Patients' experiences of well-being when being cared for in the intensive care unit—An integrative review

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Abstract

Objective: The aim of this integrative review was to identify facilitators and barriers to patients' well-being when being cared for in an ICU setting, from the perspective of the patients.

Background: To become critically ill and hospitalised in an ICU is a stressful, chaotic event due to the life-threatening condition itself, as well as therapeutic treatments and the environment. A growing body of evidence has revealed that patients often suffer from physical, psychological and cognitive problems after an ICU stay. Several strategies, such as sedation and pain management, are used to reduce stress and increase well-being during ICU hospitalisation, but the ICU experience nevertheless affects the body and mind.

Design: Since research exploring patients' sense of well-being in an ICU setting is limited, an integrative review approach was selected. Searches were performed in CINAHL, Medline, Psych Info, Eric and EMBASE. After reviewing 66 studies, 12 studies were included in the integrative review. Thematic analysis was used to analyse the studies. The PRISMA checklist for systematic reviews was used.

Results: The results are presented under one main theme, 'Well-being as a multidimensional experience—interwoven in barriers and facilitators' and six sub-themes representing barriers and facilitators of well-being in an ICU. Barriers identified were physical stressors, emotional stressors, environmental disturbances and insecurity relating to time and space. Facilitators were meeting physical needs and activities that included dimensions of a caring and relational environment.

Conclusion: Our main findings were that experiences of well-being were multidimensional and included physical, emotional, relational and environmental aspects, and they were more often described through barriers than facilitators of well-being.
**INTRODUCTION**

This integrative review highlights patients’ fundamental care needs that enhance well-being when being cared for in an intensive care unit (ICU). To become critically ill and hospitalised in an ICU is a stressful, chaotic event due to the life-threatening condition itself, as well as therapeutic treatments, pain and the environment (Egerod et al., 2015; Engström et al., 2018). Several strategies (e.g. sedation and pain management) are used to reduce stress and increase well-being during the ICU stay, but the ICU experience nevertheless affects the body and mind (Berntzen et al., 2020; Egerod et al., 2015). Patient experiences are influenced by dependency and a lack of control of bodily functions that are exacerbated by muscle wasting, severe weakness, being restricted by tubes and wires, and inability to communicate (Baumgarten & Poulsen, 2015; Lykkegaard & Delmar, 2015; Moen & Nåden, 2015; Radtke et al., 2011). A patient’s inability to communicate might also trigger anxiety and discomfort (Engström et al., 2012). The patient’s mind is often affected by thoughts and feelings of insecurity, fear and loneliness, resulting in a sense of vulnerability and powerlessness (Egerod et al., 2015; Karlsson et al., 2012; Moen & Nåden, 2015). Other factors adding to the patient’s experience of being critically ill are pain, delirious episodes, nightmares, memory gaps, delusional memories and sleep deprivation (Baumgarten & Poulsen, 2015; Svenningsen et al., 2016; Train et al., 2019; Wolters et al., 2015). Delusional memories are described as false or unreal memories, nightmares and hallucinations, with a high reported prevalence varying from 24%–73% (Aitken et al., 2016). These memories are frightening, hard to differentiate from reality and can persist for many years after ICU admission (Train et al., 2019; Zetterlund et al., 2012).

A growing body of evidence has revealed that patients often suffer from physical, psychological and cognitive problems after staying in an ICU (Dinglas et al., 2018; Rattray, 2014). Physical problems include intensive care acquired weakness, fatigue and neuromuscular dysfunctions, which have a prevalence of up to 80% (Confer et al., 2012; Trees et al., 2013). During the first year after critical illness, post-traumatic stress disorder (PTSD) has been estimated to affect 4%–62% of patients, while 62% had symptoms of anxiety and 30% of depression (Jones, 2013, 2014). Psychological problems are closely linked to factors such as pre-ICU psychological stress, mood symptoms and stressful experiences in the ICU (Karnatovskaia et al., 2015; Nikayin et al., 2016). The research presented above highlights patients’ extensive care needs that can enhance well-being as a means of restoring or promoting health while the patient is cared for in the ICU.

### 1.1 Well-being

Well-being is closely associated with an individual’s health. The World Health Organization definition of health is ‘A state of complete physical, mental, and social well-being, not merely the absence of disease’ (Janca, 1998, p. 3). Well-being is considered to be a broad concept that extends beyond traditional biomedical views of a mere absence of disease to a holistic view comprising physical, mental and social determinants of health (Knight, 2011; Monsen et al., 2015). This reflects personal meanings, strengths and interactions of individuals, families and communities, with individual levels of importance and impact based on a subjective evaluation according to the context of the culture and settings in which it is used (Keifer, 2010; Knight, 2011; Monsen et al., 2015; Smith et al., 2006).
Well-being is closely connected to the experience of health, and when an individual is ill or suffers from a disease, the illness affects their overall experience of well-being (Keifer, 2010). Well-being has its justification in medical research by measuring the impact of chronic diseases, effectively identifying a whole-person assessment of strengths and needs, supporting patients towards well-being as a goal in itself, providing insight into patient perspectives, evaluating costs and benefits of rehabilitation programmes, and comparing study treatments (Keifer, 2010; Monsen et al., 2015; Paris et al., 2006).

From an existential perspective, well-being is a specific way of being in the world (Galvin & Todres, 2013), and furthermore, how this specific way of being is experienced by individuals. Well-being can be understood as a state of being on an ontological level, which goes beyond health and illness. Accordingly, well-being is a potential in human life to feel anchored, a feeling that might be threatened by, for example critical illness, bodily traumas or detachment from one's everyday life. Galvin and Todres (2013) also elaborate using metaphors such as ‘peace and adventure’, and ‘mobility and dwelling’ to describe the essence of well-being. They emphasise that the interplay between these metaphors constitutes well-being. Subsequently, in the context of critical care, well-being can be understood as how patients find their own, unique way of moving forward towards health and recovery. Exploring patients’ well-being in an ICU setting is of particular interest as it creates knowledge of ethical significance, which provides a direction for care provision based on humanistic values.

Survivors of a critical illness are at risk of never regaining their pre-morbid health and well-being (Jónasdóttir et al., 2018; Umberger, 2019). Poor well-being results in low quality of life and affects health negatively (Keifer, 2010), which collectively adds to the burden of being an ‘ICU survivor’ (Dinglas et al., 2018; Jónasdóttir et al., 2018; Umberger, 2019). In a recent study exploring research trends and recommendations related to intensive care, Egerod et al. (2019) argued that future research should investigate patient well-being, including what well-being means and how it can be provided for the critically ill patient.

1.2 | Fundamentals of care

The fundamentals of care framework (FOC) is a possible approach towards understanding well-being in a holistic perspective. FOC represents an interrelationship between three key aspects of care provision for the critically ill patient, the physical, psychological and relational dimensions (Kitson, 2018). Thus, there is an interplay between how practical tasks are performed, how they physically and psychologically affect patients and the relationship between patients and nurses. The interconnection of these dimensions aligns with the extensive caring needs of ICU patients, and how these should be met to potentially enhance well-being, when well-being is understood holistically to include physical, psychological and relational aspects of being.

In summary, to our knowledge, no previous research has elaborated on ICU patients’ experiences of well-being. A review of current literature is needed to map the landscape of how well-being has been described seen from a mix of research methodologies (qualitative, quantitative and mixed methods). This review will focus on well-being at the individual level seen from the perspective of the patients themselves during ICU treatment.

2 | AIM

The aim of this integrative review was to identify facilitators and barriers to patients’ well-being when being cared for in an ICU setting, from the perspective of the patients themselves.

3 | METHOD

3.1 | Design

Since research exploring patient experiences of well-being in the ICU setting is limited, we chose to use an integrative review design (Coughlan et al., 2013; Whittemore & Knafl, 2005). In this paper, we have included empirical qualitative, quantitative and mixed-method studies. This integrative review is protocol-driven, as recommended by Knafl and Whittemore (2017) and Whittemore and Knafl (2005).

3.2 | Data collection

3.2.1 | Search strategy, eligibility criteria

The literature search was conducted between March 2017 and September 2019. Inclusion criteria were peer-reviewed empirical studies published between 1 January 2000 and 3 September 2019, in English, Danish, Swedish or Norwegian, irrespective of the research methodologies used, that included the perspectives of adult patients in an ICU setting/context. We excluded non-empirical studies (i.e. reviews, theoretical studies, grey literature), and studies focussing on children, patient’s relatives or ICU nurses’ perspectives, and those not reflecting the ICU context. We conducted two literature searches from March 2017 to September 2019. The first search was to gain an overview of the literature, while the second search was a systematic literature search in five databases (CINAHL, MEDLINE, PsychINFO, Eric and EMBASE). A final search was performed in September 2019 to search for possible new studies. Both literature searches were performed in collaboration with two independent librarians. The overview of the literature was used to ensure that the right keywords were used to scope important perspectives of patients’ experiences of well-being in the subsequent systematic search. For all of the databases, the search terms were used as both keywords and MeSH terms according to the different
3.2.2 | Selection of articles

The systematic literature search identified 66 articles, and two articles were identified by a hand search of the reference lists of eligible articles, as shown in Figure 2, that is in total 68 articles. Twenty-six records were assessed at the full-text level, resulting in the inclusion of 12 studies. Identification (n = 68) and screening (n = 47) of the articles were performed by the first and last authors (KH, TE), and full-text assessments (n = 26) were shared among the authors and discussed until agreement was reached on which studies to include.

Guided by the aim, the full-text assessments were structured by the following questions:

- How did well-being emerge in the texts?
- In which ways and in what situations was the concept of well-being presented?
- Was well-being presented directly or indirectly?
- How was it described or measured?
- Which instruments were used?

In general, it was important to be sensitive to how barriers to and facilitators of well-being, and nurses’ actions were described in the dataset. The main reasons for excluding studies were that they were either theoretical, did not include the patient perspective, or their findings were not relevant to well-being. The process led to the included studies (n = 12), as presented in Table 1. Reasons for exclusion are stated in the PRISMA flow chart (Figure 2).

3.3 | Data analysis

3.3.1 | Critical appraisal

A critical appraisal of all the included articles was performed by the first and last authors (KH, TE), using the Johanna Briggs Institute Critical Appraisal Tools (Johanna Briggs Library), and the most relevant appraisal tool for each study was selected. Articles of good quality were given a ‘yes’ on all relevant questions in the appraisal chart. Reasons for medium quality were either a small sample as in Rose et al. (2014) or an indirect description of well-being. Another reason for medium quality was whether the articles were unclear in response to relevant questions in the JBI appraisal tool (see Table 1).

3.3.2 | Investigating the data

As recommended by Whittemore and Knafl (2005), the 12 selected studies were read, re-read and discussed by the research team throughout the analytical process. The analysis started by analysing each paper in turn and then comparing the results across all of the studies included. We identified the aim, setting, context, method and results from each study, and recorded their degree of conformity according to how each paper fitted with the concept of well-being. Well-being was understood as what each paper reported as well-being or lack of well-being, through different measured variables, outcomes and experiences. Patient experiences were defined as the ICU patients’ self-reported outcomes and qualitative data from patients regarding their ICU stay.

During the analytical discussions, the authors drew up a ‘working map’ elucidating how well-being was mentioned in the studies. This map highlighted topics most often related to well-being in the ICU setting. Moreover, the working map guided the extraction of relevant themes. Table 2 presents a quantitative mapping of perceived factors for well-being as facilitators and barriers from the included studies. This mapping only included direct factors for well-being.

<table>
<thead>
<tr>
<th>Search ID#</th>
<th>Search terms</th>
<th>Search modes and limitations</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>S1</td>
<td>&quot;critical care OR intensive care&quot; OR &quot;critical care patient OR Intensive Care Patient&quot;</td>
<td>Boolean/Phrase</td>
<td>12.284</td>
</tr>
<tr>
<td>S2</td>
<td>&quot;Critical illness OR critically ill patients&quot;</td>
<td></td>
<td>14.127</td>
</tr>
<tr>
<td>S3</td>
<td>&quot;Psychological well-being OR well-being OR spiritual well-being&quot;</td>
<td></td>
<td>28.084</td>
</tr>
<tr>
<td>S1 AND S2 AND S3</td>
<td>Peer reviewed; Human; Danish, English, Norwegian, Swedish language</td>
<td></td>
<td>21</td>
</tr>
<tr>
<td>S5</td>
<td>&quot;well-being&quot;</td>
<td></td>
<td>5.345</td>
</tr>
<tr>
<td>S6</td>
<td>&quot;emotional well-being&quot;</td>
<td></td>
<td>1.255</td>
</tr>
<tr>
<td>S7</td>
<td>S5ORS6</td>
<td></td>
<td>31.944</td>
</tr>
<tr>
<td>S8</td>
<td>&quot;S1 AND S2 AND S5&quot;</td>
<td></td>
<td>34</td>
</tr>
</tbody>
</table>

FIGURE 1 Search strategy in CINAHL
described during the ICU stay, which resulted in the exclusion of four studies that described well-being after the ICU stay through long-term follow-up.

The overall analysis covers both quantitative and qualitative results of experiences of well-being. The emerging themes were compared, contrasted, split and merged (Whittemore & Knafl, 2005), before we agreed on the final themes and sub-themes reflecting different perspectives and aspects of patients’ experiences of being cared for in an ICU setting. A PRISMA 2009 checklist was used to answer questions relevant to this integrative review (Appendix S1).

4 | RESULTS

The dataset comprised 12 studies; they were from Belgium (n = 2), Canada (n = 1), Denmark (n = 1), France (n = 1), Estonia (n = 1), UK (n = 2), USA (n = 1) and Sweden (n = 3), as shown in Table 1. The design of the studies was quantitative (n = 7), qualitative (n = 4) and mixed methods (n = 1) (Table 1).

The scope of the different studies varied. However, common to all of them was patient experiences of being cared for in an ICU in terms of well-being, either directly or indirectly. The quantitative studies by Sackey et al. (2008) only measured well-being directly using the WHO Well-Being Index combined with the ICU memory tool (ICU-MT), the Hospital Anxiety Scale (HADS) and the Impact of Event Scale (IES). In the other quantitative studies, well-being was measured indirectly by instruments such as the Environmental Stressor Questionnaire (ESQ), HADS, PTSD, IES or self-constructed questionnaires. The qualitative studies (Olausson et al., 2013; Samuelson, 2011; Sørensen et al., 2013; Van Keer et al., 2017b) had specific qualitative findings corresponding to patients’ experience of well-being.

The sample size in the studies also varied in terms of the numbers of ICUs and patients included. All of the quantitative studies had quite small samples. The largest patient sample among these was in Aro et al. (2012), with a sample of 168 patients across 16 ICUs, and the smallest was in Rose et al. (2014) with a sample of 27 patients in a single-centre study. The study with the largest patient sample was the Swedish qualitative study by Samuelson (2011), which included 250 telephone interviews. Olausson’s et al. (2013) phenomenological study had the smallest sample with nine in-depth interviews with patients being cared for in an ICU.

4.1 | Well-being as a multidimensional experience—interwoven in barriers and facilitators

Based on the extracted data from each paper, factors for well-being were categorised as either facilitators or barriers, as shown in Table 2.
<table>
<thead>
<tr>
<th>Authors (year)</th>
<th>Country</th>
<th>Aim</th>
<th>Design, setting, sample, measures</th>
<th>Key findings</th>
<th>Critical appraisal score (Johanna Briggs Institute)</th>
</tr>
</thead>
</table>
| Abuatiq (2015) USA | To investigate patients’ perceptions of stressors in the ICU, as well as healthcare providers’ perception of what constitutes a stressor from the patient’s perspective | Design: Part of a mixed-method comparative descriptive survey  
Sample: ICU patients and healthcare providers, n = 70/70  
Instruments: Environmental Stressors Questionnaire (ESQ)—50 items  
Context: 2 medical and surgical critical care units in 2 different hospitals | The study concludes that the following stressors inhibit well-being  
Most stressful items:  
- Being in pain (n = 41, 58.6%; mean 4.37)  
- Not being able to sleep (n = 23 33.3%; mean 3.87)  
- Financial worries (n = 19, 27.1%; mean 3.5)  
Patients with family scored lower overall ESQ (p = 0.001) | Medium (well-being is indirect and not measured) |
| Aro et al. (2012) Estonia | To describe ICU patients’ perceptions of the importance of needs and how these are met | Design: Descriptive questionnaire survey  
Sample: ICU patients, n = 168  
Convenience sampling  
Context: 16 ICUs in acute hospitals | Meeting aspects of patients’ needs to achieve well-being.  
Most important needs:  
Physical comfort (relieve pain, maximise comfort, prevent from suffering) was most important, followed by feeling safe (staff always present, responding sensitively to their signals and responding adequately to changes in their situations), emotional support, to be informed and to be respected as a unique individual.  
Less important:  
Privacy, involvement of family and friends, including active involvement in decision-making. | Good |
| Burtin et al. (2009) Belgium | To investigate whether a daily exercise session is a safe and effective intervention to prevent decreasing functional capacity and status, and quadriceps force | Design: Randomised controlled trial  
Sample: ICU patients, n = 90, Adults ≥7 days in ICU  
Convenience sampling  
Context: 2 surgical-medical ICUs  
Intervention in treatment group: passive or active exercise training session for 20 min/day using bedside ergometer. | Well-being is highlighted as an indirect result of early mobilisation  
1. Quadriceps force and functional status, weaning time, ICU stay, hospital stay  
2. 6-min walking distance, isometric quadriceps force, and the subjective feeling of functional well-being favouring the intervention (p < 0.05) at hospital discharge  
Mortality rate during hospital stay = similar (16% in controls vs. 24% in intervention, p = 0.29) | Good |
| Eakin et al. (2017) USA | To describe the survivorship experience of patients who had acute respiratory failure. | Design: Semi-structured telephone-based interviews  
Sample: A total of 48 adult patients who had acute respiratory failure  
Context: 5 and 18 months after their stay in the intensive care unit.  
Participants were asked about overall well-being and important health outcomes | Important for well-being: physical health, mental health, and social health. Prominent themes were: mobility impairments, pulmonary symptoms, fatigue, anxiety and depression symptoms, and decreased ability to work and participate in valued activities. Impacts on overall well-being and on relationships with friends and family members varied among the survivors | Good |
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</tr>
</thead>
<tbody>
<tr>
<td>Van Keer et al. (2017b)</td>
<td>Belgium</td>
<td>To investigate the state of mental well-being of patients from ethnic minority groups and possible related risk factors for the development of mental health problems among these patients during critical medical situations in hospital</td>
<td>Design: Qualitative ethnographic design. Triangulation of negotiated interactive observation, in-depth interviews with healthcare professionals, and the reading of patients' medical records. Sample: 84 ICU staff members, 10 patients from ethnic minority groups and their visiting family members. Context: One ICU in a multi-ethnic urban hospital in Belgium</td>
<td>Important basic needs to achieve well-being expressed by patients: The need for social contact Non-medical information exchange The need to increase comfort and alleviate pain The need to express desperation and to participate in end-of-life decision-making</td>
<td>Good</td>
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<tr>
<td>Knowles and Tarrier (2009)</td>
<td>United Kingdom</td>
<td>To evaluate the effectiveness of a diary intervention on levels of anxiety and depression in a group of intensive care unit survivors.</td>
<td>Design: Pragmatic randomised controlled trial. Sample: Patients admitted to the ICU of the Royal Bolton Hospital, remaining in the ICU for at least 48 h (n = 36) Context: ICU</td>
<td>Well-being is indirectly connected to ICU diaries. The diary intervention showed a significant positive impact on anxiety and depression scores almost 2 months after patients' discharge from the ICU.</td>
<td>Good</td>
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<td>Mirabel et al. (2011)</td>
<td>France</td>
<td>To evaluate outcomes, health-related quality of life and frequencies of anxiety, depression and post-traumatic stress disorder symptoms in fulminant myocarditis patients rescued by mechanical circulatory assistance.</td>
<td>Design: A retrospective, single-centre, observational study and a cross-sectional survey to assess health-related quality of life using the Short Form-36 questionnaire, frequency of anxiety and depression using the Hospital Anxiety and Depression Scale and post-traumatic stress disorder symptoms using the Impact of Event Scale. Sample: 41 hospitalised patients Context: One ICU in a university hospital</td>
<td>Early identification of anxiety, depression and PTSD symptoms might improve patients' long-term well-being. 1/3 of the patients reported severe anxiety, depression, and/or PTSD symptoms.</td>
<td>Good</td>
</tr>
<tr>
<td>Olausson et al. (2013)</td>
<td>Sweden</td>
<td>To reveal the meaning of the ICU as a place of care.</td>
<td>Design: Photovoice methodology Sample: 9 patients from 3 different ICUs Context: 3 general ICUs with open visiting hours.</td>
<td>Well-being is connected to patients' experiences of room, place and space. There is an ever-present tension between well-being and suffering A place in between A place of trust and security A life-affirming place A place of tenderness and care An embodied place</td>
<td>Good</td>
</tr>
<tr>
<td>Authors (year) Country</td>
<td>Aim</td>
<td>Design, setting, sample, measures</td>
<td>Key findings</td>
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<tr>
<td>Rose et al. (2014) Canada</td>
<td>To describe memories and recall of ICU experiences to characterise HRQOL and psychological morbidity, and to examine the relationship between HRQOL and morbidities.</td>
<td>Design: Questionnaires to assess memory and recall of care locations, anxiety, depression, post-traumatic stress symptomatology and health-related quality of life. Sample: Participants were identified through the Prolonged-ventilation Weaning Centre database ($n = 27$). Context: PWCS (small sample)</td>
<td>Well-being is inhibited by considerable psychological morbidity in ICU survivors. Delusional memories and anxiety were prevalent and associated with each other, suggesting interventions designed to ameliorate delusional memories may reduce anxiety. Participants continued to experience anxiety for over three years after discharge.</td>
<td>Medium (low sample)</td>
<td></td>
</tr>
<tr>
<td>Sackey et al. (2008) Sweden</td>
<td>To compare memories of patients sedated with two different sedatives during the ICU stay.</td>
<td>Design: Prospective long-term follow-up after randomised controlled trial. Sample: 40 patients in need of sedation during ventilator treatment. Context: One general ICU. The Well-being Index has been used.</td>
<td>Reduced well-being correlates with depression and memory loss. The inverse correlation with the Well-being Index confirms that patients with high IES or HADS scores also had a reduced subjective quality of life.</td>
<td>Good</td>
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<tr>
<td>Samuelson (2011) Sweden</td>
<td>To describe unpleasant and pleasant memories of the ICU stay in adult mechanically ventilated patients.</td>
<td>Design: Qualitative interviews. Sample: 250 patients were interviewed (interviews lasted from 5–30 min). Sample: Patients 3–5 days after ICU discharge. Context: 3–5 days after discharge, place unknown</td>
<td>Reduced well-being is reported with unpleasant memories, while experience of well-being is reported together with pleasant memories. 10 categories emerged: Physical distress and relief of physical distress, emotional distress and emotional well-being, perceptual distress and perceptual well-being, environmental distress and environmental comfort, and stress-inducing care and caring service.</td>
<td>Good</td>
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</tr>
<tr>
<td>Sørensen et al. (2013) Denmark</td>
<td>To present a theoretical account of the pattern of nurse-patient collaboration during NIV.</td>
<td>GT Data collected from 3 Danish hospitals (3 ICUs and 1 general respiratory ward). All patients with ARF or COPD and treated with NIV were included. Participant observation and patient interviews (11 male and 10 female). A nurse sample of 27.</td>
<td>Well-being is reported with well-being-oriented collaboration. Four types of collaboration and non-collaboration were identified. 1. Twofold oriented collaboration, 2. Well-being-oriented collaboration includes well-being in the foreground of patient care. Health professionals accommodate patient support to optimise well-being 3. Outcome-oriented collaboration 4. Absent collaboration.</td>
<td>Good</td>
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</table>
Overall, factors reported in the studies were often barriers, and few reported facilitators for patient experiences of well-being during ICU stay. All of the included studies evaluated well-being with surrogate markers/endpoints. Four studies investigated barriers only (Abatiq, 2015; Eakin et al., 2017; Rose et al., 2014; Samuelson, 2011), three studies examined facilitators (Aro et al., 2012; Sørensen et al., 2013; Van Keer et al., 2017b), while one explored a mix of factors (Olausson et al., 2013). We excluded four studies that investigated indirect factors of well-being because their outcomes were well-being factors seen from a long-term perspective, such as evaluating the effectiveness of early ICU mobilisation (Burtin et al., 2009), ICU diaries (Knowles & Tarriers, 2009), a retrospective cohort study (Mirabel et al., 2011) or long-term follow-up after a randomised controlled trial (RCT) (Sackey et al., 2008). Table 2 presents many factors that contributed to a deteriorating of well-being, and these results show that barriers could be eliminated by relieving negative symptoms (e.g., pain, emotional distress, missing loved ones, restrictions). Facilitators illustrated factors that might help to increase patient well-being. These factors might be feeling safe, being respected as a unique person, being involved as a family in the decision-making process, a more naturalistic setting in the ICU or attention to the environment, including a trusting relationship with nurses and other staff. An interesting finding was that physical comfort was more important to some ICU patients than, for example involvement in decision-making.

The overall analysis is presented in Table 3.
2015; Aro et al., 2012; Mirabel et al., 2011; Olausson et al., 2013; Rose et al., 2014; Samuelson, 2011; Sørensen et al., 2013; Van Keer et al., 2017b) and embodiment (Olausson et al., 2013).

The sub-themes emerged by analysing which factors were reported in each paper (e.g. physical, emotional, relational and environmental well-being for patients in an ICU setting). Most of the studies revealed an interwoven picture of what might enhance well-being for patients in an ICU, illustrated by the main theme: ‘Well-being as a multidimensional experience – interwoven in barriers and facilitators’. Several of the studies addressed barriers to well-being that needed to be identified to create an environment that focussed on patient well-being (Abuatiq, 2015; Aro et al., 2012; Mirabel et al., 2011; Rose et al., 2014; Samuelson, 2011; Van Keer et al., 2017b). However, some studies investigated what promoted well-being (Aro et al., 2012; Burtin et al., 2009; Knowles & Tarrier, 2009; Olausson et al., 2013; Sørensen et al., 2013; Van Keer et al., 2017b). Table 3 provides an overview of these themes.

4.1.1 Barriers to well-being

**Physical stressors and conditions**

Several studies mentioned physical stressors or symptoms as barriers to well-being in the ICU. A mixed-method study by Abuatiq (2015) revealed patients’ perceptions of stressors in the ICU. Abuatiq identified stressors such as being in pain and unable to sleep, discomfort due to the room temperature and restricted movement due to tubes and wires. Furthermore, he described thirst and difficulties in mobilisation as other significant physical stressors (Abuatiq, 2015). The discomfort from bodily restrictions and experiences of thirst and pain were also important findings in the studies by Rose et al. (2014) and Samuelson (2011). Abuatiq (2015), in line with several of the other studies (e.g. Rose et al., 2014; Samuelson, 2011), refers to difficulties in communication as a substantial physical barrier to patient experiences of well-being in an ICU setting.

Pain alleviation is highly valued as a contributing factor to well-being in the study of Van Keer et al. (2017b). In a qualitative interview study by Samuelson (2011) that included 250 ICU patients five days after discharge, the patients described their physical distress as life-threatening, having their vital functions threatened due to being unable to breathe and feelings of being choked. When investigating health-related quality of life, Mirabel et al. (2011) found that patients with acute myocarditis on mechanical circulation support had significantly poorer scores on physical health status than the control group. Bodily pain was the only aspect where these patients scored lower on than the control group. The patients’ poor physical health was also associated with comorbidity and factors such as higher body mass index, sepsis score and, in general, more severe diseases (Mirabel et al., 2011).

**Emotional stressors**

Anxiety, depression and emotional worries were described as important barriers to emotional well-being in ICUs (Abuatiq, 2015; Knowles & Tarrier, 2009; Rose et al., 2014; Sackey et al., 2008). Emotional stressors were often related to both physical and emotional burdens in the ICU setting.

Delusional memories seemed to be an obvious threat to patients’ well-being. In the study by Rose et al. (2014), anxiety and depression were closely related to both delusional and factual memories. Moreover, intrusive memories and panic were revealed as reasons for feeling anxiety and depression. Thirty-nine per cent of the included patients had symptoms of anxiety after discharge, while nine per cent had mood disorders during a period of 0.9–3 years after discharge (Rose et al., 2014). In line with Rose et al. (2014), Mirabel et al. (2011) found that up to 38% of patients with acute severe myocarditis had anxiety and depression after discharge from the ICU, of whom 27% were at risk of PTSD. Most susceptible were patients with comorbidities such as type 2 diabetes. Samuelson (2011, p. 80) describes patients’ delusional memories as perceptual distress and as a frightening unreality, distortion and bewilderment, where patients described trying to escape from death, violence and injured body parts. In their dreams, they could meet surrealistic or alien characters and have frightening experiences of dangerous journeys.

 Loss of control was described in the dataset as emotional distress (Abuatiq, 2015; Rose et al., 2014; Samuelson, 2011). Furthermore, Samuelson (2011) highlights how emotional distress is connected with acute existential fear of death and dying, emotional agitation and depressive feelings, while in the study by Abuatiq (2013), fear of dying was less prominent. Abuatiq (2015) also identified financial worries as a major stressor, an issue not identified in the other studies.

**Missing close family**

Abuatiq (2015) and Rose et al. (2014) focussed on barriers to relational well-being in terms of patients missing those closest to them. Abuatiq (2015) found that not being able to fulfill family obligations was a significant stressor for the patients in her study. The authors of these studies mention the problem of communicating with their family as an emotional challenge, as well as seeing close family members so worried about their illness.

**Environmental disturbances**

Several of the included articles pointed to environmental disturbances as an important barrier to well-being (Abuatiq, 2015; Olausson et al., 2013; Rose et al., 2014; Sackey et al., 2008; Samuelson, 2011). Rose et al. (2014) found that 65% of the included patients described noise as the most unpleasant memory that affected their psychological well-being. Other examples of environmental disturbances were confusion between night and day, unfamiliar lights, alarms, frightening sights and room temperature (Abuatiq, 2015; Olausson et al., 2013; Sackey et al., 2008; Van Keer et al., 2017b). Sackey et al. (2008) found that patients remembered ‘frightening bags of blood’ and sights in the room they were unable to give any meaning to. Rose et al. (2014) found that 65% of the included patients described noise as the most unpleasant memory that affected their psychological well-being. Sounds from alarms and ventilators and lighting in the
rooms both night and day increased sleep deprivation and decreased well-being (Rose et al., 2014).

Insecurity of time and space
Only one study explores the impact of the room, time and place explicitly in relation to well-being (Olausson et al., 2013). The findings demonstrate how important it is to understand the multidimensional meaning of the ICU room as an existential place when a person is critically ill. The room reflects vulnerability in the tension between life and death. It mirrors suffering from neighbouring patients, extending the burden beyond oneself and escalating fear. Furthermore, the absence of sound and silence was just as alarming. The ICU room was experienced as a place that impeded the maintenance of integrity, due to its design and impersonality. Patients expressed the feeling of being in a place ‘in between’ and that they felt bodily extensions to other places and situations, in and outside the hospital. These feelings could be very frightening, creating feelings of loss of control and loneliness, as well as being barriers to well-being. As described by Olausson et al. (2013, p. 239), the critically ill patients were ‘homeless’ in the room and obedient, with a weak voice that was barely heard.

4.1.2 | Facilitators of well-being

Meeting physical needs and activities
In the Estonian study by Aro et al. (2012), the authors found that providing physical comfort and accommodating physical needs were the most important factors in patients’ well-being. Meeting their physical needs was significantly more important than, for example, patient involvement in decision-making. However, these authors reported that patients’ responses corresponded to some degree with their awareness of needs, which in turn was negatively associated with the patients’ educational level. The lower the patients’ level of education, the more they described their needs as being met (Aro et al., 2012). Samuelson (2011) described how activities that gave patients relief from physical distress were felt to be life-saving and could provide pleasant memories and promote well-being.

Mirabel et al. (2011) found that long-term follow-up had a significant positive association with physical health and well-being among patients with acute myocarditis. An RCT by Burtin et al. (2009) demonstrated that early exercise with in-bed cycling during ICU increased the subjective feeling of functional well-being 6 months after discharge. Abuatiq (2013) concludes that more focus on all dimensions is interwoven in patients’ experiences and are facilitators of well-being in the ICU setting.

4.1.3 | Dimensions of a caring environment

A caring environment has many dimensions, including acts of care and the patient’s perception of the ICU room, staff and family members. All these dimensions are interwoven in patients’ experiences and are facilitators of well-being in the ICU setting. ICU diaries seemed to be an important aspect of a caring environment that promotes patients’ well-being. In a pragmatic RCT (n = 36) by Knowles and Tarrier (2009), the correlation between anxiety, depression and ICU diaries was explored. The diary group (n = 18) had lower anxiety and depression scores 3 months after ICU discharge than the patient group that did not receive a diary (n = 18). It is thus possible that the use of diaries has a positive effect on patients’ emotional well-being. Additionally, the qualitative feedback on diaries was positive (Knowles & Tarrier, 2009, p. 188). Sackey et al. (2008) found that the type of sedation used was linked to delusional memories and well-being, as they discovered that patients who had been sedated with isoflurane had fewer hallucinations and delusional memories, and achieved a higher score on the well-being index. Patients’ inner strength was also an important factor in improving emotional well-being, as illustrated by patients’ realisation that they had survived. In the study by Samuelson (2011), some of the patients talked about enjoyable dreams and memories, although they were delusional. These were dreams and memories that gave them energy to keep on struggling (Samuelson, 2011).

Van Keer et al. (2017b) investigated mental well-being from the perspective of ethnic minority groups and shed light on many dimensions of well-being that could be facilitated by acts of caring, reflecting basic human needs regardless of ethnicity. Nevertheless, patients mainly described negative factors that were barriers to well-being. Patients in the study by Van Keer et al. (2017b) described how they longed for social contact and closeness with their family members and proximity to others. They longed to be touched and hugged. Patients from ethnic minority groups additionally highlighted the necessity of being able to communicate, including expressing their feelings and concerns in their native language. Further, they called for caring acts that increased their comfort in their ‘mother tongue’ and a more profound sensitivity to their non-verbal expressions of pain, discomfort and hopelessness, which were cultural forms of expression. Non-medical and non-task-oriented conversations with staff were also highlighted by Van Keer et al. (2017b). On the other hand, patients stated that it was important for their well-being to know that they could participate in decision-making on the withdrawal of life-prolonging treatment. They felt, more than others, that they as an ethnic minority group were excluded from these decision-making processes, yet they considered themselves to be central decision-makers (van Keer et al., 2017). These authors are the only ones in our dataset to bring up the issue of end-of-life decision-making in relation to patient experiences of well-being.

The relationship with the staff and the security they provided are emphasised in several of the included studies, both quantitative and qualitative, as being important to well-being (Abuaat, 2015; Olausson et al., 2013; Sørensen et al., 2013). Patients described the intensive care room as a place of trust and security due to positive interaction with the staff. Trust was manifested by caring activities, and by being touched and spoken to in a kind manner. Activities that gave patients a sense of being taken care of, being in good hands and having ICU staff around were important for patients to feel safe and calm, which increased their emotional well-being (Samuelson, 2011).
Sørensen et al. (2013) describe collaboration with nurses in managing non-invasive ventilation. The patients described a well-being-oriented collaboration if the staff focussed on preventing discomfort, being aware of bodily expressions and being available for them. Patient experiences of feeling safe were enhanced by having staff around and knowing that staff would be there in a crisis. The staff and technology seem to represent a line and are very important facilitators of well-being. This is given particular emphasis in some of the studies (Aro et al., 2012; Olausson et al., 2013; Van Keer et al., 2017b). Patients expressed pros and cons regarding family visits in the ICU. Some patients felt concerned and worried about their family members seeing them so ill, while others described it as an individual need that was a very important contributor to their well-being (Abuatiq, 2015; Van Keer et al., 2017b). Abuatiq (2013) found that family presence had a major impact on patients’ reported well-being (Abuatiq, 2013; Van Keer et al., 2017b). Patients expressed pros and cons regarding family visits in the ICU. Some patients felt concerned and worried about their family members seeing them so ill, while others described it as an individual need that was a very important contributor to their well-being (Abuatiq, 2015; Van Keer et al., 2017b). Abuatiq (2013) found that family presence had a major impact on patients’ reported stress scores, where the patients with high family presence had significantly lower stress scores.

5 | DISCUSSION

In this paper, we have identified aspects that enhance patients’ well-being when being cared for in an ICU setting, from the perspective of the patients themselves. In our analysis, the WHO description of well-being and a phenomenological understanding of the concept underpinned our interpretation. This implies a broad description and understanding of the concept, underlining that when well-being is only understood as the absence of physical health, essential dimensions are omitted.

When interpreting findings from all the articles, we found that experiences of well-being are multidimensional and include physical, emotional, relational and environmental aspects more often described through barriers than facilitators of well-being. Overall, findings from the studies underscore that well-being in an ICU setting should be met with a holistic understanding. We would argue that patient experiences of well-being in the ICU include an interplay between physiological, psychological and relational dimensions of care, such as the dimensions in FOC, described by e.g. Kitson and Athlin (2013) and Kitson (2018). However, neither of the articles fully elaborates these strong connections. Moreover, most of the included articles describe poor care and barriers to well-being rather than positive caring and well-being experiences.

An important finding regarding experiences of patient well-being in an ICU was the relationship to the ICU nurses, feeling safe and trusting the nurses (Aro et al., 2012; Ingrid Egerod et al., 2013; Olausson et al., 2013; Sørensen et al., 2013; Van Keer et al., 2017b). These findings imply that time and space must be allocated for ICU nurses to provide care that promotes well-being for patients. A major threat to the possibility of enhancing patient well-being is the high workload in ICUs (Siffleet et al., 2015). We would argue that this might be one reason why barriers to well-being were given more focus than facilitators in the included studies. In the Nordic countries, there is currently a lack of registered nurses with further education in intensive care, leading to greater workload and responsibilities (Sundberg et al., 2017). This is likely to affect the possibility of addressing all aspects that contribute to patients’ well-being. When time is limited, caring tasks such as mouth care, mobilisation or just being close might be given less attention, as found in several studies on care left undone and missed care (Ball et al., 2016, 2018). Furthermore, these tasks represent important aspects of FOC. We would argue, in line with Kitson (2018), that when nurses over time leave these ‘more invisible’ tasks undone, there will be a greater focus on more technical and biomedical tasks in nurses’ caring actions and attitudes. Well-being and holistic care will thus be threatened. Moreover, it is claimed that ICU nurses who experience job satisfaction are more likely to be able to address the well-being of critically ill patients (Sundberg et al., 2017).

Physical discomfort such as thirst, being unable to communicate, sleep deprivation, dysphagia and general discomfort were mentioned in several studies (Abuatiq, 2015; Rose et al., 2014; Samuelson, 2011; Sørensen et al., 2013). These findings correspond with other research on patient experiences (Egerod et al., 2015). It is imperative to be aware of these aspects of patient care and continuously act upon them to improve patient well-being. Providing care that reduces physical discomfort is seen as meeting the patient’s basic care needs, which is a clearly stated ethical demand for nurses (ICN, 2012) and is one of the strong arguments in FOC (Kitson, 2018).

Several of the studies emphasised the necessity of being aware of and acting upon physical, emotional, relational and environmental factors to promote patient well-being (e.g. Abuatiq, 2015; Olausson et al., 2013). A crucial question in this regard is: What caring actions can be performed to enhance patients’ well-being during the ICU stay? Well-known nursing non-pharmacological interventions to promote well-being are early mobilisation protocols, as found by Burtin et al. (2009) and writing patient diaries (Knowles & Tarrier, 2009). The importance of writing diaries has been emphasised in several studies in recent decades (e.g. Egerod et al., 2011; Johansson et al., 2019). However, the use of patient diaries is not standard procedure in all ICUs and is reported to be an activity that can be excluded due to time pressures (Halvorsen et al., 2008; Holme et al., 2020). Knowing the importance of diaries for patient well-being and ICU recovery, this might be of significant concern.

Our findings highlight the meaning of position, space and room in relation to patient experiences of well-being in the ICU. Olausson et al. (2013) explored what it meant for patients to have a view from their window and how this experience linked the patient to a bigger existential picture. Often, patients have little to look at except staff going back and forth. Moreover, windows are often located behind the patient’s head. However, we argue that the benefits of interventions to improve patients’ views are underrated as a source of enhancing well-being and ICU nurses should be more aware of this. Some of our studies emphasised how fear of dying, loneliness and missing loved ones are barriers to well-being (Abuatiq, 2015; Rose et al., 2014). Perhaps having a view, and thus being able to see natural daylight and something beautiful, could counteract the negative thoughts and feelings of ICU patients and in some cases increase their sense of well-being.
As long ago as 1984, Roger Ulrich published the findings of an empirical study where patients' recovery after surgery was found to be more positive if the patient had a view of a garden rather than of a brick wall (Ulrich, 1984). Compared outcomes were, for example, consumption of analgesics, anti-emetics and length of stay. These findings have later been developed and summarised in several review studies (Allison et al., 1998; Ulrich, 2006; Ulrich et al., 2008), but we would argue that the relevant recommendations have only to a limited degree been implemented in ICU practice. In a review of literature collected from nursing, medicine, psychology, architecture and environmental science, Minton and Batten (2016) state that ICU nurses have a variety of ‘nature-based’ interventions that they can implement in practice to counteract environmental stressors, and thus create well-being. Such interventions could include noise and sound reduction, facilitating access to daylight and placing the bed to give the patient a view of natural scenery. These components were among those taken into consideration in a Swedish ICU complex intervention programme (Lindahl & Bergbom, 2015) focusing on healing environments and evidence-based design in ICUs (Engwall et al., 2015; Johansson et al., 2017; Sundberg et al., 2019). These findings relating to environmental aspects correspond with findings in several of the studies in this review where, for example, noise, environmental stressors, room and bed position were relevant to the absence of well-being (Abuatiq, 2015; Eakin et al., 2017; Rose et al., 2014; Samuelson, 2011). Being concerned about and acting upon how to minimise environmental distress are important factors to enhance ICU patients’ well-being.

Another important finding in some of the studies was related to the patient's family. Having the family around could be both a facilitator and a barrier (Abuatiq, 2015; Sørensen et al., 2013; Van Keer et al., 2017b). The patients felt, on the one hand, worried about their families seeing them so sick and, on the other hand, a great deal of comfort from having them around. However, the findings showed that the presence of the family had to be adjusted to the patient's experiences and needs to contribute to well-being (Abuatiq, 2015; Rose et al., 2014). These findings correspond with research on family presence in the ICU (Olsen et al., 2009; Wong et al., 2019), showing that both families and patients’ individual needs have to be met, and that fixed visiting hours are counterproductive to achieving optimal well-being for patients and families.

The term ‘comfort’ is closely related to ‘well-being’, as described in the study by Olausson et al. (2013). This has also been found in more recent studies by Olausson and colleagues (Olausson et al., 2019), where they explored the meanings of comfort in an ICU using both a theoretical and an empirical dataset. The concept of comfort was found to be closely related to nature as it gave a feeling of harmony, peacefulness and revitalised energy. Wood was found to be the most appealing material as it reminded the research participants of a feeling of at-homeness. The authors argue for the importance of a view of nature, but also that nature should be incorporated in the ICU when interior building materials are chosen. In a survey of 42 families of ICU patients, Ulrich et al. (2019) found that access to and breaks in a flowery hospital garden reduced stress, and promoted relaxation and well-being for the visiting family to a higher degree than when they had a break in the hospital café or waiting area. These findings have also been endorsed in a study investigating the connection between acts of caring and the design of the ICU patient room (Sundberg et al., 2019). In this study, the authors stress the importance of a supportive environment and of nurses acquiring an attentive and attuned gaze and attention to the suffering person.

We would argue that there is significant evidence to indicate acting upon environmental aspects, such as design, nature and view, in the daily care of patients in an ICU setting. Moreover, we believe this is of significance in planning for future ICUs, both in terms of delivering evidence-based care and to reduce hospital costs and patient challenges post-ICU.

To sum up, several closely intertwined aspects contribute to well-being in an ICU setting, and the ICU nurse plays an important role in enhancing patients’ well-being. Creating time and space for patient well-being also involves the ICU leadership, which must define the possible caring frameworks for nurses and an environment that enhances the well-being of both patients and nurses. We believe that the FOC framework might be a suitable model to investigate and analyse patient experiences of well-being in the ICU, as it has a holistic and multidimensional approach to patient care (Kitsos, 2018). Adams et al. (2019) scrutinise the role of ICU nurse managers in supporting staff well-being. They claim that a relational leadership style can improve nurses’ well-being, which in turn is likely to affect patients’ well-being.

5.1 Study strengths and limitations

In this integrative literature review, we have sought to map patients' experiences of well-being while being cared for in an ICU. To our knowledge, we are the first to review this important topic in the context of ICU care. However, most of the included articles did not investigate well-being per se, and we might therefore not have recognised or identified some aspects that enhance well-being. It was a challenge that well-being was mainly found in terms of what inhibits well-being, rather than what enhances it. This constituted an analytical challenge and may have resulted in erroneous interpretations.

However, the analysis of the data was discussed within the group of authors to ensure a valid interpretation. Moreover, prior to data collection, the research group critically discussed definitions and meanings of well-being and what constitutes well-being in the ICU setting. In addition, several terms (Mesh) and keywords were piloted and compared before data collection. The included studies were read and critically discussed and evaluated before an agreement was reached in the group. While the heterogeneity of the studies in terms of design, quality and the total population provided a broad overview of the topic, it was a limitation for the generalisation of the findings (Whittemore & KnafI, 2005), which also influences the validity of the evidence. The fact that most of the studies elaborate barriers to well-being is an obvious weakness and calls for more studies on experiences of well-being and of good care. Another
Experiences of well-being are multidimensional and include physical, emotional, relational and environmental stressors for each patient.

Another limitation is the fact that the studies were conducted at different times after ICU discharge, which might have affected the identified factors related to well-being. All the studies included in this review have methodological flaws and shortcomings, which may thus weaken the overall outcomes of this paper. However, we have made an effort to be transparent in describing the studies in both tables and text to allow readers to critically assess the data themselves. Another limitation of this study is that all the data were collected before the COVID-19 pandemic. Much has happened during the pandemic especially in the care of ICU patients. Lack of professionals qualified to work with these critically ill patients and many more patients than usual has affected the quality of care to promote well-being. The lack of visitors is an additional factor that has had an impact on patient well-being. New studies need to be conducted that include perspectives of the pandemic.

Despite several limitations and weaknesses, we believe that we have contributed knowledge of the importance of providing multifaceted and holistic care for patients cared for in the ICU to enhance their well-being. We would argue that this knowledge is highly relevant for key actors, such as ICU nurses, managers and health policy makers.

6 | CONCLUSION

In this paper, we have identified aspects that contribute to patients’ well-being while being cared for in an ICU setting, from the perspective of the patients themselves. Our main findings are that experiences of well-being are multidimensional and include physical, emotional, relational and environmental aspects, and are more often described in terms of barriers than facilitators of well-being. The main physical barriers to well-being were identified as pain, sleep deprivation, thirst, dysphagia, and physical and functional distress. Emotional barriers were mainly described as depression, delusional memories, loss of control, emotional and perceptual distress, loneliness, fear of death and the unpredictability of the situation. Patients described how they missed and were concerned about their family but were sometimes distressed by having the family around. Environmental aspects inhibiting well-being were related to procedures, equipment, technology and the inability to communicate. Facilitators of well-being were, in particular, related to the experience of being cared for and feeling safe, and being in a place of tenderness and security. To enhance well-being for ICU patients, there is a need for a complexity of nursing activities and care that will ensure that each patient’s individual care needs are met.

7 | RELEVANCE TO CLINICAL PRACTICE

This integrative review has shown that it is necessary to adopt an individual focus on patient well-being in an ICU setting, by considering the physical, emotional, relational and environmental stressors for each patient.

- Nurses need to think and act holistically to provide patient well-being.
- Well-being can be provided by focussing on all aspects of care ranging from mouth care to advanced technological procedures, and relational care involving family and staff.
- Focus on the patient’s relationship with the ICU team to provide a safe and trustful environment is imperative to well-being.
- Considerations of bed position, views of nature, and sounds and light in the environment are highly relevant to enhancing patient well-being.
- An individual approach to family presence is needed as a balanced act of caring.
- ICU nurses have to be aware of the fact that family presence may be very comforting but may also cause worries and concern.
- Providing diaries to patients, in particular in post-discharge recovery, has proven very valuable for many patients.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

AUTHOR CONTRIBUTIONS

Study design, selection and analysis of all included articles, agreement on final manuscript, all figures, tables and supplementary files: All authors. Manuscript writing: KH.

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