Creating a Sustaining Culture for Patient Engagement

Créer une culture d'engagement des patients durable

COMMENTARY

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ABSTRACT

Engagement-capable environments enable strategies and processes supporting patient engagement. However, research using this framework has not fully explored how leaders can help to shape organizational cultures that sustain engagement over

time, even during crises such as the COVID-19 pandemic. Using interviews and documents from the Holland Bloorview Kids Rehabilitation Hospital in Toronto, ON, prior to and after the pandemic, we examine the maturation of their engagement practices and culture to illustrate how a supportive culture developed and shaped their responses to this crisis. Further exploration of such dynamics could inform leaders designing engagement strategies with greater impact and sustainment.

RÉSUMÉ

Les environnements propices à la participation permettent la mise en œuvre de stratégies et de processus favorisant l'engagement des patients. Mais les recherches basées sur ce cadre n'ont pas examiné en détail la façon dont les leaders contribuent à façonner des structures organisationnelles qui pérennisent l'engagement à long terme, même en situation de crise telle que la pandémie de COVID-19. À partir d'entretiens et de documents prépandémiques et postpandémiques de l'Hôpital de réadaptation pour enfants Holland Bloorview à Toronto, en Ontario, nous examinons l'évolution des pratiques d'engagement et de la culture de l'organisme afin d'illustrer l'établissement d'une culture solidaire et la façon dont une telle culture a modelé les réactions à cette crise. Une analyse approfondie de ces dynamiques pourrait guider les leaders concevant des stratégies d'engagement aux retombées et au potentiel de pérennisation encore plus importants.

Key Takeaways

- Many healthcare organizations struggled to sustain patient engagement during the COVID-19 pandemic. Several studies suggest that organizational culture was key to sustaining a mature patient-engagement environment, but this analysis often lacks substantive detail.
- Our case study underlines the critical roles that leaders played in shaping Holland Bloorview's organizational culture, one that valued patient engagement, ensuring that staff were supported in co-designing and collaborating with families and patients, as well as embedding patients and family members into key roles and structures that reinforced the importance of this engagement.
- Leadership support (from both senior leaders and family leaders) for the continued engagement of patients and family during the COVID-19 pandemic succeeded at Holland Bloorview because of the widely accepted values and governing assumptions in their culture that developed over decades.

Introduction

Patient engagement has been identified as a major contributor to high-performing health systems (Carman et al. 2013; WHO 2016). Using a case study of Holland Bloorview Kids Rehabilitation Hospital (Holland Bloorview) in Toronto, ON, we examine the maturation of their engagement practices and their culture, built over decades and nurtured by various leaders. The broad expectations for patient engagement that were created across the organization enabled them to expand and diversify *how* and *with whom* they engaged during the COVID-19 crisis. The insights gained from this case further amplify the work of Kuluski et al. (2024), highlighting the dynamics and linkages of the three pillars of "engagement-capable environments" (Baker et al. 2016: 19–23; Fancott et al. 2018). Specifically, we highlight the significant role for leaders in shifting organizational culture to support the ongoing engagement and impact of clients and families.

Data for this article were gathered from interviews with executives, senior leaders, family leaders and Holland Bloorview staff who supported the programs at the hospital. Data collection began prior to the COVID-19 pandemic, with additional interviews conducted in 2022–23 that focused on the impact that the pandemic had on their engagement practices. We also gathered data from published materials on the hospital- and family-engagement programs.

The Organization and Development of Family-Engagement Roles and Programs

Holland Bloorview provides in-patient and outpatient care to children and youth with a broad range of disabilities, who often require ongoing care for years, with close involvement of family and other informal caregivers. Holland Bloorview was an early adopter of engagement practices, creating one of the first family advisory committees in Canada in the 1980s that gave parents and caregivers a forum to discuss their children's care and offer ideas for improving these services. Holland Bloorview's structures to support child/youth/family engagement have expanded greatly since the first family council, now supported by a Family Leadership Program. This program became the hub for client and family engagement and partnership, with dedicated staff, including family leaders, to advance partnerships in care and across all levels of the organization.

One critical step that has reinforced a philosophy of care essential for engagement has been the addition of a half-day session about client-centred care in new staff orientation, which includes family leaders sharing their lived experiences with new employees and teaching principles of client and family-centred care. One former staff leader noted:

> I think we try to win hearts and minds [of staff] early, so it informs practice from the first moments you enter the door. So, I think that [initial orientation] is a milestone and an important educational practice that creates a baseline across the organization for folks.

Another staff leader underlined this point, saying:

> From the moment of onboarding, one of the first voices you engage with in the new staff orientation is a family leader, taking you through … the basics … and core concepts and practices of client-centred care and partnership, to interview processes where family leader presence is built into quality improvement, etc. So, I think that kind of steady exposure [to patient partnership] is important.

Clients and families are involved across all levels of the hospital: at the direct level of care with wide involvement of families in the care of their children and at organizational levels with the presence of family leaders on decision-making committees across the hospital, including the board and board committees. The Family Leadership Program is placed in the Programs and Services portfolio, resulting in a crucial linkage of engagement with service delivery and clinical care. As one senior leader explained:

> [Client- and family-integrated care] is a corporately embedded set of activities, structures, partnership, but its home is within clinical care. And so far, I think that that's become a really good way of investing in true partnership. So, we're co-designing solutions based on what we elicit and learn from kids and families and staff and have the means to, kind of, put change in action … partnered with operations. I think, here [that] has been very effective.

Holland Bloorview has also invested in family leaders through the Family as Faculty program that prepares family leaders to partner with staff to co-design, deliver and teach in a variety of initiatives across the organization (Ho et al. 2024), an initiative recognized as a leading practice by the Health Standards Organization. The Family Leadership Program continues to grow: in 2023, its 119 family leaders contributed close to 2,700 hours to engagement and partnership initiatives (Holland Bloorview Kids Rehabilitation Hospital 2023). Similarly, Holland Bloorview has also created and supports a Youth Engagement Strategy, with a Youth Advisory Council, Youth Mentorship Program and internal employment opportunities. The youth leaders offer insights from their own experiences to current clients, their families, staff and learners about their care experiences and about preparing for their transition to adult life (Holland Bloorview Kids Rehabilitation Hospital 2023).

In all these ways, Holland Bloorview has been actively building on the three pillars of engagement-capable environments, preparing and enabling partnerships among clients, families and staff. Leaders have demonstrated the value of such engagement efforts, providing the requisite structures and resources for meaningful engagement, and have set expectations for this work.

The COVID-19 Response

The emergence of the COVID-19 pandemic had a dramatic impact on operations at Holland Bloorview, where "family leadership receded dramatically and immediately … even with all of our strengths in family leadership," noted Julia Hanigsberg (Personal interview, October 12, 2023), president and the chief executive officer (CEO) of Holland Bloorview, a reaction paralleling the experience of many organizations across Canada (Tripp et al. 2022). However, this initial response quickly led to the realization that even during an emergency, the voices of family leaders continued to be essential. The near-absence of family leaders in the early days of the pandemic undermined the organization's commitment to client- and family-integrated care in the development of hospital policies and practices to address COVID-19. Hanigsberg described the situation this way:

> We [the members of the COVID-19 pandemic response committee] were … meeting on a probably twice-daily basis at that stage in an extended large committee across the organization, making incredibly important decisions very rapidly and we were making bad decisions [about family presence] because no family leaders were at the table. ... I think the benefit we had … is we have deeply scaffolded foundational family leadership throughout our organization. And so, I think that's why we realized as quickly as we did that we were failing our clients and families because of the want for family leaders at our pandemic response leadership table.

Indeed, it was the *absence* of family leadership in the early weeks of the pandemic that was seen as aberrant. Senior leaders recognized and valued the experience and expertise that family leaders brought to decision-making processes, including those related to family presence and rapid changes made to ambulatory services.

In reaching out to family leaders, Holland Bloorview leaned on the strength of relationships and the trust already built with family leaders over the decades. As the CEO remembered it:

> We went to … family leaders with essentially two requests. One was we needed

> family leaders on this committee, this pandemic response committee. And the second [was that] we needed something that ended up being called "rapid response family leaders." And those were a rotating group of family leaders who would be able to give us feedback on new policies, processes, etc., in six hours, a very rapid turnaround.

How Holland Bloorview navigated through family presence policies is a telling example of the existing foundations for engagement, balancing views seen as risky by some staff who felt that family presence was "putting them in harm's way, and … putting them and their families at risk" at a time where other hospitals were adopting more restrictive policies. But as the CEO later noted, she could not recall any member of the staff who said anything critical about family engagement:

> For sure there were moments of balancing between what staff apprehended as the best approach and what our family leaders advised us. But it never felt like we had to make a choice, and it never felt to me like our staff were saying, "families don't know what they're talking about or we [staff] hold all the expertise." That was never what I was faced with. … I did hear nervousness from some staff saying our family caregiver presence policy [during COVID-19] needs to be built by … tomorrow or we have to pivot this program to become virtual in two weeks [but we were] understanding that family partnership at its best works on its own timeline. We're not going to rush anything, and sacrifice process or respect built into that process. And how do we reconcile that with what was a very rapid environment [required for the] COVID[-19] response?

Recognizing the impact of the COVID-19 pandemic on clients, families and staff, family leaders also volunteered to participate in "experiential rounding" where staff leaders and family leaders visited in-patient and outpatient areas to check in with families and to ask about their experiences. These conversations generated a list of improvements to care and in support of family members, including providing meals for bedside caregivers, creating a business centre so family members could work remotely at the hospital and a grocery-to-go section in the cafeteria to support caregivers in preparing meals and staff who were unable to get to the grocery store because of the work pressures during the early phase of the pandemic.

While their initial response was to dramatically decrease engagement efforts as they focused on the pandemic, as noted earlier, their efforts to quickly re-engage family leaders rebounded and, surprisingly, grew. As the family engagement staff lead noted:

> Ultimately … with certainly some hiccups at the very beginning … we were very proud that at the end of the first year of [the] pandemic, March [2020] to March [2021], there was a 30% increase in partnership initiatives that we were co-creating. [This was] not what we expected, but certainly a positive sign, … a year into the pandemic we [had been] able to rebound and not let some of those engagement structures and processes atrophy.

In addition, like many other organizations, Holland Bloorview transitioned many formerly face-to-face activities to virtual meetings, including the Family Advisory Committee and the Youth Advisory Council, which also signalled their importance to the organization. The transition to virtual

engagement opportunities facilitated broader participation of family and youth leaders who had previously been unable to engage because of other commitments or travel time required to attend. New COVID-19 town halls for family leaders were added to keep them appraised of current actions in the pandemic response and to gather rapid feedback. Family leaders also joined the hospital's working groups to develop virtual care strategies and tools and co-facilitated resource navigation and funding assistance workshops. Concurrently, leaders were also conscious of the *digital divide* and sought solutions to support broader participation.

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Discussion

Kuluski et al. (2024) identified five themes that enabled the sustainment or resumption of patient engagement in the COVID-19 pandemic, but the nature of the context that enabled these organizations to be successful – when many others failed – remains to be specified. The case of Holland Bloorview helps to uncover *how* and *why* they succeeded in their ongoing engagement efforts, shining a light on their organizational culture, nurtured over decades by leaders, staff and family leaders to co-create an environment that was able to support continuing roles and ongoing impact by family and youth leaders, even during times of crisis.

The dominant culture at Holland Bloorview incorporated client and family engagement as "the heart of everything we do" (Holland Bloorview Kids Rehabilitation Hospital n.d.). Engagement occurred across the organization – in clinical settings and across a broad range of management and support functions. The norms, values, structures and processes of client and family engagement were well-developed when the COVID-19 pandemic struck in March 2020, along with long-standing relationships, trust and goodwill between hospital leaders and staff and family leaders. This maturation enabled leaders, staff and family leaders to revitalize and transform the role and impact of family leaders at Holland Bloorview early in the pandemic period. More fundamentally, the sustained experience and intentional efforts to foster client and family engagement had created a foundational culture that supported the roles of clients and families in a range of activities across the organization and spurred a quick reversal when their absence was noted in the early days of the pandemic.

Organizational scholars have explored the role of culture extensively, viewing organizational cultures as socially constructed and serving as "the great stabilizing force that cannot be manipulated with quick fixes" (Schein and Schein 2019: 53). Cultures are resistant to change, incrementally adaptive and continually in flux (Meyerson and Martin 1987), features that can slow desired changes. Many healthcare leaders aim to create and sustain a culture that enables safe and effective care, where patients, clients, care partners and families can fully participate and co-design their interactions with providers and the care environment. Yet leaders often struggle to identify the levers that promote desired long-lasting culture changes, and these efforts are frequently hampered by the continuing impact of professional autonomy, performance pressures and inertia.

Ed Schein, a leading scholar of organizational culture and leadership, argues that organizational culture incorporates three interrelated levels (Schein 1992: 16–27). The first level consists of the *governing assumptions* about the nature of the organization, its relationship to the environment and people's relationships with each other. These, largely invisible, governing assumptions guide everyday thinking and action in the organization. At a more conscious level are the *values and norms* that influence behaviour and can be taken for granted over time. Finally, at the most visible level are the *artifacts*, the physical, behavioural and verbal manifestations of values and norms. Governing assumptions shape the norms and values, which, in turn, influence behaviour and the visible artifacts. At the same time, new behaviours and new norms may shift governing assumptions (Alvesson and Sveningsson 2015; Schein 1984, 1990, 1992).

Over more than 20 years, Holland Bloorview's leaders integrated family leaders into operational, policy and governance roles across the organization, expanding and growing the level and impact of engagement. Staff increasingly saw that family leaders were important partners, both in daily work and in longer-term efforts to improve care experiences. Over time, the engagement of family leaders and the actions of the family and youth leadership programs shifted behaviours and influenced values, norms and the underlying governing assumptions across the organization.

In retrospect, Holland Bloorview's success in sustaining and growing client and family engagement against the pressures to focus solely on the COVID-19 priorities was not surprising. The pivot back to established practices and the incorporation of new practices was led by leaders who supported the continuing presence of family leaders as integral members of the Holland Bloorview team. Family leaders also recognized and voiced the need for their help, and they assumed new roles and responsibilities to support the ever-changing needs of the organization and its clients and families during the pandemic. Leadership support (from both senior leaders and family leaders) for this continued engagement succeeded because of the widely accepted values and governing assumptions developed over two decades that valued lived experience perspectives and expertise. Senior leaders role-modelled the norms and behaviours they expected of others by creating space for family leaders at decision-making tables, creating clear normative expectations across the organization to involve family and youth and creating "artifacts" in structures (e.g., youth and family leadership committees and governance positions) and resources (e.g., staffing, training and orientation) dedicated to engagement activities.

The concept of engagement-capable environments provides a framework for identifying the strategies and processes supporting the implementation of patient engagement. The framework consists of three interrelated key processes that facilitate the formation of authentic relationships between leaders, staff, patients and caregivers in a patient-centred environment (Baker et al. 2016; Fancott et al. 2018). However, not yet fully articulated in the current model of engagement-capable environments is the bedrock of organizational culture that shifts over time to reflect, and then support, the changing norms, values and governing assumptions. Leaders in organizations create structures and processes that bring engagement to life, but continued engagement relies on the transformation of the organizational culture in microsystems and leadership structures to sustain and develop these practices.

The data on the diminished role of patient and caregiver partners in many healthcare organizations during the COVID-19 pandemic suggest that the failure of these organizations to sustain engagement stems from the fragility of their patient engagement efforts and their nascent, underlying organizational engagement cultures (Tripp et al. 2022). Moreover, in times of crisis, organizations may "snap back," reverting to previous ways of working (Kania 2021; Zimmerman 2015). Holland Bloorview illustrates an alternative path where leadership creates new processes and supports new roles and relationships between clients, families and organizational staff. These actions reinforced the tangible value of lived experience perspectives in the work of the organization. In turn, the new roles, relationships and activities influenced new values and new ways of working. At Holland Bloorview, organizational leaders placed family leaders into key roles and helped staff to understand the value of their roles and contributions. As Schein and Schein (2019) note, as an organization ages, "it develops strong beliefs … about what kinds of talent are needed and then recruits only those people. Talent management ... then becomes a subtle process of the culture just re-creating itself" (p. 56). The organizational culture at Holland Bloorview matured over more than 20 years, supporting patient engagement as a fundamental ingredient in excellent client care and experiences and enabling new levels of partnership in care and at organizational and policy levels.

Conclusion

Organizational culture is key to sustainable patient engagement. Creating an organizational culture that is committed to patient engagement in organizational, system or network settings requires persistent leadership and broad involvement by staff, leaders, patients and caregivers learning how to work effectively together. Disruption and disequilibrium can upset established routines and expectations if the leaders, staff and patients are not fully committed to these norms and routines. However, the culture in mature engagement-capable environments enables leaders to formulate strategies and practices that adapt engagement to meet these challenges. Further research to identify how the practices of leaders and staff develop organizational structures and practices that influence the values and norms of organizational culture in different settings will advance knowledge of how to create resilient patient-engagement cultures.

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