OXFORD

Perspectives

Unpacking 'the cloud': a framework for implementing public health approaches to palliative care

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Summary

Designing and implementing population-based systems of care that address the social determinants of health, take action on multiple levels, and are guided by evidence-based principles is a pressing priority, and an international challenge. Aging persons are a priority demographic whose health needs span physical, psychosocial and existential care domains, increase in the last year of life, are often poorly coordinated and therefore remain unmet. Compassionate communities (CCs) are an example of a public health approach that fully addresses the holistic healthcare needs of those who are aging and nearing end of life. The sharing of resources, tools, and innovations among implementers of CCs is occurring globally. Although this can increase impact, it also generates complexity that can complicate robust evaluation. When initiating population health level projects, it is important to clearly define and organize concepts and processes that are proposed to influence the health outcomes. The Health Impact Change Model (HICM) was developed to unpack the complexities associated with the implementation and evaluation of a Canadian CC intervention. The HICM offers utility for citizens, leaders and decision-makers who are engaged in the implementation of population health level strategies or other social approaches to care, such as compassionate cities and age or dementia-friendly communities. The HICM's concepts can be adapted to address a community's healthcare context, needs, and goals for change. We share examples of how the model's major concepts have been applied in the development, evaluation and spread of a complex CC approach.

Key words: framework, population health, public health, palliative care, compassionate communities

INTRODUCTION

International healthcare clinicians and decision-makers are increasingly challenged to manage the complex demographic, environmental, technical and sociological factors that impact the healthcare needs and provision of care to populations within increasingly unsustainable healthcare systems. By 2050, the number of people over the age of 60 years is expected to double; meeting their needs will require significant changes in how societies organize healthcare [World Health Organization (WHO), 2015]. Even with medical advances, the majority of these older adults have multiple co-morbidities, and require a broad scope of health services because of complex physical, cognitive, psychosocial and spiritual needs that increase risks in daily living (Lunney *et al.*, 2003; Stajduhar, 2011).

Despite these differences in health risks and needs, care for the aging tends to be delivered in a uniform, 'one size fits all' system [Institute for Healthcare Improvement (IHI), 2018] that is provider-driven, disease-focused and often lacks consideration of the important contextual factors that influence health (Suter *et al.*, 2009). There is therefore an urgent global need to integrate and evaluate comprehensive health-promoting approaches to palliative care that fully address holistic health by supporting individuals to identify their own needs, achieve their goals, leverage social and personal resources, while recognizing health as 'a resource for everyday life, not [just] the objective of living…' (WHO, 1986, paragraph 3). Fostering investment in theory development and evaluation will be needed to advance this work (Carpiano and Daley, 2006). We report supporting background and rationale, and conceptual challenges and opportunities in the following text.

Background and rationale

According to the WHO (WHO, 2017), rapid global aging of will have a profound impact on all stakeholders of society, and it will require 'doing business differently' (p. 2). Currently, policy makers are largely focused on acute alterations in health of the aging (WHO, 2017), and the standardization of health system design and delivery. Yet, these systems often fail to address the unique needs of aging persons and their families (WHO, 2017). Many healthcare delivery approaches address only pieces of the healthcare system, are not sufficiently integrated, and/or lack the sufficient breadth and depth to make a true impact at the community or population level (Grossman and Alper, 2013; WHO, 2017). Most are not focused on the whole scale of factors and/or do not take into account the social determinants of health.

Therefore, they have limited impact due to low implementation, and low ability to effect system changes. Furthermore, single interventions often fail to demonstrate any clear, direct benefits, and many not be scalable (Milat *et al.*, 2013).

A public health approach to palliative care is a solution to the gaps and challenges described in the previous sections. This approach provides the mechanism and structure for promoting a population health system of care across the trajectory of wellness, the onset of a life-threatening condition, and end of life (Kellehear, 2005). It is enhanced by person-centred processes that base the system on a person's goals, within the context of one's social network, and the communities in which one resides (Hurn *et al.*, 2006). Therefore, communities become key stakeholders in enabling aging people to set goals and act on things that they value (WHO, 2017). This social progress towards population health can be activated by collective impact (Stoto, 2014; Tamarack Institute, 2018), the power of which 'lies in the heightened vigilance that comes from multiple organizations looking for resources and innovations through the same lens, the rapid learning that comes from continuous feedback loops, and the immediacy of action that comes from a unified and simultaneous response among all participants' (Kania and Kramer, 2013, p. 2). This aligns with WHO's (WHO, 2017) assertion that healthy aging innovations must connect stakeholders from multiple sectors to create opportunities and engage in shared learning. Thus, health leaders in two health regions in Canada began sharing tools and processes to better address the community and population health needs of their aging citizens, and that combined the aforementioned approaches. In the early phases of collaboration, the need for a theory to drive the change became a priority.

Conceptual challenges and opportunities

Theory building is critical for advancing population health research (Carpiano and Daley, 2006). Despite the availability of many health promotion theories, their usefulness and ability to guide complex and multi-level solutions to address population health is criticized (King, 2015), and no single conceptual framework comprehensively addressed the challenge of making the sustained, iterative, and meaningful health impact change at the population level.

> Looking at human behavior is like running into a cloud whose origins and direction is unknown. You can see the cloud…but when you reach out to grab a handful to test you come away with nothing visible but a clenched

fist…I can see the cloud…but how do I study it? ([Wright, 1966](), p. 244)

Developing a conceptual model that would support the implementation, evaluation and scale-up of a complex health-promoting palliative care intervention was a clear priority for several reasons. Conceptualizing helps clinicians and researchers comprehend phenomena that are elusive, difficult to describe and understand ([Chinn and Kramer 2011]()). It provides a process for explaining processes and predicting outcomes ([Mills, 1959]()) and also promotes creative thinking about how to develop knowledge, imagine opportunities, and uncover patterns and relationships ([Chinn and Kramer, 2011]()). Practically speaking, it was a process through which we could close the divide between social science and medical research by unpacking the complexities of grant writing, research design and implementation, while simultaneously developing and revising programming. This work enables us to truly understand the 'cloud' and communicate our learning to others engaged in similar population health level initiatives.

PURPOSE

This paper describes the Health Impact Change Model (HICM), its development and adopted elements, and a working evaluation framework. The utility of the model to population health is demonstrated through an exemplar compassionate community (CC) approach whose core model concepts and processes are mapped to an evaluation framework.

FRAMEWORK DEVELOPMENT

To develop the HICM, we examined models that fit the following criteria: (i) applied a community lens; (ii) showed relationships between determinants, actions and outcomes; (iii) had demonstrated impact based on a body of evidence; (iv) accepted by policy and decision-makers; (v) could address complex and high-risk needs, and (vi) traversed levels of impact across individual, community and population health levels ([King, 2015]()). The Population Health Promotion Model ([Hamilton and Bhatti, 1996]()), Accountable Communities for Health ([Mikkelsen *et al.*, 2016]()) and the Chronic Care Model ([MacColl Center for Health Care Innovation, 2003]()) were selected and integrated to inform our work. We describe these models in the following text. A summary of each model's concepts, structures and processes is also provided in Table 1.

Population health promotion

Health promotion has been repeatedly shown to positively impact the health of populations ([Epp, 1986](); [Hamilton and Bhatti, 1996](); [Government of Canada, 2001](); [Scharlach *et al.*, 2014](); [WHO, 2018]()). Countries with a strong emphasis on population health have realized better health outcomes, lower mortality rates, and lower overall costs of healthcare ([Aggarwal and Hutchison, 2012]()). The Population Health Promotion Model, supported by the Ottawa Charter, outlines a comprehensive set of strategies based on identifying on what to take action, how to take action, and with whom ([Hamilton and Bhatti, 1996]()). Key assumptions of the model include social responsibility for taking action, the need to act on the determinants of health, taking action across multiple levels, and applying evidence-based principles to support decision-making ([Hamilton and Bhatti, 1996]()). Rather than prescribing actions, the model is a starting point for identifying factors that influence population health, creating dialogue about shifting cultural and historical beliefs about health, healthcare, and its delivery, and creating new or related frameworks ([Government of Canada, 2001]()).

Accountable communities for health

To be truly effective, primary care must be patient-centred with well-coordinated teams that deliver care in a safe, efficient and effective manner ([Davis *et al.*, 2010](); [Aggarwal and Hutchison, 2012](); [Naylor *et al.*, 2013]()). Volunteers are now recognized as team actors in healthcare delivery, and models that engage citizens in community strategic and research planning can reach people on a large enough scale to have an impact on major social problems ([Mikkelsen *et al.*, 2016]()). The Accountable Communities for Health model addresses the funding, governance and shared accountability structures that are a requisite for promoting health within a community ([Mikkelsen *et al.*, 2016]()). The model explicitly addresses the social context in which behaviours occur, and the potential to modify the norms, values, and policies influencing health and well-being. Its integration enhances sustainability and impact because programmes draw on existing community resources and help generate local ownership and empowerment. Its use increases the ability to reach inaccessible populations by activating informal community networks, augmenting diffusion of interventions and their effects, ensuring programmes are implemented in real environments, and providing community-tested evidence of feasibility and effectiveness ([Merzel and D'Affitti, 2003]()).

Table 1: Single model core concepts, strengths, structures and processes embedded in the HICM

Model	Core concepts	Strengths and usefulness	Structures and processes embedded in the HICM
Population health model	What: determinants of health How: comprehensive action strategies based on Ottawa Charter With whom: individual, family, community, sector/system, society Evidence-informed decision-making	Draws on population health and health promotion to provide a blueprint for a comprehensive action strategy Emphasizes action on the full range of health determinants Incorporates the Ottawa Charter set of action strategies Recognizes evidence-based decision-making as driver for population health promotion Values holistic care, social justice, equity, respect, caring, meaningful participation of citizens in development and operationalizing programmes	Determinants of health Levels of action: individual, family, community, society Strategies: building healthy public policy; creating supportive environments; strengthening community actions; developing personal skills; reorienting health services
Chronic care model	The community The health system Self-management support Delivery system design Decision support Clinical information systems Evidence-based change	Looks outside the healthcare system to leverage community Emphasizes organized partnerships with community programmes, resources to fill gaps in services, avoiding duplication Assumes patient adopts central role and responsibility for managing his or her own health Prioritizes individual patient care planning and follow-up Recognizes collaborative approach to care involving communication, care coordination, and data-sharing among patients and providers Emphasizes proactivity vs. reactivity, health literacy, cultural sensitivity, advocacy Embeds evidence-based change in the model elements	The community: 1. patient participation 2. community partnerships The health system: 1. comprehensive system change 2. community participation 3. focus on care improvement Self-management support: 1. patient at centre 2. linkages with community 3. social networks Delivery system design: planned interaction Decision support: primary care platform Clinical information systems: 1. individual patient care planning 2. proactive care based on needs 3. information sharing 4. performance monitoring 5. audit and feedback
Accountable communities for health	Awareness of services addressing health-related social needs Assistance with referral to services to address health-related social needs Alignment partnerships to address health-related social needs and optimize community capacity	Addresses gap between clinical care and community services in healthcare delivery Involves screening of unmet needs, referral, increased awareness of community services, service navigation and alignment of clinical and community services Model assumptions: 1. Addressing health-related social needs (food insecurity, housing) through enhanced clinical-community linkages improves health outcomes (chronic disease), reduces costs and prevents avoidable healthcare utilization. 2. Involves diverse types and sizes of community organizations from various locations and serves variations in population demographics	Processes for universal and comprehensive community care: 1. awareness 2. assistance 3. alignment Outcomes: 1. healthcare costs 2. healthcare utilization

Chronic care model

The Chronic Care Model (MacColl Center for Health Care Innovation, 2003) introduces the elements that support implementation: healthcare organization and leadership, linkage to community resources, support of client self-management, coordinated delivery system design, clinical decision support and clinical information systems. A body of literature on patient-centred, internet-facilitated self-management approaches shows that patients can and will engage in their own healthcare (Chodosh *et al.*, 2005; McMahon *et al.*, 2005). Furthermore, self-management using patient-centred support can enable a collaborative care approach that empowers patients to manage their own chronic illnesses (Bodenheimer *et al.*, 2002).

Outcome evaluation

The HICM's evaluation metrics are informed by the Triple Aim (Stiefel and Nolan, 2012). The Triple Aim Framework has been adopted widely to optimize health system performance in three domains that can be measured across all levels of a system: (i) improvements in the patient care experience; (ii) improvements in population health and; (iii) reduction in the per capita cost of healthcare. As target domains, its metrics are congruent with the models described in the previous section, as they broadly reflect the potential impacts of an upstream, coordinated and flexible system of care that comprehensively addresses the burden of illness at a population health level. While the IHI proposes specific outcome measures and targets, others were selected for theoretical and methodological rationale (Figure 1).

APPLICATION OF THE HICM

The HICM initially evolved from Health TAPESTRY, an innovation that began as a home-grown system to address gaps in healthcare by connecting people, communities and primary care teams. Led in development by family medicine researchers, the programme recruits and trains volunteers who visit people where they live, to learn about and document what matters most to that person and their health (McMaster University, 2012). Needs, goals and strategies are captured using specialized software and shared with the primary care team through the electronic medical record (EMR). Although the team is anchored in primary care, it can include community, specialist, hospital and other care providers. This supports the care team's ability to work with people to promote and achieve desired health goals. Health is promoted through five central structures/processes: (i) intentional, proactive conversations about a person's life and health goals and health risks; (ii) a plan of care that supports risk reduction and goal achievement; (iii) collaboration among interprofessional primary care team, community service providers and informal caregivers; (iv) trained volunteers who link people with their primary care team; and (v) using the EMR, Personal Health Record (PHR) and other technology to share health information with other providers (McMaster University, 2012).

The Windsor-Essex Compassionate Care Community (WECCC) initiative extends the work of Health TAPESTRY, and it is an implementation example of a CC theory of practice (Kellehear, 2005). The CC movement is a way of comprehensively addressing aging and end of life across a community, and a population-based theory of practice for palliative care that mobilizes citizens in partnership with healthcare and others, to address these universal needs as issues of public health (Kellehear, 2005). CC initiatives are inherently complex webs of interactions across and between community sectors. These relational interactions can be intentionally mobilized to create practical policies that promote quality care for those with life-threatening illnesses and their families.

Since its launch in fall 2014, WECCC has since mobilized over 100 organizations and 300 volunteers to improve the health of aging patients and caregivers living in the city boundaries and its surrounding municipalities. Registration occurs through four agency streams—tele-palliative, home and hospice, vulnerable persons and Health TAPESTRY (WECCC, 2017). As displayed in the HICM, the project leverages five core interventions components: (i) volunteerism is enacted through the training and integration of coaches who support citizens in meeting their own social and practical needs; (ii) interprofessional care is enhanced through the coordination of referrals, service navigation and alignment of clinical and community services; (iii) electronic PHRs are created for each citizen using the Health TAPESTRY platform. The record is personally owned and is updated by the individual, his or her care partner or trained coach. The individual makes decisions regarding the sharing of his or her health information; (iv) social networks are identified for each citizen using a computer algorithm. Gaps and responses to service can be tracked dynamically to optimize the network; (v) citizens, care providers, organizations and decision-maker are engaged in co-creating actions and policies that effect positive change and scalability. Its implementation and evaluation is guided by the HICM. Table 2 shows the relationships among the concepts, processes, intervention components and outcome domains.
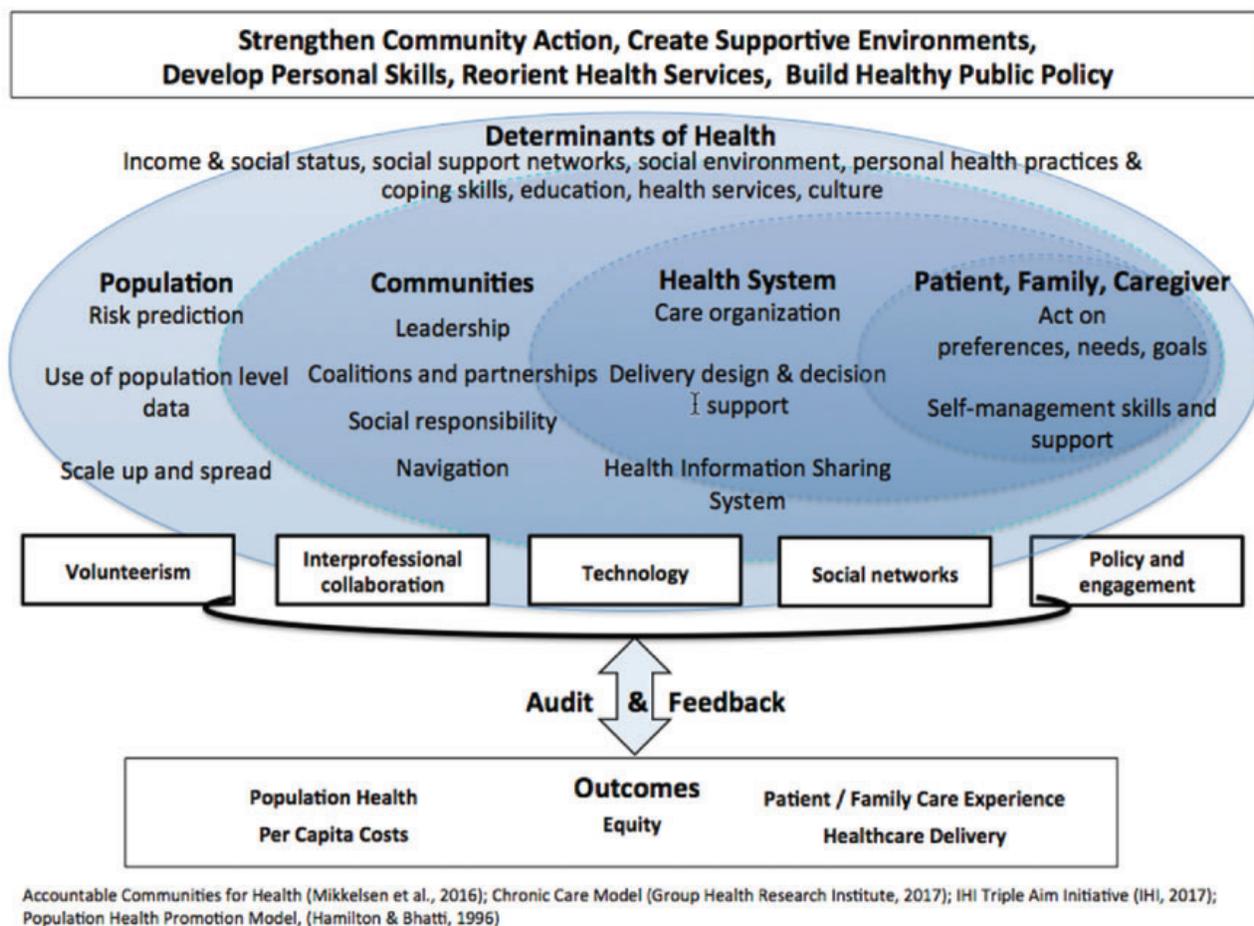
Fig. 1: The health impact change model.

DISCUSSION

The process and output of this work has enabled our team to better understand the multi-level, interrelated and non-linear nature of the complex intervention. The organization of the constructs within the HICM has enhanced our understanding of health change that we posit can begin and spread in different but predictable ways. It is also a work in progress that will continue to be refined through ongoing inquiry and discovery. In the following section, we discuss the utility of the HICM and discuss its current and potential contributions to system-level implementation research.

Utility for promoting population health

The HICM assumes a health-promoting approach to care and takes into account the inevitability of constant change, the fluidity, variability and differences in the individual patient and family care journey. Core assumptions of the HICM also include accommodation for individual values, preferences and trade-offs, and an emphasis on health and wellbeing, self-awareness, empowerment and

self-management for care that may or may not be complemented with professional care. Care delivery can involve formal and informal care that is integrated across settings and systems.

The model emphasizes the social determinants of health (Hamilton and Bhatti, 1996) and community as 'a place for care' versus a setting of care. The model is applicable to the unique contexts of different communities and community-based movements, such as CCs, age-friendly and dementia-friendly communities, and it can be applied regardless of health infrastructure. It is also relevant for evaluating holistic primary healthcare approaches to health and social care delivery. It is structured such that it is possible to operationalize at scale, and population health impact can be tracked over time, and across communities. The HICM can be used by a range of actors, including programme developers, health promoters and regional health authorities. These healthcare leaders will be instrumental in refining the HICM, advancing its transferability to other innovations, approaches and system re-design.

Table 2: Relationship among the HICM's concepts, processes, intervention components and outcome domains

Elements	Concepts	Processes examples (awareness, assistance alignment)	Intervention components: volunteerism, interprofessional care, technology, social networks, policy and engagement		
			Exemplar outcomes and indicators (triple aim)	Outcomes	Measures
Population	Risk prediction Use of population level data Scale-up and spread	Awareness of: • At-risk groups/populations Alignment with: • Population health data and work of other jurisdictions	Improvements in population health: • Self-reported health • Health risk prediction • Use of preventive and supportive care • Disease burden • Caregiver burden • Life expectancy • Premature death Improvements in care experience: • Preferred place for care/death Reduction in per capita cost of healthcare: • Total healthcare spending per person	Population health: • Self-reported health • Health risk prediction • Symptom management • Caregiver burden Care experience: • Satisfaction with care • Social connectedness and support	• McGill QoL—Revised • Family caregiver QoL • Euroqol 5D–5L • Personal well-being Index • RESPECT mortality risk calculator • Edmonton Symptom Assessment Scale • Palliative Performance Scale • Zarit Caregiver Burden Instrument • Satisfaction with care survey • Social disconnectedness scale
Community	Leadership Coalitions and partnerships Social responsibility Navigation	Awareness of: • Community needs, gaps, redundancies, and opportunities (citizens, organizational leaders, decision-makers, service providers) Assistance with: • Navigation of services • Volunteer training Alignment of: • Processes and tools • Community needs with resources	Improvements in community health: • Participation in leadership, coalitions and partnerships • Shared information and processes • Rates/numbers of volunteers/trained coaches Improvements in care experience: • Social connectedness and support Reduction per capita cost of healthcare: • Total healthcare spending per person		• Change in size/composition of social network (social network analysis) • Alignment of social network with patient/family needs (qualitative data)

(continued)

Table 2: (Continued)

Elements	Concepts	Processes examples (awareness, assistance alignment)	Intervention components: volunteerism, interprofessional care, technology, social networks, policy and engagement		
			Exemplar outcomes and indicators (triple aim)	Outcomes	Measures

Health system	Care organization
	Coordinated delivery design
	Decision support
	Health information sharing system
		Awareness of:
		• Risks/vulnerable groups
		• Service gaps and redundancies
		Alignment of:
		• Patient/family needs and services
		• Planning and organization of service organization around patient needs
		• Personal electronic health record (PHR)
			Improvements in care delivery:
			• Responsiveness of healthcare system
			• Care coordination
			• Organizational sharing of data, resources, processes
			Improvements in care experience:
			• Patient involvement in decisions about care
			• Preferred place for care
			Reduction in per capita cost of healthcare:
			• Total healthcare spending per person
			• Service use by patients and families
			  • Hospital readmissions and unnecessary ED use avoided
			  • Reduced premature admission to long-term care
				Care delivery:
				• Goal planning and attainment
				• Improved care coordination
				• Increased numbers of volunteers/trained coaches
				Per capita cost:
				• Hospitalizations and ED visits
				• Total healthcare spending per person
					• Care planning uptake
					• Number of advance care plans completed
					• Uptake of electronic PHR
					• New registrations
					• Feedback from organizations (qualitative data)
					• Number of trained coaches/volunteers
					• Frequency of unnecessary hospital admissions and ED visits
					• Cost of healthcare/person (comparison with population health level data)

Patient/care partner	Acting on person and family preferences needs and goals Empowering self-management skills and support	Awareness of: • Needs, preferences and goals Assistance with: • Volunteer coaching • Support with navigation • Engagement in self-management skills and activities • Social network analysis and network building	Improvements in health: • Self-reported health • Caregiver distress • Increased patient and family participation in health promoting/self-management practices Improvements in care experience: • Patient-centredness • Social connectedness and support • Preferred place for care		

With regard to system change, the HICM provides a roadmap for shifting the current system from one that is focused on managing complex health states to one that views the system through a health promotion lens (Catford, 2014). It is compatible with other health management approaches such as chronic disease, elder care and disability, and can enhance personalized care delivery by providing a framework for how new interventions can be layered onto existing systems without whole-scale start-up change. It addresses solutions to gaps in singular models: (i) quality indicators, (ii) public value measurement (collective benefit) and (iii) the relationships among health behaviour, public value and population health impact. Variations in the HICM's processes, outcomes and indicators allow for differences in policy, financing structures and the levels and types of health system resources in adopter communities and organizations.

Utility for system-level implementation research

There is growing international interest in advancing public health approaches to aging and end-of-life care (Kellehear, 2013; Sallnow *et al.*, 2016; WHO, 2017). This is evidenced by the launch of new CCs, the expansion of CC programming and CCs of practice. As described through the WECCC example, the HICM has particular utility in the evaluation of CC initiatives. While many jurisdictions around the world have embraced and are utilizing CC and other social approaches to care, their evaluation is methodologically challenging. As a unifying framework, the HICM addresses a critical gap in understanding how models can be operationalized to obtain robust scientific evidence, and that can inform health policy (Merzel and D'Affitti, 2003).

To foster system change, and enable broad society support, credible system performance evaluation remains a consistent and pressing need (Sallnow *et al.*, 2016). Learning health systems are emerging as entities that promote innovation, advance improvement science [Institute of Medicine (IOM), 2007] by providing the rigorous evaluation needed to improve care quality and strengthen healthcare systems (Children & Young People's Health Partnership, 2017). A learning health system is one in which science, informatics, incentives, culture and best practices are seamlessly aligned in programme delivery, and new knowledge is simultaneously generated, evaluated and fed back into the system to promote change and scale (IOM, 2007). WECCC is an example of a learning health system, and the HICM serves as its blueprint for increasing the

likelihood of achieving effective, scalable and sustainable population health level change (Friedman, 2014). As a framework, it supports the evaluative work by identifying the relationships among the inputs, processes and outcomes, and how they can be tested (De Silva *et al.*, 2014). It is also enabling our ability to organize and interpret the findings in meaningful ways that can then be applied to change practice (De Silva *et al.*, 2014) and improve quality (IOM, 2007). Simply put, as part of a learning health system, the HICM 'not only helps to keep us honest, it helps us progress' (Carpiano and Daley, 2006, p. 567).

Limitations

As an evolving framework, the HICM has a number of limitations. Although the model provides organization to the broad range of factors that require consideration when implementing population health interventions, it is conceptually complex. It does suggest propositions to guide scientific inquiry, but its ability to isolate the contributing 'dose' of an individual factor may pose methodological challenges depending upon design. Although the singular models included in the HICM demonstrate strengths, each has limitations that persist in our meta-model. For example, volunteerism and community service are not normative behaviours in all communities (Scharlach *et al.*, 2014). Collective action is more likely to occur in communities where citizens share social justice norms (Children & Young People's Health Partnership, 2017) are motivated toward action, and believe in collective efficacy (Friedman, 2014). Finally, health promoting behavioural change is difficult (MacColl Center for Health Care Innovation, 2003; WHO, 2018), and collective cultural change by a community will require shared focus, time and commitment (Gongaware, 2012; Kania and Kramer, 2013; van Zomeron, 2013).

CONCLUSION

Flexibility and integration of various existing and practical conceptual models, in tandem with programme development, can help promote the scalability and sustainability of complex interventions, such as CC approaches. The HICM can support the development and evaluation of population health level interventions, such as those applied in CCs. The HICM's concepts, processes, structures and outcomes can be adapted to address a community's healthcare context, needs, and goals for change. Adopters of the HICM should embrace a pragmatic and longitudinal approach to its application.

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