Critically ill patients' experience of agitation: A qualitative meta-synthesis

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Abstract

Background: Acute episodes of agitation are frequently experienced by patients during critical illness, yet what is not understood is the experience of agitation from the patient and family perspectives.

Aims and objectives: To search existing literature, appraise it and then provide a synthesized interpretation to broaden the understanding of patients’ and their families’ experience of agitation during an adult critical care admission.

Design: Qualitative meta-synthesis.

Methods: A qualitative meta-synthesis based on a systematic literature search registered with PROSPERO. The search conducted between July and September 2019 was applied to ProQuest, Cumulative Index to Nursing and Allied Health, British Nursing Index, Cochrane Library, Ovid Medline, Web of Science, and PsycINFO databases. We appraised the selected literature and presented a synthesized interpretation. Analysis was based on the approach of Gadamerian hermeneutics. Due to the lack of data identified; the family experiences of agitation could not be addressed within the review.

Results: In total, 8 studies were included capturing the experiences of 494 patients, aged between 18 and 92 years, with 225 (45%) women. The analysis generated three core themes: (a) What is real, what is not, (b) loss of communication and dependency, and (c) what helps, what does not. Fear of death, the emotion of anxiety, and feelings of pain alongside transient periods of fluctuating conscious levels provoked a feeling of intense vulnerability. The loss of effective communication and the feeling of dependence incite agitation and distress.

Conclusions: The patient's recollection of their critical illness can be completely or partially absent and disjointed with uncertainty around what is real and what is not. Family members observe the full effect of the patient's critical care illness and could be a wealth of untapped information.

Relevance to clinical practice: Increasing awareness of the critically ill patients' experience of agitation highlights possible contributing factors to agitation development, such as staff interaction and communication skills, and the critical care environment.

Keywords

adult intensive care, critical care nursing, psychological care of patients
1 | BACKGROUND

Agitation, a condition of psychomotor disturbance, is common in the critical care setting, observed in 16% to 52% of the critical care patient population. The patient can show unintentional and purposeless movement stemming from anxiety and accompanied by disorganized thought. An agitated patient can exhibit behaviour such as restlessness or thrashing, placing themselves at risk. The presence of agitation has been linked to the unplanned removal from organ support treatments, such as intravenous infusions or ventilatory circuits, higher rates of nosocomial infection, and increased length of both critical care and hospital stay. This reinforces the need for constant observation and vigilance on the part of the healthcare team. However, when faced with a critically ill, acutely agitated patient, practitioners have limited evidence on which to base decisions about the most appropriate action to take. Additionally, some actions taken may exacerbate agitation rather than reduce its occurrence.

Agitation in critical care remains a complex under-researched health experience. The complexity stems from the fact that there are numerous reasons for agitation and identification of the cause is challenging. The presence of agitation is often linked to delirium; however, agitation is not delirium and agitation without delirium is common. However, the outward manifestation of agitation and hyperactive delirium hold the same clinical challenges. Critical care research has tended to concentrate on delirium, intensive care unit (ICU) syndrome, or post-traumatic stress disorder rather than agitation.

Additionally, over the last decade, sedation practice within critical care has undergone a significant shift to managing patients with lighter sedation regimes. Current evidence and clinical standards support targeted light sedation to decrease the complications related to critical care admission. Yet there has been little consideration of contextual factors and the impact related to the introduction of such a significant change within individual critical care departments. Patients may be more aware of their surroundings, and critical care units are stress-inducing environments with patients reporting feelings of fear, pain, and anxiety, which may induce agitation. The management of agitation potentially experienced by the patient is, therefore, of paramount importance.

Critically ill patients are difficult to reach population in terms of research as the critical care experience is overwhelming for those affected and, for some, due to illness or impact of sedation, memories of their stay cannot be recollected. These factors drove the decision to search existing literature and develop a synthesis of patients' and their families' experience of agitation during a critical care admission.

2 | AIM

This qualitative meta-synthesis aimed to systematically search existing literature, appraise it, and then provide a synthesized interpretation to broaden the understanding of patients' and their families' experience of agitation during an adult critical care admission.

3 | DESIGN AND METHODS

The qualitative meta-synthesis approach was adopted to construct a more detailed narrative without the need to obtain further data from a difficult to reach population. The review team consisted of three-experienced researchers, two nurses, and one doctor, all with critical care experience and two with experience in qualitative research and conducting literature reviews.

3.1 | Methodological framework

The purpose of a meta-synthesis is to offer a coherent description or explanation of a particular phenomenon. The inherent nature of the approach is to facilitate knowledge development. Meta-synthesis is not an accumulation or averaging of results across studies, the aim is patently interpretive. We chose a hermeneutic approach, a process of interpretation. The approach seeks to find a deeper meaning of a phenomena. The concept offered by Gadamer of the hermeneutic circle and the fusion of horizons was used as a frame of reference to guide the meta-synthesis process. The hermeneutic circle refers to the process of repeatedly reading the text while conducting a reflexive dialogue with the text. During this process of exploration, there is a development of an understanding of the phenomena's various aspects, both as they are experienced individually and as they correspond to reveal the whole. We undertook the process of dismantling our understanding, comparing it to other views, and
reconstructing our understanding in order to produce a new understanding or horizon. The concept of the fusion of horizons offered by Gadamer represents this development of understanding from old horizons to new. We explored the interpretation of the patients’ experience of agitation during an adult critical care admission using the interpretations from previous researchers to move our understanding, or horizon, to develop new understanding of experiencing agitation.

3.2 Data generation

The first stage of a meta-synthesis is ensuring the inclusion of studies that are related to the same substantive phenomena (Sandleowski and Barroso, 2007). We conducted a qualitative meta-synthesis based on a systematic literature search, registered with PROSPERO (23 July 2019 Ref: CRD42019140483). Qualitative (ENTREQ) research checklist supported the review at various stage of the process. The sample (S), phenomena of interest (PI), design (D), evaluation (E), and research type (R) tool were used to develop the search terminology, as advised for qualitative reviews. This was developed a priori for conducting the search and was supported by an information scientist. Key words used were as follows: (S), Adult patient AND/OR family AND/OR loved one AND/OR carer in anywhere; (PI), Agitat* was used as the main search term. In addition, OR Anxiety OR Deliriu* were used as the terms and are often used interchangeable. This was complimented by AND Intensive care unit OR Critical Care OR Intensive therapy unit OR Critical illness OR critically ill in anywhere; (D) Interview* OR Focus group*; (E) View OR Opinion OR Experience OR witness* in anywhere; (R) Qualitative.

A systematic literature search was conducted between July and September 2019 using the following databases: ProQuest, Cumulative Index to Nursing and Allied Health, British Nursing Index, Cochrane Library, Ovid Medline, Web of Science, and PsycINFO. Inclusion criteria were peer-reviewed publications, using qualitative methodology in English. The search set a publication date between 2010 and 2019. We utilized a broad definition of qualitative studies, including all studies using qualitative methods for data collection and analysis. Truncation was applied to keywords, “adj” was applied to ensure search terms were adjacent and Boolean operator terms AND/OR plus Medical Subject Headings (MeSH) terms employed including: “critical illness,” “critical care,” “intensive care units,” “experiences,” and combination of sets from these categories mentioned earlier. Agitation was not a MeSH term in Medline, however delirium was. Additionally, research into the outward presentation of acute agitation and its management in critical care is under-researched; therefore, the terms delirium and anxiety were also used (Table 1).

Due to the small body of work in this area, the search was not limited to the abstract or title but across “All text.” Grey literature, reviews, editorials, and mixed-method studies were excluded. Studies were included if they referred to the patients’ and/or families’ experience of agitation and/or delirium during an adult critical care admission. Excluded was any study with a focus on the non-critical care setting, patient population under 18 years of age, care of those living with dementia, or experiences of health care professionals. There was no exclusion based on country of origin; however, non-English text with no available translation was excluded. Within the search, four literature reviews were identified. The reference list of these reviews were explored, and two more studies were identified.

3.3 Study screening

One reviewer performed the initial screening by title and abstract to exclude off-topic papers. The subsequent papers were then screened by two reviewers for potentially relevant text by title and abstract, and if necessary, full text using the inclusion and exclusion criteria. A third reviewer was available to discuss any potential disagreement, but this was not required. The Consolidated Criteria for Reporting Qualitative research checklist was applied to underpin the critical appraisal of the selected studies. One author (S.F.) conducted the critical appraisal and discussed queries with J.Y. and P.D. An overview of the selection process is illustrated in Figure 1. Due to the lack of available qualitative data, the family experiences of agitation could not be addressed as part of the review.

3.4 Data extraction and analysis

The first stage was to read the studies exploring the different voices within the text, the participant, the author, and the review analysts. A qualitative meta-synthesis requires the research team to extract the data presented by each of the studies and separate these from the original interpretations. This process began with a second read-through of the studies and we extracted all raw data, in the form of the presented direct quotes and the researcher’s themes from across the studies, maintaining the original wording. We subsequently created a matrix capturing the first-order constructs, the research participants’ original quotes, and second-order construct in the form of the original researcher’s interpretation. This was to ensure the context of the original research was accurately represented. This activity aligned with the ethos of working within the hermeneutic circle, exploring an experience via an understanding of various aspects, where the parts (selected studies) illuminate the whole (phenomena of interest). This also maintained a clear audit trail from the original data to any final interpretative findings. All three researchers had previous professional experience of critical care with two researchers having experience of managing agitation in this clinical setting. Therefore, we directed attention to explore our own preunderstanding of agitation as a distressing episode to experience and observe. Our preunderstanding stemmed from the perspective of ensuring person centred care is enabled. The stance was reflected upon throughout the interpretative process. We interpreted this complete data set constantly moving between first-order construct, second-order constructs, and our preunderstanding. This process resulted in the generation of third-order construct of newly generated analytical themes. We then framed this meta-synthesis in a
way that we believed would clarify and illustrate the critically ill patients' experience of agitation to provide an account for clinicians to consider, with the aim of promoting person-centred critical care. Our analysis of the data generated three themes, offering new interpretations of the sample as a whole. For an example of the steps taken using data generated relating to theme 1, see Table 2.

4 FINDINGS

4.1 Study characteristics

In total, 8 studies fulfilled the inclusion criteria. A total of 494 patients, aged between 18 and 92 years, were included with 225 (45%) women. All selected studies were of Western origin. The descriptive details of the selected studies' methodologies, analysis, and generated themes are outlined in Table 3.

4.2 Methodological critique of the studies

Appraising qualitative research is controversial as even studies with flaws in methodology can provide valuable information. All the included studies presented their aims and objective. As all included studies were qualitative, approaches to sampling was either purposive or convenience. Five studies did not explicitly state their methodological approach, but this was clear in the description. Although purposive sampling was applied, it should be noted that Gutormson's work was secondary analysis of previously generated...
A researcher, who had no involvement in the participant's previous care, carried out recruitment to most studies. Only the recruitment in Karlsson et al.'s study was carried out by the nurse caring for the patient, so in this study, participants may have felt a degree of obligation to participate.

The sample size in qualitative studies is dependent on the philosophical approach. However, it is germane to highlight that two studies had larger than expected samples size, given the philosophical approach by Svenningsen et al. with \( n = 114 \) and by Samuelson with \( n = 250 \). The researchers in the Samuelson study did not audio record the interviews, but the analysis relied on the notes written during the interviews. It was noted that interviews lasted between 5 and 30 minutes, although the number of shorter interviews was not disclosed, with all interviews conducted by the same person. The amount

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**FIGURE 1** Process of study selection based on preferred reporting items for systematic reviews

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**Data.** A researcher, who had no involvement in the participant's previous care, carried out recruitment to most studies. Only the recruitment in Karlsson et al.'s study was carried out by the nurse caring for the patient, so in this study, participants may have felt a degree of obligation to participate.

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### TABLE 2  An example of theme development: theme 1: what is real, what is not

| References          | First-order construct—participants original quote                                                                                     | Second-order construct—original research interpretations                                                                 | Key common concepts                  | Third-order construct newly generated interpretation for theme 1 |
|---------------------|------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------|--------------------------------------|-----------------------------------------------------------------|
| Olsen et al14       | “I had fantasies and was horrified: the nurses were dangerous. I was attending my own funeral.” (ID 2) “I was dreaming I passed the border; it was the end, and everything turned dark.” (ID 22) “I was part of a research project, locked up. People in dark coats were sitting against the wall taking notes.” (ID 17) “I heard people talking. I don’t know what was real and what wasn’t.” (ID 27) “I was moving in a circle. Suddenly, crowds of people in yellow suits gathered around me.” (ID 21) “It was like glitter floating in the air; I tried to catch it with my hands. Everything was in complete chaos. I had no sense of day or night.” (ID 31) “I know the bad dreams are...yes only bad dreams and never actually happened.” (ID 24) “The horrible button on my throat opened and closed all the time.” (ID 13) “It was like a new and unknown world. I gained enormous respect for the job the critical care nurses perform.” (ID 24)  | Theme 1 being on an unreal, strange journey Subtheme: floating between facts and delusion Subtheme: To understand and to be understood Theme 2: Normalizing the abnormal Subtheme: valuing family Subtheme: doing it my way | Altered reality Dreams Hallucinations Frustration Panic Anxiety Terrifying Overwhelming | What is real, what is not                                      |
| Svenningsen et al29 | “My worst nightmare was the light at the end of the tunnel: ‘stop breathing and you will get there.’ In the other direction was my pregnant daughter was willing me to live. This nightmare has been very disturbing to me ever since.” (ID 11) “It was mostly flashbacks from my life where I got younger and younger.” (ID 1006) “My son and daughter-in-law came up. I was sent to an apartment where they controlled me with a joystick.” (ID 505) “I was visiting some friends. I was lying in the hallway and could see my friends at work, but in reality, I saw the nurses.” (ID 387) “I lay in bed and kept sinking—the more I tried to move, the more I sank.” (ID 427) “I climbed around in the mountains and had to kill a lot of people to return. It felt so real and frightening. I couldn’t get away and I couldn’t find the solution.” (ID 1151) | The ever-present family Dynamic space Surviving challenges Constant motion | Altered reality Delusions Hallucinations Panic Not knowing | What is real, what is not                                      |
| Samuelson30         | “I couldn’t speak...terrible...I wanted to explain that I felt like I was dying and didn’t get any air, but I couldn’t.” “I got help...the fact that I got proper help when I was gasping for air...and survived.” “When they gave me a small piece of ice to suck on...oh...it was wonderful.” “Why did this happen to me? What will happen to me? Will I live or die?” “I was like a vegetable, without being able to do anything by myself. It made me feel very defenseless and helpless.” “It felt so strange...I didn’t know if I was alive or dead.” “Yes, the worst thing of them all was all the talking...with each other...all the time, it was really annoying and most disturbing...then, just when you have fallen | Physical distress and relief of physical distress Perceptual distress and well-being Environmental distress and comfort stress-inducing care and caring service | Unable to communicate Nightmares Unsure if dead or alive Terrifying Overwhelming | What is real, what is not                                      |
The timing of the interviews was post-critical care but before discharge from hospital, Samuelson's study noted that this could either mean that the memories were still clear or that the patient has had time to process what happened. Conducting interviews during this timeframe was justified by Whitehorne et al. as it would allow the participant to recount the experience in a supportive environment. The Svenningsen et al. study accessed three sites and Samuelson's study accessed two sites. Although qualitative findings are not intended to be generalized, this potentially could increase the transferability of these studies' findings to other settings. All other studies were single site only. Researchers not involved in the care delivery conducted most interviews across the studies. However, in the

### TABLE 2 (Continued)

| References          | First-order construct—participants original quote                                                                 | Second-order construct—original research interpretations                                                                 | Key common concepts       | Third-order construct newly generated interpretation for theme 1 |
|---------------------|----------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------|---------------------------|-----------------------------------------------------------------|
| Guttormson          | “I dreamed I was in a little car and we were shackled down, with our feet and wrist tied. This went on for several days it seemed to me” (ID 3) | Frequency of delusion memories                                                                                         | Altered reality            | What is real, what is not                                      |
|                     | “you know, I’d wake up. Well like somebody is holding your head underwater or strangulation was a major theme of the scary dreams I had.” (ID 39) | Content of delusional memories                                                                                       | Delusions                  |                                                                |
|                     | “I know it’s a hallucination, part dream, but at the time you’re going through it, to me, it was very real.” (ID22) | Patents’ Interpretation of delusional memories                                                                        | Hallucinations             |                                                                |
|                     | “Now I realise they were bad dreams. Now I realise I was hallucinating.” (ID3)                                         |                                                                                                                          | Panic                      |                                                                |
|                     | “I was locked up and it was like a black cage with a black veil over it. Every time I tried to get out that person would try and stick me with a pitchfork.” (ID22) |                                                                                                                          | Terrifying                 |                                                                |
| Van Rompaey et al   | “The crazy thing now is that this is not possible and cannot be true, the ambulance drops me at the farm and the farmer’s wife makes me pray naked.” (ID8) | Contact and communication                                                                                             | Altered reality            | What’s real, what’s not                                        |
|                     | “Afraid yes and you didn’t understand why, how long did I have to stay imprisoned.” (ID6)                              |                                                                                                                          | Delusions                  |                                                                |
|                     | “I was sitting in a car with a little girl... I drove off with her then I entered somewhere with her not knowing where I was.” (ID20) | The implication of the delirious episode                                                                             | Hallucinations             |                                                                |
| Whitehorne et al    | “It felt like I was living in a bubble. I could move my arms and legs and there were people around me but no one answered me.” | I cannot remember                                                                                                     | Altered reality            |                                                                |
|                     | “The one that was most upsetting was the monkeys. Up in the lights. You could hear them jumping up and down and the were bawling like they were trying to get at me” | Tring to get it straight                                                                                             | Delusions                  |                                                                |
|                     | “The nurse would ask me ‘do you know where you are?’ and I would say [place] and the would say well that very good. But I thought [place] was the name of this boat I was on.” | Fear and safety concerns                                                                                              | Hallucinations             |                                                                |
|                     |                                                                                                                      |                                                                                                                          | Panic                      |                                                                |
|                     |                                                                                                                      |                                                                                                                          | Terrifying                 |                                                                |
|                     |                                                                                                                      |                                                                                                                          | Overwhelming               |                                                                |

of useful data captured in the shorter interviews is unclear. The Karlsson et al.'s study also had some shorter interviews with interviews’ time ranging from 7 to 45 minutes. They acknowledge that the shorter interviews may not have been long enough to capture meaningful data. All studies had documented ethical approval from an appropriate ethical committee. Three of the studies expanded on the potential ethical issue related to the interviews and the strategies employed to support participants.

The timing of the interviews was post-critical care but before discharge from hospital, Samuelson noted that this could either mean that the memories were still clear or that the patient has not had time to process what happened. Conducting interviews during this timeframe was justified by Whitehorne et al. as it would allow the participant to recount the experience in a supportive environment. The Svenningsen et al. study accessed three sites and Samuelson's study accessed two sites. Although qualitative findings are not intended to be generalized, this potentially could increase the transferability of these studies' findings to other settings. All other studies were single site only. Researchers not involved in the care delivery conducted most interviews across the studies. However, in the
| Reference, country | Study aim | Qualitative approach taken | Recruitment and data collection method | Analytical approach | Sample size, gender, age | Data collection timing and capture | Type of unit and length of stay (LOS) in the unit | Themes |
|-------------------|-----------|---------------------------|----------------------------------------|---------------------|--------------------------|-----------------------------------|------------------------------------------|--------|
| Olsen et al (2017), Norway | To investigate how adult patients experience their intensive care stay, recovery period, and usefulness of an information pamphlet | Qualitative, exploratory design | Semi-structured interviews | Qualitative content analysis | Sample: 25 Men: 18 Age: between 20 and 80 y | Audio recorded interviews on the ward following discharge from intensive care unit (ICU) | One site—14 bedded mixed ICU LOS range not stated | Being on an unreal, strange journey Normalizing the abnormal |
| Schmitt et al (2017), USA | To describe common burden experiences among patients, family caregivers, and nurses in order to provide knowledge that can be used to develop delirium burden measurements | Qualitative design | Semi-structured interview | Interpretive description of themes | Sample: 18 Men: 8 Women: 10 Age: Mean age of 79 y (range 70-92) about half were female (56%), and most were white (83%) Caregiver (family) n = 16 They also recruited staff* | Audio-recorded 30-45 min interview. Face-to-face interview 1 mo after discharge from hospital | One large acute-care facility LOS not reported | Symptom burden Emotional burden Situational burden |
| Svenningsen et al (2016), Denmark | To describe the content of former ICU patients’ memories of delusions | Qualitative design | Face-to-face (after 2 wk) and telephone interviews (after 2 and 6 mo) | Phenomenological hermeneutic analysis using Ricoeur’s interpretive theory | 114 included in the study Men: 57% (65) 59% post-surgical, mean age 61 y 56% were CAM-ICU positive (delirious) at least once in the ICU | Audio recorded. Conducted 2 wk, then 2 mo, then 6 mo after discharge from ICU via face to face or telephone | Three ICU LOS not reported | The ever-present family Dynamic spaces Surviving challenges Constant motion |
| Van Rompaey et al (2016), Belgium | To describe the intensive care patients’ perception of a delirium | Hermeneutic qualitative design | Semi-structured interviews | Themes and subthemes derived from the text Hermeneutic spiral | 30 Men: 56.7% (17) 43.3% Age: between 18 and 88 (mean 65.2 y) | Face to face interviews audio-recorded and conducted in the ICU or on transfer to the ward | One site LOS not reported | Contact and communication Feelings Sleep and time The implication of delirious episode |
| Whitehome et al (2015), Canada | To understand the lived experience of intensive care for critically ill patients who experience delirium | Heideggerian hermeneutic phenomenology approach | Semi-structured interviews | Used van Manen’s guidelines for phenomenological analysis | 10 Men: 7 Women: 3 Age: 46–70 y old | Audio recorded face-to-face interview after transfer from the ICU to a medical or surgical unit | One site LOS not reported | I cannot remember Wanting to make a connection Trying to get it straight Fear and safety concerns |
### Table 3 (Continued)

| Reference, country | Study aim | Qualitative approach taken | Recruitment and data collection method | Analytical approach | Sample size, gender, age | Data collection timing and capture | Type of unit and length of stay (LOS) in the unit | Themes |
|--------------------|-----------|----------------------------|----------------------------------------|---------------------|--------------------------|-----------------------------------|---------------------------------------------|--------|
| Guttormson (2014), USA | To describe ICU patients’ delusional memories and interpretations of those memories | Secondary analysis of qualitative data set | Structured interview | Qualitative content analysis | 35 Women: 51.4% (18) Age: mean 66 y | Audio recorded interviews. Conducted after ICU discharge either in the hospital ward or on a long-term ventilator unit in a rehabilitation hospital | One medical-surgical ICU LOS range 2-34 d, median 7.4 d | Frequency of delusion memories |
| Karlsson et al (2012), Sweden | To illuminate the lived experience of patients who were conscious during mechanical ventilation in an ICU | Qualitative design | Semi-structured interviews | Phenomenological hermeneutic analysis using Ricoeur’s interpretive theory | 12 Men: 9 Women: 3 Age: between 23 and 88 y (mean 58 y) | Audio recorded carried out on the ICU or on the ward (who was discharged) | One site general ICU LOS between 2 and 23 d (mean 7 d) | Being dependent on mechanical ventilation to survive |
| Samuelson (2011), Sweden | To describe unpleasant and pleasant memories of the ICU stay in adult mechanically ventilated patients | A descriptive study using a qualitative approach | Interviewed using open-ended questions | Qualitative content analyses inspired | 250 Men: 51% (128) Age: mean age 63 y | Interviews were carried out between 3 and 5 d after discharge from 2 general adult ICU LOS range 1-37 d, median 3.4 d | Physical distress and relief of physical distress Emotional distress and well-being | (Continues) |
studies by Olsen et al\textsuperscript{14} and Schmitt et al\textsuperscript{15} it was unclear who conducted the interviews. Interviews were audio recorded and transcribed apart from Samuelson\textsuperscript{30} Only in the Whitehorne et al\textsuperscript{33} study, participants were invited to check transcriptions. Establishing how representative the included quotes were of the whole data sample is challenging, with only one study offering access to additional information.\textsuperscript{15} Clarifying participant representation using identification codes was also difficult as the allocation of participant identification codes was only provided in the studies conducted by Karlsson et al\textsuperscript{34} Guttormson\textsuperscript{31} Van Rompaey et al\textsuperscript{32} Svenningsen et al\textsuperscript{29} and Olsen et al\textsuperscript{14} The majority of studies had two or more independent researchers generating the themes\textsuperscript{14,15,29,32,34} The study conducted by Guttormson\textsuperscript{31} appeared to have only one researcher undertaking the thematic analysis and completing the subsequent publication. Similarly, Samuelson\textsuperscript{30} appears to have undertaken the study alone but does mention a second researcher involved in the discussion about coding and categorization.

4.3 | Meta-synthesis findings

In this section, the three developed themes are presented. The findings are supported by selected quotes with reference to the original data set, using, where available, the participant identification code (ID) allocated by the original research team. The themes were (a) what is real, what is not, (b) loss of communication and dependency, and (c) what helps, what does not.

4.3.1 | Theme 1: what is real, what is not

In data extracted from six of the eight selected studies, patients recalled experiences linked to the sensations of being drowned, suffocated, or strangled. They used terms such as “terrifying” and “overwhelming,” with the resulting feelings of “panic” and “anxiety.”\textsuperscript{14,29-33}

You know, I’d wake up. Well like somebody is holding your head underwater or strangulations was a major theme of the scary dreams I had. (ID 39\textsuperscript{31})

I was restrained and forced to be treated. A mask with too much air was forced on me—like holding the head out the car door—panic! The nurse got suspicious because I wasn’t supposed to touch my throat. (ID 1159\textsuperscript{29})

I was afraid, I held on to everything I could grab for not falling asleep. Then, I tore loose everything. (ID 12\textsuperscript{32})

Many accounts acknowledged what patients had experienced were hallucinations. At the time, the experience was so real to a
feeling of frustration and anger. These emotions were mainly directed at themselves for not being able to understand what was happening.

You didn’t know what to believe like...are they [monkeys] really up there in the lights or is that just your mind and then you look at [sister’s name], is she really there or is that just my mind? I couldn’t get...what’s real and what’s fake right...It’s confusing. (No ID33)

I heard people talking, I don’t know what was real and what wasn’t. (ID 2714)

I was upset with myself because I could not catch what was happening. (ID 2632)

The experience of such uncertainty of their reality impacted on the patients’ ability to sleep and communicate with the staff. There were also delusions involving the staff leading to patients’ distrust, mainly of the nurses.

I had fantasies and was horrified: the nurses were dangerous. I was attending my own funeral. (ID 215)

Those terrible, terrible nightmares...oh, when you woke up, it was an overwhelming experience, so strong and frightening, I was out of my mind...I didn’t dare to sleep because of them. (No ID28)

Some of the staff abducted me and tried to kill me. I didn’t think my family knew where I was. (No ID29)

The inability to establish time within this new reality contributed to the patient’s anxiety. Patients expressed existential feelings of uncertainty around their existence and an overwhelming sense of vulnerability.29-33

4.3.2 Theme 2: loss of communication and dependency

Data provided by six of the selected studies identified the loss of speech and the barrier to communication as a factor, which induced feelings of fear, panic, anxiety, and a loss of control.15,29,30,32-34

I couldn’t speak...terrible...I wanted to explain that I felt like I was dying and didn’t get any air, but I couldn’t. (No ID29)

I was angry at the nurses because they did not do what I wanted. The nurses were brutal; they completely did not understand me. (ID R1512)

Even when communication was possible, for one participant, this seemed superficial and ineffective.

Nurses would come and ask me “do you know where you are?”... And, ah, I would say [place], and they would say well that’s very good. But I thought [place] was the name of this boat that I was on. (No ID33)

The inability to effectively communicate resulted in a heightened sense of dependency on the staff. Several participants compared their level of dependency as being treated like a child or feeling like a vegetable.30,34 This dependence induced a sense of loss of control.

Weak in my body. And (brief hesitation) I felt like a child, you know, who doesn’t think too much, can’t do anything; I can’t pee by myself, poo by myself, I can’t do anything. (ID P234)

I was like a vegetable, without being able to do anything by myself. It made me feel very defenceless and helpless. (No ID35)

I like to be in control of me at least, and I was not allowed to be. (No ID15)

There was nervousness expressed by participants around the level of trust they placed in the staff and the dependency on the machinery to keep them alive.

So obviously, I was a little worried... that it would pack up...Yes, it was like “if this packs up...so will I...Or...I’ll stop breathing...”. (ID P434)

The anxiety and frustration expressed appeared to stem from an acute sense of dependence and vulnerability.

4.3.3 Theme 3: what helps, what does not

Data from four of the selected studies did offer insights into strategies that may be helpful to support patients.14,30,33,34 They also offered reflections of negative behaviours contributing to the feeling of fear, anger, and anxiety.

Three participants across two of the studies expressed the importance of therapeutic touch, hand-holding, feeling cared for, and comforted.30,33

I can remember the nurse...rubbing her hand over my head...and she was smoothing my hair down, her words were so kind...even when I was in that state, I could feel someone taking care of me. (No ID33)

They did everything they could to help and support me. Like they were carrying me through...through all the hard and terrible ordeals. Like something warm and human in the middle of chaos. (No ID35)
I remembered one nurse, stroking and then holding my hand, speaking in a friendly way to me. It felt wonderful and comforted me. (No ID)

The importance of effective communication and contact was reinforced as a strategy to help patients through this time. The suggestion that pictures could be used as an aid to reorientation was also offered.

Everything is so unreal, and pictures would have made a difference. (ID)

The one most important thing was to have eye contact with the nurse. Some of them only needed a glance to understand what I wanted. (ID)

Negative reflections of unhelpful behaviours linked to development of agitation focused on the lack of experience of the nurse, lack of consistency in the nurse caring for them, and overhearing nursing staff discussions. One unpleasant experience was suction of the airway, with the anticipation of the procedure causing distress and agitation. Additionally, the level of expertise the nurse possessed to carry out the procedure impacted on the patients’ experience.

Some of them go to work on it [tube] like it was some bloody sewer that had to be cleared, yeah. And they pushed it all down until it was completely blocked. And I couldn't breathe because of it either...and I had to breathe then so...Some of them were really good...so it was...in my experience, they had very different ways of managing the suction. Yes, absolutely! (ID)

To reduce feelings of anxiety and agitation, participants wanted consistency in care delivery and in the nurse delivering care.

I experienced many temporary nurses; think I had 10 different ones in a row - one after the other. I had language problems with many of them, and it was difficult for them to read my lips. (ID)

Negative behaviour and comments made by nurses were noted across several delusions. There were also memories recalled when this, the participant felt, was not a delusion but a true event. Overhearing negative communication had a significant impact particularly on the individual’s ability to sleep, increasing the sense of vulnerability and agitation.

I heard sarcastic and malicious comments, and they talked a lot about private stuff, they didn’t care a bit about me...I didn’t dare to...Oh, I couldn’t get to sleep because of that. (No ID)

During an agitated episode, the impact of competent, compassionate staff had a lasting effect on the person’s memory of critical care.

It was like a new and unknown world. I gained enormous respect for the job the critical care nurses perform. (ID)

The clever and competent staff...wonderful...they counterbalanced the unpleasantness...without them, I’d gone crazy. (No ID)

The nurse’s connection with the patient on a human level and maintaining this connection may mitigate the feeling of anxiety and prove vital to support the individual through a frightening and, at times, unreal experience.

5 | DISCUSSION

We aimed to systematically review existing qualitative evidence, appraise it, and then provide a synthesized interpretation to broaden the understanding of patient agitation during critical illness from the patient and their families’ perspective. As research into the outward presentation of acute agitation and its management in critical care is under-researched, we assumed that delirium and anxiety would render the person agitated. Our analysis generated three core themes relating to participants’ perceptions of what was real and what was not, loss of communication and dependency on staff, and possible strategies which may help.

Delusional memories are not uncommon following a critical illness. Hallucinations and delusional thoughts are believed to stem from the presence of delirium. These experiences of hallucinations and delusional thoughts are among the more traumatic aspects of critical illness. In one of the selected studies, patients described the delusions as distressing, scary, and very real in the moment. The person’s understanding of reality may be affected by the closeness they have been to death. A grounded theory study exploring survivorship following critical illness described the experience as an “unscheduled status passage of being taken to the threshold of life.” Fear of death, the emotion of anxiety, and feelings of pain being a constant, alongside transient periods of conscious levels provoke the feeling of intense vulnerability. This level of anxiety, stress, and fear may contribute to the development of agitation.

The loss of effective communication and the feeling of dependence can create anxiety, distress, and agitation. The experience of being non-vocal has been described as one of the worst consequences of ventilation, contributing to the feeling of despair and helplessness. The need for effective communication by the health professional is vital but by no means a new finding. The feelings of loss of control could be exacerbated by poor
communication between the clinician and patient. Additionally, patients may not be actively involved in the decisions they make about their care perpetuating feelings of dependence and lack of control. In the exploratory study conducted by Alasad et al, 13 47% of patients reported that they were not offered a say in their care. Alternate approaches to verbal communication such as writing on a pad, lip reading, and communication boards are common communication strategies in critical care. 10 Yet a significant degree of anxiety related to ineffectual communication remains evident. The impact of ineffective communication is not only felt during the patient's critical care stay, it contributes to reducing optimal recovery after discharge. 38

The effect of environmental factors such as inability to distinguish day from night and noise have been associated with the development of delirium. 13 Alongside effective communication, supportive strategies such as reorientation to time and place, providing reassurance and consideration of the environment, may have a positive impact. This multicomponent non-pharmacological approach is recommended in the updated Clinical Practice Guideline for the Prevention and Management of Pain, Agitation, and Delirium. 39 In our interpretation, patients reflected positively on the use of touch, eye contact, and feeling cared for. This presence of the nurse is described by Karlsson et al, 34 as “standing by.” It is a caring action to promote stimulation of the patient's inner strength and to alleviate suffering arising from the feeling of dependency. 34 Potentially, nurses and the wider health care team may not consciously consider the act of simply being present with the patient as a strategy to help alleviate suffering.

The feeling of loss or lack of control has been described in the critical care patient literature.10,26 Being involved in care decision-making when in critical care can make patients feel human and re-establish the feeling of control.24

One noticeable gap in our data is the involvement of the family in supporting the patient through this period of their critical illness. Family members can support a person’s sense of self and help them understand what has happened.26

6 | STUDY LIMITATIONS

Our aim was not only to broaden the understanding of patients’ experience of agitation but also their families’ experience of observing agitation during an adult critical care admission. Only one of the selected studies had data on the family experience. As the family perspective was not adequately represented, this part of the review aim was not achieved. The inherent purpose of a meta-synthesis approach is to facilitate new knowledge development, a critique of this may be that the deconstruction of the original work may result in a loss of original meaning. 40 However, the aim was not to provide a summary of data, it was to present new perspectives on agitation via this interpretation. The strengths of the study are that we undertook a robust search strategy and maintained a clear audit trail of theme development. Due to the absence of research focusing on agitation, none of the selected studies centred solely on agitation but on delirium. Of the studies included four focused on delirium yet did not differentiate between the subtypes of delirium, hyperactive, hypoactive, and mixed between the type of delirium (Svenningsen et al, 2016).15,29,32,33 The review may be biased towards a Western perspective as papers with no available translation of non-English text were rejected. Additionally, across the research included several counties were represented with international variation in critical care delivery such as nurse to patient ratio and approaches to sedation, which may impact on the patient experience of agitation.

7 | IMPLICATIONS AND RECOMMENDATIONS FOR PRACTICE

The management of patients’ agitation is complex and challenging within critical care. The heterogeneity of the patient population creates an additional layer of complexity when trying to understand and manage individual patient needs, while also supporting the family. Increasing awareness within the health care team of the patient experience may allow the team to reflect on their practice and consider positive changes. These clinical reflections can influence decision-making around the strategies employed to pre-empt and manage agitation. The incorporation of the patients’ experience of agitation in critical care during reviews of policy would help inform practice, for example, in policy related to the promotion of family involvement in care and visiting. An understanding of the patient experience of agitation across pre- and post-registration education would also support learning about the care of this patient group.

8 | CONCLUSION

The main finding of our study is that critically ill patients continue to experience agitation, delusional thoughts, and hallucinations. They continue to have increased level of anxiety and agitation related to loss of control and poor communication with the health care team. We aimed to gather, synthesize, and interpret knowledge that already existed on the experience of agitation in critical care from both the patient and family perspectives. In part, we have achieved this and identified a clear gap of the family members’ views and experience. The patient’s recollection of their critical illness can be obscured and disjointed with uncertainty around what is real and what is not. Family members sit and observe the full effect of the critical care illness on their loved one and are a wealth of untapped information. Information may provide further insight into how we can improve the psychological well-being of critically ill patients.
AUTHOR CONTRIBUTIONS

Study design: Samantha Freeman, Janelle Yorke, Paul Dark; data collection: Samantha Freeman; data analysis: Samantha Freeman, Janelle Yorke, Paul Dark; manuscript preparation: Samantha Freeman, Janelle Yorke, Paul Dark.

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