Health Quality 5.0: The Global Health Workforce Crisis – First Things First

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Abstract

The future of quality is personal. Health Quality 5.0 moves people-centred, integrated health and social care systems to the forefront of our post-COVID-19 agenda – and that cannot happen without addressing our global workforce crisis. Building back a stronger, healthier workforce is the first of the five big challenges we address in our special series. Starting with the global health workforce crisis is fitting, given it is the most fundamental and formidable barrier to health and quality today. As we put the pieces of the Health Quality 5.0 puzzle together, a picture of a more resilient health system will emerge and a new leadership agenda to get there will take shape.

Introduction

There is no quality of care without a healthy, competent workforce. So, when healthcare leaders and workers worldwide unequivocally concur that we are in the midst of a workforce crisis, we know that addressing it is universally and uniquely urgent. Every one of my recent conversations with health providers, organizational leaders, academics, patients and policy makers across multiple countries has reflected and reinforced that. My survey may not be scientific, but the voices are authentic and the views are rooted in reality.

Commissioned reports by provincial, national and international bodies back this up. Media headlines capture the pervasive and personal consequences of the crisis. Members of the health workforce, weakened by the pandemic and its aftermath, are struggling to do the job they love. That means shift shortages, longer wait times, clinical errors, mistakes in judgement and negative effects on patients. At the same time, when workforce warnings and calls for help go unheeded and harm happens, providers become more distressed psychologically and morally and their trust in leadership wanes. All this makes healthcare practitioners more likely to leave their place of work – or quit their profession entirely.

Two things strike me about this: (1) no one is surprised by where we find ourselves and (2) we keep coming up with the same types of recommendations that we failed to act on in the first place and yet, somehow, we expect different responses. Why is it so hard to make progress? How are we to understand, account for and alter this stasis? Where are the bright lights to beckon us onward? And what, if anything, can leaders do today to help turn things around?

These are some of the questions we set out to address in this second installment of our series, "It is Time for Health Quality 5.0: Are You Ready?" The global health workforce crisis is the first of the five big challenges we examine in this series – a fitting choice, given it is the most fundamental and formidable barrier to health and quality today. In our introductory article, we highlighted a handful of daunting issues facing global leaders today and laid out our case for change: create a new agenda that responds to changing realities and ushers in a new era for health quality (Thompson 2023). The commentary seemed to speak to people, many of whom appreciated the self-declared optimistic bias in looking to the future. Thank you for taking the time to read it and for sharing your feedback and positive comments.

Trying to tackle such complex issues – the workforce crisis, planetary health, equity, co-production and the retreat on quality – is ambitious. It calls for diverse input, big-picture perspectives, prudent leaps of faith and practical problem solving. We could also really benefit from inventive strategies to build on promising initiatives from the past and bring them to fruition. This is not a solo mission; we need teams of teams, partners and new networks to make collective action happen and succeed. Let us get started. Step one is understanding the problem and how it became the crisis it is today.

Understanding the Problem

In 2009, the World Health Organization (WHO) described the serious health workforce shortage as "one of the most critical constraints to the achievement of health and social development goals" (WHO 2009).

For those of us who spent the previous two decades implementing cutbacks and layoffs and *leaning* out a healthcare system that was deemed unaffordable, this was a reckoning. Workforce supply problems had been growing for years; the signs were all there but they went unheeded. The opportunity to tackle the tough issues head on, with an eye to the future, was lost (along with seats in medical and nursing schools). Short-sighted decision making and quick *fixes*, viewed as more valuable, won. The seeds of today's crisis found fertile soil.

Three seminal reports (Kruk et al. 2018; World Health Organization et al. 2018; National Academies of Sciences, Engineering, and Medicine et al. 2018) published about a decade later revealed the consequences of that short-sighted approach, including negative impacts on critical priorities such as patient safety. The reports called for better working conditions, national workforce strategies and updated competency and curriculum requirements. While the authors acknowledged that the recommendations were not new, they warned that failing to act on them would seriously compromise the resilience and sustainability of healthcare systems, putting patient safety more at risk.

Two years later, the COVID-19 pandemic hit and, as we all know, the compounding effect on an already vulnerable system was crushing. The pandemic exposed the fault lines in our health systems and across society. It exacerbated existing workforce challenges and produced new ones with unprecedented levels of risk, including higher threats for increased infection, physical and psychological harm and death. Despite all this, healthcare workers showed up – and then some. That took its toll on the workforce. Over the past several years, workforce retention rates have worsened while early retirements, medical leaves, mental health struggles and suicide rates have increased. The next wave of the crisis is right around the corner. The demand for healthcare workers is projected to rise to 80 million by 2030 (WHO 2016, 2017). The WHO (2016, 2017) also predicts a worldwide shortage of 18 million health workers by 2030, which will result in a shortfall of more than 20% of the people we will need (Britnell 2019; Refsum and Britnell 2023).

The estimated gap is concentrated more in low- and middle-income countries, raising issues related to cross-border recruitment and the migration of healthcare workers to higher-income countries. It appears that it is harder to help when your own house is on fire. The Organisation for Economic Co-operation and Development (OECD) issued yet another call for greater global collaboration and planning to address the workforce crisis in early February 2023 (OECD 2023a).

The heightened attention to "healthcare heroes" (Cox 2020) so evident during the pandemic has now faded, but the challenges facing the health workforce – and the health system that relies on it – clearly have not. The pre-pandemic complacency around health workforce issues has no place in the world today.

So where do we go from here? It's easy to be discouraged, but sitting on the sidelines is unacceptable. Waving our hands and saying, "I told you so," or demanding that other people act is not leadership. Each of us must stand up, step in, try new strategies and test new approaches, and when things do or do not work, learn from that. We keep going until measurable improvements are made – ones that healthcare workers can see and experience in the short and long term. It will be a long journey but as the following sections show, we *are* on the way.

The Challenge: Context

The following points may be patent, but they are pivotal to understanding and resolving the global health workforce crisis:

1. The workforce crisis is global, but we need local solutions that fit the context and capabilities of each country, province or community.
2. This workforce crisis is like no other. The sheer number, size, severity and complexity of the problems mean old solutions are not fit for purpose.
3. The pandemic's impact on the physical and mental health of healthcare providers cannot be underestimated or sustained. This inhibits people from coming to the table to collaborate on solutions. Healthcare workers' trust in the system has been shaken, and the public's confidence is also in steep decline.
4. The healthcare system does not exist in a silo (although it often works in them); it is affected by trends in other industries and world affairs at large. Boundaries between sectors are increasingly blurred, which makes designing solutions for complex, adaptive systems even more complex.
5. Facing facts means having access to data that are timely, relevant and transparent. Without data, we are working in the dark again, destined to repeat historic mistakes.

A recent OECD (2023b) report on lessons learned from the COVID-19 pandemic calls out three major vulnerabilities weakening the resilience of health systems: health systems were unprepared, understaffed and underinvested when the pandemic hit. It will take all healthcare stakeholders working together to identify, design, implement, coordinate and evaluate the investments, interventions, reforms and cultural shifts that the health workforce needs to recover, rebuild and reorient itself toward a rapidly evolving healthcare future. To do that, we will need to be properly prepared, equipped with the right resources, infrastructure, tools and competencies, including leadership skills. With that in mind, I interviewed two leaders with national and international mandates for workforce change – supporting the healthcare workforce through this crisis and strengthening it for the future.

Deborah ("Deb") Gordon is a registered nurse, with years of experience in front-line practice and change leadership, and the recently appointed interim chief executive officer (CEO) of Health Workforce Canada (HWC). The newly created independent agency aims to strengthen health workforce data and long-term planning, working with experts and partners in the field. She shared her early aspirations for the agency and what we could expect to see over the coming months. She has taken on this position with an optimism stemming from the deep respect and confidence she has for the people who – despite the obstacles they face – make healthcare happen every day.

Her message to the members of the healthcare workforce is as follows:

> We know how hard you work and saying thanks is not enough. You need leaders to mobilize to support you in real and influential ways in the work you do. (Deborah Gordon, personal communication, January 16, 2024)

Pedro Delgado, vice-president (VP) of the Institute for Healthcare Improvement (IHI), provided his international insights into what strengthens and weakens the health workforce. Delgado serves as the IHI lead in Europe and Latin America. After hearing him speak at the 2023 International Hospital Federation's (IHF's) 46th World Hospital Congress (IHF 2023), I wanted to explore the tension I saw between his focus on the joy in work and the realities facing healthcare workers today (see "A Conversation with Pedro Delgado").

True to the Health Quality 5.0 era of personalization, both leaders see healthcare as an endeavour that is fundamentally human – or "humane" to use Delgado's word – requiring a people-centred lens for every action and issue. The leaders agree on the need for new leadership competencies (and a renewed emphasis on some old ones), different management styles and more comprehensive health human resource (HHR) planning – efforts that are long overdue. Rather than shying away from difficult issues, they are drawing people together to solve them, focusing on everything from front-line improvements earmarked for early implementation to big-picture policy changes and targeted strategies to achieve better regional and population health outcomes.

Solutions: Where to Look and What to Look for

The health workforce crisis is multi-faceted, international and interconnected. It requires cross-jurisdictional responses, shared resources and efforts that are aligned or, at least, not at cross-purposes. We need interventions targeted to all levels and levers, strategies for every challenge and early and inclusive input into solutions. The answers are not all at hand. The ongoing impact of the pandemic and other unfortunate factors affecting the workforce have made the issues more difficult to resolve, especially by a healthcare community whose energy and resources need replenishing.

The report *Ready for the Next Crisis? Investing in Health System Resilience* (OECD 2023b) lays out six policy recommendations to reduce the risk and impact of future shocks and to strengthen health system resiliency. I like the focus on resilience because it is about future proofing the system. The full report is worth a read. Each policy recommendations is relevant to the way Health Quality 5.0 is taking shape. Addressing all of them would positively impact workforce issues. The recommendations outlined in the report's Executive Summary (OECD 2023b: 16–20) follow:

1. Promote the health of the population: Vulnerable populations make for vulnerable health systems.
2. Promote workforce retention and recruitment: Staff are the key to making systems resilient.
3. Promote data collection and use: Without the right data, decision makers are flying blind.
4. Promote international co-operation: Responses will be better together than alone.
5. Promote supply chain resilience: Getting products and services to where and when they are needed.
6. Promote governance and trust: Without trust, whole-of-society approaches are less effective.

What does this mean for Canada? While we do not yet have a well-articulated action plan and solutions, we do have key elements of these recommendations in motion that can help generate and sustain successful results. While that is cause for some optimism, there is still a long journey ahead.

First, we need a pipeline of healthcare workers well prepared with competency profiles that are fit for purpose in a changing health system. We have many strong institutions with expertise in education, training and curriculum development to ensure that we have a future workforce ready and able to function in current, and changing, work environments.

The CanMEDS Framework (Thoma et al. 2023) – identifying and describing attributes that physicians require to meet the needs of the people they serve – is world-renowned. Competency profiles of other professions are taking similar shape. Accreditation Canada engages with regulators, professional associations and academic institutions while fulfilling its role as the accreditor for post-secondary colleges and university programs for 18 professions. This article is not about the education sector, but we will never meet the demand for high-quality graduates in Canada and beyond, without addressing supply-side issues.

Once students graduate and enter the workforce, we need to ensure that they have the skills to thrive and practise to their full potential. Health workforce shortages have a profound impact on healthcare delivery and on the lives of individuals, which our systems are intended to protect.

We need solutions for the health workforce crisis that are supported by good data (good data, not perfect data). Canada has work to do on that front – which is why we wholeheartedly welcome the HWC and its timely mandate. We need to secure the kind and quality of data that can spur targeted actions to bring the healthcare workforce – in all its diversity – out of crisis. With HWC's work underway, Canada could join other countries presenting national perspectives and putting approaches in place to support local efforts.

HWC's CEO says she considers accessible, understandable baseline data to be an essential starting point for progress and the key to building trust among the many stakeholders instrumental to driving change. The agency is working in partnership with the Canadian Institute for Health Information to release updated HHR data in early 2024 as a foundation for identifying opportunities for change. Stakeholders will be brought together to help interpret the data and identify priorities for action.

This is a positive step – if we do not get caught in a swirl of data analysis while problems persist and grow. Supply and demand data and HHR statistics are useful, but they need to be married with the authentic voice of healthcare workers.

Amplifying and listening to the voices of healthcare workers

Research has established a clear and close association between staff well-being, patient outcomes and an organization's safety culture – an association well supported by several studies. A recent commentary (Kapur 2023) called for a stronger focus on staff well-being in the "NHS 2023 Long Term Workforce Plan," noting that it is needed to avoid negative impacts on recruitment and retention, financial liability and workload.

> If staff well-being is negatively impacted, patient care will suffer as a result and vice-versa. (Kapur 2023: 1911)

The finding is significant, underscoring the value of capturing the voices and views of the healthcare workforce to prompt improvements in workplace safety culture, staff well-being and patient outcomes. We also know from leading Canadian researchers that while safety efforts have increased significantly, safety has not improved (Sauro et al. 2021). We need to tease out the interconnected issues to understand why. Better data on the relationship between the well-being of the workforce and safety in its broadest sense – physical, psychological and cultural – can help.

Health Standards Organization (HSO) and Accreditation Canada have developed a new workforce safety survey that is the only tool that ties worker well-being to safety culture. The HSO Global Workforce Survey (GWS)[1] gathers, evaluates and benchmarks health and social services workforce perceptions on a range of issues, generating meaningful, actionable data for improvement. Findings from the GWS can provide a more precise picture of an organization's health workforce and a better understanding of the views, feelings and needs of healthcare workers.

High participation rates within individual organizations can allow data to be assessed by profession, province/country, type of setting, age of workers and more. HSO looks forward to working with HWC, clients and other partners to capture and amplify the voice of healthcare workers in a way never done before.

Questions from the GWS are being used in a longitudinal evaluation of 150 Canadian hospitals, which is part of a new Canadian Institutes of Health Research study that identifies hospital-level factors impacting patient safety called "HARM Evaluated: Hospital characteristics & Adverse event Rate Measurement" (Parshuram et al. 2023). The GWS questions explore factors associated with safety culture, including safety strategies, staffing, volume and capacity. This instrument was chosen because it is considered the most comprehensive and integrated workforce assessment tool available for worker well-being and safety.

During the early testing phase, more than 10,000 responses were gathered from direct and non-direct care staff, including physicians, across 300 locations that covered most sectors and provinces. Findings indicate high rates of burnout, insufficient time to complete job expectations, lack of positive recognition, limited trust in senior managers/executives and work environments that are not psychologically healthy and safe.

HWC's CEO says that trust makes quality improvement, workforce satisfaction and engagement possible. It would be a serious mistake, she says, and a strategic error to take the focus off the needs of the health workforce and the support and changes they need.

> People say, "Well, it's not about them (health providers)." Well, it is! Unless we have staff and doctors [who] can do their jobs, we have no healthcare. (Deborah Gordon, personal communication, January 16, 2024)

Healthcare workers need to be assured that they can answer truthfully and provide input without backlash for speaking truth to power. Likewise, only opportunities for input that are real, well-designed and respectful of people's time, efforts and ideas will prompt change. Without genuine, informed and actionable engagement with the healthcare workforce, no amount of infrastructure or investment will get to the issues keeping the workforce crisis alive and well. We need that kind of engagement to build trust, which should be a top priority for all health leaders. That trust can open the door to hope – for better workplaces, better health and better systems for all.

With those conditions met, we can uncover thoughts and feelings that explain stalled progress or point out more promising avenues for success. Misconceptions and attitudes can get aired, adjusted and corrected – or simply acknowledged – making it more likely that people will come together to work on resolving the identified problems.

Shaping the leadership agenda

A thorough understanding of the realities and dynamics of the workforce crisis can help build a more resilient health system and better prepare leaders for the future. That may mean monitoring how the workforce is adapting to technological trends or anticipating the need for new competency requirements or new workplace supports. The questions that follow are meant to prompt leaders to think ahead about how they can support and strengthen today's workforce while anticipating the needs of future workforces.

- Do we have quality data to identify and understand who our workforce is, and how they think, feel and perform?
- Are we making it possible for healthcare workers to share their views freely?
- Are we hearing what they say – and heeding it? Every voice matters. Every action we undertake to respond to what we hear matters. To build trust and solve problems together, we must listen, hear and act.
- How do we help leaders strengthen their abilities to handle tough issues fairly and confidently – especially when results are unexpected or unduly negative?
- Are we working inclusively, engaging with everyone who can contribute to improvements in health and care? Are we aware of the barriers to change – and are we addressing them?
- What outcomes and impact do we observe from our organization's focus on workforce well-being and safety culture? What can we learn from others?
- Are we partnering and co-creating solutions with our own workforce and others? How do we avoid reinventing the wheel?
- Are we helping shape healthcare's future and the healthcare workforce? How?
- Are there new, potentially promising leads that we should pursue but prudently? How do we know if we are solving one problem but creating another?

It helps to be calm, curious and open-minded when answering these questions, as well as genuinely interested in understanding and accepting what we hear. It also takes courage to stay the course when conversations get challenging or emotional. It is easy to become defensive or drawn into political blame games when reviewing the data and sorting through the *why*.

These are not easy issues; we instinctively avoid any possibility of conflict. But when more people commit to discovering what the data really mean to people and engage meaningfully with healthcare workers who know that they are being heard, we can help make change happen. Simple questions can be powerful; do not overcomplicate things. Think about the disarmingly straightforward inquiry that Pedro Delgado (personal communication, December 14, 2023), IHI's VP, puts to a broad range of people working in healthcare organizations: "What are the pebbles in your shoes, and how can I help you get rid of them?"

Conclusion and Next Up: Co-Design/ Co-Production and Health Quality

Good data, combined with objective, independent analysis and transparent sharing of results can provide a solid foundation for meaningful engagement with the people who first raised their voices. Engagement can point to areas for improvement, but it can also build on identified areas of strength. When our words and deeds demonstrate that we value and respect the voices of the workforce, we help make change happen. When we strengthen our support to leaders navigating difficult times and issues, we accelerate the pace of change and sustain its results.

There are many layers wound around the healthcare workforce crisis; we have unpacked only some. Four other drivers of quality are integral to our vision for Health Quality 5.0. The whole notion of co-production, for instance, which depends on the joint engagement of staff and patients, is a natural topic for us to explore next. Like a healthy, competent workforce, co-production is essential for Health Quality 5.0.

Our next article sets out the key components of co-design/co-production, reviewing recent research findings and looking at innovations that are faring well – or faltering – and finding out why. Naturally enough, patient perspectives will be embedded into our examination of the issue.

Meanwhile, we would love to hear from you. Tell us if this article resonated with you or missed the mark; weigh in on our first article's (Thompson 2023) case for change – for Health Quality 5.0; and share your experience with co-design and co-production. Your voice matters. HQ

A CONVERSATION WITH PEDRO DELGADO

Leslee J. Thompson (LT) talks with Pedro Delgado (PD), the vice-president of the Institute for Healthcare Improvement (IHI). The IHI lead in Europe and Latin America, Delgado is based in England and spoke with us from Ireland late in 2023 (the following has been edited for length and clarity).

LT: Reflecting on the realities of health provider burnout – the sheer stress – and the lack of autonomy and other difficulties, one could question whether speaking about joy in work is out of touch. How do you reconcile that and make joy feel real and possible?

PD: That dissonance can create distance as opposed to proximity – exactly what we do not want. People say, "Enjoy work? What are you talking about? Don't call and tell me about joy when I'm barely surviving." So, you're right. ... [With the IHI Framework for Improving Joy in Work] we've opted to bring opportunities to improve health and healthcare into challenging conversations, framing them with a question that pertains to all of us: "So what matters to you?" The question provides a platform to have a conversation about the possibility of improving what matters to them (Perlo et al. 2017).

LT: There is no quality without a healthy, confident and engaged workforce. Does this premise resonate with you?

PD: We talk about quality improvement being a contact sport. It is a humane endeavour, a beautiful privilege. But it is also physically, intellectually and emotionally demanding. We feel empathy and compassion but also tiredness and burnout. For the healthcare workforce to give empathy and compassion and leverage their intellectual power, we all need to be healthy. So, absolutely, there is no healthcare without healthy staff.

LT: People talk about resiliency as a personal and professional characteristic and as the ultimate quest for health systems – resiliency increases your chances of achieving the goals and outcomes associated with quality. How do joy and the healthcare workforce relate to the notion of resiliency?

PD: Joy and resilience are interconnected concepts – both dynamic. We pursue resilience, joy and safety as a daily occurrence and as a daily opportunity. We know our work around resilience and joy will never be done. It is the work of every single day – how we look at each other, speak to each other, demonstrate commitment to each other, how we create psychological safety and so on (Perlo et al. 2017).

LT: HSO has a new instrument for measuring workforce well-being that is tied to the culture of safety. In last year's survey of 10,000 participants from across all sectors of the healthcare system, 25% said that their work area (direct care) is not psychologically healthy and safe. Are these findings about psychological safety common in countries around the world?

PD: Absolutely, I see the same and higher. Psychological safety starts with how we train healthcare professionals. Our education systems invite us to either pass or fail, be either right or wrong, to live in the black or the white. [With] healthcare, there is often a grey area and we do not have the answer. It is going to be impossible to find solutions that are scientifically sound and humanely possible unless we listen to the people we serve.

LT: What competencies and capabilities do the workforce and educators of the future need? How do we help the next generation develop them? Can they be hardwired into the curriculum and training to prepare people appropriately for the future? Are there things we can do on that front?

PD: Yes, 100%. There are three or four things I would highlight. Start early; include humility, curiosity, teamwork, psychological safety and so on, early on; and commit to co-production and co-design from the very start. ...

Recognize that we know a lot but don't know it all. Be curious and learn to ask good questions and listen with empathy. Accept that this job, healthcare, is not a superhero's job. It is not about one individual, profession or gender. It is always about teamwork. Commit to co-design and co-production; ingrain it as value. Once the patient becomes an integral part of the conversation, you create a dynamic that is a lot healthier for professionals too.

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Note

[1] The HSO GWS will be launched and available in the fall of 2024.

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The Price of Love: Understanding the Financial and Psychosocial Costs of Caring for Children with Medical Complexities

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Abstract

Parents of children with medical complexities (CMCs) report significant challenges affecting their financial, emotional and social well-being in relation to caring for their child's medical needs. The Complex Care Navigator Program was designed to provide social, emotional and economic support to parents of CMCs. This paper describes the results and outcomes of the program and the challenges experienced during the evaluation process. Overall, results suggest that the program had a positive impact on the parents' psychosocial functioning and social connections. The results demonstrate the importance of providing early screening, psychosocial intervention and peer support.

Introduction

Children with medical complexities (CMCs) have multiple chronic medical conditions with many specialty care teams involved and are fragile and dependent on technology or 24-hour care or supervision in the home (Provincial Council for Maternal and Child Health 2019). Their families experience difficulties above and beyond those directly related to caring for their child's medical condition. They report concerns impacting their economic (e.g., loss of employment, financial stress) (Foster et al. 2021), psychological/emotional (e.g., burnout, anxiety, depression, post-traumatic stress disorder [PTSD]) (Bayer et al. 2021; Rotberg et al. 2020) and social well-being (e.g., social isolation) (DeRigne 2012; Kuo et al. 2011, 2013; Mesman et al. 2013; Pilapil et al. 2017; Thomson et al. 2016). In addition, they frequently experience difficulties learning about and accessing key supports that their children require (Charlton et al. 2017). All these factors impact their ability to thrive.

In this article, we describe the evaluation of the Complex Care Navigator Program, which was developed to help address the pressing needs of parents of CMCs and their impact on the psychosocial well-being of parents. Through consultation with families and literature reviews, goals and types of supports provided by the program were identified. In addition, each of the goals identified by the parents maps onto different social determinants of health (SDoH). A full description of the program, which was developed and implemented in 2015 and provided support to parents until 2020, has previously been published (Krantz et al. 2021).

Methods

Program

The program was designed to support the emotional, economic and social health of parents/care providers of CMCs through three pillars: system navigation, parent navigation (peer support) and knowledge navigation. With partial funding from Employment and Social Development Canada, the program

aimed to serve 150 parents. The team consisted of two social workers (system navigators) and two parents of CMCs with lived experience (parent navigators), complementing an established team of physicians, nurse practitioners and registered nurses who focus on integrating and coordinating community and hospital-based care for these children. The system navigators provided psychosocial support to help families achieve their goals and counselling to address chronic stress and trauma. They led "Caring for the Caregiver" groups and organized local and provincial workshops for health professionals to build capacity to support families. The parent navigators provided peer support to families to decrease social isolation through home visits and get-togethers in the community. They organized health and wellness activities (e.g., PTSD yoga, meditation, sound bath), self-care challenges and inclusive events for the entire family.

Participants

Parents could self-refer or be referred by healthcare providers. The system navigators reviewed each referral and spoke with parents to determine if they met the inclusion criteria. Parents chose the service stream(s) they required (i.e., peer support, system navigation or both) and identified the goals they wished to pursue (documented in Krantz et al. 2021). Parents provided consent for research staff to contact them to participate in program evaluation activities.

We evaluated programming for two groups of participants: those who received direct support from the system navigators and those who only attended activities and group events. The research staff assisted families to complete the evaluation surveys, and families were always given the option not to respond to a question.

Measures

Our health is influenced by many factors, including life experiences, the workplace, the environment and the social and economic conditions of our lives or SDoH. Research shows that the SDoH can be more important than healthcare or lifestyle choices in influencing mental and physical health (Mikkonen and Raphael 2010). Our intake assessments focused on evaluating SDoH using two forms: a demographics form and a participant profile form. Parents completed these forms at intake with a system navigator through a REDCap (web application) link sent by e-mail or with support from research staff by phone. Additional measures listed below were used to evaluate the program:

- The *demographics form* asked about gender, language spoken at home, mother's and father's countries of birth, month and year of arrival in Canada (if not born in Canada) and any cultural or religious information that could help the program meet the overall needs of the participants.
- The *participant profile form* collected information on factors such as education level, employment status and household income. This form was completed at intake and annually or when the families left the program (see Table 1, available online at longwoods.com/content/27257).
- *Outcome Rating Scale (ORS)/Session Rating Scale (SRS)* (Miller and Duncan 2004). The ORS was administered at the start of every session with parents to determine how they were coping on an individual, interpersonal and social level and overall. The SRS was administered at the end of each session to get feedback on how well the session met parents' needs, by having them rate the therapeutic relationship, progress toward goals, topics discussed, appropriateness of the approach or method employed and an overall rating of the session (results from this measure can be found in Appendix 1, available online at longwoods.com/content/27257).
- *Participant experience survey: A* was administered to participants who were being followed by the parent navigator and/or system navigator every six months and asked about the supports received (Table 2). It also asked participants to comment on the strengths of the program and to suggest improvements, which were reported previously (Krantz et al. 2021).
- *Participant experience survey: B* was administered only to participants who were being followed by the system navigators. Participants were asked to rate their experience working toward their specific goals that were identified at intake (Table 2).

Research shows that the [social determinants of health] can be more important than healthcare or lifestyle choices in influencing mental and physical health.

Data analysis

Data were collected between 2016 and 2020, initially in paper form and later through electronic surveys. It was entered in REDCap and analyzed using Excel and Statistical Package for the Social Sciences (SPSS) (version 27, 2020). Most of the data are pre-pandemic, with the exception of some ORS and SRS that were collected between March and October 2020. During the evaluation period, 205 families were enrolled in the program. On average, 48 families met with the system navigators and 42 families interacted with the parent navigators each month. Five families had multiple CMCs.

Demographics form

Demographic information was available for less than 50% (n = 88) of families who took part in the program. The vast majority of the primary caregivers were biological mothers (86.41%; n = 76). English was spoken at home in 77.3% (n = 68) of the families, 17.1% (n = 15) spoke French and 23.9% (n = 21) spoke another language (some spoke more than one language at home). Neither French nor English was spoken at home for 12.5% (n = 11) of the families. The most frequent other language spoken at home was Arabic (11.4%; n = 10).

The majority of the mothers were born in Canada (68.2%; n = 60). On average, the mothers born outside Canada (n = 28) had been here for 9.91 years (SD = 8.71). Their length of time in Canada ranged from one to 33 years, with 37.5% (n = 9) having been in Canada for five years or less. Most fathers (68.3%; n = 56) were born in Canada, and on average, fathers born outside Canada (n = 26) had been in Canada for 9.0 years (SD = 7.4), with eight (42%) being here for less than five years. Details about country of birth can be found in Appendix 1.

Participant profile form

This form was completed for 88 families at intake, and we collected one or more follow-up profiles for 36 participants, with a 41% response rate. The purpose of this analysis was to define the population served and also to compare the baseline (T1) profile with the last (T2) profile completed.

Marital status and education

The marital status, age ranges and education levels of the primary caregivers and their spouses/partners are shown in Table 1. Of the 36 participants with T1 and T2 assessments, three participants who had returned to school or training at baseline completed their studies and three who wanted to return to school had either completed it or were attending school during the post-intervention assessment. This was a highly educated group; 74% of primary caregivers and 79% of spouses/partners had completed college or university.

Employment status

To document the employment status of the primary caregiver and their spouse/partner, parents could endorse all that applied (Table 1). Only 36% (n = 32) of the primary caregivers had some paid employment, while 80.5% (n = 62) of partners/spouses had paid employment at intake. Of the 36 participants with T1 and T2 assessments, at T2, the numbers had improved slightly from T1, with 44.4% (n = 16) of primary caregivers working at least part-time. Of the 27 families who had a second care provider at baseline, 88.9% (n = 24) were employed full-time or self-employed while the others were receiving financial assistance (n = 2) or were on paternal leave (n = 1). At T2, 92.6% (n = 25) were employed full- or part-time or were self-employed.

Household income and financial concerns

The average number of individuals supported by the annual income was 4.2. Family size ranged from two to 10. Forty-one percent of the families had a low income, and 32% were below the poverty line. The proportion of families in each income bracket is shown in Table 1. Only 19 participants had T1 and T2 data on their annual income. While the incomes of 42.1% (n = 8) stayed the same, 26.3% (n = 5) had increased income at T2 and 31.6% (n = 6) had reduced income.

The system navigator assisted families to apply for all funding for which they qualified. Table 1 shows the number of families receiving funds from various organizations to help with expenses related to their child's healthcare needs. Other funding sources included private insurance, the Disability Tax Credit and the Children's Aid Society (https://www.ontario.ca/page/childrens-aid-societies). From the information available for those families with T1 and T2 data, we can see that the proportion of families receiving funding increased over their time with the program.

Even with the funding that they secure from other sources, families spend over and above what they receive to meet their child's healthcare needs. Table 1 shows the extra amount that families spent annually to meet their child's needs. Only 11 participants provided information at both T1 and T2 about their annual extra spending. At T2, the extra spending had stayed the same for 54.6% (n = 6), increased for 18.2% (n = 2) and decreased for 27.3% (n = 3). Many of the families simply did not have extra money to spend.

Most of the families (65.1%; n = 54) reported having financial concerns relating to caring for their child. Only 15 participants responded to financial concerns – related questions at both T1 and T2. At T1, 73.3% (n = 11) had concerns, while at T2, this had decreased to 53.3% (n = 8). The costs associated with special formula, therapy, respite care, accessibility renovations to their home, equipment as the child grows, transportation and rent or mortgage payments were all concerns for the families. Those who were on parental leave did not know how they would manage when they returned to work, and changing work was not possible for some parents because they would lose their extended health coverage.

Housing concerns

The housing situation of 77 parents is shown in Table 1. Of the 28 participants who completed T1 and T2 questions about their type of housing, 28.6% (n = 8) had a change in their housing at follow-up. A larger proportion owned their home at follow-up. One family in a private rental market moved in with their parents and one got subsidized housing. The family that was living in a shelter obtained subsidized housing.

While most homes (79.2%; n = 61) only needed regular maintenance, 20.8% (n = 16) required either major or minor repairs. While 12.8% (n = 10) had already made accessibility

adaptations to their homes, 30.8% (n = 24) needed adaptations to the house to support their child. The most common adaptation was for a stair lift (n = 7), followed by wide doorways (n = 4) and internal ramps (n = 4). For 42.5%, their housing situation presented a difficulty for the child or family. Some of these concerns were around the accessibility of the home; for example, many parents needed to carry their child up and down the stairs multiple times a day if the only bathroom was upstairs or when elevators in apartment buildings were broken. The size of the home was an issue, especially for those with a child who needed a lot of equipment or those with large families. Some rental properties were very poorly maintained, and issues such as mold and leaks were reported.

Transportation concerns

Concerns about transportation were reported by 31% (n = 26) of the families. Twenty-nine participants completed T1 and T2 questions about transportation concerns, and the proportion with concerns decreased from T1 to T2. The concerns included not having a vehicle or not being able to drive, therefore relying on public transportation, which was not always reliable, or taxis, which were too costly for many families. Other concerns were not having an accessible vehicle and needing to take a wheelchair in and out of the trunk and requiring two people to get the child into the vehicle during the trip. Parking expenses for multiple hospital appointments per month were also an issue.

Participant experience survey: A

The survey aimed to evaluate participants' experience in the program. About 73–82% of the families reported receiving support to increase knowledge of, improve access to and make more timely connections to key services and resources. Most (92.6%) had knowledge of the availability of peer support (Table 2). Parents were also invited to comment on the strengths or weaknesses of the program. These comments were used by the team to improve the program or to let the team know that they were appreciated. One participant described the program as "a place to seek resources, a supportive ear that has the experience to understand how living with complex medical issues feels like."

Participant experience survey: B

Parents who received system navigator services to address their goals rated how well the program helped them address the goals that they identified as priorities at intake. Over 70% of the parents rated the assistance provided as good or excellent (Table 2).

TABLE 2.
Participant experience surveys: A and B

Participant experience survey: A	Strongly agree/agree % (n)	Strongly disagree/ disagree % (n)	Not applicable/ do not know % (n)
I received support connecting to key support services/resources for my identified goals.	82.1 (78)	5.3 (5)	12.6 (5)
I have increased knowledge of key services/resources required to support me in achieving my identified goals.	82.1 (78)	8.42 (8)	9.47 (9)
I have experienced improved access to key services/resources required to support me in achieving my identified goals.	76.6 (72)	7.5 (7)	16.0 (15)
I have experienced a timely connection to key services/resources required to support me in achieving my identified goals.	73.7 (70)	8.4 (8)	17.9 (17)
I have knowledge of peer support services offered through the program.	92.6 (88)	3.2 (3)	4.2 (4)

Participant experience survey: B	Excellent % (n)	Good % (n)	Average % (n)	Poor % (n)
Knowledge and access to key supports	47.8 (11)	47.8 (11	4.3 (1)	0 (0)
Expanding one's social support network	38.9 (7)	44.4 (8)	11.1 (2)	5.6 (1)
Coping with stress	27.8 (5)	55.6 (10)	16.7 (3)	0 (0)
Managing day-to-day issues	28.6 (4)	50.0 (7)	14.3 (2)	7.1 (1)
Connecting to peer support	30.0 (3)	60.0 (6)	0 (0)	10 (1)
Strengthening one's relationship health	28.6 (2)	28.6 (2)	42.9 (3)	0 (0)
Creating self-care techniques	22.2 (2)	77.8 (7)	0 (0)	0 (0)
Finding accessible recreation	57.1 (4)	14.3 (1)	28.6 (2)	0 (0)
Achieving employment or education goals	66.7 (2)	0 (0)	33.3 (1)	0 (0)
Other	16.7 (1)	50.0 (3)	16.7 (1)	16.7 (1)

Discussion

Our data demonstrate the positive impact of the program on the families' economic and financial situations. The percentage of families at intake falling into the low-income category was 41% (n = 36). Because we used income brackets rather than the exact amount of annual income, this is likely an underestimation. In contrast, the proportion of families in Canada in the low-income bracket is only 12.3% (Statistics Canada 2020). This was a highly educated group of caregivers, yet a high percentage were in the low-income bracket due to a combination of factors, including high medical expenses, reduced work hours, limited job opportunities, limited social support and inadequate government support. The early intervention provided by the system navigators and parent navigators helped avoid delays and financial strain on parents, improving their knowledge and access to key supports, especially financial support. The process to apply for funding is cumbersome and time consuming. Receiving early intensive resource counselling is necessary to help parents navigate the different systems and to help advocate for simpler access to funding.

Consistent with Foster et al. (2021), our data confirmed that having a child with medical complexities negatively impacts the parents' participation in the workforce, especially for women. While the proportion of mothers in Canada who are not in the labour force is 18.1% (Uppal 2015), 49.3% of the mothers in the program were not working. A similar disparity was also seen with the fathers, with 19.7% not in the labour force, while nationally the rate is 2.9% (Uppal 2015). In addition, in Canadian families with two parents, 50.9% have both parents working, while only 16.9% of the program's families had two parents working. The program addressed this barrier by connecting parents to community resources to find better-suited employment or additional funding to cover extraordinary expenses related to their child's needs.

Parents of CMCs may have limited social support, as their child's condition may make it difficult for them to attend social events or activities. This can lead to feelings of isolation and limit opportunities for networking and job advancement. Being socially isolated is a reality for a great majority of parents. Our program aimed to break this isolation and the results of our surveys validate that families appreciate the informal peer support offered by the parent navigators. The families found that being able to talk with other parents who understand what their lives are like is very important. This component of the program helped the parents stay connected to others, be part of a community of families and relate to others going through similar life events.

Bayer et al. (2021) found that parents of CMCs were at a greater risk of reporting mental health issues than parents of non-complex children with special medical care needs or children without special medical care needs. They also found that parents were less likely to know where to find community resources and more likely to have lower incomes than the other two parent groups. This highlights the importance of the parents connecting with a system navigator as early as possible to receive psychosocial support. The system navigators in the program were trained to offer support to parents with medical trauma on a longer-term basis than other hospital programs. These parents have ongoing psychosocial needs that can also increase over time. Early connections are essential to establish a solid therapeutic relationship and are instrumental, especially when parents are struggling or experiencing a life-or-death crisis.

The COVID-19 pandemic resulted in the program switching to 100% virtual programming and support because these children and families were at greater risk from this disease. We managed to pivot very quickly, and the families appreciated this virtual support. As we move forward, it is evident that a hybrid model would best meet their needs.

Policy makers and leaders should consider early intervention programs and protocols for parents, prioritize training for providers and continue to offer programs and resources that can proactively help families address the financial, social and emotional challenges that they are likely to experience. Having training modules for providers helps raise their awareness of the challenges and provides simple strategies to help support families. Policies should ensure collaboration between health and social/community resources to help promote system integration. Government funding programs should simplify access to much-needed funds as current processes are resource-intensive and very complex to navigate.

As we know that meeting new providers can be a challenge, focusing on continuity of care is important. Program sustainability is also key to ensuring that families can access the supports and services they need.

Limitations

There were many challenges in evaluating this program. Being reliant on temporary funding made it hard to retain staff, which impacted data collection and created uncertainty about the future of the program. At some points, it also impacted program continuity and onboarding of new families. In addition, having families complete the surveys at specific time points was difficult, and this led to a lot of missing data. Families caring for CMCs are very busy and asking them to complete questionnaires can add to their burden.

Conclusion

In conclusion, caring for CMCs can have significant financial and psychosocial impacts on families. The financial burden can be substantial, with expenses related to medical care, equipment and lost income due to caregiving responsibilities.

In addition, the psychosocial impact can be immense, with caregivers often experiencing elevated levels of stress, anxiety and depression.

Despite the challenges that come with caring for CMCs, there are also many rewards. Parents/care providers often report a strong sense of purpose and fulfillment and the opportunity to develop close bonds with their child. Programs such as ours demonstrate the importance of early screening of parents and providing adequate support to ensure that they have the tools to cope with the challenges they will face and to maintain their own physical and mental health.

Efforts to improve the financial and psychosocial well-being of families caring for CMCs must involve a multi-faceted approach. This includes peer connections, providing early financial assistance and offering support services to address the emotional needs of parents/care providers. By taking a holistic approach, we can help alleviate some of the challenges that they face and improve their overall well-being. HQ

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