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Research Article

Do health care professionals worry about delirium? Relatives' experience of delirium in the intensive care unit: A qualitative interview study

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ABSTRACT

Objectives: In intensive care units, there is a high incidence of delirium, which relates to the risk of complications. Engagement of relatives is an acknowledged part of handling delirium, but knowledge of relatives' perspectives is lacking.
Aim: To explore relatives' experiences of delirium in the critically ill patient admitted to an intensive care unit.
Research design: A qualitative design with a phenomenological approach. Semi-structured interviews with eleven relatives of critically ill patients who had delirium during admission to the intensive care unit.
Setting: An intensive care unit in Denmark.
Findings: Three categories emerged: '*Delirium is not the main concern*', '*Communication with health-care professionals is crucial*', and '*Delirium impacts on relatives*'. Relatives had a lack of knowledge of delirium. Symptoms of delirium were thought of as a natural consequence of critical illness and seemed to be a secondary problem. Health-care professionals did not talk about delirium and information was requested. Delirium and the manifestation of it was experienced in different ways and brought different ways of coping.
Conclusion: Findings give a new insight into relatives' experience of delirium in the intensive care unit. Relatives need more information to better understand delirium. Future research must investigate the potential in helping relatives to cope with delirium, to the benefit of both patient and relatives.

Implications for clinical practice

- This study highlights that relatives are an acknowledged part of handling delirium, but research of relatives' perspectives of delirium in the intensive care unit is lacking.
- Findings generated from this study show that relatives experienced that delirium was a secondary concern which health care staff did not involve them in, therefore relatives developed their own way of coping.
- Findings highlight the need for relatives to be included in the treatment of and have information about delirium as they urge health care professionals to verbalising it and being less distant about it.
- Future research must investigate the potential of helping relatives to cope with delirium, to the benefit of both patient and relatives.

Introduction

The incidence of delirium in intensive care units (ICU) ranges from 45 to 87% and appears to be strongly influenced by mechanical ventilation in critically ill patients, as this is an important risk

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factor for delirium (Cavallazzi et al., 2012). Delirium is defined by the American Psychiatric Association in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) as a disturbance in attention and awareness with additional disturbance in cognition (American Psychiatric Association, 1995). The condition develops over hours to days and fluctuates throughout the day and cannot be explained by pre-existing neurocognitive disorder (American Psychiatric Association). Delirium in ICU is related to the risk of morbidity, length of stay in hospital and mortality (Salluh et al., 2015). An evidence-based multicomponent bundle has been proposed in the literature and is associated with reduction in delirium in ICU (Barnes-Daly et al., 2017). The evidence-based bundle consists of the following steps: A: *A*ssessment, prevention and management of pain. B: *B*oth spontaneous awakening and breathing trials. C: *C*hoice of sedatives and analgesia. D: *D*elirium assessment, prevention, and management. E: *E*arly mobility/exercise. F: *F*amily engagement and empowerment (Marra et al., 2017; Ely, 2017; Pandharipande et al., 2017). Despite that the ABCDEF bundle has evolved to include, 'F', family engagement as a part of the bundle of how to manage critically ill patients and prevent delirium, there is a lack of research to investigate the thoughts and perspectives of relatives on their experiences of witnessing delirium (Marra et al., 2017; Marandi et al., 2017). Recently, a multinational, interprofessional perspective on what research is needed in the field of ICU delirium concluded that family experiences should be explored in future studies (Pandharipande et al., 2017).

Relatives play a vital role for patient recovery why knowledge of the relatives' experience of delirium in ICU is needed to identify relative's needs and provide new insights to be considered while delivering the bundle of care primarily for the critically ill patients but may also benefit of relatives as well. The aim of this study was to explore relatives' experiences of ICU delirium in critically ill patients.

Methods and materials

Design

A qualitative semi-structured interview study design with a phenomenological approach was used to collect data from relatives of critically ill patients with delirium in an ICU setting. The study is reported in accordance with the Consolidated Criteria for Reporting Qualitative (COREQ) research checklist (Tong et al., 2007). Phenomenology investigates the lived experience and the life-world of a person to achieve a deeper understanding of the person's everyday life existence (Laverty, 2003). In methodology, phenomenological research is descriptive and focuses on the structures of experience and seeks to elucidate them as they appear in consciousness (Laverty, 2003).

Preunderstanding

The researchers must strive to achieve phenomenological reduction and be aware of their own impact on the material in order to be loyal to the experiences of the participants without the researchers' interpretations. However, a complete phenomenological reduction in its pure form is considered to be unachievable in practice, but by making the researchers preconceptions visible, it is thereby kept at a distance (Malterud, 2011).

We remained conscious of our own preconceptions from our background in nursing and medicine, and from working with delirious patients and their relatives in ICU. From our knowledge of the serious risk of consequences of delirium for ICU survivors and experiencing delirium to be a major center of attention for the nurses and physicians in the ICU, we initially expected this to be reflected in the description from the relatives.

Participant recruitment

To be eligible for study participation, the participant had to be a relative of a patient ($\geq$18 years) admitted in ICU for at least 48 hours and having delirium by DSM-IV identified with a positive score by Confusion Assessment Method for the ICU (CAM-ICU) (Gusmao-Flores et al., 2012), at least during two days of their ICU stay. Inclusion criteria for relatives were that they were an adult (>18), and a spouse, family member or close friend with a patient with the above criteria. Relatives were excluded if they lacked the capacity to consent, or if they did not speak Danish fluently. Non-participation and the reason for people refusing to participate or to reconsider participation was registered (Fig. 1).

Potential participants received information about the study through a researcher and handout pamphlets, if they were agreed to be contacted. In the information the term delirium was used as a term but was not fully explained to minimize the influence on the later responds during the interview.

Setting

The study was carried out in a Danish 11 beds general medical/surgical level II ICU at Herlev XXX Hospital, Herlev. The unit had a 24 hour a day open visiting policy and all patients stayed in single patient rooms. Patients in the ICU received standard medical and nursing health care, that included a delirium-bundle. Nurses and physicians at the unit had received instructions to the bundle before the study started. The bundle was focussing on pain management, no/light sedation, twice a day a routine of delirium assessment using the CAM-ICU, circadian rhythm/sleep, and early exercise.

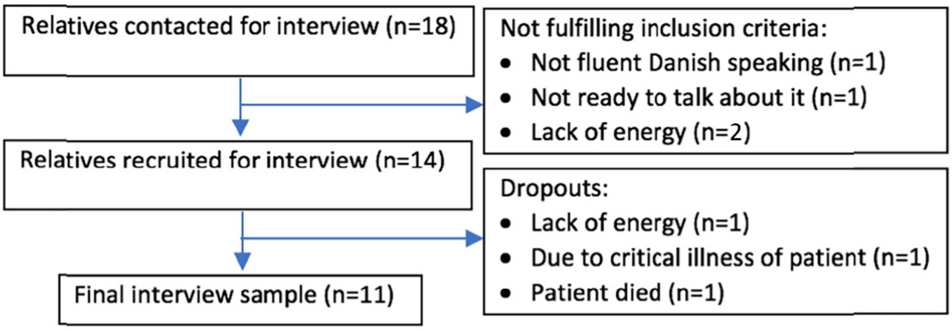

Fig. 1. Flow of participants.

Data collection

The interviews were conducted from December 2017 to April 2018 using an interview guide with ten research questions (Table 1). Questions were generally broad and open ended and followed the structure of Method of Phenomenological Interview based on themes of experience contextualisation, apprehending the phenomenon and its clarification (Bevan, 2014). Content validity of the interview guide was gained by a review of the literature, clinical experience of both the research team and fellow nurses from the ICU. A pilot testing on two relatives was made with subsequent modification of the wording of the questions. The modification consisted primarily of adding synonyms to the wording of the questions, as relatives was not familiar with delirium as a term. The clarification of delirium came after the second question in the interview guide.

The participants were interviewed at the hospital at their preference. Interviews were recorded using a digital voice recorder. Field notes were taken to document issues that could not be captured by audiotape such as the participants' gestures or facial expressions. All interviews were transcribed verbatim and organised with NVivo 11.4.2 software. Data saturation was discussed between the researchers to clarify when themes were recurring and no new themes seemed to emerge, then the inclusion of new participants was stopped. After the interviews, the participants were asked to complete a short, written questionnaire to provide basic demographic details and background of being a relative in the ICU.

Data analysis

Analysis was based on Kirsti Malteruds description of a four-step systematic text condensation (Malterud, 2011; Malterud, 2012): 1) The text was read several times to obtain an overall impression of experiences related to delirium in ICU from which the preliminary themes emerged. 2) Units of meaning were identified based on preliminary themes and sorted in to code groups across individual participants. 3) Condensing all code groups was sorted in subgroups to visualize different perspectives. 4) Finally, categories were made based on a summary by the essence from code groups (Malterud, 2011; Malterud, 2012). The four steps of systematic text condensation analysis method are described and illustrated through an example of the process of the analysis (Table 2). All authors participated in analysing the data and finding categories through discussion. Quotes were chosen on the bases of what clearly represented issues of what was mentioned in the results.

Ethics

This study complied with the Declaration of Helsinki. Prior to participation written and verbal information was provided and participants were required to give written consent. Danish Data Protection Agency approved the study (I-Suite no.:06022, ID-no.: HGH-2017-113). According to Danish law formal approval of qualitative studies is not necessary, however we notified the Ethics Committee in the Capital Region, Denmark (file no 17029440). Every interview ended with a short session of debriefing and in cases where it was relevant the interviewer helped to initiate a meeting between relevant health care personal and the relative. This was relevant in two cases.

Findings

Participants

In total 11 relatives were interviewed (Table 3), eight during ICU admission and three the day after the patient was transferred to the ward. The interviews lasted between 28 and 59 min.

Categories

Three categories emerged from the analysis. The categories and underlying subgroups are illustrated in Table 4.

Category 1: Delirium is not the main concern

This category refers to relatives' knowledge and pre-understanding of delirium, and how this condition was found to be a natural consequence of critical illness and was considered secondary among other concerns.

Pre-understanding of delirium

Most of the participants had never heard about delirium as a term used in ICU. They had experienced the patient being different or doing/saying things out of the ordinary and from health staff this condition was spoken off as "being confused", "having fatigue", "being sad or restless".

> *"Most of them [health care professionals] did not say anything. But when they did say something about it [delirium] they said, 'he is a bit sad today', 'he is a little confused today', 'he is very tired today'. These were the words that were used." (Informant 10)*

Participants had different pre-understandings of delirium as a term. Typically, participants associated delirium with alcohol withdrawal or alcohol intoxication, but not in a context related to the ICU. Some participants explained they had looked the term delirium up to gain some knowledge about the phenomenon prior to the interview. Some participants referred to family members or colleagues who had had a relative in an ICU and from this they had some knowledge of delirium. The exploration of knowledge about delirium took place for some participants *before* they were asked to participate, and for others they had not heard the word before they were invited to participate in the study.

Table 1
Interview guide.

Research questions:
1. Please, tell me how you came to be a relative in the intensive care unit?
2. Tell me, what do you think delirium is?
3. Tell me, how does your loved one attention and awareness differ from normal?
4. What do you experience when your loved one is having delirium?
5. What worries do you have when your loved one is being delirious?
6. What do you do when your loved one is being delirious?
7. How do you experience health care professionals is dealing with your loved one is having delirium?
8. How did you experienced to be supported when your loved one was dealing with delirium?
9. What kind of needs do you see your loved one is having when dealing with delirium?
10. We have covered several things in this interview, is there anything else you would like to add to your story?

Table 2
Description and illustration of the analysis process.

Systematic text condensation by Malterud (2011, 2012)	Illustration of the analysis process from the present study
Step 1 ‘Total impression-from chaos to themes’: A general impression of material was made by reading and rereading all transcripts, and preliminary themes associated with participants experiences with delirium on ICU was summarised.	Preliminary themes: Information, uncertainties, powerlessness, anxiety/fear, preunderstanding, healthcare staff, symptoms, severity of delirium.
Step 2 ‘Identifying and sorting meaning units- from themes to codes’: Systematic decontextualisation. Transcripts were reviewed systematically line by line, and ‘meaning units’ were identified and systematically coded with a label. Preliminary themes from step one where in mind when ‘meaning units’ were identified. When new codes were identified previously text was reread, so all possible meaning units entered the code.	The process of developing and synthesizing codes. The text was read and reread to synthesize codes into new and fewer codes: “Health staff, preunderstanding, treatment, relatives’ role, information, early signs, not the most important, future, relatives’ needs, symptoms, patient needs, hope, affects relatives, natural consequence, reason for the development of delirium, patient recognizes relatives, made the process harder, changing staff, missing voice, powerlessness, a relief, patient afraid”. ↓ “Health care professional, pre-understanding, treatment, role of relatives, information, early signs to delirium, not the most important, future, symptoms, patient needs, impact on relatives, causes of delirium, patient recognizes relatives, made the process harder”. ↓ “Health care professional, treatment, pre-understanding, communication/ information, delirium not the most important, causes of delirium”. ↓ “Communication, Pre-understanding”. ↓ “Preunderstanding, Communication, Deliriums impact on the relatives”.
Step 3 ‘Condensation-from code to meaning’: Each code group is studied and sorted in sup-group	Code groups and underlying subgroups: Preunderstanding: • What is delirium? • Delirium as natural consequence • Delirium is secondary Communication • Health care professionals • Medication as the articulated treatment of delirium • Need of information • Talking about it is a relief Deliriums impact on relatives • First encounter with delirium • When the patient seems like a stranger • Coping styles • What about the future?
Step 4 ‘Synthesising- from condensation to descriptions and concepts’: Categories were developed from synthesizing the essence from code groups. Subgroups got its own underlying section. Recontextualised was made by rereading the transcripts and holding it up to the results.	Results from the analytic text is represented in the section ‘Results’.

Table 3
Demographics for participants (n = 11).

Participants, (n = 11)	Age, years	Gender	Relation to patient	ICU, days	Length of interview, minutes
Informant 1	70	Male	Brother	42	44
Informant 2	51	Female	Ex sister-in-law	42	29
Informant 3	54	Female	Daughter	5	59
Informant 4	64	Female	Spouse	21	42
Informant 5	76	Female	Spouse	14	47
Informant 6	58	Female	Spouse	9	39
Informant 7	58	Female	Daughter	3	44
Informant 8	55	Male	Brother	6	28
Informant 9	65	Female	Close friend	6	29
Informant 10	75	Female	Spouse	10	30
Informant 11	74	Male	Spouse	5	44

> *"I have never heard the word before! I read this [information material from the project], I do know what delirium is, it’s some abstinence that you’ll get if you have drunk too much, right? But I am not sure. Nobody has never mentioned that word." (Informant 10)*

Delirium as a natural consequence

Most relatives perceived symptoms of delirium as a natural reaction to critical illness. Like other organ failure, the brain could also fail.

Table 4
Overview of categories and subgroups.

Categories	Subgroups
(1) Delirium is not the main concern	(1.1) *Pre-understandings of delirium* (1.2) *Delirium as a natural consequence* (1.3) *Delirium is secondary to life and death*
(2) Communication with health care professionals is crucial	(2.1) *Health care professionals don't seem to worry about it.* (2.2) *Medication as the articulated treatment of delirium* (2.3) *Need of information* (2.4) *Talking about it is a relief*
(3) Delirium impacts on relatives	(3.1) *First encounter with delirium* (3.2) *When the patient seems like a stranger* (3.3) *Ways of coping* (3.4) *What about the future?*

> *"I think it [delirium] has something to do with him being unconscious for so long. Just like all the other organs, that his body has been shut down, the kidneys have shut down or something like that. Maybe it could be that the brain needs some kind off reset. You could say it needs to get running again. That's what I think about it." (Informant 4)*

There were many narratives where participants had an explanation to what they believed had caused delirium. These were mainly created from the relatives' own hypothesis and some from information given by health care professionals. Typically, participants attributed the causes of delirium to the effect of drugs, ventilator treatment or the patient being afraid.

> *"Well, I think there are many factors. Partly, that he has had difficulty breathing...he has had extremely high oxygen supply. Partly, that he suffers from anxiety." (Informant 6)*

Delirium is secondary to life and death

For most of the relatives, delirium was not the main concern in ICU. The greatest concern was whether the patient would survive and in that context symptoms of delirium were dealt with later on.

> *"But in some ways, you realised that as ill as he was, the delusions were not the most important thing at that time. It was that he was breathing and surviving. So, the brain could be taken care of afterwards." (Informant 2)*

Category 2: Communication with health care professionals is crucial

This category refers to relatives' experiences of the way delirium is communicated in the ICU. As we found delirium was an unfamiliar term for relatives, health care professionals communication about delirium influenced relatives perception of it.

Health care professionals don't seem to worry about delirium

Typically, participants were in general well-informed about the overall condition of patient, but issues related to delirium were left unspoken. This left participants with the impression that delirium was not a central concern of health care professionals.

> *"They haven't talked to me about it [delirium], because then I would have remembered something about it, and they have not. But otherwise, they have informed me about the medication and the physiotherapist and they were going to do this and..." (Informant 5)*

Overall, there was incongruence in relation to how participants experienced the talk of delirium and what approach health care professionals had to it. One participant, who had been a relative to a patient with severe symptoms of delirium over several days, experienced health care professionals handling delirium in several different ways (i.e. one physician increased the dose of haloperidol and shortly after the medical treatment was stopped by another) and with different impressions of the severity depending on which doctors and nurses were on duty. Few participants had heard the term: 'delirium' used directly and in these cases relatives were told by health care professionals that it was a normal condition in ICU and health care professionals gave the impression that it was not a serious condition and it was temporarily.

> *"...the nurse came and said, 'can you feel she's different?' So, I said, 'Yes, I can. She is irritated and...restless...and angry about all this'. So, she said to me, 'Well, this is delirium. You should not be worried about it. It will pass'." (Informant 7)*

Medication as the articulated treatment of delirium

Most of the participants mentioned the pharmacological treatment, but did not talk about non-pharmacological approaches and said they did not notice anything being done. They said, they would like to be involved if they could do anything to diminish symptoms of delirium, but nobody experienced an invitation to become involved.

> *"Well, it has mostly been on the medical treatment that you could see that they have tried to treat it. I can't think of anything more... Some have been good, telling him what they were doing around him and said, 'Now I'm just right behind you and will make some noise'. Explaining what they were doing might make him feel more comfortable." (Informant 6)*

Need for information

Participants seemed to become increasingly aware of the lack of knowledge they had about delirium during the interview. If they had had the possibility, they would have preferred more information and expressed a need for information specifying pathologies, possible treatments and assumed causes. Information about delirium was beneficial by dialog with health care professionals or/and standard written information.

> *"Is it a normal situation? How common is it? Is it rare? Is it critical? Is it not critical? Is it dangerous? Is it not dangerous? I want to know what it is." (Informant 11)*

Although, several relatives wished for more information about delirium, some said they were of the impression they could ask nurses and physicians about delirium if they wanted to, but often they didn't. As one participant described there were plenty of other things to be concerned about.

> *"If I had asked more about it, then perhaps they would have told me more. But I thought...my impression was, that they handled it well. I thought so." (Informant 2)*

Talking about it is a relief

The few participants who experienced being informed by health care professionals about delirium as a condition, described it as being a relief as it helped them to process the changes in patients' awareness or attention they already were witnessing. Explanations about delirium that were recognisable and learning it is a well-known condition in ICU that health care staff are used to treat was considered reassuring.

> *"I was relieved when I heard about delirium because it explained what I have been seeing. I'm not an expert in this area, but I could see he was not himself." (Informant 6)*

Category 3: Delirium impacts on relatives

This category refers to what the participants experienced when they witnessed symptoms of delirium for the first time and the way it affected them.

First encounter with delirium

The first sign of delirium was noticed by relatives at very different time points during the period of hospitalization. Some relatives initially said they had not noticed any delirium, however, when they talked about what they had experienced they described symptoms of delirium (e.g. different strange behaviour, irritated or agitated behaviour etc.), they just did not recognize it as delirium at the time.

> *"I thought she was very restless, and I thought it was strange that she pulled in the lines [IV-lines, monitoring-lines]. I thought, why is she doing that? And I said, 'you must not pull in all the lines'." (Informant 7)*

When the patient is like a stranger

Some described the patient had become as a stranger. In cases where they could not recognise the patient behind the changes in attention and awareness, it seemed to affect and bring concerns to a higher level. One relative described the patient as being mentally absent, which the participant said was the most worrying part.

> *"It's not the person that I knew before he came in [to Hospital]. That's what worries me the most." (Informant 8)*

In contrast, some participants seemed content if only the patient could recognize the family members. They experienced symptoms of delirium like an extension of the patient's personality, which made it easier to cope with.

> *"He has been confused about where he was and what had happed, and what floor he was on. Well, he has been able to recognise us who have come visit him. He has been able to do that all the time. I have had the feeling, he was himself, behind that blurry, very weakened state he was in." (Informant 2)*

Ways of coping

As recognition of delirium differed among the relatives, it affected participants ways of coping in various ways. Several participants described how they tried not to demand too much of the patient, and some were precautious of what they said to the patient as they did not want to create more worries or anxiety. They balanced between just letting things slip or correcting if the patient said or did things that were abnormal.

> *"I am trying just to let it go, unless there is something that can be said, 'it's like this and that', then I would tell him, and then he'll say, 'oh, yes'. . .So I won't let him drive out in that nonsense. . .I will just follow all the nonsense, unless it is totally chaotic." (Informant 2)*

What about the future?

Most relatives expected the patient to recover from delirium, but still most of them were filled with uncertainty if that really was true and what the future would bring. These kinds of thoughts were mainly described by participants with patients who had survived the most critical state of illness, which seemed to open up thoughts of long-term consequences.

> *". . .things are difficult, but. . .but I wonder a lot about how it's going to be at the end. It's clear, if he continues to be a bit strange in his head, to say it straight out, I would be really upset about that. But I don't think so. . .because some things he says, shows me he is there." (Informant 4).*

Discussion

Main findings

'Delirium is not the main concern'

Findings indicating that relatives have little knowledge about delirium have been found in studies from non-ICU settings (Toye et al., 2014; Namba et al., 2007). Toye et al. (2014) indicated in a qualitative study from a hospital ward setting, that the lack of understanding of the patient's delirium condition challenged the relative's wish to participate in the treatment of the patient (Toye et al., 2014). Furthermore, a need for information was also constantly demonstrated, and relatives sought information elsewhere, because this need had not been met by health care professionals (Toye et al., 2014). In present study relatives also sought information elsewhere. However, some of them where first aware of their lack of knowledge when they were introduced to the term delirium during the invitation to participate in the study.

Furthermore, a need for information was also constantly demonstrated, and like this present study, relatives sought information elsewhere, because this need had not been met by health care professionals (Toye et al., 2014). Relatives in our study considered symptoms of delirium to be a natural consequence of critical illness, in consistence with a qualitative study in a non-ICU setting of relatives of terminally ill cancer patients with delirium, that also recognized delirium as a natural part of the process in critical illness (Namba et al., 2007). In contrast to our study, relatives in non-ICU settings seemed to have delirium as a main concern (Namba et al., 2007; O'Malley et al., 2008; Day and Higgins, 2015). It is possible that this difference in results may be related to timing. Many of the participants in our study were interviewed during a critical state of the patients' condition, where it was first and foremost a matter of survival.

'Communication with health care professionals is crucial'

The lack of communication and the need for health care staff to be more communicative about delirium has been identified consistently in other studies in non-ICU settings (Namba et al., 2007; O'Malley et al., 2008; Smithburger et al., 2017). In line with our study, other qualitative studies in ICU settings found that relatives have a desire to be involved in the care of the patient in general (Smithburger et al., 2017; Garrouste-Orgeas et al., 2010; Azoulay et al., 2003). Providing information to relatives has been shown to be an effective way of improving relatives' satisfaction and comprehension and gives the relatives the opportunity to actively participate in the care of the patient (Azoulay et al., 2002). Furthermore, this could help relatives in ICU to gain control by building reasonable expectations about patient outcomes and to cope with possible distress (Azoulay et al., 2002; Maillet et al., 1993). Better comprehension does not generate more symptoms of anxiety or depression in the relative in ICU (Azoulay et al., 2002). It has even been seen to be able to reduce the distress of relatives by providing knowledge and tools to make them participate in care giving (Skoog et al., 2016). This is in line with the relatives in this present study who had been informed of delirium as they described information about delirium as a relief. It helped them to verbalise what they already could see was different and difficult to understand and handle. Relatives in our study described a need for information about delirium, in context of dialog with health care professionals as well as standard written information. In a study from a hospital ward written information about delirium was available, however, relatives emphasised the need for dialogue with health care staff (Toye et al., 2014) as the written information cannot stand alone.

As in all other respects, the health care professionals approach to relatives and patients should be caring and respectful when informing of delirium. However, health care professionals must be aware of the consequences of delirium in ICU that is related to the risk of morbidity, prolonged length of stay in hospital and increased mortality (Salluh et al., 2015). So, for many cases it is not just a condition that will pass, as one of the participants said she where told.

'Impact on relatives'

In line with present study, Smithburger et al. demonstrated that relatives intuitively had ideas of their own on how to cope with delirium in ICU, although it was not something they had discussed with health care professionals (Smithburger et al., 2017). Garrouste-Oregeas et al. found in ICU settings that almost all relatives (96%) wanted to be a part of the care of the patient, but only a few started an activity on their own (13%) without counselling with health care professionals (Garrouste-Orgeas et al., 2010). This underlines that despite relatives willingness to take part in actions to reduce delirium, it is of great importance that they are guided by health care professionals. Moreover, involvement of relatives has shown to be an effective way of eliminating delirium and has a potential to prevent or shorten episodes of delirium (Rosa et al., 2017). In line with our study, other studies from non-ICU settings discover various findings in the relative's experiences of delirium (Toye et al., 2014; Namba et al., 2007; Day and Higgins, 2015). Namba et al. (2007) described that some relatives thought that the patient was the same as usual even when the patient was delirious. Opposite in other studies relatives describe the delirious person becoming strange and unfamiliar (Day and Higgins, 2015). Confirming that delirium may appear in different clinical ways and be perceived in just as many by relatives. Unlike this present study, relatives in non-ICU settings seemed to be more affected by the patient's delirious condition, especially when it came to speculation about the future (Toye et al., 2014). This indicates that focus moves when the patients most likely have overcome the life-threatening situation, why ICU nurses must prepare relatives for this.

Methodological considerations and limitations

To our knowledge this is the first study to examine how relatives experience delirium in the critically ill patient in ICU. The qualitative methodology used is a valid design to reveal relatives experience of delirium that cannot be captured by quantitative methods. Credibility of this study was strengthened by investigator triangulation during analysis with varying backgrounds in professions and experience that ensured a broader understanding of the phenomenon. Furthermore, the transparency of every step in the data analysis is reported in Table 2 and demonstrates how interpretation was grounded in data.

The qualitative methodology is not valid in making generalisable results. However, results can be transferable as participants seem to have a demographic data similar to the literature of relatives in ICU, in relation to the higher rate of female relatives, age and proportion between spouses and other relatives (Bohart et al., 2018). This is a single centre study why results need to be interpreted in the local context.

We approached and asked 18 relatives to participate and 11 agreed. The main reason for non-participation was a lack of energy due to the critical illness of the patient. Similar non-participation rates and reasons have been found in studies with relatives in ICU's (Bohart et al., 2018; McAdam et al., 2012). Studies have shown that non-participants usually have less resources than participants (De Jong et al., 2004; Rosted et al., 2016). This perspective must be taken into consideration as our results might overestimate relatives' ability of coping with the illness of the patient.

Conclusions

The findings of this study provide a new insight into relatives' experience of delirium in an ICU setting. Relatives have sparse knowledge of delirium as a concept. Symptoms of delirium were described as a natural consequence of critical illness in a patient and seemed to be a secondary problem in the context of ICU. When healthcare professionals did not talk about delirium, relatives perceived it as if delirium was unimportant. However, in hindsight information about delirium was requested by relatives, as this was found to give them a sense of better understanding and relief. Delirium and the manifestation of it was experienced in different ways and brought different ways of coping forward. Uncertainty of possible long-term consequences after hospital admission appeared.

When ICU in the future are approaching delirium by evidence-base bundles, we emphasise the importance of the ABCDE-bundle also includes relatives by adding the F, family engagement. Further investigation is needed to extend the knowledge of relatives' experiences of delirium as future research must investigate the potential in helping relatives to engage and cope with delirium, to the benefit of both patient and relatives.

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Conflict of interest

No conflict of interest has been declared by the authors.

Author declaration

The authors meet the criteria for authorship, have approved the final article and all those entitled to authorship are listed as author.

Ethical statement

Prior to participation written and verbal information was provided and participants were required to give written consent. Danish Data Protection Agency approved the study (I-Suite no.:06022, ID-no.: HGH-2017-113). According to Danish law formal approval of qualitative studies is not necessary, however we notified the Ethics Committee in the Capital Region, Denmark (file no 17029440).

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.iccn.2019.04.010.

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