

The home care conversation we're not having

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Governments have been keen to invest in home care as a cheaper alternative to nursing homes, but are we counting the true costs?

Canadians are deluding themselves about the quality and true costs of home care, even as governments shift more of seniors' care away from institutions, said experts at the recent Canadian Association for Health Services and Policy conference.

Despite major federal and provincial cash injections in recent years, seniors often receive home care too late and/or stay in it for too long — past the point when they would be better served in long-term care. There are also major problems

with the quality and consistency of care, as well as limited data on the true costs for female family members who shoulder most of the care.

Health officials are “deliberately deceiving the public with respect to living independently at home and they're deluding themselves that they're successfully offloading the costs onto people like me,” said Kathy Bugeja, managing director of Spi Group, a Toronto-based health-care consulting firm, who has been an informal caregiver for family members.

Most Canadians say they would prefer to age at home, but that assumes they would be healthy enough or have adequate supports to do so, she said. Many seniors only receive formal home-care support after major disability or deterioration, Bugeja explained.

In reality, “the care is all incremental and reactive, so only when you get to the desperate stage, do you get the next crumb,” said Bugeja. Home is not the best place for many seniors, she added, “but there's this dogma that we're keeping you at home at all costs, even when the client is well past that stage.”

Home-care coordinators are “continually changing” and seldom close enough to a case to tell when a senior's health is worsening at home, she said. Meanwhile, family members

aren't prepared for the intensity of care or the frequency of abuse from older relatives, Bugeja said. “There's a lot of hitting, kicking, punching, yelling and trapping the caregiver. I've had to develop emergency plans to help those caregivers get out of the home safely.”

“I'd like to segment the home-care market and plan accordingly,” she added. This might mean more daycare programs where caregivers can drop off complex patients for bathing, social activities, meals and check in with a primary care team.

As the focus of public funding shifts away from long-term care, nursing homes are increasingly becoming a place of last resort. Tougher admission criteria mean many complicated cases must be managed at home until a crisis occurs. “The resource intensity has gone up substantially,” both in home care and long-term care, says John Hirdes, professor at the School of Public Health and Health Systems at the University of Waterloo in Ontario.

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Nursing home residents are more likely to have severe physical disabilities compared to home-care clients, but people in home care have much less stable health, he said. About 20% of home-care clients are categorized as highly unstable compared to about 7% of long-term care residents. In Ontario, about 70% of home-care clients will have a major clinical change that requires intervention within six months of receiving services.

Access to clinical services may help reduce the risk of decline at home but “overwhelmingly, the service that people get is a personal support worker,” Hirdes said. “That’s very helpful for assisting caregivers to offset their responsibilities ... but bathing isn’t going to help you with heart failure.”

Governments are keen on home care because it’s cheaper, but that’s only the case if you ignore the private costs, he

added. “About 70% of the care comes from family members, so home care only works when family members do the heavy lifting.”

Stagnant incomes, smaller families, high divorce rates, people living further from family, and greater participation by women in the workforce are making it harder for younger generations to shoulder that burden. “There’s this concept that informal care by family members somehow doesn’t count” when tallying the costs of home care,” said Colleen

Flood, the University of Ottawa Chair in Health Law and Policy. “We have to actually count what that costs us in dollars and cents, and human experience.”

Women face the greatest pressure to pony up for their parents’ private care or provide it themselves, Flood notes. “I’m sure there’s data that some five guys do this as well, but I think we need to be more realistic” about what the assumption of family caregiving means for women’s participation in the workforce.

Other countries like the Netherlands and Japan have created social insurance plans for seniors’ care, instead of expecting women to bear the brunt of personal and financial costs. Citizens contribute a percentage of income into a fund that’s arms-length from government to protect financing from cuts “as government fortunes wax and wane,” explained Flood. In the Netherlands, the plan is “well-loved

and seen to be working well; however, it costs a lot,” with the country spending 3.2% of gross domestic product on long-term care. In Japan, people start paying into the plan once they hit 40 to ensure “intergenerational equity.”

Germans also pay into a social insurance plan for seniors’ care and spend “about half as much” as the Dutch, but there’s a stronger expectation of informal care by family members, Flood added. “In fact, if you’re childless, you have to contribute more.” As a trade-off, families have the option of receiving about half of the cost of services in cash. “You can do whatever you want with that money; you can pay your daughter-in-law or put in a swimming pool,” explained Flood. Some 43% of Germans take the cash; however, “there are concerns about misuse of the funds and this may remove impetus for state action.”

Whether Canada chooses to follow these models or not, it’s impossible for individuals to predict how much is enough to save for seniors’ care. “Therefore, some risk pooling is essential to avoid serious hardship and premature death,” said Flood. Before we can decide what shape that will take, Canadians need to have an “honest conversation” about the real costs of shifting the bulk of senior care onto informal caregivers.

The bottom line is that home care won’t erase the need for long-term care or solve the quality issues that have made Canadians regard nursing homes as “way-points to the crematorium,” Flood said.

Hirdes agreed. “Quality has to go up in both settings, so that people won’t feel the need to stay in a bad circumstance in home care for fear of going into some awful place.”

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