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Pediatric epidemic crisis: Lessons for policy and practice development

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Abstract

Objectives: This research study addresses health policy and patient care considerations, and outlines policy and practice implications resulting from a crisis in a pediatric setting. This crisis, an epidemic outbreak of Severe Acute Respiratory Syndrome (SARS), dramatically impacted the delivery of health care in Canada. Despite the passage of time since the last diagnosed case of SARS in April 2004, researchers have warned the global community to be prepared for future outbreaks of SARS or other infectious diseases.

Methods: Qualitative interviews were conducted with 23 participants representing key stakeholder groups: (a) pediatric patients with probable or suspected SARS, (b) their parents, and (c) health care professionals providing direct care to SARS patients.

Results: Participants conveyed key areas in which health policy and practice were affected. These included the development of communication strategies for responding to SARS; easing vulnerability among all stakeholders; and the rapid development of practice guidelines.

Conclusion: Given the continuing threat of current and future airborne viruses with potential for epidemic spread and devastating outcomes, preparedness strategies are certainly needed. Effective strategies in pediatrics include practices that provide family centered care while minimizing disease transmission. Toward this end, lessons learned from previous outbreaks merit consideration and may inform future epidemics.

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The delivery of health care was confronted by the outbreak of Severe Acute Respiratory Syndrome (SARS) in Toronto, Canada, in 2003. The SARS-associated coronavirus (SCV) which has been identified as the primary aetiologial agent of SARS is rapidly progressive and sometimes fatal, particularly among adults [1]. While the first known cases of SARS occurred in Guangdong province, China, in November 2002, SARS became recognized as a global threat in mid-March 2003 [2]. The condition transcended borders quickly after this date, as a patient traveled to Hong...
Kong and infected other travelers, who then journeyed internationally to countries such as Vietnam, Singapore, Germany, and Canada. By July 2, 2003, SARS had claimed 812 lives and affected 8445 individuals, across 30 different countries [3,4].

The SARS outbreak of 2003 was characterized by its unprecedented rapid, airborne, and global transmission; however, its localized impact was particularly felt within health care facilities [5–7]. Infection control leaders and researchers have warned the global community to be prepared for future outbreaks of SARS or other widespread infectious diseases [8,9]. While several studies have identified biomedical data and psychosocial impacts, lessons learned from SARS for both health policy and patient care, have received little research attention. Accordingly, this paper addresses this gap in the literature and outlines policy and practice implications of SARS, specifically from a pediatric perspective. This research was achieved through a series of descriptive qualitative interviews with key stakeholders, including pediatric SARS patients, their parents, and health care providers who provided direct care to SARS patients.

1. Background

SARS presented a health care crisis, within affected regions, by requiring rapid responses to unknown questions, with devastating consequences for patients, health care providers, and health care systems. As new struggles emerged on a daily basis, responses and implementation were immediately necessitated. Policy considerations that affected day-to-day patient care comprised infection control and patient care protocols as well as integrated change and in some cases a sense of systematic chaos. Virus spread was ultimately contained in hospitals through restricted entry as well as limited movement within and between health care facilities. Screening processes elicited information about individual exposures, symptoms, and epidemiologic links to SARS [5], and hospital entry was restricted on the basis of this reported information. Visitors to hospitals were largely eliminated except for immediate family members of critically ill, dying, birthing or pediatric patients [5]. Even in these critical situations, pediatric patients were limited to only one parent visitor at a time, although in some cases, children had no visitors.

To limit virus transmission, health care providers deemed ‘non-essential’ were restricted from pediatric care. ‘Essential’ hospital caregivers were permitted to work at only one health care facility to reduce the risk of virus transmission, and were required to wear protective masks and gowns in patient care areas [5,6]. When treating patients with suspected or probable SARS, double isolation gowns, hair caps, masks, face shields, and gloves were required [5]. Negative pressure isolation rooms with antechambers were used for patients thought to have SARS, and staff were required to remain outside negative pressure isolation rooms as much as possible [10]. Clearly, SARS resulted in substantial changes to health care practice and frequent shifts in infection control requirements, with health care providers reporting substantial frustration and anxiety [6].

Direct face-to-face clinical communication between physicians and families was interrupted and replaced by increased reliance on the telephone as the primary mode of communication [11]. World regions varied in terms of methods and policies implemented to foster communication. Visitation restrictions in an identified Asian hospital were mitigated through video conference and e-mail technology [12], while Canadian hospitals generally relied on telephone communication [13]. In pediatric care, some children with SARS reportedly kept the phone line open with parents and families over extended periods of time. Phone connection emerged as a key factor in reducing isolation and despair yet even with phone support, children often and dramatically suffered extended negative psychosocial symptoms [12,14].

Systems of health care delivery were dramatically affected by the SARS crisis; however, few studies have focused on the policy and practice implications of the outbreak. To address this gap, a descriptive, qualitative investigation was conducted to examine the experiences, impacts, and implications of SARS-related health care policies for patients, parents, and health care providers.

2. Methods

Given the limited research in crisis response within pediatrics, a descriptive qualitative study was conducted in determining issues of salience that emerged
during the epidemic of SARS [15]. Semi-structured, qualitative interviews were conducted with 23 participants from key stakeholder groups affected by pediatric SARS as follows: pediatric patients between the ages of 5 and 17 years \((n = 5)\), their parents \((n = 10)\), and frontline pediatric health care providers \((n = 8)\). As the pediatric crisis of SARS in Canada was relatively localized, we attempted to include all eligible pediatric SARS patients and their parents, as well as the respective health care provider. All participants were interviewed 2 months after hospitalization to provide time for experiential reflection and patient recovery. Interview questions invited participants to systematically document and identify their experiences; perceived policy and practice implications of SARS; and lessons learned in the event of a future outbreak. Patient participants were recruited from a database of all children in Toronto admitted to hospital for suspected or probable SARS (a classification clinically determined by fever and/or radiographic evidence of chest pathology). While children under 6 years of age were also admitted with probable or suspected SARS, they were not interviewed due to their young age; however, parents of these young patients \((n = 5)\) were included in the sample of interviewed parents. Sampled children and parents represented a range of cultural backgrounds, and all children ultimately recovered from SARS. Health outcomes for parent participants ranged from full recovery to death.

Interviewed health care providers comprised physicians and nurses who provided direct care to pediatric SARS patients. In terms of young children interviews were adapted for developmental level, and skilled child life specialists utilized play, hospital/medical photographs and toys for engaging children and eliciting their reflections as guided by methodological guidelines for qualitative interviewing with young children [16–18].

The semi-structured interviews were conducted in person, were audio-taped and were transcribed verbatim. A semi-structured interview schedule provided a series of open-ended questions to ensure coverage of similar topical content among all interviewees [19]. Qualitative research computer software assisted in data analysis, and inter-rater reliability was achieved through blinded reviews of data, followed by reviewer agreement on emergent findings. Institutional ethical approval was received prior to study commencement.

Interviews were subjected to content analysis, concept saturation, and theme generation, using McCracken’s [19] well-established ‘long interview’ method comprising the following sequential analytical processes.

1. Line-by-line coding seeking notable observations in the text that address the research questions.
2. Developing each observation in and of itself from evidence within a single transcript through data categorization.
3. Examining the interconnection of observations in subsequent transcripts through inter-transcript categorization. By this point, themes and an organizational schema were emerging.
4. Emergent themes were scrutinized in collective form for “patterns of intertheme consistency and contradiction” (p. 42). Redundancy was eliminated and themes were organized theoretically. By this time, the focus was no longer on particulars of individual perspectives, but rather on principles inherent in themes.

3. Results

Data provided a range of participant experiences and perceptions about their experience of SARS. Perceptions yielded both experiential and descriptive information, but also important issues for consideration in health policy and practice planning. Key themes include: interrupted informational flow during the SARS outbreaks; vulnerability and moral doubt; need for effective and responsive leadership; and expeditious development of practice guidelines in the shifting landscape of pandemic outbreak. Each dominant theme is documented below, along with the frequency of identification (presented in percentages) and verbatim quotes (in italics) that demonstrate their application within interviews. Each theme is clearly supported with ‘thick description’ [20] from interviews/transcripts.

3.1. Information flow

Information about SARS was disseminated through various global, national, and regional sources includ-
ing the World Health Organization (WHO), provincial health authorities, and local health care administrators. Information was relayed to health professionals providing SARS care in an attempt to quickly adapt patient care and limit transmission. While participants required and appreciated the ongoing updating of information, the frequency of incoming and shifting information yielded difficulty in its assimilation and implementation. The majority of health care providers (88%) reported substantial workplace stress given frequently changing patient care standards in the face of a life-threatening illness. They described vicarious strain when implementing and justifying restrictions and then, in some cases, enacting policy changes. A health care provider explained:

It was hard in terms of the families. One day you would be doing something and another day it would be different. And explaining that to the families was difficult... I know it’s scary for patients and families when they see you do one thing one day and something different the next day.

Participants described continuous informational updates during SARS, resulting in frequent changes of practice expectations. Central coordinating structures for information dissemination were reported as insufficient, resulting in discontinuity in how information was transmitted. Clearer information was advocated by 60% of these children. Many of these children who had been admitted to, and isolated within, the SARS unit experienced little or no physical symptoms characteristic of SARS. As such, their ability to make sense of policies which mandated their hospitalization and separation from parents was confusing, particularly for the younger children. They repeatedly expressed in interviews the need for clear explanations to help children understand these realities: “(Children) should know what is going on and why little kids have to be quarantined.” In some cases, children expressed misconceptions in terms of their understanding of SARS and associated infection control procedures. The following excerpt from an interview with a child admitted to the SARS unit illustrates some of the confusion and mystery surrounding reasons for quarantine:

Child: “It was like no one could leave the room so you can’t leave your room.”

Interviewer: “What do you think would have happened if you left your room?”
Child: “I’d get into trouble.”

Increased understanding about the unknown infection risk may have increased this child’s understanding of the reasons for isolation and quarantine. As time progressed during the crisis, children increasingly understood the rationale for patient care policy changes and visitation restrictions. This resulted in children being more informed and understanding, and also expressing fewer fears over the changes in health care. However, explanations directed to children could have occurred much earlier which, participants suggest, would have fostered adherence. This finding is consistent with earlier SARS literature which suggests that greater explanation of reasons for protocols such as quarantine, is linked to increased compliance [21,22], and highlights the significance of ensuring that children, as major stakeholders, receive the information they need in developmentally appropriate ways. These findings suggest that the flow of information in pediatric settings presents unique challenges for health care providers, particularly in ensuring that information is as comprehensible as possible, yet also as simple and clear as possible even for the very young child.

3.2. Vulnerability and moral doubt

The majority of health care providers (88%) recognized the importance of their work, yet grappled with concerns related to personal vulnerability and the impact of SARS policies on patients and families. The uncertainties about SARS transmission ignited anxiety in every health care provider (100%), while simultaneously fostering a sense of obligation and commitment to patient care. As one health care provider explained,

I do it for the kids, as long as I knew that I was helping them and they developed such a trusting relationship with us. We were the ones they were seeing most of the time. So if you could make them smile, or if you could just be in there to comfort them, then it was worth it. You kind of put aside your fear knowing that the kids are probably 100 times more afraid than you are. So I would go in there and do what I needed to do. Make them happy. That’s what it was like for me. My priorities were always the child, the patient and
you do your best and make them as comfortable as possible.

All health care providers (100%) expressed heightened turmoil as a result of seeing children in isolating and vulnerable circumstances. They were aware of parents’ serious health conditions, sometimes more so than the children. Tensions among health care providers included moral conflicts when withholding information or enforcing limitations on family involvement in children’s care. Policies resulted in quarantine and isolation for children and their families, and families (100%) reported experiencing anxiety and loss. These findings are congruent with previous research which has also found that patients quarantined for SARS experienced feelings of uncertainty, separation, rejection, and stigma [21]. A parent exemplified this loss by stating, “being separated from (your children during hospitalization)... you almost feel like you’ve lost them. You feel hopeless.” In turn, most frontline health care providers (75%) grappled with the conundrum of being responsible for enforcing policies of isolation and quarantine, while realizing the devastating impact on children and families.

Beyond experiencing moral and family-centered care dilemmas, health care staff (100%) worried about becoming infected by the virus and taking it home to their own families. A health care provider described a pervasive sense of stress and fear:

I was mostly afraid because I have a family. I have a young child and I was afraid of bringing this, whatever it was, home. So when I came home, I would quickly shower before my child would see me and put my clothes in the laundry... I was more fearful than I would admit to others.

This sense of fear and vulnerability were re-ignited when precautionary measures were intensified, as a health care provider illustrated below.

At one point in time, we went to double masking, double gloving and double gowns. It made us second-guess all the days before that we hadn’t done that. Had we put ourselves at risk? Had we put our staff at risk?

The intensity of perceived risk and workplace hazard left health care providers feeling, “vulnerable... physically, mentally and emotionally.” To address these needs, most staff (75%) reported the importance of collegial support and camaraderie, as illustrated by a health care provider’s comment, “The way the team functions is important in supporting team members, and recognizing, or helping people recognize, when perhaps they are overdoing it and becoming too stressed.” Yet several health care providers (63%) described a lack of support from colleagues and others in the community. Despite placing themselves at risk by providing SARS care, some health care providers perceived limited institutional recognition, which resulted in, “unrest [among health care providers] who thought they were not appreciated and that nobody listened to them.” While support from colleagues was generally acknowledged, collegial respect and etiquette was, in some cases, lacking.

In some cases, the emotional toll of these difficult experiences was described to be substantial and long-standing. Beyond workplace strain, nearly all health care providers (88%) were often advised by family and friends to “stay away” from social or family events. They described ostracism and loneliness in being unwelcome at a time when informal support and workplace distraction was acutely needed.

3.3. Effective and responsive leadership

Most health care providers (63%) outlined the importance of strong, focused leadership and effective crisis management during health crises such as the SARS outbreak. Regional leaders and decision makers were praised for their diligence, yet their professional preparedness for this role was also questioned. As one health care explained,

This is a kind of infectious epidemic situation that requires a stronger public health input, a stronger infection control input, and a stronger infectious diseases input — working together with someone who understands crisis management. And although at the time it sounded logical, I’m not sure that emergency room people really understand the broader scope of crisis management.

Coordination of SARS-related decisions and resulting tasks required new solutions and systems for unprecedented problems [23]. As an example, a health
care provider described a decision-making process for obtaining sufficient infection-control masks:

Someone said, ‘we’re going to need 5,000 masks’, and someone else asked, ‘how many masks?’ He looked to someone with him and asked, ‘how many do we have?’ And that person said, ‘200. How are we going to get 5000?’ The response was, ‘we’ll tell you tomorrow.’ The next day’s report was, ‘we have 2,000 coming from the U.S. On Friday, we can get another...’ So that’s the way people worked. ‘So and so is responsible for setting up the screeners. Who’s going to educate the screeners?’ ‘I’ll take care of that’.

In responding to immediate demands, flexibility, and camaraderie resulted from working together toward timely solutions. A health care provider described effective teamwork as essential to crisis management and patient care. The need for rapid solutions and decisions necessitated central coordinating systems for distilling incoming information and implementing responses. Cohesive and decisive leadership, as well as using effective communication and dissemination methods, were crucial. Unfortunately, the rapidity and apparent imminent risk, inherent in SARS, limited long-range strategic planning in establishing systems of coordination. One health care provider explained,

I think the whole thing has made us all a lot more aware that unexpected things do happen. You can’t always be prepared for it. You do the best you can do working together as a team.

3.4. Expedient development of practice guidelines

Due to the unprecedented nature and magnitude of the crisis, practice guidelines had to be rapidly developed and immediately implemented. This included infection control policies as well as staffing orientation and care practices. Developing practice guidelines was particularly unsettling given that there was little precedent or evidence to guide decisions and policies, which often had a monumental impact on care delivery. A health care provider described the local approach for pediatrics:

Quite early on we established our own set of guidelines, what we thought was the most reasonable approach based on what the adult-centered institutions were doing and in part on what Hong Kong was telling us. By then we had admitted some of our early cases who were kids. But we didn’t know what was going to happen to them.

Toward the development of practice guidelines, international communication was immediately mobilized using advanced technology. Websites provided localized patient care guidelines and teleconference meetings brought together key stakeholders in affected regions. In providing responsive and decisive leadership, networking was critical in spreading site information and soliciting guidance for local treatment strategies. Advanced telecommunication clearly added capacity for the immediacy of information dissemination and, as such, technology permitted a timely forum for developing and sharing practice guidelines. Yet while immediacy of information increased clarity, it simultaneously informed the health care community of the ‘moving target’ of SARS; thereby, increasing confusion and uncertainty, as a health care provider reported below.

(Macro-level health bodies) sent out directives and expected hospitals to comply with the directives. Then the next day another directive came, which might contradict the first one. There was a lot of confusion and it was hard to interpret what they were saying. Sometimes we would look at the directives and say ‘that doesn’t make any sense’ or ‘that doesn’t really apply to us, I don’t see how we can implement something like that.’

Confusion, inconsistency and sometimes irrelevance of guidelines, were described at various levels of patient care. A parent reported that constant changes in infection control procedures became “a new norm.” Accordingly, inconsistent patient guidelines during SARS appeared to preclude ease of understanding, integration and appreciation of the imposed restrictions.

In recommending preparation for any future outbreak of SARS or similar infectious disease, participants advocated the rapid development of protocols and procedures. Fostering an organized and systematic response to a crisis with clear guidelines was viewed
as a means to potentially ease patient care ambiguity, as a health care provider explained below.

Hopefully there won’t be as much confusion the next time around (because of the development of) protocols. We know what the routine will be; it’ll be a lot more organized.

Health care providers described ‘relief’ over the eventual development of concrete SARS protocols. They stated that protocols established frameworks upon which decisions could be based. Accordingly, such protocols were thought to offer the potential to diminish the chaos that prevailed during much of the SARS outbreak.

4. Discussion

Health care responses to the SARS crisis yielded clear implications for patients, families, health care providers, and the larger community. Imposed restrictions had far-reaching and substantial impacts on community and health care functions. The family-centered nature of pediatric care emphasizes the importance of openness and accessibility among children, parents, and health care providers. However, the health care response to SARS necessarily constrained this bedrock of pediatrics due to communal uncertainty and the risk of virus spread. Patient and family isolation emerged, as did shifts in professional roles and levels of vulnerability. Simultaneously, confusion at best, and chaos at worst, emerged for patients, their families, and health care providers.

Participants conveyed key domains in which many were profoundly affected; each domain yielding implications for health policy and clinical practice in the event of a future major disease outbreak. Accordingly findings speak clearly to the need for: systematic and well-orchestrated information flow; communication strategies in responding and disseminating relevant information; means to ease vulnerability among stakeholders; strategies for ensuring effective and responsive leadership; and the development of practice and policy guidelines for treatment and contingency planning for an unknown patient care path. Although these findings specifically apply to, and are drawn from, a pediatric perspective, they also have relevance for consideration in an adult-based care.

Lessons learned from the recent SARS outbreak can inform pandemic and crisis planning. In the management and containment of SARS, for instance, communication technology necessarily and exponentially increased the rapidity of information flow within the health care community. However, this knowledge dissemination often simultaneously left insufficient time to assimilate and adjust to presenting circumstances and new information. There is a need for information translators and communication strategies that can swiftly respond to shifts and apply criteria to information dissemination and application. Including an ethical framework seems important in managing competing priorities according to relevant pathways of decision making. For example, equipment use in the event of shortage or rationing will require ethically-based criteria that simultaneously and perhaps, in tension, grapple with multiple and complex considerations for best decision making amidst competing demands. SARS clearly exemplified value-based crisis, particularly as we looked at issues and conflicts from the perspective of multiple stakeholders at different organizational positions.

Applying a systems perspective [24], whereby feedback to the system is recognized [24–26], the occurrence of SARS constituted a massive environmental ‘shift’ within the local and global community. In the case of SARS, the environment provided stimuli and feedback that was exceedingly divergent and unprecedented to be easily managed within existing health policy, communication structures, and response systems. Current health policies and communication structures appeared unprepared to integrate and manage the immense volume and fluctuations of incoming and outgoing information amidst intensified uncertainty and risk.

The responsive nature of systems, within a systems theory orientation, is typically viewed as adaptive and able to respond to environmental feedback [24]. However, feedback relating to SARS strained existing policy and practice frameworks of logic during the outbreaks. The daily shifts in infection control and patient management procedures often surpassed professionals’ ability to assimilate, let alone master, new tasks of ‘routine’ care. Status quo was negated and a new norm emerged comprising change, confusion, and disequilibrium. Stability of policy thus became an ‘unattainable anomaly,’ which was echoed
in frequent policy shifts, detailed media portrayals of a regional health crisis, and a prevailing environment of uncertainty and unknown risk. Rather than moving toward stability and homeostasis, chaos emerged as the expected yet irreconcilable ‘norm’ [27] of daily health care delivery.

For frontline health care providers, uncertainty and anxiety were heightened as infection control precautions intensified. Fear of personal exposure to SARS increased as individuals realized that new standards of infection control had heretofore not been followed (prior to the intensification of the infection control policy). Perceived vulnerability appeared to be pervasive, yet a sense of duty to patient care motivated continued work and, therefore, risk. Ongoing confusion and tension were expressed by frontline staff who described existing within an environment of risk, workplace chaos, and personal emotional strain.

SARS related policies sought to routinize patient care within non-routine conditions. This required attempts to balance risk management and quality of life through continual justifications of the system to accommodate changing information. While stakeholders understood the need for policy shifts, they lacked an understanding that chaos was, under the presenting risks and uncertainty, a reasonable “norm” [28] and they did not appear to have accessible means to ‘streamline’ or control the presenting volatility. As an example, information was transmitted through various means and sources. Systematizing the flow of information, a means of adding predictability and order, may have increased health care staff’s ability to rapidly assimilate, apply new learning and routinize constantly shifting data. Moreover, increasing stakeholders’ collective knowledge about means of managing this new state of disequilibrium may have ‘normalized’ or provided tools for handling chaos during this time of abnormality [28].

In future planning, developing contingencies and frameworks to minimize and/or routinize environmental chaos, as experienced during SARS, may assist stakeholders in assimilating information, managing uncertainty, and developing contingency plans. Consistent lines for the incoming flow of information, analysis, and outgoing dissemination may foster coordination by effectively discerning emergent circumstances, their parameters and best practices in information dissemination.

At times of outbreak and crisis, human resource sustainability and morale maintenance are crucial, particularly when health care providers themselves are at considerable risk of disease infection. Based on widespread vulnerability, fear and social stigma, stakeholders, including patients, family members and health care providers, emerged as populations at emotional and physical risk. The development of patient, family and workplace risk assessment processes and psychosocial assistance are critical. In the SARS crisis experience, tangible appreciation and recognition for frontline health care providers appeared to be desirable and needed. Finding ways to meaningfully recognize the fortitude and contribution of direct practitioners may go a long way in encouraging and sustaining these key stakeholders.

5. Conclusion

The crisis of SARS clearly had a multifaceted impact on health policy and practice as well as on the personal and professional lives of affected individuals and families. Examining the occurrence of the recent SARS outbreaks provides experience for future crisis contingency planning. Planning strategies include rapid virus containment, seamless and coordinated communication, humane and accessible care, effective leadership, and the timely development (or adaptation) of practice guidelines. Toward this end, strategies include the creation of preparedness guidelines, competency and capacity-building, and the development of a quorum of skilled and deployable health care professionals and epidemiologists. Given the continuing threat of current and future airborne viruses with potential for epidemic spread and devastating outcomes, preparedness strategies are integral to responsible health care planning. The SARS crisis provides us with tangible lessons and a template from which innovation can incorporate practical, ethical and multisectoral elements in devising a pandemic plan.

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