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Practice of Family-centred Care in Intensive Care Units before the COVID-19-Pandemic: a cross-sectional analysis in German-speaking countries

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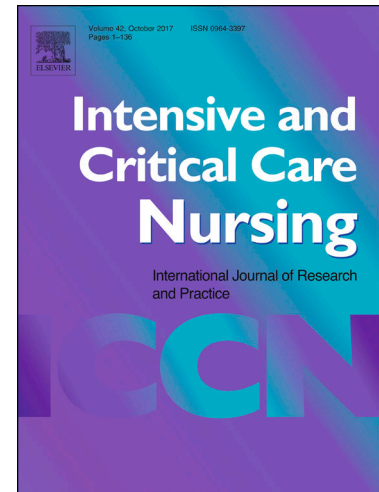
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Title:

Practice of Family-centred Care in Intensive Care Units before the COVID-19-Pandemic: a cross-sectional analysis in German-speaking countries

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Abstract

Objectives

To provide insights into visiting policies and family-centred care practices with a focus on children as visitors in Intensive Care Units (ICUs) in German-speaking countries.

Methods / Design

Online-survey with a mixed approach were used. Leading clinicians (n=1,943) from German-speaking countries were invited to participate. Outcomes included the percentage of ICUs with open visiting policies, age restrictions, family-centred care activities and barriers.

Setting

Paediatric, mixed and adult ICUs.

Results

In total, 19.8% (n=385) of the clinicians responded. Open visiting times were reported by 36.3% (n=117), with significant differences between paediatric (79.2%), adult (21.3%) and mixed-age (41.2%) ICUs ($p<0.001$). Two-thirds of clinicians stated that their ICUs had no age restrictions for visiting children as visitors (n=221, 68.4%). The family-centred care activities most frequently implemented were open visiting times and dissemination of information. Significantly more German ICUs have open visiting policies and more Swiss ICUs allow children as visitors, compared to the other countries (both $p<0.001$). Barriers to family-centred care were concerns about children being traumatized, infection and workload.

Conclusion

The majority reported that family-centred care policies had been implemented in their ICUs, including open visiting policies, allowing children as visitors without age restriction and other family-centred care activities.

Keywords: Attitude, Child, Crisis Intervention, Critical Care, Patient-Centered Care, Family, Visitors to Patients

- Family-centred care activities, and should be discussed by healthcare professionals
- Healthcare professionals should consider discussions with parents in bringing children with them to visit patients in the ICU.
- Clinicians expressed the ambiguity of the possible harm to and benefits for children as visitors and should be supported during change projects.
- The heterogeneous results between adult and paediatric clinicians, countries and settings stimulate reflection on our own practices and policies.

Introduction

The role of the families of patients in Intensive Care Units (ICUs) has changed in recent decades. Since 1970 there has been a shift from disease-centred care, including the passive roles of patients and families, towards involvement in treatment and decision-making (Olding et al., 2016). In 2007, a guideline for patient-centred care was published by the American College of Critical Care Medicine Task Force, focusing on the active participation of patients in their care (Davidson et al., 2007). This approach was extended to families in subsequent years (Davidson & Strathdee, 2019). Parallel changes can be observed since 1955 in paediatric care, when attention focused on the importance of parents' presence in enhancing the sensorimotor and emotional development of new-born children (Gomez-Cantarino et al., 2020; McAndrew et al., 2020). Family-centred care considers patients' complexity, including the psychosocial, economic and genetic context of their families, with consequences for their medical history and present condition (Davidson et al., 2017). Consideration of these aspects in the care of critically ill patients led to more humane critical care and family-centred care (Galvin et al., 2018; Karnatovskala et al., 2015; Meert et al., 2013). The Society of Critical Care Medicine (SCCM) defines family-centred care as an approach "that is respectful of and responsive to individual families' needs and values", and the term family as "individuals who provide support and with whom the patient has a significant relationship" (Davidson et al., 2017). Additionally, in the paediatric setting, family-centred care contributes to "mutually beneficial partnership among patients, families, and providers", which recognizes the importance of families for the children (Abela et al., 2020; Meert et al., 2013). In general, a patient's family can consist of genetically related persons, close friends and others (Gibson et al., 2012). Societies such as the British Association of Critical Care Nurses (BACCN) and others support family-centred care and encourage implementation (Davidson et al., 2017; Gibson et al., 2012).

The approach to family members in ICUs can be complex, including aspects of co-suffering, potential roles or burden. As immediate social contacts of the patients, family members often suffer from critical illness too, and are at high risk for anxiety, depression, post-traumatic stress disorder (PTSD) or complicated grief, known as post-intensive care syndrome-family (PICS-F) (Hoffmann et al., 2020; Johnson et al., 2019; Needham et al., 2012; Yuan et al., 2020). The prevalence of long-term sequelae in family caregivers ranges from 4% to 94% for depression, 2% to 80% for anxiety, and 3% to 62% for PTSD. Family members can be seen as part of the team, can offer support to patients and staff and play an important part in the decision-making process (Donovan et

complaints against healthcare providers and the team (Athanasidou et al., 2014; Chapman et al., 2016; Ramos et al., 2014; Riley et al., 2014; Li et al., 2020). All these different aspects can lead to different extents of family-centred care activities. A recent survey by the World Federation of Societies of Intensive and Critical Care Medicine (WFSICCM) in 40 countries reported varying family-centred care practices, with many ICUs implementing aspects to differing extents (Kleinpell et al., 2018).

Regulations governing visiting times and the associated conditions are heterogeneous in ICUs. Visiting times may be restricted to hours per day or days per week, flexible based on individual needs, or open with or without any time limits (Davidson et al., 2017). While there is already a lot of evidence of family-centred care in the international literature (Alonso-Ovies & La Calle, 2017; Anzoletti et al., 2008; Eriksson et al., 2010; Garrouste-Orgeas et al., 2016; Kean, 2010; Ning & Cope, 2020; Rosa et al., 2019), children and adolescents (defined as “children” aged 0-17 years) are often not included in these studies, especially when it comes to their role as visitors. But children are a part of the family. Studies show that in the majority of cases it is the parents who initiate visits with their children (Desai et al., 2020; Knutsson & Bergbom, 2007a). The evidence for benefits and harms of children as visitors is still conflicting (Lamiani et al., 2021). Healthcare professionals still tend to be more critical of visits by children, believing that their presence distracts their attention and disturbs their routine (Desai et al., 2020; Knutsson et al., 2017). Children in fact are able to cope with the situation very well, but clinicians frequently fear a risk of cross-contamination, psychological trauma of the children especially when they see the patient, or other risks such as overprotection by staff and parents, misunderstandings, a frightening environment, feelings of relief, fear or ignorance, boring waiting times, unprepared confrontation with death and suffering, the compromised health of children, and others (Clarke & Harrison, 2001; Hanely & Piazza, 2012; Horikoshi et al., 2018; Lamiani et al., 2021; Karp et al., 2020; Knutsson et al., 2008; Knutsson et al., 2017; Milner et al., 2021). Implementation of specialized professions such as child-life specialists for supporting pediatric presence in the ICU is developing (Romito, 2021). However, the recent WFSICCM survey reported limited information about the extent of family-centred care and visiting policies in paediatric ICUs compared to adult ICUs (Kleinpell et al., 2018). Moreover, it is unclear how children under the age of 18 are involved as visitors to ICUs. Data about practical aspects of family-centred care and related visiting policies in adult and paediatric ICUs are limited. Therefore, the aim of the present study is to gain insights into visiting policies and family-centred care practices with a focus on children as visitors in paediatric, mixed and adult ICUs, in German-speaking countries in Europe (Austria, Germany, Luxembourg and the German-speaking part of Switzerland) prior to the Covid-19 pandemic.

Methods

A mixed approach using quantitative and qualitative methods was used. The report on this survey complied with the guidelines for conducting online surveys (Eysenbach, 2004) (supplementary table E3). The authors used a previously used English online questionnaire with the author’s permission (Kleinpell et al., 2018). The questionnaire was developed by the authors of the previous survey (Kleinpell et al., 2018), pretested and validated (face validity) by ten clinicians. The authors of the present survey extended the questions and adapted them for use in German and to local conditions. The new questions focused on visiting policies of children, since

related knowledge was limited. The primary outcome was the percentage of ICUs with open visiting policies. Seco and facilitators of family-centred care.

The online questionnaire consisted of 27 questions. Metric data such as the number of hospital beds were gathered in seven questions, two multiple-choice questions investigated structures and processes, two questions comprised ratings of the implementation of ten and eight items respectively, two open questions asked about barriers and possible strategies for enhancing family-centred care practices, and the remaining 13 were single-answer questions.

The questionnaire comprised different categories. Sociodemographic data included country, profession, age (in categories), place of work, management responsibility, years of experience, and whether the respondents have children of their own. ICU data included type of hospital, discipline, age of patients, and number of beds in the hospital and ICU(s), mean admissions per year, mortality, length of ICU stay, and presence of an intensive-care specialist. We asked about several aspects of the implementation of family-centred care practices, using a 3-point Likert-type scale (“fully”, “partly” or “not at all implemented”), and about visiting hours per day. In addition, local policies regarding children as visitors were recorded, including age limits, hygiene and other requirements, specific structures and processes.

The adapted questionnaire was pretested as a pilot survey online by 33 international clinicians with different levels of experience. The result was a refinement of the wording in a structured process. The order of items in the online questionnaire differed from the order of presentation in this publication, and the questions were not adaptive or randomised. Here, they are listed by the hierarchical number of answers.

The closed invitation to participate in the questionnaire was sent to 1,943 leading clinicians (senior physician, staff nurse, etc.) from all 1,943 ICUs in Austria, Germany, Luxembourg and the German-speaking part of Switzerland by e-mail. The questionnaire was distributed via professional organizations such as the Austrian Society for Internal Medicine and General Intensive Care and Emergency Medicine (ÖGIAM), the German Society of Critical Care Medicine (DIVI) and the Swiss Society for Intensive Care Medicine (SGI) to their registered leading ICU clinicians. All these organizations are part of the WFSICCM. The people contacted either responded to the questionnaire themselves or disseminated the email throughout their team. The e-mail included a short description and a link to the questionnaire website, using Survey Monkey. Participants were informed about the voluntary approach and the time required to fill out the questionnaire. Participation was counted as consent. Participants could go back and forth but had no access to the overall results. For data protection, IP addresses and cookies were not used. The questionnaire was conducted in autumn 2019, lasted seven weeks, and included two electronic reminders. No incentives were offered.

Regional ethics committees from three countries approved the study (Austria: 31-534 ex 18/19, Germany: D 512/19, Switzerland: Req-2019-00691). The study has been registered in the German Register for Clinical Trials (DRKS 00018861).

Statistical analysis

Categorical data are reported as absolute and relative frequencies, whereas metric parameters are summarized using

the number of non-missing answers. Attitude towards children as visitors consisted of eight items, each answered with “no”, “rather no”, “rather yes”, or “yes”, coded from 1 to 4. We calculated a sum score from these eight items, inverting the coding for several items such that higher values indicate a more positive attitude towards children as visitors (32 points = maximum positive attitude). Differences between groups were assessed using Fisher’s exact test for categorical data or the Mann-Whitney U-test or Kruskal-Wallis test for metric data, respectively. The overall significance level was 5%. The statistical analyses were performed with R version 3.6.1.

Results

In total, 385 (at most 19.8%) clinicians answered the questionnaire with a completion rate of 89.3% (n=344). Most respondents (n=193, 50.3%) worked in university and academic hospitals. The country with the most responses was Germany (n=151, 39.2%). The median (IQR) reported hospital bed capacity was 380 (205-783) beds.

Respondents were mainly from ICUs specialized for adults (n=280, 72.7%), but also from mixed-age (n=21, 5.5%) and paediatric (ages 0-17 years, n=79, 20.5%) ICUs; five respondents (1.3%) did not disclose this information. The participants’ ICUs were most often of mixed disciplines (n=263, 69.0%), had a median (IQR) of 10 (8-16) ICU beds, 800 (500-1368) ICU admissions per year, a 4-day (3-6.4) length of stay in the ICU, and 5 (2.5-10) per cent mortality. An intensive-care specialist was reported to be present during the whole day by 328 (85.9%) participants (Table 1: Hospital data).

INSERT TABLE 1 “Hospital data” HERE

Most participating clinicians were physicians (n=213, 57.3%), were in a senior position (n=310, 82.9%), older than 50 years (n=175, 47.0%), and had more than 15 years of experience in critical care (n=250, 67.2%). It is worth highlighting the high proportion of those who have children themselves (n=267, 71.6%) (supplementary table E1: Sociodemographic data).

ICUs with no visiting restrictions were open 24 hours a day, 7 days a week (24/7) and accounted for 36.3% (n=117) of all responses, with a significantly higher proportion of open ICUs in the paediatric setting (adult ICUs 21.3%, mixed-age ICUs 41.2% and paediatric ICUs 79.2%, $p<0.001$). Significantly more ICUs were open 24/7 in Germany (50.4%, n=61) vs. Austria (27.4%, n=23) and Switzerland (29.1%, n=32) ($p<0.001$).

The median visiting hours of visitor-restricting ICUs were 6 (4-8) hours, with significantly more visiting hours in paediatric ICUs (adult ICUs 5 (4-8) hours, mixed-age ICUs 5 (3.3-9.5) hours and paediatric ICUs 21.5 (14.5-22) hours, $p<0.001$).

Significantly fewer clinicians reported that visiting children have to provide evidence of being free of transmissible illnesses in adult ICUs (2.4%) compared to mixed-age ICUs (31.6%) or paediatric ICUs (29.2%) ($p<0.001$). Most respondents who provided this information reported that their ICUs had no age restrictions for visitors (n=221, 68.4%). There were significant differences regarding ICU specialization (adult ICUs 62.0%, mixed-age ICUs 68.8% and paediatric ICUs 90.0% unrestricted, $p<0.001$). In ICUs with age restrictions (n=102, 31.6% of 323

answers provided) the median (IQR) minimum age for visiting was 12 (7.2-14) years, with no significant differences and paediatric ICUs 12 (7-14) years, $p=0.423$). Children were accepted as visitors without age restrictions in more ICUs in Switzerland (80.9%, $n=89$) than in Germany (56%, $n=70$) ($p<0.001$).

Clinicians reported having adopted a family-centred care approach by fully implementing the following (top three responses that were not “other”): disseminating information and providing support to families regarding ways to assist with the care of their loved ones ($n=166$, 46.5%), open visiting ($n=161$, 45.0%), and patient and/or family ICU diaries ($n=100$, 27.8%) (Table 2: Family-centred care practices).

INSERT TABLE 2 “Extent to which family-centred care practices have been adopted in the ICU” HERE

Regarding the implemented structures and processes, some ICUs provide toys for visiting children ($n=94$, 24.4%), or have adults in attendance during the visit ($n=246$, 63.9%) (Table 3: Structures and processes for visiting children). However, 45.2% ($n=174$) do not offer any supporting structures such as child-centred furniture in the visitors' room, films, toys or brochures.

INSERT TABLE 3 “Structures and processes for visiting children” HERE

Asked about their attitudes towards children as visitors to ICUs, most respondents reported that children should have a right to receive explanations and information, but should be prepared for the visit properly, and that a visiting child would have a positive impact on the patients and might even be less afraid as a result of the visit (Figure 1: Opinions of participants).

INSERT FIGURE 1 “Opinions of participants” HERE

The sum score “attitude towards children as visitors” was calculable for 337 (87.5%) responses. The median (IQR) score was 27 (25-29), indicating a very positive attitude. There were no significant differences between respondents with/without children of their own ($p=0.729$), with/without managerial function ($p=0.067$) or above/below 40 years of age ($p=0.368$). However, physicians and nurses differed significantly (27 (25-28.5) vs. 28 (25-29.3), $p=0.009$), indicating that nurses have a more positive attitude towards children as visitors.

In the open questions, respondents reported the following major barriers: concerns about the possible traumatization of the children when they see the patient, concerns about the mutual risk of infection, and increased workload of ICU staff when a child comes to visit the patient. The main facilitators to improving family-centred care practices reported by the respondents were convincing evidence, education and communication.

Discussion

In this survey about the practice of family-centred care involving nearly 400 critical care clinicians, carried out in autumn 2019 and before the Covid crisis, we found that there are differences in visiting policies between adult

and paediatric ICUs. Over one third of respondents stated that their ICUs were open 24/7, with significantly more open siting children. The most widely implemented practical aspects of family-centred care were open visiting models, the provision of information, dissemination, and other tools. Most respondents had a positive attitude towards children as visitors and mentioned specific processes and structures for enabling visits. Country-specific aspects may have an effect on the attitude of clinicians.

The low response rate of 20% raises some questions. In general, survey response rates above 60% are considered to be reliable in enabling valuable insights (Eysenbach, 2004). The response rate in the present survey is much lower. We calculated the minimum number of ICUs that would be representative of all ICUs with a 95% confidence interval and found a minimum of 321 ICUs; the number in our survey is much higher. On the other hand, the ICUs were not selected on a randomized basis, leading to a likely recruitment bias and overestimation of the implementation rate. The WFSICCM's survey was conducted using a snowball system and included 345 ICUs from 40 countries; it was not able to calculate a response rate but was published in a high-ranking journal. Our survey had fewer countries and even more ICUs, used a more stringent method, but had a low response rate (Kleinpell et al., 2018). A recruitment bias seems to be likely and should be considered when interpreting the results.

One third of the respondents' ICUs have open visiting times 24/7, with more open ICUs in the paediatric setting. Other countries reported rates ranging from 3% in Switzerland, 4% in Spain, 10% in the USA, 14% in Italy and the Netherlands, and up to 70% in Sweden (Anzoletti et al., 2008; Escudero et al., 2015; Liu et al., 2013; Speroni et al., 2015; Spreen & Schuurmans, 2011; Knutsson et al., 2004). The recent survey by the WFSICCM in 40 countries reported open visiting times in 40% of ICUs (Table E2) (Kleinpell et al., 2018). A survey of 188 ICUs in France reported nearly one quarter of ICUs being open 24/7; the authors explain this fact by an ongoing shift towards family-centred care, illustrated by an increasing volume of publications, statements and guidelines in recent years (Garrouste-Orgeas et al., 2016). Our results may confirm this shift towards family-centred care, and it might be interesting to repeat similar surveys in a couple of years to consolidate this tendency. It should be considered that asking for visiting policies is not the same as evaluating the practice of family-centred care: Milner et al. (2020) identified that more than the half of ICUs with open visiting policies had some restrictions in visiting practice. Family members are increasingly valued as surrogate decision-makers, may contribute to the quality of care and have a substantial meaning for patients, but implementation is still heterogeneous (Gerritsen et al., 2017). The differences between professions towards family-centred care might be due to a lack of organization of care, a common view or skills (Garrouste-Orgeas et al., 2008; Kleinpell et al., 2018; Knutson & Bergbom, 2007 b), but other studies found no differences (da Silva Ramos et al., 2013; Hanley & Piazza, 2012). The implementation of open visiting models is complex and can be explained by different staff perceptions and attitudes, patient protection and orientation, family and cultural considerations and organizational challenges (Ning & Cope, 2020). It is easier to introduce liberal visiting regulations for children when staff are trained accordingly (Gerritsen et al., 2017; Knutsson et al., 2008). It seems that the USA and northern European countries implement family-centred care and include children as visitors to a greater extent. The higher rates in paediatric ICUs might be explained by a different attitude of clinicians and more visits by children as siblings

The publication of these different rates for adult and paediatric clinicians might facilitate a reconsideration of policies, adoption of more open visiting policies, and updated statements by professional organizations such as the BACCN and WFSICCM. Future research should also compare different policies at an international level and consider the different viewpoints of patients and families at the local level. Open visiting policies might show no beneficial effects on patients, or may even be perceived as a conflicting burden by families, who must weigh being present at the bedside the whole day against being employed, caring for (other) children, managing the household etc. (Clarke, 2000; Riley et al., 2014; Rosa et al., 2019).

The majority of respondents to our questionnaire reported no age restrictions for visiting children. This result is similar to France, where 87% of ICUs allow children to visit, 59% of them without any age restrictions (Garrouste-Orgeas et al. 2016). This is higher than in Italy, where 22 % (Anzoletti, 2008) allow children under 12 to visit, or Sweden, with a rate of 34% (Knutsson, 2004). International heterogeneity in visiting policies towards children seems to be likely and requires further research. Current guidelines do not recommend generally admitting children as visitors, but suggest that the question should be discussed with family members (Davidson et al., 2017; Gibson et al., 2012). The evidence of benefit and harm for each population, children, parents, patients and staff is still conflicting (Capitulo et al., 2012), but a cultural change towards admitting children as visitors seems to be likely, with a paradigm shift from “supervisor-centred care” to “patient-” or “family-centred care” (Gibson et al, 2012). More research is needed to understand and thus support the specific mechanisms of cultural development in critical care.

The majority of the respondents’ paediatric ICUs offer child-centred structures like toys, colouring books or brochures. It is known that it is very important for children to have a place where they can play, to regulate their emotions and express their sorrows in a child-centred way. Children are often unable to express their feelings, but can express themselves through play, drawing and similar activities (Lanz, 2003). For children, a prolonged waiting time before the visit is perceived as difficult. It intensifies the feeling of insecurity, exclusion and separation (Knudson et al., 2008). A child-centred waiting room could make this difficult time appear shorter by offering the children an opportunity to play. The evidence relating to children’s’ visits is still weak (Gerritsen et al., 2017; Azoulay et al., 2020), representing a barrier to implementation. This area needs further research, especially in terms of the benefits and harm for all involved persons.

This article was written after the first Covid-19 outbreak in Europe. Despite existing position statements about the ethics of family-centred care in pandemics, published short before the Covid crisis (Papadimos et al., 2018), most clinicians, patients, and families felt unprepared how to deal with the crisis. Relatives were not admitted to hospitals in German-speaking countries (and elsewhere) from early March 2020, with the exception of visits to children (where only one parent was allowed as an accompanying person) or in terminal situations. In many ICUs terminal patients - especially on Covid-19 wards - were not able to receive support from relatives in their final hours because of the visiting ban.

However, this crisis shows how important and essential the integration of families in the ICU is. Unfortunately, it also shows how great human suffering is when nobody from the family can be there for the patients (Kentish-Barnes, 2021). Distributing information about ICUs on the internet for relatives (Hoffmann et al, 2019) and offering a reliable flow of information via (video) telephony may be a lifeline for relatives in these times of crisis. Hopefully, the Covid-19 crisis represents a chance to begin new and intensive discussions about visiting times and caring for families, and not the opposite (Azoulay et al., 2021).

Strengths and limitations

The study has the strength of providing an extensive overview because it was addressed to all existing ICUs in German-speaking countries. As far as the authors know, this is the only study that analysed visiting policies and family-centred care in German-speaking countries prior to the Covid-19 pandemic. Therefore, these data can be used in post-pandemic comparative data.

The main limitations, however, are the low response rate and a possible recruitment bias of visitor-positive clinicians. Therefore, we cannot make statements about the distribution of the ICUs but rather of the respondents themselves. The total number of 385 respondents provides valuable insights, but it is questionable whether the results can be generalized to all ICUs. The questionnaire has not been tested for reliability, and a repeated survey might have led to different results. On the other hand, the questions focused on existing structures and processes in the ICU and should be clear. Hence, we estimate the bias effect as minor. Furthermore, we cannot exclude the very low possibility of a double response from 3-5 single ICUs, but this would not affect the main results. Lastly, the authors are aware of their own positive attitude towards family-centred care and tried to minimize this bias by avoiding all suggestive phrases; despite this, a tendency in favour of family-centred care cannot be excluded.

CONCLUSIONS

According to participating clinicians from *adult* ICUs, open visiting policies such as *24/7 open for visitors* have been implemented in one in five ICUs. Open visiting policies have been implemented to a varying extent with significant differences between countries. Paediatric ICUs more commonly have open visiting policies, offer more visiting hours per day and employ more family-centred care practices compared to adult ICUs. In paediatric ICUs, too, visiting policies differ between countries.

These policies are adapted to multiple factors, especially national structures, processes and culture, leading to heterogeneous implementation and making comparison challenging.

In adult ICUs, most participating clinicians allowed children to visit without any age restrictions. In adult ICUs with age restrictions, teenagers but not younger children were allowed as visitors. The majority reported some degree of family-centred care activities.

Clinicians in all settings expressed the ambiguity of the possible harm to and benefits for children as visitors, with nurses having a more positive attitude. The heterogeneous results between countries and settings stimulate

reflection on our own practices and policies. The different implementation of family-centred care practices can be e Journal Pre-proofs sses. Furthermore, knowledge, consideration and implementation of guidelines, recommendations from critical care societies and increased knowledge of evidence-based medicine among participating clinicians may play a role in determining the extent and variety of family-centred care practices.

More research is needed to evaluate the benefits of practical aspects of family-centred care for patients, families, clinicians and hospitals; to estimate the possible harm of restrictive vs. open visiting policies; to evaluate the possible benefits and harm of visiting children for patients, parents, the children themselves and staff; to discover efficient methods for delivering evidence-based knowledge; and to implement and evaluate family-centred care in adult and paediatric ICUs. But more than ever there is also a need for clear recommendations from intensive care societies on how to deal with children as visitors in adult ICUs after the Covid-19 pandemic.

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Journal Pre-proofs

Table 1: Hospital data by specialization of the ICU

Item	Journal Pre-proofs			
		(n=280)	(n=21)	ICUs (n=79)
Country				
Austria	97 (25.2%)	72 (25.7%)	4 (19.0%)	20 (25.3%)
Germany	151 (39.2%)	105 (37.5%)	10 (47.6%)	34 (43.0%)
Luxembourg	129 (33.5%)	96 (34.3%)	7 (33.3%)	24 (30.4%)
Switzerland	4 (1.0%)	3 (1.1%)	0 (0.0%)	1 (1.3%)
Other	4 (1.0%)	4 (1.4%)	0 (0.0%)	0 (0.0%)
Type of hospital				
University and academic hospitals	193 (50.3)	118 (42.1)	16 (76.2)	57 (72.1)
Public hospitals	144 (37.5)	125 (44.6)	3 (14.3)	15 (19.0)
Military/government hospitals	7 (1.8)	5 (1.8)	0 (0)	2 (2.5)
Other hospitals	40 (10.4)	32 (11.4)	2 (9.5)	5 (6.3)
Discipline				
Mixed discipline	263 (69.0%)	197 (70.4)	15 (71.4)	50 (63.3)
Surgical discipline	33 (8.7)	28 (10)	5 (23.8)	0 (0)
Medical discipline	58 (15.2)	45 (16.1)	0 (0)	13 (16.5)
Other	27 (7.1)	10 (3.6)	1 (4.8)	16 (20.3)
Intensive care specialist present 24h				
Yes	328 (85.9)	240 (85.7)	18 (85.7)	68 (86.1)
No	53 (13.9%)	39 (13.9%)	3 (14.3%)	11 (13.9%)
Don't know	1 (0.3%)	1 (0.4%)	0 (0.0%)	0 (0.0%)
Hospital beds	380 (205-783)	387 (245-761.5)	292 (117.5-1200)	360 (200-742)
ICU beds	10 (8-16)	10 (8-16)	10 (9-16)	10.5 (8-16)
ICU admissions per year	800 (500-1368)	950 (600-1500)	550 (395-925)	475 (300-700)
ICU length of stay (days)	4.0 (3.0-6.4)	3.9 (2.6-5.0)	5.0 (4.2-7.0)	8.0 (5.0-16.5)
ICU mortality (%)	5.0 (2.5-10.0)	8.0 (4.0-15.0)	4.0 (1.4-5.8)	2.0 (1.0-3.9)

^a Data are reported as n (%) or median (IQR). Due to missing data, the sum of observations does not always add up to the column total. Missing values were not considered in the denominator for calculation of percentages. Proportions may not add up to 100% due to rounding.

^b Total column contains 5 additional observations with unknown type of ICU.

Table 2: Extent to which family-centred care practices have been adopted in the ICU

Item	Journal Pre-proofs			
	adopted	adopted	adopted	data
Disseminating information and providing support to families regarding ways of assisting with the care of their loved one (i.e. providing assistance with oral care, mobility or nutrition)	39 (10.1)	152 (39.5)	166 (43.1)	28 (7.3)
Open visiting (flexible family presence or non-restricted ICU hours)	65 (16.9)	132 (34.3)	161 (41.8)	27 (7)
Does your hospital utilize any additional patient- and family-centred care or practices?	83 (21.6)	160 (41.6)	115 (29.9)	27 (7)
Patient and/or family ICU diaries	172 (44.7)	88 (22.9)	100 (26)	25 (6.5)
Structured patient and family care conferences to jointly establish or review the goals of care for all patients with a high risk of mortality or a prolonged ICU stay	97 (25.2)	182 (47.3)	81 (21)	25 (6.5)
Integrative therapies, such as music or pets, in the ICU	221 (57.4)	88 (22.9)	50 (13)	26 (6.8)
Family presence during resuscitation	221 (57.4)	85 (22.1)	49 (12.7)	30 (7.8)
Family participation in rounds (family-centred rounds that enable the family member to listen to rounds and participate by offering information and/or asking questions)	192 (49.9)	120 (31.2)	48 (12.5)	25 (6.5)
A functioning patient and family advisory group that meets regularly	268 (69.9)	62 (16.1)	28 (7.3)	27 (7)
Family presence during invasive procedures	248 (64.4)	90 (23.4)	19 (4.9)	28 (7.3)

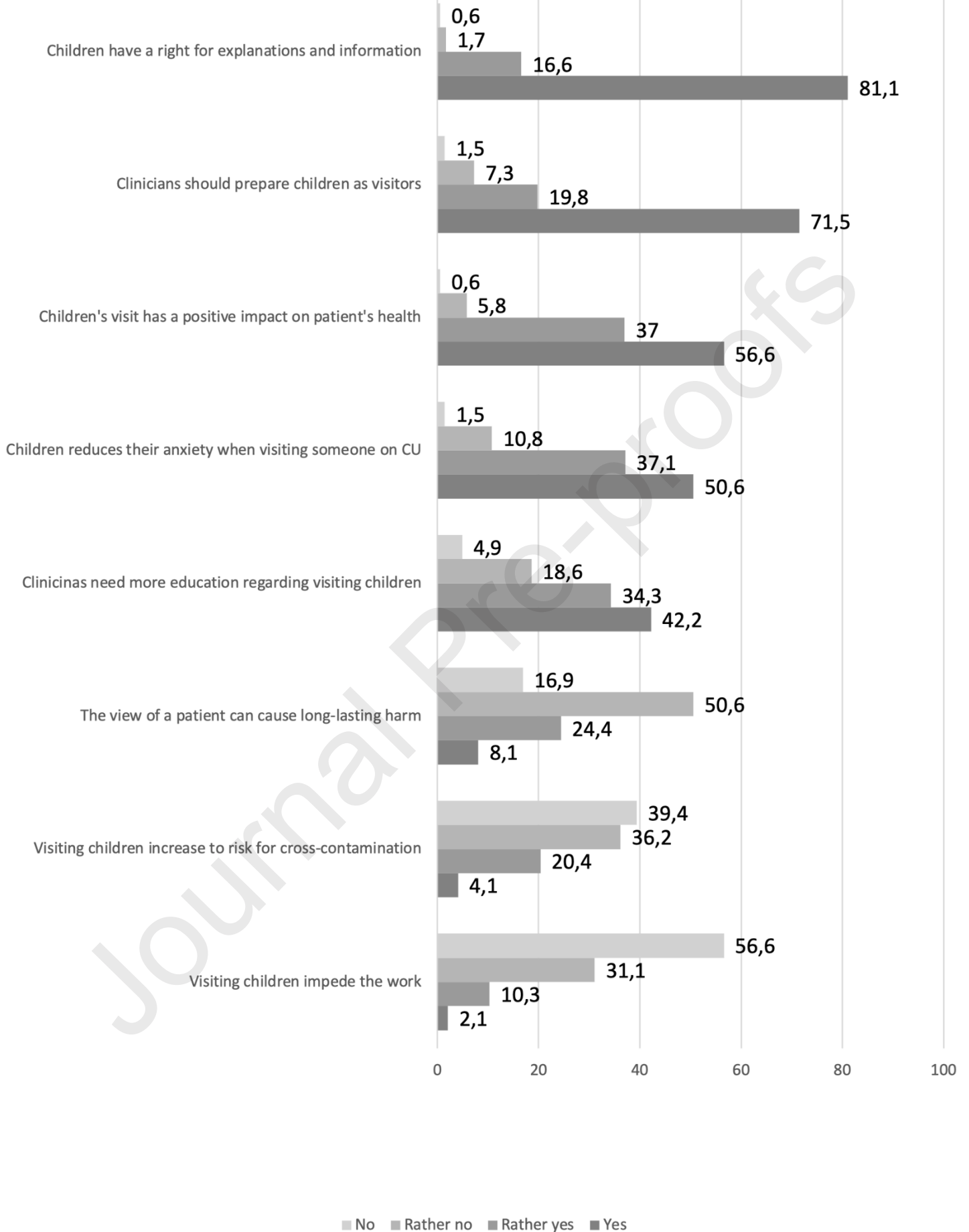
^a Data are reported as n (%). Proportions may not add up to 100% due to rounding.

Table 3: Structures and processes for visiting children by specialization of the ICU

Item	Journal Pre-proofs			
	(n=385) ^b	(n=280)	(n=21)	ICUs (n=79)
Structures provided				
Toys	94 (24.4)	34 (12.1)	10 (47.6)	50 (63.3)
Colouring books	89 (23.1)	37 (13.2)	6 (28.6)	46 (58.2)
Books	79 (20.5)	31 (11.1)	6 (28.6)	42 (53.2)
Brochures	67 (17.4)	35 (12.5)	6 (28.6)	25 (31.6)
Furniture for children	23 (6.0)	2 (0.7)	4 (19.0)	17 (21.5)
Scrubs for children	19 (4.9)	5 (1.8)	3 (14.3)	11 (13.9)
Information on the internet	15 (3.9)	5 (1.8)	3 (14.3)	6 (7.6)
Movies	13 (3.4)	2 (0.7)	2 (9.5)	9 (11.4)
Other	34 (8.8)	23 (8.2)	2 (9.5)	7 (8.9)
Nothing	174 (45.2)	155 (55.4)	8 (38.1)	9 (11.4)
Processes provided				
Attendance of adults during the visit	246 (63.9)	179 (63.9)	12 (57.1)	54 (68.4)
Preparatory talk	165 (42.9)	137 (48.9)	7 (33.3)	18 (22.8)
Talk after the visit	69 (17.9)	63 (22.5)	0 (0)	6 (7.6)
Attendance of specialized clinician	28 (7.3)	20 (7.1)	2 (9.5)	6 (7.6)
Visit without attending adults	27 (7.0)	19 (6.8)	1 (4.8)	6 (7.6)
Presence of a child-care worker	22 (5.7)	13 (4.6)	2 (9.5)	7 (8.9)
Other	19 (4.9)	10 (3.6)	3 (14.3)	6 (7.6)
Nothing	42 (10.9)	32 (11.4)	2 (9.5)	8 (10.1)

^a Data are reported as n (%). Since participants had multiple choices, percentages refer to column totals.

^b Total column contains 5 additional observations with unknown type of ICU.



Objectives

To pr Journal Pre-proofs ors in
Intensive Care Units (ICUs) in German-speaking countries.

Methods / Design

Online-survey with a mixed approach were used. Leading clinicians (n=1,943) from German-speaking countries were invited to participate. Outcomes included the percentage of ICUs with open visiting policies, age restrictions, family-centred care activities and barriers.

Setting

Paediatric, mixed and adult ICUs.

Results

In total, 19.8% (n=385) of the clinicians responded. Open visiting times were reported by 36.3% (n=117), with significant differences between paediatric (79.2%), adult (21.3%) and mixed-age (41.2%) ICUs ($p<0.001$). Two-thirds of clinicians stated that their ICUs had no age restrictions for visiting children as visitors (n=221, 68.4%). The family-centred care activities most frequently implemented were open visiting times and dissemination of information. Significantly more German ICUs have open visiting policies and more Swiss ICUs allow children as visitors, compared to the other countries (both $p<0.001$). Barriers to family-centred care were concerns about children being traumatized, infection and workload.

Conclusion

The majority reported that family-centred care policies had been implemented in their ICUs, including open visiting policies, allowing children as visitors without age restriction and other family-centred care activities.

Keywords: Attitude, Child, Crisis Intervention, Critical Care, Patient-Centered Care, Family, Visitors to Patients

Ethical Statement

Title:

Practice of Family-centred Care in Intensive Care Units before the COVID-19-Pandemic: a cross-sectional analysis in German-speaking countries

Ethical Statement: Not applicable

Clinical Trial registration number: Not applicable