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My youngest child has had 46 surgeries. Years ago Child Life therapists gave a doll my kiddo owned a tracheotomy and g-tube. A therapist enlisted her husband to use his drill on a doll in order to place the trach and g-tube. Other dolls received IVs and had oxygen masks placed before going back with my child to induction. Often, the Surgeon would serenade my kiddo, singing opera on the way back to the Operating Room. These efforts actually were therapeutic. They helped reduce my child's anxiety and ease stress overall.

I served on the Speaker's Bureau for the local children's hospital fundraising efforts. We used to show our audiences a video clip where an oncology nurse talked about not wanting to work with adults, because he couldn't

make balloon animals for adults. At the time, I thought, "Why not? Wouldn't adults also benefit from play or recreational therapy?"



Since that time, more adult facilities, including hospitals and care facilities, have integrated music, art, pet and other allied therapies into treatment. Especially during this time of limited visitation, these therapies can make all the difference in a patient's or resident's recovery and well-being. Comagine Health featured an excellent webinar offering expert examples of how to implement Innovative Activities: Preserving Functional Ability During the COVID-19 Crisis.

The American Therapeutic Recreation Association defines what their members do as, "(A) systematic process that utilizes recreation and other activity-based interventions to address the assessed needs of individuals with illnesses and/or disabling conditions, as a means to psychological and physical health, recovery and well-being. Further, "Recreational Therapy" means a treatment service designed to restore, remediate and rehabilitate a person's level of functioning and independence in life activities, to promote health and wellness as well as reduce or eliminate the activity limitations and restrictions to participation in life situations caused by an illness or disabling condition." (https://www.atra-online.com/?)

Music Therapy is the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program. (https://www.musictherapy.org/about/musictherapy/) Music Therapists know that whether a person prefers Elgar, Elton John or Billie Eilish, music may help patients and family members express feelings, provide emotional support and promote movement.

In this Newsletter, read on for:

- Our interview with Richard Scholtz and his amazing work connecting community and healthcare.
- How you may support the Vizient survey of COVID experience.
- Resources curated by the John
 A. Hartford Foundation.
- The popular **Graphics Garden**.

This month we profile Richard Scholtz who has long used music to support his community. I met Richard at an IHI Forum. He helped persons from diverse backgrounds connect through their common memories of playing "Itsy Bitsy Spider," as very young children. That little ditty is known across many cultures. While the finger motions that go with the verse may differ, everyone found some common connection in a pre-school memory. Finding connections helps to fight inequity. We can more easily see others humanity when we make human connections.

During this season, consider exploring how your practice can be enhanced through providing connecting, therapeutic outlets for your patients (and staff, too). CAPS hopes all our members may find Peace during the Holidays. -Lisa

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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.

Thank you for your support! -Lisa Morrise

CAPS Consumer Advisory Panel Profile



Richard Scholtz describes himself as having been self-employed. Although his degree is in Psychology, he is also a musician, with his primary instruments being the autoharp and dulcimer. Richard uses his insights into humanity as he shares his music and positivity in entertainment, education and medical venues. He has had the same life partner, Helen, for over fifty years and they have two grown children. Richard lives in Bellingham, Washington.

CAPS: When did you start your advocacy?

Richard: In 1987 I started playing music every Friday in the waiting room of a Cardiologist's office. I had felt extremely well cared for by the Physician who had taken care of me when I needed a new heart valve. I felt money alone could not adequately thank him for giving me more years of life and being so kind to me and my family. This

Doctor was in a practice with ten other providers. They chose Friday because they felt the music may help them when they were the most tired. Two or three of the doctors came out to the waiting room the first day and said, "Keep up the good work! When you're playing our patient's blood pressure is lower!" Some persons sat close to me when I played, and others sat across the room. I chose music based on the feelings I got from the people around me.

In the early 2000s, I participated in a Robert Woods Johnson Pursuing Perfection grant. At the time, ours was the largest single RWJ project to create patient centered care. My county, Whatcom County, Washington was one of several grantees. Whatcom County was the only grantee building connections between different healthcare businesses. (All other grantees, at that point, were HMOs or part of a National health system.) With the grant, we were all inspired to think about new ways of collaborating. Older patients with several chronic conditions were included in the study and one of those patients was my Mother. I became a volunteer with the project.

I'm different in healthcare advocacy because I did not come to it after something bad happened. I really got involved during a period of incredible generosity funded by Robert Woods Johnson. I became a community partner in reimagining healthcare. I'd note that many of my friends who work in healthcare have encouraged me to call myself a "patient advocate." I've resisted that because I feel it implies an oppositional relationship.

CAPS: How has your advocacy evolved?

Richard: We got to know a fellow grantor from RWJ in Sweden. They made health systems maps as part of their project. We decided to make similar maps of healthcare involving the human and physical resources for health in Whatcom County. Mapping the system in Whatcom County seemed like a good way to develop a shared understanding of integrating our community healthcare resources.

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Initially, we just mapped healthcare organizations, but the focus on patient centeredness led to learning that patients and their families and friends were actually active providers of healthcare. That meant figuring out how to include them on the map as "providers" as well as "receivers."

Health is not a PLACE. People can be living life, then something happens to their health. Suddenly you have no idea about your future, you have a modified understanding of self. New habits become part a part of your life with a new diagnosis and you may have a new understanding of your future.

As well as creating a map of the system that would be useful for administrators and planners, we thought about creating a navigable map for people who wanted to use healthcare. It would be a first step in creating a "user's manual" that would describe simple things like "how do you turn it on or off?" Most of the healthcare places we think of like hospitals and clinics may not be on a persons' healthcare map. Since we were interested in a broad understanding or resources, we chose not to focus on health care but asked about people, information sources and services that were important for that person's health, not specifically "healthcare" resources. The prompt is intentionally very open-ended and asks people a question they are not used to answering.

For healthcare workers to see their places of business were not on patient maps was super transformative. The mapping project spread, and we collected 165 maps and recorded interviews from persons over age 65. After that, I have done the activity with many groups and have collected several thousand maps. A friend brought me a fantastic collection of maps done in Africa. The prompts for the maps were used by various organizations including the University of Washington, the Global Health Program, and in British Columbia. We ended up collecting thousands of maps. It is such a simple exercise! You can't tell by looking at a person's map if they are a healthcare worker or a patient. A few persons included their genetics as a component on their map. Many included their pets. One person included the liquor store. (To see prompts and sample maps from the mapping project, go to https://www.youtube.com/watch?v=gStHYws7E 0)

CAPS: What projects have you been involved in?

Richard: I continued working on mapping projects. We did a show once where persons age 8 to 92 were table to do maps. 2500 to 3000 persons came to the show. We had an integration of art, theater, music, dance and poetry as languages of humanity. I collaborated with choreographer Pam Kuntz and we shared interviews from different persons interwoven with dance pieces. We had community participants make a map and then we recorded a one to two-hour conversation with them about their map. That became the recorded narrative which, when combined with music, shaped performance pieces that were performed by those community members in collaboration with trained dancers.. The audience understood more about the people with serious illness than they were familiar with healthcare narratives in general. We did a mapping project for the Cardiology department at the Mayo Clinic.



I was a founding board member for a six-year collaboration between the Hospital and the local University called the Critical Junctures Institute. I also was on the board to create the Palliative Care Institute.

With the arts, the hierarchy of authority is leveled, and persons can talk to each other easier. I started to do events where professionals and citizens meet with the arts. The events focused on aging, health and death. Through music, song, dance, ink and paper communication happened in a way that doesn't happen with just charts, graphs, and analytic language. Using the arts as a form of communication rather than entertainment alone is a new approach for many folks.

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I have come to understand that these arts are all essential human languages. They are much older than medicine and have developed over generations because we need them in order to communicate about the fullness of life. I have also talked, using just words, about issues like anti-coagulant management for a medication management program.

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

Richard: I'd like to see more people think beyond what we have now as standard recommendations and options for patients. For example, when my Mom was 92, she fell and broke her arm right below the shoulder. When we went to the orthopedic surgeon, he said we could do surgery and it would be fixed. He encouraged us to think about that option. But we decided to not do the surgery due to the recovery and potential issues. The Doctor thought we made the right decision. He said that her recovery would have been longer, and she would not feel significant improvement. But, he said, He needed to offer us that option and that most of his patients would have chosen surgery.

I'd like to see more persons be comfortably assertive as partners in decisions made about their health. The context for healthcare should be life and living, not living for healthcare. Persons formerly known as patients could be more actively aware of their choices. I think this would make healthcare safer. Ideally, we would take aspects of confrontation out of the meeting of persons and healthcare providers.

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

Richard: I've decided I don't want to have a test for something unless I am willing to have a treatment for abnormal results. For example, my cholesterol kept being the same small amount outside of the standard "acceptable" level. I tried statins, but experienced side effects. So, I opted to stop taking the medication. If I'm not going to take the medicine to lower cholesterol, I don't see any reason to measure my cholesterol. I don't want to know what the level is because I'm not going to do anything to "treat" the situation. It is what it is.

I have similar feelings about my annual follow-up with my heart valve. My heart valve function could be assessed without doing an EKG, although that was a regular practice for the Doctor. Since I was there to asses the valve function, I asked the doctor why we did an EKG every time. I don't see any reason to do an EKG, because I don't plan to have any further interventions with my heart. I discussed the value of the EKG given my specific needs and he agreed it was not necessary. He would not have thought of skipping it on his own. I haven't had an EKG in years.

I am at risk for an aortic aneurysm. My cardiologist said he could check on that with an echocardiogram. But I wasn't sure that in my 70s I wanted to have a second open chest surgery, depending on what he would see. So, I talked to my kids and my family. With their input, we decided to do the echo. It turned out that my heart was fine. But I made that choice, it wasn't made for me.

It's a simple thing, really, to be more clear about the implications of test results and see if the person would even want to follow up with a treatment. The key is to acknowledge that persons actually have authority for themselves. We need to reframe health and healthcare in terms of the experiences we want to have as part of our life.

There are so many cracks and spaces in industrial healthcare. It's easy to see things that don't work. Everyone feels frustrated and wants to figure out how to improve what we have. To me, the real issue is how do we as citizens feel. The context for life is not the healthcare system. It is life as people live it. I've come to believe that working in healthcare is bad for people's health – but that we "citizens" can help them and ourselves at the same time. And, of course, people who work in healthcare are citizens too. In many ways, I think change is more easily accomplished from outside the system: you don't have to send it up to the top and wait for a decision to come down. Persons – including clinicians - need support not just from clinicians but from the persons around them.

CAPS: What are your future plans?

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Richard: I still am involved in Palliative Care. We are currently doing the Portraits of Age Project. We are recording persons who share their experience of life. We plan to edit the interviews and post each with a portrait of the person



painted by a local artist.. I prefer to make a difference by being engaged with people more than be involved in corporate bureaucracy. I feel like not everything needs to be scaled with an eye on who is the best person to do it. The concept of "best practice" can make it difficult to make the essential adjustments for a local/individual situation. I am much more inclined to think in terms of "what can we do with the people who are here now?"

I want to help others stay human and not get burned out. I'm not running music camps anymore. But I want to continue to see music be an important part of persons life. Integrating music into different aspects of life helps persons be more awake to life. I want to see persons focus on more than reform. We need to focus on life and living and see how reform fits into that.

Thanks, Richard! Contact Richard at rscholtz@aol.com.

When they are available, we will post Richard's Portraits of Age recordings on the CAPS YouTube Channel. See the Mapping Project prompts, hear from participants and see their maps here:

https://www.youtube.com/watch?v=gStHYws7E 0

Information about the Whatcom County, Washington, Pursuing Perfection Initiative funded by the Robert Wood Johnson Foundation:

- http://www.ihi.org/Engage/Initiatives/Completed/PursuingPerfection/Pages/default.aspx
- https://www.modernhealthcare.com/article/20050228/NEWS/502280327/pursuing-perfection-the-pursuit-continues
- https://www.pbs.org/remakingamericanmedicine/bryson.html

Link to the project gallery on Pam Kuntz's web site: Project Gallery — Kuntz and Company

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:

Vizient would like to bring feedback from patients and families to its member health care organizations regarding how they feel about the safety of accessing health care during the COVID-19 pandemic. They welcome patients, families and care givers from across the U.S. to give feedback by completing this short pulse survey (less than 20 short questions that should only take 5-8 minutes to answer). They would like to get as much feedback as possible by December 31st, so please pass this survey along to any patient or family care giver you know. Vizient will create a report (with aggregate

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results only) and make it publicly available on its website for use by its members, patients and families, and any other interested stakeholders.

Take the pulse survey here: Patient and Family Feedback Survey

Vizient, and its health care intelligence subsidiary Sg2, is the nation's largest member-driven health care performance improvement company with more than 3,000 health care organization members, including 95% of the nation's academic medical centers. Vizient has engaged with its members in the past several years to bring the voices of patients and families into health care strategic planning and improvement efforts nationally.

If you have any questions, you may contact Kellie Goodson at kellie.goodson@vizientinc.com.

The John A. Hartford Foundation (https://www.johnahartford.org) has curated the following excellent list of resources: What Older Adults and Their Family Caregivers Should Know:

Administration for Community Living (ACL)

- What do Older Adults and People with Disabilities Need to Know?
- Eldercare Locator
- Voluntary National Guidelines for Respite Care Agencies, Providers, Family Caregivers, and Respite Care
 Recipients

Centers for Disease Control and Prevention (CDC)

- People at Risk for Serious Illness from COVID-19 Older Adults
- Resources for Home: Plan, Prepare, and Respond to Coronavirus Disease 2019

AARP

- What you need to know about the Coronavirus Outbreak
- Health, Coronavirus and Caregiving
- COVID-19 Spanish Language Resources
- Preparing Caregivers during COVID-19

Alzheimer's Association

- Coronavirus (COVID-19): Tips for Dementia Caregivers
- Emergency Preparedness: Caring for persons living with dementia in a long-term or community-based care setting
- Coronavirus (COVID-19) and Dementia: Tips for Public Health Community

Archangels

COVID-19 Resources: To Read & Share

Caregiver Action Network

COVID-19 and Family Caregiving

Diverse Elders Coalition

COVID-19 Community Resources

Family Caregiver Alliance

Coronavirus (COVID-19) Resources and Articles for Family Caregivers

National Foundation for Infectious Diseases

- Frequently Asked Questions About Novel Coronavirus (COVID-19)
- Common Questions and Answers About COVID-19 for Older Adults and People with Chronic Health Conditions

Prepare for Your Care

COVID-19 Resources and Hospital Go Bag in English and Spanish

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News and Articles to Keep You Informed:

Kaiser Family Foundation

- Coronavirus (COVID-19)
- What Share of People Who Have Died of COVID-19 Are 65 and Older and How Does It Vary By State?

Kaiser Health News

COVID-19 Latest News on the Coronavirus Outbreak

Next Avenue (PBS' Online News Platform for Older Adults)

The Coronavirus Outbreak: What You Need to Know

Health Affairs

COVID-19 (Coronavirus Disease)

What Long-Term Care Providers Should Know:

Centers for Disease Control and Prevention (CDC)

Interim Guidance for Nursing Homes

LeadingAge

Coronavirus and COVID-19 Information

American Health Care Association (AHCA)

Coronavirus

The Society for Post-Acute and Long-Term Care Medicine (AMDA)

Update on COVID-19

World Health Organization (WHO)

Policy Brief: Preventing and Managing COVID-19 Across Long-term Care Services

What Health Care Professionals Should Know - Federal Guidance:

Centers for Disease Control and Prevention (CDC)

- Information for Healthcare Professionals
 - Resources for Hospitals and Healthcare Professionals Preparing for Patients with Suspected or Confirmed COVID-19
 - Interim Infection Prevention and Control Recommendations for Patients with Suspected or Confirmed
 Coronavirus Disease 2019 (COVID-19) in Healthcare Settings
 - Interim Guidance for Implementing Home Care of People Not Requiring Hospitalization for Coronavirus Disease 2019 (COVID-19)
 - Guidance for Retirement Communities and Independent Living

Centers for Medicare and Medicaid Services (CMS)

- Coronavirus (COVID-19) Partner Toolkit (includes Coronavirus (COVID-19) Stakeholder Calls)
- Hospice Quality Reporting Program COVID-19 Public Health Emergency (PHE) Tip Sheet (on HQRP Requirements and Best Practices webpage)
- Medicare COVID-19 Data Release Blog
- Current Emergencies Website (COVID-19)

Health Resources and Services Administration (HRSA)

Emergency Preparedness and Recovery Resources for Health Centers

What Health Care Professionals Should Know - Geriatric Care:

American Geriatrics Society (AGS)

- AGS Coronavirus Disease 2019 (COVID-19) Information Hub
- Allocating Scarce Resources In the COVID-19 Era

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The Journal of the American Geriatrics Society Publications on COVID-19

Home Centered Care Institute - for Home-Based Primary Care Providers

COVID-19 Information Hub

Geriatric Emergency Department Collaborative

COVID-19 Links and Resources

Gerontological Society of America (GSA)

National Adult Vaccination Program COVID-19 Updates

What Health Care Professionals should know - Serious Illness Care:

Ariadne Labs

Serious Illness Care Program COVID-19 Response Toolkit

Center to Advance Palliative Care (CAPC)

CAPC COVID-19 Response Resources

Coalition to Transform Advanced Care

Resources to Support Serious Illness Population

National POLST

POLST and COVID-19 (Facility Guidance)

Respecting Choices

Resources to have Planning Conversations in COVID-19

The 3 Wishes Project

The 3 Wishes Project

The Conversation Project

COVID-19 Resources

VitalTalk

COVID-Ready Communication Skills: A Playbook of VitalTalk Tips

National Hospice and Palliative Care Organization

Emergency Preparedness: COVID-19 Information

What Health Care Professionals Should Know - General:

American College of Physicians (ACP)

Coronavirus Disease 2019 (COVID-19): Information for Internists

American Hospital Association (AHA)

Updates and Resources on Novel Coronavirus (COVID-19)

American Pharmacists Association (APhA)

Pharmacists' Guide to Coronavirus

Better Care Playbook

Addressing Complex Care Needs Amid COVID-19

Center for Medicare Advocacy

COVID-19: An Advocates Guide to Beneficiary Related Medicare Changes

Institute for Healthcare Improvement

COVID-19 Guidance and Resources

University of Washington Medical Center (UW Medicine)

COVID-19 Resource Site for Healthcare Workers

National Academy of Medicine

Resources on Health Equity in the Context of COVID-19 and Disproportionate Outcomes for Marginalized Groups

The Center for Connected Health Policy (CCHP)

National Telehealth Resource Center

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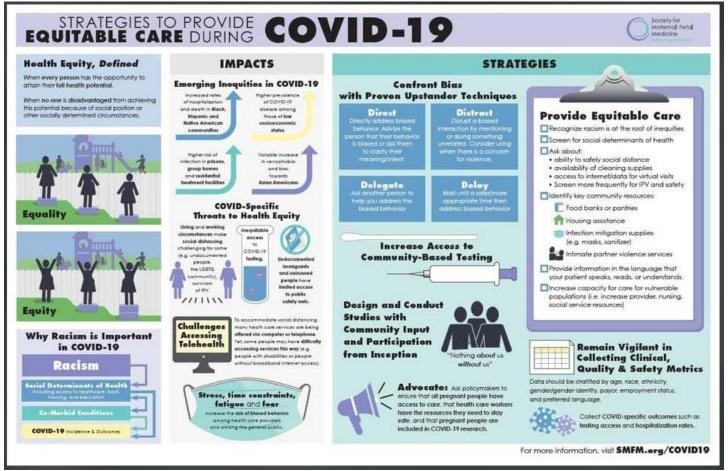
The Hastings Center

 Ethical Framework for Health Care Institutions & Guidelines for Institutional Ethics Services Responding to the Coronavirus Pandemic

The Joint Commission

Coronavirus (COVID-19)

The Graphics Garden:









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Self-Care During COVID-19





















Adapted from a resource created by the Regents at the University of Michigan

GrieveWell.com

Please visit:

Our web page at www.patientsafety.org. Find resources, archived recordings, and a form to share your story or sign up for this newsletter!

And, please like our Facebook Page: https://www.facebook.com/patientsafety.org/?ref=bookmarks

To Donate to CAPS:

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. Venmo at CAPS-PatientSafety

Paypal at www.paypal.me/patientsafety

Do you have information for the CAPS Newsletter?

Please send us information about what you are doing to Advance Patient Safety. Send it to capspatientsafety@gmail.com

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