Nurses' Perspectives on Family Involvement in Intensive Care

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ABSTRACT

Objective: The purpose of this study was to explore how nurses perceive the role of the family while caring for the patients admitted in intensive care of Raja Isteri Pengiran Anak Saleha (RIPAS) Hospital, Brunei. **Methods:** An exploratory, qualitative design was used to explore nurses' insights on the inputs of family in intensive care. Ten nurses who fit the inclusion criteria were invited using a purposive sampling method. They were individually interviewed and were audio-recorded with the consent of the nurses. These interviews were coded and thematically analysed. **Results:** Three major themes emerged from the study, including importance of family presence, concern over patient safety and question about family readiness. **Conclusion**: The results of this study concluded that the family role is expressed through their 'presence' in intensive care which is significant in patient care. The study also identified concern over patient safety and query into the family readiness to get involved in the intensive care.

Keywords: Involvement, Family, Qualitative, Intensive Care, Readiness, Patient

INTRODUCTION

Family involvement in caring for patients is strongly recommended in most hospital guidelines and policies. Within the health care system itself, numerous efforts and interventions have been made to increase patient and family involvement in patient care, for example, the intervention may include access to informational resources, educational seminars and behavioural approaches. Such interventions are intended to improve patients' and families' ability to participate in inpatient care (1). One study, amongst others, have recommended five critical components of family and patient involvement: presence, having ones needs to be supported, communication, decision-making and contributions to care (2). Family involvement varies by stakeholder: some families perceive being present as involvement, while others view it solely as physical involvement in the provision of care. The study argues that family involvement tends to be oriented towards relatively passive forms of involvement, such as family presence. By contrast, some families expressed the need to perform caring tasks for the patient, despite the patient's condition, and the need to have this care supervised by the patient's nurse (3). Two quantitative studies were carried out from the families' perspective, indicating that family members often participate in performing care, such as dressing and feeding the patient (4, 5). Patients often receive unskilled and non-professional nursing care from their family members (5). Family members also play a part in decision-making when patients in intensive care are critically ill and unable to speak on their behalf; in this case, the family can help decide upon treatment options. A limited number of articles, however, address the involvement of the family as a decision-maker. One study conducted in North America reported that the family's involvement in decision-making is the least frequently addressed elements in nursing care (6). This study highlighted that shared decision-making was viewed as an important area for quality improvement in intensive care.

Nurses play an essential part in engaging family members in patient care; their perceptions of the involvement of the family in patient care; however, often vary. Several quantitative studies

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have established that nurses have a positive attitude regarding inviting a patient's family to provide simple routine care (7, 8, 9, 10). Family involvement is appreciated and seen as a great resource by both patients and intensive care nurses (11). The nurses believe that family participation is both voluntary and positively encouraged. Not only that the presence of family members in intensive care facilitates a better understanding of the patients, but it is particularly significant when patients cannot speak for themselves. The patients get comfort from the presence of a relative beside them (5).

On the other hand, a qualitative study conducted reported that intensive nurses expressed resistance to involving family caregivers in care, even though they expressed the desire to participate (3). Although intensive care nurses may be reluctant to involve family, they suggested that having clear policy guidelines was critical before engaging families in safe and effective care (3, 8). There have been limited policies and procedures to guide nurses in implementing family engagement in caring for the patient (10). While the involvement of the family is central to patient care, such participation must be based upon a planned and structured framework to ensure a safe and satisfying experience for patients, families, and the health care team (12). Although the literature has highlighted nurses' positive attitudes towards family presence, little empirical evidence has been provided to show how nurses fundamentally attempt to involve family members in care.

Meanwhile, several factors may hinder family involvement in care. For example, nurses are hesitant to involve families in care due to their perceived impression that families' are interfering in care and exhausting the patient (10). A family's acting as a decision-maker may influence health-care decisions but also can be a source of conflict for the patient and clinician (13), as their views on the types of care provided may differ. Additionally, conflicts cannot be exclusively linked to cultural differences, but they do relate to differences in participants' views on what defines 'good care' based on different care approaches (14). A survey identified several barriers from the perspective of intensive care nurses, including fear of harming the patient or family member, the time required to train and supervise family members, the desire to preserve the patient's modesty and the availability of family members to participate (9). Meanwhile, restricted visiting hours may also hinder family involvement in care, as the vast majority of intensive care settings strictly limit the number of visitors at any one time to two (15). Restricting visitor access protects staff space and privacy, enabling staff to focus on the urgent needs of patients (16). Nonetheless the barriers can possibly influence the individual intensive care nurse decision in involving the family in the caring activities (17). Hence, in order to develop better insights about family involvement in intensive care, we undertook a qualitative study using semi-structured interviews. The broader goal was to explore views among nurses in intensive care at RIPAS Hospital, which is the main hospital in Brunei. This objectives of the study were: (1) to explore how nurses perceive family involvement in intensive care (2) to examine the significance of family involvement in patient care and (3) to identify challenges of family involvements.

METHODS

Design

A qualitative approach with a qualitative design was chosen for the study to explore robust views of the intensive care nurses of family role in caring for the patient (18). Data were collected through individual semi-structured interviews and analysed by employing descriptive qualitative content analysis (19).

Sample and recruitment

The study participants were recruited using a purposive sampling strategy, and the inclusion criterion was that the nurses had to have had at least one year's work experience as a nurse in the intensive care setting to increase the probability of them having adequate clinical exposure. The nurses were recruited from three adult intensive care units in the largest teaching hospital of Brunei. A series of recruitment briefings were held whereby a written participant recruitment sheet with information about the study was given to 17 nurses in total and, of these, ten has agreed to participate. Nurses were also informed that the interviews would be audio-recorded. The nurses were aged 26 – 48 years and included two-man and eight women, as well as they, had worked as nurses for between 1-22 years.

Data collection

Semi-structured individual interviews (20) were used to enable the nurses to deliberate on family involvement and contribution in intensive care. An interview-guide with semi-structured and open-ended questions were developed and discussed by all researchers, guided by the

literature review. The interviews started with the question: What is your stance of family involvement in intensive care? Subsequent questions were asked about the importance of family involvement in patient care and what the challenges of family involvement are. Depending on the interview, further follow-up questions were used for clarification when needed, such as "Can you tell me more about that?" and "Can you give an illustration of the common challenges?" A rehearsal of the interview was performed before the actual collection of data.

The interviews were conducted during January 2018 by the researchers, BX and YZ. The nurses chose the date and place for the interviews, which were carried out at the respective workplaces, lasted between 28-54 minutes and were audio-recorded and transcribed verbatim. All interviews were conducted in English, and therefore no translation process is required.

Data analysis

The data were analysed and guided based on Graneheim descriptions of qualitative content analysis (19, 20). All the researchers read the interviews numerous times to ensure that they had a robust grasp of their overall content. Then, meaning units and statements, which described nurses' views of family involvements in intensive care were coded and abstracted by converting the nurses' expressions into total units. These total units were compared, and those with similar meanings were grouped. Groups with similar meanings were then assembled to form categories, which were named with content-characteristic words (19).

All of the researchers participated in the analysis process whereby there was a constant movement back and forth between the complete dataset and the analysis pieces. Three developed themes were carefully deliberated repeatedly by the researchers in order to achieve mutual consensus. In the results section, these themes, which describe the core meaning of nurses' perspective of the family role are presented first, followed by the categories describing further aspects and nuances in detail; these are illustrated with quotes from the interviews.

Rigour

The four aspects of trustworthiness in qualitative research, credibility, dependability, conformability and transferability (21) have been recognised and applied in this study. The nurses were guided through the interviews with semi-structured open -ended questions that allowed them the choice to speak as much as they wanted regarding their views. The interviews strived for encouraging conversation and asked for clarification of the narratives to achieve credibility. Furthermore, the analysis process was conducted in a reflective dialogue between the researchers. To accomplish dependability, all of the researchers conducted the data analysis, that is, the recordings were transcribed verbatim, and quotes from the nurses are presented in the findings for the conformability. The findings might be transferred to inform other nurses' understandings of the perceived family presence, the concern over patient safety and family readiness (21). However, the individual reader has to assess the suitability of transferring the study results.

Ethical considerations

The Joint Ethics Committee approved the research at the Institute Health Sciences Research Ethics Committee (IHSREC) of the Universiti Brunei Darussalam and the Brunei Ministry of Health's Medical Education Research Ethics Committee (MHREC) with the reference number UBD/ PAPRSBIHSREC/2017/032. The four ethical principles of respect for autonomy, beneficence, non-maleficence and justice were considered. The Chief Executive Officer of the hospital and Head of Department of the intensive care units gave their approval for the study. All nurses were given both verbal and written information about the aim of the study, including its design, that their participation was voluntary and that they had the opportunity to withdraw their participation at any time before the start of data analysis. Written informed consent was obtained from the nurses. In order to protect the privacy and confidentiality of the data collected, only the research team granted access to the data, and all personal information is kept anonymous by using a code number for each participant.

RESULT

The results of the analysis generated three themes that illustrated intensive care nurses' perceptions of the family role in patient care: (1) importance of family presence (2) concern over patient safety and (3) question about family readiness.

Theme 1: Importance of family presence

The findings of the study described the general consensus that family involvement in the intensive care is closely related to the family presence. Majority of the nurses indicated that the family presence is positively welcomed. They recognised that the family's presence helps to improve the overall experience of the patient through the psychological support given by the family. To some nurses, being in the intensive care environment can be relatively terrifying and increase anxiety among patients.

> *Young patients generally have a high level of anxiety. To have parents around helps a lot. We are still strangers to them. Therefore, having familiar faces is so rewarding for the patient's overall experiences (Nurse 2).*

More than half of the nurses agreed that the family presence in patient care as primarily being about providing spiritual support to critically ill patients, for example, through the recital of prayers. The nurses elaborated on various forms of spiritual support according to the religious beliefs of the patient and his or her family.

> *That all depends on the background of the patient. A priest is to put a Christian family together. They will perform prayer songs for Chinese people. For Muslims, the family has often asked the intensive care setting for a religious person (Nurse 1, 3, 9).*

On several interviews, the nurses spoke about the family presence contribute to address the psychological and spiritual needs of the patient through the interaction between family and patient. The nurses would usually encourage the family to continue talking with the sedated patient as if he or she could hear them.

> *While the patient is unconscious, the family may still interact with the patient. This can somehow stimulate them in some way by talking to the patients (Nurse 1).*

Despite the recognition on the value of such interaction, most of the nurses however admitted that this can be particularly difficult for the family since sedated patients are most likely unable to respond, but positively believed that it is the nurses' critical role to reassure them on the importance of patient hearing and recognising familiar voices even if the patients do not appear to respond.

Theme 2: Concern over patient safety

At the outset of the interview, the nurses described that some family get involved in giving simple care such as applying of body lotion or giving light massage to the patient. According to the nurses, some family are more willing to provide personal care, such as performing oral care and attending to patients' hygiene.

> *In some occasion, there are families who would go the extra-mile, just by giving simple care, rather than just being presence. They provide some personal care on the patient (Nurse 1, 2, 5).*

The nurses established the importance of engaging family in the caring activity, no matter how trivial. This kind of engagement is regarded as central because the family can gradually develop confidence in providing patient care once the patient leaves the intensive care environment. However, while such engagement is needed, the nurses also echoed concerns over patient safety as they deliberated on further involvement of family. Patient safety is the nurse's top priority, as maintained by majority of the nurses. In a setting like intensive care, where patients are attached to wires or leads, the nurses recognised that they typically do not allow the family to provide any physical care. They expressed concerns when leads or wires can place the patient in harm's way if the family mistakenly tries to take the wires out. One nurse pointed out that the problem was the family's lack of expertise and skills in providing patient care.

> *The family is not permitted to carry out physical care because they are not appropriately qualified. This is a major concern (Nurse 4).*

Furthermore, some families appear anxious about doing anything that could potentially hurt the patients.

> *We do most of the care. Because of the wires on the patient, the families are afraid to dislodge the tube, which is understandable. Thus, we help turn the patient. Only then can the family apply lotion to the patient (Nurse 5).*

Not only that, but around half of the nurses in the study also reported that they feared the family's transmitting infection during treatment, owing to their paucity of awareness around maintaining hand hygiene during visitation.

At the end of the day, this is an intensive setting for critical patient. We believe that the family is at risk of spreading the infection to patients through handwashing (Nurse 2, 7, 10).

Theme 3: Question about family readiness

When interviewed about the challenges of involving the family in patient care, nurses questioned the readiness of the family to be involved in patient care. They shared stories in which families who took the initiative and are ready to get involved in patient care. However, not all families are ready to participate in any care, no matter how simple the caring task is. This single factor in some way influences the nurses' response to involve them again. Some nurses were not certain if the reluctant is related to their lack of knowledge and confidence.

I am not sure if this is a confidence issue or lack of knowledge. Applying lotion, for example, is a simple caring task. But they decline to do them (Nurse 4 and Nurse 7).

Some nurses speculate the family may be hesitant to be in any part in patient care because they feel that caring role is the exclusive responsibility of the nurses. Several nurses deliberated on this point further.

The reluctant may to do with the perception that the caring is full responsibility of the nurses. Perhaps, they don't really see the benefits of their involvement or contribution. (Nurse 5 and Nurse 8).

However, the majority of the nurses acknowledged that the rigid visiting hours observed in intensive care are perceived as an obstacle to the family's readiness to get involved in patient care. In most interviews, the nurses made it clear that they will try their best not to interrupt the visiting hours because they want to allow the family to spend time with the patient. The nurses, however, recognised the value of encouraging the family to engage in long-term care. This kind of engagement is seen as necessary because the family is in a better position to understand the condition of the patient and slowly develops trust in providing patient care once the patient leaves the critical-care environment.

I would like to see the family taking part in providing physical treatment after they leave the vital environment. We will allow the family to provide simple tracheostomy care, for example. This early caring experience will encourage the family to care outside of the critical-care environment (Nurse 2).

DISCUSSION

The first theme of the study findings indicates that nurses consider the presence of the family as most essential in the intensive care setting. Nurses have presented positive attitudes towards the family presence whereby they stated that the family could relax the patient by talking with him or her, and most nurses assumed that patients could hear them when they were sedated.

Although the nurses agreed that the family played a minimal involvement in providing care, they recognised the family presence is helpful in giving psychological and spiritual support for the patient. In particular, this study showed that nurses perceive the involvement of the family in delivering care as a source of psychological support and reassurance for patients. This critical role of family in patient experience is reflected in several studies. For example, Boyle (22) offers some thoughtful insights not only into the value of family in the patient experience overall, whereby being a family, they would have an advantage over the health professionals because the family members know their patient well. Furthermore, findings of a previous study have also shown that families are involved in treatment, their anxiety is lowered (23). In addition, Brunei is an Islamic country with a mainly Muslim population, and Islamic values and beliefs are intricately linked to cultural norms that form the understanding of health and disease among patients (24).

Meanwhile, reflecting on the second theme, many nurses shared stories where families tend to take part in providing care such as oral care, body massage, lotion application or assistance for patients in bed-bathing. Different studies have found that nurses decide on practices appropriate for family involvement in primary day-to-day care, such as lotion application, massage, positioning, and bed-bathing (9). However, at the same time, the nurses expressed on the concern over patient safety when involving the family. In this study, several nurses associated this to nature of the intensive care climate, hence they did not fully uphold family involvement in patient care. This has been the most frequent hesitation faced by nurses in previous research: their fear of harming patients due to the spread of infection (7, 9). Family awareness of the importance of hand hygiene during visits is lacking, according to this research. Furthermore, several nurses reported that the family often lacks the expertise and skills

to provide safe and reliable care because they are not appropriately qualified. They asserted that, when families provide care, tubes, or wires can be dislodged accidentally. Family members frequently offered more unqualified and non-professional nursing care for patients (4).

Drawing on the third theme, the nurses have questions about family readiness to be involved in patient care. In this study, some family illustrate positive attitudes in wanting to get involved in as much as possible. It was also recognised that family participation in patient care would help enhance the health outcomes of patients (25). Some nurses, however, viewed that not every family wants to engage in patient care due to either lack of confidence or knowledge. Accordingly, previous studies have demonstrated the need for family participation, even though nurses are hesitant to include family members (26) due to established obstacles (3, 17). On the other hand, the restricted hospitals' policy on visiting is another obstacle discussed by staff nurses that may impede family involvement. Similar findings among nurses indicate that a hospital's visitation policy could impede a family's involvement in care (15). This study seems to suggest that the awareness of the nurses on the value of family involvement by minimising any interruption during the visiting hours because they want to allow family members the opportunity to spend time with patients. This could be one way of realising the family needs by supporting and involving families in the care of the critically ill family member (26).

In general, the findings suggest that the intensive care nurses have demonstrated positive attitudes towards the family's involvement through their presence, and involving the family to provide simple patient care. However this is somewhat constrained with concern over the patient safety. Meanwhile, one primary question faced by nurses is about the family readiness to get involved in the simple care. The findings highlight that nurses attempt to improve family involvement in long-term care and play a significant part in training, directing and supervising families to carry out simple care.

LIMITATION

The nurses included in this study reflect a general representative of intensive care nurse population in terms of age, gender, and history. Some issues, however, restrict the study's results and interpretation. For instance, a relatively low number of nurses volunteered to participate. At the same time, it would have taken a long time to recruit more nurses for additional interviews. While the findings of the ten interviews may be comparatively small, this research has sought to capture some of the nurses' views of family involvement in intensive care. The sample was deemed appropriate because of the exploratory nature of this research and the focus on identifying underlying views about the topic. When new data appears to no longer contribute to the findings due to the repetition of themes and comments by nurses, data collection was terminated. In addition, this research focused solely on the perception of adult intensive care nurses and not a general ward setting.

CONCLUSION

In this current study, the perceived involvement of the family in intensive care is embedded within their presence by the patient. The nurses made encouraging and positive outlook on the involvement of family. While nurses encourage the involvement of family in giving simple care task, they also expressed concern over patient safety. At the same time, the nurses also questioned the readiness of family to get involved in patient care. This study has extended our understanding of the perceived involvement of patients' families in providing physical care and emotional and spiritual support, through their presence and involvement in giving simple care. This is however may be constrained through concern over patient safety and readiness of family to be involved. Further research should be undertaken to examine family members' views of their position; this can, in turn, improve the experience and quality of care for the patients and their families.

CONFLICT OF INTEREST

None

REFERENCES

1. Mackintosh N, Davis R, Easter A, Rayment-Jones H, Sevdalis N, Wilson S et al. Interventions to increase patient and family involvement in escalation of care for acute life-threatening illness in community health and hospital settings. Cochrane Database of Systematic Reviews. 2017; 10.
2. Olding M, Mcmillan SE, Reeves S, Schmitt MH, Puntillo K, Kitto S. Patient and family involvement in adult critical and intensive care settings: a scoping review. Health Expectations. 2015; 19(6):1183–202.

3. Fateel EE, Oneill CS. Family members' involvement in the care of critically ill patients in two intensive care units in an acute hospital in Bahrain: The experiences and perspectives of family members' and nurses' - A qualitative study. Clinical Nursing Studies. 2015; 4(1).
4. Bhalla A, Kaur P, Kaur S, Suri V. Involvement of the family members in caring of patients an acute care setting. Journal of Postgraduate Medicine. 2014; 60(4):382.
5. Khosravan S, Mazlom B, Abdollahzade N, Jamali Z, Mansoorian MR. Family Participation in the Nursing Care of the Hospitalized Patients. Iranian Red Crescent Medical Journal. 2014; 16(1).
6. White DB. Toward Shared Decision Making at the End of Life in Intensive Care Units. Archives of Internal Medicine. 2007; 167(5):461.
7. Duran CR, Oman KS, Abel JJ, Koziel VM, Szymanski D. Attitudes Toward and Beliefs about Family Presence: A Survey of Healthcare Providers, Patients' Families, and Patients. American Journal of Critical Care. 2007; 16(3):270–9.
8. Al-Mutair AS, Plummer V, Obrien A, Clerehan R. Family needs and involvement in the intensive care unit: a literature review. Journal of Clinical Nursing. 2013; 22(13-14):1805–17.
9. Turner K, Anderson, WG, Lipshut, A, Cimino J, Pathak C, Schell-Chaple H, Gropper M. ICU Clinician Perspectives on Involvement of Family Members in the Care of Critically Ill Patients. American Journal of Respiratory and Critical Care Medicine, 2016; 193.
10. Hetland B, Hickman R, Mcandrew N, Daly B. Factors Influencing Active Family Engagement in Care Among Critical Care Nurses. AACN Advanced Critical Care. 2017; 28(2):160–70.
11. Engström B, Uusitalo A, Engström Å. Relatives' involvement in nursing care: A qualitative study describing critical care nurses' experiences. Intensive and Critical Care Nursing. 2011; 27(1):1–9.
12. Nayeri ND, Gholizadeh L, Mohammadi E, Yazdi K. Family Involvement in the Care of Hospitalized Elderly Patients. Journal of Applied Gerontology. 2013; 34 (6):779–96.
13. Siminoff LA. Incorporating patient and family preferences into evidence-based medicine. BMC Medical Informatics and Decision Making. 2013; 13(S3).
14. Keer R-LV, Deschepper R, Francke AL, Huyghens L, Bilsen J. Conflicts between healthcare professionals and families of a multi-ethnic patient population during critical care: an ethnographic study. Critical Care. 2015; 19(1).
15. Hunter JD, Goddard C, Rothwell M, Ketharaju S, Cooper H. A survey of intensive care unit visiting policies in the United Kingdom. Anaesthesia. 2010; 65 (11):1101–5.
16. Rippin A. Evidence-Based Design: Structuring Patient- and Family-Centered ICU Care. The AMA Journal of Ethic. 2016; 18(1):73–6.
17. McConnell B, Moroney T. Involving relatives in ICU patient care: critical care nursing challenges. Journal of Clinical Nursing. 2015; 24(7-8):991–8.
18. Patton MQ. Qualitative research & evaluative methods: Integrating theory and practice. Thousand Oaks, CA: SAGE Publication Inc., 2015
19. Graneheim UH & Lundman B. Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. Nurse Education Today, 2004; 24(2):105-112
20. Graneheim UH, Lindgren BM & Lundman B. Methodological challenges in qualitative content analysis: A discussion paper. Nurse Education Today, 2017; 56: 29-34
21. Polit DF & Beck CT. Study guide for essentials of nursing research: Appraising evidence for nursing practice. Philadelphia, PA: Wolters Kluwer, 2018.
22. Boyle B. The critical role of family in patient experience. Patient Experience Journal. 2015;2(2):4–6.
23. Mitchell M, Chaboyer W, Burmeister E, Foster M. Positive effects of a nursing intervention on family-centered care in adult critical care. American Journal of Critical Care. 2009;18(6):543–52; quiz 553.
24. Marzband R, Hosseini S, Hamzehgardeshi Z. A Concept Analysis of Spiritual Care Based on Islamic Sources. Religions. 2016; 7 (6):61.
25. Smith, M, Saunders R, Stuckhardt L. Engaging patients, families, and communities. Best care at lower cost: the path to continuously learning health care in America. 2013, National Academies Press
26. Hardin SR. Engaging Families to Participate in Care of Older Critical Care Patients. Critical Care Nurse. 2012; 32(3):35–40.