Resilience and Engagement in Crisis: Fostering Trauma-Informed Care and Patient Partnerships Into the Future

Résilience et mobilisation en situation de crise : favoriser les soins tenant compte des traumatismes et les partenariats patients pour l'avenir

COMMENTARY

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ABSTRACT

The COVID-19 pandemic has significantly disrupted patient engagement and exposed long-standing inequities within Canada's healthcare system. As a patient partner and caregiver, the author reflects on the exacerbated challenges during the pandemic, particularly for hardly reached communities and those managing chronic conditions. The crisis highlighted the absence of opportunities for patient partnership, with healthcare organizations halting engagement activities despite an increased need for communication and community involvement. The pandemic underlined the necessity of trauma-informed care and engagement-capable environments (ECE). To address these challenges, the author advocates for integrating trauma-informed practices with ECEs, thereby promoting a healthcare model that is both structurally supportive and

responsive to individual trauma and resilience. By focusing on compassion, recognizing trauma and fostering engagement, such an approach could enhance patient outcomes and create a more adaptive, inclusive healthcare environment.

RÉSUMÉ

La pandémie de COVID-19 a bouleversé l'engagement des patients et exposé des iniquités anciennes au sein du système de santé canadien. Personne patiente partenaire et proche aidante, l'auteurice revient sur les défis exacerbés au cours de la pandémie, en particulier pour les communautés difficiles à atteindre et les personnes atteintes de maladies chroniques. La crise a mis en exergue l'absence d'occasions de partenariats avec les patients, puisque les organismes de santé ont suspendu les activités de mobilisation malgré le besoin accru de communication et de participation de la communauté. La pandémie a fait ressortir le besoin de soins tenant compte des traumatismes et d'environnements propices à la participation. Pour répondre à ces défis, l'auteurice prône l'intégration des pratiques tenant compte des traumatismes aux environnements propices à la participation pour un modèle de soins de santé à la structure solidaire et sensible à la résilience et aux traumatismes individuels. Cette approche privilégiant la compassion, reconnaissant les traumatismes et favorisant la mobilisation pourrait améliorer les résultats cliniques et mener à un environnement de santé plus adaptatif et inclusif.

Key Takeaways

- The COVID-19 pandemic disrupted patient engagement efforts, revealing existing tensions in healthcare systems.
- Healthcare disparities worsened during the pandemic, affecting marginalized communities disproportionately.
- Integrating trauma-informed and resilience-activating practices is crucial for fostering effective patient engagement and partnerships.

Introduction

The COVID-19 pandemic has had a significant impact on patient-engagement efforts, as healthcare organizations were forced to adapt quickly to the crisis and prioritize urgent patient care needs. The pandemic challenged the culture of patient engagement efforts, exposing tensions that exist in creating person-centred policies and practices during times of crisis (Genuis et al. 2022). However, these tensions were not new to patients and caregivers. The COVID-19 pandemic merely emphasized with a big yellow highlighter what most of us already have experienced and continue to experience as patients and caregivers in Canada's healthcare system: a lack of trust, transparency and collaborative decision making, be it at the bedside, the board room and, dare I say, the legislative floor.

Discussion

When I reflect on my own experience as an activated patient partner and caregiver during COVID-19 along with the communities around me and consider the lessons noted by Kuluski et al. (2024), a few things became true: the pandemic exposed and, sometimes exacerbated, inequities in healthcare access and outcomes. These disparities were seen

and experienced in various dimensions, including access to care, outcomes and the broader social determinants of health. Equity-seeking and equity-deserving groups and underserved communities often faced greater barriers to healthcare access and higher rates of COVID-19 infection and mortality. The pandemic had a disproportionate impact on racial and ethnic minority groups, as well as economically disadvantaged populations. We experienced higher rates of infection, hospitalization and mortality.

Patients and caregivers like me with chronic conditions or caring for those with chronic conditions – often more prevalent in equity-deserving communities – faced significant challenges. Disruptions in routine care, fear of accessing healthcare facilities and resource reallocation away from non-COVID-19 care adversely affected the management of conditions such as diabetes, hypertension and cardiovascular diseases.

As a patient partner, my existing partnerships came to an abrupt halt. New opportunities were noticeably absent. In the realm of patient partnerships, we often discuss the importance of having a seat at the table to inform and influence programs, services and systems; however, during the COVID-19 public health crisis, we were not even allowed in the building. Healthcare organizations – some previously recognized as advocates and leaders in patient partnership and engagement – appeared to suspend all partnership activities, both internally and externally. Yet, there was a paradoxical surge in the need for public and community communication. This dichotomy was clear to those of us working and partnering in healthcare. Patients, families, healthcare staff, leaders and the system itself were, and perhaps still are, experiencing and responding to trauma.

Patient partnerships, like many social change initiatives, originated at the grassroots, the community level. Despite the progress made over the past two decades, we – patient partners and caregivers – found ourselves returning to these grassroots to advocate for ourselves and our loved ones. Four to six weeks into the pandemic, a group of us from across Canada, all involved as patient partners and advocates in healthcare and research, self-organized to meet via Zoom. We aimed to connect and check-in, but also to brainstorm ways to underscore the increasing importance of patient and family partnerships during the pandemic. Along with another patient partner active in patient-oriented research, I started a podcast called SPORcast[1]. The series discusses the standard for patient-oriented research and strives to inspire patients, families, clinicians, academics and decision makers to get involved and create their own impact through patient-oriented research, thereby making healthcare research more relevant and meaningful.

As we reflect on how to support the system to engage with populations, we must acknowledge two current realities with respect to trauma[2]. The impact trauma has had on the populations that we want to engage with and that have also experienced the most health inequities, and the impact trauma has had on the healthcare workforce during COVID-19. If we do not acknowledge and address this trauma, we risk creating relationships and environments where people may be re-traumatized and feel unsafe.

When I consider this initial experience of exclusion, isolation and lack of opportunities as an activated patient public partner during the COVID-19 pandemic, I am inclined to explore the relationship between the principles of trauma-informed care, as explicated by Sandra Bloom (Bloom 2005), and the concept of engagement-capable environments (ECE) (Baker et al. 2016), articulated by Baker et al. (2024), particularly with respect to their

implications for patient and public engagement during the COVID-19 pandemic. The current health crisis has exacerbated the need for a resilient healthcare system that can adequately respond to traumatic stress and ensure effective public engagement. This exploration reveals points of convergence and divergence between these two frameworks and discusses strategies to promote and activate resilience in healthcare.

The COVID-19 pandemic has highlighted the critical need for trauma-informed approaches in healthcare systems. Bloom's (2005) trauma-organized systems theory emphasizes understanding the impact of trauma on individuals and institutions. Simultaneously, patient public engagement has emerged as a crucial strategy to foster trust, transparency and collaborative decision making during the pandemic. However, trust is fragile – it is created slowly, and once it is lost, it takes a long time to rebuild (Slovic 1999).

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The healthcare sector's ability, even inability as noted earlier, to engage the public effectively during public health emergencies, such as the COVID-19 pandemic, is pivotal in ensuring community resilience. Bloom's (2005) trauma-organized systems and the concept of ECEs (Baker et al. 2016) may provide critical insights into this engagement process. Bloom's (2005) work focuses on the detrimental impacts of trauma on organizations, arguing for trauma-informed care as an essential element of system resilience. Meanwhile, ECEs aim at facilitating active patient and public involvement in healthcare decisions. ECEs "are created by organizations and networks that build the necessary infrastructure and support the underlying values that encourage an active, ongoing and meaningful engagement of patients and families/caregivers with staff and leaders to collaborate in delivering high-quality care and a respectful and dignified patient experience" (Baker et al. 2016: 20).

Bloom's (2005) work on trauma-organized systems emphasizes the detrimental impacts of chronic, unresolved traumatic stress on both individuals and institutions. COVID-19, with its significant implications for health and life, fits these criteria, with potential for widespread traumatic impacts. The uncertainty, fear and loss associated with the pandemic can lead to what Bloom describes as a "parallel process" (Bloom 2010: 140), where the trauma experienced by individuals is mirrored in the health institutions tasked with addressing the crisis, thereby leading to systems that may inadvertently perpetuate trauma. The lack of family presence policies and practices during the initial wave of the pandemic is a perfect example.

ECEs, on the other hand, are founded on the notion of fostering robust patient-public interactions and enabling individuals to take an active role in their healthcare. The COVID-19 pandemic has highlighted the importance of these environments, as misinformation and fear have frequently impeded public health measures.

Both frameworks recognize the importance of trust, safety and communication in shaping effective healthcare responses. However, while Bloom's (2005) model emphasizes the systemic recognition and healing of trauma, the ECE Framework focuses on enabling engagement/partnerships at all levels of care, along with creating the structure to support said engagement. This

can create potential tension when patients and public members, affected by the trauma of COVID-19, struggle to actively engage in their care or public health measures due to heightened stress and anxiety.

Taking a deeper look into my experiences over the past several decades as an active caregiver and patient partner, tension could occur for a variety of reasons: (1) expectation versus reality – engagement structures often rely on the assumptions that individuals are ready and able to participate. For those affected by trauma, there is a gap between the expected level of engagement and what some may realistically be able to offer; (2) one-size-fits-all approach – structures that do not account for individual differences in the ability to engage can feel alienating to those who are struggling, making them feel as though their experiences and difficulties are not acknowledged; (3) overlooked emotional states – systems that emphasize engagement may inadvertently prioritize operational efficiency or measurable outcomes over the emotional and psychological well-being of individuals, which can exacerbate feelings of stress and detachment; and (4) barrier to access – when engagement is a prerequisite for receiving full benefits from healthcare, those who are unable to engage may not receive the care they need, thus widening health disparities.

To alleviate such tensions, I am suggesting an alternative approach that could focus on trauma-informed practices that are sensitive to the barriers faced by those struggling to engage. This approach would weave trauma awareness into the fabric of engagement structures and ECEs, beginning with recognizing that trauma affects how individuals perceive and interact with healthcare systems. This understanding could inform all aspects of care and engagement efforts, promoting psychological safety by creating an environment where individuals feel safe to express their concerns and participate to the extent that they are able. This may involve facilitating different levels of participation and offering various modes of engagement. Imagine if we trained healthcare workers to approach patients with empathy and self-compassion, recognize the signs of trauma in both themselves and their patients and respond in ways that prioritize wellness and connection.

By focusing on practices rather than rigid structures, healthcare systems can create more adaptive and responsive engagement strategies. This approach acknowledges the reality of trauma's impact on engagement and seeks to build a bridge between the healthcare system and the individuals it serves, fostering a more inclusive and effective healthcare environment.

Healthcare systems worldwide are facing unprecedented challenges, ranging from the impact of infectious diseases to the rising burden of chronic conditions. The concept of resiliency has gained traction in healthcare as an essential factor in managing these challenges effectively. Patient-public engagement plays a pivotal role in building resilient healthcare systems. Engaging patients in the development and evaluation of healthcare policies, programs and services ensures that their unique needs and perspectives are considered. This process also fosters a sense of ownership and trust between patients and healthcare providers, leading to a more patient-centred and resilient healthcare system.

Resilience, in the context of healthcare, refers to the capacity of individuals, healthcare providers and systems to adapt positively to adversity and maintain their well-being. Resiliency is critical to the success of healthcare organizations and the provision of high-quality and safe patient care. I believe there

are two distinct approaches to resiliency in healthcare: (1) building resiliency and (2) activating resiliency.

Building resiliency refers to the proactive steps healthcare organizations take to create a culture and environment that supports resiliency. This approach focuses on developing the skills and resources needed to cope with adversity before it occurs. Building resiliency involves fostering a supportive environment that empowers individuals to cope effectively with stressors, uncertainties and adverse events.

Activating resiliency is a strengths-based approach that focuses on identifying and leveraging individuals' inner resources to enhance their ability to cope with challenges and promote well-being. By recognizing and activating their inherent strengths, individuals can better navigate stressful situations and enhance their resilience (Brown et al. 2010; Werner 2005).

The convergence of activating and building resiliency in healthcare, inspired by the works of Joel Brown and Emma Werner, I believe, represents a transformative approach to healthcare delivery and partnership (Brown et al. 2010; Werner 2005). By integrating and activating resiliency techniques and promoting patient-public engagement, healthcare providers, healthcare leaders and decision makers can enhance patient outcomes, strengthen community well-being and build resilient healthcare systems capable of withstanding future challenges. As the healthcare landscape continues to evolve, the pursuit of resiliency remains a fundamental aspect of ensuring the health and well-being of individuals and populations worldwide.

This brings me back to today and this commentary. I am here as a patient partner – a patient partner who has been navigating our Canadian healthcare system for decades in the pursuit of providing my daughter, Sophia, with compassionate care. Sophia, ultimately and sadly, lost her life to the rare disease that encompassed her little body. In the years that have passed, patient and family partnerships and engagement have evolved. Our understanding and acknowledgment of trauma and resiliency have deepened.

My hope and experience suggest combining ECEs with trauma- and resiliency-informed practices represents a holistic approach to enhancing patient engagement and partnerships within healthcare systems. ECEs prioritize the creation of structures that facilitate active collaboration across various levels of care and partnerships, promoting a culture whereby patients, families and healthcare professionals work in concert. By integrating trauma- and resiliency-informed practices, these environments become attuned to the psychological and emotional needs of individuals, recognizing the pervasive impact of trauma on a person's ability to engage and participate. My hope is this synergistic approach acknowledges that the capacity for engagement is contingent upon a sense of safety, empowerment and trust, which I believe are the core principles of trauma-informed care.

Moreover, resiliency-informed practices contribute to this model by fostering an individual's ability to recover and adapt in the face of adversity, built through supportive, reliable and responsive healthcare relationships and community connections. I know that when I perceive my environment as capable of supporting my engagement and resilient growth, I will be more likely to partake actively and benefit from partnerships aimed at improving those partnerships and, ultimately, health outcomes.

Conclusion

I am encouraged when I consider an integrated model that combines ECEs with trauma- and resiliency-informed practices and how it ensures that healthcare systems are not only structurally prepared to support engagement but are also responsive to complex and nuanced human experiences of trauma and resiliency. I believe such an approach promotes a more inclusive, adaptive and supportive healthcare framework, one that is capable of meeting patients where they are and supporting us in moving toward where we need and wish to be in our healthcare journey. The COVID-19 pandemic was and still is many things to patients and caregivers – I would like to consider the experiences of the past few years both a wake-up call and permission to not just consider but to embody approaches that have the potential to serve patients and families in compassionate and just ways.

Notes

1 www.sporcast.ca.

2 Trauma is a term used to describe the challenging emotional consequences that living through a distressing event, series of events or set of life circumstances can have for an individual, group or community. In simple terms, trauma is any experience that overwhelms a person's or community's capacity to cope (https://www.camh.ca/en/health-info/mental-illness-and-addiction-index/trauma).

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