

## REVIEW

# Patients' experiences of delirium: A systematic review and meta-summary of qualitative research

Eero Kuusisto-Gussmann<sup>1</sup>  | Carolin Höckelmann<sup>1</sup>  | Verena von der Lühe<sup>1</sup>  | Roman Schmädig<sup>1</sup>  | Marion Baltes<sup>1,2</sup> | Astrid Stephan<sup>1,2</sup>

<sup>1</sup>Institute for Health and Nursing Sciences, Martin Luther University Halle-Wittenberg, Halle (Saale), Germany

<sup>2</sup>Uniklinik RWTH Aachen, Aachen, Germany

## Correspondence

Dr. Astrid Stephan, Institute for Health and Nursing Sciences, Martin Luther University Halle-Wittenberg, Halle (Saale), Germany.

Email: [aststephan@ukaachen.de](mailto:aststephan@ukaachen.de)

## Abstract

**Aims:** The purpose of this systematic review and meta-summary was the aggregation of the empirical qualitative literature on patients' experiences of delirium in order to support the development and implementation of patient-oriented delirium management and to guide future research.

**Design:** We conducted a systematic literature review of qualitative research published between January 1980 and June 2019.

**Data sources:** In June 2019, we searched in Medline, CINAHL, SSCI and PsycInfo to identify relevant reports. In addition, we conducted searches in three dissertation databases (BASE, DART and ProQuest) and Google Scholar.

**Review methods:** We used methods developed by Sandelowski and Barroso to construct a meta-summary of the findings by extracting them from the reports, abstracting them into meta-findings and calculating their manifest interstudy frequency effect sizes.

**Results:** Out of the 742 identified records, 24 reports based on delirium experience accounts of 483 patients met our criteria and were included. One thousand ninety-seven findings were extracted from these reports and abstracted into 92 meta-findings. These were grouped to the five emerging themes 'perception', 'emotions', 'interaction with others', 'dealing with delirium' and 'influence on further life'.

**Conclusion:** Delirium is commonly perceived as an overall distressing condition, which can accompany and influence patients even after hospital discharge.

**Impact:** This systematic review and meta-summary is the most comprehensive aggregation of qualitative research of the patient delirium experience to date. It allows us to better understand, extract meaning from, and weigh the qualitative findings in their context by calculating their manifest frequency effect sizes. This can be used to support the development and implementation of delirium management concepts.

## KEYWORDS

delirium, nursing, qualitative research, systematic review

Eero Kuusisto-Gussmann, Carolin Höckelmann, Verena von der Lühe, and Roman Schmädig contributed equally to this work.

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## 1 | INTRODUCTION

Delirium is a state of acute mental confusion that is associated with several adverse outcomes (Martins & Fernandes, 2012; Salluh et al., 2015). According to the American Psychiatric Association (2013), delirium is defined by the following components: disturbance in attention and awareness which develops over a short period of time and tends to fluctuate in severity during the course of the day. It is accompanied by disturbance in cognition which may manifest as a deficit of memory, language or visual perception. These disturbances cannot be explained by a pre-existing neurocognitive disorder and represent an acute change from baseline attention and awareness. A distinction is made between the hypoactive, hyperactive and a hybrid form of delirium (American Psychiatric Association, 2013).

## 2 | BACKGROUND

The prevalence of delirium varies in the literature and ranges from 17.6% to 28.4% in adult acute inpatient care (Krewulak et al., 2018; Ryan et al., 2013; Schubert et al., 2018). Delirium is most likely to be observed in intensive care unit (ICU) with a prevalence of 31.0%–54.0% (Krewulak et al., 2018; Mehta et al., 2015; Rueden et al., 2017). According to a recent meta-analysis, the most common subtype in adult ICU population is hypoactive delirium with a prevalence of 17.0% (Krewulak et al., 2018).

Risk factors of delirium can be divided into predisposing and precipitating factors. Most common predisposing risk factors include dementia, higher age and cognitive or functional impairment. Known precipitating factors include polypharmacy, psychoactive medication use, surgery and use of physical restraints. The significance of these factors may vary across patient populations (Inouye et al., 2014; see also Oh et al., 2015; Ryan et al., 2013).

Delirium may have serious and permanent consequences. Adverse events like increased mortality, prolonged hospitalisation, increased readmission rates, decrease in cognitive functions and loss of quality of life are, among others, associated with an episode of delirium (Crocker et al., 2016; Martins & Fernandes, 2012; Salluh et al., 2015; Schubert et al., 2018).

Delirium increases the cost of hospitalization and the need for post-acute care, resulting in higher healthcare expenditure and places a possible financial burden on informal caregivers. Prevention of delirium not only reduces the cost of delirium but also may decrease subsequent rates of dementia (Caplan et al., 2020).

While quantitative indicators are important for evaluating delirium outcomes, they cannot completely capture the complexity of the phenomenon. Evidence from qualitative research is used to address questions, which cannot be sufficiently answered from a purely quantitative perspective (Lewin & Glenton, 2018; Lewin et al., 2019; Williams et al., 2019). Literature reviews play an important role since they aggregate the qualitative evidence and bundle it in an

accessible form for practitioners and decision makers. Thus, the aggregation of findings from qualitative research is gaining importance for evidence-based healthcare (Noyes et al., 2018).

In this context, the perspective of those affected by delirium comes into focus. The ability to remember an episode of delirium ranges from total amnesia to concrete reproduction of a detailed description of the experience (Fuller, 2016; Partridge et al., 2013). These insights into the subjective delirium experience help to better understand the patient's perspective, hence enabling the development of adequate concepts to better accompany and support them as well as their relatives (Partridge et al., 2013).

Qualitative research on delirium experience has been aggregated in reviews before. However, most of them are not systematic reviews; they do not solely focus patients' experiences and mostly exclude non-ICU settings (see, e.g., Bélanger & Ducharme, 2011; Fuller, 2016; O'Malley et al., 2008; Partridge et al., 2013). Furthermore, new research has been published in recent years that provide important contributions to the previous body of knowledge, which until today has not been the subject of a literature review (e.g., Instenes et al., 2017; Weissenberger-Leduc et al., 2019).

## 3 | THE REVIEW

### 3.1 | Aim

This present work provides deeper insights into the subjective experience of delirium by aggregating the empirical qualitative literature on patients' experiences and memories of delirium. This meta-summary can be used to support the development and implementation of patient-oriented delirium management and to guide future research. The review question is: "How do patients experience and recall delirium in acute care settings?"

### 3.2 | Design

A qualitative meta-summary is a quantitatively oriented aggregation of qualitative findings. It reflects a quantitative logic by also discerning the frequency of these findings across the target domain of research (Sandelowski & Barroso, 2007). The used techniques in a qualitative meta-summary include: (a) extracting and separating of relevant findings from each primary research report, (b) editing of findings to make them accessible, (c) grouping of findings in typically similar domains, (d) abstracting and formatting the findings and (e) calculating manifest effect sizes (Sandelowski & Barroso, 2007; Sandelowski et al., 2007). Frequency effect sizes are a unique feature of this method, as it adds numbers to the qualitative process. Effect sizes assess the prevalence of findings within the literature, which allow searching for patterns or hypotheses and offer a quick overview (Ludvigsen et al., 2016). A qualitative meta-summary can serve as an endpoint of research or be used as an empirical foundation for a meta-synthesis (Sandelowski & Barroso, 2007).

A review protocol was developed by all authors in March 2019 and guided the research process.

### 3.3 | Search methods

We searched Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycInfo and Social Sciences Citation Index (SSCI). We developed and tested the search strategies in each of the databases against a sample set of articles ( $n = 16$ ) that were identified from the references of the previously published reviews. Table 1 shows an example of our search string.

Our inclusion criteria for the literature were as follows:

- Qualitative research, published between 1980 and 2019, which focuses on adult patients' experiences of delirium in acute care settings.
- Mixed-methods research provided that the qualitative findings are reported separately.
- English or German language reports worldwide.

To limit the scope of the search to qualitative research, we used the recommended filters from University of Washington Libraries (2019). In case of SSCI, we could not find a validated filter and created our own based on the available Medline (PubMed) filter by translating its syntax. We also tuned all used filters more sensitive by adding the search term 'interview'. Our filters and the exact search string for each database can be found in the appendix. The searches were restricted to English and German language and to references published after January 1980. This restriction was due to the fact that delirium was first included in the Diagnostic and Statistical Manual of Mental Disorders (DSM) in that year (European Delirium Association & American Delirium Society, 2014). All articles in the sample set were found with our strategy—with the exception of one older report, which did not include any description of the used methods in its abstract and was therefore not caught by our filters. The final searches were performed in June 2019 by two reviewers independently from each other. The results were then compared to make sure they were an exact match.

In addition, we conducted supplementary searches in three dissertation databases (BASE, DART and ProQuest) and Google Scholar. We also undertook a backward and forward citation tracking using the articles that we did include as well as all known previous reviews. The backward citations were collected manually. We used the R package *citecorp* (Chamberlain, 2019) to download all

forward citations from OpenCitations Index of Crossref open DOI-to-DOI references.

The abstracts and titles of the found records were then screened independently by two reviewers using the online platform Rayyan (Ouzzani et al., 2016). The same procedure was followed during the assessment of the full-text articles. Conflicts were resolved by a third reviewer. In the case of two articles, a fourth reviewer was also consulted. If a full-text article was not available, we contacted the authors to request a copy.

### 3.4 | Search outcome

Our searches in electronic databases yielded 1,156 results in total. Nine further potentially relevant references were identified through our supplementary searches (dissertation databases, backward and forward citation tracking). After removing duplicates, we screened the titles and abstracts of 742 references.

Fifty full-texts were assessed for eligibility and 24 of those are included in the meta-summary (Table 2). Two reports of interest were not available as full-text. However, they were both dissertations that had also been published as journal articles—both of which are included. Two further dissertations were also excluded because the relevant results were already published in the form of a journal article (see Figure 1 for a PRISMA Flow Diagram with a complete list of exclusion reasons).

Three articles were excluded due to the type of their findings. Two of them did not interpret their material in a way that would qualify as qualitative research in the typology of Sandelowski and Barroso (2007). On the other hand, in one article, the findings were too abstract to be included in a meta-summary ('interpretative explanation'). Figure 2 shows a visualization of the types of findings included in this meta-summary.

### 3.5 | Quality appraisal

All included articles were appraised independently by two reviewers using the Critical Appraisal Skills Programme (CASP) checklist for qualitative research. Conflicts were resolved by discussing them after the comparison of the outcomes or by a third reviewer. Following Sandelowski and Barroso's (2007) advice, no report was excluded because of poor quality. The outcomes of the appraisal are available as Supplementary Material.

### 3.6 | Data abstraction

We used a 25-item data extraction sheet, which was developed in accordance to the recommendations of Sandelowski and Barroso (2007). To allow a better comparison of the included reports, the extracted information was then used to build a comprehensive characteristics table, which included bibliographical and methodological

TABLE 1 Search string without filters in Medline (PubMed)

```
Delirium[MeSH Terms] OR deliri*[TIAB] OR acute confusion*[TIAB]
OR temporary confusion*[TIAB] OR "ICU syndrom*[TIAB]
OR "ICU psychosis"[TIAB] OR "ICU-psychosis" OR "ICU-
Syndrome" AND Memory[MeSH Terms] OR experienc*[TIAB]
OR memor*[TIAB] OR recall*[TIAB] OR recollection*[TIAB] OR
perspectiv*[TIAB]
```

TABLE 2 Included reports and their main characteristics

Report ID	Author (year), country	Aim	n (f/m)	Mean age	Setting	Stated method	Type of findings
1	Andersson, Hallberg, et al. (2002), Sweden	To illuminate lived experience of having been in an acute confusional state	50 (39/11)	84.7	Orthopaedic care	Phenomenological hermeneutic	Thematic survey
2	Andersson, Norberg, et al. (2002), Sweden	To illuminate the pattern of confusional episodes with regard to the content of elderly patients' actions and speech	51 (39/12)	84.6	Orthopaedic care	Manifest and latent content analysis	Thematic survey/conceptual thematic description
3	Claesson Linge Hall et al. (2015), Sweden	To illuminate experiences of undergoing cardiac surgery among older people diagnosed with postoperative delirium	49 (17/32)	78	Cardiac surgery	Qualitative content analysis by Graneheim and Lundman	Thematic survey
4	Cohen et al., (2009), USA	To develop a better understanding of delirium-related distress among patients with advanced cancer and their caregivers	34 (18/16)	63	Palliative care	Phenomenological hermeneutic	Topical survey
5	Darbyshire et al., (2016), UK	To explore themes relating specifically to sleep and delirium	40 (16/24)	52.2	ICU	Secondary thematic analysis	Topical survey/thematic survey
6	Fagerberg and Jönhagen (2002), Sweden	To describe how older people experience the phenomenon of temporary confusion and their reasoning	5 (1/4)	73.8	Acute care (mixed)	Phenomenological method by Giorgi	Thematic survey
7	Flynn et al., (2014), UK	To explore the narratives of people who have had a heart or lung transplant and who report experiencing delirium in the ICU	11 (4/7)	n.a.	ICU	Narrative analysis	Thematic survey
8	Granberg et al., (1999), Sweden	To describe and illuminate patients' experiences of acute confusion, disorientation, dreams and nightmares or so-called 'unreal' experiences during and after ICU stay	19 (6/13)	62	ICU	Hermeneutic approach	Thematic survey
9	Hartwick (2003), USA	To explore a patient's and his family's perspectives related to ICU delirium	1 (0/1)	42	ICU	Case study	Topical survey
10	Instenes et al., (2018), Norway	To explore and describe how octogenarian patients with post-aortic valve replacement delirium experience interactions with healthcare professionals and relatives	10 (5/5)	83	Cardiac surgery	Qualitative content analysis	Thematic survey
11	Instenes et al., (2017), Norway	To explore how octogenarian patients experience postoperative delirium	10 (5/5)	83	Cardiac surgery	Phenomenological approach by Giorgi	Thematic survey

(Continues)

TABLE 2 (Continued)

Report ID	Author (year), country	Aim	n (f/m)	Mean age	Setting	Stated method	Type of findings
12	Laitinen (1996), Finland	To describe and reflect upon the patients' real descriptions of their unique experiences of confusion in the ICU	10 (n.a.)	n.a.	ICU	Phenomenological hermeneutic	Thematic survey
13	Magarey and McCutcheon (2005), Australia	To explore the memories of patients who had a short-term admission to the ICU, with a particular focus on dreams, nightmares and confusion	8 (2/6)	54.2	ICU	Thematic analysis by Morse and Field	Topical survey/thematic survey
14	McCurran and Nones Cronin (2003), USA	To describe the phenomenon of delirium based on the lived experience of hospitalized elders	14 (4/10)	75.2	Medicalsurgical	Phenomenological approach by Colaizzi	Thematic survey
15	Pollard et al., (2015), Australia	To explore and recount the experience older people had of being delirious following orthopaedic surgery	11 (3/8)	n.a.	Orthopaedic care	Qualitative description by Sandelowski	Thematic survey
16	Schmitt et al., (2017), USA	To describe common delirium burdens among older patients, family caregivers and nurses	18 (10/8)	79	Acute care (mixed)	Interpretive description by Thorne	Thematic survey
24	Whitehorne et al., (2015), Canada	To understand the lived experience of intensive care for critically ill patients who experienced delirium	10 (3/7)	n.a.	ICU	Hermeneutic phenomenology by van Manen	Thematic survey

FIGURE 1 PRISMA flow diagram

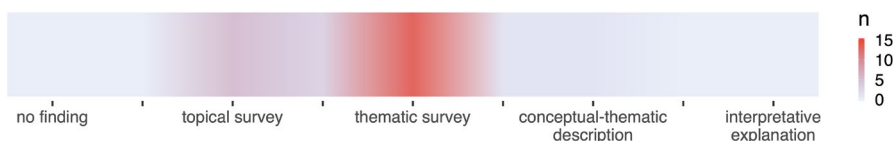
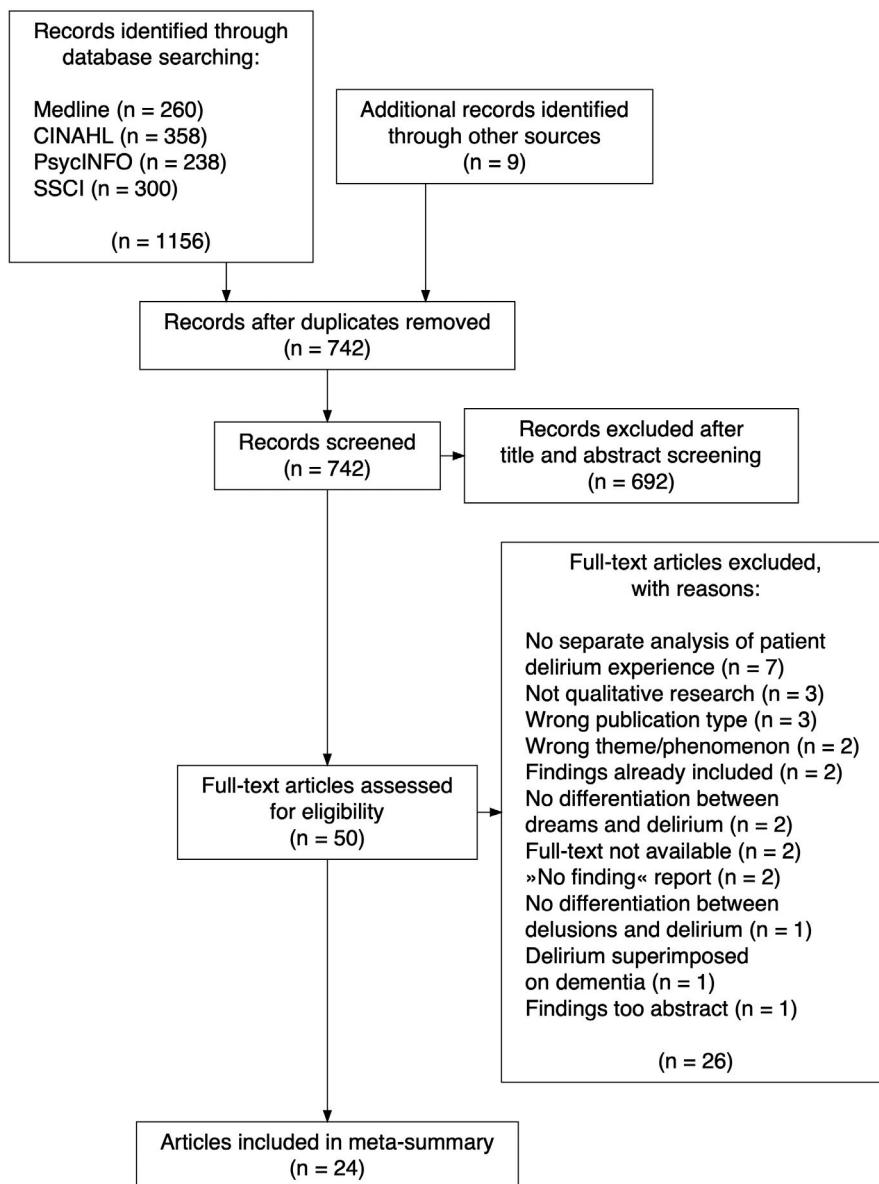


FIGURE 2 A heat map of the types of findings in the included reports projected onto the typology of qualitative research by Sandelowski and Barroso (2007)

information (e.g., author, year, country, aim, data collection method, stated research method, delirium assessment method, sample size, mean age and setting). Table 2 is an abridged version of that table.

### 3.7 | Synthesis

According to Sandelowski and Barroso (2007) qualitative research can be classified based on the degree of abstraction—

independent from the stated method of the study. Two reviewers classified the findings independently from each other. In case of conflicts, a third reviewer was consulted.

The typology of qualitative findings can be presented as a continuum (depicted in Figure 2). Reports which present ‘raw’ data without interpretation (e.g., stories and quotations) are considered as ‘no-finding’ reports and should be excluded. Topical surveys remain close to raw data and typically use classification systems to organize topics mentioned by participants. They briefly define the topics and illustrate

them with a few quotations. Thematic surveys show a discernible step away from categorizing towards describing themes. It is done by using everyday language of participants or by importing empirical or theoretical concepts. They are followed by conceptual/thematic description, which go beyond the organisation and description of data towards the interpretation of a phenomenon. While topical and thematic surveys are characterized by a more nominal use of classifying data, conceptual-thematic descriptions use concepts to reframe and integrate data. Rightmost on the continuum are the reports classified as interpretative explanation. While topical surveys, thematic surveys and conceptual/thematic descriptions represent one or more elements of an experience, interpretive explanations offer an integrated, comprehensive penetration of the fundamental nature of events or experiences (Sandelowski & Barroso, 2003, 2007).

The findings were extracted and separated from the section *Results* of all reports independently by two reviewers using designated finding extraction sheets. After a comparison of the extraction sheets, a third reviewer was consulted if there were conflicts about the inclusion of a finding in the meta-summary. In a next step, extracted findings were edited to be accessible to any reader. Each separated finding was coded sequentially and grouped into topical domains in an inductive process. This was done following methods of qualitative content analysis by Kuckartz (2016) in MAXQDA (VERBI Software, 2018). First, all findings were roughly coded into main categories. Then, subcategories were shaped. In a repetitive process, after the differentiated category system was formed, all findings were coded again. As this part is a reflexive process, the grouping of findings was done together, allowing a dialogue between the reviewers.

Abstraction of findings into meta-findings was at first done together by two reviewers in one category to reach a mutual understanding of the process and subsequently done by two reviewers separately. To ensure the validity of the separately abstracted meta-findings and categories, we compared and discussed the results with all authors during the process. We then calculated the manifest interstudy frequency effect sizes for each meta-finding by dividing the number of reports contributing to the meta-finding by the total number of included reports with unique samples. If two reports using an identical or overlapping sample contributed to the same meta-finding, it only counted once.

During the process the definition of 'experiencing delirium' was discussed and adapted. In addition to the lived experience during delirium, patients' reflections about their perceptions afterwards were included into our definition of the phenomenon.

## 4 | RESULTS

All 24 included reports are journal articles published between 1996 and 2019. Ten of them focused on delirium experience in ICU, the rest in various acute care settings, e.g., mixed wards ( $n = 4$ ), orthopaedic care ( $n = 4$ ) and cardiac surgery ( $n = 3$ ). Almost half of the studies ( $n = 11$ ) were conducted in the Nordic countries: Sweden ( $n = 7$ ), Norway ( $n = 2$ ), Finland ( $n = 1$ ) and Denmark ( $n = 1$ ). The remaining studies were done in the United States ( $n = 4$ ), the United

Kingdom ( $n = 2$ ), Australia ( $n = 2$ ), Canada ( $n = 1$ ), New Zealand ( $n = 1$ ), Austria ( $n = 1$ ), Belgium ( $n = 1$ ) and Iran ( $n = 1$ ).

The sample sizes varied between one and 114 patients (median: 11). Collectively, the reports were based on 483 individual patient accounts (215 females, 249 males—two articles did not report the gender of the participants). In all cases, these experiences were collected with different forms of interviews. In one case, non-participant observation was used in addition to interviews and published separately (Andersson, Hallberg, et al., 2002, Andersson, Norberg, et al., 2002). Two articles did not report the age of the participants at all, whereas four reports lacked information about the mean age. The pooled mean age of all reported participants was 68.7 years with a range between 18 and 98 years.

See Table 2 for more information about the characteristics of the reports. Each report was assigned a specific report ID to transparently link them with the respective meta-findings they contributed to.

### 4.1 | Findings of the meta-summary

A total of 1,097 findings were extracted from 24 reports. These findings could be abstracted into 92 meta-findings. Table 3 shows 68 meta-findings which yield a frequency effect size of  $\geq 10\%$ . The meta-findings below this threshold are available as Supplementary Material.

During the process of grouping, five main themes emerged: *Perception*, *Emotions*, *Interaction with others*, *Dealing with delirium* and *Influence on further life*. The meta-findings are categorized into these main themes and sorted according to their frequency effect sizes as shown in Table 3. The reports, which contributed to each meta-finding, are indicated by showing the respective report IDs after the meta-findings. Each meta-finding was assigned a meta-finding-ID as displayed in Table 3. These IDs are used in the following text to refer to meta-findings (e.g., E1 refers to the finding with the highest frequency effect size in category *Emotions*: 'Patients experience feelings of fear and anxiety').

*Perception* is the most common theme across all included articles and encompasses as a category both the highest number of meta-findings ( $n = 32$ ) and the meta-findings with the greatest frequency effects sizes (P1: 95%, P2: 87%). *Emotions* is the second biggest category ( $n = 15$ ), but the frequency effects sizes are not as high and half of them are lower than 20%. The remaining categories, *interaction with others*, *dealing with delirium* and *influence on further life*, each contain less than ten meta-findings. With the exception of meta-findings I1 and D1 all frequency effect sizes in those categories are  $\leq 50\%$ .

### 4.2 | Perception

Crucial to the delirium experience is the patients' self-awareness and the perception of their environment. This includes disorientation in

TABLE 3 Meta-findings sorted according to their frequency effect sizes in the main categories

Meta-finding ID	Meta-finding <sup>Report ID*</sup>	Frequency effect size
P1	<b>Perception</b> Patients recall having vivid unreal experiences, which they describe as hallucinations, visions, fantasies, fuzziness or as unusual dreams and/or nightmares, which can occur even in an awake state. <sup>1,2,3,4,5,6,7,8,9,10,11,13,14,15,16,17,18,19,20,21,22,23,24</sup>	95%
P2	Disorientation is generally described during delirium. <sup>1,2,3,4,5,8,9,10,11,12,13,14,16,17,18,19,20,21,22,23,24</sup>	86%
P3	Patients felt unable to control the situation or themselves while being delirious. <sup>1,2,3,6,7,11,13,14,15,16,18,19,21,22</sup>	59%
P4	The delirium experience was perceived as real and unreal at the same time, or as moving on a continuum from reality to unreality, as a struggle to distinguish real from unreal. <sup>1,5,6,7,8,9,11,13,17,18,19,24</sup>	54%
P5	Patients differ in their ability to recall their experience of delirium; their descriptions vary from having detailed recollections to not remembering anything at all. <sup>1,4,5,9,11,12,13,15,17,19,21,24</sup>	54%
P6	Perceiving themselves during delirium, patients see themselves as being confused. <sup>1,2,3,4,5,8,11,12,13,14,17,22</sup>	50%
P7	The types of visual hallucinations vary from living beings, concrete places and surroundings to abstract forms, geometric shapes and colours. <sup>1,2,3,4,7,9,13,16,19,22,23</sup>	45%
P8	Negative hallucinations are perceived as life threatening experiences, such as being trapped, imprisoned or killed. <sup>3,5,7,8,13,15,16,17,19,21</sup>	45%
P9	Spatial disorientation manifests in patients not knowing where they are. <sup>1,2,3,4,8,12,14,16,21,22</sup>	40%
P10	Patients describe positive hallucinations such as creatures or colours. <sup>1,3,7,8,13,15,17,21</sup>	36%
P11	Patients describe disorientation in space as thinking they are somewhere else than the hospital, or they are at two places at the same time. <sup>4,8,10,11,14,17,19,24</sup>	31%
P12	Temporal disorientation manifests itself in patients not knowing what time it is. <sup>3,8,9,11,12,21,22</sup>	31%
P13	Situative disorientation manifests itself as a misinterpretation of events and an inability to place them in context. <sup>5,10,12,14,16,17,21</sup>	31%
P14	Trying to cover the whole delirium experience in their description, patients referred to being in another, strange world. <sup>1,3,8,11,14,15,21</sup>	31%
P15	Auditory hallucinations include rain, voices and music. <sup>2,9,14,16,22,23,24</sup>	31%
P16	Patients describe moving around in space and time during their unreal experiences. <sup>2,5,8,17,19,22,24</sup>	31%
P17	Patients feel unable to communicate and to express their needs. <sup>5,8,16,17,21,22,24</sup>	31%
P18	Patients felt unable to think clearly and retain information during delirium. <sup>6,8,16,18,22,24</sup>	27%
P19	Patients describe merging the current situation with events, memories or people from their past. <sup>1,2,10,17,19,23</sup>	22%
P20	Death is a re-emerging theme in patients' hallucinations (e.g., meeting the deceased, dying or being killed). <sup>7,11,13,17,21</sup>	22%
P21	Patients perceive themselves as being lucid during delirium. <sup>3,8,14,17,23</sup>	22%
P22	A disturbed day-night rhythm evokes difficulties in distinguishing day from night and being awake from being asleep. <sup>8,11,14,21</sup>	18%
P23	Disorientation in time includes differences in the perception of passage of time, which can be perceived as time standing still or that time is completely missing. <sup>8,13,14,18</sup>	18%
P24	Patients describe travel in time as altering between present and past, or multiple events taking place simultaneously. <sup>2,14,17,19</sup>	18%
P25	By trying to give the delirium description a shape, patients struggle to capture it, as its boundaries are blurred. <sup>1,3,7,17</sup>	18%
P26	Patients see themselves as an outsider, a stranger and feel separated from their surroundings. <sup>5,8,10,18</sup>	18%
P27	Patients' behaviour during delirium differs from their behaviour in daily life. <sup>1,3,15,16</sup>	18%
P28	In their delirious state, patients are unable to understand the situation. <sup>1,2,18,22</sup>	13%
P29	Ordinary things appear dangerous and unsafe without any reason. <sup>3,5,17</sup>	13%
P30	Patients remember the beginning and ending of delirium differently (e.g., sudden or gradual). <sup>16,17,21</sup>	13%

(Continues)



TABLE 3 (Continued)

Meta-finding ID	Meta-finding <sup>Report ID*</sup>	Frequency effect size
P31	Delusional beliefs and hallucinations are intensified and/or triggered by isolation, paranoia, falling asleep, day of time, unfamiliar activities due to hospital setting and impaired ability to communicate. <sup>5,8,24</sup>	13%
P32	Patients question their personality during delirium. <sup>6,15,16</sup>	13%
<b>Emotions</b>		
E1	Patients experience feelings of fear and anxiety. <sup>2,3,5,6,7,8,10,11,13,14,15,16,17,21,22,23,24</sup>	72%
E2	Patients experience feelings of threat, distress and insecurity that either persist and/or fluctuate for brief periods or for days and weeks at a time. <sup>1,2,4,5,6,8,11,13,15,16,17,18</sup>	50%
E3	Perceived reasons for anxiety and fear were as follows: imminent death, hallucinations and nightmares, incapacity to understand, to act or to locate situations correctly, feelings of vulnerability, worries of permanent changes in behaviour or 'going crazy' again. <sup>4,7,8,11,12,13,16,17,19,21,24</sup>	50%
E4	Loss of control and autonomy, hallucinations and nightmares are common causes for irritation, anger, aggression, powerlessness, helplessness, dependency and frustration. <sup>2,3,4,8,14,15,16,17,21,22</sup>	45%
E5	Patients describe strong emotional feelings of loneliness, abandonment, hopelessness and isolation, which are amplified if they feel alone, can't rely on family or friends, are unable to communicate or if they are confined to bed. <sup>3,5,6,8,12,15,18,21</sup>	36%
E6	Patients experience feelings of shame, embarrassment, remorse and guilt towards staff, family and friends during delirium. <sup>1,3,6,14,16,17,21,24</sup>	36%
E7	Patients can experience feelings of security and confidence when they recognize the actions as routines, get used to the delirium state, realize they are not alone, possess familiar objects or have a feeling of a higher power beyond their control. <sup>1,2,3,8,18,24</sup>	22%
E8	Patients' experiences are connected with a variety of positive (pleasant) and negative (unpleasant) emotions. <sup>17,20,22,23</sup>	18%
E9	Patients recognize delirium subjectively as a negative (unpleasant) experience, but the descriptions differ in their intensity and scope. <sup>1,14,16,23</sup>	18%
E10	Patients feel restless during delirium. <sup>3,9,11,21</sup>	18%
E11	Patients experience a threat directed against themselves, their spouse or against values and interests vital to them. <sup>6,7,17,24</sup>	18%
E12	Relief and liberation is experienced at the moment when patients become aware that their experiences aren't true. <sup>3,15,17,21</sup>	18%
E13	Patients experience the episode of delirium as emotionally neutral or sometimes completely without feelings of discomfort (e.g., because they expected that delirium might occur). <sup>2,4,11</sup>	13%
E14	Patients think they are going mad and describe an emotional chaos because of delirium and nightmares. <sup>3,8,15</sup>	13%
E15	Feelings of panic can be triggered by a sense of being alone or by the frightening discovery of changes in their own personality. <sup>11,16,17</sup>	13%
<b>Interaction with others</b>		
I1	Barriers are created between patients and staff (e.g., when staff behaves disrespectfully and insensitively, use a harsh tone of voice, show rejection, exclude patients from their care, ridicule and not take them seriously, try to reorient the patients or when they sense a lack of information, explanations, support or trained hospital staff). <sup>3,5,6,10,14,15,16,18,19,21,22,24</sup>	54%
I2	Patients feel supported by relatives if their presence creates a calm and positive atmosphere, if their relatives are understanding, supporting, trusting, comforting and reassuring or if they can help them putting things into perspective. <sup>1,2,6,8,10,12,13,14,18,19,21</sup>	45%
I3	Patients feel supported by healthcare staff if they are positive, pleasant, adaptable, supportive, self-confident, understanding, communicative and familiar or if they provide explanations to what is happening. <sup>2,6,10,12,13,14,18,21,24</sup>	40%
I4	Barriers are created between patients and their relatives if the relatives are ashamed of the patients' behaviour, try to control or reorient the patients or if patients perceive a lack of help or disrespectful behaviour or a lack of willingness to communicate with them. <sup>3,6,8,10,15,18,19,22</sup>	36%

(Continues)

TABLE 3 (Continued)

Meta-finding ID	Meta-finding <sup>Report ID*</sup>	Frequency effect size
I5	Patients become suspicious and mistrustful towards other people (including staff, relatives and fellow patients). <sup>2,6,7,14,15,18</sup>	27%
I6	Patients feel heard but not understood from staff and relatives; this provokes the feeling of being alone in their struggle. <sup>5,6,15,17,18</sup>	22%
I7	Patients need constant interaction with healthcare staff and their relatives. <sup>8,10,12,15,24</sup>	22%
I8	Interaction with others is difficult and is experienced as unequal, especially when patients' experiences are questioned or the interaction is linked to hallucinations. <sup>2,14,18,21</sup>	18%
I9	Patients use different strategies to hide their delirium during interactions (e.g., they show little willingness to answer questions or to communicate, but also ask the nurses questions to ensure that they give a correct answer). <sup>2,3,22,23</sup>	1%
<b>Dealing with delirium</b>		
D1	Patients try to understand their experiences by communicating with others and by rationalizing their experience and thoughts (e.g., by asking questions to get information about time, place and situation, by incorporating delirium into a meaningful whole, by narrating their memories to others or by withdrawing to find quietness). <sup>1,2,5,6,7,8,9,10,13,14,17,18,21,22,24</sup>	63%
D2	Patients try to find reasons for delirium within themselves (e.g., in age, in illness or in their private life), in factors related to their hospitalization or in medication. <sup>1,4,5,6,8,15,17,18,21</sup>	40%
D3	Factors that evoke feelings of control and security and that improve orientation before and during delirium include: familiar everyday routines, an emotionally neutral or familiar voice, daylight, characteristics of the environment, situation awareness, self-determination (decision-making autonomy) and increased knowledge (informedness). <sup>2,4,8,11,18,20</sup>	27%
D4	Patients do not want to talk about their experiences because they try to escape and distance themselves and to forget the memories. <sup>1,14,15,17</sup>	18%
<b>Influence on further life</b>		
F1	Even after recovery, feelings of anxiety and fear still persist, which patients describe as a fear of reoccurring delirium, fear of never forgetting the experience and as a constant occupation of their mind with the experience. <sup>1,3,6,7,12,15,16,17,21,24</sup>	45%
F2	Talking about their experience gives a feeling of taking control over delirium and is perceived as helpful. <sup>1,12,15,17,21,24</sup>	27%
F3	Patients vary in their ability to leave delirium behind and to look at it with detachment; for some delirium still occupies their minds, or affects them emotionally—others remain indifferent about their experiences. <sup>1,6,11,12,13,21</sup>	27%
F4	Patients report a permanent loss of their dignity after recovering from delirium; they still remember the awkwardness of the situation, see their loss of self-control in the situation as painful, which results to long lasting feelings of shame. <sup>3,6,7,11,12,15</sup>	27%
F5	Even in the interview situation patients want to keep their delirium a secret and neglect or suppress their experiences (e.g., the respondent blocks the conversation and changes the topic). <sup>1,7,17,21</sup>	18%
F6	Patients avoid behaviour that could trigger another episode of delirium (e.g., avoid seeking medical support, taking sleep medication or going back to the hospital where they experienced delirium). <sup>7,15,24</sup>	13%
F7	The delirium experience can have positive influence on patients' life (e.g., they can draw strength from it, feel less stressed or worried in their daily life after the experience or see it as a learning occasion). <sup>15,17,21</sup>	13%
F8	Patients describe how delirium affected their personality after their experiences as being changed forever or having a disturbed sense of oneself. <sup>7,15,21</sup>	13%

\*Report IDs are displayed in Table 2.

the current situation (P2), which can be divided into the interpretation of time (P12, P23, P24), space (P9, P11) and current situation (P13, P19, P29). In addition to disorientation as a misinterpretation of the environment, patients report unreal experiences without direct stimuli from their environment (P1, P16, P20, P31). Visual (P7)

and auditive (P15) hallucinations are reported, which can have negative (P8) or positive (P10) content. The theme 'death' reoccurs across reports in patients' descriptions of their hallucinations, which has positive (e.g., meeting deceased loved ones) or negative connotations (e.g., being killed) (P20).

In contrast to the perception of their environment, patients give detailed descriptions on how they are aware of themselves in their delirious state (P26, P27, P32). The main focus is their inability to act (P3, P17, P18, P28) and seeing themselves either as confused (P6) or lucid (P21) while being delirious. From a retrospective position, patients try to capture the whole experience with words and refer to more general aspects of delirium (e.g., recalling the beginning and ending of delirium) in the meta-findings P4, P5, P14, P25 and P30.

### 4.3 | Emotions

The theme *emotions* incorporates all of the patients' feelings caused by delirium. These could arouse during their delirious episodes or while reflecting their experiences retrospectively. Most articles describe patients being emotionally affected, but there are exceptions that report emotional neutrality (E13). A wide range of positive and negative emotions are reported (E8). Most common are fear and anxiety (E1, E3, E17, E18). Other negative emotions reported are feeling threatened (E2, E11), insecurity (E2), panic (E15), anger (E4), restlessness (E10), powerlessness (E4), helplessness (E4), frustration (E4), loneliness and hopelessness (E5), vulnerability (E16), guilt, shame (E6), 'going mad' and emotional chaos (E14). Feelings of threat, distress and insecurity can persist either for brief periods or days or even weeks during the delirious phase (E2). Delirium is recognized as a negative experience, but the individual experiences differ in their intensity and scope (E9). Although most reports describe negative emotions (E9), there are also some positive emotions associated with the delirium experience, such as feeling confident or secure (E7). Relief is also a common emotion at the moment when patients realize that their experiences are not true (E12).

### 4.4 | Interaction with others

The theme *interaction with others* describes social interactions during the delirious state and reflects how patients experience themselves in these interactions. It shows that they are aware of and can recall their encounters with relatives, staff and fellow patients. On the one hand, patients perceive interaction with others as unequal and difficult (I8), feel heard but not understood (I6), develop feelings of suspicion and mistrust (I5). On the other hand, patients can need constant interaction (I7) and describe supportive (I2, I3) as well as inhibiting (I1, I4) aspects in their contact with relatives and staff during delirium. A loving, understanding, trusting, respectful, participating, reassuring and positive encounter seems to be the scaffolding for supportive interaction (I1–I4). Patients use strategies to hide their delirium because they feel a lack of trust and understanding during the encounter, feel that they are not allowed to disclose their mental state or are afraid and ashamed of their strange behaviour (I9).

### 4.5 | Dealing with delirium

During as well as after recovering from delirium, different strategies of coping are reported, which build the theme *dealing with delirium*. These mechanisms include coping strategies both to confront and to ignore or avoid the experience. The confronting coping mechanisms are based on patients trying to better understand the situation by communicating with others and by rationalizing their experiences and thoughts (D1). Beyond that, patients try to find a reason for their delirium (D2). Coping mechanisms based on avoidance include patients not wanting to talk about their experiences because they try to distance themselves and forget the situation (D4).

But there are also external factors (facilitators) that can have a positive influence on dealing with delirium. This includes, among other aspects, familiar everyday routines, daylight, an emotionally neutral or familiar voice, decision-making autonomy and being informed about delirium symptoms and progress (D3).

### 4.6 | Influence on further life

The delirium experience does not end at discharge from the hospital. Patients take their memories with them into their everyday life, which means that they continue to reflect these experiences even afterward. The experience can either benefit (F7) or directly or indirectly harm (F1, F4, F6) patients in their present and future situation. Patients' descriptions of being emotionally affected by their experience vary; some remain indifferent, and for others, it still occupies their mind (F3). The most dominant emotions while being delirious—*anxiety and fear*—are still present and can influence patients' actions (F1), as they avoid behaviour that could cause another episode of delirium (F6). Patients continue using coping mechanisms to deal with their experiences (F5, F2). Some influences might have a permanent impact on patients' life and personality (F8).

## 5 | DISCUSSION

The patient delirium experience has been gaining interest as a subject of qualitative research in recent years, with half of our included articles published in the past 5 years. Several of them have not been included in a review of the literature prior to this meta-summary. In comparison to previous reviews, which all examined the topic from slightly different points of view, this meta-summary offers a broader perspective by aggregating experiences from different settings, with a sole focus on patients' experiences. Nevertheless, our meta-findings are supported by the core results of these previous reviews (Bélangier & Ducharme, 2011; Fuller, 2016; O'Malley et al., 2008; Gaete Ortega et al., 2020; Partridge et al., 2013). We also did not encounter any contradicting findings that would suggest the need to conduct a separate analysis based on the setting or patient population.

This current meta-summary further contributes to the body of knowledge by calculating the frequency effect sizes, which allows us to better understand, extract meaning from, and weigh the qualitative findings in their context. This kind of quantification of qualitative data is a controversial topic (Maxwell, 2010) with no consensus on what constitutes an 'effect size' or even what the unit of analysis is (van Grootel et al., 2020). The manifest frequency effect sizes make the implicit verbal counting of findings ('in several cases', 'most articles', etc.) explicit (Onwuegbuzie, 2003) and therefore help avoid common pitfalls such as overweighting vivid description or underweighting aspects that do not conform to the expected patterns (Sandelowski, 2001). Thus, they offer a transparent method of indicating the support for each meta-finding in the literature. For example, delirium is commonly perceived as an overall distressing condition, which is supported by our findings with the largest effect sizes in each of the categories. Most of the previous reviews report only these negative aspects (e.g., Fuller, 2016; Gaete Ortega et al., 2020; Partridge et al., 2013). There are however meta-findings that suggest a more differentiated view: despite a predominantly negative impact, some findings imply that patients can also be neutral to the situation—or even have positive associations with delirium. Similar findings have also been reported in previous reviews (e.g., O'Malley et al., 2008). The frequency effect sizes reveal that neutral or positive perspectives on different aspects of delirium experience exist but are in the minority and reported only in 12%–16% of the reports.

We chose a rather low effect size cut-off ( $\geq 10\%$ ) to illuminate some of these infrequent aspects that otherwise would be overshadowed by the more prevalent findings. This also underlines that frequency effect sizes should not be used to value or devalue the findings (Herber et al., 2017). They can assist in making decisions but are to be interpreted cautiously: an aspect with a low frequency in the literature can be crucial on an individual level or a high effect size meta-finding might be irrelevant for the development of a delirium management concept.

The theme *influence on further life* arose during the process of grouping and abstracting findings into meta-findings. Our original working definition of 'delirium experience' was stricter and more focused on the recalled experiences during delirium. In accordance with Sandelowski and Barroso (2007), we allowed these findings to change our definition during the process, hence enabling their integration into the meta-summary. They are presented as an independent category that can be regarded separately from the experiences during delirium but are still an essential part of the whole delirium experience, which accompanies and influences patients even after hospital discharge. Seeing these findings as a part of the delirium experience is also supported by Gaete Ortega et al., (2020) and O'Malley et al., (2008). Because these 'post-delirium' experiences were not our – nor the primary reports' -main focus, the calculated frequency effect sizes are however relatively low. Most of the literature investigating lasting effects of delirium focuses on ICU patients and adverse outcomes (e.g., PTSD) that can be measured with validated assessments (see, e.g. Kiekkas et al., 2010; Nouwen et al., 2012). Further research is needed to assess the more subtle

long-term psychological consequences like lingering feelings of anxiety and fear or avoidance behaviour.

## 5.1 | Limitations

Our database searches were restricted to English and German language reports by use of filters. We did not apply filters in dissertation databases and Google Scholar, and no report was excluded based on language during our screening process. There still may exist more literature in other languages that was excluded from this review by not specifically searching in these languages, as well as grey literature, that we were not able to locate.

Looking at the countries the reports originate from, it is obvious that the vast majority of the literature ( $n = 23$ ) underlying this meta-summary provides a rather western perspective on the subject, with a disproportionate part of the articles coming from Northern Europe ( $n = 15$ ). The ethnicity of the participants was rarely reported, so we can only assume that the participants in these studies were predominantly Caucasian. The only report presenting a different cultural background (Vahedian Azimi et al., 2015) gave insights into a more middle-eastern perspective on experiencing delirium in an Iranian hospital. They reported religious aspects (e.g., Quran recitations as part of the daily hospital routine) which had an influence on the delirium experience. Their findings did, however, fit well to our other findings; the aforementioned religious aspects were subsumed under 'familiar everyday routines' (D3), and we could not extract any findings that would contradict or expand the more western view of all other included reports. Nevertheless, a more diverse scope of publications could illuminate further aspects that would be relevant for culturally sensitive nursing practice.

Another limitation of this review is that the findings were extracted only from the *Results* section of the reports (including tables and figures). If new findings were presented in other parts of the articles, they are not included in this meta-summary. We also did not use a validated delirium assessment as an inclusion criterion, as we wanted to enable the inclusion of older articles, some of them which did not use—or report using—any validated assessments.

During the process, we found relationships between all categories and found most of the meta-findings being interwoven or built upon each other. For example, patients perceive themselves as behaving differently in delirium than they are used to (P27), which can lead to feelings of shame (E6), which then might result in patients trying to hide their delirious state from family and staff (I9). The experienced emotions are also strongly related to the categories *Perception*, *Interaction with others* and *Dealing with delirium*. For example, a loss of control over the situation (P3) can evoke feelings of helplessness and fright (E4); patients feeling heard but not understood (I6) can result in loneliness and hopelessness (E5). Due to the nature of our methodology, we were not able to explore and display these relationships in an adequate way. This would call for a meta-synthesis of the literature, which could be used to develop a theoretical model of the delirium experience.

## 6 | CONCLUSION

Our findings support the notion that giving patients the possibility to talk about their delirium experience both during (D1) and after (F2) delirium can have therapeutic value and should be offered in a sensible, empathic way because not everyone wants to talk about the experience (D4). This is backed by the findings of Fuller (2016), Bélanger and Ducharme (2011) and Gaete Ortega et al., (2020). Our results do not support reorienting the patients forcefully (e.g., questioning their experiences or hallucinations), which has been discussed in the literature previously (e.g., O'Malley et al., 2008), as this can result in barriers between patients and people around them (I1, I4). The focus should be on giving patients the possibility to orient themselves by familiar routines and voices, daylight, decision-making autonomy and offering information (D3). Providing information about delirium symptoms and progress—both before and after occurrence—is also supported by the findings of Partridge et al., (2013) and Bélanger and Ducharme (2011). This also applies to family members who need guidance in contact with delirious patients (O'Malley et al., 2008). Our findings underline that their presence during delirium can have a supportive and soothing effect on patients' emotional state, as also reported by Bélanger and Ducharme (2011).

This present systematic review and meta-summary provides the most comprehensive aggregation of qualitative research of the patient delirium experience to date. It can also be seen as a 'quantitative transformation of qualitative data' (Sandelowski & Barroso, 2007), which can be used to extract more meaning from qualitative findings and to assess their relevance to the development and implementation of complex interventions, such as delirium management concepts.

This meta-summary represents the endpoint of our current project. Further research is needed to explore the relationships we encountered between the individual components of the delirium experience. We encourage others to take on the challenge of conducting a meta-synthesis of the literature and building the first theoretical model of the patient delirium experience.

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### CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

### AUTHOR CONTRIBUTIONS


The review protocol was written by EK, CH, RS and VL and approved by the supervisors MB and AS. EK and RS developed the search

strategies, conducted the searches and screened the literature. CH and VL performed the quality appraisal, classified the literature and conducted the main analysis. RS and EK validated the results of their analysis. EK calculated the effect sizes and created the tables for the meta-summary. MB and AS provided feedback during the process and were consulted in all phases of the project. EK, CH, RS and VL drafted the manuscript. The final version was written by EK based on feedback from MB and AS and approved by all authors.

### PEER REVIEW

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### ORCID

Eero Kuusisto-Gussmann  <https://orcid.org/0000-0002-9178-954X>

Carolin Höckelmann  <https://orcid.org/0000-0003-3624-3621>

Verena von der Lühe  <https://orcid.org/0000-0001-5385-522X>

Roman Schmädig  <https://orcid.org/0000-0002-1564-7611>

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Additional supporting information may be found online in the Supporting Information section.

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