According to the Worldometers website (1), the world population is approaching 7.5 billion and annual births are exceeding deaths by about two to one. This expansion in population has been dramatic. The global population grew from 1.65 to 6 billion during the 20th century. Population changes on this scale, coupled with similarly dramatic changes in longevity, have profound implications for individuals, societies and our world. It represents a wonderful achievement by past generations, gifted to both ours and future generations as new challenges and opportunities. There is no doubt that there is much to do – and no easy or quick fixes – as we transition to larger and older populations. Healthcare is but one issue. High income countries are seeking solutions to largely fixed retirement ages and to health and social care systems that are currently inefficiently and ineffectively configured. The impact of population aging on healthcare expenditure varies between countries: age-related increases are much higher in Canada and the United States, much lower in Spain and Sweden (2). These variations reflect different provider systems and incentives but give confidence that some traction might be possible through an age-focused strategic response. A largely unacknowledged consequence of existing service configurations in high income countries is the considerable and widening inequality in health experience in later life (3). There is, in effect, a structural conveyor that produces unhealthy aging, causes unnecessary distress for individuals and families and causes excessive expenditure for healthcare funders.

A further consequence is “frailty creepage.” Frailty is the natural consequence of aging, when multiple physiological and organ systems function at the very limits of their tolerances. Creepage has been, and continues to be, the predominant reaction to frailty in health and care systems internationally.

Health and care services in high income countries were developed to provide a response to infections, trauma, acute illness and surgical repairs. Then along comes “Mrs. Smith” with her five long-term conditions and frailty, for whom the national guideline “best practice” is to offer at least 10 medicines, 9 lifestyle modifications, 8 to 10 primary care appointments per year, 8 to 30 psychosocial interventions, smoking cessation and pulmonary rehabilitation (4).

Clearly ridiculous, but this is the lived reality of applying a healthcare system designed for situations that are largely single, bounded and medically understandable to predicaments that are multiple, unbounded and medically fuzzy: that is, people with frailty. We have muddled along and tolerated frailty creepage in our health and care systems. Some adaptations and innovations have been possible; most notably, an entirely new specialty — geriatric medicine — has been spawned. But the creepage has now reached a completely new dynamic in which our health and care systems are toiling: offering a largely undifferentiated service both to fit older people and old people living with frailty. We urgently need smarter, more differentiated health and care systems. The collection of five frailty-themed papers published in this edition of the Journal is therefore particularly welcome.

As Rolfson and colleagues (5) point out, we have over two decades of conceptual thinking and field research relating to frailty. Whether we consider frailty as a syndrome or a health state, we are fortunate to have an embarrassment of assessment tools available to us. The time has come to deploy these tools in mainstream care. Indeed, not to do so will continue to expose older people with unrecognized frailty to unintended harms from the panoply of modern medicine interventions. The consequence is poor outcomes that diminish quality of life for the individual and are expensive to healthcare funders. So a frailty identification tool or, more reasonably, frailty tools (the needs of an oncologist are likely to differ from those of a primary care practitioner) must become a routine and embedded component of all new health encounters with older people.

There are, of course, unintended traps and pitfalls aplenty. The ethical and legal implications of a screening process for frailty are discussed in detail by Reid and colleagues (6). We risk nourishing a new, covert form of ageism in which older people identified as frail might be subjected to stigma, paternalism and discrimination: a real sense that individual autonomy is diminished. Safeguards might be drawn from two quarters. First is the purposeful and active involvement of older citizens in designing new services. Note that the term “frailty” is totally rejected by older people themselves (7), so a key step will be to develop a shared language. The obvious common ground is that of sustaining functional independence and social connectedness in later life — aspects that are highly valued by older people (7) and that neatly prioritize holistic care models over disease-based care models. Secondly, screening for frailty...
should not be casually introduced as a standalone process. To do so risks the label of frailty becoming a barrier rather than a gateway to better and higher value care. There is a deceptively obtuse asymmetry here in which the quick win of routine frailty screening (relatively easy to introduce) has a seductive appeal that displaces service innovation and redesign (an altogether tougher challenge).

Indeed, it may be tempting for healthcare planners to be drawn into “a little more of the same”: a bit more acute care efficiency, a few more long-term beds, a few more primary care staff. All laudable and necessary, but insufficient to address the now critical situation that is the consequence of the culmination of years of frailty creepage. Even the commonly articulated approaches (better chronic disease management, better dementia care, better prevention of falls, better care for urinary incontinence, etc.) will potentially spawn an array of silo-based services that salami-slice the older person. These are the antithesis of the holistic care model required by older people with frailty, as discussed by Andrew and colleagues (9). They take a social ecology perspective in which the older person with frailty is situated in a wider context: the individual, family, friends, caregivers, institutions, neighborhoods, communities and wider society. This has obvious parallels with the disability movement of the 1970s and 80s, in which disability became understood not simply as a consequence of impairments in an individual but located in the wider social context. This is an important conceptualization because it implies that putting all our eggs in the healthcare basket is unlikely to be successful.

The possible responses to frailty are developed further by Grimes and colleagues (10). They offer a range of policy recommendations, grounded in a literature review and interviews with key informants. These recommendations include the need to develop new funding models that more fully support the type of personalized “more than medicine” care suggested by Andrew et al (9). Activity-driven, fee-for-service approaches will need to be replaced by, for example, capitation-based models. These funding models have an advantage in that they require professionals, services and agencies to collaborate and coordinate their work. A further advantage is that the funding can be directly related to measured outcomes and form the basis of a contract with a provider or an alliance of providers. The International Convention on Health Outcome Measurement recently offered a consensus-based solution to the question of what outcomes might be measured for older people’s services (8).

Finally, Downar and colleagues (11) address the perplexing problem that the most common cause of death in high income countries is frailty (12) but the gateway to palliative care services is still largely through a cancer diagnosis. Because the greatest expenditure for older people occurs during the last year of life (13, 14), driven in the main by a sequence of admissions to hospital, there is obvious scope to implement a more robust proactive care model. This again will require partnership working with older people and their families.

We have reached a tipping point in our health and care systems internationally. Years of frailty creepage and muddling through are finally catching up with us. We need to be bold and purposeful. These five frailty-themed articles provide evidence-based and common sense responses to achieve higher value services for older people living with frailty.

Conflict of interest: None

References


**IMPLEMENTING FRAILTY MEASURES IN THE CANADIAN HEALTHCARE SYSTEM**

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ON BEHALF OF CANADIAN FRAILTY NETWORK

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**Abstract:** Canadian healthcare is changing to include individuals living with frailty, but frailty must be better operationalized and better framed by sound data standards and policy. Frailty results from deficit accumulation in multiple body systems, with exaggerated vulnerability to external stressors. A growing consensus on defining frailty sets the stage for consensus on operationalization and widespread implementation in care settings. Frailty measurement is not yet integrated into daily clinical practice in Canada. Here, we will present how this integration might occur. We hope to demonstrate that implementation must appeal to inter-professional practice needs in different settings or circumstances. In some settings, methods for frailty case finding are expected to evolve as deemed to be most appropriate to the front-line users. In this “hands-off” approach, care providers, supported by emerging knowledge translation on frailty operationalization, would be informed by their setting and local practices to establish patterns of ad hoc case finding and component definition of frailty. This more nimble case finding strategy would be opportunistic, and would appeal to expert clinicians and self-directed teams who emphasize an individualized health care experience for their patients. In other settings, we can shape frailty case finding by building care algorithms around existing standardized practices and data repositories, leading to a systematic application of frailty measures and a more coordinated process of component definition and care protocols. Here, recommended instruments and data standards must be endorsed by health networks locally, provincially and nationally. The interRAI suite of assessment instruments has pan-Canadian standards in place and its pervasiveness makes it the most obvious starting point, especially in home care and long-term care. We anticipate the evolution of an integrated model informed by stakeholders and settings, where policy makers focus on system supports for frailty case finding, while front-line clinicians use case finding strategies to pinpoint and act on key frailty components.

**Key words:** Frailty, measurement, case finding, standards.

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It is difficult to overstate the importance of employing meaningful frailty criteria in the Canadian healthcare system. Our healthcare system was designed to respond to acute illness in otherwise healthy individuals or to aid those with a single stable disease or disability. However, frail older adults typically have multiple interacting health issues and, when they become acutely ill, they manifest illness in atypical ways. With a rapidly expanding population at risk, policy makers, researchers and healthcare providers must understand the characteristics of older adults who live with frailty. An understanding of frailty and guidance on how to respond must be better communicated so that its impact on health-related decisions can enter everyday dialogue and so that improved models of care can be re-imagined and integrated. To realize this, the way that frailty is operationalized in health records and employed to inform care practices will need to be fit to purpose.

Frailty is a state of exaggerated vulnerability, resulting from accumulation of deficits in multiple body systems, and it is manifest as a multidimensional syndrome (1). As such, frailty is both a state of vulnerability and a clinical syndrome (2). This duality in the nature of frailty helps to explain historical challenges in settling on a single definition or measure, but equally informs the discussion on whether case finding ought to be opportunistic, systematic or both.

The state of frailty develops gradually over the life course as deficits accumulate. A robust individual possesses a repertoire of homeostatic responses to stressors, thus maintaining their independence. As more deficits accumulate, the impact on independence is minimal as long as other assets are sufficiently abundant to compensate. Eventually, the compensatory repertoire narrows, hastening accumulation of more deficits and leading to emergence of apparent vulnerability and frailty. Clinical instincts alone may be inadequate to recognize early vulnerability and mild frailty or to anticipate or prevent associated adverse outcomes. Expert clinicians are trained to look for more discrete illness scripts and may only recognize frailty after external stressors are at play and when the consequences are in full force. This is why augmentation of...
Clinical instincts with frailty measures that capture the nature and severity of frailty, including its silent early state, hold such promise.

In the eyes of healthcare providers, the illness script of frailty is a clinical syndrome rather than a quiet state of vulnerability. The syndrome may be more reductionist, as in the well-known Cardiovascular Health Study (CHS) physical phenotype model (3). In the same family of measures, an even more simplified case finding approach is gait speed (4, 5). Judgment-based measures such as the CSHA Clinical Frailty Scale (6) allow clinicians to anchor their intuition in a reliable measure. Multidimensional measures of frailty are the most authentic clinical operationalization of the full syndrome of frailty.

In past years, very few frailty measurement options were available, of which the CHS Frailty Phenotype (3) and the CSHA Frailty Index were most utilized by researchers and certainly best known. Neither of these have found widespread use in clinical practice, however. Three systematic reviews (7-9) have compared the many other frailty tools that exist, and no consensus has yet been reached on a single measure superior to the others.

The high prevalence of frailty in populations seen by specialized geriatric services or in other chronic care settings obviates the need for case finding. However, when frailty is discovered in mixed populations with a spectrum from fitness to frailty, clinical teams can be empowered to better define the issue, address the particular components and, as needed, seek further guidance from experts. Examples here include primary care, home care, emergency care and acute care. In such settings, there is a need for simple, acceptable and trustworthy measures. Frailty measurement may motivate meaningful person-centered decisions (Table 1). For example, identifying frailty in clinical settings would permit earlier access to innovative and personalized processes of care, adaptation or avoidance of inappropriately aggressive medical treatments, and meaningful discussions with individuals at any stage of frailty about their overall goals of care.

Table 1
How Frailty Identification May Inform Person-Centered Decisions

| * Leads to early interventions to prevent or slow further decline |
| * Prompts meaningful discussions regarding goals of care |
| * Informs prognosis to assist in care planning well before end of life |
| * Allows early access to innovative care processes |
| * Ensures that appropriate medical treatments proceed while accounting for additional hazards |
| * Emphasizes choice for less invasive but appropriate medical treatments |
| * Leads to avoidance of inappropriately aggressive medical treatments |
| * Provides a helpful way to determine the impact of therapies |

Frailty is a latent variable, and its existence must be inferred by measuring other more observable variables such as a physical characteristic, a performance measure, a biological marker or responses to a series of questions. Hogan et al. (10) proposed a taxonomy to better group candidate measures for frailty. A comparison of the characteristics of frailty measures relevant to widespread clinical usage is presented in Table 2. Table 3 compares the requirements of these measures and their proposed suitability for opportunistic and systematic use. Clegg et al. (11) emphasized the need to develop efficient methods to detect frailty and measure its severity in routine clinical practice. These included judgment-based measures, physical performance-based measures, multidimensional measures and the electronic frailty index.

Judgment-based measures presuppose that the operator, informed by clinical information, is able to make an independent clinical judgment about the presence and degree of frailty (12). This strategy formalizes traditional intuition about frailty in clinical settings where rapid decisions need to be made by busy clinicians. A judgment-based tool makes sense for rapid opportunistic case finding as an adjunct to a clinician’s assessment. As such, judgment-based measures are most useful to competent operators who are not necessarily experts in the care of older adults. Evidence about the psychometric properties of these measures is lacking, with the notable exception of the CSHA Clinical Frailty Scale or CFS (13). If the target population has a higher prevalence of frailty, a more standardized approach to frailty case finding is preferred, as operators in such circumstances may not be qualified to rely on clinical judgment.

Discrete physical performance measures such as gait speed, grip strength and chair stands have been used as surrogates for frailty and have the appeal of simplicity and speed. Thus, less-experienced operators can learn to perform these tests quickly in a variety of settings. One caution with performance-based measures is the possibility of false positives in acutely ill patients with sudden changes in physical function. The question of diagnostic accuracy for performance measures was settled for both gait speed and the “Timed Up and Go” test, which both show excellent sensitivity and moderate specificity (14) against the CHS phenotype as the criterion standard. Performance-based measures could be used opportunistically or systematically. Because the content validity of performance-based measures is poor, these measures have a role in case finding and prognosis, but not in grading severity or capturing the nature of frailty or its components. Despite widespread adoption of physical frailty measures such as the CHS Frailty Phenotype in research settings, the uptake has been disappointing in clinical settings. This may be because of the need for a dynamometer, the need for training or the narrow scope. In some ways, the physical performance measures have inherited this role of case finding in physical frailty.

Multidimensional measures are designed to capture the richness of frailty and align closely with the emerging concept
of “intrinsic capacity” as recently articulated by the World Health Organization (15). These measures not only case-find and grade frailty but also illustrate the component domains that are relevant to individuals. These components may include motor (gait, strength, balance), sensory, cognitive and psychological aspects. Even functional ability or external factors such as social variables may be included in such a measure. These have good content validity and many have been shown to be valid and reliable in clinical settings, making them useful for case finding by non-experts. Administration time tends to be short and minimal training is required. When it is desirable to first screen for frailty, then drill down to the components(s) of interest, multidimensional scales add real value for clinicians. However, these scales are cumbersome when applied to existing databases for research or policy purposes because the items are often challenging to reconstruct. Examples in this category are the EFS (16), and the FACT (17, 18). These measures could be used opportunistically or systematically, as the operator need only be familiar with the clinical setting, and the application could be in target groups at immediate high risk or in vulnerable populations with a higher prevalence.

Finally, the CSHA Frailty Index is by far the most flexible for research and policy applications. It has not yet found widespread use in clinical settings, perhaps because it lacks content that many clinicians expect and requires at least 30 health status items in the database that cover a range of systems and that increase (but do not saturate) with age. Clinicians may also have found it cumbersome to employ a prior database of searchable deficits that meet specific criteria. A promising solution is the electronic Frailty Index which can be integrated into existing electronic medical records and administrative databases, then presented to clinicians with prompts as a decision aid (19-21). This method has been employed in different settings, including home care (19), acute care (20) and primary care (21).

So far, we have highlighted the frailty measures that could be used opportunistically or systematically in clinical practice. We now ask what would be required to include measures of frailty in electronic health records and in the full range of care

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**Table 2**

Characteristics of Frailty Measures by Category

<table>
<thead>
<tr>
<th>Frailty Measure Category</th>
<th>Example</th>
<th>Requirements</th>
<th>Suitability for Opportunistic Use</th>
<th>Suitability for Systematic Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Judgment-based Measures</td>
<td>Clinical Frailty Scale</td>
<td>Prior Clinical Assessment</td>
<td>+++</td>
<td>+</td>
</tr>
<tr>
<td>Physical Performance Measures</td>
<td>Gait Speed</td>
<td>Training on administration and interpretation</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Physical Frailty</td>
<td>Frailty Phenotype</td>
<td>Training on administration and interpretation</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Multidimensional Frailty</td>
<td>Edmonton Frailty Scale</td>
<td>Training on administration and interpretation</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Frailty Index</td>
<td>Electronic Frailty Index</td>
<td>Training on interpretation</td>
<td>+</td>
<td>+++</td>
</tr>
</tbody>
</table>

Characteristics: + (present, advantageous); - (absent, disadvantageous)

**Table 3**

Suitability and Requirements of Frailty Measures by Category for Different Clinical Settings

<table>
<thead>
<tr>
<th>Frailty Measure Category</th>
<th>Example</th>
<th>Requirements</th>
<th>Suitability for Opportunistic Use</th>
<th>Suitability for Systematic Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Judgment-based Measures</td>
<td>Clinical Frailty Scale</td>
<td>Prior Clinical Assessment</td>
<td>+++</td>
<td>+</td>
</tr>
<tr>
<td>Physical Performance Measures</td>
<td>Gait Speed</td>
<td>Training on administration and interpretation</td>
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<td>++</td>
</tr>
<tr>
<td>Physical Frailty</td>
<td>Frailty Phenotype</td>
<td>Training on administration and interpretation</td>
<td>+</td>
<td>+</td>
</tr>
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<td>++</td>
</tr>
<tr>
<td>Frailty Index</td>
<td>Electronic Frailty Index</td>
<td>Training on interpretation</td>
<td>+</td>
<td>+++</td>
</tr>
</tbody>
</table>

Suitability (+++ Suitable ++ Adaptable + Challenging)
practices and protocols that support the intended population.

The status quo is to simply allow heterogeneity in the operational definitions and measurement tools used, such that preferred choices by clinicians vary by practice or care setting. Typically, the decision on whether to use a particular frailty instrument in a clinical setting would be judged opportunistically by the clinician and team to inform, but not to make, decisions. Here, clinicians and teams are using frailty measures as “part of the work-up”, the way they might use blood tests, imaging or other bedside instruments to refine diagnostic reasoning from initial presentation to formulation to care plan. However, if frailty is to be used for past and future comparisons, the heterogeneous use of frailty tools might fail to capture the ever-changing health state of the individual, and meaningful frailty information might not be carried from one setting to the next.

Table 4
Common Component Domains in Measuring Frailty as a Syndrome

<table>
<thead>
<tr>
<th>Component Domain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nutritional Status/ Weight Loss</td>
</tr>
<tr>
<td>Physical Performance (Gait Speed, Grip Strength)</td>
</tr>
<tr>
<td>Physical Activity</td>
</tr>
<tr>
<td>Subjective Energy Levels</td>
</tr>
<tr>
<td>Number of Comorbidities</td>
</tr>
<tr>
<td>Mood</td>
</tr>
<tr>
<td>Cognition/ Motor Processing</td>
</tr>
<tr>
<td>Urinary Incontinence</td>
</tr>
<tr>
<td>Activities of Daily Living</td>
</tr>
<tr>
<td>Medication Management</td>
</tr>
<tr>
<td>Social Support</td>
</tr>
<tr>
<td>Self-rated Health</td>
</tr>
</tbody>
</table>

The challenge with the purely opportunistic approach is that the majority of frail older persons likely receive care or support services from a range of clinicians or sectors of the health system. Within a relatively short time, such a person may be in contact with a primary care provider, home care agency, emergency department, acute care hospital and long-term care home. If clinicians in each of those settings chose a different frailty scale, the costs and assessment burden on the person could rise, communication between settings could be inefficient, allocation of resources could be inconsistent and the use of change in frailty levels as an outcome measure could be difficult. Any inferences about the care experience of older persons with frailty would be frustrated by questions about the comparability of the groups. Hence, when considering frailty from both a policy and health research perspective, the need for agreement on a common standard measure of frailty or bundle of interacting measures becomes apparent.

Another gap in this approach is that many front-line care providers, having identified frailty, do not necessarily know how to respond to it or to problems within its component domains. This gap lies within the aforementioned larger challenge on how to respond to different frailty measures across the continuum of care. Some degree of heterogeneity in case finding by setting and care provider is inevitable when frailty is first considered. Frailty case finding can enhance existing future processes of care, such as emergency room visits in both general and personalized ways. The British Geriatric Society published Best Practice Guidelines (22) that proposes the use of frailty case finding in all older persons followed by a holistic medical review based on the principles of Comprehensive Geriatric Assessment. A simultaneous call for widespread changes in the British Health Care System to fit the aging population was applauded here in Canada with a proposed shift in the acute care hospital to other models of care (23). All individuals with frailty stand to benefit when their primary care team uses frailty as a trigger for appropriate care practices (Table 1). Persons who are identified as having more severe frailty or frailty associated with significant complexity may also undergo a comprehensive geriatric assessment by a specialist. In a step beyond case finding, a multidimensional measure could then help define particular components (Table 4, Figure 1), which in turn motivate an individualized care plan that could be physically or electronically carried from one setting to the next.

Figure 1
An Integrated Model for Identifying Frailty

If standard measures of frailty were employed across care settings, incorporating frailty in a comprehensive electronic health record would become feasible. This would provide the information needed to develop effective national responses to frailty as has been done through previous public reporting initiatives to improve the quality of long-term care (25). Achieving a uniform national consensus on the operationalization of any concept as complex as frailty will be difficult. However, there are many other factors to address before such a tool can be used both at the individual level by clinicians and at the population level by managers and policy makers.
The way to national standards that would meet the needs of care providers, policymakers and scientists would include at least two major efforts. The first is a broad-based consensus process on a core data set, similar to the OMERACT group that for 20 years has done this for various rheumatologic conditions (26), or the even more broadly scoped COMET initiative (27). While processes such as this would raise trust by front-line users, the transition from optional ad hoc local uses of clinical scales to routinely administered information standards that are deployed to support performance measurement systems across the continuum of care also requires attention to a number of considerations (28-35). These include:

1) Standardization of measurement. Clear definitions of each item in the instrument are needed, including time frames for observation, inclusion and exclusion criteria, strategy for ascertaining responses and anchor points for response values.

2) Specifications of data standards and coding rules. Once measures are precisely defined, and after appropriate licensing, those measures need to be translated into data standards that can be used by software vendors selling products to support the instrument and employ data warehouses to receive, analyze and report on those data.

3) Training. Any effort to employ a common standard as a national measure of frailty will depend heavily on an effective strategy to support ongoing education of the clinicians responsible for completing the scale and of stakeholders who use those data to inform decision making. The education strategy must be flexible, as updated coding standards may be implemented from time to time. Without such a training strategy, data quality may deteriorate over time and the utility of the data may fall for all stakeholders.

4) Reporting standards. If the data are to be aggregated for use at the organizational, regional, provincial or national level (e.g., for quality reporting) it is important that common reporting standards be employed. These should also have mechanisms for preserving the capacity to maintain comparisons over time.

5) Cross-sector consistency. Because frailty is pervasive across the continuum of care, it is not enough to have a common standard measure within one sector alone. Instead, there has to be an ability to compare frailty consistently across all the major settings that provide services.

6) Data sharing. The transitions through various degrees of frailty lead to encounters with different sectors of the health system over time. To obtain a longitudinal view and to reduce redundant reassessment, a mechanism for sharing data between clinicians and service agencies involved in the individual’s care is essential. Records linking multiple comparable measures of frailty over time provide a sense of the baseline and clinical trajectory. This means that all parties must have convenient access and trust the assessments of frailty done by others.

7) Timing of initial and reassessments. Frailty status can gradually change over time. Therefore, it is important to standardize when frailty should be first measured and reassessed. For example, individuals transitioning from one care setting to another may require timely reassessment.

8) Data quality. There is a considerable difference between the quality of data obtained in highly controlled research studies and data that are recorded by clinicians as part of normal, day to day practice. Therefore, it is essential to have continuous, real-time mechanisms available to ensure that data from frailty assessments continue to measure what they are intended to measure and that they do so reliably. Such a system would allow rapid identification of and response to erroneous assessment practices that may emerge over time.

9) Key stakeholders. Any effort to establish a national common standard for measuring frailty that becomes part of the electronic medical record should engage at least three major stakeholders: (a) provincial and territorial ministries of health under whose auspices provincial implementation of a standard may be undertaken; (b) the Canadian Institute for Health Information (CIHI), which manages numerous national reporting systems for health data across the full continuum of care and (c) Canada Health Infoway, which provides national support and standards for the electronic medical record.

To front-line clinicians, the need for consensus statements on a core dataset and the additional standardization, training and engagement processes would seem to require far too much time. The rising demographic of octogenarians is now upon us, so we cannot afford to wait for a decade. We will now provide practical suggestions on how to move deliberately yet expeditiously, meeting the immediate needs of clinicians who are starting to use opportunistic frailty measures, while also addressing the need for trusted and acceptable measures with strong psychometrics, implemented systematically across our nation.

Recommendations

1. Construct frailty measures from existing electronic databases. Single case finding measures such as gait speed or multidimensional components may already be collected. For example, in critical care settings across Alberta, the CFS has been collected for all admissions for a few years. Likewise, in home care and long-term care settings across Canada, interRAI assessments already capture the key components of frailty. It has already been demonstrated that deficit accumulation can be extracted from existing electronic databases across sectors and a frailty index calculated, provided that the candidate items in each database adhere to appropriate definitions. Existing clinical information systems could be used with supplementary items, if needed, to derive frailty algorithms based on relevant domains that are already measured. If an existing standard already has the items that most frailty researchers agree on, it may be possible to use that data source to derive frailty scores from the existing standard. For widespread adoption, we should strive to select frailty data that simultaneously meets the needs of front-line clinicians, policy makers and researchers. Supporting this recommendation is evidence in systematic
reviews (7-9) that frailty measures have many component domains in common (Table 4) and many also have common properties (Table 5), though the specific items and coding rules may differ (36).

Table 5
Common Properties of Frailty Measures

<table>
<thead>
<tr>
<th>Property</th>
</tr>
</thead>
<tbody>
<tr>
<td>Right-skewed density distribution</td>
</tr>
<tr>
<td>Nonlinear increase with age</td>
</tr>
<tr>
<td>Dose-response relationship with five-year mortality</td>
</tr>
<tr>
<td>Sex differences, with women having higher frailty scores but better survival</td>
</tr>
<tr>
<td>Actual scores never reach the theoretical maximum</td>
</tr>
</tbody>
</table>

2. Expand systematic frailty measurement in Home Care and Long-Term Care using interRAI. In the last two decades, the interRAI suite of assessment instruments has emerged as the pan-Canadian standard for home care and long-term care, with implementation in eleven Canadian provinces and territories (Table 6, 37). In addition, interRAI instruments for mental health (inpatient and community), community support services and palliative care have been implemented in one or more of these provinces. Several provinces have already implemented or begun to implement interRAI instruments to assist intake into home care from hospital settings or adapted versions of the home care instrument to support placement into long-term care from hospital settings. Based on CIHI data holdings by 2016, over 9.6 million interRAI assessments had been done on over 3.3 million Canadians in 1,827 different care settings, and about 600,000 assessments are added each year (Table 7). These instruments have already been designated as Canadian Approved Standards for the electronic medical record by Canada Health Infoway, and CIHI supports three national reporting systems for the home care, long-term care and mental health instruments.

All the domains described by Sternberg et al. (7) are addressed in the interRAI suite of instruments, and at least four frailty algorithms have already been developed for these instruments. Frailty has been measured using the interRAI Home Care Assessment in the general home care population (19) and in people with intellectual disabilities (38). Hubbard et al. (20) used the interRAI Acute Care assessment to measure frailty in acute hospitals. All three groups used interRAI data to create frailty index scores matching the framework put forward by Sternberg et al. (7). Using a cross-walk algorithm, Armstrong et al. (19) coded a multidimensional frailty scale using interRAI home care assessment items. Luo et al. (39) used data from the RAI 2.0 for long-term care to derive the FRAIL-NH algorithm for long-term care. Finally, the interRAI CHESS scale (40-42) provides a clinician-oriented frailty measure that predicts mortality in diverse community-based and inpatient populations. Newer interRAI instruments include a gait speed measure or grip strength.

It should be noted that interRAI assessments are used on only a limited scale in acute hospital settings, except perhaps in assessments for individuals in hospital awaiting placement into long-term care (43) or for those persons being discharged

Table 6
Use of interRAI Assessment Instruments and Screeners in Canada

<table>
<thead>
<tr>
<th>Instrument</th>
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<th>NWT</th>
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<td>RAI 2.0 (Long-Term Care)</td>
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<td>interRAI Long-Term Care Facility</td>
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<td>interRAI Home Care</td>
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<td>interRAI Community Health Assessment</td>
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<td>interRAI Palliative Care</td>
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<td>interRAI Community Mental Health</td>
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<td>interRAI Emergency Screener for Psychiatry</td>
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<td>interRAI Brief Mental Health Screener</td>
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<td>interRAI Intellectual Disability</td>
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<td>interRAI Child/Youth Mental Health</td>
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<td>interRAI Acute Care</td>
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<td>interRAI Quality of Life</td>
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○ - Mandated across province/territory; ◊ - Recommended or mandated regionally only; * - Pilot or local implementations only; ○ - Research use
to home care from hospitals (44). The second notable gap in use of interRAI assessments in Canada is in primary care. Here, only small scale studies have been done with the interRAI Contact Assessment, and a recent larger study used the interRAI Assessment Urgency Algorithm to screen for frailty in primary care settings (45). Further research is needed to better define why primary care settings have proved to be challenging contexts for the interRAI approach. Promising opportunities would include the electronic Frailty Index or other rapid opportunistic case finding measures such as the CFS, gait speed or a multidimensional tool.

3. Explore a cross-sectoral approach of frailty assessment in acute and primary care. For both acute care and primary care, a mixed approach of new assessment of frailty in some contexts and data sharing related to frailty in others may be most sensible. For example, given that home care is an important sector adjacent to both acute care and primary care, sharing of assessments by home care professionals with their counterparts in these other settings should be of paramount importance. Many clinical problems encountered by home care assessors may be best addressed by enhanced communication and partnership between home care and primary care providers. For individuals admitted to acute care, recent assessments by home care professionals can be an essential source of information about the individual’s premorbid status. Indeed, the point of entry into acute care may not be the best starting point for assessment of frailty when the individual’s current condition is highly changeable.

4. Develop mechanisms to imbed Electronic Frailty Indices across sectors. Like InterRAI, the Frailty Index also has a family of scales that could be used in association with one another in both opportunistic and systematic ways. Using Frailty index methodology, the FI-CGA was derived from a standardized dataset of comprehensive geriatric assessments and demonstrated graded prediction of distal outcomes such as death and institutionalization (46, 47). Both a social vulnerability index (48) were developed on this same model. In front-line care, the Clinical Frailty Scale (13) is closely associated with the Frailty Index in predicting mortality or the need for institutional care in community settings (6) and mortality, disability and cognitive decline in long-term care settings (50). It has also been used to predict morbidity and mortality in acute care settings such as intensive care (51).

The CSHA Frailty Index itself is the only stand-alone frailty measure that has been shown in various national and international settings to be easily derived from existing clinical and research databases (21, 52) including those based on interRAI assessments. It has been demonstrated that, regardless of the dataset, there is a predictable logarithmic accumulation of deficits (53) despite the use of very different numbers and types of variables in different datasets. Increasing degree of frailty is highly associated with an increased risk of death (54-56). By definition, the CSHA Frailty Index lacks specific emphasis on particular component domains of frailty but, like other scales, it covers the common characteristics (Table 5; 57) and can be derived directly or indirectly from comprehensive geriatric assessment, including interRAI assessments (19, 20, 58). Next to the CHS Frailty Phenotype, the CSHA Frailty Index is the most commonly cited measure for frailty. However, the Frailty Index is dependent on the existence of a database of appropriate clinical items and its content validity is poor. It could not be used alone to screen for component domains of frailty nor to predict outcomes specific to these components.

Frailty as a Multidimensional Construct

If we accept that existing comprehensive assessment systems can be used as data sources to derive frailty algorithms, a remaining issue is whether frailty should be operationalized as a single construct or as an umbrella term for risks of different adverse outcomes in multiple domain areas.

Simple frailty measures can predict adverse future outcomes such as death, disability, institutionalization and hospitalization (7). The clinical value is estimating prognosis.
The challenge with those outcomes presumed to be related to frailty is that they may not all have the same causal pathways or sets of risk factors. For example, within interRAI, the CHFSS scale is highly predictive of mortality in home care, long-term care and post acute hospital settings (41), but it is not an especially strong predictor of long-term care placement. Conversely, the Method for Assigning Priority Levels (MAPLe) has been validated as a strong predictor of long-term care placements and caregiver distress in Canada and other countries (59-61), but it tends not be associated with hospitalization (62).

In other words, there is considerable risk that single scores to measure frailty as a unidimensional construct may underperform in predicting specific adverse outcomes of frailty compared to algorithms that are intended to best predict only one or closely inter-related outcomes. This dilemma expands the scope of the problem in case finding for frailty. We may reasonably accept that single, unidimensional measures can predict a variety of poor outcomes related to frailty and motivate a more full multidimensional assessment. On the other hand, if one prefers to maximize the prediction of each of an array of adverse outcomes, the approach should also assign independent meaning to the various components of frailty measured.

An Integrated Model

Frailty measurement itself appears to be no less complex than the entity it is intended to capture. To help move forward, we propose an integrated approach (Figure 1) that starts with rapid case identification using judgment-based measures, physical performance-based measures or an electronically derived Frailty Index. Depending on the prevalence of frailty in the population and the readiness of the care setting, this case finding might be a standard practice for an identified risk group, or it may be an opportunistic practice as a part of dynamic clinical decision making. Opportunistic case finding makes sense in primary care or acute settings where frailty is less frequent but must be discovered. As the prevalence of frailty rises in the target population, the case finding should be more standardized, such as in a home care or assisted-living setting. Either way, when a better understanding of the nature of the frailty is desired, the subsequent use of a multidimensional tool is recommended to define component issues such as cognition, balance or nutrition, which in turn may prompt appropriate decisions such as comprehensive geriatric assessment (see Table 1). Finally, the impact of clinical decisions and treatments in frail individuals can be tracked using various measures appropriate to the setting.

We affirm the growing burden of frailty in the Canadian healthcare system and hope to draw attention to the sophisticated and complex array of options for its measurement. We call for national standards in measuring frailty that adhere to the highest expectations of data stewardship. We certainly continue to promote the heterogeneous use of frailty case finding instruments that are fit to purpose for settings and individual circumstances. However, we also suggest a pragmatic approach to national standards of measurement building on existing electronic platforms. Frailty can be derived from the interRAI standards already used throughout Canada in many settings, including primary care, home care, long-term care, acute care and emergency care. Complementary to this, frailty can be captured using health records data to derive the Frailty Index where interRAI assessment data are not available.

**Conflict of interest:** Dr Rolfson is the original author of the Edmonton Frail Scale and holds the copyright. The EFS is not available for proprietary use. Dr Hirdes is the senior Canadian Fellow and a board member of interRAI.

**References**
IMPLEMENTING FRAILTY MEASURES IN CANADIAN HEALTHCARE


Whether we think of a vulnerable isolated senior living alone in an inner city apartment and teetering on the edge of dependence, a couple aging in place in rural Canada, or the policy landscape that supports (or further disadvantages) informal and formal caregivers, the social context of frailty clearly matters. This discussion paper aims to explore both the social context of frailty (how social factors contribute to and contextualize frailty) and the broader societal impact of frailty (implications for policy and planning), including impact for Canadian healthcare systems.

Frailty can be defined and measured in many ways; the details of this debate are beyond the scope of this paper but are addressed in other papers in this series (1). For the purpose of this discussion, frailty is defined as a state of vulnerability with contributors across multiple domains (2, 3). For simplicity we frame our discussion around frail older adults, although many of our points and recommendations are relevant to older adults who are not yet frail but who are at risk of frailty.

When we think about frailty, our focus often rests on assessing frailty in individuals and considering its impact on their health outcomes. However, frailty does not exist in isolation. The social circumstances of a frail older adult will have important implications for both the experience and the outcomes of frailty, and will be significant contributors to overall vulnerability. Here, social circumstances can be understood both as risk factors and as practical facilitators or barriers to intervention and support (as would be encountered, for example, in the course of planning discharge from hospital). From a systems perspective, frailty has significant implications for health and social care policy, and strikes to the core of discussions around health systems’ sustainability and design.

Given this complexity, consideration of the social implications of frailty benefits from (and indeed demands) a broad perspective that incorporates these various levels of influence. A social ecology perspective is a useful starting point to frame discussion of these influences and of resulting social vulnerability. The ecological perspective considers the social impact of frailty at many levels, from the individual, through relationships with family and friend caregivers, institutions, health systems, neighborhoods and communities, to society at large. We conclude by arguing that attention to these issues at a policy level is critical. We identify three target actions: 1) Social dimensions of frailty should be systematically considered when frailty is assessed. 2) Action is needed at the level of policies and programs to improve support for caregivers. 3) Policy review across all portfolios will benefit from a social frailty lens.

Key words: Frailty, social, social vulnerability, social environment, aged, frail elderly.
Social and Societal Implications of Frailty at the Level of Individuals

Frailty is of importance to the healthcare system, caregivers and care providers. However, frailty is most important for older people themselves. Regardless of the definition and model of frailty considered, being frail is a state of vulnerability to numerous adverse health outcomes (7). Frailty predicts mortality in population-based settings (8, 9, 10) and clinical settings (11, 12), along with functional decline (13) and institutionalization (9, 14). Frailty is also associated with depressive symptoms (15), loneliness (16) and reduced life satisfaction (17). However, the causal nature of these associations remains unclear because relatively few long-term prospective studies have been completed. For example, frailty may be a risk factor for depression; conversely, depression may contribute to changes in health that worsen frailty. Perhaps most likely is a vicious cycle of worsening frailty causing depression and changes in health habits that reinforce the cycle. Regardless of the causal pathway, the association is important for clinicians. Addressing all relevant domains – psychological, social and medical – is key in the care of older adults (18). For frail older adults, this often necessitates a full team for coordinated health and social care.

Note also that, although an association exists between frailty, loneliness (16) and life satisfaction, a substantial proportion of older adults maintain high levels of life satisfaction. In the Wolverhampton Inquiry, Sheldon noted that: “While those in the normal [health] plus group are remarkable for their general vigour and hardness, those in the subnormal group are sometimes even more remarkable for the indomitable persistence with which they attempt to carry on in spite of sometimes severe or painful defects of health (p13).... In considering the physical state of the old people, one of the dominant impressions formed during the survey was of their almost incredible determination and ‘guts’. They virtually never struck their flag in the face of physical defects that as a younger individual one would have thought impossible to over-ride, but made the best of things and kept doing as well as they could.” (p155; 19) This notion of indomitability closely parallels the current notion of resilience. Because it is unlikely that frailty (or some of its components) will be completely prevented, it is important to understand how older adults cope with different levels of frailty. Learning from the experience of vulnerable older adults is essential for designing health and social care systems to prevent or delay frailty and the adverse health outcomes linked to frailty. Qualitative research suggests that frail older people are acutely aware of how the realities, perceptions and labels of their health status affect their lives, and that their attitudes shape their experiences (20, 21).

Conceptualizing supportive social circumstances as assets that help older adults to compensate for health deficits may help to explain differential outcomes within grades of frailty. A supportive social environment can allow an older frail person with a given level of frailty to enjoy better health outcomes and living circumstances than a similarly frail person in unsupportive social circumstances (22). This is seen for example when we stratify outcomes of frailty by level of social vulnerability, which is an independent predictor of health outcomes (6, 23). Similarly, health beliefs and attitudes to health and disability may be associated with frailty. Modifying these may alter rates of frailty or help mitigate some of the adverse consequences of frailty (24). On a practical level, understanding a vulnerable older adult’s social situation is crucial to planning any transitions in care.

Social position, including socioeconomic status, education and perceived income adequacy, may be another factor that affects the risk of frailty or that modifies some adverse effects of frailty. In cross-sectional and prospective studies using various measures of social position and frailty, a strong association between social position and frailty is apparent (25, 26, 27). This effect appears to be graded across the ranges of income and education. However, the relationship may be complex and may operate over time horizons both long and short (28, 29). The impact of changes in social policy on frailty levels may be therefore difficult to predict and may only become apparent decades after the changes.

Future research should focus on understanding the experience of frailty and its social implications. A large and consistent body of literature demonstrates that frailty predicts death, institutionalization and a reduced quality of life. These associations are important, but their study is complicated because the causal pathways are likely to be multifactorial and bidirectional, and may well operate over long time frames. Large-scale, long-term studies will be needed to fully understand these complex associations.

Social and Societal Implications of Frailty at the Level of Families and Caregivers

Personal factors are hard to tease apart from an individual’s relationships, particularly when functional dependence...
increases an individual’s reliance on caregivers. Family and friend caregivers are pivotal in the lives of frail and vulnerable older adults, therefore understanding these relationships is pivotal. An estimated 70% to 80% of the care provided to older people living in the community is provided by family, friends and neighbors (30, 31). At the level of the individual caregiver, the more hours of care provided, the greater the risk of health and economic consequences to the caregiver. For example, caregivers who provide 20 hours of care or more per week to an older person experience increased stress, leading to negative impact on caregiver health (32). The interpersonal relationship between the caregiver and care receiver may mitigate or accentuate these consequences. With frail older spouses, the labeling of who is the caregiver may become increasingly difficult. Spouses are least likely to self-identify as a caregiver but, if they are available, they should much of the care and report greater health consequences and psychological distress (33). Adult children and children-in-law are critically important as caregivers and, in their absence, other family members, friends or neighbors are more likely to be involved (34).

Institutions and workplace policies can have positive or negative consequences on the experience of the caregiver; many caregivers combine work and care responsibilities. In 2012, 80% of caregivers were employed in the paid labor force and, within this group, 69% (women) to 72% (men) were employed full-time (35). The consequences of combining work and care responsibilities may be both immediate and longer term. For example, work interruptions and having to leave work early or come in late may affect productivity; taking unpaid leaves, reducing hours of work or not seeking promotions have both short-term and longer-term economic consequences (36). Workplaces do develop family-supportive policies that may include family leave days, modified work weeks and unpaid extended leave, but challenges remain in getting access to these policies (35).

We also need to consider the environment in which these care relationships occur. For example, in Atlantic Canada 40% to 50% of the population resides in rural environments (37) and may have less access to the range of home care supports available in urban settings. On the other hand, informal community supports and social ties may be stronger in rural areas. We must also consider the context of the population characteristics in both urban and rural areas, particularly the diverse ethnic composition of the population, in understanding caregivers’ cultural expectations for providing care.

Formal (or paid) caregivers also face many challenges within our healthcare systems. Unfortunately, caregiving is often viewed as low-value and low-prestige work. Wages tend to be low, leading to problems with recruiting and retaining workers in the sector (38). Safety concerns may lead to further stress, such as when caregivers are lifting or transferring clients or caring for those with behavioral disturbance (39, 40).

On a policy level, the availability of public policy to support caregivers is limited. Although workplace policies may enable a caregiver to continue in the paid labor market, few national policies exist to support caregivers. Policies available include non-refundable tax credits and employment insurance, specifically the Compassionate Care Benefit available if the person being cared for is at the end of their life (expected to die within six months; (35, 41). Provincial and Territorial programs for public home care typically offer respite care services within the home or through a temporary stay of the frail person in a long-term care facility, to give caregivers of frail older people a break from their caring responsibilities. Yet the societal (and often implicit policy) expectation is that family or friends are available to provide care (41). The needs of the caregiver are often not included in assessing what is needed for the frail older person to remain in the community. To include caregiver needs would require a shift in how we value and expect family and friend caregivers to care for frail older people (35, 41).

The shifting demographic profile of our population fuels the need to fundamentally change how we conceive of caregiving, to enable regular care in the community. Along with greater numbers of older people have come fewer adult children, changes in cultural values and expectations, changes in economic stability, globalization and movement of populations. These all contribute to the changing nature of caregiving and the need to prepare for a greater reliance on formal systems to provide care (34). We need to recognize, celebrate and support caregivers in their work, not just view them as resources or care delivery units. On a policy level, it is imperative that we find innovative ways to support caregivers.

Social and Societal Implications of Frailty at the Level of Institutions

Implications for continuing care and residential care

Many older people accessing home care and residential care are frail. Ideally, assessing frailty could help to tailor these support services to individual older adults’ needs, although measuring and assessing frailty in these settings presents certain challenges. Understanding social circumstances and how social vulnerability contributes to health and quality of life in various populations is key to developing person-centered care structures and processes, including care plans for home care services.

Relative to community-based studies of older adults (42), studies exploring frailty among residents of assisted living or long-term care facilities remain fairly few in number (43-50). Residents in assisted living and long-term care would be expected to have relatively high levels of vulnerability, compared with similarly aged persons in the community, but older adults with varying degrees of frailty live in all these settings (44, 46, 49, 51). Ideally, consideration of frailty in assisted living and long-term care settings would capture diverse domains, including social factors, in accordance with the multidimensional nature of frailty. Measures that include indices of social vulnerability, such as limited social relationships and low social engagement (45, 46), are likely
Social and Societal Implications of Frailty at the Level of Health Services and Systems

The mismatch of Medicare

Canadians are proud of their healthcare system. Medicare came of age in the mid 1960s and still informs an important part of the country’s sensibility (59). However, Medicare was established when the focus was acute catastrophic illness. Dealing with single acute problems such as trauma or infection made sense at that time, and our system still does this exceptionally well. In clinical practice this typically translates as ever-greater specialization. Such specialization has been beneficial; across a wide range of interventions, outcomes are better when care is centralized and delivered in the high volumes that promote focused, interdisciplinary, collaborative expertise (60, 61). In many older adults, however, that focus is now too narrow.

Now we call upon our healthcare systems to manage chronic disease and the multiple interacting problems that define frailty; here the acute “one-thing-at-a-time” care model often falls short. It is thus imperative that Canadians come to grips with the healthcare challenges posed by population aging (62). One key is to recognize that as people age, they are more likely to accumulate a range of health deficits (63). Many of these deficits become disabling or otherwise limit quality of life. They require approaches that are rooted in understanding and managing complexity (64), a challenge in a healthcare system largely organized around single-system disorders.

We increasingly recognize that frail older adults are badly served by a system that, although itself complex, cannot manage their complexity (65). The “one-thing-at-a-time” focus that has brought better outcomes can also fragment care and become harmful to frail persons, with their multiple, interacting medical and social problems (2). Addressing the challenge of complexity requires important shifts both in how care is delivered and how it is conceptualized. it is sobering to reflect on the difficulties encountered, for example, in delivering age-appropriate, integrated care for older adults with multiple vascular risk factors (66).

Are we up to this challenge? Although controlled clinical trials have demonstrated the benefits of a more comprehensive care (61), it is not yet clear how to translate that. The same pressures that can arise from a narrow focus by medical specialists can be recapitulated by other health professions. Coming together in a team conference is not the same as interprofessional collaborative practice. Helping frail persons recognize that their risk is increased is not the same as helping them decide how to avoid a risk, if that risk has been properly disclosed. Proper disclosure needs to begin with tracking outcomes that are relevant to the person at risk: not just mortality risk, but the risk of disability, cognitive impairment and the need for long-term care, for example (67). Here we begin to explore some of frailty’s consequences for how society provides health and social care.

Health services planning, shared decision making and care planning

As we have seen, managing frailty within healthcare systems demands attention to the social circumstances and relationships of frail and vulnerable persons. Along with efforts to systematically assess frailty (1) must come efforts to clarify older adults’ goals of care and to share decision making, with particular attention on the social factors that contribute to and shape older adults’ experiences of frailty. As a starting point, family and friend caregivers can have key roles in supporting shared decision making and continuity of care.

The model of shared decision making proposes that clinicians and individuals in their care make joint decisions. Those decisions are based on the best evidence for benefits and harms of all available healthcare options and on the individual’s values and preferences regarding those options (68). To build up or maintain an individual’s capacity for autonomous choice, clinicians should present a frail senior, caregivers and support persons with the best available information in a format that
makes it easy for them to choose an option that is consistent with the senior’s values and preferences (69).

To improve continuity of care, systematic assessment of frailty should be implemented concurrently with referral systems and support and training for primary healthcare providers. Primary healthcare providers do generally assume responsibility for coordinating care and information throughout the care system (70). However, they often find caring for seniors difficult because of seniors’ medical complexity and chronicity, personal and interpersonal challenges, and administrative burden (71). In particular, they report that the interprofessional nature of care and the need to communicate with families makes managing of functional decline and frailty challenging (72-74). Primary healthcare providers should thus be better supported and equipped to manage frailty and, when necessary, refer frail persons to geriatric clinics, rehabilitation clinics or community-based resources. They should also be trained in how to communicate with and support family and friend caregivers, who play key roles in securing medical, social and financial resources (75). The key is attention to the multiple levels at which social factors contribute to frailty, its outcomes and management, as in the ecological perspective presented here (Figure 1). The most recent studies on improvements that target care coordination in Canada have all shown some benefits at the level of the person supported (76-78), the healthcare provider (79) or the use of resources (78-81).

**Social and Societal Implications of Frailty at the Level of Neighborhoods and Communities**

As frail older adults strive (and struggle) to age in place, a number of social and environmental factors determine their success. The notion of aging in place has garnered much attention in the past few years. Government decision makers, researchers, families and older adults confirm that aging at home provides many health benefits, is the preference of older adults, and costs less than institutionalization. While biological health affects aging in place, a number of social and environmental factors are also determinants of success. Recognizing the influence of these factors on vulnerability or frailty of older adults in the community is essential.

Older adults are at higher risk of vulnerability in the context of aging in place if they speak a minority language, have a low income, have less than a high school education, require extra hours of home care services, do not have family members close by or do not have a car (82). Older adults who live in rural communities may be witnessing out-migration of young people, the collapse of a local economy, closure of local bank branches, closure of corner stores and gas bars, and relocation of social activities to distant larger communities (83). Older adults in rural communities who rely on services close to their homes to age in place are left vulnerable by the demise of their local economy.

Home maintenance and transportation seem to have the most impact on older adults’ ability to age in place. A number of locales have embraced the concept of an age-friendly community to promote independent living. However barriers to aging in place need to be addressed: uncleared ice and snow on sidewalks, on driveways and in parking lots; risks for falls; cost and location of activities; poor access to transportation; and complicated access to information through telephone systems (84). Further, housing features such as stairs (85) or multiple storeys are mobility barriers for aging in place.

Social vulnerability (the combination of lack of support, older adults’ living conditions and withdrawal from the community) generates high-risk situations for older adults aging in place (4). These persons are tackling multiple social and environmental challenges and are at risk for adverse effects of aging in place: loneliness and social isolation. Persistent loneliness and social isolation may lead to frailty, which presents unique challenges for older adults wanting to age in place. Further, the Canada Health Act lacks provisions for home care services, creating inequalities for older adults and their families who require services in the community. Ideally, home care services would be part of an integrated health and social care system (86). Although the majority of older adults successfully age in place, social and environmental influences may contribute to vulnerability and frailty. Age-friendliness of communities is a key contributor to successful aging in place. (87)

**Social and Societal Implications of Frailty at the Level of Governments and Society at Large**

Having reviewed the many social and societal implications of frailty across all levels of the ecological framework (Figure 1), we conclude by arguing that attention to these issues at a policy level is critical. This demands comprehensive attention across portfolios, not just in health and social domains. Supports for frail older adults and their caregivers may take the form of direct services and benefits, yet efforts will be incomplete without attention to broader issues such as housing infrastructure, transportation and the value society places on its senior members. A frailty lens, particularly a social frailty lens, will be crucial if we are to get to grips with the pressing challenges at hand.

**Next Steps and Target Actions**

- **Social circumstances and dimensions of frailty should be systematically included in assessments of frailty, to inform and enable person-centered care and care planning.** Developing and evaluating frailty assessment tools for clinical use is an important goal.
- **Caregivers are pivotal in supporting frail older adults, therefore action is needed to improve support for caregivers at the level of policies and programs.**
- **Policy review across all portfolios will benefit from a social frailty lens.**
SOCIAL AND SOCIETAL IMPLICATIONS OF FRAILTY

Conflict of interest: None

References


This paper explores ethical and legal concerns and opportunities associated with screening for frailty.

The goal of screening for frailty is to ensure that healthcare provided is consistent with people’s needs, circumstances and capacity to benefit. This goal aligns not only with good clinical care but also with the fundamental definition of formal justice (1) and in some jurisdictions, human rights law (2). Screening for frailty has the potential to equip us for responding positively to the magnitude of challenges that older adults will face in the coming decades: it can motivate high-value care, situate appropriate health and social system responses, and promote preventive and targeted interventions (3). Accompanying the anticipation of benefits from screening, however, are concerns that screening itself poses risks and gives rise to ethical questions about the extent to which the goals of screening must incorporate concerns with both doing good and avoiding harm – with both beneficence and non-maleficence.

The goal of providing health-related benefits to individuals, by whatever means (medical or social), is fundamental to medical practice. Beneficence also provides justification for interventions in individuals’ lives and for the use of public resources. However this goal is complemented by a duty of non-maleficence: the responsibility to minimize the harms of any intervention and to ensure that the unavoidable harms are balanced with anticipated benefits.

The duty of non-maleficence is related to the general moral principle to avoid causing harm, but it has a special interpretation in medical ethics (4). Many medical interventions carry the risks or the certainty of unintended harmful effects, including screening. For example, recent ethical analyses related to screening have been prompted in part by concerns about the modest benefits of and the prevalence of potentially harmful over-diagnoses in cancer screening (5-8). Parker et al. (9) argue that beneficence has been the focus of screening programs, to the neglect of non-maleficence and informed choice. This paper aims to consider these ethical imperatives as they are relevant to screening for frailty.

The recent call to action for healthcare systems to systematically screen for frailty is motivated by concerns that the care needs of many older adults are not being met (3). Key goals of screening articulated by proponents include (a) promoting healthy aging and preventing frailty (secondary prevention), (b) improving social and medical responses to those who are frail and (c) preventing inappropriate medicalization, in the form of excessive interventions based on guideline-driven care that may be insensitive to individuals’ capacity to benefit (10).

Defining a syndrome or state of health detriment where previously none was identified (a process typically termed medicalization) may entail both positive and negative consequences (11). In particular, medicalization may divert attention from the social determinants of health or reinforce stigmatization of vulnerable populations. These consequences are far from the intentions of frailty screening proponents. However, to maximize the benefits of frailty screening and minimize its harms, and to work in accordance with applicable legal principles, we must anticipate and address the specific ways in which the processes of medicalization may work against the goals of frailty screening proponents.

We start by considering the concept of medicalization as it applies to any definition of a clinical condition or syndrome, and then show its relevance to frailty. Concerns...
about medicalization, we argue, are affected by choices about how frailty is conceptualized (as a pathological condition or as a normal life stage) and by decisions about how the goals of screening are matched with frailty assessment within appropriate healthcare system settings. We then draw on recent analyses of the ethics of screening to identify specific risks of harm for the integration of frailty assessment into the healthcare system. Proponents should mitigate these risks and policy makers should consider the remaining risks in deciding on the use of frailty measurement in clinical and community decision making.

If one goal of screening is to reduce inappropriate medical management, the question of how assessment for frailty should affect medical decision making is important. Assigning people the status of “frail” raises fundamental ethical, legal and conceptual questions about the autonomy of older adults. These concerns are generally relevant to older adults but are heightened in the case of suspected or diagnosed frailty. In light of this, we consider the role that supported or shared decision making can play to assure that the results of screening promote the benefits of screening and minimize its harms, as this goal is pursued within the concept and principles of informed consent.

The Medicalization of Frailty and Demedicalization of Aging

When a condition is medicalized, a disease entity is defined as opposed to a specific syndrome, we might describe the condition as a pathological condition or as a normal life stage and by decisions about how the goals of screening are matched with frailty assessment within appropriate healthcare system settings. We then draw on recent analyses of the ethics of screening to identify specific risks of harm for the integration of frailty assessment into the healthcare system. Proponents should mitigate these risks and policy makers should consider the remaining risks in deciding on the use of frailty measurement in clinical and community decision making.

If one goal of screening is to reduce inappropriate medical management, the question of how assessment for frailty should affect medical decision making is important. Assigning people the status of “frail” raises fundamental ethical, legal and conceptual questions about the autonomy of older adults. These concerns are generally relevant to older adults but are heightened in the case of suspected or diagnosed frailty. In light of this, we consider the role that supported or shared decision making can play to assure that the results of screening promote the benefits of screening and minimize its harms, as this goal is pursued within the concept and principles of informed consent.

The Medicalization of Frailty and Demedicalization of Aging

When a condition is medicalized, a disease entity is defined or its boundaries are extended such that people who were previously considered medically normal (or who had not drawn medical attention) are labeled as unhealthy. Medicalization is beneficial when it leads to appropriate responses to care needs, but it also raises a variety of specific concerns (analyzed in Verweij, 11), some of which are relevant to frailty. Medicalization was initially understood as placing common experiences of daily life (such as pregnancy, menopause and aging) under medical authority, and it was analyzed by sociologists as a kind of threat to autonomy and independence (summarized in Verweij, 11, pp. 84–87). A contemporary understanding sees medicalization as potentially destabilizing individuals’ perceptions about their own health and autonomy but also as empowering them to make claims on the healthcare system for response to the medicalized condition.

Another concern about medicalization is that it may reframe social problems as medical conditions. Social problems thus become individualized, decontextualized and positioned as objects of medical intervention. Remedies for social problems are similarly individualized, leaving relevant underlying social structures and inequalities unacknowledged and unaddressed. As detailed in an accompanying paper in this series (12), health deficits associated with frailty may be influenced more significantly by broader social determinants than by disease or illness themselves. The socially determined nature of frailty and its associated deficits suggest that responses to frailty must also consider options outside the healthcare system and therefore beyond the direct control of those diagnosing the condition (13). Medicalization of frailty could legitimiz individual and social claims for frailty to be addressed primarily by the healthcare system, whether or not that system is well-suited to respond. These concerns are also raised by other papers in this series (12, 14).

Finally, while medicalization has sometimes de-stigmatized conditions previously subject to moral or religious stricture (such as addictions), it may also stigmatize the population captured under the new diagnostic label. A diagnosis of frailty runs the risk of stigmatizing older adults, negatively impacting their self-concept and bolstering pre-existing ageist attitudes (15, 16). Older adults already risk the assumption of having diminished capacity to make healthcare decisions, based on stereotypes of dependency and incapacity associated with old age (17). As Andrew et al. (12) have pointed out, research demonstrates that frail older adults themselves are aware of the impact that labeling and perceptions about their health have on their lives (18, 19). Medicalization would present the concept of frailty as a scientifically validated construct and could, despite the intentions of proponents, heighten existing negative associations, including real or perceived paternalism and discrimination within the healthcare system (described in Hall, 20). Screening or case finding could expose a larger number of older adults to pejorative attitudes. Through the process of self-stigmatization, this could have a corrosive effect on their physical and cognitive function and self-image (15, 21, 22). In fact, many older adults do not identify with the term frailty as it is applied to them (23). If screening accentuates these risks and stereotypes, it could impair informed decision making by undermining legally mandated and prevailing ethical norms associated with meaningful choice (24).

None of these harms are intended by those who have devised measures of frailty and who advocate for screening. Rather, proponents seek to expand the appropriate care for frail older adults beyond the realm of specialist medicine and to promote a more holistic picture of health and ill health among this population. Routine care that considers only isolated physiological indications for medical intervention may cause more harm than benefit in the case of frail older adults (10). Furthermore, as medical interventions and technologies become more advanced, readily available, less invasive and less risky, their uptake as standard procedure for people of increasingly advanced age is taken for granted (25, 26). Frailty is associated with shortened life expectancy and a trajectory of declining health status over time, and it is appropriate to take this into account in decision making (10). However, the lack of clinical outcomes evidence specific to frail older adults makes it difficult for physicians to adequately advise patients and for patients and families to meaningfully choose whether or not to treat. One aim of identifying frailty is to support appropriate medical care and decision making (15, 27). In this sense, and if we conceptualize frailty as a state of increased vulnerability as opposed to a specific syndrome, we might describe the
medicalization of frailty as having the goal of demedicalizing a normal life stage by making it less subject to inappropriate medical intervention. Medicalization depends on how frailty is conceptualized and measured (28). The risks of medicalization may be mitigated (i.e., demedicalization may be achieved) by conceptualizing frailty relationally and situationally, rather than ascribing a global trait to individuals. Promoting the appropriate integration of the needs of frail older adults into both the community and healthcare systems reduces inappropriate medical treatment of the specific medical conditions to which frail older adults are vulnerable and to which that medical treatment in turn renders them even more vulnerable.

**Conceptualization and Measurement of Frailty**

Frailty can be conceptualized and measured as a syndrome or as a state (29), or in relation to the normal aging process, as described below.

The original phenotypic definition of frailty (30) is an example of frailty as a syndrome, and the criteria outlined by Fried as indicating the presence of frailty are still elements of many contemporary measures (29). Alternatively, frailty can be conceptualized as a general state of increased vulnerability to adverse outcomes after exposure to stressors (15) or, as stated by Rockwood and Mitnitski (31), “a nonspecific state of increasing risk, which reflects multi-system physiological change” (p. 722). Deficit accumulation is the most common way of identifying or diagnosing frailty as a state (29). Frailty conceptualized as a syndrome is primarily binary; frailty conceptualized as a state (the deficit accumulation model) is a continuum.

Whether understood as a syndrome or state, frailty is conceptualized as a pathological condition (15) that can and should be the target of prevention in order to facilitate healthy or successful aging (32, 33).

Frailty is also conceptualized in relation to the aging process (15). While some functional decline is inevitable over the life course (15), variation exists in the rate and scale of decline experienced by older adults. Frailty in this understanding represents differing vulnerability to adverse health outcomes in people of the same chronological age (15, 27). Viewed in this way, and in contrast to conceptualizations of frailty as pathological, frailty is barely distinguished from normal aging; it indicates the rate at which people reach a stage that we will all reach if we do not die of conditions that foreshorten this decline.

While proponents for measuring frailty in clinical settings focus on the fact that either kind of measurement may be predictive (28), how we conceptualize frailty has implications for how it is both measured and managed. For example, emphasizing multidimensional functional decline and variation in decline within the aging process may prompt more holistic responses, including ameliorating the social conditions that contribute to the extent of frailty and the seriousness of the associated deficits. Conversely, viewing frailty as a pathological condition may bias our response toward medical intervention and away from social intervention. Furthermore, it may inappropriately place the burden and responsibility to cope and to protect and promote one’s own health on individual older adults and their families. This may leave unacknowledged society’s inadequate response to the needs of those who are frail. Approaches to frailty that emphasize its social dimensions may be less susceptible to reinforcing the pejorative and stigmatizing connotations of being labeled frail than approaches that view frailty as a medical condition.

**Implementing Frailty Measurement**

**Surveillance, Screening, Assessment and Case Finding**

It may seem reasonable to assume that screening a population to identify health needs and acting to meet those needs is beneficial. However, decades of experience with screening for chronic disease has demonstrated that, as Wilson & Jungner (34), authors of a landmark publication on screening, suspected, this is not always the case. The harms and benefits of screening depend (among other factors) on disease dynamics, available interventions, test performance, social acceptability and costs in relation to the capacity and priorities of the health system. Ethical analysis of problems of false positives, false negatives and over-diagnosis is a new and rapidly growing field (e.g., Harris et al., 35). What proponents call “frailty screening” in fact includes case finding, surveillance, integration of frailty measures in clinical outcomes research and (ultimately) guidelines and care pathways, assessment for psychosocial needs and classic screening for primary or secondary prevention (see 36, 28). The balance of harms and benefits for any particular proposal will depend on the particular instrument, the setting, the intervention and the goal. In this section we illustrate basic principles of screening ethics to alert proponents to pitfalls that may accompany the benefits they seek.

According to Juth & Munthe (37), screening is: “The use [or promotion of the use] of medical investigation or testing methods at the initiative of health care or society for the purposes of investigating the health status of individuals, with the aim of selecting some of these for possible treatment [or preventive measures] … from a large population of people not united by previously recognized risk or symptoms of disease. (pp. 10–11)”

The core of this definition usefully distinguishes means from goals in screening, case finding or assessment so that we can ask and answer these questions: Does the process achieve its goals? At what financial, medical or social cost?

To illustrate ethical concerns with screening, assessment and case finding, we first explain the problem that arises when measurement and intervention are applied on a population-wide basis, and then focus on two proposals for the clinical application of frailty measures: a) screening or case finding with the goal of reducing inappropriate medical interventions.
in the older adult population, for which we will use the label “quaternary prevention” (38), and b) assessment for appropriate psychosocial support and targeted interventions (e.g., Comprehensive Geriatric Assessment). In quaternary prevention, concerns arise about cost and social acceptability; in assessment for psychosocial support, questions arise about the availability of beneficial interventions.

**The Problem of Population-wide Implementation**

Frailty screening proponents focus on the number of persons who could benefit from prevention or intervention (3). Success in prevention, however, depends on the actual benefits experienced by a large enough proportion of those we identify in advance as exhibiting risk factors. There may be a large gap between these numbers (the number of those whose care we wish could have improved and the number of those identified in advance whose care we are actually able to improve) due to the timing of screening or case finding, the performance of our screening instrument and the dynamics of the condition in question.

“Perfect” test performance cannot be assumed. False positives and false negatives are intrinsic to measurement. Frailty indices lack a gold standard diagnostic test (39). Purely formal reasoning (34, pp. 24–25) supports the concern that implementation of a measurement instrument in a lower risk population generates many false positives and increases the identification of borderline cases; this has been borne out in cancer screening (6). Wilson & Junger argue that is incumbent on healthcare providers to determine the appropriate management of borderline cases in order to avoid causing more harm than good (34, pp. 24–26). The “problem of borderline cases” that they identify encompasses what we now call over-diagnosis.

The potential for bias on the part of providers less experienced in care for older adults exacerbates this concern. Positive predictive value (the chance that a person screened as frail actually experiences the outcome of concern) for existing frailty scores is estimated at 6% to 49%, while the reliability of screen negatives is much better at 73% to 96% (40), indicating that false positives are more likely to be a problem than false negatives. Thus, a substantial number of those identified in screening or case finding as frail would not have experienced the outcome we seek to prevent or address by screening. This has two adverse consequences. First, the identification of these persons as “frail” constitutes labeling (with all its potential negative consequences, discussed above) for potentially limited individual preventive benefit. Second, in attempting to assist a group we believe to need early intervention, we may divert energy and resources from them to a much larger group who exhibit risk factors but who would not in any case have experienced the outcome we seek to prevent.

**Screening or Case Finding for “Demedicalization”**

Quaternary prevention goals (38)—reducing inappropriate medical interventions in frail older adults—could be met through case finding at different points within the healthcare system. In primary care, physicians and other healthcare providers can begin discussions about goals of care. In emergency departments, pathways of care can be more appropriately informed. In long-term care residences, goals of care can be updated.

There is a risk the public will perceive the goal of helping people avoid inappropriate medical care as rationing, and that this will render frailty screening socially unacceptable. Quaternary prevention may be seen as akin to age-based allocation such as QALYs (41) or “fair innings” or lifespan approaches (42, 43). Rationing withholds beneficial care from individuals, regardless of their wishes, based on societal decisions about distributing scarce resources. Basing the rationale for frailty screening on healthcare expenditures that flow to elderly people could exacerbate the perception that frailty screening is a form of rationing. Individualizing decision making, rather than excluding individuals unilaterally from medical interventions, would combat this perception. The goal of frailty screening must be clear: is it a form of rationing or does it aim for appropriate care for older adults?

If frailty assessment replaces arbitrary measures in clinical guidelines (chronological age or life stage) with measures that are directly pertinent to the individual’s needs, circumstances and capacity to benefit (24), this may result not just in “ruling out” certain medical interventions for individuals who would be harmed, but also in “ruling in” medical treatment for older adults who are not frail and who might otherwise have been denied treatment based on age-related criteria. Increased access to beneficial medical interventions for non-frail older adults may be clinically appropriate and in accordance with formal justice, but the social question of resources and priorities of the healthcare system remains. In general, screening for chronic disease is not cost saving (44). Policy makers are increasingly aware of this (45). Screening proponents must present plausible modeling to support claims that preventive measures will achieve benefits at an acceptable cost.

**Assessment to Meet Social Needs**

Assessment to meet social needs may take place in tertiary care (to identify needs for enhanced nursing support in the hospital or discharge planning) or in primary care (to identify the need for community-based services). Optimal value from screening for these goals depends on the availability of beneficial interventions: in tertiary care, on the availability of enhanced nursing support, personal care workers, and resources for discharge planning; in primary care, on strengthened links to the broader healthcare system and a network of community-based providers and services to support and care for those who are frail.

Attending to these links is critical, particularly given that
medicalization can shift expectations from other sectors to the healthcare sector. For example, frailty indices often include nutritional status (46) and sometimes include weight loss (33). The determinants of nutritional status or weight loss could be structural (food insecurity for older adults) or social (social isolation affecting eating), compounding the physiological changes accompanying frailty. Providers and healthcare systems are generally responsive to the expectations that are shifted to them, applying the tools at their immediate disposal. For example, a good solution to weight loss in older adults identified as frail might be inter-sectoral work on food security or on social isolation. In tertiary care, this could involve addressing food quality and the social experience of eating in hospital. Instead, the response in either sector could be the “quick fix” of nutrition supplementation. The expectation of older adults themselves for a clinical solution to a clinically-defined condition may legitimize and exacerbate this dynamic.

Summary

Whether a frailty index is used for screening, case finding, or assessment, the goal is to generalize the benefits of a process that was typically performed in a specific setting with a high-risk population and resources for response (e.g., Geriatric Assessment in tertiary care) to broader settings and populations. This generalization entails a more diverse set of assessors, with a lower risk population and different resources for response. Meanwhile, depending on the dynamics of the underlying condition, the harms we intend to prevent and the setting and time frame for screening or case finding, we may or may not be able to intervene effectively to prevent the outcome we seek to prevent. Necessary interventions may originate outside the healthcare system, such as home care and social supports; even if they do exist, they may not be accessible. In a worst-case scenario, a lack of access to these types of options could result in frail older adults being triaged out of the very system that establishes their frailty status, into a social care system that may or may not be equipped to respond. Lack of operational alignment between healthcare (where the screening happens) and social care (where the responses are allocated) could prevent frailty screening from leading to appropriate and demedicalized responses to care needs even where social care exists and is properly funded.

Proponents might argue that assessment and the interventions that result from it (social support, goals of care discussions) are so low-risk that the issues we raise are inconsequential. However, screening, case finding and assessment for social needs may be socially and emotionally intrusive: they raise questions of mental capacity, ability to live safely in the community, impending death and family caregiver dynamics. They also introduce the labeling effects described above (21, 22).

Implementing the Results of Screening: The Role of Supported (or Shared) Decision Making

The Changing Understanding of Individual Autonomy in Relation to Informed Consent

Frailty screening that justifies a move away from excessive or harmful medical intervention toward appropriate care can be ethically defended. However, this conclusion is subject to an important caveat: the individual, not the care provider or healthcare system, must make the choice to forgo or to undergo “inappropriate” medical interventions and to opt for “appropriate” alternatives based on assessment of relative frailty. Properly designed and conducted screening sets the stage for satisfying this caveat; it allows providers to give individuals more of the information that is relevant to both the choices they must make and the care they should ask for and receive.

Screening that expands or situates choice in this way aligns with ethical obligations to respect the autonomy of individuals by equipping them to consider healthcare choices on the basis of more complete information relative to a more complete range of options (4, 47). In other words, the applicability of these obligations is a critical protection for individuals screened as frail against the risk of being arbitrarily denied treatment on that basis (24).

At the same time, frailty can connote or imply dependency and vulnerability. Screening could contribute to or reinforce tendencies to equate age with the incapacity that (in Canadian law) triggers the delegation of decision making to a substitute decision maker, typically a family member (17). If this were to happen, screening results (including false positives) could legitimize substituted decision making in place of a more robust engagement with the elements and process of informed choice that maximize a frail individual’s existing capacity and autonomy.

Conversely, older adults (especially those who are frail) sometimes are attributed more capacity for decision making than they objectively possess. One factor contributing to this may be a temptation to avoid the complications of finding and dealing with a substitute decision maker. Another factor is the unwillingness of health providers (or their institutions) to risk real or perceived coercion of individuals. Coercion violates a key responsibility associated with informed choice. Yet if individuals who truly lack sufficient decision making capacity for the choices they face are left to decide on their own to avoid risking coercion or its appearance (48), this too can be harmful. Older adults who are cognitively impaired, and who have more autonomy in decision making foisted upon them than they are equipped to exercise, risk making decisions that are not appropriately responsive to the implications of their frailty or that are unacceptably determined by those implications.

Inappropriate assumption of either incapacity or capacity jeopardizes attainment of one of screening’s ultimate goals: protecting the frail elderly from both harmful medical
entanglement and denial of care. This dilemma reflects the binary quality of capacity determination, which providers face in applying the concept of informed choice (as it is generally configured) to individuals who are decisionally compromised (49). Individuals are either assumed to be fully capable or fully incapable relative to each decision that must be made. This reflects the origins of the concept of capacity in the traditional and individualistic liberal model; each individual is conceptualized as rational, self-sufficient and materially and emotionally independent (50). An extension of this is the notion that vulnerability and dependency are the antithesis of autonomy (50).

In healthcare, individuals have been recognized as able to act intentionally, with understanding and without controlling interferences, for the purposes of healthcare decision making (4). This has been the basis for displacing paternalistic models of decision making (49). However, it may also have left healthcare providers with inadequate options for navigating individuals’ vulnerability and dependency in ways that respect their continuing but diminished capacity and therefore their autonomy.

More relational accounts of personhood and autonomy are gaining ground (50-52) in which personhood is understood to be socially constituted and situated, embodied and relative (50). The relational self is imagined as individual but also interdependent and constructed in relationships with others (52). Autonomy is conceptualized as a process in which one’s sense of self is confirmed in interactions and experiences, as opposed to being entirely individuated and free of constraint (51, 52). Conceiving of autonomy in this way opens possibilities for those with limited capacity to still exercise autonomy and retain selfhood (52).

Capacity itself can also be re-imagined as relative or situational, and this has important implications for the autonomy of those who are decisionally impaired. In the disability literature, the notion that disability is a property of individual bodies is replaced with the idea that disability, including mental disability, is socially constructed and perpetuated based on disabling social structures and barriers (50, 53). Under this view of disability, experiences of both capacity and limitation are relative and socially situated, in that they depend on the socially constructed environment in which an individual lives, the supports available to that individual and the kinds of capacities that are valued and differences that are tolerated in a given social context (50).

Frail older adults experience similar limits in capacity and ability based on the interaction of physical and cognitive impairments with social circumstances and supports. Their dependency, like that of people who are mentally or physically disabled, is relational and situational as opposed to based purely on physical, mental, or emotional deficits (54).

**Models of Decision Making for Frail Older Adults**

Frailty assessment will call upon individuals to make more complex choices, from a wider range of choices, than might have been offered in the absence of an identification of frailty. If the anticipated benefits of screening are to be ethically realized, decision making that is truly informed will be required by and on behalf of those who are determined to be frail or on the frailty spectrum. While decision making that both respects individual autonomy and is sufficiently supportive is of concern for many older adults, we argue that the issue is of particular relevance in the case of older adults who have been deemed frail. As outlined, a diagnosis of frailty may bring with it especially damaging assumptions of dependency or incapacity. The implications of these assumptions must be taken into consideration.

In the face of the dependency and vulnerability that accompanies a diagnosis of frailty, frameworks for decision making cannot rely on liberal conceptions of individualized autonomous agency. Informed decision making in this context is most likely to be supported or shared decision making. Typically these approaches are called for on normative grounds, as a right of individuals to have their capacity and therefore their autonomy respected to the fullest extent possible (49). We argue they are also called for on more functional grounds, as potentially necessary enablers of the decision making that is responsive to the results of screening, including those which prevent or minimize undue entanglement in potentially harmful medical intervention.

The standard response to concerns about capacity is to move to a substituted decision making model. In substituted decision making, a person makes decisions on behalf of an individual on the basis of their understanding of how that individual would want to be treated (55). The substitute decision maker is ideally the person with the most in-depth knowledge of the individual’s will, values and preferences. Theoretically, this equips the substitute decision maker to make the same decision the individual would make if the individual were able to decide (55). If a suitable substitute decision maker cannot be determined, decisions are made according to the individual’s “best interests” (55, 56). Both substituted decision making and the best interests approach run the risk of coercion if they result in decisions that an individual would not have wanted (55-57).

Even more fundamentally, however, these models of decision making may compromise individuals’ basic freedom and human rights (55) if they are applied to individuals who would be capable of making decisions for themselves. They may also result in decision making that favors either a family member’s concern to ensure that everything that can be done is done for their loved one or a caregiver’s concern about their capacity to care for their loved one.

In the Canadian literature, particularly in the disabilities context, supported decision making models are a favored alternative both to substituted decision making and the alternative of leaving the decisionally impaired with more
choice and responsibility than they are equipped to handle. Supported decision making is called for in Article 12 (3) of the Convention on the Rights of Persons with Disabilities (58). The Convention requires that State Parties provide the supports necessary for people with disabilities to exercise the legal capacity they are deemed to enjoy, on terms of equality with all others (56, 59). On a supported decision making model, legal capacity is at no point lost, and it is not dependent on mental capacity (48). While frailty is considered to be distinct from disability (60), discussions of decision making and capacity in the literature on disability may give the closest analogy to frailty, given the lack of literature pertaining specifically to decision making among frail older adults.

The objective of supported decision making is to provide individuals with the support and accommodation they require to make their own decisions. Support persons are guided by the individual’s will, the individual remains central in the decision making process and the individual retains the final say (48, 56, 61). In the context of frail older adults, the more specific rationale for maximizing autonomy and informed choice through supported decision making has two components. It can protect vulnerable individuals (as well as their providers and care systems) from being denied options on the basis of their frailty status. It can also support those individuals in avoiding the harmful medical entanglement, which is one critical ethical rationale for frailty screening.

Models of supported decision making therefore are sensitive to conceptions of autonomy, competence and capacity as contextual or relational and as existing on a spectrum, rather than as individual attributes that are either present or absent. A variety of supported decision making models encompass myriad forms of support such as single support persons, support groups, circles, boards or networks (often a person or persons with whom individuals have a trusting and caring relationship). However, several commonalities are apparent between most models. First, individuals are able to choose and change their support person or persons at will (56, 61). Second, supported decision making typically involves presenting information to individuals in a form that best facilitates their understanding, helping them appreciate the information, apply it to the decision at hand given their beliefs and values and facilitate communication of their decision to others (56, 57, 59, 61, 62). Third, the role of the supporting person or persons is to support decision making by the individual, not to decide for the individual, and to make sure decisions are respected and implemented (49, 56, 59).

Shared decision making is another recognized alternative to substituted decision that also avoids leaving a decisionally impaired person to decide on their own. Andrew et al. (12) suggest shared decision making may be useful in the case of frail older adults. Like supported decision making, it aims to be respectful and protective of individual autonomy (63). It is seen, particularly in the medical profession, as an ethical option in the era of informed choice, patient centered care and evidence-based medicine (64-66). This model of decision making has been linked to improved individual outcomes, both clinical or functional and in terms of individual satisfaction, from as early as the 1960s (67, 68). Shared decision making is a joint process between an individual, one or more healthcare professionals and often a family member or significant other (67). The individual communicates their values, views and desire for information to the healthcare professional, who in turn brings to the table their expertise in evidence-based treatment options (67). The individual, healthcare professional and any other parties involved work together and engage in two-way information sharing and dialogue about treatment options, risks, alternatives and the individual’s values in order to reach a decision that is mutually acceptable given the presence of clinical choice (65, 67). Individuals participate in decision making to the extent they desire, and their preference for more or less participation in the decision making process is part of the information the individual shares with the healthcare professional. It is these principles, not a specific set of protocols or practices, that characterize shared decision making (67).

Supported decision making aims to facilitate individuals’ ability to decide and to communicate their decisions whatever their apparent decisional impairment, while shared decision making is designed to address different individual preferences in their role in the informed consent process (49). Both models carry risks that have to be recognized and considered. As described above, the key justification for treating individuals as autonomous decision makers is to prevent the paternalism of earlier eras (49). With both supported and shared decision making, attending to the inherent vulnerability and dependency of individuals runs the risk that support or sharing could lapse into persuasion or even coercion (48, 49). At an even more basic level, it is recognized that healthcare practitioners bring their own values into the decision making process and hence may unintentionally impose their own values and opinions about the best course of treatment onto individuals (67). Furthermore, both shared and supported decision making require healthcare providers with strong communication skills and a willingness and ability to actively listen and to deliberate (49, 68). This places a significant burden of responsibility on the shoulders of providers and the healthcare system. Constraints on time and resources may render such intensive decision making processes difficult to implement and to follow.

Conclusions

In broad terms, screening for frailty, in the right context and with careful planning for interventions, has the potential to align the care offered to older adults by providers and systems (formal and informal) with older adults’ actual needs, circumstances and capacities to benefit. Frailty screening therefore has the capacity to increase equity in health and social care. Screening also has the potential to harm older adults by accentuating stigmatization and stereotyping, legitimizing
denial of care and unnecessarily medicalizing the aging process. Responding appropriately to the needs of individuals identified by screening as “frail” requires an informed consent process that incorporates shared or supported decision making and that maximizes autonomy to the greatest possible extent. Shared or supported decision making approaches may also be crucial to achieve the quaternary prevention goals that are key to the ethical defensibility of screening for frailty.

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POLICY AND ECONOMIC CONSIDERATIONS FOR FRAILTY SCREENING IN THE CANADIAN HEALTHCARE SYSTEM

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Abstract: Canada faces significant policy and economic challenges related to healthcare for frail older adults. Annual per capita healthcare costs for people over age 65 are five times those for people under 65. Flat economic growth and an aging workforce decrease tax revenue, which funds 70% of health spending. Governments are shifting policy to enhance person-centered care and shifting spending from hospitals to primary and community care. Recognizing that frailty and evidence-based frailty screening can contribute directly to reform initiatives, what are the policy and economic considerations, both nationally and internationally, around frailty screening that will benefit patients, families and/or the wider health system? Based on key informant interviews, we present recommendations for approaching policy and economic challenges in frailty through the following healthcare policy instruments: financing, funding, legislation, regulation, technology, interdisciplinary care, person-centered service and health promotion.

Key words: Frailty, screening, older adults, policy, economic.
estimated that between 14% and 37% of those waiting for long-term care could be supported safely and cost-effectively at home (14). Public policy around the support needed by informal caregivers for their unpaid work is becoming a necessity.

The combination of flat-lined economic growth and an aging work force will decrease tax revenue. For example, in 1971 there were 15 seniors for every 100 working-age people; in 2006, there were 21. In another 50 years, projections forecast 50 seniors for every 100 workers (15). The specific impact of an aging population on overall tax revenue will be significant, especially as this large cohort of aging baby boomers retires, many lacking sufficient savings outside of defined pension plans (16). Canada needs to devise strategies to keep older Canadians productive for longer (17), and the federal government’s decision to move the age of eligibility for the Old Age Security pension from 67 years back to 65 years will impact those strategies.

Technological changes are another significant cost driver in healthcare, though the impact has been difficult to quantify. A survey of technology and its impact on healthcare spending concluded that technology-related changes have contributed to the growth of per capita healthcare spending in the United States by 38% to 65%. While technology can increase costs in the short term, technological advancements can also significantly reduce medium- and long-term costs (18).

Overall price effects, such as rising costs of drugs and increased compensation for health providers, have been the most significant driver of overall health spending (9). Seniors still account for a high proportion of public drug program spending. For example, in 2011, seniors accounted for 60% of government spending on prescribed drugs (19). Polypharmacy is a growing concern and contribution to frailty, with many more seniors on multiple drugs from multiple providers. Polypharmacy increases the probability that a senior will require emergency medical attention as a result of adverse drug reactions and incidents such as falls (20). Pharmacists are playing a more active role in strategies to de-prescribe drugs, notwithstanding financial incentives to the contrary (21).

These changes in context are requiring governments to embrace new policies and strategies around person-centered care and to move spending from acute settings to primary and community care. Frailty feeds directly into many reform initiatives. However, frailty remains under-recognized and not well understood. In particular, few understand that not just older adults are frail and that frailty is often the consequence of unmanaged chronic disease. The progression of frailty can be delayed by combining evidenced-based health assessments with prevention strategies such as physical activity and exercise, coaching, community engagement and wellness plans (22). A well-thought-out integrated strategy for frailty can be powerful. For example, the pilot study of CARES (Community Actions and Resources Empowering Seniors; 23) in British Columbia and Nova Scotia shows that primary care providers in the community are critical to stemming the tide of frailty.

Feeding into the frailty discussion are validated screening tools for frailty, some electronic and some paper-based. These tools, such as the Rockwood, interRAI, Edmonton Frail Scale and Fried Phenotype, are administered in different settings and by different providers: nurses, physicians or individuals themselves (24). Different settings across the care and service continuum, from primary to acute care and across provider groups, require different strategies and tools (24), but such an approach creates much confusion. Given the economic challenges that face our health system, it is becoming apparent that scaling up frailty screening practices requires policy and economic changes or instruments.

HealthCareCAN (www.healthcarecan.ca) is the national voice of healthcare organizations and hospitals across Canada, with the goal to improve the health of Canadians through an evidence-based and innovative healthcare system. In January and into early March 2016, HealthCareCAN, on behalf of the Canadian Frailty Network (formerly the Technology Evaluation in the Elderly Network), undertook a series of key informant interviews to accompany a brief literature review on the following research question:

“What are the policy and economic considerations, both for Canada and internationally, to be taken into account around frailty screening that will benefit patients, families and/or the wider health system?”

The methodology and results of this process are presented here.

**Methods**

An advisory committee, consisting of experts in frailty and policy in Canada from organizations including the Canadian Nurses Association, the Canadian Medical Association, the Canadian Pharmacists Association and the Canadian Hospice Palliative Care Association, guided this work. Our multi-pronged approach provided wider insight, given the scope of the research question.

**Key Informant Interviews**

Sixteen individuals were recruited through HealthCareCAN networks and participated in interviews lasting approximately 45 minutes. These key informant interviews proved foundational for the insights and recommendations in this paper. Key informants were selected to balance multiple criteria:

- Extensive knowledge of Canadian health policy, health economics or frailty issues.
- Stakeholder group type: policy maker, researcher, provider or individual.
- Geographic diversity.
- Level: macro (government), meso (institutions) or micro (provider, individual and family) viewpoints.
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Telephone interviews were conducted using a standardized interview guide that was validated and pilot-tested with the Advisory Committee (Appendix 1). To help inform the key informant interviews, a literature review was undertaken in which national and international peer-reviewed and grey literature was searched. While the information collected proved invaluable, the aim of the literature review was to contextualize the key informant interviews. A second round of interviews was not deemed necessary given that data saturation was achieved with the sixteen interviews completed and common themes and comments were achieved.

Webinar
On April 12, 2016, preliminary key findings from our literature review and key informant interviews were shared at a webinar hosted by HealthCareCAN and the Canadian Frailty Network. Presenters were Dr. John Muscedere, Mr. Bill Tholl, Ms. Jennifer Kitts and Ms. Kelly Grimes. Over 180 people registered and almost 90 participated in the webinar. The questions and feedback from the webinar helped to frame the top recommendations in this paper.

Policy and Economic Opportunities in Canada

Numerous policy instruments are in place to advance public policy for the health system, including: financing and funding, legislation and regulation, partnerships and networks, technology, and evidence-based public awareness campaigns and other communication strategies. Typically, a combination of instruments is the most effective in achieving desired results.

Our key informant interviews brought to light the many policy and economic challenges and opportunities in Canada regarding frailty and frailty screening. Key informants noted that, with continuing growth of our aging population, frailty has long been on policy agendas yet has not been addressed as a whole in policy and economic mechanisms. Nearly two-thirds of Canadians are worried that our healthcare system is falling behind our needs (25).

Outlined here are the most prevalent policy and economic themes cited by our interviewees as shaping the focus on frail older adults, both now and in the future. Other forces in play, such as health provider supply, education and training, are not explored in depth.

Canada’s Federated Health System

Canada has 14 different health systems through provincial, territorial and federal funding for health programs, each system with its own structures and processes. Marchildon (26) notes that this is one of the most decentralized health systems in the world. Internationally, Canada’s health performance continues to decrease. The 2014 Commonwealth Fund International Health Policy Survey of Older Adults (27) ranked Canada 10th out of 11 countries. Many programs for seniors fall outside of the Canada Health Act, resulting in large and growing interprovincial discrepancies around prescription medication coverage, home care and long-term care. Frail Canadians can wait many months to access long-term care facilities. An Economist report (28) on palliative care rated Canada 11th, down from 9th five years prior.

The mandate letter for the federal Minister of Health continues to highlight the need for better home care services, including access to high-quality in-home caregivers and financial supports for family care. Pan-Canadian collaborations, including those on health innovation, will make addressing the deficiencies in our health system a priority. Dr. David Naylor’s Advisory Panel on Healthcare Innovation (29) states that Canada must unleash innovation in order to provide excellent healthcare for all. To achieve this, the Panel argues that the federal government must make changes to its current means for pan-Canadian collaboration, in addition to major investments to support provinces and territories in implementing fundamental changes to their systems. However, the Conference Board of Canada’s report on How Canada Performs (30) gives Canada a “C” overall on innovation. Ontario is a top performer, after Sweden, Denmark, Finland and the United States. These policy directions of innovation, home care and palliative care will become increasingly important.

The following priorities emerged from the key informant interviews:

- Complete the dialogue and achieve consensus on a common language for frailty among healthcare providers, researchers, policy makers, administrators and, especially, individuals and their families (31, 32). Frailty is a multifaceted and multidimensional concept.
- Link health and social services. To improve accountability and lessen the impact of frailty, we require a more systematic approach across public policies and at all levels of the health system (macro, meso and micro). Health and social services are often administered by separate government ministries within provinces.
- Scale up and spread leading practices in frailty screening through an ongoing pan-Canadian advocacy strategy based on government mandates. Promote frailty as a level one policy that crosses settings, similar to advanced care planning in Alberta.
- Act to shift reform from population aging to chronic disease management with a health promotion and disease prevention focus and a team-based approach. Link productivity and performance to frailty.

Financing and Funding Models

Public sources, primarily taxation, finance 70% of Canadian health expenditures (9). Tax and loan policies could be considered to support individuals and their families living with frailty (although perhaps not specifically screening), including caregiver tax credits, physical activity tax credits, reverse mortgages or home capital upgrades. Caregiver tax credits are seen as one method to support informal caregivers financially
and could be built on the existing Canada Caregiver Tax Credit and the Canada Family Caregiver Tax Credit. Internationally, paid or unpaid leave from work and pension tax credits are more common (33).

Some countries are looking at prefunding services for seniors through mechanisms such as long-term care insurance that is publicly administered (possible in Canada through the Canada Pension Plan) or personal health savings accounts. A 2010 Canadian Medical Association survey (34) asked citizens about their interest in a tax shelter such as a Registered Long-Term Care Savings Account. Sixty-five percent of respondents with a Tax-Free Savings Account indicated that they would be very or somewhat likely to use an analogous long-term care savings account, but only 47% of respondents without a Tax-Free Savings Account indicated interest (34).

Provincial health funding models vary widely. With the exception of physicians, health providers are typically remunerated by salary. Historically, physician services have been primarily funded through fee-for-service systems, but the percentage of total clinical payments through fee-for-service has dropped over time and flat-lined in the last five years at about 72% (35). Over time, alternative payment plans such as capitation have grown, with physicians paid a specific amount (possibly risk-adjusted) for each individual enrolled under their care. Team-based remuneration, particularly in primary care, is also on the rise. Ontario uses Family Health Teams, although physicians are still compensated through either Family Health Organizations or Family Health Networks; Alberta uses Family Care Clinics and Primary Care Networks, although most physicians are still compensated through fee-for-service with supplemental per capita funding. In 2015, delegates to the Canada 2020 Summit asked the federal government to encourage structural reforms such as shifting payment for health services “from fee-for-service and volume-based funding to payment based on patient and value outcomes.” (36).

In Ontario, Community Health Links provide individualized, coordinated care to patients with complex needs. Under the Health Links model, hospitals, family physicians, long-term care homes, community organizations and others work as a team to provide patients, often suffering from multiple complex conditions, with improved coordinated care. Providers design individualized care plans for each patient and work with patients and their families to ensure they receive the care they need. Health Links managed by health service providers shifted to a Local Health Integration Network (LHIN)-managed funding approach where LHINs were granted discretion to plan and fund Health Links according to their regional priorities. Health Links led by primary care teams continue to be funded directly by the ministry and work collaboratively with LHINs to ensure consistency with regional Health Links priorities (37).

British Columbia has embraced the New Zealand-based Divisions of Family Practice Model, which has built-in flexibility to reimburse for health interventions that benefit the wider population (such as interventions for diabetes, mental health or chronic disease). Thirty-five divisions in British Columbia tailor projects on the basis of community need. This is a noteworthy endeavor to monitor and evaluate.

The following priorities emanated from the key informant interviews:

- Encourage frailty screening within the widening scopes of practice of other healthcare provider groups, especially physician assistants and nurse practitioners.
- Promote frailty screening as a standard of care both in legislation and in standards (including through Accreditation Canada).

**Regulation and Legislation**

Self-regulation of health professionals varies considerably across the country; it ensures the accountability of many, but not all, professionals. For example, physician assistants are not regulated in Ontario but are in Manitoba. Legislation outlines scope of practice for each type of professional, although the respective College is responsible for overseeing licensing and registration for practice. The trend is to widen scopes of practice, such as pharmacists now administering influenza immunizations, but new education models must accompany such changes.

Legislation to govern health delivery organizations also varies. For example, in British Columbia some long-term care homes (contracted care homes) fall under the Community Care and Assisted Living Act, whereas others fall under the Health Authorities Act. As a result, different standards of care are applied; the Hospital Act is less stringent in requirements for regular medication reviews in residential homes. One key informant noted that assisted living is more like “unassisted living” because the incentive in private care is to keep individuals in care longer.

The following priorities emanated from the key informant interviews:

- Advocate that age be a determining factor in health transfer payments to the provinces and territories.
- Further explore granting tax credits for supporting individuals with frailty and prefunding health services for seniors through mechanisms such as a tax-free long-term care savings account.
- Given that most physicians are still remunerated through fee-for-service, advocate to governments to adjust current fee code structures to include assessment of pre-frail seniors annually as a preventive screening practice.
- Encourage team-based funding models that embrace frailty screening as a preventive screening tool.

**Technology**

Electronic health record data is now available for 93.8% of Canadians (38). However, Canada still is behind other jurisdictions in many ways, including the use of digital resources, securing access to individuals’ records, individuals’ access to their own records, and the development of virtual...
Interdisciplinary and Collaborative Care

Growth of demand for labor in the continuing care sector is predicted to far exceed general labor force growth (33). To meet this demand and combat escalating costs, staff mixes are being adjusted in long-term care centers. For example, in New Brunswick, professional staff ratios are shifting from 20% to 15% registered nurses, from 40% to 25% licensed practical nurses, and from 40% to 60% personal care workers.

Interdisciplinary team-based care is increasingly prevalent, in particular in the primary care sector. Primary healthcare is often burdened with being viewed as the panacea for all healthcare problems and, as stated by one key informant, “the solution to world peace.” However, resources have shifted only minimally from acute care. Community-based upstream interventions such as family health teams are embedding health promotion and prevention into their team-based care. British Columbia’s pilot study for CARES is a powerful example of promoting teams and linking to community services (23).

Many key informants spoke to linking frailty screening to standards and care pathways, especially in transitions between care settings. Settings requiring frailty screening tools include the community, supportive settings, assisted living, long-term care, emergency medical services, emergency departments, acute care, restorative care and palliative care (41–47). Screening results must also be linked to interventions such as exercise, diet or wellness plans. This linking is being addressed through multiple provincial strategies:

- Alberta has implemented a Seniors Health Strategic Clinical Network and has identified frailty as a “Robust” Clinical Knowledge Topic for its Clinical Knowledge and Content Management team.
- In 2010, the Council of Academic Hospitals of Ontario launched the Adopting Research to Improve Care (ARTIC) program to build care pathways. One is MOVE ON (Mobilization of Vulnerable Elders in Ontario), the aim of which is to implement and evaluate the impact of an evidence-based strategy to promote early mobilization and prevent functional decline in older patients admitted to hospitals in Ontario (42).
- In Toronto, Mount Sinai Hospital has in place the Acute Care for Elders (ACE) Strategy that spans the care continuum. This strategy aims to address the needs of the elderly beyond acute care and presenting illness to prevent the decline of cognitive and physical functioning. In this way, patients can return to an equivalent care setting after they have been discharged from hospital. The program is being expanded across the country.
- Nova Scotia’s PATH (Palliative and Therapeutic Harmonization) is another exemplary practice for older adults. The PATH model is designed to improve appropriateness of care and use of resources across the healthcare continuum. PATH places frailty at the forefront of evidence-informed decision making. This approach has been translated into clinical programs that have been implemented in the community, tertiary care, home care and long-term care. The end result is that patients and families feel empowered to make decisions about surgery, medical interventions, dialysis, nursing-home placement and end-of-life care that are appropriate for their frailty burden.

The following priorities emanated from the key informant interviews:

- Advocate to colleges and universities for more sharing of
- Find consensus on who should be screened for frailty. Is it a heavy use of the health system, change in living situation and many more criteria (48, 49)? No consensus approach arose from our interviews.
- Make the business case because, in the short term, applying assessment tools and developing interventions may increase costs. The ever-present question is who will bear the burden in paying for these tools.
- Adopt a right people, right tool, right setting and right time approach based on evidence. A one-size-fits-all approach is difficult to achieve for frailty screening, and choosing the best tools to be used in each setting can be confusing. Consider developing one simpler, overall and more generic tool to be applied by lay people and families across settings. Other tools are also needed that are more specific to setting and team or provider.
frailty knowledge at both the undergraduate and postgraduate levels. Training and education should be more collaborative among provider groups but also among topic areas such as gerontology and palliative care.

**Person-Centered Care**

Key informants noted that healthcare has focused on the business model of delivery, especially around improving process efficiencies (e.g., Lean) and utilization outcomes (e.g., length of stay, alternative level of care days, patient flow). A move to more person-centered care is needed, and most provincial/territorial governments are demanding this transformation. For example, Ontario has Patients First, a person-centered strategy that strengthens integration and equity, offering more consistent and accessible home and community care. Ontario also has Community Health Links to provide coordinated, efficient and effective care to people with complex needs.

Each individual’s desires and goals for care (often to be home longer) must be heard. The Way Forward is an integrated palliative care approach to care that ensures that the caregiver voice is heard; the Canadian Home Care Association (49) consulted extensively on supports required to carry out this strategy. Another initiative, Choosing Wisely, is trying to engage individuals and their care providers in conversations about unnecessary tests and treatments, to help them make smart and effective choices for high-quality care.

The following priorities emanated from the key informant interviews:

- Place the individual and family at the center of any policy action required around frailty.
- Integrate the collective voice of the individual in frailty screening work. This may be achieved via numerous partnerships, such as IMPACT BC’s Patient Voices Network and Patients Canada.

**Policy Options**

The economics of frailty screening are not clear, although the policy implications are more so. Evaluation is needed for the impact of frailty screening and the potential return on investment to the individual, provider and the health system (50). Evaluation data to feed into a business case or impact analysis is warranted, in particular for further public policy and engagement strategies. Evidence-based public policy options are needed to scale up frailty screening in Canada.

For any approach chosen to develop policy options, key informants offered four pieces of sage advice:

- Integrate work into jurisdictional strategies on chronic disease management, continuing care and seniors’ healthy aging.
- Pilot test options or undertake small samplings first through an organization at arms length from government.
- Keep pilot tests small and nimble, with shorter timelines such as six months.
- Apply implementation science and innovation principles to build the evidence base.

**Recommendations**

Frailty screening allows healthcare providers to better assess and treat the underlying causes of frailty. The ability to identify these health problems early and to recognize the appropriate treatment measures will improve not only life expectancy, but quality of life. Using information and feedback from our key informants, advisory committee members and webinar participants, we evolved five top recommendations for action on frailty and frailty screening:

1. Complete consensus dialogues on:
   a. a common language for frailty
   b. the best tools to be used in each setting, applying a right people, right tool, right setting and right time approach
   c. who should be screened for frailty.

2. Build a business case on the potential impact of frailty screening in various settings. Include analysis of both direct and indirect costs and impact on comorbidities.

3. Develop a pan-Canadian advocacy strategy to scale up and spread leading frailty practices. Key pieces to advocacy are to:
   a. ensure the individual and family are at the center of an action
   b. promote frailty, based on reform priorities, as a level one policy priority that crosses settings and ministries
   c. shift advocacy discussion from population aging to chronic disease management, especially for the most vulnerable members of our population
   d. make frailty screening a standard of care both in legislation and in standards.

4. Encourage team-based funding models that embrace frailty as a preventive screening tool linked to care pathways and remunerate these models of care appropriately.

5. Encourage the computerization and digitization of frailty screening tools. Integrate tools into electronic medical records to support data aggregation across systems and settings, for population-level analysis.

Everyone is touched by the challenges of frailty. Given the economic challenges that face our health system, frailty provides a compelling platform for policy action. The time is now to scale up frailty screening practices across our federated health system.

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IMPROVING END-OF-LIFE CARE AND ADVANCE CARE PLANNING FOR FRAIL OLDER ADULTS IN CANADA

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Abstract: We present five Key Concepts that describe priorities for improving end-of-life care for frail older adults in Canada, and recommendations based on each Key Concept. Key Concept #1: Our end-of-life care system is focused on cancer, not frailty. Key Concept #2: We need better strategies to systematically identify frail older adults who would benefit from a palliative approach. Key Concept #3: The majority of palliative and end-of-life care will be, and should be, provided by clinicians who are not palliative care specialists. Key Concept #4: Organizational change and innovative funding models could deliver far better end-of-life care to frail individuals for less than we are currently spending. Key Concept #5: Improving the quality and quantity of advance care planning for frail older adults could reduce unwanted intensive care and costs at the end of life, and improve the experience for individuals and family members alike.

Key words: Frailty, end-of-life care, palliative care, advance care planning, health policy, health professional education.

Introduction

Palliative care focuses on person-centered care: promoting understanding of illness, educating the person with illness and their family and caregivers, monitoring and treating symptoms, discussing values, and addressing goals of care and advance care planning. Palliative care is generally provided by an interdisciplinary team, and not every team has dedicated palliative care specialists. In Canada, the majority of palliative care is delivered by primary care providers (1).

Chronic illnesses such as congestive heart failure, chronic obstructive lung disease, dementia, neuromuscular diseases and end-stage kidney disease account for 70% of deaths in Canada (2). These life-threatening illnesses are associated with progressive decline in physical and mental functioning, increased dependence, increased risk of inter-current illnesses, repeated hospital admissions and death. The complexity of managing these chronic illnesses is compounded in people who are frail.

Key Concept #1: Our end-of-life care system is focused on cancer, not frailty.

Clare’s story: “It was such a shock to us when Clare received her diagnosis. She’d been tired for a few months but when she got pneumonia we never thought it could be cancer. After the tumor was found, it seemed like we were suddenly on a conveyer belt. First it was test after test and then chemotherapy. Her doctors and nurses were so good at making sure we understood what was going on and what was going to happen next. We had several months where Clare seemed to bounce back. We had a great vacation with the kids because we had been told the cancer might return. When it did, Clare got so sick so fast. Her breathing was short and she had a lot of pain. Her home support worker was able to access daily care for her at home and I was grateful because it meant I could spend less time as her caregiver and more time as her husband. She was clear she wanted to stay at home and the palliative care team made regular visits and phone calls. I was surprised at how we could do so many things at home that I thought needed a hospital. We were all there together that last week. It was devastating but I knew we had done everything we could.”

Ann’s story: «When I look back on it, it seems so much clearer what was going on, but the last year of mom’s life was
so full of chaos and uncertainty for us. She’d had heart disease and lung disease for many years. In her later years, arthritis and memory loss started to have a major impact on her life. At one point it seemed like she was seeing a specialist every week, but I still had no idea we were so close to the end. Mom’s family physician retired and when we found a new one, she didn’t do house calls. Every time we ended up in the ER, it was like we were starting from scratch. Before she got dementia, mom had been so careful to plan ahead. Her living will said that she didn’t want any heroics if there was no hope of recovery. The problem was that none of us, even her doctors, really understood what that meant. All they seemed interested in was whether she wanted to be resuscitated or not. I spent a lot of nights awake worrying about whether I made the right decisions on her behalf. I remember the last time she went to the ER. She had a bowel blockage. They were about to whisk her off to surgery, when someone told me that it was cancer causing the obstruction. To be honest, I felt relieved. Even though I knew we wouldn’t be doing cancer treatments, we finally, «fit» somewhere in the system. I told the doctors no surgery; that I wanted to talk to a palliative care doctor. They helped relieve mom’s pain and her agitation. She lived for two more weeks in the hospital. I wish I’d known she was so unwell at home. We would have spent less time in waiting rooms and more time in her living room.»

Noncancer illness (including frailty) accounts for more than two-thirds of all deaths in Canada (2, 3), but accounts for only 20%–30% of palliative care consultations and palliative care unit admissions (4, 5). Palliative care is a specialty derived from the needs of people with cancer, and typical palliative approaches do not always translate easily into noncancer illness. Canadians dying of cancer are five times more likely to receive palliative care in hospital than those dying of noncancer illness. The Royal College of Physicians and Surgeons recently approved a two-year subspecialty training program in Palliative Medicine to replace the twelve-month residency program that was conjointly accredited with the Canadian College of Family Physicians. This new program will add training to address noncancer illness, but the one-year Certificate of Added Competency program from the Canadian College of Family Physicians will continue to provide the bulk of palliative care providers, and they will need skills in addressing noncancer illness.

**Palliative care training is oncology-focused**

Most postgraduate training in palliative care occurs within clinical services that focus on cancer. As a result, many current palliative care specialists have had little training in palliation of noncancer illness. The Royal College of Physicians and Surgeons recently approved a two-year subspecialty training program in Palliative Medicine to replace the twelve-month residency program that was conjointly accredited with the Canadian College of Family Physicians. This new program will add training to address noncancer illness, but the one-year Certificate of Added Competency program from the Canadian College of Family Physicians will continue to provide the bulk of palliative care providers, and they will need skills in addressing noncancer illness.

**Recommendations**

1. Any person with an incurable illness and significant symptoms or support needs should have access to a palliative approach to care, without recourse to the emergency room and acute care settings. Palliative care settings should expand the scope of people they serve and the medical supports they offer, to include common and less-invasive life-sustaining therapies with symptomatic benefit.

2. Palliative Medicine residency training programs should include training in the management of people who have chronic noncancer illness, dementia and frailty.

**Key Concept #2: We need better strategies to systematically identify frail older adults who would benefit from a palliative approach.**

The medical and social factors that contribute to frailty can present challenges in knowing when and how to apply palliative principles at the individual level. Individuals and their families may be unaware of the benefits of palliative care for noncancer illness, or uncomfortable with the images that the word “palliative” may invoke. Clinicians relying on diagnosis- or prognosis-based triggers to begin conversations about palliative care will fail to identify many people who could benefit. Models that rely on needs-based triggers may be more appropriate in frailty and may also identify those people who are more likely to benefit from a palliative approach, while avoiding the perception that palliative care is synonymous with end-of-life care.

Diagnosis-based triggers, such as metastatic cancer, are
commonly used in cancer care where clinicians can reasonably anticipate the increasing palliative care needs of a person with cancer over time. This approach also assumes that it will be obvious when the utility of therapies with curative intent are outweighed by their side effects. These assumptions do not apply in terminal noncancer illness, such as chronic lung disease, dementia or congestive heart failure, or in frailty, where multiple other interacting health issues can affect the trajectory. People with terminal noncancer illnesses have significant support needs long before the final year of their life (10) and the risk/benefit balance of therapies is harder to gauge (11).

Prognosis-based triggers are even more challenging to use in frailty. For example, the six-month life expectancy criterion necessary to enroll a person in a hospice-based program in the US has proven problematic for frail people. Clinicians can rarely prognosticate with the necessary precision in this population (4) and may not want to risk the penalties associated with a frail person exceeding their anticipated life expectancy (12).

The Surprise Question, “Would you be surprised if this person died within the next 12 months?” (13), can identify people at risk of death even in the face of clinical uncertainty, and may provide a trigger for clinicians to complete a more in-depth assessment of a person’s health trajectory and needs (14). But it can be challenging to use in frailty, where few deaths would be truly surprising. Highly-accurate prognostic models based on large laboratory and administrative datasets

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Cancer</th>
<th>Organ Failure</th>
<th>Frailty</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trajectory</td>
<td>Progressive, accelerating deterioration</td>
<td>Unpredictable, with exacerbations and recoveries</td>
<td>Slow, progressive deterioration punctuated by incomplete recovery from each subsequent acute health issue</td>
</tr>
<tr>
<td>Treatment</td>
<td>Curative or life-prolonging therapy often stopped at the time of a transition to palliative care.</td>
<td>Disease-modifying therapies also provide symptom control and are usually continued even for palliation.</td>
<td>Frailty is the result of life-sustaining treatment. No effective disease-modifying therapies. Treatment is primarily supportive.</td>
</tr>
<tr>
<td>Prognostication</td>
<td>Well-recognized syndromes or functional decline associated with prognosis of less than six months.</td>
<td>Prognostication challenging, especially for more than three months. People can survive for years with end-stage disease on life support such as dialysis.</td>
<td>Prognostication challenging because population-based models for life expectancy do not inform individual decision making.</td>
</tr>
<tr>
<td>Needs and Concerns</td>
<td>Pain and symptom control; fear of death; social and physical supports typically needed only in final weeks or months.</td>
<td>Symptom control; decisions about life-sustaining therapies for organ failure (ventilation, dialysis, organ transplant); social and physical support needs often longstanding and may exceed symptom burden.</td>
<td>Dependence related to functional decline or cognitive impairment is more concerning than fear of dying; symptoms variable but less common.</td>
</tr>
<tr>
<td>Typical Patient Demographics</td>
<td>Aged 45–75 years, often living with family caregiver.</td>
<td>Aged 70–85 years; partner more likely to be deceased or elderly and unable to provide support.</td>
<td>Aged 75+ years; partner more likely to be deceased or elderly and unable to provide support. Increasingly younger people are identified as frail.</td>
</tr>
<tr>
<td>Typical Patient Location; Composition of Medical Team</td>
<td>Community-dwelling, with increasing visits to acute care medical facility; care provided by single specialist (e.g. oncologist), with transition to palliative care specialist associated with tertiary care facility.</td>
<td>Community-dwelling, with frequent visits to acute care medical facility; care provided by multiple specialists or coordinated by family physician and a specialist; care may be focused on tertiary center or community family physician.</td>
<td>Often housebound or residing in care facility; less frequent visits to acute care medical facility; care generally provided by family physician based at long-term care or assisted living facility, less affiliation with tertiary center.</td>
</tr>
</tbody>
</table>
(15) offer the possibility of using data-based triggers, through automated mathematical models that assess prognosis from clinical datasets. These models showcase the power of big data to provide accurate and automated population-based predictions, but like all prognosis- or diagnosis-based triggers, they do not necessarily identify individual people with needs that can be met by a palliative approach.

Needs-based triggers may include evaluation of burdensome symptoms, psychosocial needs and functional dependence. These triggers offer the advantage of being highly individualized, but they can be resource intensive to implement. A needs-based assessment may be performed at routine intervals or triggered by sentinel events often associated with the last year of life, such as hospital admission or admission to long-term care. Many cancer programs now screen routinely for uncontrolled symptoms and unmet social needs among outpatients. This may translate well to the acute care noncancer setting, but we still lack appropriate triggers for community-dwelling people with organ failure or frailty.

**Recommendations**

1) Palliative care services for noncancer illness should move from prognosis- or diagnosis-based triggers to needs-based triggers. Supportive programs should be extended to accommodate individuals with frailty and noncancer illnesses.

2) Needs-based assessments should be administered routinely at sentinel points in frailty, such as hospital admission, acute health crisis or entering a long-term care facility. This would promote integration of palliative care principles into care planning.

**Key Concept #3: The majority of palliative and end-of-life care will be, and should be, provided by clinicians who are not palliative care specialists**

Frail older adults with multiple comorbidities require an integrated approach to care. Single-system disease models, with each specific illness managed in isolation, do not allow a holistic approach to care for the medically complex person (16). To provide integrated care, interprofessional primary care teams, specialists and community healthcare providers must be competent in recognizing clinical frailty and integrating palliative care principles in the care of frail adults. Yet, with the exception of oncologists, most specialists receive little postgraduate palliative care education. Including a mandatory rotation in palliative care for trainees in programs where chronic illness and frailty is prevalent (e.g., family medicine, internal medicine, geriatrics) would likely improve their ability to provide palliative care, foster more academic collaboration between palliative medicine and these specialties, and lead to innovative interventions and integrative care models. Continuing education in palliative care such as the Learning Essential Approaches to Palliative and End-of-Life Care (LEAP) course provides opportunities for non-palliative care clinicians to acquire palliative care competencies that support interprofessional team-based care (www.pallium.ca). Further, primary healthcare teams must also possess the skills to deliver palliative care, and must be structured appropriately to support clinicians in this work. Primary healthcare teams also require timely access to medical subspecialists and palliative care consultants for both clinical and educational support.

Just as palliative care teams cannot be the sole providers of palliative care to people with complex medical needs, palliative care units and hospices should not be seen as the preferred location of death for frail people. To allow people with frailty to die in their setting of choice, good quality palliative care should be provided at home, in retirement homes, in assisted-living care and in long-term care. The prevalence of frailty in long-term care is high, but a number of significant barriers exist to providing quality palliative care in long-term care facilities. These include a lack of relevant experience and expertise, poor access to medications and medication-delivery devices, and poor availability of palliative care specialists. Education opportunities in long-term care such as LEAP-LTC (www.pallium.ca) are being developed to build expertise, but facilities must also be given adequate funding and staff to use this expertise to provide comfort care. Medications used for pain and symptom management must be available without barriers to access, and special delivery systems such as ambulatory infusion pumps must be available. Funding is also needed to support the availability of consulting palliative care clinicians. Current funding levels are not adequate for any of these purposes, which often leads to frequent and unnecessary transfers to hospital acute care as people approach the end of life.

**Recommendations**

1) Long-term care facilities and home care services should be funded and staffed adequately to allow more people with frailty to die in their setting of choice or the setting that best meets their needs (see funding recommendations under Key Concept #4).

2) Both the Canadian College of Family Physicians and the Royal College of Physicians and Surgeons of Canada should encourage continuing medical education in palliative care to ensure that all practicing non-palliative care physicians are competent providers of basic palliative care.

3) Both the Canadian College of Family Physicians and the Royal College of Physicians and Surgeons of Canada should include mandatory palliative care rotations in family medicine residencies and in the subspecialty training requirements for cardiology, respirology, gastroenterology, geriatrics, nephrology and general internal medicine, as well as in the Diploma programs in hepatology, advanced heart failure and cardiac transplantation, and solid organ transplantation.
END-OF-LIFE CARE FOR FRAIL OLDER ADULTS

Key Concept #4: Organizational change and innovative funding models could deliver far better end-of-life care to frail older adults for less than we are currently spending

Funding models in many provinces are contingent on a person’s location rather than a person’s need. In this type of system, the person ends up “following the money” in search of appropriate care, rather than the funding following the person. If the funding were to follow the person, each person would be more likely to receive the care they want and need in the most appropriate setting.

A further complication is that funding for palliative care services, whether residential hospice, palliative care unit or home care, is conditional on having a short life expectancy. With palliative care changing from an oncology-based practice to one serving people with frailty or multi-morbidity (people for whom a determination of life expectancy is less certain), funding models need to change as well. People dying of heart failure, dementia, lung disease, kidney disease or a combination thereof characteristically have a trajectory marked by periods of stability followed by sudden exacerbation, hospitalization and a period of recovery. Eventually, they will have an exacerbation or event that results in death, but distinguishing a terminal event from an exacerbation can be difficult until very late. With such uncertainty, many people with a noncancer diagnosis have problems in accessing palliative care services.

When dying people are denied access to palliative care services, they must resort to more costly alternatives. The Office of the Auditor General of Ontario (17) recently estimated that caring for terminally ill people in an acute care hospital is more than 40% more costly than providing care in a hospital-based palliative care unit, more than twice as costly as providing care in a hospice bed, and more than 10 times as costly as providing at-home care. In particular, their report noted average costs of providing palliative care in the last month of a person’s life:

- $1,100 per day in an acute care hospital bed
- $630 to $770 per day in a hospital-based palliative care unit (at the two hospitals visited that tracked this information in a comparable way)
- $460 per day in a hospice bed
- $165 per day in a long-term care facility
- under $100 per day in at-home care

The inability of long-term care facilities and home care services to provide palliative care may also drive people toward more costly alternatives. We should not be surprised when a resident of a long-term care facility ends up in an emergency department at night, when their own facility may have only one nurse looking after 100 people. Nor should we be surprised when families caring for a dying person at home, with only three hours of personal support per day, ask to have the dying person moved to an inpatient facility with 24-hour care.

Our US counterparts recognized this problem and created the Medicare Hospice Benefit in 1986, making high levels of funding available to individuals who want to die in a place other than the hospital. This policy led to a dramatic decrease in the proportion of people with cancer in the US dying in acute care hospitals, to the current level of only 22.2%, compared to 52.1% in Canada (18). However, an important limitation of the US Medicare Hospice benefit is that it is still tied to a prognosis for survival of less than six months, whereas people with organ failure or frailty may have high-intensity care needs for years prior to death. Canada’s current levels of home care funding are inadequate to meet this need but, rather than increasing home care resources, we admit people to better-funded facilities at a higher overall cost to the system.

Increasingly, the concept of “capacity planning” is gaining traction in reviewing and adjusting the mix of services available to meet patient needs more cost-effectively. As part of its Patients First Agenda, the Ontario Ministry of Health and Long-Term Care announced its intention to develop a full province-wide capacity plan (19). The plan aims to estimate and map out the types of health and community services that will be needed by its diverse, growing and ageing population in future, and the system-wide savings that could be achieved by rebalancing the provision of these services. In the Mississauga Halton Region, 56% of deaths among people aged 65 or older were in hospital, slightly higher that the provincial average of 52% (20). If this percentage were reduced to the US average of 29% (18), this would mean a reduction of 614 in-hospital deaths, accounting for $9.3 million in hospital funding (based on length of stay and estimated costs of $838 per day). If those admissions and deaths occurred in a hospice ($460 per day), the total costs for these 614 deaths would be only $4.8 million, for a savings of roughly $4.5 million. If those deaths occurred in the home, the savings would be even greater.

The Palliative and Therapeutic Harmonization (PATH) model, described in detail under Key Concept #5, has also shown dramatic savings among seriously ill and frail people. Although the primary objective of the PATH model is to improve the care experience of frail people and their caregivers, its guided approach to decision making has translated into cost savings and cost avoidance in acute care. On average the program saves $7,000 per person enrolled, with the highest savings in those with moderate frailty ($11,000 per person enrolled, based on audit by Deloitte). By promoting a system that encourages the right care in the right place at the right time, we can save money and give people and family members what they are looking for. But as long as healthcare funding remains siloed by location, we will continue to move people to follow the money, delivering the wrong kind of care in the wrong place and at higher costs to the system.

Recommendations

1) Canadian jurisdictions should adopt a funding model in which the funding follows the person rather than the physician, hospital or program.
Key Concept #5: Improving the quality and quantity of advance care planning for frail older adults can reduce unwanted intensive care and costs at the end of life, and improve the experience for individuals and family members alike

Advance care planning is a process that supports people in understanding and sharing their personal values, life goals and preferences for future medical care. The goal of advance care planning is to help people receive care that is consistent with their values and preferences during serious illness. To achieve this goal, advance care planning should focus on preparing the individual and – in particular – their future substitute decision maker for “in-the-moment” decisions about treatment by clarifying the individual’s values. What is most important to an individual in his or her life? What constitutes an acceptable quality of life? This contrasts with outdated models of advance care planning that focused heavily on completing forms (advance directives) to specify decisions about future treatment such as cardiopulmonary resuscitation (21, 22). Advance care planning can improve an individual’s experience, align treatment with an individual’s preferences, avoid unwanted and costly invasive treatments near end of life, and improve psychological outcomes for family members during bereavement (23).

When people become frail, advance care planning becomes especially relevant because the need for decisions about care become prominent. First, frail elderly individuals are at higher risk of having people speak for rather than with them, highlighting the need for preemptive advance care planning (24). Many frail individuals will develop cognitive impairment and lose decision-making capacity over time (25). Advance care planning needs to take place when individuals who are frail are still well enough to share their values with their future substitute decision makers and their clinicians (26).

Second, when frail individuals are faced with treatment decisions, tradeoffs between benefit and harm are sensitive to the values of individuals and to changing priorities over time. A treatment decision that may be right for one individual may be wrong for the next because of differences in what each considers to be a successful outcome (27). Treatment decisions may also change with changes in life circumstances or function in the same individual over time. Advance care planning, with regular updates and support for in-the-moment decision making, is critical to appropriate decision making.

Although advance care planning is critical to improve the care of frail older adults, levels of uptake for advance care planning in Canada are low (28). Nearly half of physicians feel unsure of what to say when doing advance care planning and almost one-third report having no formal training in advance care planning or end-of-life communication (29). Aside from polls or audits of medical records, both of which are more resource-intensive, no other mechanisms exist to track uptake of advance care planning at a population level. Most provinces do not have a specific physician billing code for advance care planning, and none have an accessible repository of advance care planning records that could be used to inform an urgent decision. To achieve the potential benefits of advance care planning, we need to create mechanisms to increase the quantity of advance care planning, monitor its quality (22), and improve accessibility of advance care planning records across the health system.

Supporting in-the-moment decisions about care for frail older adults has some unique issues. Most Canadian seniors (93%) still live in private dwellings (30). Frail older adults can experience long periods of relative stability, with very little contact with the hospital system, until a health crisis occurs. However, people who are frail are precarious and have little reserve to maintain health in the face of even a relatively minor health stressor such as pneumonia or a fall. They are therefore at continual risk for an acute decline. At such times, the informal family caregiver is usually called into action on short notice to make decisions about care. During a crisis, the caregiver or substitute decision maker needs “just-in-time” navigation to support decision making that is informed by an individual’s prior expressed values and goals. Decisions must also be grounded in a collective understanding, between care providers and the decision maker, of the illness trajectory and tradeoffs between risks and benefits of the available and medically appropriate options.

The PATH model of care is designed to help frail Canadians, and those within their circle of care, navigate complex decision making in frailty to optimize the ultimate experience of frailty by an individual and a caregiver. PATH aims to address the gap in care for people who have an indeterminate life expectancy but are at high risk of suddenly worsened health by virtue of their frailty. The PATH model recognizes the need for a holistic understanding of health in areas of the system with a high prevalence of frailty and a high likelihood of interventions. PATH is designed to be implemented by non-geriatrician and non-physician care providers with support from physicians. The model uses structured assessments to get an overview of each person’s health and explicitly considers frailty to inform decision making. A key part of PATH is that individuals and caregivers can access the PATH team for assistance with decision making as health changes, including during a health crisis. The PATH model enhances the experience of individuals and caregivers, improves the appropriateness of decisions about care, and reduces demands for costly medical and surgical interventions (31).

**Recommendations**

1) Improve the education of health professional trainees in communication skills for advance care planning. For example, advance care planning communication should be identified as an Entrustable Professional Activity for physicians similar to other medical procedures.

2) Prioritize engagement in advance care planning when an
individual is identified as frail, with regular updates over time.

3) Institute system changes to support tracking of activity in advance care planning.

4) Adopt a framework of quality indicators for advance care planning activity.

5) Create a physician billing code that is specific to advance care planning.

6) Create or adopt evidence-informed scalable resources to promote best practices around discussions and documentation for advance care planning. This may include an enhanced role in advance care planning for other members of the healthcare team.

7) Implement evidence-informed models such as PATH that can support frail individuals and their caregivers in navigating in-the-moment decisions about care, when health changes.

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References


