Nurturing Resilient Health Ecosystems: What Can We Learn From Patient and Professional Experience?

Cultiver des écosystèmes de santé résilients : que peut-on apprendre de l'expérience des patients et des professionnels?

COMMENTARY

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ABSTRACT

Patients and professionals face important crises through their "normal" experiences of illness and care, which can either prepare them or make them more vulnerable to global crises. What can we learn from these experiences to nurture more resilient health ecosystems? In this commentary, we reflect on resilience in times of crisis,

based on our lived experience as patient and physician. We learned that identifying "who is strong" and "who is vulnerable" can be surprising and unexpected, that patients and professionals can lean on one another at different stages of crises and that resilient health ecosystems require reciprocal, caring relationships at the individual and collective levels.

RÉSUMÉ

Au cours des expériences « normales » de la maladie et des soins, patients comme professionnels font face à des crises majeures qui peuvent les préparer aux crises mondiales… ou les rendre plus vulnérables. Que pouvons-nous apprendre de ces expériences pour cultiver des écosystèmes de santé plus résilients? Dans ce commentaire, nous nous penchons sur la résilience en temps de crise, à partir de notre vécu expérientiel en tant que patiente et médecin. Nous avons appris que la catégorisation des personnes comme étant « fortes » et « vulnérables » s'avère parfois surprenante et inattendue; que les patients et les professionnels peuvent s'épauler mutuellement à différentes étapes des crises; et que les écosystèmes de santé résilients demandent des relations bienveillantes et réciproques, aussi bien à l'échelle individuelle que collective.

Key Takeaways

- While often perceived as "vulnerable," patients often build strong resilience through their experience of health and life challenges.
- While often perceived as "strong," health professionals can be particularly vulnerable to crises, which disturbs their sense of control and puts at the forefront the need to also care for oneself.
- Patients, health professionals and system leaders are all individually vulnerable to crises. A key lever of health ecosystem resilience is our collective capacity to lean on one another, recognize each other's strengths and care with one another, especially when the sea is rough.

Introduction

The COVID-19 pandemic was a "cluster of crises" that disrupted our personal lives, health systems and communities. Although the crises were unprecedented in many ways, they were not entirely unfamiliar for some of us. Indeed, patients and professionals face important crises through their "normal" experiences of illness and care. These events can either prepare them or make them more vulnerable to global crises. What can we learn from these experiences to build more resilient health ecosystems?

In this commentary, we reflect on resilience in times of crisis, based on our lived experience as patient and physician. We learned that identifying "who is strong" and "who is vulnerable" to crises can be surprising and unexpected and that lived experiences of crises can provide important lessons for nurturing resilient health ecosystems. Our stories illustrate many of the key concepts introduced by Kuluski et al. (2024) in this special issue: the critical importance of relationships as a foundation of health and care; the interconnectedness of patients, health professionals, system leaders and community members; and the importance of learning from a crisis from an asset-based perspective (what helped us survive and foster resilience?), rather than a deficit perspective (what was lacking?).

Building Resilience Through Personal Life Crisis: A Patient's Journey

March, 1980, in the emergency room of one of the biggest hospitals in Montreal, QC

Are you divorced?

Excuse-me?

Answer the question, please.

Well, yes, but …

I knew it! You women are all the same. You cannot handle stress so you need to blame it on someone or something. What happened is that you probably had heavy menstruation. You should be ashamed of yourself to come to the ER, fake pain and take the place of a real patient in need of my care! Go home. Now!

May, 1980, in a trauma centre in the US

I just got remarried and was happy.

I was transported unconscious by helicopter to the centre for the exact same reasons I came to the emergency room (ER) in March. During urgent surgery, they discovered double cancer: ovaries and uterus with metastasis, during which time I had a cardiac arrest. It was followed by months of palliative sedation.

Then the nightmares really started. Who was I? From speaking numerous languages, I went to understanding only one. I did not recognize my own daughter nor anyone. It took me two years of re-education, rehabilitation and re-adaptation to come back to what I am now, more or less.

Why? Because one person, who was supposed to care for me, put his own disrespect for and hatred of women before his oath. That day, my entire life changed forever. Even now I still suffer the consequences of his action, or lack thereof.

I thought often of the other doctor present with me that day. A young resident in the ER in Montreal who was in partnership with me, long before the patient partnership started. He knew and saw the cancer, he wanted me to go to another hospital, he wanted to denounce his boss, but I made him promise me he would not. That man would have destroyed him. I am sure that this resident is a wonderful doctor now, because he was an incredible human being from the start.

This event had an impact on the way I envisioned health professionals for many years to come. I realized then that what makes a "good" doctor is definitely not the years of studies but who he is as a human being: his humility, his respect for others regardless of gender, religion and race and his empathy. In fact, it is his humanity doubled by his scientific knowledge. Without humanity, this doctor became an impostor, a dangerous one for that matter. My trust was shattered. I became more assertive, more demanding as I realized that caring and curing are not a gift but a right. As such I made sure that patients' voices can be heard, especially women's voices.

As a child, I promised myself that I will never be a victim. Never will I behave as such. Instead, I will try to understand what is happening, knowing that from every negative event, positive sprouts. All you need to know is that you have a choice in everything in life. Logically, you cannot accept illness since you cannot refuse it, but you can tame it, learn about it, grow from it and decide once and for all how you are going to live with it. The illness should not dictate how you live. You should choose how you live with it.

I am alone with it, even surrounded by staff, family and friends. No one knows truly what it is that I feel, what my pain is. It belongs to me. It is sacred and it demands respect. If we want to survive and live a decent, healthier life, we need to give ourselves the right to take care of ourselves, before thinking of others around us. Healthy selfishness is a must. Attitude in life is everything. The perception of an event triggers the

outcome. If one behaves like a victim, one becomes a victim. I chose not to and made sure to help my peers ever since. I have this strong personality that helps me deal with life's surprises. But not everyone is the same. I have a huge intellectual curiosity, a huge appetite for life and an enormous love for my fellow human beings. When combining these three ingredients, one becomes so much alive even when we are dying inside a little bit at a time.

Every day, everywhere, people suffer tremendous events, traumas, illnesses, aggressions, and so on. We are truly alone with them. They belong to us and to us only. They are intimate. But if you are lucky like I was, you meet people who will change your path. For that, you have to be open to changes, curious about the unknown and believe in your own destiny. Before "finding" myself, instinctively, I listened to the power of my broken mind and spirit. Later, I believed in faith, that attitude and openness of the mind will bring you to a new path in the acceptance of things you have no power to change. Attitude and recognition of one's limits are key factors in your survival. I had the great privilege to encounter and trust some incredible persons who took the time to rebuild me, to truly care and to teach me how to be a human being again. It took two long years.

Having learned from previous life experiences, refusing as always to be a victim, when the COVID-19 pandemic halted the world, I was somehow prepared mentally and emotionally; no panic, no anxiety and no fear. I had no power in controlling it, but I had the power to be part of the solution by following what was required of me, of each one of us. I immersed myself into survival mode – action, reflection, respect and learning about it from the right people, not making it a political theme, nor a treaty on liberty. It was about coming to terms with what you cannot change while at the same time, participating in a solution for yourself first and society, second. The COVID-19 pandemic gave me another powerful opportunity of experiencing what resilience is all about: making and living your best life in spite of traumatic experiences and embracing whatever outcomes show.

My approach is one of humility and respect, trying to learn one day at a time what life brings, good or bad; riding the wave of life, not fighting it but truly surfing with it; enjoying the good and learning from the rough moments; and accepting that with every new wave comes great knowledge, satisfaction, pride and joy, until that one day when your final ride will come making you realize that you have done everything with such love and hunger for this wonderful journey that you cannot regret anything. Life, per se, is an incredible gift that we should cherish during and until our last breath.

Attitude and recognition of one's limits are key factors in your survival.

Building resilience through professional crisis: A physician's journey

Ghislaine's contribution to this written dialogue is a humbling story of resilience and survival in the face of struggles and illness, of facing injustice with grace, of turning anger into gifts for others, of focusing on what can become, rather than what has been lost, of hope rather than despair and of resilience in times of crisis. For me, Ghislaine's life is an invitation to flip our professional care narrative on its head, to recognize patients and citizens as the first caregivers in society, as people with power, knowledge and strengths, and to reframe our roles as facilitators rather than saviours.

This cultural shift is easier to write on paper than to enact in daily life. In this second

part, I share my personal physician's perspective on resilience during the pandemic crisis.

When crisis disrupts caring relationships

Throughout my medical training, I was taught that I was "in charge" of patient care: responsible for identifying the problem and finding the solution. I often feel alone in front of "my" patients, projecting a strong outlook on the outside, stethoscope around my neck, "MD" at the end of my name, with the power to prescribe, refer and advise. On the inside, however, I often feel clueless, powerless and uncertain of the nature of the problem and the appropriate course of action.

These feelings of uncertainty are acutely exacerbated in times of personal and global crisis, as they were during the pandemic. Our clinic was shut down and then reopened with everyone isolated, compartmentalized and fragmented. We lost support and contact with each other as we moved to teleconsultation behind closed doors – no more corridor conversation to discuss complex cases, no more chats at the coffee machine to debrief about the emotional toll of care and no more team lunches to laugh, relieve stress and share stories.

Oh yes, we did "replace" all of those interactions with Zoom meetings and an incalculable number of e-mails about changing protocols and guidelines. The *information flow* surged as the *relationship flow* dwindled. Caring relationships were hampered by face masks and team relationships were constrained by social distancing, each eating alone while scrolling on our phones, maintaining two metres of distance between our speechless bodies.

The crisis weakened the social fabric of care at the same time as the pressure for care increased. Patients were scared, isolated at home, uncertain of where to find a trusting ally in an ever-changing system and worried that clinical consultation might carry more harm than good. How can we build trust over the phone? Where is the caring gaze and the reassuring presence on the answering machine and the government website? Crisis not only transformed the *service supply chain*, but affected the *trust supply chain*.

Finally, crises not only affect the *professional* caregiver but the *personal* caregiver as well. When COVID-19 hit, my partner took a full-time job in public health, working over 12 hours a day, for months. Vacations were forbidden by the same policy makers who hailed us as "guardian angels" a few months earlier. Our four children were at home for weeks: no schools, no friends and no parents available because we were too busy caring for others. Our families and friends were scared. Caring for ourselves, caring for our children, caring for our families, caring for our patients and caring for our communities became an unsustainable burden. I was on a high-speed train, *productively* and *effectively* racing into a wall.

Caring for One Another in Times of Crisis

Faced with overwhelming responsibilities, I switched my own paradigm and *let the patient care for the physician*. Ghislaine and I had been working together as colleagues for a few years (Boivin and Rouly 2020): a patient and a physician joining forces to care for others, building a partnership that was strong enough to disclose my own vulnerabilities as a caregiver with her. Ghislaine became the compassionate voice who reminded me that it was okay to draw limits in my own care practice, that I could take a break during weekends, catch my breath, focus on myself and my family and then offer help to others within the limits of my own energy and abilities.

Ghislaine suggested that the first step toward resilience was to become a good caregiver for myself, to put the oxygen mask

on me before trying to save others. This is difficult when your whole life and professional identity is built on the idea of caring rather than being cared for. In my personal life, I started opening my door to the help of others. Our neighbour offered to cook a few meals for our family. Grandparents started offering bedtime stories and daily presence to their grandchildren through videoconference. I started singing and playing the guitar again.

Around the same time, a small group within our clinical team transformed itself into a "mutual support team" through weekly interprofessional meetings to discuss complex cases. Facilitated by our psychologist, these meetings became a *lifeboat*, where we rediscovered the power of caring for one another, of caring with each other. Ghislaine's presence in these meetings was a catalyst for opening up about our own challenges and vulnerabilities as caregivers.

Slowly, this spirit of *caring for one another* extended to other teams in our community. The idea of a patient and a physician joining forces to care with each other gained traction. Ghislaine and I were approached to support a local community health centre in the integration of a peer with lived experience of homelessness (Panaite et al. 2024). Daniel, a wonderful human being with lived experience of homelessness and a strong ability to care for others *and* himself, started working in partnership with the medical director of the clinic. He brought this same spirit of "taking care of each other" as Ghislaine did in our clinic. Shelters were closed – the damages of the virus were compounded by a curfew leaving the homeless without a roof. Daniel landed in a care team that was exhausted. But, like Ghislaine, he had learned the value of caring for himself and to support each other. Rather than throwing himself into the fire, he kept his balance, started cross-country skiing and encouraged his teammates to take a weekend off to sustain their energy throughout this marathon of care.

Finally, we slowly built relationships with a broader ecosystem of community care, nurturing reciprocal relationships with diverse caregivers in our community: Indigenous navigators, harm-reduction peer-support workers, migrants, informal caregivers, community workers and their allies. Ghislaine – slowly and respectfully – brought us together through a circle of care, where we support and learn from each other.

I realized that those of us who appeared the most "vulnerable" – like Ghislaine and Daniel – were in fact the most resilient to this global crisis. Meanwhile, the "strong" healthcare professionals were struggling to maintain personal and professional balance.

Nurturing Resilient Health Ecosystems Through Relationships and Engagement

In reflecting on how to nurture a resilient ecosystem of care, we learned a few things together.

First, we will always feel overwhelmed by crises if we frame healthcare providers as the first, only, "strong" and "invulnerable" caregivers in society. What we have learned from caring together over many years is that patients are not only "vulnerable people in need of care" but also resourceful caregivers who have built knowledge and resilience through personal life crises. Similarly, experienced family members, informal caregivers and community members are not only "visitors" but also "essential care partners" who we can join forces with. As pointed out by Kuluski et al. (2024), engagement is a human endeavour built on relationships among all actors in the healthcare ecosystem. None of us have all the answers. Nobody is invulnerable. We all have good and bad days, and we

are much stronger and resilient when we care together.

Second, we need to recognize our own vulnerabilities as healthcare professionals. The heroic figure of healthcare professionals and "high-performing" institutions is an illusion that masks our inherent fragilities and interdependencies. Resilience also requires spaces to share those vulnerabilities and support each other. Sometimes, it is patients who can support health professionals and system leaders. This is one of the reasons why we need to create space and moments for patient partners to take the lead and share power with them.

Finally, resilient ecosystems have a broad perspective on health that goes beyond service delivery. Caring is relating, trusting and being present for one another. Our personal lives are not detached from our professional lives. Health is intimately connected to the living conditions and social fabric of our communities. Fostering partnership and distributed leadership among patients, community leaders, health professionals and system decision makers are needed. And we need to balance the inherent power that shapes how these relationships evolve.

Resilient ecosystems are caring ecosystems; they are living systems that do not see people as machines and numbers; in these living systems we recognize our mutual strengths and need to care for one another. These strengths, knowledge and relationships are already there. What is most needed is a shift in culture that allows us to see beyond the surface and care with each other.

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