What Gets in the Way of Person-Centred Care for People with Multimorbidity? Lessons from Ontario, Canada

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Abstract

Person-centred care is becoming a key component of quality in health systems worldwide. Although the term can mean different things, it typically entails paying attention to the needs and background of health system users, involving them in decisions that affect their health, assessing their care goals and implementing a coordinated plan of care that aligns with their unique circumstances. The importance of practising a person-centred approach in care delivery dominates policy and research rhetoric worldwide, yet competing goals set by policy planners to save money, eliminate waste and sustain the healthcare system challenge the implementation of such an approach. In this commentary, we begin by exploring the concept of person-centred care and its importance among people who frequently use healthcare, such as those with multimorbidity. We then provide a brief overview of the evolution of Ontario’s healthcare system and its emphasis on achieving cost savings. In doing so, we illustrate the implications for health system users, particularly people with multimorbidity, their carers and formal care providers. Finally, we reflect on examples of innovations that are striving to deliver person-centred care, despite a constrained healthcare environment. While a step in the right direction, we conclude that these “one-off” strategies are unsustainable in the absence of supporting policy levers.

Patient (or Person)-Centred Care – What Is It?

While patients need medical things (treatments and medicines), persons need social things (ability to partake in activities of importance to them, supportive networks, a sense of belonging and purpose and respectful encounters with others). The tendency to use the term patient-centred instead of person-centred signifies a fundamental disconnect between healthcare and social care, even though the two are required to achieve overall health. Although limited, the practice of patient-centred care is still an improvement over provider-centred care – a paternalistic relationship where patients take what providers give them.

The concept patient-centred care has roots in many disciplines, including family medicine. The Department of Family Medicine at the University of Western Ontario designed a framework for patient-centred care over 30 years ago in an effort to guide physician–patient consultations. It defined patient-centred care as encompassing six interacting components: exploring the disease and the illness experience; understanding the whole person; finding common ground; incorporating prevention and health promotion; enhancing the patient doctor relationship; and being realistic (Stewart et al. 1995). This definition highlights that such an approach extends beyond the sum and severity of physical ailment(s) presented upon assessment.
Patient-centred care (or what we prefer to call person-centred care) entails more than a physician–patient visit, it is a way of being, a practice that values the person and their support networks (including family and the extended network of friends, neighbours, partners, etc.) and considers their needs within the broader context in which they work and live. The Health Innovation Network in London England (London HINS 2015) defined person-centred care as: “not just about giving people whatever they want or providing information. It is about considering people’s desires, values, family situations, social circumstances and lifestyles; seeing the person as an individual, and working together to develop appropriate solutions.” (p. 1).

A need for (or expectation of) person-centred care is fuelled by demands for timely access to care, greater access to information via the internet and, in some cases, a yearning among consumers to play a key role in decision making. Person-centred care is also a reaction against reductionism perceived in evidence-based medicine and other forms of predominantly biomedical models. Person-centred approaches are particularly crucial for people with multimorbidity, not just because they happen to use more healthcare (Rosella et al. 2014) but because of the high disease burden, uncertainty in their care trajectory, the many treatment decisions they face and the constant weighing of risks and benefits which warrants the identification and revisiting of goals of care (Berntsen et al. 2015; Bower 2014; Upshur and Tracy 2008). As noted in a recent editorial in the New England Journal of Medicine, in a clinical context, weighing the pros and cons with patients and exploring their personal priorities is not always easy to achieve and may work against natural tendencies to either tell patients what to do when there is strong evidence for a particular solution or put the onus on patients to decide when there is a lack of clear evidence (Fried, 2016). Clearly, understanding the social aspects of a person (their priorities and goals beyond their medical needs) may help guide this complex decision-making process. A family physician who participated in one of our recent studies stated, “We do too many investigations without standing back and asking [the person], ‘What do you want?’” (Gill et al. 2014).

Multimorbidity is “socially patterned,” occurring at a much earlier age among people who experience financial strain (Moffat and Mercer 2015) and tends to coincide with mental health needs (Barnett et al. 2012). Unique combinations of conditions and social determinants (which differentially affect people with multimorbidity) preclude simple reduction to guidelines (Upshur and Tracy 2013). A burgeoning literature on multimorbidity illustrates a lack of clinical guidelines to support patient care (Barnett et al. 2012; Upshur and Tracy 2013; Osborn et al. 2015; Sinnott et al. 2013), little attention to goal setting (Upshur 2010), a lack of care coordination, insufficient follow-up and overall poor care experiences when compared with those with single or no chronic conditions (Pefoyo et al. 2015; Burgers et al. 2010). Providers commonly feel unsupported and unprepared to manage the needs of people with multimorbidity and their carers (Osborn et al. 2015; Sinnott et al. 2013). Patients and families may defer to providers, particularly primary care physicians, to provide guidance or solutions to their complex medical issues, when in fact there may be no clear trajectory forward. Needless to say, person-centred care, particularly in the context of a growing population of people with multimorbidity, is difficult to achieve. Nevertheless, if person-centred care is such a great idea, what gets in the way of implementing this type of approach?

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Healthcare Reform in Ontario and Barriers to the Implementation of Person-Centred Care
The difficulty in achieving person-centred care is, in part, a product of the acute-episodic healthcare system in which these patient–provider interactions are embedded. Our healthcare system, hardwired in an acute “one disease at a time” model, makes it particularly difficult to be person-centred for the growing number of people aging with multimorbidity (Pefoyo et al. 2015; Upshur and Tracy 2008; Upshur 2010).

Canada’s healthcare “system” is historically oriented to deliver acute and episodic care. Medicare (Canada’s publicly funded insurance model for hospital and physician care) became institutionalized in the 1950s and 1960s and remains firmly embedded despite attempts to broaden its scope and better align services to the needs of people who are living longer with multiple health and social care needs. The original intention of Tommy Douglas, the founder of Medicare followed by Justice Emmett Hall just over a decade later, was to build a health system in two phases. The first phase culminated into Medicare, Canada’s 13 interconnected healthcare “systems” which provide “medically necessary” hospital and physician care, based on uniform terms and conditions for all insured Canadians. In the second phase they were to “implement public policies for keeping people well, not just patching them up once they get sick” (Raphael 2009). While the second phase failed to materialize into a robust institutional structure, there was never a shortage of evidence on the importance of prevention and upstream factors that influence health, notably the social determinants of health. The 1970s saw a wave of documents, including Canada’s Lalonde Report (Lalonde 1974) which drew attention to a variety of factors that influence health (the majority of which lie outside the healthcare system) as well as a call for greater citizen engagement in the healthcare system. In the decades leading up to and following
this time frame, a wave of empirical literature connected the social determinants of health to health outcomes (Bosma et al. 1997; Fitzpatrick et al. 2015; Marmot et al. 1991; Marmot 1993; Mikkonen and Raphael 2010; Raphael et al. 2008; Raphael 2009; Stringhini et al. 2012). Accounting for the social determinants of health through healthcare assessments and delivery arguably aligns with a person-centred approach but seldom occurs.

Particular structures (aka: levers) create barriers to movement beyond biomedical and single-disease frameworks. Examples include: fee-for-service models of reimbursement for physicians (although primary care physicians are increasingly moving toward blended payments), length of stay targets in hospitals incentivizing expedient discharges back to the community (with few resources to respond), wait-time targets for specific conditions (knee, hips, heart, etc.) and hospital funding models that set length of stay targets for single diseases and ailments (Palmer et al. 2014). Such incentives place the focus on disease and body parts as opposed to on people who are part of broader social and geographical contexts. These broader contexts are critical, given that one’s ability to manage health and engage in broader society, including the workplace, depends on the level of integration and support within these broader realms. Indeed, 75% of the factors that influence health lie outside the healthcare system (The Standing Senate Committee on Social Affairs 2002), but a reactive approach characterized by treating/curing/fixing using a biomedical lens continues to have a strong foothold in healthcare. Although we are starting to steer the ship away from this highly reactive model by way of blended payment schemes for physicians, greater emphasis on team-based care, investments in primary healthcare models (e.g., including nurse-led clinics, allied health and community-based care) with a focus on prevention, there remains a historical array of institutional factors (e.g., policies and associated incentives) which limit the extent to which person-centeredness can feasibly occur.

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When the patient-centred framework was introduced in Family Medicine, Ontario moved (in a policy sense) in the opposite direction. The Health Services Restructuring Commission (HSRC) was appointed in 1996 by the Harris Conservative government and was given a 4 year mandate to (1) make decisions on how to restructure Ontario’s public hospitals and (2) make recommendations to the Minister of Health on how to reform other parts of the healthcare system (Sinclair et al. 2005). What culminated was the closure of 43 hospitals (a combination of public, private and psychiatric facilities), the removal of 10,000 hospital beds, medical school admission caps and downsizing of many nursing positions to part-time/seasonal contract positions (Ingelhart 2000). The imperative to discharge patients “sicker and quicker” became a matter of survival for a fiscally constrained hospital climate.

The Community Care Access Centres, Ontario’s main organizer of professional home care services, did not receive budget increases commensurate with the influx of people who were being discharged and were subsequently forced to strategically realign their priorities to meet the needs of mostly post-acute patients. Accompanying legislation precluded the CCACs from operating with a deficit and limited eligibility for lighter care (e.g., homemaking) to those who had heavier care needs. These policy changes shifted the home care sector into primarily a “post-acute” operation, aimed at those who were more medically complex. At the same time, recommendations made by the HSRC, to build and/or restore 20,000 long-term care facility “places” (interpreted by the Ontario government as beds), were implemented (Coyte et al. 2002). This policy decision represented a misalignment between the needs of the system (the growth of long-term care beds, mostly in the for-profit sector) and the needs of people who largely preferred to age in their homes (Williams et al. 2016).

The 2006 Aging at Home Strategy was a promising 1.1-billion-dollar initiative dispersed to each of the 14 Local Health Integration Networks (aka: regional health authorities) to create and sustain programs that aimed to keep people in their homes as long as possible and prevent or delay long-term care (LTC) and hospital use. However, in 2009, a proportion of “aging at home” funds were re-directed to acute-care hospitals to address alternate level care (ALC) patients—individuals who were occupying an acute-care bed but no longer required acute care. From that end, “aging at home” morphed into “not aging in hospital,” a more reactive measure of home support, mirroring the post-acute home care foci of the earlier policy reforms in the 1990s.

A program of research on the Balance of Care conducted in Ontario by Williams et al. (Kuluski et al. 2012; Williams et al. 2009a, 2009b) shed light on the potential unintended consequences of this policy decision. Williams et al. examined the characteristics of individuals wait-listed for facility-based LTC in nine jurisdictions across Ontario and worked with panels of health and social care providers to build community care packages. This exercise offered a sense of the proportion of people who were “destined” for LTC who could potentially age at home safely with a community care package at a similar or lower public cost than LTC. The researchers found that between one-quarter and one-half of people on the wait-list (depending on the region) could potentially remain in their communities with a home care package at a similar or lower cost than LTC. Ironically, much of what was required in the
care package was lighter care (e.g., medication help, meal assistance, transportation, housekeeping and respite for caregivers), services that were much harder to get following the Harris (conservative) reforms and notably absent from provincially funded care packages at the time of study. It is important to note that even the liberal reforms (“aging at home” which morphed into addressing hospital issues) did not restore these service needs. Care providers who participated in the expert panels for this research stated that there was a fundamental disconnect between what they were mandated to do (i.e., what services were available) and what home care clients actually needed (Williams et al. 2016).

The disconnect between what people need and what is provided in home care packages was illustrated by a care provider in our study of the experiences of people with multimorbidity, their carers and care providers (Gill et al. 2014):

“…once they need [home care], they don’t seem to get as much as they really need. They’ll come in for an hour a week and help you with a bath. And if you don’t need help with a bath, they don’t come in…They may need help with the food shopping. They may need help with food prep. That stuff is hard to get support for.”

These findings were recently echoed by the Ontario Expert Group on Home and Community Care (2015), who stated that care continues to be driven by the needs of the system and not its users (including unpaid family carers and broader support networks). As noted in the sections that follow, home care reform sits within a broader quality improvement agenda in Ontario.

Healthcare quality improvement, with patient-centeredness as a core aspect, was front and centre in Ontario’s 2012 Action Plan for Health Care (Ministry of Health and Long-term Care 2012). Described as “obsessively patient-centred,” the Action Plan outlined a commitment to improve access to care, integrate services and provide care “in the right place at the right time.” The latest policy document Patients First (Ministry of Health and Long-Term Care 2015), released in 2015, outlines a commitment to involve people and their families in care planning, invest in the community care sector and to improve access to end-of-life care (among other things). In early June 2016, the Ministry of Health and Long-term Care (2016) proposed the Patients First Act, new legislation that would presumably help move these initiatives forward. These policy documents/plans emerged from a broader provincial commitment to improve quality in the healthcare system (mirroring a global effort). Foundational to this was the creation of Health Quality Ontario, a government-funded agency formed after the passage of Ontario’s Excellent Care for All Act (ECFA) in 2010. Under ECFAA, annual quality improvement plans and public reporting of key quality indicators are required for hospitals and, most recently, home care organizations, primary care and LTC facilities. These sectors are held accountable in measuring and meeting pre-specified targets (minimizing exposure to infectious disease, lowering rates of ALC, etc.). Although patient experience is one domain of quality that is measured, unpacking this can be challenging in time-constrained environments. For instance, there may be a tendency to adopt indicators that are easier to measure such as “tick the box” patient satisfaction surveys that assume satisfaction is synonymous with experience, painting an inaccurate or misleading picture of the adoption of person-centred care.

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A relatively recent approach to embed a “low rules” strategy to integrate care for Ontario’s growing number of people with complex health and social needs is Health Links. In contrast to previous “top down” efforts to reform care, the strategy voluntarily brings together health and social care service providers who work in close geographic proximity to develop and implement integrated, person-centred strategies for their heaviest healthcare users (Evans et al. 2014). While it is too early to determine the effect of such a strategy on the ability to execute a person-centred strategy in care delivery, it has been rated positively by care providers and managers (though not without its challenges) as an approach providing a foundation to better coordinate services for patients with complex care needs and their families. Geographically based coordinated services are also the intention of Community Based Hubs, which were endorsed by the Ministry of Health and Long-Term Care in its 2014 Mandate Letter (Ministry of Health and Long-Term Care 2014). Community Based Hubs entail cross-ministerial (i.e., health, education, municipal affairs and housing) developments of geographically based, ground up initiatives to support the health and well-being of citizens. Community Based Hubs share some commonalities with Health Links. The key difference is that Health Links are intended to focus on the top/high cost users of health resources (Evans et al. 2014), while hub models seem to take a life-course approach by leveraging the capacity of communities to keep people healthier over the long-term and not just pick them up once already quite complex. As these models continue to emerge, it is important that they do not become exemplary “silos” like other components of health services.

Alongside community-based reforms, hospital-funding reforms are underway in Ontario. Referred to as Activity Based Funding (ABF), a predetermined fee is provided to hospitals for each episode of care and client type, but client type is typically categorized by disease/reason for current health visit (e.g., pneumonia, hip fracture and child birth) with little attention to multimorbidity, mental health and social needs. A recent systematic review on the implications of ABF in 10 countries
found that the introduction of this funding model was associated with a 24% increase in discharge from hospitals to post-acute services (including home care) (Palmer et al. 2014).

Quicker hospital discharges can be looked at in a positive light, given that prolonged hospitalization can be associated with unnecessary exposure to infectious disease, other adverse events and emergency service back-logs (Sutherland and Crump 2013). On the other hand, if the discharge happens too quickly without the necessary supports in the community, hospital readmissions may be the result. Further to that, a 24% increase in discharge to post-acute care cannot be successful if this sector is not adequately resourced to meet the increasing influx of people. If history repeats itself in Ontario, ABF may have perverse consequences for providers, people and their support networks.

Given that episodes of care typically expand beyond the hospital, Ontario is now experimenting with integrated funding models (i.e., bundled care) which include hospital care and the window of time (e.g., 30 days) following discharge. While this incentivizes a more integrated approach, it is not clear if services will be aligned with the needs of healthcare system users and their support networks. A study that is currently underway to assess the user experience of integrated funding in Ontario provides an important opportunity to draw on the user experience to provide insight into gaps and future directions of this model, including how it can connect to ongoing supportive care beyond the time frame of the bundled payment.

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**Person-Centred Care: A Matter of Personal Will in Constrained Healthcare Environments?**

In a healthcare system heavily constrained by lack of resources and time, it seems that person-centred care becomes the “luck of the draw” or (as articulated by a person with multimorbidity), “a lottery [in terms of] who you get” (Kuluski et al. 2013). It seems that it comes down to personal will and concerted effort by care providers to overcome the barriers to deliver person-centred care. For instance, in a recent study conducted by the lead author (KK) and her team on the care delivery experience of people with multimorbidity (Kuluski et al. 2013), many people recognized that providers worked in a busy environment with few resources, but that it came at the expense of personal dignity:

“They are understaffed here … I really think they are great nurses. I do. But because they have such a high patient load, generally I wish some of my needs had been met a bit faster. And the very basic one is toileting.”

Others in this same study outlined the characteristics of providers who delivered care that was consistent with a person-centred approach compared with those who did not:

“A good listener. They actually listen to what you’re saying. Non-judgmental. They actually are there to help you. Whereas some of them, they’re just here for the buck […] It’s hard to describe it but there’s no rapport, and a bit of a chip on the shoulder.”

“So professionally she follows up on any changes that are happening with me… she’s in a role that provides care and caring, which are 2 different things, she actively cares. She is caring. And I believe that that is the minimum standard of operation for somebody in healthcare.”

In addition to the day-to-day examples of providers who go above and beyond to deliver person-centred care, there is also considerable effort across the province to develop and test models of care that are more person-centred. For example, Toronto Central CCAC’s Integrated Client Care Program (Goldhar et al. 2014) targets people with complex care needs and their families and assigns them a “quarterback” (care coordinator) to help bridge the gap between various services and providers. Patients and families are involved in co-designing a care plan, goals of care are assessed and an emergency transfer package comprising medicines and pertinent patient information is put together. Each patient is assigned to a single pharmacy, emergency department and hospital, thereby fostering a more integrated experience.

Likewise, Seniors Managing Independent Living Easily (SMILE) program offered out of South East LHIN begins by asking what is most important to clients and their caregivers. Drawing on a modest budget SMILE improves access not only to formal providers but also to non-traditional providers such as neighbours, as a means to lever local capacity and expand beyond the traditional basket of services (Williams et al. 2016).

These are only two of the many “stand alone” examples in Ontario that include principles that align with a person-centred approach. In addition to recognizing the work of these efforts, it is critical to acknowledge that the sustainability of these programs, including their ability to “scale up” and “spread,” will continue to be threatened by a policy climate that favours cost-cutting, acute-episodic care, provider-centred approaches and quick fixes.

**Conclusions**

Person-centred care is a key component of quality in healthcare systems but difficult to achieve in practice. Using Ontario as a case example, we illustrate competing foci on cost containment and cost shifting from hospital to the community and the ongoing tensions between a heavily institutionalised Medicare
model (which incentivizes treatment of diseases and body parts over whole person care) and a push toward more innovative approaches that respond to both the health and social needs of people and their support networks. Although innovations that support a person-centred model of care delivery exist, these appear to be the exception and not the rule. As Ontario moves ahead with various reforms in the hospital (e.g., ABF) and community sectors (integrated funding, Health Links and Community Health Hubs) paying attention to the ways in which a person-centred focus can be implemented and supported by key policy levers (e.g., funding and accountability frameworks) will be critical to making this mode of practice the rule and not the exception; otherwise well-intentioned policy goals and strategies may continue to morph into reactive, episodic-based care.

Acknowledgements

Much of the research discussed in this paper was funded by the Ontario Ministry of Health and Long-Term Care, Health System Performance Research Network Grant. The views expressed in this paper are the views of the authors and do not necessarily reflect those of the funder.

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