

- FTT POT - FBS OFE GPS 1 FEJBUSJD 1 BOEFNJD 1 \$BTF 4 UVEZ

Laura Beaune ^{1*}, David Nicholas ² and Jodi Hocken ³

¹Palliative and Bereavement Services Research Coordinator, Palliative and Bereavement Care Service, The Hospital for Sick Children, 555 University Avenue, Toronto, Ontario, M5G 1X8, Canada

²Faculty of Social Work, Central and Northern Alberta Region, University of Calgary, #444, 11044 82nd Ave., Edmonton, Alberta, T6G 0T2, Canada

³Child and Family Therapist Women's Crisis Services of Waterloo Region, 700 Heritage Drive, Kitchener, Ontario, N2H 6M3, Canada

Abstract

Aim:

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-centered transparent and timely communication

