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Dana G. Cable

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Caring for the Terminally Ill: Communicating with Patients and Family

Dana G. Cable, PhD

Effective care of a patient with a life-threatening illness is far more than just correct diagnosis and appropriate medical/surgical treatment decisions. The patient’s long-term survival and comfort also depend upon his psychological state and his psychosocial resources. The emotional state of the patient as well as that of the family, along with the sensitivity and perception of the physician and his staff, are crucial variables that affect the outcome of attempts at communicating.

Most patients want to be informed about a life-threatening illness (1). Today, most physicians provide more honest and complete information than was the custom in the past (2).

The Partnership of Communication

Only if a patient is provided with honest information can he work together with the medical staff in the treatment care program (3). If true information is not provided, the physician works alone. Physicians must assess psychological factors in the treatment of a life-threatening illness. Because we tend to think so much in terms of controlling and eradicating a disease, we may unintentionally ignore the importance of psychosocial variables. Excluding the patient from the critical communication process involved in planning and implementing treatment can intensify his feelings of helplessness and affect the outcome of therapeutic efforts adversely (4).

In providing information to a patient with a life-threatening illness, we may communicate paradoxical messages. On the one hand, we give the patient the impression that although his condition is serious there is strong hope for effective and even curative treatment. However, at the same time, the patient receives verbal and nonverbal messages that death may result.

One can apply the concept of the “double bind” to such patients (5). The double bind involves communication between two or more individuals in a significant relationship. One individual communicates an implied threat to the other if a certain injunction is not carried out. At the same time, that injunction is negated by a second message. The recipient of the two conflicting messages is not only confused and unable to resolve the conflict, but in some cases his activity is almost paralyzed by the process. For example, we inform a patient that a given procedure is safe and routine, but he then observes anxiety among the staff. He is concerned and perplexed. What was stated to be safe and routine now appears as risky and experimental.

Dying patients are often put into an emotional conflict and the professionals do not always allow them to share their true feelings. Rather, they are forced to participate in formalities and to exchange platitudes (6). With good communication, patients will generally cooperate and the treatment program can proceed as a true partnership.

Communication Patterns and Types

Glaser and Strauss (7) suggest four awareness contexts that can exist between patient, medical staff, and family. These represent interaction patterns between the patient and the caregivers (medical and family).

1. Closed Awareness Context: In this context, the medical staff and the family know the true condition of the patient, but the patient is not informed. Everyone controls their facial expressions when confronting the patient in order not to allow him to learn the truth. All attempt to protect the patient, when they may not have the right to do so. The closed context means the patient has no influence over the management of his illness, nor will he be allowed to come to grips with his condition. Why does closed awareness exist and persist? Sometimes it is simply a case of the patient not being aware of the signs of impending
him and begins to guess what is happening. He will test people by his questions and statements, making them uncomfortable and afraid that they will give away the truth. In order to avoid that situation, they avoid the patient. They spend less and less time with him. The patient becomes more suspicious of the expressions he sees in others' faces and of the way they avoid him and his questions. This becomes an uncomfortable situation for everyone.

3. Mutual Pretense Awareness: In this context, the medical staff, the family, and the patient all know the situation, but everyone pretends that all is well. Games are played, rather than having honest communication. Despite the games, the positive factor here is that the patient knows his true situation and can have some say in what happens to him. However, the situation lacks a sense of true closeness among all of the involved parties.

4. Open Awareness: In this situation, everyone knows the diagnosis and prognosis and open communication exists. Time is spent in valuable interaction and the patient has control over the end of his life. Energy can be devoted to appropriate treatment and to relationships.

Usually, communication moves from closed to open awareness. It is the responsibility of the medical professional to help make that transition and to facilitate open communication by everyone involved in the patient’s world.

Should all patients be informed of their diagnosis and prognosis? Only in the rarest of cases is it appropriate to withhold such information. Patients are human beings with a need to be allowed to deal with those issues that affect them. The patient’s health and body is his property, not his physician’s nor his family’s. The patient must make the decisions concerning his body and treatment. The relationship between a doctor and patient must be based on mutual trust. The patient has shown trust in the physician by choosing him as his primary caregiver. That trust must be respected and the physician must trust the patient with the truth. Finally, only the patient knows his obligations and unfinished business which must be completed or resolved before death. By withholding the truth, we deny the patient the opportunity to complete the unfinished business of his life.

Communication by patients typically takes one of three forms: verbal, symbolic nonverbal, and symbolic verbal (8).

In verbal communication, the patient talks directly and clearly about what is happening to him and of his fears and concerns. This style of communication is good because we have no doubt about what the patient knows and understands. However, straightforward communication from the patient gives us no escape. We cannot pretend we did not hear what the patient said. We must respond to the communication.

In symbolic nonverbal communication, the patient uses actions or other symbolic styles (e.g., artwork, writing) to express what he knows and how he feels. For example, a woman is in a hospital bed with her eyes closed and her arms folded over her chest. She explains she is imagining that her husband has just brought her many flowers. In reality, she is imagining her own funeral and her body lying in the casket. Other examples are drawings of cemeteries and death symbols. We can choose whether or not to "hear" the message, depending on where we are in our own acceptance. The patient is protecting us. If we choose not to hear the message, the patient will try to communicate with someone else.

In symbolic verbal communication, the patient talks about one thing to symbolize something else. For example, a former smoker who quit many years ago and who talks to everyone about the negative health effects of smoking suddenly asks for a cigarette. He is communicating that it no longer matters. Life will end whether he smokes or not. Again, this form of communication provides protection for us. We can "hear" the words and "listen" to the message or read only what is said verbally and miss the underlying words.

In all communication, we must remember never to take away patients’ defenses. They will use their own timetable, not ours, to accept and deal with what is happening to them. Their defenses will take many forms. They will often deny or ignore what they have been told. They may rationalize that what is happening or what they are feeling is totally unrelated to their illness. They may use a defense of denial until they are ready to hear and accept reality. They may project their feelings onto someone else. In all instances, these defense mechanisms serve a useful purpose for the patient.

Allowing the patient his defenses does not negate the "need to know." A patient can still be informed of the diagnosis and prognosis. The appearance of defense mechanisms does not mean that the patient hasn’t heard what was said. Rather, it indicates that he needs time to process and accept the situation.

The Importance of Communication

The importance of communication with patients is evident in the three therapeutic goals suggested by Verwoerdt (9). The first goal relates to the illness and its symptoms. Good communication will usually result in the patient cooperating and working together with the caregivers in recommended therapeutic procedures. The patient will be more willing to listen to the medical professional and follow the advice given.
The second goal involves the patient’s awareness of his disease and likely death and his psychological reactions. The patient needs to maintain and protect his emotional equilibrium. Open communication will not only accomplish this but also will help his emotional distress and assist in providing effective coping techniques.

The third goal involves the interactions of the patient with those around him. Open communication will assist him in building his relationships. By so doing, much of his emotional distress will be relieved.

**Communicating Effectively**

There are many basic rules for effective communication with patients (10).

1. Keep the information simple. We must avoid using technical language and jargon. Those terms are protection for us, but they do not help the patient.
2. We must consider what the diagnosis means to the patient. Patients base information on their previous experiences and pre-conceived notions. Thus, a diagnosis of cancer, for many people, is an automatic death sentence, based upon their knowledge of cancer. Some people have a lifetime of facing difficulties and deal with them straightforwardly. Other individuals have poor coping techniques.
3. Do not try to give all the facts and information at once. People need time to process what they are told and to deal with it. To provide too much information at one time may mean that none of it is processed and the attempt at communication has failed. It is often better to wait for questions. We must learn to let the patient lead us. Patients will ask for more information or specific answers to those questions that are important to them. More will be gained by answering questions than by trying to give too much information.
4. Do not argue with denial. Denial is a defense mechanism and, to an extent, is healthy. It gives a patient time to prepare himself to deal with the information. He will let down his defenses in his own time. If we try to destroy denial, we may only make it stronger.
5. Ask questions to confirm that the patient has heard what was said. We may have said the right words, but the patient may have heard something different. Before we leave the patient, we need to make sure that the patient has heard the correct message.
6. Don’t destroy all hope. Despite the seriousness of the diagnosis, all cases allow for some level of hope. It is important that patients maintain that hope. We are not trying to give unrealistic hope but are simply recognizing that we do not have all the answers.
7. Don’t say anything that is not true. Giving false information is worse than giving no information at all. Eventually, the truth will emerge and we will have destroyed any chance at an honest and trusting relationship with the patient.

Several points should be remembered regarding our communicating with the family. Family members need to understand what the patient is experiencing. Only then can they develop effective ways to help the patient. Family members need an opportunity to express their feelings, and they need help in communicating with the patient. In life-threatening illness, it is important to maintain a model that includes the entire family as our patient.

**Communication to Build Relationships**

Long and Prophit (11) have suggested several ways of facilitating communication and building relationships. We must attend to another person. We cannot anticipate his reaction, but rather we must be accepting of him and interested in him and his communication.

We must listen, not only to the words the patient says but also to his thoughts and feelings, whether they are expressed or implied. Listening requires concentration. We must be sensitive and understanding, and withhold our judgment. We must step out of our own prejudices and biases.

We must demonstrate our caring. In all we do, we are trying to help the patient grow. Just as with children, growth comes about when one perceives that others care and are concerned.

We must be willing to disclose ourselves. If used judiciously, self-disclosure can be useful. Clearly the patient is our primary concern and we cannot let our issues get in the way. Yet some of our own experiences and thoughts may be helpful to the patient.

We must accept the patient’s feelings. Remember that feelings are never right or wrong. The patient is allowed to feel whatever he needs to feel without our invoking judgment of him.

We need to empathize. Putting ourselves in the patient’s situation will help us to understand why he reacts as he does.

We must be real. It is important to be genuine with the patient. Don’t try to be something you are not.

**Good communication will not cure a patient, but it can relieve much of the anxiety associated with life-threatening illness. It can obtain the necessary cooperative stance we need in the patient to pursue appropriate treatment. Physicians have an obligation to develop good communication skills and to practice those skills with all their patients.**

**Communication Guidelines**

It is helpful to understand some communication guidelines that come from the realm of counseling. They are useful in all communication but are perhaps particularly important in the doctor-patient communication.

1. Stop talking. Only one person can talk at a time.
2. Eliminate distractions. Don’t let the message be lost in the background.
3. Look at the speaker. Much is communicated by eye contact, facial expression, body posture and position, and voice.
4. Listen for the main point. Sometimes many words are said that almost mask the real message.
5. Listen to how the message is given. Feelings are as important as actual words.
6. Listen for what is avoided. Often what is not said is as important as what is said.
7. Respect the patient as a person. Don’t respond to him as an object.
8. Be careful with interpretations. We need to clarify what the patient is saying, as opposed to what we interpret from his words.
9. Avoid interruptions. The patient needs your undivided attention. Make sure beepers are turned off before visiting with the patient.
10. Reflect feelings. Let the patient know what you sense he is feeling.
11. Paraphrase. Communicate back to the patient the essence of what he has said. This helps provide clarification and avoids misunderstandings.
12. Summarize. This helps the patient pull together the communication.
14. Focus on solutions. Lead the communication in the direction of the issue of what to do.
15. Accept silence. Silence can be therapeutic. Allow for it and don’t try to fill it.

We must always maintain a perspective on the importance of communication. Good communication will not cure a patient, but it can relieve much of the anxiety associated with life-threatening illness. It can obtain the necessary cooperative stance we need in the patient to pursue appropriate treatment. Physicians have an obligation to develop good communication skills and to practice those skills with all their patients.

References