Nurses’ experiences of caring for the relatives of patients in ICU

TO DATE, there have been no published qualitative studies looking solely at the experiences of nurses providing care for the relatives of patients who are critically ill. This phenomenological study, undertaken as part of an MSc, explores such experiences from the nurse’s perspective.

The study was an attempt to discover the ‘lived experience’ of nurses when caring for the relatives of patients who are critically ill. This in-depth study is not presented here in its entirety. Instead, I have attempted to present a selection of the findings that capture the world and experiences of nurses working in intensive care units.

Background
The ICU is a dynamic setting and a potentially life-saving environment, but its patients and their families are experiencing psychological crises. Many patients in ICU are rendered unconscious by illness, accident or sedative agents and may be unaware of their fragile and critical state. However, the patients’ families are always aware of the situation (Hardicre, 2003).

Literature review
There is an abundance of literature discussing how nurses can meet the needs of the families of patients who are critically ill and the effects of their relatives’ critical illness on the families themselves (Holden et al, 2002; Mendonca and Warren, 1998; Wilkinson, 1995; Coulter, 1989; Moller, 1979). Studies have shown that family members experience high levels of anxiety and feelings of disorganisation in response to the critical illness. These feelings are not only experienced during their relatives’ immediate crisis but also for months after the event (Curry, 1995; Evans, 1995).

Caring for the families of patients who are critically ill is an essential component of the critical care nurse’s role and is also a professional obligation (Hardicre, 2003; NMC, 2002). However, although critical care nurses are the professionals generally cited as being responsible for meeting the needs of the families of patients who are critically ill, little is known about how nurses view this role or about what effects it has on their ‘person’.

Method
In order to investigate the ‘family caring’ role of nurses it was essential to find a research design that would capture the reality – that reality being the world of the critical care nurse. I was keen to explore the ‘lived experience’ of critical care nurses participating in the study, to see their world through their eyes and to capture feelings, experiences and meanings. In order to capture these in an open, non-biased way I decided to use a qualitative method. I selected an approach known as the phenomenological method for the study.

The phenomenological method is concerned with the value of meaning and the social world from which meaning is derived (Taylor, 1993). It aims to capture individuals’ perceptions, attitudes, beliefs, views and feelings on the subject in question.

The great strength of the phenomenological method is that the data it captures is subjective and rich. It favours holism and uncovers the total structure of lived experiences, including all the meanings that these experiences have for the individual participants. It attempts to disclose the essential meanings of human experience.

Participants and setting
Three ICUs in the North West of England were included in the study and nine nurses took part. The study sample was recruited using a volunteer sample method. This involved circulating letters asking for participants, to nurses who had a minimum of three months’ experience of working in intensive care, in each of the three units.

Nurses with less than three months’ experience in the ICU setting were excluded because they may have had minimal ‘in-depth’ dealings with patients’ relatives and families. This is partly due to the fact that novice ICU nurses are overseen by more experienced nurses, which means there may be an element of ‘shielding’ them from families.

Morse (1991) describes a good informant as one who is articulate, reflective and willing to share his or her experiences with the researcher. This guided me to select the volunteer method to recruit the study sample. Nurses wishing to take part in the study were accepted if they fulfilled the above characteristics.

Written consent was obtained from all participants, and they were given assurances of confidentiality and anonymity. Internal ethical approval to undertake the study was obtained from the research governance committee via the research and development directorate for each hospital trust. In addition, one of the trusts required that I be given an honorary staff contract in order to study the nurses in its ICU.

The trusts’ clinical nurse managers were happy to be included in the study and assisted with the recruitment of participants by circulating letters on my behalf.

Data collection
Participants were asked to attend individual, tape-recorded, unstructured interviews. The use of the tape recorder was discussed with participants, who were able to decline its use if they found its presence intimidating. All participants agreed to have their interviews recorded. The unstructured interview is a flexible and adaptable
method of finding out about a subject – in this case, the experiences of critical care nurses. Unstructured interviews can be as natural as having a conversation with someone, but only if participants are made to feel comfortable enough to speak freely.

Although the interviews were unstructured, I devised a set of subject prompts to ensure the conversations stayed within the subject area being researched. Questions were posed in an open format and flowed from dialogue with the nurse being interviewed. Each interview lasted between 45 minutes and one hour. Interviews were conducted at a number of different sites, including the nurses’ homes if requested.

Data analysis
The interpretation of the raw data was initially guided by Van Manen’s (1994) process of thematic analysis, which states: ‘Thematic analysis refers to the process of recovering the theme or themes that are embodied and dramatised in the evolving meanings and imagery of the work.’ Additional guidance was sought from the work of Ely et al (1999).

Discovering the meaning or essence of a phenomenon is not a straightforward or easy task. The volume of data generated in a 45-minute interview and the time needed to analyse this data should never be underestimated. Although it is interesting, this time-consuming phase involves the researcher being submerged in data for long periods.

All the interviews were transcribed verbatim and read and re-read to look for the development of emerging themes. A theme can be defined as a statement of meaning that runs through all or most of the pertinent data, or through the minority of the data that carries emotional or factual impact (Ely et al, 1999). The themes that were developed in the interviews were shared with five of the participants for the purpose of validation. The following section discusses these themes and uses sample quotes from participants to give a flavour of the way they were expressed by the participants. Participants’ names have been changed to ensure confidentiality.

The world of the ICU nurse
I tried to explore what, if anything, the critical care nurses enjoyed about undertaking the role of providing care to the families of patients in ICU. It began to emerge that the nurses were able to get to know more about their patients through the eyes of the relatives and found that by doing this they knew everything about them – what they like, what they do – pretty much everything... yeah, you get to know them... their personality and you can put meaning to the person who is in the bed.

Jo Green discussed a similar motivation:

... the more they [the relatives] say the more you get to know the patient. You care for them in a strange way in ICU. You virtually take over all their bodily functions. You care for them and their machinery and the drugs that are keeping them alive – but you don’t know them. They are just there – lying there – and you do everything for them and to them. It’s the relatives who tell you about them... the more they tell you the more you view that body in the bed as a person... They really give an identity to the person you are caring for... which is great.

These two participants raised an extremely important area for critical care nurses: getting to know your patient through the eyes of the relatives, giving them an identity, a personality and a history.

The ICU can be a very mechanistic environment and the quote below from Jill Spinks clearly demonstrates the dichotomy between technological mastery versus the therapeutic art of nursing:

Of course we are supposed to be nursing holistically and individualistically – but you can become very robotic in ICU – you tend to do things to people – you can’t ask them if they feel better – you just look at the monitors and the gases and all that. When you have got to know the family more you tend to view the patient in a totally different way. I think that’s wrong really because we should view them like that anyway... but you don’t.

Another participant, Kelly Richardson, identified this phenomenon in one of her colleagues:

I was chatting to a new nurse... when they start here they learn about things, the ventilators, the pumps, the drugs, what inotropes do and all that. But they can forget that there is actually a patient there – you know... a human being.

Despite the fact that the nurses admitted to depersonalising and dehumanising care, they stressed the importance of relatives in helping them to humanise and personalise their practice again. Many of the participants described having experienced sadness and dissatisfaction when they had been nursing a critically ill or dying patient where there was no family involvement at all.

The majority of the nurses interviewed discussed how close they became to the families in their care, while a minority preferred not to get too close at all. Ms Green disclosed the motives behind her choice to develop close relationships with her patients’ families:

You develop this strange relationship with them... they...


**REFERENCES**


Not being able to make it better

It became apparent that not being able to make things better for their patients’ families was a significant and constant source of distress for the participating nurses. Several of them discussed experiencing feelings of powerlessness and inadequacy. Ms Ryan said:

...sometimes they are just helpless. They reach out for an answer but sometimes you just can’t give them an answer, can you? You can’t give them an outcome. They are just wanting for you to say that it will be alright and he will live – but you can’t say that because you don’t really know... they seem uncomfortable with that because they feel sometimes that you should know – when none of us really do.

Some of the nurses felt that not being able to give a definitive prognosis led the family to believe they had inadequate knowledge and questioned their practice as a result of fear and mistrust.

Breaking bad news

The nature of the ICU dictates that the nurses are constantly faced with death and the demands of breaking bad news to patients’ relatives. Nurses work to support the relatives through this upsetting and stressful time in spite of feeling the stress and sadness themselves. Christine White explained:

**The worst part is watching them grieve. When you have told them bad news and you have got to know them – I find that hard... even though it is very upsetting to me as a nurse and a person I would still choose to do it. I find it very hard sometimes... if you have got close to the relatives you get upset along with them.**

Ms Ryan felt the same way:

**You can’t help but be touched by someone else’s sadness... surely that’s not possible – you would have to be really hard not to get affected by another human grieving... It’s sometimes so sad, just looking after someone – trying your best – especially when someone young dies – that – well, that drives you mad.**

Not getting on with relatives

Of course, it is only natural that nurses do not get on with some of their patients’ family members. They are only human, and no one can get on with everyone all the time. To the critical care nurse this can be a real problem as they are still duty bound to provide these people with the same level of care as other family members. This issue was discussed frequently by many of the nurses. Mr Hall pointed out:

**It’s not that I don’t get on with them... most of them I...**
do. Some of them annoy me because I find them very intense...I am never nasty or anything like that. I always tell them what they need to know. I just don’t get too close to them. There are some you never have the banter with...some you never get to know. Some you just don’t want to because you don’t get on with them all that well.

Ms Green’s feelings about relatives were similar:

Sometimes when you know you are going to have to face them [the family] again on your next shift it makes you not want to come to work. I don’t think it’s on because it distracts you from what you are really there for.

Fear, distress and family dysfunction can lead to the nurse being in the ‘firing line’, with families displaying anger and animosity towards the nurse. The close proximity of the visiting family, combined with prolonged visiting hours, can make this a stressful time for the nurse. Mr Wood discussed how he deals with this:

Well, I tend to just act in a very professional manner and just give them information but nothing more. I don’t get close to them or anything like that and I don’t tell them anything about myself. I don’t think they have the right if they are nothing but nasty to you. Of course I don’t treat them in a bad or unfriendly way. I just do what is necessary.

Finally, nearly all of the participating nurses discussed taking ‘time out’ as a method of coping with the demands of the families. Ms Green summarised this:

I must admit I often have to have a rest from them. If I ask them to leave, let’s say to do a dressing or a turn, I don’t rush and I don’t rush to send someone out to get them. I just wait for them to buzz the buzzer. I don’t think that’s cruel or anything. It’s good to have a break because sometimes it’s on the tip of your tongue to say something like: ‘Oh just give me a break and leave me alone to do my job for a bit.’

Poor preparation and training
Some of the nurses interviewed felt that they were not adequately prepared, either educationally or psychologically, to provide care to their patients’ families. Some also felt their colleagues did not support them in this role. Ms White stated:

None of us receive any kind of training and I think that’s poor. I’d be interested to know what other units do, but we don’t do anything. There must be something available either to teach people how to do it or how to cope with it when we are doing it.

Ms Green said:

I don’t think I was prepared at all. I came from a different area where the relatives’ needs were different...it’s much harder here. You get all the stress and family rows in front of you...you know, mistresses and all that...because everyone thinks they are going to die, so people come out of the background, men, women, sons, daughters. That can be really difficult to handle sometimes and something you don’t really get on the wards.

And Mr Wood said:

I do think there should have been some kind of bereavement training – or [training on] breaking bad news or something like that. You need to get used to being so blunt and forward because it can be so hard.

Limitations of the study
This paper focuses on the experiences of a small group of nurses working in the critical care setting. Although the study was performed on three sites, its findings cannot be generalised to all nurses working in these areas. In accordance with Paley (1997), phenomenological research cannot claim to represent the universal ‘lived experiences’ of all nurses.

Implications for practice
Although this is a small-scale study, it has clearly demonstrated the importance of nurses providing support and care to the families of patients who are critically ill. Many nurses, including those who took part in this study, recognise the benefits of performing this role.

However, we must also try to understand the effects this role may have on the nurses themselves. It is known that the work of the ICU nurse is stressful and there is an abundance of research papers discussing burnout and high turnover rates (Foxhall et al, 1990; Rodney, 1988). The comments from the nurses participating in this study have demonstrated that caring for their patients’ families can be a source of considerable stress. These nurses also said they felt ill-prepared to fulfil this role.

Critical care training does tend to be competency-based, and this is important given the environment and the highly technical skills required by critical care nurses. However, the specialty also requires nurses to have ‘people’ skills to support their patients’ families – and their patients as they begin to recover. Perhaps there is a need for a little more emphasis to be given to the psychological aspects of the care-giving role – including the family care-giving role – in training courses. This would not only help nurses to develop the skills they need to perform this role effectively but would also teach them how to cope when stressful events occur.

Caring for colleagues is just as important as caring for patients’ families, and both groups would benefit from improved training for critical care nurses in how to care for their patients’ families. Perhaps those responsible for devising and teaching critical care nursing courses should examine their curricula to see how well this is covered. If it is not adequately dealt with, it may be time to care for their colleagues by revisiting the drawing board.