

WEBINAR CHAT NOTES

April 16, 2020

What Matters Most to Patients and Families During the COVID-19 Pandemic?

Moderator

Tiffany Christensen, CPXP, Vice President, Experience Integration, The Beryl Institute

Panelists

Dr. Grace Cordovano, Patient Advocate/Healthcare Navigating Solutionist

Erin Moore, CF Mom and co-design advocate

MaryAnne Sterling, CEA, Advocate and Family Caregiver

Melissa Thomason, Patient Advocate & Advisor

Given the challenges you are facing, how are you able to take care of your own emotional and mental health during the COVID-19 crisis?

Frances Jones- Alaska Native Medical Center: We are finding our staff are on information overload with COVID-19 info. One staff member suggested phone text alerts, like Nixle alerts .

Dan Spofford: Our health system provides an update each day to all staff on COVID-19. Also including positive real time comments.

Brittany Hendrickson: We have had many staff also say that there is information overload and it is hard to keep up with the changes. How are you all helping staff keep track of what is current

Dan Spofford: There is common IT area on our intranet for historical info and new info is in the daily updates. Marketing and our senior leadership is doing a great job communicating.

Lillian Wright: Our system CMO sends out a daily update that includes an inspirational quote, updated stats for our system facilities as well as something positive to provide staff with encouragement. It also includes links for further information if staff and leaders want more information. Encouraging them to separate facts from fiction.

Frances Jones- Alaska Native Medical Center: We have an internal webpage dedicated to COVID19 updates with key information for staff.... but it is still a lot to read. We even made videos with some of the information which was well received. But it makes me nervous thinking that all staff are reading the information. and getting what they need. I still hear rumors that would not be occurring, if the information was read. That tells me that posting information for staff is not covering all the bases.

Cathy B: EXACTLY Melissa!! That is what I would love to come up with a solution for. The patients that are passing can't work the technology and the clinical staff is so busy.

THE BERYL INSTITUTE

Tara Bristol Rouse: Thank you so much, Melissa, for being so candid regarding your experience and fears. Virtual hugs, my friend!

Dan Spofford: I am so proud of you, my colleagues, your hearts and passion for great care.

Brittany Hendrickson: Melissa you touched my heart and it is very insightful to hear things from your point of view

Susan Lee-Shareef: Melissa's testimony spoke volumes--thanks so much for sharing.

JoAnn Burnetttr: Melissa, thank you sharing your fear and concerns. Prayers, love and hugs to you.

David Garrett: Rory Ditzler, how are y'all staffing your patient rounding with ipads?

Susan Kemp: Thank you Melissa...you expressed all the fears and concerns our patients and families share. Especially in our pediatric hospital.

Erica 2: How can hospital volunteers (now not allowed in the hospital) help patients at your facilities from afar? We are a third-party org that helps to coordinate hospital volunteers.

Dorothy Rice: The virtual connections for our patients and families at a minimum are a connection for them and decreases the chance of one being alone.

Brittany Hendrickson: Erica we are having our volunteers record themselves read stories for our pediatric patients

Lauri E Santiago: Erin i now who you feel because two weeks ago i was at ER at Puerto Rico with my aunt and it was so sad for me to be outside and not be able to know what was going on inside

Joy: Social Workers have the i pads. Nurses have also used their phones to help patients have facetime with families.

Rory Ditzler, Mercy Iowa City: We are using dieticians to do that rounding, this way the patient can have communication with someone other than their primary care givers. Using people out of the labor pool

JoAnn Burnetttr: Tele health, will increase after Convid-19.

Susan Kemp: Telehealth has been a huge help in our facility. This has allowed our patients and parents to be seen without the risk of exposure.

Kathy Deevers: our IT dept has been awesome and within just a few weeks implemented telehealth/virtual follow up visits for patients

Pamela Mertz: CF families have advocated for telehealth for years for well-visits, when appropriate. How can Patients and Families help with developing these models of care? What learning is happening that we can tap into and collaborate, so it's not happening in silos?

Erin Moore: We've had to deal with limitations of telemed due to state licensure issues, creating an unnecessary burden on patients and families to travel to spaces that aren't necessary and actually put them at risk. This is a big opportunity to find efficiency and observe improvement

Frances Jones- Alaska Native Medical Center: Hopefully insurance companies will continue paying for Telehealth (like they are with COVID19 legislation and advocate!)

Dan Spofford: Patient feedback on telehealth has been positive on Real Time.

Kellie Wilson: Most of our patients have been very pleased with Telehealth.

Stuart Winston: Tele-health will never be a substitute to an in-person visit in all cases. But it will endure to accomplish a few things: better access, bridging gaps created by physical distance, and perhaps better and more expeditious triage of ailments.

Pamela Mertz: Kellie Wilson, how are you capturing PX in telehealth?

Wendy Bonilla: Tele-health should be the new normal.

Laura Kolmar: I agree telehealth is the future- there are HIPPA issues with certain platforms

Kellie Wilson: Pamela Mertz, up until now, we were surveying, although we stopped. Our practices are very invested in PX work, so it's been part of the conversation since we implemented it.

Dan Spofford: We capture patients to survey in Real Time at check-in. This process is the same for office and telehealth visits.

Kathleen Ferguson: Definitely a challenge with telehealth is reimbursement - inconsistencies with private insurance, Medicaid, Medicare and the creation of some "temporary" codes during the pandemic that may not be available long-term

David Garrett: Blessings to you, Melissa Thomason - I think the fear and actuality of dying alone has come to the forefront like never during this crisis. It is happening more than anyone knows or understands. It's very hard for patients and families both.

Brittany Hendrickson: It is really cool because we have a weekly town hall meeting focused on COVID and at the end of each meeting we have section on how to take care of yourself. Last week we did a mindfulness activity live and it was refreshing

Linda Biondini: Elderly are not very efficient with technology: ordering goods, face time, etc.

Cara Hitt: I feel this hard.

Pamela Mertz: Thank you, Kellie Wilson. Interested in best platform to use for telehealth PX data. Thanks!

Kellie Wilson: Pamela, since we paused formal surveying, we are trying to figure that out. We just had a call about it today, but don't have a solution yet.

Dan Spofford: We use NRC Real Time.

Cherie Solie: Can those that have paused formal surveys provide insight into why you made that decision?

Brittany Hendrickson: We paused NRC because they had a breach in privacy and we were waiting for them to investigate. We will be launching again soon

Dan Spofford: we have started an Emotional Support Team for our staff.

Sarah Gilstrap: Grace - love your point about grief, this was a great article I came across on the topic: <https://hbr.org/2020/03/that-discomfort-youre-feeling-is-grief>

Cathy Almost BC Patient Safety & Quality Council, Canada: Melissa we have collaborated with our Health authority to direct the public and patients to the best resources for online platforms- simple links. We have recorded a session on zoom and we are trying to spread the word so that the public can hop on board. The challenge ends up being the for those not owning smart phones or computers or who don't have wifi access

Brittany Hendrickson: Wow! I never thought of this as grief, but it is so true. It has been hard to find the words to describe my life right now and grief is spot on.

Lauri E Santiago: here in PR is very hard for elderly patient to stay at home they are use to go to the bank to the grocery store and is almost impossible trying to explain to them the importance to stay at home and the use of the internet for them to order grocery or medication is almost impossible

T H E B E R Y L I N S T I T U T E

Susan Lee-Shareef: This is emotionally and mentally draining...so, I try and stay positive! Prayer and getting fresh air helps!

Brittany Hendrickson: One of the things that our organization is pushing is to be nice to each other and have grace with your coworkers

Brittany Hendrickson: I love that! Dance away!

cathy G: As the Patient Advocate in a major hospital, I have made sure that I energize myself by staying spiritually grounded, scheduling zoom mtgs. with family that leave at a distance & making sure that daily I recount to myself a reason why I'm blessed. Then I can better support staff & patients and their families that are calling because they cannot visit.

Terry Harrington: If you find it, you'll have to share it! We need some good/fun positivity

Loretta Melvin: Dancing in the store sounds like perfect therapy. I'm going to give it a try

Kathy Deevers: Grace you're a busy lady! Bless you. Take some time for you even if it's just 15 minutes. You deserve it!

Heather Purvis: Trying to keep CREDIBLY updated is exhausting in itself...but turning off all my technology every night for a period of time has been helpful.

David Garrett: Some days are especially tough, and I'm not even on the front lines. I have found that prayer and being outside or playing catch with our dog helps the most!

JoAnn Burnettr: Love, dancing in the grocery store. Find joy in the moment.

MaryAnne Sterling: We all need a reason to smile through this!

Nicole Kirchhoffer: @MD In NYC patients giving birth are allowed to have one healthy support person during delivery.

Grace Cordovano: Dancing in the aisles is always a good plan MaryAnne!

Dorothy Rice: I agree with you Heather, getting a break from the news and technology for a while in evening helps.

Pamela Mertz: Faith is a large part of how our family copes with the stress. We have also adapted to be serving when and where we can, and that helps shift the self-focus onto others. Practicing prayer and gratitude is important for mindset shifting as well. Multiple walks during the day, the dog loves this!! Gardening helps too!

T H E B E R Y L I N S T I T U T E

Nicole Kirchoffer: Biggest challenge is improving staff morale during this time when they have valid fears during this time.

Joy: Gratitude; focusing on what we do have, instead of what we don't have.

Brittany Hendrickson: Nicole we have been asking patients for inspirational messages and pics to staff and displaying them in the hallway, offering free food and trying to provide discounted or free hotel stays if needed

Rory Ditzler, Mercy Iowa City: We all need to find something to laugh about in order to deal with the anxiety of this situation

Lorena: This is very helpful! I had to stop watching news and need to be in contact with my family. I always had someone knocking at my door and I miss that-- Loving ZOOM, even had a karaoke night! And having God in my life and being thankful for LIFE has helped during this trying time!

Susan Kemp: A break from the news and just relying on our command center in our hospital to give me information has helped so much with my stress level during this whole situation. This gives me one source of information that gives me the important changes that our government, CDC, Department of Health and our facility has for us all in one without the contradiction of information.

Gary Jones: Joy, great point on gratitude!

Jennifer Symon: Dr Jody Carrington always says we are built to do hard things.

Lillian Wright 2: I live in a small rural area in NC and it is very peaceful and i love being surrounded by peaceful pines and birds singing. It's a welcome break from the healthcare facilities I'm in during the day. I get to spend the evening sitting on my back porch with my dogs. It's very serene.

Dan Spofford: Also, I have to limit screen time at home to keep my spirits up.

Jennifer Symon: and show others how to celebrate successes.

Susan Kemp: YES!!! Celebrate the small wins!!!

Melissa Thomason: That makes me smile, Lillian. I would enjoy that too.

Pamela Mertz: Yes, celebrating the little things is key!! Wins are important to share! I have a personal coach that helps me with this, too!

T H E B E R Y L
I N S T I T U T E

Kathy Deevers: Lillian, I'm going to pretend I'm sitting on the back porch with you! lol

Grace Cordovano: Yes! Find things to celebrate and don't feel guilty about it. We have enough heaviness and hard emotions that carry

Linda Biondini: Use the good china. Light the candles.

Gary Jones: We have to take care of ourselves to be able to take care of others. Just like on the airlines with putting on your oxygen first and then putting it on the other person!

Lauri E Santiago: how we deal with the teens because they feel they are missing so much of their lives

heather edwards: Are most PX offices working from home?

JW: Agreed...this not a normal time...and we can allow ourselves to live in ways we may not have prior to this moment

Gary Jones: Celebrations are so important no matter how small!

Melissa Thomason: Gratitude is an enormous help right now! Daily, I take time to write in my journal and list those things I am grateful for.

Kristee Mines: Sarah Gilstrap, thank you for sharing the article on coping with grief.

Joy: I am px and working from office, not home, but have minimum contact and wear a mask.

Kathy Deevers: agree Melissa... gratitude is huge!

AMANDA R CLOUD: We are not working from home. We work from office and call patient rooms.