COMMUNICATION IN PALLIATIVE CARE
Objectives

- Describe the concepts and components of communication in palliative care
- Describe the types of communication
- Describe the barriers to communication
- Discuss the principles of communication in PC
- Describe communication skills
- Discuss communication with children
- Describe the consequences of ineffective communication - PC
- Discuss some special consideration in HIV and AIDS
GP task
One way communication

• Yesterday it rained cuts and dogs
• All the ladies were on top of the world
• The commissioner will share his wealth with girls and not the boys.
WHAT IS COMMUNICATION?

• Is exchanging information
• It is the process by which people attempt to share meanings of symbolic transmissions
• Communication (as a generic process) is a two-way process between two or more persons in which ideas, feelings and information are shared, with the ultimate aim of reducing uncertainties and clarifying issues.
• Communication only becomes complete when there is feedback.
The Communication process:

- **Source**
- **Message**
- **Medium**
- **Receiver**
- **Feedback**
Types of communication

- **Verbal communication** is the exchange of ideas through spoken expression in words. It is a medium for communication that can entail using the spoken word or written.

- **Non-verbal communication** involves the expression of ideas, thoughts or feelings without the spoken or written word. Usually expressed in the form of body language (gestures, facial expressions and where appropriate, touch).

- **Both verbal and non-verbal** communication are important in palliative care.
Communication

- Talking
- Transmitting
- Repeating
- Summarising

Verbal

- Listening
- Transmitting
- Facial expressions
- Gestures
- Reflected feelings
- Genuineness
- Respect

Non-Verbal
Verbal and Non-Verbal Communication

• Includes body language, eye contact, gestures, tone of voice
• N.B; 80% of communication is nonverbal

Ersek, 1992
Communication;

- Advises on the **resources available** to address holistic needs and concerns;
- Provides patients with a sense of **security, consistency and comfort**;
- **Educates** family members and care providers on caring aspects
- Aims to **improve relationships** at all levels
- Ensures a good **flow of information** within and between organisations involved in service delivery
E.g; One needs to;

• Greet the patient’s and relatives using their names
• Introduce yourself and your role
• Be clear with the purpose of the session
• The key things you wish to cover
• How long it is likely to take
Example

• E.g. Hello Mr. John, My name is Mrs. Omondi and I’m the nurse counselor for this unit. I’d like to spend around 20 minutes or so with you to get an idea of the main problems and concerns you have. I’d like to take some notes as we go along. Would that be all right?
N.B. Asking the patient ‘would that be alright’, allows the patient to say, ‘Well I’m feeling absolutely exhausted after my treatment; could you come back later?’
Effective Communication in Palliative Care

• Identifies and aims to address all the needs of the patient, family and care provider (i.e. psychological, spiritual, social, cultural and physical issues);
• Provides information according to the patient’s preferences (whether good or bad news);
• Invites the patient to share their agenda in a conversation;
• Aims to communicate the truth by means of accurate essential information;
Cont...

- Recognize that while a HCW has medical authority, he or she does not have cultural or spiritual authority.
- Role of a traditional healer (alternative medicine)?
Power Dynamics

• As an authority figure expected to play the lead role, the HCW must elicit shared decision making with patients and families.

• Avoid jargon, which exaggerates the imbalance in knowledge between the HCW and patient.

• Ensure that there are always more family members than staff at family conferences or meetings.

• Ensure that you and the patient are at the same eye level.
  - If the patient is lying in bed, prop him or her up and sit down, though preferably not on the bed, in order to maintain comfortable personal space.
Expectations

- Realize that both parties have expectations, and they are not necessarily the same.
- Understand that the patient wishes to hear a certain message, and the HCW wishes to convey one, but they are not always the same.
Key aspects targeted in communication

• All aspects which make an individual complete, i.e. psychological, spiritual, social, cultural and physical
• Prognosis and goals of care
• Disclosure, diagnosis, prognosis
• Patient’s fears and concerns
• Disease progression and end-of-life care issues e.g. aggressive treatments in the end-of-life stage, decisions on readmission, review of medications, family rituals and the family’s role
Cont...

• Patient and family styles and practices for coping with grief, loss and bereavement
• Discussions about the future- will writing
• End-of-life issues and the anticipation of the death of a child patient- honestly discussions with the child and their family.
• The opportunity to say goodbye and express last feelings and wishes.
• Bereavement counselling and support for children
Communication Skills

• There are mainly 3 types of communication skills,
  1. Expressive skills
  2. Listening skills
  3. Skills for managing the overall process of communication.

- The Basic fundamental of all these types of communication is emotional skills.
When the Health Care Worker (HWC) is the Sender:

– Recognize that communication starts with the self, identifying your own barriers and baggage.
– Be prepared by having the correct facts and, if possible, a suggested plan of action.
– Demonstrate honesty, consistency, and trustworthiness.
– Speak with confidence and believe your own message.
– Think before you speak!
– Do not talk down to the patient or relatives.
– Create a comfortable atmosphere conducive to communication.
Cont…

– Bring barriers into the open.
– Do not share your own feelings of sadness or hopelessness.
– Move at the person’s own pace. Do not force a person to listen to more information if he or she is not interested or ready for it.
– Check that the message is received and understood.

When the HCW is the Receiver:
– Listen well and actively.
– Show persons that you enjoy their humour, but avoid making culturally inappropriate jokes.
Reflection on listening

You are not listening to me when …

• You do not care about me.
• 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 feel critical of my vocabulary, grammar, or accent.
• You are very eager 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.
You are listening to me when . . .

• 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 realise 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.
Cont…

- 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.
Questioning

• Use mainly **open-ended questions**, i.e. those that are thought provoking, that invite a person to talk and explain a situation, and that offer the opportunity for a variety of responses. Such questions might be ‘What makes you feel bad?’, ’How did you feel when you were diagnosed with cancer?’ or ‘What worries you the most?’

• You can use some **closed-ended questions** if necessary: these are brief and restricting and are used to obtain facts rather than knowledge of feelings – for instance, ’Does this part of your body hurt?’

• Avoid **leading questions**: these suggest a preferred answer or desired response – e.g. ‘You must be feeling a lot of pain, mustn’t you?’
Barriers to communication
Can happen at every stage of the process...

- Language and culture
- Making judgments statements.
- Conflicting medium
- Recipient Problem
- Lack of self awareness of the HCW expressing frustration, hopelessness, and disempowerment about the health care system.
- Fear of discussing the illness
Communicating with Children

- It is important to note that communication with children;
  - Uses an honest and open approach as the basis of all communication
  - Enables parents to be central to a child’s well-being; guided by the age and wishes of the child
  - Provides information to a child and their family about the signs and symptoms of approaching death in a manner appropriate to their individual needs and circumstances.
Process of Communicating with Children:

• Introduce self as the person who talks to & helps children
• Take some time to get to know the child (play a game, talk a bit)
• If child is not verbalizing, divert & introduce child to other materials in the room that can be used for communication
• Allow child to explore toys/activities/room at his/her own pace
• Ask about the demographic data of child (name, age, No. of siblings, school, favorite food, the parents, best friends)
• Don’t feel rushed when working with the child. If you are impatient, the child will sense this!
• Use of self by adjusting to child’s physical level
Cont...

- Utilizing play, drawing & other art mediums
- Observe what toys the child is handling
- Ask open-ended questions regarding the toys and regarding what you observe the child doing with the toys (*What is happening there?*)
- *Actively participate with the child in playing with toys*
- Notice the theme of the child’s play (e.g. themes of nurturing and aggression)
Consequences of ineffective communication in pc

• Not communicating accurate essential information to patients may provoke greater problems / Risks

• Protecting patients from the reality can lead to inconsistent messages being given by other members of the interdisciplinary team.

• Hiding the truth often leads to conspiracies of silence that build up to a heightened state of fear, anxiety and confusion, rather than provide one of calmness.

• Poor communication is a threat to patient care and can lead both to mistrust and to a source of staff stress.

• Not communicating about the nature and seriousness of an illness can lead to a lack of planning for the future – e.g. not writing a will, not planning who will take care of the children.
Be Aware …

- Most attempts by service providers to protect patients from the reality of their situation create further problems for patients, their relatives, and their friends.
- Realistic hopes and aspirations can only be generated from honest disclosure.
- The extent to which patients and families cope with information relating to illness largely depends on how effectively it is delivered and the relationship created between them and the care provider.
- Considerable suffering is caused by poor communication; much of this is avoidable.
Why is it good to tell the truth?

• To maintain a relationship of trust. Lying destroys trust.

• To reduce uncertainty. People usually cope better with truth than with uncertainty, even if the truth is painful.

• To prevent unrealistic hope. Sometimes people spend much time and money going from clinic to clinic looking for treatment because no one has been brave enough to tell them that there is no cure for their illness.
Cont…

• To give opportunity for mending difficult relationships or exploring spiritual issues.
• To allow patients and families to prepare for the future
Questions for Discussion:

• In the Kenyan context, is it true that patients “want to know”?
• How do we work with families who want to shield their patient-colluding?
• What are the advantages to truth-telling?
• What are the obstacles?
SOLER/ROLES

Non-verbal body language to show you are attending

• **S**- sit squarely to communicate presence and availability

• **O**- open posture to signify that you are open to the client and to what the client is saying. This is seen by others as a non-defensive posture.

• **L**- leaning forward towards the client is a natural sign of involvement

• **E**- eye contact. There should be eye contact but this should not be confused with starring. It is a way of communicating your presence, interest and that you want to hear what the other person wants to say.

• **R**- being *relaxed* and natural when doing all the above is important. It means becoming comfortable with your body and the situation
RESPONDING SKILLS-(CLEAR)

- **C- Clarify**
  - Clarify what you say. Explain your point so that the patient can understand.

- **L- Listen**
  - Listen to your patient and show them you are listening by giving them your attention and not getting distracted while they are talking.

- **E- Encourage**
  - Encourage the patient to speak freely by asking open-ended questions.

- **A- Acknowledge**
  - Acknowledge what your patient is saying. Let them feel that what they say is important and valuable, or that it was okay for them to talk to you.

- **R- Reflect and repeat**
E.g. ‘In finishing, I’d just like to check that I’ve understood the main points you have told me. You went to your doctor three years ago and were referred to the hospital for surgery for cancer of your bowel. At the time there seemed every hope that the cancer had been cleared, but recently some secondary deposits have occurred. This was something of a shock to you and your family, but you have been able to talk about it, though not yet to your daughter who is at university. This is a concern to you, but your main problem is the abdominal discomfort you are currently getting."
Summary

- It is good to check we have understood and summarize what the patient has said,
- e.g. “Do you mean that...”
- “I think what you are saying is...”
- “So the main things worrying you are...”.
Conclusion

“Suffering is not a problem that demands a solution, it is not a question that demands an answer, it is a mystery that demands presence”

All what entails in palliative care is “to cure sometimes, to relieve often, to comfort always.”