

SYSTEMATIC REVIEW

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Impact of restricted family presence during the COVID-19 pandemic on critically ill patients, families, and critical care clinicians: a qualitative systematic review

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Abstract

Background We aimed to synthesize the qualitative evidence on the impacts of COVID-19-related restricted family presence policies from the perspective of patients, families, and healthcare professionals from neonatal (NICU), pediatric (PICU), or adult ICUs.

Methods We searched MEDLINE, EMBASE, Cochrane Databases of Reviews and Clinical Trials, CINAHL, Scopus, PsycINFO, and Web of Science. Two researchers independently reviewed titles/abstracts and full-text articles for inclusion. Thematic analysis was completed following appraising article quality and assessing confidence in the individual review findings using standardized tools.

Results We synthesized 54 findings from 184 studies, revealing the impacts of these policies in children and adults on: (1) Family integrated care and patient and family-centered care (e.g., disruption to breastfeeding/kangaroo care, dehumanizing of patients); (2) Patients, families, and healthcare professionals (e.g., negative mental health consequences, moral distress); (3) Support systems (e.g., loss of support from friends/families); and (4) Relationships (e.g., loss of essential bonding with infant, struggle to develop trust). Strategies to mitigate these impacts are reported.

Conclusion This review highlights the multifaceted impacts of restricted visitation policies across distinct care settings and strategies to mitigate the harmful effects of these policies and guide the creation of compassionate family presence policies in future health crises.

Registration https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=290263.

Keywords COVID-19, Intensive care unit, Visiting restrictions, Pandemic, Qualitative research, SARS-CoV-2, Critical care, Family centred care, Relatives

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Background

Restricted family presence policies enacted by hospitals to limit the spread of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) had unintended but damaging consequences for critically ill patients, families, and healthcare professionals. Though previously published studies demonstrate the negative psychosocial impacts of these policies, the full breadth of impacts on patients, families, and healthcare professionals are not fully understood. During the 2002–2004 SARS-CoV-1 epidemic, data demonstrating the negative impacts of visitation was generated [1–4] but not synthesized or widely disseminated, thus limiting the impact on informing policies during the SARS-CoV-2 pandemic. Overly restrictive visitation policies will continue to be enacted in future pandemics unless policy makers have access to a synthesis of the available evidence to best inform the balance between mitigating the risk of disease spread and the negative impacts to patients, families, and healthcare professionals.

Prior to the COVID-19 pandemic, family presence in the neonatal intensive care unit (NICU), pediatric intensive care unit (PICU), and adult intensive care unit (ICU) was increasingly encouraged in many hospitals through the implementation of open (i.e., 24-hr) visitation policies [5–9]. These visitation policies were supported by evidence-based models such as patient- and family-centered care (PFCC) [10], which focuses on the involvement of patients and families in health care, and family integrated care (FiCare) [11], which advocates for the integration of parents into the NICU care team. Family presence is an essential component of care for all ages. Families, often defined in policies as essential care partners or designated family/support persons, provide emotional, psychological, or physical support to a patient and are active partners in care. This support may reduce a patient's risk for developing delirium and has been demonstrated to moderate a patient's (and family's) symptoms of anxiety and stress during their ICU stay [12–18]. Additionally, family participation in ICU care has been shown to reduce the prevalence of post-intensive care syndrome, which affects both patients and their families with lasting cognitive, psychological, and physical impairments well after their ICU stay [19]. Family involvement in a patient's care and decision-making improves family and ICU care team interactions [20] and often helps families cope with their loved one being admitted to an ICU [21].

Families experience immediate stress and anxiety due to the uncertainty and unpredictability of health outcomes and survival when a loved one is admitted to the ICU. These feelings are further intensified by the uncertainty associated with leaving a suffering loved one behind during times of restricted family presence. Additionally, the number of family members and visitors

permitted at the bedside varied day-to-day as hospital leaders adjusted policies based on government directives. This disproportionately impacted those families who are used to experiencing illness as a collective or who rely on spiritual or religious practices. The absence of families in the ICU is therefore not a trivial matter and health outcomes of both patients and families are negatively impacted when we exclude families from the bedside [22–24, 23, 25–30]. Restricted family presence policies were especially detrimental to hospitalized children and newborns who have a greater dependence on families for emotional health and well-being [31, 32]. Absence of family at the bedside made it more challenging for the healthcare team to keep families informed of patient progress [33]. Consequently, families were less prepared to participate in shared decision-making, particularly when the patient's condition necessitated the re-evaluation of their goals of care [34].

The lived experiences of patients, families, and healthcare professionals should inform policy decisions, and is best captured using qualitative methods. To maximize the utility of these insights for policy decisions, a rigorous approach to synthesis of qualitative literature is essential. As such, we aimed to synthesize the available qualitative evidence reporting the impacts of restricted family presence policies during the COVID-19 pandemic, from the perspective of patients, families, and healthcare professionals from neonatal (NICU), pediatric (PICU), and adult ICUs. The secondary objective was to generate actionable policy recommendations for any situation which restricts family or caregiver presence (e.g., future infectious disease outbreaks, threatening situations, or mass casualty incidents), based on this evidence synthesis.

Methods

We registered the protocol for this review on PROSPERO prior to data extraction and analysis (https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=290263). We report the findings of this systematic review according to the items included in the PRISMA 2020 checklist [35] (See Supplementary Table 1, Additional File 1) and the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) statement (See Supplementary Table 2, Additional File 1) [36].

Inclusion criteria

Participants Patients and/or families (i.e., relatives, friends, or designated visitor) who were in an NICU/PICU/ICU during the COVID-19 pandemic, and/or healthcare professionals (including administrative personnel) who worked in an NICU/PICU/ICU during the COVID-19 pandemic.

Phenomena of interest Studies that presented the self-reported perceptions (e.g., perceptions on mitigation strategies, effectiveness of restricted family presence policies) and experiences (e.g., physical, psychosocial, financial, spiritual) of patients, families, and/or healthcare professionals with restricted family presence policies enacted during the COVID-19 pandemic.

Context All studies conducted in any NICU/PICU/ICU in any country in which the phenomena of interest (i.e., patient, family, and/or healthcare professional's perceptions of and/or experiences with restricted family presence policies during the COVID-19 pandemic) was explored.

Types of studies Any study that used qualitative methods for data collection (e.g., observation, interviews) and/or qualitative methods for data analysis (e.g., thematic/content analysis). We included English-language peer-reviewed journal articles and excluded conference abstracts, narrative reviews, editorials, and expert consensus documents. Inclusion/exclusion criteria are listed in Table 1.

Information sources

We searched MEDLINE, EMBASE, Cochrane Databases of Reviews and Clinical Trials, CINAHL, Scopus, PsycINFO, and Web of Science for studies published from December 2019 (documented beginning of SARS-CoV-2 cases) to May 17, 2023, using terms related to COVID-19, NICU/PICU/ICU, and hospital policy. We used an adaptation of a search strategy from a related study conducted by our research team [37, 38] (See Supplementary Table 3, Additional File 1) and screened reference lists of relevant papers to identify other potential studies.

Study records

Data management

We uploaded all identified citations into EndNote X9 (Clarivate Analytics, PA, USA) and removed duplicates using the strategy outlined by Bramer et al. [39]. Unique records were uploaded to Covidence systematic review software (www.covidence.org; Veritas Health Innovation, Melbourne, Australia) for title/abstract and full-text article review.

Selection process

Prior to title/abstract screening, 50 random records were selected to be reviewed by three researchers (KK with two research assistants trained in systematic review methods). All researchers discussed the discrepancies until 100% agreement was reached. No changes to the inclusion/exclusion criteria were made during this process as discrepancies were due to researcher errors (e.g., missing that the context was not an ICU, studies that include medical students). The same three researchers reviewed the remaining titles/abstracts independently and in duplicate for inclusion. We included any abstract identified by at least one researcher as potentially relevant for full-text review. The same researchers reviewed full-text articles independently and in duplicate for inclusion. We captured reasons for exclusion at full-text review. When there was disagreement regarding eligibility or the exclusion reason between reviewers, we used a third reviewer for blinded adjudication. We did not exclude studies based on the quality assessment.

Data items

We extracted the following information from each article: (1) Study characteristics (author, date of publication, location of study [continent/country], study design, date of study conduct, data collection methods, data analysis

Table 1 Inclusion and exclusion criteria

Variable	Inclusion criteria	Exclusion criteria
Language	English language	Not written in English
Types of studies	Any peer-reviewed, original study that used qualitative methods for data collection (e.g., observation, interviews) and/or qualitative methods for data analysis (e.g., thematic/content analysis).	Conference abstracts, commentaries, opinions, editorials, letters to the editor
Participants	Patients and/or families (i.e., relatives, friends, or designated visitor) who were in an NICU/PICU/ICU during the COVID-19 pandemic, and/or healthcare professionals (including administrative personnel) who worked in an NICU/PICU/ICU during the COVID-19 pandemic.	
Phenomena of interest	Discussed the self-reported perceptions (e.g., perceptions on mitigation strategies, effectiveness of restricted family presence policies), experiences (e.g., physical, psychosocial, financial, spiritual), and impacts of patients, families, and/or healthcare professionals with restricted family presence policies enacted during the COVID-19 pandemic.	Not related to self-reported perceptions of and experiences/impacts with restricted family presence policies during COVID-19 pandemic
Context	All studies conducted in any NICU/PICU/ICU in any country in which the phenomena of interest (i.e., patient, family, and/or healthcare professional's perceptions of and/or experiences with restricted family presence policies during the COVID-19 pandemic) was explored.	

techniques, theoretical approaches, sample size); (2) Population/setting information (inclusion/exclusion characteristics, hospital type, participant characteristics); (3) Results (themes, subthemes, quotations, and text labelled as “results” or “findings”). One researcher (KK) created a data extraction sheet in Microsoft Excel and a data dictionary (e.g., integer, number, text) for the study characteristics and population/setting data.

Data synthesis

Three researchers (KK with two research assistants trained in and with experience in systematic review methods) pilot tested the data extraction form and data dictionary using the same subset of studies ($n=10$). We compared extracted data and adapted the data extraction form and associated data dictionary as required to ensure consistency. We extracted data from the remaining articles, independently and in duplicate. We resolved disagreements in data extraction using discussion, and third-party adjudication, if required.

We entered the results (i.e., textual data) from included studies into NVivo-12 (QSR International, Melbourne, Australia) for data storage and analysis. These textual data from NICU, PICU, and ICU settings were analyzed separately to identify distinct themes for each group. Two researchers (from NICU: JSL, PICU: LL, or adult ICU: KK, ML, NJ, OD) conducted the thematic analysis using NVivo-12 and Thomas and Hardens’ three stage thematic synthesis approach to analyze the summary data (Table 2), which includes the following steps: (1) Line-by-line coding of the extracted textual data to develop a list of codes and concepts between studies; (2) Organizing the list of codes into related categories to develop a list of descriptive themes; and (3) Comparing categories with other categories, and merging related categories into higher level constructs and then analytical themes [40]. To ensure the analytical themes represented the data, researchers met to discuss the initial list of codes. Subsequent meetings focused on organizing the list of codes into themes, and lastly key findings.

Appraisal of study quality

We (KK, ML, OD, NJ) evaluated the quality of each included article using the 10-item Critical Appraisal Skills Program qualitative studies checklist (CASP) [41] independently and in duplicate. Disagreements were resolved by discussion and, if necessary, involvement of a third researcher. We assessed confidence in the findings using the GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research) approach to contextualize the findings of the review [42]. Initially, two researchers (JSL, LL, KK, ML, NJ, OD) assessed four components of CERQual based on our concerns (no or very minor concerns, minor concerns, moderate concerns, serious

concerns): (1) Methodological limitations (we evaluated the potential biases and weaknesses in design and execution, consistent with CASP criteria such as the appropriateness of the research design, recruitment strategies, and data collection methods of each study contributing to the key finding), (2) Relevance (we evaluated the extent to which the evidence from individual studies support a key finding based on the context (perspective or population, phenomenon of interest, setting) specified in the review question), (3) Coherence (evaluating the consistency and support of the key findings by examining the themes from each studies contributing to the key finding), and (4) Data adequacy (evaluating the richness and volume of data supporting each finding). After assessing the CERQual components, we consolidated all evaluations and determined our confidence level in each finding, categorizing it as either high, moderate, low, or very low.

Changes from the original protocol

The protocol was developed a priori and made available on PROSPERO prior to conducting data extraction and analysis. There are three changes from the original study protocol. Originally, we planned to summarize the experience of restricted family presence. However, while extracting data, we noticed that most studies described the outcomes and consequences of these policies. As a result, we revised the wording of the stated objective to better reflect the data. We also planned to do a separate sub-analysis for patients, families, and HCPs. However, we did not proceed with this plan because the available data was insufficient to support meaningful sub-analyses. Last, we originally specified we would use the Joanna Briggs Institute Critical Appraisal Checklist for Qualitative Research. We made the shift to CASP because it better aligned with the [methodological limitations](#) section of the GRADE-CERQual.

Results

Characteristics of included studies

From 17,886 unique citations, we included 184 studies (Fig. 1). These studies included NICU ($n=28/184$, 15.2%), PICU ($n=8/184$, 4.3%), or ICU ($n=144/184$, 78.3%) populations. Three studies ($n=3/184$, 1.6%) included a mixed age population and one ($n=1/184$, 0.5%) did not specify which population was included. The included studies described the experiences of patients ($n=225$, 16 studies), family members ($n=3,135$, 67 studies), or healthcare professionals ($n=7,335$, 124 studies). Included

studies represent six continents (Africa, Asia, Europe, North America, Oceania, South America), of which most studies were conducted in Europe ($n=82/184$, 44.6%) or North America ($n=65/184$, 35.3%). Most studies collected qualitative data via interviews ($n=124/184$, 67.4%)

Table 2 Qualitative data analysis process

Step	Description	Examples
Qualitative data collection	Gathering text from included studies (e.g., participant quotes, authors' interpretations)	Data excerpt: "There are several dimensions of 'not being able to be there' that affect the participants. Most profound is the fear that their loved ones will die alone: But what struck me most it was that I find it so awful to die alone[...] It was really the hardest thing for us. Not to be allowed to see her and that she does not get the feeling that we are there(P4). As expressed in this quote it is awful to think that one's loved one should die without the presence of family members:"
Free line-by-line coding	Reading the text of the included studies and coding the text line-by-line to generate initial codes that describe the content and meaning of each line of text. Each study was coded independently and in duplicate by two researchers. Researchers met regularly to discuss these codes.	Code from data excerpt: Fear of loved ones dying without the presence of family members
Developing descriptive themes	Grouping the initial codes into related areas to construct descriptive themes.	Grouped codes: Fear: Fear of loved ones dying without the presence of family members Anxiety: In the absence of family members, the anxiety, stress, and fear of own health are amplified. Worry: I could not see my family or even talk to them on the phone and this was worrying for me. Loneliness: I suffered from not having someone to chat with.
Generating analytical themes	Comparing categories with other categories, and merging related categories into higher level constructs (descriptive themes). Interpreting the descriptive themes to provide insights and explanation that address the research objectives (i.e., create key findings). To ensure these findings represented the data, researchers met regularly to discuss the key findings.	Descriptive theme: Emotional impact and mental health consequences of restricted family presence Analytical theme: Patients, families and healthcare professionals described mental health consequences (i.e., anxiety, stress, fear) due to restricted visitation policies limiting family presence during periods of high emotional burden.

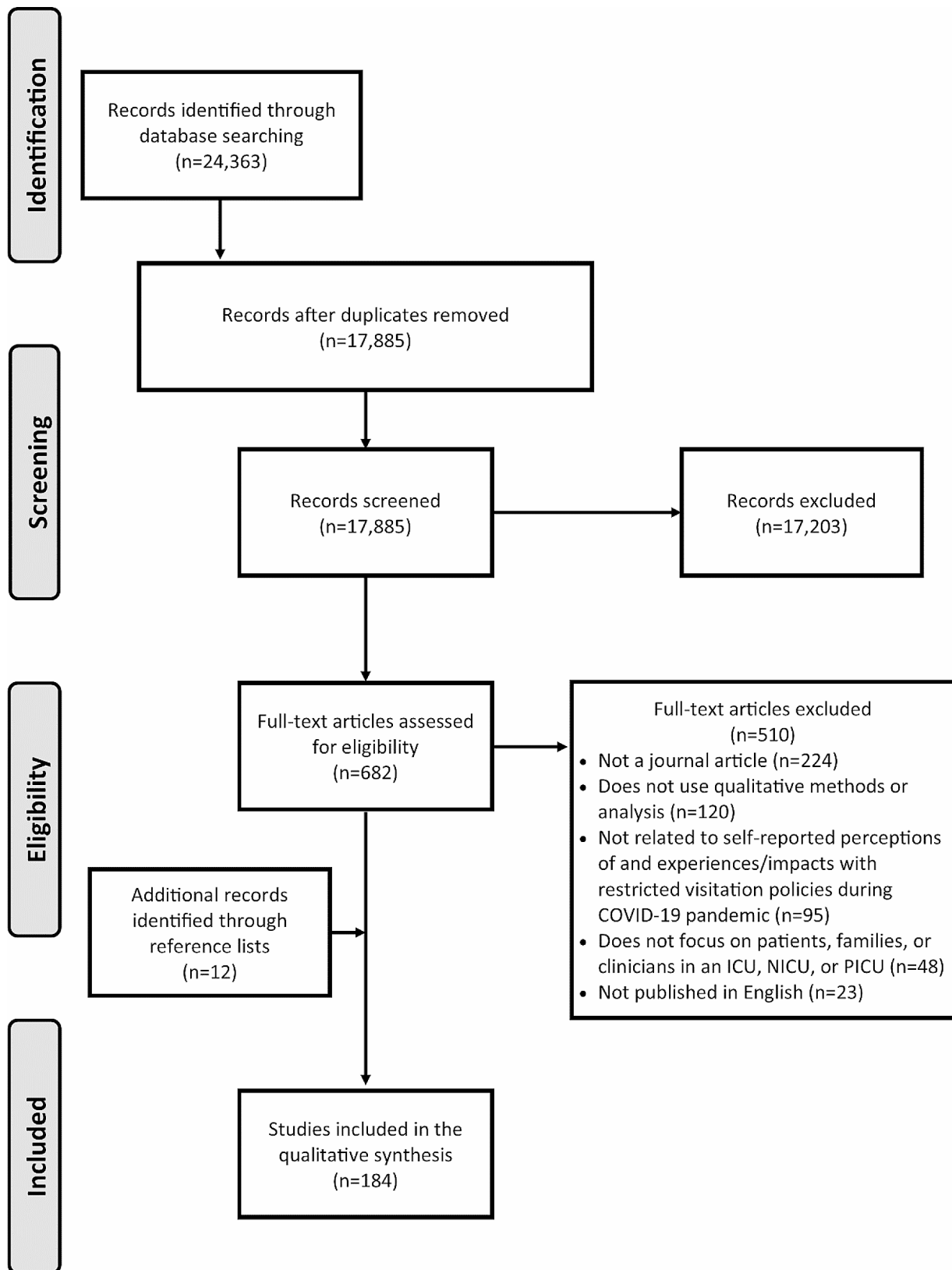


Fig. 1 PRISMA flow diagram

or free-text survey questions ($n=40/184$, 21.7%). Complete study characteristics and references are listed in Supplementary Tables 4–6 (See Additional File 1). The level of restrictions varied across NICUs, PICUs, and ICUs as the pandemic progressed. In ICUs, this varied from extreme restrictions (barring all visitors, even at end of life) to policies which permitted one designated visitor. Generally, NICUs and PICUs did not bar all visitation, although this varied from policies where parents were restricted from entering the NICU/PICU to instances where only one parent was allowed entry or the duration of the visit was limited (e.g., length of time, visiting hours).

Methodological limitations

Nearly all ($n=180/184$; 97.8%) studies included a clear statement of the aims of the research and included sufficient details for a researcher to assess whether ethical standards were maintained ($n=164/184$; 89.1%). Most studies did not report (i.e., “No” or “Can’t Tell”) if the relationship between the researcher and the participants had been adequately considered ($n=151/184$, 82.1%) and, as such, the potential for bias (i.e. influence) is unknown. CASP assessments for individual studies are displayed in Supplementary Table 7 (See Additional File 1).

GRADE-CERQual assessments

Key findings from the NICU ($n=18$), PICU ($n=8$), and ICU ($n=24$) settings were divided into the following 8 categories: (1) Impacts to Family Integrated Care (FiCare-NICU) or patient and family-centered care (PICU/ICU) or; (2) Personal and professional impacts; (3) Transitioning to virtual communication; (4) Impacts to support systems; (5) Impacts to relationships; (6) Equity, diversity, inclusion (EDI) or related impacts; (7) Policy-specific factors; and (8) Strategies to mitigate impacts. Synthesis of key findings and contributing studies are displayed in Supplementary Tables 8–14 (See Additional File 1). Based on the GRADE-CERQual assessments, we had high or moderate confidence in key findings in NICU ($n=17$), PICU ($n=4$), and adult ICU ($n=17$) settings. The main limitations leading to low or very low certainty findings were data relevance (e.g., studies represent only one/two continents or the views of only one impacted group [patients/families/healthcare professionals]) or adequacy (i.e., few studies contributing to the finding). We also identified issues related to coherence as in some cases, the data supporting the findings were conflicting.

Impacts to FiCare or PFCC

There are six descriptive themes and 13 findings under this category from the NICU ($n=6/13$, 46.1%), PICU ($n=1/13$, 7.7%), and adult ICU ($n=6/13$, 46.2%) (Fig. 2; Supplementary Table 8, Additional File 1). This category

demonstrates how restricted family presence impacted the provision of FiCare (NICU) or PFCC (PICU/ICU) around the world.

Restricted family presence policies impacted the provision of FiCare in NICUs, particularly in the pillars of parent education, NICU environment, and psychosocial support. Eleven studies described the impact that restricted family presence had on parent education (e.g., other partners [often the father] missing out on opportunities to learn about how to care for their baby and parents not feeling prepared to care for their baby at home). Families reported being left out of usual care decisions made during daily medical rounds, one parent (often the mother) having to make decisions about baby’s care due to single visitor policies, and disruptions to breastfeeding (i.e., when COVID positive mothers were unable to visit or when visits were restricted to certain hours) and kangaroo care (i.e., skin-to-skin care; when COVID positive parents were restricted from visiting). Lastly, supportive measures (e.g., parent rooms and groups) were discontinued, resulting in reduced psychosocial support.

“ They didn’t seem to acknowledge that it’s a very difficult time to have a baby in NICU never mind during the pandemic. Some nurses were mean and nowhere near as supportive as they should have been. A couple of nurses were AMAZING. Some doctors were also harsh and only seemed to see us as another number and not humans needing individual care.” (Mixed-race mother NICU patient) [43].

Restricted family presence policies impacted the provision of PFCC in PICUs and ICUs. For example, these policies impacted the PFCC core concept of respect and dignity. Participants from thirty-four ICU studies from four continents perceived that restricted family presence dehumanized patients (i.e., treated in ways that disregard their humanity and individuality) and the family to the healthcare professionals caring for them.

“ First, it was the total de-identification of the patient. There was a common thread between these patients; they were “COVID patients” but many of them had something more. Many had heart failure and other diseases, but everyone became a COVID patient. The other thing that I thought was perhaps the worst was the absence of relatives. These relatives who previously gave an identity to the patient and who were almost always at the ICU. You get to know he, the patient, likes to fish; he likes to do more than one thing. It is a person, when you talk to relatives, and then you could almost talk to the patient as if “yes, now it’s starting to look like it would be good fishing weather today.” This totally disappeared!

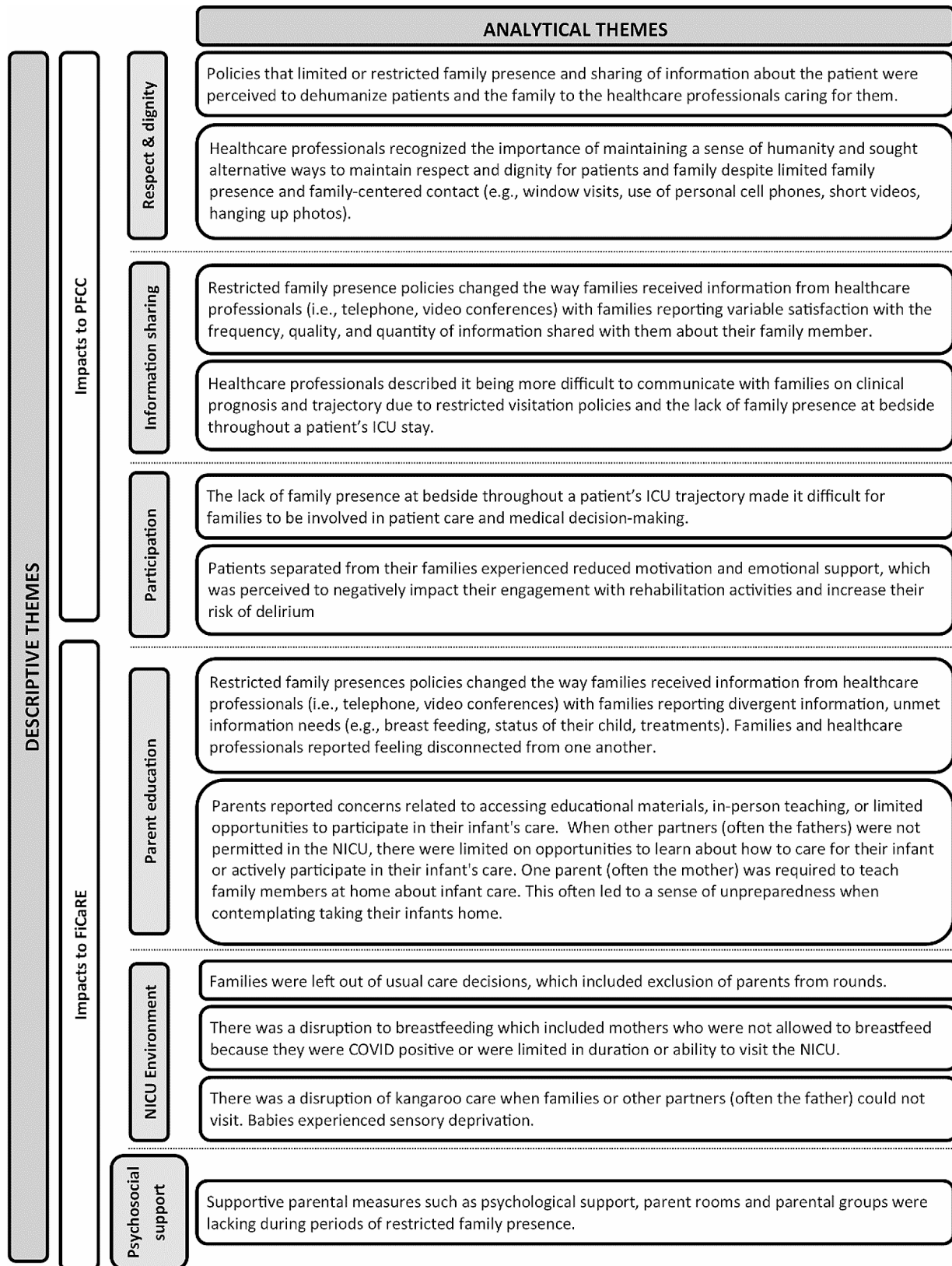


Fig. 2 Descriptive and analytical themes for impacts to patient and family centered care (PFCC) and FiCaRE

”(ICU nurse) [44].

Twenty-three studies described how healthcare professionals were aware of the dehumanizing effects of restricted family presence and the efforts that they made to mitigate those effects (e.g., window visits, using their personal cell phones to facilitate calls between families and patients, or hanging photos).

Restricted family presence policies also impacted information sharing (e.g., difficulty describing clinical prognosis over the phone, unmet information needs) and participation (e.g., participating in patient care and medical decision making).

“Before the Covid, it was already difficult to make the family understand the health situation of their relatives, despite they could see them. During the pandemic it was absolutely impossible” (ICU physician) [45].

Personal and professional impacts

There are three descriptive themes and six findings under this category from the NICU (n=1/6, 16.7%), PICU (n=2/6, 33.3%), and adult ICU (n=4/6, 66.7%) (Fig. 3; Supplementary Table 9, Additional File 1). Patients (ICU) and families (NICU, PICU, ICU) used the following words to describe their experience of being separated

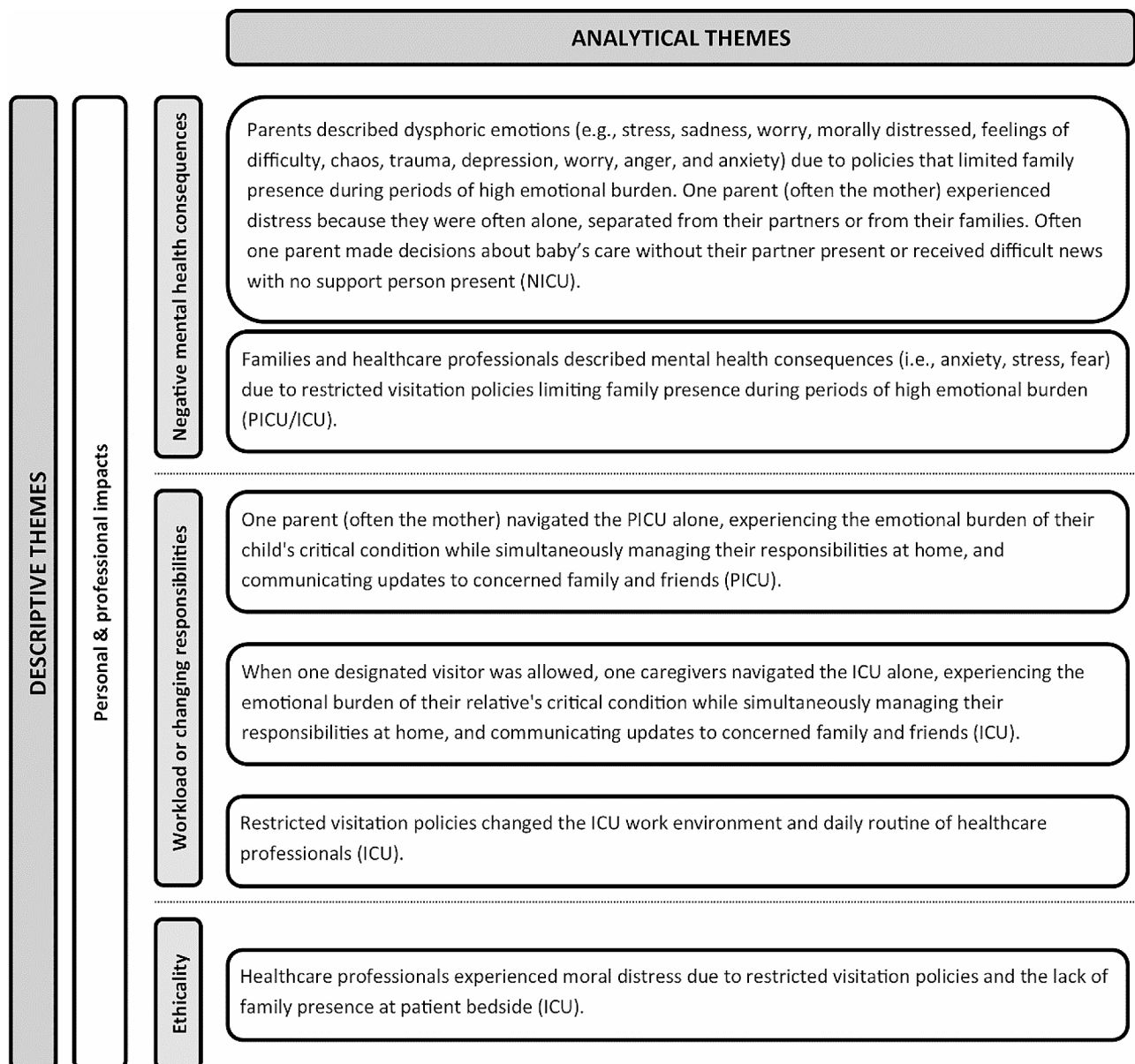


Fig. 3 Descriptive and analytical themes for personal and professional impacts

from their loved one: fear, traumatic, abandoned, anxious, stressed, sadness, anger, worry. Healthcare professionals described the moral distress they experienced:

“It goes against most nurse’s beliefs and values that patients should not have to die alone with no family/loved ones present. This has been the biggest stressor while working.” (ICU nurse) [46].

There were also changing responsibilities that impacted all groups. Mothers (NICU), parents (PICU), and relatives (ICU) navigated the ICU alone, experiencing the emotional burden of their infant/child/relative’s critical condition alone. ICU family members shared the added responsibility of sharing regular updates with family back

home. Thirty-two studies included ICU healthcare professionals commenting on how restricted family presence policies impacted their workload. Of these studies, 25 ($n=25/34$, 73.5%) studies described the intensified workload (e.g., frequent phone calls when families could not be at the bedside) and seven ($n=7/34$, 20.6%) studies described the eased workload (e.g., could schedule interactions with families when not present).

Transitioning to virtual communication

There are three descriptive themes and eight key findings under this category from the NICU ($n=4/8$, 50%), PICU ($n=2/8$, 25%), and adult ICU ($n=6/8$, 75%) (Fig. 4; Supplementary Table 10, Additional File 1). Studies described how, although telephone and virtual communication provided a form of contact and communication

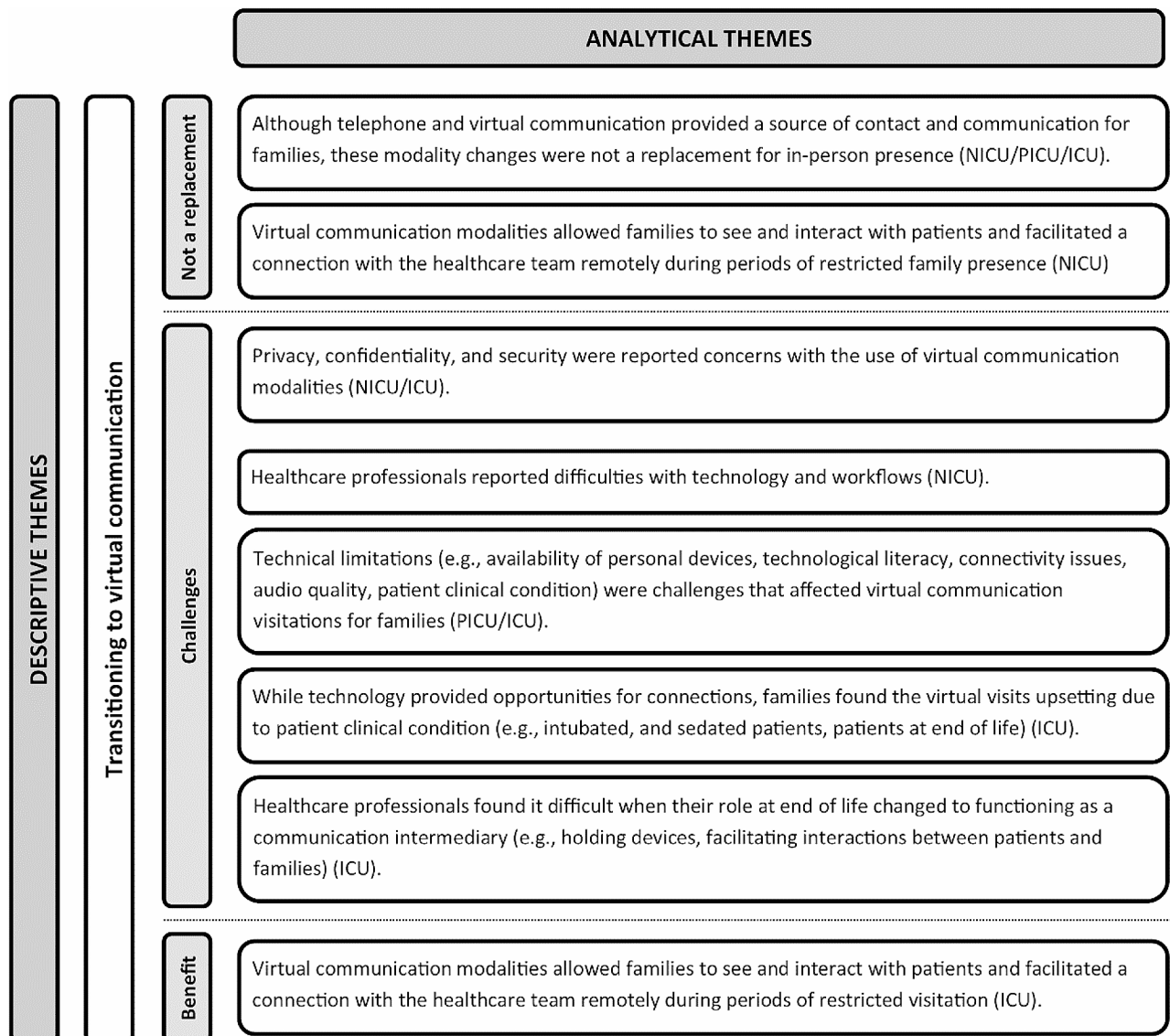


Fig. 4 Descriptive and analytical themes for pivoting to virtual communication

during restricted family presence, patients, families, and healthcare professionals felt these communication modality changes were inferior replacements for family presence. While 80 studies reported advantages of virtual communication when family presence (e.g., patient seeing their family at home, family interacting with the patient and healthcare team) was restricted (ICU [$n=69$], PICU [$n=1$], NICU [$n=10$]), there were 18 studies [ICU ($n=15$), PICU ($n=1$), NICU ($n=2$)] that reported the anxiety and distress experienced by families visiting their loved one virtually.

"I FaceTimed with my baby. She had a hard time breathing. I can't get it out of my head." (Father of NICU patient) [47].

"Seeing it just over a screen, I think would just be just much more horrible. And there is no comfort I can give her, that's just going to be etched in my mind." (Daughter of ICU patient) [48].

In 10 ICU studies, healthcare professionals described their distress when their role at end of life changed to functioning as a communication intermediary (e.g., holding devices, facilitating interactions between patients and families) compared to when families were there in person for last goodbyes (and the healthcare professionals could step out of the room).

"I think it's really taking a toll on our nurses...And now literally the nurses are in there holding up the iPad as all the family are crying. Because we are right at the bedside doing all these things, you know, can you put the scarf on my mother, can you brush her hair, can you hold her hand." (ICU nurse) [22].

Forty-five studies (ICU [$n=38/45$, 84.4%], PICU [$n=3/45$, 6.7%], NICU [$n=4/45$, 8.9%]) described technical limitations (e.g., availability of personal devices, ambient noise, patient clinical condition, technological literacy, connectivity issues) that impacted virtual communication with families. This included four adult ICU studies that described inequitable access to technology and individuals lacking familiarity with technology, which hindered the ability of patients and families to participate in virtual visits.

Impact to support systems

There are two descriptive themes and five key findings under this category from the NICU ($n=3/5$, 60%), PICU ($n=1/5$, 20%), and adult ICU ($n=1/5$, 20%) (Fig. 5; Supplementary Table 11, Additional File 1). Studies across NICU, PICU, and ICU settings reported how restricting family presence to only one person at the bedside

effectively eliminated vital emotional and practical support for families. Included NICU ($n=13$), PICU ($n=4$), and ICU ($n=3$) studies described the lack of emotional support when only one family member was allowed at the bedside. This included the inability to take turns being at the bedside with another caregiver (ICU, PICU), and leaving it to a single caregiver to ensure the patient was not left alone during critical moments (NICU, PICU, ICU). There was also a lack of organizational supports (NICU, ICU) during periods of restricted family presence, which strained communication and trust between families and healthcare providers.

Impacts to relationships

There are three descriptive themes and six key findings under this category from the NICU ($n=2/6$, 33.3%), PICU ($n=1/6$, 16.7%), and adult ICU ($n=3/6$, 50%) (Fig. 6; Supplementary Table 12, Additional File 1). This included NICU fathers experiencing a loss of essential bonding with their critically ill infant (NICU) or lost opportunities for siblings to bond with the infant (NICU) or support their critically ill sibling (PICU).

"Some decisions from the Trust have made an extremely heart-breaking situation worse. It has split our family apart and isolated our son from time with his sister." (PICU Mother) [49].

"To allow just family bubble to visit there [sic] brother his now 9 weeks and has never met his sisters only by video call" (NICU parent) [50].

Twenty-seven ($n=27/145$, 18.6%) ICU studies described the changes to relationships between patients/families and healthcare professionals. Families struggled to develop trust when they were unable to see the healthcare team or the healthcare team enforced restricted family presence (e.g., at end of life).

"We just had to believe whatever the nurse or the doctor was saying...I got so stressed out that I even asked one of the doctors to see a picture of him because I was doubting myself that he was still alive." (ICU sibling) [51].

Forty-four ($n=44/145$, 30.3%) ICU studies described health care professional's shift towards a therapeutic presence, acting a patient's hospital family (e.g., holding hands at end of life).

"... When we first told him that his family wasn't able to come in and visit, he just took my hand and looked at me and he goes, 'Don't worry, I'm never going to be alone. You're my hospital family.' I though

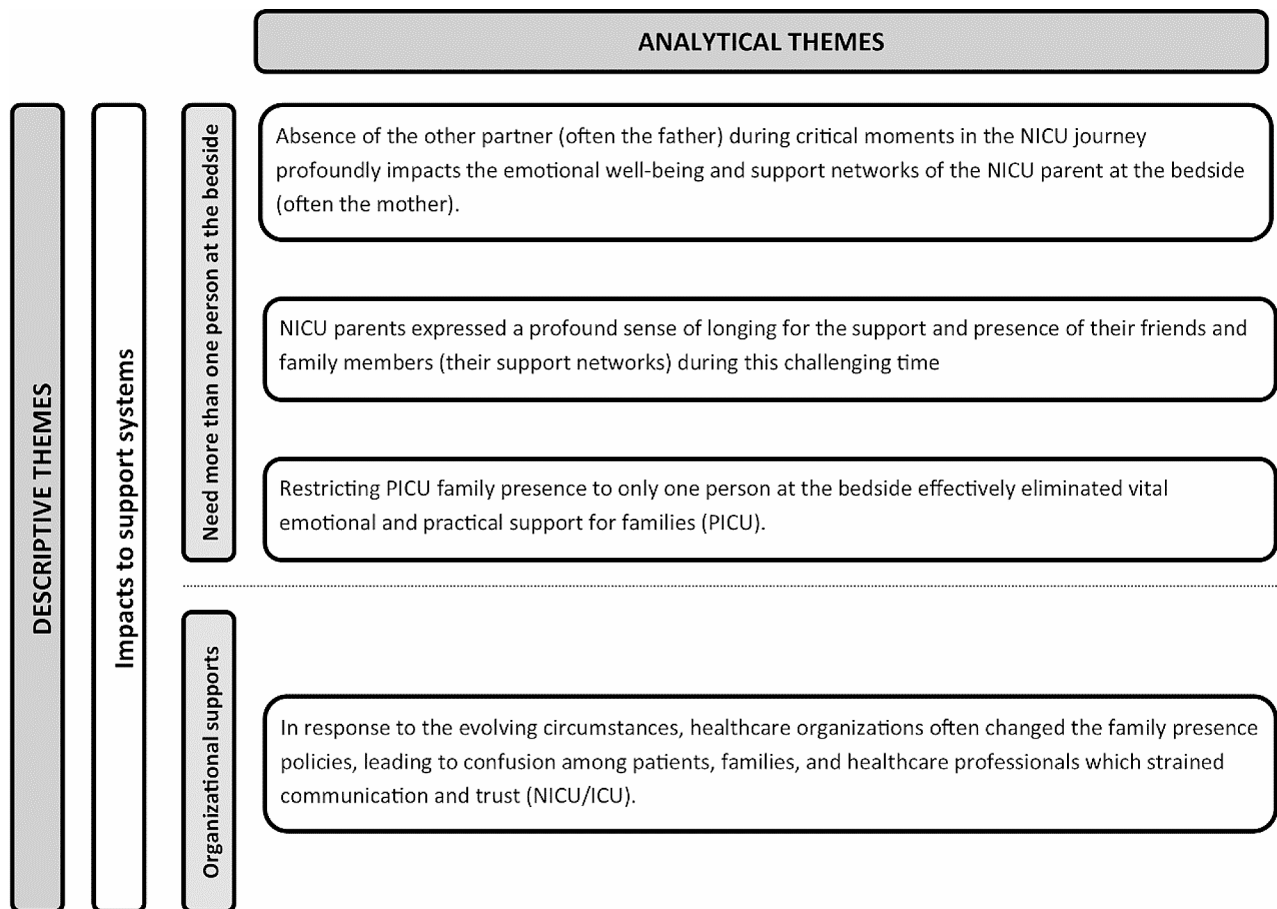


Fig. 5 Descriptive and analytical themes for impacts to support systems

that's what we are—hospital family—and we'll be with him every day and even if it's just sometimes, [to]sit in the room and hold his hand.” (ICU nurse) [52].

Equity, diversity, and inclusion or related impacts

There is one descriptive theme and key finding under this category from the adult ICU (Fig. 7; Supplementary Table 13, Additional File 1). During restricted family presence, 19 adult ICU studies described language, cultural, and disability barriers that challenged communication with patients and families during periods of restricted visitation. This included patients who were unable to communicate with the care team due to language barriers or cognitive impairment. Though these barriers were overcome with interpretive services or virtual visits with family, they provided another layer of complexity to communication.

“...the vast majority of people we have in the ICU that were really sick don't speak English or their family doesn't speak English which is adding to the communication challenges. like I was on service one week with 10 COVID patients and 9 of the 10 their primary language

was not English, and the 1 who's primarily language was English was African American. So, it was just such a striking thing... We fortunately at [this hospital] have really good interpretive services, so in general you still can communicate, but it feels like another layer like not only can you not see families in person, now you're also doing it with an interpreter on top of it.” (ICU physician) [53].

Other EDI-related impacts include families who could not be present at end of life to participate in cultural rituals and families who, due to socioeconomic status, did not have access to communication devices.

“...[families] couldn't be present when stopping [life support] and they couldn't have the rituals they wanted performed” (ICU nurse) [54].

Understanding of mitigation strategies/policies

There are two descriptive themes and three key findings under this category from the NICU ($n=2/3$ 66.7%), PICU ($n=1/3$, 33.3%), and adult ICU ($n=3/3$, 100%) (Fig. 7; Supplementary Table 14, Additional File 1). Nine studies (ICU [$n=1$], PICU [$n=1$], NICU [$n=7$]) described how patients, families, and healthcare professionals

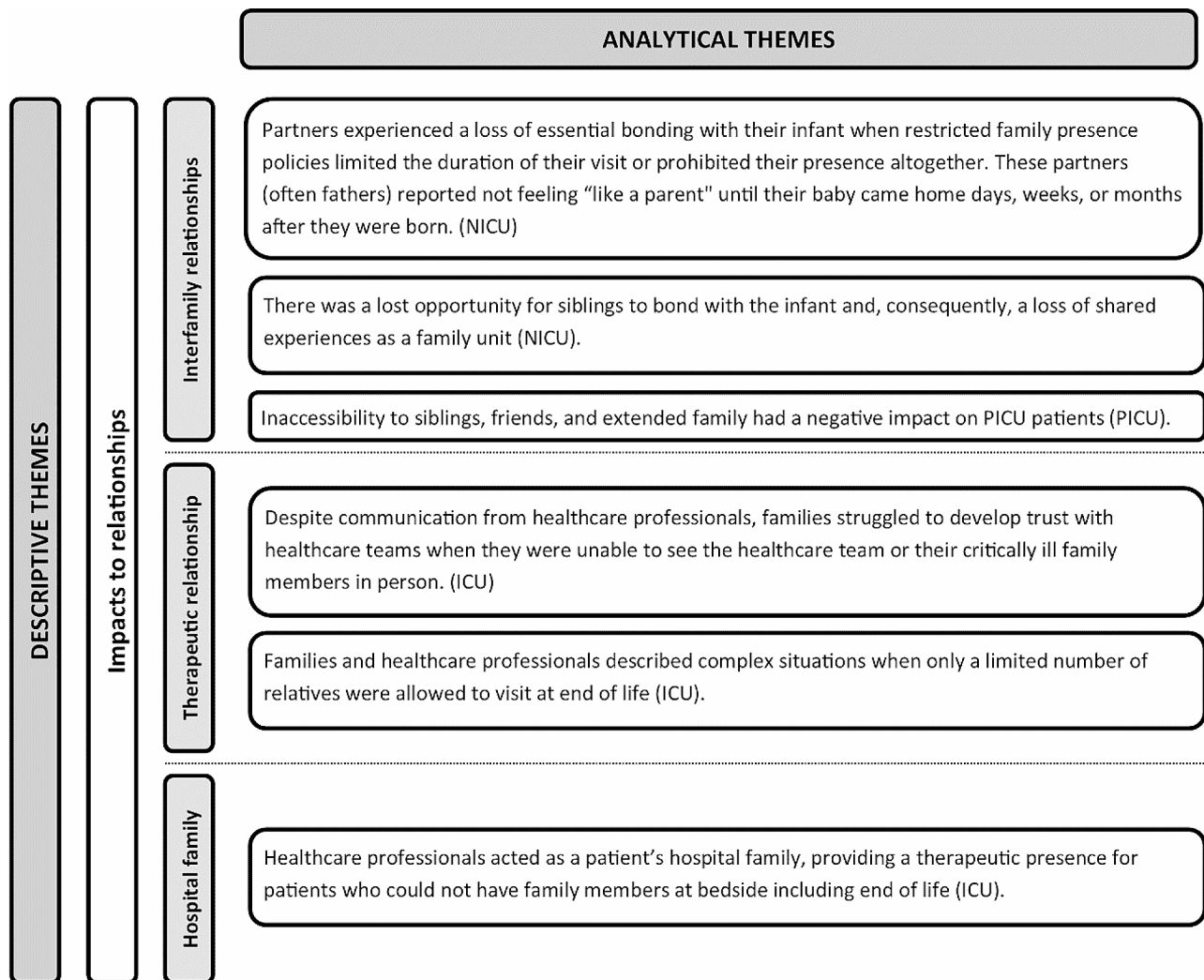


Fig. 6 Descriptive and analytical themes for impacts to relationships

understood the importance of restricted family presence to ensure the safety and well-being of patients, healthcare professionals, and the broader community. Conversely, six studies (ICU [$n=1$], PICU [$n=2$], NICU [$n=3$]) described how patients, families, and healthcare professionals did not understand the rationale of restricted family presence policies. For example, the participants did not understand how multiple family members were not allowed to visit when they were in the same household. When there was a lack of understanding about the purposes of restricted visitation, this eroded trust between families and healthcare providers.

“Why is it possible to provide pastoral care for a Methicillin-resistant *Staphylococcus aureus* patient [...] and NOT for a COVID-patient? In my opinion, everything is possible as usual with appropriate care and hygienic measures.” (ICU healthcare professional) [55].

Strategies to mitigate impacts

Across included studies, we identified a total of 21 strategies that were proposed to mitigate the impacts of restricted family presence (Table 3). This included strategies to preserve FiCare or PFCC ($n=9$), mitigate mental health impacts ($n=2$), support virtual communication ($n=5$), mitigate impacts to relationships ($n=1$), and help with the implementation and adherence to family presence policies ($n=3$).

Discussion

We synthesized NICU, PICU, and ICU patients, families, and healthcare professional's experiences with restricted family presence policies. The findings demonstrate that restricted family presence policies during the COVID-19 pandemic impacted the delivery of FiCare/PFCC and had mental health consequences on patients, families, and healthcare professionals. Provision of virtual communication modalities, though appreciated and found

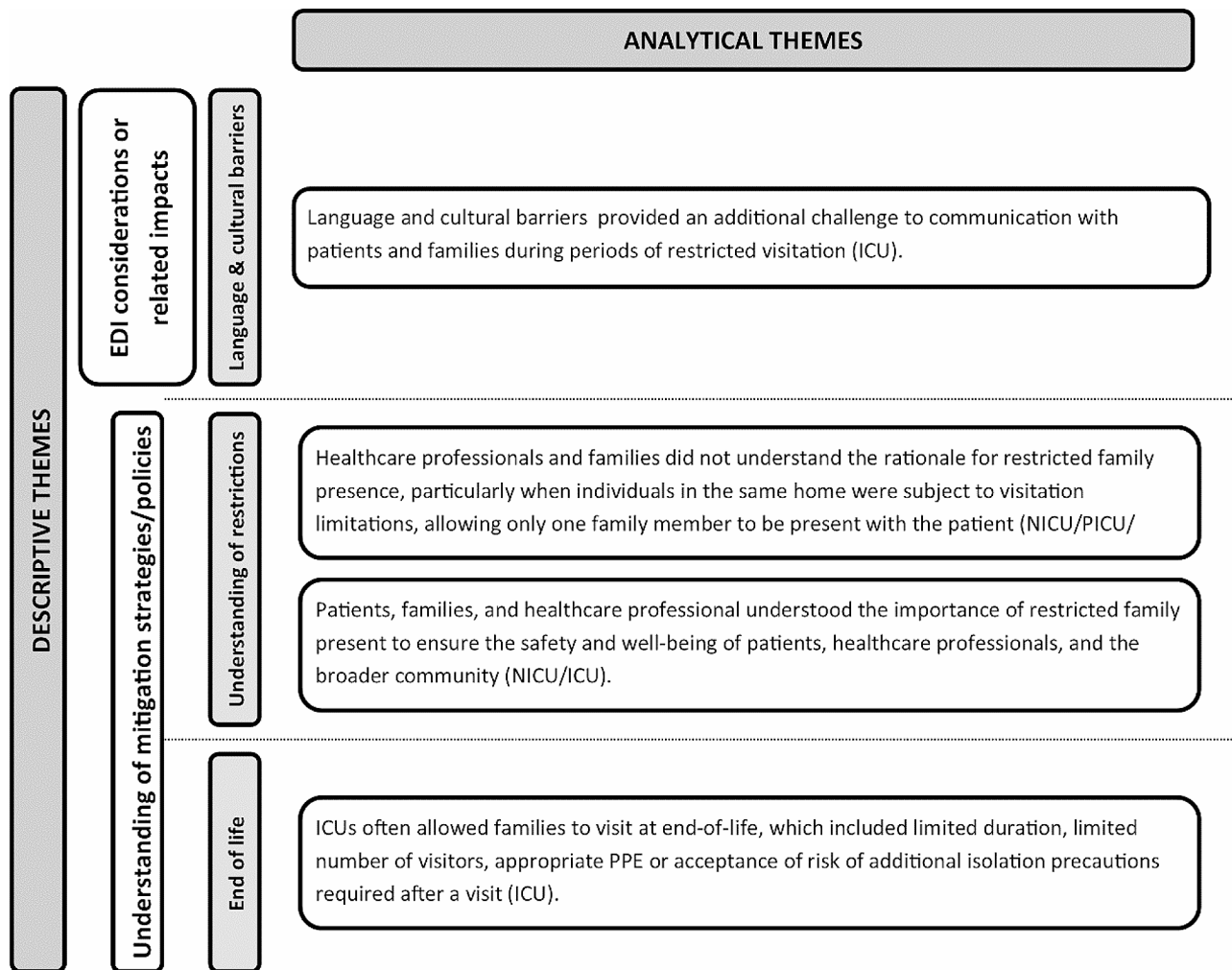


Fig. 7 Descriptive and analytical themes for equity, diversity, and inclusion (EDI) considerations or related impacts and policy-specific factors

beneficial by some, was not an adequate replacement for family presence and often was limited by availability (e.g., healthcare professional availability, device

access) and capability (e.g., reliance on WiFi, ability to deal with background noises). Virtual communication also had the potential to increase stress. Qualitative evidence addressing the impacts of these restricted family presence policies is important to guide the creation of compassionate family presence policies going forward.

Despite their potential role in infection control, the restricted family presence policies implemented during the COVID-19 pandemic undermined the standard of PFCC/FiCare in the NICU, PICU, and adult ICU settings. These high-stress healthcare environments require a supportive environment that acknowledges the emotional and psychological needs of patients and families and actively involves them in care decisions and planning. In the NICU, parents may experience stress due to the events leading to admission (e.g., unexpected birth of preterm infant, birth injury, or other complications) and

fear for their infant's wellbeing. Parents' presence is paramount to gain the skills and confidence in preparation for their infant's discharge. The Family Integrated Care (FiCare) model, known for its positive impact on infant and parent outcomes [56–59], highlights the importance of parents' active involvement in neonatal care and suggests that parents should act as their infant's primary caregiver. Moreover, evidence and best practice guidance [60] include engaging parents in care, 24/7 parental presence, early skin-to-skin contact, and breastfeeding support. We summarize the negative impact of restricting parents' access (e.g., one parent allowed, limited duration, COVID-19 positive mothers restricted from visits) on infants and parents. Drawing on these experiences, policymakers (i.e., infection and prevention and control physicians, hospital executives, government representatives) should consider the impacts of restricted family presence and make every effort to support a minimum of two parents/guardians at the bedside during regular times and during emergencies where restricted family

Table 3 Strategies to mitigate the impact of restricted family presence policies*

Strategy	NICU	PICU	ICU	References
<i>PfCC/FICare</i>				
Families should be considered an essential member of the care team and their presence should always be supported with proper protective measures (e.g., personal protective equipment, physical distancing) and acknowledgement of risk.	ü	ü	ü	NICU: [43, 50, 78, 79] PICU: [23, 49, 80] ICU: [26, 28, 33, 34, 52, 73, 81–97] NICU: [98–101]
Parents should have access to in-person teaching and a dedicated platform where they can access instructional videos to enhance skills to care for their infant.	ü	ü	ü	NICU: [79, 102]
An infant should always be with its mother; mothers and infants should be considered one unit.	ü	ü	ü	NICU: [98, 100, 103, 104]
The provision of humanistic care to patients and their families should be maintained during periods of restricted visitation (e.g., window visits, telephone calls, video calls).	ü	ü	ü	ICU: [30, 52, 67, 70, 86, 88, 89, 94, 105–109]
Communication between healthcare professionals and families could be improved by ensuring there is a consistent point of contact from whom families receive regular medical updates.	ü	ü	ü	ICU: [33, 53, 66, 73, 81, 84, 86, 88, 95, 106, 107, 109–115]
Designate a single, family spokesperson, particularly during situations of crisis like a pandemic.	ü	ü	ü	ICU: [116, 117]
Guidance for families to manage communication expectations during periods of restricted family presence or if family cannot be present.	ü	ü	ü	ICU: [58]
Healthcare professionals would benefit from formal training programs on family communication including how to facilitate difficult conversations or compassionate interaction over a phone call.	ü	ü	ü	ICU: [22, 33, 45, 70, 71, 93, 112, 114, 115, 117–122]
Open (e.g., treatment limitations, patient care decisions, goals of care planning), routine, regular, consistent, and clear communication with family members is important for high-quality communication that meets family's information needs.	ü	ü	ü	ICU: [48, 66, 70, 74, 81, 84–86, 88, 91, 94–96, 105–107, 109, 110, 112, 115, 118, 119, 123–132]
<i>Mental health impacts</i>				
In-person visits should always be allowed at end of life, despite restricted family presence, and while the patient is lucid and awake.	ü	ü	ü	ICU: [28, 45, 52, 88, 95, 105, 109, 123, 133–136]
The emotional and psychological toll experienced by patients, families, and healthcare professionals underlines the necessity of comprehensive mental health services, which includes distinct resources for symptoms of mortal distress.	ü	ü	ü	NICU: [25, 47, 99, 103, 137–140] PICU: [23, 32, 141] ICU: [58, 67, 73, 94, 142–145]
<i>Pivot to virtual communication</i>				
Use multi-modal communication strategies that best suit the patient's and family's physical and cognitive state.	ü	ü	ü	NICU: [50, 146–148] PICU: [149]
Prepare families by providing clear information, emotional support, and guidance before initiating a video call with their critically ill relative.	ü	ü	ü	ICU: [58, 66, 71, 84–86, 94–96, 112, 113, 116–120, 123, 125, 126, 130, 131, 144, 150–153] NICU: [100, 140, 147] PICU: [154]
Provide robust technical support and education to support virtual communication between patients, families, and healthcare professionals during periods of restricted family presence.	ü	ü	ü	ICU: [33, 108, 117, 155, 156] NICU: [157]
Provide guidance for the use of video calls to address issues such as consent, data security, and the protection of confidential medical information.	ü	ü	ü	PICU: [154]
Ensure equitable access to smartphones or devices to facilitate communication for patients and families from diverse backgrounds and promote equitable access to the benefits of virtual visits.	ü	ü	ü	ICU: [33, 66, 69, 84, 94, 96, 108, 112, 113, 128, 129, 158] NICU: [100] PICU: [154]
<i>Impacts to relationships</i>				
Ensure equitable access to smartphones or devices to facilitate communication for patients and families from diverse backgrounds and promote equitable access to the benefits of virtual visits.	ü	ü	ü	ICU: [53, 108] NICU: [100]
Ensure equitable access to smartphones or devices to facilitate communication for patients and families from diverse backgrounds and promote equitable access to the benefits of virtual visits.	ü	ü	ü	ICU: [58, 71, 96, 115, 156]

Table 3 (continued)

Strategy	NICU	PICU	ICU	References
Siblings or broader support network should be allowed to visit to promote family bonding & provide essential support during a difficult and uncertain time.	ü	ü	ü	NICU: [50, 101, 138] PICU: [32, 49] ICU: [58, 108, 113, 143, 156, 159]
<i>Policy-specific factors</i>				
Those who are impacted by the policy should be included in the decision-making process.	ü	ü	ü	NICU: [43, 146] ICU: [96, 132]
Create a dedicated and easily accessible platform where patients, families, and healthcare professionals can access up-to-date information on the family presence policies.	ü	ü	ü	NICU: [98] ICU: [58, 96, 127]
During periods of restricted family presence, there should be explicit definitions of roles within care teams (e.g., communication of the policy, enforcement).	ü	ü	ü	ICU: [33, 58, 70, 73, 81, 95, 96, 108, 115, 121, 131]

*The table displays suggestions that were reported (ü) or not reported (ü) in the included neonatal, pediatric or adult intensive care unit (ICU) studies

presence may be considered (e.g., pandemic, infectious disease outbreak, mass casualty event).

Both children and their parents benefit from proximity to each other [61, 62]. Research examining the needs of families of critically ill children demonstrates that families want information, assurance from staff, and proximity to their critically ill child [63, 64]. Siblings of critically ill children experience stress related to parental absence, and lack of information of their sibling’s illness [65]. Like the NICU, PICUs often had a one-parent visitation policy. Like the NICU, future family presence policies should allow both parents to be present, and include an approach to sibling visits. The recognition of the child, centered within the family, is essential in considering future hospital-based policy development.

In the ICU, families act as an essential emotional support for patients. Restricted or limited family presence impacts communication between families and healthcare professionals [66], which may lead to misunderstanding about critical illness [67] and has been shown to impact goals of care conversations [68]. Future family presence policies should maintain respect and dignity of the patients and families, include an approach to meet information needs, and consider alternatives to include families in patient care and decision-making through virtual rounds [69], regular phone calls [70, 71], designated COVID-19 and non-COVID-19 areas to facilitate access for shared decision-making [72], or discharge planning as an exception for a visitor to be able to be present in the ICU [73].

We also synthesized the moral distress experienced by healthcare professionals during restricted family presence. ICU healthcare professionals perceived they were unable to provide adequate care due to restricted family presence policies that contributed to a high workload (e.g., frequent phone calls, facilitating virtual visits), patients dying alone without their family present, and lost connections with families. Moral distress may contribute to high turnover rates and staff burnout [74, 75] or result in moral injury defined as “a durable mental wound characterized by symptoms such as guilt, shame, existential or moral conflict, a loss of trust in goodness, moral detachment and/or moral disorientation” [76]. Future restricted family presence policies should consider the balance of the perceived benefits of restricted visitation against the known negative impacts. Further resources should be allotted to address symptoms of moral distress and identify strategies to deal with these symptoms (e.g., peer support mechanisms, moral requirements/frameworks [76], should restricted visitation be deemed unavoidable.

Amidst the pandemic, decisions regarding family presence happened rapidly and sometimes with little evidence to support their implementation. Now is the opportune time to establish a foundation for deliberate

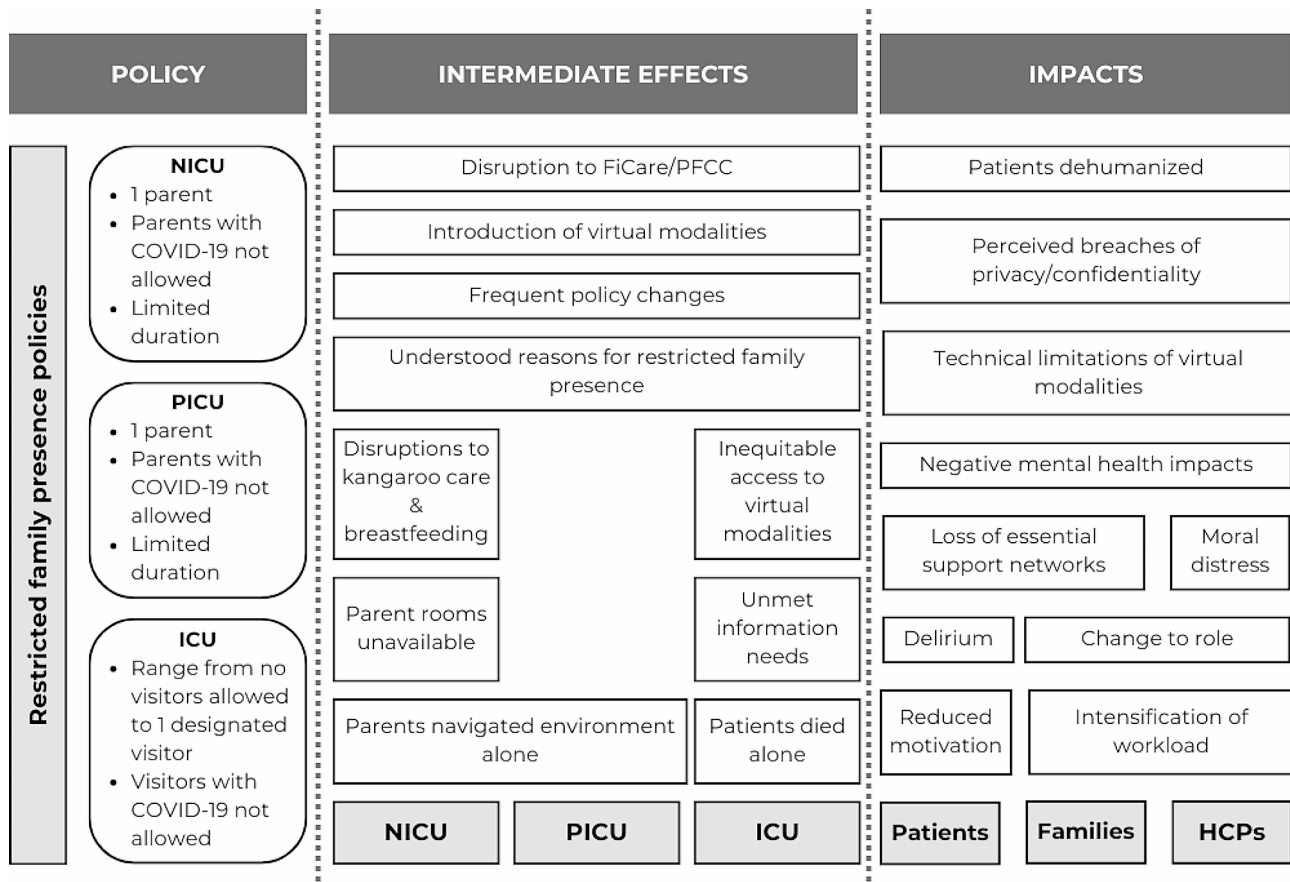


Fig. 8 The reported impacts of restricted family presence policies

and thoughtful policy decisions for future emergencies where restricted family presence may be considered (e.g., global pandemic, infectious disease outbreak, mass casualty event). This review supports the value of including impacted persons (i.e., patients, families, healthcare professionals) in the development and implementation of NICU, PICU, and ICU family presence policies. By actively engaging with the experiences and perspectives of these impacted persons, policymakers gain valuable insights into the multifaceted negative sequelae of restricted family presence policies in each of these distinct care environments. Involving healthcare professionals can provide insight on the impacts of restricted family presence policies and potential solutions to mitigate these impacts. For NICUs, involving impacted persons can provide insight on the essential support needed for parents and infants from admission through discharge. In PICUs, it can elucidate the important role that both parents and siblings have in the care and recovery process. In adult ICUs, it can reveal the indispensable role families play in patient care and considerations related to end-of-life decision making (e.g., dignified death). Moreover, the study emphasizes the need for policymakers to recognize the limitations of virtual visits (i.e., lack of physical touch

such as holding hands or hugging, impersonal, limited non-verbal cues or emotional exchanges) when used as a replacement for in-person presence and acknowledge the additional workload and support required to facilitate these types of visits. Future policies that use virtual visit should include allocating resources and support systems to manage the increased workload and enhance the effectiveness and availability of this approach. Figure 8 represents a logic model which demonstrates how restricted family presence policies can lead to immediate (i.e., intermediate effects) and lasting impacts reported in included studies [77]. Careful planning of family presence policies is crucial to ensure that policies are well-planned using available evidence (quantitative and qualitative), ultimately leading to better health outcomes and experiences for patients, families, and healthcare professionals.

This review has several strengths and limitations. We performed a comprehensive and up to date search to incorporate enough time for studies describing the impact of restricted family presence to be published. The findings are likely generalizable to multiple jurisdictions as we included 184 studies from six continents and a wide range of settings and participants. However, it's possible we missed terms that represent caregivers in other

countries (e.g., attendant) and missed including articles. Also, there were few studies conducted within PICUs, thus further work is needed in this setting. The studies included in this review used a qualitative design which made it difficult to describe if the impacts were related to the restricted family presence policies (vs. the pandemic). Another limitation is that we only accessed and analyzed the published quotes and research interpretations, not the entire transcripts or free-text responses used in the original studies. Lastly, we included only English language studies, which primarily focused on the reporting and impacts of restricted family presence studies in countries of the Global North with limited contribution from South America, Africa, and Asia.

Conclusions

This comprehensive qualitative review synthesizes and highlights the multifaceted impacts and negative sequelae of restricted family presence policies across NICUs, PICUs, and adult ICUs. The harmful effects of these policies are demonstrated across all impacted persons examined in this review: patients, families, and healthcare providers. It provides valuable insights into strategies and adaptations that can help mitigate challenges during times of crisis. Balancing infection control measures with compassionate, family-centered care remains paramount. These findings contribute to the growing body of knowledge on optimizing patient care and family support in unprecedented healthcare situations.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12913-024-11398-x>.

Additional file 1: Supplementary Table 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Checklist. **Supplementary Table 2.** Enhancing transparency in reporting the synthesis of qualitative research: the ENTREQ statement. **Supplementary Table 3.** MEDLINE search strategy. **Supplementary Table 4.** Characteristics of included adult intensive care unit (ICU) studies, alphabetical by study first author. **Supplementary Table 5.** Characteristics of included pediatric intensive care unit (PICU) studies, alphabetical by study first author. **Supplementary Table 6.** Characteristics of included neonatal intensive care unit (NICU) studies, alphabetical by study first author. **Supplementary Table 7.** Critical Appraisal Skills Program qualitative studies checklist (CASP) appraisals for included studies ($n=184$), alphabetical by study first author. **Supplementary Table 8.** Synthesis of findings (impacts to patient and family-centered care [PFCC] and Family Integrate Care [FiCare]) **Supplementary Table 9.** Synthesis of findings (personal and professional impacts). **Supplementary Table 10.** Synthesis of findings (transitioning to virtual communication). **Supplementary Table 11.** Synthesis of findings (impacts to support systems). **Supplementary Table 12.** Synthesis of findings (impacts to relationships). **Supplementary Table 13.** Synthesis of findings (EDI considerations or related impacts). **Supplementary Table 14.** Synthesis of findings (Policy related factors).

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Author contributions

Conceptualization, KDK, NJ, LL, JSL, and KMF; methodology, KDK, NJ, LL, JSL, OD, CD, DJN, KKSP, BR, AW, HTS, JPL, and KMF; formal analysis, KDK, NJ, LL, JSL, OD, MPL; data curation, KDK, NJ, LL, JSL, OD, MPL; writing—original draft preparation, KDK, NJ, LL, JSL, OD, KMF; writing—review and editing, KDK, NJ, LL, JSL, OD, MPL, CD, DJN, KKSP, BR, AW, HTS, JPL, and KMF; supervision, KMF; project administration, KDK; funding acquisition, KMF. All authors have read and agreed to the published version of the manuscript.

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Data availability

The data that support the findings of this study are available from the authors.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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