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Effective communication in palliative care

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Summary

This article focuses on the definitions of communication and an examination of their relationship to palliative care nursing. The underpinning theory is analysed as a means of understanding the communication process. The communication process in nursing is considered in the context of nurse/patient/family communication. While the focus of the article is on palliative care, the principles of communication as outlined also have relevance and applicability to nurses working in a variety of other clinical settings.

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Aim and intended learning outcomes

The aim of this article is to raise nurses' awareness of the communication process and to encourage them to reflect on their own practice when communicating with patients and family members during the palliative stage of illness. After reading this article you should be able to:

- ▶ Discuss the communication process.
- ▶ Explain the core elements of interaction for effective practice.
- ▶ Summarise the complexities involved when

communicating with patients and family members in the palliative stage of illness.

- ▶ Make a case for the development of communication skills within palliative care nursing.

Time out 1

Working with a trusted colleague discuss palliative care terms and concepts. Choose a phrase or term such as 'palliation' or 'symptom management':

- Describe how you would explain this concept to lay carers.
- Identify why it could prove confusing for patients and their supporters.

Introduction

Communication is the process by which information, meanings and feelings are shared by persons through the exchange of verbal and non-verbal messages (Brooks and Heath 1985). Groogan (1999) asserts that communication is not something that people do to one another, but rather it is a process in which they create a relationship by interacting with each other. Adler *et al* (1989) describe communication as being 'a continuous, transactional process, involving participants who occupy different but overlapping environments and create a relationship by simultaneously sending and receiving messages, many of which are distorted by physical and psychological noise'. There are a number of elements in this description of communication that have relevance to nurses and other healthcare professionals in the palliative care setting and require closer examination.

Communication as a 'transactional process' implies that we encode and send messages while we

are receiving and decoding other messages. The process of interaction is two-way and is happening continuously and simultaneously (Hargie 1997). Nurses in the palliative care setting need to be aware of the equal input that patients have in the communication process and that encoding and decoding is a complex process. We have to make sense of, and prepare messages for, one another using both verbal and non-verbal means.

Second, the suggestion that communication has 'different but overlapping environments' is relevant to palliative care patients and their families. In nurse-patient and family interaction there is much common ground and understanding but there are also differences that need to be recognised if misconceptions and misunderstandings are to be avoided. Language and terminology – use of medical terms – become all-important in the overlap of the nurse-patient and family relationship so that those with whom the nurse is communicating do not experience isolation and exclusion.

Third, the belief that communication creates a relationship is, according to Groogan (1999), concerned with a holistic approach to care that involves meeting the social, psychological, spiritual and physical needs of the patient. This is especially relevant in palliative care nursing where the emphasis is on care that encompasses the whole person.

Time out 2

To explore the concept of 'noise' consider the following scenario. Louise is being cared for in the community and is in the final stages of illness after being diagnosed with bowel cancer. She copes with pain which is adequately controlled, the embarrassment of unplanned bowel movements and mild wound odour. She is also at the centre of an unpleasant divorce between her daughter and son-in-law. Louise is trying to protect her granddaughter from excess hurt. What constitutes 'noise' here? Make notes on how you think this influences the support relationship that a nurse might offer.

Fourth, the notion that communication can be distorted by 'physical and psychological noise' has major significance for nurses when communicating with dying patients and their families. Adler *et al* (1989) suggest that physical noise – environment, inability to hear – can detract from the message being communicated, while psychological noise – form of address, presentation of self – can also

affect the communication process. The nurse needs to be sensitive to the context in which communication is taking place with the family unit and do everything in his or her power to include them in all aspects of the communication process.

Communication in the context of nursing

The United Kingdom Central Council for Nursing, Midwifery and Health Visiting (UKCC) (now the Nursing and Midwifery Council) stated in 1996 that: 'Communication is an essential part of good practice in nursing and is the basis for building a trusting relationship that will greatly improve care and help to reduce anxiety and stress for patients and clients, their families and their carer' (UKCC 1996). It is important that nurses develop their communication skills so that they can become more skilled in their interpersonal contact with patients and others.

Burnard (1996) writes: 'Not to be interpersonally skilled as a healthcare professional is to be ineffective as a healthcare professional.' This caveat should not be ignored because communication is the medium through which nurse-patient relationships are established and some nurse theorists view the interpersonal relationship with patients as the central focus of nursing activity (Meleis 1997).

Peplau (1988) defined nursing as a therapeutic interpersonal process, while Parse (1992) suggested that nursing is a subject-to-subject interrelationship – a loving true presence with the other to enhance the quality of life. Travelbee (1966) posited that nursing is an interpersonal process between two human beings, one of whom needs assistance because of an illness and the other who is able to give such assistance. The goal of the assistance is to help a human being cope with an illness, learn from the experience, find meaning in the experience and grow and develop through the experience.

King (1971) defined nursing as a process of human interaction between nurse and patient, whereby each perceives the other in the situation and, through communication, sets goals, and explores and agrees on means to achieve these goals. Rogers (1988) added the perspective that nursing is a science of unitary human beings and that the goal of nursing is to promote 'symphonic' interaction between a human being and his or her environment through participation in a process of change. This theory considers the whole individual and is based on the belief that humans are at the core of nursing. This theory challenges the nurse to work on mobilising individual or family resources, heightening his or her integrity and strengthening the human environment or family relationships (Rogers 1988).

Time out 3

Think back to your most recent nurse education course and the theory that was used to describe nursing. What part does communication play within that theory? Have you been able to communicate in the way that the theory espoused?

Many empirical studies on the concept of caring in nursing have identified communication as one of the defining attributes. Fosbinder (1994), in a quantitative study, concluded that caring in nursing involved getting to know the patient, translating, informing, explaining, instructing, teaching the patient, and establishing trust in the relationship.

Qualitative studies using phenomenological or grounded theory approaches identified that talking, listening, touching and information giving were central aspects of caring in nursing (Clarke and Wheeler 1992). McCance *et al* (1997), in a concept analysis of caring in nursing, identified one of the defining attributes of caring as 'getting to know the patient', which incorporates identifying what is important to the patient through the medium of communication.

Morrison (1991) concluded that the interpersonal approach and concern for others were part of caring. Forrest (1989) identified the importance of 'being there' for the patient, interacting, touching and picking up on cues as core elements of caring in nursing. Hanson and Cullihall (1995) contend that palliative care nursing clearly endorses a humanistic approach in which the helping relationship between nurse and patient plays a central role.

Communicating, interacting and being there for patients have emerged as integral components of nursing practice. Slevin (1999) has articulated the centrality of presence – being there – as a therapeutic core in nursing. He defines presence as a 'way of being' that promotes a therapeutic (healing) relationship between the nurse and the patient. This notion of presence builds on the phenomenological-existential view of human existence (Buber 1958) that focuses on 'I-Thou' relating. I-Thou relating is placing ourselves completely into a relationship, to truly understand and 'be there' with another person. In a similar vein, Long (1999) argues that nursing and communication are symbiotic. She goes on to explain: 'It would be very demanding for nurses to demonstrate that they effectively "care" for another human being without communicating. Equally, it would be very difficult to communicate effectively and compassionately without "caring".'

Long (1999) concludes that if we believe this to be true then the manner in which nurses communicate with people has either a positive or

negative impact on the quality of care and consequently on the success or failure of the healing process. In palliative care nursing, a great deal of healing (inner peace), that is, serenity and calmness, needs to take place towards the end stages of an illness. This healing is important and, as demonstrated by Steele (1990), the healing that is required before death has a major impact on the grieving process and grief resolution for a patient's family. This emphasises the need for nurses in palliative care to engage in effective, meaningful and interactive dialogue with patients and their families so that as much healing as possible can take place before the person dies.

Time out 4

Discussion of 'presencing' highlights that it would be naive to think of communication solely as 'speaking'. We communicate in different ways and sometimes through being present and saying nothing. With your colleague discuss how the silent presence of the nurse with a dying patient is different to the silence of strangers in a railway waiting room. Make a list of what is qualitatively different about this that enables you to claim that you are caring for the patient.

The nurse-patient and family communication context

Many patients and their family members experience difficulty in communicating with healthcare professionals. The Audit Commission (1993) has stated that poor communication between patients and healthcare professionals is one of the main reasons for complaint and litigation in the health service. The National Cancer Alliance (1996) also identified deficiencies in healthcare professionals' communication skills with cancer patients. Other publications relating to cancer care and palliative care have emphasised the need for better and improved communication between patients, families and professionals (Department of Health (DH) and Welsh Office 1995, DH and Social Security 1996, National Council for Hospice and Specialist Palliative Care Services (NCHSPCS) 1996, DH and Social Services and Public Safety 2000, National Institute for Clinical Excellence 2004).

The psychosocial aspects of care as an integral part of the palliative care approach have also been highlighted as a core aspect of care for the family unit. The NCHSPCS (1997) has identified that psychosocial care is concerned with specific factors (Box 1).

Communication therefore involves not only sharing information but also emotional support

and care. The great stress, emotional tension and fatigue that attend a life-threatening illness often make it necessary for patients and families to hear information several times so that they can absorb it and feel reassured (Latimer 1998). Buckman (1998) states that the fear of dying is not a single emotion but rather it is composed of many different fears as listed in Box 2.

Patients may want help to express their fears but some healthcare professionals have difficulty in communicating with dying patients and their families (Maguire 1985). Studies by Wilkinson (1991) and Farrell (1992) found that many healthcare professionals have high levels of anxiety about death, which may account for their unwillingness to engage in meaningful interactions with patients and families. Both these studies demonstrated a significant correlation between a high level of death anxiety and negative attitudes and behaviours towards the family unit. Buckman (1998) also identified several fears that healthcare professionals experience when communicating with patients in the palliative stage of illness (Box 3).

BOX 1

Key elements of psychosocial care

- ▶ The psychological and emotional wellbeing of the patient and his or her family carers (including issues of self-esteem).
- ▶ Insight into and adaptation to the illness and its consequences.
- ▶ Communication, social functioning and relationships.

(NCHSPCS 1997)

BOX 2

Fears associated with dying

- ▶ Fears about physical illness – pain, nausea, disability.
- ▶ Fears about psychological effects – not coping, breakdown.
- ▶ Fears about dying – existential fears, religious concerns.
- ▶ Fears of being a burden or not being able to provide for family, especially where the patient is the main breadwinner.

(Buckman 1998)

BOX 3

Healthcare professionals' fears about communicating with palliative care patients

- ▶ Fear of being blamed (blaming the messenger).
- ▶ Fear of the untaught.
- ▶ Fear of eliciting a reaction (tears, anger).
- ▶ Fear of saying 'I don't know'.
- ▶ Fear of expressing emotion (crying).
- ▶ Fear of medical hierarchy.
- ▶ Fears and anxieties about their own death.

(Buckman 1998)

There is an apparent assumption that these fears form a significant barrier to effective communication. Field and Copp (1999) reported fears and anxieties among professionals, especially when they had to communicate with patients and family members in a closed awareness context (Box 4). Jassak (1992) argues that a lack of communication between the healthcare professional and the caregiver and/or patient may be caused by information given to the family not being received, processed, interpreted correctly or retained accurately. There are also suggestions that patients and families may be reluctant to ask questions because they think nurses and doctors are too busy to answer them and they do not want to be perceived as complaining (Meissner *et al* 1990).

Time out 5

Dying people and their significant others can feel very isolated. In what ways do you use communication to understand the world of your patient, his or her needs and fears? How do you share your experience in a way that helps to support patient dignity?

Communication with dying patients and their families is, to some extent, also dependent on the level of awareness they have about prognosis. Glaser and Strauss (1968) identified four types of 'awareness context' from their study of dying patients in an American hospital setting. These are described in Box 4.

These categories of awareness are in keeping with common experiences and were based on sound methodology. The awareness context focuses on the degree to which the person is aware of his or her prognosis and acknowledges it and the extent to which that awareness is

shared or denied by his or her family or significant others. Open awareness suggests that all concerned are fully aware of the position and act, speak and behave in keeping with the fact they have open awareness.

However, many patients and their family members are given all the information pertaining to the situation and, for whatever reason, cannot make sense of what they have been told or find it too difficult to accept the inevitability of death (Jassak 1992, Hinton 1999). Timmermans (1994), in an autobiographical ethnographic study on the death of his mother, demonstrated that the open awareness context (Glaser and Strauss 1968) was too broad and general in character, and did not take account of the emotional aspects of patients' behaviour. Subsequently, he proposed three types of open awareness (Box 5).

BOX 4

Four types of awareness associated with patients who are dying

1. **Closed awareness** – where the patient does not recognise or denies that he or she is dying although everyone around knows.
2. **Suspected awareness** – where the patient suspects what others know and attempts to confirm or negate it.
3. **Mutual pretence awareness** – where everyone knows that the patient is dying but pretend to each other they do not know.
4. **Open awareness** – where the patient, staff and relatives admit that death is inevitable and speak and act accordingly.

(Glaser and Strauss 1968)

BOX 5

Timmermans' three types of open awareness

1. **Suspended open awareness** – where the patient and family disregard the information given to them, and are in denial. This may be a transient early reaction as a result of getting the 'bad news'.
2. **Uncertain open awareness** – where the patient and family overlook the negative aspects of the information and hope for a good outcome.
3. **Active open awareness** – where the family unit accepts the reality of the information and acts and behaves accordingly.

(Timmermans 1994)

This recontextualisation of the open awareness category (Timmermans 1994) gives more scope for the reactions that patients and family members might have as a result of being told 'bad news'. However, Field and Copp (1999) comment that patients appear to move 'in' and 'out' of open awareness, because at times they appear to acknowledge they are dying and at other times deny the fact they are dying. It has to be remembered that where healthcare professionals maintain an open awareness context with the patient and family, the patient and family members may decide how they manage such awareness in communication with others (Field and Copp 1999).

Furthermore, Wilkinson (1991) carried out an analytical relational study with hospital nurses ($n=54$), to examine their communication skills when caring for cancer patients at three different stages of the illness trajectory: on admission; at the stage of recurrence of the cancer; and in the palliative stage. She wanted to find out to what extent the nurses used facilitating and blocking tactics when communicating with this group of patients.

The findings showed that the majority of nurses demonstrated poor facilitative communication skills with cancer patients. Wilkinson (1991) also identified a small group of nurses whom she labelled 'ignorers'. These were nurses who, during their interviews with the patients, ignored the patient cues and changed topics throughout the interview. The author concluded that the ward environment, the nurse's religious beliefs, and attitudes to death had an influence on the way nurses communicated with patients, rather than specific education on communication.

Time out 6

Working with your chosen colleague, think back to episodes where you have demonstrated 'facilitative communication' with dying patients and their loved ones. What was the characteristic of that communication and what resulted for the patient?

Similarly, Booth *et al* (1996), in a prospective study of hospice nurses ($n=41$), demonstrated that blocking behaviours were especially evident in nurse-patient interactions when patients disclosed their feelings. Costello (1999), in a more recent ethnographic study of older terminally ill patients ($n=22$), found that nurses did not provide patients with an opportunity to ask about their treatment. A climate of closed awareness prevailed as nurses and medical staff colluded with relatives not to disclose information to the

patient. Seale (1991), on the other hand, concluded that communication skills in hospice nurses were better than in conventional care. There is some conflict in these reports as to the degree, level and effectiveness of communication in palliative care.

Jarrett and Payne (1995), in a selective review of literature on nurse-patient communication, concluded that the majority of research had concentrated on the nurse's communication skills in the nurse-patient relationship. They identified that there has been a reluctance to consider the patient's perception of nurses, what they wish to tell the nurse and how contextual and environmental factors, for example, power relations, control of knowledge, and ward ethos, may influence the patient. This is an interesting conclusion and points to the need for nurses to make an assessment of each individual situation so that they are aware of whether the patient desires information. Hunt and Meerabeau (1993) cautioned that some patients might not want to have emotionally intense conversations with nurses, and prefer to keep conversations mundane.

Baile *et al* (2000) advocate that discussing information disclosure with patients at the appropriate time in the illness is important because not all patients want all the details about their diagnosis and prognosis. Their maxim is 'before you tell, ask'. Open-ended questions, they suggest, can be used to facilitate this process. For example, 'What have you been told about your illness so far?' or 'What is your understanding of the reasons we did the scan?' The responses to such questions will indicate the patient's understanding of his or her illness to date, will allow for the correction of misinformation and can also help to determine whether or not the patient has, for example, unrealistic expectations, illness denial or gaps in information about his or her illness. If patients are to be treated as individuals and have their concerns dealt with, then nurses should use the following skills (Rogers 1980, Burnard 1996):

- ▶ Active listening.
- ▶ Open-ended questioning.
- ▶ Reflection of feeling.
- ▶ Empathy building.

The empathic response is a core skill in communication, especially when offering support to the patient and family members. Egan (2002) asserted that empathy as a form of

communication involves listening to patients, understanding them and their concerns to the degree that is possible, and communicating this understanding to them so that they might understand themselves more fully and act on their understanding.

Rogers (1980) stated that empathy is about sensing the patient's world 'as if it were your own', without ever losing the 'as if' quality, which relates to an ability to understand in an emotional way what another person is feeling. In a concept analysis of empathy in the nurse-patient relationship, Hsiu-Yueh and McKenna (2000) identified the defining attributes of empathy as active listening, understanding and accepting the patient's feelings without offering an evaluation of them. However, Reynolds and Scott (2000) argue that while empathy is central to both caring and the nurse-patient relationship, a low level of empathy is offered to many patients. They suggest that nurses need to understand the needs of patients before they can begin to show empathy, which, they concluded, is the ability to communicate an understanding of the patient's world.

Time out 7

What do you understand by the term 'empathy'? Give some examples of when you, as a nurse, were empathic with a patient. How did you feel when you were able to identify with that patient and make a real difference to his or her situation?

Effect of education on communication skills

The literature refers to the impact of education and training on nurses' communication skills. Heaven and Maguire (1996) used a pre-test post-test design to examine the effect of assessment skills training on hospice nurses ($n=44$). The study was carried out in two different hospices. The purpose of the study was to determine how assessment skills training would affect the nurses' ability to determine patients' concerns. Although 44 nurses were recruited to the study, 22 (50 per cent) dropped out for the following reasons: staff turnover ($n=11$); sickness ($n=4$); equipment failure (not specified) ($n=1$); and other reasons (not specified) ($n=6$). The findings of the study demonstrated that basic skills training was insufficient to have a major impact on the nurses' ability to determine patients' concerns.

In a contrasting study, Wilkinson *et al* (1998) carried out an evaluation of a communications skills programme on nurses' communication skills. A 26-hour training programme over a

six-month period was implemented for 110 registered nurses (99=female, 11=male), who were undertaking a specialist qualification at diploma or degree level in cancer care/palliative care nursing. Data were collected and analysed using various techniques at different points throughout the course.

The results demonstrated that the nurses had moderate anxiety about death. Wilkinson *et al* (1998) also reported a significant improvement in the mid-test and post-test assessment scores for the nurses in the study. Between pre-test and mid-test 79 per cent of nurses showed improvement, from mid-test to post-test improvement occurred for 70 per cent of the nurses, while 90 per cent of nurses improved from pre-test to post-test. Wilkinson and colleagues attributed this improvement to the experiential learning (role-play) element of the course and to its six-month duration. This allowed for reflection and critique of performance over time. The most significant improvement was in the area of psychological assessment, and the patients' awareness of prognosis/diagnosis. The communications skills

training course had therefore a significant impact overall on the nurses' ability to illicit patients' problems on assessment.

However, for 10 per cent of the nurses the training had little effect and in some cases nurses' performance worsened. This group of nurses, however, admitted that they did not want to get involved with patients' concerns because it caused them too much stress.

While Wilkinson *et al* (1998) and colleagues acknowledge limitations in the study, there is significant evidence to illustrate that communication skills can be taught to the majority of nurses who do not have fears about talking with dying patients and their families, and who are willing to engage with people at a meaningful level. There is also a need to continue updating qualified nurses so that they maintain their level of practice in communicating with dying patients.

Conclusion

Communication is the medium through which interpersonal interaction takes place. It is

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necessary in the daily lives of almost every human being. In palliative care the uniqueness of the situation to the individuals in the family can never be overlooked and highlights the need for effective patterns of communication between them and the professionals with whom they come into contact. However, the communication process is complex and involved. It is well recognised that communication is central to the nurse-patient relationship, but in practice there is significant evidence that many nurses experience difficulties when caring for the patient and his or her family during the palliative stage of disease.

In addition, many patients have fears and anxieties about death and find it a problem to talk about it, not only with professionals, but also with their loved ones. The family's level of awareness about diagnosis and prognosis has been highlighted as an important variable in the communication process, although it has been demonstrated that even when an open awareness

context existed, communication difficulties were apparent for patients and family members.

The evidence demonstrates the need for nurses and other health professionals to develop their communication and interpersonal skills so that they can facilitate the process of communication with the patient, rather than engaging in blocking and distancing tactics that hinder effective communication. The skills of active listening, open questioning and reflection promote better communication and encourage empathy building. When these skills are used, they enhance the communication process and help to ensure that events leading up to death are well managed. This is a central factor in helping bereaved individuals cope with grief following the death of their loved one **NS**

Time out 8

Now that you have completed this article, you might like to write a practice profile. Guidelines to help you are on page 68.

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