1 Some of the problems experienced by patients with life limiting illness include:

- low self-esteem due to distorted body image
- problems of self-perception
- mismatched feelings
- loss of libido

- painful intercourse
- exposure to violence
- sexual abuse
- inability to achieve or sustain erection
- exhaustion
- Failure to achieve orgasm.

Sexual feelings and expression may be inhibited by problems such as poor communication between spouse, difficulty negotiating condom use, fear of re-infection or infecting a partner and either fear of or great desire for pregnancy.

Body image

Feeling good about one's body enhances sexual well-being and promotes sexual activities. But if people have negative attitudes about their bodies, it can interfere with sexual activities. Feelings of worthlessness may make it difficult to be aroused sexually. Continued counseling and support are needed to help couples open up to each other/communicate freely as they walk through the journey of illness.

Self-perception

Patients with life limiting illnesses often experience negative feelings about themselves, affecting their sexuality and sexual activities, particularly if they are experiencing social stigma

- They may feel unworthy to be seen as a man or woman in the community.
- A woman who shows the signs of AIDS before her husband may be accused of not being faithful to him, even if it was he who infected her.
- Society tends to perceive women with AIDS as unfaithful if they are married and indecent if not married, which can affect the women's self-worth and cause depression.

Provide counseling and support, help the family and spouse to understand the situation rather than becoming angry.

Mismatch of feelings

Worries caused by terminal illness may result in a loss of interest in any form of sexuality. While one partner may have a need for sex, the other partner may not be interested at all, causing a mismatch in feelings. Because sexual activity starts in the mind, an individual's worries or pains of any kind can affect his or her sexual activities and decrease the libido. This affects the spouse, who may think the individual is cheating on him or her.

Cultural perspective

In the African context, the sexual losses associated with HIV/AIDS have deep implications for patients, especially women.

- Women are culturally expected to provide sex to their partners and produce children.
- If they can not do these things, their partners regard them as no longer worthwhile.

- They may be forced to have intercourse even when their condition does not permit it, resulting in painful sex, bleeding after sex and sometimes additional treatment costs.
- In some cultures in Africa a man is never denied sex; denying him sex leads to rape and domestic violence

Penetrative sex can be extremely painful if one has penile, vaginal or vulva sores or herpes simplex, yet partners or couples who do not have these problems may expect the affected partner to engage in painful sex.

Since sexual matters are regarded as private issues, such problems are not revealed to outsiders (community Volunteers/Health worker) it made worse by health workers who do not feel comfortable to discuss sexuality issues. Hence sexual problems are often not addressed yet they are a source of social, psychological, spiritual and physical pain.

5. ASSESSMENT OF SEXUALITY NEEDS

To offer holistic care to our patients, we must stop being shy and learn to encourage our patients to talk about their sexual problems. We must encourage our patients' to discuss sexual needs and problems.

Some questions that can help to start the conversation could be:

- How has the illness affected your sexual life?
- How has treatment affected your sexual life?
- How has the sickness interfered with your relationship?
- How does your partner feel about your sickness?
- How is your sexual performance during this time of illness?

These questions will start a conversation about sexual issues with the person. Once he or she has gained trust and realizes that you are comfortable and ready to talk about the topic, the conversation can move into more specific aspects of intimacy. Initiating the conversation helps patients to verbalize their problems and feelings about sexuality and it can be therapeutic. Sexuality must be assessed, advice given and problems solved routinely, because failure to intervene in this important aspect of holistic care creates great distress for patients and their loved ones.

Goals of intervention should include:

- helping individuals feel accepted as sexually worthy, loved and wanted
- increasing sexual self-esteem by helping individuals maintain their appearance
- clarifying misinformation and providing information and privacy
- assuring that people with advanced life limiting illness are not denied having their sexual needs met

Practical strategies

- provide information i.e other forms of expressing sexuality.
- Practical suggestions can include providing lubrication for dry vagina to reduce irritation and pain
- suggesting different positions or styles to be tried during intercourse to help increase the patient's comfort and satisfaction.

- For men, careful discussion of the cause of erectile dysfunction may help in providing solutions to diminished sexual potency.

With the deep-rooted cultural influences on sexuality, some of the practical strategies may not be applicable in some parts of Africa.

Some of the sexual practices

- **Vaginal sex:** The most widely used and accepted practice in Uganda. It can be a serious problem if a female partner has vulva sores or a male partner has penile sores.
- **Mutual masturbation:** A common practice in which couples stimulate each other's genitals to orgasm.
- **Masturbation:** Stimulating oneself by rubbing or stroking the genitals until one reaches orgasm.
- **Oral sex:** Partners use their mouths to stimulate each other's genitals; practiced by both heterosexuals and homosexuals.
- **Anal sex:** Some men enjoy this practice and at times they go with young teenagers, and it can be painful if one has penile or anal sores.
- **Frottage:** A common practice among teenagers, involving rubbing against the clothed body of another for sexual gratification.
- **Breast sex:** A practice in which the woman's breasts and nipples are stimulated and the penis is rubbed against the breasts, and both partners can achieve orgasm.

Being knowledgeable about the different sexual practices enables discussion about alternative sex practice if a couple has a problem with their usual sex practices. But we need to be aware of differences in cultural traditions. The most important thing we can do is to encourage spouses/partners to be open with each other about their sexuality problems. This can lead to mutually satisfying alternative activities.

Interventions should aim at reassuring the partner and the patient that they may engage in some physical activity that allows them to express their love and affection. Just lying comfortably close can impart security and a sense of belonging. Patients and their partners need to be reassured that feelings of guilt as well as sexual desires are natural even during life-threatening illness, and that the patient may engage in the amount and kind of sexual activity that s/he desires and feels strong enough to handle.

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SESSION 5.7 BREAKING BAD NEWS

Learning objectives:

This session presents an overview of issues pertaining to breaking bad news and practical recommendations for male care givers wishing to improve their skills in this area of communicating bad news.

At the end of the session the reader should be in a better position to:

- Define bad news
- Identify skills required to break bad news
- Discuss how to break bad news to patients, their relatives and others.
- Describe the challenges of breaking bad news.

1. Introduction:

Communicating bad news or Breaking bad news (as it is commonly referred to) to patients and/or their families is one of the most difficult responsibilities in the practice of palliative care.

Although virtually all care givers including those in the community encounter situations entailing bad news, there is little formal training in how to discuss bad news with patients and their families. Understanding how to effectively communicate bad news, is extremely important especially to male community care givers since culturally men are expected to be able to handle difficult situations including breaking bad news.

2. What is Bad news?

Bad news can be defined as "any information, which adversely and seriously affects an individuals view of his or her future" or, in situations where there is either a feeling of no hope, a threat to a person's mental or physical well-being, risk of upsetting an established lifestyle, or where a message is given which conveys to an individual fewer choices in his or her life'.

Examples include:

- A patient who is told they are HIV positive.
- The man who is told his wife has cancer.
- The patient who is told the treatment for cancer and/or HIV is no longer effective and that there are no other options.
- A woman with cancer of the breast whose treatment might involve removal of the breast.

(Can you think of other examples of bad news?)

Bad news is a message which has the potential to shatter hopes and dreams leading to very different lifestyles and futures. Bad news situations can include:

- disease recurrence,
- spread of disease,
- failure of treatment to affect disease progression,
- presence of irreversible side effects, etc.

The issues of who to tell the bad news has been well debated and it remains a dilemma. It is important however, to know that that some patients with cancer and/or HIV want to know if their illness is cancer, and others want to know as much as possible about their illness, often more than care givers assume they want to know. It is common

practice in some areas to give relatives large amounts of confidential information without the expressed permission of the patient, and sometimes before the patients themselves are aware of their diagnosis. This is wrong practice and it needs to stop.

3. What skills are required in communicating bad news?

Breaking bad news is a complex communication task that requires expert verbal and non-verbal communication skills. This complexity of breaking bad news can create serious miscommunications, such as the patient misunderstanding the prognosis of the illness or purpose of care. When bad news is delivered poorly the experience may stay in a patient's or family's mind long after the initial shock of the news has been dealt with. Learning general communication skills can enable care providers to break bad news in a manner that is less uncomfortable for them and more satisfying for patients and their families.

It is always important to communicate bad news in a language that the patient fully understands and in case you do not speak the language, you should get an interpreter.

4. Why is breaking bad news difficult?

There are a number of reasons why physicians have difficulty breaking bad news but a common concern is how the news will affect the patient.

This is often used to justify withholding bad news. Some of the reasons why breaking bad news is difficult include:

- Feeling incompetent especially in being able to communicate the right information properly;
- Fear of causing pain; no one wants to hear that they are going to die or that they have lost something dear to them;
- The fear of getting blamed: patients or relatives can get angry with the health worker and blame them for ineffective care, or that treatment has been stopped.
- Wanting to shield the patient from distress by saying “I'm sure everything is well”. Fear of destroying the patient's hope.
- Feeling awkward about showing empathy as a professional.
- Feeling embarrassed about how to behave when someone is very upset – e.g. patient bursting out into tears etc.
- Fear of their own inadequacy in the face of uncontrollable disease.
- Not feeling prepared to manage the patients anticipated emotional reactions.

The process of breaking bad news can also have an adverse effect on those delivering the news and this is particularly evident when the person is inexperienced, the patient is young, or there are limited options for treatment.

Communicating bad news to patients well is not an optional skill; it is an essential part of professional practice.

5. A Strategy for Breaking Bad news:

Step I: Getting Prepared:

It is natural for the bearer of the bad news to be uncomfortable and anxious about the interview with the patient and/or carer.

Before starting to communicate any news, you need to familiarize yourself with the patient's background, medical history, test results etc, to plan what will be discussed.

- Confirm the medical facts of the case.
- Ensure that all the needed information is available. If this is an unfamiliar task, find a colleague who will play the part of patient so that you can practice.
- Try to create an environment in which the patient is comfortable and where there is enough privacy.
- Do not stand over the patient. Sit down, as this is less intimidating and shows that you are not going to be rushed. It is important to have no barriers between you and the patient; a desk between you and the patient might act as a barrier.
- Have a box of tissues (if available) which you can offer if there are tears.
- Negotiate the time you have for the interview. It will help the patient to know that you are allowing adequate time, but will also encourage them to prioritize their concerns.
- Make every effort to prevent interruptions. Switch off your mobile phone and use a "Do not disturb" notice if you are using a general office. Negotiate with colleagues so that they will not interrupt you.
- Ask the patient who, if anyone, they would like to have with them. This need not be the official "Next of kin", but a same sex friend, a confidant, or a specific member of the community care team.
- If the patient is a child the information about disease, prognosis and treatment, belongs to the parents. Negotiate if they are happy for the child to be present, as this will encourage openness and avoid later collusion. If not, ensure that another member of staff takes care of the child during the consultation.

Step 2: What Does the Patient Know or Suspect?

Most patients will have some idea of what their symptoms might mean. Others may have had some previous information from their doctor.

While many patients increasingly want to have details about their disease and diagnosis, some patients do not and this should be respected and appropriately managed. One mechanism to help you is to assess the level of information the patient wants.

Establish what the patient knows or suspects before giving further information.

These questions might help you establish what the patient knows:

- Have you any idea of what might be wrong?
- How would you describe your illness?
- How worried have you been about your illness?
- What did you understand about your condition from the other doctor?
- What tests have you had?
- When you first had symptom X, what did you think it might be?
- What did the doctors tell you when they sent you home?
- When did you first think something serious was going on?

Occasionally a patient (or a parent if the patient is a child) will fall silent and seem completely unprepared or unable to respond. It may help to acknowledge this e.g. "You seem to be finding it hard to talk about this".

Give the patient some time before speaking again, and if there is still no response (unlikely), offer to see the patient again, with a chosen person present. Acknowledge that it can be hard to talk about distressing issues. Use silence effectively and do not be tempted to rush on with the interview

Step 3: Give Information at Patient's Pace:

To give information at the patient's pace may mean that they will not receive all the information at the same time. However, they are more likely to accurately absorb the message if it is given in manageable chunks.

You will know when the patient has heard enough because they will block any further disclosure, by changing the subject or asking a question about an earlier piece of information. They may ask you not to go on, giving reasons such as "I don't understand all this. You'd best talk to my daughter" or "All I'm interested in is how you are going to cure it".

Only give the information to someone other than the patient if:

- a) the patient's mental state is such that they could not understand or
- b) the patient requests that you give the information to a specific person, designated by them.

Possible questions include the following:

- a. Are you ready for us to have a discussion about the results of your tests?
- b. We need to talk about your results. Is there anyone else you would like to have with you?
- c. Do you want me to go over the test results now, and explain exactly what I think is wrong?

Step 4: Sharing the Information:

Give the information clearly, in manageable chunks and in response to the patient's questions.

Give a warning of the seriousness of the information, and observe their reactions, both verbal and non-verbal.

Stop if the patient indicates that they have heard enough.

No one likes breaking bad news, so there is a temptation to give the whole message, usually too quickly. Although you cannot give the news gently, you can be sensitive and show your awareness of the likely impact on the patient.

Use simple language, but avoid euphemisms, such as "little wart" when you mean cancer. Silence is a powerful tool to encourage the patient to respond.

You might choose to begin breaking bad news by using language like:

- We have your test results back, and I'm afraid that it is more serious than I hoped.
- I'm afraid the news is not good. Are you ready for me to discuss it with you?

The patient may respond in one of several ways:

- So it's cancer then?
- What did you find?
- I'm not sure that I want to know

- How will you treat it?

You will then be able to respond to the patient with appropriate information, or check out what they mean if there is any ambiguity in their response:

- You say you are not sure that you want to know, what is your biggest worry?
- I'll come on to treatment, but can I tell you some more about what the doctors found?

By progressing at the patient's pace, there is a greater chance that they will absorb the message and only be required to deal with what they can manage at any one time.

Sometimes it is difficult to gauge a patient's reactions. Their words might indicate acceptance of a situation, but their body language suggests something quite different. To check the situation, it is useful to "say what you see" e.g. *"You say that understand, but you look very puzzled to me."*

This allows the patient to respond with any worries or concerns e.g. *"I do understand that you have found cancer in my breast, but you also mentioned lymph nodes and I don't know what they are"*

Remember, the more information you give at any one time, the less will be remembered. You should therefore start with the salient facts and only move on when the patient shows a readiness for more, and relevant, information.

Giving Space:

Even when bad news is expected, there will be an element of shock when the reality is put into words. This may last only a few minutes but may last for a considerable time, depending on the seriousness of the news and its impact on the recipient. During this time, the patient is unlikely to retain any further information or even hear what is said. For this reason they need space, and time to think before any progress may be made.

During this time, the patient may be motionless and silent. Try not to fill this space with more information, reassurance and hope. What is required is that the silence be respected. If it goes on for long, you could say what you see:

- a) This news seems to be hard for you to take in;
- b) You seem to be quite shocked;
- c) I guess you need some space to take it all in.

These statements are all educated guesses, but are useful in that they break what may otherwise be a difficult silence, and also give the patient the opportunity to express their feelings, if they are ready.

On a busy day, it may be difficult to give enough time to someone who seems unable to grasp the situation. It might be possible, then, to suggest that the patient sit outside and when ready, talk to another member of the team e.g. a specialist nurse. This team approach can be very successful and means that the person handling reactions may not be the same as the one who breaks the news.

Step 5: Handling Reactions:

Remember, Bad News will cause a shock reaction, even if it is expected.

The patient will need time to absorb the news before they react to it. Ideally, the patient should be able to sit quietly, perhaps with a cup of tea, before disclosing their reactions, fears and worries. The shock may last only a few minutes, but sometimes may last longer and mean that the first reaction is an inability to talk about their feelings. Even when you think you have very little time, some time should be allowed for bad news to be absorbed. Resist the temptation to fill the silence with more information, since it is unlikely that more information will be retained by the patient at this time.

Patients and their families react in a variety of ways when they hear bad news.

Typical reactions include:

- anger,
- guilt and blame,
- fear and anxiety,
- tears and sadness, along with
- grief and the need to escape from the situation.

For those who have to relay the bad news to other family members, there is the emotional conflict of handling the situation, and the feeling of responsibility that this carries. For example, disclosing HIV status to a spouse and/or family.

Outbursts of strong emotion may be directed at members of the care team, and it is important to realize that these are seldom meant personally.

The patient and their family need time to adapt to the new situation.

Reactions need to be acknowledged and handled in a sensitive way.

It is important to listen attentively, and to acknowledge their reactions.

Use open questions to encourage them to disclose their feelings, worries and concerns:

- This must be difficult for you. Can you tell me how you are feeling?
- I can see that you are angry, and I guess I would be too, in this situation.
- You seem frightened. What is it that you find frightening?
- Tell me more about how you are feeling just now.
- What worries you most?
- What does this news mean to you?

Although we may see the various reactions to bad news as "normal", each person will believe that their feelings are unique.

Do not say *"I know how you feel"*. Even if you have had personal experience of the disease or condition, you cannot know how an individual feels. It does not help to tell the patient that most people feel like they are feeling. Rather, you should acknowledge and work with individual feelings.

Empathy can be shown by using terms such as "I think I understand how you must be feeling"

Comfort can be derived from simple supportive measures, such as appropriate touch, an empathetic approach or even a cup of tea, if this is possible.

Encourage and allow the patient time to express their emotions and let the patient know you understand and acknowledge their emotions. This reduces the patient's isolation, expresses solidarity and validates their feelings or thoughts as normal and to be expected^{4,5}

Step 6: Planning and Follow up.

When you are sure that the bad news has been absorbed and first reactions have been addressed, it is important to discuss the future in terms of further investigations, treatment options and support. Honesty is an important element of these discussions rather than being over optimistic. If you are not sure of other options, it is acceptable to seek for an opinion from the health worker that has been taking care of the patient in the hospital.

The patient will need realistic reassurance about the future. Even when it is not possible to offer a cure, plans can be made for symptom control and support.

A follow-up appointment should be made and a contact number given so that the patient may access a member of the community care team.

If the bad news has been broken in a place other than the patient's home e.g. an outpatients department, it is important to check that the patient is not in shock when they leave, perhaps to drive home alone.

If the patient appears very distressed, it could help to offer to contact a friend or relative to come and be with them and take them home.

Remember that, later, the patient may ask questions about treatment, prognosis and other aspects of their future. This could mean more bad news and the need for you to check understanding and, perhaps, to reiterate information to reinforce the message.

Hope is an important concept in the bad news situation. Often the patient is given inappropriate reassurance in order to maintain hope. For someone facing a life-threatening diagnosis or a terminal illness, do not provide unrealistic hope. When the patient has accepted the reality of their situation, they should be encouraged to set realistic goals for the future.

Avoid expressions such as "What you need to do is." since only the patient knows what is most important to them.

The Do's and Don't's of Breaking Bad News:

The Do's:

- ⇒ Have the facts to hand
- ⇒ Clear enough time
- ⇒ Control potential interruptions

⁴ Buckman R, Korsch B, Bailie WF. (1998) A Practical Guide to Communication Skills in Clinical Practice. Toronto: Medical Audio Visual Communications CD-ROM (Pt 2) Dealing with Feelings.

⁵ Ptacek JT, Eberhardt TL. (1996) Breaking Bad News. A Review of Literature. JAMA 276: 496-502

- Switch off mobile phone
- Ask colleagues not to disturb you
- Divert phone calls;
- Use 'do not disturb' sign if in general office
- ⇒ Check if patient wishes anyone else present
- ⇒ Negotiate approx time consultation will take and explain need to take notes
- ⇒ Clarify what patient knows or suspects
- ⇒ Be prepared to follow the patients agenda
- ⇒ Observe and acknowledge patient's emotional reactions – nervousness, fear, etc.
- ⇒ Stop if patient indicates that they do not wish to continue
- ⇒ Check patient's understanding of what you are saying.

Don't:

- ⇒ Make assumptions about:
 - The impact of the news
 - Patients readiness to hear news
 - Who else should be present
 - Patients priorities
 - Patients understanding
- ⇒ Give too much information at one time;
- ⇒ Decide what is most important for the patient
- ⇒ Give inappropriate reassurance
- ⇒ Answer questions unless you have the facts to hand
- ⇒ Hurry the consultation
- ⇒ Use euphemisms e.g. 'little ulcer' when you mean 'cancer'
- ⇒ Block emotional expression from the patient
- ⇒ Break bad news to relatives before telling the patient
- ⇒ Agree to relative's demands that you withhold information from the patient

Conclusion:

Despite following these guidelines patients may not be able to absorb the detail of the news being delivered. A well informed multi-disciplinary team is the key if the news is to be reinforced ensuring the patient and where appropriate, the family, have the fullest understanding possible.

Taking the time to prepare for an interview to break bad news to patients will help ensure the process is more effective. That said it has to be acknowledged that receiving a diagnosis of bad news may be overwhelming for the patient and their family or carers regardless of the care the doctor or professional takes in communicating it.

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Ptacek JT, Eberhardt TL. (1996) Breaking Bad News. A Review of Literature. *JAMA* 276: 496-502

¹ Ptacek JT, Eberhardt TL. (1996) Breaking Bad News. A Review of Literature. *JAMA* 276: 496-502

Recommended Further Reading:

<http://www.breakingbadnews.co.uk/guidelines.asp>

Gregg K. Vandekieft. *Am Fam Physician* 2001;64:1975-8

SESSION 5.8 DISCLOSURE IN ADULTS

Learning objectives:

- Define disclosure
- Discuss why disclosure is important in adults
- Describe the forms of disclosure
- Identify factors influencing disclosure
- Discuss current challenges to disclosure

I. Definition of Disclosure;

The process by which the person who has had a positive blood test for HIV/AIDS is informed of the results or he/ she is able to inform other(s) about the results.

An action of making something known to someone else and more especially in public. To disclose means to reveal, make known the unknown or share out the information to other.

NB: Disclosure in HIV/AIDS is a process, this involves the person living with HIV/AIDS, tested his/her blood and informed of the results by the trained personnel, health worker, a well prepared relative or a friend and others as they may be determined.

Remember disclosure is not automatic; it needs preparation of all people involved.

It is up to the client to decide if they want to share the HIV test results with anybody else, it's also up to the client to decide when to share the results with another person.

The role of the health worker is to discuss with the client the **pros** and **cons** of disclosure and the timing of disclosure.

Some treatment programs are family based and having a treatment supporter is a requirement, in this case disclosure is necessary in order to join the program. This should therefore be explained so that the patient understands that she/he is free to opt out if he/she strongly against disclosure.

The counselor or any other health worker should discuss with the client the advantages and the disadvantages of various options of disclosure such as provider-assisted notification **vs.** client notification.

Results can be released only subject to the patients' consent for a proper disclosure, when the patient is mentally capable of making decision.

About couple: - when testing a couple, results should be given to both partners or in presence of both/ together. Counselors and clinicians should strongly encourage their clients to disclose their results to each other. Despite the hindrances, appropriate counseling and social support can enhance the disclosure process.

2. Forms of Disclosure:

2.1 Non-disclosure; Client does not disclose status to anyone, remains silent and keeps it to him/her self.

2.2 False disclosure; here client tells individuals or public false information, for example if the client tested HIV positive, then instead tell people that he/she tested negative.

2.3 Partial disclosure; client only tells certain people about his/ her status, for example the spouse, a relative, a counselor or a friend. However, the information revealed might be full or partial.

2.4 Full disclosure; here client publicly reveals status. The information might be fully revealed to individuals, a group of people or an organization.

2.5 Voluntary disclosure; client voluntarily shares information about his or her HIV status, this may be full or partial disclosure.

2.6 Involuntary disclosure; client's status is revealed without his/her approval.

- Situations considered for disclosure:
- Illness like HIV (inself or in the family)
 - Joining PMTCT program
 - RX, such as on ARVs, Anti TB RX/ drugs
 - Problems with a partner
 - Domestic violence
 - Incases of moving from one country to another and status is a requirement
 - Pregnancy
 - Rape
 - Disclosure to the child (refer to the guidelines for child disclosure)

3. Who Should An Adult Consider Disclosing?

Due to various reasons, individuals may reveal the HIV status to different categories of people.

- Spouse/partner
- Relative(s)/friend(s)

- Children ie an elder child or any one they trusts if she/he understand the meaning/information being passed on.
- Some one who shares the same experience (e.g. peer)
- Church member(s)
- Traditional healer
- Community
- Public/media
- Health care provider/counselor
- Employer

4. Factors Influencing Decision To Disclose:

These are both personal and external factors;

4.1 Personal factors

These largely depend on the individual's values, beliefs and attitudes such as;

- Self reliance/self sufficiency
- Not wanting to be a burden to others
- Need for privacy and protection from judgment
- Use of denial as a copying tool
- Fatalism
- Mistrust of others or systems
- Culture
- Shared support **vs.** individual support
- View of illness and infirmity
- Religion
- Belief that faith heals all
- Taboo about sex and disease transmission
- Punishment and judgement
- Prior experience
- Sexual activity
- Age
- Marital status
- Pregnancy

4.2 External factors;

- Environment
- Relationship between counselor/health worker and the client
- Relationship with medical team
- Partner
- Family
- Other HIV/AIDS infected or affected persons in the family
- Social support
- Policies at the work place

NB: Advantages and disadvantages of disclosing one's HIV status should be considered in the context of each client's life situation.

Individualization (taking each client as an individual and in his/her own situation) should be closely observed.

5. Benefits of Disclosure:

- A problem shared is a problem halved or even solve (remember, as more people disclose their HIV status, it will help them reduce the stigma, discrimination and denial that still surround HIV and AIDS.
- Disclosure builds trust and confidence. In most cases the recipients are already suspicious.
- It relieves the individual from the burden of keeping secrets and answering difficult questions.
- Disclosure also helps an individual accept the status and learn to cope with the stress.
- It enables the person access medical services, care and support they need. Disclosure promotes prevention of further infection to themselves and others. In particular, openness about HIV may help women negotiate for protected sex.
- It creates an entry point for recipients to think, find out or share about their own HIV situations. Disclosure also enhances support of significant others.
- It encourages planning together and promotes courage to help others avoid the infection.
- Openness about HIV status can stop rumours thus reducing the stress caused by keeping a “secret”
- Disclosure also promotes responsibility i.e. the person and loved ones plan for the future.
- Lastly, disclosure provides an opportunity for developing coping strategies before the time of serious illness and likely death, this may help an individual plan for future of his/her loved ones.

6. Benefits Of Not Disclosing:

There are also advantages of not disclosing that explains why some people keep their status to themselves;

- To maintain a secret
- To maintain status quo. i.e. “normalcy” or current situation
- A protection against;
 - Stigma
 - Isolation
 - Rejection
 - Loss of income
 - Violence
 - Blame
 - Change in social status
 - Being prevented from having children in future
 - Not needing to seek to medical care

However, Not Disclosing has various possible negative outcomes that it comes along with:

Discussions and feedback in pairs:

What are the current challenges to disclosure in your setting? How can these be overcome and what role can you play as male care givers.

SESSION 5.9 DISCLOSURE IN CHILDREN

Learning objectives:

By the end of the session participants will be able to:

- Explain disclosure of HIV and AIDS test results to children and adolescents
- Identify challenges of disclosure in HIV infected children and adolescents
- Explain the benefits of disclosure in children
- Describe the consequences of non – disclosure in children
- Explain the role of male caregivers in the disclosure process
- Demonstrate knowledge and skills to disclose to HIV infected children.

1. Introduction:

HIV and AIDS disclosure in children has been found to be challenging to most health care providers and parents/guardians. On the other hand experience has shown that if properly done disclosure; facilitates positive living in which adherence and positive coping mechanisms are enhanced.

There is thus need to build capacity of caretakers and male care givers to facilitate disclosure among HIV infected children.

2. What is disclosure in children?

This is when a parent, guardian, next of kin or health care provider discusses issues of HIV/AIDS with the child and informs him or her about their HIV test results.

Note: In disclosure for children, parents/ guardians of children with the support of health care providers should be the ones to inform the child about his or her HIV sero status. Your role as a male care giver is to facilitate the process.

Group discussion and presentation

Group 1: Identify challenges of disclosure in HIV infected children and adolescents

Group 2: Explain the benefits of disclosure in children

Group 3: Describe the consequences of non – disclosure in children

3. Challenges of disclosure in children

- Parents own fears that informing children their HIV positive test results is like disclosing their own sero status

- Fear of blame from children about getting infected by their own parents.
- Most adults fear that children will not keep disclosure information as secret
- Fear that children might have negative emotional reactions like committing suicide
- Fear that children are too young to understand the information.

4. Benefits of disclosure in children

- Allows children to cope better with HIV. For example they child can report to you when not feeling well.
- It helps children to accept that they have HIV
- Increases self esteem among children & adolescents
- Helps children adhere to treatment
- It makes it easy for for parents and health care providers to provide care including psycho social support
- Helps adolescents make informed safe-sex decisions when contemplating sexual intercourse with a partner
- Children & caregivers psychologically adjust to living with HIV/AIDS
- Works towards reducing stigma, discrimination, & misconceptions/myths regarding HIV/AIDS
- Family-centered disclosure builds trust in relationships & improves healthy communication
- n between parents & children.

Disclosure is very important in facilitating positive living positively, reduces the burden of keeping secrets from children. Children disclosed to cope better than those who are not disclosed to.

5. Consequences of non- disclosure in children

- Children start to wonder why they take drugs every day, why they have to visit clinics more often and end up getting emotionally isolated.
- Develop self stigma for looking sick
- Develop inappropriate actions e.g. refuse to take drugs
- Get to know their HIV status from wrong sources.
- Loss of confidence and trust in parents
- Poor child parent relationship, communication etc

6. Explaining the role of male caregivers in disclosure to children:

Open discussion – please share the role of male care givers in children.

Disclosure of HIV /AIDS status and other long term illness is a process but not a one time event. Male caregivers need to work hand in hand with the parents/ guardians.

Note: Disclosure to children should take into consideration the age of the child, developmental level of the child, psychological well being of the child as well as readiness and participation of the parent/ guardian.

7. Roles and responsibilities of male caregivers in the disclosure process to HIV infected children.

- Assess current barriers & reasons for delayed disclosure (fears, stigma)
- Assess caregiver's willingness to take central role in treatment process
- Explain and give information on the benefits of disclosure to children.
- Facilitate the process of disclosure.
- Enlist the support of parents and care takers for disclosure
- Work hand in hand with care takers to assess the child's understanding of their illness.
- Refer children and caretakers to health facilities for disclosure
- Participate in offering psycho social support to children after disclosure
- Refer children to support groups to facilitate coping and positive living mechanisms.

8. Demonstrating knowledge and skills to facilitate the disclosure process

Case scenario for the role play;

James 12 years old is a total orphan staying with his grand parents. He lost both his parents to HIV at a tender age. His mother died when James was 1 year old and his father passed away when he was two and a half years old. James developed skin cancer 3years back when he was 9 years old. He was later tested for HIV and found to be sero positive. His test results were only disclosed to his grand mother who consequently found it hard to disclose to James. Currently James has started complaining looks isolated most of the time, he has started refusing to take his ART medication because he feels that he is now ok. Today morning the grand mother explained to you the situation while on home visit to her home.

As a male caregiver handle the situation in a role play.

Three volunteers : One to act as a male caregiver, another one to act as a grand mother to James and the 3rd participant volunteer to act as James.

References:

1. MOH Uganda (2006) National guidelines for implementation of family support groups in PMTCT.
2. Tindyebwa D, Kayita J, Musoke P et al (2006) Handbook on pediatric AIDS in Africa.
3. ANECCA. AIDS Relief & RCQHC (2008) : Psycho social care and counseling of HIV infected children and adolescents: Training manual – Un published

SESSION 5.10: SPIRITUALITY IN PALLIATIVE CARE FOR PLWHA

Learning objectives:

- Define spirituality and religion
- Identify the common spiritual needs of PLWHA
- Discuss ways of supporting PLWHA and their families to meet spiritual needs

1. Introduction:

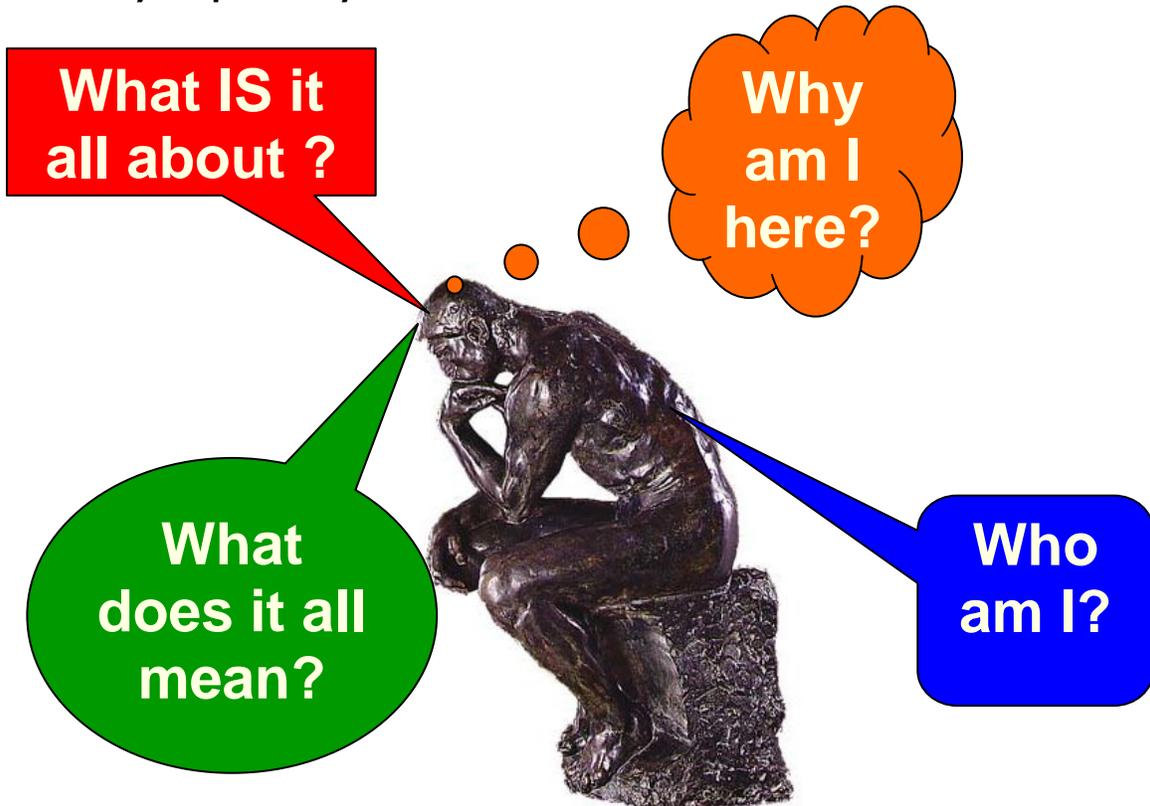
For some people, spirituality is how they see themselves in relation to others, the earth and the universe. For others, a spiritual power is at the heart of these relationships. This spiritual power may be God, Allah or any of the many supreme beings that are worshipped. Even within a specific religion there may be some who pray differently and have differing ways of relating to this spiritual power. Spiritual needs of a person living with HIV/AIDS may be obvious at times and not so obvious at other times. A common spiritual need no matter what a person's belief system is the search for the meaning of life and purpose of living. In providing spiritual care it is therefore very essential to support people to see a meaning in life they are living and in the lives they have lived before.

2. What is spirituality?

- It encompasses beliefs & needs unrelated to organised religion that can be expressed outside a religious context. (Dudley J, 1995)
- The lived experience that gives meaning to life (Catteral R.A et al, 1995)
- Spiritual needs may range from religious rituals such as prayers or holy communion, to secular observances like music/poetry, or nature (O'Connor P, 1988 in Dudley J, 1995)
- The life force springing from within that pervades our entire being (Amenta M, 1998 in Dudley J et al, 1995)
- It is my being: my inner person. It is who I am unique and alive. It is me expressed through my body, my thinking, my feelings, my judgments and my creativity (Goldberg B, 1998)
- Search for meaning & purpose in life
- Identity, thoughts & feelings, & the ability to accept & be comfortable with who you are.
- relationships with others, friends & family, as well as connection with the community, the world & the natural order, this may include a search for an ultimate other eg God
- Each and every one of us ...will interpret spirituality according to our own culture, beliefs, experiences and social background.
- The meaning of spirituality may change as we journey through life. (Carroll B, 2001)
- Spirituality defines a relationship that grows throughout life and often comes to a greater meaning during times of crisis, especially when coming towards old age or death.
- Spirituality is our relationship with God. It is very personal to a person.

- It is not Religion, although our spirituality may grow out of our religion
- It means that a person can turn to God, outside of religion for any joy or sorrow in life.

Summary of spirituality:



3. Religions:

- Religions give us structures in which to develop our spirituality. We must respect spirituality developed throughout life in our patients and families.
- Usual path to introduce us to God
- Offers formal structures/rules to reach spirituality
- Offers exemplary lives of spirituality for us to emanate
- Ideally includes love for all if based on holy books
- Gives basics of spirituality
- Gives comfort to those who do not wish to question
- Gives pain to those who do wish to question
- Has often been abused by people seeking power
- All formal religions try to help people in their search for inspiration and insight when they are forced to grapple with the great existential questions provoked by suffering (Becker 1973)
- The sense of purpose and meaning that religion provides is a comfort in the face of adversity. (Kushner 1981)

3.1 Religion is the mode of transport



4. Your own spirituality:

- Your own spiritual needs, fears and limitations
- The general spiritual needs of those who are terminally ill
- Assess the spiritual needs of your patient in particular
- Consider working with a team or the immediate family as much as possible

5. Important questions:

- How do I feel about persons with terminal illness?
- Am I comfortable with them?
- Do I sit with them or avoid them?

Reflection:

Take three patients in a hospital setting:

Patient 1: Is acutely ill but improving although still a challenge for the health workers

Patient 2: Is much better is going home today

Patient 3: A person with HIV/AIDS or cancer still in hospital

Reflect on real life experiences, who of these patients is given more time and attention and why? Who should be given more time?

6. Some basic Spiritual Needs

- Need for meaning to life
- Need to receive love
- Need to give love
- Need to have a sense of forgiveness
- Need for hope and creativity
- A sense of completion

- A sense of responsibility and control

Patients with spiritual pain may appear:

- Lonely, isolated, silent, helpless, shut in, and far from God.
- Maybe restless, experiencing acute anxiety or guilt.
- Maybe projected or displaced anger, demanding, hostile and irritable.
- Fearful – dreams & nightmares

There may be a sense of...(Kaye, 2006)

- Unfairness (why me?)
- Unworthiness (I don't want to be a burden.)
- Hopelessness (What's the point?)
- Guilt (it's a punishment.)
- Isolation (No-one can really understand.)
- Vulnerability (I'm a coward.)
- Abandonment (God doesn't care.)
- Punishment (But I've led a good life.)
- Confusion (Why does God allow suffering?)
- Meaninglessness (My life has been wasted.)

7. What you need to know:

Some people understand or seek meaning for their suffering within the context of their religious belief system. Others look for meaning elsewhere.

- A person may have lost contact with a faith community but want to return
- The person may wish to re-establish broken ties with a spiritual power.
- For some, the longing is for a relationship with a previously unknown spiritual power.
- The person may express guilt, remorse and a desire for forgiveness in a search for inner peace and peace with others or a spiritual power.
- The person may ask "why" either of the spiritual power or the universe at large. This question may not be asked aloud but suggested by what is being said.
- If prayer has been a big part of the person's life, this need for prayer may change. The person may no longer feel the comfort of a close bond with a spiritual power.
- For a religious person, there may be deep spiritual anguish either spoken or unspoken, over the perceived absence of a spiritual power. These feelings are not a denial of beliefs but an attempt to understand why this suffering is permitted.
- The person may start to look back on life and look ahead to the unknown. There may be hopes of a miracle or of immortality, either in a life hereafter or a human legacy.

8. How you can help people to meet spiritual needs:

- Listening and helping the person sort through the varied emotions that accompany a terminal illness
- Help with prayer if required and after permission from the patient

- Do not strive to change the person's beliefs, instead be accompany her/him within their current belief system.
- There are questions you may not be able to answer and don't be afraid to say "I don't know"
- Explore whether the person wants to speak to a spiritual or religious leader in regard to spiritual matters and link them to the right person.
- Reassurance that feelings of guilt and doubt can be normal at this time.
- Accept the person's need to talk about dying or saying good-bye.
- Ensure you have your own spiritual resources to help you.

You need to show:

- Compassion, companionship & meaningful relationships
- Understanding
- Empathy
- Listening
- Being present and listening is often answering the need of the patient.
- By listening in an empathetic way, we come to know the spiritual needs of the patient. This calls for an empathetic response
- Patients may ask you to pray. Be prepared to do so.

Prayer

- Do not suggest prayer to an obviously angry patient or who has demonstrated negative feelings to God. Sometimes a word of scripture or Koran can be very consoling.
- Would you like members of the community or Church to come and pray with you? If so try and contact.

9. Finally, Helping patients in their Search for Meaning

Working as carers for the sick and the dying we need to understand their spirituality. Spirituality refers to our relationship with God and not to our religion. When we are dying this is what counts more than our religion
However there are certain rituals that may need to be carried out by our religions, which make our patients more comfortable.

- A readiness on the part of the care giver to listen is important. Listen to what is most important of all, their inner griefs, guilts and longings
- There is an urge in many of those who are dying to set to rights whatever is still wrong
- This takes time and good listening skills, and 'being with' the patient.
(Saunders)

10. Conclusion

- We may not understand or accept the religious beliefs of our patients, but we can respect them
- Religious needs may be more important to the person than medical or nursing care
- Always ask about prayer, rituals, festivals, diet, fasting

- Distinguish between spiritual and religious support
(Kaye, 2006)

References:

Macmillan, Peden, Hopkinson and Hycha (2004). A Caregivers Guide: A hand book about end – of – life care. The Military and Hospitaller Order of St. Lazarus of Jerusalem and The Canadian Hospice Palliative Care Association

SESSION 5.1 I: MALE SUPPORT GROUPS

Learning objectives:

By the end of the session participants will be able to;

- Describe/define support groups
- Describe the benefits/importance of men’s support groups
- Identify the benefits of support groups and what male care givers can do to promote support groups.
- List the challenges of starting and running a support groups
- Identify strategies and actions for meeting the challenges
- Identify strategies for sustaining a group and mobilizing members
- Identify steps for starting support groups

This session is a critical part of the manual as it provides the opportunity to discuss how to establish, run and sustain support groups of men affected by HIV or life long illness.

1. Defining support groups:

Support groups can also be called Peer support groups. It is support for people by people in the same situation. Peer support includes people who are facing the same challenges such as the client. These can be men or men living with HIV, partners of HIV+ people, or newly diagnosed people.

Peer support can be between someone who is facing a challenge for the first time and someone who has already managed it. This means linking someone who is starting ART to someone else who has already started ART and is managing well. It is a group of people affected by a common problem, challenge or condition, coming together to share in a guided way for therapeutic purposes.

2. The importance of starting men’s support groups of PLWHA

- For Self-help, support and action.
- Helps people feel that they are not isolated and alone with their problems.
- Provide a way to meet people and make friends.
- Helps individuals to become more confident and powerful.
- Provides a basis to organize activities led by the members
- Make links between people from different backgrounds and increases understanding and tolerance

- Helps to share resources, ideas and information for instance about the latest available treatments or local support services.
- Makes other in the community more aware of the situation facing people in the group by increasing the visibility of the PLWHA'S.
- Leads to change by creating a Public or Political voice.

3. Benefits of male support groups:

Support through such groups reduces:

- isolation
- Increases social support
- Reduces stigma
- Less intimidating source of support
- Helps to share experiences
- Helps people see that living with HIV is possible.
- Reduces reliance on health services
- Reduces the workload of the health workers Increases the quality of life for people living with HIV

While clients learn a lot from health workers, some things are better learned from those who have experienced the same problems and addressed the same barriers. Whether in the hospital, health centre or home community, clients find peer support to be a vital part of the care provided.

4. Promoting Peer Support: What you can do

- Talking to clients regularly about peer support and encouraging them to access it .
- Emphasizing the benefits of peer support
- Acknowledging their fears
- Finding out what is available locally and knowing the details of the clubs/groups in that area
- Establishing peer support groups for: positive women, positive men, partners of people with H IV, people on ART
- Establishing post test clubs
- Running group education sessions
- Identifying individuals who are prepared to act as peer supporters

4. The challenges of starting men's support groups

- In some places, it's not possible to be public about HIV status, which makes people reluctant to join a group in case other people find out
- Many groups fail because the biggest need of their members is money and other materials and economic support - a small support group may be unable to solve this problem alone.
- Group members often have different needs and expectations, which can lead to conflict and disappointments.
- Often a few dynamic individuals set up the group and when these people are no longer involved the group can lose its direction.

- Group members can burn out, especially if the few openly HIV+ people have many demands on them for public speaking, planning services and other activities.
- The issue of acceptance; by the community, their relatives, in the work place and especially by the wife.
- Denial of HIV status by men

5. **Why People Stop Using Peer Support:**

- Fear of confidentiality being broken
- Fear of meeting new people
- Fear of meeting other people with HIV
- Not knowing that peer support exists
- Being too busy to have peer support
- Not being able to get to the peer support meetings
- Not having transportation money
- Needing to care for children
- Not having partner support to attend
- Having to explain where they are going to others
- Having other commitments

6. **Useful strategies**

6.1 **Group Education**

A group education is best described as an extended health centre visit where not only physical and medical needs are met, but educational and psychological concerns are also dealt with in a group setting.

Group education sessions can help clients to make the most of scarce time in the health centre. Care givers should arrange for clients to make use of group appointments to:

- Educate clients about their conditions
- Develop peer support and expertise
- Promote self management
- Conduct clinical follow-up
- Address difficulties

You can organize education sessions and invite a health worker to facilitate them.

7. **Important in running support groups:**

- Ensure the group has clear aims and that these are understood
- Use the benefits of support group to promote the idea to community leaders
- Recruit informally in places men have time to talk
- Make formal links with service providers that have difficulty reaching men [VCT, clinics, ANC etc]

- Hold meetings at times and places convenient to men

7.1 Action planning

Strategy	Action	When
Have clear Aims	Agree aims at inaugural meeting of potential leaders and consult on these aims with potential and early members	
Recruit informally	Agree best locations; discuss whether permissions necessary or desirable ; work in pairs and report back after a week	

7.2. Running successful meetings

Preparing for the first meeting

Exercise:

- 1. When members attend the group for the first time, what do you think goes on in their minds?**
- 2. What will make them want to come for a second and third meeting and to keep coming in the future?**
- 3. In small groups, draw up an agenda for the first support group meeting, including time required for the meeting and how a balance between providing important information and making it a participatory event will be achieved.**

7.3 Leading Support groups:

i. Promoting the groups first meeting

- Communicate details directly to the group members already recruited
- Tell counselors, health workers, hospitals and VCT centers.
- Talk to counselors, health workers, hospitals and VCT centers.
- Put up posters, Brochures in waiting places e.g. VCT, reception areas.
- Contact local AIDS support organizations.
- Advertise in the Media
- Put up you story in the Media both Print and Electronic.
- Talk to people one to one or in groups.
- Visit people in their homes
- Give out the correct information about the activities of the group.
- Plan on when the group meets the time and place
- And of whether the meeting will be confidential that is (Closed or open).

- Contact details for people who may be nervous for the first time

Group Identity – members can identify a name of their choice which is not necessarily indicating the HIV positive status.

Helping to lead the group

Exercise:

- *Think of three things you can say as a leader of a new group in your first meeting with members*
- *What preparations would you make for the first meeting?*

Important questions:

- Where is the meeting?
- How do they want the room arranged?
- Will there be any refreshment – if so when?
- Who will record the attendance?
- Expectations

As leader of the group meeting, you need to share ensure the following:

- Ground rules must be laid down
- The agenda should be explained
- Keeping records of attendance
- New members should feel welcome
- All members should have equal status
- Share the time
- Encourage each other to speak
- Win trust by trust by showing respect and listening properly
- Be responsible for yourself
- Be patient take one step at a time
- Get involved but also know when to stay quiet.
- Help the group to stay on the topic.
- Reflect or repeat ideas or statements that might otherwise get lost.
- Disagreement is healthy- even with you
- Large groups may need to be divided for some activity

8. Keep the group going by ensuring that;

- The group sets up aims and activities
- There is open communication and discussion within the group
- Every one participates in discussions and exercise
- Group members attend regularly
- Methods of coping with new members
- Evaluation and feedback is encouraged in the group
- Acceptance of all group members is encouraged
- There is high level of trust in the group

- Conflict or disagreement is open and constructive
- There is learning in the group for example on problem solving skills
- All group members have equal status in the group
- No one dominates the group and no one is left out.
- Group members are prepared for life outside and after the group.

9. **Growth and Change;**

- No group stays the same forever.
- The number of regular attendees and the experience level may change as members come and go.
- Review group agreements and ground rules regularly.
- When new members join make them feel welcome.
- When a topic is repeated for new members keep the interest of other old members by presenting the same material in a different new way.
- Members may outgrow the group; make them feel comfortable about moving on and show that their contribution have been appreciated.
- If a group grows too big for everyone to be able to participate, try splitting into two groups, or split into two for just sometimes.

10. Basic Steps for Starting a Support Group

Step 1: Deciding the "Mission Statement" for your support group.

- Deciding the purpose or function of your support group will help you to organise.
For example
 - Will this be a group that aims to provide support for volunteer caregivers?
 - Will it be a group that aims to provide support to carers living with HIV?
 - Will it be a support group for female/male carers?
- An example of a mission statement is: "The mission of the ___ support group is to provide support and respite care for PLWHA who provide care in the community".

Step 2: Deciding who your support group "members" will be.

- Develop the 'criteria for membership' which can be information such as:
 - Who will your support group members be? For example, deciding if the support group will be for CBVs only or for all caregivers in the community including the Primary caregivers of your clients.
 - What sort of characteristics should group members have? For example, you may want support group members who have experience providing care, understand principles of confidentiality .. etc.
 - What is the maximum number of members you think your support group should have?

Step 3: Deciding when and where to hold support group meetings.

- Deciding when and where support group meetings will be held is important information that should be provided to people before joining your support group, as it will address issues such as:
 - Will support group meetings be held during working hours?
 - Will support group meetings be held at a location that group members can reach (i.e., availability of transportation, walking distance from their homes)?
 - How many times a month will meetings be held?

Step 4: Developing Guidelines for Support Group Meetings

- Developing guidelines for support group meetings will help to ensure that your support group provides reaches its "Mission Statement" and provides the type of support you want to give to group members.

The following are guidelines for peer support groups which CBVs can use or adapt to suit their needs:

Step 5: Hold Regular Meetings and Strengthen Your Support Group

- Engage group members in discussions that assess whether support group activities are meeting the individual needs of members
- Know of additional resources in the community to help with group activities
- Create working committees within your support group tasked with compiling additional information
- Network with other support groups and organisations working within HIV and AIDS and/or home based care
- Learn strategies for resolving conflict within the support group.

References:

IRC, SFAIDS & WHO,(2006). "HIV Prevention, Care and Support. A Training Package for Community Volunteers"

MODULE 6.0: CULTURAL ISSUES IN CARE GIVING

SESSION ONE: CULTURAL SENSITIVITY IN CARE GIVING

Learning objectives:

- Define culture and cultural sensitivity
- Discuss examples of different cultural practices, rituals, beliefs and ceremonies which relate to illness, death and dying
- Discuss the importance of respecting people's cultures while providing care and strategies for providing care to people from different cultures.
- Identify cultural barriers to care giving and how these can be overcome

1.0 Introduction:

A person's cultural roots, ethnic background, religious and spiritual orientation will impact on their attitudes at a time when they are struggling with a life threatening illness. Culture shapes beliefs about the meaning of death, and the care of the sick. For example, some cultures feel free to cry and express their sadness when death occurs, while another culture may consider the display of emotions unacceptable. It is therefore important for a care giver to understand the cultural beliefs and practices of the patient and family and most importantly acknowledge and respect them.

The care giving role in Africa is a predominantly feminine role yet with the current burden of caring for the sick and those who are dying of AIDS, there is a need for both women and men to take a central role in care giving. Although men are currently providing care for PLWHA and their families, there are still cultural barriers affecting their full participation in care giving.

This session therefore aims to provide you with support important aspects of working with people from different cultures. Indeed care givers find themselves caring for people from different cultures, but also different from their own cultures. The session aims to discuss the important considerations that should be taken note of by the male care givers in order for the patients and families to be comfortable with the care they receives, as well as for the care giver to be comfortable to give the care. But also identifies the cultural barriers male care givers are facing in care provision and possible solutions.

1.1 What is culture and cultural sensitivity or culturally competent care?

Culture refers to learned patterns of behaviours, beliefs, and values shared by individuals in a particular social group. It provides people with both their identity and a framework for understanding experience. In its broader sense, a culture is a group of people with similar ethnic background, language, religion, family values, and life views.

The goal in providing culturally – competent care is to be sensitive and aware of the beliefs, practices and traditions of others and respect them when providing care. This includes self awareness, cultural knowledge about illness and healing practices, communication skills and behavioural flexibility.

- Families pass on rituals and beliefs about illness and death from generation to generation
- Tribes/ethnic groups differ from each other in what they believe and in how they behave.
- It is important to be sensitive to other people's beliefs and to be non-judgemental

Culture has a significant role to play in issues of illness and death. A person's culture may influence:

- The expression and meaning of pain and suffering
- Attitude towards disclosure and awareness

- Beliefs around the cause and meaning of illness
- The choice of healing and treatment
- Attitude towards death and dying
- Beliefs about the after life, the value of human life and the body
- Expressions of loss and grief
- Death rituals, including preparation for death, burial, funeral practices or memorial services, customs for disposal of the body and mourning rites

I.3 Why it is important to understand, acknowledge and respect the culture of patients and their families:

- Peoples' behaviour, perceptions and responses to a life threatening illness are influenced by their cultural backgrounds including the way they express pain, suffering and grief. It is therefore important to understand their culture so that care provided is suitable to their cultural context.
- It is impossible to know about every culture. As a care giver, it is important to ask questions which will help you to understand the patient's culture and how this is influencing their responses to the illness.
- When interacting with people from a different culture, unfamiliarity may create an attitude of superiority and viewing persons from another culture as being ignorant or inferior. It is important to approach people from another culture or ethnic group with respect and humility and a desire to understand their culture and perspective. This is very important in palliative care as patients and their families are anxious and fearful.

I.4 Strategies for working with different cultures:

- Do not make assumptions; ask the patient and family to be sure of what is suitable for them. Observation of their cultural practices is equally important.
- The same care may not always be appropriate for persons from a particular culture. It is therefore important to provide individualised care as opposed to generalised care.
- Try a variety of approaches in partnership with the patient and the family.
- Remember that many cultures have specific rituals or traditions that surround their illness and death experiences e.g.
- Be sensitive to the way in which a patient's past may affect his reaction to the care given in the present
- Values around care giving vary from community to community as well as from family to family
- Spend time getting to understand the basic value orientation of the patient's cultural group.
- Remember that the patient's and family's attitudes, values and beliefs may be different from your own. It is therefore important to put the values and beliefs of the patient and the family at the centre of care and not your own.
- In partnership with the patient and family, identify the cultural values that are very dear to them and ensure that they are supported to fulfil these.

- Explain to the patient and the family and ensure understanding of the care they will receive from you and other care available to them.
- If any cultural issues arise, do not deny or diminish it. Instead listen and understand the patient's experiences and how they would like you to help.
- It is important for the patient and the family to fulfil their rituals or ceremonies relating to illness, end of life or death.
- Religious beliefs and rituals of the patient and family are also part of their culture and should be acknowledged and respected.

1.5 Culturally competent behaviours required of a male care giver:

- **Self awareness** – Be aware of your cultural beliefs and values and how these influence the care you give. It is important that you do not impose your values on others.
- **Avoidance of stereotyping** - Avoid assumptions, levels of participation in specific traditions and adherence to certain beliefs and values can vary.
- **Exploration of cultural values and beliefs** - discover the uniqueness of each person by asking questions about things such as family lifestyle, patterns of authority and communications and expectations of care givers.
- **Facilitation of meaningful practices** – Make referrals to appropriate persons, groups or institutions and support the practice of specific rituals, customs or traditions.
- **Determine the persons's preference for disclosure and any other important information** – the desire to tell or know about illness or death is a cultural value that is not shared by everyone. Remember that people have the right to know or not to know if this is their wish.

Identify and list some cultural practices relating to illness and death in your communities:

Examples of rituals and practices based on religion:

Rituals, Beliefs	Diet/feeding	After death
Christianity		
Most Christians believe in God and within God there are three co-equal persons Father, Son and Holy Spirit	There are no special dietary requirements	The body is displayed for viewing and for people to offer prayers
Islam		
Islam means peace, purity, obedience and total submission to the one and only One God , His prophets and His laws (Quran)	- Eat meat of an animal or bird slaughtered in a Muslim way after proclaiming the name of Allah - Muslims fast during the	- As death approaches it is important for the dying person to proclaim or recite the Creed – Oneness of God (Shahad) or be helped to do so.

	<p>month of Ramadhan if there are no medical contradictions.</p>	<p>- After death, eyes are shut, mouth closed with a bandage running under the chin and tied over the head and the body straightened. The body is cleaned by a close muslim relative or friend.</p> <p>- Only a wife and husband can wash their partners, all other washing must be done by someone of the same sex.</p> <p>- The body of a male person is wrapped and buried in 3 sheets while that of a woman in 5 sheets</p>
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1.6 Some useful questions in exploring people’s cultural practices and beliefs:

1. Are there last rites in the person’s cultural or religion?
2. Are there rules or practices around dying and death?
3. What types of rituals are performed?
4. How can you support the patient and family to fulfil their cultural rituals and practices?

1.7 Conclusion:

It is important to understand, acknowledge and respect the religious and cultural values of the patient and the family as this contributes to achieving peace and dignity as well as overall quality of life. Practical support or permission for the patient and family to practice their rituals adds value to the care and support give.

The central principle of culturally sensitive care is respect for the patient and his or her individuality, emphasising the fact that good, respectful communication is the foundation of quality palliative care.

References:

1. Peden, DeMoissac, MacMillan and Mushani-Kanji (2006), 99 Common Questions About Hospice Palliative Care: A nurse’s handbook. 3rd edition. Regional Palliative Care Program, Capital Health, Edmonton, Canada
2. Canadian Hospice Palliative Care Association (2006), Training Manual for Home Support Workers
3. Waliggo, Gwyther et al (2006), Spiritual and cultural care. A Clinical Guide to Supportive and Palliative Care for HIV/AIDS in Sub-Saharan Africa

SESSION TWO: GENDER ISSUES IN HIV/AIDS

GENDER BASED VIOLENCE/DOMESTIC VIOLENCE

The objective of this module is to provide information on the concept, forms and extent of gender based violence, and their relations to HIV infection in order to understand and appreciate the need for urgent action.

LEARNING OBJECTIVES

By the end of the sessions in this module, participants will be able to:

1. Define gender and gender construction
2. Define violence, gender based violence and violence against women.
3. Identify and explain the different forms of violence, their common victims and perpetrators of violence and their root causes.
4. Analyse the consequences of violence at the personal, societal and higher levels, including the cost of violence to victims, HIV infection, perpetrators and the whole society.
5. Describe the contexts and magnitude of gender based violence at personal, societal and higher levels.
6. Analyse the perceived and root causes of gender based violence and identify ways of demystifying the myths and highlighting the facts.

Step One: Gender as a Social Construct

Whereas we are born male and female, society constructs us into men and women. Being a man connotes power, strength, prestige and all that goes with priority. On the other hand, being a woman connotes powerlessness, inferior status and a lesser claim to opportunities of leadership, influence and ownership. The construction of gender is systematically done, justified, maintained and perpetuated.

Step Two: Patriarchy, Matriarchy, Equality

Gender is constructed in line with the prevailing ideology, in this case, patriarchy. This is a system of thought that positions the male above the female in all respects. Denotatively, patriarchy means the rule of the fathers. Matriarchy is the opposite. But there is hardly any society that practices matriarchy. Equality is the ideology that accords both sexes similar treatment.

Step Three: Institutions, Agents and Processes of Social Construction

Various factors are at work in constructing masculinities and femininities. Also called agents of socialization, they play a big part in inculcating the behaviours, attitudes, roles, expectations and entitlements that we have as either women or men. The process of achieving this is multi-dimensional and life-long. Examples of such institutions and processes are: the family, school, religion, rites of passage, marital practices, work place, the mass media, language and folklore.

Step Four: The Concepts of masculinities and femininity

Step Five: Implications of Social Construction of Gender.

Social construction of gender creates a world of difference for women and men. The world of women is that of subservience, subordination and inferiority while for men it is that of domination and superiority. The manifestations of this include: assignment of low value to females and their work, traditions that deny females opportunities to own and control resources, justification of violence against women and practices that entrench the culture of inferiority among females.

Masculinity and femininity

- Many cultures socialise their male children to be aggressive and competitive and train their female children in non-violence and, frequently, in the passive acceptance of masculine violence. Young men are impelled to adhere to codes of bravery and fierceness that force them to compete and fight, to hide their emotions and to be self-sufficient. Masculinity concepts entail that men be the heads of their households. Unemployment and narrow options for men to forge a livelihood have brought poverty, which in turn has made men in the developing countries lose pride in their manhood or masculine identity. As a result of this loss, men have developed stress and frustration has turned into aggression and hence violence toward their wives and other female members of their family.
- Sexual prowess and high levels of sexual activity are very often seen as a paramount way to re-affirm masculinity both to men themselves, women and other men.
- Women are denied curiosity about sex and sexual knowledge, they are not supposed to initiate sex, feel any desire or enjoy sex. Since men consider their sexual desires as a biological instinct, they have been socialised to believe that women are there to fulfil this natural desire.
- Sexual practices have been defined in terms of men's needs. For example, if a woman insists on condom use for her own protection, she goes against the construction of sexual intercourse as a man's natural pleasure and a woman's natural duty.
- These sexual beliefs have led to a social acceptability of any kind of sexual behaviour by men, including violence and abuse. Since sex is considered to be a male need and undesired obligation on the part of the wives, men force their partners to have sex with them.
- Concepts of masculinity and fatherhood also breed violence towards the children. Masculinity entails that fathers should be authoritarian towards their children.

Step Five: Conclusion

The social construction of gender is a lifetime process of learning, applying, experiencing and reaping the consequences of the construction. On the other hand it offers the opportunity to transform society and construct it within the principles of human rights, equality, and social justice Gender based violence, gender discrimination, the spread of HIV/AIDS and other ills facing society's to-day stem from distorted humanity as a consequence of the social construction of gender and power relations. Understanding the concepts and processes of social construction, patriarchy, masculinities, femininity, gender and power relations is critical to finding the solutions.

Gender Based Violence: Definitions

a) Violence: The World Health Organisation (WHO) defines violence as “The intentional use of physical force or power, threatened or actual against oneself, another person, or against a group or community that either results in or has a high likelihood of resulting in injury, death, psychological harm, maldevelopment or deprivation” (World Health Organisation, Geneva 2002).

b) Violence Against Women: The Beijing Platform For Action (PFA) defines violence against women as "any gender-based violence that results in, or is likely to result in, physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or private life."

c) Gender-based violence: Gender based violence refers to all forms of violence that happen to women, girls and men because of the unequal power relations between them and the perpetrators of such violence. Gender, which is inherently about relations between men and women, is a determinant of social relations that legitimises and sustains men’s power over women.

Forms of Violence

- Domestic violence refers to acts of violence that are perpetrated in the domestic sphere and includes: pphysical violence such as battering, beating, punching, choking, slapping, shoving, kicking, etc; psychological and emotional abuse including verbal abuse, intimidation, servitude, eviction, destruction of personal property, threats, accusations, humiliation, isolation, control and desertion; and insulting the modesty and integrity of a woman’s body.
- Economic violence consists of: trafficking of women and girls, property grabbing, deprivation of basic necessities, controlling earnings or forbidding employment, using victims as unpaid labour and exclusion from decision-making.
- Socio-cultural violence includes: harmful traditional and cultural practices such as Female Genital Mutilation (FGM), wife and property inheritance, early and child marriage, forced sexual exposure and training, and dowry and bride price abuse.
- Sexual abuse refers to: all forms of forced sexual acts including: rape (systemic, date, gang and marital rape), defilement of girls and boys, incest, abduction, forced prostitution, forced dry sex, sodomy and bestiality.
- Political and collective violence affects women and girls because of their sexuality and are the victims of : war-related rape and abuse, violence by law enforcement forces including border officials, state-perpetrated violence including ethnic clashes and organised crime such as banditry and abductions.

Factors that Cause or Perpetuate Violence

- Socio-cultural factors, e.g. unequal power relations, low status of women in society, socialisation, traditions, customs, beliefs, attitudes, illiteracy and limited education.
- Legal factors, e.g. dual legal systems, archaic laws, lack of commitment to international instruments, inadequate legal provisions, inaccessibility of legal services, attitudes of judicial officers and ignorance of rights and responsibilities.
- Policies and practices, e.g. negative policy environment, gender insensitive policies and lip-service to international commitments.
- Economic factors, e.g. economic dependence, poverty, limited opportunities and income sources, lack of control of own resources and drug and alcohol abuse.
- Institutional factors, e.g. lack of or inadequate victim support services and distances from courts, health facilities, police services, etc.

Consequences of Violence

- Health effects include: physical injury, death, sexually transmitted infections (STI) including HIV/AIDS, unwanted pregnancies, mental health and behavioural problems and sexual dysfunction.
- Psychological effects include: suicidal tendencies, depression, loss of self-esteem, feelings of shame and guilt, alcohol and drug abuse, poor performance in schools and fear and anxiety.
- Economic consequences include: loss of productivity, cost of health care and cost of legal and judicial investigation and prosecution.
- Social consequences include: ostracization and stigma, forced marriage to rapist or abductor, imprisonment and loss of self and social-esteem.

The contexts and magnitude of gender-based violence

The availability, quality and usefulness of data on gender based violence varies considerably because countries are at different stages with regard to programmes on gender based violence. Understanding the magnitude and impact of the problem is therefore is one of the major challenges facing gender based violence programmes.

However, the following can be stated.

1. Domestic violence often happens in the privacy of homes and families and is perpetrated by relatives or friends.
2. Economic violence happens in different contexts including the family, the work place, institutions and the global arena.
3. Socio-cultural violence happens in all contexts including the family, community, institutions, work places, political and policy spheres.
4. Sexual violence also occurs in both private and public domains and is perpetrated by both familiar acquaintances and strangers.

5. Political and collective violence accompanies social and political events such as riots, wars, etc.

Facts and myths about gender based violence

Gender based violence is condoned, rationalised, explained and justified through myths that are passed on as truths and which often are not challenged. Effective action to stop gender based violence including quashing these myths and replacing them with the facts. For example, there is a myth that violence is part of our culture. The fact is that violence is a crime that is culturally condoned but is punishable by law.

Key perpetrators and victims of gender based violence

- Intimate partners
- Close family members and relatives
- Strangers
- Gangs
- Caregivers
- Law enforcement agents
- Combatants
- Media

Summary

Violence against women is a global problem affecting millions of women and girls of all cultures, religions, socio-economic strata, educational levels and other diversity. It is recognised as a human rights issue which manifests itself in physical, psychological, sexual, social and cultural forms. Violence is the result of the complex interplay of individual, relational, social, cultural and environmental factors. The root cause of violence is the unequal power relations between females and males, in most societies, which makes violence a critical gender issue. Other factors include legal, policy, political, economic and institutional.

Violence against women has serious consequences which are far reaching and include the erosion of self-esteem, self-worth, physical, mental and psychological health, loss of productivity, costs of health care, unwanted pregnancies, infections, legal and judicial costs. Effective strategies for dealing with gender based violence can only be developed when the concepts, forms, consequences, factors and the impact of violence are understood.

SESSION THREE: CARE FOR PEOPLE WITH SPECIAL NEEDS

Learning objectives

- To identify people with special needs.
- To identify their special needs.
- To raise awareness within societies to create an environment that enables care and support for people with special needs (PWSNs).
- Promote total care for people with special needs.
- Discuss the role of male caregivers in caring for people with special needs.

1. Introduction

Throughout the world, people with special needs are often marginalized within their social setups. As such meeting their care needs remains a challenge to be addressed. This topic seeks to address these challenges and brings to the limelight the importance of care for this category of people. It concludes with consideration of possible opportunities for improvements in provision of care for them.

2. Special Needs definition: -

Who are "people with special needs"?

In this context this means members of our community with little or no ability to address their own preparedness, response and recovery and people whose life circumstances leave them needing more than what traditional HIV service providers can avail. These are needs that a person has because of mental or physical problems.

3. Categories of people with special needs include:

- Physically disabled (ranging from minor disabilities causing restriction of some motions or activities, to totally disabled requiring full-time attendant care for feeding, toileting, and personal care.)
- Mentally disabled (ranging from minor disabilities where independence and ability to function in most circumstances is retained, to no ability to safely survive independently, attend to personal care, etc.)
- Blind, visually impaired, low vision
- Deaf, hearing impaired, hard-of-hearing
- Frail/elderly, seniors
- Children, unattended minors, runaways, latchkey kids
- Geographically isolated - no access to services or information, limited access to escape routes
- Undocumented persons, political dissidents, and others who will not avail themselves of government or Red Cross facilities or services due to a variety of reasons
- Ex-convicts, registered offenders and other clients of the criminal justice system
- Culturally isolated - includes people with little or no interaction or involvement outside of immediate community. This is the broad meaning of the words

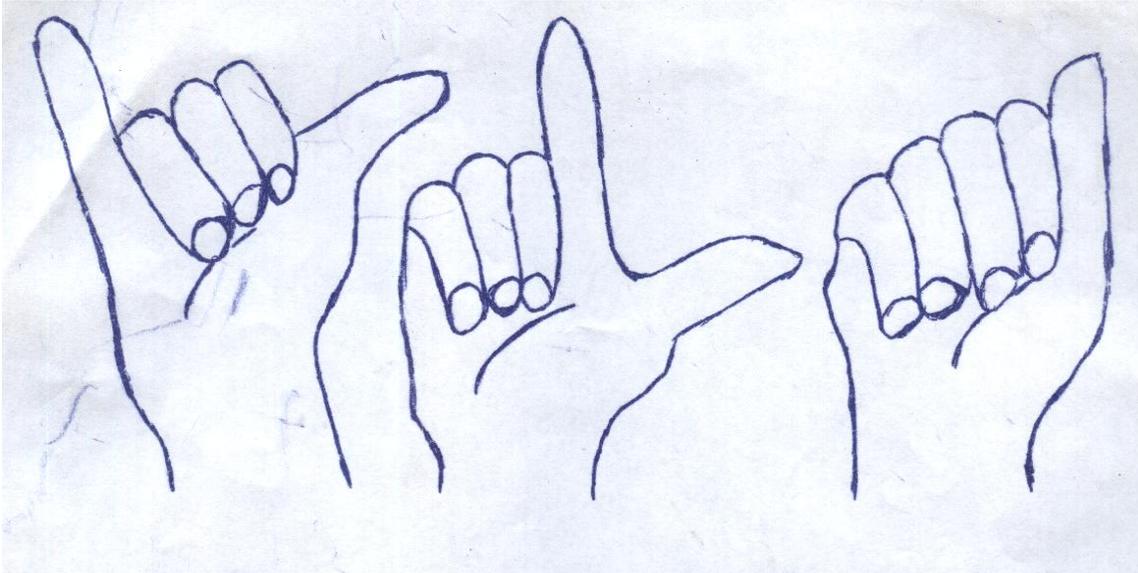
- 'culture' and 'community', including religious, ethnic, poverty, sexual orientation, etc.
- Medically dependent - includes those dependent on life sustaining medications such as with HIV/AIDS and diabetes, or are dependent on medications to control conditions and maintain quality of life such as pain medications, allergy medications, seizure control medications etc.
 - Chemically dependent - includes substance abusers and others who would experience withdrawal or other symptoms due to lack of access, such as methadone users.
 - Homeless, shelter dependent - including shelters for abused women and children
 - Poor, extremely low income
 - Single parents with no support systems
 - Emergent special needs - includes those developing special needs because of the disaster, such as spontaneous anxiety/stress disorders, or recurrence of a dormant health condition, etc.

The main objective of the session is for the MCG's to understand the existence of these groups of people and the various needs of these categories of people.

4. Special Needs include:-

- Effective communication skills using sign language between the care giver and the patient especially for the deaf and people with hearing impairment.
- Equipment for mobility – including clutches, wheelchair, walking stick, walker etc for the physically handicapped.
- Hearing equipment – that is hearing aid for people with partial hearing impairment.
- Reading equipment that is the Brail for the blind.
- Artificial limbs or hands for the lame.
- Support in decision making for people with Down's syndrome.
- Guidance, care, support and security for the blind

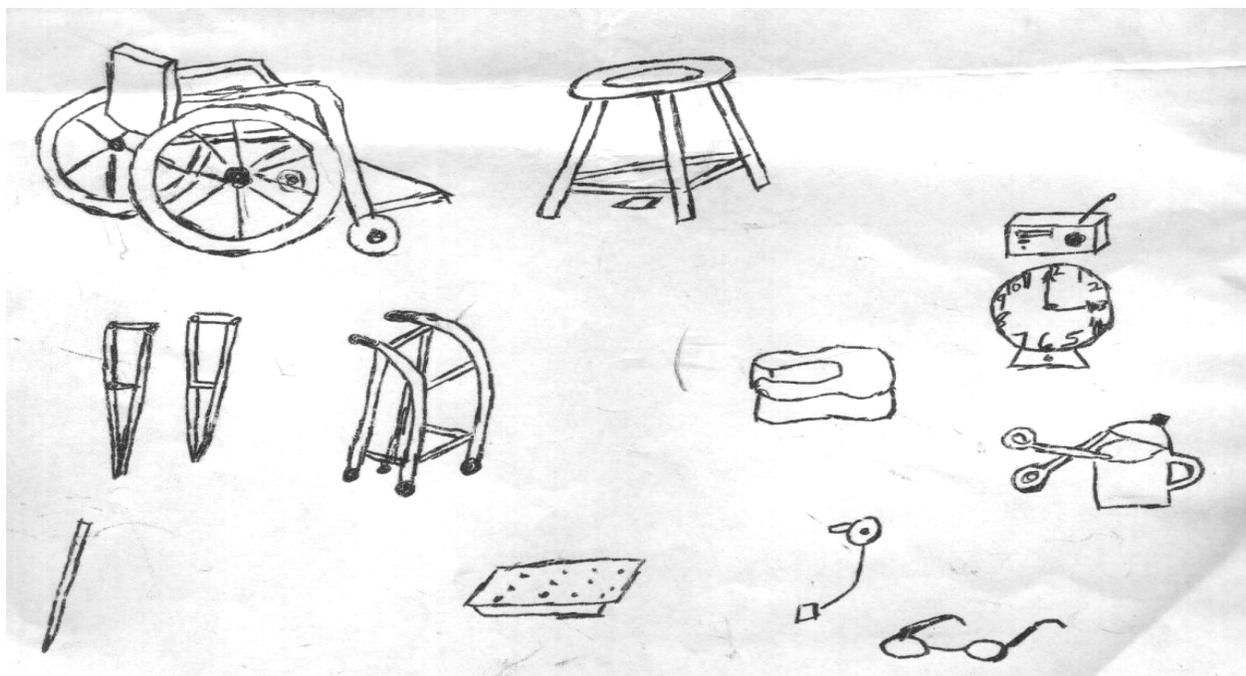
MIND READING THEM



WHAT DO THEY MEAN?

Form left to right

- Letter Y
- Letter L
- Letter E



Supplies for special care for PWSNDS include;

Wheel chair, plastic pan, radio, clutches, walker, bedside commode or bed pan, plastic urinal, special walking stick for the blind, Brail, hearing aid, spectacles.

5. Comprehensive care and support programmes for PWSNs that MCGs need to know include the following; (Role of the Male Care giver)

- Medical care that includes access to preventive and clinical health services, palliative care, nursing care, home based care nutrition needs and supportive care.
- Socio-economic support- includes income generating activities (IGAs), entrepreneurship skills etc.
- Policies and laws (be developed) to ensure care and protection of (PWSNs) to include clauses to prohibit discrimination in access to medical services, employment, education, housing etc.
- Home visits to provide palliative care, family counseling services, nutrition counseling, monitoring of drug adherence etc.
- Material support i.e. mosquito nets, food, nutrition support.
- Communication and exchange of information using sign language provide a radio or TV, newspapers, to keep the patient abreast of current affairs.
- Assessment of physical needs
- Assessment of family and social needs
- Care of general hygiene of the patient and environment.
- Explore ways of identifying and helping people with special needs within their communities.

- Understanding that HIV infection can affect them and that they need the same basic information on HIV prevention, care and support.
- Also understand that the same people could also be primary carers for people living with HIV.

6. Benefits of care giving to people with special needs

- It makes them feel wanted and loved
- It eliminates the negative attitude towards them
- Helping and guiding the patient to access facilities or palliative care services promotes their health.
- Effective use of sign language by the caregiver to communicate with the patient promotes care, love and confidence among them.
- It helps the patient avoid acquiring secondary disability i.e. being stigmatized.
- Use of gadgets i.e. alarm clock to remind the patient when to take medication, especially for the blind patients may enhance drug adherence.

7. Challenges/barriers to care giving for PWSNs

- Lack of sign language skills among care givers may deprive the patient of confidentiality of information when the care giver seeks the services of a 3rd person to interpret.
- Lack of equipment i.e. for the physically handicapped, wheel chairs, walkers, clothes etc.
- High levels of stigma and discrimination by society towards these people.
- Inaccessibility of health facilities i.e. hospitals which do not provide walkways for the physically handicapped (or lifts especially on storegeed buildings).

8. Recommendations

- The male care givers should get some basic training in sign language skills.
- Equipment should be mobilized from available human resources for these people i.e. walking sticks, hearing aids, wheel chairs where the patient lacks them.
- The society should be sensitized on stigma, discrimination and negative attitude against PWSNs.
- To involve them (PWSNs) in this male care givers programme in order to help them change society's negative attitude.
- Planners of health facilities and other public facilities should provide dual access i.e. walkways, lifts to adjacent steps.

GROUP DISCUSSION

- Do you know or live with anyone who has special needs?
- How do you treat these people in order to show them care and love?
- What have you learnt from this experience?
- What do you plan to do to care for people with special needs

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MODULE 7.0: INTRODUCTION TO PAIN MANAGEMENT

SESSION ONE: BASIC PRINCIPLES OF PAIN

Learning objectives:

By the End of the session participants will be able to:

- Define pain
- Describe pain assessment
- List management at community level as male care givers.

I. Introduction

“There is nothing I can do for a patient with terminal cancer and AIDS.”

This is what most carers and non-health professionals feel when they meet a very sick patient. The awareness of palliative care has increased in Uganda now more than ever before and we have learned how to do something for terminally ill patients.

The role of a male care giver in pain control is to offer support to the patient and their family so that their minds need not be focused on pain. They can apply simple measures at home to help reduce pain and need to know when to refer the patient to health professionals for further help. Hence, adequate pain control is essential.

Male care givers are essential link between the family and the professional staff. Caring for terminally ill cancer/AIDS patient who have prolonged illness before death is a strain on carers and require multidisciplinary (team) and a holistic approach to enable patient and family to reach the stage of open communication and acceptance.

2. Definition of Pain

- Pain is an unpleasant body sensation
- Pain is what a patient says hurts
- It is your body's way of saying that something is wrong

3. Types of Pain:

i. Acute Pain

- Pain that one has for a short time, such as after an accident or surgery.
- In the person with HIV/AIDS, acute pain can come and go frequently.
- Signs of acute pain include protecting and rubbing the area that hurts, moaning, facial expressions showing agony, agitation, fast breathing, and tense muscles or fear of movement.

ii. Chronic Pain

- Pain that one has for a long time, and increases as the disease gets worse
- It is seen in chronic diseases such as arthritis and also in terminal illnesses like cancer and AIDS
- The chronic pain is distressing to the patient and the family. The usual painkillers often stop working therefore adequate pain and symptom control, and support from the team can overcome the distress. Chronic pain maybe associated with frustration, depression, worry, irritability decreased appetite, suicidal thoughts.

4. Many factors affect pain in the HIV/AIDS or Cancer patient and his /her family.

All these constitute Total pain for the patient and/or his/her family

These include-

- Physical factors e.g. the disease
- Psychological factors
- Social / cultural factors
- Spiritual factors



5. **Why Should Pain be controlled?**

- To allow the patient to have a good night rest by creating pain free nights
- To become pain free at rest during the day
- To allow pain free movement.
- To reduce overall anxiety and irritation

6. **Misconceptions about pain**

- Children do not feel pain
- Sometimes patients exaggerate the severity of their pain
- Some people think that use of morphine causes addiction

7. **Ways of assessing pain**

Each patient is different, and the management of each pain is also different. It is important that the community volunteer worker/traditional healer works together with the health professional.

8. **When to Get Medical Help**

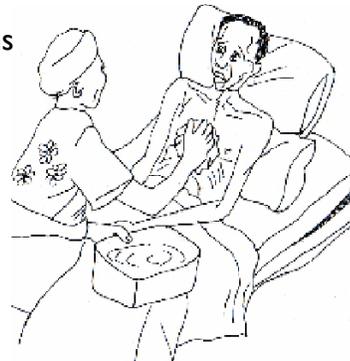
As soon as possible if;

- The pain gets worse
- If the person has a bad headache lasting more than 2 weeks or begins to vomit with the headache
- The person cannot move because of bad pain
- Bad pain in the hands or feet develops suddenly
- The pain causes the person to become extremely tired or weak
- If pain comes from a trauma e.g. fracture

9. **Managing pain - incl. drug and non-drug management**

If the pain is mild and no serious symptoms are present then give care at home. Here are some things that can be done:

- Give gentle massage. Encourage the sick person to relax by taking regular, deep breaths
- Offer bed baths or place cool cloth where it pains



- For mild pain in adults, give paracetamol (2 tablets up to 4 times a day for adults, or as directed by the nurse or health worker). If not effective, try Ibuprofen. If bad pain continues, they should go to the health centre. Never give more than 8 tablets of paracetamol a day.
- Elevate the patient's feet and legs – if they are swollen
- If the sick person is bed bound, turn them every two hours frequently. Do not allow them to lie in the same position for a long time.
- Provide comfort to the patient. For example, play soft music, tell stories, or be quiet and stay calm.
- For skin that hurts when touched, line the bed with soft covers and pillows and be gentle when touching the person
- For headache give Paracetamol regularly and keep room quiet
- Avoid things that make the pain worse. For example if a dressing on a wound is stuck, soak it in water before removing
- Move the sick person with care
- During the management of pain health providers should explain to the patient, what is causing the pain and how the treatment works.
- After discussing with the health providers, the male care giver will be able to give correct information and support what the health providers have instructed.
- At all times, the patient should be allowed to contribute to decisions about management and medical treatment Hence, communication, openness between team members, patient and family is required.

10. Morphine use in a pain control

- Morphine is a strong painkiller, which controls severe pain that cannot be controlled by the usual painkillers.
- Counseling patients often means reinforcing the advice of the medical team particularly regarding fears about the use of morphine.
- Morphine can only be prescribed by a trained palliative care health worker and a doctor.
- Patients and family often fear using morphine, making it difficult for carers to control the pain.

11. Role of male care givers in pain assessment and management

- Identify patients in pain
- Look at the patient for any signs of pain

- Ask a few questions about pain e.g. where is the pain? When did the pain start? Are you taking any treatment?
- Find out if they are taking drug as instructed
- Assist/ educate patients on taking medication
- Monitor the pain
- Ask the patient if the drugs are giving him/her any problems
- Refer the patient to the Health worker.

MODULE 8.0: OPPORTUNISTIC INFECTIONS (OIs)

SESSION ONE: MANAGEMENT OF COMMON OIs

Session Objectives

By the end of this session, participants will be able to:

- Define what an OI is
- List the common OIs in Africa
- Identify the common presentation of the most common OIs
- List the Best Practises in OI prevention
- Identify clear roles of caregivers in the management of OIs
- List measures that caregivers should practice to limit acquiring infections from patients (infection control)

1. Introduction

The Human Immunodeficiency Virus (HIV) is currently a source of considerable pain and suffering. This results from damages to the immune system that protects the body against disease causing germs and leaves it vulnerable to infections that normally do not occur in HIV-negative persons. Such infections are referred to as opportunistic infections (OIs).

Despite the burden of OIs among persons living with HIV/AIDS (PHAs), these infections can be readily identified (diagnosed), have known treatments and most can be easily prevented. Yet if due attention is not paid to OIs, they can lead to very rapid disability and death.

Because HIV infection is quite common in Africa, it is important that caregivers, including males, are empowered with the basic knowledge regarding particularly the common OIs. This will result in earlier recognition of OIs by caregivers, better control of symptoms and timely referral to the trained health care worker for appropriate treatment. Additionally, care givers must be aware of the infection control measures so that they do not acquire or pass on infections to the persons they care for

2. What are Opportunistic Infections (OIs)?

- OIs are Infections that are not seen in persons with a well functioning immune system.

- When the immune system is damaged by HIV and other causes like immuno-suppressive drugs, the OIs begin to appear in such persons
- OIs are different from other infections in that they occur more frequently in immuno-suppressed people and are more difficult to treat compared to other infections. Many OIs are life threatening and will lead to death unless they are treated promptly.

3. What are the common OIs?

- The most common OI in terms of occurrence is **tuberculosis (TB)**. It is also the OI that accounts for the highest number of deaths among PHAs in Africa
- Other Common OIs include
 - **Cryptococcal Meningitis:** This is caused by a yeast-like organism (a fungus) that infects the brain and leads to meningitis.
 - **Oral Candidiasis (thrush):**
 - **Herpes Zoster:** Also locally known as “ekisippi”
 - **Pneumocystis jirovecii (previously carinii) pneumonia (PJP)**
 - **Cryptosporidiasis**
 - **Cerebral Toxoplasmosis**
 - **Kaposi’s Sarcoma**
 - **Cytomegalovirus (CMV) Retinitis**

4. How do I know that someone has an OI?

- OIs occur in people who know that they are living with HIV as well as in those who may be unaware of their HIV sero-status
- The common presentation of the more common OIs is described below:

i) Tuberculosis (TB)

- Presents with a cough. The cough is usually productive.
- TB should be strongly suspected in someone who has been coughing for more than 2 weeks, particularly if there has been no response to antibiotic treatment.
- The presence of fevers in the evenings, profuse sweating at night, a very poor appetite and considerable weight loss in such a coughing patient increase the likelihood of TB

ii) Cryptococcal Meningitis (CM)

- Presents as a severe headache. Usually patients with CM are treated for malaria and typhoid because of the headache and fevers. This usually delays the recognition of this life-threatening infection and contributes to the high mortality in CM patients
- CM may lead to blindness if not recognized and treated in a timely manner

iii) Pneumocystis jirovecii pneumonia (PJP)

- This is a chest infection that presents with severe difficulty in breathing. This develops over days to a few weeks.

- Many patients seek medical assistance when they are so breathless that they can not complete a sentence. This occurs with a dry cough.
- The patients may or may not have a fever.

iv) Oral Candidiasis

- This OI presents as a whitish coating of the mouth (see Picture 1)
- This condition is usually painless but it interferes with the taste of the food and may affect the appetite of the patient.
- Oral candidiasis may spread from the mouth to the tube that channels food down to the stomach (oesophagus). When this happens, the patient will complain of a difficulty in swallowing food and may become malnourished because of this

v) Cerebral Toxoplasmosis

- This is another common brain infection in HIV among PHAs.
- It commonly presents with inability to use the limbs on one side of the body (like a stroke, only that the stroke occurs suddenly while this condition develops over several days).
- It responds quite well to medical treatment and therefore need for early recognition is key is disability from the condition is to be avoided

vi) Cryptosporidiosis

- This OI is the commonest cause of diarrhea among severely immunosuppressed PHAs.
- The diarrhea is persistent and does not respond to the usually treatments for diarrhoeal diseases.
- The infection is an indication that the patient needs to start anti-retroviral therapy since other treatments will not help alleviate the condition.

vii) CMV Retinitis

- The commonest cause of blindness in PHAs. It is caused by a virus. Leads to gradual loss of vision in one eye and may occur in the other eye as well. Care giver has the opportunity to save the other eye by helping determine if there is early loss of vision in the first eye and alerting the health care worker.

viii) Herpes Zoster

- This infection due to a virus is usually one of the earliest indicators that some one is HIV-Infected.
- It presents as a skin eruption with small fluid-filled swellings (usually on the trunk) and is very painful.
- Caregivers can readily recognized this condition based n the observation that the skin eruption is does not cross the middle of the body (see Picture2)

ix) Kaposi's Sarcoma (KS)

- This form of cancer is a very common occurrence among PHAs. The cancer is caused by a virus and this justifies its description here among OIs. The condition affects the skin, mucous membranes (mouth, eyes), but may affect the internal organs of the body. The skin swellings are dark red and are usually raised (see Picture 3).

5. What are the Best-Practices in the Prevention of OIs?

Prevention is always better than cure. It is cheaper, safer and easier to manage.

The following measures lead to prevention of OIs in PHAs:

- Daily use of cotrimoxazole (sepin, bactrim) prevents diarrhoeal diseases, malaria PJP and toxoplasmosis
- Chlorinated water and a safe-water vessel: Prevents diarrhoeal diseases
- Medicated bed-net: Prevents malaria
- General hygiene measures like hand washing before meals and after toilet use

What Roles may Male Caregivers play in OI Prevention?

- Reminding PHA to take Septrin
- Ensuring other general measures are taken
- Picking up medications on behalf of the PHA in case they can not go to the health facility

Among PHAs with significant immuno-suppression (CD4 count less than 200 cells,/ WHO stages 3 and 4), initiating Antiretroviral Therapy Vs is the best way to prevent OIs

6. The Roles of the Caregiver(s) in the treatment of OIs

- Identification of OI symptoms: The recognition of the common presentations mentioned above enables timely recognition of the common OIs. The caregiver may then alert the health care workers to intervene.
- Symptom relief: Some OIs lead to very painful symptoms. For example a fresh Herpes Zoster eruption is very painful. So caregivers can administer pain control medication.

Are there any experiences from the class to be shared?

- Identification of Danger Signs and timely referral

Care givers need to act very fast when they recognize danger symptoms as these may signify severe life-threatening situations requiring immediate medical attention !!!

Danger Signs (in Life threatening OIs)

- Seizure/Convulsions
- Collapse
- Severe Difficulty in breathing
- Loss of Vision

- Reinforcing Adherence to secondary prophylaxis of OIs:
 - Some OIs (CM, PJP) require daily preventive medication after they have recovered from the OI. This is called secondary prophylaxis. The caregiver has a crucial role in ensuring that PHAs maintain adherence to this preventive medication. If not, the PHA may experience a second episode of the illness with serious consequences.

7. Infection Control Measures

- As caregivers assist PHAs to prevent and manage OIs, they must bear in mind that their own safety is of paramount importance.
- Since OIs are infectious; measure must be taken to prevent the caregivers from getting infected with HIV particularly.
- In the same spirit, PHAs must be protected from acquiring infections from caregivers.
- The following measures are recommended:
 - When TB is suspected (based on description above) refer the patient for medical attention. Avoid such a patient sharing a room with other people especially children.
 - Use gloves when you come into contact with the body fluids of PHAs.
 - Wash hands before and after contact with the patient as this will limit the spread of infections from the patient to you and vice versa.

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MODULE 9.0: SEXUALLY TRANSMITTED INFECTIONS (STIs)

SESSION ONE: MANAGEMENT OF COMMON STIs

Learning Objectives:

- To get an understanding of the common sexually transmitted infections
- The common causes of STIs
- The disease burden caused by STIs
- Signs and Symptoms of STIs

I. Introduction:

Sexually Transmitted Disease (STD) and Sexually Transmitted Infection (STI) are two terms for the same thing.

The term STI is now commonly used in the place of STD. STI is more encompassing, including infections that may be asymptomatic. The term STI is used more frequently on this site but please note that the term STD may still be used in some other literature. STIs or STDs, can affect the general health, well-being and reproductive capacity of those infected.

2. Causes of STIs:

STIs might be caused by a number of organisms – bacteria, viruses, protozoa, as well as fungi.

Bacterial pathogens:

- Neisseria gonorrhoea - Causing Gonorrhoea
- Treponema pallidum - Causing Syphilis
- Chlamydia

Viral Causes:

- HIV
- Herpes simplex Type 2 –Causing genital sores
- Human papilloma virus (HPV)
- Hepatitis B – Causing Hepatitis and Hepatocellular carcinoma

Protozoal agents:

- Trichomonas vaginalis – causing trichomoniasis.

Fungal:

Candida Albicans – Causing Candidiasis

3. Problem in Africa:

STIs impose an enormous burden on morbidity and mortality in Africa.

⇒ Directly – through their impact on reproductive and child health.

⇒ Indirectly – through their role in facilitating the sexual transmission of HIV infection.

Greatest impact is among women and infants

STIs are also responsible for the two commonest cancers in Africa (cancer of the uterine cervix and liver cancer)

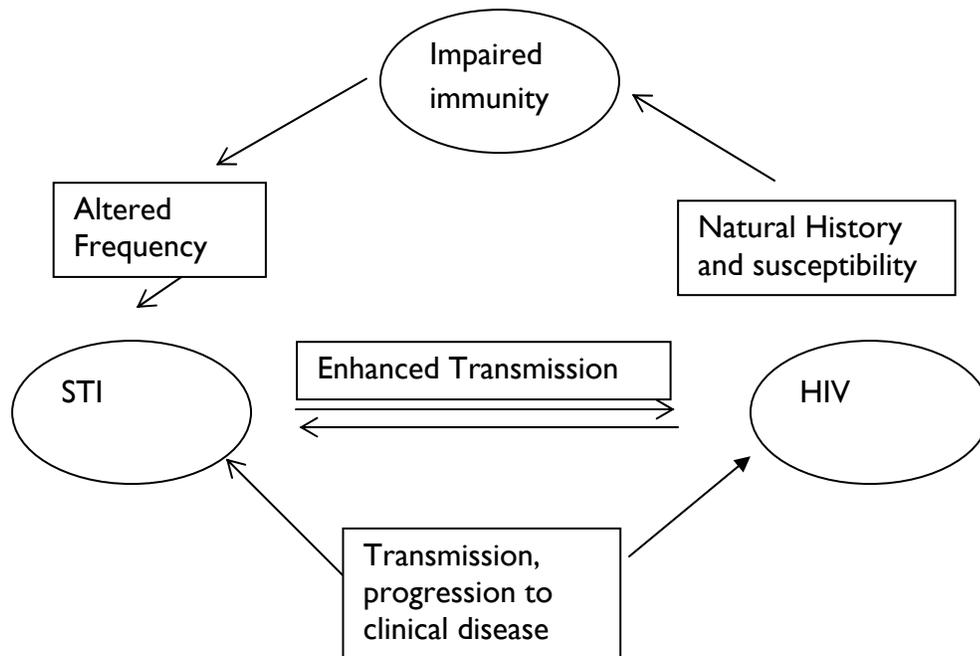
4. Factors underlying the high prevalence of STIs in Africa

- A large young population which is sexually active.
- Urban migration with accompanying social – cultural changes.
- Migration and displacement (wars and natural catastrophes).
- Increased in level of prostitution through economic hardships.
- Multiple and concurrent sexual partners.
- Lack of access to effective and affordable STI services.

5. STI – HIV Interactions

- STIs increase levels of HIV in genital fluids and treatment of STI decreases HIV genital excretion.
- HIV, by causing immune suppression can modify the natural history (duration), clinical presentation (severity), and response to treatment of certain STIs notably Herpes Simplex.

- STI's by causing ulcerations or inflammation of the genital tract may enhance the transmission of HIV by increasing the infectiousness of HIV positive individuals and/or the susceptibility of HIV negative persons.
- Many STI's increase HIV viral loads in the genital tract and /or activate target cells for HIV.



6. Signs and symptoms of common STIs:

Gonorrhea:

In Men:

Most men develop symptoms within 2 to 5 days of infection, incubation ranges from 1 to 10 days. Common symptoms are:

- Urethral discharge {often profuse and purulent}
- Dysuria
- Frequency of micturition (passing water);
- Late complication of urethral stricture – difficulty passing urine.

In Women:

Most women (up to 80%) with gonorrhea have no symptoms. Early symptoms of uncomplicated gonorrhea include:

- Increased vaginal discharge
- Dysuria – pain on passing urine.
- Complications include pelvic inflammatory disease and later ectopic pregnancies and tubal infertility

Trichomonas Vaginalis:

Symptoms:

- Vaginal watery discharge
- Vulval itching
- Dysuria

- Painful coitus
- Post-coital or inter-menstrual bleeding
- In men the infection is asymptomatic.

Candidiasis:

In women the commonest presenting symptom is vulval itching with a white discharge with curd-like plaques adhering to the vaginal wall and does not smell.

Men with Candida infection often have no symptoms.

Syphilis:

Syphilis is highly prevalent among antenatal clinic attendees and in the general population in Africa.

Clinical features:

Incubation period 10-70 days after which there is a primary chancre at the site of inoculation (Chancre is typically painless, indurated, with a clean base and a raised edge and does not bleed on contact. There is usually only a single lesion in the males commonly on the glans, the foreskin or the shaft of the penis, and in females on the cervix or vulva. The primary chancre resolves spontaneously over several weeks.

Secondary Syphilis features:

Occur 3-6 weeks after infection and they include;

- Rash
- Generalized lymphadenopathy
- Oral ulcerations
- fever

7. Control of STI:

STI control programmes have 3 objectives:

- To interrupt the transmission of STI's
- To prevent the development of diseases, complications and sequelae
- To reduce the transmission of HIV infection.

Health education and condom promotion can modify behaviour and hence reduce the incidence of STI's.

Improved access to care and improved case management can prevent complications, and also reduce transmission by shortening the duration of infection.

8. Prevention:

(a) Behavioral interventions:

- a. Primary prevention aims to modify sexual behavior towards "safe sex" through information, education and communication (IEC) or peer-assisted education programme.
- b. Barrier methods: When used properly and consistently condoms are one of the most effective method of protecting against STI's
- c. Vaccines – Hepatitis B is the only STI for which an effective vaccine is currently available.
- d. STI case management: One of the cornerstones of STI control is accessible, affordable and effective STI case management for patients presenting with symptomatic infections.

- (b) Counseling patients on ways to reduce the risk of STI's and their complications
 - a. Use condoms, including in marital relationships during the course of treatment.
 - b. Complete the full course of treatment
 - c. Refer sexual contacts for treatment

9. Treatment of sexual partner

Partner notification, or contact tracing is the process of contacting sexual partners of index STI cases in order to offer them STI screening and /or treatment.

This strategy aims to avoid complications and sequela in partners who may have asymptomatic infections, to avoid onward transmission of the infection and to prevent re-infection of the index case.

Treatment is given irrespective of symptoms and should be similar to that received by the index patient.

MODULE 10.0: NUTRITION IN HIV/AIDS

SESSION ONE: HIV INFECTION AND NUTRITION IN ADULTS

Learning objectives:

By the end of this module, male caregivers should be able to;

- Demonstrate knowledge on the role and importance of nutrition in the general welfare of individuals;
- Understand the link between nutrition and HIV/AIDS;
- Understand types of locally available foods that make up a healthy diet and the role these play in the management of HIV/AIDS;
- Demonstrate knowledge and skills on food safety, preparation and serving;
- Explain nutrition management of common HIV/AIDS related symptoms and illnesses with emphasis on home dietary remedies
- Understand the interaction of nutrition and drugs

1. Introduction

The purpose of this module/topic is to give an overview of how o nutrition and HIV/AIDS relates and how the effects of HIV/AIDS affect nutrition. It is also aimed at giving male caregivers knowledge on how to deal with nutrition concerns for PLWHIV.

2. Importance of nutrition

Question I: What is the importance of food to a human being?

Question II: Mention benefits of good nutrition care to PLWHIV

Food is important for everyone in health and sickness. When the body does not get enough food, it becomes weak and cannot develop or function properly. When we eat

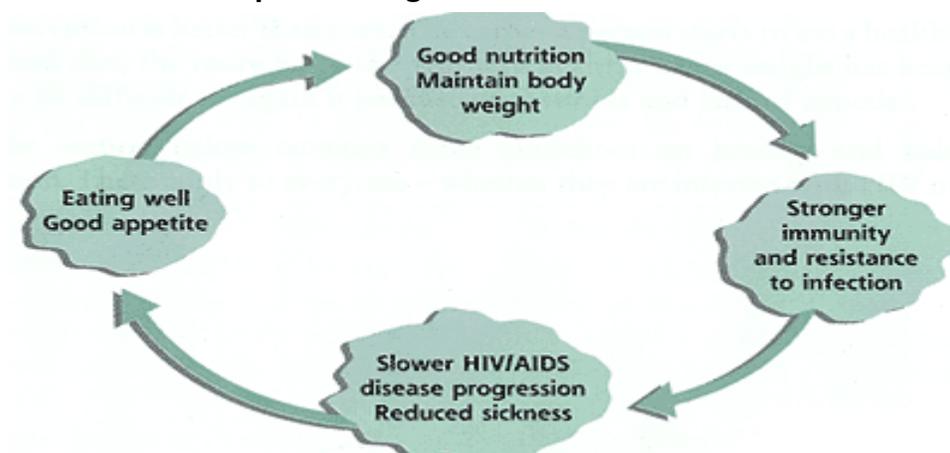
the right foods we feel well. Food provides the energy and nutrients that our bodies need to:

- Develop, replace and repair cells and tissues
- Produce energy to keep the body warm, move and work
- Carry out chemical processes such as the digestion of food
- Protect against, resist and fight infection and recover from sickness

Good nutrition care improves the quality of life in PLWHIV by maintaining body weight

- Replacing lost minerals and vitamins
- Improving functioning of the immune system
- Delaying progression from HIV to AIDS
- Improving response to ARVs and any other treatment
- Keeping a patient alive
- Keeping PLWHIV active

3. Relationship between good nutrition and HIV/AIDS



Source: adapted from Piwoz and Prebel, 2000

4. Relationship between HIV and nutrition

Question I: Do you think there is any link between nutrition and HIV/AIDS?

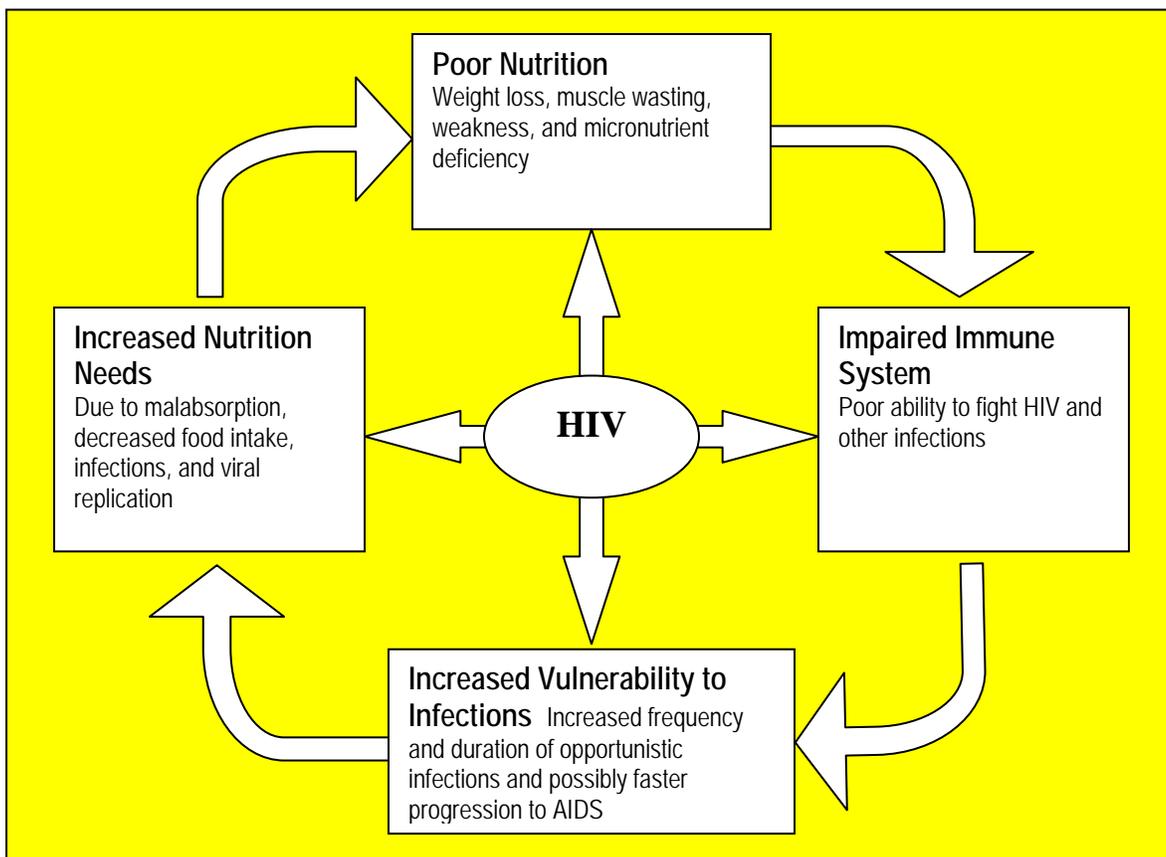
Question II: If there is any link, what affects the other and how?

Nutrition and HIV are strongly related to each other because any immune impairment as a result of HIV/AIDS leads to malnutrition by affecting appetite leading to weight loss and consequently to malnutrition. Malnutrition weakens the immune system and leads to further immune impairment and worsening the effects of HIV. Poor nutrition contributes to a more rapid progression from HIV to AIDS. Most of the defense mechanisms are altered in malnutrition and this in a way can predict AIDS-related mortality.

HIV acts by replicating inside the white blood cells from the point of infection, through sero-conversion to asymptomatic and symptomatic phases (To be emphasized in topics before nutrition). To eliminate the infection, the immune system plays an important role in recognizing and destroying this infection. In fighting the disease, free radicals are formed which damage normal body cells due to their oxidative nature. Food nutrients mainly those found in fruits and vegetables such as vitamins A, C, E and minerals like selenium, zinc, and copper acting as anti oxidants can be provided through the diet to help wipe out the oxidants. Both the immune system and the levels of the nutrients are correlated with the progression of the disease. This implies that malnutrition results in increased replication of HIV and the former is a result of HIV itself.

In acute cases, the body uses stored nutrients to attack the viral infection and since there is also a general loss of appetite, the muscles become wasted. In other words, HIV/AIDS affects nutritional status and nutrition affects HIV progression like in the figure below (draw this figure in advance):

The vicious cycle of malnutrition and HIV

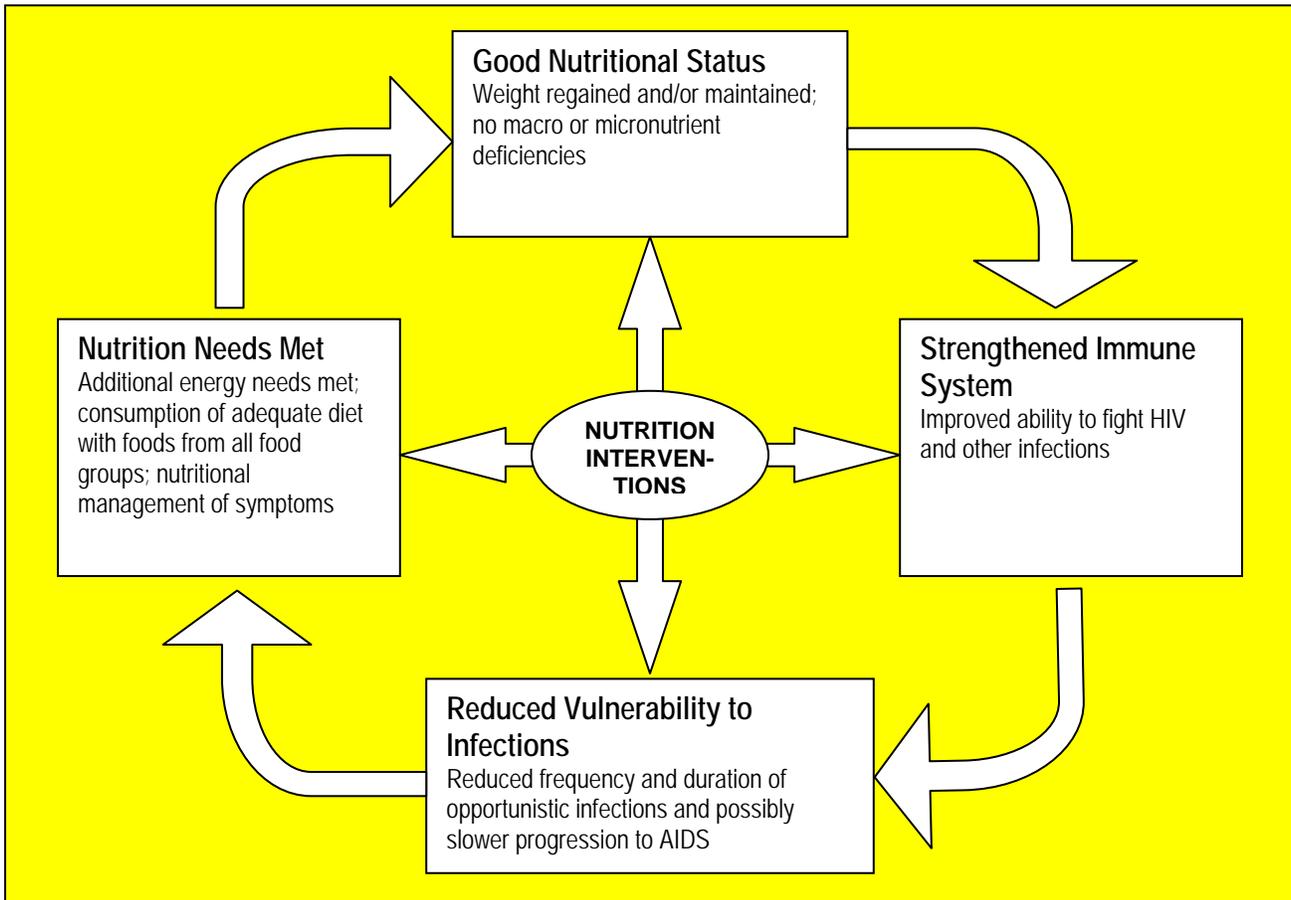


Adapted from RCQHC and FANTA (2003)

Proper Nutritional care and support helps to break this cycle by helping individuals maintain and improve nutritional status, boost immune response, manage the frequency and severity of symptoms, and improve response to ART and other medical treatment.

The figure below illustrates how effective nutrition interventions can help transform the vicious cycle of HIV/AIDS and malnutrition into a positive relationship between improved nutritional status and stronger immune response.

Relationship between Nutrition and HIV/AIDS: BENEFITS OF NUTRITION INTERVENTIONS



5. Locally available foods that make up a healthy diet

Question I: Who knows what proper nutritional care means?

Question II: What is the importance of water to life?

5. Importance of nutrition

Proper nutritional care and support promote well-being, self-esteem and a positive attitude to life for families and people living with HIV/AIDS. Good nutrition should be one of the goals of care for people at all stages of HIV infection. Healthy and balanced nutrition means eating the right type of foods in the right quantities to keep healthy and keep fit. Eating well means eating a variety of foods. No single food contains all the nutrients that our bodies need, except **for breast milk for babies up to the age of six months.**

6. Elements that make up a good and healthy diet

Eat staple foods daily

Staple foods should make up the largest part of a meal. These foods are relatively cheap and supply a good amount of energy and some protein. Staples include rice, maize, millet, sorghum, wheat, potatoes, cassava, yams, plantain/green bananas (matooke in Uganda) among others. However, staple foods are not enough to provide all the nutrients the body needs.

Eat legumes if possible daily

These foods provide a person with the proteins needed to develop and repair the body. They are good sources of vitamins, minerals and fibre. Legumes include beans, peas, groundnuts and soybeans.

Eat animal and milk products regularly

Foods from animals and fish should also be eaten as often as you can afford them. These foods include all forms of meat, poultry, fish, eggs and dairy products such as milk and yoghurt. If insects, like grasshoppers and ants (nswa in Uganda), are part of your diet, they also provide good nutrients.

Eat vegetables and fruit every day

Vegetables and fruits supply the body with vitamins and minerals that keep the body functioning properly as well as the immune system strong. These foods are especially important for people living with HIV/AIDS to fight infection. Eat a wide variety as each one provides different vitamins and minerals.

Use fats and oils as well as sugar and sugary foods

Fats, oils and sugar are good sources of energy and can help one gain body weight, which can be particularly important for those living with HIV/AIDS. They also add flavour to food, thereby stimulating appetite. **However these must be used and eaten sparingly.**

Drink plenty of clean and safe water

Water is important for life and is necessary every day. A person needs about eight cups of fluid per day. When it is very hot, while working, sweating or suffering from diarrhoea, vomiting or fever, a person needs to drink even more to replace the water that has been lost. It is important to boil and store water in a clean container.

Do not smoke or take alcoholic beverages

Alcoholic drinks remove water from the body and should therefore be avoided. They can also interfere with the action of medicines. Alcoholic drinks should also not be taken.

Micronutrients, importance and the food sources

Micronutrient	Role	Common food source
Vitamin A	Growth and function of T and B cells for immunity; maintenance of mucosal epithelial cells, including the lining of the respiratory, gastrointestinal and gastro urinary tracts. Vitamin A deficiency is associated with accelerated HIV progression, increased adult mortality, and increased mother to child transmission, higher infant mortality and child growth failure.	Liver and dairy products, dark green leafy vegetables, kidney, eggs, some fishes, sweet potato, pumpkin, palm oil and carrots. Fruits such as papaya.
Thiamine Vitamin B1	Important for energy metabolism; support appetite and nervous system functions.	Cereals, beans, meat, fish, chicken, eggs.
Riboflavin Vitamin B2	Important for energy metabolism; support normal vision, health and integrity of skin.	Milk, yogurt, meat, green leaves, whole-grained cereals; fish, beans.
Niacin Vitamin B3	Essential for energy metabolism; support health and integrity of skin, nervous and digestive systems.	Milk, eggs, meat, poultry, peanuts, groundnuts, whole-grained cereals, fish.
Pyridoxine Vitamin B6	Facilitates metabolism and absorption of fats and proteins; helps to make red blood cells.	Sweet potato, white beans, maize, avocados, cabbage, meat, fish.
Cobalamin Vitamin B12	Important for new cell development and maintenance of the nerve cells.	Red meat, fish, chicken, shellfish, cheese, eggs, and milk; fermented products.
Ascorbic Acid Vitamin C	Important for immune function and iron absorption.	Oranges, tomatoes.
Vitamin E	Protects cell structures and facilitates resistance against diseases.	Leafy vegetables, vegetable oils, peanuts, egg yolk, vegetables, liver.
Iron	Transports oxygen to the blood, eliminates old red blood cells and builds new cells.	Red meat, poultry, shellfish, eggs, peanuts, groundnuts, lentils, beans, some cereals and dried fruits.
Calcium	Builds strong bones and teeth. Important for functioning of heart and muscle functions, blood clotting and pressure and immune defenses.	Milk, green leaves, shrimp, dried fish, beans, lentils, peas, whole grain millet, oil seeds, okra.
Zinc	Reinforces the immune system. Facilitates digestion. Transports Vitamin A.	Meat, chicken, fish, cereals and vegetables.
Selenium	Prevents impairment of the heart muscle.	Seafood, liver, meat, carrots, onions, milk, eggs.
Iodine	Ensures the development and proper functioning of the brain and of the nervous system.	Fish and other seafood, salt with iodine.
Magnesium	Strengthens the muscles, important for nervous system function. Involved in bone development, maintenance of teeth.	Cereal, dark green vegetables, seafood, nuts, legumes, groundnuts.

Source: Network of African People Living with HIV/AIDS (November 1997)

7. Food; safety, preparation and serving

7.1 Personal cleanliness (hygiene)

People who are handling food should take proper care to make sure they do not pass on germs.

7.2 The male caregivers should educate their clients on the following:

- Always wash their hands after using the toilet, before preparing food and before eating. Clean water with soap or ashes should always be used to wash hands
- Washing hands with just water is not enough to kill germs
- Wash hands carefully after changing a baby's nappy, or helping a child use the toilet
- Keep nails short and clean. Wash under the nails each time you wash your hands
- If you have a wound on your hand, cover it up with a bandage so that any infection in the wound is not passed on to food during preparation and handling
- Hands should be washed under flowing water and not still water in a basin

7.2 Cleanliness in the House

- Always use a latrine or toilet. Keep the toilet and its surroundings clean and free from flies
- Keep animals out of the house
- Keep garbage in a covered bin and empty the bin frequently
- Household vegetable gardens should not be grown near bathroom exits, garbage or open sewage

7.3 Drinking Water

- Only use drinking water from a protected well or tap if one is available
- All drinking water should be boiled for at least 10 minutes before drinking it.
- In some countries such as Uganda, water in both rural and urban areas should be boiled
- Storing drinking water in a clean and covered container
- Not dipping hands into a container meant as drinking water
- Use water guard/Chlorin correctly for all who can access it (either freely or commercially)

7.4 Food preparation

- Make sure all food pans and utensils used to prepare food are clean
- Clean vegetables with running water (from a tap or poured from a cup or container) rather than soaking them in a bowl
- Meat should be well cooked, not pink or bloody in the middle
- Eggs should be hard boiled. People should not eat eggs with runny yolks or uncooked foods prepared with raw eggs
- Washing cutting boards and knives well before using them on other food (especially after cutting meat like chicken, fish or pork)

- Do not use wooden cutting boards for cutting meat, use plastic boards or plates
- Serve food immediately after cooking
- Do not keep food for a long period of time, especially if you do not have a fridge
- Eat food while it is still warm
- Food leftover from the night before should be kept in a fridge and eaten the next day (within 24 hours)
- Cover food when not eating
- Food should be reheated only once after it has been cooked.

7.5 Food storage

- Cover and store foods away from insects and pests
- Fruits and vegetables should be checked often to see if they are 'over-ripe'. Soft or decaying pieces should be removed from the bunch to prevent further spoiling
- Foods such as milk and eggs that absorb odors should be kept away from foods that give off odors, such as fish and onions
- Food should be stored in such a way that oldest foods are used first
- Prevent blood from raw meat from dripping on other foods
- If you have a fridge, do not remove and then re-freeze what you have not eaten. Pack meat into smaller daily food portions before freezing to prevent wasting food
- Remove frozen meat inside a fridge rather than keeping it at room temperature
- Food left over from the night before should be kept in a fridge and eaten within 24 hours. Those without a fridge should eat leftovers the same day
- All leftovers should be re-heated thoroughly before serving
- Leftover food should be avoided.

8. Foods and their special preparation consideration

Examples of foods	Special preparation consideration
<i>Green banana, cassava, irish potatoes, maize, cereals, roots, sweet potatoes, yams, chappati, posho/maize flour, rice, bread, millets.</i>	<ul style="list-style-type: none"> • Avoid deep frying
Beef, goat, milk, pork, chicken, fish, liver, kidney, beans, peas	<ul style="list-style-type: none"> • Cook all animal foods till ready • Do not eat raw eggs
Green vegetables	<ul style="list-style-type: none"> • Avoid cutting vegetables into very small pieces before washing them. • Cook immediately • Cook for a short time • <i>Avoid adding a lot of water</i> • Eat immediately after cooking
Banana, pawpaw, water melon, mango, guava, passion fruit, pineapple, orange, tangerine, apple, jackfruit, tomato, avocado.	<ul style="list-style-type: none"> • Wash properly before eating • Do not eat rotten fruits
Fruit juice, water, tea	<ul style="list-style-type: none"> • Boil drinking water and that for making juice • Alcohol should be avoided <p>Keep drinking water in a clean covered container.</p>

9. Nutrition management of common HIV related symptoms and illnesses with emphasis on home dietary remedies

Question I: Mention some of the common HIV/AIDS related symptoms you know of

Question II: Who of us manages any of the symptoms differently and it has worked?

(Learning from experience)

Illness	Food	Care and nutrition practices
Anorexia (appetite loss)	Try to stimulate appetite by eating favorite foods, eat small amounts of food more frequently, select foods that are more energy dense & avoid strong smelling foods	If loss of appetite is due to illness, seek medical attention for treatment.
Diarrhea	<p>Drink lots of fluids to avoid dehydration. Drink juices such as passion fruit; avoid strong citrus (orange, lemon) because it may irritate the stomach. Eat starchy foods like rice, maize, sorghum, potato, cassava and blended foods like corn-soy blend. For protein, eat eggs, chicken or fish. Drink light teas, boiled water. Boil or steam foods, avoid fried foods. Consume fermented foods like porridges, yogurt. Drink nonfat milk if no problem with lactose.</p> <p>Foods to avoid: Some dairy products, such as milk. Avoid caffeine (coffee and teas) and alcohol. Reduce intake of fatty foods. Limit intake of gas-forming food such as cabbage, onions, carbonated soft drinks (sodas). Avoid excessively fried foods and extra oil.</p>	<p>Prevention Drink plenty of clean boiled water. Wash hands with soap and water before handling, preparing, serving or storing foods and after using a toilet or latrine or cleaning a child after defecation.</p> <p>Treatment Drink more fluids to prevent dehydration. Prepare rehydration solutions using oral rehydration salt packets or a homemade solution of 2 cups of boiled water, 1 cup of sugar and 1 teaspoon of iodized salt (1 cup roughly equals one handful; 1 teaspoon roughly equals one pinch). Eat small amounts of food frequently and continue to eat following illness to replace lost weight and nutrients.</p>
Fever	<p>Eat soups that are rich in foods that give energy and nutrients, like maize, potatoes and carrots. Drink plenty of liquids. Drink teas from lemon. Drink more than usual beyond thirst.</p>	<p>Drink fluids to prevent dehydration, particularly clean boiled water. Bathe in cool water and rest; continue to eat small frequent meals as tolerated. Go to the health center.</p>
Nausea & vomiting	<p>Eat foods like soups, unsweetened porridge and fruits like bananas. Eat lightly salty and dry foods like to calm the stomach. Drink herbal teas and lemon juice in hot water. If available, drink ginger root: crush ginger in cold water, boil in water for 10 minutes; place in a covered container; strain ginger and drink liquid. Avoid spicy and fatty foods. Avoid caffeine (coffee and tea) and alcohol. Drink liquids, such as clean boiled water.</p>	<p>Eat small frequent meals. Nausea is worse if nothing is in the stomach. Avoid lying down immediately after eating; wait at least 20 minutes to avoid vomiting. Rest between meals. Drink after eating and not while eating.</p>
Thrush	<p>Eat soft mashed foods, such as carrot, scrambled eggs, mashed potatoes, bananas, soups, porridge. Eat room temperature foods. Avoid spicy, salty or sticky foods; these may irritate mouth sores. Avoid sugary foods; these cause yeast to grow. Avoid strong citrus fruits and juices that</p>	<p>Seek medical attention for treatment. If available, use a spoon or cup to eat small amounts of foods. Tilt head back when eating to help with swallowing. Rinse mouth with boiled warm salt water after eating to reduce irritation and keep</p>

	may irritate mouth sores. Avoid alcohol.	infected areas clean so yeast cannot grow. Drink liquids.
Anemia	Eat more iron-rich foods, such as animal products (eggs, fish, meat and liver) green leafy vegetables (greens), fruits and vegetables, legumes (beans and groundnuts), oil seeds and fortified cereals.	Seek medical recommendation to take one iron tablet once a day with some food for adults. Best if taken with a source of Vitamin C such as tomatoes or orange juice to help with absorption. Treat malaria and hookworm.
Muscle wasting	Increase food intake by increasing quantity of food and frequency of consumption. Improve quality and quantity of foods by providing a variety of foods.	Eat small frequent meals. Eat soft liquid food if mouth sores present. Increase protein in diet. Slowly introduce fat in the diet. Increase intake of starchy foods in cereals and other staples.
Constipation	Eat more foods that are high in fiber content, such as whole maize, whole-wheat bread, green vegetables and fruits with the skin. Drink plenty of liquids. Avoid processed or refined foods.	Avoid using cleansing practices, such as enemas and medications. Drink plenty of fluids including boiled water.
Bloat/ Heartburn	Eat small frequent meals. Avoid gas-forming foods (cabbage, peas, soda). Drink fluids.	Eat long enough before sleeping so food can digest.
Loss of Taste And /or Abnormal Taste	Use flour enhancers, e.g., salt, spices, herbs and lemon. Chew food well and move around mouth to stimulate receptors.	Seek medical attention immediately. Consult medical personnel about taking food with medications. If taking isoniazid for treating TB, take a Vitamin B6 supplement to avoid deficiency of this micronutrient.

Adapted from: Castleman T, Seumo-Fosso E and Cogill B (2003) Food and Nutrition implications of Antiretroviral Therapy in Resource limited settings. Washington D.C.: FANTA Project, AED, 2003

10. Interaction of nutrition and drugs

Question I: In the absence of ARVs can good nutrition be sufficient for quality life of PLWHIV?

Though good nutrition can help maintain and improve the quality of life of PLWHIV, it is not sufficient on its own. Food helps boost and maintain immunity. However, when the viral load in the body is high, nutrition alone cannot help replace the lost immunity. Prevention and proper treatment of HIV related infections is important to avoid weakening the nutritional status further. ARVs are vital because they reduce the viral load and the rate at which the body immunity is destroyed.

Usually medication that is both traditional and modern is used in treatment of infection. However, drugs can interact with food and nutrients and negatively affect the nutrition status of PLWHA. The side effects can affect the clients' adherence to medication. Food can also interact with drugs and affect drug efficacy. Nutritional implications of drug therapies need proper addressing in order to prevent malnutrition thus affecting the patient nutrition statuses further.

Side effects can limit and reduce nutrient absorption also lead to poor adherence in the long run. Proper nutritional management of side effects can help to minimize and improve clients' adherence to treatment.

Modern medications

ARVs are the medications used to treat HIV/AIDS. They drastically reduce the replication of the virus in the body and slow the disease progression.

The food and drug interactions include:

- Food effects on drug efficiency
- Drugs effect on nutrient absorption and metabolism
- Side effects of medication on food intake and absorption
- Medication and food can interact to cause unhealthy side effects.

All the above can have negative impacts on the nutrition status of PLWHA.

The introduction of Highly Active Antiretroviral Therapy (HAART) in 1996 raised the important issue of optimal nutrient absorption and blood levels of medications. Adverse food-drug interactions can compromise the effectiveness of medication. The medications themselves can produce complicated gastrointestinal side effects. Nutritional strategies, including food choices appropriate for the individual medication schedules, can improve adherence and enhance the effectiveness of drug therapies, as well as help manage gastrointestinal symptoms (Fenton, 2001).

II. Recommendations for the proper management of drug and food interactions

- ⇒ Different drugs have different food interactions so be drug specific.
- ⇒ If several drugs are being taken, refer to food drug interactions of each of the drugs.
- ⇒ Discuss and involve the client in finding solutions in addressing side effects and food drug interactions.
- ⇒ Consider food security constraints that interfere PLWHA from meeting optimal food and nutrition responses.

Careful consideration and management of drug and food interactions is required to ensure drug efficacy, client adherence and prevention of negative effects on nutritional status of clients. The successful management of these drug food interactions requires understanding clients individual food access as well as eating habits. Delivering dietary management of Interactions between ARVs and Food and Nutrition in a clinical setting.

11. Food and nutrition implications of ARVs

Medication Generic Name	Food consideration	Food to avoid
efavirenz (EFZ)	<ul style="list-style-type: none"> • Can be taken without regard to meals • Do not take with a high fat meal. (A high fat meal increases drug absorption.) 	Alcohol
nevirapine (NVP)	<ul style="list-style-type: none"> • Can be taken without regard to food. 	St. John's wort.
Abacavir (ABC)	<ul style="list-style-type: none"> • Can be taken without regard to food 	
Didanosine (ddl)	<ul style="list-style-type: none"> • Take 30 minutes before or two hours after eating. • Take with water only. (Taking with food reduces absorption.) 	<ul style="list-style-type: none"> • Alcohol. • Do not take with juice. • Do not take with antacids containing Aluminum or Magnesium.
Lamivudine (3TC)	Can be taken without regard to food.	Alcohol.
Stavudine (d4T)	Can be taken without regard to food.	Limit the consumption of alcohol.
Tenofovir (TDF)	Take with a meal.	
Zidovudine (ZDV/AZT)	<ul style="list-style-type: none"> • Better to take without food, but if it causes nausea or stomach problems, take with a low-fat meal. • Do not take with a high-fat meal. 	Alcohol
Indinavir (IDV)	<ul style="list-style-type: none"> • Take on an empty stomach, one hour before or two hours after a meal. Or take with a light, non-fat meal. • Take with water. Drink at least 1500 ml of fluids daily to prevent kidney stones. 	Grapefruit. St John's wort.
Lopinavir (LPV)	Can be taken without regard to food.	St John's wort.
Nelfinavir (NFV)	<ul style="list-style-type: none"> • Take with a meal or light snack. • Taking with acidic food or drink will cause a bitter taste. 	St John's wort.
Ritonavir (RTV)	Take with a meal if possible	St John's wort.
Saquinavir (SQV)	Take with a meal or light snack. Take within two hours of a high fat and high calcium meal.	Garlic supplements St John's wort.

Sources: Pronsky,Z., Meyer SA and Fields-Gardner C (2001) *HIV Medications Food Interactions, 2001.*

- Look for specific food and nutrition interactions in the drug combinations being taken. Address the dietary needs of the interactions, always ensuring that the PLWHA and primary caregivers understand the dietary implications of these interactions.
- Identify locally available foods that meet the nutritional needs imposed by the drugs. Identify and explain to the client those foods that are contraindicated by the drugs

- Plan a diet and a drug and meal timetable that address the drug food interactions and that meet the PLWHA’s overall nutritional needs. The plan should account for food security and other constraints faced by the household and the PLWHA. Involve the PLWHA and caregiver in this planning process.
- Follow up is always important and to assess whether the PLWHA is facing any problems in following the planned diet and timetable, and whether there have been any changes
- Adjust the planned diet and timetable if necessary, based on changed conditions or in order to make the plan more feasible in terms of food recommendations for the proper management of food and drug interactions

NOTE: Considering ARVs and the effects of food and drug interactions on drug efficacy and nutritional status, health providers and counselors should know how to manage these interactions.

12. Counseling about Food and Nutrition and ARVs

It is important that the following issues are discussed during counseling:

- Explain the importance of good nutrition for PLWHIV and are on ARVs and this will often include information such as the effect food has on treatment as well as the complementing action on ARVs
- Explain how HIV affects nutrition of PLWHIV and this includes the Vicious cycle between HIV/AIDS and Nutrition. Also discuss the side effects that are associated with taking drugs and how this can in turn affect Nutrition status, as well as drug nutrient interactions.
- Always ask the client the drugs they are taking and ensure that they are adhering to the prescribed drugs. Explain as clearly as possible the dietary recommendation for each drug. Here remember to encourage the clients to always take the drugs with clean boiled water.
- Always explain the increased appetite that accompanies taking ARVs, which can lead to stress if the household is food insecure or to excess weight gain.
- Encourage the clients to develop a drug-food timetable that will help them to adhere to their treatment. And this should include the foods that should be avoided and those that should be increased.
- When taking ARVs the following foods should be reduced/avoided and this includes the following: alcohol, too much coffee/tea as this can increase fluid loss and interferes with nutrient absorption such as iron.

13. Foods to avoid or take in small quantities when taking ARVs

Foods	Why?
Alcohol	Reduces effectiveness of drugs and can cause dangerous side effects
Too much coffee/tea	Increases fluid loss and interferes with absorption of some nutrients
Undercooked meats and raw eggs	Can cause food borne illnesses

Expired processed foods	Can cause food borne illnesses Reduces effectiveness of some drugs
Garlic (for those who take saquinavir)	Reduces the effectiveness of saquinavir

- Always remember to discuss the constraints identified such as food security. Discussing options to overcome household food insecurity constraints should follow this.
- Discuss any conditions that may prevent the client from adhering to the ARVs taken. Such conditions may include poor social support structures, stigma and poor coping mechanisms.
- Address factors such as changes in body shape and sizes e.g. increased weight, enlarged breasts. And encourage the client to seek medical treatment and increase physical activity.

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- 1 **Castleman T, Seumo-Fosso E and Cogill B (2003)** Food and Nutrition implications of Antiretroviral Therapy in Resource limited settings. Washington D.C.: FANTA Project, AED, 2003
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- 1 **Piwoz EG and Preble EA (2000)** HIV/AIDS and Nutrition, A review of the list & recommendations for Nutritional Care & Support in Sub-Saharan Africa. Support for Analysis & Research in Africa (SARA) Project, Academy for Educational Development, Washington DC 20009. III: 8-21
- 3 **Pronsky,Z., Meyer SA and Fields-Gardner C (2001)** *HIV Medications Food Interactions*, 2001
- 4 **Nerad J, Romeyn M, Silverman E, Allen-Reid J, Dietrich D, Merchant J, Pelletier V, Tinnerello D, and Fenton M (2003)** “General Nutrition Management in Patients Infected with Human Immunodeficiency Virus.” *Clinical Infectious Diseases*. 2003:36
- 5 **Network of African People Living with HIV/AIDS** (November 1997)
- 6 **WHO (2003)** *Scaling Up Antiretroviral Therapy in Resource-Limited Settings: Treatment Guidelines for a Public Health Approach*. 2003 Revision. Geneva, December 2003.

SESSION TWO: NUTRITION AND FEEDING IN CHILDREN

Handout to be obtained from the facilitator!

MODULE 11.0: DEATH AND DYING

SESSION ONE: PREPARING THE PATIENT AND THE FAMILY FOR DEATH

Learning objectives:

By the end of the session participants should be able to:

- Describe the signs of approaching death
- Explain the appropriate care of the dying patient and family
- State signs of death



I. INTRODUCTION

I.1 The concept of death

Death is the end of life. However, how and when it occurs remains a mystery throughout our lives. Individuals can react very differently to the fact they are soon dying when entangled with life threatening illness. What worries us about death? How about those surrounding us as we face our own death?

There will come a time when none of us will be alive. However most of us shy away from considering how to face our own death. Instead we leap at the opportunity to consider how to accept the death of those whom we love, for most of us outlive some loved one.

I.2 Reflection on own death

This unit discusses issues concerning facing and dealing with our own death. In order to empathize and support patients with terminal diagnoses it is helpful for us on our own spiritual and psychological level to have considered our own death.

For many people thinking about the prospect of their own non-existence is close to the unthinkable.

I.3 What makes people not want to talk about their own death?

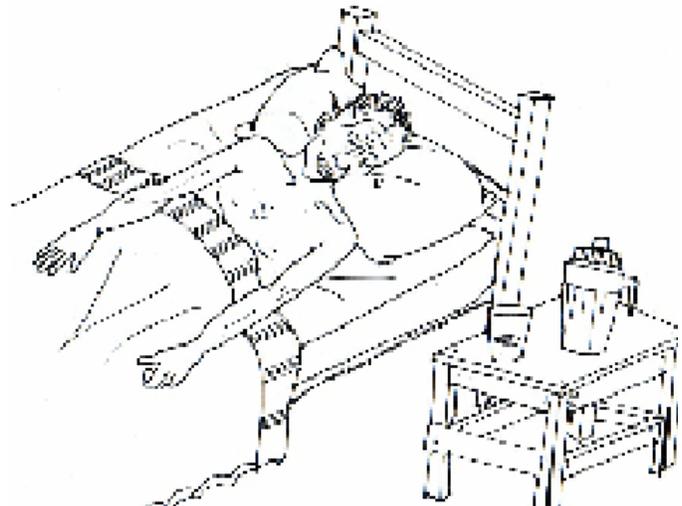
- How and when it will happen
- Existential fear of death
- Worry about leaving their loved ones
- To some people talking about death is a bad omen

The main concern people have about death, is how and when it will happen. The existential fear of death, of ceasing to be, lies deep in everyone and usually remains unconscious. Its presence profoundly influences people's behaviour as the knowledge becomes inescapable in terminal illness. They may worry about leaving their loved ones among others:

1.4 Signs of Approaching Death

These are the ways warning somebody that death is near.

- Decreased social interaction. The patient may not have the energy to socialise and is preparing for the final separation. They will still want some companionship and find that someone is with them when they wake up.
- Increasing weakness and sleepiness and change in consciousness. The patient may still be aware of his surroundings but this awareness may be reduced. The patient may stare into space, mumble, pluck at the bedclothes and have odd hand movements.



- Decrease of appetite. The patient no longer feels hungry and may feel very little thirst
- Change in urine and bowel movements. Urine may decrease or even stop and there are fewer bowel movements. Incontinence of both is also possible.
- Respiratory changes. There are many changes in the breathing pattern. Cheyne-stokes breathing, grunting, and the “death rattle” are all possible at this stage.

- Circulatory changes. Extremities (hands and feet) may be cold and blue.

2. Appropriate care of the dying patient and family

2.1 Physical Care near the End of Life

- Give only essential medicines
- Pain control drugs may be continued even if unconscious
- Moisten lips, mouth and eyes
- Keep patients bed clothes clean and dry
- Eating little is ok if the patient is near death

2.2 Emotional Support near the End of Life

- Keep the patient's surroundings familiar
- Be aware that the patient may experience many different feelings such as anger, fear, sadness and finally acceptance
- Listen actively to the patient's concerns and show them that you care and understand what they are going through
- Encourage other family members to continue to talk and listen to the patient, saying farewells and helping them to let go of life peacefully
- Discuss worrying issues such as custody and support of children, school fees and funeral costs
- Arrange spiritual / religious support for the patient if he requests it, and pray with them if they wish

2.3 Support to the Loved Ones

In caring for the patient, do not forget to care for the patient's friends and family members.

- Take time to explain to the family members what is happening with the patient's condition, showing them that the changes in the patient's body are normal
- Make sure the family understands when death is near, and that it is not uncomfortable for the patient
- Arrange counseling for the patients loved ones. Be prepared to address their fears including:
 - Fear of not being able to cope with death
 - Fear of the patient dying in pain
 - Fear of feeling responsible in some way for the death
 - Fear of how life will go on after the death
 - Encourage the loved ones to be with the patient until the end

3. Care for Children Who Have a Parent near the End of Life

- Children need to talk about the loss of their parents. If they don't, they may suffer more later
- Talk in a way that they can understand
- Do not take children away from their dying parent, as they both need to be close to each other
- Make them feel they will still be loved and cared for, even after the parent dies

4. Signs of Death

We must be aware that not everyone has experienced death and that each death is different. The family may not realize the patient has died. Explain to the family members the signs of death:

- Breathing stops entirely
- Heartbeat and pulse stop
- Patient is totally unresponsive to shaking or shouting
- Eyes may be fixed in one direction, open or closed

SESSION TWO: CULTURAL ISSUES RELATING TO DEATH CULTURAL ISSUES RELATING TO DEATH

Objectives:

- To help male care givers know common perception, prejudices and myth about cultural I issues fin the society.
- To explore some of the participants' own concern about cultural issues this may cause death.

I. Introduction

Death comes to us all, but the ways in which we end our lives varies enormously, depending on our personal circumstances. Dearth is one of the most universal and mysterious experience it is not surprising therefore although sorrowful. There are so many myths about its origin and so many ideas seeking to explain.

In this topic we are going to look at more on **cultural issues relating to death** and what can be done to enable African people fulfill their rights to a dignified death to day.

When you talk about cultural issues relating to death many African people tend not to fear now since they believe in preparing the body through western religions who preach that death does not alter or end the life or the personality of an individual, but only causes a change in its conditions. However through cultural issues to some people have expressed in the concept of "ancestors," people who have died but who continue to "live" in the community and communicate with their families and they believe in it.

Under cultural issues relating to death hundred and hundreds of myths all over Africa concerning ideas about the origin of death especially those related to cultural issues have been said although still many have remained uncollected and unrecorded.

2. **How death is caused in human life in relation to cultural issues in Africa?**

Even though people believe that death comes into the world at a very early date in the history of mankind, they believe also that every time a person dies this death is caused and they are several ways in which it is caused.

Most African people believe that rewards and punishments come to people in this life and not in the hereafter and that is why the correct burial rites have been observed always, however, many Africans still believe that if a person is a wizard/witches, a murderers, thieves, one who has broken the community code or taboos, or one who has had an unnatural death or an improper burial, then such a person may be doomed to punishment in the afterlife as a wandering ghost, and may be beaten and expelled by the ancestors or subjected to a period of torture according to the seriousness of their misdeeds, much like the Catholic concept of purgatory. However in this topic encourage participants to think of cultural issues in their areas which can cause death and how we can improve them through palliative care.

- i. **Growth:** - It is the custom in African societies for mother to breast –feed her baby. If she is not, present or if she does not produce enough milk, another woman with milk will normally feed the baby or be given the goats or cows milk in areas where these animals are kept. The used to worker but it could cause and heritance disease which can lead to the baby's death.
- ii. **Circumcision and Initiation:-** Involves cutting off the foreskin of the boy's male organ while clitoridectomy involves cutting some portion of the girls female organ and in both cases, blood is spilt, and the operation is very painful since often no pain killing herbs or other preparation are used.

To many practicing tribes of circumcision one is shameful and isolated no matter how old he or she might have be but the public see you as one who lack experience of life and young. Though this is a community and public affair occasion, but it is also a cultural practice which leads to death because of the unseteralized circumcision knives and stones.

- iii. **Death by curse:** - Curses, broken taboos or oaths are sometimes believed to cause death. Therefore they are feared, and people endeavour to avoid being cursed or breaking oaths. In the breaking of oath there was/is an exchange of blood between the two parties involved to show that strong new bondage created as family. This has transmitted disease to many of our people due to the many diseases coming up every day.
- iv. **Inheritance of widow and widowers especially in Rwanda, Ankole and Busoga kingdoms in Uganda:** - Traditionally in some African countries when the

partners part/ die the family members gets one person to replace the deceased. This cultural practice caused diseases to many African societies which believe in it, this practice is done since many African societies believe that after paying dowry and bride price, the woman family property in her new family.

- v. **Tribal body location and marks:** This is also another common cultural practice to many tribes / societies in Africa which you find that cause death. The marks are normally on the face and others are on the chest, back stomach, ears hands or elsewhere on the body. However you should put in mind that many practicing societies do it as belief dealing with African religion which has to be handed down from generation to generation. As male caregiver you should only come in with palliative care since traditionally they use an sterilized machine.
- vi. **Twins and triplets:** In the past every 50 – 80 births produces one twins and may be one out of every 6,400 births produces triplets and other multiple births, but they were rarer. Because these were unusual births, African people give special to twins, triplets and other multiple births. In to some societies in the past, twins were considered to be a sign of misfortune and one or both would be killed or the mother would be killed. To other societies they would be allowed to live, but people regarded them as people with special power from God.

One reason why twins were disliked in some parts of Africa is that their chances of survival are generally less than those of single birth; and the chances of survival for triplet are even less. In practice the twins and triplet died more often in infancy than did babies of single birth, therefore peoples were shocked when twins or triplets were born, and every one feared that they would die which often happened. So this frequency death created the belief that it was unfortunate or abnormal to produce twins and triplets.

- vii. **Pre- and early marriage:** This is when a child below 18 years gets married either to older persons or to younger person of the same age. In many cases you find that due to colonial poverty to the many of our parents pre and early marriages have come up in favour gifts (bride price and dowry)
- viii. Denial of nutrients (foods) refusal of eating some foods i.e. chicken etc.
- ix. Sacrifice / kidnap
- x. Harmful sexual cultural practices. In this we have societies who are attach children as partners at an early age as their culture. so these children play sex at that age and in return they get early pregnancies and diseases

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- Introduction to African Religion by John S. Mbiti 1975
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MODULE 12.0: ANTI RETROVIRAL THERAPY (ART)

SESSION ONE: BASIC PRINCIPLES/CONCEPTS

Learning objectives:

By the end of the session, the participants will be able to:

1. Define ART
2. Outline the common types of ARVs available in their setting
3. Outline the benefits of ARVs
4. Describe the side effects of ARVs and how to manage them
5. Identify persons who are not adhering to their treatment in respective communities and how to manage them

1. Introduction

The aim of the session is to equip participants with knowledge, skills and attitudes in antiretroviral therapy (ART), so enable the male caregiver (s) to care and support persons living with HIV and AIDS to foster improved quality of life.

2. What Does ART Mean?

ART = Antiretroviral therapy

ARVs= Antiretroviral drugs.

The abbreviation ART and ARVs can be used interchangeably as they refer to the same thing.

ART is Medicine That Makes the HIV Sleep

When the HIV sleeps, your body can build up its body soldiers to fight other diseases better

3. PRINCIPLES OF ART

- Reducing plasma viral load as much as possible and as long as possible
- Start before irreversible damage of the immune system
- Balance early treatment with possibility of toxicity
- Strict adherence to regimens
- Use of acceptable combinations
- Take into account tolerability and convenience

4. What Do the ARVs Do? Group discussions and feedback

- The concerns of PHAs regarding myths about what ARVs do
- How a male caregiver can support a PHA in dealing with the myths regarding ARVs.

4.1 The group discussion may this yield or similar answers:

- ✓ When the ARVs are taken, they attack the HIV that has been hurting your body soldiers

- ✓ When the ARVs attack the virus, it becomes so weak, the virus will not move
- ✓ The virus will not die
- ✓ It will remain dormant and weak
- ✓ Once the HIV becomes weak, your body soldiers can be stronger again and your immunity can start going up
- ✓ Now your body soldiers can fight the TB, herpes, pneumonia, meningitis, and these other new infections that might want to come
- ✓ As long as you keep taking all the ARVs at exactly the right time, the HIV stays asleep
- ✓ Now you can live longer
- ✓ You can look after your children
- ✓ You can be like another person who is not sick
- ✓ But the HIV is still inside you and it can still infect other people
- ✓ You must remember that ARV has a lot of rules in it
- ✓ You have to follow the rules of ARV

ARVs

- ARVs fight the virus which causes AIDS
- ARVs can control the virus but not kill it
- ARVs are not a cure
- The virus is always still in the person's body and can be transmitted to other people

CASES:

- There is a man who is taking ARVs
- The woman he is having sex with has HIV/AIDS also, but she is not on ARVs
- So her HIV is awake
- If they have sex the awake HIV will make things worse for the man whose HIV has gone to sleep
- If you are going out and playing unprotected sex, you are wasting your time on the ARV and you infect others

- *There are people with very bad hearts who think they did not invite HIV and AIDS, so they will just take it out on others*
- *This is what some big men are doing in town*
- *They give people's children AIDS*
- *They think they are safe because they are on ARVs*
- *They think they are just infecting other people's children and yet it can happen to their own children as well*
- *Not only are they hurting these young girls, but they are making new awake HIV add to their sleeping HIV*
- *So now they are putting others in danger and they are making the ARVs useless for themselves*

So do ARVs cure HIV/AIDS?

NO! ARVs are not a cure for HIV. The ARVs just put the HIV/AIDS to sleep. If you take ARVs, you still have the virus and you can still infect other people. If you are having unprotected sex, the other person's virus that is "awake" can hurt you even while your own virus is sleeping.

Can ARVs cure all sicknesses?

ARVs do NOT cure all sicknesses associated with HIV. You can still get sick with TB, diarrhea, malaria, or different infections. Some diseases, such as TB, are better treated with other types of medication. You must treat them separately and continue taking your ARVs at the same time.

ROLE PLAY TO UNDERSTAND HOW ARVs WORK (10 minutes):

- There is a role play we can act out to understand ARVs better:
- Provide the large index cards to the participants
- Ask the participants to volunteer to write on the index cards "ARVs" or "HIV" or "TB" or "Malaria" or other diseases common in HIV/AIDS.
- Demonstrate how ARVs work to make the HIV sleep by asking participants with "ARVs" tags to attack the other tags and observe how they correlate to the two questions above.
- Be sure to guide them along to understand how ARVs actually work

WHY ART?

- Improved care
- No cure identified so far in all the ART drug combinations
- HIV hides in some body parts like the lymph nodes or the brain
- Better viral load control
- Better CD4 recovery
- Better quality of life
- Combination can be used for longer

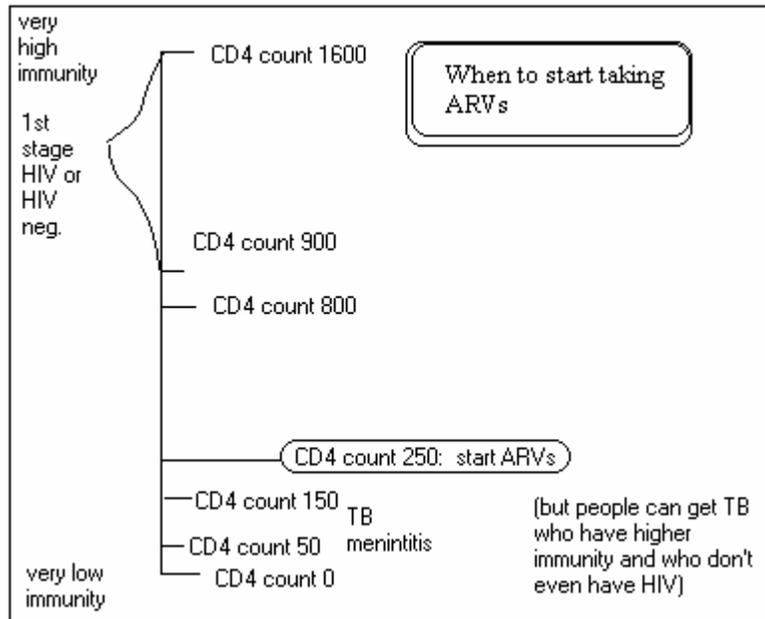
WHO IS STARTED ON ART? Group discussions

Some answers:

- Not everyone who has HIV needs ARV
- ARVs are taken when the CD4 count is low
- What is CD4 count?
- CD4 is certain good body soldiers that help our body to fight HIV itself.
- When the CD4s are so few, you can begin to take the ARVs
- You only start ARVs once you reach such a high risk of dying from other illnesses because you have so few body soldiers

- When your CD4 count is 250 or below, you should start the ARVs. Remember that you need to consult your Doctor so that he will know which ARVS to give you.

The different CD4 counts from what is normal down to when a person should go on ARVs



- It is a machine that determines the blood level—Not a person—No one can decide, only the machine
- No one can look at a person and say, it is time for ARV
- You must know the person is HIV positive and know their CD4 count
- Once you start ARVs, you have to take them for life

WHICH ART IS USED

Every health facility will provide ARVs according to what is available in their own setting. However, the commonest one include the following:

AVAILABLE ARVS AT ONE HEALTH FACILITY IN UGANDA



COMBIVIR + NEVIRAPINE



COMBIVIR + NEVIRAPINE



COMBIVIR + NEVIRAPINE



COMBIVIR + NEVIRAPINE



TRIOMUNE 30



COMBIVIR TABLET

This medicine is a white, oblong, film-coated tablet imprinted with "logo KC". film-coated tablet imprinted with "GX FC3".

TRIOMUNE 30



KALETRA 25-100 MG TABLET (Alluvia)

This medicine is a pale yellow or red, oval, film-coated tablet imprinted with "logo KC".



SUSTIVA 600 MG TABLET (Efavirenz)

This medicine is a yellow, oblong, film-coated tablet imprinted with "SUSTIVA" and "SUSTIVA".



VIRAMUNE 200 MG TABLET (Nevirapine)

This medicine is a white, oval, scored tablet imprinted with "54 193".



VIRACEPT 250 MG TABLET (Nelfinavir)

This medicine is a light blue, oblong,

film-coated tablet imprinted with "VIRACEPT" and "250 mg".



EMTRIVA 200 MG CAPSULE (*Emtricitabine*)

This medicine is a white, oblong capsule imprinted with "200 mg" and "GILEAD".



VIREAD 300 MG TABLET (*Tenofovir*)

This medicine is a light blue, almond, film-coated tablet imprinted with "GILEAD 4331" and "300".



ZIAGEN 300 MG TABLET (*Abacavir*)

This medicine is a yellow, oblong, film-coated tablet imprinted with "GX 623".



CRIXIVAN 400 MG CAPSULE

This medicine is a white, oblong capsule imprinted with "CRIXIVAN" and "400 mg".

WHEN IS ART STARTED?

TESTS REQUIRED BEFORE STARTING ART

- ✓ Confirm diagnosis of HIV infection as you consider initiating anyone on ART. This could be through routine counseling and testing.

- ✓ Those who are unaware of their HIV status can be offered voluntary counseling and testing at an identified center within their vicinity.
- ✓ Other tests can be done to identify the virus itself, known as viral load estimations.
- ✓ Measuring the immune suppression by determining the CD4 cell count. The level can help to determine when to start, if too low ($<200/\text{mm}^3$) and also to monitor response to treatment.
- ✓ Clinical evaluation can be made carefully along with signs and symptoms that are present in the patient. This is commonly used in areas where CD4 tests are not possible.
- ✓ About 90% of children get HIV from their mothers. So HIV antibody tests are used only if child is 18 months and above and stopped breastfeeding for over six weeks.
- ✓ Another test for children is DNA PCR or RNA PCR for children who are above six weeks old.

OTHER REQUIREMENTS FOR STARTING ART.

- WHO \Stage IV disease irrespective of CD4 cell count
- Advanced WHO stage III disease
- WHO stage I,II or III with CD4 cell counts of <200 where CD4 tests are available
- Tuberculosis and CD4 cell count between $200 - 350/\text{mm}^3$
- Interest and motivation in taking therapy
- Financial barriers
- Psychosocial barriers – alcohol use, lack of food support
- Potential for adherence (attending ARV education sessions , peer support groups, personal adherence plan)
- Lab tests to make sure there is no anemia, liver disease, looking out for persons taking anti - cancer drugs which may have severe side effects.

Remember, you need a complete medical evaluation, physical examination, laboratory investigations and counselling before starting ARVs to see if they are right for you. If you are thinking about buying ARVs for yourself or for a family member, please come and talk to the Doctors and Nurses. We want to help you make the best decision for you and your family.

FOR HOW LONG DO I NEED TO TAKE NY ARVs?

ARVs do NOT cure HIV/AIDS. They must be taken for life. ARVs do not work if taken for only 2 weeks or 1 month. Do not start on ARVs unless you have prepared to take it for the rest of your life.

WHERE TO ACCESS ART?

Remember that only those health facilities that are accredited to supply ARVs should provide it to the public. They may include the following:

- Government hospitals
- Private hospitals
- National medical stores
- Non-governmental organizations
- Private clinics

HOW TO START ART AND APPLICATION

ASSESS FOR READINESS:

- What does the patient know about ART?
- Is he/she interested in receiving ART?

GIVE ADVICE:

ARVs are life saving drugs and this is heavily dependent on how well one takes them.

- Need for complete adherence and getting a treatment buddy to remind about time for taking the pill and also to encourage him/her. Warn the missing does increase the chances of failure.
- Time set for taking the ARVs should be suitable for the patient. The healthworker may guide in choosing the appropriate time. Instruct each patient according to the regimen suitably chosen for them.
- If you forget to take a dose, do not take double dose as the levels in the blood can get too high and harmful to the body. If you forgot, take within 4 hours from the time you should have taken.
- Must be taken right on time, every 12 hours or for some, once at night. Give advice on diet as need arises.
- This is a lifetime treatment and it should not be stopped as this may make you very ill over time.
- Inform about the possibility of side effects of ARVs and their likely duration and instruct on what to do when severe side effects arise
- Explain the limits of alcohol and drug use
- It's very important to disclose about your positive HIV status to at least one adult in the family whom you are comfortable sharing this information with.
- Do not share the drugs with the family members as the patient must take a full dose of all the ARVs as expected.
- Remind the patient that they can still transmit HIV even while on ART, hence need to have protected sex.

AGREE:

Ensure that the patient is ready to initiate ARVS, depending on whether he/she is going to buy it by themselves or is planning to obtain it from a facility that supplies it for free.

- Has the patient been keeping their appointments and adhering to other medications well? If not, this is a risk to adhere poorly to ARVs.
- Has the patient disclosed their HIV status? (Depends on the programme).
- Does the patient fully understand the treatment they are about to undertake. Remember this is a lifetime commitment.
- Is the patient willing to come for regular clinical review as will be planned?

ASSIST:

This is in relation to additional support i.e. Social, emotional, resources, etc

- Discuss how the patient will come for follow up visits.
- Is there any stigma at work place or home that does not allow taking the ARVs comfortably?
- Is there a regular supply of free medications or is the patient buying it? If buying, is there a steady source of income to support this lifetime plan?
- Does the patient have family and friends to support adherence to the ARVs.
- The treatment buddy or supporter needs to attend at least one counseling session with the patient about his ARVs so as to provide adequate support.
- Follow up the patient on home visit if possible to assess their adherence and to offer any necessary support.

ARRANGE:

When the patient is ready to start ART, discuss at a clinical team meeting then make a suitable plan for the patient.

- Arrange a follow up visit in clinic or home or health facility as may be feasible.
- Ensure the patient understands where and when they will see the health worker next.

SESSION TWO: ART MANAGEMENT

SIDE EFFECTS AND THEIR MANAGEMENT

Are ARVs really too strong?

ARVs have strong side effects and are difficult to take. You must be ready. But when your body's immunity is so low, the ARVs will help to bring more years to your life.

If you do have bad side effects do NOT keep quiet and stop taking the ARVs. You must tell your caregiver and the clinic immediately.

- Side effects are different for different people
- That is why you must prepare the client
- Help them to know what side effects could come and which ones are harmful
- You will learn these things in session 4

Signs and symptoms

What to do

Nausea – feel like vomiting	This is common with all ARVs. It usually stops on its own. Take the medicine (except DDI and IDV) with locally available foods like roasted potatoes, cassava. Offer drinks like tea, juice. Drink slowly and more frequently. Avoid cooking close to the patient.
Headache	Give paracetamol (Panadol). If headache is severe, seek medical advice. Common with EFV and ZDV
Diarrhoea	Give plenty of fluids by mouth, like ORS, rice soup, porridge, clean water, other soups, yoghurt but avoid sweet drinks. Common with ZDV
Fatigue	This can last 4-6 weeks especially when starting ZDV. Call for advice if it lasts longer than this.
Anxiety, nightmares, depression	This may be due to EFV. Give at night and counsel as it usually lasts <3 weeks. Amitriptyline may help.
Blue/black nails	Counsel the patient.
Rash	If on NVP or ABC. If generalized or peeling, seek immediate medical advice as there may be need to stop this drug.
Fever	Call for advice or refer. This could be a new infection, a side effect or an opportunistic infection. Give Aspirin, Ibuprofen or Paracetamol to reduce fever. Wear light clothes. Cool body with warm water.
Yellow eyes or abdominal pain	Stop drugs. Call for advice or refer
Pallor (anaemia)	If possible, measure the blood hemoglobin. Refer if severe pallor
Pricking pain in feet or hands or numbness	If new or worse on treatment, call for advice or refer. Common with d4T/3TC//NVP – Triomune or Maxivir
Cough or difficulty breathing	Call for advice or refer. This could be a side effect of ABC and if so, stop the drug, call or refer. You may use extra pillows or some back support, open windows for some fresh air, fan with a newspaper or cloth, avoid crowding
Changes in fat distribution	Discuss carefully with the patient if he/she can accept it

ADHERENCE

How should I take my ARVs?

ARVs must be taken exactly as the doctor tells you. If you miss a dose or share your pills, the ARVs will not work. You cannot economize and take half a dose.

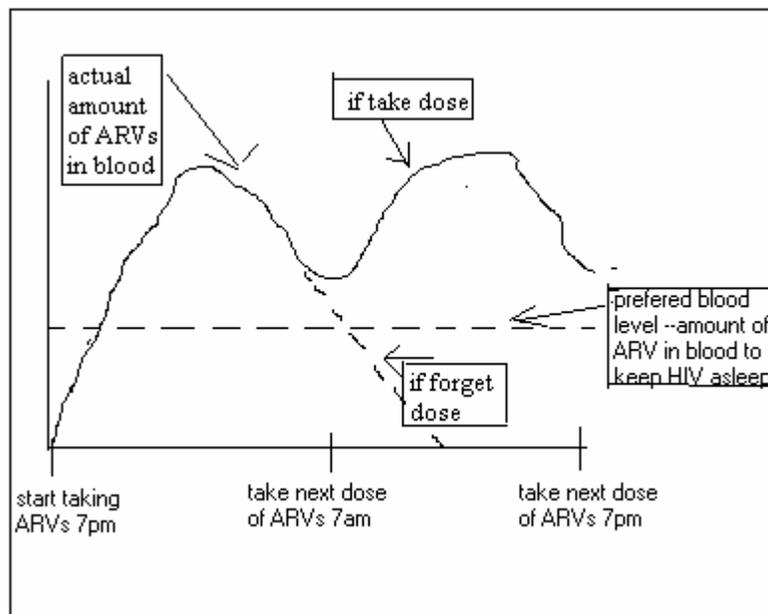
Everyone must take the right dose at the right time!

ARVs are very expensive in Uganda and other African countries but the prices are coming down. If you are interested but do not have the funds, have hope!

If we use them correctly we have a much better chance of receiving the ARVs for many more years.

- ✓ ARVs must be taken exactly as doctor tells you
- ✓ You must take the right dose at the right time
- ✓ If you don't take it well, it won't work for you later
- ✓ ARVs are not like these other drugs like cotrimoxazole or other medicines you may be taking. You will need to keep time.
- ✓ Once you are starting on ARVs, select time that is convenient for you because if you take them at 7am you must take them at 7pm.
If wait an hour later, ARV is finished from your bloodstream
- ✓ If you miss that 1 hour of ARVs, the virus is waking up
- ✓ That's why you are supposed to follow the time exactly
- ✓ That is also why you should not share medicine

TAKING ARVs



HOW MUCH ADHERENCE IS REQUIRED FOR GOOD RESULTS?

The patient needs at least 95% adherence for the ARVs to work well.

This means:

- A client taking once daily treatment has missed not more than one dose in a month.

- A client taking treatment twice a day has missed no more than three doses
- A client is taking treatments three times a day has missed no more than four doses in a month.

CHALLENGES OF ART

- Life long therapy is one of the biggest challenges
- Some side effects of the ARVs can pose a challenge to adherence
- In children, the doses of ARVs are given according to weight, so as the child gains weight, the doses need to be adjusted accordingly.
- In children, liquid formulations may be difficult to administer especially if they are looked after by an illiterate grandmother. They require special training sessions to get the doses right.
- Financial challenges in the family may lead to inability to keep appointments if the health facility is far.
- Patient adherence to therapy is a big determinant for success of ART.
- Sustainable ARV supplies and delivery systems may make it difficult to access the drugs as punctually as they need to be.

ROLE OF CAREGIVERS IN ART

- ✓ Visit your patients at least weekly when they have just started ART and eventually monthly or when feasible.
- ✓ Check the patient's ARV treatment and any other medications they may be taking to ensure good adherence to the drugs.
- ✓ Teach the client how to take their medication correctly following the time and food requirements.
- ✓ Check their appointment card to remind the patient of their appointment at the clinic
- ✓ Agree with the patient what day will be suitable to come back and check on them the following week or so.
- ✓ If some clients need more attention, visit them as many times that week as needed
- ✓ Get to know the patient more and encourage them to talk about their problems.
- ✓ When they miss their doses, do not scold them. Instead try to find out the reason why they missed their doses and counsel them.
- ✓ Work as a team with the clinic team, any community supporters, family, the counselors and any other person who may help in supporting this patient.
- ✓ Know your limit with the patient and communicate that clearly
- ✓ Know the limit of the organization you are working with and let the patient know what services are available.
- ✓ Record whatever you have seen when you visit each client
- ✓ Have regular meetings as male caregivers and share your experiences with each other.
- ✓ Discuss any difficult problems and find solutions together
- ✓ Report on any abrupt journey a patient takes, any bad side effects, or any problems immediately

Key Messages

- ARVs are NOT a cure for HIV/AIDS—the virus is always present and can still be transmitted to other people
- ARVs are taken for life
- ARVs take time to work and clients may still get sick in the first few months on treatment
- ARVs treat only some diseases the client already has—ARV mostly prevent new diseases from starting
- Adherence is the key: ARVs must be taken correctly or they will stop working and the same drugs cannot be used again—It is important to do the treatment right the first time!
- Drugs cannot be shared with friends or family—Three stones will hold a cooking pot but not one or two! The client must take ALL the pills or NONE of them

REFERENCES

Comprehensive HIV care including ARV therapy, Chronic HIV care guide for first level health facility health workers, Ministry of health, Uganda, May 2004.

Manual for Training CATTs (Community ARV and TB Treatment Supporters), Reach Out Mbuya, Kampala, Uganda, April 2004.

National Antiretroviral treatment and care guidelines for adults and children, Ministry of Health, Uganda, November 2003.

Palliative care: Symptomatic management and end of life care, Interim guidelines for first level facility health workers, World Health Organisation, May 2004.

SESSION TWO: ART IN CHILDREN

Learning objectives:

At the end of the lesson the Learner should:

1. Be able to understand the concept of antiretroviral therapy (ART) and appreciate that it is not a cure for HIV.
2. Have an idea of some of the common antiretroviral drugs (ARVs) especially those used in 1st line regimes.
3. Know when to initiate ART in children;
4. Appreciate the importance of adherence to antiretroviral treatment as well as the dangers of non-adherence.

5. Be aware of the major issues in ART namely: the common side effects; (what to do when these occur), drug resistance (causes and consequences), drug-drug interactions (consequences), etc.
6. Identify the role of male care givers in ART in children.

I. What is Antiretroviral Therapy (ART)?

ART stands for ‘antiretroviral therapy’.
It is the standard treatment for HIV/AIDS.

It involves treatment of HIV/AIDS with antiretroviral drugs (ARVs). These drugs are used in combination and never as a single drug. We now have ARVs that are taken as single tablets, but these are already having more than one drug – could be two in one or even three-in-one.

ARVs do not cure HIV but they help a patient live a healthier and productive life by:

1. Reducing the viral load (VL) which is the amount of virus in the body.
2. Increasing the level of an individual’s CD4 count, thereby improving the body’s ability to defend itself and hence:
 - a. reducing the incidence of HIV- related complications (reducing the rate at which opportunistic infections and conditions such as cancer develop);
 - b. helping the body to fight off already existing opportunistic infections and conditions.
3. Reducing the rate at which HIV is transmitted to others via mother-to-child-Transmission (MTCT), sharps injuries etc (Epidemiological goal).

Types of ARVs:

There are currently 3 main types of antiretroviral drugs (ARVs) used in Uganda namely:

Table 1: Commonly used antiretroviral drugs in Uganda

Nucleoside Reverse Transcriptase Inhibitors (NRTIs)	Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs)	Protease Inhibitors (PIs)
Zidovudine (AZT)	Nevirapine (NVP)	Ritonavir
Stavudine (d4T)	Efavirenz (EFV)	Saquinavir
Lamivudine (3TC)		Indinavir
Didanosine (ddI)		Amprenavir
Abacavir (ABC)		Lopinavir
Zalcitabine (ZCT)		Lopinavir/Ritonavir (Kaletra)
Tenofovir (TDF)		Nelfinavir

3. How are ARV drug combinations decided on?

NRTIs are the backbone of antiretroviral therapy.

When selecting drugs for first therapy, 2 drugs are normally selected from this class and one from the NNRTIs

There are guidelines followed while selecting which drugs may or may not be combined with others. This depends primarily on whether or not they interact with desired or adverse effects.

Drugs such as AZT with ZCT independently have high potential to cause low blood levels (anemia) thus making their combination more risky in terms of the risk of development of anemia. Their combinations are thus not recommended.

D4T and DDI together pose a higher risk of a patient developing mitochondria toxicity.

The host's factors such as pre-existing conditions also guide the selections of drugs for the patient. For example Efavirenz is not recommended in patients below 3 years of age, in children below 13 Kilograms of body weight, in patients with history of severe psychiatric illness and in women of child-bearing age especially adolescents.

Table 2: Recommended First Line Antiretroviral Regimens for Children and Infants:

Regimen	Comments
ZDV/3TC + NVP or EFV	If <3 years or <13 kg, use NVP
OR	
d4T/3TC + NVP or EFV	If ≥3 years or ≥13 kg, use NVP or EFV

Many healthcare providers who have had training in the field of ART have the skills of making safe combinations and should be consulted in case need arises.

When do we Start ART in Children?

The initiation on ART in children takes into consideration several factors that may be combined or used singly depending on the condition of the patient (disease stage, presenting illness, etc) and resources available among others.

For resource limited settings according to the WHO guidelines and according to the guidelines on the use of ART by the Ministry of Health of Uganda, the following criteria are followed:

A positive HIV test: confirmatory or presumptive.

- i. For children aged 18 months of age and above, a positive HIV antibody test is considered confirmatory (Common antibody tests used in Uganda include: STAT PAK, UNIGOLD and DETERIME- Parallel tests involving the 3 tests as is done in Mildmay increases the reliability and validity of the results).
- ii. For children below the age of 18 months, a positive antibody test is not confirmatory as it may be indicating maternal antibody response that was transmitted from the mother to the baby via the placenta during intrauterine life and not the child's response. It is considered presumptive and to confirm the test a more sophisticated test that detects the HIV genetic material such as an RNA/DNA **PCR** (polymerized chain reaction) test may have to be done on such a child. The PCR test is relatively expensive costing about \$25.00 per test and it is only carried out at specialized laboratories.
- iii. A child born to an HIV positive mother with advanced HIV disease (WHO stage 3 and 4) qualifies for ART on presumptive grounds.

Clinical criteria: ART could also be started in a child basing on the clinical picture of the child. The World Health Organization (WHO) and the CDC have developed clinical classification of HIV/AIDS infection in children. Children with WHO clinical stage 3 and 4 may be started on ARVs regardless of the CD4 count.

Immunological criteria: this implies starting a child on ART basing on the CD4 count. The specialists in children ART will use terminologies – absolute or percentage of CD4 cells and/or total lymphocyte count (TLC) as determinants for initiation of ART. CD4 percentages that would qualify a child for ART:

- i. Below 1 year a percentage below 25%;
- ii. From 1 year to below 3 years below 20%;
- iii. From 3 years to below 6 years, below 15%

From 6 years onwards an absolute CD4 cell count of below 250 cells/mm³

5. *Important Issues to Know/Observe When Dealing With ART:*
Drug interactions:

Reflection:
What happens when co-wives are accommodated in the same house/room?

ARVs may interact with some other drugs with the following effects:

- I) A reduction in the amount of ARV- drug or the other drug in the body thus reducing its intended effect in the body. Common examples of drugs that reduce

the amount of ARV in the body include Rifampicin an anti-Tuberculosis drug, Ketoconazole commonly sold as Nizerol, an antifungal drug; omeprazole a commonly used antacid; carbamazepine an anticonvulsant drug; simvastatin an anticholesterol drug, etc.

- 2) An increase in the length of stay of drug in the body thus causing undesired effects.
- 3) A formation of a toxic or poisonous substance that are harmful to the body
- 4) An exaggeration of a particular side-effect due to a synergetic action of drugs such as anemia when drugs like septrin and AZT are used together in some patients and mitochondrial toxicity when DDI and D4T are used together. Mitochondrial toxicity involves damage to the power-generating unit of the body manifesting as severe weakness, vomiting and death among others.

Importance of adhering to prescriber's instructions:

- ⇒ In order to gain maximum benefits from ART and avoid unnecessary negative outcome from it, one should adhere to the prescriber's instructions meticulously.
- ⇒ Remember ART is for a life time and it is not a cure.
- ⇒ Regarding dosing the dosages indicated by the prescriber should be followed as an under- dose may lead to resistance and an overdose to adverse effects.
- ⇒ If the instructions say one tablet 8hrly, the drug should be administered at intervals of 8 hours and not 6 hourly or 12 hourly or else negative outcomes such as those due to overdosing or drug- resistance due to lack of sustaining a correct amount of drug in the body, may occur.
- ⇒ If the instructions say 'on an empty stomach' then the drugs should be given on an empty stomach with an interval of 2-3 hours after the previous meal and about 1 hour before the next meal.
- ⇒ If the instructions say 'Take with food then the drug should be taken when the stomach has some food contents i.e. within 2- 3 hours of a meal or else the drug may cause severe irritation to the lining of the gut or severe hypoglycemia.

Duration of ART, drug holiday, change of regimen, cessation of ART:

- ⇒ It is very important to know that ART is to be taken for a life-time.
- ⇒ Do not stop administration of the drugs unless instructed by a healthcare provider. Stopping is only done in such circumstances as in severe/ life-threatening adverse effects such as hypersensitivity to drugs (e.g. Nevirapine, Abacavir) or during drug studies etc during which they are called structured holidays.
- ⇒ A qualified healthcare provider may change regimen to second line or change one drug in the 1st line or other regimens based on circumstances such as the occurrence severe anemia with the use of AZT.

What to do if child vomits after taking drugs or doses are missed:

- (a) Repeat dose if the child vomits within 2-3 hours of after taking he drug.
- (b) Administer the dose immediately within 2-3 hours of missing the dose and wait till the time of the next dose if the time of missing the dose is longer than this.

Adverse effects of ARVs, contra-indications to the use of some drugs

Common adverse effects of ARVs include:

- ⇒ Gastrointestinal disorders such as diarrhoea, nausea, vomiting, loss of appetite, etc, most of these disappear with time.
- ⇒ Aneamia with such drugs as AZT, ZCT thus they should be avoided in patients with low levels of blood.
- ⇒ Mitochondrial toxicities with the use of drugs such as DDI thus they should not be used with other drugs which cause the same and in patients with already pre-existing anemia
- ⇒ Teratogenic effects (Damage to the unborn child): They should thus not be used in patients who might conceive such as adolescents while using the drugs despite having information on the effect of the drugs.
- ⇒ Lipoystrophy – a condition in which there is an abnormal fat distribution in the body leading to cosmetic concerns, predisposing the patient to Hypertension and other diseases such as diabetes. This complication is common with drugs like D4T. They should thus not be used in patients with pre-existing such conditions.
- ⇒ Psychiatric disorders: This is common with the use of drugs such as Efavirenz and should thus not be used in patient with pre-existing or history of severe psychiatric illness as the drugs may precipitate psychiatric disorder.

Contra-indications to drugs / conditions to be cautious about while administering ART:

- a) Drug resistance:
 - Causes of drug Resistance:
 - Resistant HIV strains (primary resistance) e.g. a newborn may be born with an already resistant strain of the virus from the mother.
 - Poor adherence to drugs is a common cause of drugs resistance.
 - Administering ARVs with drugs that reduce the bio-availability of the drug in the body; for example administering some ARVs with anti Tuberculosis drugs.
 - Consequences of drug resistance:
 - Sometimes there is no second line drug available.
 - Many drugs considered for second line have adverse effects on the patient (that may be the reason they were not selected for this particular patient for the 1st line- regimen in the first place). They have more rules such as do not take with fatty foods etc, which may encourage poor adherence and further resistance.
- b) Monitoring progress:
 - Monitoring the progress on ART is very important. Both Clinical and Immunological changes are monitored. Incase of no improvement investigations are carried out to try and establish the cause against which interventions such as change in drug regimen are carried out if the cause is drug resistance, or counseling with the aim on improving on adherence if the cause is poor adherence.

- Parameters such as weight gain in children are used, frequency with which opportunistic infections occur compared to the baseline when in terms of clinical monitoring.
- Parameters such as CD4 count and viral load are some of the immunological and virological parameters used regarding the immunological parameters and these are done in health facility.
- A child should be returned regularly at least twice a year to have these tests done.

c) Immune reconstitution syndrome

Depending on how low the child's immunological status is when they start on ART, they may develop an abnormal immune response at around week 3 of starting on ART. This is characterized by symptoms like fever, swollen lymphnodes a worsening of the general health of the patient, etc. A course of corticosteroids and supportive treatment such as the administration of drugs such as ibuprofen to control inflammation and pain may help to control the symptoms. ARVs should not be stopped but the child needs to be admitted to the hospital for specialist care.

Immune reconstitution syndrome usually subsides after a few days or months and should thus not be a cause for cessation of therapy.

What is your role as male care givers in ART in children?

- ⇒ Monitor children in the community i.e. weight gain or loss, frequency of infections etc
- ⇒ Advise family to take the child to the facility if there are any problems seen or are complaining of
- ⇒ Advise the family to take child for regular CD4 check, at least twice a year
- ⇒ Support the family or child in taking drugs in a timely manner
- ⇒ Advise on regular feeding
- ⇒ Provide feedback and relevant reports to the health workers seeing the child
- ⇒ Know when side effects are there and refer to health facility or provide support at home where possible
- ⇒ To encourage patients and their care givers at home to declare any other drugs the patient is taking i.e. traditional or western to the health care providers so that potential drug interactions are avoided

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MODULE 13.0: COMMON LEGAL ISSUES IN HIV/AIDS

SESSION ONE: COMMON LEGAL ISSUES IN HIV/AIDS AND INTERVENTIONS

Objectives of this session:

By the end of the session, male caregivers should be able to:

- Identify common legal issues/needs of PLWHA and their families
- Discuss ways of assisting PLWHA to meet legal needs
- Link them to possible sources of legal assistance.
- Discuss rights, benefits, and opportunities available to persons living with HIV and AIDS in their country.

1. Introduction

It is well known that people living with HIV and AIDS and their families experience emotional and physical difficulties, but they also frequently face severe financial problems related to their inability to work, loss of benefits, and the costs associated with care and treatment that eventually call for legal attention. The loss of a job and a drastic reduction in income clearly add to the burden of stress for the patient and family even as they try to cope with life-threatening illness.

The ultimate aim of this manual is to equip male care givers with knowledge and skills in managing and handling common legal issues and in turn that they can use to help patients and their families address the range of issues they face, including the legal and financial problems that HIV and AIDS brings upon them; in addition to improve their quality of life .

Male care givers can assist in the following ways:

- Assist PLHIV access any benefits due to them thus helping know their rights and responsibilities
- Link them to possible sources of legal assistance.
- Male caregivers must understand and acquaint themselves rights and responsibilities of children infected and affected by HIV and AIDS.
- Male caregivers must understand rights, benefits, and opportunities available to persons living with HIV and AIDS in their country.

2. Situations where people with HIV and AIDS need legal support

- Both the person coping with life-threatening illness and their families struggle with various issues that may require legal as well as financial assistance.

- In Africa however the extended family system can be a potential source support for the patient legally and financially where family members mobilize funds. In the era of antiretroviral drugs, patients may sell their property to purchase treatment, leaving families without shelter and other needs this may provoke psychological reactions as anger, depression, anxiety, and isolation which eventually can break down communication within the family, such reactions if not well handled may lead to situations that require legal attention.
- It is common for people with HIV to sell their property, including their homes, to purchase ARV treatment, in addition to meeting other personal and family basic needs

Patients have specific needs related to addressing their legal and financial burdens and can be assisted by male caregivers:

- **Information**

PLHIV can benefit from services in that certain organizations offer opportunities to inform people of the local resources available to them since most of them are ignorant of such services and need help in identifying and making use of them.

- **Assistance**

Even when patients are knowledgeable about their benefits, they may be too weak to begin the often bureaucratic and in some cases corrupt process of accessing them. Therefore male care givers can make a big difference at the end of life by offering assistance that will eventually relieve the patients of legal and financial related stress.

- **Emotional support**

This is important not only for the patient but the family as well. Much as patients are receiving entitlements as terminal benefits and pensions, they may still need advice and advocacy to help address their practical needs, reduce their stress, and enable them to concentrate on their medical and emotional needs.

3. ROLES OF MALE CARE GIVERS IN LINKING FAMILIES TO LEGAL ASSISTANCE

Male care givers play important roles in assisting patients and their families to obtain legal assistance from concerned authorities. (A group discussion to probe the trainees on their understanding of what role they can play in assisting PLHIV access legal assistance and or what are the areas that they may be confronted with daily as they assist PLHIV)

- **Guiding and advising**

- I. Patients often need help and encouragement to make the necessary claims and to ensure they receive the entitlements due them.
- II. They also need assistance in rational decisionmaking in situations of too many legal needs to help them avoid decisions that are detrimental to their families

and children.

- **Facilitating communication**
 - I. Male care givers play an important role in enhancing communication within the family.

- **Referring to local resources**
 - II. Male caregivers can also be helpful in assisting patients and their families to make use of available resources in their communities. These include the local council, local networks of lawyers and other resource persons who can assist them.
 - III. Male care givers can as well maintain a network of all local, national, and international level caring organizations can help mobilise resources including financial and legal for HIV/AIDS patients and their families.

- **Assisting to navigate bureaucratic systems**
 - I. Male care givers can play an important role to bridge the gap within systems like In some African countries where the social security benefits system is weak, often inaccessible, and sometimes non-existent.
 - II. This is worsened by ignorance about where the services are available. This may include assisting the patients in what may be the lengthy process of obtaining the birth certificates, death certificates, hospital reports or other identity documents needed to access financial and or legal entitlements.

Brainstorm: What areas should male caregivers be knowledgeable about while assisting patients with legal issues?

In order to play an active role in helping patients and their families with financial or legal problems, male caregivers need to be knowledgeable about:

- Their country's social security and labor laws.
- Procedures for claiming benefits
- Any special rules for claiming benefits for people with terminal illnesses
- Documentation needed to apply for various government benefits, including the locations and operating hours of relevant offices.
- Any new changes including contacts of persons who are to assist.

Actions male caregivers can take:

- Holding discussions with patients' former employers
- Helping patients to understand and sign relevant claim documents
- Sensitising relevant community leaders, employers and others on the need and urgency for claims
- Offering patients practical assistance, such as transport and organising documents

Below is shared information from Uganda that may be similar to other African countries:

Case Study

Uganda's National Social Security Fund (NSSF)

Uganda's NSSF is a compulsory savings scheme which covers all employees in the private sector, including non-governmental organisations and parastatal bodies that are not covered by the government pension scheme. Every worker is entitled to subscribe to the NSSF (NSSF Act, Cap 222), which administers and pays qualified contributing persons the following benefits:

- Old age benefit
- Invalidity benefit
- Survivors benefit
- Emigration grant
- Withdrawal benefit

The NSSF identifies people with HIV/AIDS as physically or mentally incapacitated and, therefore, as potential beneficiaries of the invalidity benefit upon fulfilling such requirements as possessing certification from a medical doctor that they have HIV/AIDS, which the NSSF can verify.

The NSSF acknowledges the financial constraints caused by HIV-related hospital admissions, treatments, and transport to health facilities. Patients desperately need their savings to meet these needs and to plan ahead for their families. Despite the limitations of the law and NSSF policies, patients with HIV/AIDS are encouraged to file claims for their benefits from NSSF with minimum difficulty.

NSSF makes all the information necessary for filing a benefits claim available to professional carers, patients, and families. A supportive letter from the organization providing health care services can facilitate the claim process. For patients who are too weak to reach the claims office, arrangements can be made for NSSF officials to visit the patient at home and obtain relevant information and legalities, such as the required thumbprint.

Key message to Note:

Uganda: Uganda includes HIV/AIDS as an occupational disease under the Workers Compensation Act Cap. 225. A general campaign is underway on workplace HIV/AIDS policies which is hoped to make a positive contribution to HIV/AIDS employees in their workplaces. Such policies relate to financial contributions to treatment, particularly ARVs, granting of sick leave, period of continued salary payment, issues of psychosocial support, workplace stigmatisation, and facilitating access to other available services.

Uganda: In Uganda, a few programmes such as the Federation of Women Lawyers (FIDA), the Legal Aid Project, and the Legal Aid Clinic are responding to the legal

problems of HIV/AIDS patients without requiring clients to pay for services. It is useful to investigate similar programs in other countries.

Through knowledge and training, male caregivers are better placed to discuss legal issues with people living with HIV/AIDS. Such discussions give patients and families an opportunity to make rational decisions for their own and their ill loved one's protection, both during the period of illness and after the person's death. Palliative care professionals must be well informed about the unique laws and benefits in their own countries to be able to assist them.

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SESSION TWO: SUCCESSION PLANNING – THE WILL, MEMORY BOOK ETC

Introduction

Aim of the session

The aim of this session is to equip participants with knowledge and skills necessary for succession planning including all the related importance of wills and memory projects

Learning objectives

By the end of the two sessions (Will and Memory Project) participants should be able to;

Session One: WILL

- Define and understand what is meant by a will.
- Define and understand what dying intestate imply
- What are the important points to note while will writing
- Advantages and disadvantages writing not writing a Will

Session Two: MEMORY PROJECT

- Define and understand what is meant a memory book.
- Who is the memory book for, of what importance is this memory book
- What facts are noted in a memory fact book, for who and why?

What is a Will

A Will is a written document, made by a person, that contains instructions and wishes of that person about what will happen to his/her people and/or property after his/her death.

Importance of making a Will

It is very important to write a will because of the following reasons:

- a. To leave clear instruction on how his or her affairs will be managed after death.

- b. To provide for the husband/wife, children and dependants.
- c. To identify the deceased's properties, money owing and owed, children, wives, and other partners.
- d. Peace of mind for the will maker over the future of his or her property, after death.
- e. The best way to safeguard one's family's interests after one's death.

Who can make a Will?

A Will can be made by a man or woman in Uganda, whether married or single.

- With or without property to distribute.
- Aged 21 years and above.
- Of sound mind i.e. who understands what he or she is doing at the time of making the Will.
- Not too sick or drunk to understand what he or she is doing at the time of making the Will

The following special cases should be noted

- Making the Will freely and by choice
 - a. In the case of mariners at sea or soldiers in battle, a person aged 18 can write a Will.
 - b. A person who sometimes suffer from mental health problems can write a Will at a time when he or she is of sound mind and it will be accepted.

Types of Wills

There are two types of Wills namely;

1. A written will
2. A privileged will: This type of Will may be written or spoken that is made orally; by any members of the armed forces in actual warfare or on an expedition or a mariner at sea. Oral (spoken) Wills expire one month after the Will maker is no longer engaged in war or when a mariner is no longer at sea.

Who does a will protect?

A Will protects the rights, duties and responsibilities of the following persons.

- Surviving husband, wife, or other partner
- Children
- Relatives
- Dependants
- Guardians
- Friends
- Executor(s) (person or people managing the Will)
- An organization or association
- The deceased person

Who MUST benefit from the Will maker's property?

According to the Succession law, there are categories of people who MUST be provided for by a Will maker who has property to leave to them unless the Will maker has very good reasons for not doing so. These include

- A surviving wife (wives) or husband
- All children and dependant relatives of the deceased below 21 years are entitled to be provided for.

Key information to be contained in a Will

A Will must be written according to the requirements of the law of Inheritance and Succession in Uganda. A legally recognized Will must contain.

1. The name and address of the person making the Will. Other details about one's tribe, clan and religion may be included for clarity.
2. The date when the Will is made. Each later Will replaces all earlier Wills and this is determined by the most recent date. A Will maker can add to the Will by writing a CODICIL.
3. The age of the Will maker. This is to ensure that the will maker is legally capable to write a will.
4. Name of wife or wives, or the husband, as appropriate. If the Will maker is separated or divorced, this can be mentioned in the Will for clarity.
5. Name(s) of children, whether adopted or born in or outside marriage.
6. People/guardian(s) who will look after the children who are still young e.g. less than 18 years or still school going age. This may be a surviving husband or wife, or a trusted friend or relative.
7. Names of relatives whom the Will maker has been providing for necessary items that are required for living and whom the Will maker wishes to continue providing for even after death.
8. Property owned by the Will maker. This may include land, livestock, crops, household items, business items, and shares in a company or partnership. As property increases or decreases during the lifetime of the Will maker, he or she can make changes to the Will accordingly.
9. The way the property will be distributed i.e. how much and to whom.
10. The name (s) of the person who will distribute the property of the Will maker and ensure that all wishes in the Will are followed exactly as they are written. This may be the surviving husband or wife, trusted relative or friend, and this person is referred to as the executor / executrix of the Will. A person below the 21 years or one who is mentally unhealthy cannot be an executor.
11. Signature or thumbprint of the Will maker should be put on every page.
12. Signature of at least two witnesses.

A will is essentially valid if it meets the requirements mentioned above.

What happens if a Will does not contain all the key information mentioned above?

Failure to observe the strict requirements of what to include in the Will may result in the will not being recognized as a legally binding document.

A Will may not be recognized a lawful if:

- a) it is not dated, signed or marked with the thumbprint of the will maker.
- b) the witnesses do not sign the Will.
- c) it is proved that the Will maker was not of sound mind or was forced or threatened to write the Will.
- d) a surviving husband, wife (wives), children or relative who depends wholly or partly on the Will maker for basic necessities have been omitted, it may be challenged in the High court of Uganda.
- e) the Will maker made the Will before marrying and after marrying, did not change the Will.
- f) the wishes of the Will maker are not clearly stated, contradictory, or confusing.
- g) the Will maker was under the age of 21 and did not fall under the special categories.

In case the Will is not accepted by a court of law, then the property of the Will maker will be divided as if he or she did not make a will (interstate). The details of how this division is carried out are discussed further ahead in this guide.

A Will maker can include her/his other wishes in the Will such as;

- a. Details of burial procedures and last funeral rites that the Will maker may wish to be followed.
- b. A customary heir under the traditional practices of the Will maker.
Note: The heir is not automatically the executor of the Will unless the Will maker states so.
- c. Names and addresses of the people or the places where other copies of the Will have been kept.
- d. Name of partner i.e. any unmarried person with whom the Will maker has been living with in an intimate relationship.
- e. Any other information the Will maker wants to make known when he/she is dead.

Can another person write a Will for the Will maker?

A Will maker who cannot write a Will personally can request a trusted friend to write down his or her wishes and sign the document or make a thumbprint mark and certify that the contents were read back to the Will maker who seemed to understand.

Can a will be changed?

A Will can be changed whenever the Will maker desires to do so. This usually happens when circumstances change in one's life. For example:

- A man or woman acquires more property or loses some of the property.

- A man or woman marries or remarries.
- The Will maker has more children and dependant relatives or less children and dependant relatives.
- The Will maker changes his or her mind about certain parts of the Will.

A Will maker can change part or all the Will and should clearly state so in the Will. In absence of clear dates in the Will, the Will with the most recent date will be taken as the legally recognized Will.

Where can you keep your Will?

The Will maker has to decide where to keep his/her Will. The common places include:

- A bank
- A lawyer
- A husband or wife
- A trusted friend
- Religious institutions and leaders eg. Reverend, Imam
- Executive of Local Council
- Head Teacher
- Legal NGOs like FIDA (U), Legal Aid project of Uganda, law society (LAP), Legal Aid clinic (of the Law Development Centre) which offer legal aid services.
- A trusted relative
- The high court of Uganda
- The Administrator General's Offices

It is important to leave the Will with at least more than one trusted person and instruct them to open it soon or immediately after the Will maker has passed away in order to avoid confusion and failure to observe the wishes of the Will maker.

What follows after the death of the Will maker?

1. Those whom the will maker gave copies should produce the Will and notify the family of the Will maker about it. This may be important especially if the Will maker made specific instructions in the Will relating to the burial ceremony.
2. The person(s) named in the will as the executor(s) (implementer of the will) or any other responsible person should report the death to the Office of the Administrator General or the Chief Administrative Officer (CAO) is the representative of the Administrator General at the district level.
3. The Executor must apply to a court of law within two months of the death of the Will maker for permission to effect the wishes of the deceased as stated in the Will.
4. The Executor after being introduced to the court produces the Will and presents the witnesses to the will before the court.
5. The executor is required to advertise in a newspaper or gazette his or her application to the court and notify all interested parties.
6. After the advertisement has run for 14 days, the executor is given legal authority by the court to effect the Will maker's wishes.

7. The Executor must collect the property of the deceased and pay debts to those whom the Will maker owed money at the time of death.
8. The Executor must distribute the property of the Will maker to those whom the Will maker left property.
9. The executor must report back the out come of his or her activities to the court within six months of receipt of court authority.,
10. If the Executor misapplies or causes loss to the property of the deceased he can and may be taken to court by the concerned parties.

DYING INTESTATE

What step should be taken in the case of a person who died without making a Will? (Intestate)

1. The family of the deceased must inform the office of the Administrator General or the Chief Administrative Officer (CAO) in the district of the death of the deceased family member.
2. The family of the deceased must chose one person or more to apply to a court of law for letter of administration in order to manage the property of the deceased.
3. The chosen person or people must apply for a CERTIFICATE OF NO OBJECTION from the office of the administrator General.
4. The administrator after being introduced to the court presents the family of the deceased to the court.
5. The administrator is required to advertise in a newspaper or gazette his or her application to the court and notify all interested parties.
6. The administrator after being granted letters of Administration must collect the property of the deceased and pay debts to those whom the Will maker owed money at the time of death.
7. After the advertisement has run for 14 days, the administrator is given legal authority (Letters of Administration) by the court to manage the property of the deceased.
8. The administrator must distribute the property of the Will maker to those whom the Will maker left property.
9. The administrator must report back the outcome of his or her activities to the court within six months or receipt of Letters of Administration.

ADVANTAGES AND DISADVANTAGES OF WRITING AND NOT WRITING A WILL

The following table shows the advantages of writing a will and disadvantages of not writing a Will.

ADVANTAGES	DISADVANTES
The Will maker has peace of mind over the future, knowing that his or her wishes will be known after death.	A person who is dying without having made a Will may suffer anxiety over the future of his or her family, relatives and friends especially if aware that disputes normally arise out of

	inheritance issues.
The Will maker can provide for a husband or wife, children and dependant relatives according to what he or she feels will be the most suitable way.	The property is divided according to the amounts set out under the Succession law. All mentioned categories share in the estate automatically.
The family of the deceased knows where the deceased's property is, who owes the deceased money and whom the deceased owes money. This can help them to plan	The family of the deceased can only guess about the property and business details of the deceased, and may be tricked out of property by people claiming the deceased owed them money.
Young children can be well looked after by the person named as a guardian in the Will	Relatives and friends often neglect young children especially if their inheritance has been grabbed. They are often left to be looked after the widows/widowers, who may not have access to the deceased's property.
The Will maker can decide how he or she will be buried and the manner of burial, the time and place. This is important to some people who may wish certain things to be done in a special way at their burial	The law of Succession only applies to legally married wives and if a man and woman live together and are not married at the time of the deceased's death, he or she does not have a claim to the deceased's property unless she or he can prove dependency.

It is clear that a Will is the best way to safeguard your family's interests after death. In order to make it easier to write a will, a copy of a will form has been attached to this guide.

Important points to note when writing a will and the role MCG can play?

- I. It is an offence for anyone who is not legally given permission by a court of law to interfere with the management of the affairs of a deceased person.
- II. The residential holding of the deceased is not part of the property to be distributed. The person who has Letters of Administration holds this property on behalf of the legal heir.
 - a) The widow has a right to remain in the residential holding unless she remarries or freely chooses to leave the residential holding or if she does not occupy the residential holding for a continuous period.
 - b) A female child has a right to remain in the residential holding until he is 18 years, unless he stops living in the residential holding for a continuous period of six months.
 - c) A male child has a right to remain in the residential holding until he is 18 years, unless he stops living in the residential holding for a continuous period of six months.
- III All widows must share equally in the property of the deceased that is given to the wives, if they were legally married to the deceased under customary law or the Muslim religion, both of which recognize that a man may marry more than one wife.

- IV. All children of the deceased, whether born in or outside marriage, are entitled to share in the children's share of the property.
- V There are cases where a wife may have separated from her husband before his death for more than three months. If he dies without making a Will, she will not automatically be entitled to a share of his property.

However, she can apply within 6 months of the deceased husband's death to a court of law and show that she had a good reason for being separated from her husband and request to share in his property.

THE MEMORY BOOK

What is a Memory Book?

This is where important family history and precious childhood memories about both parents and the child is documented.

WHO IS IT FOR?

The Memory Book was originally designed to help parents record important information for their children when they were likely to become separated because of illness, death or marriage breakdown. At times of crisis there is a risk of children being moved from place to place and it is all too easy to break the thread of the family's history, to lose important contacts and for the child to be what really happened in the past. Filling in the pages of the *Memory Book* ensures that children have the facts in their parents' own words information which will be vital to them in years to come.

WHY DO IT?

The Memory Book will contain your words, your memories of your child, your hopes for his or her future. It is something tangible which you can prepare, so that whatever the future holds, the child will have the family history and the small but meaningful details which are so easily lost when there are major changes in the family's life.

A BOOK FOR EACH CHILD IN THE FAMILY

If you have more than one child it is important to make a *Memory Book* for each of them because, as they grow and move away, each of them will want their share of the memories. You can have extra copies made of shared information and photographs, but write separately the information which is personal to each child.

MEMORY BOOK FACTS.

WHAT TO INCLUDE

The most important ingredients in the *Memory Book* are the facts you provide about yourself and the early life of your children. There is space for historical facts, family stories and jokes, your hopes for your children's future, a family tree and maps, space to include addresses of people of your child might want to contact in the future – maybe a friendly neighbour or school teacher as well as the relations.

ABOUT THE FAMILY

THE FAMILY HISTORY (A full family history should include information on:

- Both the father and mother, including information about family background, growing up experiences, school days, work, interests, health, beliefs, hopes and fears.
- Brothers and sisters and other close relatives, including ages, present circumstances and addresses.
- Detailed information about the child you are writing for including facts about birth, early childhood and history up to date.
- A family tree showing how these people are related.
- Information about close friends and other important people in the family circle – with their addresses.
- If the Memory Book is being written because of a family crisis, illness or death of a parent, it is very important to explain what has happened so that the child will get accurate information, wherever possible in the exact words of the parents.

MODULE 14.0: ETHICAL ISSUES AND THE MALE CARE GIVER

SESSION ONE: ETHICAL ISSUES IN CARE GIVING

Learning Objectives:

At the end of the session the care giver should be able to understand:

- (a) The meaning of ethics;
- (b) The simplified pillars of medical ethics;
- (c) The importance of ethics.
- (d) An idea on some of the ethical dilemmas encountered in palliative care.

What is Ethics?

Simply defined ethics refers to a code of conduct in what ever profession. Doctors, nurses, lawyers, teachers, social workers, etc, all have a code of conduct that they follow during the practice of their profession.

Ethics are, agreed or commonly held rules that help any group of people to know how they should behave – a moral code of conduct.

Ethics are based on a system of values that are believed to be right and good, and discussions about ethics help us to make decisions, when two or more conflicting courses of action are possible.

The Four Pillars of Medical Ethics

1. Beneficence – to do good
2. Non-maleficence – do no Harm.
3. Autonomy – the patient’s right to make a decision.
4. Justice – being fair

These are the fundamental pillars of medical ethics. Community volunteer workers encounter ethical issues in their day-to-day work with clients, as part of the team looking after patients and their families.

Other important ethical principles:

- Confidentiality
- Truth telling
- Informed consent
- Integrity

Terminally ill patients have rights that need to be respected. Not all caregivers would agree on these rights. Community Volunteer Worker may have cultural or religious beliefs that lead them to make decisions which are different from the wishes of the patient. As a community care giver you might encounter situations that we could refer to as ethical dilemmas as given by the following examples:

(a) Patient’s Refusal of Treatment:

Some patients may refuse treatment even when they are mature, sane and the treatment has fully been explained to them. They may refuse treatment because they feel worse while taking it. That is their right and we must respect their wishes. However, there is always a reason why a patient might refuse treatment and it is your responsibility to explore more why they are refusing. The commonest reason to refuse is the patient’s failure to understand the importance of taking such treatment and this is common where the health worker has not taken a responsibility to explain the importance including the expected side effects.

(b) Withholding or Withdrawing Active Treatment

For many dying patients, active treatment (drips, major operations, etc.) may need to be discouraged because at this stage of the illness the body systems are very weak and may not be able to cope.

There are exceptions however: a patient with HIV/AIDS, for example may appear to be dying yet if managed aggressively, might improve. Therefore, it is very important to make a serious and informed judgment on whether to treat or not to. This judgment must come from a medically qualified member of the client's team.

(c) Euthanasia

Euthanasia is the act of killing someone who has an incurable illness, or assisting that person to die. This is sometimes referred to as "mercy killing". A patient might ask a doctor to help them end their life because they are finding it unbearable with uncontrolled suffering.

There are debates in many countries about whether euthanasia should be legalized. Some feel it is the right of the patient (autonomy) to choose whether to die, when they feel too much pain and suffering from an incurable condition. Others feel that it is unnatural and goes against God and society.

Patients who request euthanasia usually feel that they have a choice of either suffering in agony until death, or being spared the suffering by dying quickly and early.

The palliative care approach aims to allow a third choice: to alleviate the pain and suffering, under the care of Community care providers and the family. It allows the patient to spend precious time with loved ones, to calmly consider and accept the coming departure, and to say goodbye as they would wish.

(d) Confidentiality

Any information about a client, or which a client may share with you, should be kept confidential, unless the patient has given you permission to share that information with someone else. Without confidentiality, there is a danger of exposing the patient to being stigmatized and isolated, contributing to their pain, stress and general suffering.

If the patient gives you permission to share his or her experiences with others, you must do so in a way that does not reveal your patient's identity. You can do this by using "my patient" instead of using the name.

There are situations when confidentiality may be broken if:

- You feel that the patient may be in real danger and that you need to intervene by telling another party;
- You feel that the patient may cause themselves or others physical harm.

- By sharing the information it will benefit the patient's quality of life.

Before breaking confidentiality, you should get advice from your supervisors or other community volunteers.

(e) Integrity and Telling the Truth

As a community volunteer worker, it is important to maintain your integrity. This means that you need to be honest, and your behaviour should match what you say. If you promise to meet or visit a patient on a particular day, it is important to keep your appointment, and arrive on time.

If you are unable to go for a good reason, then you need to inform the patient and family as soon as you can. Honesty and keeping promises increases the patient's trust in you. Integrity also means that you must be trustworthy in whatever you are doing including keeping accurate records.

If a patient asks you a question that you cannot answer, it is better to say that you do not know, and promise to ask a health worker, than to tell a lie or pretend to know. Lies can be very harmful. As a community volunteer, you can support a patient by being present when he or she is being given difficult information, for example, when they are being told by the health worker that they have cancer or HIV/AIDS.

ETHICS: CASE SCENARIO

Instructions;

Split into groups for discussion of the case. You are the Community Volunteer looking after your allocated case.

For your case scenario:

- Try to determine which ethical principle(s) apply
- Discuss and decide on an ethical course of action or way forward
- Report back in an imaginative way, for example, role play or write a letter to one of the persons concerned (and read it to the other participants)

Case Scenario: Malibuttole

Malibuttole is a 30-year-old welder from Katwe. He has a wife, Monica, aged 26 and two daughters, Mumbajja (7) and Luusi (5) and twin sons, Wasswa and Kato (2).

Malibuttole was admitted in the local hospital with a severe headache and mild confusion. He was told he had Cryptococcal meningitis (which is found in AIDS). He left hospital without permission, and went home because of the bill. His neighbours call you in as the Community Volunteer. You discover the following facts:

1. He has known that he is HIV positive for 5 years now.
2. He has not told Monica, and he does not want her to know.
3. Malibuttole's brother working in Kenya has offered to send ARVs (AIDS drugs), but can only afford drugs for Malibuttole.
4. Monica is pregnant.

What ethical principles apply in Malibuttole's case?

Describe an ethical way forward for his case.

Answers for Case Scenario: Malibuttole

I. Autonomy (Patient's Right to decide):

Malibuttole's right to keep his diagnosis to himself. Related to this is Confidentiality: the Community Volunteer Worker's responsibility not to tell anyone about Malibuttole's diagnosis, without his permission.

2. Do no harm (non-maleficence):

- a. It will harm Monica and her unknown baby, if Monica does not know her HIV status or Malibuttole's status. If Monica knew that her HIV status was negative, she would practice safer sex by using a condom and likewise if she is HIV positive and does not know, then she will not seek treatment to prevent her baby from being infected (PMTCT)
- b. It may be harmful to Malibuttole's marriage if he tells Monica his HIV status now, more so when she discovers that he has known his status for five years but has not protected her or told her.
- c. It may be harmful for Malibuttole to receive ARVs from his brother without proper blood tests, planning and follow up.

3. Do good:

- a. It would be good if Monica knew her own HIV status, so that if she is HIV positive, she can seek care and treatment for herself and protect her unborn child from infection (PMTCT).
- b. It would also be good to know the status of all her children, so that the family can receive care and support together.
- c. It would be good if Malibuttole was encouraged to tell the truth to his wife, so that his relationship may be healed and open. They would need counseling through emotional hurts.

4. **Fairness/Justice:** If Monica and any of the children were also found to be HIV positive, it would not be fair for Malibuttole alone to receive ARVs.

Ethical way forward:

- Community volunteer can counsel Malibuttole personally tell his wife his status, or with the support of the CVW, or a health worker/counselor.
- If Malibuttole refuses, then the CVW can tell him that Monica still needs to know.
- Can refer Monica to an Antenatal clinic without telling her anything, where she should receive routine counselling and testing for HIV, and may know her status that way.
- If Monica discovers she is HIV positive, then she may be asked to bring her husband for testing, offering them both an opportunity to tell one another
- At all stages, Malibuttole and Monica must be supported and encouraged to tell each other the truth.

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MODULE 15.0: ALTERNATIVE THERAPIES

SESSION ONE: ALTERNATIVE THERAPIES AND HIV/AIDS

Introduction.

This topic relates to alternative therapies and HIV/AIDS issues. It is aimed at equipping male caregivers' knowledge on how to deal with HIV/AIDS related symptoms but more especially refer these clients to an experienced therapist. The male caregivers should be able to;

- (1) Describe and understand what alternative/complimentary therapies are.
- (2) Understand types and benefits of alternative therapies to PLWHA
- (3) Understand the barriers and challenges to alternative therapies.

15.1.1 Description, types and benefits of alternative therapy

Question I. What is alternative/complimentary therapy?

Question II: Define the different types of alternative therapy.

Question III. Mention benefits of alternative therapy to PLWHA

Alternative therapy descriptions, types and benefits.

Therapies considered alternative or complimentary to “western”- or allopathic medicine can include ingested natural substances or extracts, physical manipulation systems, culturally based medicinal systems, religious healing methods, and philosophical /meditative practices. Examples of alternative therapies can be found in acupuncture, yoga, homeopathy, aromatherapy, chiropractic, reflexology, meditation, spiritual healing and Traditional Chinese medicine.

Alternative therapy

- The term used to describe therapeutic practices that are not an integral part of conventional allopathic medical practice.
- Alternative systems of medical practice refers to types of health care ranging from self-care according to folk principles, to care rendered in an organized health care setting based on traditions or practice.
- Complimentary meaning along side the conventional practices
- Alternative meaning in place of conventional practices
- Designed to ' complement' our traditional services, complementary therapies are offered with the intention of improving the comfort and well-being of patients and family members.
- For health promotion, therapeutic treatment for chronic and acute illnesses, pain management and palliative care.

15.1.2.Types of Alternative/complimentary Therapy

Types of Complementary/alternative Therapy.

Like earlier shown there are different types of alternative therapies though one should bear in mind that treatments should be undertaken only after gathering information and discussing the treatment with their primary care provider. If possible one should discuss the treatment with those in similar circumstances who have utilized the same therapeutic method both recently and in the past, then explain to the client and the family members the importance of that therapy.

The different types include.

- **Aromatherapy** -involves the use of essential oils
- **Chiropractic**- Involves manipulation of bones to relieve pain.
- **Acupuncture** -Is a technique that uses stimulation by fine needles on specific points of the body to relief symptoms and improve energy levels.
- **Reflexology** -Is a system of manipulation of pressure points in the feet
- **Herbal Medicine** - Is a system of medicine that uses various remedies derived from plants and plant extracts to treat disorders and maintain good health (phytotherapy).
- **Homeopathy**- is a therapy based on the theory of treating like with like.
- **Yoga** – Is a system of adopting postures with related exercises designed to promote spiritual and physical wellbeing.
- **Meditation** - Is a sense of mental techniques used to relax a patient to facilitate deep reflection and clearing of the mind.
- **Spiritual Healing** - Is a system of healing, sometimes based on prayer and religious beliefs that attempts to tackle illness through non-physical means, usually by directing thoughts towards an individual that often involve laying of hands.

15.1.3 Effects/benefits of Complementary/alternative Therapy

Then one goes ahead to explain that alternative therapy has got different benefits to PLWHA in regard to the different symptoms that come with the disease especially stress and anxiety disorders that are diagnosed in up to 38% of HIV positive individuals (Elliot1998).

Symptoms of excessive anxiety include chest pain, headache, numbness and insomnia.

- It is through this integrated approach to complete care that these therapies play an important role in reducing symptoms and ultimately improve quality of life
- Positive Mental Attitude.
- Improved immune response
- Reduced symptoms

15.4.1 Barriers and challenges to alternative therapies

Question 1. What precautions should one bear in mind before administering these therapies?

Question 11. Mention challenges encountered with these therapies.

The precautions of alternative therapies.

Despite the benefits that come with administering these therapies, they have also got the don'ts that one has to be aware of before they start treating the client meaning that one should properly examine the patient. Below are the important conditions in which these therapies should be avoided and these include: -

- **Pregnancy**
- **Acute pain**
- **Chemotherapy that the patient is receiving**
- **Conditions.**

15.4.2 Challenges of alternative therapy.

These challenges come especially from lack of enough scientific backing since most scientists have not so much been interested and ignorant about these therapies and these include: -

- Failure to treat the diagnosed problem but instead deals with symptoms.
- Costly form of therapy since most of the health insurance schemes do not cover them.
- Limited proper source of information since there is little research to back the practices.
- Limited numbers of well-trained personnel to administer the treatment.
- People's attitudes towards the practices.

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SESSION TWO: USE OF TRADITIONAL MEDICINE IN HIV/AIDS 15.2 THE ROLE OF TRADITIONAL MEDICINE IN HIV/AIDS

Introduction:

This is intended to equip THPs including MCGS with comprehensive knowledge and skills to integrate biomedical knowledge of HIV/AIDS with emphasis on PMTCT, VCT, ART, TB, CB – DOTS

What is Traditional Medicine (TM)

It is the sum total of the knowledge, skills and practices based on the theories, beliefs and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illnesses (WHO)

Definitions Cont'd

- Traditional Health Practitioner (THP)
- One recognized by his community
- Uses indigenous knowledge handed down from generation to generation orally and or through spiritual means
- To alleviate all forms of human suffering

Some of the major types of THPs include;

- Herbalists
- Spiritualists
- Bone-setters
- Traditional Birth Attendants
- Diviners

NB: Many healers belong to more than one of the above types.

- Studies and surveys show that the majority of the terminally ill in the rural communities found at THPs workplaces were transferred from urban areas.
- The cost of accessing Palliative care services from modern health care providers in rural areas makes it not even an option for most families in rural areas

Important to note in traditional medicine are safety & efficacy issues:

- Some medicinal plants like worm wood, Garlic Asafeotida, sopium ellepticum, warbugia ugandensis and so many others have been known to treat various diseases for many decades
- These same plants have been used to extract some important ingredients for treatment of various diseases.
- For instance, worm wood is used in production of Artemether for treatment of Malaria fever, yet it is used in treatment of cough as well as a dewormer.
- Extracts have limited scope of diseases to treat where as the natural form treat a number of infections.

- Medicinal plants contain natural corticosteroids that users say have less side effects compared to conventional medicines.

MCGs must note that Herbal Packaging & Processing (HPP) exist; in Uganda for example THETA has;

- New protocol tested for skin rash, oral thrush, persistent cough & Malaria
- THETA ensures availability and accessibility of tested products:
 - Dissemination
 - Marketing
 - IP rights

Different forms (preparations) for herbal medicine

- Ointments
- Tinctures
- Powder
- Syrups
- Oils
- Soap

The role of herbal medicines in HIV/AIDS

- Treatment/ Curative (OIs) Some herbal preparations have been found effective in the management of opportunistic infections like cough, Herpes zoster, skin rash, chronic diarrhea and Malaria. Examples include; Albizia coriaria, psorospermum februgum, solanum dulcamera, Aloe vera)

Benefits for Herbal Medicine use that MCGs should note:

- Nutrition - Many plants have both medicinal & nutritional values (Carrisa edullis, Abelmoschus esculentus, Lycopersicon esculentum, Amaranthus dubius, Rhus vulgaris, Physalis peruviana, Solanum indicum)
- Management of side effects of allopathic drugs; e.g. patients on ARVs use herbs for skin complications, fevers e. t. c

Role of MCGs in HIV and AIDS:

Once MCGs are trained by technical persons they can;

- Offer on-going counselling to patients
- Offer treatment adherence support
- Offer nutritional advice & give physical support
- Assess their conditions & effect referrals to BHP
- Offer improved PC services to the communities around them

NOTE: Traditional medicine is instrumental in complementing efforts of conventional medicine and it is high time the health workers recognized this role

MODULE 16.0: WORKING WITH COMMUNITIES: REFERRALS AND NETWORKING

SESSION ONE: EXISTING REFERRAL AND NETWORK SYSTEM FOR PALLIATIVE CARE REFERRALS, FOLLOW UP AND NETWORKING

Objectives:

By the end of the session participants should be able to:

- Discuss the different needs of PLWHA and their families which require networking and referrals
- Identify available services where PLWHA can be referred for holistic services
- Identify challenges for networking and referrals and strategies for improvement
- Discuss basic information that should be included in a referral form/tool
- Discuss the importance of networking and referrals

Introduction:

Through knowledge of services available to PLWHA, community based male care givers can make a significant contribution to facilitating access to comprehensive palliative care services in their communities, and countries. They can undertake appropriate referrals of patients and their families to services that can meet their holistic needs.

- **Referral:** Is a process by which individual's need for comprehensive care are assessed and helped.
- **Follow up:** To receive feedback on service and care given e.g. did the patient go where he/she was referred or was the patients needs met?
- **Continuum of care:** Is the need of the patient and family span to continue with the care.
- **Networking:** Refers to groups of individuals or organizations working together to achieve a common goal

Referrals for PLWHA can be made to the following services:

Post-Test Clubs Post-test clubs and peer support groups offer a private and safe space to help people with HIV by sharing experiences and providing mutual support. Post-test clubs are usually centred around HIV Testing and Counselling services and provide ongoing counselling and support for people after they have used the services.

Peer Support Groups - Peer support groups are a safe environment for PLWHA to discuss their situation with others that understand and empathise with what they are going through. Peer support groups play an important role in discussions surrounding sex and sexuality as PLWHA feel they are in a confidential and safe environment.

Male care givers should suggest involvement in peer support groups for:

- Clients who have tested HIV positive
- Couples affected by HIV/AIDS
- Older children whose parents are positive

Community-based Care, Support and Prevention services: these are care, support and prevention services in the community such as:

Other available auxiliary services

- Home based care services
 - Support groups for people affected by HIV/AIDS
 - Religious support groups
 - Orphan care and support programmes
 - Income generating activities
 - School support programmes
 - Food assistance programmes
 - Adherence support groups

Screening and Treatment of Sexually Transmitted Infections (STIs):

Screening and treatment of STIs with testing, counselling and treatment of HIV is a key area of positive prevention. Male care givers should inquire about the following symptoms of STIs and refer PLWHA to a health facility if present:

- Vaginal discharge
- Bleeding between periods
- Genital or anal sores or cuts
- Anal pain, burning, discharge, or bleeding
- Lower abdominal pain with or without fever in women

Male care givers play an important role in referring clients to clinics and hospitals where ART treatment is available and supporting adherence to ART.

Other services where referrals can be made:

- Counseling services
- Child care services
- Financial Support
- Legal support i.e. FIDA
- Post exposure Prophylaxis
- PMTC
- Clinical care
- Education/Schooling
- STI service
- TB service
- Prevention service
- Material support
- Hospice

THE IMPORTANCE OF NETWORKING & COLLABORATION

- Leads to better patient management
- Increases effectiveness of the work of a care giver
- Gaps in services can be identified and addressed through networking with other organizations
- Knowing and supporting each other
- Sharing of patients care
- Allows prompt treatment, for cases that cannot be provided by the referring person/organization
- Prompt care in the community
- Patients benefits from comprehensive care
- Reduce duplications and services

Information to be included in the outgoing referral form

Referring facility's details

- Names, address of the organization

Patient socio-demographic information

- Age
- Sex
- Name (optional)
- Patient's address

Brief medical history

- Patient's complaints/symptoms
- Treatment given so far
- Working diagnosis if available
- Referral service requested
- Investigations done and findings if available

Other details

- name and signature of the referring person
- Date of referral
- Consent from patient and family
- **Referral response/ follow-up section**
- Investigations done
- Treatment given
- Diagnosis
- Remarks
- Name and contact details of officer receiving referral
- Date and signature

A good and successful referral

- Identify the condition that requires attention.
- Offer counseling by talking and listening if patient is suffering from psychosocial problem
- If the problem is physical find out if it can be treated at home or hospital.

- Help the patient choose the most suitable service

How to work together

- Meetings and visits
- Understand and appreciate the importance of each other
- Use referral forms
- Explain to the patient the reason for referral
- Together identify gaps and challenges

Barriers to referrals, networks follow-ups and collaboration

- Lack of mutual respect
- Language barrier
- Difference in the modes of treatment administration
- Different views/attitude
- Lack of coordination of other service providers

Problems when referrals are made

- Lack of drugs and medical supplies
- Distance to the health facility creating transport issues
- Lack of mutual respect on part of health workers
- Inadequate information content on referral forms

Summary of key points

- Referrals, follow-ups, Networking and collaboration are crucial in medical field
- These mentioned above are tips to achievement of quality care for the patient and family as these addresses the patient and family not only physically but as a whole being thus, physically, Psychologically, socially and spiritually

An example of a referral form is included in the appendices.

SESSION TWO: COMMUNITY MOBILISATION

Learning Objectives

- Understand the importance of community mobilization
- Identify effective methods of community mobilization
- Identify different communities for specific purposes
- List the barriers to effective community mobilization

What is community Mobilization?

Community mobilization is a process of capacity building through which community individuals, groups or organisations plan, carry out and evaluate activities on a participatory and sustainable basis to improve their health and other needs, either by their own initiative or with stimulation from an external source.

Key tasks involved in successful community mobilization include:

- Developing continuous dialogue between community members regarding issues affecting them
- Creating and enhancing community structure aimed at improving community functioning in all aspects.
- Helping in creating an enabling environment, individuals can empower themselves to address self and community challenges.
- Encouraging and promoting community members' participation in ways that bring about respect for diversity and equity, particularly of those most affected by the problem at hand.
- Operating in partnership with the community members and their structures in all phases of the project to create appropriate responses to the problems at hand.

Identifying and supporting community innovations and potentials in order to come up with a variety of strategies and approaches to problem solving.

Helping communities to access external resources to aid the efforts to improve their quality of life.

Refer to handout from facilitator:

MODULE 17.0: MONITORING AND EVALUATION

SESSION ONE: INTRODUCTION TO M&E, DOCUMENTATION AND REPORTING

Monitoring, Evaluation and Reporting (MER)

Learning Objectives

This module is intended to avail participants with key learning information to about monitoring, evaluation and reporting in palliative care programmes including HIV/AIDS prevention and care programmes.

At the end of this Module & sessions, participants will be able to:

- Understand MER concepts, approaches and tools for intensive and participatory monitoring and evaluation of palliative care programmes.
- Learn about how to document and report outputs and outcomes arising from the implementation of palliative care interventions.
- Identify key stakeholders in MER, and the barriers to conducting effective programme MER and also devise ways of overcoming such barriers.

- Be in a position to undertake basic palliative care monitoring and evaluation using appropriate methods and tools taking into consideration your donor, country, site, and government requirements

The following illustrates the roles and responsibilities at each level/approaches – Note MCG should be able to appreciate these and see where they fit in, within M&E

Implementing Agencies (e.g. Hospices)

- Formative needs assessment
- Monitoring of inputs, process, and outputs
- Collecting and aggregating data from frontline project personnel (e.g., peer educators, outreach workers, and home-based care volunteers)
- Feedback of results to target populations
- Reporting to sponsors and partners
- Using results for ongoing program implementation

Country Offices of Collaborating Partners (e.g. APCA)

- Formative needs assessments
- Aggregating and synthesizing results from all implementing agencies
- Coordinating M&E activities across projects
- Feedback of results to communities and target groups
- Reporting to donors (based on reporting requirements)
- Reporting to government agencies as required
- Providing support and technical assistance for district-, regional-, or national-level M&E activities (e.g., behavioral studies and biologic surveys)
- Disseminating results
- Using program results for ongoing program implementation and advocating for required policy changes

National Level (e.g. MoH)

- National formative needs assessment
- Aggregating results from collaborating partners
- Providing feedback to collaborating partners and implementing agencies on results of M&E activities undertaken by the government
- Maintaining ongoing biologic and behavioral surveillance system
- Using M&E results to advocate for policy formulation and changes

Case Study: Men Care Givers Local Chapter against HIV/AIDS

The Men Care Givers Local Chapter against HIV/AIDS has received funds from APCA to ensure that people living with HIV/AIDS in the community get all the care and support they need to live positively. Some of their activities include training more family carers, 'capable/expert patients, sensitisation of the community, providing physical care and support to patients, advocacy and spiritual support.

Goals, Objectives and Questions in MER

Goals and Objectives

The core of any M&E system is the **goals** and **objectives** of the programme to be monitored, evaluated and reported upon.

What is the difference between a goal and an objective?

- **Goal**—General statement that describes the hoped-for result of a programme (e.g., increased quality of life for patients through pain reduction, reduction of HIV incidence). Goals are achieved over the long term (5–10 years) and through the combined efforts of multiple programs.
- **Objective**—Specific, operationalized statement detailing the desired accomplishment of the programme. A properly stated objective is action-oriented, starts with the word “to,” and is followed by an action verb. Objectives address questions of “what” and “when,” but not “why” or “how.” Objectives are stated in terms of results to be achieved, not processes or activities to be performed.

SMART Objectives

Programme or project objectives have to be ‘SMART’ and this means the following: -

S — Specificity — Is it specific? Does it cover only one rather than multiple activities?

M — Measurability — Can it be measured or counted in some way?

A — Attainability — Is the objective actually doable? Can we achieve this goal?

R — Relevance — How important is this objective to the work that we are doing? How relevant is it to achieving our goal?

T — Time — Does the objective give a timeframe by when the objective will be achieved, or a timeframe during which the activity will occur?

Indicators are clues, signs, and markers as to how close we are to our path and how much things are changing.

Examples of indicators for a palliative care programme: -

of health workers trained in pain and symptom management in the last 3 months

of trainings conducted in last 3 months

Documentation and Reporting, and stakeholders

Documentation of project activities takes different forms in different settings. There is no superior way of documenting project results, challenges and lessons learnt. The most appropriate documentation method depends on the organisations resources but a combination of methods can be effectively used to document and report.

Group Work: Documentation

Using the case scenario seen earlier (**Case Study: Men Care Givers Local Chapter against HIV/AIDS**) discuss possible ways of documenting results, challenges and lessons learnt from this particular project. If time allows, let them also discuss the possible benefits of undertaking proper documentation and reporting for a project like that.

Different forms of documentation and Reporting

- Compilation of reports (Written progress reports/updates, stories)
- Written performance/evaluation reports
- Compilation of brochures/pamphlets/leaflets
- Visual presentations (video shows, films, etc.)
- Making of oral presentations
- Discussion sessions
- Informal contacts
- Press and media releases
- Formal academic papers, books & articles
- Internet, e-mails and websites

Reporting/Feedback

Project activity data normally flows from activity implementers to (field) to other stakeholders or the other way round on regular basis (monthly or quarterly) using standardized tools/approaches as indicated above. In addition, regular monthly or quarterly reports are produced to feed databases. Mechanisms for regular feedback to all stakeholders are usually established through regular reports and dissemination workshops. Simplified policy statements can also be made out of the M&E reports to inform policy and management decisions.

However, M&E often tends to be demand-driven, i.e. with requests from 'others' for information/data. It also often becomes a process of information collection with little understanding of the motivation behind it. The information collected (data, stories, etc) needs to be of use and used by whoever collects it in order for it to be meaningful.

If M&E information is understood, owned and analyzed at each level before it is passed on it has a lot of potential to bring about shared learning.

**Stakeholders Identification, Information needs and reporting requirements
(see table below)**

Example: Stakeholders identification, documentation of Information needs & reporting requirements for the Mens' Caregivers Project

Audience	WHAT data they need from Project	WHY they need the data	WHEN they need the data from Project	HOW data will be provided
Staff members	<ul style="list-style-type: none"> • Updates on project activities • Updates on financial issues. • Lessons learned 	<ul style="list-style-type: none"> • For planning and implementation • For motivation and corporate identity 	<ul style="list-style-type: none"> • Weekly, monthly • On-going basis e.g. meetings and as appropriate 	<ul style="list-style-type: none"> • Meetings • Workshops/Presentations • Monthly reports • Periodic updates
Member organisations	<ul style="list-style-type: none"> • Periodic reports • Update on progress • Membership information e.g. constitution etc. 	<ul style="list-style-type: none"> • To monitor the efficiency and effectiveness of the project, services and impacts. • To provide guidance. 	<ul style="list-style-type: none"> • Quarterly • Annually 	<ul style="list-style-type: none"> • Quarterly reports • Teleconferences • Meetings • Quarterly newsletters
Donors	<ul style="list-style-type: none"> • Progress of grant activities • Results of grant activities • Financial data • Lessons learned 	<ul style="list-style-type: none"> • To approve transfer of funds. • To monitor project progress. • To learn about project impacts. • To monitor and evaluate their project. 	<ul style="list-style-type: none"> • As per requirements • End of programme (final evaluation). 	<ul style="list-style-type: none"> • Financial reports/statements • Reports • Teleconferences • Meetings
Media/ General Public	<ul style="list-style-type: none"> • Press releases re project results • Briefings re palliative care and relevant information 	<ul style="list-style-type: none"> • To inform them about the work of male care givers • To raise awareness re men's' role in care-giving 	<ul style="list-style-type: none"> • As appropriate • Quarterly 	<ul style="list-style-type: none"> • Manuscripts(Articles), Abstracts , Press releases • Oral/poster presentations
Patients/ Beneficiaries	<ul style="list-style-type: none"> • Services available from male caregivers • Support linkages • Project results 	<ul style="list-style-type: none"> • To learn more about how men can provide care to PLWHA • To raise awareness re men's' role in care-giving 	<ul style="list-style-type: none"> • As appropriate • Quarterly 	<ul style="list-style-type: none"> • Meetings, Workshops, stories, reports/updates & newsletters

Monitoring and Evaluation Methods and Tools

Methods for Monitoring and Evaluation

What do we mean by methods? These methods may be *quantitative* or *qualitative*.

Common Methods used in M&E: -

- Surveys - using questionnaires
- Documents reviews - Implementation Reports, peer educator activity sheet
- Focus Group Discussions – using FGD guides
- Interviewing – using interview guides
- Site visits/Observation – using observation checklists
- Support supervision – using referral review/client referral form
- Review of training/training sign in sheets/tally forms/evaluation forms
- Reviewing other monitoring forms/tools eg IEC materials distribution logbooks/forms

Tools for Monitoring and Evaluation

Whereas a **method** refers to the scientific design or approach to a monitoring, evaluation, or research activity, a data collection **tool** refers to the instrument used to record the information that will be gathered through a particular method.

Some common *quantitative* M&E tools include: (These can be used by MCGs)

- Sign-in (registration) logs
- Registration (enrollment, intake) forms; checklists
- Program activity forms
- Logs and tally sheets
- Patient charts
- Structured questionnaires

Examples of *qualitative* M&E tools include:

- Focus group discussion guide
- Direct observation checklist
- In-depth interview guide

Appendix I: Sample Monitoring and Evaluation Tools

A) Male Caregivers Project - Training Check-list

Country: Time period

Facilitator/Trainer.....

Date.....

No	Activity to be monitored	Output #	Comment
1	Number of training sessions conducted	e.g. 3 trainings conducted	
2	Number of people/health workers trained Category: - 1. Doctors..... 2. Clinical Officers..... 3. Nurses..... 4. Local leaders 5. Social Workers 6. Others.....		
3	Number of participants completing training		
4	Topics covered in training		
5	Number of partners involved in the trainings		
6	Number of TOTs trained to train others		
7			
8			
Total			

B) Male Caregivers Project – Patient Registration Check-list

INSTRUCTIONS

A copy of this check-list must be completed for every patient visited or cared for by a male care-giver.

1. Country _____ 2. Caregiver's Name _____

3. Site _____

PATIENT SOCIO-DEMOGRAPHIC DATA

4. Patient name _____ 5. Date _____

6. Age

7. Gender Male Female

8a. How many members are there in the household (including yourself)?

8b. Of the total number in Q.9a, how many are children under 18?

8c. Of the total number in Q.9a, how many are dependents (over 18 yrs old) are there?

PATIENT CLINICAL RECORD

9. Is this the first time ever this patient has been seen as part of the Men's Caregiver project (please check and complete your 'New Patients' form)

Yes, the patient is *new* to the Men's Caregiver project.

No, the patient has been seen before as part of the CHAT project.

10. If NO in 9 above, this is visit number: 1 2 3 4 5 6

11. Is the patient infected (presumed or diagnosed) by HIV / AIDS? Yes No

Over the last one **month**, has the patient:

12. Received support and care from male care givers at home or at health facility? Yes No

APPENDIX 2: SAMPLE WILL FORM

1. The last will of(Name(s))
 (Physical & Postal address)

This.....day ofyear.....

Make this will and revoke any former wills made by me.

I have made this will voluntarily while of sound mind

i. Father’s name.....

ii. Mother’s name.....

iii. Grandparents.....

a. maternal.....

b. Paternal.....

iv. My clan is.....

v. My tribe is.....

vi. My religion is.....

2. a) I was born on the.....day
 of Month.....year, at.....village/Town.....

Sub-county.....

District.....

My home district is.....

Village/town.....county.....

.....

Signature/Thumbprint

Date

3. a) I am

Married

Single

Widowed

Divorced

Separated from my husband/wife

Other (please specify).....

(Answer this section if you are legally married)

b) The names of my husband/wife (wives) ~~cancel~~ whichever does not apply):

1)

2)

c) We got married as follows; (state the time and place e.g. church/mosque/place of customary marriage where ceremony took place).

i. On, (date) at.....(place)

In the case of a man who has more than one wife, please fill in details

On, (date) at.....(place)

On, (date) at.....(place)

On, (date) at.....(place)

.....
Signature/Thumbprint

.....
Date

d) I am married/divorced/separated from my wife/husband named (cancel whichever does not apply)

- Married
- Divorced
- Separated
-

4. a) These are my children:

NAMES	SEX	DATE OF BIRTH	NAMES OF MOTHER/FATHER
1.			Father..... Mother.....
2.			Father..... Mother.....

Add lines or use back page

.....
Signature/Thumbprint

.....
Date

b) These are my dependants; (these should be relatives or other people whom you would like to provide for in your will)

	FULL NAME	RELATIONSHIP	ADDRESS/RESIDENCE
I.			
II.			
III.			

SECTION TWO

5. I have chosen.....(specify the name) as my Executor(s)
Executrix(es)

6. I have chosen. (cancel whichever does not apply) my
son/daughter/grandchild/brother/sister/other ^{9specify} the
name).....to be my heir/heirress.

7. Appoint the following person(s) to be guardian(s) of my young children

NAMES OF GUARDIAN	ADDRESS OF GUARDIAN	NAME OF CHILD
1.		
2.		

8. I have acquired the following property:

PROPERTY	PARTICULARS	LOCATION

.....

Signature/Thumbprint

.....

Date

9. I give my property to the following:

Note: My principal residence located at

And all properties in it shall remain with my spouse and my children who are currently residing therein.

FULL NAMES	RELATIONSHIP	PARTICULARS OF PROPERTY GIVEN	CONTACT ADDRESS

10. a) I want my property to be distributed by my executors (executrix as follows;
(write in this space if you have any special conditions for distributing your
property)

.....

b) My property I have given to my children below the age of 21 years will/will not be distributed to them immediately. It will be dealt with as follows: (cancel whichever is not applicable.) (If you wish, you may leave guidelines for your wife/husband, executor(s) or your children's guardians on how to maintain the property for the children until they are of age.

.....

.....

Signature/Thumbprint

Date

c) I am self employed (give details).....

.....

d) I am employed by:.....

Name of employer.....

Address.....

as on.....(date) at(place)

(Position of employment)

(Position of employment)

11. a) I have the following bank account(s):-

ACCOUNT NO.	TYPE OF ACCOUNT	BANK BRANCH

b) I have a shareholding / interest in the following business:

NAMES AND ADDRESS OF BUSINESS/COMPANY/INSURANCE POLICY	PERCENTAGE OF SHARE HOLDING/INTEREST

NSSF no.....

PROVIDENT FUND NO.....

.....

.....

Signature/Thumbprint

Date

12. I have the following creditors/debtors

	CREDITOR'S NAME AND ADDRESS	PARTICULARS	AMOUNT OWING
I.			

2.			
----	--	--	--

DEBTOR'S NAME AND ADDRESS	PARTICULARS	AMOUNT DUE
1.		
2.		

13. I wish to be buried at.....
 Village/town.....
 Sub-county.....
 District.....
 County.....

13. Any other information/wishes related to your funeral ceremony or any other matter not previously mentioned.

.....

Signature/Thumbprint

Date

14. Any other information/wishes related to your funeral ceremony or any other matter not previously mentioned.

.....

Signature/Thumbprint

Date

I.....HAVE MADE
 THIS WILL WHILE OF SOUND MINDTHIS.....DAY OF
 (MONTH).....(YEAR)
 NAMES.....

.....
Signature/Thumbprint

.....
Date

WITNESSES
WITNESS NO. 1

Full Names:
 Postal Address:
 Residential Address:
 Occupation:

Signature/Thumb

WITNESS NO. 2

Full Names:

Postal Address:

Residential Address:

Occupation:

Signature/Thumbprint

Date.....Day of(Month).....(Year)

EIGHT DAY PILOT PALLIATIVE CARE TRAINING FOR MALE CARE GIVERS: ZAMBIA, UGANDA AND KENYA APRIL – MAY 2008

Day 1 Monday 28	Day 2 Tues 29	Day 3 Wed 30	Day 4 Thurs 1	Day 5 Frid 2
8 – 8.30 am Registration	8 – 8.30 am Review of day 1	8 – 8.30 am Review of day 2	8 – 8.30 am Review of day 3	8 – 8.30 am Review of day 4
8.30 – 10.00am - Self introductions - Official Opening – Dr. Faith MP - Course expectations, objectives, assessments - Ground rules- Rose & Fatia	8.30 – 10.30 am Communication & counselling adults <i>incl. role plays</i> Rose N	8.30 – 10.30 am Basic principles of pain assessment and management Rose K	8.30 – 10.30 am HIV/AIDS & nutrition in adults Hanifa N	8.30 – 10.30 am Care for people with special needs in HIV/AIDS Mr. Ojapen J.M
10 – 10.30 Tea Break	10.30 – 11.00am Tea	10.30 – 11.00am Tea	10.30 – 11.00am Tea	10.30 – 11.00am Tea
10.30 – 11.30am Introduction to the Hospice & Palliative care concepts Rose K 11.30 – 1.00 pm Models of Palliative care delivery Fatia K Questions and discussion	11 – 12.00pm Communication & counselling children <i>incl. role plays</i> Rose N 12 – 1.00 pm Breaking bad news Fatia/Rose	11 – 12.00pm Management of common OIs Dr. Kambu 12 – 1.00pm Management of common STIs Dr. Maria Nanyonga	11 – 12.00pm Nutrition in children Dr. Jennifer 12 – 1.00pm Alternative therapies in HIV/AIDS and use of traditional medicine Isac Kasozi	11 – 12.00pm Spirituality Fatia K 12 – 1.00pm Sexuality in palliative care Rose K
1 – 2.00pm Lunch	1 – 2.00pm Lunch	1 – 2.00pm Lunch	1 – 2.00pm Lunch	1 – 2.00pm Lunch
2 – 3.00pm Concept of care giving among men: <i>Group discussions & feedback</i> Rose K	2 – 3.00pm Disclosure in adults Dr. Musoke	2 – 3.00 pm ART in adults: principles and management- Evelyn Eleku	2 – 3.00pm Ethical principles and good qualities in care giving Fatia 3 – 4.00pm Gender issues in HIV/AIDS Rose	2 – 3.00pm Common Legal issues in HIV/AIDS Hawa/Fatia 3 – 4.00pm Succession planning: Will making, memory book etc Mr. Waguti
3 – 4.00pm Basic facts on HIV/AIDS – Incl. VCT, PMTCT & role of male care givers- Dr. Musoke	3 – 4.00pm Disclosure in children Rose N	3 – 4.00pm ART in children: principles and management Dr. Jennifer S		
4 – 4.20pm Tea	4 – 4.20pm Tea	4 – 4.20pm Tea	4 – 4.20pm Tea	4 – 4.20pm Tea
4.20 – 5.00pm Basic HIV/AIDS facts contd. - Positive Living - Stigma & discrimination Richard Serunkuma	4.20 – 5.00pm Role plays: Breaking bad news and disclosure issues	4.20 – 5.00pm Group discussions: ART challenges in communities, the role of male care givers etc	4.20 – 5.00pm Cultural sensitivity in care giving Fatia	Domestic violence in HIV/AIDS William Mulindwa

EIGHT DAY PILOT PALLIATIVE CARE TRAINING FOR MALE CARE GIVERS: ZAMBIA, UGANDA AND KENYA APRIL – MAY 2008

Day 6: Practical Day Mon 5	Day 7 Tues 6	Day 8 Wed 7
8 – 8.30 am Review of day 5	8 – 8.30 am Review of day 6	8 – 8.30 am Review of day 7
8.30 – 10.30am Basic Nursing care & activities of daily living: <ul style="list-style-type: none"> - Wound care - Mouth care - Bed bath Beatrice & Rose 	8.30 – 10.30 am Grief, loss and bereavement in adults Rose Nabatanzi	8.30 – 10.30 am Existing referral, networks and community mobilisation for palliative care: <i>Open discussion</i> Juru/Rose
10 – 10.30 Tea Break	10.30 – 11.00am Tea	10.30 – 11.00am Tea
10.30 – 1.00pm Nursing care contd. <ul style="list-style-type: none"> - Bed making - Positioning/lifting/transfer - Pressure area management - Skin care Beatrice and Rose	11 – 12.00pm Grief, loss and bereavement in children Rose Nabatanzi/Mildmay 12 – 1.00pm Cultural issues relating to death: Group discussions and feedback Richard Semanda	11 – 12.00pm Monitoring and evaluation of services: documentation, reporting, tools etc Richard Kaye/Juru 12 – 1.00pm Evaluation of the pilot training and key recommendations
1 – 2.00pm Lunch	1 – 2.00pm Lunch	1 – 2.00pm Lunch
2 – 4.00pm Nursing aspects contd. <ul style="list-style-type: none"> - Toileting – urinary, faecal incontinence - Breathlessness - Support with medication Beatrice and Rose	2 – 4.00pm Preparing the patient and family for death Berna Basemera	2 .00pm - Closing remarks - Presentation of certificates - Departure Someone from Ministry of Gender if possible
4 – 4.20pm Tea	4 – 4.20pm Tea	
4.20 – 5.00pm Infection control: Universal precautions, Post exposure (PEP) Beatrice Juru	4.20 – 5.00pm Stress management among male care givers and the role of male support groups Berna Basemera : <i>Group discussions</i>	