

Home sweet homeless

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I stared at my phone after my aunt hung up. I had called to ask her for help with treating my few remaining belongings for bedbugs. She had declined, with little hesitation, to make the trip to the “belly of the beast,” as she called the downtown Toronto homeless shelter where I was staying. I couldn’t bring myself to protest. I had been a burden to my family and friends for years; they owed me nothing.

I looked up at the fluorescent light above my fold-out cot. The shelter, a former juvenile detention centre, was at capacity. For those fortunate enough to sleep in a cell, the lights went out at 11 pm. But the light in the common area for overflow beds, where I lay, burned 24/7.

I thought of the young man I had met outside the shelter who had offered to sell me his McDonald’s coffee card for two dollars. When I lied and told him I didn’t have my wallet on me, he implored me to go get it, saying that he just needed a few bucks to buy crack. Shaking my head as I started to move away, I watched his eyes follow me, unblinking and burning with an intensity I had never seen before. They were the eyes of someone who has only one thing left to live for, and I was preventing him from getting it.

I wondered how far I was from a similar state. I had been a daily binge marijuana user for more than a decade but had never experimented with anything “harder.” In my four months of homelessness, though, I had seen people under the effects of everything from meth to fentanyl. I worried that if my future was as bleak as the last four months had been, I, too, might turn to a new, more potent substance.

I saw two choices before me, and only one contained any hope for a better life. It was this understanding that led me to contact the detox centre.

In the bed near my feet, roommate number 1 murmured something in his sleep, coughed explosively, then fell silent. In the bed to my right, roommate number 2 held his phone close to his face as he watched videos, the volume clearly audible from where I lay, less than six feet away. The room’s fourth single bed was vacant, roommate number 3 having been kicked out earlier that day when his urine tested positive for drugs.

I stared blankly at the crumbling plaster of the unfamiliar ceiling. This was my first week staying in transitional housing, the type of housing available to those who have completed rehab but have nowhere else to go.

I sighed. At least here I had a bit more freedom than in rehab. They had even let me keep the lancets for my glucometer.

I thought about the poster I had seen the other day in the common room of the house: “Are you dealing with homelessness while also managing diabetes? Researchers want to hear from YOU about your experiences and what you need to better manage your diabetes.”

When I was housed, I had rarely worried about my diabetes. When I became homeless, I had had so many other problems to contend with that diabetes hardly even entered my mind. I didn’t think I could bring much insight to the group ... however, seeing as the poster stated “participants will be compensated,” I thought maybe it would be worth contacting them.

Rachel brought the coffee pot over and refilled my mug, pausing to top off Amy as she passed. Amy looked up warmly in thanks, her mouth full. The food was

even better than usual that week; a variety of assorted panini sandwiches and a large spinach salad with strawberry vinaigrette dressing. Sure beat the hell out of shelter food.

Dillon watched as I took a sip. “I don’t know how you can drink that black. I always get a triple-triple.” Three sugars, three creams.

I grimaced at the thought. “Nah. I like it bitter.”

Dillon grinned. “Clearly, you like some sweet things, though.”

I chuckled and rolled my eyes at him.

“Ohh!” Amy exclaimed. “You know what I love at Tim’s? The mocha iced cappuccino.”

Dillon let out a sigh. “Oh my God, those are so good!”

“Yeah!” I chimed in. “Hey, Dave, can we get some of those for our next group meeting?”

Dave looked at me with a mix of amusement and exasperation. “It might be hard to justify money for Iced Capps in our diabetes study.”

That got a laugh from all of us.

I looked at the smiling faces around me. It was moments like this that really made me glad I had joined the research group.

Ten people in total filled the small but comfortable room: Dave and Rachel, the academic researchers, and the eight participants, or “co-researchers,” all people with diabetes who had experienced homelessness. Two months ago, when I’d attended my first meeting, Dave had explained that this was more than just a focus group — that we were going to conduct research on a topic of our choosing related to our experience of being homeless and having diabetes. At first I wondered how people with zero research experience, people like us, could be trusted to direct the focus of a study over

two academic researchers. Dave said that, while he and Rachel were experts in methodologies and held abstract concepts about homelessness and diabetes, they lacked the lived experience that we possessed; we were veterans of actually facing these challenges.

At the top of the hour, Dave started the group with his usual diabetes education session. Today's topic was retinopathy and the importance of getting your eyes checked regularly when you have diabetes. This came as a shock to many of the co-researchers. Most reported it had been a long time since they had had their eyes examined. Some confessed they never had.

Afterward, we transitioned into an overview of research ethics. Our group had decided to use photovoice as our research method: pictures with accompanying narratives to illustrate the particular challenges we faced while having diabetes and experiencing homelessness. We talked about the importance of getting someone's consent before taking their photograph, especially if that picture would be made public and shared widely.

Near the end of the session, Rachel asked for our input on what to call our photo exhibit.

"It should be something snappy," I spoke up, after some silence, "and also bring to mind diabetes ... I don't know ... Maybe something like ... 'Home Sweet Home.'"

"Home Sweet Homeless," Dillon said, almost without pause.

Excited murmurs of agreement filtered through the room. We knew we had a winner.

Dave and Rachel smiled. "Well, now that the hard part's over," Dave said, "the rest will be easy."

The photo exhibit became multiple exhibits. Soon after, I presented along with Dave and Rachel to medical doctors and researchers working in the field of homelessness at various events, including an hour-long session at the Canadian Alliance to End Homelessness in Edmonton, Grand Rounds in Toronto and an interview with CBC Radio.

It's been more than two years since the last group meeting with Dave and Rachel. My time in the group has made me realize not only how powerful participatory research can be, but also how much I enjoy it. I've since continued to work in research as a patient partner and, over the last year, I've been working as a peer facilitator for a new community-based participatory research group. Dave tells me that having me there to facilitate the group is a "game changer." By talking about my experiences with new co-researchers, I've noticed that they become more comfortable sharing their own stories. This fall, I'm excited to pursue formal research training when I begin a Master's of Science in Community Health. My family, including my aunt, are all ecstatic.

When I stop and reflect on where I've been and where I am now, the gratitude leaves me breathless. I wonder where I might be if I had never seen that poster advertising a research study.

In September 2022, I will be coming up on four years of abstinence from drugs and alcohol. For about a year and a half after getting out of rehab, I attended weekly Narcotics Anonymous meetings. The meetings provided me with a network of healthy, supportive people who could

empathize with what I had been through. Participatory research group meetings serve a similar function. For most of my adult life, I've struggled with depression and feelings of low self-worth. However, when I consider my accomplishments over the last few years and the fact that people I admire believe I am capable of achieving even more, I can't help but smile.

Sometimes, I still think about that young man and his McDonald's coffee card. I hope he got the help he needed. I hope he found some peace. I hope he found something like I did in these research groups.

Matt Larsen BA BEd

University of Calgary, Class of 2024,
Calgary, Alta.

This article has been peer reviewed.

Editor's note: This article and the accompanying, "Rethinking patient-oriented research," by David J.T. Campbell, articulate the researcher and co-researcher's perspectives behind a *CMAJ* Research article: Campbell RB, Larsen M, DiGiandomenico A, et al. The challenges of managing diabetes while homeless: a qualitative study using photovoice methodology. *CMAJ* 2021;193:E1034-E1041. Available: <https://www.cmaj.ca/content/193/27/E1034> (accessed 2022 June 28).

David and Rachel consented for their story to be told. Amy and Dillon are both pseudonyms. Amy provided written consent; Dillon is now deceased.

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