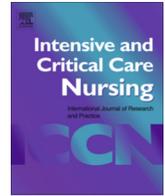




Contents lists available at ScienceDirect

Intensive & Critical Care Nursing

journal homepage: www.elsevier.com/icc

Research article

Intensive care nurse-family engagement from a global perspective: A qualitative multi-site exploration

Rahel Naef^{a,b,*}, Petra Brysiewicz^c, Natalie S. Mc Andrew^{d,e}, Patricia Beierwaltes^f, Vico Chiang^g, David Clisbee^h, Jennifer de Beerⁱ, Junko Honda^j, Shota Kakazu^k, Martin Nagl-Cupal^l, Ann M. Price^m, Sandra Richardson^{n,o}, Anna Richardson^p, Tara Tehan^q, Amanda Towell-Barnard^{r,s}, Sandra Eggenberger^t

^a Institute for Implementation Science in Health Care, Faculty of Medicine, University of Zurich, Universitätsstrasse 84, 8006 Zurich, Switzerland

^b Centre of Clinical Nursing Science, University Hospital Zurich, Raemistrasse 100, 8091 Zurich, Switzerland

^c School of Nursing & Public Health, University of KwaZulu-Natal, King George Mazisi Kunene Road, Glenwood, Durban 4041, South Africa

^d College of Nursing, University of Wisconsin-Milwaukee, Cunningham Hall, 1921 East Hartford Avenue, P.O. Box 413, Milwaukee, WI 53201-0413, USA

^e Froedtert & the Medical College of Wisconsin, Froedtert Hospital, 9200 West Wisconsin Avenue, Milwaukee, WI 53226, USA

^f College of Allied Health and Nursing, School of Nursing, Minnesota State University, 360 Wissink Hall, Mankato, MN 56001, USA

^g School of Nursing, The Hong Kong Polytechnic University, 11 Yuk Choi Road, Hung Hom, Kowloon, Hong Kong

^h College of Science, Engineering and Technology, Computer Information Science Department, Minnesota State University, 273 Wissink Hall, Mankato, MN 56001, USA

ⁱ College of Nursing-Jeddah, King Saud bin Abdul Aziz University for Health Sciences-Jeddah, Makkah Highway, Al Haramain Road, Mail Code 65 65, PO Box 9515, Saudi Arabia

^j Child Health Nursing, College of Nursing Art and Science, University of Hyogo, 13-71, Kitaaji-cho, Akashi, Hyogo 673-8588, Japan

^k Child Health Nursing, Graduate School of Nursing Sciences, St. Luke's International University, 10-1 Akashi-cho, Chuo-ku, Tokyo 104-0044, Japan

^l Department of Nursing Science, University of Vienna, Alser Strasse 23/12, 1080 Vienna, Austria

^m School of Nursing, Midwifery and Social Work, Faculty of Medicine, Health and Social Care, Canterbury Christ Church University, North Holmes Road, Canterbury, Kent CT1 1QU, United Kingdom

ⁿ School of Health Sciences, College of Education, Health and Human Development, University of Canterbury, 276 Antigua Street, Christchurch 8011, New Zealand

^o Emergency Department, Christchurch Hospital, Canterbury District Health Board, 2 Riccarton Avenue, Christchurch 8011, New Zealand

^p Bachelor of Nursing Programme, Department of Health Practice, Manawa, Ara Institute of Canterbury Ltd, 276 Antigua Street, Christchurch 8140, New Zealand

^q University of Massachusetts Medical School, Graduate School of Nursing, 55 Lake Ave North, Worcester, MA 01655, USA

^r School of Nursing & Midwifery, Edith Cowan University, 270 Joondalup Drive, Western Australia 6027, Australia

^s Sir Charles Gairdner Hospital, Centre for Nursing Research, Hospital Avenue, Nedlands, Western Australia 6009, Australia

^t College of Allied Health and Nursing, Glen Taylor Nursing Institute for Family and Society, Minnesota State University, 360 Wissink Hall and 351 7700 France, Mankato, MN 56001, USA

ARTICLE INFO

Article history:

Received 23 December 2020

Revised 31 March 2021

Accepted 5 April 2021

Available online xxx

Keywords:

Family nursing

Family engagement

Family involvement

Family-centered care

Intensive Care Units

Critical care nursing

Qualitative content analysis

ABSTRACT

Background: Critical illness is distressing for families, and often results in negative effects on family health that influence a family's ability to support their critically ill family member. Although recent attention has been directed at improving care and outcomes for families of critically ill patients, the manner in which nurses engage with families is not fully understood.

Objectives: To describe nurses' perceptions and practices of family engagement in adult intensive care units from a global perspective.

Design: A qualitative-descriptive multi-site design using content analysis.

Settings: The study was conducted in 26 intensive care units of 12 urban, metropolitan, academic medical centers in ten countries, spanning five continents.

Participants: A total of 65 registered nurses (77% women, age of $M = 39.5$, $SD = 11.4$ years) participated. Most held intensive care certification (72%) and had worked on average 10 ($SD = 9.6$) years in the ICU.

Methods: Semi-structured, individual interviews ($M = 38.4$ min, $SD = 12.0$) were held with ICU nurses at the hospital (94%) or their home using an interview guide. Qualitative interview data were analysed using inductive content analysis.

* Corresponding author at: Institute for Implementation Science in Health Care, Faculty of Medicine, University of Zurich & Centre of Clinical Nursing Science, University Hospital Zurich, Raemistrasse 100, 8091 Zürich, Switzerland.

E-mail addresses: rahel.naef@usz.ch (R. Naef), brysiewicz@ukzn.ac.za (P. Brysiewicz), mcandre3@uwm.edu (N.S. Mc Andrew), patricia.beierwaltes@mnsu.edu (P. Beierwaltes), vico.chiang@polyu.edu.hk (V. Chiang), david.clisbee@mnsu.edu (D. Clisbee), jbeer@kfsrhc.edu.sa (J. de Beer), junko_honda@cnas.u-hyogo.ac.jp (J. Honda), shota@slcn.ac.jp (S. Kakazu), martin.nagl-cupal@univie.ac.at (M. Nagl-Cupal), ann.price@canterbury.ac.uk (A.M. Price), sandra.richardson@canterbury.ac.nz (S. Richardson), anna.richardson@ara.ac.nz (A. Richardson), tara.tehan@umassmed.edu (T. Tehan), a.towell-barnard@ecu.edu.au (A. Towell-Barnard), sandra.eggenberger@mnsu.edu (S. Eggenberger).

<https://doi.org/10.1016/j.iccn.2021.103081>

0964-3397/© 2021 The Author(s). Published by Elsevier Ltd.

This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Please cite this article as: R. Naef, P. Brysiewicz, N.S. Mc Andrew et al., Intensive care nurse-family engagement from a global perspective: A qualitative multi-site exploration, Intensive & Critical Care Nursing, <https://doi.org/10.1016/j.iccn.2021.103081>

Results: We found that nurse-family engagement was an *ebb and flow of relational power* that needed to be carefully negotiated and balanced, with nurses holding and often exerting more power than families. Constant *fluctuations in nurses' practices* of engagement occurred in day-to-day practice from shift-to-shift and from nurse-to-nurse. Family engagement was dependent on individual nurses' attitudes and perceptions of family, the patient's condition, and workload. Lastly, family engagement was *shaped by the ICU context*, with team culture, collaborative relationships, unit structures and organizational resources either enabling or limiting nurses' ability to engage with families.

Conclusions: This global study provides an in-depth understanding of the way nurses engage with families in ICU and reflects many different cultures and health systems. We found that nurse-family engagement was marked by a shifting, yet often unequal power distribution in the nurse-family relationship, inconsistent nurse engagement practices, both of which resulted in variable family engagement in intensive care. Our research contributes a detailed description of engagement as practiced in the everyday delivery of health care. A more concentrated team effort, based on a shared culture and defined framework of family care is needed to ensure that families of critically ill persons are fully engaged in all aspects of intensive care.

© 2021 The Author(s). Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Implications for clinical practice

- Intensive care nurses at the bedside should move beyond the patient and unequal distribution of power within the nurse-family relationship, recognize families' contribution to the process of patient recovery, consistently encompass families in care and ensure that families receive adequate support.
- A more supportive organizational environment and a concentrated team effort is needed to develop a shared culture of family engagement that consistently meets families' needs for involvement in care.
- Interprofessional team-based implementation and improvement strategies, such as shared educational opportunities and training are essential to move the intensive care family engagement culture forward.
- Intensive care nurses across the globe should take the lead in revising existing and developing new guidelines and policies for family care in the intensive care setting given their continuous presence with families and the emerging research in this area.

Introduction

A patient's admission into an intensive care unit (ICU) is often unexpected and causes feelings of stress, exhaustion, and confusion in their family members (Alsharari, 2019, Davidson et al., 2012, Nolen and Warren, 2014). Factors such as uncertainty (Wong et al., 2017), exclusion (Vandall-Walker and Clark, 2011), inadequate communication (Hetland et al., 2018, Riley et al., 2014, Gaeni et al., 2014, Wong et al., 2015), and an unfamiliar environment (Wong et al., 2017) contribute further to family concerns. Emotional distress associated with this experience can create lasting effects on family health (Davidson et al., 2012), impact family satisfaction with care (Chapman et al., 2016) and affect the family's ability to support their ill family member (Wetzig and Mitchell, 2017).

Families and health care systems have identified nurses as key professionals who can meet the needs of family members and offer support for family coping during this difficult experience (Davidson et al., 2012, McAndrew et al., 2019). Recent attention has been directed at advancing nursing and collaborative practice in ICU settings to improve the care and outcomes for families of critically ill patients (Bridges et al., 2017, Benzies et al., 2019), with organizations developing guidelines to support family engagement (Davidson et al., 2017, Mitchell et al., 2015). However, research highlights a lack of clarity in nurses' understanding of family nursing interventions (Eustace et al., 2015), gaps in the translation of family nursing research into practice in hospital settings (Svavarsdottir et al., 2015), and inconsistencies in the practice of ICU family engagement in adult ICUs (Hetland et al., 2018). Even though nurse-family relationships and development of partner-

ships are central to high quality patient and family care (Coats et al., 2018, de Beer and Brysiewicz, 2017, Wong et al., 2017), the need to involve families in ICU continues to be under-fulfilled (Hetland et al., 2017, Segaric and Hall, 2015, Nolen and Warren, 2014). Nurses often express a challenge and lack of knowledge in how to work with families (Nelms and Eggenberger, 2010, Knutsson et al., 2017, Leung et al., 2017) or reluctance to allow family to be present (Santiago et al., 2014).

A call for family engagement that is meaningful, and involves families during the acute illness experiences, is gaining momentum (Burns et al., 2018, Kleinpell et al., 2018, Brown et al., 2015). However, the art and science of family engagement in ICU is in its early stages of development. Engagement can be viewed as patients, families, and health care professionals working in active partnerships at various levels across the health care system to improve health and health care (Carman et al., 2013). Recent attentions to family engagement in ICU has demonstrated insufficient implementation (Kleinpell et al., 2018, Kleinpell et al., 2019), with health care teams facing multiple barriers (Hetland et al., 2017, McAndrew et al., 2020). A large body of research is focused on understanding the experience and responses of family members to critical illness, with a paucity of studies examining how nurses engage with families. Even though a nurse-initiated collaborative approach with families has been identified as central to family nursing interventions (Eustace et al., 2015), there is limited research that examines practicing nurses' perspectives. While engagement activities with patients have been viewed on a continuum ranging from consultation to full partnership (Carman et al., 2013), a more complete description of engagement with families from a global perspective is needed to guide practice.

Methods

Aim

The aims of this study were first, to describe nurses' perceptions and practices of family engagement in adult ICUs from a global perspective; and second, to identify the common attributes of this family engagement across cultures.

Study design, settings, and participants

Using a qualitative-descriptive multisite design, the study was carried out in 26 adult ICUs of 12 metropolitan, academic medical centers in 10 countries (Table 1). ICUs that provide the highest level of patient care, including patients who are haemodynamically unstable, require ventilation with multiple-organ failure, or need multidisciplinary intervention were purposively chosen together with considerations around researchers' access to study sites.

Study participants were registered nurses working in ICU who spoke English, German, Chinese or Japanese. To be eligible for the study, nurses needed to (1) hold a diploma or baccalaureate degree in nursing; (2) be employed by the institution in which the study

took place; (3) work in that particular ICU environment for at least six months; and (4) provide direct patient care. Excluded were ICU nurses without involvement in clinical care delivery or with temporary employment. A sample size of at least 50, or around five nurses per country was expected to be sufficient to achieve redundancy and completeness of data (Fusch and Ness, 2015).

Recruitment and data collection processes

Purposive and snowball sampling strategies were used to invite potential nurse participants (Patton, 2015). Data were collected between July 2018 and December 2019. An overview of recruitment and data collection processes is displayed in Table 1.

Data collection

Individual interviews explored ICU nurses' descriptions and practices of family engagement to learn how nurses perceive their engagement and how they act to engage families in their clinical practice. We also wanted to elicit their perceptions of enabling and limiting factors in engaging families. A semi-structured

Table 1
Overview of recruitment and data collections processes.

Country	Setting	Recruitment	Time period	Interviewers	Interviews
Australia	One adult ICU with 23 beds, University Hospital (600 beds)	Purposive invitation through Clinical Research Nurse	03/2019–10/2019	Local investigator (PhD)	4 interviews (median duration 39 min)
Austria	Two ICUs with 8 beds, University Hospital (1800 beds) with 13 ICU and 100 ICU beds	Email invitation by Nurse Director	09/2018–10/2018	Local investigator (PhD)	5 interviews (38 min)
England	One adult ICU with 10 beds, University hospital (470 beds)	Purposive invitation through ICU Nurse Manager	11/2018–05/2019	Local investigator (MSc, doctoral candidate)	7 interviews (27 min)
Hong Kong	One adult ICU with 20 beds and two locations, University Hospital (1706 beds)	Purposive invitation through ICU Nurse Consultant	10/2018–06/2019	Local investigator (PhD)	8 interviews (41 min)
Japan	One ICU with 20 beds, University Hospital (934 beds)	Purposive invitation through ICU Nurse Manager	01/2019–03/2019	Local investigator (PhD), research nurses with MS, and Certified Nurses for Intensive Care (n = 3)	5 interviews (50 min)
New Zealand	One adult and pediatric ICU with 18 beds, Tertiary Teaching Hospital (360 beds)	Purposive invitation through ICU Clinical Nurse Educators	10/2019–12/2019	Local investigator (PhD)	4 interviews (50 min)
Saudi Arabia	Four adult ICUs with 27 beds, Tertiary Hospital (531 beds)	Purposive invitation through the Director of Nursing	04/2019–07/2019	Local investigator (PhD)	5 interviews (31 min)
South Africa	Two adult ICUs with 20 beds, State Tertiary Hospital (8460 beds)	Purposive invitation through ICU Nurse Manager	03/2019–04/2019	Local investigator (PhD)	6 interviews (22.5 min)
Switzerland	Six ICUs with a total of 72 beds, University Hospital (900 beds)	Purposive invitation through ICU Clinical Nurse Specialist	08/2018–10/2018	Local investigator (PhD) & MScN student	9 interviews (51 min)
United States	Site one: One adult ICU with 18 beds, Academic Medical Center (1000 beds) Site two: One adult ICU, Academic Teaching Hospital (484 beds) Site three: Five adult ICUs with 107 beds, Academic Medical Center (500 beds)	Email invitation by Nurse Researcher, Nurse Director or ICU Nurse Manager	08/2018–08/2019	Local investigators (PhD) (n = 4)	12 interviews (37 min)

interview guide was used to ensure that interview questions were consistently covered across study sites.

Interviews took place in a quiet area of the ICUs (58%), a hospital meeting room (36%), or in nurses' home (6%), either on or off duty depending on the participant's preference ($n = 55$). Interviews lasted on average 38.4 min (SD 12.0, min. 15, max. 69, $n = 60$) to complete. Nurses were also asked to complete a demographic form. Interviews were audio-taped and transcribed verbatim by local research staff or a professional transcriptionist. Transcripts were anonymized and checked for their accuracy.

Data analysis

Qualitative interview data were analysed using an inductive content analysis method (Graneheim and Lundman, 2004, Erlingsson and Brysiewicz, 2017). Individual researchers read and re-read the data s/he collected to make sense of the data as a whole and attention was given to both the manifest and latent content of the interview text (Graneheim and Lundman, 2004). Next, each researcher coded the data in English and generated a coding sheet that was then shared in discussion with three to five researchers who together made up one of the three interpretive teams led by the three lead researchers. During the online interpretive team discussions, similar codes were discussed, collated and then used to code the meaning units of further interviews. Codes were subsequently grouped into preliminary categories. Preliminary categories were then examined for further refinement with the raw data by the individual researchers. An interpretive text was written to highlight the country-specific meanings and to capture main interpretive insights in the text. Next, the preliminary categories were discussed by an analysis group of seven researchers of the international study team, who then ordered the preliminary categories into categories and themes. The findings structure was then reviewed by all members of the research team and quotes anchored in. Interpretive efforts moved between individual interpretive activity and group dialogue until a consensus about the thematic findings structure was reached.

Trustworthiness

As this is a multi-site, multicultural and multilingual study, the work of Erlingsson and Brysiewicz (2017) was used to assist the researchers and their interpretive teams in maintaining consistency and managing the complexities of qualitative content analysis in a systematic and methodological way. All participating researchers had considerable expertise in qualitative research and those based in non-English speaking countries had experience in doing qualitative analysis in English. The team-based research approach increased the confirmability of the data (Elo et al., 2014). Dependability was ensured by keeping field notes, tracking research decisions, and discussing the analytic process and validity of findings in the different groups (Graneheim and Lundman, 2004). The lead researchers had oversight of the larger analytic process and ensured that findings were representative of the data as a whole (credibility). To ensure authenticity, the researchers provided a clear and distinct description of research contexts, selection and characteristics of participants, data collection, and analysis processes. Rich description of the findings with representative quotes across countries ensure transferability (Graneheim et al., 2017, Elo et al., 2014).

Ethical considerations

This study was reviewed and approved by the responsible ethics committee at each site (refer to supplementary file 1 for ethics submission numbers).

Findings

A total of 65 nurses participated, ranging from 4 to 12 participants per country (Table 2).

We identified three common themes that depict how nurses perceived and practiced family engagement in ICU. First, family engagement entailed an ebb and flow of relational power between nurses and families; second, constant fluctuations in nurses' practices occurred depending on individual nurse attributes; and third, family engagement was shaped by the ICU context

Theme 1: Ebb and flow of relational power

Nurse-family engagement was found to be suffused with power that needed to be negotiated and carefully balanced within the nurse-family relationship. The relational power constantly shifted as both the nurse and the family held varying degrees of power at different times. However, relational power was primarily nurse-driven. When families challenged nurses' authority and control, nurses felt disempowered. This theme entailed two categories.

Information-sharing and communicating with family:

Information-sharing denoted one form of relational power, which shifted depending on who needed what information and who had the information. Most often it was the nurse who, as gatekeeper of information, decided who would hear the information, when and how much to share. One nurse explained:

I like to speak to the family, talk to them, inform them about the caregiving, I also instruct them to do something. (Austria)

Other times the family had information needed by the health-care team and the nurse initiated engagement (Table 3, quote 1a).

Communicating with families was sometimes a struggle for the nurse and hindered the engagement process. One participant explained:

"Sometimes when relative A comes he is told about something; and then relative B was told something else at another time. This is not very ideal because what the family receives is different information". (Hong Kong)

Communication was also complicated by language and cultural differences (1b). While recognizing the difficulties such a fractured communication brought for the nurse, some participants expressed empathic understanding for family (1c).

Nurses also discussed personal and professional rewards of communicating with families; "I feel connected to families" (US, Site 1). With proactive communication, trust and understanding surfaced. For nurses, ongoing and open communication resulted in a more equal distribution of relational power (1d).

Negotiating and collaborating with family: Nurses have a unique role as they hold the power to decide to engage or refrain from working with families. Deciding how much to involve families in decision-making or direct care, address emotional responses or develop support systems for the family was influenced by the individual nurse-family relationship. Family presence in ICU and the amount of time patients are on the unit can facilitate more collaborative relationships (2a). However, apprehensiveness about family presence together with power struggles were commonly described as concerns for nurses. When nurses perceived actions by the family jeopardized the patient, nurses took control:

"When I see that [family presence] doesn't do the patient any good, I ask family members to leave. I tell them that it's enough because the patient is a bit tired and suggest that they say good-bye. I do that, taking the patient's side." (Austria)

At times, nurses were protective and hesitant to involve families in patient care due to what they perceived to be a risky practice in this complex setting:

Table 2
Participant characteristics.

	Total (n = 65)	Europe (n = 21)	Asia (n = 13)	Africa/Middle East (n = 11)	North America (n = 12)	Oceania (n = 8)
Age mean (SD)	39.45 (11.41)	41.95 (12.67)	32.62 (7.36)	41.64 (8.45)	34.36 (11.18)	48.00 (10.09)
Female gender n (%)	50 (76.9)	18 (85.7)	9 (69.2)	8 (72.7)	7 (58.3)	8 (100)
Highest degree n (%)						
Diploma	18 (27.7)	13 (61.9)	0 (0)	4 (36.4)	1 (8.3)	0 (0)
Bachelor's Degree	38 (58.5)	7 (33.3)	8 (61.5)	7 (63.6)	9 (75.0)	7 (87.5)
Master's Degree	9 (13.8)	1 (4.8)	5 (38.5)	0 (0)	2 (16.7)	1 (12.5)
ICU certification, yes n (%)	47 (72.3)	17 (81.0)	6 (46.2)	8 (72.7)	8 (66.7)	8 (100)
Years of work experience mean (SD)	16.68 (12.47)	20.19 (13.29)	9.08 (5.24)	17.64 (9.32)	11.88 (12.64)	25.75 (14.69)
Years of work experience in current ICU mean (SD)	10.08(9.59)	13.26 (10.76)	6.73 (5.86)	7.73 (5.50)	8.92 (12.56)	12.19 (9.60)
Training in family engagement, yes n (%)	13 (20.0)	0 (0)	4 (30.8)	4 (36.4)	3 (25.0)	2 (25.0)
ICU policy on family engagement, yes n (%)	20 (31.3)	6 (28.6)	7 (58.3)	1 (9.1)	6 (50.0)	0 (0)
Type of ICU n (%) (n = 60)						
General	39 (60.0)	7 (33.3)	13 (100)	5 (45.5)	6 (50.0)	8 (100)
Surgical	13 (20.0)	6 (28.6)	0 (0)	4 (36.4)	3 (25.0)	0 (0)
Medical	5 (7.7)	2 (9.5)	0 (0)	2 (18.2)	1 (8.3)	0 (0)
Other (i.e. burns, trauma, neuro)	8 (12.3)	6 (28.6)	0 (0)	0 (0)	2 (16.7)	0 (0)

"In ICU I think we're a bit scared to let patients, or relatives do too much because I think we're scared they might touch something by accident or pull something out." (England)

Some nurses shared specific situations where they were fearful of family member's actions posing a risk (2b). Nurses also described situations where they viewed families as initiating a negative interaction (2c). Such adverse perceptions of family then strained interactions between nurse and family, and often led to nurse disengagement from the family. When families expressed what they needed or wanted nurses to do, some nurses felt disempowered, and engagement was impeded. One nurse explained:

"What is difficult for me is when family members approach me and basically tell me what they want. And how they want us to do it. Well, that evokes resistance." (Switzerland)

Perceived threats to the nurses' authority and power were therefore challenging for nurses to handle (2d). Shared relational power and negotiation of engagement required nurses' careful consideration of the individual family members, as a nurse stated

"I think I take a lot of cues from them, some people are very, you know you can usually get a feel for it... what people are prepared for." (Australia)

Family health literacy influenced the amount of mutual negotiation that occurred between nurses and families. Although not always acted upon, nurses had opportunities to actively involve a family to empower their decision-making (2e). In contrast, in some situations, shared decision-making was difficult to accomplish:

"In critical situations, families do not want to make [the] decision. They ask for nurse's opinion, or even ask nurses to make [the] decision for them." (Hong Kong)

These challenges can also be directly related to cultural considerations:

"A lot of women do not feel empowered to speak out... It is usually the male who speaks on their behalf." (Saudi Arabia)

Moreover, family internal relations may also cause difficulty in collaborating with families, particularly when a family has fractured relationships (2f).

Theme 2: Fluctuations of nurse practices

Engagement with families was characterized by constant fluctuations in nurses' practices, vacillating from day-to-day, shift-to-shift and nurse to nurse. Variations in engagement practices were influenced by the individual nurse's attitudes, beliefs, fears and insights. Family engagement was an inconsistent nursing practice that lacked anchorage in a shared culture around caring for families.

Variations in nurse attributes and practices: Variations of family engagement were evident with some nurses being comfortable with families while others avoided and limited their interaction. A participant noted:

"You can divide the nurses into those that think about family and those that don't". (US, Site 1)

Variations occurred due to differences in attitudes, knowledge, confidence, and skills (Table 3, quote 3a). Prior experiences often shaped nurses' perceptions of a family (3b). Family engagement was further influenced by a nurse's insight into the family's situation. If nurses understood the family experience with critical illness, they were able to identify direction for engaging the family.

"It depends on case by case and how people are handling it. Some families are super emotional and crying and really upset at the bedside so I try to get them more engaged just by talking, showing them certain things, and talking them through things to make them more comfortable which might help them calm down a little bit". (US, Site 3)

Confidence emerged as a key factor (3c). Nurse skills in family engagement practices developed through experience rather than training:

"Obviously some of that [engaging with families] goes with experience... I also think some juniors probably wouldn't do that as quick compared to the most senior nurses who know from experience." (England)

Variations in interpretations of policies related to families also influenced engagement. While some nurses were flexible in their approach, others described a rule-based perspective to practice with families:

"I am very open with visiting hours (...) but I know from colleagues who simply say "No, visitation starts at 3 pm". Who really send people away because it is not three o'clock". (Austria)

Table 3
Thematic findings with selected quotes.

Themes	Categories	Quotes
Ebb and flow of relational power	Information-sharing and communicating with family	1a) We phone only when there's a change in condition and only when there is information that we need, like previous history (South Africa). 1b) If they [family] don't understand what I am trying to say then I obviously call on of my colleagues who can interpret and then we get the message across" (South Africa). 1c) You just kind of have to realize that maybe the family just feels like they're not in control of the situation, but that sometimes makes it hard (US, Site 3). 1d) I think communication and like having that rapport, I think it's important to keep them informed and to have like this transparency and sort of communication and dialogue with them about what's going on, you know not like you're keeping secrets from them about what the prognosis is. I think you know to be open on this with them that's important (Australia).
	Negotiating and collaborating with family	2a) If you have been working with the family for a couple of weeks...you know them a little bit and they trust you and know you know what you are doing (US, Site 3). 2b) I had a family member who wanted to feed the patient water even though the patient had an endotracheal tube (Saudi Arabia). 2c) Sometimes the relatives will come and not ask you anything, they won't greet or introduce themselves. Then they will just open the chart... If you try to tell them not to open the chart they will just give you a hard time. They will just be angry and react negatively (South Africa). 2d) It's hard because I take that a little personally. I think I've had to develop thick skin (US, Site 3). 2e) When people understand what's going on with their loved one, they can make more informed decisions... I think that as providers and as nurses we make a lot of assumptions that people understand things and when you actually get to talk to them, they really don't (US, Site 2). 2f) The family dynamics that they've got themselves I think sometimes can be really difficult. We've had a few situations where the dynamics of the family have just been so prevalent that it's nigh on impossible to get everyone in one room to try (England).
Fluctuations of nurse practices	Variations in nurse attributes and practices	3a) Some of us are good at what we do, like liaising with the family and answering questions...Some of us won't go to the family at all (South Africa). 3b) Your personal attitude is definitely a major factor together with how open a person you are. If my inner voice tells me: "Oh no, not them again, not now, I still have so much I need to do". You can be sure they sense that somehow, even if you think you don't show them. They do sense if they are welcome or not (Switzerland). 3c) A nurse should have a bit more confidence at the bedside to engage families because then I think they are not worried so much about somebody judging them (Australia). 3d) I would encourage someone to do something and then the next nurse would come on and they are not into that at all and that really annoys me immensely and so I think it's those sorts of things, even to the fact of like visiting, some people want two at a bed and that's it. Me, I don't care if the whole whanau's [extended family] there (New Zealand). 3e) When they approach me and ask me: 'What can I do, I feel so helpless to just sit by the bedside'. Then it's helpful for all if you tell them: 'Here's a lotion, try to rub his feet'. Simple things like that (Switzerland). 3f) And often, just about being present and listening, that helps them a lot, the families, but also the patient. In situations of loss, nurses often provided support (Switzerland). 3g) The family had been crying and could not accept that he was dead. But after crying together, I told family "Please touch him, hold hands..." I think this time is last time family can touch him...When family got a handshake with him, family cried again, but they told me "Thank you so much" when they left (Japan).
	Patient- and family-related variances	4a) People that had a sudden unexpected admission, whether it was trauma or an expected surgery I feel like they have a lot more patient family presence (US, Site 2). 4b) It's really hard to predict when the patient may die... sometime overnight. We tell the family that you may try to see whether one or two people would like to stay overnight in the family sitting room (Hong Kong).
Shaped by the ICU context	ICU culture and team collaboration	5a) We [nursing staff] facilitated them [family] taking this patient to the healing garden, giving popsicles to his daughters. Like things went really beautifully...It was the night before he passed away...the nurse told the patient's wife 'get in bed with him' and they watched a movie together. We [nursing staff] went to the funeral (US, Site 2). 5b) Sometimes different patient teams want to see the family. You can't help what they're going to say. This team may say about this and the other about that. It's then necessary to tell team B what team A has said (Hong Kong).
	ICU structures and resources	6a) That is why we have visiting hours because otherwise, we can't ensure the privacy of fellow patients (Switzerland). 6b) There are families in Saudi Arabia, who are really close and some of the policies here allow the families to be present even whilst we are administering care (Saudi Arabia). 6c) We do have a policy where it is only two relatives at the bed space and that is because of all the machinery and if anything was to happen we'd need to be able to get into the bed space easily (England). 6d) I am relieved that we have this policy, fixed visiting hours (Switzerland). 6e) An attending [charge] nurse... I think they're always thinking about the family, who's been in contact with the family? Who can meet, like what's appropriate for reaching out to the family? And what the patient wants when it comes to family... Having somebody who's exclusively kind of thinking about that for each patient (US, Site 2). 6f) I couldn't offer it [a place to stay] to them [family members]. So that was a bit difficult because I didn't really know what to suggest other than maybe staying at a Travelodge (England).

Such randomness was evident as one participant stated

"It varies a lot, depending on who is on the shift. You have the freedom to determine the extent of involvement depending on what fits, you and how family members are perceived. It depends on me, on how I feel that particular day." (Switzerland)

Randomness in practices led to inconsistencies in family care, When some nurses are not supportive of family involvement in care, it becomes difficult to practice family engagement (3d).

Despite the variations in nurse attributes and randomness of engagement practices, nurses described several different nursing

actions used to proactively engage families in the ICU. Early interactions with families were seen as important:

"We start with making a rapport . . . we explain things at the bedside and if they wanted to have a chat, we take them outside into the room and talk through what they wanted and their wishes." (England)

During their care of the patients some nurses described inviting family members to participate directly in care (3e). Such simple actions could comfort families. The importance of knowing how to display concern for the family during critical illness was frequently highlighted, particularly the behaviors of listening and being present (3f, g).

Patient- and family-related variances: A patient's condition and nurses' perception of the family also contributed to changeability in family engagement practices. Nurses shared strong thoughts about care of the patient being their focus in the critical care setting. A nurse stated

"They [family] should not be allowed to stay all the time as they can affect the care." (Saudi Arabia)

The unstable or changing condition of the patient created unsettling feelings for the nurse and obstacles to engaging the family:

"It so challenging because in the hospital setting you want to be there emotionally, and obviously physically for the patient's family members because of what they are going through. But it's also really difficult if the patient's not doing well and you first off have to take care of the patient." (US, Site 3)

Circumstances surrounding the hospitalization affect family presence and need for nurse engagement (4a). Particular patient-family situations, such as end-of-life care prompted a shift in the nursing care, and was a significant time for engagement with families (4b). Nurses also noted the impact of the family's coping and emotion on their perception of the family and engagement:

"In the acute period when everything is still really new, emotions are higher, routine is unknown. . . that stress is there. The anxiety is contagious. And so when family is really tense, you have to really check in to yourself as a nurse, to try not to absorb that and portray stress. It takes extra effort to do that." (US, Site 1)

Theme 3: Shaped by the ICU context

We found in the data that engagement between the nurse and family is shaped by the ICU context; a dynamic interaction between the team culture and collaborative relationships and ICU structures and resources. The ICU context affects nurses' ability to successfully engage with families; systems-based factors can promote family engagement or create barriers.

ICU culture and team collaboration: ICU family culture, the overall unit response to family involvement in care, arose as essential in enabling or limiting family engagement practices. Many nurses told powerful stories of how the unit worked together to promote family engagement and this was particularly true for end-of-life experiences (Table 3, quote 5a). However, nurses also expressed concerns that the culture of the unit was not conducive to family engagement:

"We don't really have a culture [for family engagement]. . . We are a bunch of very different people. Most are open [towards family]. . . . but many persist on strict rules." (Switzerland)

Team collaboration – healthcare professionals working together delivering family care – further drives family engagement and is more successful when nurses have support from nursing colleagues and interprofessional team members. A nurse shared:

"I think there's a lot of mutual respect and the nurses are certainly always involved, say if the doctors are going to have a chat to the family they would usually always come and find the nurse at the bedside and ask them do you want to come? Very much collaborative as a team when it comes to family." (Australia)

In contrast, there are times when nurses need to facilitate the collaboration with the team, particularly when multiple specialists are involved (5b).

ICU structures and resources: We found that ICU structures and resources influence the practice of engagement and may influence the overall culture of ICU family engagement. Limited family access and inadequate space for families in the ICU can affect invitations for family members to stay overnight at the bedside or remain present in the patient's room (6a). For example:

It's just the set-up of the ICU. . . they have to buzz in, they have to sit and wait. . . their involvement is certainly going to be interrupted." (US, Site 2)

ICU resources included nursing time to engage families, family presence, guidelines and policies to support family engagement and access to consultants who can provide additional support. Ensuring adequate time for nurses to engage with families depended on staffing. A nurse explained:

"Often you do succeed in taking time to listen to families, to involve them. However, if the unit is short staffed or very busy, opportunities for family engagement are limited." (South Africa)

In addition to overall staffing, the nurse's individual responsibilities may affect perception of whether s/he has the time to spend with the family.

Guidelines and policies promoted family engagement for some (6b). However, many policies defined limits for family visitation rather than serving as a guide for family engagement (6c). Some nurses appreciated policies to provide guidance (6d), but policies could also create conflicts for nurses:

"We're caught also in the middle between the patient, their unique needs, family wishes, and the policies of the institution of this hospital." (US, Site 3)

The accessibility of other hospital resources for families also played a role in engagement. Nurses with access to other professionals who can assist the family may be better able to engage with families (6e). In contrast, when resources were not readily available for families, nurses experienced frustration (6f).

Discussion

This multi-site study with ICU nurses from five continents found that nurse-family engagement in ICU is marked by a shifting, yet often unequal power distribution in the nurse-family relationship. A high changeability in nurses' engagement practices occurred based on individual nurses' attributes, insights, and skills, resulting in inconsistent family engagement practices. The context of ICU care, including culture, physical layout, policies or available staff and resources amplified fluctuations of family care, either encouraging or disabling nurses in working collaboratively and supportively with families. Our findings provide an in-depth understanding of the way nurses engage families in ICU, contributing a detailed description from different contexts that complements research regarding best practice recommendations and enabling and limiting factors to family engagement (Hamilton et al., 2020, Hetland et al., 2017, Hetland et al., 2018, Kleinpell et al., 2018).

To our knowledge, this is the first study to use a qualitative approach to obtain a rich, comprehensive, global description of

critical care nurses' perceptions and practices of family engagement in ICU across various cultures and health systems. Although cultural variances existed, the practice of and challenges associated with including and partnering with families in ICU were universally shared. Our study extends the findings of prior literature and highlights the importance of addressing overall ICU family engagement, including the relational, cultural and structural context in future research and improvement efforts (Hamilton et al., 2020, Hetland et al., 2017, Hetland et al., 2018, Kiwanuka et al., 2019, van Mol et al., 2017, Scott et al., 2019, Østergaard et al., 2020).

A key finding of our study is that engagement practices are embedded within nurse-family relational interactions, with the location of power circulating between those engaged. Participants described acting from a position of power, which was constituted by knowledge, expertise, attitudes, perceived decision-making authority and a gatekeeping role (Baptista et al., 2017, Mattar et al., 2020, O'Shea et al., 2019). The nurses regulated access to critically ill patients, took control of the physical body, and filtered or restricted access to further knowledge (Collyer et al., 2017, Jolanki and Tynkkynen, 2018). Families in the ICU have indeed identified issues such as inadequate updates on patient progress from the healthcare team, feeling excluded from decision-making, lacking a person to "go to", with nurses and physicians sometimes identified as being "rude" and using "power over", not making eye contact or speaking over the patient (Hansen et al., 2016). However, at times it was the family who held the power through knowledge, thus necessitating information-sharing for the benefit of both the nurse and family (de Beer and Brysiewicz, 2017).

Family engagement also seemed to depend on the patient condition and family dynamics, with nurses making decisions to engage or disengage families based on their appraisal of family need, behavior and patient acuity. Nurses shared challenging family care situations that made communication impossible. Communicating with families has been described as challenging due to cultural backgrounds and an inability to access appropriate interpreters in the case of language difficulties (Listerfelt et al., 2019, Van Keer et al., 2020, Zurca et al., 2017). Nonetheless, many of the nurses in our study acknowledged their role in meeting families' needs, including offering insight, facilitating understanding, and effectively communicating the difficult realities of healthcare for families. They provided family interventions reflecting supportive engagement practices, such as listening to families' concerns, offering advice, or enabling presence and family caregiving tasks, which have been found to increase family well-being (Khalaila, 2014, Skoog et al., 2016).

Our study highlights the immense fluctuations in nurse-family engagement practices occurring in ICU (Hamilton et al., 2020, Kleinpell et al., 2019). Engagement was fraught with randomness and a high changeability in nurses' caring practices. Some nurses were more comfortable to yield power, engage families as partners, communicate openly and offer support, whereas others felt disempowered when families expressed their preferences for involvement in care and decision-making, avoiding or limiting interaction with families using the power they held, which invited conflict and discord rather than a relational connection (Segaric and Hall, 2015). As a consequence, nurses struggled to manage what they experienced as expectations of families (Van Keer et al., 2020, Akroute and Bondas, 2016, Schubart et al., 2015), increasing their sense of burden when interacting with families (Segaric and Hall, 2015). We found that engagement practices were a result of individual experiential learning, rather than one of professional knowledge around the implications of critical illness for family health and well-being. This is supported by a study in which

older nurses with more critical care experience (more than 15 years), and those with advanced degrees viewed family engagement more favourably than younger nurses with less experience (Hetland et al., 2017). Our findings suggest that ICU settings must provide the opportunity for nurses to learn about family experience of critical illness, practice communicating with families, address attitudes such as 'unconscious bias' and develop negotiation skills to share power. An ICU culture that promotes reflection, mutual learning and collaboration may help overcome the difficulties of and variances in family care. Nursing leaders and interprofessional team members must ensure nurses can discuss concerns in an open manner to gain support, reassurance, and to develop a common set of family interventions in a collaborative way.

Our findings highlight the importance of the ICU culture that undergirds the depth and breadth of family engagement. We found a dynamic relationship among team culture, ICU structure, and available organizational resources for family care, which is similar to other recent investigations into the structural and cultural factors influential to ICU family engagement (Hamilton et al., 2020; Hetland et al., 2017, 2018; Kiwanuka et al., 2019; Kleinpell et al., 2019; Olding et al., 2016; Schubart et al., 2015). The interprofessional team's perspective and approach to families in the ICU plays a role in nurse-family engagement (Hamilton et al., 2020, Kiwanuka et al., 2019, Kleinpell et al., 2019). Indeed, interprofessional care has become a priority area for improvement in the ICU (Donovan et al., 2018), and our findings support the supposition that interprofessional teamwork is foundational to the creation of a sustained milieu of family engagement in the ICU practice setting. In our study, ICU clinicians who worked collaboratively had many positive family engagement stories to tell. However, overall we found a lack of a consistent and collective team approach to family engagement in the ICU.

Nurses in the current study described many situations in which ICU resources and structures directly enabled or limited family engagement practices suggesting that organizational and unit-based policies are directed at limiting the role of families in ICU, used to justify exclusion rather than promoting inclusion of families, posing barriers to the family's access. A recent systematic review of barriers to family-centered care cites organizational factors such as unhealthy work environments, high nurse to patient ratios, poor ICU design, lack of role models for family care, and a lack of policies and guidelines as major hindrances to high quality family care (Kiwanuka et al., 2019), which was also found in our study. Inadequate staffing and increased workload have also been found to negatively affect engagement practices (Hetland et al., 2017, Hetland et al., 2018). Despite decades of research that point to the importance of families' close proximity to patients (Leon and Knapp, 2008; Leske, 1986, 1991; Mitchell et al., 2019), many families remain limited in their access and involvement in the care of their family member in ICU (Scott et al., 2019; van Mol et al., 2017). ICU design and supportive family engagement guidelines are important elements to target in a collective effort to change the culture and practice of engagement with families (Mitchell et al., 2016). Policies and guidelines should be developed in accordance with current evidence and with the goal of "thinking family" (Davidson et al., 2017), and then translated into real life practice, using novel approaches to implementation (Beierwaltes et al., 2020). ICU environments should be designed in a way that invite family to be present; including adequate space for families to wait, meet with clinicians, and to be with their family member. More research could be undertaken to see if specific roles or support structures improve family perceptions of inclusion and their satisfaction with ICU care (Naef et al., 2020; Naef et al., 2021).

Study limitations

The international nature of the study means that there were numerous researchers contributing to the study. Hence, the interview process could have varied, although this was mitigated by a semi-structured approach. The sample was purposeful, yet the small number of staff who participated in each site may have been nurses with a particular interest in family care, which may have influenced the findings. The interviews captured rich data but were recorded and transcribed in the four different languages, and selected quotations were translated into English. It is possible that some of the meaning may have been influenced during this process since findings were not reviewed with participants. However, the multi-site consistency, and presentation of diverse cases through the study results, demonstrates rich sources of data to confirm findings.

Conclusions

From a global perspective, family engagement is a complex relational and fluctuating process that holds many similarities and few differences across contexts. Important facilitators of family engagement include nurse openness to and skills in family care, support from fellow colleagues in the delivery of family care, and resources such as guidelines and policies that support family care. Future efforts to improve family engagement should focus on educational preparation for ICU family engagement, ways to promote a shared understanding and practice of family engagement among nursing and interprofessional teams, and purposeful structural support for family engagement with adequate resources and formalized guidelines and policies of inclusion rather than exclusion.

Funding source

This work was supported by the Froedtert Foundation and the Glen Taylor Nursing Institute for Family and Society (USA), the British Association of Critical Care Nurses (BACCN) in the UK, and the JSPS KAKENHI Grant Number JP19K19643 (Grant-in-Aid for Young Scientists) in Japan.

Ethical statement

Institutional Review Boards provided approval for the research at each individual study site where required by national law (see supplementary file for list of approvals).

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgments

We would like to thank all the ICU nurses who participated in this study, and clinical staff who assisted the recruitment. We also would like to acknowledge the International Family Nursing Association, which supported the researchers to connect and form a Family Care in Acute/Critical Illness Cluster, which conducted the here reported study.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.iccn.2021.103081>.

References

- Akroute, A.R., Bondas, T., 2016. Critical care nurses and relatives of elderly patients in intensive care unit-Ambivalent interaction. *Intensive Crit. Care Nurs.* 34, 59–72.
- Alsharari, A.F., 2019. The needs of family members of patients admitted to the intensive care unit. *Patient Pref. Adherence* 13, 465–473.
- Baptista, M.K.S., R.M., Duarte, S.J., Comassetto, I., Trezza, M.C., 2017. The patient and the relation between power-knowledge and care by nursing professionals. *Escola Anna Nery*, 21.
- Beierwaltes, P., Clisbee, D., Eggenberger, S.K., 2020. An educational intervention incorporating digital storytelling to implement family nursing practice in acute care settings. *J. Fam. Nurs.* 26, 213–228.
- Benzies, K.M., Shah, V., Aziz, K., Lodha, A., Misfeldt, R., 2019. The health care system is making 'too much noise' to provide family-centred care in neonatal intensive care units: Perspectives of health care providers and hospital administrators. *Intensive Crit. Care Nurs.* 50, 44–53.
- Bridges, E., McNeill, M.M., Munro, N., 2017. Research in review: advancing critical care practice. *Am. J. Crit. Care* 26, 77–88.
- Brown, S.M., Rozenblum, R., Aboumatar, H., Fagan, M.B., Milic, M., Lee, B.S., Turner, K., Frosch, D.L., 2015. Defining patient and family engagement in the intensive care unit. *Am. J. Respir. Crit. Care Med.* 191, 358–360.
- Burns, K.E.A., Misak, C., Herridge, M., Meade, M.O., Oczkowski, S., 2018. Patient and family engagement in the ICU. Untapped opportunities and underrecognized challenges. *Am. J. Respir. Crit. Care Med.* 198, 310–319.
- Carman, K.L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., Sweeney, J., 2013. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff (Millwood)* 32, 223–231.
- Chapman, D.K., Collingridge, D.S., Mitchell, L.A., Wright, E.S., Hopkins, R.O., Butler, J.M., Brown, S.M., 2016. Satisfaction with elimination of all visitation restrictions in a mixed-profile intensive care unit. *Am. J. Crit. Care* 25, 46–50.
- Coats, H., Bourget, E., Starks, H., Lindhorst, T., Saiki-Craighill, S., Curtis, J.R., Hays, R., Doorenbos, A., 2018. Nurses' reflections on benefits and challenges of implementing family-centered care in pediatric intensive care units. *Am. J. Crit. Care* 27, 52–58.
- Collyer, F.M., Willis, K.F., Lewis, S., 2017. Gatekeepers in the healthcare sector: Knowledge and Bourdieu's concept of field. *Soc. Sci. Med.* 186, 96–103.
- Davidson, J.E., Aslakson, R.A., Long, A.C., Puntillo, K.A., Kross, E.K., Hart, J., Cox, C.E., Wunsch, H., Wickline, M.A., Nunnally, M.E., Netzer, G., Kentish-Barnes, N., Sprung, C.L., Hartog, C.S., Coombs, M., Gerritsen, R.T., Hopkins, R.O., Franck, L.S., Skrobik, Y., Kon, A.A., Scruth, E.A., Harvey, M.A., Lewis-Newby, M., White, D.B., Swoboda, S.M., Cooke, C.R., Levy, M.M., Azoulay, E., Curtis, J.R., 2017. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. *Crit. Care Med.* 45, 103–128.
- Davidson, J.E., Jones, C., Bienvenu, O.J., 2012. Family response to critical illness: postintensive care syndrome-family. *Crit. Care Med.* 40, 618–624.
- de Beer, J., Brysiewicz, P., 2017. The experiences of family members during critical illness of a loved one admitted to an intensive care unit. *Africa J. Nurs. Midwif.* 19, 56–68.
- Donovan, A.L., Aldrich, J.M., Gross, K., Barchas, D.M., Thornton, K.C., Schell-Chaple, H. M., Gropper, M.A., Lipshutz, A.K.M., et al., 2018. Interprofessional care and teamwork in the ICU. *Critical Care Medicine* 46 (6), 980–990.
- Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utraiainen, K., Kynäs, H., 2014. Qualitative Content Analysis. A Focus on Trustworthiness. *Sage Open*, January 2014.
- Erlingsson, C., Brysiewicz, P., 2017. A hands-on guide to doing content analysis. *African J. Emergency Med.* 7, 93–99.
- Eustace, R.W., Gray, B., Curry, D.M., 2015. The meaning of family nursing intervention: what do acute care nurses think? *Res. Theory Nurs. Pract.* 29, 125–142.
- Fusch, P.I., Ness, L.R., 2015. Are we there yet? Data saturation in qualitative research. *Qualitative Rep.* 20, 1408–1416.
- Gaeni, M., Farahani, M.A., Seyedfatemi, N., Mohammadi, N., 2014. Informational support to family members of intensive care unit patients: the perspectives of families and nurses. *Glob. J. Health Sci.* 7, 8–19.
- Graneheim, U.H., Lindgren, B.M., Lundman, B., 2017. Methodological challenges in qualitative content analysis: a discussion paper. *Nurse Educ. Today* 56, 29–34.
- Graneheim, U.H., Lundman, B., 2004. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ. Today* 24, 105–112.
- Hamilton, R., Kleinpell, R., Lipman, J., Davidson, J.E., 2020. International facilitators and barriers to family engagement in the ICU: Results of a qualitative analysis. *J. Crit. Care* 58, 72–77.
- Hansen, L., Rosenkranz, S.J., Mularski, R.A., Leo, M.C., 2016. Family perspectives on overall care in the intensive care unit. *Nurs. Res.* 65, 446–454.
- Hetland, B., Hickman, R., McAndrew, N., Daly, B., 2017. Factors influencing active family engagement in care among critical care nurses. *AACN Adv. Crit. Care* 28, 160–170.
- Hetland, B., McAndrew, N., Perazzo, J., Hickman, R., 2018. A qualitative study of factors that influence active family involvement with patient care in the ICU: Survey of critical care nurses. *Intensive Crit. Care Nurs.* 44, 67–75.

- Jolanki, O., Tynkkynen, L.-K., 2018. Primary health care nurses' views on patients' abilities and resources to make choices and take decisions on health care. *Health Policy* 122 (9), 957–962.
- Khalaila, R., 2014. Meeting the needs of patients' families in intensive care units. *Nurs. Stand* 28, 37–44.
- Kiwanuka, F., Shayan, S.J., Tolulope, A.A., 2019. Barriers to patient and family-centred care in adult intensive care units: a systematic review. *Nursing Open* 6, 676–684.
- Kleinpell, R., Heyland, D.K., Lipman, J., Sprung, C.L., Levy, M., Mer, M., Koh, Y., Davidson, J., Taha, A., Curtis, J.R., 2018. Patient and family engagement in the ICU: Report from the task force of the World Federation of Societies of Intensive and Critical Care Medicine. *J. Crit. Care* 48, 251–256.
- Kleinpell, R., Zimmerman, J., Vermoch, K.L., Harmon, L.A., Vondracek, H., Hamilton, R., Hanson, B., Hwang, D.Y., 2019. Promoting family engagement in the ICU: experience from a national collaborative of 63 ICUs. *Crit. Care Med.* 47, 1692–1698.
- Knutsson, S., Enskär, K., Golsäter, M., 2017. Nurses' experiences of what constitutes the encounter with children visiting a sick parent at an adult ICU. *Intensive Crit. Care Nurs.* 39, 9–17.
- Leon, A.M., Knapp, S., 2008. Involving family systems in critical care nursing: Challenges and opportunities. *Dimensions of Critical Care Nursing* 27 (6), 255–262.
- Leske, J.S., 1986. Needs of relatives of critically ill patients: A follow-up. *Heart & Lung: The Journal of Critical Care* 15 (2), 189–193.
- Leske, J.S., 1991. Internal psychometric properties of the Critical Care Family Needs Inventory. *Heart & Lung: The Journal of Critical Care*, 20 (3), 236–244.
- Leung, D., Blastorah, M., Nusdorfer, L., Jeffs, A., Jung, J., Howell, D., Fillion, L., Rose, L., 2017. Nursing patients with chronic critical illness and their families: a qualitative study. *Nurs Crit Care* 22, 229–237.
- Listerfelt, S., Fridh, I., Lindahl, B., 2019. Facing the unfamiliar: Nurses' transcultural care in intensive care – a focus group study. *Intensive Crit. Care Nurs.* 55, 102752.
- Mattar, E.S.T.W., Velloso, I.S.C., Araújo, M.T., Fernandes, A., 2020. Configuration of power relations in physicians and nurses' professional practices. *Rev. Bras. Enferm* 73, (Suppl 1) e20180629.
- McAndrew, N.S., Schiffman, R., Leske, J., 2019. Relationships among climate of care, nursing family care and family well-being in ICUs. *Nurs Ethics* 26, 2494–2510.
- McAndrew, N.S., Schiffman, R., Leske, J., 2020. A theoretical lens through which to view the facilitators and disruptors of nurse-promoted engagement with families in the ICU. *J. Fam. Nurs.* 26 (3), 190–212.
- Mitchell, M.L., Coyer, F., Kean, S., Stone, R., Murfield, J., Dwan, T., 2016. Patient, family-centred care interventions within the adult ICU setting: an integrative review. *Australian Critical Care* 29, 179–193.
- Mitchell, M.L., Dwan, T., Takashima, M., Beard, K., Birgan, S., Wetzig, K., Tonge, A., 2019. The needs of families of trauma intensive care patients: A mixed methods study. *Intensive and Critical Care Nursing* 50, 11–20.
- Mitchell, M.L., Gill, F., Greal, B., McCutcheon, C., Greenwood, M., Tramm, R., 2015. Partnering with Families in Critical Care. ACCCN Australian College of Critical Care Nurses.
- Naef, R., Massarotto, P., Petry, H., 2020. Family and health professional experience with a nurse-led family support intervention in ICU: a qualitative evaluation study. *Intensive Crit. Care Nurs.* 61, 102916.
- Naef, R., von Felten, S., Petry, H., Ernst, J., Massarotto, P., 2021. Impact of a nurse-led family support intervention on family members' satisfaction with intensive care and psychological wellbeing: A mixed-methods evaluation. *Austral. Critical Care*. <https://doi.org/10.1016/j.aucc.2020.10.014>.
- Nelms, T.P., Eggenberger, S.K., 2010. The essence of the family critical illness experience and nurse-family meetings. *J. Fam. Nurs.* 16, 462–486.
- Nolen, K.B., Warren, N.A., 2014. Meeting the needs of family members of ICU patients. *Crit Care Nurs Q* 37, 393–406.
- Olding, M., McMillan, S.E., Reeves, S., Schmitt, M.H., Puntillo, K., Kitto, S., et al., 2016. Patient and family involvement in adult critical and intensive care settings: a scoping review. *Health Expectations* 19 (6), 1183–1202.
- O'Shea, A., Boaz, A.L., Chambers, M., 2019. A hierarchy of power: the place of patient and public involvement in healthcare service development. *Front. Sociol.* 4.
- Østergaard, B., Clausen, A. M., Agerskov, H., Brødsgaard, A., Dieperink, K. B., Funderskov, K. F., Nielsen, D., Sorknaes, A. D., Voltelen, B., Konradsen, H., 2020. Nurses' attitudes regarding the importance of families in nursing care: A cross-sectional study. *J Clin Nurs*, 29, 1290–1301.
- Patton, M. Q. 2015. Sampling, Qualitative (Purposeful). *The Blackwell Encyclopedia of Sociology*.
- Riley, B.H., White, J., Graham, S., Alexandrov, A., 2014. Traditional/restrictive vs patient-centered intensive care unit visitation: perceptions of patients' family members, physicians, and nurses. *Am. J. Crit. Care* 23 (4), 316–324.
- Santiago, C., Lazar, L., Jiang, D., Burns, K.E., 2014. A survey of the attitudes and perceptions of multidisciplinary team members towards family presence at bedside rounds in the intensive care unit. *Intensive Crit. Care Nurs.* 30, 13–21.
- Schubart, J.R., Wojnar, M., Dillard, J.P., Meczkowski, E., Kanaskie, M.L., Blackall, G.F., Sperry, N., Lloyd, T., 2015. ICU family communication and health care professionals: a qualitative analysis of perspectives. *Intensive Crit. Care Nurs.* 31, 315–321.
- Scott, P., Thomson, P., Shepherd, A., 2019. Families of patients in ICU: a Scoping review of their needs and satisfaction with care. *Nursing Open* 6, 698–712.
- Segaric, C.A., Hall, W.A., 2015. Progressively engaging: constructing nurse, patient, and family relationships in acute care settings. *J. Fam. Nurs.* 21, 35–56.
- Skoog, M., Milner, K.A., Gatti-Petito, J., Dintyala, K., 2016. The impact of family engagement on anxiety levels in a cardiothoracic intensive care unit. *Crit Care Nurse* 36, 84–89.
- Svavarsdottir, E.K., Sigurdardottir, A.O., Konradsdottir, E., Stefansdottir, A., Sveinbjarnardottir, E.K., Ketilsdottir, A., Blondal, K., Jónsdóttir, A., Bergs, D., Guðmundsdottir, H., 2015. The process of translating family nursing knowledge into clinical practice. *J. Nurs. Scholarsh.* 47, 5–15.
- van Keer, R.L., Deschepper, R., Huyghens, L., Bilsen, J., 2020. Preventing conflicts between nurses and families of a multi-ethnic patient population during critical medical situations in a hospital. *J. Transcult. Nurs.* 31, 250–256.
- van Mol, M.M., Boeter, T.G., Verharen, L., Kompanje, E.J., Bakker, J., Nijkamp, M.D., 2017. Patient- and family-centred care in the intensive care unit: a challenge in the daily practice of healthcare professionals. *Journal of Clinical Nursing* 26, 3212–3223.
- Vandall-Walker, V., Clark, A.M., 2011. It starts with access! a grounded theory of family members working to get through critical illness. *J. Fam. Nurs.* 17, 148–181.
- Wetzig, K., Mitchell, M., 2017. The needs of families of ICU trauma patients: an integrative review. *Intensive Crit. Care Nurs.* 41, 63–70.
- Wong, P., Liamputtong, P., Koch, S., Rawson, H., 2015. Families' experiences of their interactions with staff in an Australian intensive care unit (ICU): a qualitative study. *Intensive Crit. Care Nurs.* 31, 51–63.
- Wong, P., Liamputtong, P., Koch, S., Rawson, H., 2017. Barriers to regaining control within a constructivist grounded theory of family resilience in ICU: Living with uncertainty. *J. Clin. Nurs.* 26 (23–24), 4390–4403.
- Zurca, A.D., Fisher, K.R., Flor, R.J., Gonzalez-Marques, C.D., Wang, J., Cheng, Y.I., October, T.W., 2017. Communication with limited English-proficient families in the PICU. *Hosp. Pediatr.* 7, 9–15.