



Retrospective Perspective

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About this time last year, my adult age children and I had a difficult conversation. I experienced COVID infection and weeks of illness. We couldn't know what my course would be. We discussed potential issues and scenarios. I felt the lingering impact of the illness for many months.

Many are looking back right now on the last year of the COVID-19 pandemic. Well known Asset Based Community Development (ABCD) consultant Cormac Russell recommends looking not at just what went *wrong*, but what was *strong* in evaluating community responses. When I think about what went well, I like to think of my colleagues who moved easily into a virtual platform with their Patient and Family Advisory Council (PFAC) meetings. Places like Children's Mercy Hospital in Kansas City and University Hospitals in Cleveland asked their PFAC's how to best meet patient and caregiver needs. They discussed policies around visitation, end-of-life care, even signage in their virtual meetings. These facilities

indicate their patient and caregiver advisor input supported their facilities being both more welcoming and safer.

Sadly, some facilities discontinued their PFACs during the last year. Understandably budgets and staffing have been tight. However, PFACs often save a facility funds in the long run by helping identify policy and process that will work best with patients and families. For example, one hospital found, thanks to the keen eyes of their PFAC members, that their COVID-19 messaging differed considerably from department to department. Solving that issue by having consistent signing throughout the hospital meant fewer confused persons and increased understanding.

Recently, many have been looking back at the twenty years since the Institute of Medicine report "To Err is Human." It detailed the startling amount of medical harm experienced annually. What has changed since then? While errors continue to occur, we have seen some improvement.

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For example, the CMS effort The Partnership for Patients and The Hospital Improvement Innovation Networks worked from 2011 to 2019 to improve quality and safety along several domains. Integral to these programs were Patient Engagement Metrics, including adoption of collaboration with patient advisors in hospital policy, practice and governance work. Safety and quality did improve during the effort, with metrics showing thousands of lives saved.

Our patient profile in this issue features a CAPS Founder, Marty Hatlie. Hatlie's contributions to safer healthcare through patient collaboration have been foundational. He has led the charge across many organizations for transparent, safer, just cultures in healthcare.

While retrospection can offer valuable information, we also need to look forward and plan for the future. How will you and the organization you work with foster collaboration between patients and their caregivers and the healthcare community? How will you continue to move toward zero preventable harm in healthcare? -Lisa Morrise

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's 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.



CAPS Consumer Advisory Panel Profile

Marty Hatlie Newsletter - May 2021



Martin (Marty) J. Hatlie, JD, grew up straddling the border of North Dakota and Minnesota. He attended Carleton College and Boston College Law School. Hatlie, who sometimes describes himself as a "recovering lawyer," advocates for patients and coaches healthcare providers and policymakers on patient safety and medical liability issues. He was a co-founder of Consumers Advancing Patient Safety and now serves on the boards of several organizations focused on patient safety, including The Patient Safety Movement Foundation, The Leapfrog Group, Smart Patients, Loyola-MacNeal Hospital in Chicago, and the Alliance for Integrated Medication Management. He also plays advisory roles with the World Health Organization, National Quality Forum and The Joint Commission, and works with the Healthcare Patient Partnership Institute to help hospitals establish Patient and Family Advisory

Councils for Quality and Safety ®. He co-edited the <u>Patient Safety Handbook</u>, one of the first

textbooks in the patient safety field and has authored numerous white papers and articles regarding patient safety and practical frameworks for working toward zero medical harm in an environment of Communication and Optimal Resolution (CANDOR). Hatlie was recently recognized with the Michael Seres Humanitarian Award by the Patient Safety Movement Foundation. Hatlie and his husband, Charles (Chuck) Holland, Jr., live in Chicago with their Porties, Cubby and Twiggy.



CAPS: When did you start your advocacy?

Marty Hatlie: My advocacy around patient safety started in work on risk management and alternative dispute resolution at the American Medical Association (AMA). I spent over ten years there as a lobbyist trying to get protections for doctors from being sued at the federal level and we had setback after setback. After a series of very public stories of medical error in 1995 – the chemotherapy overdose of Boston Globe reporter Betsy Lehman, the missed appendix diagnosis of Libby Zion, and the amputation of the wrong foot experienced by Willie King -- I proposed a public relations strategy focused on the mistaken goal of showing how "rare" medical error was. We also wanted to show how hard organized medicine was working to keep patients safe.

One of the emerging leaders on patient safety then was Jerod Loeb, who was the lead scientist at the Joint Commission on Accreditation of Healthcare Organizations (JCAHO). Jerod and I, with others, quickly put together the first Annenberg Conference on Medical Error in 1996, and I asked Lucien Leape, MD, to speak. He had reason to wonder about my goals, but agreed to speak IF we would also invite James Reason, the world's leading expert on human error. He literally wrote the book! When I met Dr. Reason, he told me over dinner that the systems safety world had been waiting for the phone call for twenty years. He kindly and diplomatically informed me that it was embarrassing for the AMA to frame medical error as a PR problem, because it was all too real. That conversation in October 1996 was my Road to Damascus moment, a life changing experience.

More than 300 researchers, human factors experts, systems and risk thinkers, providers, insurers and patient advocates from around the world gathered at that Annenberg Center for Health Sciences in October 1996 for that conference. Prominent among them were leaders from Martin Memorial Health System in Stuart, Florida, who presented a powerful story of communication with the family of Ben Kolb, a first grader who lost his life to a medication error during elective surgery. As Doni Haas, the risk manager, explained they came to fulfill a promise to Ben's parents to tell the story so others could be saved, The conference received major press, including a New York Times Sunday Magazine cover story,

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and generated a number of new initiatives. One was the launch of the JCAHO's Sentinel Event Reporting policy. A second was the announcement by the AMA of intent to establish the National Patient Safety Foundation (NPSF). The Institute of Medicine's interest in medical error also stems from this event, culminating in its landmark report <u>To Err is Human</u> three years later. (Learn more about the Annenberg conference here in a Journal of the American Medical Association article by Leape, Hatlie and others: Promoting Patient Safety by Preventing Medical Error).

I went on to work with the AMA and establish the NPSF in 1997 and serve as its founding Executive Director.

Two years later my worldview was challenged again, when NPSF headquarters in downtown Chicago was picketed by patient safety victims from around the country, organized by Ilene Corina's organization, PULSE. (CAPS note: read about Ilene's advocacy in the January 2020 CAPS Newsletter). Doni Haas, the risk manager who had been so transparent about Ben Kolb, was now an NPSF Board of Trustees member. She and I met the picketers, who made the request that we join them for the next two days as they told their stories. And so we did, listening to story after story of patient harm and family devastation. I'll never forget that experience, in part because it was so moving, and in part because the people telling the stories were so attentive to my distress in hearing them. It was a master class in empathy to experience them taking care of my feelings, when it was they who had been so impacted by loss. In the midst of that ethos, I also was hearing things that I was not hearing from the experts in the NPSF Board room and research committee. Clear patterns in the patient/family stories involved breakdowns in transitions of care and failures to rescue. I left realizing how much we had to learn from patients and family members, and how important it was to work with them, not just for them.

CAPS: How has your advocacy evolved over the years?

Marty: I left NPSF shortly after the PULSE picket and have had the good fortune to work with patients and family members ever since, learning at every step in the journey. Two important teachers were Roxanne Goeltz and Sue Sheridan.

Roxanne was an air traffic controller at the Minneapolis/St. Paul airport who had lost a brother to medical error. Her family got no explanation of what happened and experienced pressure in her hometown community not to sue, to move on with no closure. She channeled her grief into becoming active at the State level, and her advocacy helped start the Minnesota Alliance for Patient Safety in 1997-1998. Then Roxanne was diagnosed with cancer. As an Air Traffic Controller, she quickly assessed gaps in teamwork and communication among her providers, including two doctors who disliked and avoided each other. To help manage that risk as she planned for surgery, she asked her co-workers at the airport to take shifts so that she was never in the hospital alone. Post-surgery she experienced a DVT – deep vein thrombosis – and saw that nurses were being blamed. Realizing that the fundamental problem was gaps in care and culture, not incompetence, Roxanne stuck up for the nurses. Together, we wrote up Roxanne's story and published it. To this day, it's my favorite publication as an author. (Find Roxanne's story in the article *Trial and Error in My Quest to be a Partner in My Health Care*). Roxanne eventually testified about the danger to patient safety of blame in the U.S. Senate.

My family also benefitted personally from Roxanne's wisdom about 24/7 coverage in hospitals. During the end-of-life journey of my Mom we caught errors every day, one of them a whopper that we headed off only because we were there in real time. I will be eternally grateful to Roxanne for the things she taught me.

My second teacher was Sue Sheridan, who has become a formidable patient safety advocate. Sue's son, Cal, had been born a healthy, full term baby. But he had jaundice that progressed untreated and led to him developing kernicterus, a type of brain damage that is caused by excess bilirubin in the blood. Sue, and other <u>Parents of Infants and Children with Kernicterus (PICK)</u>, took on the issue, raised awareness and got treatment and education guidelines changed. That experience is detailed in an article I co-authored with Sue and Karen Dixon, <u>Consumers as Partners: An Honest Approach to Patient Engagement</u>.

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Sue's husband, Pat, died of a second failure to diagnose, in his case an aggressive spinal cancer. The pathology, which was accurate, was lost in the hospital system and never communicated to patient or surgeon, resulting in a treatment delay that cost Pat his life.

Working with Sue, I came to deeply understand the harm caused to families who are denied the truth after harm because of litigation fears, then often blamed for harm they did not cause. I have always been interested in fairness – in fact, my senior thesis as a philosophy major in college explored whether justice and fairness were the same thing. I thank the Sheridan family for helping me see the severe misalignment between the litigation system and systems approach to patient safety in real life. Kernicterus cases are a classic example. They were happening across the country from the mid-1990s on, triggered by the onset of early discharge of Mom's and babies. They went undetected by the public health community for at least 5 years, in part because when parents settled kernicterus lawsuits they were required by "gag clauses" to stay silent. It wasn't until the PICK parents found each other and became activists in 2000 that the risk became known to the Centers for Disease Prevention and Control, the National Institutes of Health, the National Quality Forum, the Joint Commission and the publishers of prenatal health books.

It was through Roxanne, Sue and many others since that I have come to see that it's not just medical errors that harm. Hiding facts, failure to learn, and unfairness are the lynchpins that slow progress. We won't learn what we need to know from inside the health system, because hiding and unfairness have been normalized there. We need a system that structurally engages users of care, listens to them and doesn't try to shut them up. And Lisa, as you underscored in our very first conversation back in 2012 at a Patient Centered Outcomes Research Institute (PCORI) agenda setting event, it's crucial that we include those whose voices we don't usually hear from — the voices that are unfairly and unwisely marginalized as too low on the totem pole because of socio-economic status, race or other social determinants.

CAPS: What projects have you been involved in?

Marty: I'm gratified by my role in making the Annenberg Conferences happen, which brought systems engineering learning into mainstream medicine and personally helped me shift my path in life.

Then there was my rich interaction with consumers, much of which has been through CAPS. Under Sue Sheridan's leadership, CAPS was instrumental in growing a patient and family engagement with the World Health Organization (WHO). We at CAPS spent years in the early 2000s facilitating workshops around the globe, opening dialogue that challenged cultural hesitancy to talk about medical errors. We also helped develop the <u>London Declaration pledge of partnership</u>, and use it as the foundation for building the <u>WHO Patients for Patient Safety community</u>. I had so many wonderful opportunities to learn! I remember a workshop we did in Perth, Australia, where about one-third of the attendees were aborigine. I found that I had to call on persons based on their tribal rank, a very different facilitation challenge that I failed repeatedly! They were forgiving, however, and our interests as advocates united us in producing the <u>Perth Declaration</u>, where we committed as part of the global community to stay silent no longer.

I think – and hope – that the most effective work many of us have done in the U.S. was embedding robust patient and family voices into the National Partnership for Patients (PfP) Campaign, a Center for Medicare and Medicaid Services (CMS) led initiative supported by the Affordable Care Act. During the Obama Administration, it engaged about 80% of U.S. hospitals in a concentrated effort to prevent patient harm. Patients and family members became full partners in the PfP campaign, advancing patient- and family-centered care from "the right thing to do" to an outcomes improvement strategy that contributes to outcomes. A very high energy patient and family Affinity Group worked to get patients on hospital boards of directors and patient and family advisory councils engaged in patient safety projects. Affinity Group leverage also got "Person" and family engagement built into the CMS Quality Strategy and brought health equity inequalities to the forefront.

Working on Agency for Healthcare Research and Quality (AHRQ) toolkits like <u>CANDOR</u> (Communication and Optimal <u>Resolution</u>) and the <u>Guide for Improving Patient Safety in Primary Care Settings by Engaging Patients and Families</u> also



have been very rewarding. And I've had the great luck to work with patient safety advocates Victoria and Armando Nahum, helping hospitals learn to use patients and family advisors in improvement work and measure results. Together we started the Healthcare and Patient Partnership Institute (<u>H2Pi</u>) to advance this work. It's been supported by CMS, Vizient Inc., MedStar Health and several other systems.

CAPS: What would you recommend to persons who want to advocate for quality and safety?

Marty: I think the most important thing for patients and family caregivers to remember is that the health care system is supposed to work for you and those you love. It often doesn't but it's <u>supposed to</u>, and in my own family I adopt that attitude going in. It helps me muster the confidence to speak up when I see something that looks sloppy, the determination to get answers when it's not easy, and the courage to fire doctors when they don't cooperate.

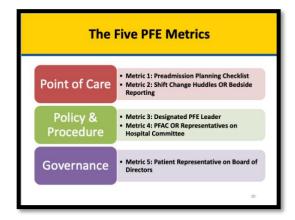
The best advice I have is don't assume the system is going to work well. What the systems engineers teach us it that complex work is "prone to failure," and nothing is more complex than healthcare. Think of yourself as driving through the system alert to what's going on, much as you do when behind the wheel on the freeway. Don't take for granted that everything works well. You have opportunities to catch errors — or help your providers do so — on just about every visit, and so need to be alert during every visit.

And right now, I'd encourage every patient to check your healthcare portal. New federal rules effective April 5, 2021 require hospitals to provide much more information about physician progress notes, medical test results and other information at "no charge' and 'without delay." That means there very well could be errors that you can catch.

CAPS: What would you recommend to health care systems to improve quality and safety?

Marty: Much of what I recommend was built into the Partnership for Patients campaign, which implemented **Five PFE Metrics** (see graphic). Patients and their caregivers need to be listened to at the point of care, included in improvement work, and heard at the governance level where priorities are set, and organizational actions and culture is overseen. A prevailing culture of paternalism in medicine – working for you but not with you – can be transformed by bringing patients into a more prominent role in the health care organization.

Also, don't hide your errors. Growing experience with CANDOR increasingly shows that being honest doesn't increase liability



<u>exposure</u>, in fact it's reduced. Towards that end, knock off the gag clauses in your settlement negotiations! Other providers get the chance to learn from your failures when transparency happens.

CAPS: What are your future plans?

Marty: At 66 I'm older than my Dad was when he died, and feel like I'm living on borrowed time. In my time left, I'll focus on promoting patient and family engagement, transparency and getting a national patient safety agency established in the U.S., so that some agency is actually tasked with ensuring patient safety. No body is in charge currently, and distributed accountability between the federal government, States, accreditors and private organizations has failed, plain and simple.

Things that excite me now are the Canadian Patient Safety Institute's <u>Conquer Silence</u> campaign, proposals from the <u>Jewish Healthcare Foundation</u> and the <u>Patient Safety Movement Foundation (PSMF)</u> to establish a federal patient safety agency, and a new <u>Global Patient Safety Action Plan from WHO that we expect to be approved in May</u>. PSMF also is walking the talk on patient and family engagement, building <u>Actionable Patient Safety Solutions</u> around real patient

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experiences. I have an appointment with the <u>MedStar Institute for Quality and Safety</u>, which is integrating patient and family advisors into its High Reliability Organization journey, and am working with the <u>Leapfrog Group</u> to actualize the full potential of a Patient and Family Technical Expert Panel established last year to help evaluate hospitals and surgicenters on their safety performance. I'll also continue to work on getting users of care onto hospital boards, working with H2Pi to build more Patient and Family Advisory Councils for Quality and Safety®, and implementing CANDOR for hospital systems ready to systemically embrace transparency, continuous learning and fair compensation when medical errors happen.

Finally, despite the Covid pandemic I helped the PSMF organize the <u>first patient safety march on Washington last year on September 17th</u>, World Patient Safety Day. We had just 25 walkers, and I'd love to see that drastically expanded this year and going forward. As of 2016, more people worldwide die now from poor quality or unsafe healthcare than from <u>lack of access to care</u>. As the pandemic makes clear, it's way past time for patients, family members and dedicated providers to recognize safety in healthcare as a fundamental public health priority, not just a project. I hope I can contribute to that!

CAPS: Thank you, Marty!

Works authored or co-authored by Marty Hatlie include:

- Lessons Learned in a Systems Approach to Engaging Patients and Families in Patient Safety Transformation
- Implementing Communication and Resolution Programs: Lessons Learned from the First 200 Hospitals
- Guide to Improving Patient Safety in Primary Care Settings by Engaging Patients and Families
- Ambulatory Safety: What we Know and Need to Know
- Creating an Accurate Medication List in the Outpatient Setting through a Patient Centered Approach
- What Exactly is Patient Safety?
- The Patient Safety Education Project: An International Collaboration
- The Patient Safety Education Project Participants Handbook
- The Medical Liability Crisis Of 2003: Must We Squander the Chance to Put Patients First?
- We're Not Your Enemy: An Appeal from a Consumer to Re-imagine Tort Reform

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

COVID-19

COVID-19

Patients, Families and Providers

Three Voices, One Conversation

to hit subscribe and notify so you will know when a new, relevant video has been uploaded!

UPDATE: Please check out the videos from the Aging project Richard Scholtz referenced in our <u>December Newsletter</u>. Here is a link to the videos: <u>The Art of Aging — Aging Well Whatcom</u>.

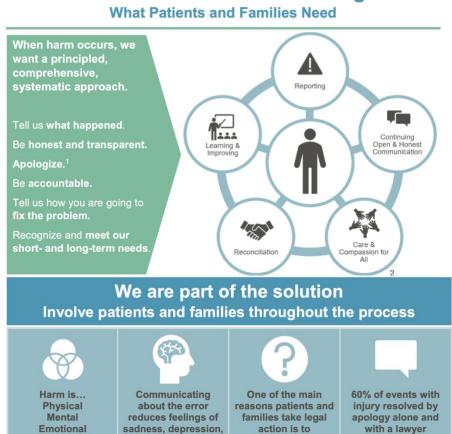


Consumers Advancing Patient Safety often partners with other organizations seeking to improve Quality and Safety. When possible, we support their efforts here:

From Carol Hemmelgarn, MS, MS:

The Collaborative for Accountability and Improvement https://communicationandresolution.org/ created a Patient and Family Advocate Committee focusing on transparency and communication after medical harm. The committee works to educate patients and families about CRP's (Communication Resolution/Reconciliation Programs). Some of the projects this group has worked on are patient/family metrics of CRP's, educational pieces like the infographic below and collaboration with Ariadne Labs on CRP tool design.

Communication & Resolution Programs



Developed by the Patient and Family Advocate Committee The Collaborative for Accountability and Improvement www.communicationandresolution.org

understand what

happened in their

care and why.4

Powell, SK. (2006) When Things Go Wrong: Responding to Adverse Events: A Consensus Statement of the Harvard Hospitals McDonald TB, Helmchen LA, Smith KM, et al. (2010) Responding to patient safety incidents: the "seven pillars". Prentice, UC, Bell, SK, Thomas, EJ, et al. (2020). Association of open communication and the emotional and behavioral impact. Vincent, C., Phillips, A., Young, M. (1994). Why do people sue doctors?

Le Craw, FR, Montanera, D, Jackson, JP, et al. (2018). Changes in liability claims, costs, and resolution times

abandonment or

betrayal.3

Psychological

Financial Spiritual.3

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present.5





Campaign Moves to "Step 2" — Keep Track of Your Medical History and Medications

The popular <u>TakeCHARGE Campaign (5 Steps to Safer Health Care)</u> (https://www.takecharge.care) enters its second month with a new task for everyone who wants to stay safe and enjoy secure medical care. In May the mission is to make and maintain an up-to-date list of medicines you take and to start keeping a personal medical history.

Why does this matter?

Suppose you are taken suddenly ill. An ambulance is called, paramedics arrive, and what's one of the first things they want to know? "What meds are this patient taking?" Many people even post their medicine list on the refrigerator door, so it will always be accessible in an emergency.

A Fuller Picture

What about a medical history? When we are sick or injured, we're not usually thinking at our best. When a doctor or nurse asks you about your problem — what happened, when did it start, what care have you received, what makes it better or worse? — it's very easy to miss out important information. But if you've written all these things down "as they happen" and can show that history to the clinician, the picture is clear. Just as a resumé helps an employer understand your suitability for a job, a personal medical history helps a clinician understand the whole picture of you as a patient. Not only does this history help the healthcare providers, it gives you a truer picture of your own long-term health. The TakeCHARGE Campaign has detailed <u>instructions</u> (https://www.takecharge.care/2-keep-track-of-your-medical-history.html) on its website about how to complete these lists. The TakeCHARGE Campaign has forms and other helpful info at https://www.takecharge.care/how-to-medication-list.html.

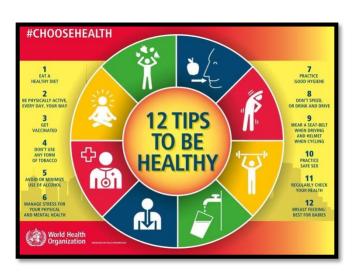
Prompts, tips, memes and videos are also being spread across the Campaign's social media platforms:

Facebook: https://www.facebook.com/groups/takechargecampaign/

Twitter: https://twitter.com/TakechargeC

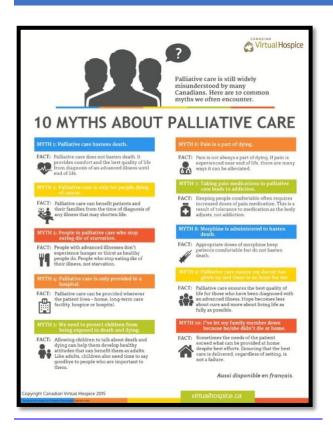
Instagram: https://www.instagram.com/takechargecampaign5steps/ LinkedIn: https://www.linkedin.com/in/takecharge-campaign-5160a31a3/

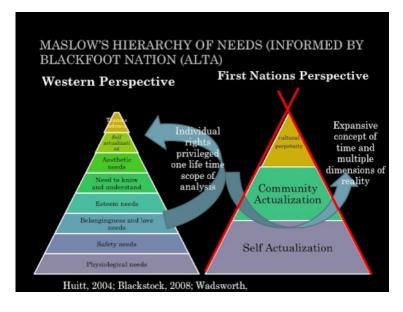
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