Meeting the needs of families of patients in intensive care units

THE INTENSIVE care unit (ICU) is a dynamic, potentially life-saving environment containing some of the most advanced technology available to nurses and medical staff. Anyone entering an ICU, particularly for the first time, may feel bombarded by the huge array of sensory stimuli (DeMayer, 1967) and within the ICU, patients and their families may experience psychological crises.

Initially, the main impact comes from the machinery – the flashing lights and the sound of the monitors and ventilators. As well as this, families see the staff using machinery, completing intricate patient-observation charts and performing life-saving tasks. Relatives are hit with the reality that their loved one is dependent on the life-support machines and on the drugs that are being administered.

This article discusses the ICU environment and the perspectives of families and nursing staff. In this article the word ‘family’ includes those visitors who are partners (married or non-married), companions and significant friends, in addition to the more traditional meaning of being related by birth or marriage.

The ICU environment

In ICU the patient is deprived of his or her familiar surroundings, while being bombarded with strange sensory stimuli (MacKinnon-Kessler, 1983). This can elicit the stress response called ICU syndrome/delirium. Signs of ICU syndrome range from disorientation to time and place, to confusion regarding the identity of their relatives, friends or even themselves.

When the syndrome is severe, the patient can experience visual and auditory hallucinations and, sometimes, paranoid delusions. Patients may also experience bizarre bodily sensations: this can be seen by watching patients attempting to pluck small, invisible, ‘bugs’ from their bodies and bedclothes (Eisendrath, 1980). To the family, this syndrome can be extremely distressing. This distress can also be caused by the patient being unable to recognise family members, or in extreme situations, believing they are harmful imposters.

Families in the ICU

Any admission to ICU signals the fragility of human life. The daily emphasis shifts from day-to-day life, and planning the future, to survival and the corresponding desire for things to be ‘as they were’. Admission to ICU can take various forms, span all age groups, illnesses and accidents. One constant factor is the need of the ICU patient to be supported through a life-threatening state of ill health. Often the patient is rendered unconscious by illness, accident or sedative agents and may be unaware of their fragile and critical state. The people who are always aware are the patient’s family.

Family members are typically in a state of fear and shock and need to be supported and cared for by nurses and other health care professionals. The need for accurate, understandable information is important, as is the provision of psychological support and guidance to all family members during such a distressing time.

There is an abundance of literature on meeting the needs of families of patients who are critically ill and the effects of critical illness on families themselves (Mendonca and Warren 1998; Molter, 1979). Studies have shown that family members experience high levels of anxiety and feelings of disorganisation in response to critical illness – not only during the experience but also for months after the event (Curry, 1995).

Visiting loved ones in ICU can create strain and tension due to the considerable time spent at the bedside. Home routines are disrupted by frequent trips to the hospital and healthy family visitors can submerge their own identities, neglect their own needs, and show signs of strain.

Commitments to their workplaces and to other family members can fall by the wayside as they channel their energies into the sick family member. This can cause emotional and financial tension, especially if the illness and recovery are prolonged.

The patient’s illness may cause members of previously dysfunctional families to be thrown together, many of whom may not have spoken to each other for many years. Within such families, long-term conflicts may be blocked out during the initial period of illness but as time goes on, underlying tensions between members may become more obvious. This can cause added stress to the family unit already visibly under strain and may be difficult for the nurse to handle fairly and tactfully.

In ICUs the staff-to-patient ratio is predominantly one to one. Under such circumstances it is common for close relationships to develop between the nurse, patient and his or her family. This nurse/family relationship can develop at a deep interpersonal level in a relatively short
time due to the threatening nature of the crisis.

At about this time, family members begin to experience the complete lack of control they have over their loved one and their own destiny. This may be further intensified by their lack of knowledge about the future.

Families will be seeking answers to questions such as: Will their loved one survive? Will there be a resulting disability? These questions are often asked of the ICU nurse who may be unable to give a definitive answer due to the unpredictable nature of the human response to any given treatment programme.

It is the ICU nurse who provides the ongoing care, support, information and assessment to help the family work through this distressing and uncertain time.

The role of the ICU nurse

Caring for the relatives of critically ill patients is an essential component of the ICU nurse’s role. The obligation to promote the well being and autonomy of patients and their relatives can be found in clauses one and four of the Code of Professional Conduct (NMC, 2002). Clearly it is something we are doing and should continue to do.

An important consideration is how this ‘family caring’ affects the nurses themselves. Despite advances in medical technology, a high percentage of critically ill patients die. Feelings of powerlessness are common among nursing staff; they become emotionally attached to their patients ofen only to see them die. The nurses may experience a sense of loss and personal failure.

Previous studies have shown that death and dying are more stressful for ICU and hospice nurses because they are more likely to experience these situations than nurses working in other areas (Power and Sharp, 1988).

Being around and dealing with ill patients and frightened or grieving relatives can be a stressful part of the ICU nurse’s role. Rodney (1988) suggests that nurses who work in ICU are at greater risk of ‘burnout’ than nurses working in other areas. Curry (1995) comments that nurses are only human and they do experience stress in dealing with psychologically traumatised people.

The closeness of the relationship forged, coupled with the care of the patient, has the potential to cause considerable distress to the nurse. The nurse has to continue to ‘give’ of him or herself and offer emotional support to all those who require it, when they require it. The nurse’s feelings of loss, hopelessness or powerlessness can be similar to those experienced by the patient’s families.

ICU nurses and families – the literature

Little is known about how ICU nurses view the family care-giving role. Most studies highlight the needs of the relatives rather than the experiences and needs of the nurses themselves. Studies such as those by Molter (1979) and Mendonca and Warren (1998) are two examples – although there are many more.

Hickey and Lewandowski (1988) undertook a descriptive study exploring the topic of families of critically ill patients from the nurse’s perspective. Nurses were asked to respond, on Likert scales, to a series of statements about their role with families. More than three-quarters (77 per cent) of those questioned indicated that it was emotionally exhausting to become involved with families who needed support, yet 86 per cent indicated that they would still become involved with families regardless of the possible costs to themselves.

Some 37 per cent of the respondents did not believe they had the required knowledge to meet the psychological and emotional needs of families and 38 per cent did not believe it was realistic to expect nurses to undertake this role at all.

O’Malley et al (1991), examined family needs from the nurse’s perspective. The study used an adaptation of the Critical Care Family Needs Inventory (CCFIN), first developed by Molter (1979). The nurses were asked which of the 44 ‘family needs’ identified were the most important to them. The categories included:

- Psychological – including relatives’ psychosocial needs, changes in condition of care and anticipatory needs;
- Cognitive – knowledge of treatment, quality of information and access to information;
- Physical and personal comfort.

Results showed that most respondents saw family needs as being important and 85 per cent felt able to meet these needs. Cognitive needs ranked higher than psychological needs.

Similarly, Hickey and Lewandowski (1988) concluded that interactions requiring little emotional involvement, such as explaining equipment and procedures, are more comfortable for ICU nurses and are more frequently done than interactions requiring emotional involvement such as discussing how family members are coping.

Both studies used quantitative methods of data collection; a research design that tends to restrict participants’ responses to a particular set of questions, statements or rating scales. Neither study really touched on the experiences and feelings of the nurses themselves, although both studies indicated a positive response to family caring, with nurses feeling that it is an important part of their role and that they should be doing it.

Conclusion

Caring for the families of critically ill patients is an essential component of the nurse’s role and a professional obligation. Although the ICU nurse is the person cited as being responsible for meeting the needs of the families, little is known about how the nurse views this role.

Most intensive care units try to offer open visiting for close family members. In practice this means family members could be by a patient’s bedside for most of the day – throughout all basic treatment and procedural interventions. How does the critical care nurse deal with the continued presence of the family members? Families can sometimes display emotions such as strong anger, although nurses understand this is a reaction to their stress due to the critical condition of their loved one.

To date there have been no published qualitative studies looking solely at the experiences of nurses when caring for the relatives of critically ill patients.

Key words

Management, ICU, Families

References


