A qualitative study on experience of nurses caring for patients with delirium in ICUs in China: Barriers, burdens and decision making dilemmas

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Abstract

Purpose: The purpose was to explore the experiences of nurses caring for patients with delirium in ICU in China.

Methods: Semi-structured qualitative interviews were conducted with 14 ICU nurses in Beijing, China. Audio recordings of the transcripts were coded and analysed thematically.

Results: The emergent themes reflected clearly similar experiences and were titled as follows: Internal and external barriers to care; Care burden: workload, psychological pressure and injury; Dilemmas in decision-making: balancing risks and benefits.

Conclusions: The results of this qualitative study have provided a rich description of the perceptions of a sample of nurses caring for patients with dementia in Beijing. Clearly, the nurses suffered from their work experiences in several aspects: they lacked the knowledge and skills required assessing and managing the patients as early as possible; they were physically and psychologically stressed while looking after the patients and faced with dilemmas and compromises in their decision-making.

Keywords:
Delirium
ICU nurse
Experience
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1. Introduction

Delirium is often seen in intensive care units (ICU) and is often accompanied by agitation. Despite the challenges associated with delirium, little has been written in regard to nursing management, experience or the best intervention strategies [1]. The aim of the study was to quantify the incidences and factors influencing delirium in ICU in a hospital in Beijing, China, as well as determine the frequency of the problem. The current understanding and the management of delirium are inadequate among the nursing staff.
The core characteristics of delirium are disturbance in the level of consciousness, changes in cognition and perceptual disruption. Delirium can present itself in three forms: hyperactive, hypoactive and mixed. A systematic review revealed the prevalence rate of delirium in patients upon admission to range from 10% to 31% [2]. Acute delirium is the most common behavioural manifestation of brain dysfunction, occurring in 60%–80% of mechanically ventilated medical and surgical ICU patients, and in 50%–70% of non-ventilated ICU patients [3]. At least 1 in 3 survivors of critical illness will experience a long-term cognitive impairment consistent with mild to moderate delirium [4]. Furthermore, ICU delirium can lead to a 3–11 fold increase in risk of death in six months even after controlling for relevant covariates such as severity of illness [5]. Delirium has been reported as the strongest independent determinant of the length of hospital stay and has been associated with incrementally higher cost [6]. Using multivariable analysis to adjust for age, comorbidity, severity of illness, degree of organ dysfunction, infection, hospital mortality and other potential confounders, delirium was associated with 39% higher ICU (95% CI, 12%–72%) and 31% higher hospital (95% CI, 1%–70%) costs [7].

The collateral damage caused by delirium can be minimized by identifying patients at-risk, such as those over 65 years, those with a known cognitive impairment, and those with hip fracture or with severe illness [8]. Although delirium is amenable to expert nursing care, it is unrecognized or misdiagnosed in up to 70% of people over 65 years [9]. Therefore, the first step in management of delirium is early recognition. Indeed, delirium assessment has been recommended as part of routine ICU management considering that mental status is an important vital sign along with body temperature, blood pressure, pulse, respiratory rate, and pain [10]. Delirium is an acute disorder which can develop rapidly with fluctuating symptoms. Nurses are in the key position to recognize specific symptoms and closely observe for early delirium signs in at-risk people. However, delirium is often overlooked or misdiagnosed due to lack of knowledge and awareness in nurses [11]. In fact, nurses were able to identify delirium in only 19% of observations. The delirium recognition rates could be improved with implementation of an educational program. The program should incorporate the delirium characteristics, patient mental status, cognitive assessment techniques, and discussion of the factors associated with poor recognition [12].

Patient safety in acute and longer-stay nursing units would benefit from early recognition of delirium. The inclusion of delirium symptoms, as part of routine nursing assessment, not only increased the delirium detection in long-term care facilities but also improved the outcome prediction [13]. An implementation of interdisciplinary nurse-led delirium prevention and management program in a trauma ward led to higher detection rates of delirium resulting in a drop in overnight care [14]. However, other studies reported that detection of delirium by nurses was significantly lower compared with the independent formal delirium assessment. An observational study revealed that bedside nurse-patient interactions did not reliably detect delirium [15].

Ample of literature suggests the importance of the nurse-patient relationship and its effect on the patient's physical and psychological recovery [16]. However, the routine bedside interaction between nurses and their patients did not lead to increase in the nurses’ ability to recognize delirium. Understanding the relationship between the quality of patient care and nurses’ experience while looking after the patients is important [17]. Literature is scarce regarding the information on experience of nurses interacting with ICU patients with delirium. It is important to recognize the cause for the discrepancy between the held belief regarding the therapeutic effect of the nurse-patient relationship and the inability of nurses to recognize delirium.

2. Methods

This study utilized a qualitative hermeneutic-phenomenological framework, as described by Annells [18], to assess the experience of nurses in intensive care setting when looking after patients with delirium.

2.1. Setting

The study was conducted in Xuanwu Hospital, which is affiliated with the Capital Medical University, Beijing, China and is a comprehensive hospital featuring clinical practice and research in neuroscience, gerontology, and general surgery. There are about 1000 beds in 34 clinical departments of traditional Chinese and Western medicine. The hospital has 12 ICU, including those for vascular surgery, neurosurgery, haematology, respiratory diseases, gastroenterology, general surgery, cardiology, orthopaedics, and emergency. A recent research project conducted in the hospital revealed a consistent influx of patients with delirium across all of the ICU.

The Capital Medical University Human Research Ethics Committee reviewed and approved the study prior to its commencement. To expedite the recruitment process and increase participants’ comfort and ease of involvement, the Ethics Committee gave researchers permission to conduct the interviews during the nurses’ regular work hours. The written consent was obtained from all of the participants.

2.2. Population and sampling methods

A purposive sampling was used to select a small cohort of ICU nurses using the following inclusion criteria: 1) employed as a nurse in Beijing, 2) working in ICU for at least one year, and 3) prior experience caring for patients with delirium in ICU. Those nurses, who met the criteria, were initially approached by the first author, who is a clinical nurse practitioner and researcher in the hospital. The researcher had access to nurses at all of the ICU and met with them regularly (at least once a week). Those nurses who indicated interest in participating in the study were telephoned at a later date to determine the dates, times and venues for the interviews.

In order to facilitate recruitment and ensure participants’ privacy and confidentiality, interviews were conducted at the
participants' own time in an office, away from their ICU. The intent was to reassure the participants that the study was not related to the conditions of their employment, and also to allow them to speak freely about their experiences.

2.3. Data collection

Each interview lasted 30–60 min and was recorded. The interviews were conducted by the project leader, a clinical nurse consultant in delirium and dementia, and an experienced Ph.D. student, all under the supervision of a senior faculty member. Common interviewing procedures and techniques were established and formalized by all three researchers prior to the interviews. For bracketing purposes, the researchers were asked to document their values, beliefs, attitudes and assumptions towards both the ICU nurses and the patients with delirium.

The two main questions used to elicit the response from nurses on delirium patient care were: (1) “Please describe your experience of looking after patients with delirium in ICU, including your feelings, thoughts and emotions” and (2) “Describe the most impressive experience you have had while caring for a patient with delirium in the ICU, including the one that stuck to their memory the best, the best experience or the worst the one that they learned from the most.”

2.4. Data analysis

The researchers transcribed all of the interviews immediately after completing them. Transcripts were then printed and returned to each participant for additional comments and clarifications to ensure content validity.

The thematic analysis of the data was done using the highlighting approach described by van Manen [19]. Each researcher identified and organized significant statements and commonalities into themes representing important aspects of the ICU nurses’ experience immediately after each interview. Emergent themes were documented and circulated prior to weekly meetings. The themes were mostly similar, signifying a high level of inter-rater reliability and saturation. If the interviewers disagreed on the interpretation of the information, the participant was then contacted to provide additional comments and clarifications. Data saturation was reached after analysis of 14 of the total of 17 interviews.

3. Results

The study participants were heterogeneous in their demographic characteristics (Table 1). The emergent themes, however, clearly reflected similar experiences and were titled as follows: 1) internal and external barriers to care; 2) care burden (workload, psychological pressure, and injury), and 3) dilemmas in decision-making (balancing risks and benefits).

3.1. Category 1: internal and external barriers to care

The participants had difficulty detecting the early delirium signs due to the lack of knowledge, absence of evidence-based nursing practice, complex symptoms, and changing shifts. Hence, nurses were unable to provide a timely intervention. The nurses expressed concerns about their shortfalls and some of the constraints imposed by the system.

3.1.1. Sub-category 1: symptom recognition

Delirium is an acute, volatile state of mind. The symptoms may emerge, disappear, or fluctuate over a 24 h period. Because of the often ephemeral characteristics of delirium, clinical nurses have difficulty accurately identifying and predicting the development of disease.

"Sometimes I feel confused, because delirium can occur in any of the ICU patients. Delirium patients don’t always show symptoms, so I don’t know when patient is awake or confused. I just don’t know! So my work is very passive. Because I’m not sure
whether the patient is confused, I don’t know when or if they will pull out their tube.” (Nurse 4)

“I am even more afraid of hypoactive delirium, because it is more difficult to recognize. When patient wants the nurse to do the same thing over and over again or has some other behavioural problems, the nurse in charge will pay more attention to him, and it’s easier to notice that patient. But if the patient doesn’t have any of the hyperactivity symptoms, it is extremely hard to identify delirium. For example, bed Four today, the potential [for delirium development] was not recognized until the patient started making noise. If she didn’t make noise while getting out of bed, I wouldn’t have known what happened.” (Nurse 11)

3.1.2. Sub-category 2: lack of knowledge
Most of the participants lacked the necessary experience and had not received formal training on delirium. Consequently, nurses were unable to distinguish between delirium and other neurological and psychiatric disorders resulting in the series of misunderstandings and inaccurate explanations. The inability to accurately recognize patient suffering from could have had dire consequences.

“It is difficult for me to distinguish delirium from other neurological disorders as I haven’t learned how to tell the difference. For example, temporal lobe damage also results in the same kind of restless movement as delirium. Therefore, I can’t tell if the symptoms are the result of cerebral haemorrhage or delirium. I don’t know what definition of delirium is.” (Nurse 7)

“Most nurses in my ICU are very young. They haven’t had experience caring for as many delirium cases (as me). Thus, they lack the experience on how to recognize delirium. Because they don’t expect delirium to occur, they have no motive to observe patients more directly.” (Nurse 8)

3.1.3. Sub-category 3: continuity of care
Dynamic observation of high-risk patients is the key to achieving accurate and timely recognition of delirium in these patients. However, split shifts interfered with accurate and continuous monitoring of the patient’s condition and mental state.

“If I look after one patient for three days, observing him, talking to him and saying hello to him during every intervention, I am confident that by day 3, I can determine if something is wrong with the patient when behaving unusual or confused. But I need to care for the patients for at least three days which rarely is the case.” (Nurse 6)

3.1.4. Sub-category 4: inadequate assessment
Although several assessment tools have been proven effective in detecting delirium, our participants failed to utilize them when caring for their patients. Rather, the judgements were often made based on the nurse’s experience.

“Individual experience is the main tool used in determining whether the patient is suffering from delirium. Our ICU doesn’t utilize other assessment methods.” (Nurse 3)

3.2. Category 2: care burden: workload, psychological pressure, and injury
While looking after patients with delirium, the participants experienced high levels of stress, heavy workload, and occasional injury. Majority of the nurses struggled with managing the patients and were prone to physical and psychological exhaustion.

3.2.1. Sub-category 1: physical burden
The participants often experienced physical burn-out due to long periods of time spent ensuring patient’s safety and their own. The physical exhaustion was compounded by the confusing instructions and lack of cooperation on patients’ part.

“It is difficult to look after delirium patients who may need a special nurse to observe them in case of accidents, like falling from bed.” (Nurse 5)

“You must give a lot of care to delirium patients, ten times more than to ordinary or critical patients because all their activities and emotions are invisible. You can’t see, and you don’t know what they are thinking.” (Nurse 10)

“Sometimes the patients do not cooperate with us. They become restless; don’t let us provide treatment or care. At times, presence of a male physician is necessary to subdue the patient.” (Nurse 2)

3.2.2. Sub-category 2: psychological pressure
Delirium symptoms significantly increased the patients’ risk of harm and compromised their safety. In order to ensure safety, these nurses felt they needed to be ready, at moment notice, for all kinds of emergencies, consequently feeling psychologically exhausted.

“Despite nurse doing her best to prevent patient from removing tubes, the incidence still leaves the nurse feeling very nervous. The nurses are always under pressure.” (Nurse 5)

“The most difficult part of my work is that I am worried about patient’s security at all times, afraid of an accident. After all, you are the nurse, the care-provider, he/she is the patient, passively accepting your care. If he/she was ill and lying in bed, it’s you who are nursing them, so it’s your responsibility to keep all of your attention on them, looking after them and avoiding any accident. It’s your job.” (Nurse 3)

“I must always keep my eyes on the patient (with delirium). I have other patients to look after, and lots of other work to do, however, I have to keep an eye on these patients, which is exhausting.” (Nurse 12)

“In the process of taking care of the patient, I am under pressure to make sure there are no accidents. Some of the family members don’t understand or accept if accidents do happen. They have no idea why patient is delirious, what risks and dangers patient may face and why we must enforce certain interventions and
prevention. Anyway, I feel stressed out all day long, from morning to the night, always afraid for the patients’ safety, worried about family members’ response to delirious patient and my handling of the incidents.” (Nurse 2)

3.2.3. Sub-category 3: occupational injury

While taking care of patients with restless or aggressive behaviour, the participants felt threatened and concerned about their well-being.

“A lot of patients are difficult to get along. When we are trying to help them stay quiet and comfortable, they may hit us. At times, they hurt our hands.” (Nurse 2)

“It happens from time to time that the patients with delirium would bite, scratch, and grab the nurse causing various injuries. It is a struggle to look after these patients as you have to be careful with them while making sure both of us don’t get hurt.” (Nurse 4)

3.3. Category 3 dilemmas in decision-making: balancing risks and benefits

At times, the participants had to make tough decisions, which bothered them. The nurses wanted to find a compromise but found it difficult and even impossible.

3.3.1. Sub-category 1: family visit: come in or keep out?

The presence of family members calms patients suffering from delirium reducing the incidence rate. However, presence of the family members puts other patients in harm’s way. This conundrum created a difficult situation for the nurses who had to decide whether to have family members present or not.

“Sometimes, we call the family member and ask them to come to the ICU to comfort the patient. This approach works well. As soon as the patients see their family members, they calm down and regain their consciousness.” (Nurse 5)

“You know, there is a problem with the bacterial infections in ICU. Their (family members) clothes have not been sterilized, increasing the risk of infection. Other ICU patients, especially patients on ventilators are then running a risk of lung infection.” (Nurse 4)

3.3.2. Sub-category 2: patients’ ability: useless or useful?

Another decision-making challenge was being mindful of the importance of activity to the patients while ensuring they remain in bed for the duration of the treatment. In most cases, nurses faced serious challenge while trying to keep patients in bed to ensure their safety.

“It is difficult for the people to accept the role of a patient, lying in bed, feeling useless. Some of them will tell you they are only waiting to die as they don’t know what they can do. They can’t move, and they can’t care for themselves so they think they can’t do anything. It is hard for patients to realize there are a lot of things they can still do. Just because one part of their body has an issue, doesn’t mean they can’t use the rest of their body. If they have an operation on their stomach, their arms and legs are still in good condition. Why not move them, use them? However, they are always told to lie in the bed, or their wound will burst open. Consequently, people around the patients keep reinforcing the idea of being a patient, not allowing for positive thoughts. I think this is a deeply rooted idea in both patients and nurses, too difficult to overcome.” (Nurse 14)

4. Discussion

The study provided a thorough account of nurse experience caring for delirium patients in Beijing, China. The nurses faced array of difficulties due to the specific work requirements surrounding delirium patients. A lot of stress was the result of lack of knowledge and skills required to assess and manage the delirium patients preventing nurses from recognizing early symptoms. The unique needs of these patients put enormous physical and psychological stress on nurses who continuously faced dilemmas and compromises in their decision-making. This left nurses feeling confused and exhausted.

In Chinese culture, the prevalent belief is that nurses are “angels with a candle,” caring, kind, patient, and loving caretakers. Through their sacrifices, nurses bring light, hope and support to the patients. The majority of nurses in China now and historically are women. The job requires devotion, similar to that which is also a part of the traditional role of women in Chinese patriarchal society [20]. However, there is a shortage of nurses and not all meet the expected standard of an “angel.” China has 1.65 million nurses yet needs 5 million more to meet the global standard for a nursing labour force. The demand far outstrips the supply [21]. Although not all nurses are understaffed, busy ICU can be. Some of the nurses enter ICU inadequately trained for the ICU work. This is obvious in their lack of knowledge and the skills necessary to provide evidence-based critical care for the patients with delirium [22].

The workload is heavy, and this has been shown to be one of the predictors of job satisfaction in Chinese ICU [23,24]. A balanced workload, one that is challenging but manageable, results in job satisfaction, while interpersonal conflict and tolerance of poor job performance may lead to job dissatisfaction [25]. Thus, the ICU nurses exhibit high work dissatisfaction. For the healthcare administrators, balancing workload and assigning delirium patients to more experienced nurses might prove helpful in enhancing job satisfaction among ICU nurses.

The patients too are in a stressful environment. They often feel confused and have behavioural problems creating a potentially threatening environment for the health-care providers. Our participants often suffered from occupational injuries caused by delirium patients. Violence and hostility are accepted as part of the day-to-day life by most nurses, who then also need to deal with anxiety and extreme work-based stress [26,27]. When compounded with horizontal violence in the nursing workplace, and the added stress of difficult patients, such as those with dementia and delirium, nurses work in a very volatile and risky environment. Furthermore, working with sometimes heavy and non-compliant patients’ places nurses at risk of acquiring occupational low back pain. Chinese ICU nurses have high
incidence rate of occupational low back pain due to high frequency of bending and twisting which is common in ICU [28].

Inconsistencies in management and treatment plans of delirium patients are a clear concern which have been a strong negative predictor of nurses’ well-being [29]. Chinese ICU nurses lack autonomy and are expected to obtain direction on patient care from physicians. All confrontational behaviours, as well as questioning of the physicians, are strongly discouraged. Hence, nurses “have their hands tied” and are reluctant to seek advice on how to manage patients with delirium as professional nurses should. Strong peer support and teamwork could create a safe and encouraging environment where nurses could obtain information on how to cope with the emotional needs of patients and how to cooperate with the patients’ family. Low job control and high job demands contribute to nurses’ dissatisfaction with the work situation [30].

5. Recommendations

Several recommendations emerged from the study. First, ICU nurses should be provided with various educational/training opportunities. These trainings should address high-risk factors for the development of ICU delirium, the best assessment tools, prevention strategies, early recognition and intervention. Consequently, both patient outcomes and job satisfaction among nurses should improve.

Second, recognizing the essential role nurses play in a successful, sustainable ICU when working with patients with delirium should improve the work environment. Nurses not only assist doctors, they have a unique opportunity to assess patients using evidence-based nursing practice.

Third, forming a healthcare team specializing in work with patients with delirium would help reduce stress, reduce conflict, and improve patient outcomes. As delirium is a very complex condition caused by many different factors, a medical team including physicians, surgeons, nurses, psychologists and recovery nurses should be formed to help these patients and their families during and after the stay in ICU.

Pre-operation visits, family visits and ward nurse visits have been shown to benefit and decrease the anxiety and fear experienced by patients while in ICU [31–34]. Doing so also demonstrates the current ideal expected in healthcare where patients’ well-being is put first.

In the past 50 years, the Chinese healthcare system has been putting more emphasis on patient safety in order to reduce the number of adverse events leading to harm and/or death of our patients. Safety, therefore, is high on the nursing agenda and the uppermost in the nurses’ thinking when planning and practicing care. Patients should feel safe, and nurses, while sometimes required to exercise control over a disturbed patient, should recognize that patients are people with emotions, families, and holistic needs. Dignity and respect for the individual are vital, especially following an episode of delirium. Involvement of family in patient care, as well as emphasizing the humanistic side of nursing care, may reduce tension and help reinforce the active role of patient in their care process [35].

Finally, it is a challenge for nurses when attempting to act with other professionals to meet patients’ expectations and needs [36]. In China, close family relations make it very stressful for family members witnessing their loved ones suffering from delirium while at ICU. Therefore, the immediate needs of the family members should also be taken into account so they could provide the support need for their loved ones [37,38].

6. Conclusion

Future studies are necessary to further our understanding of the needs of delirium patients and nurses taking care of them. We identified three categories used to examine the experiences: barriers, burdens and dilemmas in decision-making. As the ageing population size and needs grow, developing educational strategies for management of delirium patients through future evidence-based research will enhance medical care of this patient group.

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