SEXUALITY ISSUES IN PALLIATIVE CARE

WHAT IS SEXUALITY?
OBJECTIVES

By the end of this unit the participants will be able to:

• Describe sex, sexuality and sexual health.
• Explore self awareness on sexuality.
• Discuss client concerns in relation to sexual functioning.
Overview on sex and sexuality

• In Kenya, culture strongly influences sexuality perspectives.

• To provide holistic care to HIV/AIDS and cancer patients, we need to understand that sexuality *influences* and is *influenced* by the biological, psychological, sociological, and spiritual aspects of being.

• Our patients do not leave their sexuality behind when they seek our services.
• Sexuality, which is central to patients’ quality of life, remains unattended to by health professionals, intervening professionals, and family carers.

• Many health care workers (HCWs) do not consider the patient’s sexual health until the patient brings it up.

• This is perhaps due to the fact that sexuality is a private issue in most cultures, and even more so in African cultures.
DEFINITIONS-

• The words **sex** and **sexuality** are used—interchangeably and often incorrectly—to define the different aspects of sexual being.

• The word **sex** is commonly used to identify biological male or female status.

• Sexual intercourse is the physical activity in which people express their emotions, feelings---e.g. by touching.
SEXUALITY

• **Sexuality** pertains to all those things that relate specifically to being male or female.

• Sexuality is intimately associated with gender, image, self esteem, ego and a sense of being.

• It is a process of giving and receiving sexual pleasure, a feeling of belonging, being accepted, Loved and valued.
• It involves more than sexual desires, activity and orientation.
• It encompasses touching, intimacy, and the physical closeness of others, and can be an expression of warmth and caring, relationships and gender roles.
• Sexual intercourse is not the only defining characteristic of a person’s sexuality.
SEXUAL HEALTH

• A process of having maximum quality of life and satisfaction as male or female even in the face of a life limiting illness.
• A patients basic sense of confidence and self esteem may be under stress during a life threatening illness.
• Unmet sexual needs can be a great distressing symptom in terminal illness, impacting negatively on quality of life.
Model of Quality of life

- Physical Well-Being
- Psychological Well-Being
- Social Well-Being
- Spiritual Well-Being
Physical
- Functional Ability
- Strength/Fatigue
- Sleep & Rest
- Nausea
- Appetite
- Constipation
- Pain

Psychological
- Anxiety
- Depression
- Enjoyment/Leisure
- Pain Distress
- Happiness
- Fear
- Cognition/Attention

Social
- Financial Burden
- Caregiver Burden
- Roles & Relationships
- Affection/Sexual Function
- Appearance

Spiritual
- Hope
- Suffering
- Meaning of Pain
- Religiosity
- Transcendence

Quality of Life

Adapted from Ferrell, et al. 1991
Sexual Orientation

- Refers to whether a person is attracted to a person of the opposite sex (heterosexuality) or the same sex (homosexuality) or both (bisexuality), and whether a person feels that his or her gender role (male or female behaviour) is consistent with his or her biological sex (male or female).
Self Awareness

• HCWs need to be able to deal with issues of sexuality before they can help their patients.
• Developing awareness of our own feelings about sexual organs, relationships, and roles contributes to understanding and self-comfort.
• Those who are comfortable with their own sexuality will be more comfortable with another’s.
Awareness continued…

• HCWs need to reflect and learn to assist others from their own cultural /practical experiences.

• Provide information about potential sexual problems to their patients more frequently.
Barriers to sexual Health in the P/C and ELC Settings

• Attitude regarding sexuality-private issue.
• Individual values, ethics, cultural and religious convictions/inhibitions
• Limited literature on studies done on the subject.
• Lack of communication skills by the HCW - discomfort in addressing the issues.
• Gender- based double standards
Barriers Cont.

- Assumptions- ”sick people are not sexual”
- Environment and setting- lack of privacy to touch, hold, kiss
Preparing Health Professionals to Address Patient Sexual Needs

• HCWs need to allow their patients the opportunity to express the physical and emotional pain of their sexuality.
• A debate on sexuality in HIV/AIDS needs to be raised in open forum, through appropriate media.
• Good role models among men should be identified and invited to assist in raising awareness among other men.
• There is need to create openness around sexuality in life-threatening illness.
CONT.

- Discussing the issue with colleagues,
- Sharing experiences of working with patients having such discomfort,
- Identifying those colleagues who feel comfortable discussing sexuality,
- Acknowledging cultural aspects in the work setting,
- Agreeing on ways to facilitate communication with a patient or partner regarding issues of sexuality, and
- Follow-up to review and reflect on any new approach to sexuality.
CONT…

• Appropriate questioning-
  How has your illness affected your relationship with your spouse?

Do you feel your sexuality has changed from the time of diagnosis?
COPING MECHANISMS

Research suggests that many HCWs receive inadequate training, so they are embarrassed to discuss sexual issues and feel the issues are irrelevant to illness. Nurses, however, are ideally suited to carry out the role as assessor, educator, confidante, and sometimes counsellor.
Times of crisis, such as new diagnosis, recurrence, or treatment setbacks, may not be the most appropriate time to discuss sexual issues.

The literature does not suggest the best time for such discussion, though there is agreement that discussion should be a routine part of care at diagnosis, treatment, and follow up.

The assessment is important to meeting the patient’s needs. One useful strategy is to move gently from less sensitive topics to issues that are more sensitive.
COPING cont

• Sex is about effective communication.
• Effective communication is often lacking in sexual matters in African marriages and couples.
• Improved communication is a prerequisite for both partners to cope with the challenges ahead. The care giver needs to identify the sexual concerns of the patient and refer to the appropriate professional.
INTERVENTIONS

• There is a strong need to effectively probe, explore and encourage patients to express their fears and concerns, surrounding sexuality.
• Helping individuals feel accepted as sexually worthy, loved and wanted
• Helping individuals increase their sexual self-esteem by maintaining their appearance.
• Providing information and maintaining patients confidentiality.
INTERVENTIONS CONT..

- Control of other distressing symptoms e.g. wounds, pain, fatigue, nausea and vomiting, xerostomia, anxiety
- Demystifying cultural connotations and inhibitions, Clarifying misinformation
- Ensuring people with advanced HIV/AIDS are not denied having their sexual needs met.
- Use alternative ways of expressing love and affection eg.------
CONCLUSION

• Sexuality concerns in P/C and ELC are part of distressing symptoms in patients.
• HCP must be aware of this, employ comprehensive assessment strategies and interventions.
• There is need for continued research efforts in evidence based practice so as to provide culturally sensitive interventions.
• This will ensure that patients attain appropriate sexual interventions thereby, improving their quality of life.