

การพยาบาลผู้ป่วยระยะสุดท้าย

The Nursing Perspectives of Death and Dying

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Abstract

This paper aims at discussing knowledge of death and dying. Several psychologists have proposed stage models described by the dying. They are shock, denial, mitigation, anger, bargaining, depression and acceptance. Some psychologists disagree with these stage-based models. However, the terminal care knowledge of reactions is essential for nurses to support and comfort the patient and their relatives during their crisis.

Keywords: dying, nursing, stage of dying

บทคัดย่อ

บทความฉบับนี้มีวัตถุประสงค์เพื่ออภิปรายความรู้ที่เกี่ยวข้องกับผู้ที่อยู่ในช่วงสุดท้ายของชีวิต ในการทำความเข้าใจผู้ที่อยู่ในช่วงสุดท้ายนี้ นักจิตวิทยาหลายท่านได้เสนอแบบจำลองของขั้นตอนที่ผู้ที่อยู่ในช่วงสุดท้ายของชีวิตได้บรรยายไว้ ขั้นตอนต่างๆที่บุคคลดังกล่าวได้บอกเล่าไว้ได้แก่ ช็อค ปฏิเสธ ภาวนา โกรธ ต่อรอง ซึมเศร้า และยอมรับ นักจิตวิทยาบางท่านไม่เห็นด้วยกับแบบจำลองนี้ อย่างไรก็ตามองค์ความรู้ที่เกี่ยวข้องกับปฏิกิริยาของผู้ที่อยู่ในช่วงสุดท้ายของชีวิตเป็นสิ่งสำคัญยิ่งสำหรับพยาบาลในการให้การช่วยเหลือและปลอบประโลมแก่ผู้ป่วยและญาติระหว่างภาวะวิกฤต

คำสำคัญ: ผู้ป่วยระยะสุดท้าย, การพยาบาล, ขั้นตอนสุดท้ายของชีวิต

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Introduction

The essence of nursing is caring (Larson, 1987; Mayer, 1987; Timmermary, 1993). However, for dying patients, nurses encounter a great demand place on his or her skill in the control of pain and other symptoms experienced by the dying. Caring for dying patients and their families requires the congregation of all the fundamental skills a nurse can have: for example, in confronting ethical issues and, in catering for the spiritual and religious needs of patients and their families (Corner, 1994; Degner, Gow & Thompson, 1991; Wilson-Barnett & Raiman, 1988).

Habermas, cited in Emden, (1991), proposes that there are three categories of inquiry for which a specific connection between logical methodological rules and knowledge which may fundamentally apply to ways of knowing in nursing: 'technical knowledge', 'moral or communicative knowledge' and 'emancipatory knowledge'. Technical knowledge is the knowledge that incorporates the approach of the empirical analytic science Moral or communicative knowledge helps to preserve and expand shared understanding with each other. Emancipatory knowledge may help to reflect on issues and secures freedom from self-imposed constraints and distorted communication.

In addition to the nurse own emotional encounter with that of their dying patients, nursing the dying can be very stressful experiences for the nurses (Corner, 1994; Degner, Gow & Thompson, 1991; Jones, 1993; Larson, 1987; Littlewood, 1992). As nurses are the main care givers for dying people and their families,

they should have insights into the sociological variables that can affect their patients' responses to death and death preparation.

Emden (1991) also suggested that nurses need to be aware of these three types of knowing in nursing because the appropriate knowledge can be used in order to maximise the patient's sense of well-being. These emerging knowledge basics are essential, and act as the guiding principle of the philosophies and practices of care for the dying.

The reflective nurse, through reflecting-in-action, or constantly re-framing perceptions of patients, is able to put on one side common sense understandings of professional practice and diversify the strategies which can be called to assist the patients to address their needs (Clinton, 1992). As Clinton pointed out, reflection-in action refers to the process that occurs when professionals in their daily practice encounter a situation which is in some way out of the ordinary and in some sense surprise them. Short, Sharman and Speedy (1993) stated that reflective nursing knowledge involves the care for the patients' physical, psychological, social and spiritual needs.

In order to cover the field of nursing care for the dying, this paper is to be set within the concepts of death and dying and the impact of nursing care on the dying.

Concepts of Death and Dying

Concepts of death and dying are multiple and varied. It is difficult to organise concepts in terms of a logical sequence of events because a diagnosis of terminal or life threatening

illness places tremendous psychological, social and physical strains on the patients and their families. After conducting interviews with dying patients, Kubler-Ross (1969) developed a five-stage model of phases commonly experienced by people after they are told they are going to die. These stages are denial or isolation, anger, bargaining, depression and acceptance. Denial or Isolation is the initial stage. Kubler-Ross suggested that there are quite a few cases of terminally ill patients who carry denial till the end of life. The patient experiences an initial feeling of shock and numbness because of intense disbelief. The patient often claims that 'the tests are wrong' or 'it can't be me'.

Anger, unlike the initial denial stage, is a very difficult phase for family to cope with. The patient is angry and frustrated. Bargaining is a time to make atonement, appeasements and promises to their god. To postpone the inevitable and buy more time, the patient is willing to barter and bargain with anyone and anything. Depression, as outlined by Kubler-Ross, is of two types. First, depression focusing on future loss is called preparatory depression, about the future welfare of a spouse or children. The second type of depression is where the patient focuses on the past or past events and is called reactive depression. The final stage is acceptance or resignation. This phase is characterised by increased tranquillity. The patient seems void of outward feelings.

Weisman cited in Gonda & Raurk (1984) has addressed the various reactions of the dying as phases which tend to occur primarily in a particular order. There are five stages. Weisman's first phase is existential

situation. It refers to the initial shock of an abrupt confrontation with evidence of one's own vulnerability and mortality. Weisman's second phase is mitigation and accommodation. Patients and families tend to shift toward achieving a satisfactory balance between new roles as potentially dying patients with their associated skills and coping techniques. The third phase is decline and deterioration. This period of a terminal illness may be the most difficult for many patients because the signs of advancing illness have become unavoidable. Finally, the fourth phase is preterminality and terminality. Responses to treatment become minimal and everyone begins to realise and be aware of the limitations of the time they have left together. Gonda & Raurk, (1984) pointed out that the Weisman's phases are more likely to take place sequentially than the stages of Kubler-Ross because they are more closely tied to the course of the disease itself.

However, several researchers have found no support for a stage theory as proposed by Kubler-Ross and Weisman (Kastenbaun, 1986; Corr, 1991-92; Kellehear, 1990); rather the individual conforms to his or her life time behaviour, while in the process of dying. The experience of dying is intense and is shaped by the individual's history of illness, and the interactions with others during the dying period.

Kastenbaun, (1986) also argued against the Kubler-Ross stage-based model based on the following reasons: the existence of these stages as such has not been demonstrated, no evidence has been presented that people actually do not experience from stage one through to stage five, the eliminations of

the method have not been acknowledged and there is insufficient distinction between description and prescription.

Obviously, the work of Kubler-Ross is on psychological or psychosocial dimensions and on the perspective of psychotherapy. Moreover, Kubler-Ross overemphasised defence mechanisms. It is important to argue that dying is not a psychiatric illness. Dying is a normal process in human life. Field, (1898) noted that the dying patients need to be comforted and relieved from distressing symptom of disease. In addition, there is no reason to think that there are simply four or five stage ways in which human beings cope with death and dying.

However, we could still learn from some aspects of Kubler-Ross's and Weisman's work. Stage-based models help us to learn more about the dying persons and those who are coping with dying. Stages-based models also contribute to some extent to helping us understand such coping which is the fundamental importance. Sociologists attempt to characterise dying in terms of phase. For example, for Goffman cited in Sweeting and Gilhooly, (1991-92), the terminal phase begins when the dying individual starts to turn from the outside world and withdraws into the internal self. There are different levels which divide the invisible line between life and death. These are the physical, the psychological, the social and the sociological levels of life and deaths.

Physical death tends to be the main immediate area of concern for physicians. Vital organs no longer operate. Clinical death occurs when the signs of death appear upon examination. When discussing the meaning of clinical

death, many medical doctors and nurses refer to brain death or the 'Harvard criteria' which means twenty-four hours of unresponsiveness to pain; a flat EEG, no reflex, and no spontaneous respirations (Kohut & Kohut, jr, 1984; Sweeting & Gilhooly, 1991-92). Biological death takes place when the cellular activity ceases (Littlewood, 1992; Sweeting & Gilhooly, 1991-92). Of the other types of death described above, the most discussed and debated type is brain death. There is growing agreement that the significant point in the process of death is brain death, even through the total person, might not be completely dead (Littlewood, 1992)

Psychological death occurs when the person ceases to be aware of his or her own existence. In certain cases psychological death will be reversible (Sweeting & Gilhooly, 1991-92). Social death presupposes an externally valid criterion rather than a lack of awareness. Self-perceived social death occurs when the individual believes that his /her role in the world has stopped (Littlewood, 1992; Sweeting & Gilhooly, 1991-92).

Sociological death takes place when patient withdraws and separates from others and the community believes the individual had ceased to exist. Social death, unlike sociological perspective, occurs when the individual believes that he or she is as good as dead and that his or her roles in life have ceased (Kalish cited in Sweeting & Gilhooly, 1991-92) while Sudnow (1967) defined social death as a corpse though perhaps the individual is still clinically and biologically alive. Social death normally starts when the physician gives up hope for a patient's recovery and circumscribes the time for the

patients' survival.

From illness and disease models, on the other hand, researchers attempt to characterise dying in terms of it being a disease. Disease is defined within the medical model and refers to a physical phenomenon that lends itself to scientific explanation and control. Disease, therefore, helps us to understand physiological impairment or organic dysfunction. In contrast, illness is a human experience that can only be understood adequately with a moral and communicative context. Illness incorporates the psychological and social component of sickness or ill-health (Short, Sharman & Speedy, 1993). While few people would view dying in terms of it being a disease, many people who are dying describe their experience in terms of being physically injured. However, dying is not a physical illness in itself, it may be associated with the onset of an illness. There is no separate classification for complicated dying processes.

In recent years there has been a gradual development of the personal construct theory and cognitive models to explain and modify behaviour. These models reflect a confluence of learning theories (Littlewood, 1992). From this perspective, dying involves a person relinquishing his set of assumptions about the world and developing new ones to fit new circumstances. The new circumstances lead to major changes in his behaviour.

According to the theory, constructs are arranged in interrelated systems and the sum total of a person's construct system is that person's self. The fundamental premise of the theory is that a person's behaviour is

psychologically determined by the ways in which they anticipate events, from the perspectives people relate to the past in order to reach out to the future. Cognitive factors are also relevant to the dying person's need to come to some acceptable understanding as to why the death is going to occur. These models would help us to develop a mutual and acceptable understanding of the dying event.

The impact of nursing care on the dying

In view of what death and dying are discussed in contemporary societies, it is not surprising that nursing the dying is not only a difficult but an unappealing experience as well. One of the difficulties is that the data of dying may be presented and assimilated in a reasonably objective fashion. However, somewhere in the middle of all this is the fact that nurses who have a professional identity and a professional way of going about a day's work, while at the same time having a personal identity and a personal way of responding to the world. Because nurses have a unique contribution to make and special responsibilities, they want more understanding in these areas which might help to promote excellence in care. How does this help our nursing?

From the psychoanalytic point of view, loss causes some imbalance in the individual's psychological reaction. The emphasis may be on disintegration of the ego, primitive fear of destructiveness and abandonment; we should pay attention to interaction with patients. Such an approach would emphasise the patient-nurse

relationship and a means of providing interpretations and enabling the patients to gain insight into the cause and nature of their problems. Knowledge of the psychological responses to an impending death is quite advanced. Nurses can help patients and families feel less emotionally distressed. Thus in terminal care knowledge of psychological reactions and expertise is essential to inform support and comfort the patient. Wilson-Barnett (1988) stated that 'the function for nursing is the provision of continuous psychological care during illness or critical event' (p,6).

Furthermore, Glaser and Strauss (1968) support that explicit planning and review should be given to the psychological, social and organisational aspects of terminal care. The psychological and the social aspects of terminal care are carried out on the basis of private initiative and judgment. This means that medical and nursing personnel need to understand the characteristic trajectories of dying that occur on their specific wards. When they have recognised and understood these patterns, there should be explicit planning for coping with them, and provision for reviewing the results (Glaser & Strauss, 1968).

In addition, any nurse trying to help someone who is dying must pay attention to the context of intervention. Improving the social environment of care of the dying has had a great impact on attitude to death. Corner (1994) added that social attitudes and lack of experiences are likely to affect those caring for the dying as health care professionals. Death is actually a complex sociological phenomenon that is affected by many sociological variables

including age, gender ethnicity and social class (Holcomb, Neimeyer & Moore, 1993; Short, Sharman & Speedy, 1993). The sociological variables, therefore can affect their patients' responses to death and death preparation.

As society changes, attitudes towards death and dying, illness behaviour, clearly patients and their families each have a quite particular set of views. The context for care and the combined influence of the family must be understood in order to provide relevant care. As Wilson-Barnett (1988) suggested, the first nursing function is 'to understand illness and treatment from the patient's viewpoint and situation' (p,4)

Another aspect which impacts upon nursing is that the many situations in which patients' experience needs to be amplified and deepened in training so that they can meet the needs of the dying at all stages of their nursing careers (Corner, 1994). Glaser and Strauss (1965) and Corner (1994) pointed out that the training that nurses receive as students equips them principally for restricted technical aspects of dealing with dying and death. This emphasis is on the necessary techniques of medicine or nursing, not on the fact of dying itself. As Corner (1994) reported that

Many of the courses identified, particularly in the American literature, are within the field of death education. These focus closely on attitudinal, individual, and social belief system, in relation to death, with the aim of reducing death-associated anxieties, increasing feelings of comfort in relation to death and dying, and reducing the impact of the taboo of death. (p,783)

Corner (1994) commented that these approaches can be criticised for failing to provide nurses with the knowledge and skills to provide physical care for the dying. This perspective I would support by researches from Larson, (1987) and Mayer, (1987) that the findings have shown that the most important behaviour for nurses in providing care was 'Knows how to give shots IV, etc, and how to manage the equipment like IVs, suction machines, etc. In fact, nurses ranked it lower in these areas while the most important behaviour for the nurses' view point was listen to the patient, touches the patient when she/ he needs comforting and allows the patient to express his feelings about his/ her disease and treatment fully. I would end up with Mayer's comment in her research that 'patients may not be open or receptive to the expressive caring behaviours until basic physical needs have been met through instrumental activities' (p,51).

Conclusion

Working with dying patients involve several areas of knowledge and practice. In terms of the context, nurses might have knowledge about organisational requirements and value systems. The obtainment of relevant knowledge and skill means that nurses are in an advantageous position to help the dying patients and their families. Understanding reality and the meaning of patients' experience are therefore focal concerns' of nurse practice and require cognitive as well as effective application. Some usually regress both physically and emotionally, perhaps the greatest contribution of nursing in this context is to apply those three areas of knowledge to help each patient maintain a sense of identity and self-esteem in the face of total loss.

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