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Title: Family presence in Canadian PICUs during the COVID-19 pandemic: a mixed methods environmental scan of policy and practice
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Reviewer 1
General comments (author response in bold)

1. Overall comments : Descriptive study of family presence in Pediatric ICUs during COVID-19 pandemic. Sample restricted to physicians chief and operation managers.

Cross-sectional nature of the sample (vs. longitudinal design including if/when restrictions loosened) would have been insightful. Impact of the findings beyond COVID-19 not clear. Impact on patient and families is central to the argument brought forward by the research team, but the study would have been much more powerful by including them in the survey.
We thank the reviewer for the time taken with this manuscript. As can be seen, we have made many changes to make the intention of the work clearer. The impact of the restrictions on patients and families is central to the rational for this study, though the present work was done to describe the environment of policies and practices and therefore provide context for any future work examining the impacts on families and patients. Improvements to the design and implementation of policies and practices must be done with an understanding of "where we have been". By providing as thorough a description of the restrictions as possible, we hope to assist the pediatric community in identifying the most problematic components and finding ways to ameliorate future policy and practice.
Our group has completed data collection for both a survey and a qualitative descriptive study of family member experience with restrictions in PICUs, and we are currently enrolling participants in a phenomenologic study of pediatric PICU patient experience with family presence and restrictions. We are eager to share what we have learned about the experiences and impacts.

2. Abstract
Well written, clear.
We thank the reviewer for the comment. We have had to make multiple changes to the abstract in keeping with the overall manuscript changes and hope the current abstract retains the clarity.

3. Introduction
Well-written. Brief mention of a similar study in the U.S. More data (if available) from other jurisdictions would have been welcome. And while I understand the rationale for looking at PICU specifically, the literature review could be broadened to include inpatient wards and or NICU.
We thank the reviewer for this comment and agree that there is a need for broader literature review. The US data did examine US children's hospitals in general. We have added mention of NICU-specific policies (Mahoney, 2020) in the introduction and discussion. Additionally, since the review of this paper, an environmental scan of the policies in Canadian adult ICUs has become available (Fiest, 2021),

and an international survey of PICU policies was published (Camporesi, 2021). We have referenced and discussed these works. (Addition of PICU-specific references for restrictions: Introduction, lines 107-108; Interpretation, lines 321, 338, 348. Addition of NICU-specific references for restrictions: Introduction, line 106; Interpretation, paragraph 2, line 338. Discussion of policies in children's hospitals: Introduction, lines 107-108)

Methods

4. Interviews were conducted from Aug et Dec 2020 but was the evolution of policies between March 2020 and the period of interview considered, or only the 1st wave of the pandemic (March-May 2020) considered?
We thank the reviewer for the question. We did seek to understand the evolution that had occurred from the beginning of the pandemic to the time of the interview. We asked participants about changes to specific aspects of the policies at the time of interview. These changes over time are outlined in tables 3, 4, and 6. (Description of eras being queried: Methods, Data Sources, Survey Questionnaire, Lines 159-160; Appendix 1, question 28; Changes to policy elements: Table 3; Changes to rounding practices: Table 4; Changes to PPE requirements in patient room: Table 6)

5. It is not clear if the data collected was more factual or perception-based? It seems like some data was qualitative, yet there is no formal qualitative data analysis method described.
We thank the reviewer for pointing this out. This comment is in keeping with the editor's comments, and led our team to reconsider our analysis and study type. We have now more formally presented the document review portion of the environmental scan which presents factual information.
The survey presented a perception of practices. Although we had intended and hoped that it would have presented actual practices, and we had asked PICU leaders to check their documents, policies, and to send us actual policies wherever possible, we still noted discrepancies between chiefs and managers in the recollection and/or perception of policy. Therefore, it is a presentation of the perceptions of policy. We have indicated this through the results.
In addition, we have formalized the analysis of open-ended questions and described this in the methods. (Indication that survey results are perception of policy: Results, Survey results, pandemic policy creation and dissemination, Line 212; Results, Survey results, policy and practice elements, Lines 251-255; Results, survey results, policy exceptions, Line 300; Interpretation, Lines 385-88. Description of qualitative analysis of open-ended questions: Methods, Data Analysis, Lines 186-190)

Results

6. The quotations starting each section of the results is from a participant?
We have noted that there are problems with using these quotations, which were used primarily for poignancy and interest but do not add to the results in a significant way. Therefore we have removed these quotations. (Removal of quotations: Results, start of each section, lines 211, 224-225, 236-240, 257-258, 285-288)

7. Sentence like “Restrictions changed through the pandemic as disease understanding and local epidemiology fluctuated” hint to the fact that policies did change and vary by unit, but are too vague to draw useful insight.
We appreciate this feedback and removed the sentence. Instead, we have inserted several sentences indicating perceived changes through the pandemic. (Removed vague sentence: Results, survey results, policy and practice elements, Line 255-256.)

8. The agreement/disagreement within a given unit and the reason for them is not explored. While it may reflect different experience, it leaves the reader wondering if the methods used for the study (semi-structured interview) contributed to these puzzling results.
The reviewer raises an excellent point. We agree that the disagreements were puzzling. We have explored the reason only briefly in the discussion as a result of word limitations.
While we do agree that the different experience and perception of both policy and practice likely led to the differences in results, we cannot provide useful comment on whether researcher-administration of the surveys contributed to the discrepancies. We did encourage all participants to check the policies and any communications they had received with respect to them before completing the survey, enabled looking up answers during the survey (and some respondents did) and after the survey was complete we encouraged participants to look up answers they hadn’t known and either send us changes or change their answers when we had sent the completed form for response verification. We have included a sentence to describe some of this process. (Consideration of reasons for agreement/disagreement within a given unit: Interpretations, Lines 350-362. Description of encouragement of participants to look up and provide factual information: Methods, Setting, Lines 168-169)

9. Figure 1&2: Here there is a mention of early vs. late COVID period, but this is not mentioned anywhere else in the manuscript. My copy of Figures 1 & 2 includes acronyms that are both incomplete (PU??) and not described in the legend
We have removed the two figures and included the data in a table of pandemic-related practices. As in point #4, the two periods (early pandemic and mid, at the time of interview) have been outlined in the manuscript. (Removed Figures 1 and 2. Inserted Table 4)

Reviewer 2
General comments (author response in bold)

Introduction

1. p.4 l.71. I don’t understand the utilitarian approach rather than based on the precautionary principle, the references doesn’t seem appropriately quoted (link with the editorial from Michael Klompass?)
We appreciate the argument the reviewer is making, and we certainly did not wish to suggest that there was no need to implement restrictions. We have removed the relevant sentence. (Removed sentence: Introduction, lines 90-92.)

Methods

2. Structured questionnaire administered via interviews (phone/virtual) 8-12/2020 Study design is appropriate. Building of the questionnaire and pre-testing well done.
Research question is clear.
Observational, non-statistic.
Which are the units who participated? How were they chosen? Are they representative of the whole country? This should be mentioned in the text.
We appreciate the reviewer pointing out that we were not clear enough in our description that this study included all Canadian PICUs. We have included all 19 PICUs in Canada, which are within 17 hospitals. We have clarified that this is all PICUs in the description of our sampling frame. We have described that we interviewed at least one representative from all of the Canadian PICUs (100%) in the results. (Clarified that we included all Canadian PICUs: Abstract, methods, line 53; Abstract, results, line 63; Methods, Data sources, sampling frame, 134-135. Indicated that all PICUs were represented by at least one chief or manager in the survey: Results, Survey results, lines 207-208; Interpretations, lines 379-380.)

Results

3. Participation good: 100% of units, however less than half managers (9/19) Do we observe provincial differences?
The reviewer has asked a reasonable question. Managers were represented in each region (1*Atlantic, 1*Quebec, 3*Ontario, 3*Prairie, 1*Pacific), as were chiefs. We have not, however, done a formal assessment of provincial differences and so we have not presented this data.

4. Interestingly, responders from only 2 institutions perceived that families had been consulted for overall PICU specific visiting policies (top down before the pandemic)
In table 2, where pre-pandemic practices were highly heterogeneous between units, they became quite uniform during the pandemic but evolved in a heterogeneous way in the "evolved pandemic practice". This questions about local cultures of units and the way they deal with family presence. It would be interesting to see if the units initially more open were also the ones which evolved with a more liberal family presence policy during the pandemic.
We agree entirely with the reviewer. It was both interesting and disappointing that most respondents did not perceive that families had been consulted for pandemic-related policies.
The reviewer raises a very interesting point – do the units that start pre-pandemic with liberal presence policies also evolve to more liberal policies through the pandemic?
While we do not have adequate data to analyse this formally, we have added a descriptive comparison of pre- and mid-pandemic number allowed at the bedside. All 5 respondents who indicated unlimited pre-pandemic presence had relaxed to 2 support people (non-COVID-19 patients) mid-pandemic. Three (38%) of the 8 respondents who perceived strict pre-pandemic limitations to 2 at the bedside indicated ongoing mid-pandemic restrictions to 1.
The other elements of the policies – switching, who can switch, frequency of switches, ability for family members to move around the hospital, sibling presence – would require complex cross comparisons and are beyond the scope of this description. (Added descriptive comparison of number allowed at bedside pre-pandemic to mid-pandemic for units that were liberal versus strict at a baseline: Results, survey results, policy and practice elements, Lines 252-255)

5. The mobility restriction problems are very interesting to explore, and it would be noteworthy to explore if these problems resulted in modified practice in the units where they were noted.
The reviewer raises another excellent idea for consideration. We have assessed this in our descriptive qualitative study of healthcare provider and family member experience which we are hoping to have published within the next year.

6. Figures: Somehow difficult to read. Legends (ie: Bedside/outside door) should be aligned under the 2 groups they define (Non.COVID-19 / COVID-19 +/PUI) Define abbreviations: FCC, PUI
We have taken this feedback and that of other reviewers and have removed the figures and instead placed the data about rounds into a table. (Removed Figures 1 and 2. Added data to Table 4.)

7. Rounding practice:
Interesting to see the evolution through time and the use of communication technologies not being a success or adapted to many families over time.
Poor agreement between respondents regarding the participation of parents during rounds and the use of alternate technologies seriously challenges these results and highlight possible communication problems within units. This poor agreement is an element that would deserve further reflections and discussions in regard of how such policies are implemented and experienced in the clinical setting. Regarding rounds, could this mean that parent's participation is also highly dependent on the personal values of the intensivist leading the rounds?
We agree with the reviewer on these points. The poor agreement between the 5 chiefs and managers on elements of non-policy-based practice – rounding practice including family involvement, ability of family members to leave their room – does highlight potential communication problems within units. We postulate that the managers were aware of the policy elements and what was planned to be done while chiefs, who practice at the bedside and tend to interact more directly with families and healthcare teams in clinical practice, were likely more aware of actual practice. We also agree that parental participation in rounds is likely dependent on the intensivist or charge nurse on service on a given day, and therefore it is possible that the chief perception of family involvement may be dependent on their own practice. We have added to the discussion of these point in our interpretations.
…we did note multiple discrepancies across eras. This may arise from differences between leaders who do and do not work at the bedside, differences in bedside practice and experiences, or may reflect communication breakdown and underscore a need within organizations to ensure alignment between policy and practice (39,40). (Brief discussion of possible reasons for discrepancies: Interpretations, lines 356-360)

8. Policy exceptions: The fact that 75% of respondents were unaware of a list of acceptable reasons for exceptions is troubling. Do the authors have a way of comparing these results with the actual policies of each institution?
On reanalysis with double coding, we found that 83% were unaware of an initial list of acceptable reasons for exceptions, though this was reasons beyond end of life. All 24 leaders (100%) indicated that exceptions would be made at end of life. 10/19 hospitals' publicly accessible early pandemic policy information indicated

that exceptions would be made for end of life or extenuating circumstances. It is possible that those hospitals that did not publicly announce exceptions at end of life still had an informal approach to it, but we do not have this information. Unfortunately, none of the publicly-accessible documents mentioned a list of allowable exceptions. We have adjusted the presentation of the survey results related to exceptions to read as follows:
Although most respondents were not aware of a list of acceptable reasons for exceptions (n=20, 83%), all leaders (n=24, 100%) indicated that exceptions were needed in extenuating circumstances and would be granted at the end of life.
(Clarified respondent knowledge of list vs. allowances for end of life. Results, Survey results, Policy exceptions, Lines 294-296.)

9. Overall, this is a very interesting article, giving insight on a relatively poorly documented practice of how visiting policies evolve during critical situations. It shows important discordances among units and within units with many disagreements between leaders.
It would have been interesting to compare these practices with the actual written policies of such units, although I understand it would have been quite a different process.
We thank the reviewer for these comments, and agree that a more formal comparison with the policies of the units would be preferable. Despite asking all survey respondents for copies of their unit policies, we did not receive any of these outside our own institutions', and so limited the presentation of results to those that were publicly accessible. We also made the decision to present publicly accessible rules and policy because this information would have determined parental decision-making. All of the clinicians on the research team had experienced turning away a parent who had driven over 100km to see their critically ill child, fully expecting that they could be at the bedside of their critically ill child. The information provided by hospitals and PICUs to the public matters.

10. It is important to pursue such studies to emphasize the importance of FCC, in this regard, it would certainly have been significant to have included patients-partners in the design, analysis and discussion of these results.
We completely agree with the reviewer's point, and so we did include patient partners. We have two patient partners who were involved in the design and interpretation of this study, and three patient partners (including a youth) who are involved in the design, analysis, and interpretation of the other studies in our program of research on COVID-19-related restricted family presence. We have added clearer information about the patient partner to the methods section.
(Added information about role of patient partners: Methods, design, lines 131-132)

11. Although evaluating situations in PICUS, main results can be easily transposed to other settings, the pediatric settings adding supplemental challenges in contrast with some adult settings.
We thank the reviewer for this observation.

Reviewer 3
General comments (author response in bold)

The authors surveyed PICUs across Canada to determine the impacts of COVID-19 on their family presence policies. As is well established, the presence of parents or guardians in a PICU can have positive impacts on both the child socially and on their

health outcomes. This article is timely because it is unclear what impact any restrictions related to COVID-19, including general hospital policies, had on families' abilities to visit and stay with their children who were admitted to PICU. The article has several strengths, including the involvement of an established research network and the team's ability to get data from all PICUs across Canada. Overall, the article makes a useful contribution to the literature in this area. Listed below are some suggestions to consider for improving the article.

Abstract

1. Awkward sentence: "Pre-pandemic, all units reported 2 or more family members and a high degree of flexibility for siblings, extended family, and visitors."
We thank the reviewer for noting this and have changed the sentence as follows in the next comment. We believe that the two sentences together are clear.
Pre-COVID-19, all units allowed presence of ≥2 family members. (Changed sentence: Abstract, lines 68-69)

2. Unclear: "Reported initial pandemic practices limited presence to 1 (88% COVID-19 negative, 96% COVID-19+/suspect), or 2 adult support people with no siblings (100%)."
We thank the reviewer for noting this and, with accompanying changes to the preceding sentence, believe that the two sentences are now clear. Changes to the sentence in this comment are:
Reported initial pandemic practices limited presence to 1 (n=21[88%] non-COVID-19, n=23[96%] COVID-19+/suspect), or 2 adult support people, and no siblings (n=24[100%]).
Together the sentences now read:
Pre-COVID-19, all units allowed presence of ≥2 family members. Reported initial pandemic practices limited presence to 1 (n=21[88%] non-COVID-19, n=23[96%] COVID-19+/suspect) or 2 adult support people, and no siblings (n=24[100%]).
(Changed sentence: Abstract lines 69-71)

3. Unclear: "Restrictive, top-down policies limited family-centeredness of care, though demonstrated responsiveness."
We have attempted to improve the clarity of this statement which now reads:
Restrictions may have threatened family centered care, though were adapted
(Changed sentence: Abstract, lines 79-81)

Methods

4. You could move this line to the end of the methods section. "The Research Ethics and Institutional Review Board of IWK Health approved this study (REB #1025836)."
We thank the reviewer for this suggestion and have moved the sentence to the end of the methods section, under the subheading: Ethics approval (Moved line regarding ethics approval to the end of the methods section: Methods, Ethics approval, lines 195-196)

5. "the interview through the following domains: family presence policy and practice; pandemic policy creation and dissemination; patient care rounds ("rounds"); intra-hospital mobility; and personal protective equipment." Check to see if this description reflects the objectives identified in the introduction. For example, one talks of patient

care rounds as being a priority, the other granting exceptions. The data on PPE / safety measures does not appear to be reported on in the article.
We thank the reviewer for noting this discrepancy. We have adjusted our statement of objective to be broader and to encompass the concepts within the domains that were developed:
Thus, we designed this study to describe COVID-19 pandemic-related family presence policies and practices in Canadian PICUs, including their development, dissemination, and variation.
We did include policy exceptions in our original description of domains ("family presence policy and practice; pandemic policy creation and dissemination; patient care rounds ("rounds"); intra-hospital mobility; policy exceptions; and personal protective equipment") and so have not made changes at this location. We have added a table to describe the results of questions related to PPE, and a description of this table in the results. (Changed wording to encompass the broader concept of our objective: Introduction, lines 112-113. Added description of PPE through a table: Results, survey results, screening and PPE, lines 305-306. Added table describing reported screening and PPE requirements: Table 6)

6. There are no references given to support any of the study team's methodological choices.
We have modified the study design from the time of this review. We have formalized the process as an environmental scan, and have provided a reference for this, as our study followed the option of both a document search/literature review and a survey.
For the development of the survey, we followed the methods of Burns et al (CMAJ, 2008) and have added this reference to the manuscript.
For our approach to analysis of open-ended questions, we used a general inductive approach, as outlined by Thomas (Am J Eval, 2006). We have added this reference in the methods. (Environmental scan reference: Methods, design, line 124. Survey development reference: methods, Data sources, survey questionnaire, line 157. Qualitative analysis of open-ended questions: Methods, Data analysis, Line 186-190)

7. Given that they were qualitative interviews, was there any coding conducted on the participants' elaborations? It is another potential source of data for the study.
We thank the reviewer for pointing this out. We had not intended the interviews to be qualitative, but rather researcher-administration of the questionnaire. Our epistemological orientation was positivistic, and so we did not ask participants for their thought, experience, opinions, or meanings they placed on the data they were providing about policies and practices; only what the practice was (recognizing that our results provide the participants' perception of practice, rather than actual practice).
We did include multiple methodologic choices that are frequently associated with purely qualitative inquiry (e.g. audio recording, response verification) and we included participant quotes and we understand that we were not clear enough in our description of our methods.
We have addressed this issue by 1. Re-analysis of all open-ended data using a more formal qualitative approach; 2. Removal of quotes; 3. Improved description of our methods of analysis for the open-ended questions (see response to #6). Therefore, we did not analyse or code the participants' elaborations beyond answers to the questionnaire. We had identified several quotes that seemed rather

poignant, but as we did not perform a formal analysis of other quotes or elaborations, we have removed these from the manuscript. (Description of analysis of open ended questions: Methods, data analysis, Lines 186-190. Removed quotes: Results, start of each section, lines 211, 224-225, 236-240, 257-258, 285-288)

8. Describe how the quotes used in the results section were selected.
As in # 7, we recognize that our approach to these quotes was not systematic and have removed them. (Removed quotes: Results, start of each section, lines 211, 224-225, 236-240, 257-258, 285-288)

9. "Where perceptions rather than actual or verifiable policy were solicited, we presented results for all respondents followed by the % agreement for the units with chief/manager dyad response." Please expand on why and what you did here. My sense is that reporting this level of agreement throughout is a little confusing. I wonder if it is better to discuss this issue only when there is a disagreement, maybe as a potential limitation to the article's findings.
We thank the reviewer for pointing out potential confusions around this point. We have endeavoured to make it clearer. We have removed the sentence in question and replaced it in the analysis description with the following:
For questions with chief/manager dyad responses, we calculated the % agreement.
We have expanded on why it was important to seek agreement and demonstrate the disagreement between the chief/manager dyads.
"We purposively invited both the chief and manager of all 19 Canadian PICUs, targeting a census of PICU practice and to examine consistency of responses."
"As previous descriptions of visitation policy have relied on the report of single institutional representatives(25,31,41), we sought to examine consistency of manager-chief dyad responses and noted multiple discrepancies across eras. This may arise from differences between leaders who do and do not work at the bedside, differences in bedside practice and experiences, or may reflect communication breakdown and underscore a need within organizations to ensure alignment between policy and practice (42,43)"
We recognize that the reporting of the chief-manager agreement was confusing when we have only reported the results of a few respondents (e.g., where 2 respondents perceived that PICU families were consulted in designing PICU policies and the remainder did not perceive that they had been consulted, and chief-manager agreement is 80%, it is confusing to only report the results of the two respondents but the chief-manager agreement for the entire sample. Therefore, we have removed reporting of chief-manager agreement where this occurs.
We have added a sentence in the discussion to address the limitation in our ability to interpret the findings that arises from chief-manager dyad disagreements:
As the questionnaire provided perceptions of the PICU leadership and we demonstrated multiple disagreements within units, policy-based information must be interpreted cautiously. (Altered description: Methods, data analysis, line 184-5. Explain that we intended to seek consistency of responses: Methods, Participants, Line 171. Discussion of importance of examining more than one respondent per centre for an environmental scan: Interpretation, lines 347-360. Remove reporting of chief-manager agreement where the results of the entire sample are not specified: Results, Lines 218-222. Added to study limitations: Interpretations, limitations, lines 385-388)

10. “Regarding PICU-specific policies, two respondents (8%) from 2 institutions (chief-manager agreement 80% perceived that PICU families were consulted.” If there are only 2 respondents from 2 different institutions, why is there agreement reported for them? I thought this agreement was only for dyads at the same institution.
We understand the reviewer’s point here and agree that it was presented in a confusing way. We have addressed this point in #9, above, and have removed the reference to chief-manager agreement. (Remove reporting of chief-manager agreement where the results of the entire sample are not specified: Results, Lines 218-222.)

11. “Inter-hospital policy variation existed pre-pandemic and marked variation in development, communication, implementation, and practice of pandemic-related policies existed even within the same hospital, city, or province.” This variation within the same hospital, city, or province should be presented in the results or referenced.
We thank the reviewer for pointing out that this sentence is not backed by results. We have removed this sentence from the Interpretations (Removed relevant sentence: Interpretations, lines 312-316)

12. Another limitation was that you never talked with families affected by this policy, who likely could have given another valuable perspective.
We whole-heartedly agree with the reviewer on this point. For this study we did not speak with families, as the intention was to define the policies and practices. We believe that the family members’ perspective on the impact of the policies, and their narratives of experience are of utmost importance when assessing the policies and practices. As such, our research group has completed data collection for both a survey of family member experience and the impact of the restricted family presence policies (in manuscript preparation), and a qualitative descriptive study of the experience and impact of restrictions on family members (data analysis ongoing). We hope to present this data in separate manuscripts within the year.

13. I would probably only include either Figure 1 or Figure 2 in the text, with the other figure as an appendix.
We agree with the reviewer. All reviewers have commented on these figures, and we have removed them from the manuscript and presented the data in a table of practices instead. (Removed Figures 1 and 2. Added data related to family presence practice (rounding) to Table 4: Family presence practices)

14. Maybe include Figure 3 as an appendix.
We have taken this suggestion into consideration. After eliminating the other 2 figures, and recognizing that the journal has an online format, we have kept this figure as a Figure, now labeled Figure 1. However, if the editor believes the figure would be better suited as Appendix 4, we are fine with this.

15. Define the abbreviations PUI and FCC in the text.
We thank the reviewer for pointing out undefined abbreviations. We have removed all references to PUIs (person under investigation) and have defined FCC as family centered care. As this is the only instance, we have removed the abbreviation (Spelled out family centered care: Interpretations, line 329)