

COMMENT

MCMASTER STUDY

Cancer's cost to patients adding up

Outta pocket expenses financial, emotional toll

CHRISTOPHER LONGO

"All I have is my condominium — and I've thought about selling it, which I don't want to. It's the only thing I have."

Those are the words of a Canadian cancer patient struggling to pay for treatments and all the related expenses. It is a story we think could never happen in Canada, but it does.

The critical question is, how often are these types of decisions happening, and is there anything that can be done to address it?

We know of the terrible tolls cancer takes on our physical and emotional well-being, but there has been little research investigating the financial impact on patients and families. Work done in the early 2000s in Ontario revealed that these costs were significant, particularly for those who were under the age of 65 and/or without private insurance.

Average patient costs were found to be more than \$600 a month for treatments, travel, parking and accommodation. The impact can also include lost time from work, resulting in significant financial stress. In fact, for 30 per cent of the sample investigated these costs were "significant or unmanageable," with many patients spending in excess of \$20,000 during the course of their treatment.

Today, these issues are becoming more common and certainly more expensive.

This is partly due to a number of factors: rising drug prices for cancer medications (often exceeding \$800,000 for the full treatment course), increasing pressures on governments for community-based health services, which result in reduced hours of service per family, and even a tightening of private plans as corporations attempt to control their rapidly growing health budgets.

In recent years some qualitative research has shown these financial problems persist and may be getting worse. This research identified new types of costs to patients, which included impact on food costs, home modifications or change of residence, and suggest that earlier published studies on financial burden likely underestimated the true cost to patients and their families.

Outside this study, very little research has been undertaken in this area in the past five years, nor has anyone compared these effects across provinces until only recently.

The Canadian Centre for Applied Research in Cancer Control (funded through the Canadian Cancer Society) has funded a "Pan-Canadian study of cancer patients' out-of-pocket costs," led by researchers at McMaster University.

This study is national in scope, examining patient costs and lost income for the four most common cancers: breast, colorectal, lung and prostate. Information on patients' burden is being captured with the intent to better understand how these burdens have changed, and how provinces have addressed these issues through policy mechanisms.

It is hoped that by observing differences among provinces in terms of patient costs and existing policies, researchers may identify best practices in order to mitigate some of these costs for patients and their families and improve their financial status at a time when the emotional and physical costs are already high.

Christopher Longo is an associate professor of Health Policy and Management at the DeGroote School of Business at McMaster University. More detail on the ongoing study, including access to the questionnaire for cancer patients on active treatment, can be found at <http://psafe.mcmaster.ca/>

The study will look at the costs, lost income from the top cancers: breast, colorectal, lung, prostate.

MINIMUM WAGE

Hamilton gets a failing grade on living wage

Misguided thinking allows city council to ignore economic realities that hit women hardest



DEIRDRE PIKE

I've worked a range of part-time jobs since I first acquired my SIN (not my original sin, but my social insurance number).

I started off as a stock boy and cashier at my dad's store; taught swimming lessons at a few different pools; cleaned the apartment of the couple who owned the health food store where I worked selling vitamins and bulk food; and conducted door-to-door marketing research on canned fruits and vegetables.

However, the one PT gig I recall with the most favour this time of year is my role as a Shabbos goy for a Jewish family. That means I was hired as a non-Jew to take care of work that Jewish religious law prohibits adherents from taking care of themselves on the Sabbath.

During the days leading up to Passover (which this year ends on Tuesday night), I was engaged with zeal in dishwashing, housecleaning and food prep with the women as they switched over to the special dishes used only on these holy days.

Once Pesach officially started, I was often on my own in the kitchen, especially the first two nights when the Seder meal would be eaten. On those nights, I would lean in tightly to hear the words of the Haggadah through the

closed door to the dining room where that and the other 13 steps of the ordered ritual were underway.

It is one of the positions I had in life that will impact my whole being till my dying days. Not only am I grateful for what I learned about Judaism, families, rituals, and my own faith, many people who have heard me talk about that experience have also said how lucky I was to have had such a great opportunity. All of that is true.

It is also true I needed the money. I had those jobs in university which, for the most part, I had to take care of financing myself. While my parents always seemed to be pretty well off, I started at Brescia in 1981, just as the deepest economic downturn since the Great Depression hit Canada and elsewhere around the globe. It would only take a few years until they were forced to claim bankruptcy, selling our family home in Strathroy and moving to a rented townhouse in London.

My PT jobs were essential for me to make ends meet, and so are those of the mostly female part-time workers at the City of Hamilton.

Unfortunately, some city councillors here seem to think PT positions in the City are held by women who are financially sustained by husbands but need a little something to keep them busy during the day that could help pay down that cottage on Lake Erie.

It's because of that misguided thinking and more that I stood embarrassed as a facilitator of a panel on living wage at a national conference on poverty hosted right here in Hamilton

last week. As a host participant and an original partner in Hamilton's Living Wage Coalition, I had to tell the gathering that Hamilton city council had recently voted against adding just over \$1 million to our annual budget to raise PT workers to \$8.85 an hour, Hamilton's living wage.

Equal Pay Day, marked April 1, was an opportunity for the OFL and some other partners to use data for some truth-telling. These facts that may have helped our councillors vote better.

Women represent two-thirds of part-time workers in Ontario. Over 60 per cent of the 1.7 million Ontarians who earn minimum wage are women.

Since women make 30 per cent less on average than men in Canada, a woman will have to work almost four months longer into the new year to earn what men were able to bring home in just 12 months last year.

It's even worse for women who are racialized, older, disabled, indigenous, migrant and immigrant, or LGBTQ. They will have to work into May or June to get a man's salary.

If you believe women are just taking on part-time jobs for the fun of it or for the gravy on the table and not the bread, you might also be expecting an Easter bunny to deliver your chocolate tomorrow morning. I wish you well and a living wage.

Deirdre Pike doesn't work part-time but does freelance for the Hamilton Spectator as a Bi-Weekly columnist. She can be reached at dpikethespec@gmail.com or @deirdrepikethespec.

BACK TO CANADA

Returning to Hamilton, Ugandan treasure beside us

We try not to worry because tomorrow, you know, always brings enough worries of its own



THOMAS FROESE

MUKONO, UGANDA — I will miss the light of Africa as much as I will miss anything. I will miss the water too.

This, even as I'll miss Africa itself, the birthplace of our youngest daughter, the place where the light shines so beautifully on her skin.

Ugandans have beautiful skin, anyway. But put my daughter in water, and the light shimmers especially dramatically, like raindrops in sunshine. It's a rare occurrence in nature, but maybe more common here where, even in rainy season, the sun's never far away.

You might remember Hannah from this space. My wife and I had once prayed in our Hamilton kitchen for an African girl to adopt. We'd name her Hannah Laura, to honour my late mother.

Later, at a Ugandan orphanage, a little girl, with a face as sad as this world has ever seen, walked up to us. She looked up and tapped me on the leg. I asked, "So who might this be?"

"This girl," an orphanage worker said, "is Hannah."

It was something. Hannah was three. After three years of fostering her in our Ugandan home, two years of uncertainty followed. Ugandan court files were "lost." Hearings were cancelled. Judges, absent. Travelling across borders, a nerve-racking nightmare.

Finally, court approval came on, of all days, Hannah's 8th birthday. What are the odds? (One in 365, I suppose.)

These are the two bookends in Hannah's story, a good news story from a place with enough hardship. Uganda has two million orphans. Precious few will ever be adopted.

We know little of Hannah's origins, why her mother left her in hospital at birth. One Christmas we took her some hours to that birthplace to learn more. What we know with greater certainty is that Hannah loves water. In Canada (she's now a Canadian citizen), she's skilled at skating on it. And in Uganda, she loves swimming in it.

Ugandans rarely swim. They do, however, readily get baptized. You might arrive at some pool on any day and find an entire gaggle of Ugandan men and women, fully gowned, one-at-a-time, dunked and dripping, leave the water before breaking into some song other-wise reserved for the most striking of African birds.

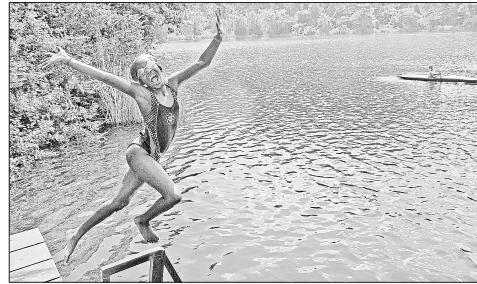


PHOTO BY DR. JEAN CHAMBERLAIN FROESE

Hannah Laura Froese has been part of the Froese family since she was three years old. This weekend Hannah, 11, leaves her familiar waters of Africa to take up residence in Hamilton.



PHOTO BY DR. JEAN CHAMBERLAIN FROESE

Hannah in 2009, at the age of 3, at an orphanage in Jinja, Uganda, where she first met the Froese family.

In some places, such a public display would seem extravagant, if not courageous. Here it's an interruption. I just wanted to swim my lanes.

Another day I was swimming lanes when a Ugandan girl about Hannah's age said, "OK, you swim. I'll climb on your back. You carry me and I'll learn." I knew she was hopelessly mad. There's a deep end! We'll drown! But we didn't. Not any more than any soul carried through the mysterious waters of Easter will drown.

I'm a very average swimmer. I swim because I have a bad back, a certain pain. But swimming, I've discovered, clears the head as

much as anything. Lucky to live near a pool even when overseas, I calculate that over the years I've swam more than 3,000 km. That's Toronto to Niagara-on-the-Lake 28 times. And 28 times back.

We're early risers. It takes an hour to drive the kids to school. When not driving, after running the dog, I've often sat on the porch and watched the sunrise and thought about all this: Africa's light and water, Hannah's future, what she'll learn while living in Canada permanently.

This Easter Monday, the plane flies. Our family will fly over the water and through the light toward Canada.

The three children say goodbye to, among other things, their longtime international school. Call it the UN. It's an exceptional mix of more than 50 nationalities. Bonds of world friendships have been dear. This is what Hannah from Uganda is leaving behind. She's shed tears. Who wouldn't?

But we try not to worry because tomorrow, you know, always brings enough worries of its own. The water always seems most threatening before you jump in.

Of course, we're bringing a few things to our Canadian home. Some keepsakes. Furnishings. Some African art. But our finest treasure is the ebony girl who once had the world's saddest face. She's our forever reminder of the gentle people who shimmer in the water.

She'll go beside us and with us. And we'll be better for it.

Thomas Froese writes about travel and fatherhood. Find him at www.thomasfroese.com

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