

How Big Is Our System?

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THE LEAD ESSAY by Williams and colleagues – along with a wealth of thoughtful and insightful commentaries – makes clear that informal caregivers (friends, family members and even neighbours) are a critical resource to our healthcare system. Although debate remains on how best to support caregivers, the essays in this issue of *Healthcare Papers* also make it clear that we could be doing it better. At long last, policymakers appear to have accepted the fact that the informal provision of care, as one facet of the health system, can no longer be ignored. A number of policymakers, including some writing in this issue, emphasize the importance of caregivers in announcements and programs designed to support caregivers. Although progress is slow in some jurisdictions, it is hard to find a jurisdiction where

caregivers have not been subject to some new innovative program. Likewise, health charities across the country are re-enforcing the importance of caregiving through the funding of research and support initiatives.

So is it time to declare victory on the issue of caregivers? Is caregiver policy a success story where we can point to the impact of thoughtful analysis in identifying a problem and wise policymaking in eliminating the attendant problems of caregiver burden and alienation? The short answer to these questions is “no.” Increased awareness of the importance of caregiving and the launch of scattered policies do not signal success, specifically, for three reasons.

First, informal caregivers interact with our system throughout the care trajectory.

Caregivers lead patients to their first radiotherapy appointment and support patients right up to their last palliative care visit. While the Patient Engagement Movement has done a great service to healthcare by forcibly arguing that the patient voice be heard throughout the whole patient journey, we still focus much of our attention on caregivers towards the end of the journey when frustration with repeated recitation of the patient's needs to successive providers and a great need for respite – arguably the two most acute problems for caregivers – set in. We need to make sure that the cultural changes occurring in our health system today include caregivers from the beginning. As many of us will end up in caregiving roles, whether we plan for them or not, it is hard to imagine a better issue than informal caregiving to support the case for greater cross-sectoral collaboration among ministries of social services, health services, finance and even education.

Second, we often medicalize the problem of caregiving. When we do intervene to support caregivers, we justify that medicalization by using terms like “burnout” or arguments to incentivize reduced healthcare system use and the resultant system stress. We determine eligibility for caregiving programs based on the health status of the person under care. In contrast to other countries that make caregiving as much a problem of social policy as health policy, in Canada, we keep caregiving policy largely within the domain of health ministries, where, not surprisingly, it gets side-stepped by the day-to-day pressures of ensuring access to primary and acute care and the fiscal constraints of a tepid and turbulent economy.

Finally, we have not yet grasped the enormity of our future caregiving challenge. The demographic and sociological changes underway in our system today mean that we will find ourselves, in a few short years,

with such a great imbalance between people needing care and the loved ones who can provide it. Yet we continue to focus on support for traditional caregivers, loved ones and close friends who are willing to commit time to help patients whom they already know. In the future, these relationships may not be able to support the demand for caregiving. As it stands, there exists no health and social care system that has the budgeted funds to afford to pay every informal caregiver (Poh Wah et al. 2013). How, then, do we respect and support caregivers?

Drawing on results from our 2009 survey of more than 12,000 Canadians, finding almost 28 percent of Canadians reporting they would spend more than five hours each week doing simple chores for a sick neighbour, we argued that we could enlist new voluntary unpaid caregivers from unlikely sources using tools as simple as Facebook (Seeman and Brown 2012). Countries like Japan are profoundly changing how they view the challenges of caregiving to usher in new solutions and approaches that sit well outside of the healthcare paradigm, while The Netherlands is experimenting with communities that keep people with dementia living in a supportive environment. In many emerging economies, mobile solutions assist caregivers in obtaining psychosocial supports through multimedia communications. Mobile games can assist caregivers in the physical rehabilitation of the elderly, social networking and mobile access to networks to give comfort to the emotional drain of caregiving (Kwan 2013).

Without a significant forward-looking strategy to cope with the future challenges of caregiving, today's good ideas will likely be overwhelmed by tomorrow's needs.

Fundamentally, we need to redefine our notion of the healthcare system to include informal caregivers so that we embed them in every policy and process improvement

effort. This means that capacity planning, policy development and broad health strategies should start not by focusing on doctors, nurses, pharmacists and therapists, but with the entire population of those who could – and likely will – end up working to help a loved one or friend manage health problems. If we do not embrace those who want to help us through formal yet low-cost policies, we may find, paradoxically, that they are not there to help us when we most need them.

References

Poh Wah, L., M. Britnell, Lien Foundation and KPMG Healthcare International. 2013. *An Uncertain Age: Reimagining Long Term Care in the 21st Century*. Retrieved October 14, 2015. <<http://www.kpmg.com/ca/en/issuesandinsights/articlespublications/pages/an-uncertain-age.aspx>>.

Seeman, N. and A.D. Brown. 2012. “We Are Not Bowling Alone.” *Policy Options* 33(10): 13–16.

Kwan, A. 2013. *mhealth Transferring the Burden of Caregivers to Mobile Technologies*. Retrieved October 14, 2015. <<http://www.mhealthknowledge.org/resources/mhealth-transferring-burden-caregivers-mobile-technology>>.

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