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# Surveying pediatric caregivers' readiness for dyad isolation in the hospital during COVID-19

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Research

# Surveying pediatric caregivers' readiness 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 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 promotes the benefits of parental presence and reduces separation effects. However, sudden admission with strict movement restrictions poses stress to 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 polled caregivers' general perception of the situation, and also used questions adapted from the SARS Fear Scale and the Hospital Anxiety & Depression Scale (HADS). 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 these caregivers too.

**Keywords**
Patient experience, caregiver well-being, parents of patients, COVID-19

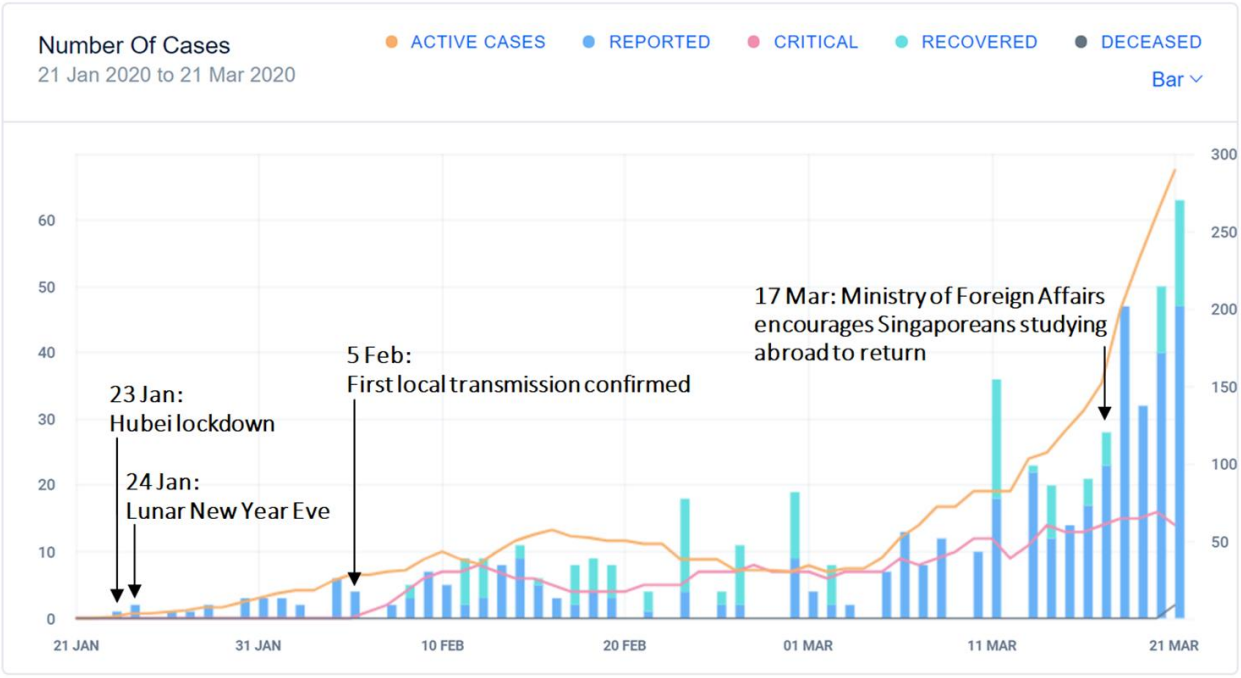
## Introduction

The coronavirus disease (COVID-19) pandemic has become a global pandemic, affecting individuals regardless of their demographics and age. Singapore was one of the earliest countries greatly affected by the disease, with the number of cases rising exponentially within the span of months starting in January 2020 (Figure 1). Singapore health authorities initiated surveillance testing, contact tracing and isolation of cases to help limit the public health impact of COVID-19.

As part of national disease management efforts, all suspect and confirmed cases were promptly admitted and isolated at designated hospitals. Unique to pediatric cases, an adult caregiver (usually a parent or adult family member) would enter into dyad isolation. This meant that the caregiver would join the young patient to be isolated together throughout the hospital stay. No visitors were allowed, and caregivers were not permitted to leave the room. Given the pandemic situation, these isolations typically took place promptly and suddenly so as to minimize risk of spread. This approach was similar during the SARS pandemic of 2003.

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] Particularly for contact isolation, children cope better when there was parental presence, and parents would experience guilt for leaving their children confined alone in the room.[8] In another interview study, when children undergoing isolation were asked, "Is there anything that has made it easier for you when you can't go to the playroom and have to stay in your room?," responses included having their parents together with them.[9] Despite the uncomfortable situation, entering dyad isolation has benefits for both the parents and their young children. Whilst an effective strategy for infectious diseases, isolation has shown to be associated with uncertainty and

**Figure 1. Timeline of COVID-19 cases in Singapore from Jan 21 to Mar 21, 2020 (Source: co.vid19.sg)**




social restriction, which potentially contributes to anxiety, frustration, and distress.[1,8-18] During isolation, both young patients and their parents were known to experience hospital-related anxiety and depression. Being isolated due to a disease outbreak of unknown etiology such as COVID-19 added additional stresses beyond physical separation, with new revelations each day causing more anxiety and fears of stigmatization.[16-18] Parents who also experienced isolation along with their children were more likely to suffer from issues related to post-traumatic stress disorder.[14]

This study aims to capture any emotional concerns and psychological problems that caregivers may face as they undergo sudden isolation with their child during a pandemic. Such insights would help promote the need for healthcare services to not just attend to young patients but also their caregivers too. Understanding what these stresses and concerns might look like can help direct interventions more effectively.

## Method

We conducted an anonymous survey consisting of 3 parts . 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. Caregivers are defined as the adult who was chosen by the family to remain isolated together with the patient. This could have been a relative or domestic helper, but all the caregivers we accommodated were parents of the young patient. Recruitment criteria for this survey were caregivers in isolation after having stayed the first night in the isolation unit 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 statements regarding the caregiver's situation of being isolated with their child in the hospital. These statements were a mix of positive and negative expressions or were otherwise fairly neutral to manage acquiesce bias (tendency for survey respondents to respond positively). Similar to other qualitative studies,[19,21] these survey questions were descriptive by design, developed by the authors based on observations gathered during care delivery. Participants ranked each statement on a 5-point Likert scale ranging from "Strongly Disagree" to "Strongly Agree". Examples include:

- " I am aware of the latest COVID-19 news"
- "I have made preparations for myself to join my child to be isolated in the hospital"
- "Being in the isolation unit is good for my child and me right now"
- "The lack of freedom in the isolation unit frustrates me"

The second part comprised elements of the SARS Fear Scale.[21] 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.[13,22,23] 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.

Recruitment and hard copy paper survey forms were distributed to the caregiver during breakfast or at the same time as morning clinical duties after staying for one night. The first night's stay was crucial, as we considered the possibility of caregivers adapting to the situation after subsequent nights. Participants were surveyed only once and were never repeated. 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. Aside from HAD scores and correlation analyses, each question would be described individually. As participants were anticipated to be fairly homogeneous, non-response bias was deemed unlikely, but monitored, nonetheless. Surveys with missing entries were omitted for pair-wise correlation and HADS analysis. IRB was obtained in line with hospital and cluster policy (iSHaRe CIRB Reference 2019/2747).

## Results

A total of 181 surveys were collected (132 female and 49 male). Nobody rejected participation (we lightheartedly attributed this to boredom). Item non-responses were noted to be low and still allowed for descriptive analyses—responses for each question ranged from 95% (172 responses) to 100% (181 responses). 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. 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). Fig 2A

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).

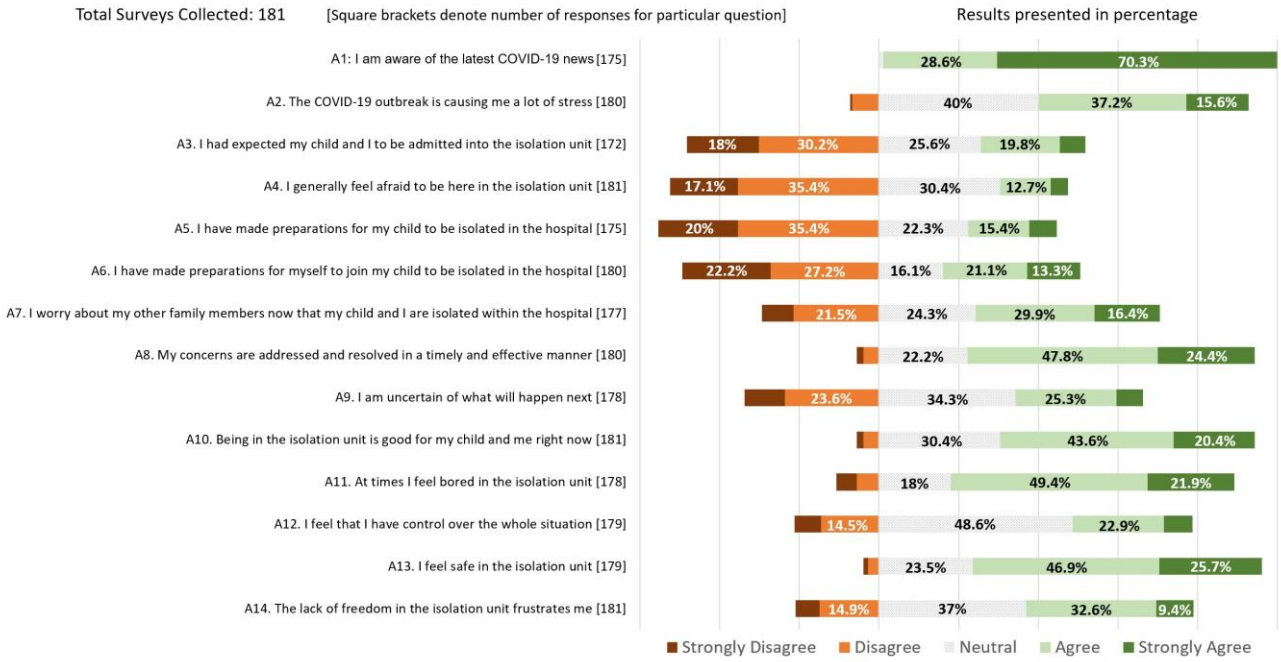
Questions A3, A5, A6 and A7 explored how well-prepared parents are for dyad isolation. 48.2% of 172 responses had not expected their child and themselves to be admitted into the isolation unit (Question A3) and 55.4% of 175 responses had not made preparations for their child to be isolated in the hospital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

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

**Figure 2A. A diverging stacked bar chart showing the responses for each of the 14 questions in Part-A of the survey**




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 are 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).

***Part B: SARS Fear Scale***

Part B of the survey was an adaptation of the SARS Fear Scale, consisting of six polling questions that began with "COVID-19 makes me …". Figure 2B breaks down the percentage of each response for each of these questions. Majority agreed or strongly agreed to the statements

**Table 1. Correlation coefficients among the responses to the questions in Part-A**

Bolded numbers indicate statistical significance ($p<0.05$), and the shaded cells highlight moderate-to-strong relationships (correlation coefficient 0.4>).

| | *Age* | *A1* | *A2* | *A3* | *A4* | *A5* | *A6* | *A7* | *A8* | *A9* | *A10* | *A11* | *A12* | *A13* | *A14* |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| *Age* | 1 | | | | | | | | | | | | | | |
| *A1* | -0.069 | 1 | | | | | | | | | | | | | |
| *A2* | 0.090 | 0.005 | 1 | | | | | | | | | | | | |
| *A3* | **0.165** | -0.050 | -0.099 | 1 | | | | | | | | | | | |
| *A4* | 0.026 | **-0.184** | **0.356** | -0.068 | 1 | | | | | | | | | | |
| *A5* | 0.052 | **0.224** | -0.027 | **0.457** | -0.122 | 1 | | | | | | | | | |
| *A6* | 0.060 | 0.089 | 0.070 | **0.410** | -0.066 | **0.740** | 1 | | | | | | | | |
| *A7* | 0.031 | -0.083 | **0.306** | -0.111 | **0.390** | -0.007 | -0.056 | 1 | | | | | | | |
| *A8* | 0.080 | **0.243** | -0.066 | **0.253** | -0.151 | **0.380** | **0.301** | -0.152 | 1 | | | | | | |
| *A9* | -0.105 | **-0.217** | **0.220** | -0.149 | **0.319** | -0.079 | -0.070 | **0.515** | **-0.274** | 1 | | | | | |
| *A10* | 0.053 | **0.227** | 0.013 | **0.191** | -0.074 | **0.260** | **0.217** | -0.082 | **0.306** | -0.086 | 1 | | | | |
| *A11* | 0.049 | -0.123 | -0.005 | -0.077 | 0.060 | **-0.232** | **-0.199** | 0.116 | -0.067 | **0.267** | 0.025 | 1 | | | |
| *A12* | -0.066 | **0.226** | -0.068 | 0.108 | **-0.183** | **0.270** | **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 | **0.314** | **-0.306** | **-0.284** | **0.182** | **-0.219** | 0.147 | **-0.258** | **0.512** | **-0.371** | **-0.338** | 1 |

"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 encountered COVID-19, many caregivers feared infecting others, more so than becoming infected themselves.

***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 (Snaith, 2003), "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 neither suggested probable onset of mood disorders.

## Discussion

Infectious disease outbreaks throughout the years have had a major impact not just on the physical wellbeing, but also on the psychological health of people.[24,25] In preparation for a pandemic of unknown etiology, pediatric hospitals may recognize the role of caregivers in the child's hospitalization.[1,2,4,8,26] However, coping and support interventions for caregivers in an isolation setting may be neglected or lacking. This is particularly evident in our specific context, as we discuss the findings of our study.

Most caregivers in Singapore were familiar of the pandemic situation and have expressed stress and concern. According to the survey, a large 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. Many reported boredom and frustration 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.

A notable insight was the concern that caregivers might have been a vector for the disease and possibly infecting other family members. Results from the SARS Fear Scale showed similarities between the polled caregivers during this COVID-19 outbreak and Hong Kong healthcare workers during SARS--both shared a greater concern of infecting others (especially family members) than being self-infected.[21] This insight might also be supported from an earlier survey question (Question A7), in which 46.3% of responses generally agreeing to worrying about their family members now that they were isolated. Extending the comparison between COVID-19 and SARS, SARS patients in a Toronto hospital reported feeling both our participants and SARS patients in a Toronto hospital reported feeling "guilt, anger and fear for the welfare of friends and family" and complained of boredom and loneliness.[27] The caregivers we surveyed echoed the same sentiments.

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

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

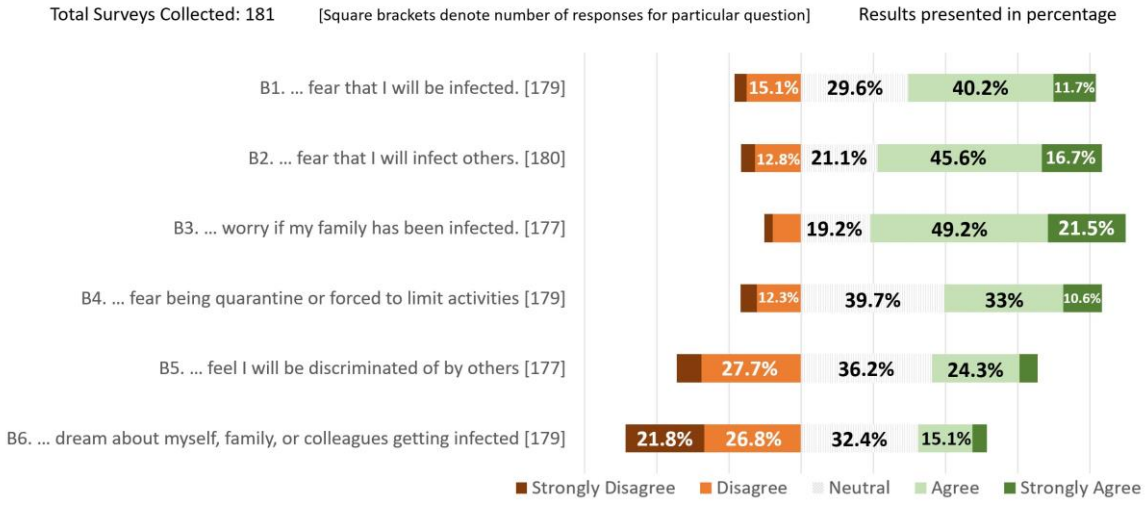


**Table 2. A breakdown of average scores in the HADS portion of the survey (n=167)**

| **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** | |
| 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) |

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.

Conversely, parents may possess a general optimism for their own child's situation amid the outbreak now that they were being cared for professionally. Our correlation analysis revealed significant relationships among the following areas in which healthcare services may explore further 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
4. Having concerns resolved timely and effectively by the medical team.

Preparing young patients and their families for hospitalization and medical treatment are beneficial.[28,29] However, this can appear challenging and required more effort to succeed in the context of pandemic isolation. The sudden hospital stay disrupted prior plans, which may include providing care of other family members. Attempts to minimize disruption while being isolated in a foreign environment can be difficult. Correlation data also revealed statistically significant relationships between preparation for isolation and stress due to COVID-19 as well as boredom in the isolation unit, further advocating the need to pre-empt caregivers for admission as early as possible.

Pre-empting caregivers or even the general public could at least facilitate mental and logistical preparation. Parents should be briefed as early as possible regarding the heightened precautionary measures so as to reduce stress and confusion. A recommendation list may also be crafted to aid caregivers in preparing for hospitalization. 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. Care packs could be made available for both the sick children as well as the adult caregivers. This would in turn relieve some of the anxieties coming from both patients and caregivers which healthcare professionals would have to deal with.

Incidentally, we do not anticipate the forewarning of dyad isolation to deter appropriate attendances and consequent community transmission. Results from the survey were positive, as caregivers believed it was for the well-being of their children and themselves to be isolated under medical attention. Singapore's public health messages focused on managing the pandemic in the community and getting the public to seek medical attention appropriately. These messages could further reassure the public about the importance and benefits of isolation under medical care, before advising the public to be mindful of possibly getting admitted. Such messaging would tie in well with existing efforts to prevent stigmatizing COVID-19 patients.[30]

Findings from this project helped fuel efforts by our hospital to improve patient as well as caregiver experience during COVID-19. Incoming caregivers were contacted as early as possible to alert them about the dyad isolation.

These opportunities were typically in the Children's Emergency department, during which guidance and checklists were provided to help coordinate logistics. New processes were established to allow relatives to drop off items at the screening reception for service staff to porter up to the ward. Due to infection control, items from within the isolation unit were generally not allowed to be passed out and were brought home only when the patient was eventually discharged.

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.

Beyond COVID-19, we reiterate the importance of parents as part of pediatric patient experience. In preparation for this research, we consulted our colleagues at pediatric oncology on our interest to study caregivers entering dyad isolation. It turned out caregivers of patients preparing for transplant, for example, were extensively briefed and well-supported by the clinical team days in advance leading up to the eventual isolation. Parents reportedly acclimatized well to being isolated. This scenario differed greatly from COVID-19, which was sudden and unknown. Extending support and attention towards caregivers, on top of quality pediatric care, can differentiate between good and great children's hospitals.

Some limitations were acknowledged. 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

Being isolated due to an unknown viral infection during an early onset of a pandemic is stressful. While there is much focus on patients undergoing isolation in hospitals, less attention has been paid to caregivers suddenly becoming isolated with their pediatric charges. Results from our survey should provide some insights on how the caregiver experiences can be improved.

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