

"Covid" choices: children transferring from hospital to hospital and "into the unknown"

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I recently spent the early hours of this morning with the mother of a father of an infant who has spent almost the majority of her young life living through the COVID era, and so therefore have her parents. I suppose Julia and her parents could be thought of as some of the lucky ones, as none had COVID up until this point. Nevertheless they were caught in the cortex within a large Boston hospital preparing for the surge. Having spent some part of almost each and every day with them since Julia's birth, in person, by phone, email, or by text, I was one of a handful of their medical confidantes helping steer Julia's parents through wholly unfamiliar terrain for any family who has never experienced having to care for a complex needs child. The list of specialists involved in Julia's care had grown steadily over the weeks as her problem list evolved from being born with too narrow nostrils to breath properly, to having too small a jaw not to obstruct her airway, not being able to breath in part due to congenitally weak lungs, to needing a surgical breathing tube placed, to not being able to eat, to vomiting incessantly, to needing a surgical feeding tube placed, now to just undergone a several hour surgery to repair a perforation of her intestines. I had been the surgeon who helped rebuild her bony skull to widen the hole in the skull, the piriform aperture, that allowed air into her airpipe through her lungs, and then I had later placed her surgical breathing tube, a tracheostomy tube, in her neck. It is my very biased opinion that if pediatrics is a special field of medicine, it is because of the deep bonds we often form with parents of the children we treat, forged as we work together

over many a day and night. So how to help Julia's parents come to terms with the short term issues of the stormy post-operative course Julia might well face, her need for strong intravenous antibiotics, her possible need for being on a ventilator for some time, with the pressing issue that Julia and her parents would soon be transferred to another hospital which was where as many children as possible were being sent, to make way for the wave after wave of sick adult patients that would soon need the bed Julia currently occupied?

Despite wave after wave of medical bad news wrought upon Julia and her parents, the hours we had spent together weighing the pros and cons of each problem and possible solution, had built a stable foundation of trust. One of the issues her lung doctors, her nurses, pediatricians, and I kept overtly addressing was Julia's parents deep seated fear that Julia needed a ventilator to be able to go home and breathe better and more safely, that that would keep her from bouncing back to the hospital for re-admission and that somehow this was not being done because the ventilators were being saved for coming crisis and those more in need (or to use Julia's mother's words "somehow more worthy"). To address these concerns square on, we had convened a team meeting to discuss with Julia's parents all the options and address that she might need a vent, that we get one for if she needed one (and we acknowledged that we were not 100% sure we would be able to but would do everything in our power to if needed), but that even in the non-COVID era, a time that now seemed a pre-historic long time ago, we would not have advised being on a long term ventilator yet. Now that part of her intestine had ruptured and she had required emergent surgery, all bets were off and a new baseline would need to be established and we all acknowledged that she might now need that vent.

One of the aspects of COVID life is getting used to the ground being unstable under your feet, and shifting daily. Each morning's email blast of

information could be radically different from the day before... who could or should be tested for COVID, when you could go back to work if you had COVID, where patients were being moved as entire wards were shifted overnight to erect make shift ICU wards. Each day before coming to round on your patients, I first had to find out where they were. As I had been walking over to meet Julia's parents, I had read the news that all children who could be would be transferred imminently to another hospital in the city. News in hospitals travels almost as fast as rumors, so Julia's parents also knew this new data point before I entered their room to speak with them. They had not yet even heard if she was stable as her abdominal surgery was not even finished, and they were already having to come to terms with this new reality. Julia's mother was at first resistant, and ready for a fight. Had a decision been made to prioritize others over Julia?

The COVID era has forced almost every hospital in the country (and perhaps the world) to make difficult decisions many thought would never need to be addressed or made. The first challenge hospitals had to face was the incoming surge of COVID positive patients that would soon be flooding in, overrunning the physical resources of ventilators, Personal Protective Equipment (PPE) such as N95 masks and gowns amongst other, and personnel resources such as the doctors, nurses, and respiratory therapists needed to care for the COVID patients, staff the ICUs, and oversee the vent settings (even as more and more health care professionals themselves became infected and were forced to drop out of the workforce at least temporarily). To face this rising surge, as well as the intermediate era mid-COVID when the surge had passed but when there remained a long list of COVID, now fortunately off ventilatory support but needing to recover in defined COVID hospital wards and step down units (where they would receive care but not need the amount of doctor and nursing oversight they had in the ICUs), and the need to not forget and continue to care for the

non-COVID patients who were either currently in the hospitals or who would fall ill during these times, another set of decisions had to be made. Pregnant women were still delivering during COVID; adults needed treatment for their cancer or other medical concerns. Children still had accidents, got non COVID fevers, and needed care. So, on Sunday April 5th, the administration at Massachusetts General Hospital (MGH) emailed the health care community to inform them of these difficult set of challenges that had to be faced, and the decision to move all children currently hospitalized without COVID but either needing chronic ventilator support or critical care to either Floating Hospital for Children or Boston Children's Hospital (depending on bed availability at these institutions and with discussions between the pediatric staff and the parents). Within two days, 7 newborn children needing long term ventilator support (for reasons other than COVID) were packaged (ventilator and all) to one of the two named institutions after discussions with frightened parents. This number would rise in the days that followed. The stated timeframe for these transfers before Massachusetts General Hospital for Children (MGHfC) would return to caring for all children was 4–6 weeks, but the no one expected the ground underneath to be stable or today's decisions to be reflected in tomorrow's as the only thing that was clear was that we all were reacting to the surges and waves and to survive was to be nimble and to adapt. Julia herself was not on a ventilator but did require what is defined as "critical level of care". She had made it out of the operating room, but, now would have a different post-operative recovery, than any child I have cared for previously, as she would need to convalesce, but do so elsewhere. COVID-19 was forcing health care systems to face incredible shortages, and to have re-draw lines that had not been crossed before. When Andrew Cuomo spoke of how hospitals in New York City would need to respond to the surge, he had articulated a radical notion that when one hospital filled up with sick COVID patients, or ran out of supplies, that those patients would need to be transported to other

hospitals that historically had no connection to where the patients currently were, or supplies from other hospitals would simply need to be shifted to the hospitals and patients in need, with personnel and supply accounting left for later days when the storm had passed over. Boston was fortunate to have its surge slightly later than New York's; its doctors and hospital administrators had had the time to listen to Cuomo's daily briefings. Radical, new, uncomfortable decisions were needed. So Julia's mother and father not only were dealing with an incredibly sick and fragile child, but now felt they were being thrown out there into the unknown. Julia's parents may not have been the only parents (or patients) having to come to terms such a displacement, and they were certainly aware of the crazy, chaotic ever changing world of infection and fear that now currently defined their days, but this did little to soften the blow.

One of the many aspects of Julia's mother's character I had come to admire was her inner strength that allowed her to face issues directly. After describing the past night hell of watching Julia suffer before a decision had been made that she needed to go to the operating room for repair, Julia's mother questioned whether such a decision would have been made earlier in a non COVID time. Has she done everything she could have? Should she had pressed harder? We talked through the hour by hour timeline and eventually agreed that her most probably would have been the same. I saw Julia's mother breath just a little more deeply, and watched her exhausted body give in towards just a moment's relaxation. Then, her anxiety returned. If they did move hospitals, who would help look after Julia as we had been doing, and how would they who knew her and them as well as we did, remain part of her care? I told her how wonderful the other hospital was, how good and caring the staff there were, and also how often I had seen patients from there over the years, and how much inter-hospital communication there existed, even in the days before COVID. I knew Julia's

mother heard me; her body chemistry told me she remained unconvinced. I continued on therefor to tell her how she could continue to reach me by email, text, or phone just as she had been doing up until now, and so could the new medical team. She drew quiet for a moment as I knew she was inwardly processing this and this resonated somewhere deep within.

"But doesn't this mean we will be starting all over again with a new team? While they learn who Julia is, and who we are, isn't there a chance something else will go wrong that your team who have uncovered sooner?"

There was no answer to this question that would be every parents' deepest fear. Gently, I acknowledged her question to which there was no perfect reply, but I also told her that the thing Julia needed most of all right now was her, Julia's mother herself, and there were already 2 adult COVID positive patients, on the ward where we were speaking. In all my years of working at an institution I admittedly am biased towards feeling gives perhaps the best level of care to children, I told Julia's mother that both she and Julia might actually be better off at this unprecedented time in a children's ward in a children's hospital away from a hospital where steadily increasing streams of adults were being ambulated in, put on vents, and sadly dying. I told her that the greatest gift she and her husband could give Julia was to keep themselves well, and shelter as best they could, even while needing to be at any hospital at all, a prospect which already raised such fears. I thought that she, and her husband, and not only Julia had a better chance of catching COVID in a hospital full of sick adults. As a pediatric surgeon now practicing for twenty odd years, and as a parent myself of three, I am and continue to be struck by the incredibly powerful innate protective mechanism parents have that surges up to help them defend their children. Julia's mother immediately told me she was ready for the transfer.

Post-script: When Julia was 24 hours post transfer from MGHfC , her mother texted me that she was pleased as Julia receiving terrific care. She did want to know one thing: "I know we will be working with a different team but just want to be sure you can still be involved in her care". In this era of COVID and of physical isolation, and patients and parents needing contact and connection, I surprise myself with just how grateful such moments make me feel to be living in an era of cell phones, texting, and zoom!