



At this time of year in many countries we celebrate Thanksgiving. At my home on Thanksgiving Day we talk about the Father of our Pilgrim ancestors, the Vicar of a large parish in Cranbrook, England in the late 1500s called St. Dunstan's. His writings about the Black Death remain and it's interesting how he commented on how behaviors impacted outcomes. William Eddy wrote in 1598, "This infection was got into all the inns and victualing houses of the town places then of great disorder... Together with this infection there was a great dearth at the same time, which was cause also of much heaviness and sorrow." Unlike the poorly understood plagues of the Middle Ages, the new-age COVID-19 plague is being fought with the best of science and patient care. Learning how to prevent and treat the COVID-19 virus grows month to month.

Our CAPS members feel mixed emotions as COVID-19 cases continue to surge in the United States and Europe. Advisors report everything from attentive patient-centered care for COVID and other needs to dismissive, unfortunately non-patient-centered care hiding behind supposed COVID precautions. Persons in the general public remain confused about things like Mask Wearing and Hand Washing. The hope of vaccines and new treatments remains a reason for thanks, along with the good work that many of our colleagues like **Dee Jo Miller** and **Sheryl Chadwick** at Children's Mercy in Kansas City, found in this month's CAPS Advisor profile.

Kellie Goodson from Vizient shared a report on a study of patient and caregiver attitudes about safe care during this time. The report, *Connecting with Patients During Covid-19: Perspectives on Safety*, is excerpted below. One point that was made that stood out to me was this truth, "Specifically, a 'one size fits all' approach will not work during these uncertain times, and patients will look to their physicians to help them fully understand when they should proceed."

Several **CAPS** members have come together in the past several months to work on developing the Partnership for Healthcare Justice, a program to deliver care that will be more than one size fits all and will teach about providing equitable care, especially for vulnerable patients. To date, hundreds of hours of pro bono time has been donated in co-creation. As we move to developing education materials that may be piloted in hospitals, we reach out to you for support. **Consumers Advancing Patient Safety is a 501c3 not-for-profit organization that envisions a partnership between consumers and providers to create global healthcare systems that are safe, compassionate and just. CAPS champions patient safety led by consumers in partnership and collaboration with providers.**

To support CAPS work, please consider donating through your VENMO account to @CAPS-PatientSafety. If you prefer to use PayPal, our account is under Consumers Advancing Patient Safety or go to www.paypal.me/patientsafety.

We feel thankful for your support! -Lisa Morrise

In this Newsletter, read on for:

- Our interview with **Dee Jo Miller, Program Manager, Children's Mercy Kansas City.**
- An excerpt from the Vizient report *Connecting with Patients During Covid-19*
- Telehealth resources from Comagine Health
- Information from CAPS President, Helen Haskell, on the importance of taking patient experience feedback seriously and input on that topic from the NHS and the Patient Experience Library.
- The **Graphics Garden** focuses on Mask Memes for you.

CAPS Consumer Advisory Panel Profile



Dee Jo Miller and her colleague, Sheryl Chadwick, have been leaders in Patient and Family Engagement for a number of years. In their positions as Program Managers, their innovative programs at Children's Mercy Hospital include a hospital wide Family Advisory Board and eighteen total Advisory Councils. One is a Spanish speaking council, El Consejo de Familias Latinas/Hispanas.

Dee Jo's background is in Early Childhood Education. She went back to school after starting work at Children's Mercy Hospital to earn an additional degree in Management and Human Relations. She is also supporting CAPS as a member of the Consumer Advisory Panel.

CAPS: When did you start your advocacy?

Dee Jo: In my heart I started on September 7, 2004. That is the day my husband and I were taken into a small conference room and given the news that my thirteen-year-old daughter had cancer. At that moment, without knowing it, I put aside my pre-conceived ideas of what being an advocate meant. I became Hannah's defender and voice. Those experiences led to work beyond what I did for Hannah. I joined the Family Advisory Council at Children's Mercy Hospital in Kansas City in 2007. In 2008, myself and my fellow parent, Sheryl Chadwick, were hired by Children's Mercy Hospital to develop and help manage the Family Advisory Board and other programs in the Patient and Family Experience department.

CAPS: How has your advocacy evolved?

Dee Jo: I went from very personal advocacy to being invited to be a part of the hospital-wide advisory committee. I learned that Children's Mercy Hospital valued my perspective and experience. I also learned by being a part of the Family Advisory Board that not everyone had the same experience I had. Hannah had a good outcome in part because of my advocacy. I wanted to change the system so everyone could have more equitable care.

On February 13, 2008, Children's Mercy Hospital hired me and Sheryl Chadwick at the same time. We later realized that best practice is having two advisors on committees. We have learned together and supported each other over the years. Sometimes, it's hard to know what to do and it helps to have a team approach where many viewpoints can be heard. I've learned so much talking to Sheryl and other local parent advisors and going to conferences.

We have worked with staff to support their partnership with family advisors. One concept Sheryl and I have been able to help staff understand is that our families already know that not everything goes smoothly all the time. In working together, advisors and staff can help improve our work. Also, staff hears feedback about what goes well, too!

Every patient is completely unique. We need to evolve healthcare to meet each unique experience in the moment. We want to support our staff, patients, and families to be empowered in individual experiences. Then we achieve better outcomes.

I've been a real proponent for equity, diversity and inclusion. We advocate for a diverse faculty and employee base. It matters so much for the population we serve to see themselves in our staff. I gave a tour once to a Mom who ran into one of our Child Life staff who also happens to have Down's Syndrome. When I told the Mom that yes, the staff member with Down's was a paid employee, the Mom started to cry. She said that was the first time she saw a future for her granddaughter who also had Down's Syndrome. She said her world had just become bigger.

The visual matters. Seeing people in roles that are equal and valued is important. Employees need to understand why diversity and inclusion is important. Families feel more comfortable seeing persons they identify with among the healthcare provider community.

CAPS: What projects have you been involved in?

Dee Jo: There's been so many! I tend to favor what I am working on right now.

One thing we are focused on now is succession planning. Sheryl and I became aware that around the country, strong patient and family advisory programs had often been scaled back or even disappeared without the presence of the original family leader champions. We began working on "succession" planning, to ensure that the concept of our eighteen advisory councils, family members on all quality and safety committees and other representation was hard wired into the system. We now have a Director and Medical Director for our program. We are imbedding the concepts of co-production into our culture and moving beyond just two Moms who have a cause.

We are really fine-tuning our Family as Faculty program to capture data and explore impacts on participants. For over ten years we have had Resident Doctors go into the homes of our families that have children with chronic/complex conditions. We have data from all those years of feedback from program participants. We are working now to capture and quantify how the program has been impactful to the Resident learner. We are looking at what they think will change about their practice as a result of their visits. So far, the highest ranked response is that they feel their practice will be more patient and family-centered. They report increased respect for information sharing from patient to provider as well as provider to patient.

We are making progress in capturing and recording the engagement of our advisors. We want to develop metrics that can be shared and use those metrics to show the value of having parents on staff and how quality and safety outcomes have been impacted by having parent advisors on committees. We are quantifying the dollar value to the hospital of our volunteer advisors and the return on investment of having over 200 advisors working on quality improvement across the hospital. We want to put a numerical value to engagement and look at outcomes. We are examining the correlation between engagement and outcomes.

CAPS: What do you recommend to a person who wants to advocate for Quality and Safety?

Dee Jo: Speak up! If your hospital has a Council, make a connection with someone. We even get advisors from other hospitals.

Start learning. Learn through your work on the council and the work that other hospitals are doing. Sign up for the CAPS Newsletters!

Build confidence in what you have to offer. Sometimes when we are working with healthcare professionals, we get intimidated by their many degrees and initials after their name. But we have experience some professionals have only read about. By hearing from us, they are able to make an emotional connection to their work.

We need to believe and understand what we are sharing. I asked a nurse what parts of my story were most impactful to the clinical team. I share those aspects of my and Hannah's story as part of my quality improvement work. So, I think it's important to find out from the staff team what resonates with them. That then guides what you will say.

Think about the environment you are creating. Remember the people we work with are all vulnerable. We all have a goal of care that is a best possible outcome.

CAPS: What do you recommend to Healthcare Systems that want to improve Quality and Safety?

Dee Jo: If you haven't started yet, reach out to peer hospitals who have started strong patient engagement programs. Ask how they did it and where they find value in their work. Address concerns your organization may have with responses from their peers.

Educate staff that will be liaisons to advisors. Teach them how to engage with advisors and what to expect so there is a comfort level with co-production.

Create an environment where everyone has a voice at the table. Share with advisors what is impactful about what they are saying.

Children's Mercy Hospital made a commitment to have a parent advisor on every hospital acquired condition committee. We asked each committee what they were looking for in terms of an advisor's experience (for example a parent with experience with central line infections). At first, they were concerned about sharing the challenges of problems with advisors, but the advisors know there are issues. They appreciate helping to improve process.

The advisor then learns about the hospital and staff view of these situations and helps build a bridge between their personal experience and the staff experience. This is different work than serving on the Family Advisory Board. The committees are a subset of that team. We share results from the committee work with the Family Advisory Board.

CAPS: What are your future plans?

Dee Jo: I want to continue to do the work as long as I can be impactful. I want to find new layers of the work and keep learning. I enjoy having national opportunities to share what Children's Mercy Hospital has been able to do. I'm particularly excited about our work to quantify patient and family engagement and advisory work.

Thanks, Dee Jo! Contact Dee Jo Miller at dkmiller@cmh.edu.

Here are links to some of the great Patient and Family Engagement programs at Children's Mercy Hospital:

<https://www.childrensmercy.org/about-us/advisory-boards/family-advisory-board/>

<https://www.childrensmercy.org/your-visit/caring-and-coping/support-groups-and-programs/pops/>

<https://www.childrensmercy.org/about-us/equity-and-diversity/equity-and-diversity-programs/>

Articles that Dee Jo Miller and Sheryl Chadwick have worked on with colleagues from Children's Mercy Hospital include:

<https://pxjournal.org/journal/vol7/iss2/17/> (Teleboard: The move to a virtual Family Advisory Board)

<http://pxjournal.org/journal/vol5/iss2/13/> (Family Experience Tracers: Patient Family Advisor Led Interviews generating detailed qualitative feedback to influence performance improvement)

Consumers Advancing Patient Safety

November 2020

The videos in a series of COVID-19: Patients, Families and Providers in Conversation may be found at this link:

<https://www.youtube.com/channel/UC7f7J8ynAwpDQpJWQX9mjQQ>

These videos are a collaboration of three organizations:

Consumer Advancing Patient Safety (CAPS), Project Patient Care (PPC) and Healthcare and Patient Partnership Institute (H2Pi).



You can view all of these videos on the Consumers Advancing Patient Safety YouTube Channel. Please go the link and be sure to hit subscribe **and** notify so you will know when a new, relevant video has been uploaded!

Consumers Advancing Patient Safety often partners with other organizations seeking to improve Quality and Safety. When possible, we support their efforts here:

Kellie Goodson, MS, CPXP, Director, Performance Improvement Networks, Vizient, Inc., shares:

The perceptions of patients regarding the safety of elective procedures has steadily improved since May, as shown in Vizient’s updated report [Connecting With Patients During COVID-19](#). Vizient® and Sg2® have been connecting with patient and family advisors (PFAs) from health care organizations across the country during the last six months to learn their perspectives about the safety of health care services, specifically elective procedures, and how they will make decisions in the “new normal.” These PFAs participated in a series of activities—one webinar and two surveys—to give us their thoughts regarding their health care delivery preferences in relation to the COVID-19 pandemic. One of the many things we learned is that it is imperative to leverage the voices of patients and families as we try to improve the utilization of health care services because we cannot speculate about patient behavior during this unprecedented time. Health care organizations that engage PFAs/PFACs in strategic planning understand this deeply. “By connecting with PFAs/PFACs during the COVID-19 pandemic, Vizient has learned that open, honest and frequent communication will be required to build trust with patients and families and, honoring the relationship between a patient and their doctor may accelerate the utilization of elective health care services,” said Kellie Goodson, director, performance improvement programs.

Vizient has broadly disseminated these results through a [press release](#), which was picked up by [Healthcare Purchasing News](#), a [blog](#), and an upcoming [Modern Practice Podcast](#).

Here is an excerpt from the report:

Summary of key insights

Connecting with patients and families about their perceptions of the safety of health care services during the COVID-19 pandemic has taught us several things; 1) the biggest concern for patients and families seeking health care is getting COVID-19, 2) patients and families feel safest visiting their doctor’s office versus the ED, urgent care, and retail care settings, 3) telehealth is the preferred method of receiving care, but not from new providers – patients and families want their existing doctor to provide these services, and 4) in order for patients and families to feel safe receiving in-person preventive screenings (e.g., mammography, colonoscopy), they want to hear directly from their current doctor about it.

Perceptions of the safety of elective procedures has steadily improved since May. Most patients and families surveyed indicate they feel safe having an elective procedure now, even in states that are currently having or have experienced a resurgence of COVID-19. However, this has not necessarily translated to increased utilization of health care services. Thus making the webinar discussion themes found in May still relevant. Specifically, a “one size fits all” approach will not work during these uncertain times, and patients will look to their physicians to help them fully understand when they should proceed.

To see a return to elective health care services by patients, communicating data about COVID-19 as well as current safety protocols and practices is key. Health systems must continue to thoughtfully plan to deliver care safely while considering how patient perspectives regarding their risk of exposure to COVID-19 versus the benefits of receiving care effects their decision making. Patients want to hear about the safety of health care services and procedures directly from their existing doctor – not from hospital marketing, media sources or their friends/family – but directly, and personally, from their current doctor.

Patients feel safer going to their physician’s office versus the ED, which has been demonstrated in the utilization patterns of patients. PFAs surveyed indicate that they prefer virtual scheduling with no waiting room exposure along with traditional face-to-face provider visits. However, telehealth is the most preferred method of receiving care. A new learning from the September survey is that PFAs want telehealth and virtual care services, but not from new providers (e.g. MDLive). They want their existing doctor to provide these services.

Integrating telehealth or virtual visits in order for patients to interact with their current doctor may create a competitive advantage and a loyalty for providers that lasts far beyond the COVID-19 pandemic. Additionally, services that keep patients connected with their doctor and minimize exposure to COVID-19, such as remote patient monitoring, may create a short-term improvement in utilization of elective procedures and surgeries.

It is imperative to leverage the voices of patients and families when planning and communicating the safety of health care service delivery. Engaging PFAs/PFACs is one way providers can effectively integrate patient and family feedback into strategic planning. Vizient has learned, by connecting with patients during the COVID-19 pandemic, that open, honest and frequent communication builds trust with patients and families, and honoring the relationship between a patient and their doctor may accelerate the utilization of elective health care services. © 2020 Vizient, Inc. All rights reserved. ##

Great Links for Telehealth Information from our colleagues at Comagine:

<https://comagine.org/resource/938> (Making the Most of Your Virtual Care Visit)

<https://comagine.org/resource/942> (Maintaining Person-Centered Care: A Guide to Tele-Health Etiquette)

<https://comagine.org/resource/877> (Telehealth in Long-Term and Post-Acute Care Facilities: Do our part to keep everyone safe!

The Importance of Patient Experience

Helen Haskell quotes the British website The Patient Experience Library on the **Mothers Against Medical Error** Facebook Page:

2020 is seen as the year of coronavirus. But it has also been a year of large scale avoidable harm in healthcare. The report on rogue breast surgeon Ian Paterson was released at the start of the year, followed by the Cumberlege review of harms arising from pelvic mesh, sodium valproate and Primodos. In both cases, women's voices were ignored and suppressed over years, even decades.

In the meantime, a huge investigation into maternity deaths at the Shrewsbury and Telford NHS Hospital Trust continues, while a similar investigation has started at the East Kent University NHS Foundation Trust. In these places too, the voices of patients and bereaved relatives appear to have gone unheeded.

Against this background, our latest report asks why healthcare seems unable to accept patient feedback as a valid form of evidence.

NHS strategies emphasise the importance of "person-centred care" - and at a one-to-one level with patients, staff offer deeply personal and compassionate care. But the cases listed above - along with Mid Staffs, Morecambe Bay, Gosport and more, are signs of an institutional culture that finds it hard to hear concerns raised by patients.

The report points to a double standard which takes medical research seriously, while dismissing the experiences of patients as "anecdotal". We call for steps that would strengthen evidence-based practice and ensure that the patient voice is better heard. These include better research prioritisation, improved analytical tools and a professional learning infrastructure for patient experience work.

We continue to do all that we can to help put patient experience work on the same kind of evidence-based footing as clinical work. As we do, we are inspired by these words, from the Cumberlege review:

"Patients often know when something has gone wrong with their treatment. All too often they are the first to know. Their experience must no longer be considered anecdotal and weighted least in the hierarchy of evidence-based medicine."

Link to the Patient Experience Library report on the importance of the patient voice, "[Inadmissible Evidence.](#)"

<https://www.patientlibrary.net/cgi-bin/library.cgi?page=Blog;top=184>

See also Helen Haskell's article in the BMJ: <https://www.bmj.com/content/370/bmj.m3099>

The Graphics Garden:



5 benefits of wearing a mask:

- 1 You can eat all the onion and garlic you want.
- 2 You save money on lipstick.
- 3 Who doesn't love accessorizing?
- 4 It brings out the color of your eyes.
- 5 It keeps you and the people around you safe.

Spread knowledge. Save lives.



HOW TO WEAR A NON-MEDICAL FABRIC MASK SAFELY

Do's →

- Clean your hands before touching the mask
- Inspect the mask for damage or if dirty
- Adjust the mask to your face without leaving gaps on the sides
- Cover your mouth, nose, and chin
- Avoid touching the mask
- Clean your hands before removing the mask
- Remove the mask by the straps behind the ears or head
- Pull the mask away from your face
- Store the mask in a clean plastic resealable bag if it is not dirty or wet and you plan to re-use it
- Remove the mask by the straps when taking it out of the bag
- Wash the mask in soap or detergent, preferably with hot water, at least once a day
- Clean your hands after removing the mask

A fabric mask can protect others around you. To protect yourself and prevent the spread of COVID-19, remember to keep at least 1 metre distance from others, clean your hands frequently and thoroughly, and avoid touching your face and mask.

who.int/epi-win World Health Organization



STOP THE SPREAD OF GERMS
Help prevent the spread of respiratory diseases like COVID-19.

Stay at least 6 feet (about 2 arms' length) from other people.

6 ft



 cdc.gov/coronavirus

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