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Position statement of the international network for child and family centered care: Child and family centred care during the COVID19 pandemic

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ABSTRACT

It is the position of the International Network for Child and Family Centered Care (INCFCC) that COVID19 restrictions pose tremendous challenges for the health care team in their efforts to provide child and family centered care (CFCC). COVID-19 restrictions impact on the family's right to be present with their ill child and to contribute to the caring process. A limited number of articles have discussed challenges about the successful delivery of CFCC during the COVID-19 pandemic. Based on current literature, the INCFCC stresses the need for continuous facilitation implementation of child and family centred care as, it is essential for children's physical and psychological wellbeing. Furthermore we believe that the families' presence and participation holds more benefits than risks to the health of children, their families, and the health care team.

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Position

It is the position of the International Network for Child and Family Centered Care (INCFCC) that COVID19 restrictions pose tremendous challenges for the health care team in their efforts to provide child and family centered care (CFCC). COVID-19 restrictions impact on the family's right to be present with their ill child and to contribute to the caring process. A limited number of articles have discussed challenges about the successful delivery of CFCC during the COVID-19 pandemic, namely shortage of personnel, failure to integrate technology into care, and adhering to strict regulations made by various authorities (Frampton et al., 2020; Murray & Swanson, 2020; Raphael et al., 2021). Based on current literature, the INCFCC stresses the need for continuous facilitation implementation of child and family centred care as, it is

essential for children's physical and psychological wellbeing. Furthermore we believe that the families' presence and participation holds more benefits than risks to the health of children, their families, and the health care team. Our position reflects the underpinning philosophical stance of the *American Academy of Pediatrics (AAP) (2020)* and the *Royal College of Pediatrics and Child Health (2021)*. Where children are concerned, decision makers should not only consider the risks of family presence, but also the risks of their absence. Therefore the INCFCC recommends that health care organizations support CFCC and advise on strategies to reduce the barriers that arise with COVID19 restrictions. It is the general presumption that family involvement during this pandemic carries additional challenges beyond those that already exist with CFCC. To address this issue, it is important to start with the shared goals of all members of the health care team. The Position Statement presented in this article is consistent with the World Health Organization (WHO) whose recommendations emphasize that, "All countries must strike a fine balance between protecting health, minimizing

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economic and social disruption, and respecting human rights” (WHO, 2020, p.1).

Introduction

The unpredictable circumstances, and the abrupt implementation of rapid containment procedures and policies implemented worldwide due to the COVID-19 pandemic have significantly affected the way healthcare is delivered, with children's hospitals being equally affected (Lemmon et al., 2020). Although the number of infected children was low, the COVID-19 restrictions affected pediatric nursing through adversely impacting the core principles of child and family centered care (Tedesco et al., 2021). Many pediatric units restricted families' presence at the bedside across all age groups (neonates to adolescents), and at all levels of health care (from primary to tertiary care, and from prevention to palliation) (Dokken & Ahmann, 2020). Although these restrictions were brought in to decrease the spread of the virus, they essentially prevented the delivery of CFCC due to the families' inability to participate in care, which resulted in separation anxiety, increased psychological and emotional distress, and loss of family continuity, advocacy, and decision-making (Andrist et al., 2020; Bainter et al., 2020). A survey of 227 health care organizations found that hospital COVID-19 restrictions significantly limited parental presence for infants in the Neonatal Intensive Care Unit (NICU) that consequently limited parental participation in care (Darcy Mahoney et al., 2020). In some settings, mother-child bonding and attachment were affected as for example, newborn babies were separated at birth from their mothers who tested positive to COVID-19 and were only reunited when their mothers tested negative (Centers for Disease Control and Prevention [CDC], 2020). The Chair of the International Alliance of Patients' Organizations (IAPO) reported that COVID-19 has greatly altered the patient experience, shifting people more than ever from an active to a passive role in their health care, especially in the initial stages of the pandemic (IAPO, 2020). The pandemic has also posed tremendous burdens on pediatric health care professionals both physically (Quigley et al., 2020) and mentally (Chen et al., 2020; Rana et al., 2020). These burdens required changes and adaptations while ensuring continuity of care for children and their families. It has been recommended that adaptations to health care systems due to the COVID-19 pandemic requires input from experts, clinicians, and clients for more comprehensive and inclusive delivery of care (Montes & Herranz-Rubia, 2020). As an international group, the INCFCC is working to highlight the challenges for children and families in accessing health care due to the COVID-19 policy restrictions. A set of recommendations to promote and foster the inclusion of families in the caring process is proposed. To ensure optimum CFCC, the health care system, the health care professionals, children and their family members must collaborate in the most highly efficient and coordinated way, using every tool at their disposal to deliver CFCC, while keeping everyone healthy and safe.

This paper examines the quality of the CFCC approach as a model established around the collaborative presence of the health care team, the affected child, and their family (Foster & Shields, 2020). The general scene in the pre-COVID-19 era was that “family members were always available and at the bedside of their ill child”, but with COVID19 restrictions the scene has changed. Thus the question that needs to be asked, is: have the core components of CFCC been jeopardized since then, and how have the subsequent challenges been addressed? This international position paper provides recommendations on actual measures to be taken/ followed to ensure CFCC is provided to children and their families while ensuring necessary safety during the restrictions and regulations that govern this pandemic.

International network for child and family centered care (INCFCC)

Formally established in 2017, the INCFCC is an international collaboration of nurse-academics and practitioners working with children and

families, and serves as an expert group to provide professionals and international personnel with information on a variety of cultural practices and initiatives on CFCC, and through regularly distributing updates about CFCC (Foster et al., 2018; International Network for Child and Family Centred Care, 2020). This includes communicating, discussing, and debating research and clinical practice concerning CFCC. The INCFCC produced this position paper following discussions during our network meetings concerning the impact of the COVID-19 pandemic on CFCC, and how this may affect the quality of care provided to children and their families. The paper reflects the objectives of INCFCC as an international network to provide discussion, knowledge exchange, and collaborative research from an internationally informed perspective. This paper is primarily concerned about the COVID-19 pandemic and the challenges it poses for pediatric health care delivery.

Child and family centered care and COVID-19

The active participation of children and families is a key concept in the delivery of CFCC in the pediatric setting (Carter et al., 2014; Coyne et al., 2016). It refers to both the children's and family members' participation in the decision-making and the care, which includes their physical presence during doctors' ward rounds, during simple procedures, and during active care delivery. While CFCC emphasizes the positive aspects of the interaction of family members during the caring process, particular problems arise associated with the COVID-19 restrictions (CDC, 2020). In response to COVID-19, Hart et al. (2020) provided a toolbox of strategies for both communication with, and engagement of families, during physical distancing. Although it was acknowledged that FCC “is more, not less, important during a pandemic” (p. e96), Hart et al. recommended that families should be supported in non-physical ways to achieve the goals of FCC. An editorial by Zimmermann et al. (2020) discussed the COVID-19 restrictions that have threatened the crucial strategies that may improve the health of infants born preterm such as having the parents present, involving them in both the process of decision-making and in the physical care of their baby for example, through breastfeeding, and promoting skin-to-skin care/contact. Erdei and Liu (2020) discussed the importance of considering the psychological effects of the COVID-19 pandemic on families within the NICU, and recommended interventions to enhance current family-centered developmental care practices. Recommendations included “shared decision-making for every aspect of care”, “increase support to mitigate stress contagion”, and “prioritize stress mitigation for health care professionals, so that they can themselves remain resilient and provide emotional support for NICU families” (Erdei & Liu, 2020, p. 1284).

The FAMILY health in Europe-Research in Nursing (FAME-RN) group (2020) reported on the challenges and the losses (income, freedom of movement, community support, access to resources, planned activities, or celebrations) experienced by families due to COVID-19 policy restrictions. The FAME-RN group believe that the knowledge nurses possess, in relation to holistically nursing the family, provides them with the skills required to promote healing and recovery from both the known and (as yet) unknown effects of the COVID19 pandemic. A project in Sweden called “COPE” was developed to increase understanding of COVID19 infection during pregnancy (COPE, 2021). Bouchoucha and Bloomer (2020) discussed the measures taken within the adult population to protect public health, particularly in relation to restricting family visits and the adverse impact these have on the implementation of family centred care in the era of COVID-19. To redress the balance of the adverse impact between these public health measures and restrictions on family visits, health care workers used technology to connect the patient with their family. This not only effectively increased familial communication and connection, but provided health care workers with a tool that facilitated family centred care (Bouchoucha & Bloomer, 2020). Decision makers should therefore not only consider the risks that family presence may pose, but also the risks that restrictions on

such presence may cause (Planetree, 2020). For example, in countries with a chronic shortage of nurses, families often provide non-technical physical care to children including reporting observations they make, and usually more than one family member is at the bedside of the admitted child, but with COVID-19 only one family member is allowed to stay in hospital and this has led to their emotional and physical fatigue. Family members also play an important role in facilitating children's involvement in their own care, which is an essential component of CFCC that honors the rights of the child (United Nations, 1989). Where family members are not present to support children's participation in their own care, it may be difficult for children to advocate for themselves in environments where professionals hold all the power. Children's voices may therefore go unheard and care delivered without their assent. Frawley et al. (2020) argued that without a networked, integrated approach across traditional professional boundaries, the success of the nursing response to COVID-19 may be diminished.

Discussion and application for practice

This paper reflects an affirmative position by the INCFCC that the COVID-19 restrictions have an effect on the facilitation of CFCC. While the scientific community is waiting for more evidence from robustly designed clinical trials on outcomes, the worldwide disruptions in child health services due to COVID-19 restrictions might be under-estimated, resulting in detrimental outcomes in the overall health and wellbeing of many children and their families. Thus excluding families from the caring process could be far more psychologically damaging for the children and their families than their inclusion. Although the policies underpinning the practice of including families in the caring process during this global pandemic differ widely between different countries, most, if not all, health care practices have been affected in one way or another (Hart et al., 2020; Tedesco et al., 2021). Therefore, preventing families from being present or participating in the caring process or allowing only one parent to be with the child requires further investigation. In addition to the careful use of resources, sound collaboration is required to ensure that children and their families remain central to the decision-making process, and care of children in health care settings during the COVID-19 pandemic. This Position Statement of the INCFCC recommends:

- a consideration of the ethics of limiting families' rights during times of crisis and threats to society (for example, intentionally hiding their illness to avoid the COVID-19 restrictions),
- greater awareness among clinicians and health care attendants of the benefits and importance of a CFCC approach, and the potential harm of not using this approach,
- considering the benefit of adopting other approaches where institutions endorse and support nurses to address and ameliorate illness suffering in individuals and families through brief therapeutic conversations (Bell, 2013).
- re-conceptualizing what is necessary to achieve FCC versus what is a luxury in times of crisis, particularly in the context of supporting families. Policy makers should acknowledge that education that positively influences the attitudes and beliefs of health professionals would facilitate the involvement of families, and subsequently, better health outcomes for children (Al-Motlaq, 2021),
- caution in making quick decisions not based on research evidence,
- continued attention to detail regarding FCC and CFCC considering participatory approaches (Al-Motlaq et al., 2019),
- more specific evaluation and comparative studies,
- interdisciplinary collaboration,
- increased targeted funding to meet additional needs created by the COVID-19 pandemic that impact on CFCC such as staffing levels, provision of PPE and access to technology to support continued contact with all family members,

- staff and family education to enable them to support CFCC safely during the COVID-19 pandemic,
- Flexible guidelines, and
- better collaboration between public and private sectors.

Although the INCFCC, like the AAP (2020), recognize that COVID-19 policy restrictions will place limitations on CFCC, these limitations should only be applied where there is evidence that they are necessary to protect others from infection, and it is not possible to mitigate these risks through making adaptations to care delivery.

It is well-documented that health care workers experience higher levels of stress during a pandemic (Ji et al., 2017; McAlonan et al., 2007; Poon et al., 2004; Wu et al., 2009). Unlike epidemics, which are localized, the global effect of COVID-19 has had a significant impact on many health care workers, some of whom may exhibit post-traumatic stress even when the pandemic has eased. Where the capacity of the health care workforce is reduced, efforts should be made to encourage the workforce to prevent staff burnout. Short training courses or Continuing Professional Development (CPD) learning activities that relate to the implementation of CFCC during the COVID-19 pandemic would ensure that all principles of CFCC are practised while complying with the necessary policy restrictions. In addition, financial, administrative, psychological, social, and emotional support structures need to be provided as appropriate. These support structures will facilitate the coping strategies of both the health care team in the development of appropriate COVID-19 policy restrictions, and the health care workers in the delivery of high quality care to children and their families within the remit of these restrictions.

Summary

While the pandemic has an end in sight, there will likely continue to be situations that require a careful balancing of risks to individuals and families with risks to public health and health care providers. This paper presents the Position Statement of the INCFCC on the provision of CFCC during the era of COVID-19, as children and families are most likely to be affected due to restrictions being placed on family presence and involvement in care of their children. To ensure appropriate provision of CFCC, health care systems should acknowledge the importance of family presence and the participation of both the child and family in the caring process. Health care systems also need to develop safe systems and processes that uphold children's rights to family life, to be informed, and to participate in decisions about themselves (United Nations, 1989). This Position Statement complies with the general precautions imposed by authorities and supports the World Health Organization recommendations on the family's rights to be part of the caring process. While standing against restricting families from the caring process, the INCFCC stresses the need for a critical review of COVID-19 legislation and the state of the science on a CFCC approach to direct contextually-relevant and safe evidence-based CFCC interventions and practices inclusive of careful use of resources.

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Declaration of competing interest

The authors declare no conflicts of interest.

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