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SOCIAL AND SOCIETAL IMPLICATIONS OF FRAILTY, INCLUDING IMPACT ON CANADIAN HEALTHCARE SYSTEMS

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Abstract: Frailty has many social and societal implications. Social circumstances are key both as contributors to frail older adults' health outcomes and as practical facilitators or barriers to intervention and supports. Frailty also has important societal implications for health systems and social care policy. In this discussion paper, we use a social ecology framework to consider the social and societal implications and impact of frailty at each level, 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.

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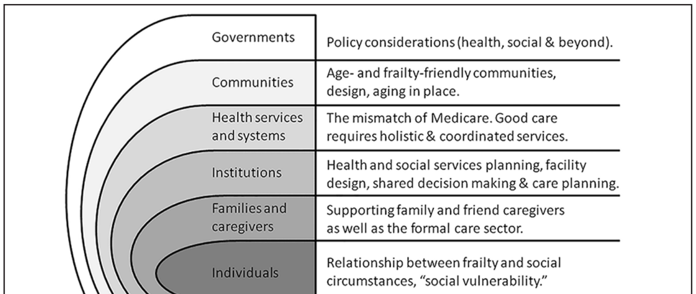
Whether we think of a vulnerable isolated senior living alone in an inner city apartment and teetering on the edge of dependence, a couple aging in place in rural Canada, or the policy landscape that supports (or further disadvantages) informal and formal caregivers, the social context of frailty clearly 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 expanding spheres of family, friends and caregivers, peer groups, institutions, neighborhoods and communities, to society at large (Figure 1; 4, 5).

Figure 1
Ecological Perspective of Social & Societal Implications of Frailty



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Here we will use the social ecology perspective (4) as a framework for considering the social and societal impact of frailty through each level in Figure 1 in turn. This approach allows us to focus on the role of social and societal factors that are extrinsic or external contributors to health at each level, with frailty as an important intrinsic contributor. «Social vulnerability» is discussed here as a summative extrinsic contributor to health and can be understood as the degree to which a person's overall social situation leaves them susceptible to health problems (4, 6). We recognize that the boundaries between levels of impact are often blurred. We see this not as a weakness of the model but rather as an opportunity to reflect and marvel at the complex interrelationships to be found when we set to thinking about the many and varied social and societal implications of frailty.

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 hardiness, 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 shoulder 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 polices 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 to be particularly important in these care settings (52-54). Despite philosophical shifts in favor of a social (rather than biomedical) model of care in assisted living and long-term care, a significant need remains to increase awareness in staff and family members of social vulnerability and opportunities for meaningful resident engagement. Staff training and continued professional development could present opportunities to integrate social aspects of frailty into curricula. We expect that a better understanding of social vulnerability as a core consideration in frailty would help significantly in developing person-centered care structures and processes in assisted living and long-term care (55-57).

From an infrastructure perspective, design and location of residential care facilities are particularly relevant to facilitating (or impeding) both formal and informal opportunities for residents to engage socially. Residential facilities can be seen as potential "modes of delivery" of social capital for frail residents (58). This is made clear when we imagine two contrasting facility designs. A facility in which resident rooms are spaced out along long corridors with few common spaces would present mobility and space barriers for social interactions; a facility in which pods of resident rooms surround common spaces could facilitate informal and formal interaction and social engagement. This language of social participation has entered into the discourse of designers and planners, who now speak of "neighborhoods" within facilities (58). Likewise, the location of residential facilities within communities benefits from analysis through a social lens. Should facilities be built in business parks on the edge of town, potentially further isolating frail older people from society at large by limiting their opportunities to engage with the outside world? Or should facilities be integrated into walkable communities and neighborhoods?

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.

Conflict of interest: None

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