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Empowerment from the perspective of next of kin in intensive care

Abstract:

Aims and objectives. The aim of the study was to describe next of kin empowerment in an intensive care situation.

Background. Next of kin is important in reducing intensive care patients' fear and anxiety. However, admission to an intensive care unit is often recognised as an extremely stressful event, causing next of kin to experience shock, fear, anxiety and vulnerability. More knowledge is needed about how next of kin in intensive care can be empowered.

Design. The study was conducted using a phenomenological method.

Methods. Ten interviews were conducted with intensive care patients' next of kin.

Findings. Perceptions of both a genuine will and a capacity to help and relieve were found to be essential for next of kin's experiences of empowerment in an intensive care situation. All informants were empowered by a caring atmosphere in which they received continuous, straightforward and honest information that left room for hope and in which closeness to the patient was facilitated and medical care was experienced as the best possible. Some of the informants were also strengthened by support from other family members and/or by being involved in caring for the patient.

Conclusions. Next of kin empowerment was found to be associated with being met with human warmth and sensitivity. This emphasise the importance of discussing attitudes and behaviours as well as surveillance and treatment when trying to improve the care of next of kin in ICU and when working with staff development.

Relevance to clinical practice. Knowledge of how to empower next of kin in an intensive care situation allows caring staff to support these persons in a more sensitive and appropriate way. Findings underline the importance of creating caring relations with patients' next of kin.

Key words: nurses, family, empowerment, interview, experiences, critical care

Introduction

Admission to an intensive care unit (ICU) is often associated with severe acute illness and is recognised as an extremely stressful event, for both the patient and his/her next of kin (McKinley *et al.* 2002, Paparrigopoulos *et al.* 2006). Wright *et al.* (1996) stated that illness is a family affair, as it influences the whole family and the family influences the experiences of illness. Next of kin may play a critical function in intensive care patients' illness and it is important to consider them in patient care (Hammond 1995). When interviewing ICU patients about the role of those nearest them during their ICU stay, Bergbom and Askwall (2000) found that the presence of next of kin could give intensive care patients feelings of security and protection when they felt powerless, insecure and exposed. Patients expressed feelings of an 'inner calm' when their next of kin was with them. Even when they were asleep, they could 'feel' the presence of a family member and however good and kind their caregiver was, this was not the same as the very special contact they had with their next of kin. The next of kin provided an input of positive energy and strength, contributed to the patient's well-being and helped encourage them to not give up (Bergbom & Askwall 2000, Wåhlin *et al.* 2006). Next of kin have also been found to be important in reducing patients' fear and anxiety (Hupcey 1999, Wåhlin *et al.* 2006) and in increasing patients' experience of safety, value, motivation, joy of life and will to fight (Wåhlin *et al.* 2006).

Calm and well informed next of kin can transfer knowledge about the patient, calm him/her down and constitute a link between the patient and reality (Williams 2005). They are thus a valuable resource for not only the patient but the caring staff as well (Söderström *et al.* 2003). However, admission to the ICU is often a traumatic experience, causing next of kin to experience shock, fear, uncertainty, vulnerability, worry (Engström & Söderberg 2004, Hughes *et al.* 2005), unreality, anxiety and depression (Leske 1998). With a high level of

stress it could be difficult to concurrently support the patient (Leske 1998). Communication between physicians and next of kin is not always adequate and next of kin often do not understand the medical information (Azoulay *et al.* 2000). This also restricts their ability to support the patient, as does any participation in decision-making when a patient's condition restrains his/her own participation (Azoulay *et al.* 2004). Nurses can either facilitate or hinder the family in supporting the ICU patient and through their behaviour often maintain a position of power in relation to next of kin (Hupcey 1999).

Empowerment has been widely used in different disciplines including psychology, social work, education and nursing, although no unambiguous definition of the concept exists (Ellis-Stoll & Popkess-Vawter 1998). Rappaport (1984) considered empowerment easy to define in its absence (powerlessness, helplessness, alienation, loss of sense of control), but more difficult to define positively because it takes on different forms in different people and contexts. Mok (2001) described empowerment as a process whereby patients develop a sense of inner strength through connection with others, including families, friends and health care professionals. Empowerment has also been seen as a process of overcoming a sense of powerlessness or a model through which people may develop strengths and strategies to face current problems (Man *et al.* 2003). An empowering relationship is mutual and supportive (Finfgeld 2004) and generates increased knowledge and skills (Man *et al.* 2003), self-determination and power within oneself (Mok *et al.* 2002, Bulsara 2004). An empowered person does not pretend to have more power, but feels more powerful (Kieffer 1984).

Next of kin have to be empowered and receive support to allow both internal and external resources to cope with the situation (Johansson *et al.* 2005), but more studies are needed to provide descriptions of the experiences of family members and to enable an understanding for

the optimisation of family and patient care in ICU (Verhaeghe *et al.* 2005). The aim of this study was to describe next of kin empowerment in an intensive care situation. Empowerment is reflected as experiences of inner strength and power and of participation in care.

Method

Design

A phenomenological approach was chosen because of its ability to reveal how we experience the world we live in (Rapport & Wainwright 2006). Phenomenological analysis is based on presences or experiences, not in their objective sense but in the meaning the phenomenon has for the subjects experiencing it (Giorgi 1997). To know the phenomenon as it shows itself, pre-assumptions and theories must be set aside (bracketing) so that the phenomenon can be met in as free and unprejudiced a manner as possible (McNamara 2005). In accordance with Karlsson (1995), the researcher's pre-theoretical lived understanding of the phenomenon is, however, a prerequisite for being able to perform the specific investigation with its specific interest and aims and an understanding of a phenomenon takes form in the tension between the researcher's pre-understanding and his/her striving to be as open as possible.

Context and data collection

The study was conducted at two general ICUs in southern Sweden. There was an open visitation policy in the study units and the work schedule was flexible and prepared periodically by the staff group. Most patients were cared for in a single room or a two patient room. Patients and their next of kin were not linked to any special nurse or contact person.

Inclusion criteria were next of kin to a patient, cared for in ICU for three days or more due to failure in vital organs. Ten interviews were conducted during 2006. As two family members were present during three of the interviews, a total of 13 informants were involved. A purposeful sample with maximum variation was used to obtain as wide a range of the phenomenon as possible (Coyne 1997). This strategy aimed at capturing and describing the central themes that cut across a great deal of variation, as common patterns that emerge from great variation are found to be valuable in capturing central shared dimensions of a phenomenon (Patton 2002). Next of kin (further described as informants) of different ages, genders and relationships to the ICU patients were selected in collaboration with ICU nurses in each department. Informants were contacted by the first author within two weeks after discharge from ICU to another department, as memories from the ICU period then were expected to be fairly fresh. When a patient was still in poor condition or had died, the informant received a new request later. No patient died in ICU, but some of the patients deteriorated after discharge. All informants were given the opportunity to choose when they wanted to be contacted again, as well as when and where they wanted the interview to take place. Informants were between 35-75 years old and were spouses, siblings, parents or children of the ICU patients. Patients were between 16-81 years old and had been cared for in ICU between eight and 21 days. The interviews were conducted by the first author in a quiet room at the hospital or at the informants' homes or workplaces, between one and 60 days after the patient had been discharged from ICU. Differences in when the interview took place depended on differences in when informants had time and felt strong enough to participate in an interview. During the interviews, informants were asked to narrate their experiences from the ICU period in as much detail as possible (Kvale 1996). Follow-up questions were posed according to their stories. When informants for example talked about staff as fantastic, follow-up questions were posed about what staff did when experienced as fantastic and about

thoughts and feelings experienced in these situations. When they talked about being sad or broken they were in a similar way asked to tell more about these situations. Each interview lasted between 30 and 65 minutes and was recorded and transcribed verbatim.

Data analysis

Data analyses were conducted in accordance with the empirical phenomenological psychological method, developed by Karlsson (1995). First, the transcribed interviews were read until a good grasp of the whole had been obtained. The text was then divided into smaller meaning units reflecting different meanings in the text, according to the aim of the study. The meaning units did not follow linguistic or grammatical rules, but instead divided the text where a shift in meaning was discerned. One meaning unit could consist of a few words and another of several sentences. Each meaning unit was transformed from an informant's concrete expressions into a new more common text based on a nursing perspective. Giorgi's (1997) clarification, that each researcher has to analyse the description from the perspective of his/her discipline and transformation has to be expressed in terms relevant to the scientific discipline being used, is also suitable to Karlsson's (1995) method, used in this analysis. After transformation, meaning units were synthesised into one specific description of the phenomenon for each interview. Lastly, the ten specific descriptions were compared and synthesised into one description of the next of kin's experiences of empowerment in intensive care. During the whole process, an attempt was made to remain as open and free from pre-assumptions as possible. The analysis was performed by the first author. Co-authors read the interviews and analyses and findings were discussed within the author team several times during the analysis process. Analysis resulted in general and typological structures (characteristics). The five themes running through all interviews were called general structures, while two themes found in some but not all interviews were called typological

structures. An essential structure reflecting all general and typological structures was also identified.

Ethics

All informants received verbal and written information before choosing whether or not to participate. They were informed that all information would be handled with confidentiality, that no specific individual would be recognisable in the final results and about their ability to discontinue participation whenever they wanted, without giving a reason. The study was approved by the local ethics committee in southeast Sweden.

Findings

Experiences as next of kin to an acute, seriously ill intensive care patient strongly affected informants. The ICU period was sometimes expressed as the most terrible time in their life, but descriptions of this period as including some of the best experiences in their life also occurred. Findings showed that all informants were empowered by a caring atmosphere in which they received continuous, straightforward and honest information that left room for hope and in which closeness to the patient was facilitated and medical care was experienced as the best possible. Some informants were also empowered by family support and/or participation in caring for the patient. All these things contributed to experiences of inner strength and power and increased next of kin's ability to handle the traumatic situation. An essential structure for the next of kin's experiences of empowerment in an ICU situation was found to be the experience of both a capacity and a genuine will to help and relieve.

General structures

A caring atmosphere with human warmth and sensitivity

A warm and positive atmosphere at the ICU, with good relationships between patient, staff and next of kin, was essential to next of kin's experience of empowerment. Good relations generated energy and contributed to increasing next of kin's experience of inner strength and power. Informants were satisfied to see staff being careful, gentle and tender with their ill family member by talking and listening to him/her, encouraging, commending and stimulating him/her to fight, coaching for physical and mental recovery or expressing joy and appreciation at improvements.

Informants needed to always feel welcome and appreciated and to be recognised by the staff. It was valuable to be met with empathy in an unaffected manner and, when needed, to receive support or advice. Even those who usually experienced themselves as strong were not so in their role as next of kin at the ICU. They needed consideration and support from the staff and wanted to feel that the staff cared. As the needs of informants vary, support ought to be adjusted to each individual. A question about how the next of kin feels could serve as an invitation to talk about feelings and experiences for those who need it. A hug, a relieving conversation, comprehension or sympathy was often appreciated. When the next of kin spent a great deal of time at the ICU, with limited ability to communicate with the patient, chatting with caring staff about everyday things could be experienced as relieving, as was even a joke or a laugh. It was also valuable to receive support in saving some energy for time after the ICU:

So, we felt, well, it's difficult for me to explain how thankful we are...and how good they acted, brotherliness, love, love to humans they didn't know, it was such, such a good time - it's one of the finest things I have ever experienced and can hang on to. (Interview 2)

Even if the next of kin were met with kindness in most cases, negative meetings sometimes occurred and could even overshadow the good ones. It happened that individual staff members were regarded as unsuited for a healthcare occupation. They could be experienced as heavy-handed, uninterested, unpleasant and neglectful to both patient and next of kin. However, informants tried not to say anything because they did not want to hurt their ill family member or risk him/her receiving a lower level of care:

I completely understand that everyone has bad days, that's not strange. But in this case...those two I happened to meet here, I don't think it has to do with bad days, if that's the case they have bad days all the time. It feels like they simply are not suitable for working in healthcare. (Interview 3)

Closeness to the patient is facilitated

Next of kin were allowed to stay at the ICU as much as they wanted to. The ability to be close to the critically ill family member was said to be of greatest importance. Their struggle to manage the situation was facilitated and they were empowered when they felt welcome at any time. While at home, the informants sometimes became anxious and upset and one way to maintain self control was to go to the hospital and see how things actually were. During critical periods, some informants wanted to be at the hospital all the time. As they often, in this distressing situation, felt neither hunger nor the need to sleep, they required support in the form of something to eat and information on how to find a bed nearby. As the patient was

often connected to several tubes and instruments, the informant also needed guidance about where to sit without being in the way of the caregivers' work and about touching and talking to their ill family member, even if he/she was not conscious:

...and yeah, said what you could do and things like that, like even when he was sedated, you could talk to him and hold his hand and things like that, but that I shouldn't try to wake him up, but he could feel our presence anyway in, in his sleep... and it's good when you get that.

(Interview 11)

Experience medical care as the best possible

Reliance on medical care as top quality was found to be essential. This was attained when experiencing staff as competent and caring and as taking the time necessary, together with sufficient medical resources. The next of kin realised that their critically ill family member was absolutely dependent on technical equipment and staff with skills in supervising and knowledge about how to address any instance that may occur. A registered nurse or enrolled nurse always close to the patient, paying attention to his/her needs, whether it be pain relief, treatment regulation or psychological support, was important for the next of kin's experience of good and safe care. Information from physicians on considerations about medical care plans and consultations with other specialists, when applicable, also contributed to a belief in the high quality of the medical care:

...[staff] remained close to the bed and then constantly looked at these curves and made sure everything was all right and they could adjust and all that. So many technical aids! (Interview 2)

Receiving continuous, straightforward and honest information

Continuous information was found to be of crucial importance for the next of kin's experience of empowerment in an intensive care situation. Anxiety and uncertainty caused energy loss, while knowledge about the patient's condition, treatment, analysis and future plans reduced anxiety, increased next of kin's experience of inner strength and power and contributed to feelings of safety in an often quite chaotic situation. The opportunity to receive information through personal meetings as well as by telephone, in accordance with the informant's actual need, was invaluable.

The next of kin often felt uncertain before their first visit to the intensive care unit and feared the sight they would be met with. If they had been prepared by professionals' explanations of the patient's state of ill health and of connected machines and instruments before being accompanied to the ward room, they experienced the situation and environment as a bit less frightening:

Then, it's been maybe an enrolled nurse who opened the door and fetches a registered nurse...and then tries to explain before going in...how it is, why that machine is there and why that machine is there...so when I enter the room, I won't be afraid of the machines (pause, sobbing). And then, they accompany you in...and likewise when the visit is over they come and...ask how I felt (pause, crying). So, that feels...good... (Interview 9)

All informants wanted straightforward and honest information about what was going on and what was expected to happen in the nearest future, but not everyone wanted knowledge about the prognosis from a longer perspective. They wanted to be invited to meet a doctor and ask

questions. Even if registered nurses and enrolled nurses were mostly accessible for information, some informants experienced a lack of physician information and of information about social and economic entitlements.

Each member of staff was important in the information sharing process. Enrolled nurses had to explain what went on in the ward room, as well as about surveillance equipment.

Registered nurses told about what had happened during the day, test results and ongoing treatment, while doctors informed more comprehensively about reasons, operation details, plans and prognoses.

Possibility to feel hope

Recurrent deterioration, waiting and continuous worry tormented the next of kin, as did conceptions of a future in which the ill family member remained unconscious or incapable of moving. Feelings of uncertainty, anxiety and disappointment emerged, but were often repressed to handle the situation, be positive and coach the sick family member. Hope and despair often took turns, but the next of kin always needed to feel some small ray of hope, even if they understood that the situation was critical. Hope increased and they felt happy when the patient began to show some sign of life, for example moving his/her hands or legs, squeezing a hand, looking up or breathing without assistance. It was valuable for informants to always find something that had improved, despite the patient's condition having deteriorated in other aspects. Helplessness and anxiety decreased and next of kin were energised and empowered when they received support in maintaining some hope:

There was always some parameter that had improved, that you could console yourself with for a while. Despite something else maybe having deteriorated, or worse, there was something

you could say and that felt..., you grasp at those kinds of straws all the time when you are...to manage, to be able to go on, it happens like that. (Interview 5)

Typological structures

Support from other family members

Incessant travel, trying visits at the ICU, ongoing responsibility for ordinary work, home, pets and so on, made the next of kin exhausted, even if they often did not permit themselves to experience these feelings until the ICU period was over. Although it could be trying to see another family member sad or to console and take care of others, when they themselves were sad they often found support from other family members of great importance. Family members shared things such as anxiety, decision-making and joy. They accompanied each other or took turns at the hospital. Sometimes, family members served food or took care of children. Some informants experienced that family members became more closely knit when rallying around a critically ill family member. They saw each other more and in the gravity of the situation talked about things they usually did not discuss:

...and then I felt, no, I can't manage this. I don't want to be here alone. I wouldn't have been able to manage that...then David (assumed name) stayed too. It was always nice when there were two of us. And it was the two of us the whole time. (Interview 4)

Being involved

Through always being informed and following developments, the next of kin felt involved in the care process, even if they were never asked their opinion regarding the treatment. They often experienced themselves as being able to support and calm their ill family member by

being present, holding their hand or talking to them and staff sometimes told them how essential this was for the patient. Some informants were allowed to choose whether or not to stay in the room while the bed was being made or the patient's sores were being dressed and some got involved in caring for the patient by lubricating their lips, wetting their mouth, bathing their forehead or bringing them something to drink. Sometimes, they even learned to interpret certain measurements and values themselves:

When he wanted to drink... one of the staff came with this little jar, it looked like some kind of skin cream and said you can take this and lubricate his mouth because it feels nice.... and then I got to, she showed me how to do it. (Interview 2)

Essential structure

Capacity and a genuine will to help and relieve

The unfamiliar environment in combination with the gravity of the situation made next of kin feel dependent and exposed. How different acts were performed became just as important as what was performed. In a caring atmosphere in which both next of kin and patient were met with compassion, respect and human warmth and caring staff showed an ambition to interpret and satisfy their needs, informants experienced a genuine will to help and relieve. This was also the case when closeness between next of kin and the patient was facilitated and when continuous, straightforward and honest information was provided. Excellent medical care, including qualified medical staff and advanced technical equipment, was experienced as a sign of capacity. Experiences of both capacity and a genuine will to help and relieve were found to be essential for next of kin's experiences of inner strength and power. This also

constituted the foundation of a trusting and supportive relationship, necessary for the empowering process.

Discussion

This study aimed at describing next of kin's experiences of empowerment in an intensive care situation. The main findings were that perceptions of both a genuine will and capacity from the staff to help and relieve were necessary for next of kin to experience inner strength and power. It did not help if medical care and technical equipment were excellent if the next of kin did not experience that the patient and they themselves were met with human warmth and sensitivity. This emphasises the importance of discussing attitudes and behaviours as well as surveillance and treatment within development in ICU.

A warm and positive atmosphere was found to be of greatest importance. Informants were very sensitive to signals transmitted by caring staff. They became empowered when staff showed a genuine interest and tenderness for them and the patient, when their presence was appreciated and when staff attempted to interpret and satisfy their needs as well as those of the patient. The importance of atmosphere has previously been described for example by Edvardsson (2005). He found that feeling welcome and being seen, as well as experiencing not only that you are being cared for but also that you are cared about, were valuable components in a caring atmosphere. Rushton (2007) advocated that when creating healing environments, we have to build up a workplace with authentic and respectful norms among patients, families and healthcare professionals. When environmental aspects are discussed within intensive care, emphasis is often given to the physical environment such as planning, colour, light, sound and pictures (Fontaine *et al.* 2001, Stichler 2001). Even if the physical

environment of care impacts the way the care is provided, initiating and sustaining a therapeutic relationship with patients and their families is central in a caring and healing environment (Felgen 2004) and there is a need for further discussion about this topic within intensive care.

Information was found to be of crucial importance to next of kin's experience of empowerment but it needed to be continual, straightforward and honest. Besides a caring relationship, knowledge is often regarded as one of the cornerstones in an empowering process (Ellis-Stroll & Popkess-Vawter 1998, Florian & Elad 1998, Man *et al.* 2003) The importance of information has also been focused on in accordance to next of kin's needs in intensive care by, e.g., Verhaeghe *et al.* (2005) and Alvares and Kirby (2006). About half the items in the commonly used Critical Care Family Needs Inventory (Molter 1979) involve information. Even if the importance of information is well known and the next of kin in the current study mostly experienced good information, a few informants seemed to feel that information from physicians was lacking. This was perhaps because some informants were at work during the day and only the emergency physician was present when they visited their ill family member in the evenings. If we only are aware of this problem it can be solved by, for instance, booking an information time in advance or holding a telephone meeting.

Findings indicated the importance for the next of kin in the study to always maintain some small ray of hope, even when the situation is critical and the prognosis is bleak. Similar findings have been described by Molter (1979) and Coulter (1989), for example. ICU staff could, however, be afraid of giving too much hope – simultaneously satisfying next of kin's needs to feel hope and providing straightforward and honest information is undeniably a balancing act that demands both skill and experience.

Participation has mostly been discussed in association with decision-making (Azoulay *et al.* 2004, Levy & McBride 2006) or involvement in physical care (Hammond 1995, Eldredge 2005). Even if next of kin, through being involved in physical care, could demonstrate their love and affection for their relative and at the same time feel less frustrated at not being able to do anything to help (Eldredge 2005), it is important to note that not all next of kin want to take an active role in physical care and one must be sensitive to this, so that no one is pushed into doing something they do not want to do (Hammond 1995). In the current study, participation was experienced not only when engaged in caring activities, but also when involved in what was going on and when allowed to be present. None of the informants had any experience or wish concerning involvement in decision-making regarding the medical care at the ICU. On the other hand, this topic is discussed mostly in regard to the withdrawal of life-supporting treatments when the chance of recovery does not exist and no informant had experienced this type of decision at the ICU as no patient died until after discharged from ICU.

Relevance to clinical practice

Knowledge of how to empower next of kin in an intensive care situation allows caring staff to support these persons in a more sensitive and appropriate way. Findings underline the importance of creating caring relations with patients' next of kin.

Study limitations

A limitation of this study was that only next of kin who were present at the ICU were asked to participate and were interviewed. Perhaps those who did not visit their ill family member

during their ICU period had other experiences of strength, power and participation. On the other hand, it is perhaps only those we as ICU staff members meet whom we are able to help.

It is also important to be aware that empirical data are always limited in relation to the experiences themselves, due to the impossibility to recall or narrate all details of an experience. The time between departure from ICU and interview could have influenced informants' memories and stories, but many similarities in meanings of experiences were found, independent of when the interviews were performed. The study included patients with failure in vital organs. Length of stay in ICU was eight days or more and findings derive from this group of patients.

Conclusions

Experiences from intensive care strongly affected next of kin and if memories from this period are to be mainly good or bad seems to have less to do with the result of the care than with experience of how the care was performed. It did not help if the medical care and technical equipment were excellent and next of kin did not become empowered, without experiencing the patient and themselves being met with human warmth and sensitivity. This emphasises the importance of discussing attitudes and behaviours as well as surveillance and treatment when working with staff development in ICU and when trying to improve care of ICU patients and their next of kin.

Contributions

Study design: IW, A-CE, EI; data collection and analysis: IW, A-CE, EI; manuscript preparation: IW, A-CE, EI.

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