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BCMJ
A Doctors of BC Publication

Taking serious illness conversations seriously:

Unveiling South Asian perspectives on advance care planning using the *Serious Illness Conversation Guide*

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Original Research: Health outcomes of patients in the Complex Chronic Diseases Program

Premise: The United Nations Convention on the Rights of the Child in Vancouver’s inner city

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New approaches and research are urgently needed to improve therapeutic interventions for patients with complex chronic diseases. "Health outcomes of patients in the Complex Chronic Diseases Program" begins on page 174.

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ON THE COVER

Two incense sticks rest on a traditional pooja tray with their smoke forming a South Asian tree of life. Culture and tradition contribute to health care–related decisions for South Asian community members. Clinicians should consider acculturation levels and adapt language to improve engagement in serious illness conversations with South Asian Canadians. Article begins on page 166.

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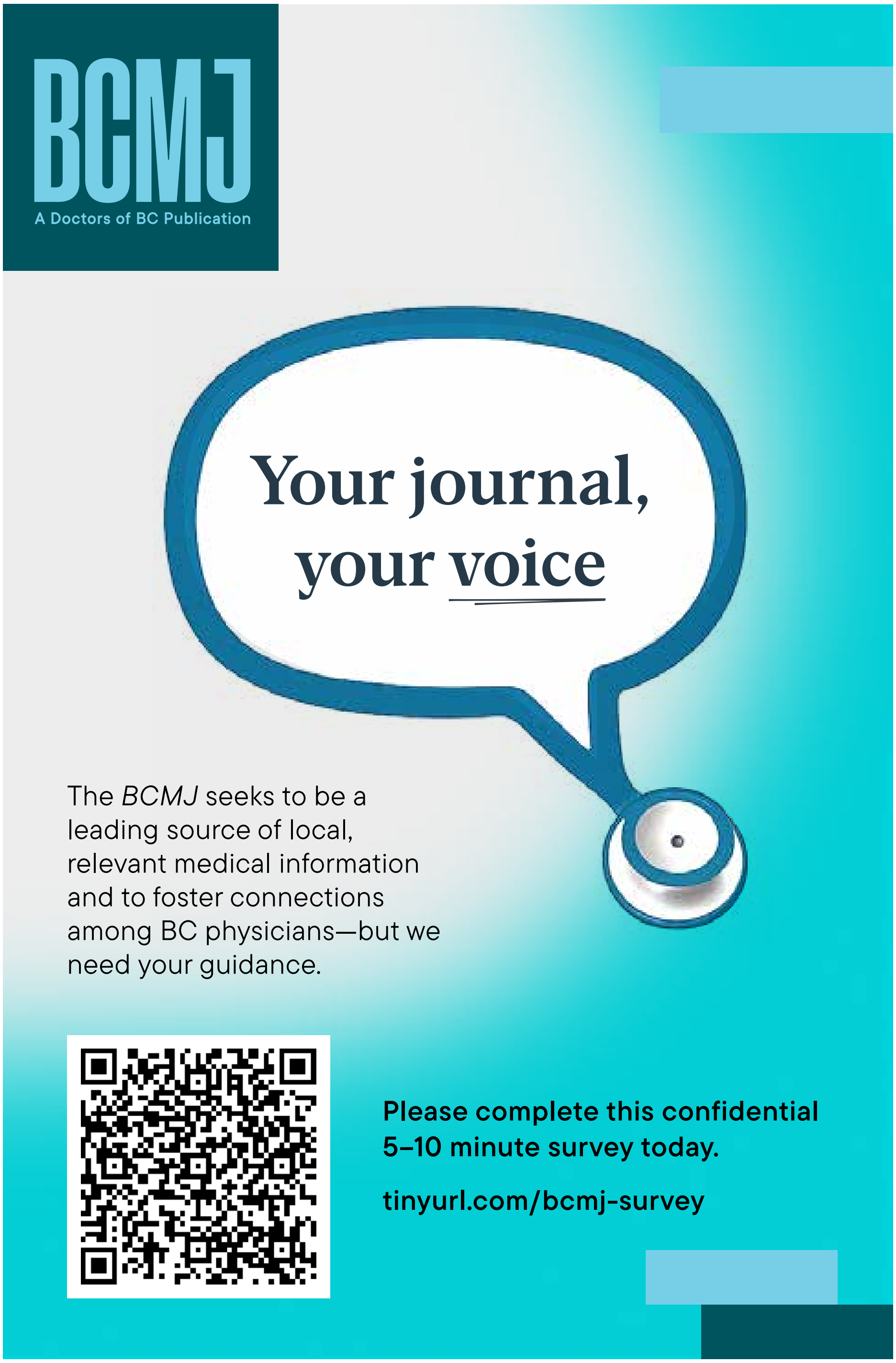

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Celebrating Indigenous culture and heritage

In 1996, the governor general of Canada proclaimed 21 June as the official day to celebrate Indigenous culture and heritage, following calls from the National Indian Brotherhood (now the Assembly of First Nations) in 1982, the Sacred Assembly in 1995, and the Royal Commission on Aboriginal Peoples in 1995.[1] This is a day for Indigenous people and communities to celebrate Indigenous culture and heritage. It aligns with the summer solstice, which holds significance for Indigenous communities across Canada as a time of celebration, gathering, and harvesting. Non-Indigenous people are encouraged to participate in public events, support Indigenous businesses, and build their own cultural awareness and humility.

National Indigenous Peoples Day celebrates three distinct groups: First Nations (both status and nonstatus), Métis, and Inuit. *Indigenous* is used as an umbrella term for these three groups, which have distinct histories, cultures, and spiritual beliefs.[2] *First Nations* replaced the term *Indian*, which is still the legal term for someone registered under the Indian Act and having distinct rights associated with their Nation(s) of origin. Métis people are descendants of distinct communities that developed from the union between First Nations people and Europeans after contact. They developed their own unique language and cultural practices, and Métis people are descendants of these distinct communities. The Inuit are from the Arctic regions of Canada, the US, and Russia (Siberia). They also have a distinct culture and language that have connected them to and allowed them to thrive on their lands, which have some of the harshest conditions on Earth.

In recent years, the importance of understanding who Indigenous people are and who has the right to claim Indigenous heritage has become more important, due to several individuals who have claimed to be Indigenous when they were not. The slang term for people who falsely claim Indigenous heritage is *pretendian*. Mainstream media have picked up many stories of high-profile individuals who falsely claimed to be Indigenous, allowing them to benefit financially, academically, and professionally.[3] Due to Indigenous people being underserved and oppressed for generations, there are many programs and services across the health care, education, and social sectors designed to help reduce barriers for them. Pretendians occupy positions and take resources intended for Indigenous people, which is fraudulent and unethical. Another harm comes from increased mistrust and division among Indigenous people. The increased vigilance to validate people's identity can also cause harm, especially for those who have lost connection due to colonial harms like the Sixties Scoop.

Pretendians threaten Indigenous legitimacy and impose barriers for those reclaiming what was lost. Colonization resulted in a large percentage of Indigenous people dying, with those who remained being forced to relocate from their traditional lands, children being removed from their families, and our culture being outlawed. For many decades, Indigenous people hid their identities to avoid the racism and persecution that were common at that time.

These practices have led to generations of our people being disconnected from who they are as Indigenous people. To compound the issue, the Indian Act is an assimilation policy.[4] It was created to "manage the Indian problem" until there were none left. First Nations people have fought to address many of the systemic biases and sexism built into the Indian Act. Bill C-31 (1985) and Bill C-3 (2011) tried to address the gender discrimination and practices of disenfranchisement due to marriage, for example;[5] however, they also introduced the second-generation cut-off. This meant that when one person entitled to be registered parented with someone *not* entitled to be registered, the third generation was not entitled to registration. In her book *Becoming Kin*, Patty Krawec reviews in detail how colonial policies and laws like the Indian Act are designed to erase Indigenous people because of our inherent rights to what is now known as North America.[6] Our existence is an inconvenience and a threat.[7]

British Columbia has the most First Nations diversity in Canada, with 206 distinct communities, 36 distinct languages, and many more dialects.[8] The 21st of June is a time to celebrate the incredible diversity in BC and across Canada. Developing an understanding of the distinction between the various groups, their beliefs and practices, and their unique rights is an important step in developing cultural awareness and humility. ■

—Terri Aldred, MD

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Is medicine a calling? Or a career?

In today's world, is medicine still a calling, or has it become a career? For some physicians, perhaps it is both. For others, the distinction is blurrier than ever.

In the May issue of the *BCMJ*, in honor of National Physicians' Day, I wrote about Dr Emily Stowe, the first woman in Canada to openly establish a medical practice. She exemplified one version of what it means to follow a true calling. Despite persecution and tremendous personal sacrifice, Dr Stowe was unwavering in her desire to heal people.

I've heard more contemporary stories that echo this sentiment. *BCMJ* readers have shared experiences of caring for multiple generations of the same family, attending patients from birth to end of life, being on call 24/7, and serving as a pillar of the community—the sole physician in a small town.

I once heard a retired colleague reflect that, in his day, medicine wasn't just a job; it was an identity. He would ensure that "Dr" was engraved on his tombstone.

When I chose medicine, I believed I was following my passion. As clichéd as it sounds on medical school applications, I truly wanted to help people. We all do. But over time, experience has shown me that I was both naive and privileged not to have considered what life would look like in my thirties, emerging from 14 years of postsecondary education and training.

I once heard a retired colleague reflect that, in his day, medicine wasn't just a job; it was an identity. He would ensure that "Dr" was engraved on his tombstone.

The notion of medicine as a calling has contributed to a culture where financial discussions are often avoided. Talking about money became taboo, and, as a result, many physicians have had little to no financial education. In my time (*Oh gawd, did I just say that!?*), few medical students graduated with a clear understanding of earning potential across specialties. Practice management and financial literacy were virtually absent from the curriculum.

Today, burnout is widespread. While patient care demands are certainly a factor, other stressors—administrative burdens, overhead costs, regulation, and inadequate remuneration—contribute significantly. Medicine may be a career, but all too often, we're expected to treat it like a calling.

Many *BCMJ* readers have shared how conflicted they feel—torn between their commitment to their patients and the toll the job takes on their own health. The fulfillment that comes from helping others is still a powerful motivator, but it may come at the cost of personal well-being.

Physicians are now increasingly advocating for sustainability: part-time work, remote practice, shared call duties, and reduced administrative burden. These shifts are not about entitlement; they're about longevity. To continue delivering excellent care, the system must evolve to support the people within it. Ultimately, a health care system that values patient care *and* nurtures the passion for medicine will best ensure the calling endures for generations to come. ■

—Caitlin Dunne, MD, FRCSC

CELEBRATING INDIGENOUS CULTURE

Continued from page 157

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Letters to the editor

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Re: The OurCare Standard

Kudos to Drs Mitra, Pham, and Lavergne for promoting long-overdue transformation in Canadian primary care so there can be equitable access for everyone [*BCMJ* 2025;67:109-112]. Their description of the changes in the provision of primary care over the last 50 years is insightful. In this time of scarcity, the solution cannot be more doctors, more nurse practitioners, more nurses, more money, alone. It requires a refinement, selecting appropriate work for the doctor or nurse practitioner, and expansion of the portion of primary care demands being cared for by other members of a robust primary health care team so that patient panels can grow.

—Rick Potter-Cogan, CCFP
Comox

Name change suggested for the College of Physicians and Surgeons of BC

As we review proposed bylaw changes of the College of Physicians and Surgeons of BC (CPSBC) under the 2022 Health Professions and Occupations Act, we might want to reflect on and recommend a new name for the CPSBC that is more congruent with what it has become. Despite its recent rebranding, the word *college* no longer seems to fit.

The *Oxford English Dictionary* defines *college* as "an organized society of persons performing certain common functions and possessing special rights and privileges; a body of colleagues, a guild, fellowship, association."[1]

When I gratefully received my licence to practise in 1987, I was registered as a member of the CPSBC. We are no longer considered *members* but are now *registrants*. Under the new bylaws, we will be referred to as *licensees*.

Ten years ago, the CPSBC stopped supporting the Physician Health Program. In 2022, the CPSBC surveyed its registrants and found that only one in five thought it was trusted, fair, and accessible; only 14% considered it approachable; and only 12% said it was transparent.[2] None of this fits well with "a body of colleagues, a guild, fellowship" or even an "association" to which one would voluntarily belong.

Another definition of *college* is "a society of scholars . . . formed for purposes of study or instruction."[1] Last year, the CPSBC closed its medical library and ceased its services that supported the research and continuing education of its registrants.

Perhaps Doctors of BC can advocate for a name change for the CPSBC that more accurately reflects its evolving function. We have only to look to other jurisdictions, like the United Kingdom or Australia, for inspiration. For example, we could be proud licensees of the new General Medical Council of BC or the BC Medical Licensing Board.

—Eugene R. Leduc, MD
Victoria

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Re: Prescription factors contributing to new long-term opioid use in BC

We appreciate the contribution of Dr Xu and colleagues in their article "Prescription factors contributing to new long-term opioid use in British Columbia between 2013 and 2017."[1] Their work highlights historical prescribing trends and invites dialogue about opioid prescribing and policy in our province.

We offer this letter in the spirit of collaboration, hoping to deepen the conversation around the role of prescribing in the context of BC's complex and evolving toxic drug crisis.

We would like to clarify a few points raised in the article. The introduction references a report that shows a 17.6% national prevalence of long-term opioid use; however, the source cited is referring to the proportion of individuals *already prescribed* opioids who go on to longer-term use.[2] In contrast, the 7.2% prevalence reported in this study refers specifically to opioid-naive patients—an important distinction that could easily be misinterpreted without additional context. In the discussion, these figures appear to be conflated, which may lead readers to overestimate the prevalence of long-term opioid therapy in the broader population.

We also note that the study may have included opioid formulations typically used for cough suppression (e.g., codeine syrups) or opioid agonist therapies (e.g., methadone, buprenorphine). Long-term adherence to medications used in managing opioid use disorder is clinically appropriate and often lifesaving. Clarifying whether these formulations were excluded would help readers better understand the findings, especially in interpreting unexpected prescribing patterns (e.g., among pediatric patients).

We encourage attention to the role of opioids in evidence-based care. Opioids remain a cornerstone of cancer pain and palliative care. In 2022, more than 237 000 people in BC were living with cancer,[3] and many rely on opioids for effective symptom management.[4] Understanding the clinical indications behind prescribing—and how they relate to patient outcomes—is key to evaluating the appropriateness of current practices.

The article references US-based trends in opioid mortality to frame the significance of the findings.[5] We respectfully suggest caution here. While international comparisons can be informative, BC's public health landscape is notably different. Overdose deaths in BC are now overwhelmingly driven by the unregulated drug supply, particularly illicit fentanyl and its analogues. A BC-based study found that nearly 79% of drug toxicity deaths in BC involved nonprescribed fentanyl, while only 2% were linked solely to prescribed opioids without any illegal substances.[6] Contextualizing local prescribing data within this broader public health reality is essential to avoid misdirected policy responses.

Finally, recent BC-based research, including work by Dr Slaunwhite and colleagues,[7] shows that prescribed opioids can reduce mortality among people with opioid use disorder. Prescribing metrics that do not account for clinical context may unintentionally undermine care for patients who already face significant stigma and structural barriers.

We thank the authors for their work and hope these additions help support an even more nuanced and patient-centred conversation about opioid use and policy in British Columbia.

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Authors reply

We thank Drs McCracken, Hawley, Panagiotoglou, Lavergne, and Gomes and Ms Peterson for their thoughtful letter about our article on new long-term opioid use in BC.[1] Our understanding is that they are concerned our study may result in a policy response that would negatively impact patient populations benefiting from prescribed opioids. This was not our intention. We hope our reply to each discussion point will provide clarification. In our article, we aimed primarily to describe the specific BC data we had access to, and we were cautious to provide recommendations given the limitations of our data set.

We presented the prevalence of national long-term opioid use from the Canadian Institute for Health Information in the introduction to provide readers with context about long-term opioid use in Canada.[2] We agree this is a different patient population from the 7.2% of opioid-naive users that became new long-term opioid users within our 4-year study period.[1] Our focus was to determine the BC-specific initial opioid prescription practices, as this has been shown to be a strong predictive factor in ongoing opioid use.[3,4] Initial prescribing practices across the world vary substantially.[5] Opioids, in excess of clinical need, increase the risk of opioid dependency, recreational opioid use, opioid sharing and diversion, accidental overdose, and death.[6]

Our 2025 article was the second of two on this subject, and our methodology section was therefore more succinct, as we referenced our previous, more detailed report from 2021.[7] We used the World Health Organization Collaborating Centre for Drug Statistics Methodology's Anatomical Therapeutic Chemical classification system to create a list of possible opioids.[8] For our study, only the classifications of "opioids" and "drugs used in opioid dependence" were used. "Cough and cold preparations" were excluded.

For our 2025 article, we felt our definition of new long-term users was clear: individuals who were opioid naive (no opioid prescriptions in the 180 days prior to the first opioid prescription) and not initially prescribed methadone or buprenorphine.[1]

In a previous study by Crabtree and colleagues, the authors found that for fatal drug overdoses in BC during the period of 2015–2017, only 2% were associated with a prescribed opioid (within 60 days of death), and another 6.7% were associated with a combination of prescribed and nonprescribed opioids.[9] While this is an important finding, the toxic drug crisis in BC has evolved, with more involvement of other drugs.[10] Moreover, in Gomes and colleagues' analysis of opioid-related deaths between 2013 and 2016 in Ontario, 1 in 3 deaths were associated with an active opioid prescription, and 75% of deaths were associated with an opioid dispensed within the 3 years preceeding death.[11] Although the aforementioned studies differ in how they analyzed opioid prescriptions in association with fatal drug overdoses, it's important to recognize the possibility that opioid users often start their opioid journey with prescription opioids related to an acute injury or illness. Nonetheless, we agree that contextualizing our study data within a local context is key for any policy response.

Dr McCracken and coauthors emphasized the key role that opioids have in patient care, and we completely agree. We were careful not to comment on the appropriateness of long-term opioid therapy, given that we were not permitted access to prescription indication data.[1] Moreover, we did not specifically look at the patient population that would benefit from prescribed opioids for opioid use disorders, as described by Slaunwhite and colleagues.[12]

Despite not having data on indications and outcomes, we were still able to outline prescribing practices. We agree with Dr McCracken and coauthors that the article on its own should not lead to a specific policy response. Rather, we hope that future work will build on this study's findings by incorporating indications, outcomes, and more recent data to better understand opioid prescribing practices.

Thank you again to Dr McCracken and her team for their letter. We also thank the *BCMJ* Editorial Board for providing our team an opportunity to reply.

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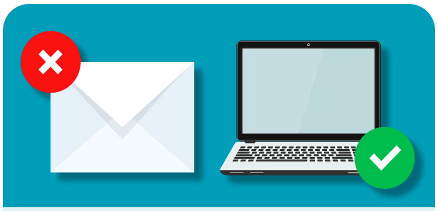

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Maintaining your purpose during transformative times

To every physician on the front line—whether in a bustling urban hospital, in a small community clinic, or on call in a remote village—this is a time of transformation within British Columbia's health care system. Although it is also a time of strain, uncertainty, and fatigue, it's during these transformative times that your voice, resilience, and leadership are more vital than ever.

The past few years have tested our health care system in ways few could have imagined. From the relentless demands of the COVID-19 pandemic to rising patient complexity, staff shortages, and administrative burdens, the toll has been heavy. And just as the crisis began to ease, the system has entered yet another phase of change—this time in structure, leadership, and policy direction. These shifts bring added challenges and disruption and real personal cost.

Change is hard, but we've already seen firsthand the opportunity that lies within it. Telehealth, once a novelty, is now a mainstay, thanks to your adaptability. Integrated care models, like Foundry youth centres and rural primary care networks, work because of your willingness to collaborate, innovate, and lead. Through the years, one thing has remained constant: *you*. Your commitment—continuing to show up, not just as clinicians, but also as leaders. And your resilience—not just pushing through blindly, but also standing firm in your values, adapting when needed, and continuing to advocate for what's right for your patients, your colleagues, and yourself.

Even good change—change that aims to improve care—can create significant emotional and mental strain. You are expected to adapt quickly, stay current, care deeply, and lead calmly, even as the ground beneath your feet keeps shifting. In these times, self-care becomes a clinical responsibility. It enables you to keep going, not just today, but also for the long road ahead. Whether it's taking protected time to recharge, setting boundaries on your workload, or simply talking to someone who understands, these acts of self-care are part of what sustains the healer.

Resilience is not the same as endurance, though. True resilience means knowing when to rest and when to ask for help. It means practising compassion, both for others and for yourself, in a profession that often makes space for everything except one's own well-being. Yet, physician well-being is a foundational part of a sustainable health care system. We cannot talk about improving patient care without also investing in the well-being of those who deliver it.

If we view change not as an enemy but as an opportunity, we can collectively steer through it with compassion and intention.

So, please remember that you are not alone during these times of transition and change. Our medical community is stronger when we lean on one another. Whether it's checking in with a colleague, seeking mentorship, or having an honest conversation with a peer, connection is powerful medicine. So is asking for help. If you are struggling, resources are available. The Physician Health Program, offered through Doctors of BC, provides free, confidential support for physicians, residents, and medical students. From counseling and mental health support to help with burnout, substance use, and navigating life transitions, the Physician Health Program is there for you. You don't have to face it alone.

At the heart of any change, one thing remains steady: our shared commitment to our patients and to one another. This commitment has carried us through crisis and will carry us through transformation.

To all BC physicians, stay rooted in your purpose. Be steadfast in your values, but gentle with yourself. Prioritize self-care. Reach out. Support each other. You are not only navigating change; you are also leading it. We have weathered storms before and have emerged stronger. And while systems change, your purpose does not. That constancy—your dedication to healing, advocating, and improving—has always been the bedrock of our health care system.

If we view change not as an enemy but as an opportunity, we can collectively steer through it with compassion and intention. By staying rooted in our shared goal of better patient care and by giving physicians the voice and support to lead, we can navigate these transitions, not just to survive them, but also to build something better on the other side. ■

—Charlene Lui, MD
Doctors of BC President

The United Nations Convention on the Rights of the Child in Vancouver's inner city

Results from a survey exploring an inner-city community's knowledge of and experience with the United Nations Convention on the Rights of the Child.

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The United Nations Convention on the Rights of the Child

In 1989, the United Nations General Assembly adopted the United Nations Convention on the Rights of the Child (UNCRC) **[Figure 1]**.[1] The UNCRC was informed by previous declarations, including the 1924 Geneva Declaration of the Rights of the Child and the 1959 United Nations Declaration of the Rights of the Child.[1] These early documents were limited in scope, with 5 and 10 articles, respectively, and they did not define the start or end of childhood. The much-expanded 54 articles of the UNCRC outline the rights of all humans under the age of 18, or the age of majority, to fully develop their personalities; assume community responsibilities; and live with equality, dignity, and peace.[1]

The UNCRC is significant because it recognizes children as people with rights who play an active role in their own well-being, as opposed to passive objects in need of adult protection.[2-4] The UNCRC is widely approved, with 196 countries ratifying it.[1] Despite this, the UNCRC does have limitations. It has been criticized for assuming Western ideological notions of childhood as universal, and directly linking UNCRC articles and implementation to indicators of a child's well-being remains controversial.[4,5]

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The UNCRC in Canada

The Canadian government ratified the UNCRC in 1991, with two reservations.[4] The first reservation concerned article 21, which suggested that children might be adopted by caregivers in other countries, potentially limiting their access to their culture, language, and religion (articles 20 and 30). The second reservation pertained to article 37 (detention), because detaining children separately from adults may not always be feasible in the context of the Canadian judicial system. Today, the UNCRC informs areas of Canadian law such as citizenship and divorce; Indigenous law at the federal level; and education, health care, and child welfare at the provincial and territorial level.[4,6]

Canadian delegates played a key role in drafting the UNCRC, and Prime Minister Brian Mulroney co-chaired the subsequent World Summit for Children in 1990; however, Canada still fails to honor the rights of vulnerable children and youth.[6]

The UNCRC in Vancouver's Downtown Eastside and associated inner-city community

In collaboration with Elders and community members, we developed a survey, including a visual summary of the UNCRC and numeric, descriptive, smiley-face Likert scales, to investigate individuals' experiences with knowledge and access to child and youth rights in Vancouver's Downtown Eastside (DTES) and associated inner-city community. The survey was approved by the University of British Columbia Research Ethics Board (UBC REB #H20-00987).

After exploring participants' overall familiarity with the UNCRC, participants were asked to consider access to specific

UNCRC articles: article 6 (potential), article 12 (views), article 23 (disability), article 24 (health), article 28 (access to education), article 29 (aims of education), article 31 (rest, play, and culture), and article 42 (knowledge) **[Table 1]**. Elders and community members chose to highlight these articles in our dialogues due to their significance in the community context.

Between September 2020 and November 2021, we used convenience sampling to recruit 45 DTES and associated inner-city community members to participate in the survey (18 youth, 16 caregivers, and 11 staff members). Participant demographics are included in **Table 2**. Most study participants reported English as their preferred language (84%). Of participants who reported cultural identity (82%), the most prevalent cultural identities were Indigenous (19%) and Canadian (19%); 32% reported multiple identities.

Overall, 72% of youth reported they did not know the UNCRC existed prior to participating in our survey. All participants reported that children and youth of all ages had the most access to rest, play, and culture, and the least access to respect for their opinions and views. Disappointingly, only about half the participants believed that most or all rights outlined in the UNCRC were protected in their community, and almost all reported that the COVID-19 pandemic impacted children and youth's access to those rights. Most reported increased access to one right—rest—during the pandemic, versus decreased access to play, culture, disability, access to education, and aims of education **[Figures 2 and 3]**.

Engaging the voices of children and youth was challenging due to the perception from the academic community that they were too vulnerable to participate or provide informed consent. While protecting children and ensuring age-appropriate engagement is of utmost importance, barriers to engaging young children in a discussion of their rights can disempower this vulnerable group further and violate children's right to have a voice.

FIGURE 1. United Nations Convention on the Rights of the Child poster.

Knowledge is power

Knowledge of rights among children and youth has been linked to better self-advocacy and social well-being.[7-9] A 2017 study asked over 54 000 children in 16 countries about their knowledge of their rights and found that 64% of them did not know about the UNCRC, and only 52% thought adults respected their rights.[8] Knowledge of the UNCRC among youth in our community was lower than in the 2017 study, which is concerning, but not surprising. Education about children's rights is often sporadic or absent, particularly for children experiencing vulnerabilities.[8,10] Clearly identifying knowledge gaps among children and youth with respect to their rights emphasizes the importance of research and education initiatives that engage the voices of children to help communities realize their rights.[2,8,11]

We must continue to engage equity-deserving youth and communities in dialogue about child and youth intersecting rights to bolster education, advocacy, and well-being.

To mobilize learning from our survey results into meaningful action, the survey and research methods developed in this project will be used to foster ongoing dialogue about access to child and youth rights in the DTES and associated inner-city communities and with additional populations, including children and youth with complex health and developmental conditions at BC Children's Hospital.

We call on readers to engage in dialogue about the UNCRC in their communities to help children fully develop their personalities; assume community responsibilities; and live with equality, dignity, and peace. This could include familiarizing yourself with the UNCRC articles, hanging posters featuring the UNCRC in your office or clinic to educate others, and role-modeling respect for children's rights.

Many BC organizations provide resources and opportunities to engage further with human rights. British Columbia's Office of the Human Rights Commissioner has created book club facilitation guides for adult and preschool-aged books and several awareness campaigns for community members.[12,13] The Office of the Representative for Children and Youth has a number of reports, statements, and recommendations that may be incorporated into professional development programs.[14] The Society for Children and Youth of BC has examples of child- and youth-friendly community programs, including walking school buses, where community members volunteer to walk groups of students to school along a predetermined route, contributing to UNCRC articles 24 and 29.[15] In conclusion, we ask you to consider how you would rate your level of familiarity with child and youth rights. ■

TABLE 1. United Nations Convention on the Rights of the Child (UNCRC) articles of interest to Vancouver's Downtown Eastside and associated inner-city communities.

Article	Description (short form)	Rationale for inclusion
6	Children should grow to their greatest potential (potential).	This is a key goal for community and staff members.
12	Children's views should be heard and respected (views).	This is one of the four guiding principles of the UNCRC and has implications for all other articles.
23	Governments should remove obstacles so children with disabilities can enjoy the best possible life in society (disability).	Health promotion for all children, particularly those who are at a disadvantage because of a disability, is a core mandate at the heart of the ambulatory clinic run in partnership with the community, adjacent to the RayCam Co-operative Centre and the Responsive Intersectoral Child and Community Health Education and Research program.
24	Children and adults have the right to the best health care and health information possible (health).	
28	Children should have access to education (access to education).	These rights were identified by community members as being particularly impacted by the COVID-19 pandemic.
29	Education should help children fully develop their personalities, talents, and understanding of others' rights and differences (aims of education).	
31	Every child has the right to rest, play, and cultural activities (rest, play, and culture).	
42	Everyone should know about the rights outlined in the UNCRC (knowledge).	This is a key goal of this dialogue and future studies.

TABLE 2. Survey participant demographics.

Group	Participants (count)	Age (years)			Gender (count)			
		Mean	Min.	Max.	Woman	Man	Other	Not reported
Youth	18	16.4	12	25	9	9	0	0
Caregivers	16	37.5	29	70	7	2	1	1
Staff	11	45.1	29	66	13	1	1	1
Total	45				29	12	2	2

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Competing interests

None declared.

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FIGURE 2. Are child and youth rights being protected? Survey participants (*n* = 45) were asked to rank how well the child and youth rights set out in the United Nations Convention on the Rights of the Child were being protected in their community (5-point Likert scale).

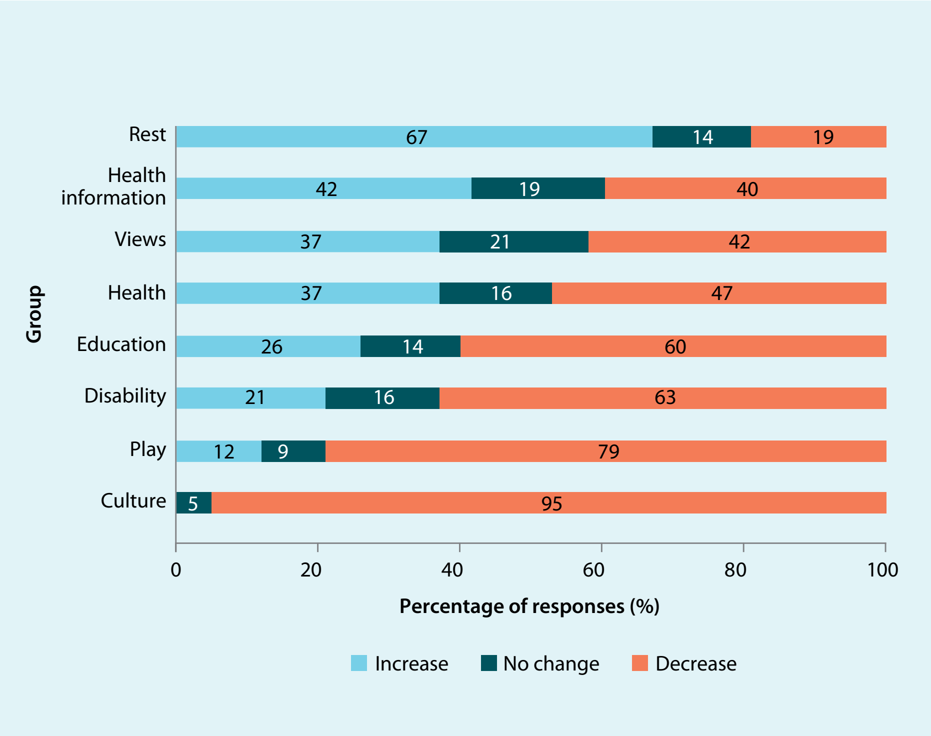

FIGURE 3. Impact of the COVID-19 pandemic and resulting public policy on child and youth rights. Participants (*n* = 45) were asked whether access to particular child and youth rights set out in the United Nations Convention on the Rights of the Child had increased, decreased, or not changed in their community in the context of the COVID-19 pandemic.

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Taking serious illness conversations seriously: Unveiling South Asian perspectives on advance care planning using the *Serious Illness Conversation Guide*

Clinicians should consider acculturation levels and adapt language to improve engagement in advance care planning and advance directives discussions with South Asian Canadians, particularly older adults and new immigrants.

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ABSTRACT

Background: Advance care planning and advance directives help patients define goals of care in case of incapacity or end-of-life situations and thus improve quality of life and reduce unnecessary treatments. The *Serious Illness Conversation Guide* facilitates these discussions, though cultural beliefs influence patients' values and decisions.

Methods: We used a qualitative study to explore the South Asian community's understanding of advance care planning and advance directives using the *Serious Illness Conversation Guide*. Eighteen English-speaking South Asian adults participated in focus groups and a survey.

Results: Participants identified three key themes regarding discussions of advance care planning and advance directives in the South Asian community: generational differences in the willingness to engage in such discussions, the role of family members in making health care decisions, and the power differential between patients and health care providers. Recommendations were made for providing culturally appropriate phrasing in the *Serious Illness Conversation Guide*.

Conclusions: Cultural awareness is needed in advance care planning and advance directives discussions with South Asian Canadians. Clinicians should consider acculturation levels and adapt language to improve engagement, particularly for older adults and new immigrants. Further research should explore strategies for enhancing access to advance care planning and advance directives in diverse communities.

Background

Advance care planning and advance directives involve discussions with patients and their families about their values, goals, and beliefs in advance of incapacity or when faced with end-of-life care. These early discussions in palliative care can improve the patient's quality of life, reduce aggressive interventions, and improve family and caregiver outcomes.[1-3]

Numerous factors, including cultural, social, and personal beliefs, can significantly impact the effectiveness and outcomes of advance care planning and advance directives discussions. Given the deeply personal nature of these conversations, it is crucial to consider the cultural context in which they occur.[4] Culture includes one's beliefs, ideas, and customs that are shared within an individual's community.[4] The importance of cultural knowledge when having these discussions is invaluable due to the sensitive and important nature of advance care planning and advance directives. Cultural influences are particularly significant for communities transitioning to Western countries that have different cultural perspectives, as evidenced in the South Asian diaspora. Conflicts may arise as these individuals try to balance their traditional values with those of their adopted countries, since their cultural influences pervade through multiple generations.[5] Culture also influences how difficult news is processed and how willingly an individual engages with advance care planning and advance directives.[4,6]

In many home countries of the South Asian diaspora, there is minimal exposure to palliative care services.[5] In many South Asian cultures, maintaining harmony in the clinician–family relationship means avoiding direct confrontation, minimizing distress, and preserving the family unit. This often manifests as a reluctance to openly discuss prognosis or end-of-life care, because such conversations may be perceived as disrespectful or as diminishing hope. Instead, decision making tends to be shared among family members, sometimes overriding individual patient autonomy.[4,5,7] In the West, decision making happens through discussions with the health care team and is built upon patient autonomy.[4] In contrast, South Asian communities avoid discussions about illness and death and commonly take a family-based approach to decision making.[8,9] These taboo conversations may result in family members withholding information from the patient, commonly referred to as "family autonomy" in the literature.[10] Some have argued that family autonomy embodies the holistic meaning of autonomy because of its relational nature. This "relational autonomy" identifies and protects a patient's best interests within the South Asian community; it acknowledges an individual's relationships with their family in decision making.[4] Unsurprisingly, the shift toward Western-informed patient-driven care confuses the South Asian diaspora. This confusion stems from the shift in power from the medical team toward the patient and a separation of the individual from the family unit. This is considered a foreign concept since the patient and family are commonly seen as entities within South Asian communities.[5,11]

Understanding these cultural nuances is crucial, especially in the context of integrating Western health care practices with those of the South Asian diaspora. Standardized tools, which include the *Serious Illness Conversation Guide* (SICG), have been developed to facilitate patient-centred discussions when a patient is faced with a serious illness.[6] The SICG is a structured framework developed by Ariadne Labs to support health care providers and patients with serious illnesses in exploring the patient's values and goals and the delivery of medical information.[6] However, while this tool is used in Western health care settings, its effectiveness among diverse cultural groups, such as the South Asian community, remains underexplored. Given that cultural beliefs influence how illness, prognosis, and decision making are approached, there is a need to evaluate whether the SICG's language and structure also benefit South Asian patients and their families.

The South Asian community is the largest visible minority group in Canada, particularly in British Columbia; it comprised 28% of the province's total visible minority population in 2021.[12] With the anticipated increase in demand for palliative care within Canada, it is crucial to provide culturally sensitive and culturally appropriate care to these communities.[13] However, there is limited research on how the SICG is perceived and used within the South Asian community, particularly among English-speaking individuals. We explored how South Asian patients and families understand advance care planning and advance directives in the context of serious illness discussions using the SICG. Our findings will inform strategies for improving advance care planning and advance directives conversations within this community.

Methods

Study design

We recruited English-speaking members of the South Asian community from the Lower Mainland of BC.[8] Participants were 18 years of age or older. Recruitment materials were disseminated through community partners, and subsequent recruitment occurred through chain-sampling recruitment.

For this qualitative study, we used a survey **[Figure S1, available at bcmj.org]** and focus groups to explore participants' understanding of advance care planning and advance directives. The survey included questions about demographics and awareness of advance care planning and advance directives. During the focus groups, participants witnessed a role-play exercise that simulated a conversation between a patient and a physician using the SICG. Facilitators used natural pauses in the SICG to prompt participants to reflect on each question's meaning, clarity, and cultural appropriateness **[Figure S2, available at bcmj.org]**. Participants were then encouraged to suggest alternative wording that might better align with South Asian cultural norms. The discussions were facilitated by using semi-structured questions, which allowed direct responses to SICG content and encouraged open-ended dialogue about broader themes of advance care planning and advance directives. Focus group discussions used prompts from the 2016 SICG **[Figure S3, available at bcmj.org]**, the version used by the research team's health authority at the time of the study.[6]

Data collection and analysis

Qualitative research seeks to understand phenomena through personal experiences.[14] We used interpretive phenomenological analysis to identify themes from interviews and describe how individuals of South Asian heritage approach advance care planning and advance directives discussions using the SICG.[15]

Five focus groups, which were shifted to an online format due to COVID-19 restrictions, were conducted with all researchers present. Sessions were audio-recorded, transcribed, and analyzed using NVivo 12 (Lumivero, formerly QSR International Pty Ltd.).[16] Two researchers of South Asian heritage facilitated and demonstrated the SICG. All four researchers, experienced palliative care clinicians, contributed to the process. Data analysis followed an inductive approach, using a reflexive lens to identify concepts and patterns from participants' perspectives. Field notes and researchers' shared experiences informed the process. Codes were developed based on consensus after thematic saturation, grouped into categories, and later refined into the study's key themes.

The University of British Columbia Research Ethics Board approved this study (H19-02322). Informed consent was obtained from all participants before the study began.

Results

Eighteen individuals participated in the focus groups, but one survey was left blank (n = 17). Most participants were female (76%), were aged 18–50 years (76%), had a university degree (82%), had lived in Canada for at least 10 years (88%), and identified as Hindu (59%) **[Table 1]**. No gender-specific patterns were observed in the data.

Key themes

Participants shared the following themes: the generational differences in the willingness to engage in advance care planning and advance directives discussions; the family structure during discussions; and the power differential between patients and health care providers **[Table 2]**. Quotations that illustrate these themes are attributed using the format (G#-P#), where G# refers to the focus group and P# indicates the participant.

TABLE 1. Demographics of survey respondents.

		Number of participants (%) (*N* = 17)
Country of birth	Canada	5 (29)
	India	4 (24)
	Nepal	4 (24)
	Sri Lanka	2 (12)
	Pakistan	1 (6)
	UK	1 (6)
Time in Canada	< 1 year	0 (0)
	1–5 years	1 (6)
	6–10 years	1 (6)
	11–20 years	6 (35)
	> 20 years	9 (53)
Gender	Male	4 (24)
	Female	13 (76)
Age	18–30	7 (41)
	31–50	6 (35)
	51–65	3 (18)
	> 65	1 (6)
Education completed	High school	3 (18)
	University degree	10 (59)
	Postgraduate degree	4 (24)
Religion	Hinduism	10 (59)
	Sikhism	3 (18)
	Buddhism	2 (12)
	Islam	1 (6)
	Agnostic	1 (6)
Have a will	Yes	0 (0)
	No	17 (100)
Have heard of advance care planning/ advance directives	Yes	12 (71)
	No	5 (29)

TABLE 2. Key themes in advance care planning and advance directives discussions.

Theme 1: Generational differences in the willingness to engage in discussions	
Older generation	• There was a reluctance in the South Asian community to engage in advance care planning and advance directives discussions, especially among older generations. • The elders expected the younger generation to make decisions on their behalf.
Younger generation	• Younger participants understood the importance of advance care planning and advance directives discussions. • They expressed a strong desire to have earlier advance care planning and advance directives discussions.
Theme 2: The family structure during discussions	
Collective strength	• All participants identified family involvement as paramount. Family members in the South Asian community play a major role during decision making. • This approach protects the patient and the rest of the family from unsettling news.
Respecting the hierarchy	• There are challenges commonly associated with younger family members since they are lower in the family hierarchy; they exert minimal influence. • The responsibility for making decisions is usually given to the older family members. • The risk of competing opinions increases in a large family.
Theme 3: Power differential between patients and health care providers	
Older generation and new immigrants	• For older generations and new immigrants, patient empowerment is unfamiliar. • They may not fully understand the approach of patient-centred care within the Canadian health care system.
Younger generation	• They did not perceive a power imbalance between themselves and health care providers. • They acknowledged their autonomy during the decision-making process.

Generational differences in the willingness to engage in discussions. Most participants did not have any direct experience with advance care planning and advance directives discussions. Most of their knowledge stemmed from indirect experiences—for example, previous deaths in the family, family and/or friends dealing with cancer, or family members working in health care. Yet, they knew advance care planning may involve discussions about do-not-resuscitate status and preferences for medical care.

Familiarity with Western health care models affects advance care planning and advance directives discussions. Increased exposure to Western health care perspectives positively correlates with a willingness to engage in these discussions. This was evident with the younger members of our focus groups. They understood the importance of advance care planning and advance directives discussions when making medical decisions, particularly within a Western health care model, and they expressed a desire to have earlier discussions.

Death and dying are taboo subjects in South Asian communities due to the fear that these conversations are disrespectful and remove hope, especially among older generations. One of the participants described this phenomenon as a "cultural veil":

"[There is a reluctance] to admit weakness or difficulty. . . . Personal situations are harder to admit. . . . There is a cultural veil around deeply personal conversations, making advanced care discussions even more difficult." (G2-P3)

The symbol of a veil was corroborated by other participants—a phenomenon that prevents these discussions with healthy family members and delays these conversations until an individual is too ill.

"There is a relationship of respect with elders. . . . Bringing up these topics could be seen as disrespectful or wishing harm. . . . Even thinking about it is considered disrespectful." (G2-P4)

A fatalistic belief was prevalent among our focus group participants, especially in older generations. This belief was described as a predetermined view and is a common reason for delaying or avoiding difficult conversations. "What will be will be" was an accepted rationale for not having these discussions.

"It's beyond human capacity; we shouldn't try. . . . Things will be taken care of as they will." (G2-P3)

"Whatever happens will happen. . . . The Almighty will provide the planning." (G2-P1)

Death and dying are taboo subjects in South Asian communities. . . . "There is a cultural veil around deeply personal conversations, making advanced care discussions even more difficult."

Most participants acknowledged the difference between health care delivery in Canada versus their home country. When referring to their home country—where an individual was born and raised, or their stated ancestral home—participants said that palliative care services were not well established or available. Advance care planning and advance directives discussions are embedded within but are not exclusive to palliative care services. The paucity of palliative care services in their home countries results in a decreased awareness of advance care planning and advance directives in medical care. Hence, these discussions are less likely to occur.

"In my [home] country . . . advanced care planning doesn't exist. . . . Decisions are made by family members." (G2-P3)

Filial piety was a prevalent expectation within the focus groups. Older generations expect, out of duty, that the younger generation will make decisions for them.

"We don't have to think about what will happen to us. Our kids will think about what they will do for us." (G3-P1)

"So, when we go off, when we get old and [we've] got to make [decisions], our kids will make the decision with the best of their family." (G3-P5)

Despite a lack of advance care planning and advance directives discussions, elders assume their children will know their wishes. The younger generation expressed concerns about this assumption, because it was described as a major responsibility placed upon them, yet they maintain respect for their elders and understand the reasoning behind this expectation.

"I'd be making decisions for [my parents] based on what I think they would want, but not explicitly knowing what it is." (G2-P4)

Younger participants are faced with a filial paradox in relation to their duties. Hence, they expressed a desire to have earlier advance care planning and advance directives discussions to alleviate the internal conflict of sole responsibility for decision making.

"Taking that pressure off from everybody else and making sure . . . everyone knows what your decision is. I wouldn't want my parents to take the burden on." (G4-P1)

Family structure during discussions. In the South Asian community, family members play a major role in making health care decisions. This is in keeping with the collectivist approach that is prevalent within this community, especially among older generations. This concept of filial piety was evident throughout our focus groups. In the South Asian community, autonomy is not solely about the individual, but also incorporates the interests of the family unit. This family-centred approach is known in the literature as "relational autonomy."[4,17] Between the generations, the dominance of relational autonomy varies. In our study, the younger generation understood the importance of involving family during decision making but shared their concerns about the dominance of a family-centred approach.

"I think . . . a lot of South Asian families [are] very family oriented, and [the] family [makes] decisions." (G4-P1)

"Our culture expects you to do everything with your family. They are involved in every kind of decision." (G5-P1)

In our focus groups, relational autonomy was stated to be more dominant among the older generation. It preserves hope and maintains a facade around difficult conversations. The younger participants acknowledged that love is the primary motivator for this illusion. It is described as compassionate care by protecting members of the community during times of illness.

"That desire to kind of hold on to hope would kind of shut down any conversations of 'If you become sicker, what would you do?' That would be very triggering." (G5-P2)

"In our culture, lots of people say 'Don't tell mom, dad, grandpa, grandma what's going on, because they'll lose hope.'" (G1-P2)

The family hierarchy within South Asian communities is a powerful force when making decisions regarding health. Due to this hierarchy, the responsibility for making decisions is usually given to the older members of the family. Younger participants exert minimal influence within this hierarchical structure. Furthermore, a large family increases the risk of competing opinions, as this hierarchy becomes more pronounced. These power dynamics contribute to confusion when identifying a substitute decision-maker. This complex family process can obscure the patient's wishes during the conversation.

"We have a large family; everybody has a different idea of what we should be doing. . . . There is a lot of say from the family. Because the kids are speaking on your behalf, you have your grandkids speaking on your behalf, but nobody really knows what the person would want." (G1-P3)

Power differential between patients and health care providers. Autonomy is one of the central tenets in the provision of health care in Canada. Older generations and new immigrants from South Asian communities may not fully appreciate this patient-centred approach. In South Asian countries, the health care provider takes a leading role in directing care within the therapeutic relationship. In their home countries, the physician is viewed as the expert, and their authority matters the most in decision making. A physician's paternalistic approach to care is expected and welcomed.

"In our culture, lots of people say 'Don't tell mom, dad, grandpa, grandma what's going on, because they'll lose hope.'"

In our focus groups, there were differing opinions between generations about the extent of power held by the physician. Most participants commented on how older generations view the physician as an authority figure. Hence, the younger members of our focus groups stated that health care providers, especially physicians, have a pivotal role in initiating advance care planning and advance directives discussions. For the elders, this approach can increase their willingness to engage in difficult conversations. Paradoxically, the older generations are hesitant to ask the physician questions due to this power imbalance.

"With the older generations, a physician is a means of authority. . . . They expect everything to come from the physician. There is no real expectation of two-way communication." (G2-P1)

Younger participants appreciated and expected an opportunity to partner with health care providers in their care. There was no perception of a power imbalance between them and health care providers. They were comfortable with the concept of actively being a part of their health care decisions. They understood the duty of health care teams in fostering patient autonomy and building therapeutic relationships. This understanding among younger participants was highlighted by their comfort in having these conversations independently with their health care provider. The younger generation saw the physician as a partner in making their health care plan.

"[I] might actually want to only have that conversation alone with the doctor." (G4-P3)

Within South Asian communities, there is an expectation about accompanying older members during their medical appointments. Younger participants raised concerns about language barriers and a need for an interpreter, which would be addressed by the presence of family. More importantly, the family can selectively share information with the patient and maintain the facade of hope. This is in alignment with the phenomenon of the cultural veil.

"A big part of our culture . . . [is] to shelter our older family members [from] having harsh questions presented to [them]." (G5-P2)

Recommendations for the *Serious Illness Conversation Guide*

A clinician's goal is to provide patient-centred care, which must include an understanding of the culture of their patients and their families. The intentional language used during advance care planning and advance directives discussions is important, particularly when cultural nuances exist. Words and phrases in a conversational tool must include cultural awareness to achieve its desired outcomes and prevent misinterpretation. A tool that incorporates cultural differences and an understanding of the impact of language is vital in clinical practice.

The SICG was used as a foundation for discussions during our focus groups. This tool has natural pauses within its structure. We used these pauses as opportunities for discussion. The participants provided suggestions for phrasing or wording changes in the SICG to facilitate cultural sensitivity within the South Asian community **[Table 3]**.

TABLE 3. Participant experience of the *Serious Illness Conversation Guide* (SICG) and recommended phrasing and terminology.

Sections from the SICG	Participant experience	Participant quote
Consent and information preferences	Participants said that older generations expect the physician to direct the conversation, especially for medical care and decisions. Conversely, the younger generation understood the intention behind the request for consent.	"I think my mom would feel like this is a little bit strange. . . . She would be confused why the doctor is asking if it's okay to talk to me about my health." (G2-P4)
Illness understanding	Most participants understood the intent of the question but shared a concern that the older members may not. The participants suggested alternative phrases: • This is how your condition is . . . • I will be taking this chance to talk about your condition . . .	"Health is critical; the doctor is the expert. . . . We're going to this expert to get this information, and what the doctor says is really, really important." (G2-P3)
Sharing prognosis	All participants welcomed the distinction between hope and worry within this section. However, they all expressed a concern that elders would not want to have these difficult conversations.	"I don't think [the elders] would want to engage as much as other cultures or other generations." (G1-P5)
Exploring key topics	**Goals:** Younger participants understood the intent of the question about goals. However, most felt that this question was too individualistic compared with the collectivist approach in the South Asian community. The participants suggested alternative phrases for "goals": • What are your wishes for your family . . . • What are some of the things that you would like to see or do . . .	"Things that are really important to an individual. . . . Culturally, those prompts don't really exist, especially with the older generations." (G2-P1) "If you talk about goals, they say, 'Who cares about goals; we have been already doing what we are supposed to do.' . . . There are wishes, yes, they will respond to the question better." (G3-P4)
	Fears and worries: All participants understood the intent of the question about fears and worries. However, they acknowledged the difficulties patients might have when coming from a collectivistic culture. Older family members might not want to worry their family, and some participants shared that some family members, especially older male figures, might not feel comfortable sharing their fears and worries, because it was seen as a weakness. The participants suggested alternative phrases for "fears and worries": • What are you concerned about . . . • What are you worried about . . .	"I have not experienced South Asian culture to be good about emotions in any capacity, particularly around death." (G3-P3) "I think it's a vulnerability and . . . it's not as comfortable." (G4-P2)
	Strength: The participants understood the concept of strength. They stated it was highly valued within the South Asian community. Younger participants stated that strength for them included faith and family, which also applied to the older generations. However, they stated that the older generation may equate this question with their jobs and life accomplishments.	"Strength is a good word and is well understood by our communities." (G2-P2)

Discussion

The findings from our focus groups align with the literature on barriers to advance care planning and advance directives discussions in the South Asian community. These barriers include a taboo about death and dying, particularly with elders due to power dynamics; the limited awareness and understanding of palliative care services in South Asian countries; a fatalistic view in medical decision making; a deference to family in medical conversations; and the perception of health care providers, especially physicians, as the primary decision-makers.[20-24] These barriers are more pronounced among older generations.

Racial and ethnic disparities in advance care planning and advance directives discussions are well documented in minority communities.[25-26] As the largest visible minority group in Canada, the South Asian community faces distinct challenges in these conversations. However, health care culture is evolving to improve these conversations. Tools like the SICG have been developed to facilitate advance care planning and advance directives discussions in the general population, but no research has explored its use among English-speaking Canadians of South Asian origin. Our study contributes valuable insights on the experiences of this community with the SICG.

Effective palliative care requires strong communication skills, particularly in understanding patients' goals and values. Our study builds on the SICG's foundation by emphasizing cultural nuances when using the tool with English-speaking South Asian Canadians. Participants' feedback on alternative wording and phrases provided a relativistic perspective on the SICG. Their insights will help clinicians navigate the tension between traditional beliefs from their countries of origin and the realities of health care in Canada and thus enhance the skills needed to have palliative care and serious illness conversations with the South Asian community.

Our study benefited from the diverse cultural backgrounds of our research team, which included South Asian, Chinese, and Filipino researchers. All have experience in collectivist cultures, where decision making is often shared, which strengthened the interpretation of the data from this perspective. The team's cultural background enhanced the reflexivity of the data analysis and enriched discussions during theme consensus building. While a perspective from a traditional Western lens may have added additional viewpoints, the research team's extensive experience in a Western health care system ensured both Western and Eastern perspectives were incorporated into the analysis.

All our researchers work primarily in hospice and palliative care settings and are experienced users of the SICG. However, we acknowledge that advance care planning and advance directives discussions extend beyond hospice care, as palliative care services are increasingly integrated earlier in the patient's journey. The SICG is applicable across the care continuum for all patients with serious illness, and our findings have relevance for specialists across health care sectors, particularly when engaging with the South Asian community.

Study limitations

Our study focused on English-speaking Canadians of South Asian origin from the Lower Mainland of BC. While the findings cannot be generalized to the broader South Asian Canadian community, they provide valuable insights into challenges in providing care to this group. We intentionally selected English-speaking participants to evaluate the SICG as an English-delivered tool, but we acknowledge that due to the South Asian community's diversity—encompassing a variety of beliefs, languages, and cultural practices—the findings represent only one aspect of the broader experience.

Participants were presented with hypothetical case studies, which do not fully capture the complexity and emotions of real-life scenarios. However, they were encouraged to draw on personal experiences to connect with the case study and share perspectives as family members or patients. Despite the artificial nature of those simulations, meaningful insights were gained from the focus groups.

While most participants identified as Hindu, this does not imply that the findings are representative of a specific religious perspective, because the South Asian community encompasses diverse religious groups. Additionally, most participants lacked direct experience with advance care planning and advance directives discussions, which limits the generalizability of the findings. However, the results provide valuable insights into the cultural influences that shape advance care planning and advance directives discussions within South Asian communities.

Our findings help facilitate cultural awareness and sensitivity in clinical practice among members of the South Asian community.

Further research should aim to include a broader demographic representation, including older age groups, male participants, varied socioeconomic backgrounds, newly arrived immigrants, individuals from different religious communities, and those with personal experience in advance care planning and advance directives discussions.

Conclusions

In keeping with the collectivistic nature of the South Asian community, our study highlights the predominant role family plays during advance care planning and advance directives discussions and medical decision making. It also highlights the potential barriers to and the benefits and challenges of using a Western-devised tool for having serious illness conversations with members of the South Asian community in Canada. The SICG's choice of words and phrases were viewed as predominantly individualistic. Our findings help facilitate cultural awareness and sensitivity in clinical practice among members of the South Asian community. Hence, clinicians can appreciate the impact of the culture and family during advance care planning and advance directives discussions. ■

Competing interests

None declared.

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Health outcomes of patients in the Complex Chronic Diseases Program

New approaches and research are urgently needed to improve therapeutic interventions for patients with complex chronic diseases.

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ABSTRACT

Background: Complex chronic diseases affect almost 3% of Canadians and lead to persistent, debilitating symptoms. The BC Ministry of Health funded the Complex Chronic Diseases Program to address service gaps for affected individuals. We evaluated health outcomes of the program's patients.

Methods: Analysis of data from the Complex Chronic Diseases Program Data Registry (June 2017–September 2022) focused on patient-reported outcomes and clinical measures at baseline, 6-month follow-up, and discharge, and on changes in symptoms across these time points.

Results: Among the 668 participants included in the study, slight improvements in overall physical and mental health were observed between baseline and discharge. However, symptoms such as sleep dysfunction, fatigue, and pain showed no significant changes.

Conclusions: While participation in the Complex Chronic Diseases Program yielded some health benefits, further research and interventions are required to address symptoms and optimize patient outcomes. The further development and use of objective outcome markers are needed for improved program evaluation.

Background

Complex chronic diseases affect approximately 2.9% of Canadians, or approximately 855 000 people 12 years of age or older.[1] These diseases include myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia, and chronic Lyme-like syndrome. ME/CFS manifests as persistent, disabling fatigue and general malaise (e.g., feeling unwell, flu-like symptoms), which are worsened by physical or mental exertion, and involves sleep dysfunction and impaired cognitive function that typically presents as "brain fog" or difficulty concentrating and processing information.[2] Fibromyalgia is characterized by widespread chronic pain that persists for at least 3 months, with patients frequently experiencing increased sensitivity to pain (hyperalgesia) or pain from typically nonpainful stimuli (allodynia).[3] Chronic Lyme-like syndrome develops following acute Lyme disease; it shares many symptoms with ME/CFS and other postviral conditions and with fibromyalgia.[4] Patients with complex chronic diseases often have persistent and debilitating symptoms coupled with functional impairment.[5,6] They experience great difficulty accessing consistent medical care in a coordinated fashion within the health care system, which frequently leaves them to advocate for themselves.

Complex Chronic Diseases Program

British Columbia's Complex Chronic Diseases Program (CCDP), established in 2012 at BC Women's Hospital and Health Centre in Vancouver, was the first tertiary care service of its kind in Canada and remains one of only three centres dedicated to the care of individuals with complex chronic diseases. The CCDP model of care includes diagnostic assessments, treatment planning, patient and caregiver education, and linkages to community and primary care resources. The program provides specialist-led care by a multidisciplinary team that includes physicians, a naturopath, and a pharmacist, who are supported by an interprofessional team of nurses, physiotherapists, occupational therapists, a dietitian, a social worker, and counseling services.

At inception, there were limited models to inform the CCDP, and care methods were continually revised to respond to the large volume of patients seeking care and the needs of the patient population. Initially, care was delivered primarily through one-on-one consultations with physicians and other clinicians. In 2019, the program moved to a group-based care model led by the interprofessional team, with individual medical visits provided based on patient needs, in response to increasing wait times and patient volume.[7] Due to continued high demand, the current wait time for care is approximately 28 months.

Symptom management: Referrals to the CCDP must be made by a clinician, typically a family physician, based on a suspected or confirmed diagnosis of ME/CFS, fibromyalgia, or chronic Lyme-like syndrome. Diagnosis at the CCDP is based on clinical criteria, including either the 2003 Canadian Consensus Criteria[2] or the 2015 Institute of Medicine Diagnostic Criteria[8] for diagnosis confirmation of ME/CFS and the 2016 Fibromyalgia Diagnostic Criteria for fibromyalgia.[3] For chronic Lyme-like syndrome, the diagnosis requires reliable laboratory evidence of Lyme infection in the past and symptoms akin to ME/CFS.

Remission rates are low for complex chronic diseases; few patients return to their premorbid functional or activity levels.[9] In the absence of curative therapies, current treatment guidance focuses on symptom management. The CCDP has treatment guidelines for clinical management informed by evidence, which are available on its website.

The CCDP Data Registry supports program evaluation, quality improvement, and clinical research by tracking patient outcomes and demographics.

Patient education and self-management are central to the CCDP model of care. A variety of resources and services are offered to patients through group activities. Patients participate in group sessions that cover key aspects of managing symptoms, including fatigue, postexertional malaise, pain, sleep dysfunction, and impaired cognitive function. Patient education and self-management approaches have been employed in many contexts and are intended to help individuals learn and apply their knowledge and skills to managing their condition, mitigating its impact on daily life, and improving symptom severity and functional outcomes.

Complex Chronic Diseases Program Data Registry: Launched in 2017, the CCDP Data Registry supports program evaluation, quality improvement, and clinical research by tracking patient outcomes and demographics. It enables the assessment of symptom progression using clinical chart data and patient-reported questionnaires collected throughout the program and up to 6 months postcompletion.

The CCDP Data Registry provided a unique opportunity to characterize BC patients with complex chronic diseases and evaluate the longitudinal outcomes of service-based care. This study provides evidence of the benefits and limitations of current care strategies for patient outcomes and highlights areas that require more focused intervention, such as persistent symptoms of fatigue, pain, and sleep disturbances.

Methods

The University of British Columbia Research Ethics Board approved this study (H16-01648). Informed consent was obtained from all subjects involved in the study.

Data Registry participants

The CCDP Data Registry included newly referred individuals who were contacted by the CCDP, were 19 years of age or older, could read and understand English, and provided informed consent to be part of the data registry. Patients were invited to participate prior to their intake assessment with a CCDP physician. Exclusion criteria included not completing the standardized questionnaires prior to intake and ineligibility for the CCDP clinical program (e.g., lack of a qualifying diagnosis).

Following ethics approval, recruitment was conducted from June 2017 to September 2022 but was paused from January to June 2019 during a care model redesign and from March 2020 to February 2021 due to COVID-19 disruptions. The COVID pandemic prompted major changes to clinical processes at BC Women's, including the adoption of telehealth and physical distancing requirements.

Data collection

Demographic information was collected prior to a patient's first in-person appointment at the CCDP. Clinical variables were captured by the Interprofessional Assessment Tool, which was completed collaboratively by physicians and allied health professionals. The Interprofessional Assessment Tool contains data about complex chronic diseases diagnostic instruments, clinical variables, health history, symptom presentation, functional status, and physical examinations.

Standardized questionnaires were used to assess patient health outcomes four times: at program entry, after 6 months, at discharge (typically after 1 year), and 3 to 6 months postdischarge. The following questionnaires were used:

- Fatigue Severity Scale—measures the impact of fatigue on daily life.[10]
- Short-form McGill Pain Questionnaire—assesses the sensory and affective dimensions of pain.[11]
- Pittsburgh Sleep Quality Index (PSQI)—assesses nighttime sleep problems and sleep quality.[12]
- RAND 36-Item Short Form Health Survey (SF-36)—measures overall quality of life, summarized into mental health and physical health scores (higher scores indicate better well-being).[13]
- Patient Health Questionnaire 9 (PHQ-9) and Generalized Anxiety Disorder 7 (GAD-7)—assess the severity of depression and anxiety, respectively.[14,15]
- Patient Phenotyping Questionnaire Short Form (PQ-12)—captures the presence and severity of ME/CFS-specific symptoms (higher scores indicate worse severity).[16]

Inventory subscales and global scores were calculated based on the instrument's cited calculation methods. Incomplete responses were excluded if key data were missing.

Data analysis

To ensure sufficient statistical power, some demographic variables were grouped into fewer categories. Descriptive statistics were used to characterize the patient population; means and standard deviations (or medians and interquartile ranges) were reported for continuous variables, and proportions were reported for categorical variables. Longitudinal symptom trends were visualized using sample means at each point in time.

Paired *t* tests were used to assess changes in symptoms between baseline and 6 months and between baseline and discharge. Tables were used to display sample sizes at each point in time to account for loss to follow-up. Normality was verified using quantile–quantile plots.

A series of univariable and multivariable linear regressions were used to examine whether disease duration at recruitment influenced baseline symptom severity and symptom changes from baseline to discharge. A confounding model approach was used, and confounders were included based on theoretical relevance or statistical criteria (i.e., association with both the outcome and the main exposure). In addition, the Akaike Information Criterion (AIC) was used to compare models, with the model showing the lowest AIC considered the best balance of goodness of fit and model complexity, helping to avoid overfitting and support robust model selection. Regression assumptions (linearity, normality, homoscedasticity, and independence) were verified.

Our results highlight the severity and persistence of illness and impairment faced by those with complex chronic diseases.

To assess the effect of the 2019 transition from individual-based to group-based care, patients were categorized based on their assessment date (before or after 17 January 2019). Two-sample *t* tests were used to compare symptom changes from baseline to 6 months (discharge data were excluded due to a small sample size for the individual-based group: $n = 35$).

A two-sided $P < .05$ was considered statistically significant, and outcome means were reported with 95% confidence intervals. Analyses were conducted using R 3.2.3 software (R Foundation, Vienna, Austria).

The data presented in this study are available on request from the corresponding author.

Results

Recruitment

Participation in the CCDP Data Registry was offered to 1962 newly referred patients prior to confirmation of their eligibility for the CCDP; 735 consented to participate. The final analysis included 668 participants (34%) due to withdrawals and study exclusion criteria. The sample size was further reduced in some analyses due to missing data or loss to follow-up.

Baseline characteristics

Diagnoses of ME/CFS and fibromyalgia were confirmed by the attending physician; 31% of participants were diagnosed with ME/CFS only ($n = 208$), 15% were diagnosed with fibromyalgia only ($n = 100$), and 54% were diagnosed with both ME/CFS and fibromyalgia ($n = 360$) **[Table 1]**. Only two participants had a confirmed diagnosis of chronic Lyme-like syndrome. One of them also had a diagnosis of ME/CFS and fibromyalgia and was categorized accordingly; the other was removed from the analyses.

Participants had an average age of 49 years. The sample was predominantly female (90%; $n = 557$) and predominantly self-identified as White/Caucasian (85%; $n = 516$) **[Table 1]**.

Health outcomes

Measures of pain, fatigue, sleep dysfunction, and depression showed overall improvement but did not change significantly at 6-month follow-up or discharge **[Table 2]**. ME/CFS-specific symptoms, measured by the PQ-12, showed a significant reduction from baseline to discharge, suggesting overall symptom relief over time. Levels of anxiety (GAD-7) also decreased significantly at both 6-month follow-up and discharge. Both the SF-36 physical and mental health summary scores had improved significantly by discharge, indicating better physical and emotional well-being by the end of the program. Quantitative changes were small, and in the case of GAD-7, the confidence interval crossed zero, indicating a possible lack of clinical significance.

Disease duration

Longer disease duration was generally associated with worse baseline symptoms, with the McGill Pain Score and PSQI showing significant associations in univariable

TABLE 1. Baseline characteristics of adult patients enrolled in the Complex Chronic Diseases Program Data Registry.

Variable	Study sample—baseline (*N* = 668)*
Diagnosis	
Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) only	208 (31.1%)
Fibromyalgia only	100 (15.0%)
ME/CFS and fibromyalgia	360 (53.9%)
Age (years)	
Mean (SD)	49.2 (13.0)
Median (IQR)	49.8 (39.9-59.5)
Biological sex (%)	
Female	557 (90.3%)
Male	60 (9.7%)
Gender identity (%)	
Woman	536 (88.4%)
Man	57 (9.4%)
Other†	13 (2.2%)
Ethnicity (%)	
White/Caucasian	516 (84.7%)
Other‡	93 (15.3%)
Disease duration (years)	
Mean (SD)	15.2 (11.7)
Median (IQR)	11.0 (6.0-22.0)
Geographic location (%)	
Metro Vancouver	240 (47.5%)
Outside	265 (52.5%)
Marital status (%)	
Married or partnered	363 (59.7%)
Separated, divorced, or widowed	120 (19.7%)
Single; never married	125 (20.6%)
Education (%)	
High school or lower	112 (18.4%)
College/CEGEP/trade school	219 (36.1%)
University graduate	276 (45.5%)
Employment status (%)	
Employed (full-time, part-time, or self-employed)	220 (35.8%)
Retired	85 (13.8%)
Long-term illness	219 (35.6%)
Other§	91 (14.8%)

* Missing values varied from *n* = 51 (7.6%) to *n* = 62 (9.3%), except for disease duration (*n* = 166; 24.9%) and geographic location (*n* = 163; 24.4%).

† Other gender identities include transgender and nonbinary.

‡ Other ethnicities include Chinese, South Asian, Black (Caribbean, African, and African Canadian), Latin American, Middle Eastern, Southeast Asian, West Asian, and Indigenous (including First Nations, Inuit, and Métis).

§ Other employment statuses include looking for paid work, student, caring for children, household work, volunteering, caregiving other than for children, and the original "other" category.

models **[Table 3]**. However, these associations weakened after adjusting for demographic factors: the PSQI remained the only significant predictor in the multivariable model. This suggests that each additional year of disease corresponded to a slight worsening of overall sleep quality (a PSQI score increase of 0.035 points).

The relationship between disease duration at baseline and symptom variable differences (discharge to baseline) were also examined, but no symptom variable changes retained a significant association after adjustment **[Supplementary Table, available at bcmj.org]**.

Model of care

Based on their assessment date, patients were categorized as taking part in either the individual-based or group-based model of care. When the differences between baseline and 6-month scores were compared across the two groups, some mental health metrics were significantly different **[Table 4]**. Patients who took part in the individual-based model of care experienced a greater reduction in both anxiety (GAD-7) and depression (PHQ-9) severity than those in the group-based model, or an approximately 1.4-point decrease in scores from baseline to 6-month follow-up. For other symptoms, the individual-based model showed more favorable trends toward improvement; however, they were not significant.

Discussion

The CCDP Data Registry population aligns with other studies of complex chronic diseases. Approximately 88% of the sample identified as women, consistent with other research that reported more than 75% of ME/CFS and fibromyalgia patients as being women.[17-19] In the literature, fibromyalgia is commonly diagnosed during middle age (40 to 60 years of age),[20] while ME/CFS has two incidence peaks: in adolescence (10 to 19 years) and in adulthood (30 to 39 years).[21] However, the CCDP enrolls primarily long-standing cases and serves only adults (19+ years), which limits direct comparison to incidence rates.

TABLE 2. Mean symptom score differences between baseline and 6-month follow-up and between baseline and discharge (paired analysis).

Variable	Sample size (baseline)	Sample size (6 months)	Sample size (discharge)	Mean difference (6 months to baseline)	Mean difference (discharge to baseline)	*P* (6 months to baseline)	*P* (discharge to baseline)
Fatigue Severity Scale score	661	479	178	−0.06 (−0.15 to 0.04)	−0.04 (−0.20 to 0.11)	.38	.37
Short-form McGill Pain Questionnaire score	632	427	160	−0.09 (−0.79 to 0.61)	−0.18 (−1.50 to 1.15)	.07	.91
Pittsburgh Sleep Quality Index global score	626	454	173	−0.22 (0.53 to 0.08)	−0.72 (−1.23 to −0.21)	.63	.13
Patient Health Questionnaire 9 score	643	450	166	−0.24 (−0.67 to 0.18)	−1.05 (−1.76 to −0.35)	.39	.24
Generalized Anxiety Disorder 7 score	647	451	165	−0.56 (−0.94 to −0.17)	−0.74 (−1.52 to 0.05)	.01*	.04*
Patient Phenotyping Questionnaire Short Form score	335	227	111	−0.42 (−1.05 to 0.21)	−1.48 (−2.65 to −0.32)	.37	.04*
RAND 36-Item Short Form Health Survey (SF-36) mental health summary score[1†]	661	459	172	0.77 (0.06 to 1.48)	2.82 (1.53 to 4.11)	.59	.01*
RAND SF-36 physical health summary score[†]	661	459	172	0.44 (−0.13 to 1.03)	1.95 (0.37 to 3.55)	.25	.03*

* Significant at $P < .05$. † An increase in score indicates improvement; the opposite holds for other indicators.

TABLE 3. Linear regression models for symptom severity by baseline disease duration (*n* = 480).

	Disease duration at baseline			
	Univariable models		Multivariable models*	
Variable	β (95% CI)	*P*	β (95% CI)	*P*
Fatigue Severity Scale score	−0.001(−0.009 to 0.006)	.722	0.001 (−0.006 to 0.010)	.660
Short-form McGill Pain Questionnaire score	0.097 (0.016 to 0.177)	.019*[†]	0.058 (−0.023 to 0.138)	.152
Pittsburgh Sleep Quality Index global score	0.033 (0.002 to 0.064)	.038*[†]	0.035 (0.001 to 0.068)	.041[†]
Generalized Anxiety Disorder 7 score	0.037 (−0.007 to 0.082)	.100	0.027 (−0.018 to 0.073)	.238
Patient Health Questionnaire 9 score	0.028 (−0.015 to 0.071)	.200	0.029 (−0.015 to 0.073)	.202
Phenotyping Questionnaire Short Form score	0.06 (−0.015 to 0.136)	.247	0.075 (−0.004 to 0.154)	.063
RAND SF-36 mental health summary score	−0.004 (−0.086 to 0.078)	.921	−0.001 (−0.085 to 0.087)	.977
RAND SF-36 physical health summary score	−0.017 (−0.097 to 0.064)	.683	−0.020 (−0.105 to 0.066)	.653

* All multivariable models were adjusted for diagnosis, geographic location, and employment status. The Fatigue Severity Scale score, short-form McGill Pain Questionnaire score, and RAND 36-Item Short Form Health Survey (SF-36) physical health summary score were also adjusted for sex. The Generalized Anxiety Disorder 7 and Patient Health Questionnaire 9 scores were additionally adjusted for level of education. † Significant at $P < .05$.

TABLE 4. Mean difference in scores for standardized health outcome variables across two program models (individual-based and group-based). *P* values are presented for *t* tests that compared baseline to 6-month follow-up.

	Individual-based (6 months to baseline) (*n* = 155)	Group-based (6 months to baseline) (*n* = 276)	*P*
Variable	Mean difference (SD)	Mean difference (SD)	
Fatigue Severity Scale score	−0.13 (0.93)	0.01 (1.06)	.131
Short-form McGill Pain Questionnaire score	−1.56 (8.00)	−0.20 (6.74)	.087
Pittsburgh Sleep Quality Index global score	−0.15 (3.31)	−0.04 (3.17)	.731
Generalized Anxiety Disorder 7 score	−1.46 (3.98)	0.00 (4.06)	< .01*
Patient Health Questionnaire 9 score	−1.44 (4.08)	0.52 (4.59)	< .01*
RAND SF-36 mental health summary score	0.57 (5.30)	−0.02 (8.73)	.371
RAND SF-36 physical health summary score	1.01 (6.06)	−0.02 (6.36)	.090

* Significant at $P < .05$. Negative results indicate improvement for all but the RAND 36-Item Short Form Health Survey (SF-36) summary scores.

Although complex chronic diseases affect all races and ages, most patients reported being White/Caucasian (85%), compared with 65.6% in the 2021 BC census.[22] The overrepresentation of White, middle-class individuals in clinical settings contrasts with population-based studies, which suggests that complex chronic diseases may be more common among people of lower socioeconomic status and minority cultural or ethnic groups.[23] These discrepancies may reflect differential health access and/or research participation rates and thus warrant further investigation.

Our results highlight the severity and persistence of illness and impairment faced by those with complex chronic diseases. Self-reported pain, fatigue, and mental health measures were substantially worse compared with a healthy population. For example, the Fatigue Severity Scale typically considers a score of 4 or higher (out of 7) as clinically significant fatigue; CCDP participants had an average score of 6, indicating that most participants were severely fatigued across all time points. Given the discrepancy between the well-being of individuals with complex chronic diseases and the well-being of both the general population and other chronic illness populations,[6,24] there is a clear need for interventions that are more finely tuned to the nuances of these conditions.

Our findings suggest a general trend in symptom improvement, including statistically significant changes in overall physical health and mental health indicators and severity of ME/CFS-specific symptoms between baseline and discharge. However, the magnitude of these changes was small, indicating that the improvements may not be clinically significant for most patients. The slight benefits to physical and emotional well-being may have been due to the educational and supportive aspects of the program and the tailored pharmaceutical approaches and resources for symptom management.

Our findings did not reveal a relationship between disease duration at intake and baseline symptom scores or symptom trajectory between baseline and discharge, except for PSQI scores, where longer disease duration was associated with poorer sleep quality. While symptom improvement is possible over time and with treatment, there are no curative treatments for complex chronic diseases, and prognosis for ME/CFS and fibromyalgia remains poor, particularly beyond the first year of illness.[25-27] Studies have been inconsistent in both methods and results, but generally, longer complex chronic disease duration correlates with poorer health outcomes.[28-30] We may not have seen the impacts of greater disease duration in our study because most participants had long-standing illness (median = 11 years), so early-stage improvements were not observed. Additionally, program enrollment may have excluded those with more favorable early-stage outcomes and those who were most severely affected, which would limit the interpretation of treatment timing effects.

Our findings suggest a general trend in symptom improvement, including statistically significant changes in overall physical health and mental health indicators and severity of ME/CFS-specific symptoms between baseline and discharge.

In our analysis, only mental health outcomes differed significantly between the individual-based and group-based models of care. Patients in the individual-based model experienced greater reductions in anxiety and depression at 6 months than those in the group-based model, possibly due to the more personalized support provided. However, external factors, particularly the COVID pandemic, during which most group-based patients received care, may have affected the results. The burden of the pandemic may have resulted in some inflation of mental health scores.

The CCDP stays informed on the latest treatment and care strategies for people with complex chronic diseases. However, evidence of effective interventions that are robust and reproducible is limited. Studies on group-based self-management programs for ME/CFS and fibromyalgia show inconsistent outcomes and levels of effectiveness.[31-33] Our results show that the CCDP also experienced mixed and modest improvements in health outcomes. New approaches and research are urgently needed to improve therapeutic interventions for complex chronic diseases. The use of objective outcome measures could enhance the assessment of program effectiveness; candidates for clinical use include biomarkers (e.g., serum creatine kinase, morning cortisol), hand grip strength, and inflammatory markers.[27] Further validation of such markers is required.

Our study's strengths included the large baseline sample and comprehensive data collection that encompassed a range of variables. The repeated measures design allowed individual and aggregate patient trajectories to be tracked throughout the program. Additionally, the cohort was well defined, with ME/CFS and fibromyalgia diagnoses clinically confirmed and recorded by trained practitioners, which minimized misclassification and missing data.

Study limitations

Because the CCDP is a provincial referral centre, our findings can be cautiously applied to other BC adults with complex chronic diseases. However, our sample was less diverse than the general BC population, and our sample size at discharge was relatively small due to high attrition and the ongoing data collection for participants currently enrolled in the CCDP Data Registry. Differential attrition bias may have influenced our findings, despite adjustment efforts. Self-reported symptom measures are subject to recall bias and may be less sensitive than objective markers. Additionally, the lack of a control group and external factors limited our ability to isolate program effects.

A major challenge for complex chronic diseases research is appropriate case ascertainment, given the absence of diagnostic biomarkers. While CCDP patients are identified using established diagnostic protocols, symptom presentation of complex chronic diseases is nonspecific, which makes it difficult to ensure a standard phenotype and to distinguish these diseases from others with similar presentations. The reliance on clinical diagnoses, in the absence of biomarkers, introduces an element of variability that future research must address. Further research should focus on identifying biomarkers and objective outcome measures to improve diagnosis and treatment evaluation, as well as improving our understanding of factors that predict better responses to care.

Conclusions

Our analysis of the CCDP Data Registry provided novel insights into symptom progression of complex chronic diseases under a clinical program and opportunities for continued exploration. While slight improvements were observed in mental health and physical health indicators and the severity of ME/CFS-specific symptoms, symptoms remained severe and persistent over time, regardless of care model, thus highlighting the long-term nature of complex chronic diseases. Individual-based care was more effective in reducing anxiety and depression, but overall symptom relief was limited.

Our findings highlight the challenges of complex chronic disease management and the need for retaining individualized care options and achieving earlier diagnosis and intervention, particularly at the primary care level. We recommend a coordinated investment and expansion of services that integrate primary care, community providers, and specialist expertise and are supported by continuing education and research. Although challenging in an environment of limited resources, improving early intervention and access to expert guidance could enhance patient satisfaction, reduce morbidity, and generate long-term economic savings.

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Our findings highlight the challenges of complex chronic disease management and the need for retaining individualized care options and achieving earlier diagnosis and intervention, particularly at the primary care level.

Competing interests

None declared.

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Cyanobacteria are a growing One Health challenge

Cyanobacteria are among the oldest organisms on Earth. They are believed to be responsible for the planet's oxygenation and the development of photosynthesis in plants.[1] Today, cyanobacteria are ubiquitous and perform many ecosystem services.[2]

The concept of One Health is the understanding that the health of animals, the environment, and humans are interdependent. Cyanobacteria can become a One Health challenge when they negatively impact the health of humans, animals, and ecosystems. In freshwater lakes, cyanobacteria can pose a threat when they produce dangerous cyanotoxins[3] or multiply rapidly, forming blooms[4,5] **[Figure 1]**. Such blooms can cause hypoxic water conditions, which sometimes result in wildlife mortality and plant die-off due to ultraviolet radiation blocking.[6] Blooms have substantial economic consequences when they impact fisheries, tourism, or livestock. Cyanotoxins are also a significant challenge for drinking water, because toxins may persist after conventional treatment (e.g., chlorination, filtration), different toxins require different treatments, and certain treatments can increase the release of toxins.[7]

Human health

There are approximately 2000 known species of cyanobacteria, and less than 5% are recognized to produce cyanotoxins, which have hepatotoxic, neurotoxic, dermatoxic, and cytotoxic effects.[8,9] Exposure can occur via ingestion (e.g., drinking contaminated water), dermal contact (e.g., swimming), and inhalation of aerosolized water droplets.

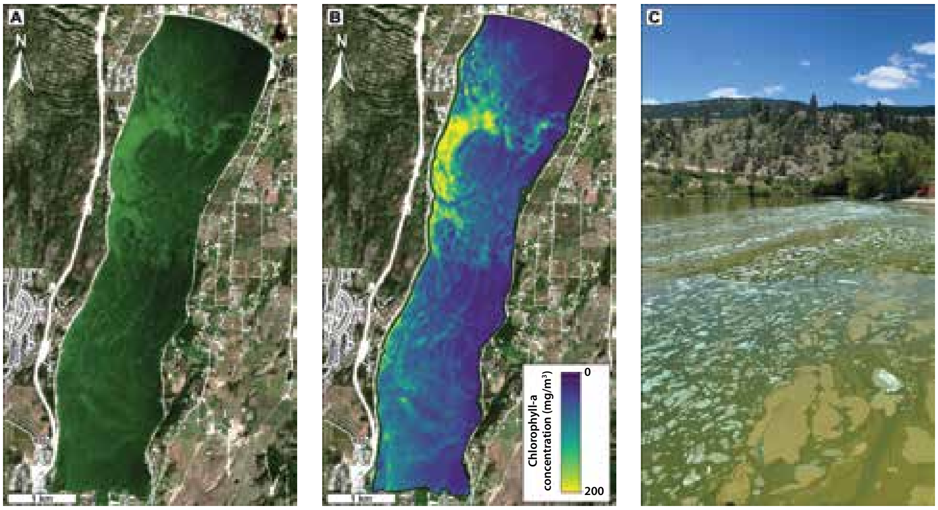

FIGURE 1. ***Anabaena flos-aquae*** **bloom in a BC lake in May 2021, shown via (A) a satellite true-color image, (B) satellite-derived chlorophyll-*a* estimates[4] indicating the concentration of cyanobacteria or algae, and (C) a field photo of the bloom die-off.[5]**

Acute health impacts range from mild self-limiting symptoms, such as diarrhea, headaches, and skin irritation, to paralysis and death.[3] There is evidence of chronic effects, such as liver damage and cancer, and impacts of repeat low-dose exposures, but these effects are less understood.[3]

Changing cyanobacteria risks

Cyanobacteria multiply in freshwater lakes under specific environmental conditions, which are often driven by anthropogenic nutrient loading from industry, agriculture, sewage, urban runoff, and waste facilities.[9,10] These sources of nutrients are likely to increase as the population continues to grow. At the same time, favorable environmental conditions, such as higher water temperatures, are being enhanced by climate change. For example, wildfires interact with higher rainfall to increase nutrient runoff from burned areas. Flooding may inundate nutrient-rich farms or septic systems. Wildfire smoke mobilizes and deposits nutrients in lakes, which has been linked to downwind blooms. Wind may transport nutrients in smoke long distances, increasing the risk of nutrient loading in lakes previously unaffected by blooms. Finally, human-mediated transport (e.g., via boat) and changing environmental conditions are allowing new cyanobacteria species to thrive in new regions.

Cyanobacteria in BC

In BC, there is a poor understanding of the burden of illness caused by cyanotoxin exposures. Illnesses are not reportable; there is no systematic surveillance; and cases are likely under-ascertained due to nonspecific, self-limiting symptoms.[9] Nevertheless, from 2012 to 2024, the BC Drug and Poison Information Centre recorded 34 calls about 43 individuals exposed to freshwater cyanobacteria, with more calls in recent years **[Figure 2]**. Most (88%) of these calls were about individuals who were exposed when swimming or recreating around fresh water, including food contact with contaminated water. The remainder

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This article is the opinion of the BC Centre for Disease Control and has not been peer reviewed by the BCMJ *Editorial Board.*

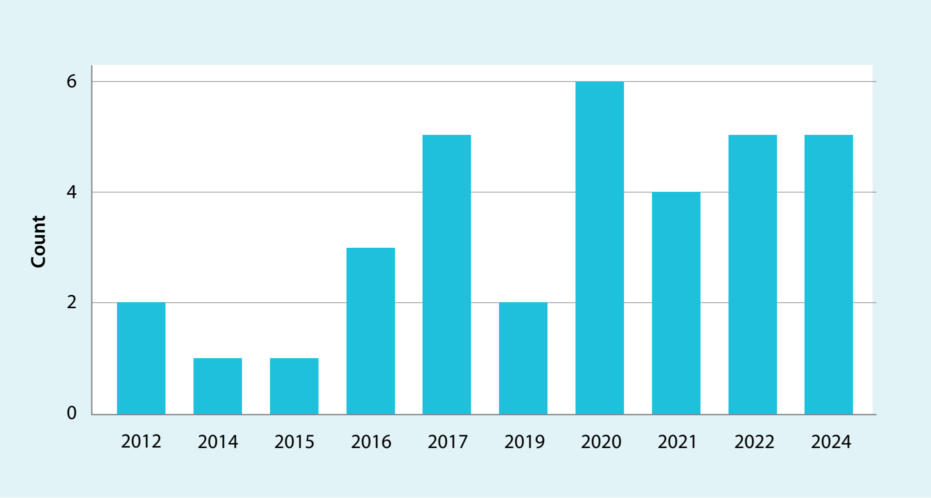

FIGURE 2. The number of annual calls made to the BC Drug and Poison Information Centre about exposure to cyanobacteria, 2012–2024. There were no cases of cyanobacteria in 2013, 2018, and 2023.

included work-related or unknown exposure sources. Two-thirds (68%) reported symptoms including abdominal pain, diarrhea, vomiting, fever, headache, respiratory distress, rash, itchiness, dizziness, fatigue, and conjunctivitis. The remaining callers were seeking preemptive advice about known exposures. Thirty-one calls were made in response to visible blooms and/or posted blue-green algae warnings, highlighting the importance of raising awareness.

Little is known about the provincial distribution of cyanobacteria and cyanotoxins or changes over time, because there is no comprehensive program of environmental surveillance. Data are collected for a small fraction of the more than 20 000 lakes in BC, and they are often disparate, time limited, and held by many different agencies.[11] There are programs that collect information on cyanobacteria specifically or blooms in general, such as the BC Lake Monitoring Network, which collects taxonomy samples twice a year for the more than 50 lakes it monitors across the province, and Algae Watch, where the public can submit photos of blooms.[5,12] Both programs indicate that blooms occur annually across BC. Routine monitoring for cyanotoxins by drinking water operators is primarily limited to a single group of toxins (microcystins), the only cyanotoxin with a Health Canada guideline limit for drinking and recreational waters. Monitoring for microcystins varies from no monitoring in many lakes to regular monitoring in some large drinking-water reservoirs.[7]

Although there is limited surveillance, cyanobacteria exposures are occurring in BC. Beyond Drug and Poison Information Centre data, there are periodic media reports demonstrating blooms and their wider impacts, including mortality among fish, pets, and cattle.[13,14] Building a robust surveillance system would support provincial adaptation and resiliency to the potential impacts of a growing population and climate change. Examples are available from other jurisdictions, such as the One Health Harmful Algal Bloom System, which collects data on blooms and related human and animal illnesses across the US. In BC, such a system would provide the foundation for a comprehensive and coordinated approach to cyanobacteria, enabling evidence-informed decision making about how and where to develop interventions and commit resources. ■

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Antibiotic treatment durations are not based on scientific reasoning; they stem from an artificially created number system

A critical look at the evidentiary basis of our modern antibiotic treatment lengths.

Davie Wong, MD, FRCPC

ABSTRACT: Antibiotics are often prescribed for longer than necessary, and treatment durations are arbitrary and inherently flawed. With the ongoing global threat of antimicrobial resistance, reducing treatment length to the minimum effective duration is a priority. However, achieving an optimum duration is not an easy feat, because the scientific underpinnings of modern antibiotic durations are weak or nonexistent.

As an infectious diseases physician, I am often asked, "How long do I treat this patient's infection?" After years of extensive medical training, clinical practice, and memorization of treatment durations from various infectious diseases guidelines, surely my answer should be based on credible scientific evidence, right? There is a plethora of randomized controlled trials comparing different treatment durations for many types of infections, including streptococcal pharyngitis,[1] community-acquired pneumonia,[2] and gram-negative bacteremia,[3] to name a few. However, is the method by which antibiotic treatment durations are selected based on scientific rationale or on a convenient and pleasing system of numbers? In this article, I take a critical look at the evidentiary basis of our modern antibiotic treatment lengths.

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How to determine duration of treatment

On 16 October 2010, Dr Daniel Gilbert, a professor of psychology at Harvard University, published an op-ed in *The New York Times* describing his encounter at a local emergency department.[4] He received a 7-day course of antibiotics for a minor ailment. As a psychologist, he rightly posed the question: "What I didn't understand was why a full course took precisely seven days. Why not six, eight or nine and a half? Did the number seven correspond to some biological fact about the human digestive tract or the life cycle of bacteria?"

On 22 October 2010, Dr Paul Sax, an infectious diseases physician and an editor for the *New England Journal of Medicine Journal Watch*, responded satirically to Dr Gilbert's question: "The answer, Dr Gilbert, is that this is highly-specialized knowledge, rarefied information that only 100% Board-Certified, USDA-inspected Infectious Diseases Doctors know. And since I'm concerned that your article might give readers the wrong impression about our scientific credibility, I'll now divulge what we've learned, and how to apply it."[5] Dr Sax then wittily revealed the seven golden rules for choosing an antibiotic duration:

1. Choose a multiple of 5 (fingers of the hand) or 7 (days of the week).
2. Is it an outpatient problem that is relatively mild? If so, choose something less than 10 days. After application of our multiples rule, this should be 5 or 7 days.
3. Is it really mild, so much so that antibiotics probably aren't needed at all but clinician or patient are insistent? Break the 5/7 rule and go with 3 days. Ditto uncomplicated cystitis in young women.
4. Is it a serious problem that occurs in the hospital or could end up leading to hospitalization? With the exception of community-acquired pneumonia (5 or 7 days), 10 days is the minimum.
5. Patient not doing better at the end of some course of therapy? Extend treatment, again using a multiple of 5 or 7 days.
6. Does the infection involve a bone or a heart valve? Four weeks (28 days) at least, often 6 weeks (42 days). Note that 5 weeks (35 days) is not an option—here the 5s and 7s cancel each other out, and chaos ensues.
7. The following lengths of therapy are inherently weird, and should generally be avoided: 2, 4, 6, 8, 9, 11, 12, 13 days. Also, 3.14159265 days.[5]

The takeaway from this comical exchange is that treatment durations are mostly arbitrary. Consider the following sequence of numbers, and fill in the blank: 2, 3, 5, 7, X, 13, and 17. The only value that makes mathematical sense is 11, as all are prime numbers. Now consider antibiotic treatment durations in these two sequences: 3, 5, 7, X, and 14 days and 1, 2, X, and 6 weeks. What goes in the blanks? Most of us would likely answer 10 days and 4 weeks, but why? Do these number sequences serve a mathematical or scientific purpose? Do they have a special meaning or magical powers? In 321 AD, the Roman emperor Constantine the Great declared that there would be 7 days in a week.[6] As humans, we have 5 digits per limb. Hence, we often choose durations that are multiples of 5 or 7 for convenience. To highlight the silliness of this prescribing pattern, one expert coined the term "Constantine unit."[6]

According to psychologists, humans have a propensity toward magical thinking that develops in childhood but can persist into adulthood.[7] The application of magical thinking to numbers is called *numerology*—the belief in the mystical and divine relationship between numbers and outcomes. Consequently, our preferences for particular treatment durations are based not on science, but rather on the way we organize numbers in our minds. We think in chunks of time based on arbitrary human constructs. In my experience, a particularly potent number is 6 weeks, as many complicated infections that demand prolonged antibiotic therapy are often treated with a 6-week course in the absence of guiding evidence. Is it logical to assume that biology, physiology, or microbes care about our arbitrary units of time?

Since our unit of time is based on the 24-hour rotational cycle of the Earth, I wonder how our treatment durations would be different if humans had evolved 2.5 billion years ago, when it took only 18 hours for the Earth to make a complete rotation about its axis. If humans were to ever become an interplanetary species, would we need to recalibrate our treatment durations to correspond to the rotational speed of the planet we lived on? This would be problematic, as some planets spin very slowly (1 Venus day = 243 Earth days), while others spin faster (1 Jupiter day = 0.42 Earth days).[8]

In clinical trials comparing two different antibiotic durations for certain infections, the short and long treatment arms are typically multiples of 5 and 7, respectively, even though study investigators can choose any numbers they desire.[9-11] The fixation on these numbers can be quite strong, potentially limiting us from prescribing durations that might be better for some patients. Note that if noninferiority of the short duration is demonstrated, it does not mean the short treatment is the optimal duration, as optimal duration varies from person to person. It would be unwise to assume a fixed duration of treatment applies to every patient, because differences in host and microbial factors affect the time to recovery. How, then, do we determine the correct duration of antibiotic to prescribe?

Our preferences for particular treatment durations are based not on science, but rather on the way we organize numbers in our minds.

How to determine when the patient is cured

The optimal treatment duration is the minimum number of days, weeks, or months of antibiotic required to cure the patient of their infection. We typically rely on clinical, biochemical, microbiological, and/or radiographic findings to determine when the patient has been adequately treated for their infection. However, these parameters do not necessarily tell us that tissue destruction/invasion by the pathogen has ceased. It is common for clinical, biochemical, and radiographic abnormalities to persist beyond the completion of the antibiotic course, because the healing process (e.g., tissue repair, immune downregulation, symptom resolution) can last much longer.[12,13] In practice and in clinical trials, the definition of *cure* is arbitrary and can include as many or as few clinical, biochemical, microbiological, and radiographic elements as one desires. The greater the number of criteria required or the more stringent they are to satisfy the definition of *cure*, the harder it is for patients to achieve it. From a microbiological standpoint, *cure* is achieved when pathogens are no longer able to invade and multiply.

The goal of the antibiotic is to kill the pathogens or render them incapable of causing further disease. How much of the microbial inoculum do you need to kill to achieve this goal—80%, 90%, 100%? Do we even know? The vast majority of patients have an intact immune system that can fight off the invading microbes too, so we are not relying on the drug to do all the work. How do you determine when enough of the pathogens have been killed off that you can stop treatment? Unfortunately, we don't yet know how to figure this out. This realization calls into question our fundamental understanding of what it means to be cured. Persistent symptoms and signs of inflammation do not necessarily indicate ongoing infection.[12,13] On the other hand, the absence of inflammatory symptoms and signs does not exclude infection either.[14,15] Moreover, patient symptoms correlate poorly with pathogen burden.[16] Therefore, we don't actually know when a patient is truly cured of their infection, and, accordingly, an optimal duration might simply be an illusion.

Treatment durations in practice

Clinicians tend to favor certain treatment durations, particularly 5, 7, 10, and 14 days.[17] These fixed durations are inadequate, as they are not individualized. Consider this hypothetical scenario: There are 1000 patients with pyelonephritis, and you know exactly how many days of antibiotics are needed to cure each patient. You plot these numbers on a histogram, ending up with a normal distribution **[Figure]**. You are tasked with writing a recommendation on treatment duration in a guideline. Should you recommend 6 days (median)? That won't work, because only half of the patients will be cured. How about 8 days, so that at least 90% are expected to be cured? Unfortunately, 8 days results in overtreatment of most patients, who require 7 or fewer days. How about a range, such as 1 to 10 days? This would seem to be the most correct answer, but it fails if the clinician is unable to determine the precise number of days required for their patient. To combat this problem, biomarkers such as C-reactive protein and procalcitonin can be used to guide antibiotic duration, but these tools have limited predictive power of when the infection will have cleared.[18] Additionally, validated clinical criteria can also be used to determine the length of therapy.[19] Treatment guided by biomarkers and clinical criteria are a step in the right direction toward personalized antibiotic durations.

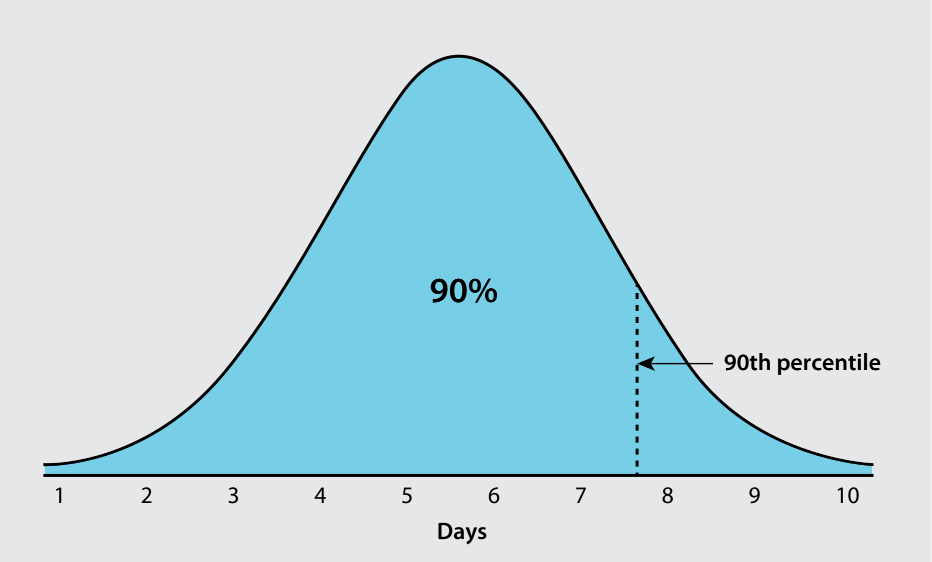

FIGURE. A hypothetical scenario of 1000 patients with pyelonephritis, with the number of days of antibiotics needed to cure each patient plotted on a histogram, resulting in a normal distribution.

Treatment durations are getting shorter

With the emergence of numerous randomized controlled trials demonstrating the noninferiority of shorter treatment durations, we now realize that many infections were historically treated for far too long.[20] It was previously thought that longer treatment was necessary to prevent infection relapse and subsequent development of antibiotic resistance, but modern clinical trials have repeatedly debunked this misconception.[21-23] Physicians tell their patients to finish a course of antibiotics even when they are feeling better, which stems from the aforementioned misconception. Considering that many patients receive antibiotic prescriptions for longer than the guideline-recommended duration and we do not yet know how to accurately individualize treatments, it is conceivable that this advice is never correct and may, in fact, be harmful. We are now recognizing that the opposite statement is true in some cases—stop the course of antibiotics when you are feeling better—but further research is needed to determine what *feeling better* means.[16,24] For example, in a clinical trial comparing 3 versus 8 days of antibiotics for the treatment of community-acquired pneumonia, patients who reached clinical stability (normal vital signs and mental status) by day 3 were randomized to either stopping treatment or continuing until day 8.[19] Those who stopped the antibiotic on day 3 fared just as well as those who stopped on day 8. Short-course therapy was commonplace in the 1940s, when antibiotic courses given for 1 to 4 days for the treatment of pneumonia were curative in most patients.[23] Eighty years later, modern evidence has proven that this is still true. Some obvious advantages of shorter treatment include reduced selection pressure that drives antimicrobial resistance, lower costs, diminished risk of *Clostridioides difficile* infection, and decreased risk of adverse drug effects. As we continue to experiment with shorter lengths of therapy, we inch closer to that coveted optimum duration.

Conclusions

Antibiotic treatment durations do not appear to have any biological basis. Although fixed treatment lengths dominate the therapeutic paradigm of infection management, they are inadequate and can result in overtreatment of many patients. With advancements in medical technology, there is hope that treatment durations can be fine-tuned to increase precision in our therapeutic decisions. Let's stop fixating on fixed durations and embrace the entire spectrum of numerals. ■

Competing interests

None declared.

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Electric micromobility devices: Balancing safety with sustainability

Electric micromobility devices, also called e-micromobility devices, including electric kick scooters (e-scooters) and electric bicycles (e-bikes) are economical, eco-friendly forms of active transportation. However, their use has raised concerns about the risk of injuries.

From 2021 to 2024, the BC government held the first phase of an e-scooter pilot project in 13 participating communities.[1] A new 4-year pilot was then initiated in more communities and to collect better health and safety data. However, people are using e-scooters across our region, regardless of whether they live in a formally participating community.[2]

In BC, e-scooter users must be 16 years of age or older, wear a helmet, not have passengers, not exceed speeds of 25 km/h, not ride while impaired, and generally not ride on the sidewalk.[3] Requirements are similar for e-bikes, which can travel up to 32 km/h. The use of lighter e-bikes with a maximum speed of 25 km/h is permitted by those 14 years of age and older.[4] However, enforcement and compliance with these rules have been challenging.

Statistics for e-micromobility device injuries are difficult to obtain due to a lack of complete, consistent, and reliable data; underreporting in charting notes; and inconsistent diagnostic coding. Several projects are underway across BC to improve injury data collection and surveillance in emergency departments, but results from these projects are not yet publicly available.

Review of e-scooter injuries shows a high prevalence of head, thorax, and extremity injuries, with low rates of helmet use[5,6] and drug/alcohol intoxication contributing to increased risk of head trauma.[6] E-bike riders had higher rates of spine and extremity injuries, higher ward and ICU admissions, a higher mean Injury Severity Score, an increased need for surgery, increased length of stay, and increased risk of death. This may be reflective of the mean age of users (i.e., generally older users).[7] Another source of injury and death related to these devices is fire from improper lithium battery recharging.[8]

From a public health perspective, a safe systems approach is critical to address the underlying determinants of road injury. Relevant components of this approach include safe road design (availability and quality of protected active transportation lanes), safe vehicles (devices designed and regulated to prevent altering or removing speed limiters postmarket), and safe road users.[9] Improving our understanding of the injury risks associated with e-micromobility devices requires better data on usage, standardized diagnostic coding, and improved reporting to better estimate injury rates.[10]

Balancing the physical health and environmental benefits of e-micromobility use while minimizing injury risk will be important as these devices become more popular. Currently, industry innovation in e-micromobility is outpacing government policy and regulation. Further government action through policies such as speed regulation and device compliance, education of drivers and vulnerable road users, and improvement of injury surveillance is required to promote and improve road safety in our communities. ■

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This article is the opinion of the authors and not necessarily the Council on Health Promotion or Doctors of BC. This article has not been peer reviewed by the BCMJ *Editorial Board.*

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Obituaries

We welcome original tributes of less than 700 words; we may edit them for clarity and length. Email obituaries to journal@doctorsofbc.ca. Include birth and death dates, full name and name deceased was best known by, key hospital and professional affiliations, relevant biographical data, and a high-resolution head-and-shoulders photo.

Dr Kurt N. Gottschling

1932–2025

With heavy hearts, we announce the passing of Dr Kurt Gottschling, who peacefully departed this life on 15 January 2025 at the age of 92. He passed away at Burnaby Hospital, surrounded by family and under the compassionate care of Dr Jamal. He has gone home to be with his Lord and Savior, leaving behind a legacy of kindness, dedication, and love.

Kurt was born in the Lublin District of Poland to German parents, Luise and August Gottschling. In August 1945, following World War II, his family relocated to Hamm, Westphalia, Germany. In April 1953, they immigrated to Prince Rupert, BC, and a year later, Kurt moved to Vancouver to pursue his passion for medicine at the University of British Columbia. He graduated from UBC's Faculty of Medicine in 1960 and completed a 1-year internship in family medicine at Vancouver General Hospital in 1961.

During his medical studies, Kurt met the love of his life, Martha Job. They married on 28 August 1959 at Ebenezer Baptist Church, building a life together rooted in love, faith, and family.

Kurt had a fulfilling and distinguished medical career. From 1961 to 2004, he maintained a thriving family practice in Burnaby, while also holding clinical privileges at Burnaby Hospital. He served as vice chief of staff at Burnaby Hospital from 1984 to 1985 and as chief of staff in 1986. From 1994 to 2002, he was an attending physician at George Derby Centre, and he later worked as a full-time surgical assistant at Burnaby Hospital and False Creek Surgical Centre, until his retirement in 2016.

Kurt was predeceased by his parents and his brothers, Dr Alvin Gottschling and Dr Gerd Gottschling. He is lovingly remembered by his devoted wife, Martha; his daughter, Gaylene, and granddaughter, Katelyn; his son, Rodney, and daughter-in-law, Eve; and his grandson, Matthew. He also leaves behind many beloved nieces, nephews, and cousins, as well as many dear friends.

A man of deep faith, Kurt was devoted to his Lord, his family, his profession, and his community. His generosity, integrity, and unwavering love of life were an inspiration to all who knew him. He found great joy in gardening, home repairs, fishing trips with his brothers and cousin George, classical and gospel music, reading, and traveling. Above all, his family was his greatest treasure, and he will be deeply missed.

The family extends their heartfelt gratitude to the nurses and care aides at George Derby Centre and Burnaby Hospital. A special thank you to Dr Jamal for his kindness and respect, which made Kurt's final days peaceful and filled with love. The family also expresses their gratitude to Pastor Albert Baerg for his hospital visits, prayers, and support.

In lieu of flowers, donations to the Burnaby Hospital Foundation in Dr Kurt Gottschling's name would be greatly appreciated. A celebration of life was held at Ebenezer Baptist Church in Vancouver on 29 March 2025.

—Gaylene Vickery
Burnaby

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VANCOUVER—GOOD SLEEP HEALTH INC.

Full- or part-time specialist physicians required to practise sleep disorders medicine in new, state-of-the-art sleep labs in Victoria, Burnaby, and Langley. We provide comprehensive sleep medicine services on Vancouver Island and in the Lower Mainland. Sleep medicine experience not required; training is provided. Excellent support is available, with physician assistants and capable, friendly staff. Remuneration includes consults and polysomnogram interpretations. Low-stress, highly rewarding work. For more information about this unique opportunity, please contact Dr Ron Cridland at 250 862-3050, email rcridland@kelownasleepclinic.ca, or visit our website at www.thesleepclinics.ca.

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RICHMOND—AESTHETIC/COSMETIC PRACTITIONER (DERMATOLOGISTS, FPs, NPs)

Our clinic in Richmond has provided trusted medical care since 1999 and is now expanding to include aesthetic and cosmetic treatments. We're seeking an aesthetic/cosmetic practitioner to join our team and offer nonsurgical treatments like Botox, fillers, and laser services. This role is ideal for dermatologists, family physicians, and nurse practitioners who would like to expand their practice. Our state-of-the-art facility and supportive environment are ideal for professionals looking to grow their practice. Opportunities to replace the retiring medical director also exist. To apply, email your CV and other relevant documents to singhal.stevestonmed@gmail.com. Join us!

SURREY—RCMP HIRING PHYSICIANS FOR OCCUPATIONAL HEALTH SERVICES, FT, PT, PERMANENT

As part of a multidisciplinary health services team at the RCMP E Division (BC headquarters) in Surrey, you'll be responsible for providing disability case management, with the goal of having members return to good health and to work. The OHS program supports members' fitness for duty through physical and psychological screening, monitoring, and risk assessment for specific occupational health conditions and hazards. You will provide advice to management on the health service needs of the membership. Experience in occupational health/preventive medicine is an asset. Provincial licensing and security clearance are required. Health/pension benefits and flexible scheduling offered. For details, contact Paulina Bjelos at 778 290-3332 or paulina.bjelos@rcmp-grc.gc.ca.

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MEDICAL OFFICE SPACE

NORTH VANCOUVER—MEDICAL OFFICE SPACE AVAILABLE

Shared office space in new office building in Central Lonsdale area; walking distance to Lions Gate Hospital. Flexible options available. Contact admin@doctorkler.com.

RICHMOND—BRAND-NEW STRATA MEDICAL OFFICES STEPS FROM CAPSTAN CANADA LINE STATION

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MISCELLANEOUS

VIRTUAL—ARE YOU WHERE YOU WANT TO BE? PROFESSIONAL COACHING FOR PHYSICIANS CAN PROVIDE POWERFUL INSIGHT

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EVENTS

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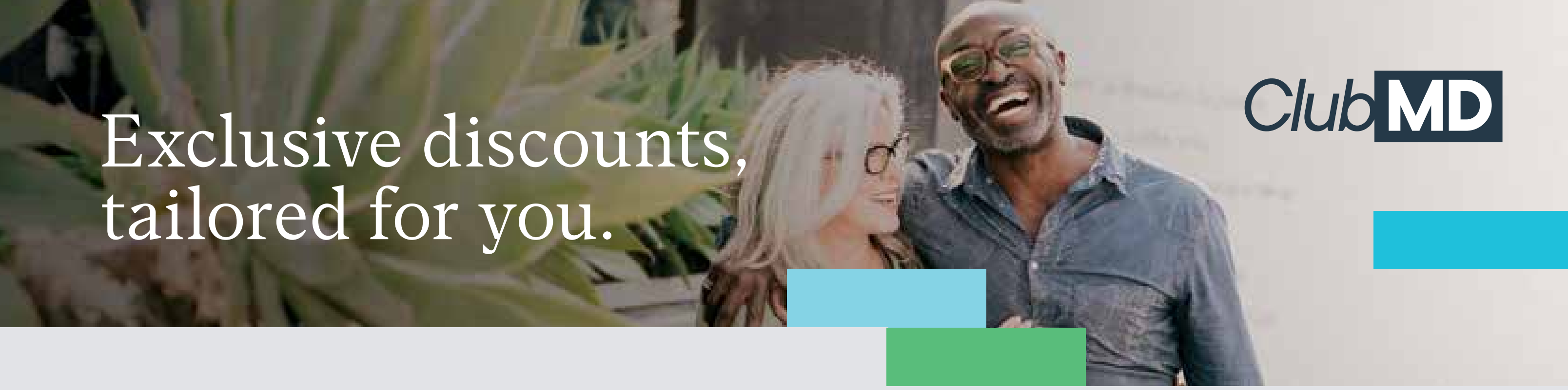

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