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Parental Response to Child's Isolation During the SARS Outbreak

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Objectives.—To examine the needs, uncertainties, and experiences of parents during their child's hospitalization with highly suspected severe acute respiratory syndrome (HSS), and to identify ways to improve their psychological preparedness and communication with health care professionals and their isolated children during future infectious disease outbreaks.

Methods.—Qualitative, semistructured interviews were conducted in July 2003 with parents of HSS pediatric patients. Seventeen HSS patients were hospitalized in a pediatric outpatient clinic of a major academic medical center in Hong Kong, between March 20 and May 28, 2003, during severe acute respiratory syndrome (SARS). Seven parents (41%) consented to participate in the study.

Results.—Four major themes were identified from the interviews: 1) fear of immediate isolation and infection control proce-

dures, 2) sources of anxiety, 3) coping, and 4) communication with children and health care professionals.

Conclusions.—Findings indicate a need to improve the psychological preparedness of the parents regarding the child's immediate isolation during hospitalization. Ample preparation and appropriate communication among parents, health care workers, and children might minimize fear and anxiety, sustain trust, and facilitate mutual understanding during an infectious disease outbreak.

KEY WORDS: communication; infection control; isolation; parental responses; severe acute respiratory syndrome

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Stringent infection control measures were implemented in Hong Kong hospitals to contain severe acute respiratory syndrome (SARS) in 2003.¹ About 6.9% of SARS patients in Hong Kong were children (aged <12 years) and teenagers (aged 12–18 years), with no fatalities reported in the pediatric age group.² Although pediatric SARS patients generally had milder symptoms than adults,^{2–4} both children and parents feared SARS and the separation anxiety arising from hospitalization in a strict isolation setting.⁵

Previous studies investigated parental needs and the stress of pediatric patients in intensive care units.^{6–8} However, these studies mainly focused on children who were seriously ill, and visiting was normally allowed because their illnesses were not infectious. Few studies have addressed the parental response to the strict isolation of highly suspected severe acute respiratory syndrome (HSS) patients that prevented visiting during the outbreak.

This study explored the needs and experiences of parents during their child's isolation to improve preparedness for future infectious disease outbreaks. This paper aims to 1) identify parental needs and experiences during the hospitalization of children with HSS, 2) describe parental perceptions of the care provided in a pediatric unit for SARS patients, and 3) identify ways to improve communication among health care professionals, hospitalized children, and their parents during strict isolation of the patient.

METHODS

Subjects

Sixty-six highly suspected/suspected SARS pediatric patients were admitted to a major academic medical center in Hong Kong between March 20 and May 18, 2003. Of the suspected cases, parents of 17 children were invited to participate in the study via telephone before attending the postdischarge follow-up. Eight parents of 7 children (6 mothers and 1 couple) consented to participate in the interview (Table) on the day of their follow-up. Interviews with semistructured questions were conducted in July 2003.

Procedures

Ethical approval was obtained from the Institutional Review Board of the University of Hong Kong and Hospital Authority (Hong Kong West Cluster), and parents provided written consent. A nurse specialist conducted 1-hour, semistructured interviews with the 7 participating families in a private room in the pediatric unit. The interview guide

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Table. Gender, Age, and Hospitalization Data of the Highly Suspected SARS* Pediatric Patients

Case No.	Sex	Age	No. of Days Hospitalized	First Time Admission to Hospital	Siblings	Subject Interviewed
1	F	8	8	Yes	Yes	Mother
2	M	7	5	No	No	Mother
3	F	3	2	Yes	Yes	Mother
4	M	9	>30	No	Yes	Mother
5	M	7	4	Yes	No	Mother and Father
6	F	13	3.5	Yes	No	Mother
7	M	6	1	Yes	No	Mother

*SARS indicates severe acute respiratory syndrome.

probed parents' needs at and during hospitalization, views of the care provided, and other parental experiences. The interviews were taped and transcribed verbatim.

Data Analysis

Two researchers independently read the transcripts and generated themes, patterns, and inductive codes following the grounded theory approach.⁹ Four themes were identified: 1) fear of immediate isolation and infection control procedures, 2) sources of anxiety, 3) coping, and 4) communication with children and health care professionals.

RESULTS

Fear of Immediate Isolation and Infection Control Procedures

Parents were very concerned about their child's general health and the possibility of deterioration. Because of the diagnosis of HSS, all their children were immediately hospitalized in isolation, and visitation was not allowed. Parents expressed fear and uncertainty as to what might have happened during the hospitalization, as related by Mother A: "I did not believe that the medical and nursing staff would watch her 24 hours. I didn't feel comfortable leaving her there. I did not feel it was right to leave her alone."

The parents were conflicted because they understood the need for hospital isolation infection control procedures but felt distressed about leaving their children alone in the hospital. The parents reported an overwhelming fear of being separated from their children: "I actually asked the medical and nursing staff if I could stay. I understood the reasons for isolation and it was my responsibility as a citizen. I would rather to have stayed with her and been treated too ... No matter what happens, I won't leave this room," said Mother C.

The immediate isolation and lack of parental presence were the most commonly identified concerns and points of dissatisfaction. Parents wished for more time to reassure their children and prepare them for the separation. They were doubtful about the need for immediate isolation, as they had already been with their child for days when the symptoms appeared. They speculated that if the children had SARS, it would have already been apparent, and they suggested that being able to observe their children

through windows or doors of the isolation rooms would have helped.

Sources of Anxiety

Parents described 3 sources of anxiety: 1) simultaneously managing the hospitalized child and home responsibilities, 2) disruption in their work life, and 3) possible side effects of medications. The hospitalization interrupted the routine of daily family life as well as the work lives of parents. Parents, especially mothers, needed to finish housework before going to see to the child in the hospital. Because the children were isolated even from the nurses and doctors, they used mobile phones frequently to call their mothers. According to Mother D, "For physical care, he had to depend on nurses. But for emotional support, he relied on Mom and Dad. We were available for the 2 days when the child was in the hospital. Honestly, if it had been during weekdays while I was at work, when he called like that ... I don't think it would have been possible. My office wouldn't have allowed me to talk with him nonstop."

Parents were also anxious about the possible side effects of medications (eg, steroids or ribavirin) that were used to treat SARS, insofar as the mass media had continuously highlighted complications of the SARS medications. "I knew he would get well but I feared that his intelligence would be compromised. That would have been the worst and I wouldn't have known what to do," said Mother E.

Coping

Parents adopted various personal strategies to cope with their stress and anxiety while their children were hospitalized with a potential deadly disease. Distractions, such as going out and buying their favorite foods, helped avoid focusing on their hospitalized children. Most parents did not seek support from other family members, believing the community was already stressed because of SARS. Some reported not telling the grandparents about the child's infectious disease and hospitalization because they did not want them to worry.

Another coping strategy was to bring personal items to the hospitalized child frequently. Generally, parents understood that hospital staff were experiencing a heavy workload and appreciated the time that it took to pass personal items to their children. Parents reported they felt

relieved to know their child's condition was satisfactory. They expressed satisfaction with the quality of care their children received, especially during this critical time.

Communication With Children and Health Care Professionals

Since parent visits were not permitted, the pediatricians called the parents of the HSS patients once a day to let them know their child's condition. One mother mentioned that the physician phone call was a source of fear. Other parents reported that having the doctors keep them informed was helpful. The hospitalized children were allowed to use mobile phones, and a call bell was provided in every room so that their needs were regularly met. Nevertheless, this approach still prevented the children from seeing their parents in person.

DISCUSSION

Our qualitative analysis provided some insights into parental experiences, such as fear, anxiety, coping, and communication, arising from their child's HSS and his/her immediate isolation during hospitalization. Although hospitalization usually causes stress and anxiety in children and their parents,¹⁰⁻¹² the "no-visiting" rule and the immediate isolation of the child could have induced further anxiety, as the children were also isolated from the health care workers.^{5,13} In Hong Kong, households are typically small in size, and young children usually sleep with their parents. Parents would worry about their child's coping with the stress of isolation.

With SARS being an infectious and life-threatening disease, the diagnosis and treatment were under frequent and often controversial discussion in the media. The infectious nature of the disease (and its death toll) generated a high degree of fear among the public and influenced the parents. Parental anxiety extended to disturbances in family and work life during the child's hospitalization. Moreover, parental response to the child's hospitalization could well be affected by other family members, friends, and colleagues. Some families did not want to tell others that their children were hospitalized due to suspected SARS to avoid stigmatization. Being able to bring favorite toys or personal items to their hospitalized children and the daily telephone calls from pediatricians provided parents with coping mechanisms, thus alleviating part of their uncertainty and anxiety.

Although parents expressed trust and satisfaction with the health care workers, they felt inadequately prepared for separation from their children, especially immediately upon admission. They were concerned about the care of their children, how they were coping in isolation, and any side effects of drug treatment. Alleviating such fear and anxiety will be a priority in future infectious disease outbreaks. Health care professionals should actively prepare parents during such admissions. Previous studies showed that specially designed programs can allow children and their families the opportunity to preview the hospital experience to reduce anxiety and enhance coping.^{14,15} Developing a multidisciplinary program for parents at times

of infectious disease outbreak on isolation procedures, environment, communication channels, plan of care and treatment, and drugs to be administered with possible side effects may help. Psychological preparation can begin in the accident and emergency department by informing parents about the admission and hospital isolation practices so that they can prepare their children. Clinical practice guidelines on preparing parents and children for total isolation might improve psychological preparation during future infectious disease epidemics.

Communication between health care professionals and parents fosters trust, facilitates mutual understanding, and is a high priority to improve the quality of care to both patient and family.¹³ Pediatricians and nurses should regularly contact parents about their child's physical condition, the treatment and medications being administered, and the child's psychological well-being during isolation. The use of advanced communication technologies such as viewing cameras, 3G mobile phones, and telephone conferencing in isolation rooms can facilitate child and parent communication.^{13,16,17}

The small sample size limits generalization to other parents of SARS patients. However, we believe the issues of infection control, isolation, and anxiety could be similar in both SARS and HSS patients. We did not explore the views of pediatricians and nurses on their care provision, the challenges in caring for a child in an isolation setting, their fear of contracting SARS, and their dilemma in providing care to the child while adhering to the minimal contact rule of infection control.⁶

The parents of HSS pediatric patients experienced fear and anxiety during their child's hospitalization. The fear arose from the infectious and life-threatening nature of the disease and the immediate isolation. Ample psychological preparedness and appropriate communication by pediatricians and nurses might minimize fear and anxiety, sustain trust, and facilitate a mutual understanding between parents and health care workers during an infectious disease outbreak.

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