

PART 3

PSYCHOLOGY OF HUMAN HEALTH

COMMUNICATION PROBLEMS WITH THE PATIENT IN HOSPICE AND MEDICAL AND SOCIAL INSTITUTIONS FOR PALLIATIVE CARE

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Abstract. The article discusses the features of communication with patients in hospices and medical and social institutions for palliative care. The role of medical personnel in communication with a dying patient and his relatives is presented. The features of communication with pediatric patients in hospices are shown, taking into account their age and state of health..

Key words: communication, palliative care, hospice, patient.

Communication is the foundation of every clinical nursing practice and the cornerstone of palliative care throughout life-limiting disease. In current palliative practice, the trend is to support patients' individual process of coping with illness or changed life situation (Kurucova et al., 2017). The Council of Europe supports the development of palliative care in European countries. According to the WHO definition (2002), palliative and hospice care is an approach that improves

the quality of life of patients and their families, prevents and measures suffering (Polednikova et al., 2013).

Nemcova states that the role of the nurse in palliative care is irreplaceable. Nurses, as the largest group of health care providers, are in a unique position to influence the quality of care at the end of life (Nemcova, 2013). Nurses have to provide quality nursing, palliative and hospice care to patients with a serious illness at the terminal stage, and the nurse-patient relationship is most important in both basic and specialized palliative care. In palliative and hospice care, effective communication is an essential tool used to build a relationship of trust between the child, the family and health professionals.

Communication in palliative and hospice care. Palliative care includes health care provided by physicians (diagnosis and treatment), nursing care, rehabilitation, psychological care, medical-pedagogical care for children, spiritual care and social counseling (Nemcova, 2013). Palliative care is intended for patients of all ages, a wide range of diagnostic categories of oncological, chronic life-threatening diseases and injuries, regardless of age, gender, race, ethnic group, nationality, political and religious beliefs, sexual orientation, ability to pay, diagnostic category, stage of the disease, type of medical facility, or need for other types of treatment (Kurucova et al., 2017).

The difference between palliative and hospice care is based on the indication or nature of the services provided. Palliative care wards set up in hospitals play a major role in acute intervention and medical stabilization, while inpatient hospices provide care to end-of-life patients who cannot be provided with care in their home environment (Kurucova et al., 2017). In Slovakia, hospices are independent medical facilities and are intended for the provision of palliative care (Act No. 578/2004 Coll.). Palliative care provided by hospices is also referred to as hospice care. There are also mobile hospices that perform the visiting service of a doctor, nurse and, if necessary, other health professionals from the hospice, in the patient's home environment (Nemcova, 2013). Hospice care is intended for patients in the final stage of the disease, ie at a time when their disease has stopped responding to causal treatment (Adamicova, 2010). Hospice care has the following features: a dying person and his close relative are in the spotlight, clients have an interdisciplinary team – doctors, nursing staff, social workers, priests and pastors, lawyers, volunteers are involved, the hospice guarantees its clients, that they will not

suffer unbearable pain, their human dignity will be respected in every situation and they will not be left alone in the last moments of their lives (Svatosova, 2001).

The main groups of patients indicated for palliative care according to WHO (2002) are patients with oncological, actively progressive disease; patients with progressive neurodegenerative disease; patients with chronic obstructive pulmonary disease; patients with end-stage chronic renal failure; patients with severe pain of non-oncological origin and patients with chronic cardiac insufficiency refractory to treatment (Kurucova et al., 2017).

There is strong evidence that palliative and hospice care is beneficial in reducing most patient suffering, as well as psychosocial and spiritual or existential difficulties in families (Sothova, 2019). Palliative nursing care is a comprehensive care provided by nurses and is focused on the management of symptoms and meeting the needs of patients with incurable diseases and the dying (Nemcova, 2013). According to Krammerr, palliative care is based on a conceptual holistic model of the suffering of the person as a whole in the physical, mental, social and spiritual dimensions. Patients with life-limiting diseases and dying should be respected as uniquely human beings (Nemcova, 2013).

The nurse and other members of the interdisciplinary team should support the patient and relatives, and help them manage their situation. As reported by Dahlon and Giansiracusa, nurses spend most of their time with a patient, have the opportunity to discover his or her problems, concerns, expectations, or desires and create an atmosphere of understanding, support, and assistance (Dahlin, Giansiracusa, 2006).

Communication is of great importance in palliative and hospice care. From a psychological point of view, communication is one of the basic social-psychological processes that is constantly evolving between two or more people. Communication is a tool for providing information about the disease, prognosis, treatment, and nursing care options, informing patients about available services, and sources of help and support. Communication is an essential tool for providing assistance in informed decisions, and through it, it is possible to clarify the patient's priorities and reach a consensus on common goals of care (Kurucova et al., 2017).

The prerequisite for communication is the possibility of a connection between the participants, establishing, maintaining this connection during the communication process. Then a communication relationship is established. In an individual communication act, we can observe a connection to the situation in which

the communication takes place (Kristova, 2009). There are the following types of communication in social interaction: non-verbal, verbal, and paralinguistic. Non-verbal communication takes place through non-verbal means, such as eye language, facial language, body language, hand movements, touch, handshake, etc. Verbal communication involves the transmission of verbal information. Words have immense value. On the one hand, they know how to motivate, encourage, and call for cooperation or faith in healing, or on the other hand, they can hurt, hurt or humiliate. Paralinguistic communication represents the acoustics of the spoken word and has its own content, emotional and informational value. Paralinguistic expressions are many, such as the strength of the voice, intonation, intelligibility of speech, etc., based on different voice qualities, sadness, joy, indecision, fatigue, surprise, fear, or anxiety can be deciphered.

Patients in palliative care need information to help them understand their diagnosis, manage the insidious disease, and address their specific needs. The ability of healthcare professionals to provide the required information to patients in an adequate way plays an important role.

Jarrett and Maslin-Prother state that three areas of competence are essential for palliative practitioners in communicating with the patient: diagnostic and assessment skills, qualified responses to patient needs and feelings, being able to respond to their need to be informed, and answering their questions appropriately (Jarrett, Maslin-Prother, 2007).

According to Dahlin and Giansiracusa, the essential elements of communication in palliative care include providing and passing on information, including reporting bad news, gathering and gathering information, active listening, sensitivity, and cultural competence (Dahlin, Giansiracusa, 2006).

The basic communication skills of nurses in palliative and hospice care include: clarifying information to be consistent and meaningful, re-evaluating all care options and alternatives, supporting decision-making, defending the patient and his family, assessing and evaluating signs and symptoms of dying, strengthening communication between patients and his family, support for survivors in times of grief and grief (Kurucova et al., 2017).

Effective communication between the patient and healthcare professionals will allow: to identify the patient's priority problems, to help pass on and receive bad news, to participate in treatment decisions, to monitor the patient's adverse reactions.

By truly informing, we show the patient's understanding, interest, and effort to help him. Guiding principles for reporting negative messages: do not provide important information by telephone; ensure sufficient time and a suitable environment; prepare an interview strategy in advance (take into account the patient's personality, state of health, intellect, and others); the information should be provided by the physician who knows and trusts the patient best; determine the level of patient information and follow it up; provide information in a comprehensible, concise and accurate manner; leave space for the patient to express himself; discuss further perspectives in treatment and care; help the patient to process adverse information; leaving the patient confident that he is not alone in a difficult situation; provide the patient with additional care based on his needs (Susinkova, 2009).

On the part of health professionals, the prerequisites for good communication are non-directive and respect, the art of silence and active listening, overcoming one's own anxiety and uncertainty, authenticity, empathy, ability to work in a team, professionalism. On the part of the patient and loved ones, it is trust in health professionals, ability to communicate openly between family members, enough information (Kristova, 2009).

But there can also be ineffective communication on the part of both the patient and the healthcare professional. Ineffective communication can negatively affect the relationship between the patient and healthcare professionals. Several problems and barriers can arise in communication between health professionals and patients in palliative care (Kurucova et al., 2017). Pollard and Swift (2005) describe possible sources of barriers in the communication process between the patient and healthcare professionals. On the patient's side, it is: reluctance to confide in problems, individual preferences of the way of communication, multicultural problems influencing communication. Barriers on the part of health professionals: values, attitudes and beliefs, lack of communication skills.

Not only adult patients but also children are encounter diseases that progress and ultimately lead to death in childhood or early adulthood. Pediatric palliative medicine is currently a rapidly developing sub-specialization of pediatrics in the world, aimed at improving the quality of life of children with life-limiting and/or threatening illnesses and their families. Pediatric palliative care is the provision of palliative care to children with life-limiting disease (LLD) (Kysel, Jasenkova, 2018).

There are respected the age and level of development of the child when is informing a child who is ill. Younger children accept the explanation that they are ill and need treatment. Older children themselves consider symptoms, appearance changes, and repeated hospitalizations. Ethical attitudes towards chronically ill children and children with malignant diseases require, in addition to a high professional level of doctor and nurse, the most sensitive, kind, and friendly approach (Kopecka, 2008).

The ethical requirements for the doctor and the nurse will be to always inform parents regularly and clearly about the nature of the disease and at the same time answer their questions with maximum tact. Especially in children with severe diagnoses and prognoses, it is important to realize how we will inform parents not to be hurt more than the actual fact of their child's serious illness (Gulasova et al, 2015).

Not only medical and nursing care, but also psychological support is important for the palliative patient. The dying person feels whether the nurse cares for him out of duty and necessity, or out of the inner conviction to accompany him on the last journey.

The nurse should provide the patient with emotional support, be honest and open to the patient and his family with regard to the situation, respect what the patient says, expects what his ideas and values are. Participatory listening, unadulterated sensitivity, mutual discovery, and communication represent the achievement of the highest goals in palliative care.

When Kristová et al. Point out, empathy, personal involvement, understanding and compassion in the approach to the patient represent the pinnacle of the maturity of the personality, the essence of humanity, the philosophy of life and the heterotypical orientation of the nurse (Kristová, 2009).

Communication with the dying patient and his family. Terminal palliative care is provided to the dying person in the last days and hours before death (Nemcova, 2013). We focus on achieving a quality of life for the patient without pain and annoying symptoms, satisfying the needs, desires, and comfort of a patient with incurable progressive disease.

Nurses may have trouble communicating with the dying person and his relatives. Patients do not want to talk about pain, anger, feelings of sadness, and fear, they are uncomfortable, they are ashamed and they feel confused.

Palliative care seeks to maintain natural social ties so that the sick can survive the last period of their lives in the company of their loved ones, in a dignified and kind environment.

The aim of communication in the borderline stage of life is to strengthen the dying man's courage for the truth, its acceptance, humility, and inner thinking towards hope, in which a "new dimension of being" is established.

In the terminal stage of care, the nurse must use emotional communication, the basic manifestations of which are: talking about what dying is interested in; not denying his hope of peaceful death; accept his opinion and not discuss what is real and what is not; use silence as an expression of participation and contemplation with the application of positive haptic expressions; respect his faith; to promise him that the last words or message will be passed on to relatives; encourage communication; respect the reactions of the dying person; not to moralize, not to repair; not to tell what to feel; help him name his feelings; offer help and show empathy (Kristova, 2009).

According to Kubler-Ross, the process of realizing the imminent death of the patient himself is to have five stages:

1. negation – shock, denial of reality, refusal to acknowledge death;
 2. aggression – rebellion, anger, attacks on the environment;
 3. negotiation – negotiating with destiny;
 4. depression – loss of hope, sadness, fear;
 5. mitigation – acceptance and consent, coping with reality
- (Kurucova et al., 2017).

The nurse should be prepared to respond to the dynamics of changes in the mood, experience and behavior of the dying patient in the various stages of dying (shock, aggression, negotiation, depression and relief).

In communication with relatives, for example we can clarify common manifestations of dying, which are often of great concern to relatives because they do not understand them and maybe misinterpreted (e.g. loss of physical and mental strength of the dying person, loss of appetite, decreased interest in social contacts, specific odor of the dying person, etc.).

Communication with the child's parents in the terminal stage of the disease is demanding and specific. Understanding death in childhood depends on age and the level of intellectual ability achieved: by the age of 2, the child lacks an understanding

of death; 3-5 year-old children understand death as something that happens to others, the concept of death is vague for them; since the age of 6, I understand death as a reality, but interpret it as a person under the influence of fairy tales; at the age of 10-11 years with the development of the concept of space and time, death is understood as the natural end of human life (Boledovicova et al., 2010).

In case of difficult diagnoses or extremely unfavorable information, such as the death or death of a child, the sensitive parents must be carefully respected, the presence of both parents is necessary because the couple is stronger and more tolerant than the individual, mental state of the parents of a severe child (Slovakova, 2015). Parents who lose a child due to a life-limiting or threatening illness are in a difficult life situation. In the process of coping with the loss of a child, it is important to give them enough time and peace to realize the impact of what happened and time to be alone with the deceased child and to say goodbye to him (Boledovicova et al., 2010).

The death of a loved one is an irreplaceable loss that can cause a variety of mental or physical problems. During the period of coping with the death of a loved one (the so-called mourning period), most of the survivors' experience stress and anxiety. They are emotionally unstable and have to adapt to this new life situation. Communication with relatives continues during anticipatory grief and also after the death of their loved one, at the time of grief. We support relatives and friends; we help them manage their grief after the death of a loved one.

Conclusion. Palliative and hospice care should be based on ethical principles so that people feel the dignity and uniqueness of the human person. The death of each person is personal and unique. Everyone needs the love, respect, and closeness of others in their final phase. It needs to be accompanied, which means helping another to live in the final stages of life, it means the daily adventure of discovering another person, it includes a sense of love and respect for the sick.

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