

Cover Sheet

Public Trust Board Meeting: Wednesday 09 September 2020

TB2020.71

Title: Patient story: Child and mother's experience of staying in the Children's hospital during the COVID-19 pandemic

Status: For Information

History: Regular Reporting

Board Lead: Chief Nursing Officer

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Confidential: No

Key Purpose: Assurance

Executive Summary

1. This paper describes the experience of a nine-year old child who was admitted to the Children's hospital with suspected appendicitis during the COVID-19 pandemic. This was her first experience of hospital care. The experience of her mother is also provided.
2. Both child and mother report the overall experience was good. The child reported that she was involved with decisions about her care and that she was made to feel comfortable. The mother reported that the nursing care was excellent and that everyone introduced themselves.
3. However, it was felt at times that the communication could have been better and the mother felt that her daughter was not always viewed holistically.
4. The child and her mother were affected by the pandemic in different ways. The main challenges for the child were that they were socially distanced from other family members and it was challenging getting used to staff wearing Personal Protective Equipment (PPE). The main challenges for the mother were the lack of explanation that they were in a COVID-negative area and that it appeared some children were able to have both parents visiting.
5. This family's experience provides an opportunity to share balanced feedback about a child's care including:
 - The provision for good and clear communication about care and treatment.
 - The holistic care of patients whilst treating their condition.
 - Greater awareness about the needs and any underlying mental health needs of carers.
 - A need for continual promotion and awareness of PPE measures used by staff in order to reassure patients, in particular children.

Recommendations

6. The Public Trust Board is asked to:
 - Note the content of the story.

Contents

Cover Sheet	1
Executive Summary	2
Recommendations	2
Patient story: Child and mother's experience of staying in the Children's hospital during the COVID-19 pandemic	4
1. Purpose.....	4
2. Background.....	4
3. M's story.....	4
4. M's mother's story.....	5
5. Positive themes in the story	7
6. Negative themes in the story.....	8
7. Areas for improvement.....	9
8. Actions undertaken and to be taken forward.....	10
9. Conclusion	11
10. Recommendations	11
Appendix 1: Poster showing staff with and without PPE	12

Patient story: Child and mother's experience of staying in the Children's hospital during the COVID-19 pandemic

1. Purpose

- 1.1. This paper presents the experience of a nine-year-old child with suspected appendicitis who stayed on an inpatient ward during the COVID-19 pandemic, and the experience of her mother.
- 1.2. The purpose of the paper is to learn from their experience during the COVID-19 pandemic, from the perspective of both the child and her mother.

2. Background

- 2.1. On 23 March 2020, The UK Government introduced lockdown measures to reduce the opportunity for cross infection of COVID-19 pandemic, caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). The lockdown measures asked people to stay at home, in order to reduce spread of the virus and ease the pressure on the NHS.
- 2.2. In line with National Guidance, the Trust introduced inpatient visiting restrictions in March 2020, to protect its patients and staff. At the time the nine-year-old was admitted to hospital, in May 2020, only one parent was able to stay in hospital with the child.

3. M's story

(As told in M's own words during an interview with the Children's Patient Experience Lead. 'M' is not her real initial)

Can you tell me about your time staying in the Children's Hospital?

I had suspected appendicitis; I had a very high temperature and lots of pain. I had to have a lot of blood tests. It was my first time staying in hospital and my first time in an ambulance. When we arrived I had to go to where they test for coronavirus. They put a swab down my throat and up my nose, it was not very nice.

My mum stayed with me the whole time. For the first three days I couldn't see anyone else as they were waiting for my COVID results to come back so for three days I couldn't come out of my room. But when it was all clear, occasionally I could go downstairs in a wheelchair and outside to see my Dad. I had to go outside to see my family; I couldn't see them in the hospital. I had to

socially distance from him so that didn't feel quite normal. My family also video called me every morning and night, but sometimes it was hard to get signal. I felt a bit unsteady with what was happening. The nurses had to put on all this equipment which they don't normally have to do. They were wearing masks, gloves and an apron, what they would normally have to wear only if they were doing surgery. They had to change it each time they came in to see me.

I was in my own room and my mum stayed in with me. On one night I had to move rooms, and the bathroom was much further away so that really made me scared and worried. I was just getting used to the room then had to change rooms, where there were so many other beds and the bathroom was so much further away and I felt so weak.

Did anyone tell you why you had to move out of your room?

They told me that my blood tests were coming back ok and another patient who had diarrhoea was coming in so they needed my room.

Did you feel you were involved in any decisions about your care?

Oh yes lots, they kept asking me about how my pain was, what I was thinking, what was happening, how I'm feeling. They asked me about a pain scale and started a drinking chart with stickers so they really encouraged me to tell them how I was feeling. They made me feel as comfortable as I could be, made me feel happy and took my mind off of it.

You wouldn't normally see all the masks and have to have the social distancing so it did feel quite a bit different. But overall it wasn't that bad.

4. M's mother's story

(As told to the Children's Patient Experience Lead)

"It started with us going in the ambulance; everyone was really supportive and very reassuring. When you get to the JR you don't get taken up to the ward straight away, we had to go into the COVID section, where we were put in our own room. They also let me and M's Dad switch over. They were very accommodating which was lovely. They made it clear that when we go to the ward only one person would be able to go up, so I knew exactly what was going on, what all the steps were. I didn't feel unsafe about coronavirus at any point during that initial stage.

What was interesting was the difference in the manner between the paediatric consultants and the general surgeons. Also what was frustrating with the

surgeons is that one would say this and another would completely contradict them 3 hours later. Every day I didn't know if we were going off to surgery or not. I felt a bit that, with the surgical team, I really had to advocate on M's behalf, that she really wasn't feeling well, because they just kept contradicting each other. I do understand though that's the nature of the beast with appendicitis. Dr X was wonderful, he took the time to step outside, show me her test results, and chat to me. He was really lovely. I honestly couldn't fault the nurses. They were superb with M and very kind to me.

I'm also breastfeeding my baby. They provided me with a breast-pump, which was really great of them. A nurse called [names nurse] was so kind, she went above and beyond. She even offered to transport my milk to my husband in the car park for me, but as I suffer from OCD I wasn't comfortable with it. I was allowed to go down and feed my baby in the car park. I'm not sure if I was meant to wear a mask or not when I was doing that but I did anyway.

One thing that freaked us both out was that we were moved quite quickly from our room into the open bay, and it wasn't actually explained why at the time, we were just told we need to move now. In our room we'd had our own bathroom and that was key, given my mental health problems. It wasn't explained to me that the others roaming around on the ward were COVID-negative.

I noticed two people coming in who were clearly together, obviously I don't know the situation or the context and I thought it was odd, as the rules were that only one parent could be on the ward. I just felt like there wasn't much control going on there. I wondered if anyone had noticed two people are coming in. I couldn't see anyone manning the doors; they just buzz you in without asking who it is.

The nurses couldn't have done more. The surgical team have a different bedside manner; they look at M and see an appendix while the paediatric doctors look at M as a whole person. We were told we would see the surgeons in the morning but then wouldn't see them until 5pm, and I needed to go and feed my baby. I didn't want to miss their rounds.

There was no explanation or communication about it. M was sat there, very anxious, as she didn't know if she was going to have surgery or not. It's a long time for a little girl to wait to find out. I do understand it's busy but it's still frustrating, and it made it more tiring as we didn't know what was going on. More regular updates would have been helpful.

I got used to people wearing masks in the end. The doctors were very good with M, introducing themselves. The first doctor we had - a consultant paediatrician - he was outstanding. He sat on the floor with her getting her bloods. We are so grateful to them. Anything I've said that's a bit negative are things just to think about.

The post hospital outpatient phone call was great. I didn't have to take time off work and battle with parking in the hospital. It was much better!"

5. Positive themes in the story

- 5.1. M felt involved in decisions about her care and described regularly being asked how she was - thinking, what was happening, how she was feeling.
- 5.2. The team used a pain scale a drinking chart with stickers to encourage M to share how she was feeling.
- 5.3. M felt the team made her feel as comfortable as she could be, made her feel happy and taking her mind off her pain.
- 5.4. M's mother felt there were processes in place to protect patients and staff from COVID-19 using measures such as reduced visiting, staff wearing Personal Protective Equipment (PPE) and testing new patients.
- 5.5. M's mother reported that everyone in the ambulance was very supportive and reassuring.
- 5.6. M's mother also reported that she felt that the process on admission to the John Radcliffe was very clear and felt everyone was very accommodating. It was made very clear that one parent would be allowed on the ward when M was admitted.
- 5.7. M's mother reported that the nursing care was excellent throughout.
- 5.8. The nursing team showed exceptional family centred care by supporting
 - M's mother to be able to stay with M for the duration of her stay.
 - M's mother to be able to continue breastfeeding her baby whilst M was an inpatient.
 - Supporting M to be able to see her Dad.
- 5.9. The majority of Nursing and medical staff showed excellent child centred practice and were praised for the way they interacted with M. They engaged with M at her level and helped reduce her anxiety of wearing PPE. It was noted that the doctors all introduced themselves to M.

- 5.10. M's mother trust in the team was significantly enhanced by the way the team interacted with her daughter, the kindness shown to her as a parent and the effort taken to explain things about M's care to her.
- 5.11. M's mother reported how convenient it was to have the outpatient appointment via the phone, rather than having to come to the hospital.

6. Negative themes in the story

- 6.1. M reported that she felt scared and worried when she had to move rooms as the bathroom was further away, which was challenging when she felt so weak.
- 6.2. Bedside manner: M's mother reported that there was a difference in manner between the paediatric consultants and the general surgeons. At times, M's mother felt she had to advocate on M's behalf to the surgical team and highlight how unwell M was feeling.
- 6.3. Lack of consistent information: M's mother reported that the surgeons contradicted themselves and at times the care pathway was not clear. She felt that due to uncertainty about the operation it would be better to have more regular updates.
- 6.4. Waiting for ward rounds: M's mother appreciated that everyone was busy, but she was told that the surgeons would come in the morning, but then they didn't to the ward until 5pm.
- 6.5. Lack of explanation when moving beds: M's mother reported that they were moved quickly from a private room to an open ward. This was because another patient who had diarrhoea needed the room, but this was not explained at the time.
- 6.6. Understanding mental health issues: M's mother reports that she has underlying mental health conditions and that it had been key for her to have their own room, with own bathroom.
- 6.7. Lack of communication about COVID-19 measures on the ward: M and her mother were moved to an open ward and they were not told that everyone on the ward had been tested for COVID-19 and were all negative.
- 6.8. Concerns about visitors to the ward: M's mother noticed that there two people who appeared to be together on the ward. This led her to think that there should have been stricter controls about who was allowed to enter the ward.

7. Areas for improvement

- 7.1. Where possible patients should be given as much warning as possible if they have to move room and listen to any concerns that they may have about this.
- 7.2. Bedside manner: Is a crucial part of patient care and every efforts must be made to ensure that healthcare professionals put themselves 'in the shoes' of the patients and always care for them holistically.
- 7.3. Consistent information - Appendicitis is difficult to diagnose, especially in children, so the clinical team would always take a conservative approach and avoid unnecessary operations. It is necessary to balance multiple sources of the clinical information to inform the decision about surgery, such as information from an ultrasound, blood tests, and clinical observation. So, whilst it may not have been clear whether M required an operation it would be beneficial if the information given to patients and their families is consistent to avoid any anxiety.
- 7.4. Ward rounds: During the pandemic, the capacity of healthcare professionals, theatre capacity, anaesthetic services and ICUs have been affected, which has meant that it has not always been possible to be completely definitive with parents about theatre times. The situation can be unclear for clinicians until quite late in the day. In these instances, it may be helpful not say a to say that ward rounds will be done in the morning, rather that they will be done as when able to. This may help with patient expectations.
- 7.5. Communication: Every effort is made to keep parents up to date. This is not always straightforward; however, regular updates must be prioritised.
- 7.6. Greater awareness of underlying mental health issues for carers. It may not have been known, or apparent that M's mother had mental health issues, but efforts need to be made to understand the needs of carers, particularly if they are staying on the ward.
- 7.7. Clear awareness of visiting policies on wards. There may be circumstances when there were exceptions to the rule about allowing one parent per child to visit. These exceptions are based on individual circumstances and the reasons are confidential. It has been considered whether the existence of confidential exceptions to visiting rules could be communicated to families through posters / leaflets in the hospital. However, this may invite requests from more families, as the experience of having a child in hospital is always very challenging.

8. Actions undertaken and to be taken forward

- 8.1. The story has been fed back to the service, and will be discussed in the Directorate's Quality and Governance meeting in September.
- 8.2. Feedback about clarity of communication will be provided to the wider clinical team. There will be a discussion about how to show empathy and understanding for the way the wait and uncertainty affects a child and their family; and how to ensure that communication is as clear as possible.
- 8.3. Praise has been passed on to individual staff.
- 8.4. The Clinical Director has reviewed this report. The issues with communication delays will be discussed with the medical team.
- 8.5. There have been changes to the way support services are provided to children since the start of the pandemic, such as increased access to play therapists, and the hospital school restarting.
- 8.6. While it may not have been possible to improve this aspect of care, it is noted that M found the measures to control the virus unsettling at times, for example:
 - It was odd to see the staff wearing so much PPE, but she got used to it nearer the end of her stay. A poster has been created to show what staff look like without and with PPE, to help children to feel more comfortable seeing staff in PPE, and to understand why it is necessary (Appendix 2).
 - Once her COVID-19 test was confirmed to be negative, she was allowed to go outside to see her Dad, but they had to socially distance.
- 8.7. It is worth noting that there have been changes to inpatient visiting for children's services since M's admission. In late June 2020, the Trust introduced 'Golden Tickets' for parents of children who are inpatients (Figure 1). These allow one parent at a time stay with their child as long as needed, and to exit and access the ward where their child is staying freely. Golden tickets have had a positive response, and they have made it easier for parents to visit their child without being challenged, while keeping patients, families, and staff safe.



Figure 1 - A Golden Ticket

9. Conclusion

- 9.1. On the whole, the M and her mother were happy with the care that was provided. They were very grateful all the support and any negative comments they made, were in their words 'just something to think about'
- 9.2. Some aspects of care could have been improved, for example, communication with M and her family.
- 9.3. Virtual appointments (for instance via the phone) can enhance patient experience as it means that they do not have many of the challenges associated with coming into hospital.
- 9.4. This story illustrates how unsettling children may find PPE. Continued awareness of this is vital.

10. Recommendations

The Public Trust Board is asked to:

- 10.1. Note the content of the story.

Appendix 1:
Poster
showing
staff with
and without
PPE



WE ARE ALL HERE WITH BIG
SMILES TO LOOK AFTER YOU...



WE NEED TO WEAR THIS TO
KEEP YOU SAFE!

