

Website tracks stories of Canada's 'medical refugees'; Survey claims to reflect needs of 'ordinary people' seeking care

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Janet Walker is a University of B.C. nursing instructor who's started collecting stories from "medical refugees."

That's the term she uses to describe Canadian patients in pain and on long waits for care who turn to the private system or leave the country for treatment.

"We're talking about ordinary people. They're not wealthy. They range in age from 25 to 91 and they tell me things like 'pain wrecks everything. It takes away your appetite for life, robs you of sleep, halts your activity and ruins your precious relationships.'"

"I thought I'd only hear from the well-heeled but I've also heard from people like loggers, pipefitters and electricians," said Walker, who has dubbed her project I Can't Wait: What Ordinary Canadians Are Doing to Get Health Care.

Walker, an adjunct professor who teaches fourth-year students a leadership and management course, is conducting the online survey (www.findinghealthcare.ca) independently. She has obtained consent from patients to use their identities in some cases but is not sharing that information at this point.

She is the first, as far as she knows, to conduct such a self-funded research project. This is what Wright declares on the site:

"This website is powered by people, informed by visitors and paid for by me. My name is Janet Walker and I am Canadian. This website is completely independent. It has no obligations to any entity or organization, public or private."

Walker, who is married to Michael Walker, the former executive director of the conservative Fraser Institute think tank, maintains she is open-minded about the kind of health care system that's needed.

But it wouldn't be a stretch for some to think she is biased in favour of a blended private and public system. Her website includes a list of private clinics across Canada, as well as a list of companies that provide medical tourism services to patients who want to go to the U.S. and other countries like India for surgery.

And she says she does not necessarily share the views of the most vocal unionized nurses who are pro-medicare and against any private medicine.

So far, she has gathered stories from 50 Canadians

who have paid to get care privately inside or outside Canada, including 10 from B.C. Patients have paid anywhere from \$500 to \$78,000. The largest sum was paid by an Alberta woman who went to Texas to have her ovarian cancer treated.

None of the respondents have been critical of the care they got privately or outside Canada, Walker said.

"That's what has amazed me the most," she said, acknowledging that her approach to collecting information is far from scientific and would never be considered statistically significant by solid research standards.

A third of the "medical refugees" needed joint replacement surgery, not surprising since the number of Canadians diagnosed with osteoarthritis is rising because of demographics. There are only 350 rheumatologists in Canada, half the number the country needs, the Arthritis Society (B.C. and Yukon division) recently reported.

Another third of those Walker has interviewed had spine and disc problems, and the remaining third had an assortment of other medical problems. Some of the anecdotes come from family members who describe the experience of loved ones who died while waiting for care.

By venturing outside Canada, the patients are "like scouts going ahead over unknown terrain" and most of them have told Walker that by leaving, they "literally bought their life back."

Walker said while she is open-minded about what the health-care system should look like, there's no doubt changes are needed.

"Medicare was a wonderful idea 30 to 40 years ago but now we need reforms," she said.

"The first waiting lists were documented in the 1980s. I know there's no magic bullet but maybe what we need is a shotgun approach in which we innovate more and allow the private system to help the public," she said.

Sun Health Issues Reporter

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A SURVEY SAMPLER

Sampler of questions asked by Janet Walker in her online survey:

- What was the medical problem for which you are seeking (or sought) care?

- What was your experience while waiting for care?

- What was the deciding factor in choosing to go private?

- Where did you go?

- How much did it cost?

- What advice do you have for other Canadians?

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