Chapter 14:

Communicating With Patients and Their Families

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At a Glance

Components of Communication
Communication Skills
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How to Talk About Palliative Care and End-of-life Issues
Suggested Resources

Overview

Communicating with patients is a challenge in most parts of Africa, where patient and health care worker (whether doctor, nurse, clinical officer, or social worker) often speak different languages, come from vastly different cultural and socioeconomic backgrounds, and may be unfamiliar with each other's culture and belief systems. In an environment where money, education, and law have historically separated people from one another, myths, misunderstandings, and preconceptions complicate the communication process.

It would be incorrect to assume that people living with HIV/AIDS have successfully negotiated the process of accepting, grieving, and living with HIV by the time they are in an advanced stage of illness and require palliative care. Often when health care workers (HCWs) first meet patients, those patients already have AIDS-defining conditions or opportunistic infections indicating advanced disease without first having been tested or counselled for HIV. Another common scenario is that people have been tested but have refused to believe the positive results and only started to deal with the reality of HIV when they are already terminally ill. Although the family is usually the best available support system, they often are not made use of until very late in the disease process because the person desires secrecy about the diagnosis.

Besides being an essential element of good quality palliative care, effective communication empowers all participants, increases their satisfaction with the interaction, and greatly increases the chance that the person with HIV will face death prepared and comfortable.

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Components of Communication

To illustrate specific barriers to good communication in an African palliative care setting, it is helpful to understand the participants and elements involved in the communication process.

Participants

The sender is the person, usually a member of the health care team, who initiates or sends a message, and then waits to receive a response from the receiver. Senders and receivers both send and receive messages.

When the sender is a HCW, barriers to communication include:

- HCW and patient not sharing a mutual language and culture.
- HCW making judgments about the sexual/life partner and/or distant, uninvolved family of the patient.
- HCW expressing frustration, hopelessness, and disempowerment about the health care system.
- Patient and/or family demanding/needing secrecy regarding HIV diagnosis.
- Change of HCWs due to staff shortages and less than perfect health care systems, making it difficult to develop a stable patient-HCW relationship.

The receiver is the person receiving or hearing the communication, and responding by sending her/his own message.

When the receiver is the person living with HIV, barriers to correctly understanding the sender's communication include:

- The person not accepting the diagnosis of HIV and not being ready to talk about end-of-life care.
- The shock of previously uninformed sexual/life partners (possibly including multiple spouses), who must process news of the person's diagnosis.
- The person's desire to focus on the family's response versus the HCW's desire to focus on issues of palliative care.
- The person not having negotiated the losses associated with HIV/AIDS, and, for example, still wanting to have children, to not use condoms, or to get married.

Relatives, who are often present or on the sidelines of communication with the patient, will almost certainly play a major role in future decision making. Family issues that create barriers to communication include:

- Family members not knowing the person's diagnosis, and the health care team not having the person's consent to talk to the family about HIV/AIDS but needing to prepare the family for home care and the person's death.
- Families already having suffered multiple losses and complicated bereavement.

Elements

The message is what is being communicated—often the diagnosis or the prognosis. The message can be complicated by:

- An HIV diagnosis made late in the disease, when the patient is already nearly at the end of life and has had no time to live with HIV, which can make the bad news interview much more emotional.
- The enormous stigma still surrounding an HIV diagnosis, which adds to the confusion and denial.

The medium is the language used in communication, which can be complicated by:

- The large number of different languages spoken in Africa, which makes it likely the HCW and patient will have different mother tongues (in South Africa alone there are 11 official languages, although most HCWs speak either English or Afrikaans)
- Body language, which must be interpreted within the individual's cultural context
- Sender and receiver meaning different things even though sharing a common language
- The use of interpreters/translators (more on this below)
- Jargon or medical language that is confusing and often scary to lay persons

The environment is the space in which communication occurs. Psychological, physiological, and physical barriers that hinder effective communication include:

- Interruptions, such as physical barriers (tables) between speakers, telephones ringing (and being answered by the HCW)
- Lack of privacy
- Interactions perceived by the person as menacing, such as the HCW crowding the patient or sitting between the patient and the door
- Lack of time to have a meaningful interaction
- Direct light from windows or other sources shining into people's eyes
- The state of the relationship among the communicators if there has been previous communication of 'bad news' or conflict
- The mental and emotional state of the patient and HCW—for example, a confused patient or a distracted HCW
- The patient's physical condition, as when the patient is in pain or uncomfortable

The Subtext

The subtext consists of unspoken factors that may not seem obvious but which play an important role in the communication process and often create barriers to effective communication. For each factor (**cultural setting, power dynamics,** and **expectations**), we offer suggestions for HCWs, to make communication more sensitive and easily received.

Cultural Setting

- Do not make assumptions based on a person's race or language, but assess people as individuals.
- Respect the common taboo against talking about death if the patient's cultural view is that doing so invites death in.
- Respect the norm of some cultures not to openly express feelings of grief.
- Realize that the information you offer can be selectively offered—and may be selectively received—depending on the person's culture and whether or not it is acceptable to talk about a particular topic.
- Recognize that while a HCW has medical authority, he or she does not have cultural or spiritual authority. Once there is no more curative care and the patient is removed from the hospital setting, the traditional healer may be involved as the sole provider of health care and advice (see Chapter 15: Traditional Medicine).
- Remember that in some areas the traditional healer might play a far more important role than any other HCW and that some persons with HIV/AIDS in rural areas may never visit a health care centre or hospital.

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Power Dynamics

- As an authority figure expected to play the lead role, the HCW must use more than usual sensitivity and patience to negotiate shared decision making with patients and families. An example is asking patient opinions on matters concerning them, or beginning with psychosocial/spiritual issues with which they are more comfortable (see Chapter 3: Principles of Clinical Assessment).
- 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. Both should be sitting down rather than one standing and one sitting. If the patient is lying in bed, prop him or her up as far as is comfortable 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.

Interpreters

Interpreters introduce additional communication issues. They are often used when there is a language barrier between HCW and patient. This is not ideal because it makes it very difficult to pick up on cues and practice patient-centred communication. It is important to remember that when the interpreter translates directly into the second language, a third element is introduced and the HCW cannot be sure the patient has correctly understood the message. The HCW relies on the interpreter to relate the message in the second language, but also in a culturally acceptable and understandable manner.

The interpreter is often not trained in either interpretation or translation skills, nor in medical matters. In fact, the interpreter is frequently a family member. To be effective, an interpreter must:

- Be acceptable to the patient and relatives
- Understand the importance of confidentiality
- Understand that his role is not in itself a therapeutic one
- Have some medical knowledge of the topic under discussion
- Have a good grasp and use of both the HCW's and patient's languages
- Not have his or her own agenda

It is the responsibility of the HCW to make use of the interpreter's skill to ensure that these elements are in place. The HCW must watch the reactions of the listeners very carefully to pick up on inappropriate reactions as a clue to whether the correct message is being communicated.

In most situations in sub-Saharan Africa, the person doing the translation may be a family member who accompanied the patient. Here, the issues are complicated by family dynamics. For example, a school-aged child may be translating for a parent, which not only reverses the traditional roles but makes discussion of intimate issues impossible.

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Communication Skills

General guidelines for improving communication are similar throughout the world. We offer advice below for enhancing the elements of communication.

When the HCW 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.
- Persevere.
- Think before you speak.
- Do not talk down to the patient or relatives.
- Create a comfortable atmosphere conducive to communication.
- 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 (more on this below).
- Show persons that you enjoy their humour, but avoid making culturally inappropriate jokes.

Message and Medium

- Speak clearly and adapt to circumstances and individuals.
- Use visual aids if required.
- Make sure body language corresponds with the verbal message.
- Ensure that interpreters, if used, understand the message (see section on interpreters).
- Avoid the subjects of politics and religion, and be careful of language that might sound racist, sexist, or judgemental.
- Give only the information needed at the time.
- Respect people's innate resilience and empower them.
- Try to create privacy (on a crowded ward, perhaps the person or family can walk down the hall with you; in a busy clinic, try turning your back to other people and speaking softly).
- When there is not enough time to talk about critical issues, say so and suggest alternatives (make a referral to a counsellor; ask the person to return on a lighter clinic day).

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Communication Techniques

Active Listening

Active listening, a technique that can be practiced and learned, involves:

- Wanting to listen/hear
- Concentrating on what is being said, without interrupting
- Being comfortable with silence
- Using words and gestures—such as nods, smiles, 'yes', 'mmm', or 'continue'—to encourage the patient to keep talking.
- Clarifying with the patient to be sure you understand what he or she means—for example, by 'weak', does that mean tired? muscle fatigue? impotence? 'Weak' blood can mean HIV-positive.
- Reflecting back what the person said, including both information and feelings. This communicates that the HCW is not only listening but hearing, and lets the person correct the HCW if she or he was heard incorrectly.
- Summarising the discussion by pulling together its main points, any decisions made, and the plan forward.

Questioning

This is a very important part of any palliative care interview. The quality and nature of the question will determine the helpfulness of the answer. There are different types of questions:

Closed question: The person answers yes or no, which provides little information—for example, 'Are you experiencing pain?'

Leading question: The HCW asks if the patient agrees with what she or he feels or thinks and discourages the person from expressing what she or he feels — for example, 'You must be very worried about what I am going to say in this interview, aren't you?'

Multiple question: This combination of two or more questions in one may lead the patient to answer only one bit or get confused and not speak at all, such as, 'What have you understood and how has it made you feel?'

Directive question: This focuses the patient on a direct topic, such as, 'When were you first diagnosed with HIV?'

Open question: This encourages the patient to talk freely, and can be broad or more directive — for example, 'Can you tell me what has been happening in terms of your health lately?'

It is important to think carefully about what it is you want to know. In most African communities it is important to ask clear, direct questions if one is to gather relevant information. If, for example, one asks a patient in Cape Town, South Africa, 'Where is your home?', the answer might be Transkei, a rural area many hundreds of kilometres away, whilst the patient lives and works in Cape Town. The word home typically means the place where you were born, where your extended family live, and/or where your family have been buried. Family relationships can also be difficult to describe clearly. For example, someone introduced as a sister may be a mother's sister's daughter, and a mother may be the primary caregiver rather than the person from whom one is born.

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How to Talk About Palliative Care and End-of-life Issues

Engaging the Patient and Family

Communicating effectively is essential for engaging the patient and family in a process with the palliative care team. Contact must not be made with the family without first obtaining the patient's permission to speak to a specific family member. Through effective communication, it is hoped that the patient will:

- Trust the HCW.
- Hear the correct message.
- Make sense of the message and grasp the implications for his or her life.
- Acknowledge the pain of the situation.
- Develop coping skills on a spiritual, emotional, social and practical level.

Through this process, members of the palliative care team can help the patient and family deal with end-of-life issues, shared decision making, symptom control, and bereavement counselling.

Holding Family Conferences

In addition to individual interviews, it is helpful to hold family conferences (see Table 14.1: Steps in the Interview or Family Conference). The goals may be to:

- Inform: of the diagnosis, prognosis, etc.
- Prepare: for the future
- Support: practical, spiritual, and emotional

The conference can be a way to assess the patient and family:

- Are they still stuck with issues of disclosure and dealing with the diagnosis of HIV?
- Are they still denying the disease?
- Are they at any of the transitional points, including admissions, deteriorations, non-response to treatment, new opportunistic infections?
- Are they preparing for death?

Points to Remember

- The team might need to hold successive conferences.
- It is probably best to try and relate to the family as a unit from the start.
- The team and patient/family might not have the same value systems. Ask and listen before deciding what kind of language to use and which problems are top priority.
- The team must communicate the same message and have the same goals and philosophy to ensure there is only one 'voice' in terms of diagnosis, prognosis, and future planning.

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Table 14.1: Steps in the Interview or Family Conference

1. Setting up the family conference	• Prepare: have the file ready and the facts available. • Let the patient decide which family members should attend. • Check with the patient beforehand on which facts may and may not be divulged and share the meeting agenda with him/her. • If using an interpreter, check that she/he does not have a 'third' agenda and understands the issues and facts. • Include other involved team members, such as social worker or home nurse, but ensure that team members do not outnumber family members. • Schedule a start time and length (usually 40 min) for the meeting.
2. Introductions	• Ask each attendee for an introduction, including relationship to the patient. • Explain that the meeting is a normal event to introduce the team, include the family, give information, prepare them, share decisionmaking, offer support, etc.
3. Inform	• Establish what the patient and family know about the condition and start from there. • Do not exceed the family's need for information; give it in layers, checking whether or not the family needs more in-depth information. • Allow time for reaction, ventilation of feelings, and questions. • Normalise reactions; for example, 'It is normal to cry or feel sad'. • Move on to the next phase if people seem ready, gauging by the questions they ask.
4. Prepare	• Prepare the family for the future, starting with the immediate treatment plan, without too much frightening information at once. • Empower the family to plan and deal with the demands of the future, such as home care, child care, changing roles in the household, financial and social issues. • Strive for a hopeful attitude; express realistic hopes, such as 'We hope to be able to send Mr. W home for a while', or 'We hope that the medication will make him/her comfortable'.
5. Support	• Offer support and practical help, such as in filling in forms, writing a letter for disability grants, controlling physical symptoms, and providing counselling and spiritual support. • Establish team and family expectations of each other, making realistic commitments to the family. • Prepare the family for an unpredictable course of illness; suggest follow-up family conferences if the situation changes and new decisions must be discussed and made. • Follow up any painful discussions the next day, perhaps with a visit or phone call from a team member.
6. Summarise and conclude	• Summarise main points, decisions made, and plans. • Check that all participants are happy to end the interview, and then conclude.

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Talking About Taboo Topics

Talking about death is regarded as bad luck because, many believe, this will make it happen. It is important to take this into account when urging people to address the 'paperwork' of dying—including wills, advance directives and powers of attorney—long before death is imminent. Table 14.1 lists tips for slowly breaking bad news to patients and their families. This may also be a barrier to encouraging parents to prepare memory boxes or to prepare their children for their imminent death. But these important issues must somehow be broached (see Chapter 24: Legal and Financial Issues). For example, it is important to discuss the future care of children to ensure that provisions are made and that the potential guardians have been consulted and are prepared to take on such a role. The wishes of a dying person are regarded as powerful, and it is 'bad luck' to ignore them. But of course in our westernised, document-driven society, those wishes must be made on paper to be valid if they concern property and guardianship. See Chapter 16: Spiritual Care for more on this subject.

Table 14.2: Breaking Bad News

S	**S**itting and listening **S**kills
P	**P**atient and family **P**erception of condition
I	**I**nvitation to determine how much **I**nformation they want to know
K	**K**nowledge; reviewing the facts
E	**E**xploring **E**motions and **E**mpathising
S	**S**ummarising and **S**trategising

Source: Adapted from Baile W, Buckman R. 1998. *Practical Guide to Communication Skills in Clinical Practice*. Niagra Falls, NY: Medical Audio Visual Communications, Inc.

Patient Advocacy

Often in communications with the family, HCWs act as advocates for the patient. Thus it is very important to establish the person's wishes regarding certain aspects of care.

Disclosure is a crucial topic to explore: What does the person wish to relate about his/her diagnosis to various relatives? People may be striving to maintain a position of respect with their children, or may be afraid of being abandoned if the whole story is disclosed. These are real fears and should be respected.

HCWs should also determine where the person wishes to die. While it is often customary to bury the person at 'home' (where the family originates and the ancestors are buried), transporting a body is very expensive compared to transporting a person who is still alive. There may be conflicting desires, with the patient fearing returning to his/her rural home that lacks formal health care and the family being anxious for him/her to die at home to avoid the cost of transporting the body.

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Suggested Resources

Doyle D, O'Connell S. 1996. Breaking bad news: starting palliative care. *J R Soc Med* 89: 590–591.

Lugton J. 2002. *Communicating with dying people and their relatives*. Oxford: Radcliffe Medical Press. Available to purchase at: http://www.radcliffe-oxford.com.