

Paediatric pandemic planning: children's perspectives and recommendations

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Abstract

Children, as major stakeholders in paediatric hospitals, have remained absent from discussions on important healthcare issues. One critical area where children's voices have been minimised is in the planning for future pandemics. This paper presents a subset of data from a programme of research which examined various stakeholder experiences of the severe acute respiratory syndrome (SARS) outbreaks of 2003. These data also generated recommendations for future pandemic planning. Specifically, this paper will examine the perspectives and recommendations of children hospitalised during SARS in a large paediatric hospital in Canada. Twenty-one ($n = 21$) child and adolescent participants were interviewed from a variety of medical areas including cardiac ($n = 2$), critical care ($n = 2$), organ transplant ($n = 4$), respiratory medicine ($n = 8$) and infectious diseases (patients diagnosed with suspected or probable SARS; $n = 5$). Data analyses exposed a range of children's experiences associated with the outbreaks as well as recommendations for future pandemic planning. Key recommendations included specific policies and guidelines concerning psychosocial care, infection control, communication strategies and the management of various resources. This paper is guided by a conceptual framework comprised of theories from child development and literature on children's rights. The authors call for greater youth participation in healthcare decision-making and pandemic planning.

Keywords: children's participation, disaster management, disease outbreak, paediatric policy development, paediatrics, pandemic planning, youth participation

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Background

Despite the widespread recognition that every child has a right to self-determination and participation in decision-making concerning issues that directly affect them, youth involvement in healthcare delivery and policies has been minimal (Coyné 2006, Savage & Callery 2007). Even in situations regarding their own health, children's views are rarely sought within healthcare settings (Runeson *et al.* 2001). Children's exclusion from these processes is particularly relevant because they are our present and future healthcare consumers (Coyné 2008).

A current and important issue within health-care involves the development of pandemic plans. A pandemic outbreak is a result of an infectious disease that spreads rapidly throughout the world in a short period

of time. Pandemics arise from a significant antigenic shift mutating the genetic makeup of a virus, manifesting in infection where immunity may be nonexistent or limited in the population (Schoenbaum 2001, Cinti 2005, AAP 2007). Historically, pandemics wreak social, psychological and economic havoc in a region, often resulting in widespread illness and mortality (Paget & Aguilera 2001, Cox *et al.* 2003, Anderson & McFarlane 2004, Doyle *et al.* 2006). Although the expected impact of a pandemic will vary based on geographic location and population, there remains international consensus on the inevitability of a future crisis (Snacken 2002, Cox *et al.* 2003, Schabas 2003, PHAC 2006). It is estimated that pandemics will cause infection in 25% of the world's population and will result in 2–7.4 million deaths (WHO 2005). For these reasons, it is imperative to redress previous experiences and

implement sustainable disaster planning for future pandemics (Couch 1999, Anderson & McFarlane 2004, Cinti 2005, Cox *et al.* 2003, WHO 2005, PHAC 2006).

A recent international experience involved the pandemic nature of severe acute respiratory syndrome (SARS) and its concentration in healthcare settings which resulted in a unique and profound healthcare crisis in 2003. SARS is an infectious, rare, fatal, rapidly transmittable and progressive respiratory disease (Maunder *et al.* 2003). There were 8096 probable SARS cases reported worldwide, 774 of which directly resulted in death, with a fatality rate of 9.6% (WHO 2005). Infection control precautions included restricted access to hospitals, limitation of visitors, cancellation of non-urgent surgeries and clinics, infection screening, mandatory protection gear (i.e. masks, gowns, etc.) and often isolation/quarantine.

Research into the effects of SARS within paediatric settings showed devastating impacts on overall healthcare delivery, management of resources, psychosocial support for patients, and communication between families and healthcare professionals (Koller *et al.* 2006a,b). Infection control precautions challenged the established norms of paediatric healthcare delivery whereby the family is seen as central to the well-being of the young patient. SARS, therefore, provided a direct affront to the principles of family-centred care which espouse the inclusion of parents and children as important stakeholders in paediatrics.

The numerous systemic failures associated with SARS provided a strong impetus for pandemic planning. Since then, under the guidance of the World Health Organisation, governments, policy-makers and healthcare providers throughout the world have renewed their commitment to address and maintain organisational, regional, national and international preparedness for future public health emergencies (Jennings & Lush 2004, Bruce-Barrett 2006, CPS 2006, Doyle *et al.* 2006). To ensure the accuracy and validity of pandemic plans, governments and health organisations have turned to stakeholders, namely healthcare professionals and infection control specialists, for input and collaboration while children's needs and perspectives have been largely excluded (AAP 2005). Although children are often identified as a vulnerable population with unique clinical and psychosocial needs, the discourse on pandemic planning primarily focuses on adult patient populations and the views of healthcare professionals (Wong *et al.* 2003). Consequently, regional and governmental contingency plans and policies have been criticised for their inattention to the epidemiological and psychosocial specificities of children (CAPHC 2006).

The rationale for including children's needs and perspectives in pandemic planning is multifaceted. For one, children often respond differently to viruses than adults

and this can include both physical symptoms and psychological responses. In the case of SARS, for example, children were not affected to the same degree as adults. Specifically, symptoms used to identify infected adults with SARS were not present in infected children or adolescents (Wong *et al.* 2003) and adult vaccines and antiviral medications administered to paediatric populations were deemed ineffective (AAP 2005). In addition, infection control practices that were unpleasant for adult patients had a devastating emotional impact on paediatric patients (Koller *et al.* 2006b). Accordingly, the lessons learned from SARS can inform pandemic plans which more adequately address the unique needs and perspectives of children (Koller *et al.* 2006a,b).

Children's involvement in pandemic planning is essential as influenza epidemics (seasonal disease outbreaks) and pandemics (global disease epidemics) have and will continue to disproportionately affect children. The American Academy of Pediatrics Committee on Infectious Diseases has proposed that children 'are inherently more at-risk for contagious respiratory diseases ... [and] we are behind the curve in finding ways to limit the spread of a pandemic in children even though they are among those most at-risk' (Trust for America's Health 2007). Furthermore, 'there remains a uniqueness that begs for the care of children to be identified and included in the extensive efforts to explore our nation's readiness for influenza pandemic' (AAP 2005, p.1). Notably absent, however, is consultation with the children for whom such policies are intended to serve (CAPHC 2006, AAP 2007, Trust for America's Health 2007). The purpose of this paper was to present a portion of qualitative data from a programme of research where children and adolescents were asked to share their experiences during the SARS outbreaks and provide recommendations for future pandemic planning. In this paper, the term children will be used to denote children and adolescents.

Conceptual Framework

The guiding conceptual framework for this paper is reflected in two streams of literature. First, child development research has shown that children's participation in areas that affect them can lead to positive child outcomes and enhanced family functioning (Adelman *et al.* 1984, Allen *et al.* 1984, McPherson & Thorne 2000, Nicholas *et al.* 2004). Second, by acknowledging the significance of children's involvement in healthcare delivery, a fundamental obligation to fulfil their participation rights is realised.

In terms of child development, there is a growing body of research which demonstrates positive outcomes associated with empowering children's voices (Skipper & Leonard 1968, Visintainer & Wolfer 1975, Lewis &

Lewis 1982, Reissland 1983, Alderson 1990, 1999, Igoe 1991). These benefits involve personal gains in the form of social and cognitive development as well as contributions to many sectors of society (Youniss *et al.* 2002). Accordingly, the literature acknowledges that children are capable of participating in complex decisions, whether it concerns personal matters or those on a broader systemic level (King & Cross 1989).

From a children's rights perspective, the widespread ratification of the United Nations Convention on the Rights of the Child (UNCRC) (United Nations General Assembly 1989) has promulgated a greater focus on children's rights. The UNCRC represents an amalgamation of views that affirm and address the basic needs and participation rights of children up to the age of 18 years. Taking into account cognitive and emotional maturity, the UNCRC recognises that children are able to form and express opinions, participate in decision-making processes and influence solutions within their families, schools and healthcare settings.

The responsibility to involve children in decision-making processes does not mean that their opinions are automatically endorsed. It does, however, require an open process in which young people are comfortable to share their opinions and to engage in dialogue with one another and with adults. The UNCRC also views participation not as a duty that should be imposed on youth, but rather as a provision made to the young person should he or she wish to do so.

Methods

Research design

This paper presents data from a programme of research that systematically examined the experiences, perceptions and impacts of the SARS outbreak within a Canadian paediatric hospital. The first study explored the experiences of children, their parents and nurses who were directly impacted by the SARS outbreaks (e.g. children diagnosed with probable or suspected SARS). Following this study, a larger study solicited feedback from a variety of stakeholders, including children who were hospitalised at the time with different diagnoses, their parents, healthcare providers and hospital decision-makers. Taken together, the purpose of this research was to ascertain how the children, their parents and healthcare staff experienced the infectious outbreaks. In addition, these studies provided a platform for stakeholders to share recommendations regarding healthcare practices during pandemics.

This programme of research adopted a grounded theory approach, aimed at generating theoretical and conceptual knowledge about the 'lived' experiences and

perceptions of the SARS outbreaks. Descriptive narratives illuminated the impacts and challenges associated with paediatric hospitalisation during a healthcare crisis. Findings presented here have not been reported elsewhere and focus exclusively on the perspectives and recommendations of paediatric patients – an area that has received little attention in pandemic planning.

The sample

Following the principles of grounded theory, a theoretically based approach to sampling was employed and thus, participants were purposively selected. Participants were recruited from a database of children hospitalised during SARS. In order to solicit a range of perspectives, children were chosen from a variety of medical specialties. As the research ethics board stipulated that participants be introduced to the study by a known healthcare provider, collaborators on the study (social workers and child life specialists) assisted in choosing families from the databases. Children were approached for participation 1 month after discharge from the hospital to allow sufficient time for readjustment and reflection. A letter detailing the purpose of the study and type of involvement was mailed to participants. Within 2 weeks, follow-up contact was made by a member of the research team.

A total of 21 children (12 male and 9 female) from rural ($n = 3$) and urban ($n = 18$) communities participated in semi-structured interviews. The age of the participants ranged from 5 to 19 years of age (mean = 11 years). For a qualitative study, a sample of $N = 8$ has been established to be sufficient in generating theme saturation (McCracken 1988). In this case, we exceeded this threshold to ensure participants had a variety of diagnoses. Participants comprised patients who received hospital treatment during the period of strict infection control practices (7 March to 12 August 2003). Specifically, participants consisted of patients treated for SARS ($n = 5$), respiratory conditions ($n = 8$), terminal illness or palliative care ($n = 2$), and transplantation ($n = 6$). In addition, participants came from a range of religious and cultural backgrounds (i.e. Muslim, Jewish, Catholic and Eastern Orthodox) and were highly representative of the patient population within this large, urban paediatric hospital (for a description of sample demographics, see Table 1).

Data collection

Data collection consisted of in-depth, semi-structured interviews and a review of healthcare records in order to document child diagnosis, illness trajectory, number of days hospitalised, treatments and psychosocial issues.

Table 1 Participant demographics

Age	Gender		Clinical area			
	Male	Female	SARS	Respiratory	Palliative	Transplant
Early childhood (0–5 years)	–	1	1	–	–	–
School age (6–8)	7	–	2	4	–	1
Latency (9–12)	2	4	1	3	–	2
Adolescence (13–18)	3	4	1	1	2	3
Total (<i>n</i> = 21)	12	9	5	8	2	6

SARS, severe acute respiratory syndrome.

Interviews comprised a series of open-ended questions which provided participants the latitude to convey their experiences and narratives. Specifically, participants were interviewed about their knowledge of SARS, their experience of hospitalisation and isolation, coping mechanisms, interactions with healthcare providers, perceptions of care received and reintegration to home and community. Participants were also asked to reflect on aspects of their experience that were perceived as helpful or harmful. These narratives provided a context upon which participants could offer recommendations aimed at attenuating the negative impacts of future outbreaks.

Interviews were conducted in person by either the research assistant or a member of the research team. The research assistant received training from one of the investigators in interview methods with children. The interview guides, one for children and another for adolescents, were specifically designed to be sensitive to varying developmental levels. In particular, interviews with children consisted of several techniques which are suitable for one-to-one interviews. For example, opportunities to use visual aids, play with toys and/or view animated picture books of children in hospital, helped to elicit memories and engage young participants during the interview process. These techniques, alongside straightforward questioning, are supported in the literature where such methods not only serve to make interviews fun and interesting for young people but are also useful in generating good and relevant data (Docherty & Sandelowski 1999, Christensen & James 2000, Punch 2002). Accordingly, the interview techniques supported the developmental needs of the participants while ensuring that salient issues associated with an infectious outbreak were explored. A sample of the child's interview guide is available (Appendix S1).

Ethical considerations

Both scientific and ethical reviews were obtained prior to study commencement. Confidentiality and security of the data were ensured. All participants were informed that they could withdraw from the study at any time

without any impact on their healthcare services. Measures were implemented to both ameliorate and address any potential emotional difficulties that could emerge from participation in this study. For example, participants were informed that emotional support could be made available to them by a social worker or child life specialist at the hospital if deemed necessary.

Data analysis

Interviews were audio-taped and transcribed verbatim. Qualitative analysis methods, appropriate to grounded theory (Strauss & Corbin 1998), included open, axial and selective coding. Open coding was conducted on the raw data for the purposes of breaking down, examining and categorising data. Axial coding entailed the integration of connections and categories within the data. Selective coding fostered category development whereby main themes emerged linking them together with theoretical models. As coding categories emerged, they were continually refined and developed until a comprehensive interpretation of the data was reached. The refinement of categories occurred considerably between the axial and selective coding stages. Interview data were subjected to analyses that predominantly included theme generation, which illuminated a range of experiences and corresponding recommendations for pandemic planning.

To ensure integrity of the data, the researchers adhered to standards of qualitative rigour throughout the research. Trustworthiness was achieved through prolonged engagement in the research, peer debriefing (inter-rater reliability), member checking and negative case analysis. In the case of peer debriefing, three interview transcripts were reviewed individually by members of the research team. At a team meeting, each transcript was reviewed by discussing codes assigned to each paragraph. A comparison of codes ensued and emerging themes were identified. This discussion was also tape recorded for future reference. Instances of negative cases analyses were also discussed where themes were compared and contrasted. In most cases, there were no discrepancies between the coding. Researchers

engaged in member checking by personally contacting a few participants in order to verify findings. In some cases, parents provided feedback on behalf of their young child. However, in all cases, participants acknowledged that the analyses reflected their recollections and experiences.

Results

Participants provided a range of experiences and perspectives regarding infectious outbreaks. In general, children perceived the need for planning in order to avert or minimise challenges in future pandemics. More specifically, participants called for pandemic plans which addressed children's unique needs during a healthcare crisis and these issues served as the foundation for many of their recommendations.

The results were categorised under the following themes: (i) psychosocial care, (ii) infection control, (iii) communication between staff, patients and families and (iv) management of resources. These themes were viewed as central to paediatric pandemic planning, policy implementation and education.

Psychosocial needs

The psychological responses to SARS were extensive, causing social and emotional difficulties for children. In particular, infection control precautions which stipulated only one visitor at a time, was extremely difficult for children and their families. Children hospitalised during SARS were isolated in their rooms for long periods of time, leaving many plagued with fear, sadness and intense loneliness (Koller *et al.* 2006a,b). As a direct result of the safety precautions and visitation restrictions, parents were prevented from being adequate sources of support and comfort for their children. These precautions posed a significant challenge for children who were separated from their parents for weeks. In some cases, parents with suspected SARS were admitted to adult healthcare facilities while their children were hospitalised elsewhere. Based on these experiences, participants identified that the presence and support of family and friends was a priority. As one participant explained:

The worst thing about SARS was not getting to see both parents or your family. I really love my sister too and I never got to see her or my cousin that I'm really close to. And just feeling kind of isolated from the world. (16-year-old female)

While recognising the importance of safety precautions, participants offered several recommendations aimed at attenuating the emotional impact of social isolation. Participants suggested that staff schedules should

be changed in order to accommodate the emotional needs of children. For example, one adolescent suggested that patients should be offered core nursing, so that children could get to know and trust consistent caregivers who were assigned to them.

Just to know that someone cares. I think like having a core nurse that knows the kid. Like when in hospital during SARS, the nurse was like a second mom. She was really protective of me and I felt like she loved me. It felt like that so it was really good. My mom even trusted leaving me. She knew I was in good hands. (16-year-old female)

Some participants recognised the extent to which healthcare providers were emotionally affected by the SARS outbreaks. They also believed that staff needed to minimise children's fears by maintaining a sense of normalcy despite their own concerns. Participants recommended that staff keep a balanced perspective and remain calm in order to help children cope with the crisis. Therefore, over-reacting to the situation was viewed as counterproductive. A 14-year-old male said, 'staff shouldn't get too worried or over-reactive', while an 11-year-old female indicated, 'staff should help kids forget about it, like think of something else, cause thinking about it is going to make you mad, it's going to make you scared'.

Participants also understood that healthcare providers were consumed by infection control procedures which could affect their interactions with children. Several participants expressed a need for patients to be viewed as 'children first'. As one adolescent noted:

I guess I was trying to understand where these rules were coming from. Like we know they want to enforce the rules, but they have to remember that this isn't just a kid with an illness. This is a child with feelings and some staff are trying to be so professional. It is important to be professional, but it's also important to have a heart. Like remember that these are kids and they have needs, and need to feel wanted, loved and cared for. (16-year-old female)

In keeping with patients being treated as children first, many participants identified play and distraction as an important component of psychosocial care, particularly during a crisis. By having activities in their rooms, children could be distracted from what was happening around them. Accordingly, engagement in play and other developmentally appropriate activities was viewed as a therapeutic intervention for children isolated during an infectious outbreak. One adolescent offered the following suggestion:

Especially during an epidemic like SARS, we need to have a little kit for every room so when a new patient comes in, there is a little bit of colouring paper or a little craft to do like those bags that the school donated. So when a new

patient comes in the room and it is clean, there is a kit on the bed waiting for that person so they have something to do especially the kids on the wards. You get bored of watching movies and playing with stuffed animals. They need a little kit. (14-year-old female)

Infection control

Despite the many challenges associated with infection control precautions, children understood the importance of these procedures. Infection control precautions required professionalism, efficiency and diligence, and this was seen as both necessary and reassuring to children.

I felt sort of isolated and different, sort of scared. You kind of get a sense of security too though. Cause they're very cautious so you feel okay, they're taking good care.... I guess that's the good thing about it, they were taking precautions to make sure nothing would happen to you. (16-year-old female)

In addition, participants identified infection control to be a collective obligation, one to be undertaken by everyone, including children. Furthermore, these responsibilities transcended all levels of government including local, provincial and federal. Some participants expressed the need for individuals to sublimate their own needs in order to protect the community as a whole. It was suggested that individuals learn to maintain a level of vigilance by encouraging people to dress warmly when necessary, to maintain hand washing practices and to avoid highly contagious public places. One adolescent offered the following advice:

You got to take it seriously, but then again not too seriously. You have to be cautious and if you are feeling sick don't wait, go to the nearest clinic even if it is not the hospital but a walk-in. Just go so that you know you are not infecting yourself and more so everyone else. A lot of kids get sick and go to school. They don't tell their parents and they don't care that they are infecting other people. You never know, so you have to take the risk that people have common courtesy and are cautious themselves. (14-year-old female)

Communication

In hospitals, communication between families and healthcare providers is a challenge, even in the absence of a crisis. The SARS outbreaks produced an environment which inhibited the flow of information from families to healthcare providers. For example, the continuous influx of changing information, mandatory protective gear and the limits on visitation exacerbated a breakdown in communications. In such an environment, children experienced a lack of information or

discrepant messages about the nature, transmission and outcome of the disease. For this reason, much of the communication received by children produced anxiety, fear and confusion. Communication challenges were made worse by healthcare providers wearing masks which concealed facial expressions that children normally relied on.

Within this context, participants believed that healthcare providers needed to take the time to listen to children's concerns and respond to questions. Recommendations for improving communication with children included offering accurate information while using age-appropriate language in a clear and sensitive manner. Information shared with patients should comprise the nature of the disease, its origins, the treatment protocol, transmission and infection control guidelines. Speaking to healthcare providers, one school age participant recommended:

To not tell children any lies about SARS. Tell them straightforward what is going to happen, but be gentle on them. Don't be like (loud harsh voice), 'oh you're gonna have SARS and blah, blah, blah'. Be like (softer voice), 'everything is gonna be okay. Nothing is wrong. We just have a little bit of a case in the hospitals that people are there for. (9-year-old female)

Participants also acknowledged that poor communication can spawn harmful misconceptions which can increase anxiety and frustration. In some cases, misconceptions elicited fears of death and dying, as the following quotes reflect:

I was so scared. I thought I could get it from everything. I thought if I touched something, I would die. (11-year-old female)

It kinda made me feel sad because I thought that the world was going to end or something. (14-year-old female)

Sometimes we thought about 'oh my god, what happens if I get it?' like it's like death coming, like walking up to you... That was kinda scary because you never know right? So you thought about the stuff you wanted to do and stuff you had already done. (9-year-old female)

Communication was further undermined by having patients isolated in their rooms with a television as their only source of information. During the time of the outbreaks, televised news reports provided regular updates on the number of individuals infected with the disease and the corresponding death toll. These types of reports focused on 'worse case scenarios' and did not always provide a balanced and accurate assessment of the situation. Accordingly, participants believed that televised news reports exacerbated their fears as the following quote implies:

Television reports made me feel scared, like if I was gonna die next or something. Cause anytime I watch the news... another lady or a man dies from SARS... (14-year-old female)

In order to augment communication and care needs, some children suggested that existing technologies such as telecommunications, particularly the telephone and internet, could be used more extensively, as illustrated below:

For people like me and other children, I just think that Telehealth care would be good especially during an epidemic. If I needed help, I would call and ask one of the nurses, 'do I have to blah, blah, blah' and they would say 'yes' or 'no' and they would tell me whether I should come in. (14-year-old female)

Management of resources

Children described a number of important resources associated with care during an infectious outbreak. Human resources, medical supplies and equipment, toys and activities, and allocation of space comprised the range of resources identified by participants. In regard to human resources, children cited concerns that some staff may be unwilling to work in certain areas, and/or tasks may become too regimented and impersonal due to excessive infection control precautions. Therefore, children emphasised that future plans should address expected shortages and as much as possible, integrate contingency planning as required.

Regarding the provision of medical supplies, several participants conveyed the importance of having adequate amounts of supplies on hand. In particular, masks were thought to be at risk of being in short supply due to excessive demand. Children also noted that other items such as drugs and specialised soaps be prepared and stored for future outbreaks. One 14-year-old female described the need to develop 'specific cleaning agents' while another adolescent suggested that regular, non-crisis related medical supplies (i.e. puffers) should also be secured for future use.

Speaking to the unique needs of young patients, participants reiterated that hospitalised children required a sufficient supply of toys and activities particularly when patients were isolated. As one participant noted, children in isolation needed to 'draw, colour, read books, play video games and watch movies' (7-year-old male) in order to provide distraction and cope with loneliness. Finally, children believed that hospitals should be creative in their use of space during infectious outbreaks. For example, patients could be moved to specially designated areas during infectious outbreaks, while creating other spaces for those who wished more privacy. In this

way, patients who required isolation from others could experience alternate surroundings and hence, improve their well-being.

Discussion

Previous studies have found that children with a chronic illness often exhibit more emotional maturity regarding serious health matters compared with their healthier counterparts thereby supporting the notion that paediatric patients are capable of engaging in complex health issues (Alderson 1990, Harrison *et al.* 1997). In this research, participants' perspectives offered cogent evidence of children's ability to address issues related to infectious outbreaks. Participants' experiences reflected a range of impacts associated with infectious outbreaks, and in turn, generated a series of recommendations for pandemic planning.

Participants identified four areas for pandemic planning, namely, greater attention to psychosocial care, collective responsibility concerning infection control, suggestions for improving communications and finally, adequate management and planning of key resources. In terms of psychosocial care, participants cited the importance of having consistent healthcare providers and allowing for therapeutic interventions which included supportive discussions and opportunities for play and normal activity.

Infection control practices were seen as everyone's responsibility, whether at home, in hospital or in the community. These data imply that a comprehensive communication strategy is deemed necessary for transmitting complex and changing information across settings. Such an approach could include regular updates from public health officials to newspapers, television networks, telehealth systems, the internet, as well as more broad-based approaches to health education in schools. The need for sharing accurate and less sensational information along with expanded use of technology were also identified. In particular, effective communication between patients and healthcare providers was viewed as integral to supportive care within a paediatric setting.

In regard to human resources, participants cited the need for sufficient staff with specialised training who were willing to work during healthcare crises. Indeed, these issues emerged during the SARS outbreaks, both in paediatric and adult healthcare settings (Maunder *et al.* 2003, Koller *et al.* 2006a). In order to adequately address this recommendation, a review of the curriculum in healthcare education is needed. For example, professional education programmes should provide additional training specific to paediatric healthcare

delivery during infectious outbreaks. Such initiatives could attenuate current gaps in knowledge across all healthcare disciplines. Although most medical schools provide training in patient-provider communications (Coyne 2008), it remains necessary to explore these issues on a broader level across healthcare disciplines. In particular, education around how to share information with children of various ages is an important consideration during an infectious outbreak. Interestingly, similar suggestions regarding the need to secure specialised resources on a variety of levels were noted elsewhere in studies with adults who had recently experienced an infectious outbreak (Maunder *et al.* 2003).

Taken together, participants identified a range of recommendations to be considered in the context of paediatric pandemic planning. Perhaps not surprisingly, many of their suggestions were attuned to the developmental needs of children and adolescents, namely, consistent care giving, sharing of appropriate medical information, adequate supplies of toys and games, and the reconfiguration of spaces within hospitals which would allow patients greater mobility. Finally, participants appeared to exhibit an understanding that pandemic planning involved a process which was ongoing, fluid and evolving as various systems (i.e., local, provincial, and federal) were expected to work together to address pandemic concerns.

Despite the salience of these findings, it should be noted that the experiences and perspectives reported here represent a relatively small sample of paediatric patients from a North American hospital. As the delivery of health-care can vary throughout the world, the experiences of children in other contexts may differ and could elicit alternate priorities for pandemic planning. Future research should address the experiences of paediatric patients in other settings in order to compare recommendations and gain insight into the associations between culture, health and child participation in healthcare decision-making.

As there is no existing literature addressing youth perspectives on infectious outbreaks, this research has contributed to our understanding of what children require from healthcare systems during crises. These findings can inform best practices and promote ethical care wherein the paediatric patient is viewed as an individual with rights to receive information and participate in decision-making whenever possible. Paediatric healthcare professionals from all disciplines need to consider how best to access and include children's perspectives on a variety of health-related initiatives. For instance, some paediatric hospitals have children's councils comprised of patients who provide advice and consultation on health-related issues. In addition to creating avenues for greater consultation with youth, a philoso-

phy of care committed to children's participation must permeate all aspects of healthcare delivery. As previous experience has shown that infectious outbreaks can have a devastating impact on children's adaptation to hospitalisation, their perspectives and recommendations for pandemic planning are among the most important to be considered.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Appendix S1 Child Interview Schedule

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