Beyond the Crisis: Transforming Health Systems Through Community Engagement

Au-delà de la crise : l'engagement communautaire pour transformer les systèmes de santé

THE AUTHORS RESPOND

Kerry Kuluski, MSW, PhD
Dr. Mathias Gysler Research Chair in Patient and Family Centred Care
Institute for Better Health
Trillium Health Partners
Mississauga, ON
Associate Professor
Institute of Health Policy, Management and Evaluation
University of Toronto
Toronto, ON

Carol Fancott, PT, PhD
Director
Patient Safety, Equity, and Engagement
Healthcare Excellence Canada
Toronto, ON

Maggie Keresteci, MA, CHE
Patient Partner and Executive Director
Canadian Association for Health Services and Policy Research
Toronto, ON

Amy Lang,[1] PhD
Executive Director
Patient-Oriented Research
Canadian Institutes of Health Research
Toronto, ON

G. Ross Baker, PhD
Professor Emeritus
Institute of Health Policy, Management and Evaluation
University of Toronto
Toronto, ON

[1] The views expressed herein are solely those of the author and do not necessarily reflect those of the Canadian Institutes of Health Research.

ABSTRACT

How can we effectively partner during crises? How can partnership with communities, patients, caregivers, providers and leaders be sustained and even evolve during difficult times? The opening paper of this special issue (Kuluski et al. 2024) probed these questions. The six response papers in this issue emphasized engagement that moves from partnership with individuals and communities to efforts that are led by communities; trauma-informed approaches at an individual and organizational level; and shed light on the interdependency of culture and leadership. By broadening our engagement efforts with communities, we are more apt to co-produce improvements in care that also address the social determinants of health.

RÉSUMÉ

Comment collaborer efficacement lors d'une crise? Comment maintenir, voire faire progresser les partenariats avec les communautés, les patients, les proches aidants, les prestataires et les leaders pendant les périodes difficiles? Le premier article de ce numéro spécial soulève ces questions (Kuluski et al. 2024). Les six articles de réponse nous encouragent à aller plus loin en soulignant le besoin d'un engagement où les partenariats avec les personnes et les communautés sont remplacés par des efforts menés par ces dernières; en employant des approches tenant compte des traumatismes à l'échelle individuelle et organisationnelle; et en reconnaissant l'interdépendance de la culture et du leadership. Élargir nos efforts d'engagement des communautés, c'est accroître notre capacité à coproduire des améliorations des soins tout en tenant compte des déterminants sociaux de la santé.

Background

Kintsugi, the Japanese art of repairing broken pottery using lacquer, is offered as a metaphor by von Plessen and Batalden (2024) for fragility, setbacks and rebuilding. The COVID-19 pandemic revealed the fragility of our health and social care systems as well as the vulnerability of patient-, caregiver- and community-engagement practices. The insights and experiences shared in this special issue showed us that sustaining and growing engagement practices were possible in some settings by harnessing the collective wisdom of leaders, care providers, healers, patients, families, caregivers and community members, including people experiencing structural marginalization. This was accomplished through bold and consistent leadership to protect and sustain a culture of partnership and reciprocity and by co-designing care delivery models and building new infrastructure. The COVID-19 pandemic exposed personal and system vulnerabilities and propelled us to think, learn and act in different ways. In this closing paper, we offer reflections on the wealth of insights offered by authors in this special edition, which we have distilled in four key takeaways: (1) relationships and partnerships are the precursors for change; (2) trauma- and resiliency-informed practices are the foundation for engagement; (3) community engagement and community leadership are necessary for social change; and (4) culture and leadership are interdependent. To carry through the kintsugi metaphor, we suggest that these takeaways represent the lacquer (the adhesive) to make a system whole.

Relationships and Partnerships Are the Precursors for Change

Principles of engagement, co-design and leadership underline the importance of relationships, building connections with others so that they feel heard, valued and respected. Rouly and Boivin (2024) provide a beautiful example of the deepening and evolution of relationships that dispel tropes that perpetuate patients as *weak and helpless* and physicians as *strong and saviours*. As noted by Boivin, vulnerability and uncertainty lie behind a mask of heroism that we place on providers and healthcare systems (Rouly and Boivin 2024). In their descriptions of roles that they took on for each other through the COVID-19 crisis, we see lived experience as expertise, and vulnerability as strength. The modelling of their relationship extended into their team, encouraging deepening relationships among their team members, who came together to support one another, including those with lived experience.

Similarly, von Plessen and Batalden (2024) draw from new models of quality (Lachman et al. 2021) to emphasize that co-production happens when people come together as "kin" (p. 61) to draw on multiple knowledge systems and challenge themselves and the systems in which they work.

Trauma- and Resiliency-Informed Practices Are the Foundation for Engagement

While Rouly and Boivin (2024) implicitly approach their relationship in ways that are trauma-informed, Pomeroy's (2024) article makes explicit links between trauma- and resiliency-informed practices as foundational to engagement-capable environments, noting the need to understand people – their histories, traumas, triggers and personal needs – to create psychologically safe spaces for engagement. These efforts also require attention to the setting in which engagement takes place and the ways these structures and processes may perpetuate trauma. Pomeroy (2024) cites psychologist Sandra Bloom who defines these "parallel process[es]" (p. 55) as the legacy of trauma and dysfunctional processes within and between organizations that parallel the trauma of people who are seeking care or service (Bloom and Farragher 2010). Bloom (2012) offers the Sanctuary Model to provide practical guidance on how individuals and organizations can deal with difficult situations, understand the depths of trauma and adversity, design a way to communicate about trauma and enhance psychological safety. Parallel processes and the Sanctuary Model signal the importance of workforce wellness, which became heightened through the COVID-19 pandemic.

Trott et al. (2024) from the First Peoples Wellness Circle (FPWC) draw on trauma-informed practices as central to their work as a national, Indigenous-led organization focused on Indigenous wellness priorities and needs across Canada. In their article, Trott et al. (2024) help us to recognize the blurred lines that exist between pillars that are described as "patients" and "healthcare teams" in the Engagement-Capable Environments Framework (Kuluski et al. 2024). As they point out, in Indigenous communities, community members may also be the healthcare providers, and the distinctions between these groups are not well defined. Harnessing the knowledge of communities and Indigenous ways of knowing and being lies at the core of how FPWC does its work, drawing from the collective wisdom of communities to create healthier spaces to live and work – for everyone. Notably, reciprocity is central to how they engage, ensuring that their work is community-led, anti-colonial and trauma-informed, meeting the needs of those who are served.

Without an enabling context and culture, individual efforts for engagement will be difficult, may lose momentum or disappear altogether over time.

Community Engagement and Community Leadership Are Necessary for Social Change

Expanding our thinking into engagement beyond individuals to communities is a consistent theme across these commentaries. Boozary and Keresteci (2024) speak eloquently of the need to centre lived experience perspectives to lead social change and address inequities in care. Boozary describes how a large academic teaching hospital centrally located in a large urban environment has been able to move beyond its walls to develop relationships with communities and community organizations to support the social determinants of health (Boozary and Keresteci 2024). Similar to Rouly and Boivin (2024) (and their work with "caring communities"), Boozary draws attention to those with lived experience in core team roles as peer support workers in the emergency department. This approach offers a supportive model of care to meet people's needs, often diverting people from the emergency room to community supports. Boozary goes on to describe additional initiatives that move beyond traditional medical models to meet the needs of those being served (including food delivery programs and affordable housing built on hospital property). These changes were made in partnership with the community, placing people with lived expertise directly into models of care delivery and redefining how we think about interdisciplinary teams and team membership. Boozary's examples remind us that different types of partnerships, outside the walls of the clinic/hospital, will be needed to address so many drivers of health (Boozary and Keresteci 2024).

Culture and Leadership Are Interdependent

At its core, engagement with patients, caregivers and communities is a fundamental culture change to how decisions are made, how power is shared and how knowledge is recognized and valued. Across all of these commentaries, we see these changes articulated – at the individual level with providers and patients, within communities and across organizations and systems. Baker et al. (2024), in their detailed case of the Holland Bloorview Kids Rehabilitation Hospital (Holland Bloorview), demonstrate how culture and leadership are inextricably intertwined. Over decades of intentional work, Holland Bloorview has built organizational structures and processes (i.e., the visible artifacts) that have become the "fabric" of how they work. While engagement-capable environments articulate the essence of leadership required to embed engagement practices, further work is required to more fully articulate the cultures that enable engagement-capable environments to flourish over time. Leadership and culture provide the enabling environment for other aspects of engagement across health and social care teams, patients, communities and caregiver partners. Without an enabling context and culture, individual efforts for engagement will be difficult, may lose momentum or disappear altogether over time.

The Way Forward

Over the past decade, engagement practices have grown, evolved and been challenged. COVID-19 revealed the fragility of many environments and their engagement practices, and simultaneously shone a light on other engagement practices that we need to continue to grow and nurture. The concept of engagement-capable environments was borne at a time when healthcare organizations were moving from *doing to* and *doing for* to begin *doing with*. While there is continued need to reinforce and strengthen engagement practices

across the continuum, what these authors have helped us see is the ongoing movement required for *doing by*, where individuals and communities can lead the way (Russell and McKnight 2022). The case studies analyzed by Kuluski et al. (2024) provide ongoing insights into elements of engagement-capable environments that need to be considered. The reflections of authors in this series help us advance our thinking and our understanding that the core of engagement is relational work – one that is trauma-informed, resilient and equitable.

As we continue to move beyond the pandemic, it is important to reflect on lessons learned and evolve our practices within the broader environments where we live, work and play, as we are all part of intersecting, complex ecosystems. Cormac Russell's Asset Based Community Development (ABCD) approach (Russell and McKnight 2022) provides an example of how we may deepen our understanding of communities and begin building relationships. The ABCD approach moves us away from a deficit-focused, problem-based orientation to a strengths-based approach that recognizes, celebrates and illuminates local assets within communities. This shift requires deep reflection on how we show up for others in our engagement activities and how this is influenced by our social positions. In addition to strengthening engagement within organizational walls, healthcare organizations need to look to their communities to identify priorities as well as solutions, drawing on the strengths of diverse perspectives. As we advance our thinking on engagement-capable environments beyond organizational walls to ecosystems – perhaps we consider a fourth pillar that points to community and its assets.

As we move toward harnessing the power of communities in our engagement efforts, we share a quote by Indigenous Elder Lilla Watson on allyship, recently referenced in a paper by Nixon (Nixon 2019: 11):

> If you have come here to help me, you are wasting your time. But if you have come because your liberation is bound up with mine, then let us work together.

This quote perfectly encapsulates the growing frontiers of engagement, though arguably, in many contexts, this is not new at all; it aligns with strengths-based approaches in social work practice, community-based participatory methods, equity and anti-oppression frameworks, Indigenous ways of knowing and being and other cultural practices. Moving beyond a traditional medical heuristic, a *new* era of engagement will also challenge our typically narrow view of leadership as being organizationally based. While organizational leadership is critically important in shifting a culture toward engagement, we must ask ourselves: "How do we also shift power to community to advance health and care for all?" We hope this special issue on lessons learned in engagement throughout the pandemic provides ideas, inspiration and perspectives on how we can continue to evolve and grow engagement-capable environments.

References

Baker, G.R., C. Fancott and A. Zarem. 2024. Creating a Sustaining Culture for Patient Engagement. *Healthcare Papers* 22(Special Issue): 28–36. doi:10.12927/hcpol.2024.27370.

Bloom, S.L. 2012. The Sanctuary Model. In C.R. Figley, ed., *Encyclopedia of Trauma: An Interdisciplinary Guide* (pp. 579–82). Sage Publications.

Bloom, S.L. and B. Farragher. 2010. Parallel Processes and Trauma-Organized Systems. In S. Bloom and B. Farragher, eds., *Destroying Sanctuary: The Crisis in Human Service Delivery Systems* (pp. 130–54). Oxford University Press.

Boozary, A. and M. Keresteci. 2024. The Power of Partnership Beyond Social Prescribing. *Healthcare Papers* 22(Special Issue): 37–43. doi:10.12927/hcpol.2024.27369.

Kuluski, K., C. Fancott, M. Keresteci and G.R. Baker. 2024. Patient and Caregiver Engagement in an Era of COVID-19: What Did We Learn and How Do We Move Forward? *Healthcare Papers* 22(Special Issue): 9–26. doi:10.12927/hcpol.2024.27371.

Lachman, P., P. Batalden and K. Vanhaecht. 2021. A Multidimensional Quality Model: An Opportunity for Patients, Their Kin, Healthcare Providers and Professionals to Coproduce Health. *F1000Research* 9: 1140. doi:10.12688/f1000research.26368.3.

Nixon, S.A. 2019. The Coin Model of Privilege and Critical Allyship: Implications for Health. *BMC Public Health* 19(1): 1637. doi:10.1186/s12889-019-7884-9.

Pomeroy, B.C. 2024. Resilience and Engagement in Crisis: Fostering Trauma-Informed Care and Patient Partnerships Into the Future. *Healthcare Papers* 22(Special Issue): 52–58. doi:10.12927/hcpol.2024.27367.

Rouly, G. and A. Boivin. 2024. Nurturing Resilient Health Ecosystems: What Can We Learn From Patient and Professional Experience? *Healthcare Papers* 22(Special Issue): 64–70. doi:10.12927/hcpol.2024.27365.

Russell, C. and J. McKnight. 2022. *The Connected Community: Discovering the Health, Wealth, and Power of Neighborhoods*. Berrett-Koehler Publishers.

Trott, N., B. Carpenter, D. Papadopoulos and B. Restoule. 2024. First Peoples Wellness Circle and the Indigenous Mental Wellness and Trauma-Informed Specialist Workforce During COVID-19. *Healthcare Papers* 22(Special Issue): 44–51. doi:10.12927/hcpol.2024.27368.

von Plessen, C. and P. Batalden. 2024. Meaningful Engagement or Co-Production, or Both? *Healthcare Papers* 22(SP): 59–63. doi:10.12927/hcpol.2024.27366.