

Pediatric Caregivers Could be Better Supported for Dyad Isolation in the Hospital during COVID-19

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ABSTRACT

The onset of any emerging outbreak is stressful for everyone. Singapore was one of many countries which was affected early by COVID-19. In response, many precautionary measures were quickly initiated, including the isolation of suspected COVID-19 pediatric cases, and their caregivers were isolated together with their hospitalized children as a result. Caregivers play an important role in facilitating their child's health in the hospital. Rooming in with their children during hospitalization also promotes the benefits of parental presence and reduces separation effects. However, this sudden admission with strict movement restrictions poses substantial stress on these caregivers too. This study ran a 3-part paper-based survey to understand the stresses and concerns which caregivers faced when suddenly entering dyad isolation. The survey included a poll on the caregivers' general perception of the situation, questions adapted from the SARS Fear Scale, and the Hospital Anxiety & Depression Scale (HADS). In general, caregivers in the COVID-19 isolation units did not expect their child to be isolated, and were not prepared for dyad isolation with their children. They were found to be more dejected, and were concerned that they themselves might have possibly infected their family and friends. Caregivers of children suspected of COVID-19 should be pre-empted to prepare for the possibility of isolation. This may include bringing in toys and personal entertainment to reduce boredom, as well as other essential needs. Patient mental wellness programs may consider extending their services to caregivers in dyad isolation due to COVID-19.

Key words: Patient experience; COVID-19; Pediatrics; Patient isolation; Patient care

INTRODUCTION

The coronavirus disease (COVID-19) epidemic has become a global pandemic, affecting individuals regardless of their demographics and age. Singapore is the earliest country greatly affected by the disease, with the number of cases rising exponentially within the span of months starting in January. Singapore health authorities initiated surveillance testing, contact tracing and isolation of cases to help limit the public health impact of COVID-19.

All suspect and confirmed cases were promptly admitted and isolated at designated hospitals. For pediatric cases, an adult caregiver usually a parent or adult family member would enter into dyad isolation. Caregivers have always played an important role in facilitating their child's health and wellbeing and influence the child's adherence to care [1,2]. Rooming in with their children during hospitalization also promotes the benefits of parental presence and reduces separation effects [3-7].

Yet any positive effects will be limited when the parent's

participation in the care is compromised by their own emotional distress [1,7]. Whilst an effective strategy for infectious diseases, isolation has shown to be associated with uncertainty and social restriction, which potentially contributes to anxiety, frustration, and distress [1,3,8-16]. During isolation, both young patients and their parents were known to experience hospital-related anxiety and depression [3,8-12]. Being isolated due to a disease outbreak of unknown etiology such as COVID-19 adds additional stresses beyond physical separation, with new revelations each day causing even more uncertainty, as well as fearing stigmatization [13-16]. Parents who also experienced isolation along with their children were more likely to suffer from issues related to post-traumatic stress disorder [12].

Gaining awareness and identifying psychological problems that caregivers face in sudden isolation with their child is vital to inform current interventions, which can contribute to improving the health of both the young patients and their caregivers? This paper describes the findings of a survey used to evaluate the impact of

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strict isolation protocols on caregivers of pediatric patients during COVID-19.

METHOD

We conducted an anonymous survey consisting of 3 parts (see Annex A). Caregivers of children admitted and requiring isolation from KK Women’s & Children’s Hospital (KKH) in Singapore were recruited from 12th March 2020 to 2nd April 2020. Recruitment criteria for this survey were caregivers in isolation after one night’s stay with a pediatric patient admitted for:

- Suspected or confirmed COVID-19;
- Respiratory symptoms or community acquired pneumonia isolated under the hospital enhanced surveillance guidelines.

The first part of the survey consisted of 14 general perception questions regarding the caregiver’s situation of being isolated with their child in the hospital. These questions were a mix of positive and negative statements, or were otherwise fairly neutral to manage acquiesce bias.

The second part comprised elements of the SARS Fear Scale [17]. The SARS Fear Scale was first used during the Severe Acute Respiratory Syndrome pandemic in 2003 to study “the nature of fear” in a pandemic situation. Six questions from the SARS Fear Scale were chosen based on relevance and not being already represented in the first part.

The third part was a 14-question Hospital Anxiety & Depression Scale or HADS [3,11,18-20]. This has been used to study patients in isolation and, while not amounting to a clinical diagnosis or anxiety or depression, helps to measure the current levels of caregiver anxiety and depression. It was also chosen as its design does not include terms generally associated with COVID-19. Each response was scored from 0 to 3, resulting in each participant acquiring a score of between 0 and 21 for either anxiety or depression, with higher scores indicating more symptoms.

Hard copy paper survey forms were distributed to the caregiver during breakfast or at the same time as morning clinical duties.

Once completed the nurse collected the forms. In order to minimize the biohazard risk, survey data was captured in 2 ways: either the nurse taped the survey on the window of the isolation room door facing outwards, where it was photographed through the window to capture the responses, or the forms were collected and stored in a purpose-made collection box and treated as biohazard risk (digital forms were initially explored but nurses felt it would encourage participants to ignore and not participate). All forms were tallied and transcribed digitally, following which the physical forms were disposed of safely and confidentially. Ethics approval was obtained in line with hospital and cluster policy.

RESULTS

A total of 181 surveys were collected (132 female and 49 male). Average age of participants was 36.5 (median age 37, standard deviation 6.08, excluding 5 with missing data for age).

Part A: General Perception

Figure 1 breaks down the percentage of each response for each of the questions in Part A. Not all caregivers responded to all the questions. Responses for each question ranged from 96.6% (2 questions) to 100% (3 questions). From the 175 responses in Question A1, 98.9% felt they were aware of the latest COVID-19 news. When asked whether they were stressed by the outbreak (Question A2), 180 responded, of which 52.8% generally agreed. 64% of 181 responses also generally agreed with the belief that being in the isolation unit is good for them (Question A10), and that they felt safe to be here (Questions A13 & A4) (Figure 1).

Questions A11 and A14 explicitly asked if caregivers felt bored and frustrated during this restrictive situation. Of the 178 caregivers that responded to Question A11, 71.3% agreed or strongly agreed to feeling “bored in the isolation unit”. 42% of the 181 responses generally agreed (37% gave a “neutral” response) to being frustrated due to “the lack of freedom in the isolation unit” (Question A14)

Questions A3, A5, A6 and A7 explored how well-prepared parents are for dyad isolation. 48.2% of 172 responses had not expected their child and themselves to be admitted into the isolation unit (Question A3) and 55.4% of 175 responses had not made

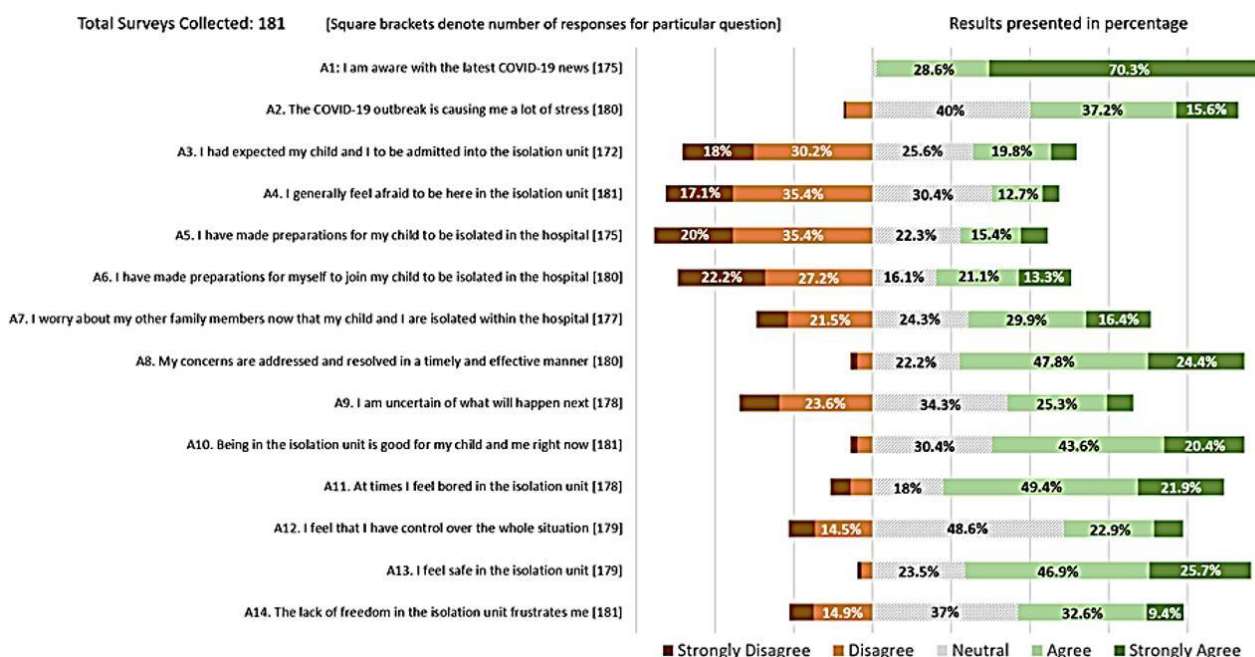


Figure 1: A diverging stacked bar chart showing the responses for each of the 14 questions in Part-A of the survey.

preparations for their child to be isolated in the hospital (Question A5). Of 180 responses 49.4% disagreed with the statement “I have made preparations for myself to join my child to be isolated in the hospital” (Question A6), with 22.2% responding “strongly disagree”. 45.4% of responses also agreed to the statement “I worry about my other family members now that my child and I are isolated within the hospital” (Question A7). Caregivers may be ill-equipped to be in dyad isolation with their children.

Questions A12 & A9 explored whether caregivers felt they were in control of their situation. Most responded neutrally (48.6% of 179 responses) to the statement “I feel that I have control over the whole situation” (Question A12). Responses to the statement “I am uncertain of what will happen next” (Question A9) were split fairly equally between generally disagreeing (33.7%) and generally agreeing (32%).

Question A8 polled whether the care team had been helpful with this statement: “My concerns are addressed and resolved in a timely and effective manner”. Majority of the responses were positive. Of the 180 responses, 47.8% were “Agree”, and 24.4% were “Strongly Agree”.

Pearson's Correlation analysis was done for all 14 questions along with the age of the participant to explore possibility of linear associations among these questions. Surveys with any missing data in Part-A were omitted, resulting in a sample size of 159. Table 1 shows the correlation coefficient for each pair, with the bolded numbers indicating statistical significance ($p < 0.05$), and the shaded cell highlighting moderate to strong correlation. The analysis revealed that if a caregiver had not expected the child to be isolated, naturally there would be a high likelihood that the caregiver would not have prepared anything for both of them for the admission (Questions A3, A5, A6). Another noteworthy finding is the positive relationships between feeling safe in the isolation unit (Question A13) and the following three opinions: having concerns resolved timely and effectively (Question A8), believing that being in the isolation unit was good for both the child and the caregiver (Question A10), and perceiving a sense of control (Question A12) (Table 1).

Part B: SARS Fear Scale

Part B of the survey was an adaptation of the SARS Fear Scale [17],

consisting of six polling questions that began with “COVID-19 makes me Figure 2 breaks down the percentage of each response for each of the questions in Part B. Majority of responses agreed or strongly agreed to the statements “COVID-19 makes me fear that I will be infected” (51.9%), “COVID-19 makes me fear that I will infect others” (62.3%), and “COVID-19 makes me worry if my family has been infected” (70.7%). Having a close encounter with COVID-19 now, many caregivers shared the fear of infecting others, more so than becoming infected them?(Figure 2).

Part C: Hospital Anxiety & Depression Scale (HADS)

Of the 181 surveys, only 167 HADS entries were complete (i.e. all 14 questions were answered). Table 2 shows the breakdown of average scores for each question, as well as the overall average score of all 167 responses. As a general reference [21]“a total score of 0 to 7 for either subscale could be regarded as being in the normal range, 11 or higher indicating probable presence of the mood disorder, and 8 to 10 being just suggestive of the presence of the respective state”. On average, caregivers scored 7.35 (SD ± 3.07) for anxiety, and 10.38 (SD ± 2.86) for depression. Caregivers are more likely to be depressed than anxious, but these negative moods are not significantly present after their first night in the isolation room (Table 2).

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Table 1: Correlation coefficients among the responses to the questions in Part-A. Bolded numbers indicate.

	Age	A1	A2	A3	A4	A5	A6	A7	A8	A9	A10	A11	A12	A13	A14
Age	1														
A1	-0.067	1													
A2	0.09	0.005	1												
A3	0.165	-0.05	0.099	1											
A4	0.026	-0.184	0.356	-0.068	1										
A5	0.052	0.224	-0.027	0.457	0.022	1									
A6	0.06	0.089	0.07	0.41	-0.066	0.74	1								
A7	0.031	-0.083	0.306	-0.111	0.39	-0.007	-0.056	1							
A8	0.08	0.243	-0.066	0.253	-0.151	0.38	0.301	-0.515	1						
A9	-0.105	-0.217	0.22	-0.149	0.319	-0.079	-0.07	0.515	-0.274	1					
A10	0.053	0.227	0.013	0.191	-0.074	0.26	0.217	-0.082	0.306	-0.086	1				
A11	0.049	-0.123	-0.005	-0.077	0.06	-0.232	-0.199	0.116	-0.067	0.267	0.025	1			
A12	-0.066	0.226	-0.068	0.108	-0.183	0.27	0.242	-0.151	0.302	-0.206	0.348	-0.096	1		
A13	-0.073	0.298	-0.103	0.201	-0.271	0.335	0.275	-0.197	0.439	-0.313	0.473	-0.135	0.416	1	
A14	0.174	-0.246	0.119	-0.033	0.134	-0.306	-0.284	0.182	-0.219	0.147	-0.258	0.512	-0.371	-0.338	1

Total Surveys Collected: 181 [Square brackets denote number of responses for particular question] Results presented in percentage

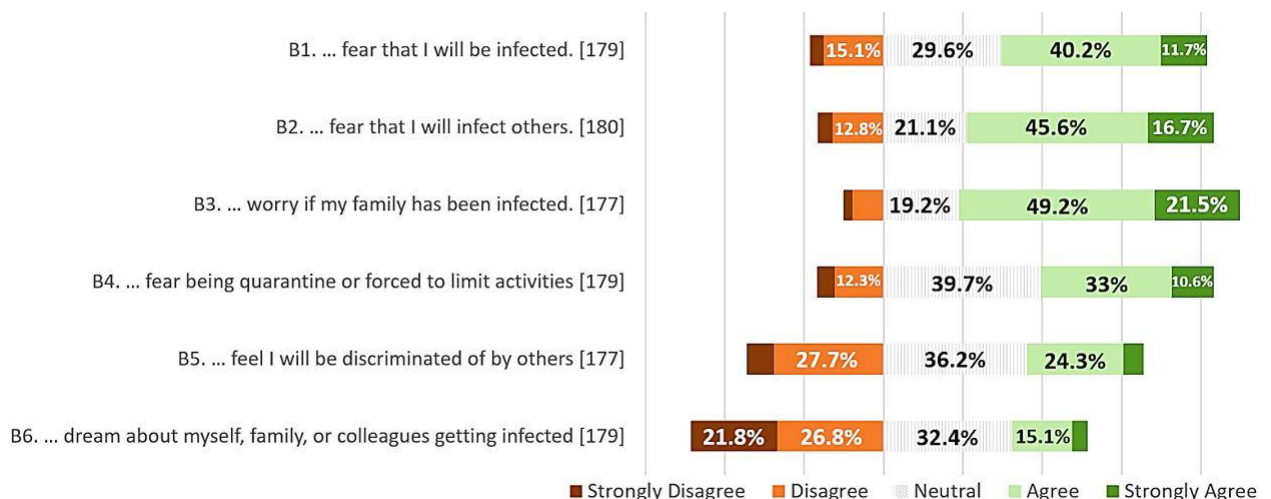


Figure 2: A diverging stacked bar chart showing the responses for each of the 6 questions in Part-B of the survey.

Table 2: A breakdown of average scores in the HADS portion of the survey (n=167).

Anxiety	Average score
C1. I feel tense or wound up	1.07
C3. I get a sort of frightened feeling as if something awful is about to happen	1.01
C5. Worrying thoughts go through my mind	1.19
C7. I can sit at ease and feel relaxed	1.61
C9. I get a sort of frightened feeling like 'butterflies' in the stomach	0.67
C11. I feel restless as I have to be on the move	1.12
C13. I get sudden feelings of panic	0.68
Average Total Score	
7.35 (SD 3.07)	
Depression	Average score
C2. I still enjoy the things I used to enjoy	1.40
C4. I can laugh and see the funny side of things	1.59
C6. I feel cheerful	1.38
C8. I feel as if I am slowed down	1.53
C10. I have lost interest in my appearance	0.95
C12. I look forward with enjoyment to things	1.84
C14. I can enjoy a good book, radio, movie, or TV show	1.68
Average Total Score	
10.38 (SD 2.86)	

to 7 for either subscale could be regarded as being in the normal range, 11 or higher indicating probable presence of the mood disorder, and 8 to 10 being just suggestive of the presence of the respective state". On average, caregivers scored 7.35 (SD ± 3.07) for anxiety, and 10.38 (SD ± 2.86) for depression. Caregivers are more likely to be depressed than anxious, but these negative moods are not significantly present after their first night in the isolation room (Table 3).

DISCUSSION

Unsurprisingly, most caregivers are familiar with the COVID-19 situation and expressed stress over the situation. A significant percentage were unaware of the isolation measures for admitted children, that caregivers would need to be isolated with them and were unprepared for the isolation. A significant percentage was reportedly bored and frustrated as a result. Nonetheless, caregivers generally felt it was right that they were in isolation, agreed that they were taken care of and their needs were being met in the

isolation ward. This might have facilitated reduction in stress and panic now that they were receiving professional care, as reflected from the low HADS Scores for anxiety.

Relationships between these observations were further revealed through the correlational analysis. Naturally an unsuspecting dyad isolation for caregivers meant caregivers were unlikely to have anything prepared for the restrictive ward stay, hinting of a possible disconnect between the hospital protocol and the public's impression of how suspected COVID-19 patients are managed. Parents may also possess a general optimism for their own child's situation amid the outbreak. The correlation analysis also revealed significant relationships among the following areas in which healthcare operations may focus on to improve caregiver experience:

1. Feeling safe in the isolation unit
2. Believing that being in the isolation unit was good
3. Perceiving a sense of control

Table 3: A breakdown of average scores in the HADS portion of the survey (n=167).

Anxiety	Average score
C1. I feel tense or wound up	1.07
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C13. I get sudden feelings of panic	0.68
	Average Total Score 7.35 (SD 3.07)
Depression	
C2. I still enjoy the things I used to enjoy	1.40
C4. I can laugh and see the funny side of things	1.59
C6. I feel cheerful	1.38
C8. I feel as if I am slowed down	1.53
C10. I have lost interest in my appearance	0.95
C12. I look forward with enjoyment to things	1.84
C14. I can enjoy a good book, radio, movie, or TV show	1.68
	Average Total Score 10.38 (SD 2.86)

4. Having concerns resolved timely and effectively by the medical team.

Results from the SARS Fear Scale showed similarities between the polled caregivers during this COVID-19 outbreak, and the healthcare workers' fears during SARS [17-22]. In the face of a pandemic, both the hospital staff in Hong Kong as well as our group of caregivers here in Singapore shared the greater concern of infecting others (especially family members) than being self-infected. This insight might also draw some associations with an earlier question in the survey (Question A7), in which 46.3% of responses generally agreeing to worrying about their family members now that they were isolated.

Comparing the HADS score with the survey responses, the relatively higher depression scores were consistent with the pessimistic outlook in the SARS Fear Scale. The bulk of participants expressed their fear of being infected by the virus as well as infecting family members and other people (Questions B1-B3). On the contrary, anxiety was not as prevalent, with most caregivers feeling neutral about "being in control" (Question A12) as well as a balanced split in perception towards uncertainty (Question A9). The positive impact of feeling safe and cared for by medical professionals in the isolation ward might have contributed too.

Caregivers of children suspected of COVID-19 should be pre-empted to prepare for the possibility of isolation. The sudden hospital stay is also disruptive to prior plans, which may include providing care of other family members. Attempting to improve their current situation while being isolated in a foreign environment would be challenging. Pre-empting caregivers would allow them time to coordinate logistics support from family and friends to help equip caregivers with the essentials they need prior to being isolated. A recommendation list may also be crafted to aid caregivers in their arrangements. Besides essentials like snacks, cell phone charger, toiletries and a change of clothes, toys and entertainment items for both child and caregiver should be considered too to manage boredom.

We do not anticipate the forewarning of strict dyad isolation to deter appropriate attendances, with consequent increased

community transmission. Results from the survey showed positive attitude from caregivers who were isolated, as they believed it was for the well-being of their children and themselves to be isolated under medical attention. Lack of awareness regarding isolation might be due to the rapid evolution of COVID-19. Priority in Singapore's public health messages was focused on managing the pandemic in the community and getting the public to seek medical attention appropriately. To avoid overwhelming the masses, it would be more beneficial to provide these isolation details in a timely manner when caregivers might have to be mindful of possibly getting admitted. An example could be prior to coming to the emergency department for issues relating to COVID-19.

Patient mental wellness programs may consider extending their services to caregivers in dyad isolation due to COVID-19. Caregivers' relatively lower anxiety may be attributed to their child finally being under professional care. However, caregivers do report a level of sadness and despair, plagued by their fears of possibly having infected others, or that other family members might be infected as well. Availing some mental support which caregivers could get in touch with during this time might greatly reduce the stress that they are experiencing during this crisis. While any sudden hospitalization is never a happy occasion, COVID-19 is an unprecedented circumstance for practically everybody.

Therein lies one of some limitations to the current report. We were unable to empirically deduce whether COVID-19 related cases were more stressful than other infectious diseases or even hospitalization in general. We could not identify an appropriate control group (e.g.: oncology long-stayers, other non-coronavirus isolation cases) within the hospital during this outbreak to make a meaningful comparison.

Hence, results from the survey remain descriptive. Nonetheless, we could at least identify some sources of stress and concerns which the caregivers had during this outbreak, and even specific areas and strategies to help caregivers. Future research may look at a broader comparison of caregiver stress and concerns, as well as evaluating support initiatives targeted at caregivers.

CONCLUSION

Infectious disease outbreaks throughout the years have had a significant impact on not just the physical wellbeing, but also the psychological health of people. The onset of any emerging outbreak filled with uncertainty and pressures to act swiftly and decisively, will always be stressful to everyone. . In the pediatric setting, this care should extend to the caregivers too, for they play a major role in supporting their child's recovery. Caregivers faced with a sick child might suddenly find themselves ushered into isolation together with the child as part of heightened precautionary measures during the outbreak. An unfortunate situation would thus be made more uncomfortable given that most caregivers would be unprepared. Our data revealed the various issues and concerns these caregivers faced, and provided some insights on how the caregiver experiences can be improved.

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