

Lessons Learned for Pediatric Pandemic Planning in Palliative Care: A Case Study

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Abstract

Aim: This study describes the experiences of parents of hospitalized dying children during the SARS (severe acute respiratory syndrome) outbreak in southern Ontario, Canada in 2003. Recommendations are generated for future pandemic planning related to paediatric palliative care.

Methods: A purposive sample of six case studies comprised parents of children who received inpatient care for a non-SARS related life threatening illness during the SARS outbreak. Parents participated in face-to-face, semi-structured interviews which took place 6 months to 1 year after their child had died. Interviews focused on parental experiences of services received during the SARS outbreak, including considerations for infection control and restricted visitation practices.

Results: The data illuminated three main themes: the impact of communication barriers and limited information; repercussions of visitation restrictions; and the importance of maintaining a high quality of care despite infection control challenges. Parents identified their coping strategies, and recommend enhanced and nuanced care for dying children and their families during health crises. Negative impacts of pandemic control strategies included isolation due to infection control, whereas recommendations promote the enhancement of family-centered pediatric palliative care.

Conclusions: Understanding parental experience can contribute to the overall development of recommendations for future pandemic planning, with respect to the unique needs of dying children and their families. Specific recommendations such as flexible family access policies and the creative use of social media technologies are recommended as health care facilities embark on pandemic preparation plans. Given the significant lack of pandemic planning in pediatric palliative care, these findings are an important first step in developing a framework that supports children with a life threatening illness during a public health crisis.

Keywords: Pediatric; Children; Palliative care; SARS; Infection control; Pandemic planning; Paediatric palliative care; Influenza; Pandemic preparedness

Abbreviations: LTI: Life Threatening Illness; PPC: Pediatric Palliative Care; FCC: Family-centred Care

Introduction

The global outbreak of Severe Acute Respiratory Syndrome (SARS) in 2003 caused significant changes in patient care and the daily procedures at most hospitals and health care facilities throughout southern Ontario, Canada. Although the SARS outbreak occurred several years ago and many pediatric hospitals experienced a subsequent infectious disease outbreak in 2009 via the relatively recent H1N1 flu virus, significant gaps in pandemic planning for pediatric care remains and, in fact, continue to exist globally. Moreover, there have been minimal efforts to date in studying the impact of such health crises on children with Life Threatening Illness (LTI) or to develop Pediatric Palliative Care (PPC) pandemic planning strategies despite demonstrated idiosyncratic challenges for this population related to resource allocation, visitor restrictions and consequences of infection prevention and control practices.

SARS is described as a respiratory tract illness caused by an infection with a novel corona virus [1]. It is characterized by high fever and rapidly progressive respiratory compromise, including difficulty breathing, and radiographic features of pneumonia [2]. An estimated 5% of all SARS cases were paediatric [3]. Fortunately however, there were relatively few reported cases of SARS and no reported fatalities among children (0-18 years). The literature suggests that SARS was milder in children, with older adolescents presenting symptoms similar to those observed in adults [1,3-6].

During the SARS outbreak, isolation and quarantine procedures that had not been in place for over 50 years were implemented within health care facilities and communities [2,7-9]. Similar to the adult literature on individuals hospitalized during the SARS outbreak either for SARS or unrelated conditions [9], Koller and colleagues [8] found that pediatric patients and their families were subjected to rigid precautions. These included potential isolation and quarantine; hospital entry screening procedures, stringent in-hospital visitor restrictions, follow-up clinic closures, potential surgery reductions, limited or unavailable home based health services, uncertainties associated with SARS contagion, gowned or masked health care providers which may have caused negative connotations or fear in children, increased illness acuity due to service unavailability, and potential under-treatment during intensified infection control practices [8,10]. The research literature further suggests that in adult and paediatric settings, patients, families, and staff members experienced isolation, insomnia, heightened anxiety and stress, disruptions and/or reduced access to services, and compromised physical and emotional health [9,11,12].

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PPC espouses Family-Centred Care (FCC) principles as its overriding approach to a child and her/his family's end-of-life, palliative and bereavement care. The FCC approach is based on an understanding that a child's primary source of strength and support rests within their family. The family is thus considered central to the child's care plan and parents are considered central in shared care decision making and planning [13]. Increasing research demonstrates the benefits of FCC in paediatrics [13-16]. This is especially salient for families who have a child with a LTI in that a FCC approach has been demonstrated to yield satisfaction with services, higher levels of well-being and lower levels of stress [17-19].

Research literature addressing the experience of SARS illuminates a needed balance during pandemics with regards to infection prevention and control practices and procedures as well as FCC [3,8,10,20]. Regardless of the relative paucity of paediatric cases of SARS, the unknown risk of infection and transmission during the outbreak resulted in strict infection control precautions. These restrictions reportedly resulted in substantial long-term practice changes in facilities throughout southern Ontario.

The literature identifies post-traumatic impacts and suggests that support to children and families during and after a pandemic is critical [21]. The experience of families with a LTI has received little research attention in the public health realm. A recent survey of Canadian pandemic plans found that although medical and policy strategies for paediatrics are in place, provisions for psychosocial supports and ethical decision-making frameworks that are unique to children and their families are largely absent [21].

To our knowledge, this study has been the first to examine families' personal experiences of SARS from a pediatric palliative care perspective. As such, its aim was to systematically address the experiences of hospitalized children with an LTI and their families during the SARS outbreak in order to better inform family support and patient care guidelines for this population in a potential future pandemic outbreak. Findings reflect six case studies in which a child with non-SARS related LTI was receiving inpatient PPC during the SARS outbreak of 2003.

Methods

These case studies are derived from a larger study [8] that examined overall pediatric health care during SARS. Each of these children in the six case studies was hospitalized at the Canadian epicentre of the outbreak. Inclusion criteria for study participation comprised families in which a child was hospitalized during the SARS outbreak due to a non-SARS related LTI, requiring PPC. Due to the unfortunate timing of their hospitalization, each child and their family were subjected to atypically heightened infection prevention and control policies universally imposed on patients and families due to the public health concerns and infection containment priorities related to SARS. In each case study, the child's LTI and hospitalization predated the child's relatively imminent death (within six months).

Families ultimately were excluded from study participation if there were known mental health conditions among parents unrelated to bereavement. In each case, an interview was conducted with a parent; and in all cases, interviews occurred less than one year from the date of the child's death as well as within one year of the child's hospitalization during the SARS outbreak. Families were identified through hospital databases, and the child's health care records were reviewed to ensure that individuals met inclusion criteria. The interviews were conducted in person and took place in the family home or at another mutually

convenient location. They comprised three general questions: (1) how did children with a LTI and their parents experience pediatric health care delivery during the SARS outbreak? (2) What facilitators and barriers to care were experienced during the SARS outbreak? And (3) how could care be enhanced in future disease outbreaks?

Semi-structured interviews were digitally recorded and transcribed verbatim, followed qualitative analysis consisting of open and axial coding as outlined in the constant comparative grounded theory approach [22]. Coding was completed by a research assistant with extensive qualitative data analysis training, supervised by the principal investigator (DN). NVivo qualitative data management and analysis software was used to support this analysis and the determination of themes. Trustworthiness was demonstrated by multiple established approaches [23,24] including: (i) prolonged engagement whereby team members cumulatively brought decades of experience in palliative care or infection control practice, (ii) member checking in which participants were re-contacted following preliminary data analysis in order to review and verify emergent findings, (iii) inter-rater reliability in which a portion of the data was independently reviewed by 'blinded' coders to verify consistent coding, (iv) an audit trail documenting key processes, procedures and decision making points in the study, (v) reflexive journaling outlining key points of learning, decision making and thematic poignancy in the research journey, and (vi) peer-debriefing whereby team members met regularly to assess the fit of emerging findings relative to clinical experience and theoretical understanding [23,24]. Institutional ethics review board approval was obtained from the host institution prior to commencing the study.

Results

All six case studies included families with a child (four females, two males) who had a LTI. Four of the children died in hospital while the other two died after discharge, but within two months of hospitalization, either at home or in another facility. Child diagnoses included prematurity, a brain tumor and neonatal complications such as trisomy 13. The ages of the children ranged from 8 days to 9 ½ years, and four were neonatal patients.

Interviewed parents described profound and difficult experiences related to PPC in the hospital, subsequent bereavement, and the role that SARS was believed to have played in the experiences of their child and family. Participants consistently indicated that they understood the complex issues surrounding the SARS outbreak and the reasons for the precautions and protocols that were in place. However, many felt that SARS-related rules were overly rigid and exceptions to hospital policies should have been made due to the severity of their child's illness and likelihood of imminent death.

Three overall themes emerged which related to: 1) communication barriers and limited information available to families, 2) repercussions of visitation restrictions, and 3) the value of quality of care and professionalism of health care providers during an outbreak emergency. Each of these themes is outlined below.

Communication barriers and limited information

The inconsistency of clear and up-to-date information to families by health care professionals during SARS reportedly caused extensive, undue frustration and stress for parents. One mother, whose first language was not English, indicated that it was extremely difficult to understand what health care staffs were saying during her child's hospitalization. She stated that the infection-controlling masks worn by staff, resulted in muffled words and phrases. This reportedly led

to an overall lack of clear messages due to poor enunciation and facial expression recognition. Her son, who had a hearing problem as a result of his medical condition, also struggled with the masks, often pulling off his mother's mask so that he could read her lips to understand what she was saying. In this case, the use of masks created a critical barrier to reading and interpreting language, important cues and facial expressions that were requisite to communication. Yet, clear communication was reportedly vital in dealing with the difficult problems of this pandemically-charged time as well as the time-sensitive discussions associated with palliative care. One mother exemplified this difficulty:

"All you could see is their eyes, and I can remember that being very hard because these are people that are making life and death decisions about our daughter, and I can't see who I'm talking to".

Parents reported confusion and distress resulting from insufficient information about infection prevention and control protocols and safety precautions. Many parents indicated that they gained most of their knowledge about SARS through the media, or that they independently had sought information from various sources including members of their health care team and/or from other parents of hospitalized children.

Parents of children transferred from a different care facility indicated that infection prevention and control protocols between hospitals sometimes differed despite being in the same community. Moreover, rules were reported to change daily, and parents described infractions such as hospital staff without infection-control masks in areas where parents were told masks were required for parents. Accordingly, parents sometimes noted a different standard of precautions for families relative to staff, which heightened a sense of inequity and fear about infection spread.

Repercussions of visitation restrictions

During the SARS outbreak, hospitalized children were limited to one parental visitor. While the reason for restricted visitors was understood, this was reportedly difficult for the ill child, parent(s), siblings and other family members. A mother indicated that her healthy son had great difficulty with the visiting restrictions, as exemplified by fears related to the ill child's possible negative health outcomes or demise.

"He was 7 (years old) ... And, he wanted to come. He wanted to come to the hospital and see what was going on with his sister and how did this treatment work and why can't I go? He didn't like being left out of the loop...now that is his personality type...that's who he is...He is a deep thinker, he needs to see stuff...walk away, process it for few days and then come up with an opinion or judgment or whatever...that's just who he is. So this whole concept of his not being able to go to the hospital really bothered him..."

Family and friends were described to often worry excessively and feel unable to meaningfully support the ill child and parent while in the hospital. Moreover in the case of newborns, several family members and friends missed meeting the hospitalized infant before his or her death and in turn, participants reported that these family members missed important rituals such as baptisms or last rites.

"I think that it was very, very difficult for my parents and [husband's] parents...For them to finally meet my baby in a funeral parlour... and really, they never met, I mean [baby] was probably almost a month old before they could start coming down to visit. So they felt very disjointed,

and I'm sure it was really hard for them cause they felt like they couldn't support me".

Of the four cases in which the patient was a newborn infant, three parents indicated that their infant was christened in the hospital prior to their death. Several parents bemoaned family members' absence during these ceremonies. Heightened sadness, a lack of closure, diminished support from extended family and heightened loss from not having family at these important moments, was repeatedly reported by family members.

Quality of care and professionalism of staff

Despite the drastic and restrictive changes in care procedures in the hospital due to outbreak precautions, parents generally were satisfied with the quality of care their children and family received. They indicated that on balance, health care providers handled this very difficult situation well, and parents appreciated the dedication, attentiveness, information, support and compassion given to them and their child. One parent said,

"I think that is what made the difference...the personalities of those nurses... They didn't just go in like they are doing their job and then leave. Every nurse went beyond their job, you know, to kind of help you through. Because we had no family there, just the two of us, and sometimes it's hard being in there".

Parents were conflicted between gratitude for the dedication and quality of care by health care staff, yet deep sadness over the restrictions and perceived loss of opportunities with their deceased child and family, as a result of their pandemic-imbued experience. Accordingly, their experiences were generally tinged with regret which, though perhaps deemed understandable, were often viewed as potentially avoidable or mitigated had a more family-centred and flexible approach been integrated in care.

Discussion

Caring for children with a LTI during a pandemic outbreak such as SARS is intensely challenging as public protection policies and family-centred palliative care practices often collide. Clearly, clinical competencies are crucial and in this case study, health care provider sensitivity and depth of clinical care were highly valued and deemed critical to PPC. This level of care acumen appears imperative as parents consistently described in hospital PPC during the pandemic as a time of heightened suffering, disruption to family-centered care, and potentially impeded anticipatory grief for families. These findings build upon earlier work suggesting that pediatric and hospital-based care is markedly hindered by infection control restrictions imposed during a pandemic outbreak [8,12,21,25].

In moving forward, these findings invite clinical guidelines supporting families and ultimately offering a scaffolding or base of direction for PPC during a potential pandemic crisis. Based on these findings, clinical considerations toward PPC during a pandemic entail emergent priorities. First, family-centred, transparent and timely communication is seen to be critical to families' understanding and navigation of imposed restrictions. Second, proactive, nimble institutional infection control policies and practices are suggested as a means to most diligently adjudicate infection risks relative to family-centred PPC. To that end, the development of policies that promote PPC care during a possible pandemic emergency are recommended, as are flexible guidelines for clinicians and administrators.

Family-centered transparent and timely communication strategies

Communication is a critical cornerstone for effective PPC, yet it can be especially challenging when infection prevention and control practices are viewed as an overarching priority. Accordingly, when discussing sensitive information such as end-of-life decision making or talking to a child about death, policies that support face-to-face interaction are advised. Such topics are deeply nuanced and complex, and need to be handled with utmost care and sensitivity, even during the public health outbreak. It is important to note that protective barriers impeding facial expression and/or communication (e.g., masks) may disrupt clarity and risk misinformation and potentially patient or family well-being. Items such as, masks thus should be used only when absolutely necessary. As needed, augmentative communication strategies such as video or web-based interfaces may be indicated, particularly when air-borne or aerosol infection spread is of critical concern (indicating strict mask use), and when language and other communication barriers also exist among families. These strategies, as well as email, telephone or videophone technology, may further serve to support family connection during times of visitation restriction. For example, enabling a sibling to speak to his/her sibling by videophone or webcast recognizes the importance of the family as a unit and creates connection and visual presence, and as needed, may crucially facilitate engagement, communication and in some cases, foster necessary anticipatory grief that otherwise might be impeded [3,26].

Children and families should receive consistent, honest and timely information about infection control policies. This will increase the likelihood that families are (and duly feel) informed, trust the institution and its staff, and adhere to appropriate infection control precautions. Web based communication such as online web posts or podcasts are examples of ways to promote timely and well disseminated information [27].

Proactive yet appropriately nimble institutional policies

Infection control policies are often required during pandemic emergencies; however practices should be flexibly considered in order to support family-centred palliative care at critical points during a dying child's hospitalization. This should include reasonable flexibility in considering access to family members for christenings, last rites, withdrawal of treatment, or when the child is actively dying. Policies regarding bereavement, family rooms, and viewing rooms should promote reasonable family access before, at and after death. As noted, a planning framework is needed in guiding pediatric palliative care. Such hospital-based guidelines have been developed by the authors to support pediatric palliative care for future pandemic planning. These are being reviewed for national consensus and publication. While jurisdictions such as Ontario, Canada have developed pandemic planning guidelines for pediatrics, specialized consideration and accommodations for PPC are urgently needed [21].

Study limitations

A limitation of this study was its relatively small sample size that was predominantly representative of infants and younger children. Future research in this area would benefit from inclusion of a wider spectrum of participants including adolescents and a broader range of diagnoses to capture breadth of experiences and needs based on developmental age, family constellation, and unique experiences related to particular LTI's. Another limitation was the use of a cross-sectional design using a single interview. Follow up interview(s) with this group of parents

may have illuminated the long term impact of pandemic-imposed policies on the families' bereavement and adjustment experiences after the child's death and over time. Future research is needed using multiple methods beyond qualitative interviews; potentially including standardized measures with larger samples.

Conclusion

This study identifies inherent challenges and tensions for the delivery of family-centred PPC in the context of a pandemic crisis. In addressing these difficulties, consideration of child and family experiences and outcomes are strongly recommended. These emerge as central if we are to effectively mediate challenges experienced by families, and move toward improving PPC for this vulnerable population. Caring for dying children during a pandemic requires a delicate balance of attending to patient and family needs amidst public protection. To that end, infection control practices that potentially result in unnecessary isolation, misinformation and family disconnection require critical review and realignment. Such a fine-grained analysis potentially will move us toward a greater balance of duly addressing outbreak risk while also minimizing negative impacts on dying children and their families. Given the dually-important priorities of pandemic and palliative care, such a careful tension is indeed worthy of pursuit.

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