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# in this issue



# Health Advocacy

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The University of British Columbia Medical Journal (UBCMJ) is a peer-reviewed, student-run academic journal with the goal of engaging students in medical dialogue and contributing meaningful discourse to the scientific community.

# on the cover

This is a painting I made while I was reflecting on how little I know about the lives and health of many of the at-risk women and children living on the downtown east side. Although reading articles about the social determinants of health and health inequalities gave me an awareness of many health issues faced by vulnerable populations, I realized I still need to avoid making assumptions. I need to engage on an individual basis to understand how people's particular circumstance impacts their health.

The physical environment is dark and unstable. In the foreground are a mother and her child, who stand out as the only human figures walking along the sidewalk. The faces are not visible, unknown. Based on all this, it is easy to make an assumption about the mother and child in the painting - would you be surprised if I told you I was the child in the picture?

Garrett Barry, *Vancouver Fraser Medical Program, UBC Faculty of Medicine, Vancouver, BC*

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# in this issue

# Defining Health Advocacy in Medical Education

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Health Advocate is one of six essential competencies of the Royal College of Physicians and Surgeons of Canada (RCPSC) that medical students should attain by the end of their training. The RCPSC explains that, "as health advocates, physicians responsibly use their expertise and influence to advance the health and well-being of individual patients, communities, and populations."[1] This description emphasizes the purpose of health advocacy rather than the nature of activities involved in fulfilling the competency. It might be vague definitions similar to the one from the RCPSC that have made it difficult for educators and students in medical programs to appreciate the importance of health advocacy and the role of physicians beyond that of providers of clinically–reasonable care.

> Through collective action, health care professionals have the capacity to help patients access the resources they need for optimal well–being and to remove systemic barriers that impede patients' right to health.

After interviewing community–responsive physicians, Ivy Oandasan proposed that health advocacy involves acting as both indirect and direct agents of change.[2] As indirect agents of change, physicians provide patients with appropriate information and resources to ensure that they feel supported in all aspects of their lives. Achieving this capacity requires a physician to understand the social determinants that contribute to a patient's state of health as well as the services available to address concerns beyond the medical scope of practice. Physician activities that promote change indirectly include completing local and governmental agency forms and contacting community organizations for purposes of residence, counseling, and other social programs.[2] As direct agents of change, physicians develop and undertake action–oriented strategies to respond to a concern that is negatively affecting members of their community.[2] Such actions might include communicating directly with decision–makers to discuss health system issues and conducting a campaign to garner support from fellow professionals and the general public.

In a more recent study, Hubinette et al. derived three conceptualizations of health advocacy from interviews with family physician preceptors: clinical advocacy, paraclinical advocacy, and supraclinical advocacy.[3] Clinical advocacy involves supporting patients by employing appropriate diagnosis and treatment approaches, providing disease–related information, and promoting lifestyle change. Similar to Oadansan's definition of physicians as indirect agents of change, paraclinical advocacy focuses on provision of information and resources beyond the immediate clinical disease. Supraclinical advocacy parallels Oadansan's description of physicians as direct agents of change, where the emphasis is on addressing population–level issues.

Thus, based on the work of Oadansan and of Hubinette et al., health advocacy involves both ensuring that patients have access to necessary services within and outside the health care system and leading strategic efforts to promote the clinical and social well–being of a community.

So how do medical students engage with the activities intrinsic to health advocacy? Students around Canada have been active participants in leading protests and in communicating directly with federal and provincial policymakers to advocate for patients. Last year, the Canadian Federation of Medical Students (CFMS) focused on lobbying for a national pharmacare program at National Lobby Day on Parliament Hill and—most recently—through an editorial in the The Toronto Star.[4,5] These efforts, however, highlight the motivation and action of only a select group of students in influencing system–level change on topical issues.

As part of its curriculum, the University of British Columbia MD program offers second–year students a community service learning option (CSLO) in the Doctor, Patient and Society course.[6] In this option, students work directly with community organizations and targeted populations to understand and sometimes address the negative impact of social disparities on health.[6] Nevertheless, similar to the CFMS, it is typically students with a pre–existing interest in social and community issues who elect to participate in the CSLO.

For most other students, health advocacy is less of a priority than learning the high volume of biomedical and clinical information tested by exams and attending physicians.[6] Although the RCPSC recognizes Health Advocate as a key competency, no MD program in Canada has developed an educational approach to ensure that all graduating students understand how to recognize and resolve gaps in a patient's system of social care.[7] In contrast, several universities in the USA support advocacy training in their undergraduate and graduate medical curricula.[7,8] Boston University and Wright State University, for example, offer medical students comprehensive

health advocacy and leadership programs that include field experience, case-based modules, an independent research project centered on the design and evaluation of advocacy tools, and faculty-led mentorship.[7,9] Similarly focused training at the residency level of medical education has shown improvement in learner knowledge and leadership skills relevant to health advocacy.[8] Further research on the efficacy and long–term impact of different training methods at the undergraduate level will be invaluable in informing the development of advocacy education for Canadian medical students.[8]

The range of articles on health advocacy in this issue underscores the expanding interest of health care professionals, researchers, and community members in this field. Student authors have examined the impact of specific social determinants of health such as parental stress on childhood development (Kalil), the importance of physician leadership (Ip), and the role of physicians in the Canadian health care system (Jones). Our feature articles include an interview with Dr. Erica Frank, MD, MPH, Canada Research Chair in Preventive Medicine and Population Health, and an opinion piece by Dr. Carolyn Bennett, by Dr. Carolyn Bennett, MD, MP for St. Paul's electoral riding.

While health advocacy training in medical education will evolve, it remains clear that physicians are essential players in addressing negative social determinants of patient health. Through collective action, health care professionals have the capacity to help patients access the resources they need for optimal well–being and to remove systemic barriers that impede a patient's right to health.

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# Health Advocacy

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As physicians, we spend our professional lives advocating for the needs of our patients: timely access to specialist appointments, affordable medication, supportive housing, disability pensions, and numerous other things that improve their health and quality of life.

This role as an advocate is squarely within the spectrum of the role of a health care provider, and it can be interpreted as a professional responsibility to the individual patients and families under our care.

As Canadians are increasingly concerned about the sustainability of Medicare, it becomes clear that health care providers need to extend their advocacy to beyond just improving the quality of care in the system. We must also focus on improving the health of Canadians and use our expertise to effectively reduce their need for health care. This means that we must become active members of the movement advocated in the 1986 Ottawa Charter for Health Promotion of exchanging a 'health care system' for a true 'system for health'.

I myself became an accidental tourist in politics. When the future of Women's College Hospital was being threatened, a number of staff members, including myself, decided that the hospital represented our vision of the future of health care. The hospital empowered patients as true partners in their care, had pioneered interdisciplinary care teams, had recognized the need to move from hospital to community care, and had focused on determinants of health like violence and the environment. When I was first asked to run for office, I expressed my lack of political experience. It was quickly pointed out to me that the campaign to maintain the independence of Women's College Hospital had indeed been 'politics'.

It is important for all of us involved in health advocacy to recognize that we firstly have to explain that the word 'health' cannot be used interchangeably with the word 'health care'. As physicians and advocates, it is our job to then explain that our goal is to increase 'health' and thereby decrease the need for 'health care'.

Sometimes we can increase Health Literacy and engage more Canadians in our "movement' by asking a few simple questions, such as:

1. Would you rather have:
   a. A strong fence at the top of a cliff
   b. A state of the art fleet of ambulances and paramedics at the bottom
2. Would you rather have:
   a. Clean air
   b. Puffers and respirators for everyone
3. Would you rather have:
   a. An effective falls prevention program for seniors
   b. More orthopaedic surgeons and private hospitals
4. Would you rather have:
   a. A government that boasts about how much they are spending on the health care system
   b. Improved health of citizens leaving no one behind

Most people get it!

The efforts of health ministers alone will not fix the health of Canadians. Advocacy and efforts across all departments, in all levels of government, and across all sectors is the only way to reach Tommy Douglas's original goal for Medicare: keeping people well instead of patching them up when they get sick.

In order to reduce the 'tyranny of the acute' and invest properly in the health of Canadians, we need effective

As physicians and advocates, it is our job to then explain that our goal is to increase 'health' and thereby decrease the need for 'health care'.

voices explaining the need to deal with the modifiable risks as well as the social determinants of health, what Sir Michael Marmot calls the "causes" and the "causes of the causes" of ill health. I think we'd all agree with him that "the worst thing for a physician is to help someone get well, and then send them back into the situation that made them sick in the first place."[1]

Lately, one of the most effective examples supporting Sir Marmot's position were the poor outcomes during the H1N1 pandemic on First Nations reserves in Northern Manitoba. Living situations often consisted of as many as fourteen people residing in one home with no running water or toilets, resulting in unconscionable mortality and morbidity.[2]

On the flip side, the decision in Ontario to close the coal–fired generators has resulted in hugely positive health outcomes and savings. In 2000, an Ontario Medical Association study estimated the cost of smog days in Ontario to be one billion dollars per year in absenteeism and visits to doctors and hospitals. In 2005, there were 54 smog days, while in 2013 there were two.[3] In this example, health advocacy proved to be successful and probably saved the government over a billion dollars.[4] Those who advocated

for this change are thrilled, but the public needs a much better understanding of this significant success.

In 2004, as we were setting up the Public Health Agency of Canada after SARS, we decided that the concept of 'putting the public back into public health' needed to be built into the framework of the organization.

Political will is clearly a determinant of health. Political will clearly improves when public opinion is onside! So it is imperative that our advocacy is not only directed at politicians. Health care providers are amongst the most trusted members of Canadian society. In order for governments and decision–makers to make healthier public policy, we need to do everything we can to get Canadians onside. We have the data. We have the stories. Consider yourself deputized! We need all hands on deck! As Dr. Elizabeth Blackwell said over a hundred years ago, "We are not tinkers who merely patch and mend what is broken. We must be watchmen, guardians of the life and health of our generation, so that stronger and more able generations may come after."[5]

**As Canadians are increasingly concerned about the sustainability of Medicare, it becomes clear that health care providers need to extend their advocacy to beyond just improving the quality of care in the system. We must also focus on improving the health of Canadians and use our expertise to effectively reduce their need for health care.**

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Janny Ke, ***Untitled***

I painted this when I was exploring shadows in the healing process. Here was an intimate scene of suffering in the shadows, and a helping hand offering support and bringing light and warmth.

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# Becoming a Health Advocate: An Interview with Erica Frank, MD, MPH, UBC Professor and Canada Research Chair in Preventive Medicine and Population Health

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**When did you first recognize that you were an advocate?**

We all have repeated childhood experiences that encourage us either to be noisy or quiet. And I was always encouraged to be noisy, to speak up if something bothered me. Probably my most seminal event was when I was 11 and I went to Nepal with my parents. We were driving through Kathmandu, and saw some children who were amputees. When I asked our guide why they didn't have any limbs, he said their parents cut their arms and legs off at birth to make them better beggars.

It was just so clearly wrong to me that a parent could be so certain of a child's dreadful trajectory that the best they could hope for was to make them the best beggars they could be. That was the first time I can remember that I was struck by something that was so burningly wrong and inequitable, where I knew I had some substantial responsibility to try to fix it. I knew their parents had made the wrong decision, I knew that I had to try to fix a world where that was the best hope for someone. There was no other way I could be there and witness that, as a North American kid, able to leave whenever I wanted to, with all the attendant privileges that came with my being able to fly there for fun and learning.

**What in your family's background and character encouraged that kind of clear mission-driven advocacy?**

My father particularly enjoyed my being a loud iconoclast and speaking up when rules were stupid, and my working to make good rules—I imagine that some of this was a celebration of the liberation of our living in the United States in the late twentieth century, rather than

## I've always been a compulsive volunteer

where my parents grew up, in Hitler's Germany. My father was a renaissance man: an engineer, sculptor, painter, and civic volunteer. When I was 12, he was a volunteer member of our local environmental design review commission (in Princeton, New Jersey), and he got me on it as a volunteer also; this was an early lesson about the opportunities and obligations of civic engagement. Relatedly, most recently, I've been elected thrice here at the University of British Columbia (UBC), serving as a city counsellor for the University Neighbourhood Association (UNA) for the last six years, which has been a magnificent way to learn about and contribute to the practice, study, and promotion of positive social determinants of health. And I've passed the lesson forward—from age 14-16 my son was my volunteer Co–Chair for the UNA Emergency Preparedness Committee.

**How do you decide what to work on?**

I've always been a compulsive volunteer, and about a decade ago, when we were contemplating moving to Canada, I came up with ten principles to help me prioritize. I decided that activities that are good choices for me capitalize on my drive:

1. Drive to work on important problems
2. Desire to make a substantial contribution to fixing those problems
3. Unique and/or greatest skills/strengths
4. Experiences and credentials
5. Interests
6. Networks and alliances
7. Drive for autonomy and leadership
8. Desire to learn, grow, and be prepared for future steps
9. Need for things to feel right, ethical, logical, and loving
10. Desire for efficiency

I'm not suggesting that other people should adopt those rules, but it's useful to consider what your own set of priorities are; it's helped me a lot with transitions. How it's played out for me is that typically I said yes to everything where I thought it was important (characteristic number 1) and felt like I brought something particular to the table, or I could take something particular away from the table (numbers 2-4). It means volunteering for causes that you believe in and that feel nurturant, and sticking with them and adding more. I started volunteering my research expertise with the Canadian Medical Association as soon as I got to UBC, but I still work with the American Medical Association, and a lot with Physicians for Social Responsibility (PSR) [Dr. Frank was PSR's President in 2008].

**How can we contribute as future physicians?**

I think it's pretty easy to contribute both time (likely more after you're out of school) and money, because most doctors in North America can fairly rapidly acquire everything they could reasonably want, or at least need; my Maslow's hierarchy is completely full, all the way to right livelihood.

When we lived in Atlanta, I asked a revered colleague why he practiced so much clinical medicine instead of doing more of the transformative research and advocacy for his findings that really interested him, perhaps hiring others out of pocket or with grants to help him with that. He said it was because he lived in a gilded cage—his manicured home and grounds had a big mortgage, his spouse loved living there, and he didn't know how to get out. That struck me as a profoundly undesirable and completely avoidable outcome. I think there are a lot of things to do with your time and money that can bring you joy and pleasure and that also bring other people joy and pleasure. Even the Scroogiest amongst us knows that, right?

**It seems like you're really interested in caring for others, and sharing what you have, and it seems like you want to do it on a large scale.**

I think that if being a good doctor to a patient is a positive outcome, then being a good doctor to a whole lot of people is a whole lot better. So that's why I've always been interested in population health, because its scalability makes it both efficient and beneficent. If it's good, I want it to be good for everybody. If you can, why not? That's what prompted me to specialize in preventive medicine, and to come up with and prove the "Healthy Doc = Healthy Patient" [1] principle, and to conceive of and implement NextGenU.org.

I think another characteristic of those interested and effective in population health, especially preventionists[2] (doctors specializing in Preventive Medicine), is that we don't see ourselves as "other", that we often have low boundaries and long horizons. In my experience, we are invested in efficient beneficence and therefore tend to create evidence–based interventions at scale, and hug each other when we're done.

**Maybe this would be a good time to tell us about NextGenU?**

Sure. NextGenU.org is essentially the world's first free university—all our courses are for credit, for free, unlike any other organization. We collaborate with leading universities, professional societies, and government organizations including the Accreditation Council on Graduate Medical Education, American College of Preventive Medicine, Grand Challenges Canada, Harvard Institute for Lifestyle Medicine, North Atlantic Treaty Organization (NATO), Science for Peace program, U.S. Centers for Disease Control and Prevention (CDC), and the World Health Organization (WHO).

We've started with a focus in the health sciences, and our courses span from college–level pre–health sciences and community health worker trainings through medical and public health graduate training, residency programs, and continuing medical education. The courses are competency–based, and include online knowledge transfer, a web–based global peer community of practice, and local, skills–based mentorships. Our accredited partners are North American universities that are outstanding in each particular course topic, and that give learners credit for this training (or institutions can adopt the courses and use them with their students), all for the first time ever cost–free, and also advertisement–free, barrier–free, and carbon–free.

We now have over 3,000 registered users in 128 countries, and over 130 trainings in development. I conceived of NextGenU in 2001, and we globally launched our first full course in March 2012, Emergency Medicine (EM) for Senior Medical Students, in partnership with Emory University's WHO Center for Injury Control, the International Federation of EM, and the Society of Academic EM. This course, and other NextGenU courses, have now been demonstrated (including in a public health course pilot at Simon Fraser University)[3]

When we lived in Atlanta, I asked a revered colleague why he practiced so much clinical medicine instead of doing more of the transformative research and advocacy that really interested him . . . He said it was because he lived in a gilded cage—his manicured home and grounds had a big mortgage, his spouse loved living there, and he didn't know how to get out.

to imbue students spanning from North America to Kenya with as much knowledge gain and greater satisfaction than with traditional courses.

In 2014, we are focusing on Graduate and Continuing Medical Education. In June we began our first residency program, Family Medicine, with the first 130 of the 10,000 residents we have agreed to co–train in the next five years with the Sudanese government and the University of Gezira. Our next two residencies will be in Preventive Medicine and Occupational/Environmental Medicine; we will pilot these starting at Pacific Northwest University (in Washington state), University of the Incarnate Word (in Texas), and Universidad San Francisco de Quito (in Quito, Ecuador). We are developing these with the American College of Preventive Medicine, Association of Prevention Teaching and Research, Accreditation Council on Graduate Medical Education–International (ACGME–I), Harvard Institute of Lifestyle Medicine, and others

to create the first globally–available and ACGME and ACGME–I accredited residencies.

In addition, NextGenU has a sustainable business model. Like most founders, I helped jumpstart us (don't be afraid to spend your own money for your prize causes!), but we have just received a $16 million endowment (from the Annenberg Physician Training Program) that covers our core expenses, and receive additional grants from governments (e.g., $1.4 million from Grand Challenges Canada), quasi–governmental organizations (e.g., the NATO Science for Peace program,WHO), individual benefactors, and our biggest donors, our volunteer course developers, advisors, and mentors, and the thousands of experts who have generously shared their learning resources online, providing this unprecedented opportunity for democratized education.

**That's great that you've found or created all these sustainable outlets for your time and resources. A big question for medical students is their career choice. Might you have any advice on what else to consider besides income, location, and prestige?**

Think about what you want to do with the entirety of your life; consider how you want to be known. Reflect on what you want to accomplish with your personal and professional life as if they are intertwined in one life, because they are: the compartmentalization and boundaries that we're often encouraged to erect in medical training have their limits. Think about what you really need and want; as any kind of physician in Canada, you're likely going to earn way more money than what you really need to support yourself and a family, and your earning potential also buys you time to spend on whatever seems most important to you. And appreciate our privilege—in an ideal world, everyone would be able to have a job where they could spend a bunch of time learning in their twenties and know that it would launch them into a right livelihood and a good living for the rest of their lives. I think that with the amount of privilege that we have been given as physicians that we have an obligation beyond just doing a competent job seeing patients: I believe we have an obligation to give back with our time and our kindness because we have so much given to us. We could all be in others' shoes if we hadn't had the multiple pieces of personal good fortune that we all must have had (in addition to other attributes) to get into medical school.

**Can we close with my favorite advocacy story, the cigar story on your surgery rotation? It's encouraging!**

Back in the dark ages (I graduated from med school in 1988), we finally managed to get a prohibition on smoking on the hospital wards. I was proud to be part of that effort, so I followed up, circulating (as a third year med student) a highly scientifically–referenced petition to get the hospital gift shop to no longer sell tobacco. It was an obvious embarrassment to me and my classmates, faculty, and staff co–signers that our hospital would make money from selling tobacco, so I gave the petition to the CEO of the hospital. This precipitated some conversation between the Dean and the CEO, and the Dean and me, but my Dean was highly supportive (he was a psychiatrist who had been Georgia's Commissioner of Health and understood our sense of moral clarity here).

Following those wonderful successes, I'm walking down the wards one day on my junior surgery rotation, and there's this guy walking in front of me, with a white coat on, smoking a cigar. So I politely said to him "excuse me sir, do you know the rules about smoking in the hospital?" And he responded, "Young lady, do you know who I am?!". I replied, "no, sir, I don't." He said, "My name is Dr. Ellis Evans and I'm the Chief of Surgery in this hospital", to which I quietly replied, "well, sir, then you should know the rules", and he extinguished his cigar.

Since you're seeking inspiration, I should tell you the consequences. My Dean of course also heard about that, but it only solidified our bond, and my comfort and pleasure at being "out" as an advocate for public health. And at the end of the surgery rotation, my assessment said all sorts of nice things, and under weaknesses, there was only one listed: "Erica has interests other than surgery" — and I was rather willing to own that weakness!

**Weren't you scared?**

In moments like the one in the hallway, I feel exhilarated, like a conquistador going into battle on a holy crusade—I suppose I seize my lance and spear his cigar! I saw that cigar, and I saw that white coat walking down the hall, and I guess it struck me in the same clear way as those limbless children. Those two things, that white coat and that cigar, or those children and no limbs, do not belong together. That dissonance matters, and I feel urgently compelled to fix it. Absent a lance, I prefer the tools of science, justice, humor, and compassion.

**Surgeons live for that moment when patients need emergency appendectomy. It seems like you're similarly drawn to those public health emergencies.**

Yes, hah, that's right—that surgeon was my hot appendix, spreading his very own sepsis down the hallway! You and your colleagues have the opportunity to stop that kind of disease promotion every day—those public health emergencies/urgencies—in a score of ways that go beyond learning the facts and skills of physician–hood. If your classmates want to be part of such a community at UBC, they could of course join our mentorship group on advocacy, or should do whatever motivates them. But perhaps anyone reading all the way to here needs no further words of encouragement to create and fix something beyond a well–feathered gilded cage!

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# A Survey of Parental Barriers to Using Pain-Reduction Strategies During Childhood Immunizations

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## abstract

Objective: Childhood immunizations represent the most significant source of iatrogenic pain in otherwise healthy children. Consequently, children make correlations between the doctor's office and the anticipated pain from immunizations and these have long-term consequences such as procedural anxiety, needle phobias, and non-compliance with immunization schedules. Clinical guidelines exist for reducing pain during childhood immunizations. Our study analyzed the use of pain reduction strategies and assessed the barriers that parents face in a family practice setting.

Methods: We surveyed parents at academic family practice units at St. Michael's Hospital. A survey was developed based on a literature search and utilizing current pain reduction guidelines.

Results: 62 surveys were recorded and most parents were moderately concerned about their child's pain. A minority of parents had experience with any pain reduction strategies and the major barriers are related to a lack of knowledge and perceptions that pain is a normal part of the immunization experience.

Conclusions: We report multiple barriers that parents face when utilizing pain reduction strategies during immunizations. While knowledge, perceptions about pain, and time represent major barriers, health care providers should take an active role in advocating for children while working together with parents

## introduction

Immunizations represent a significant source of pain and anxiety for children, parents, and health care providers.[1,2] In Ontario, immunizations begin at two months of age[3] and continue throughout infancy, childhood, and adolescence. Based on current Ontario guidelines,[3] a child will receive at least ten immunizations in his/her first 18 months of life. This represents the most common source of iatrogenic pain for otherwise healthy children. Other provinces, including British Columbia, have similar immunization schedules. Additionally, annual flu vaccinations are recommended for children over six months of age.

Immunizations can be administered by a variety of health care professionals, including nurses, physician assistants, physicians, and pharmacists (flu shots only). Consequently, children often make early correlations between medical clinics and the anticipated pain from vaccinations.[4] Children often express their distress by crying, screaming, or flailing, and parents or health care providers must frequently physically restrain them.[5] These experiences are related to future procedural anxiety, fear of needles, and non–adherence to immunization schedules.[6] Up to 25% of adults have a fear of needles, and more importantly, most of these fears develop during childhood.[5]

In 2010, a clinical practice guideline for reducing pain during immunizations was published in the Canadian Medical Association Journal (CMAJ).[6] However, the uptake of these strategies has been suboptimal,[2] and often, little is done to address a child's pain in clinical settings.[7,8] Immunizations are integral to the health of children and communities. Reducing pain might improve the acceptance of immunizations and could empower parents to take actions towards this goal. The primary objective of our study is to assess the barriers to pain–reduction strategies in a family practice setting.[6]

## methods

Between January 2012 and April 2012, we surveyed parents at two of five academic family practice units at St. Michael's Hospital, Toronto, Ontario. Ethics approval was obtained through the St. Michael's Hospital Research Ethics Board.

The study population consisted of parents with children under 16 years of age who presented at one of the clinics. To meet inclusion criteria, their child had to follow the Ontario immunization schedule.[3] Parents who did not speak English or who did not have their child immunized for any reason were excluded.

A survey was developed (Appendix A, *see page 47*) based on a literature review and the 2010 CMAJ clinical practice guidelines. Survey responses were divided into four categories: 1) demographics; 2) parental perceptions about pain; 3) experiences and barriers to using pain–reduction strategies; and 4) education about pain–reduction

strategies. Parents were asked to quantify their concerns about pain based on their child's most recent immunization appointment to minimize recall bias. Four pain reduction strategies were selected from the guidelines[6,9] based on a parent's ability to administer them independently of health care providers. These include: 1) applying a topical anesthetic; 2) breastfeeding; 3) giving sucrose (sugar water); and 4) coaching older children to take slow, deep breaths during vaccine administration.[6,9] Parents were asked whether they had any experience with each strategy. If a parent had never tried it, a list of barriers was provided in a checklist. As the final element, we asked parents if they were interested in learning more about pain reduction strategies and about their learning preferences.

## results

### 1. Demographics

Sixty-two parents responded to the survey over the four-month period (Table 1). The majority of participants were female (82%), and most participants had a post-secondary education or greater (81%). The two largest ethnic groups were from North American and Asia. Eight surveys were completed by parents with a child too young for his/her first immunization.

### 2. Parental Pain Perceptions

Parents reported their perceptions about pain on a five-point scale (Figure 1).

Average parental concern was 2.7 ± 1.0 (moderately concerned). Out of 56 responses, 36 parents (64%) were moderately to very concerned about pain during vaccinations.

For children 24 months or younger, 78% of parents were moderately to very concerned about pain. Parents were also asked to rate their child's level of anxiety from 1 (not anxious) to 5 (very anxious). Their child's perceived anxiety averaged 2.1 (less anxious), and only 11% appeared very anxious about immunizations.

For older children, only 39% of parents were moderately to very concerned about pain. Their child's perceived anxiety averaged 3.3, with 31% of children being very anxious about immunizations.

Eight parents had children too young for vaccinations, but the majority of these parents were still moderately concerned about pain.

Please rate **your** level of concern about **pain** during your child's **most recent** vaccination:

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Not concerned | | Moderate | | Very concerned |

**Figure 1**: Sample survey question

Mothers tended to be more concerned about pain, but the difference was not statistically significant ($p=0.47$). There was no significant difference in pain perception based on level of parental education ($p=0.39$).

### 3. Pain Reduction Strategies and Barriers

We asked parents about four pain–reduction strategies that can be administered independently of health care providers. The survey then asked if parents had ever used these strategies, and if not what barriers they had faced (Table 2).

With regards to barriers, "Never heard of it" and "Doctor never discussed" refers to parents who were not aware of the strategies or have never talked about it with their doctor, respectively. "Time" refers to either the parent or the health care provider not having enough time in the clinic. "Pain is okay" refers to parents who thought pain is an inherent part of the vaccination experience. "Other" includes factors such as comfort with using the strategy, cost, and thinking that the strategy would not work.

#### Topical Anesthetics

Eighty–seven percent of parents had never tried topical anesthetics. "Never heard of it" and "Doctor never discussed" were the most commonly cited barriers. Cost for the cream was only cited once as a barrier.

#### Breastfeeding

Twenty mothers (32%) reported that they had tried breastfeeding, while 34 had never tried it. One mother who had tried breastfeeding found it ineffective. "Doctor never discussed it" and "Pain is okay" were the most commonly cited barriers. One mother cited that she would not be comfortable breastfeeding in the clinic.

#### Sugar Water for Infants <1 Year

No parents had ever given their child sucrose during immunizations. "Never heard of it" and "Doctor never discussed" were the most commonly cited barriers. Five parents reported that they were not comfortable using this strategy.

#### Coached Breathing for Children >3 Years

Thirty–six parents had children who were older than three years of age. Of these, 72% had never tried coached breathing, and 22% had tried it. Two parents found this to be an ineffective strategy. "Never heard of it," "Doctor never discussed," and "Time" were the most commonly cited barriers.

#### Common Barriers to All Strategies

We also grouped the results from each strategy to analyze the barriers from a broader perspective. Again, the two most commonly cited barriers were "Never heard of it" and "Doctor never discussed".

### 4. Education About Pain–Reduction Strategies

Forty–one (66%) parents expressed interest in education around pain–reduction strategies. Sixteen (26%) parents were not interested. The majority (41% and 23%) of parents wanted to learn about pain–reduction strategies from physicians or other health care providers, respectively. Seventeen percent preferred learning from the media or pamphlets.

## discussion

Immunizations are common in primary care settings, and pain is an important issue to address in pediatric populations. Immunizations are an integral part of health promotion, and in recent years, there have been outbreaks of vaccine–preventable illnesses. From 2007 to 2011, there were five outbreaks of measles, a preventable but highly contagious illness. The biggest outbreak in Quebec occurred in 2011, where an outbreak spread from a school to the local

community, reaching a total of 678 cases.[10] In Canada, only Ontario, Manitoba, and New Brunswick have policies that have mandatory school–entry immunization laws.[10]

From a health promotion perspective, the Ottawa Charter for Health Promotion serves as a framework to enable individuals to increase control over and improve their health.[11] Minimizing pain is an important issue, and providers should advocate and create supportive environments that encourage immunizations. While parents may not vaccinate their children for other reasons, pain is a ubiquitous issue that can be effectively addressed.

The majority of parents in our study were moderately concerned about their child experiencing pain during immunizations. There were no significant differences in pain perceptions based on parental gender or level of education. A study by Kennedy et al.[12] shows that pain was the most important concern with immunizations; however, health care providers did not routinely discuss pain management with parents.[13] We hope that by educating parents, they will be empowered to make informed decisions about their child's care. When asked about specific pain–reduction strategies, the majority of parents in our study had never tried any of the strategies. Taddio et al. reports that 70% of parents have never been educated about reducing pain,[5] and our results reflect this. "Never heard of it" and "Doctor never discussed" were the most commonly cited reasons, but these responses overlap and suggest that education and awareness around pain prevention is lacking. Other studies have demonstrated a similar knowledge gap, and "parents do not know that pain management strategies are available and how to implement them."[14] This represents an important opportunity for health care providers to engage parents in education.

Topical anesthetics, sucrose, and coached breathing were scarcely used among parents, and the major barriers were around knowledge. Though breastfeeding was the most commonly attempted strategy in our study, the majority of mothers had never tried it. One parent stated discomfort with the strategy, and as such, it may not be culturally appropriate or feasible for all mothers. It may be possible for these mothers to use sucrose instead, but as our results indicate, several other barriers exist for sucrose. The majority of parents were unaware that sucrose could sooth their child's pain effectively. Other issues relate to the availability of sucrose in clinics and costs associated with it. Furthermore, several parents were not comfortable with sucrose, and this could be linked to the view that sugar may harm their child's teeth. The next most commonly cited barrier was the perception that pain is a normal part of the immunization process. This may be related to cultural views or attitudes that pain is an inherent part of the process. However, we demonstrated that pain is an important concern for both children and parents, and the evidence shows that injection–related fears can be conditioned quickly during childhood.[13] Children more than 24 months of age were reported to be more anxious by their parents, highlighting the importance of intervening to decrease pain. Less commonly cited barriers included cost, comfort with using the strategy, and beliefs that the strategy would not work.

The majority of parents were eager to learn, and they preferred health care providers to educate them. Similar opinions were reported by Kennedy et al.[12] and Taddio et al.,[15] suggesting that all health care providers play a critical role in passing information about pain–reduction to parents. An illustrated guide for parents is available

**Table 1**: Parent and Child Demographics

| Characteristics | | Responses |
|---|---|---|
| Average Parent Age, y (± std deviation) | | 35.4 (±6.4) |
| Gender of Parent | Male* | 11 (18%) |
| | Female* | 49 (82%) |
| Highest Level of Parental Education | ≥ Post-secondary^ | 47 (81%) |
| | < Post-secondary^ | 11 (18%) |
| Average Child Age | | 26 months |
| Age Range of Child | | 1 week to 12.5 years |
| Female Children** | | 26 (49%) |
| Male Children** | | 27 (51%) |

*Missing data for 2 surveys and excluded from calculation
^Missing data for 4 surveys and excluded from calculation
**Missing data for 9 surveys and excluded from calculation

**Table 2**: Parental Use of Pain-Reduction Strategies

| Strategy | Number of parents who have never tried this strategy | Most common barriers |
|---|---|---|
| Topical Anesthetics | 54 (87%) | 1. Never heard of it (41%)<br>2. Doctor never discussed (22%)<br>3. Pain is okay (17%) |
| Breastfeeding | 34 (55%) | 1. Never heard of it (31%)<br>2. Doctor never discussed (28%)<br>3. Pain is okay (13%)<br>4. Other (13%) |
| Sugar Water (<1 year) | 57 (92%) | 1. Never heard of it (41%)<br>2. Doctor never discussed (31%)<br>3. Pain is okay (9%)<br>4. Not comfortable (9%) |
| Coached Breathing (>3 years) | 26* (72%) | 1. Never heard of it (25%)<br>2. Doctor never discussed (25%)<br>3. Time (25%) |

*From the survey, only 36 children were >3 years of age

online[16] and it can be displayed in clinics and distributed online. Another resource has videos and age–specific recommendations[17]. However, 26% of parents were not interested in learning about pain reduction strategies. This represents a major barrier, and it is important to raise awareness about the consequences of untreated pain. Given the endorsement of pain–reduction strategies by the Canadian Pediatric Society and the Public Health Agency of Canada, future directions should focus on continued efforts for widespread implementation and parental education. Pain reduction strategies should be worked into a clinic's workflow, and supplies such as sucrose and topical anesthetics should be made available. Lastly, these strategies can also be applied towards other painful procedures such as venipuncture or other minimally invasive procedures.

### Limitations

This study has limitations related to our small sample size and the generalizability of our results. Parents were patients of an academic, urban family health unit, so this may limit the generalizability towards paediatric clinics, non–academic clinics, or other models of practice.

### Conclusion

Pain is an important issue for all children, but the use of pain–reduction strategies during routine immunizations remains suboptimal.[2] Many parents have never used pain–reduction strategies, and they face several barriers such as a lack of knowledge or health care providers not encouraging these strategies. Continued efforts to implement these strategies will help to promote the health of children and communities in the future.

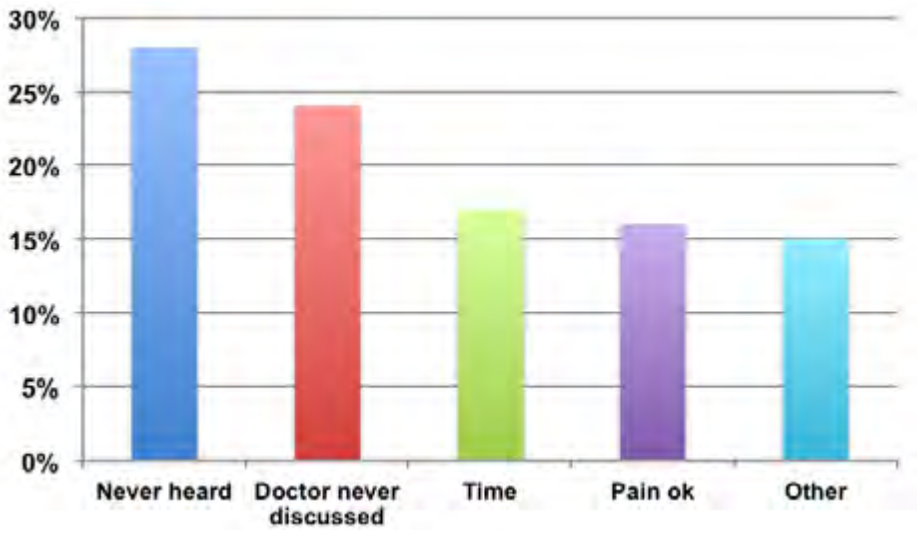


**Figure 2**: Overall barriers to using pain reduction strategies as a percentage of total survey responses

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# Length of Family Medicine Training and Readiness for Independent Practice: Residents' Perspectives at One Canadian University

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## abstract

**Objectives**: There is ongoing debate in North America around the appropriate length of training for family physicians. This pilot study presents a qualitative exploration of the viewpoints of family medicine residents at one Canadian university. Residents were asked to reflect on their level of readiness for practice following the standard two years of training.

**Methods**: Twenty–three family medicine residents completed an online qualitative survey where they ranked their self–perceived level of preparedness around the key CanMEDs–FM roles and competencies. Six residents participated in a follow–up focus group interview. A qualitative analysis of written responses to the survey and focus group data provided insight into the residents' viewpoints.

**Results**: Among the residents surveyed, there was a sense that two years of training was not enough to adequately prepare for independent practice. Residents reported feeling well prepared around competencies related to communication skills and psychosocial issues; however, they indicated that greater exposure to a broader spectrum of clinical domains and issues around practice management would better prepare them as generalists.

**Conclusions**: Lengthening training in family medicine continues to receive mixed reviews. Canadian family medicine residents need to master a wider breadth of knowledge within a shorter training period compared to their peers in other specialties. The new competency–based curriculum (Triple C) in family medicine may influence the residents' sense of readiness for practice.

## introduction

Length of residency training in family medicine varies from two to five years around the world, with two years as the present standard in Canada.[1] Issues around the duration of residency training is an important focus of the medical community to determine the most effective way to prepare family physicians.[2] The current debate around the appropriate length of training for family physicians goes back several decades.[3-9] The resurgence of interest in this debate is based on several factors, many of which are comprehensively outlined by the Chairs of family medicine departments across Canada in a recent publication.[10] The Chairs all agreed that residency training is "very short"[10] in relation to all other specialties. However, they recognize that it is becoming increasingly difficult to become a competent family physician with two years of training given the increasing complexity of the health care system and the prevalence of multimorbidity in the family practice patient population.[11]

The current two-year family practice residency program enables learners to rotate through the various specialties of surgery, obstetrics, pediatrics, internal medicine, and emergency medicine. Approximately half of the residency is spent in community-based family practice. The introduction of the new Triple C Curriculum—a competency-based curriculum centered in family medicine and framed on continuous, comprehensive care, and education[12]—has rekindled the debate on length of training. This new postgraduate family practice curriculum aims to shift more specialty rotations to the community to ensure that the curriculum is truly family practice-focused. However, the impact of such a shift on the length of training overall is unknown. The recent report on length of training by the Working Group on Postgraduate Curriculum Review indicates that the current two-year standard in family medicine is not grounded in "objective evidence,"[1] a finding also confirmed by a newly-released systematic review on length of postgraduate medical training in Canada for all specialties in medicine.[13] Though third-year training is a hotly debated proposition,[15-23] Green and colleagues found a paucity of research to inform discussions when they studied the perspectives of family medicine residents and program directors on third-year family medicine programs.[14]

Literature describing residents' perceptions on preparedness for practice is limited and generally looks at preparation in terms of the four principles of family medicine[24] or the six areas of competence by the American Accreditation Council for Graduate Medical Education (ACGME).[25] There is little knowledge about the perspectives of family medicine residents on their self-

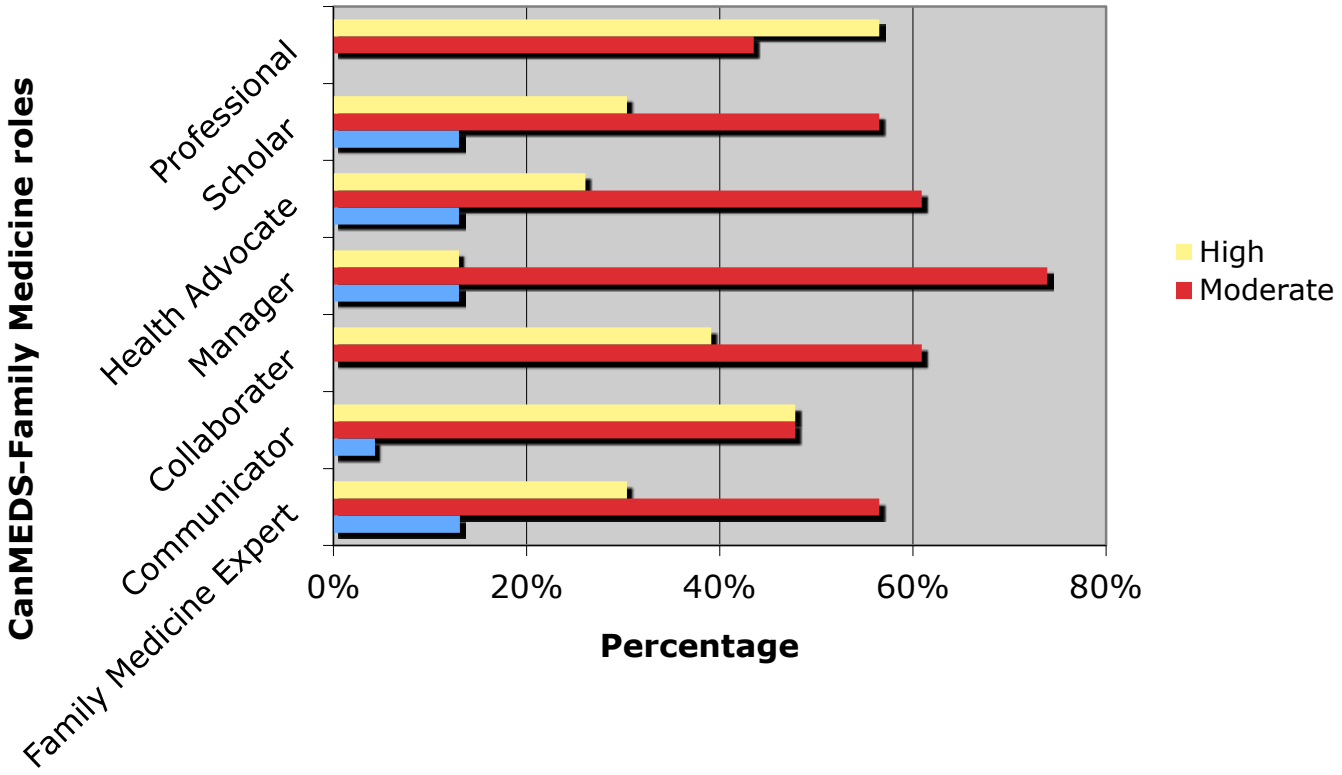


**Figure 1**: Family medicine residents' self-perceived level of competence in the CanMEDS-Family Medicine roles.

perceived level of preparedness around the framework of competencies outlined in the Canadian Medical Education Directions for Specialists for Family Medicine (CanMEDs-FM) in relation to their length of training and sense of readiness to start independent practice following graduation.[26]

This pilot qualitative study explores the perspectives of a group of family medicine residents from the University of British Columbia on their level of preparedness around the competencies outlined in the CanMEDs-FM framework and their sense of readiness for independent practice in relation to these competencies following two years of residency training.

## methods

Given the scarcity of data around resident perspectives on length of training and level of preparedness, a qualitative research design was most appropriate for this study.[27,28] Ethics approval was obtained through the Behavioural Research Ethics Board at the University of British Columbia. One hundred and twelve second-year family medicine residents were invited to participate in the study. Twenty-three residents agreed to participate. Data collection took place just prior to completion of residency training.

The participants were asked to complete an online survey. The first part of the survey asked residents to rank their self-perceived level of preparedness around the key CanMEDs-FM roles and related competencies (Family Medicine Expert, Communicator, Collaborator, Manager, Health Advocate, Scholar, Professional) using a scale of low, moderate, or high. The second part asked them to explain why they perceived their preparation in certain areas to be low or moderate and what might have influenced this. The survey also asked residents to comment on how residency training could enhance their knowledge and skills, as well as their views on the length of residency training in relation to achieving the required competencies. Six of the 23 residents agreed to participate in a follow-up focus group interview. The aim of the follow-up focus group was to explore in detail the findings of the web-based survey. The focus group lasted 90 minutes. Participants were asked to discuss three issues: their level of preparedness for practice in relation to the CanMEDs-FM competencies, their thoughts regarding the variations in preparedness for the different CanMEDs-FM roles, and their views on the length of residency training. A family medicine resident (co-author KJ) conducted the focus group interview. The focus group was audiotaped and transcribed verbatim for analysis. The quantitative data was presented as percentages of participants with low, moderate, and high levels of competence in each of the CanMEDs-FM roles. Qualitative analysis of written responses to the online survey coupled with analysis of the focus group data provided insight into the residents' perspectives on their level of preparedness in relation to the CanMEDs-FM competencies and the adequacy of a two-year training program for achieving the capability for independent practice following graduation.

Informed by Braun and Clarke's work on thematic analysis[29]—organizing, interpreting, and consolidating qualitative data in relation to the research objective—we examined the written responses to

the web-based data together with the focus group data. The data were analyzed to distinguish a pattern of recurrently-expressed ideas. The emergent patterns were examined further through independent readings of the data, as well as using an iterative process to establish significant similarities and differences. The patterns were then organized into categories of meaning, which were then compared and collapsed into major themes.

## results

The findings are organized thematically. Representative quotes and phrases for each theme are included. Results of the online survey are presented in Figure 1. All survey participants ranked their level of preparedness in both the Professional and Collaborator roles as moderate or high. The Communicator role received a low score from 4.3% of respondents, while the Scholar, Health Advocate, Family Medicine Expert, and Manager roles were ranked as low by nearly 15% of the participants. When asked about length of training, the participants expressed mixed feelings: some believed two years of training was adequate and additional time would not likely enhance their preparedness for practice in the context of the CanMEDs-FM roles. Yet, all residents expressed a desire for more exposure to a broader spectrum of clinical domains.

Written content from the web-based survey combined with results from the focus group interview yielded five themes: themes 1 and 2 highlight the residents' viewpoints around those aspects of family medicine training they felt well prepared for, i.e. the Collaborator and the Professional roles, while themes 3-5 highlight concerns regarding the remaining CanMEDs-FM roles in relation to length of training.

### Theme 1: Communicator and Collaborator Roles: The Patient-Physician Relationship

All residents felt very well prepared in establishing a strong patient-physician relationship through effective communication skills. They felt that this competency was well-emphasized in their training:

"We can take a patient who comes in with a million things and make them feel heard." [*Survey response*]

Some residents observed a striking contrast between their specialty peers in terms of comfort with and utilization of high-level communication skills. They found this surprising, as all disciplines should be able to communicate effectively. Residents also indicated that the opportunity to work with socioeconomically-marginalized populations was a key factor in helping them realize the value of effective communication. The residents all agreed that the family medicine residency program successfully developed their ability to establish and maintain effective communication and collaboration with patients, which helped them better understand and cultivate patient-centered care.

### Theme 2: Professional and Health Advocate Roles: Practicing Comprehensive, Holistic Care

There was general agreement that a significant strength of the family medicine residency was training that enabled residents to incorporate psychosocial aspects of the patients' illness into the delivery of primary care. The residents agreed that the concept of "comprehensive medicine" received considerable focus in the curriculum; this included a strong emphasis on treating or advocating for the care of the "whole person and not simply the disease." Residents also indicated that they were well prepared to gather and analyze information related to the patient's illness experience beyond simply managing the clinical symptoms.

"…We did focus on 'putting the need of a patient first' [and] figuring out the population [and] putting a patient in the centre [and] bringing their families in." [*Focus group response*]

Residents stated that an additional focus on professionalism and the humanistic philosophy of care set the practice of family medicine distinctly apart from other specialties.

### Theme 3: Medical Expert and Manager Roles: Would More Training Impact Sense of Competence?

The residents expressed mixed feelings regarding the standard two-year length of training and their perceived competence

**The introduction of the new Triple C Curriculum—a competency-based curriculum centered in family medicine and framed on continuous, comprehensive care, and education—has rekindled the debate on length of training.**

in the Medical Expert and Manager roles. Many participants said that a two-year residency program was adequate with the view that most of their clinical learning would happen while in practice:

"I think that a two-year residency is sufficient for residents that will be [*sic*] very self-directed and work hard to achieve competency in that time. I think that at some point the best way to learn is to be out doing it on your own, as long as you have the resources to continue learning and to know your limitations." [*Survey response*]

However, some residents said that an extra year of residency could help them gain more confidence transitioning into independent practice. They expressed a desire for greater exposure to different domains of clinical care, along with procedural skills in common emergency presentations.

"If we could have a month of Ophthalmology, a month of Dermatology, a month of ENT, a month of Sports Medicine so I don't feel so MSK [musculoskeletally] deprived, it would be so good. I would be so much happier finishing residency." [*Focus group response*]

Although most residents indicated moderate preparation for the role of Manager in the survey, there was a common sentiment in the qualitative responses and the focus group that there was insufficient exposure to the more practical side of running a practice.

When teaching guidelines throughout all facets of residency, they felt that a structured approach—from didactic sessions to direct application of knowledge in clinical settings with faculty supervision—would increase their sense of confidence around competencies related to the clinical application of the Scholar role.

"It would be nice to know how much things cost and how money is designated to what. We don't know what's behind that at all, like how much a lab test costs. Just managing resources—what things costs, and why this is the way it is." [*Survey response*]

"[Not knowing] almost deters us from wanting to open our own practice." [*Focus group response*]

The residents desired basic knowledge on how to start a new practice, financial planning, legal issues, remuneration options, and the general day-to-day workings of a medical office.

### Theme 4: The Scholar Role: The Family Physician as Teacher and Scholar

The residents expressed a desire for a more structured learning environment and focused training on "evidence-informed guidelines." When teaching guidelines throughout all facets of residency, they felt that a structured approach—from didactic sessions to direct application of knowledge in clinical settings with faculty supervision—would increase their sense of confidence around competencies related to the clinical application of the Scholar role.

Residents also suggested that "academic half days [be] tailored to the family medicine certification examination." To this effect, they wanted a more directed educational experience with specific instruction around what to study and how to prepare for the certification examination and the Short Answer Management Problems (SAMPS). Similarly, the residents wanted more meaningful involvement from their preceptors. Many felt that family medicine preceptors had the capacity to contribute more actively to the residency experience and should be better enabled to do so.

## discussion

Though the findings reported in this pilot study are based on a small sample size from one Canadian university, some insight can be drawn from the perspectives of final year family medicine residents on their preparedness for practice in the context of the CanMEDs-FM roles and related competencies. The residents we studied all agreed that their training prepared them to be effective communicators and to attend to psychosocial issues in medicine. Their perspectives reflect the importance of the patient-physician relationship in primary care, which is a focus of family medicine.[30] However, many felt unprepared to handle various aspects of clinical medicine. In particular, they felt unprepared to effectively manage certain components of an independent practice, such as finances and human resources. Lack of confidence in office management and the judicious use of health care resources were regarded as key barriers to readiness for independent practice following graduation. The residents wanted a more structured teaching environment, particularly in evidence-based medicine and guidelines, as well as greater involvement from their clinical preceptors in learning sessions. The residency curriculum currently uses weekly academic sessions to teach some CanMEDs-FM core competencies. The program could further develop this academic curriculum to highlight the Manager and Scholar roles. In addition, the program could ensure that these sessions are led by family physician preceptors to increase their engagement in teaching and better model the different CanMEDs-FM roles for residents. To feel better prepared in their role as generalists, residents asked for greater exposure to a range of specific clinical domains within a primary care context, such as dermatology, rheumatology, sports medicine, gynecology, and ophthalmology. The shift to the Triple C curriculum with its emphasis on community-based learning may address this aspect of residency training to some degree. Regardless of training exposure, it is likely that practitioners will gain competence and confidence in managing the breadth of family practice through independent application during the first five years of practice. As such, there is an initiative nationally to better support residents upon graduation and through their first five years of practice. Future directions of residency training may therefore focus not on ensuring that every clinical domain is embedded in curriculum, but on ways to engage residents in life-long learning.

Finally, based strictly on analysis of pass rate on family practice certification exams, there is no indication that gaps in the medical knowledge of graduating residents exist;[31] in other words, from the perspective of medical knowledge, graduating family medicine residents appear to be well prepared for independent practice. However, some studies suggest that residents who perceive a gap or feel unprepared often limit their scope of practice.[32] The importance of our findings is based on two assumptions: 1) that perceived preparedness relates to actual preparedness; and 2) that the certification exam in family medicine measures actual preparedness for independent practice.

### Limitations

There are several limitations in this pilot study. The findings here are not intended to be generalizable, but to inform further work. The response rate was small; therefore, the results do not necessarily reflect the overall experience of all family medicine residents at the University of British Columbia. The convenience or volunteer sample of 23 out of a possible 112 residents increases the possibility of

a selection bias. In addition, the resident-led design of the study may introduce a component of social desirability bias, while the focus group data can be influenced by group dynamics and intergroup bias. We also acknowledge that the three-point Likert scale (low, moderate, high) may introduce a central tendency bias. Finally, literature regarding physician inaccuracy in self-assessment should be taken into account when interpreting our findings.[33] Direct assessment of residents' abilities in the CanMEDs-FM roles would have been optimal; however, this was not possible due to time constraints and a lack of required resources.

## Conclusions

This pilot study explored the self-perceived level of preparedness among family medicine residents in the context of the CanMEDs-FM competencies, which has not yet been presented in the Canadian literature. We learned that residents felt prepared for the Collaborator, Communicator, and Professional roles; however, they described only moderate preparedness for the Scholar, Health Advocate, Family Medicine Expert, and Manager roles. Family medicine residents are required to master a wider breadth of knowledge within a shorter training period compared to their peers in other specialty residencies. Framed in the CanMEDs-FM roles, the new Triple C competency-based curriculum has been introduced to ensure that residents are prepared to practice in the complex health care system. It remains to be seen whether Triple C will influence residents' self-perceived sense of preparedness and competence for independent practice, particularly around those areas that have been identified in this study as needing attention.

Though the findings of this pilot study are limited, these are interesting initial results that require further exploration across different family medicine programs in Canada and elsewhere. The authors hope that these findings will stimulate and guide continued evaluation of the impact of the Triple C competency-based curriculum on family practice residency education.

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**Lack of confidence in office management and the judicious use of health care resources were regarded as key barriers to readiness for independent practice following graduation.**


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# The Clinical Presentation and Diagnosis of Vogt-Koyanagi-Harada Syndrome

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## abstract

Vogt–Koyanagi–Harada syndrome (VKH) is a rare inflammatory disorder diagnosed clinically that presents as panuveitis with serous retinal detachments among other systemic symptoms.[1] Treatment options for this disease vary, but pharmacotherapy with systemic corticosteroids is the mainstay. Ruling out infectious causes prior to initiation of corticosteroids is vital as immunosuppression may worsen disease of an infectious etiology. Herein, we describe an otherwise healthy 34–year–old Métis woman with a three–week history of bilateral uveitis presenting with new onset of tinnitus and skin pigment changes started on high–dose IV corticosteroids with clinical improvement of symptoms.

## introduction

Vogt-Koyanagi-Harada syndrome (VKH) is a rare systemic disease (1.5 people per million) involving melanocyte-containing organs. It is a granulomatous inflammatory disorder that affects the eyes, auditory system, meninges, skin and often presents with neurological findings.[1] VKH occurs in certain ethnic groups that possess darker skin pigmentation such as Native Americans, Asians, Hispanics, and those from the Middle East.[2] Women are usually affected twice as commonly as men and incidence is usually highest in the third or fourth decade of life.[2] VKH is diagnosed clinically, encompassing the patient's signs and symptoms while excluding other possible causes. There are four clinical stages: prodromal stage, acute uveitic stage, convalescent stage, and chronic recurrent stage. These stages of VKH are often indistinct.[3]

Initial manifestations occur with a prodromal stage that consists of headache, nausea, vertigo, fever, and meningismus.[3] Neurological features may also occur but are rare. Tinnitus and hypersensitivity of the skin generally appear early. This stage can last three to five days.[1]

The second stage is the acute uveitic stage, where bilateral blurry vision presents in 70 % of patients.[3] Most patients present in this stage when they experience ocular pain and red eyes. There can be choroidal inflammation and thickening. Multifocal detachments of the neurosensory retina can be pathognomonic for VKH.[3] Eventually the inflammation and posterior uveitis may extend into the anterior segment.

The third stage, the convalescent stage, follows the second stage gradually. This stage may last several months.[1] This stage includes extra–ocular manifestations such as vitiligo, alopecia and poliosis. Further, there can be a uveal depigmentation within two to six months.

The final stage is the chronic recurrent stage, which interrupts the convalescent stage.

There are recurrence rates of 43 % within the first three months and 52 % within the first six months, often associated with rapid tapering of corticosteroids.[4] Recurrence mainly involves anterior uveitis. In this stage, complications of VKH such as glaucoma, cataract, subretinal neovascular membrane, and subretinal fibrosis may develop.[1]

Herein, we report a patient presentation of VKH in rural northern British Columbia. The patient was treated as an outpatient with a course of systemic corticosteroids.

## case presentation

An otherwise healthy Métis 34-year-old female with a three-week history of severe bilateral uveitis, currently being treated with diclofenac (Voltaren®), prednisolone (Pred Forte®), and olfloxacin (Ocuflox®), presents as an outpatient to an ophthalmologist with new onset of tinnitus and patches of vitiligo in addition to the persistent uveitis. Prior to her initial ocular complaints, the patient had chills and headaches with an acute illness. Family history is significant for ankylosing spondylitis.

Examination on initial consultation revealed best–corrected visual acuity (BCVA) of 20/40 OD and 20/30 OS with intraocular pressures (IOP) of 11 mmHg and 12 mmHg, respectively. Biomicroscopy revealed that the cornea and lens were clear bilaterally. The dilated fundoscopic examination revealed occasional to 1+ cells in the anterior chamber and 2+ cells in the posterior chamber of the right eye. The left eye displayed occasional cells in the anterior chamber. Ophthalmological exam of the right eye showed significant optic nerve edema (360°) with serous retinal detachments superior to the optic nerve and just superior to the fovea. In the left eye,

there was significant macular edema in a serous retinal detachment.

Complete VKH Syndrome was diagnosed according to the revised International Diagnostic Criteria outlined by the American Uveitis Society (Figure 1) in which a patient must demonstrate symptoms in five distinct categories.

## investigations

Because mainstay treatment of VKH involves systemic immunosuppression, it was important to exclude other autoimmune or infectious causes associated with bilateral uveitis (e.g. tuberculosis or syphilis)[3] as immunosuppression could further aggravate the condition. Therefore, several tests were ordered, including CSF analysis, Lyme serology, syphilis serology, serum ACE, ESR, CRP, serum protein electrophoresis, serology for cat scratch, and a full 120° visual field test. The patient had slight pleocytosis in the CSF but subsequent culture for bacteria was negative. All other tests were unremarkable.

The CSF analysis was relevant because more than 80 % of patients with VKH disease exhibit a transient CSF pleocytosis within one week and 97 % within three weeks of onset.[5] The pleocytosis resolves within eight weeks of onset in most patients.

Fluorescein angiogram showed diffuse choroiditis with focal delays in choroidal perfusion and multifocal areas of pinpoint leakage, and large placoid areas of hyperfluorescence with pooling within the subretinal fluid and optic nerve staining.

The clinical findings associated with the investigations aided in the diagnosis of VKH while excluding other possible systemic causes.

## treatment

VKH is treated with systemic intravenous or high–dose oral steroids. Possible treatment regimens for VKH are listed in Figure 2. High–dose oral corticosteroids, 80-100 mg per day of prednisone or 200 mg of intravenous methylprednisone for three days followed by oral administration of high–dose corticosteroids with a slow taper are the mainstay of therapy for VKH.[1] Recurrences may prove to be corticosteroid–resistant so cyclosporine 5 mg/kg per day is instead prescribed.[1]

This patient was treated with IV methylprednisolone 1 g for three days and then oral prednisone 80 mg daily on a tapering dose. The corticosteroid treatment, in addition to her treatment for bilateral uveitis, resulted in reduced optic nerve swelling of the right eye and resolution of serous retinal detachment bilaterally. The patient's oral systemic steroids continued to be tapered over the next six months and the patient's vision continued to improve. As the patient's steroid dose was tapered, the BCVA was 20/40 OD and 20/25 OS with IOPs 15 mmHg and 16 mmHg, respectively (physiological range between 10-21 mmHg).

| |
|---|
| 1. There should be no history of ocular trauma or surgery |
| 2. There should be no clinical or laboratory evidence of other ocular disease entities |
| 3. The uveitis must be bilateral exhibiting either A or B<br>A) Early Disease<br>i) Diffuse Choroiditis with either focal or bullous subretinal fluid<br>ii) If fundal appearances are equivocal must have:<br>a) Focal choroidal perfusion delay, pinpoint leakage, placoid fluorescence and optic nerve staining on fluorescein angiography and<br>b) Diffuse choroidal thickening but no scleritis<br>B) Late Disease<br>i) Suggestive history of 3A and either ii or iii<br>ii) Depigmentation, either sunset glow or Sugiura's sign<br>iii) Nummular chorioretinal scars with retinal pigment epitherlium (RPE) clumping and migration and recurrent chronic anterior uveitis |
| 4. Active or histoy of either meningism, tinnitus, cerebrospinal fluid pleocytosis |
| 5. Alopecia, poliosis, or vitiligo |
| Complete VKH Syndrome requires Criteria 1-5, all inclusive<br>Incomplete VKH Syndrome requires Criteria 1-3 and either 4 or 5<br>Probable VKH requires Criteria 1-3 |

**Figure 1**: Revised International Diagnostic Criteria for Vogt-Koyanagi-Harada (VKH)

| |
|---|
| Corticosteriods |
| Oral prednisone 100-200 mg initially, followed by gradual taper over 3-6 months |
| Pulse dose of methylprednisolone 1 g/day for 3 days, followed by gradual tapering of oral prednisone over 3-6 months |
| Intravenous methylprednisolone 100-200 mg/day for 3 days followed by gradual tapering of oral prednisone over 3-6 months |
| Cyclosporine 5 mg/kg per day |
| Azathioprine 1-2.5 mg/kg per day |
| Biologics |
| Anti-TNF-alpha monoclonal antibody |

**Figure 2**: Treatment options for VKH[1]

## discussion

VKH is a rare systemic disease where patients present with bilateral panuveitis associated with cutaneous, neurologic, and auditory findings. Although the etiologic factors in VKH are not exactly known, the clinical course of VKH is usually preceded by an influenza–like episode, which suggests a viral or post–infectious origin. Although a viral cause has been proposed, no virus has been isolated or cultured from patients with VKH syndrome.

VKH is strongly associated with a variety of human leukocyte antigens in patients with different backgrounds. The HLA-DRB1*0405 allele has been determined as the main susceptibility allele in VKH.[2] The

exact cause of the inflammation directed at the melanocytes is postulated to be driven by T lymphocytes against an unidentified antigen associated with melanocytes.[3]

Different stages of the disease result in different histopathological changes. Initially there is diffuse infiltration of lymphocytes and macrophages. In the convalescent stage, the choroidal melanocytes decrease in number and disappear, which can result in a sunset glow of the fundus.[1] During the chronic stage, the retinal pigment epithelium (RPE) and neural retina may show degenerative changes.[1] The RPE may also reveal hyperplasia and fibrous metaplasia.[1]

## complications

Complications of the VKH are very common, with one retrospective study showing at least one complication occurring in 51 % of eyes.[7] Complications include cataracts (42 %), glaucoma (27 %), choroidal neovascularization (11 %), and subretinal fibrosis (6 %).[7] Patients developing complications are also more likely to have recurrences of VKH.

**Although the etiologic factors in VKH are not exactly known, the clinical course of VKH is usually preceded by an influenza–like episode, which suggests a viral or post–infectious origin.**

## conclusion

VKH is an idiopathic multisystem autoimmune disease against melanocytes causing inflammation of melanocyte–containing tissues in the uvea, ears, skin, and / or meninges. There is no association between mortality and this disease; however, early recognition and prompt treatment is crucial to avoiding loss of visual function.

In general, VKH patients treated with high–dose systemic corticosteroids followed by gradual tapering have a very good prognosis, where two thirds maintain visual acuity of 20/40 or better.[1] Hearing is usually restored with control of VKH, although pigment changes are permanent. These changes are treated with mainstay treatments of vitiligo.

It is important to note that causes of bilateral uveitis may not be solely limited to pathologies of the eye and that systemic causes may be the culprit. Therefore, it is important to consider the clinical picture and to inquire for systemic causes of uveitis, as opposed to limiting one's investigations to the affected eye(s) alone. A detailed medical history of this presentation can be observed as a SOAP note in Figure 3.

| |
|---|
| Subjective:<br>• Previously healthy 34 year old Métis female<br>• Three week history of pain, redness, blurred vision and increased sensitivity to light in both eyes, previously diagnosed as bilateral uveitis<br>• Prior to eye complaints, experienced chills and headache with acute illness.<br>• Significant family history of ankylosing spondylitis<br>• Recent development of mild ringing of the ears, bilateral, and patches of pale skin appearing in her inguinal area on right side. |
| Objective:<br>• Ophthalmological exam: best corrected visual acuity 20/40 OD and 20/30 OS with intra-ocular pressures of 11 and 12, respectively.<br>• Dilated fundoscopic exam: Anterior chamber revealed occasional cell and 1+ cells, left and right, respectively. Posterior chamber revealed 2+ cells, bilaterally.<br>• Significant optic nerve edema 360 degrees with serous retinal detachments in right eye. Significant macular edema with a serous retinal detachment in left eye.<br>• Fluoroscein Angiogram: diffuse choroiditis with focal delays in choroidal perfusion and multifocal areas of pinpoint leakage, bilaterally<br>• CBC, Lipids, ANA, glucose, Lyme serology, syphilis, serum ACE, ESR, CRP, serum protein electrophoresis, serology for cat scratch and 120 degree Visual Field test were unremarkable.<br>• CSF revealed pleocytosis but culture was negative for bacteria. |
| Assessment:<br>• VKH, as patient met diagnostic criteria outlined by the American Uveitis Society<br>• Bilateral anterior uveitis |
| Plan:<br>• Continue treatment for uveitis which includes diclofenac (Voltaren®) drops, prednisolone (Pred Forte®) drops and olfloxacin (Ocuflox®) drops, bilaterally. Cyclopentolate (Cyclogyl®) drops for right eye only.<br>• Systemic steroid therapy to treat VKH using IV methylprednisolone 1 gram x 3 days and then oral prednisone 80 mg daily on a tapering dose for 3-6 months |

**Figure 3**: SOAP note.

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# Case Report: Appendiceal Mucocele, an Uncommon Answer to Common Symptoms

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## abstract

A 49-year-old man presented with abdominal pain, fatigue, tachycardia, and anemia three weeks after sphenopalatine artery ligation for massive epistaxis. In light of the recent bleed, this constellation of symptoms was non-specific and therefore difficult to interpret. They were consistent with peptic ulcer disease, a very common diagnosis that can generally be worked up as an outpatient. This resulted in a delay of several months in the diagnosis and treatment of a large appendiceal mucocele, an uncommon and often benign entity involving the accumulation of mucous within the appendix with a potential for malignant spread. Although this might have been an incidental finding, all symptoms have resolved since surgical removal of the growth. This case illustrates the importance of timely diagnosis in patients with vague yet persistent symptoms. An uncommon condition can have potentially serious consequences if missed.

## case

A previously healthy 49-year-old man presented to the emergency department with massive epistaxis. After undergoing sphenopalatine artery ligation, his hemoglobin dropped from 135 g/L at presentation to 100 g/L post-ligation. Three weeks later, he returned to the urgent care centre with diffuse abdominal pain, fatigue, and tachycardia (heart rate of 100 beats per minute). His blood pressure was 118/84 mmHg without orthostatic change, and his abdomen was diffusely tender without localized pain or peritoneal signs. His hemoglobin was 118 g/L (135-170), his MCV 85 fL (82-98), and his stool tested positive for occult blood. Other laboratory tests were normal, including TSH.

Twenty years earlier, the patient had been diagnosed with peptic ulcer disease. More recent endoscopy showed gastritis. As a result, on this presentation, he was treated with intravenous pantoprazole (Pantoloc®) in the emergency department with the provisional diagnosis of a non-life-threatening upper gastrointestinal bleed. He was discharged with a prescription for pantoprazole (Pantoloc®), 40 mg per day, and an endoscopy referral.

After being discharged home, the patient returned to care three times over the following month with episodes of epigastric discomfort, tachycardia, and malaise. During each visit, he had epigastric tenderness, but no definitive diagnosis was achieved. An esophagogastroduodenoscopy (EGD) was planned, but it was not prioritized due to the negative results of the *Helicobacter pylori* breath test. A 24-hour urine sample was collected upon suspicion that a pheochromocytoma might explain his episodic symptoms, but the catecholamines and metabolite assays were normal. Other laboratory investigations were normal, including TSH, liver enzymes, liver function, renal/electrolytes, lipase, CEA, cortisol, and CRP. Absent an anatomical diagnosis, we considered psychosomatic abdominal pain due to anxiety or stress. However, the patient was mystified, given his previous perfectly normal health and enjoyment of frequent vigorous exercise.

While he awaited endoscopy, the abdominal pain worsened, and he lost 7 kg (approximately 10%) of his body weight. An abdominal CT scan was ordered two months after the initial presentation. This revealed early mesenteric panniculitis of the jejunum and massive distension of the appendix, which protruded into the cecal lumen and contained low-density debris consistent with an appendiceal mucocele. The patient was referred to general surgery.

Prior to surgery, the EGD was normal. Colonoscopy demonstrated a mass adjacent to the ileocecal valve originating from the cecal pole, and an ultrasound also confirmed appendiceal mucocele. More than three months after first seeking medical attention, the patient underwent a laparoscopic hand-assisted right hemicolectomy. There was no evidence of carcinomatosis or pesudomyxoma peritonei. However, an inflammatory process was observed in the right upper quadrant with adhesions, which were lysed intraoperatively.

Pathological analysis of the appendiceal specimen showed a 6 by 1.5 cm low-grade mucinous neoplasm confined to the appendix, without evidence of rupture or invasion into the adjacent cecum. Thirteen lymph nodes were negative for metastatic cells. The patient was symptom-free after discharge and at six-month follow-up.

## discussion

Appendiceal mucoceles are present in 0.2 to 0.3% of all appendectomy specimens and in 8% of appendiceal tumours.[1] A mucocele refers to an appendix that has dilated due to progressive accumulation of mucous within its lumen. They can be considered benign or malignant and can be histologically subdivided into four subtypes.[2] Mucoceles are often found incidentally on imaging or during surgery and are usually seen in patients over the age of 50.[1]

Diagnosis is confirmed by pathology. The first three histological types are considered benign, and the last is malignant. Type I appendiceal mucoceles are the result of proximal obstruction in the lumen (commonly a fecalith), causing a retention mucocele less than 1 cm in diameter with normal epithelium. If the appendix has mild dilatation and normal but hyperplastic epithelium, it is considered to be a type II mucocele (5-25% of all appendiceal mucoceles). Type III or mucinous cystadenomas are the most common (63-84% of all appendiceal mucoceles), and are generally less than 6 cm in diameter and lined by columnar epithelium with atypia. Type IV mucoceles (11-20% of all appendiceal mucoceles) are malignant adenocarcinomas that show severe dilatation, glandular stromal invasion, and/or peritoneal implants.[2,3]

The signs and symptoms of appendiceal mucoceles are non-specific. They include abdominal pain and mass, nausea, vomiting, and weight loss (Table 1). In one case series of 19 patients over 20 years, 11 presented clinically as appendicitis until imaging suggested a mucocele.[1] Of 135 patients identified over 25 years at the Mayo Clinic, only 65 had symptoms attributable to appendiceal pathology.[4]

While asymptomatic patients are difficult to diagnose, the literature shows that it is symptomatic patients who are more likely to have malignant disease. Certain symptoms and findings more commonly found in patients with adenocarcinomas include abdominal pain (56%), weight loss (77%), abdominal mass (86%), mucocele extravasation (83%), and diffuse intra-peritoneal spread (95%).[1]

While the definitive diagnosis depends on pathology, a presumptive diagnosis can be made from imaging and direct visualization. A low-attenuation mass adjacent to the cecum on CT (Figure 1) or an ultrasonographic image of a through-transmitting mass with echogenic content in the correct location is suggestive of the diagnosis.[5] Colonoscopy can reveal a soft submucosal lesion in

| Symptom/sign | Prevalence | Sources |
|---|---|---|
| Abdominal pain | 27-100% | *Papziogas et al. 2007, Stocchi et al. 2003* |
| Abdominal mass | 16-50% | *Rampone et al. 2005, Stocchi et al. 2003* |
| Weight loss | 5-10% | *Papziogas et al. 2007, Stocchi et al. 2003* |
| Nausea/vomiting | 5-9% | *Papziogas et al. 2007, Stocchi et al. 2003* |
| Unexplained anemia | 5% | *Papziogas et al. 2007, Stocchi et al. 2003* |
| Acute appendicitis | 8-57% | *Papziogas et al. 2007, Stocchi et al. 2003* |
| Asymptomatic or symptoms not reasonably attributable to the appendix | 25-51% | *Papziogas et al. 2007, Rampone et al. 2005, Stocchi et al. 2003* |

**Table 1**: Prevalence of presenting symptoms in patients with appendiceal mucocele.

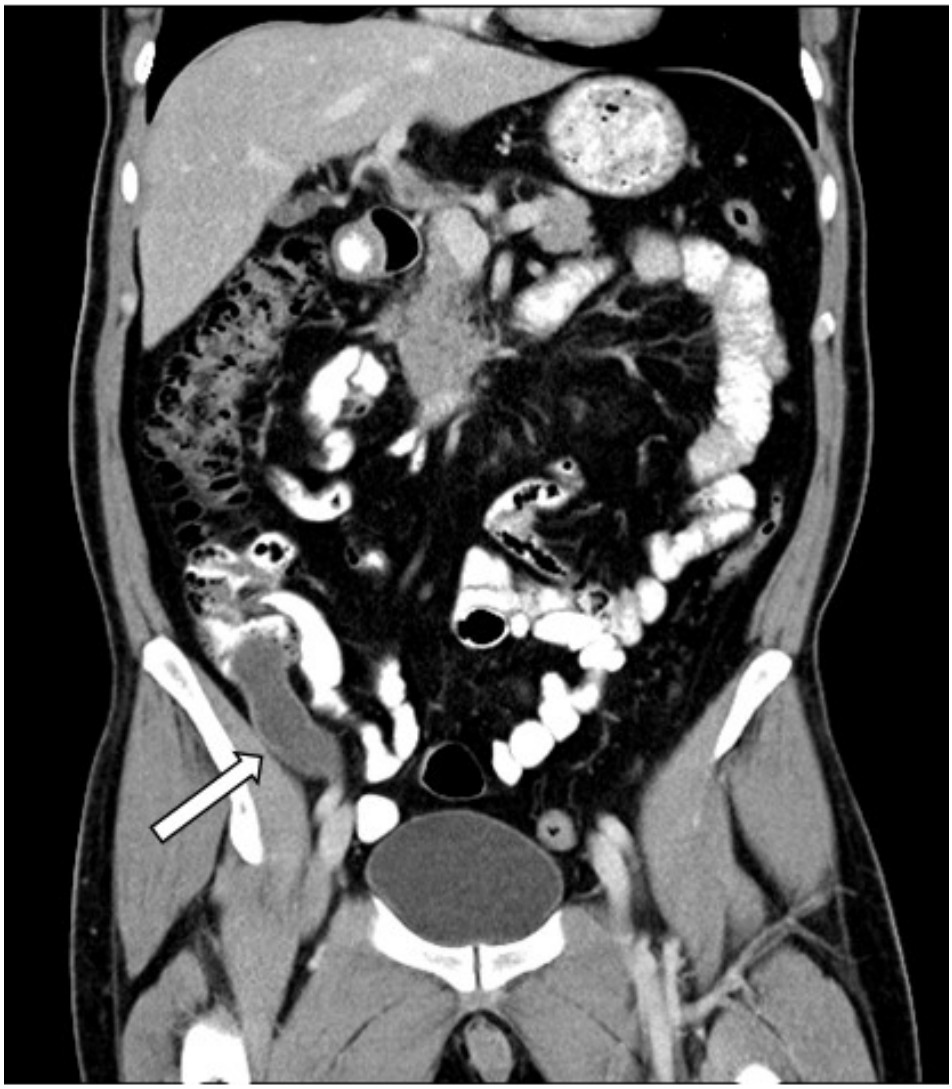

**Figure 1**: Saggital section of CT abdomen pelvis. Appendiceal mucocele (arrow) with measurements of 6 x 1.5 cm. Max dameter 2.6 cm.

the cecum with a central impression (appendiceal orifice) from which mucous can be visible as a "volcano sign".[3] Pre-operative colonoscopy is used to screen for concurrent colon tumours, reportedly found in up to 29% of cases, which can alter the surgical approach.[2] While colorectal tumours are the most common tumour associated with appendiceal mucoceles, ovarian, breast, and kidney tumours have also been linked.[6]

The major complications from untreated appendiceal mucoceles include intestinal obstruction or bleeding, intussusception, fistulization, and volvulus. One of the most serious is the development of pseudomyxoma peritonei, the accumulation of thick gelatinous mucin containing neoplastic cells in the peritoneal cavity. This can occur through the natural progression of the neoplasm by invasion through the thinned appendiceal wall or via spontaneous or iatrogenic rupture.[2] If the tumour is malignant, the material can be generalized throughout the peritoneum rather than localized to the peri-appendicular space as seen with benign mucoceles.[3]

Surgical resection is preferred to observation due to the potential for malignant transformation and dissemination. A recent literature review recommended that an open approach is generally preferred over laparoscopy to reduce the risk of iatrogenic perforation.[2] Accordingly, if the mucocele is discovered incidentally during a laparoscopic surgery, it is recommended that the surgeon convert to an open procedure. Simple appendectomy typically results in cure if the mucocele is small and confined to the appendix. When there is evidence of perforation, positive cytology, lymph nodes, or margins on pathology, a right hemicolectomy is recommended with post-operative intraperitoneal chemotherapy and long-term follow-up.[2]

The prognosis of a benign appendiceal mucocele after treatment is good, with a 5-year survivorship of 91-100%.[3] For malignant lesions, this drops to 25% at five years, usually due to complications from pseudomyxoma peritonei.[3]

Another rare condition that might have played a role in our patient was mesenteric panniculitis, a chronic inflammatory condition of mesenteric adipose tissue of unknown etiology. A large case series of patients with CT findings of mesenteric panniculitis found that 45 of 118 (38%) had concurrent malignancy, mostly colorectal, lymphoma, and urogenital tumours.[7] Mesenteric panniculitis can also have no identifiable cause, yet it can produce a variety of symptoms, including abdominal pain.[8] It is unclear whether our patient's mucocele and panniculitis were linked, as the mesenteric panniculitis might have caused his symptoms, and the mucocele may have been only an incidental finding from abdominal CT.

Our patient experienced a delay of definitive diagnosis of a potentially serious condition after he presented with persistent abdominal pain. Barriers to accurate diagnosis and definitive management included a recent but apparently unrelated emergent condition (life-threatening epistaxis) and a lack of striking physical or laboratory findings. The persistent complaint of unexplained abdominal pain in an otherwise well-looking patient ultimately led to CT imaging, yielding unexpected but significant findings.

In an era when we should question the overuse of ionizing radiation, this patient's persistent resolve that something was wrong was the catalyst to the diagnosis and treatment of uncommon conditions and to resolution of his symptoms. Sir William Osler taught, "If you listen, the patient will tell you the diagnosis."[9] In this case, the patient gave us a needed push in the right direction.

| |
|---|
| Subjective:<br>• The patient is a 49-year-old man with a history of peptic ulcer disease presenting with fatigue, malaise, and recurrent episodes of mild epigastric abdominal pain after a recent massive epistaxis requiring sphenopalatine artery ligation. |
| Objective:<br>• Heart rate is 100 beats/min, blood pressure is 118/84 mmHg without orthostatic change, and the abdomen is diffusely tender without localized pain or peritoneal signs. The hemoglobin is 118 g/L (135-170), the MCV 85 fL (82-98), and his stool tests positive for occult blood. Other laboratory tests are normal, including TSH, CRP, urine catecholamines, and Helicobacter pylori breath testing.<br>• Computed tomography of the abdomen reveals massive distention of the appendix containing low-density debris, consistent with an appendiceal mucocele. |
| Assessment:<br>• The patient is a 49-year-old man with nonspecifc abdominal complaints, normocytic anemia, and a history consistent with peptic ulcer disease. After failing to respond to empiric proton-pump inhibitor therapy, he has been found to have an appendiceal mucocele on CT imaging of the abdomen. |
| Plan:<br>• Referred to general surgery for surgical management of the lesion, for assessment of the extent of disease, and to rule out concurrent malignancy in the colon via colonoscopy. |

**Figure 2**: SOAP note.

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# Early Interprofessional Collaboration Through Student–Run Clinics

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## abstract

The current primary care system in British Columbia is challenged with an increasing number of patients with chronic and complex comorbidities. Interprofessional collaborative care has demonstrated improved outcomes for patients, providers, and the health care system, indicating the need for expanding interprofessional education. Student–driven community service learning initiatives, such as student–run clinics, offer an innovative approach to enhancing interprofessional education. Despite recognized challenges, student–run clinics may serve as an engaging learning opportunity for health professional students in British Columbia.

## introduction

Primary health care in Canada is presently challenged with an aging population, chronic care needs, and complex morbidities.[1] It is well established that optimizing interprofessional collaborative practices—when multiple health care providers contribute to patient care—is central to strengthening patient–centred care and the sustainability of our primary health care system.[2-4] Interprofessional education (IPE) is considered essential to the development of effective collaborative practice capabilities.[3] Student–run clinics (SRCs) are undeveloped within British Columbia and may represent a novel approach to providing IPE opportunities for health care professional students.

## interprofessional education

The fundamental goal of IPE is to prepare learners for future collaborative practice through developing competencies in specific domains.[5] The World Health Organization defines IPE as "two or more professions learning about, from and with each other to enable effective collaboration and improve health outcomes."[3] IPE is strategically aimed to establish collaborative framework competencies in learners: role clarification, client/community–centred care, team functioning, collaborative leadership, interprofessional communication, and conflict resolution.[5] Suggested benefits of IPE include fostering mutual respect between colleagues and better preparation for real–life interprofessional collaboration.[6] Although evidence regarding the effectiveness of IPE is still sparse, seven out of 15 studies in a 2013 Cochrane systematic review positively linked IPE intervention with improved performance of team care.[7] Improved parameters of performance noted in the studies includes better team behaviour and information sharing in operating room settings, and reduction of clinical error rates in emergency department teams.[7]

However, multiple challenges prevent implementation and long–term commitment of IPE into mainstream curricula.[4] Documented barriers across Canadian health professional schools include inflexible scheduling, crammed curricula, lack of perceived value by students, faculty and administration, logistics concerning resources and space allocation, poor understanding of other professions, and professional regulatory requirements.[4,8] It has been suggested that innovative learning opportunities that actively engage students are required to improve interprofessional learning.[4] SRCs are an example of such an innovative approach.

## student–run clinics as an interprofessional education approach

SRCs allow students in multiple health care disciplines to collaborate in clinic settings as well as take on primary responsibility for operational management. Typically based out of community health centres, SRCs have a core mandate to provide services for marginalized and underserved populations.[9] In addition to clinical services, SRCs deliver a combination of health promotion and social programs, including harm reduction, counselling, childcare and literacy.[9] Furthermore, all clinical and health promotion activities are delivered under the preceptorship of licensed health care professionals.[9]

SRCs offer an innovative IPE paradigm for development of interprofessional competencies. Clinic shift teams comprise students and preceptors of various disciplines responsible for a given client.[9] Together, the shift team devises management plans and delivers coordinated patient care.[6,9] Thus, students who participate in running the clinics have the opportunity to utilize and improve their compentencies in team functioning, role clarity, interprofessional

communication, and conflict resolution. Since students collaborate with community representatives to develop health promotion programs, community– and client–centered care is encouraged. Furthermore, student leadership and role clarification must be practiced throughout all aspects of clinic and program administration as students appropriately determine which profession has the knowledge and skills to address patient needs.[5,9] Through participation in SRCs, students gain a better understanding of their roles and those of other professions.[5]

While no studies to our knowledge have directly evaluated whether SRCs effectively develop IPE competencies, a few have systematically evaluated changes in student responses towards their interprofessional value. Bennard et al. (2004) reported that of medical student responses towards the educational value of working at an SRC, the majority (75%) found that the experience positively affected their attitudes towards collaboration with non–physician health professionals.[10] At the Houston Outreach Medicine, Education and Social Services Initiative (HOMES), student participants from public health, medicine and pharmacy programs work together in clinic teams to provide care for homeless individuals.[11] The participants similarly ranked multidisciplinary care as one of the most valuable lessons gained from the education experience, highlighting that SRCs provide a useful context for IPE and "real clinical interdisciplinary experiences" early in training.[6]

Given the importance of interprofessional clinical training, SRCs are becoming increasingly popular, yet they remain in the early stages of development in B.C.[6] Presently, there are only eight established clinics in Canada, compared with at least 110 clinics affiliated with 49 American medical schools.[9] At the University of British Columbia in Vancouver, the Community Health Initiative by University Students (CHIUS)—an interdisciplinary group of health professional students who provide health promotion workshops and services to underserved populations—currently operates an SRC at Vancouver Native Health Society. Here, students work in shifts alongside a youth drop–in program in the Downtown Eastside. However, only medical and nursing students may participate, and no other similar interdisciplinary clinic exists in B.C. Furthermore, all existing Canadian SRCs only address acute care needs, while chronic care models have been increasingly emphasized for improving health care outcomes.[6,9,12] We predict that an SRC available to students from a wider range of health professions and focused on chronic care management would enhance IPE opportunities.

One of the most challenging obstacles to SRC implementation is the issue of malpractice and liability for both students and preceptors.[9] Students must be covered under university malpractice insurance while preceptors must be covered with their personal liability insurance, which must meet specific requirements for local health authorities and SRC host clinic sites.[9] Additionally, due to high student participant turnover in SRCs, another common challenge is the issue of continuity of care.[9] A given patient may be seen by a different team of students at each visit, which may potentially impede development of trusting relationships and interrupt coordination of care.[9] Therefore, in order to compensate, it is crucial for SRCs to record health information about their patients in a thorough, consistent order, which would allow each subsequent clinic team to seamlessly follow through with appropriate care.[9]

## conclusion

SRCs deliver an innovative education model and provide a framework for developing IPE competencies. These clinics also increase social accountability by identifying the need for comprehensive health care in underserved communities facing significant barriers to health care access. Given the progression of primary care towards enhancing collaborative care models, SRCs are a potential means for embedding meaningful interprofessional experiences in the training of health professional students.

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# An Introduction to Health Professionals' Role in Addressing Human Trafficking

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## abstract

It is estimated that 2.4 million individuals around the world are trafficked each year. Human trafficking continues to be a complex issue mostly affecting those who are female, socioeconomically disadvantaged, and from marginalized ethnicities. Despite 28 % to 50 % of trafficked individuals presenting to health providers, health professionals are not well equipped to clinically assist these individuals. This paper discusses current approaches of supporting trafficked victims in Canada, and proposes improvements necessary for health providers to more effectively address this issue.

## introduction

With approximately 2.4 million humans trafficked around the world annually, the United Nations General Assembly has adopted the Convention Against Transnational Organized Crime to tackle this profitable, illicit venture.[1] Canada itself continues to be an origin, destination, and transit point for international and domestic human trafficking despite ongoing legislative efforts.[2,3] Between 2012 and 2013 alone, 30 offenders were convicted in Canada, with many offences committed against children.[4] However, these figures may drastically underestimate the impact of this issue due to relaxed legal standards and poor general public awareness.[3]

Human trafficking is very complex and is closely linked to the life circumstances of trafficked individuals. Being recruited into human trafficking is often tied to predisposing social determinants of health; those trafficked are frequently females, from disadvantaged socioeconomic backgrounds, marginalized ethnicities, and rural areas.[5,6] The UN defines human trafficking as an act related to kidnapping, forcible confinement, debt bondage, forced labour, cross–border exploitation, and the recruitment and harbouring of persons.[7,8] While some trafficked individuals may fall under this definition, its narrow scope does not account for the circumstances surrounding other marginalized populations such as Aboriginal women, youth and children, migrants, new immigrants, and teenaged runaways who also constitute a significant portion of trafficked individuals in Canada.[9] More appropriately, therefore, human trafficking is more likely to occur when life circumstances predispose an individual to exploitation by another, such that they are unable to refuse work in the context of a hostile environment.[7]

**It is estimated that 2.4 million individuals around the world are trafficked each year.**

Trafficked individuals are often subjected to physical, sexual, and psychological abuse during their exploitation.[10,11] It is estimated that 28 % to 50 % [12,13] of these individuals access health services during captivity, posing an urgent and unique opportunity for health professionals to identify, support, and refer them.[13,14] Experts have called for incorporating relevant training for physicians, nurses, residents, and other health service providers.[2,15,16,17]

## outline of current interventional strategies

Current interventions in Canada are three–pronged. The legal aspect focuses on policy advocacy and prosecution of perpetrators, mainly relying on legislators and police.[9] Second, clinical support includes identification of trafficked persons through in–person and telephone counselling or medical interviews. Such services may be provided by community organizations, primary care providers, and forensic specialists.[18] Finally, social support offers shelter and rehabilitative services, focusing on basic life skill development. Relevant organizations include government agencies, health services, and community organizations.

Not all organizations tackling this issue share the same definition or approach to human trafficking. For example, Supporting Women's Alternative Network (SWAN), an organization dedicated to the safety and rights of sex workers, recently published an article outlining the harm of the current mainstream description of human trafficking.[19] They assert that categorizing female immigrant sex workers as trafficked persons too hastily has only brought harm to women assumed to be victims. They have shown that law enforcement agencies

have mistakenly conducted raids into settings stereotyped to hold trafficked persons, such as massage parlours employing migrant sex workers. SWAN asserts that this may psychologically traumatize those affected by the raids and discourage their future usage of government services.

It is therefore important to distinguish sex work from human trafficking. When a sex worker presents for medical care, physicians should not assume that the individual is trafficked without appropriate evidence. This is important as intensive forensic measures for presumed trafficked individuals may undermine the autonomy of and rapport with a voluntary sex worker. On the other hand, it is equally important not to miss opportunities to correctly identify and support a trafficked individual. One approach that balances these considerations is for health professionals to consider trafficking as a 'differential diagnosis' that may be actively ruled in or out. This is similar to how health care providers consider cancer amongst the differential diagnosis for fever and rule it out based on further history, physical exam, and possibly investigations.

Best practice guidelines are not yet established for the screenings, interventions, and clinical considerations specific to assisting trafficked individuals. However, some guiding principles are noted periodically in the literature.[20,21] One resource available is the guide "Caring for Trafficked Persons: Guidance for Health Providers" which is a good educational tool and one way to begin equipping primary health care providers.[22] The guide can help physicians distinguish voluntary sex workers from trafficked persons and bring awareness to clinical 'red flags' associated with trafficked persons. For example, patients who demonstrate convoluted and inconsistent histories in addition to reporting little autonomy over daily activities (e.g. eating, sleeping, or showering) would require additional attention.[20] On inspection, they may appear withdrawn and anxious while exhibiting track marks and signs consistent with abuse and trauma.[21] Additionally, mental status exams may be consistent with depression or post–traumatic stress disorder.[23] If red flags are detected in the family medicine setting, based on the guide's recommended referral features, the individual may be transported to the local hospital for more comprehensive assessment with forensic support.

## moving forward to provide better care

Although experts are developing health care provider training and protocols, evidence–based approaches for assisting trafficked individuals are still lacking.[24] Health authorities currently use internal training modules to train health care providers to recognize and assist trafficked individuals.[2,17] These modules aim to introduce possible management strategies for trafficking victims incorporating the aforementioned differential diagnosis framework. While the training modules are a useful starting point, their effectiveness has yet to be verified. Secondly, these modules are vulnerable to self–selection biases, as individuals who are primarily interested in the training may have explored clinical strategies around the issue already. Training modules will help these individuals advance their understanding of their roles but do not necessarily educate the population not previously exposed to the issue. Targeting those who are not yet exposed is a crucial step for health care providers to adequately address human trafficking.

Educating Canadian health care providers about the current landscape of trafficking in Canada will improve the recognition and assistance for trafficked individuals and influence clinical interventions. In addition, raising more awareness may generate more advocacy momentum for this often overlooked group of patients in the political, academic, and clinical arenas.

We believe that a multi–level approach including current health care students and physicians, medical faculties, and provincial and federal governments is required. We recommend that medical schools and educators: 1) dedicate plenary time to the complexity surrounding human trafficking; 2) create best practice health care protocols for trafficked individuals through appropriate partnerships with other health disciplines; and 3) ensure health care professionals are sensitized to trafficked individuals' needs through training.[25] We also recommend that federal and provincial governments: 1) address the health and public health issues surrounding trafficking; and 2) develop research programs to explore best practices for identifying, treating, and supporting trafficked persons.

There are necessary improvements to be made in order to assist today's trafficked individuals, with medical students and physicians playing an essential role. Both can become effective advocates for promoting fundamental social change, while properly identifying and aiding current trafficked persons. However, the lack of evidence–based practices will continue to divide approaches for health care providers seeking to make positive interventions. Education and awareness of this complex issue is the crucial piece in confronting this global issue. Informing students, educators, and lawmakers about the issues concerning human trafficking is the first and essential step in creating an acceptable and appropriate standard of care for trafficked persons.

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# Workplace Psychological Health among Canadian Nurses

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## abstract

Due to the demanding nature of their work, nurses are at higher risk of developing work-related psychological distress and associated psychological illness when compared to the general Canadian workforce. Nurses experience high levels of physical and psychological injury, job burnout and depression, which are associated with increased levels of absenteeism, disability claims and compromised patient care. We advocate for improvements to workplace psychological health for Canadian nurses at an organizational level. This is an occupational health and safety matter that has the potential to enhance both nurse and patient health.

## introduction

The risk of psychological distress is exceptionally high among nurses.[1] The 2005 National Survey of the Work and Health of Nurses (NSWHN) found that 9% of nurses (both women and men) experienced clinical depression within the previous year, compared to 7% of women and 4% of men in the general Canadian workforce.[2] Research shows that the high physical and psychological demands of the nursing profession are strongly associated with job burnout, job disengagement, job dissatisfaction, anxiety, and depression.[3,4,5,6,7]

This results in an increased number of employee disability claims, turnover, and absenteeism, which in turn imposes additional challenges to the already burdened health care system.[8,13] Mental health claims account for 30% of short- and long-term disability claims and 70% of disability costs in Canada.[9] Arguably, the most alarming concern is the impact that nurse psychological distress has on the quality of patient care that they are able to provide.[10] Recent legislation requires health care organizations in British Columbia to enforce the Worker's Compensation Amendment Act (Bill 14), which emphasizes the protection of employee psychological health from the cumulative long-term effects of work- related stress.[11] The psychological health concerns of nurses are becoming increasingly evident, and it is therefore crucial that they are recognized and addressed.

Nurses comprise the backbone of Canada's health care system, and as such, the prevalence of workplace-related psychological distress is an occupational matter that needs to be acknowledged and managed according to the Canadian Occupational Health and Safety standards. In this commentary, we will highlight factors with the potential for organizational level improvements: physical and psychological aggression and violence, excessive workload, and organizational support. These factors were chosen based on a literature review, which explores workplace psychological risk factors among health care workers, as well as the 2005 NSWHN.

## factor 1: physical and psychological aggression and violence

Physical, psychological, and emotional violence are commonly experienced by nurses in the workplace.[12,13,14] A study conducted by Henderson (2010) found that all nurses experienced physical violence, or threat of physical violence, at least once throughout their career, as well as some form of verbal abuse on a daily basis.[13] Although physical assault is identified as the greatest risk to their physical safety, verbal assaults can result in many similar negative psychological health outcomes, including concern for personal security and feelings of anger and fearfulness.[12,14] In response to these events, study participants demonstrated an increase in sick-leave substance use, job resignation, and patient avoidance.[13,15]

## factor 2: excessive workload

A manageable workload is essential to a psychologically healthy work environment.[16] The 2005 NSWHN explored this link and found that nurses have higher workloads compared to other professions, which leads to an increased risk of poor mental health.[2] Specifically, the survey found that nurses often work overtime without full compensation, skip breaks, arrive early and leave late, and feel there is insufficient time to complete their work. In fact, 67% of nurses reported feeling that they were assigned too much work, and 45% reported that they had insufficient time to complete their duties.

## factor 3: lack of organizational support for psychological health

Organizational support offered for psychological distress, plays a key role in the psychological health of employees.[17] At an organizational level, psychological support is defined by a work environment that promotes employee psychological health and wellness, and in which supervisors appropriately respond to the psychological concerns of their employees.[19] Multiple components of workplace organization are related to poor psychological health among nurses, including strained relationships between physicians and nurses, ineffective use of nurses' skills and training, and limited autonomy.[2] These dynamics can result in decreased job commitment and productivity, and increased probability of making medical errors.[18] Unfortunately, since nurses commonly feel that administrative staff do not listen and respond appropriately to their concerns, many of these factors, including workplace bullying, often go unreported.[18]

## discussion

Awareness of the serious negative health implications that result from a failure to address the workplace psychological health of nurses at an organizational level is growing. The creation of psychologically healthy workplaces can help counter outcomes, such as nurse psychological and emotional distress, mental illness, and compromised patient care. Improved workplace psychological health has motivated the development of a national standard targeted at organizational changes intended to create psychologically healthy work environments for Canadian workers.

In 2013, the Canadian Standards Association (CSA Group), the Bureau de Normalisation du Québec (BNQ), and the Mental Health Commission of Canada (MHCC) released the National Standard of Canada for Psychological Health and Safety in the Workplace (or, more simply, the National Standard). The National Standard is a set of guidelines intended to help employers promote psychological health and prevent psychological illness and distress among their employees. It provides employers with a framework to develop strategies that enhance psychologically healthy and safe working environments. The National Standard is based on a large body of scientific evidence, which includes thirteen evidence-informed psychosocial factors.[19] It emphasizes that certain psychosocial factors, such as psychological and physical protection, workload management, and organizational psychological support, are key to safeguard the psychological health of the Canadian workforce.

It is recognized that the implementation of the National Standard can be a daunting endeavour for health care organizations. First, healthcare organizations should aim to achieve measureable psychological health and safety goals.[20] Objectives should be defined using a collaborative inter-sectorial process, and could include organizational departments such as Workplace Health and Safety and Organizational Development. Furthermore, nurse input is essential in promoting work engagement, which is associated with increased self-efficacy and reduced burnout.[21,22] Second, the implementation of the psychosocial factors should be staged and piloted. Integrating a few high priority psychosocial factors in a staged manner reduces organizational change resistance, promotes change adoption, and identifies initial challenges.[23] Third, strategies and programs aimed to improve workplace psychological health and safety should be evaluated. This will assess whether goal targets are met and identify areas in need of improvement.[20] The Centre for Applied Research and Mental Health and Addiction (CARMHA), based within the Faculty of Health Sciences at Simon Fraser University, is currently involved in research exploring the process of implementation of the National Standards across a variety of Canadian organization. The purpose of this research is to provide insight into current implementation strengths and challenges and the ways in which implementation of the National Standard can be supported in the future.

Adhering to the National Standard can lead to many positive benefits for a workplace environment, including greater job satisfaction, stronger organizational commitment, enhanced teamwork, reduced sick leave, and less turnover.[24] Healthcare organizations, nurses, and patients are stakeholders who all benefit from the promotion of psychological health and the prevention of distress in the workplace. It is important that nurses are able to participate in the discussion of actions that affect their psychological health at work. Healthcare organizations should strive to implement measurable policy objectives to reduce psychological illness related to disabilities, and increase opportunities to promote workplace psychological health and well-being.[1]

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# Physician Leadership: Learning from Dr. Bill Cavers, President of Doctors of BC

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Health care in the twenty–first century is rapidly changing. As important contributors on the front lines of patient care, physicians are uniquely positioned to influence change and improve the delivery of health care. However, more physicians are also assuming leadership and management roles within hospitals and other health care organizations. A study published in Social Science and Medicine found that topperforming hospitals, with higher scores in health care delivery and outcomes, were more likely to be led by a physician Chief Executive Officer.[1] Therefore, physician leadership is becoming an important and relevant topic to medical students. So, as medical students, are we ready to take on this challenge?

Dr. Bill Cavers, the president of Doctors of BC (formerly BC Medical Association) and experienced physician leader, was interviewed on the importance of physician leadership and how medical students can foster these skills. Dr. Cavers received his Doctor of Medicine degree from UBC and is a family physician in Victoria. He has been involved with Doctors of BC since 1995 and played a central role in reshaping primary care in British Columbia during his time as Co–Chair of the General Practice Services Committee.[2] During his time as president, Dr. Cavers will be focusing on three key areas: 1) physician leadership and professionalism; 2) specialist and facility physician engagement; and 3) physician leadership in information technology.[3]

### What are your thoughts on physician leadership? Why is it so important?

My dad taught me: "Do your best to leave something in better condition than when you found it." And, to me, being engaged in our association has been a way of working to improve the profession and the parts of the health care system we can influence. These both improve patient care, and I believe that is our professional responsibility. It is also very rewarding. Overwhelming at times, yes, but very rewarding.

### What do you have to say to current medical students in British Columbia?

Right from graduation, look past the limits of your own practice. Save some of your energy and attention, and direct it to a cause that makes the profession, your community, or even the world, a better place. As a physician you will have influence, so dedicate some time to do good!

### Should medical students be starting to look for ways to foster leadership skills? What are your suggestions on how this can be done?

The health care system is changing. Physicians are more often working together in clinics, multi–disciplinary health care teams are becoming common, and increasing pressures are being put on the limited resources within our system dictating what services to deliver and how to deliver them.

The decisions made directly affect the quality of patient care and our professional ability to deliver that care, the patient's experiences of care, and our experiences as physicians as to whether it is fulfilling and rewarding.

As a profession of influence and in this environment, physicians absolutely need to have leadership and management skills. While some of us may have innate abilities, all of us will improve with training and experience, and to that end medical school should include some leadership training. For practicing physicians, support should be provided for participation in accredited leadership courses, with a top level of Continuing Medical Education credit upon graduation. Leadership skills will be increasing in demand and applicable across the whole spectrum of physician activities, from one–on–one interaction with patients and colleagues up to system redesign.

### How did your journey go en route to becoming the president of Doctors of BC?

There was an issue that arose and I wasn't happy with the outcome. I voiced my opinion in a staff meeting, and was subsequently asked if I would participate by taking an open position on the Board of the Society of General Practitioners (SGP). I was hesitant at first as I had a young family and a busy life, but my colleague asked me, "If not you, then who? Everyone else has a busy life, too!" I thought this over, realized its truth, and remembered what my Dad said, as above. I accepted the position, and my life changed for the better.

That was 1995. I served on the Board of the SGP and became its president four years later. After completing my term at the SGP I joined the Board of the BC Medical Association and served on several committees, including the GP Services Committee. Having this variety of experience within the association, and over this surprising number of years, has given me greater understanding of issues facing our profession and association. And again, it has been very rewarding.

With the Canadian health care system evolving, every decision made to enact change comes with the potential to affect patient care and the work that we will do

as future physicians. As medical students, we are now part of the medical community and we should be aware of the issues facing our profession and association. Physicians of today are expected to possess leadership and management skills—it is a professional responsibility to improve patient care through refining parts of the health care system that can be influenced. As medical students, we can develop leadership skills through the variety of opportunities presented to us. These include but are not limited to participating in health advocacy, organizing an event or conference, sitting on an association's committee or board, and taking on a role in a club. Let us keep doing good, and remember, "If not you, then who?"

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# Looking at the Role of Physician Health Advocacy in the Canadian Health care System


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The Merriam-Webster dictionary defines an advocate as 'one who supports or promotes the interests of another'.[1] Advocacy for social justice is a long–running theme throughout the history of medicine. In 1847, Rudolph Virchow described physicians as 'natural attorneys for the poor', who can take the lead on improving health through first improving economic and social conditions.[2] This type of advocacy described by Virchow—social activism for the betterment of health—remains a core component of practice in Canada's current medical profession. However, with the evolution of more complex, integrated health care systems and changing health needs, the role of Canadian physicians as health advocates has and will continue to undergo re–evaluation and re-definition.[4,5,6] This news article will briefly review current definitions of physician health advocacy and possible ways that physicians can advocate for health within the context of Canadian health care.

While authors in academic literature recognize that health advocacy in modern medicine needs conceptual clarification,[4,5,6] there appears to be general consensus that it consists of activities intended to benefit the health of individuals and populations.[3,4,5] In a recent journal article published in Academic Medicine, the role of physicians as health advocates is explored in the context of the CanMEDS framework.[4] Here, the authors divide health advocacy into two distinct activities: agency and activism. They elaborate that through agency, physicians can assist individual patients in navigating health care systems and accessing appropriate resources, while activism addresses the broader health issues and their determinants in populations and communities.[4]

Since the inception of the 1982 Canadian Health Act, universal access and coverage for hospital, physician, and surgical-dental services have been afforded to all Canadians. While the general intention of the act is clear, universal access and coverage can be affected by policy made at the level of the health care system and decisions made during the process of health care delivery. At the delivery level, access to health care can vary according to individual patient characteristics such as gender or level of health-literacy. For example, when all other clinical considerations are equal, physicians are more likely to recommend men for total knee arthroplasty than women.[7] In consideration of health literacy, if a patient is unaware that certain treatment options exist, they essentially do not have access to these treatments unless properly consulted and counselled. In such situations, physicians can work with patients and other health care professionals to ensure that patients have the resources and information necessary to make the best treatment decisions. Likewise, physicians can also be sensitive to biases that may exist in their own decision–making processes and make an effort to ensure that access to care is determined by health need and not other irrelevant patient characteristics.

At the policy level, there remains a grey area as to whether controversial services such as in vitro fertilization or medical marijuana should be included under provincial health insurance plans. In addition to this, health care systems often struggle with achieving actualization of timely universal access (e.g. long wait times for surgeries).[8] While finite resources limit the extent of services that can be covered and the expediency with which they are delivered, there remains room for physician advocacy to inform and shape future decision–making for resource allocation. Physicians can engage in such efforts individually or collectively as groups. Suggestions for individual physicians to become involved in activism include public education of health care issues through

mainstream media, speaking at public events, and communication with executive and legislative officials. In particular, the Canadian Medical Association (CMA) is an example of a professional association with an advocacy mandate. Collectively they advocate for improved health care through research intended to inform health care policy, submissions to government outlining their stance on health care issues, and advocacy skills training for CMA members.

In summary, physician health advocacy includes actions of agency and activism. In regard to health care systems, physicians can act as agents of individual patients as well as activists on a systemic level. Discussions around the role of physicians as health advocates are likely to continue. While the central focus of physician health advocacy efforts should continue to be the health of individuals and populations, there remains a need to further develop best practices for health advocacy training as well as structures and processes to support physicians' health advocacy efforts.[8,9] As a growing field of interest and action, health advocacy is becoming an increasingly important means of providing quality care to patients, improving health care systems, and ensuring fair and equitable access to health care resources.

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# Facing Down the Threat: Canada and the Fight against Global Health Crises-Focus on the 2014 Ebola Outbreak


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This past September, a UBC-initiated event was held at university campuses across Canada to raise awareness for Ebola. While the Canadian public's general awareness of the disease and its deadly effects wasn't lacking, the participating students felt that our government's response was. They weren't the only ones who felt this way.

Just a few weeks later, the World Health Organization (WHO) reported that the virus was killing 70% of its patients,[1] and warned that without a significant increase in aid from other countries, as many as 10,000 new infections could be expected every week in West Africa by early December.[2]

Some might argue that Canada is contributing significantly to the fight against Ebola (in response to the WHO's plea, Canada would pledge another $30 million to total the nation's monetary contribution at $65 million).[3] Others believe that Canada's response was far too small and belated in its delivery, considering the urgency of the situation. While monetary donations sound appealing, they often take too long, or even fail to materialize into much needed resources in the field. For example, in the current case of Ebola, only 17% of Canada's first $30 million pledge had been delivered, three weeks after its announcement.[3] Furthermore, the biggest need according to those on the front lines is increased medical, epidemiological, and logistical personnel[4] – something the government has been hesitant to provide.[5]

While some might disagree with the extent and urgency with which Canada tackles global health crises such as Ebola, others might wonder why Canada is obliged to get involved at all. For example, why should Canada involve itself in crises that aren't a direct health threat to its citizens? In outbreak cases, this question might be asked less often, as it's easy to argue Canada will inevitably be affected if the primary countries cannot contain the outbreak. However, in situations where the potential for that physical affliction might strike Canadians at home virtually nonexistent (arguably the case with Ebola, despite widespread fear in North America),[6] the reasons to advocate for

foreign aid might become less obvious.

Whether a direct threat to us or not, it is both a moral imperative, and in Canada's best interest, to help in the most effective way possible during times of global health crises (that is, provided needs within Canada have been evaluated before focusing resources elsewhere). While the benefit that Canadians stand to gain from providing foreign aid might not be obvious at first glance, we must consider how, through past acts of altruism, Canada has positioned itself so that it can rely on many allies in times of need. While humanitarianism is inherently selfless, it can be accompanied by many secondary self-serving benefits.

Secondly, when a substantial portion of a country's population becomes ill or dies, political and economic stability is weakened and can fail. This is especially a threat to developing nations that are most affected by the current outbreak, such as Liberia, Guinea, and Sierra Leone. Dr. Peter Piot, who helped discover the virus in the 1970s, states that the current outbreak would have been quickly containable, had the Western world rallied to provide aid at the outset.[7] In part due to this initial neglect by the Western world, Piot warns of the potential for major societal and political destabilization in the affected countries and those surrounding them.[8] The World Bank estimates that without containment, the financial impact of the Ebola outbreak could reach $32.6 billion.[9] In order to prevent potential breakdowns in the infrastructure of already vulnerable areas, it is crucial that other nations step up. It should be noted that foreign aid is complex and an issue of ongoing debate, as historically it has not always led to improvements and has even been detrimental to countries undergoing development.[10,11] However, the aid in this paper refers to aid that is specifically provided in response to health crises rather than aid provided in an ongoing effort to help nations develop.

Canada has proven its ability to change the course of health crises on a global scale. For example, scientists in Winnipeg developed the trial Ebola vaccine currently being tested by the WHO,[5,12] and the 'Treatment as Prevention' (TasP) policy pioneered by UBC's Dr. Julio Montaner now serves as the basis for the Joint United Nations Programme on HIV/AIDS (UNAIDS) 90-90-90 strategy to eradicate AIDS by 2030.[13,14]

We are lucky to live in a country that has the capacity to provide resources and relief to others during times of crisis. While we might not always agree on the most effective way to distribute resources in such circumstances, as Canadians we should feel proud knowing that other nations look to us in times of need. The case of Ebola is certainly no exception. If there were ever a time to solidify our reputation as a humanitarian nation, it would be now.

**Whether a direct threat to us or not, it is both a moral imperative, and in Canada's best interest, to help in the most effective way possible during times of global health crises**

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# Esophageal Cancer and Management of Localized Disease: A Review

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## abstract

Esophageal cancer is often diagnosed in its late stages, with a 5–year overall survival rate of approximately 28 % in British Columbia. It frequently presents as either squamous cell carcinoma or adenocarcinoma. The most common presenting complaint is dysphagia, typically characterized by a worsening tolerance to solid foods.

Esophagogastroduodenoscopy with biopsy is the gold standard for diagnosis. Useful staging investigations include computed tomography scan of the chest and abdomen, 18–fluoro–deoxyglucose–positron emission tomography scan, and endoscopic ultrasound.

Esophageal cancer is a heterogeneous disease with no single optimal treatment algorithm. Esophagectomy has traditionally been the gold standard treatment in early–stage (Tis-T1) disease, but endoscopic treatment is also an option. Neoadjuvant chemoradiotherapy prior to definitive surgery should always be considered in more invasive (T2) disease, and it is recommended in late–stage (≥T3 or N+) disease. There is controversial evidence against the survival benefit and potential added morbidity of neoadjuvant chemoradiotherapy in the treatment of early esophageal cancer. Unresectable and cervical tumors should be treated with definitive chemoradiotherapy. The optimal treatment of adenocarcinomas of the distal esophagus and gastro–esophageal junction is under investigation, but it likely includes peri–operative chemotherapy.

Current research in esophageal cancer is investigating the use of early 18–fluoro–deoxyglucose–positron emission tomography scans to assess response to chemotherapy, which could have important implications in prognostication and treatment decisions.

## introduction

Esophageal cancer is often diagnosed in its late stages with a 5–year overall survival rate of approximately 28 % in British Columbia.[1] This is largely due to the lack of a serosal barrier in the esophagus, allowing for easier locoregional spread. In this instance, eliminating the microscopic disease with neoadjuvant or adjuvant treatment is very important.

Esophageal cancer frequently presents as either squamous cell carcinoma (SCC) in the proximal two-thirds of the esophagus (often in patients with a significant alcohol or smoking history), or as adenocarcinoma in the gastro-esophageal (GE) junction or the distal third of the esophagus (often in patients with longstanding gastroesophageal reflux and Barrett's esophagus). The incidence of SCC has decreased significantly in recent years in North America, likely secondary to a decrease in cigarette smoking. Conversely, the incidence of adenocarcinoma has increased considerably, believed to be in part due to increased rates of obesity and reflux disease.[2]

There is no suitable screening test for SCC. Patients with Barrett's esophagus should undergo routine endoscopic screening to rule out mucosal dysplasia, which may require ablation or surgical resection.

Patients with esophageal cancer commonly present with dysphagia to solids that may progress to dysphagia to liquids, sometimes in a matter of months. The dysphagia occurs several seconds after initiating a swallow, often with a sensation of food "sticking" in the neck, chest, or upper abdomen.[3]

## anatomical classification and lymphatic drainage

Esophageal cancers are classified by their distance from the central incisors: 15-18 cm for cervical tumors, 18-24 cm for upper thoracic tumors, 24-32 cm for middle thoracic tumors, and 32-40 cm for lower thoracic/GE junction tumors. Cervical tumors primarily drain cranially to the supraclavicular, cervical, and peri–esophageal lymph nodes. Thoracic tumors drain to the mediastinal lymph nodes. GE junction tumors drain caudally to the left gastric and celiac axis lymph nodes. Distant metastatic disease is most common in the liver, lungs, and bone.

## diagnostic workup

Esophagogastroduodenoscopy with biopsy is the gold standard test for establishing the diagnosis. Staging options include computed tomography (CT) scan of the chest and abdomen, 18-fluoro-deoxyglucose-positron emission tomography (FDG-PET), and endoscopic ultrasound. CT scan is the most frequently used imaging modality; however, it has low sensitivity in detecting subcentimetre lymph node metastases (sensitivity 57 % for detecting regional node involvement), which is problematic as diagnosis relies largely on size and shape criteria.[4,5,6]

Because metabolic changes precede structural changes in metastatic lymph nodes, it was proposed that FDG-PET could be used with higher sensitivity in detecting cancer in normal-sized lymph nodes.[7] Despite this rationale however, the sensitivity of FDG-PET for regional lymph node disease is only about 51 %.[8] Its primary use has therefore been to rule out distant metastatic disease and to save patients the morbidity of an unnecessary major surgery (29 % avoided unnecessary resection in a study by Van Westreenen et al.).[9] Interestingly, FDG–PET has been shown to alter the radiation treatment fields approximately 50 % of the time.[10]

Endoscopic ultrasound is another staging option with high accuracy in local tumor (T) staging, but it has limited utility in lymph node staging. Its penetration depth is restricted to approximately 5 cm.[11,12] It is considered to be complementary to CT and FDG–PET. It can be useful in scenarios where both CT and FDG–PET are negative for nodal disease, and accurate T–staging is required to clarify a patient's eligibility for local resection (versus esophagectomy). If the primary tumor is in close proximity to an airway, bronchoscopy is often required to rule out invasion because airway involvement precludes radical resection.

**CT scan is the most frequently used imaging modality; however, it has low sensitivity in detecting subcentimetre lymph node metastases (sensitivity 57 % for detecting regional node involvement), which is problematic as diagnosis relies largely on size and shape criteria.**

**Table 1: Staging of esophageal cancer.[13]**

| TNM Staging | | Stage Groupings | | | |
|---|---|---|---|---|---|
| Tis | High-grade dysplasia | Stage 0 | Tis | N0 | M0 |
| T1a | Invades lamina propria/muscularis mucosae | Stage IA | T1 | N0 | M0 |
| T1b | Invades submucosa | Stage IB | T2 | N0 | M0 |
| T2 | Invades muscularis propria | Stage IIA | T3 | N0 | M0 |
| T3 | Invades adventitia | Stage IIB | T1-2 | N1 | M0 |
| T4a | Invades pleura, pericardium, diaphragm | Stage IIIA | T4a | N0 | M0 |
| | | | T3 | N1 | M0 |
| T4b | Other adjacent structures (aorta, trachea) | | T1-2 | N2 | M0 |
| | | Stage IIIB | T3 | N2 | M0 |
| N1 | Regional lymph nodes (1-2) | Stage IIIC | T4a | N1-2 | M0 |
| N2 | Regional lymph nodes (3-6) | | T4b | Any N | M0 |
| N3 | Regional lymph nodes (>6) | | Any T | N3 | M0 |
| M1 | Distant metastasis | Stage IV | Any T | Any N | M1 |

## staging and prognostic factors

Tumor–Node–Metastasis (TNM) classification of malignant tumors and staging groups are shown in Table 1. The most important prognostic factor is the stage at diagnosis. Other prognostic factors include the tumor volume, the presence of lymphovascular invasion, the Eastern Cooperative Oncology Group (ECOG) score, and the response to neoadjuvant treatment.

## management

### Early Disease Management

Esophagectomy with gastric tube pull–up has traditionally been the gold standard treatment for Tis-T1N0M0 disease, but its associated morbidity and mortality has restricted its role to a minority of medically fit patients.[14] Endoscopic techniques including endoscopic mucosal resection are an alternative to those with Tis/T1a disease.

### Locally–Invasive Disease Management

In cases of ≥T3 or N+ disease, neoadjuvant chemoradiation therapy (CRT) followed by esophagectomy is the recommended treatment. The advantage of neoadjuvant treatment was demonstrated by the Chemoradiotherapy for Oesophageal Cancer Followed by Surgery Study (CROSS).[15] In the CROSS study, 368 patients with resectable esophageal or GE junction tumors were randomly assigned to either surgery alone or CRT followed by surgery. CRT involved the weekly administration of carboplatin and paclitaxel and concurrent radiotherapy with 41.4 Gy in 23 fractions. Median overall survival was shown to be significantly better in the CRT–surgery group, at 49.4 months with CRT–surgery versus 24 months with surgery alone (p=0.003). The CRT-surgery group had higher radical resection rates (92 % CRT–surgery versus 69 % surgery alone) and achieved pathologic complete response in 29 % of resected cases, without additional post-operative morbidity compared to the group treated with surgery alone.

### Controversy in Early Disease Management

The benefit of neoadjuvant CRT in early esophageal cancer remains less clear than in locally-invasive disease. The Federation

Francophone de Cancérologie Digestive (FFCD) 9901 phase III trial published its results in June 2014, comparing surgery alone versus CRT followed by surgery in patients with stage I or II esophageal cancer.[16] The authors of the trial found no difference in overall survival or disease–free survival between the two groups, and interestingly, they found a 3–fold higher thirty–day post–operative mortality rate in the CRT group (11.1 % versus 3.4 %, p=0.049). This is in contrast to previous studies, including the CROSS trial, which demonstrated a survival benefit with pre–operative CRT and no increase in post–operative mortality.[15] It has been noted that there were several differences between these two trials. In FFCD 9901, the patient population may have had poorer baseline health, and the patients predominantly had SCC, unlike CROSS, wherein 75 % of patients had adenocarcinoma. Furthermore, fluorouracil and cisplatin were used in FCCD 9901, whereas paclitaxel and carboplatin, which are thought to be better tolerated, were used in CROSS. Lastly, there were differences in radiation techniques between the two trials. In the case of T2 tumors, some physicians advocate for neoadjuvant CRT due to observations of significant under–staging of T2N0 patients in previous studies (>50 % in the Zhang 2012 study).[17]

**Median overall survival was shown to be significantly better in the CRT–surgery group, at 49.4 months with CRT–surgery versus 24 months with surgery alone.**

### Unresectable and Cervical Tumors

For unresectable tumors (such as those involving the trachea or aorta) and cervical tumors (where resection would usually require laryngectomy), definitive CRT is recommended. In these cases, the standard of care is to deliver five weeks of radiation treatment (50 Gy in 25 fractions) with two concurrent cycles of fluorouracil and cisplatin during weeks 1 and 5 and two cycles post–RT. Definitive CRT became the standard of care for inoperable disease after the Radiation Therapy Oncology Group (RTOG) 85-01 trial, which compared concurrent CRT (50 Gy in 25 fractions and two cycles of concurrent and post–RT cisplatin and fluorouracil) against RT alone (64 Gy in 32 fractions). This trial closed prematurely when an interim analysis showed a significant survival benefit with CRT (5–year survival 27 % versus 0 %).[18]

### Adenocarcinomas of Distal Esophagus and GE Junction

The best treatment option for adenocarcinoma of the distal esophagus and GE junction is unclear, and optimal management continues to be defined. The current recommended treatment is three cycles of pre–operative chemotherapy and three cycles of post–operative chemotherapy, with epirubicin, cisplatin and capecitabine (ECC) or epirubicin, cisplatin and infusional fluorouracil (ECF). This recommendation was guided by the results of the Medical Research Council Adjuvant Gastric Infusion Chemotherapy (MAGIC) trial, which evaluated peri–operative chemotherapy in resectable gastric cancer, 25 % of which were of the lower esophagus or GE junction.[19] In this study, 503 patients with at least stage Ib disease were randomly assigned either to surgery alone or to three cycles of pre–operative ECF, then surgery, followed by three cycles of post-operative ECF. Five–year overall survival favoured treatment with ECF compared to surgery alone (36 % versus 23 %, p=0.009). Of note is that the design of this trial has attracted criticism for its lack of detailed pre–operative local staging, for insufficient data regarding surgical technique, and for poor rates of commencement and completion of postoperative chemotherapy (only 42 % of patients completed all prescribed chemotherapy). The French Fédération Nationale des Centres de Lutte Contre le Cancer (FNLCC)/FFCD trial showed similar benefit with neoadjuvant chemotherapy.[20] The benefit of CRT over pre–operative chemotherapy alone is currently the topic of a multicenter randomized trial of preoperative therapy for gastric and GE junction adenocarcinoma by the National Cancer Institute of Canada (NCIC), the European Organization for Research and Treatment of Cancer (EORTC), and the Trans-Tasman Radiation Oncology Group (TROG) collaborative group.[21]

**The benefit of neoadjuvant CRT in early esophageal cancer remains less clear than in locally-invasive disease.**

## future directions

Current research is investigating the use of early FDG-PET scans to assess response to chemotherapy. The MUNICON-II (Metabolic response evalUatioN for Individualisation of neoadjuvant Chemotherapy in Oesophageal and esophagogastric adeNocarcinoma) prospective study found that PET scans taken upon initiation of chemotherapy and two weeks later were predictive of the overall response to neoadjuvant chemotherapy in patients with locally advanced GE junction adenocarcinoma.[22] Specifically, those whose tumors showed a mean standardized uptake value (SUV) decreased by >35 % were defined as chemotherapy–responders and received an additional three months of chemotherapy, whereas non–responders (mean SUV decreased by <35 %) were referred for earlier surgery after receiving only a relatively short course of salvage CRT. After a median follow–up time of 38 months, the median overall survival had not yet been reached in the PET responders, whereas the median overall survival in the non–responders was 18.3 months. The MUNICON–II study confirmed the prognostic value of FDG–PET even as early as two weeks after starting chemotherapy. The Cancer and Leukemia Group B (CALGB) 80803 randomized phase II trial will further investigate the use of PET scans in patients with locally advanced esophageal or GE junction adenocarcinoma.[23] In that

study, patients will be randomized to treatment with either carboplatin/paclitaxel or modified FOLFOX6 (fluorouracil plus leucovorin and oxaliplatin) and undergo PET scan at day 36-42. PET responders will continue chemotherapy and undergo radiation treatment. Non-responders will cross over to the other chemotherapy regimen and undergo radiation treatment. The primary objective will be to induce a pathologic complete response rate of 20 % in PET non-responders in either treatment arm.

## conclusion

The optimal management of esophageal cancer remains to be defined. The intent of this review was to present some of the trials that have influenced current recommendations. A number of trials that were not discussed had conflicting results. Esophageal cancer is heterogeneous in its presentation, and there is no single treatment algorithm that can be applied to every patient. It is apparent from the literature that SCC and adenocarcinoma behave and respond differently, yet they are often grouped together in clinical trials. There is also a lack of definitive evidence to support the 41.4 Gy radiation dose used in the CROSS trial as the optimal pre–operative dose. Additionally, there are no head–to–head trials comparing carboplatin versus cisplatin–based CRT. Many questions still exist in the management of esophageal cancer, but because most patients present with locally invasive disease, tri–modality therapy should always be a consideration.

**The benefit of CRT over pre–operative chemotherapy alone is currently the topic of a multicenter randomized trial of preoperative therapy for gastric and GE junction adenocarcinoma by the National Cancer Institute of Canada (NCIC), the European Organization for Research and Treatment of Cancer (EORTC), and the Trans-Tasman Radiation Oncology Group (TROG) collaborative group.[21]**

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# Childhood Poverty and Parental Stress: Important Determinants of Health

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## abstract

The following is a literature review examining the interaction between early–life stress and child development. First, evidence showing that early–life experiences can affect the cognitive abilities, behaviour, and health of an individual are reviewed. Next, possible mechanisms by which these changes occur are explained. These mechanisms include toxic stress–mediated dysregulation of the hypothalamic–pituitary–adrenal axis and epigenetics. Finally, up–and–coming research related to early–childhood interventions that target family stress relief and the child–parent relationship are touched upon. These interventions may impact the negative effects of toxic stress on cognition and health.

## early–life poverty

Extensive research on the consequences of child poverty over the past two decades has demonstrated that chronic poverty is a significant mediator of the future quality of life of children from both a cognitive and physical health perspective. Persistent low socioeconomic status (SES) during childhood is consistently associated with lower academic achievement and more maladaptive socioemotional functioning.[1-3] Moreover, the cumulative number of years spent in poverty during childhood is more predictive of academic outcomes than acute poverty at a certain age.[4] Evidence from twin populations suggests that this association between chronic poverty and decreased cognitive ability persists even when genetic contributions are controlled.[5] It has been shown that poverty in early–life not only affects the immediate childhood period but also has a significant role in diseases previously thought to be caused by adult behaviours. For example, in a study of over 1100 physicians followed for a median of forty years, those with a low childhood SES had a 2.4 times increased risk of developing coronary heart disease (CHD) by age 50 independent of other CHD risk factors, compared to those who did not grow up in poverty.[6] Thus, reducing rates of child poverty may help to improve both the cognitive abilities and physical health of children throughout their lifespan.

## the child–parent relationship and parental stress

In addition to chronic poverty, many large studies have demonstrated the importance of the child–parent relationship and parental stress in life outcomes. Child–parent interactions are essential to learning experiences in the home and have been found to account for up to half of the beneficial effects of both income–assistance and educational interventions on the cognitive development of children with low SES.[7,8] Moreover, the Minnesota Longitudinal Study of Risk and Adaptation—a landmark study for child development that followed individuals from birth until adulthood over 40 years—showed that measures of family stress and social support were two of the strongest predictors for life outcomes.[9] For instance, among kindergarteners who were anxiously attached to their primary caregiver as infants, the most important factor in predicting improved function over the school year was increased social support for their primary caregiver. More recent studies have corroborated these findings; they show that measures of parental stress were strong predictors of maladaptive externalizing and internalizing behaviours in children as well as decreased school engagement.[10,11] This research provides important recommendations for practice and policy. Firstly, interventions should be started at a young age if possible given the enduring influence of early relationships.[9-12] Secondly, instead of targeting the child in isolation, a complex interventional approach is required that focuses on both the child–parent relationship and the recruitment of social and community supports for parents to alleviate parental stress.

## possible mechanisms of embedding experiences

The National Scientific Council on the Developing Child and the American Academy of Pediatrics use a model called "toxic stress" to explain the long–term effects of childhood adversity on the body.[13,14] Toxic stress is defined as stress that is chronic and uncontrollable and/or stress that is experienced in the absence of support from caring adults; this can cause changes to the developing brain as well as dysregulation of the stress response system. Risk factors for toxic stress include chronic extreme poverty, child abuse/neglect, maternal depression,

parental substance misuse, and family violence. The health impact and mechanisms of toxic stress associated with dysregulation of the stress response system and up-regulation of inflammation have been well documented.[15-17] In addition, numerous studies have shown that adrenocortical and pro-inflammatory mediators were up-regulated in individuals suffering from chronic stress related to low SES, maltreatment, and social isolation.[18] This was seen in a cross–sectional study of over 200 Quebec school children where morning cortisol levels were found to be negatively correlated with SES.[19] Moreover, independent of current SES, lifestyle practices, and perceived stress level, adults with low early–life SES were found to have increased baseline daily cortisol levels, increased pro-inflammatory mediators, and significantly up-regulated genes associated with the stress response and inflammatory systems compared to adults raised in higher SES households.[18] In addition to the model of toxic stress–mediated dysregulation of the stress response system, another plausible explanation for the biological embedding of early–life experiences is seen in the field of epigenetics.

Multiple excellent reviews explain epigenetics and its role in child development.[20-25] In short, epigenetic mechanisms, such as DNA methylation and histone modification, alter gene expression by modifying the accessory structures of the genome to facilitate or block gene transcription within the lifetime of the individual. The child–parent relationship and SES–related aspects of the prenatal and childhood environments have been found to be associated with persistent changes in epigenetic patterns. For example, 60 years after being prenatally exposed to famine, study subjects were found to have different DNA methylation patterns of a gene linked closely to growth and development compared to their same–sex siblings who were not exposed.[26] Similarly, researchers have repeatedly found that DNA methylation patterns were more associated with childhood SES than adulthood SES.[27,28] For instance, McGowan et al. found increased methylation of the promoter of the glucocorticoid receptor in the hippocampus of suicide victims who had been abused as a child but not in suicide victims who had not been abused or in the control group (no suicide).[29] Thus, childhood abuse had altered an aspect of the hypothalamic–pituitary–adrenal axis function and perhaps increased the susceptibility of these individuals to the effects of stress in adulthood. To support these retrospective associations, the first longitudinal prospective study on the connection between epigenetic changes and childhood adversity was published in 2013; this study involved 109 children from Wisconsin who were followed from birth until age 15.[30] Researchers examined 14,000 genes associated with environmental stress or behaviour and found that a composite score of parental stress measured in infancy and preschool was predictive of changes in DNA methylation at age 15. In conclusion, it is likely that epigenetics is one of the mechanisms by which prenatal/childhood experiences and parental stress can affect the future behaviour and health of children.

## psychosocial interventions

The major focus of most large–scale early childhood intervention programs (ECIPs) in North America has been cognitive development.[31] However, as presented above, the current body of evidence shows that future cognitive and physical health can by significantly modified by toxic stress and the child–parent relationship. Therefore, experts in child development suggest that ECIPs are more beneficial when they target family stress relief, attachment, and education.[14,31] Traditional programs providing only low–income subsidies to combat family stress have led to a small reduction in cumulative poverty risk; however, they were not able to significantly affect the psychosocial aspects of at–risk families, including maternal depression, food insufficiency, parenting stress, and parenting behaviours.[32] ECIPs using relationship–centered therapies to alleviate family stress have been shown to be effective at improving attachment and behavioural problems, as well as biomarkers of chronic stress.

Examples of ECIPs that take a relationship–centered approach include those used by Cicchetti et al.: child–parent psychotherapy (CPP) and psycho-educational parenting interventions (PPI).[33] CPP is an attachment–based therapy that recognizes multi-generational trauma and a lack of parenting skills. Therefore, it tries to provide a "corrective emotional experience" by helping parents "form positive representations of themselves and the caregiver–child relationship".[33] PPI is a didactic intervention that teaches parents how to access social supports, including education and employment, and parenting skills to reduce parental stress. Both CPP and PPI were found to substantially improve attachment profiles of maltreated infants after 12 months of treatment in comparison to those maltreated children whose families received the standard services and to non-maltreated children.[34] Moreover, attachment/relationship–based therapies, including CPP and PPI, have been shown to normalize cortisol levels in maltreated and foster children.[17,33,35] Taken together, these studies suggest that disruptions in attachment and the HPA axis due to early–life adversity may be prevented or reversed by interventions designed to improve caregiving and the child–parent relationship. Therefore, adding interventions to educational programs that focus on strengthening the child-parent relationship, along with alleviation of poverty, may improve outcomes for at-risk children.

## conclusions

In summary, chronic poverty, parental stress, and poor child–parent relationships can have a significant negative impact on future cognitive abilities, behaviour, and physical health through mechanisms, such as toxic stress and epigenetics. As a result, interventions that take a multi-generational approach to support the child and parent individually, as well as in their relationship, may provide some added benefit to current ECIPs. It is important to note that the term, "early," used in this article is not restricted to pre-adolescence. The teenaged years are a critical time in development with ample opportunity for harm as well as intervention, but adolescent–specific research was not discussed in this article. For a comprehensive review of the entire topic, please see the 2012 report by the Royal Society of Canada and the Canadian Academy of Health Sciences expert panel in Early Childhood Development led by Dr. Clyde Hertzman and Dr. Michel Boivin.[36]

In addition to improved, evidence–based ECIPs, it is imperative that child poverty and the many other social determinants of health of children and adolescents are made a priority. Notably, the Canadian Medical Association has identified that a main priority to improve health across Canada is to create federal and provincial/territorial level action plans to eliminate poverty.[37] Other important social determinants of child and adolescent health include access to education and housing, multigenerational trauma, income inequality, racial/ethnic disparities, and community violence. To start addressing these issues, numerous evidence–based initiatives have been suggested, such as a minimum wage that reflects the cost of living, national food security program, universal publicly–funded child care, affordable housing for low– and middle–income families as well as those with mental illness, and a focus on marginalized populations.[38] Obviously, there is no simple solution to these societal problems; however, better support for children/adolescents and their parents will be essential to any effective plan.

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# Anatomy of a Stem Cell Drive: An Evidence-Based Approach to Stem Cell Drive Organization

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## abstract

Patients in need of a stem cell transplant often rely on unrelated donors. Canadians can register as donors online or at a stem cell drive by providing consent and a tissue sample for typing. To the knowledge of this author, no guidelines have been published to recommend a process for stem cell donor recruitment at drives. This article outlines an evidence–based approach to stem cell drive organization with five core components: prescreening, informed consent, registration, swabbing, and reconciliation. This approach offers guidance to medical students who coordinate stem cell drives and encourages them to act as health advocates for Canadians who need a stem cell transplant.

## introduction

Patients with a variety of blood cancers and metabolic diseases may require a stem cell transplant as part of their treatment.[1] However, 70% of patients do not have a suitable genetic match in their family.[2] Canada's stem cell donor database, OneMatch Stem Cell and Marrow Network, is used to match potential unrelated donors to patients worldwide. Individuals aged 17-35 years can register online or at a stem cell drive where they provide consent and a tissue sample (buccal–swab) for Human Leukocyte Antigen (HLA) allele typing. However, due to the overwhelming number of possible HLA allele combinations, it remains challenging to secure a compatible stem cell donor for many patients: currently, over 1000 Canadians are unable to find a match anywhere in the world.[3]

To address the need for stem cell donor registrants, I founded the UBC Stem Cell Club in 2011. As of June 2014, the club has coordinated 21 stem cell drives in a variety of settings including drives on six university campuses across BC, in the community, and in rural areas.[4,6] Altogether, we have recruited over 2300 donors, representing 2.5% of all registrants recruited across Canada between 2012 and 2014.[4] We have gained considerable experience operating stem cell drives, and we are accredited by OneMatch to run drives independently.

To the knowledge of this author, no guidelines have been published to recommend a process for stem cell donor recruitment at drives. In this article, I outline an approach to stem cell drive organization, which is applied to every UBC Stem Cell Club drive. This approach features evidence–based strategies to identify the most–needed stem cell donors and to minimize donor ambivalence and withdrawal from the registry. Our drives include five necessary stations: pre-screening, informed consent, registration, swabbing, and reconciliation (see Table 1). These stations are not necessarily physically separate from each other; rather, they represent the path that a registrant takes to sign up to be a potential stem cell donor at a drive.

## pre-screening

The first station of a stem cell drive is the pre-screening station. Here, volunteers interact with people walking by, inform them about the stem cell drive, and screen for stem cell donor eligibility. To register as a donor, individuals must be willing to swab their cheeks to provide a DNA sample and to sign a consent form to join the registry. Additionally, individuals must also meet a number of health and demographic criteria. OneMatch requires donors to be aged 17-35 years.[3] Registrants must be at least 17 years old as this is the age required to provide consent. Individuals older than age 35 are not eligible to register as studies have shown that a younger donor age is associated with improved outcomes, including increased survival rates, in the transplant recipient.[5] This evidence has guided OneMatch to focus recruitment efforts toward younger donors.[3] Individuals registering to be stem cell donors also need to be in good general health. This requirement seeks to protect volunteer donors from the risk of damage to their own health and to protect recipients from transmissible diseases.[7] Registrants also need to have

**Ineligible registrants should be redirected to help in other ways; they could be encouraged to donate blood if able, to ask their peers, friends, and family to consider registering as stem cell donors, and to volunteer at stem cell drives.**

**Table 1: Five Stations necessary for a stem cell drive**

| Station | Purpose |
|---|---|
| 1. Prescreening | Recruits individuals to consider registering as potential donors<br>Ensures donor eligibility<br>Targets the most–needed donors |
| 2. Informed consent | Ensures that donors are informed about:<br>• Stem cell donation principles and procedures<br>• Risks and side effects of donation<br>• Anonymity, confidentiality, and right to withdraw from the registry |
| 3. Registration | Guides registrants to complete necessary paperwork<br>Answers registrant questions |
| 4. Swabbing | Guides registrants to swab their cheeks for a tissue sample<br>Assembles and seals completed swab kits |
| 5. Reconciliation | Delivers final information<br>Assesses informed consent<br>Checks for errors<br>Processes kits for shipment and drive outcome reporting |

provincial health care coverage: if a registrant is selected as a match to donate their stem cells, the registrant's health care coverage pays for the medical workup and the procedure itself. International students and visitors from other countries should be encouraged to register as donors on their home country databases. Finally, stem cell donors must be willing to donate to anyone in need worldwide.[9] Donors cannot direct their donation to a patient of their choice. Ineligible registrants should be redirected to help in other ways; they could be encouraged to donate blood if able, to ask their peers, friends, and family to consider registering as stem cell donors, and to volunteer at stem cell drives.

In addition to confirming that potential registrants meet minimum eligibility criteria to sign up, volunteers at the pre-screening station should actively target the most-needed stem cell donors: donors that are young, male, and ethnically diverse. As discussed above, younger donors are associated with improved outcomes, including recipient survival.[5] Younger donors are also on the registry longer and are more likely to be in good health. Male donors are preferred as they are associated with decreased incidence of one significant transplant complication: chronic graft-versus-host disease.[5] Recruitment of ethnically-diverse donors is important as patients are more likely to find a genetic match from donors within their own ethnic community.[8]

## informed consent

Interested potential donors who meet the minimum eligibility requirements outlined above should be directed to an informed consent station. Informed consent is a moral, ethical, and legal requirement to become a stem cell donor. In addition, studies have shown that individuals are more likely to be ambivalent towards donating if they feel less informed or have unanswered questions at the time of recruitment.[10] Such individuals are more likely to withdraw from the registry if asked to proceed with the donation.[11] Informed consent includes notifying the registrant of all relevant procedures, as well as possible risks of donation, right to withdraw, and confidentiality and anonymity of the program.[12]

In addition to confirming that potential registrants meet minimum eligibility criteria to sign up, volunteers at the pre-screening station should actively target the most-needed stem cell donors: donors that are young, male, and ethnically diverse.

## registration

To sign up as a stem cell donor in Canada, registrants must complete a form that asks for demographic information (including ethnic background), contact information, and medical history. Registrants then sign their consent to join the registry. At this station, volunteers should be available to guide registrants through forms and answer any questions that may arise. It is important that registrants provide detailed contact information, including alternate contacts, so they can be contacted if they are a match.[13]

Figure 1: Registrants swab their cheeks with a cotton swab to provide a DNA sample. Four cheek swabs are collected from the registrant, each from a different area of the mouth. Swabs are flagged with a unique registrant barcode.

**Stem cell drives directly improve the Canadian stem cell donor database, an important global health resource that helps patients worldwide.**

## swabbing

Following registration, registrants should proceed to a swabbing station. Here, four separate cotton swabs are used to obtain four buccal cell samples (see Figure 1). Drive volunteers affix bar code labels to the registrants' paperwork and cotton swabs. Registrants are guided to swab their own cheeks. Volunteers should then help registrants package their swabs into a swab kit, staple the paperwork and swab kit together, and direct the registrant to the reconciliation station.

**I founded the UBC Stem Cell Club in 2011. As of June 2014, the club has coordinated 21 stem cell drives in a variety of settings including drives on six university campuses across BC, in the community, and in rural areas.[4,6] Altogether, we have recruited over 2300 donors, representing 2.5% of all registrants recruited across Canada between 2012 and 2014.**

## reconciliation

The final station of a stem cell drive is reconciliation. Here, registrants should be given another opportunity to ask questions. Drive organizers should inform registrants that they will remain on the registry until age 60. Registrants may also be called by OneMatch staff to confirm any details on their paperwork. They should be told that they are responsible for updating their address if necessary. This allows OneMatch to contact them if they are found to be a suitable match. The last step of the stem cell drive is error checking with the registrant. Errors can prevent completed swab kits from being entered into Canada's stem cell donor database. The process of redoing registration paperwork and/or cheek swabs can delay processing and testing; this can result in a delay for a patient and a matched donor. Finally, kits are processed and recorded for shipping and drive outcomes are tallied.

## conclusion: stem cell drives and health advocacy

Stem cell drives directly improve the Canadian stem cell donor database, an important global health resource that helps patients worldwide. Coordinating or volunteering at drives represents a meaningful avenue for individuals to act as health advocates for over 1000 Canadians who are in need of a transplant but cannot find a match. The five–station approach to stem cell drive organization outlined here represents a model for effective stem cell donor recruitment.

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# Zhao et al: Appendix A

**What are the Parental Barriers to Applying Pain Reduction Strategies for their Child During Routine Vaccinations?**

Please enter/circle your responses below:

1. What is your gender? Male / Female / Other
2. How old are you? _____
3. What is your ethnic background? _____
4. What is your highest level of education?
   - ☐ Less than high school
   - ☐ High school diploma
   - ☐ Some post-secondary
   - ☐ Bachelor's degree (eg. B.A., B.Ed)
   - ☐ Master's degree (eg. M.A., M.Sc)
   - ☐ Doctorate (eg. Ph.D)
   - ☐ Other (please specify): _____
5. At your most recent vaccination appointment, what was the gender and age of your child?
   Boy / Girl Age: _____
   If this is your child's first vaccination appointment, go to question 8.
6. Please rate your level of concern about pain during your child's most recent vaccination:

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Not concerned | | Moderate | | Very concerned |

7. Please rate your child's level of anxiety during his/her most recent vaccination:

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Not anxious | | Moderate | | Very anxious |

8. If this is your first vaccination appointment, please rate your present level of concern about pain during the vaccination. (if you answered question 6 & 7, go to question 9)

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Not concerned | | Moderate | | Very concerned |

9. How many children do you have and how old are they?
   Boys 1 2 3 4+ Age(s) _____
   Girls 1 2 3 4+ Age(s) _____

10. Below is a list of ways to reduce pain. Please select if you have tried any. If yes, go down to next row. If no, go across to the right column.

| Strategy | Yes, I've tried | Tried but didn't work | No, I haven't tried | If No, please select all reasons that apply: (you may choose more than one) |
|---|---|---|---|---|
| Skin numbing creams (topical anesthetics) | ☐ | ☐ | ☐ | ☐ Can't find at pharmacy<br>☐ Costs too much (about $7)<br>☐ Doctor has not discussed with me<br>☐ It won't work<br>☐ Never heard of this<br>☐ Pain is okay<br>☐ Too much time (use 1 hour before injection)<br>☐ Worried about side effects<br>☐ Worried it will interfere with vaccine<br>☐ This is our first vaccination<br>☐ Other (please specify): _____ |
| Breastfeeding the infant during injection (skip for men) | ☐ | ☐ | ☐ | ☐ Doctor has not discussed with me<br>☐ I'm not comfortable with this<br>☐ It won't work<br>☐ Never heard of this<br>☐ Not enough time for this<br>☐ Pain is okay<br>☐ This is our first vaccination<br>☐ Other (please specify): _____ |
| For children up to 12 months, feeding them sugar water during the injection | ☐ | ☐ | ☐ | ☐ Doctor has not discussed with me<br>☐ I'm not comfortable with this<br>☐ It won't work<br>☐ Never heard of this<br>☐ Not enough time for this<br>☐ Pain is okay<br>☐ This is our first vaccination<br>☐ Other (please specify): _____ |
| For children older than 3 years, coaching them to take slow, deep breaths during the injection | ☐ | ☐ | ☐ | ☐ Doctor has not discussed with me<br>☐ I'm not comfortable with this<br>☐ It won't work<br>☐ Never heard of this<br>☐ Not enough time for this<br>☐ Pain is okay<br>☐ This is our first vaccination<br>☐ Other (please specify): _____ |

11. The strategies above have been shown to be effective for decreasing pain during vaccinations. In your opinion, what are the top 5 reasons why parents don't use them? Please rank from most important (1) to least important (5).
    - ___ Doctor has not discussed with me
    - ___ I'm not comfortable using these strategies
    - ___ My doctor doesn't have time
    - ___ Never heard of these strategies
    - ___ Pain is okay
    - ___ It takes too much time
    - ___ These strategies won't work
    - ___ Other (please specify): _____

12. Are you interested in learning about strategies to decrease pain during your child's vaccinations? Yes / No

13. What would be the top 3 ways for you to learn more about ways to decrease pain? Rank from highest (1) to lowest (3).
    - ___ Discuss with doctor
    - ___ Discuss with other health professionals (eg. nurses, pharmacists)
    - ___ Educational pamphlets
    - ___ Learning from the internet, family/friends, or other media (eg. magazines)
    - ___ Other (please specify): _____

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