Toward a Person-Centred Learning Health System: Understanding Value from the Perspectives of Patients and Caregivers

COMMENTARY

Kerry Kuluski, MSW, PhD
Dr. Mathias Gysler Research Chair in Patient and Family Centered Care,
Institute for Better Health, Trillium Health Partners
Associate Professor, Institute of Health Policy, Management and Evaluation,
University of Toronto, Toronto, ON

Sara J.T. Guilcher, PT, PhD
Assistant Professor, Leslie Dan Faculty of Pharmacy, University of Toronto
Assistant Professor, Institute of Health Policy, Management and Evaluation,
University of Toronto, Toronto, ON

≈

ABSTRACT

What matters most to people who use healthcare? What matters to their caregivers? How do we use this information to support ongoing quality improvement in the healthcare system? In this paper, we explore three concepts from the current healthcare discourse, intended to drive health system improvements: person-centred care, value-based healthcare and learning health systems. We propose that key tenets from each of these concepts should be combined to create a person-centred learning health system (PC-LHS). We highlight two key points: First, in achieving a PC-LHS, the experiences, priorities and values of patients and their caregivers should be continually collected and fed into data systems to monitor ongoing quality improvement and performance benchmarking. Second, the information collected in determining value must include important contextual factors – including the social determinants of health – as patient health and well-being outcomes will ultimately be shaped by these factors, in addition to health system and disease factors. In summary, improving value for patients and caregivers, by capturing the things that matter most to them, within their life contexts, needs to be part of the continuous quality improvement cycle that lies at the heart of a learning health system.

Introduction

Health systems in industrialized nations are striving to improve care delivery for the growing numbers of people living with complex health and social needs. It has long been recognized that acute care, episodic-focused care and reactive care are mismatched with the priorities of populations with complex care needs who require input from multiple providers located across many care settings (Chouvarda et al. 2015; CIHI 2011; Coleman 2003; Guilcher et al. 2016; Hopman et al. 2016; Koné Pefoyo et al. 2015; Schiotz et al. 2016). When care is fragmented and uncoordinated, it is not only confusing for patients, caregivers and providers but also linked to poor outcomes and high healthcare system costs (Berwick et al. 2008, Berkowitz et al. 2018; Cabana and Jee 2004; Frandsen et al. 2015; van Walraven et al. 2010a, 2010b). Although achieving cost efficiencies and reducing waste are priorities for most industrialized health systems (Berwick and Hackbarth 2012; FOPH 2013; Marchildon 2013; OECD 2017), it is recognized that solely focusing on saving money or "bending the cost curve" is short-sighted (McGrail and Ahuja 2017; Porter 2010).

In this paper, we explore three important concepts from the current healthcare discourse that are intended to drive health system improvements: person-centred care, value-based healthcare and learning health systems. We briefly define these three concepts and then argue that key tenets from each of these concepts should be combined to create a *person-centred learning health system* (PC-LHS) approach. We highlight two key points: First, to achieve a PC-LHS, the experiences, priorities and values of patients and their caregivers should be continuously collected and fed into data systems to monitor ongoing quality improvement and performance benchmarking. Second, the information collected in determining value must embrace important contextual elements – including the social determinants of health – as patient health and well-being outcomes will ultimately be shaped by these critical factors and not health system and biomedical disease factors alone.

Overview of Concepts

Person-centred care

Over the past two decades, there has been a dominant focus on the concept of person (patient)-centred care as a core component of high-quality health systems (Institute of Medicine 2001). Despite this recent focus, the concept itself can be traced back to the 1940s, 1950s and 1960s to the early works of Carl Rogers (1946) and Michael Balint (1969). Rogers, a psychoanalyst, used the term *client* instead of *patient* as the latter suggested a form of dependence and perpetuated a power difference between the provider and the patient. In 1969, Balint differentiated illness-oriented medicine (diagnosing and treating illness) from patient-centred medicine (understanding the "overall" person, not just the illness) (Balint 1969). Beach et al. (2006) described a similar term, *relationship-centred care*, which speaks of the importance of understanding the context of all parties in a relationship (including providers and caregivers) and the importance of authenticity, not just going through the motions. The ideas embedded in person- and relationship-centred care are apparent in various disciplines (e.g., occupational therapy, physical therapy, social work, nursing and medicine) and are arguably more or less ingrained in the core practice of these professions. These approaches to care entail recognizing the patients and their caregivers beyond the patients' illness, understanding their preferences and values and empowering them in decision making and care planning

to the extent that works for them, in an effort to improve their experiences and outcomes. Unfortunately, current health system delivery models and approaches to care that favour cure and disease management within discrete sectors make it increasingly difficult to execute these principles in practice.

Value-based healthcare

Michael Porter and Elizabeth Olmsted Teisberg coined the term *value-based health-care*, defined as health outcomes achieved relative to dollars spent (Porter and Teisberg 2006). The focus on outcomes moves away from a traditional focus on volumes of service or cost reductions alone (Porter 2009, 2010). The challenge is that health systems often operate in silos; thus, any focus on value tends to be sector specific (such as in hospital), which is only one component of the patient's care journey (Elf et al. 2017). Work to date on value-based healthcare has primarily considered disease-specific and symptom-oriented outcomes, with little focus on understanding how patients and caregivers define value-based outcomes (Anderson et al. 2017; Ersek et al. 2017). Shifting attention to defining what matters to patients and caregivers, measuring these concepts and using these findings to inform the design and implementation (or adaptation) of models of care will require a simultaneous reduction of processes that do not work well and produce little value for patients and caregivers.

Learning health systems

Within the past few years, real-time execution of evidence-based practice with practice-based evidence has emerged as a new priority and is called a learning health system (Porter and Teisberg 2006). This *new way of healthcare* marries research with quality improvement through a constant cycle of collecting data, feeding information back to providers and decision makers, making adaptations based on this "real-time feedback" and continuing the improvement cycle (Reid 2016). Organizational culture plays a crucial role in supporting an effective learning health system approach. Specifically, organizations need to *learn as they go* and not be afraid to *"fail,"* to foster a spirit of curiosity and courage. The learning health system approach requires a new set of skills for healthcare system stakeholders (Roy et al. 2016), including researchers and organizations that are conducive to this type of evaluation (Reid 2016). The backbone to learning health systems, but one that is often the hardest to obtain, is a comprehensive data infrastructure that captures meaningful information, including patient- and caregiver-reported outcome and experience measures.

A Call to Action: Person-Centred Learning Health System

What does it look like when person-centred care, value-based care and learning health systems come together? First, to deliver care that is meaningful to patients and caregivers, we need to understand *how* patients and caregivers define "good" outcomes and overall well-being, even if beyond traditional conceptualizations of health (e.g., beyond disease, symptoms). Tseng and Hicks (2016) noted that it is important to align person-centred care and value-based care by incorporating patient data (including preferences and perspectives) into quality metrics to influence the delivery of care. We push further and argue that this can be facilitated by a learning health system approach – collecting these data, feeding the information back to clinical teams and tailoring care and future research in an ongoing quality improvement cycle. Instead of a large overhaul of care (or disruptive change), small incremental improvements can be made.

Currently, measurement tools and care

delivery approaches do not always lend themselves to understanding the *person*, his or her capacity and the social context (including knowing and understanding the caregivers' needs and preferences). Furthermore, measurement approaches and tools should be mindful of linguistic, cultural, medical, cognitive, physical or psychosocial reasons that may impact engagement and data collection. We suggest that to achieve a PC-LHS, we need to *first* identify what matters to patients and caregivers (while being mindful of engagement barriers), have processes in place for ongoing monitoring and create adaptive systems to adjust policies and models to these inputs. From this perspective, value is an input into a PC-LHS (by capturing what matters to patients and caregivers) as well as an output of a PC-LHS (through system improvements and redesign to improve the quality of care delivered).

Know, Capture and Act on What Matters Most to Patients and Caregivers

So what truly matters to patients and caregivers?

In a recent qualitative study entailing individual interviews by our team, we sought to understand what mattered most to people with complex care needs and their caregivers in an attempt to operationalize person-centred care from the users' perspective. Our study included an ethnically diverse sample from two provinces in Canada (Ontario and Quebec) and from New Zealand, including Maori, East Asian and other non-English-speaking participants. Not surprisingly, the relational aspects of care were paramount for people and their caregivers. These factors (which were mostly relational in nature) included feeling heard and comfortable during care interactions, knowing what to expect,

having someone to count on, feeling safe and independent and easily accessing health and social care that was meaningful (Kuluski et al. 2019). Provider activities were identified as being key enablers of needs being met, such as taking the time to listen intently and answer healthcare and non-healthcare-related questions, explaining why certain treatments or medications are being recommended and that changes in symptoms may not happen right away and providing a phone number of a provider who is available to answer questions, if any, arise. In addition, having the appropriate assistive devices to mobilize without fear of falling, continuing to do activities that are meaningful and getting to appointments or completing errands (e.g., banking, groceries) with ease were identified as key activities to support the things that matter to patients and caregivers. These findings are consistent with other studies that sought to capture and understand meaningful patient outcomes (Greene et al. 2012; Mead and Bower 2000; Santana et al. 2018).

Why focus on social factors?

Patients identify the social determinants of health, such as housing, food security, income and social relationships, as important aspects of their lives (things they value). The social determinants of health also play a critical role in determining outcomes such as health utilization and health outcomes (e.g., morbidity and mortality) (Casey et al. 2005; Fitzpatrick et al. 2015; Gundersen et al. 2018; Holt-Lunstad et al. 2010; James et al. 2007; Kushel et al. 2006; Meara et al. 2008; Ross et al. 2012; Weinreb et al. 1998). The impact of the social determinants of health on health utilization and outcomes is seen in Canada (Mikkonen and Raphael 2010; Raphael et al. 2008), is well documented in other countries (Mercer and Watt 2007) and can be both a cause and a result of poor health

(Frier et al. 2018). Fitzpatrick et al. (2015) examined a cohort of adults using two cycles of the Canadian Community Health Survey linked to health administrative data to identify risk factors for high needs and costs in the healthcare system. Food insecurity, personal income and non-home ownership were most strongly associated with high needs and costs in Ontario, Canada. Furthermore, a growing body of research has identified that poor social relationships (perceived social isolation and social disconnectedness) increase the risk of morbidity and mortality (Perissinotto et al. 2019). Notably, the risks of poor social relationships are comparable to those of smoking, alcohol consumption, air pollution, physical inactivity and obesity (Holt-Lunstad et al. 2010). However, social relationship data are not routinely captured in medical assessments, and arguments have been made about the necessity to gather this information and intervene accordingly (Perissinotto et al. 2019).

Within social relationships, another critical piece is the presence and capacity of caregivers. Caregivers (typically family members, partners and friends) play a critical role in capturing patient needs and context – particularly in cases where patients cannot fully participate in their care due to cognitive or physical decline or language or literacy barriers. Caregivers also have their own needs that will impact their capacity to provide care and pursue their own life goals. When caregivers experience stress, they are more likely to experience poor health outcomes, including higher rates of mortality, compared to non-caregivers (Schulz and Beach 1999). A recent study found that caregivers who experience higher levels of caregiver strain have higher all-cause mortality than those caregivers who reported some or no strain in their role (Perkins et al. 2013). Furthermore, when caregiver capacity declines, the risk of long-term care admission for their loved ones

may increase (Toot et al. 2017). Caregiver stress and a lack of capacity to provide care may also contribute to hospital discharge delays (Salonga-Reyes and Scott 2017; Tan et al. 2010; Wolff and Kasper 2004). Living alone has also been associated with increased hospital admission risk, particularly among men (Pimouguet et al. 2016). Therefore, caregiver data (availability, capacity, as well as their input on patient care and their own personal needs) should be considered in the data captured within a PC-LHS.

Discussion

In our paper, we *call to action* the PC-LHS – which combines key tenets from person-centred care, value-based healthcare and learning health systems. In enacting this approach to care, data that matter most to patients and caregivers would be continually collected in health systems to support ongoing quality improvement. However, we recognize that the implementation of a PC-LHS will not be easy. It will require substantial initial start-up funding, ongoing leadership and meaningful collaborations across sectors and disciplines.

Although it may seem daunting, there are examples of learning health systems that can be used as guiding models for the PC-LHS. In the United States, the Veterans Health Administration (VA) is an integrated learning health system, with more than 60% of scientists from basic science to translation research also practising as clinicians (Atkins et al. 2017). In an overview of the VA model, Atkins et al. (2017) provide specific examples of how the VA has been successful with the learning health systems approach, such as with mental healthcare. The integration of evidence-informed practice, measurement and quality improvement significantly improved clinical processes and outcomes for persons with mental health issues, including improved

access to care (O'Hanlon et al. 2017; Washington et al. 2011). Atkins et al. (2017) highlight that the VA system provides a rich opportunity for "natural experiments" (p. 473) to identify what is working and what is not, how processes can be improved and the resulting adjustments for improvements. However, notably absent from the description of the VA learning health systems approach is the focus on patient and caregiver engagement. Atkins et al. (2017) acknowledged in their recommendations for advancing this field the need to have patient-centred measures to ensure that we are measuring what patients and caregivers value.

Learning from other learning health systems, such as the VA, will be key to advancing this approach across health jurisdictions. As a start, organizations that are nimble and support a culture of continuous improvement are ripe for a PC-LHS approach, where components of care that matter to patients and caregivers are collected and used to adapt and test approaches to care delivery. Over the next few years, it will be important to determine the tools, processes and enabling contexts required by researchers, providers and decision makers to address the aspects of care that patients and caregivers identify as valuable. To date, a number of factors that support an enabling context for person-centred care have been identified and include providers who work in teams (Beland and Hollander 2011), co-location of services (Rumball-Smith et al. 2014), care coordination (Beland and Hollander 2011), shared values (Evans et al. 2016; Luxford et al. 2011), data infrastructure that spans settings to support communication (Steele Gray et al. 2018; Suter et al. 2009), remuneration that does not penalize providers for taking time with patients and caregivers during care interactions (Hutchison and Glazier 2013; Tsiachristas 2016) and co-design of care with

patients and caregivers (Evans et al. 2016). In a PC-LHS, when patient and caregiver data are collected, having processes in place to frequently discuss and reflect on the data will be required, particularly because ideas and goals may conflict. A point person, such as a practice facilitator, clinician researcher or quality improvement lead, could be appointed to lead data collection initiatives.

Further to that point, one core challenge in acting on, and responding to, patient- and caregiver-defined values is that these may be in conflict with the values and priorities of providers or misaligned with the organizational culture and practices in which patients receive care. Previous work on goal alignment shows that goals rarely align between patients, caregivers and providers (Bogardus et al. 2001; Heisler et al. 2003), particularly when patient needs fluctuate, compile and become increasingly complex (Kuluski et al. 2013). Given the different roles that patients, caregivers and providers play, it is expected that different aspects of the care experience will be differentially prioritized within and between groups. Thus, having the safe space to openly share, negotiate and collectively discuss goals and priorities will be key (Kuluski et al. 2013).

Another key challenge of a PC-LHS is the fragmentation of information technology and the lack of interoperability of information technology systems across the healthcare sector and between health and social service sectors (Steele Gray et al. 2018). Although a hospital system may create a user-friendly information technology platform within their institution, data capturing the full patient journey will require some level of integration with other providers and systems across sectors. In an era with strong health information privacy legislation, working through these foreseeable barriers will be critical and will require innovative thinking and risk sharing. For example, organizations (universities, acute

care hospitals, community sector, government, etc.) will need to come together to reduce the burden on research with data-sharing agreements, ethics processes, etc., which often take months of administrative burden prior to initiating research initiatives. For a PC-LHS approach to be nimble and time sensitive, improved governance and administrative structures need to be in place to facilitate research and clinical activities for these important "natural experiments" (Atkins et al. 2017) to occur. A learning health system network of university and healthcare organizations governed by patients, providers, clinicians, researchers and payers in the United States is currently working through these barriers to support comparative effectiveness research through a shared data platform and streamlined research ethics boards (Finney Rutten et al. 2017) and is an example to watch in the coming years.

Finally, a core challenge in advancing this work, particularly if social determinants of health are prioritized (such as housing, basic income and food security), is the responsibility and accountability of health and social ministries. The *Canada Health Act* guides the government to fund "medically necessary services" (Martin et al. 2018); however, as research increasingly shows the impact of social factors on health and well-being (Halfon et al. 2010; Marmot et al. 2008; Raphael et al. 2008), the boundaries between health and social systems are increasingly becoming blurred. Moreover, if patients and caregivers identify social factors as key priorities within their health system encounters, to what extent are health system providers/decision makers accountable and responsible? We argue the need to explore collaborative governance opportunities as a way to bring health and social care sectors together, to achieve more for patients and caregivers than what each organization (or sector) could

do alone (Emerson et al. 2012). This would include not only co-location of key health and social care services (e.g., primary care services, legal services, supports for new immigrants/resettlement, community gardens and housing, as seen in Ontario's community health hubs and community health centres) but also exploring the integration of data infrastructures, measurement and administrative and delivery functions to support a more streamlined experience for patients, caregivers and providers. In addition to the moral imperative for this type of health and social collaboration, there is evidence of the positive impact of social spending on health. Dutton et al. (2018) examined provincial expenditure data from 1981 to 2011 from nine Canadian provinces to assess the impact of social spending on population-level health outcomes (potentially avoidable mortality, infant mortality and life expectancy) and concluded that population health-level outcomes significantly benefit from social spending.

Operationalizing and institutionalizing a PC-LHS require explicit relationships between patients, researchers and providers who work in the same space. Hospitals or community organizations with embedded researchers who are skilled in engaging patients, caregivers and providers in co-design methods can help advance a PC-LHS approach. Starting on clinical units (or with groups of providers) that are "early adopters" may provide a good testing ground. Continual performance monitoring of key outcomes (which map onto the quadruple aim of patient experience, provider experience, costs and population health), as well as attributes of care that matter most to patients and caregivers (described earlier in this paper), should be considered part of standard data collection procedures. Having incentives in place for healthcare organizations and researchers to try innovative approaches to care and adopt a "fail

fast" approach may help instill innovation and a culture of continuous improvement.

In summary, to provide care that is meaningful to patients and caregivers, we need to understand what actually matters to them. Although there have been improvements in healthcare systems through services that adopt principles of person-centred care, value-based care and learning health systems, individually, these three concepts are not sufficient to guide transformative change. We need thoughtful, evidence-informed services and programs, adaptable to change, and ongoing evaluation. A PC-LHS that combines these three concepts may help health jurisdictions and organizations be responsive to patient and caregiver needs while also focusing on efficiency (e.g., optimizing the value of dollars spent). There need to be more discussions and engaging brainstorming opportunities with a wide range of sectors on how to address important functional (data infrastructure, privacy and data-sharing agreements) and normative (culture, trust and leadership) factors related to the implementation of a PC-LHS approach.

References
Anderson, B., J. Beckett, N. Wells and M. Comeau. 2017. The Eye of the Beholder: A Discussion of Value and Quality from the Perspective of Families of Children and Youth with Special Healthcare Needs. *Pediatrics* 139(Suppl. 2): S99–108. doi:10.1542/peds.2016-2786D.

Atkins, D., A.M. Kilbourne and D. Shulkin. 2017. Moving from Discovery to System-Wide Change: The Role of Research in a Learning Healthcare System: Experience from Three Decades of Health Systems Research in the Veterans Health Administration. *Annual Review of Public Health* 38: 467–87. doi: 10.1146/annurev-publhealth-031816-044255.

Balint, E. 1969. The Possibilities of Patient-Centered Medicine. *Journal of the Royal College of General Practitioners* 17(82): 269–76.

Beach, M.C., Inui, T. and the Relationship-Centered Care Research Network. 2006. Relationship-Centered Care: A Constructive Reframing. *J Gen Intern Med 21(Suppl. 1):* S3–S8. doi:10.1111/j.1525-1497.2006.00302.x.

Beland, F. and M.J. Hollander. 2011. Integrated Models of Care Delivery for the Frail Elderly: International Perspectives. *Gaceta Sanitaria* 25(Suppl. 2): 138–46. doi:10.1016/j.gaceta.2011.09.003.

Berkowitz, S.A., S. Parashuram, K. Rowan, L. Andon, E.B. Bass, M. Bellantoni et al. 2018. Association of a Care Coordination Model with Healthcare Costs and Utilization: The Johns Hopkins Community Health Partnership (J-CHiP). *JAMA Network Open* 1(7): e184273. doi:10.1001/jamanetworkopen.2018.4273.

Berwick, D.M. and A.D. Hackbarth. 2012. Eliminating Waste in US Healthcare. *JAMA* 307(14): 1513–16. doi:10.1001/jama.2012.362.

Berwick, D.M., T.W. Nolan and J. Whittington. 2008. The Triple Aim: Care, Health, and Cost. *Health Affairs* 27(3): 759–69. doi:/10.1377/hlthaff.27.3.759.

Bogardus, S.T., E.H. Bradley, C.S. Williams, P.K. Maciejewski, C. van Doorn and S.K. Inouye. 2001. Goals for the Care of Frail Older Adults: Do Caregivers and Clinicians Agree? *American Journal of Medicine* 110(2): 97–102. doi:10.1016/s0002-9343(00)00668-9.

Cabana, M.D. and S.H. Jee. 2004. Does Continuity of Care Improve Patient Outcomes? *Journal of Family Practice* 53(12): 974–80.

Canadian Institute for Health Information (CIHI). 2011, January. *Seniors and the Health Care System: What Is the Impact of Multiple Chronic Conditions?* Toronto, ON: Author.

Casey, P.H., K.L. Szeto, J.M. Robbins, J.E. Stuff, C. Connell, J.M. Gossett et al. 2005. Child Health-Related Quality of Life and Household Food Security. *Archives of Pediatrics & Adolescent Medicine* 159(1): 51–56. doi:10.1001/archpedi.159.1.51.

Chouvarda, I.G., D.G. Goulis, I. Lambrinoudaki and N. Maglaveras. 2015. Connected Health and Integrated Care: Toward New Models for Chronic Disease Management. *Maturitas* 82(1): 22–27. doi:10.1016/j.maturitas.2015.03.015.

Coleman, E.A. 2003. Falling through the Cracks: Challenges and Opportunities for Improving Transitional Care for Persons with Continuous Complex Care Needs. *Journal of the American Geriatrics Society* 51(4): 549–55. doi:10.1046/j.1532-5415.2003.51185.x.

Dutton, D.J., P.-G. Forest, R.D. Kneebone and J.D. Zwicker. 2018. Effect of Provincial Spending on Social Services and Health Care on Health Outcomes in Canada: An Observational Longitudinal Study. *CMAJ* 190(3): E66–71. doi:10.1503/cmaj.170132.

Elf, M., M. Flink, M. Nilsson, M. Tistad, L. von Koch and C. Ytterberg. 2017. The Case of Value-Based Healthcare for People Living with Complex Long-Term Conditions. *BMC Health Services Research* 17(1): 24. doi:10.1186/s12913-016-1957-6.

Emerson, K., T. Nabatchi and S. Balogh. 2012. An Integrative Framework for Collaborative Governance. *Journal of Public Administration Research and Theory* 22(1): 1–29. doi.org/10.1093/jopart/mur011.

Ersek, J.L., E. Nadler, J. Freeman-Daily, S. Mazharuddin and E.S. Kim. 2017. Clinical Pathways and the Patient Perspective in the Pursuit of Value-Based Oncology Care. *American Society of Clinical Oncology Educational Book 3*7: 597–606. doi:10.14694/EDBK_174794.

Evans, J., S. Daub, J. Goldhar, A. Wojtak and D. Purbhoo. 2016. Leading Integrated Health and Social Care Systems: Perspectives from Research and Practice. *Healthcare Quarterly* 18(4): 30–35. doi:10.12927/hcq.2016.24553.

Federal Office of Public Health (FOPH). 2013. Gesundheit2020 – Health2020 – A Comprehensive Healthcare Strategy. Retrieved November 18, 2019. <https://www.bag.admin.ch/bag/en/home/strategie-und-politik/gesundheit-2020/eine-umfassende-strategie-fuer-das-gesundheitswesen.html>.

Finney Rutten, L.J., A. Alexander, P.J. Embi, G. Flores, C. Friedman, I.V. Haller et al. 2017. Patient-Centered Network of Learning Health Systems: Developing a Resource for Clinical Translational Research. *Journal of Clinical and Translational Science* 1(1): 40–44. doi:10.1017/cts.2016.11.

Fitzpatrick, T., L.C. Rosella, A. Calzavara, J. Petch, A.D. Pinto, H. Manson et al. 2015. Looking Beyond Income and Education: Socioeconomic Status Gradients among Future High-Cost Users of Healthcare. *American Journal of Preventive Medicine* 49(2): 161–71. doi:10.1016/j.amepre.2015.02.018.

Frandsen, B.R., K.E. Joynt, J.B. Rebitzer and A.K. Jha. 2015. Care Fragmentation, Quality, and Costs among Chronically Ill Patients. *American Journal of Managed Care* 21(5): 355–62.

Frier, A., F. Barnett, S. Devine and R. Barker. 2018. Understanding Disability and the 'Social Determinants of Health': How Does Disability Affect Peoples' Social Determinants of Health? *Disability and Rehabilitation* 40(5): 538–47. doi:10.1080/09638288.2016.1258090.

Greene, S.M., L. Tuzzio and D. Cherkin. 2012. A Framework for Making Patient-Centered Care Front and Center. *Permanente Journal* 16(3): 49–53. doi:10.7812/tpp/12-025.

Guilcher, S.J., S.E. Bronskill, J. Guan and W.P. Wodchis. 2016. Who Are the High-Cost Users? A Method for Person-Centred Attribution of Health Care Spending. *PLoS ONE* 11(3): e0149179. doi:10.1371/journal.pone.0149179.

Gundersen, C., V. Tarasuk, J. Cheng, C. de Oliveira and P. Kurdyak. 2018. Food Insecurity Status and Mortality among Adults in Ontario, Canada. *PLoS ONE* 13(8): e0202642. doi:10.1371/journal.pone.0202642.

Halfon, N., K. Larson and S. Russ. 2010. Why Social Determinants? *Healthcare Quarterly* 14(1): 8–20. doi:10.12927/hcq.2010.21979.

Heisler, M., S. Vijan, R.M. Anderson, P.A. Ubel, S.J. Bernstein and T.P. Hofer. 2003. When Do Patients and Their Physicians Agree on Diabetes Treatment Goals and Strategies, and What Difference Does It Make? *Journal of General Internal Medicine* 18(11): 893–902. doi:10.1046/j.1525-1497.2003.21132.x.

Holt-Lunstad, J., T.B. Smith and J.B. Layton. 2010. Social Relationships and Mortality Risk: A Meta-analytic Review. *PLoS Medicine* 7(7): e1000316. doi:10.1371/journal.pmed.1000316.

Hopman, P., M.J. Heins, J.C. Korevaar, M. Rijken and F.G. Schellevis. 2016. Health Care Utilization of Patients with Multiple Chronic Diseases in the Netherlands: Differences and Underlying Factors. *European Journal of Internal Medicine* 35: 44–50. doi:10.1016/j.ejim.2016.08.025.

Hutchison, B. and R. Glazier 2013. Ontario's Primary Care Reforms Have Transformed the Local Care Landscape, But a Plan Is Needed for Ongoing Improvement. *Health Affairs* 32(4): 695–703. doi:10.1377/hlthaff.2012.1087.

Institute of Medicine (IOM). 2001, March. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academy Press.

James, P.D., R. Wilkins, A.S. Detsky, P. Tugwell and D.G. Manuel. 2007. Avoidable Mortality by Neighbourhood Income in Canada: 25 Years after the Establishment of Universal Health Insurance. *Journal of Epidemiology and Community Health* 61(4): 287–96. doi:10.1136/jech.2006.047092.

Koné Pefoyo, A. J., S.E. Bronskill, A. Gruneir, A. Calzavara, K. Thavorn, Y. Petrosyan, et al. 2015. The Increasing Burden and Complexity of Multimorbidity. *BMC Public Health* 15: 415. doi:10.1186/s12889-015-1733-2.

Kuluski, K., A. Gill, G. Naganathan, R. Upshur, R.L. Jaakkimainen and W.P. Wodchis. 2013. A Qualitative Descriptive Study on the Alignment of Care Goals between Older Persons with Multi-morbidities, Their Family Physicians and Informal Caregivers. *BMC Family Practice* 14: 133. doi:10.1186/1471-2296-14-133.

Kuluski, K., A. Peckham, A. Gill, D. Gagnon, C. Wong-Cornall, A. McKillop et al. 2019. What Is Important to Older People with Multimorbidity and Their Caregivers? Identifying Attributes of Person Centred Care from the User Perspective. *International Journal of Integrated Care* 19(3): 4. doi:10.5334/ijic.4655.

Kushel, M.B., R. Gupta, L. Gee and J.S. Haas. 2006. Housing Instability and Food Insecurity as Barriers to Health Care among Low-Income Americans. *Journal of General Internal Medicine* 21(1): 71–77. doi:10.1111/j.1525-1497.2005.00278.x.

Luxford, K., D.G. Safran and T. Delbanco. 2011. Promoting Patient-Centered Care: A Qualitative Study of Facilitators and Barriers in Healthcare Organizations with a Reputation for Improving the Patient Experience. *International Journal of Quality in Healthcare* 23(5): 510–15. doi:10.1093/intqhc/mzr024.

Marchildon, G. 2013. Canada: Health System Review. *Health Systems in Transition* 15(1): 1–179.

Marmot, M., S. Friel, R. Bell, T.A. Houweling, S. Taylor for the Commission on Social Determinants of Health. 2008. Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health. *The Lancet* 372(9650): 1661–69. doi:10.1016/S0140-6736(08)61690-6.

Martin, D., A.P. Miller, A. Quesnel-Vallée, N.R. Caron, B. Vissandjée and G.P. Marchildon. 2018. Canada's Universal Health-Care System: Achieving Its Potential. *The Lancet* 391(10131): 1718–35. doi:10.1016/S0140-6736(18)30181-8.

McGrail, K. and M. Ahuja. 2017. What Is Bending the Cost Curve? An Exploration of Possible Drivers and Unintended Consequences. *Healthcare Policy* 13(2): 20–30. doi:10.12927/hcpol.2017.25325.

Mead, N. and P. Bower. 2000. Patient-Centredness: A Conceptual Framework and Review of the Empirical Literature. *Social Science and Medicine* 51(7): 1087–110. doi:10.1016/s0277-9536(00)00098-8.

Meara, E.R., S. Richards and D.M. Cutler. 2008. The Gap Gets Bigger: Changes in Mortality and Life Expectancy, by Education, 1981-2000. *Health Affairs* 27(2): 350–60. doi:10.1377/hlthaff.27.2.350.

Mercer, S.W. and G.C.M. Watt 2007. The Inverse Care Law: Clinical Primary Care Encounters in Deprived and Affluent Areas of Scotland. *Annals of Family Medicine* 5(6): 503–10. doi:10.1370/afm.778.

Mikkonen, J. and D. Raphael. 2010. *Social Determinants of Health: The Canadian Facts*. Toronto, ON: York University School of Health Policy and Management.

O'Hanlon, C., C. Huang, E. Sloss, R. Anhang Price, P. Hussey, C. Farmer et al. 2017. Comparing VA and Non-VA Quality of Care: A Systematic Review. *Journal of General Internal Medicine* 32(1): 105–21. doi:10.1007/s11606-016-3775-2.

Organisation for Economic Co-operation and Development (OECD). 2017. *Tackling Wasteful Spending on Health*. Paris: OECD Publishing. Retrieved October 23, 2019. <https://www.oecd.org/health/tackling-wasteful-spending-on-health-9789264266414-en.htm>.

Perissinotto, C., J. Holt-Lunstad, V.S. Periyakoil and K. Covinsky. 2019. A Practical Approach to Assessing and Mitigating Loneliness and Isolation in Older Adults. *Journal of the American Geriatrics Society* 67(4): 657–62. doi:10.1111/jgs.15746.

Perkins, M., V.J. Howard, V.G. Wadley, M. Crowe, M.M. Safford, W.E. Haley et al. 2013. Caregiving Strain and All-Cause Mortality: Evidence from the REGARDS Study. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences* 68(4): 504–12. doi:10.1093/geronb/gbs084.

Pimouguet, C., D. Rizzuto, P. Schön, B. Shakersain, S. Angleman, M. Lagergren et al. 2016. Impact of Living Alone on Institutionalization and Mortality: A Population-Based Longitudinal Study. *European Journal of Public Health* 26(1): 182–87. doi:10.1093/eurpub/ckv052.

Porter, M.E. 2009. A Strategy for Healthcare Reform–Toward a Value-Based System. *New England Journal of Medicine* 361(2): 109–12. doi:10.1056/NEJMp0904131.

Porter, M.E. 2010. What Is Value in Healthcare? *New England Journal of Medicine* 363(26): 2477–81. doi:10.1056/NEJMp1011024.

Porter, M.E. and E.O. Teisberg. 2006. *Redefining Healthcare: Creating Value-Based Competition on Results*. Boston, MA: Harvard Business Press.

Raphael, D., A. Curry-Stevens and T. Bryant. 2008. Barriers to Addressing the Social Determinants of Health: Insights from the Canadian Experience. *Health Policy* 88(2–3): 222–35. doi:10.1016/j.healthpol.2008.03.015.

Reid, R.J. 2016. Embedding Research in the Learning Health System. *Healthcare Papers* 16(Special Issue): 30–35. doi:10.12927/hcpap.2016.24724.

Rogers, C.R. 1946. Significant Aspects of Client-Centered Therapy. *American Psychologist* 1(10): 415–22. doi:10.1037/h0060866.

Ross, N.A., R. Garner, J. Bernier, D.H. Feeny, M.S. Kaplan, B. McFarland et al. 2012. Trajectories of Health-Related Quality of Life by Socio-Economic Status in a Nationally Representative Canadian Cohort. *Journal of Epidemiology and Community Health* 66(7): 593–98. doi:10.1136/jech.2010.115378.

Roy, D.A., B. Candas, E. Litvak and L. Boileau. 2016. The Necessary – but Not Sufficient – Leadership of Research to Transform the Health Systems. *Healthcare Papers* 16(Special Issue): 21–25. doi:10.12927/hcpap.2016.24722.

Rumball-Smith, J., W.P. Wodchis, A. Koné, T. Kenealy, J. Barnsley and T. Ashton. 2014. Under the Same Roof: Co-Location of Practitioners within Primary Care Is Associated with Specialized Chronic Care Management. *BMC Family Practice* 15: 149. doi:10.1186/1471-2296-15-149.

Salonga-Reyes, A. and I.A. Scott. 2017. Stranded: Causes and Effects of Discharge Delays Involving Non-Acute In-Patients Requiring Maintenance Care in a Tertiary Hospital General Medicine Service. *Australian Health Review* 41(1): 54–62. doi:10.1071/AH15204.

Santana, M.J., K. Manalili, R.J. Jolley, S. Zelinsky, H. Quan and M. Lu. 2018. How to Practice Person-Centred Care: A Conceptual Framework. *Health Expectations* 21(2): 429–440. doi:10.1111/hex.12640.

Schiotz, M.L., D. Host and A. Frolich. 2016. Involving Patients with Multimorbidity in Service Planning: Perspectives on Continuity and Care Coordination. *Journal of Comorbidity* 6(2): 95–102. doi:10.15256/joc.2016.6.81.

Schulz, R. and S.R. Beach. 1999. Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study. *JAMA* 282(23): 2215–19. doi:10.1001/jama.282.23.2215.

Steele Gray, C., J. Barnsley, D. Gagnon, L. Belzile, T. Kenealy, J. Shaw et al. 2018. Using Information Communication Technology in Models of Integrated Community-Based Primary Healthcare: Learning from the iCOACH Case Studies. *Implementation Science* 13(1): 87. doi:10.1186/s13012-018-0780-3.

Suter, E., N.D. Oelke, C.E. Adair and G.D. Armitage. 2009. Ten Key Principles for Successful Health Systems Integration. *Healthcare Quarterly* 13(Special Issue): 16–23. doi:10.12927/hcq.2009.21092.

Tan, W.S., W.F. Chong, K.S. Chua, B.H. Heng and K.F. Chan. 2010. Factors Associated with Delayed Discharges after Inpatient Stroke Rehabilitation in Singapore. *Annals of Academic Medicine Singapore* 39(6): 435–41.

Toot, S., T. Swinson, M. Devine, D. Challis and M. Orrell. 2017. Causes of Nursing Home Placement for Older People with Dementia: A Systematic Review and Meta-Analysis. *International Psychogeriatric Association* 29(2): 195–208. doi:10.1017/S1041610216001654.

Tseng, E.K. and L.K. Hicks. 2016. Value Based Care and Patient-Centered Care: Divergent or Complementary? *Current Hematologic Malignancy Reports* 11(4): 303–10. doi:10.1007/s11899-016-0333-2.

Tsiachristas, A. 2016. Financial Incentives to Stimulate Integration of Care. *International Journal of Integrated Care* 16(4): 8. doi:10.5334/ijic.2532.

van Walraven, C., N. Oake, A. Jennings and A.J. Forster. 2010a. The Association between Continuity of Care and Outcomes: A Systematic and Critical Review. *Journal of Evaluation in Clinical Practice* 16(5): 947–56. doi:10.1111/j.1365-2753.2009.01235.x.

van Walraven, C., M. Taljaard, E. Etchells, C.M. Bell, I.G. Stiell, K. Zarnke et al. 2010b. The Independent Association of Provider and Information Continuity on Outcomes after Hospital Discharge: Implications for Hospitalists. *Journal of Hospital Medicine* 5(7): 398–405. doi:10.1002/jhm.716.

Washington, D.L., B. Bean-Mayberry, D. Riopelle and E.M. Yano. 2011. Access to Care for Women Veterans: Delayed Healthcare and Unmet Need. *Journal of General Internal Medicine* 26(2): 655–61 . doi:10.1007/s11606-011-1772-z.

Weinreb, L., R. Goldberg, E. Bassuk and J. Perloff. 1998. Determinants of Health and Service Use Patterns in Homeless and Low-Income Housed Children. *Pediatrics* 102(3): 554–62. doi:10.1542/peds.102.3.554.

Wolff, J.L. and J.D. Kasper. 2004. Informal Caregiver Characteristics and Subsequent Hospitalization Outcomes among Recipients of Care. *Aging Clinical and Experimental Research* 16(4): 307–13. doi:10.1007/bf03324556.