Toward an Integrated Strategy for Care in the Home for Frail Elders

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Abstract

Canada requires a strategic plan to care for frail elders in the home. The nation needs a holistic system that addresses the multiple, often unique and dynamic needs of seniors, caregivers and families. This essay introduces ethical, technological and stakeholder engagement considerations that may help Canada move forward with a strategy that offers the capacity to better understand the perspectives of different stakeholders and champions high-quality homecare services. Stakeholder engagement can draw on the concept of brokered dialogue (Parsons and Lavery 2012) as a way to study and ethically design a high-quality national homecare strategy.

Introduction

Many of us first took stock of the Canadian elder care crisis when the Canadian Armed Forces were summoned in April 2020 to help out in long-term care homes in Ontario. Could this have been prevented? Yes. Reform and refinancing for these homes are essential to ensure quality and access. But much of the pressure on elder care could be relieved by safe, effective and affordable long-term care in the home based on shared Canadian values.

In *Remaking Policy: Scale, Pace, and Political Strategy in Health Care Reform*, Carolyn Hughes Tuohy explained how "[t]he big bang of 1966, which introduced a nationwide model of universal physician services insurance to parallel the recently established hospital insurance program, had no echo in the 2000s despite the opening of a window for major change" (Tuohy 2018: 376). We need a "big bang" for elder care in the home, covered by innovative government plans with support for increasingly burdened families, protection for healthcare workers and active recruitment for a larger workforce. In this essay, I seek to introduce some ethical, technological and stakeholder engagement observations that may help Canada move forward with a strategy.

Stepping into Another's Shoes

The late Professor Sebastian Littmann, head of psychiatry at the University of Calgary, among his many other achievements (Stahnisch et al. 2019), was a mentor extraordinaire. For example, he took trainees into the room when he was seeing his patients, and they would often see him taking off his shoes. He would then say to his patient, "To really understand you, I need to step into your shoes."

Imagine stepping into the shoes of the various stakeholders needed to care for no-longer-independent seniors. These perspectives are illustrative only (and not exhaustive, as there are many other stakeholders).

Seniors

We want independence to the maximum extent possible. We want our children nearby, but the last thing we want is to burden them, either emotionally or financially. We want to be safe, be free of pain and have our health, hygiene and nutritional needs met. We want to be treated with dignity.

Caregivers

We want training to do our jobs well. We want on-the-job training to address the specific needs of our clients. We want job security – the freedom to change jobs when necessary without losing the right to stay in the country. We want fair working hours and a livable wage with employment benefits. We want to be treated with respect. We want access to healthcare and psychological support for ourselves because we are often caught in difficult personal situations.

Family members

We want our parents/grandparents to be able to stay in their own homes or in our homes safely in the care of well-trained professionals who will treat them respectfully and effectively. When they require round-the-clock care for the many complex diseases of old age, we need at least two of the caregiver shifts covered by insurance so that we can maintain our jobs knowing that our loved ones are safe and their needs tended to. We need to know that their medical needs are appropriately met, including assistance with bathing, grooming, dressing, toileting, meal preparation, grocery shopping, doing household errands, meeting medical appointments, booking vaccinations and paying bills. We need to be able to afford whatever care is required. When shifts are coordinated through a homecare agency, we need to know that the workers are adequately screened and trained in the specific tasks that they will be required to do.

Amid the pandemic, we need to know that workers are fully vaccinated and able to protect our loved ones from infection. We want, if at all possible, continuity of care. We want our government to make our options clear and to be responsive to our queries, needs and concerns. We need to understand the chain of command so that we can easily contact persons in charge. We need our own mental health supports due to being caught between worry, responsibility, financial stress and difficult decision making that often requires impossible family consensus.

Toward a New, Integrated Strategy

According to a report by KPMG Canada (2022) in May, Home Care Ontario reported that providers were able to fill 95% of initial requests pre-pandemic; the rate had dropped to 56% by the end of 2021. KPMG Canada therefore suggests digitization as a critical path forward to address the homecare workforce crunch. The report notes that "[o]ptimization of scheduling and routing can contribute to better coordination of home care services, translating into more streamlined processes from the patient perspective" (KPMG Canada 2022: 4). Unfortunately, this method may not be able to determine the fit between a specific need and an available service. KPMG Canada's (2022) report rightly points to the risk that "suboptimal matching can negatively impact patient safety" (p. 4).

Technological solutions and immigration reforms have been proposed to address care-at-home needs. At best, these are partial solutions, while what we need is a holistic system that addresses the multiple, often unique, needs of seniors, caregivers and families that are not static, but evolve over time. Home care is one level of care and needs to fit, seamlessly, with acute hospital and sub-acute rehabilitation care and, ultimately, with palliative care.

Canadian policy and healthcare leaders now enjoy an excellent opportunity (and necessity) to think like strategists so as to meaningfully address home care that lives up to the values expressed in the *Canada Health Act* (1985): public administration, comprehensiveness, universality, portability and accessibility. I say "aspire," as we are far from that in home care, despite successive reports recommending change, led by Senator Michael Kirby (Kirby and LeBreton 2002), Premier Roy Romanow (Romanow 2002) and Don Drummond (Drummond 2012).

Only after home care is an insured, affordable service (currently, coverage depends on the province you are in) can the clinical pathways, prevention protocols and health promotional components of success be defined with the same precision as they are now for acute care services. Full coverage may be neither possible, nor even desirable. Private care will always need to supplement publicly funded care, but clarity among options and their affordability – not currently present – is badly needed. Governments can then design a coordinated strategy, becoming a long-term investor in home care. What would the return on the investment be? A healthier elderly population, a more stable workforce and far less stress-related mental illness in our communities.

Government as an Investor

Provincial governments, the investors, each need a five-year plan, working in concert and specifying the milestones and interdependencies regarding how the plan will get to "scale" There are urgent contingencies. Statistics Canada (2022) reports that, as of July 1, 2021, more than seven million persons 65 years and older live in Canada, and over 861,000 people are 85 years and older. On Indeed.com, the jobsite portal, I found more than 17,000 Canadian requests for professional homecare workers (Indeed 2022).

A strategic five-year plan would examine market demand and labour supply and model the degree to which hospital-carried costs, such as alternate level of care days, could be alleviated through new services and offerings and policies.

The government as an investor may wish to imagine a new Canada in which hospital care and home care are integrated in one funding model. A pan-Canadian strategic five-year plan would examine the degree to which costs can be alleviated by enabling neighbours and friends to earn government compensation for providing home care – with appropriate consent and quality assurance. Quality depends on the tasks required and may require on-the-job training.

Another option is to pay family members out of the provincial government treasury for taking care of elderly parents or to offer a meaningful tax break in the form of a homecare tax credit or a tax-free "caregiver savings account." There may be problems here. Costs are driven by the small proportion of the most in need so that across-the-board accounts for all end up underfunding those with the greatest need and benefiting those who do not need them. One communications benefit of a caregiver savings account (even if only capable of being applied to cover a short period in the home), however, is that it forewarns all Canadians about the reality of the additional financial burden that they may one day need to incur.

Use an Ethical Framework to Solve the Principal–Agent Problem

To guide us in the context of the COVID-19 pandemic's reality, an emphasis on ethical care is vital. For home care, that would mean equality of opportunity in accessing high-quality homecare services (Daniels 2007; Rawls 1971).

But the incentives and interests of the "principal" (the homecare provider) are not always aligned with the incentives and interests of the "agent" (the homecare recipient). These need to be solved in the context of provision of quality care on one hand and equal opportunity on the other.

Scan the Horizon

To build the five-year integrated plan, government investors will need to conduct a horizon scan of new and emerging technologies. These might include wearables technology for real-time health monitoring, home dialysis and regional remote monitoring systems. Without a five-year integrated plan – understanding that one variable (e.g., training more allied health professionals) affects another (e.g., continuity of care in a homecare setting) – one is always playing catch-up.

Bring Stakeholders into the Discussion

The long-term government investor model may help reframe what we talk about when we talk about home care: set the larger strategy, align everyone to it and deliver. That requires mass-style public engagement of the sort promoted under the *brokered dialogue* model developed by Jim Lavery and Janet Parsons (Parsons and Lavery 2012). Brokered dialogue is a way to study and address divisive situations at the interface of health and society around which dialogue is either not happening at all, or is very difficult because of the social dynamics of the underlying controversy. This does not require in-person meetings.

A brokered dialogue begins by filming participants' starting positions on the issue under consideration and editing the footage until everyone is comfortable sharing it with fellow participants. In the context of home care, participants might include the person being cared for, family members involved in providing and coordinating that care, additional caregivers and representatives of public and private agencies providing care services. Brokered dialogue is a consensus-building method. The goal is for each party to step into the shoes of the other. Its aim is also to humanize issues that are often treated as merely technical. It allows the human implications of policies to be felt. Even if participants do not achieve complete agreement, Lavery and Parson's (2012) experiences with the brokered dialogue method to date suggest that participants gain insights into the experiences of the other participants.

Immigrant caregivers can share stories of migration trauma, long hours, poor pay, homesickness, loneliness and sending money back home to their families. Families of homecare recipients can share stories of the effort and sacrifice required to investigate, negotiate, coordinate and facilitate care for their loved ones. Recipients themselves share stories of need and shame at becoming needy and unravelling a burden onto their families.

Without true engagement and without sharing points of disagreement, there can be no strategy to which the public will align. Nor will there be trust, which is the bedrock for public support.

Some of the questions posed in a brokered dialogue model (Parsons and Lavery 2012) might include the following: Should all provinces contract with homecare agencies? Should homecare agencies tilt more toward full-time employment models? To what extent can provincially funded home care eliminate overhead in the context of desired virtual services? To what extent do provincial billing codes incentivize or discourage primary care physicians from referring or conducting holistic homecare visits? To what extent do physicians and nurses feel sufficiently trained to conduct homecare visits? What can be put in place to address the mental health needs of agitated care recipients, lonely care providers and overstressed family members?

In *What We Talk About When We Talk About Anne Frank*, the short story by Nathan Englander (2012), the reader shudders when exposed to socially discriminatory inequities. This 2012 essay borrows its title from Raymond Carver's (1981) classic, *What We Talk About When We Talk about Love*. Carver explained that the word "love" holds many meanings.

So, what *should* we be talking about when we talk about home care? We should talk about equity of opportunity for achieving high-quality home care and people's different interpretations of what quality means, and we should step into each other's shoes. This should lead to impactful public engagement and, ideally, a government investment in a five-year integrated strategy that fairly addresses the quality needs of all stakeholders in the homecare debate. HQ

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