

A Plan of Action: 11 Recommendations to Enhance Long-Term Care Provision in Canada

**Insights from a Project on
the Transitional Care of
Rural Older Adults**

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Executive Summary

Insights from a Project on the Transitional Care of Rural Older Adults

Older adult health and care has become a major foci of research, policy and practice in the 21st century (Allen et al., 2017). Accordingly, the World Health Organization (2015) recommends that health care systems should be designed to fit the needs, values and preferences of older populations as well as the unique contexts that shape geriatric health in local communities. These recommendations aim to facilitate national health care system reform to improve the health of older people and the support available to them in later life (Allen et al., 2017). Since the aging population will increase the number of older patients accessing health care services, better attending to chronic conditions, multi-morbidities (Banerjee, 2015) and the social determinants of health (Almeida et al., 2017) is pivotal to align Canadian health care services with the populations that they serve (Allen et al., 2017; Enderlin et al., 2013). Investigating the transitional care experiences of older adults fosters insight into how to achieve this realignment. Indeed, critical health research has exposed the connection between effective transitional care and quality health care service delivery by uncovering the system efficiencies and improved health outcomes that can be gained when transitional care is optimized (Naylor et al., 2017; Laugaland, Aase & Barach, 2012; Hirschman et al., 2015). This scholarship refocuses care on patients and their caregivers rather than on the elements and processes that more readily benefit health care organizations or professionals (Allen et al., 2014; Hirschman et al., 2015). Investigating the experiences of older adults across the care continuum then embraces the person-and-family-centred approach to care that is required to provide quality health services to Canadians now and for decades to come.

Although evidence-based transitional care strategies have been developed by leveraging current academic research (CIHR, 2017; SCN, 2017), the Canadian Institutes of Health Research Transitions in Care Initiative acknowledges that a gap exists in the application of these strategies for older populations in rural communities (CIHR, 2017). To redress this gap the “Transitional Care of Rural Older Adults” project was established. Embracing a community-based partnership between The Trent Centre for Aging & Society, Haliburton Highlands Health Services, Seniors Care Network and Haliburton Extencicare this project explored the experiences of older adults as they transferred either between:

- 1) a hospital and a long-term care home or
- 2) a hospital and a residential home in the community

Using a three-phased approach, observations and verbal accounts of these experiences were documented. This comprehensive method engaged stakeholders from multiple levels (health care providers, informal supports and older patients) and care settings (emergency care, acute care and long-term care services) within the health care system. In addition, administrators/managers, front-line care providers with different professional designations as well as ancillary staff were sought out to participate in the project to ensure the representation of multi-varied perspectives.

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In total, 99 informants participated in the study providing a contextually sensitive account of the underlying factors that contribute to quality older adult health and care in rural Ontario. These key findings will enhance the National Standards of Long-Term Care in Canada by catalyzing the health care reform that has been advocated for by health scholars across the country. This report will first present the critical findings from this project that are pertinent to the provision of long-term care services and then provide 11 best practice recommendations to enhance the provision of long-term care in Canada. Assisting in the transformation of the health care system, these considerations will provide all Canadians with quality health care that meets the demands of the 21st century.

11 Recommendations to Enhance Long-Term Care Provision:

Embrace

Embrace holistic models of care to align front-line practice with the ways in which residents define their health

Attend

Attend to the experiences of residents and their families as a process over time and place

Support

Support older adults and their informal caregivers with the emotional overlay of health and care

Respect

Respect autonomy by aligning care provision with resident priorities and increasing opportunities for choice

Adapt

Continually adapt care policies, structures and processes to ensure that front-line care provision is flexible to align with the ways that older adults define their health

Address

Address data management misalignments and communication breakdown within and between care sectors to establish collaborative care planning in practice.

Provide

Provide staff training and identify staffing models that support holistic health, quality of life and the emotional overlay of health and care

Recognize

Recognize that large catchment areas, displacement and universal models of care foster inequitable services in rural areas

Establish

Establish methods to evaluate holistic health outcomes, quality of life and the intangible aspects of care to prioritize them in front-line practice

Increase

Increase long-term care service options and access

Include

Include local communities as essential team partners

Findings

Aligning Long-Term Care Services with Older Populations & Local Communities

Appreciating how Older Adults Define their Health

In Ontario, health services do not align with the ways that older adults define their health. While health is considered to be holistic, interconnected, fluctuating, conflicted, unpredictable and unique, health services are rigid and bio-medically focused. This inflexibility is created by other aspects of health being prioritized in the current structures (e.g., target health outcomes, quality indicators, funding allocation as well as provincially and professionally driven priorities) that guide the provision of care. For example, few methods exist to formally evaluate the provision of holistic care in practice and therefore intangible aspects of health (e.g., the “feeling of care” or attention to small details/preferences) are not well attended to in contemporary models of service provision. As a result, front-line care providers face moral dilemmas in practice as they attempt to navigate the divergence between macro system goals and the personal goals of their patients. These dilemmas put pressure on older adults and their families to accept the misaligned care options available, which increases responsive behaviours, decreases mental and physical health and/or leads to the decline of formal services (“refusal of care”). Consequentially, macro driven health services greatly struggle to foster patient-and-family-centred care.

The 6 Ways that Older Adults Define their Health
Holistic- health is physical, psychological, social, spiritual and reflective of both individual identities ¹ as well as the social determinants of health ² .
Interconnected- factors that construct health are interdependent and cannot be treated or cared for separately.
Fluctuating- Individuals definitions of health and care change over time in response to their health presentations (e.g. physical/cognitive abilities, diagnoses, responsive behaviours), values, preferences, social networks, identities and the social determinants of health.
Conflicted- Individuals may define their health one way, but their actions may reflect other priorities. These conflictions can result from individual autonomy to prioritize other aspects of life (e.g. older adults may identify that exercise is important to maintain ‘good health’, but choose not to) or from societal inequities that act as a barrier to pursuing ‘good health’.
Unpredictable- Trajectories of health are not definitively predictable. As such, identifying the type of care older adults will need in the future is also not predictable.
Unique- Older adults do not prioritize their health and care needs in the same way. Similarly, trajectories of health and care are not experienced in the same way.

¹ Identity construction includes aspects such as gender, ethnicity, sexuality, socio-economic status etc. that contributes to the oppression of individuals other than the dominant norm as well as to the diversity of individuals’ wants and needs for health and care

² Based on the government of Canada’s definition of the social determinants of health (Government of Canada, 2018).

Findings

“The CCAC put pressure on me to put more long-term care homes on our list. It is only because I am a strong advocate that I haven’t. It’s a lot of pressure when that is not what we want.” (Informal Support - Community 33)

The misalignment of macro features of the health care system has impacts on the provision of long-term care. For instance, older residents indicate that social engagement is the most important aspect of their health, yet the biomedical focus of long-term care services means that subsistence is centralized in the daily routines of older residents (e.g., eating, medication, hygiene and toileting). This prioritization of biomedicine is reinforced by staffing models that are composed primarily of nursing and personal support staff, which undervalues other health professions that more actively embrace holistic models of care. Since attending to holistic health is pivotal to minimizing sun downing and engaging residents with responsive behaviours (Yous et al., 2020), the biomedical focus of long-term care fosters unsafe environments by not adequately attending to these residents’ needs and preferences. The prioritization of the biomedical care model in long-term care must then be addressed to better attend to the holistic health of older residents. This patient-and-family-centred approach will require the flexibility of macro structures to ensure that front-line practice can easily be adapted to the ways in which older adults define their health.

“I’m not sure that physical health is more important than mental health. I don’t know which is more important, but I don’t think you can separate them. You can’t feel physically well if you are mentally unwell and vice versa. Services really shouldn’t be geared to one or the other.” (Informal Support - Community 57)

Findings

Consider This: The Misalignment of Data Management leads to poor Quality Care

Formal health care providers have extensive knowledge on the social determinants of health, yet documentation and information exchange more readily reflect other aspects of care provision. The collection, use and transfer of information between care settings is then not patient-centred and does not support the holistic health of older adults. Instead, data management and communication processes prioritize biomedicine, risk management/liability and professional obligations. In addition, long-term care staff maintain that the information that they receive from other care settings is not always accurate due to the minimization of certain types of information (e.g., responsive behaviours) to avoid admission refusals. Psycho-social information on patients (e.g., preferences, informal supports other than the Power of Attorney/Substitute Decision Maker and family dynamics) is also absent from the information provided by other health services resulting in long-term care staff not feeling comfortable to continue patient care with the information they receive from other sectors. As such long-term care staff spend an exorbitant amount of time re-collecting and/or synthesizing the patient information that they need to provide care.

These aspects of data management contribute to older adults and their families frequently having to repeat information that they have already provided to other long-term care staff or to health professionals from other care sectors (e.g., family physician, acute care staff, community care staff or LHIN staff). In particular, older adults and their families repeat their personal health and care information: 1) upon entry into a new care setting, 2) after a staff shift change, 3) when meeting a new staff with a different professional designation and 4) when meeting a staff who is visiting from a different sector. Even though older adults and informal supports repeat this information frequently, they still do not feel that they are involved in the formation of their plans of care. Addressing the inefficiencies that impact the management of resident information both between and within care settings then needs to be addressed to foster a patient-and-family-centred approach.

**“Staff don’t seem to have any information. It’s frustrating because if they would look back at her medical history or looked at her old charts they would know that she doesn’t respond to that kind of antibiotic.”
(Informal Support - Community 57)**

The Emotional Overlay of Health & Care

Patient experiences are not objective or tangible, but rather are inscribed by emotional responses to health and care. These experiences are unique, fluctuate often and can also be conflicted. For example, an older adult may be relieved to move into long-term care due to the increased personal care services they will receive but may also be mourning the loss of intimacy they previously shared with their loved ones. The table below displays some of the emotions that were identified by older residents and their informal supports both prior to and after moving into long-term care:

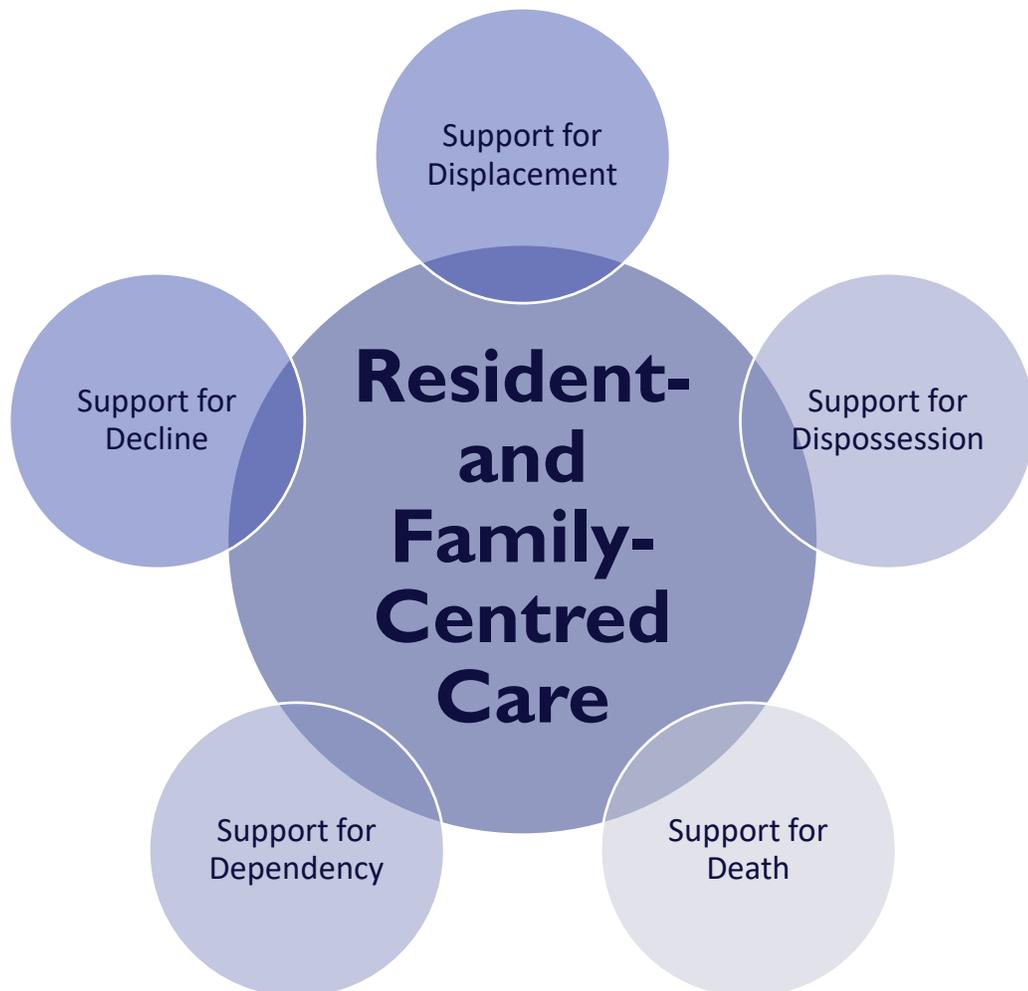
Emotions Prior to Moving in Long-Term Care	Emotions After Moving into Long-Term Care
Agitated, frustrated, stressed, worried, fine, uncertain, conflicted, confused, anxious, fearful, guilty, no choice, angry, depressed, apprehensive, terrified, complacent, torn, calm, happy, grateful, impatient, overwhelmed, drained, apprehensive, exhausted, frantic, nervous, traumatized, reassured	Agitated, stressed, frustrated, happy, calm, tired, overwhelmed, depressed, lonely, relaxed, relieved, settled, loss/grief, dying, permanency, stripped, uprooted, confused, never ending, satisfied, guilty, stressed, worried, conflicted, ongoing

Moving into long-term care is particularly emotive as it is experienced as a process of bereavement, yet health system priorities undervalue the losses experienced by older people and their informal caregivers. Certainly, emotional reactions to health and care begin well before an older adult moves into a long-term care home and for the family extends long after a resident has passed away. Although these responses are heterogeneous, there are several common emotional experiences that impact older adults moving into or living in long-term care facilities.

“They don’t recognize that needing more care means you are moving away from someone you have lived with for 23 years.” (Informal Support - Long-Term Care 26)

Culminating in sentiments of displacement, dispossession, dependency, decline as well as evoking reflection on death, older adults have intense reactions to transitions due to the bereavement of losses in later life. While transitions into long-term care evoke strong emotions, health care services do not acknowledge these experiences and the formal biomedical training of front-line staff leaves older adults and their families struggling to process this last move on their own. Pursuing resident-and-family-centred care then requires attention to the emotional overlay of health and care as well as loss in later life. The 5 Ds model (p.9) outlines the common experiences of older adults and their families, which have been thoroughly detailed in the sub-headings that follow.

The 5 Ds: Supporting the Emotional Overlay of Health and Care in Long-Term Care



Findings

Displacement

Older adults experience displacement from the intimate social networks and relationships that they maintained prior to moving into long-term care. Even older adults who move into long-term care homes in their local community experience displacement due to living apart from spouses or being estranged from other family members, neighbours, acquaintances and/or religious communities. While aspects of these relationships may be retained while residing in long-term care, the lack of intimacy and interaction with these individuals permanently alters the nature of these connections. Grieving the new parameters of these relationships is then common for older residents and their loved ones.

Rural Reflection

Rural older adults experience displacement as a relinquishing of their rurality⁴ as many older adults must move out-of-county to access long-term care services. Rural residents in long-term care experience both physical and psychological health decline due to being physically and emotionally displaced from their intimate social networks.



³ facets of rural contexts that influence residents' lives, perceptions, wants, needs, actions and attitudes fostering a connection between residents and the places that they live.

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Dispossession

Older adults experience dispossession as they must give up their property and estate to move into long-term care and leave behind the majority of their personal possessions. Older adults grieve these losses as many have accumulated belongings over their lifetime that hold sentimental value to them. Older adults connect this dispossession with the aspects of their lives that they will no longer live.

“Patients feel they have been stripped of all the things in their life. They have everything at home and they are limited in what they can bring here. They had a whole different life and it can be hard to accept care. It’s almost like they are being stripped of everything when they come through those doors.” (Front-Line Staff-Long-Term Care 61)

Dependency

Older adults experience moving into long-term care as forgoing their autonomy and independence and replacing these aspects of life with dependency. Since older adults identify and value independence as an inherent part of their identities, moving into long-term care is experienced as a bereavement of their former selves. The acceptance of personal care then requires the reconstruction of older adults’ identities, which some residents acknowledge they will never fully be able to embrace. Older residents are also triggered daily by other residents who exhibit severe cognitive and physical disabilities that they are not a custom to. This exposure results in older residents self-reflecting on what they have lost and their proximity to end of life.

“To make this better people have to recognize that it isn’t just a move. It’s not you supply me with a bed and meals and care and I’m good. It’s a huge mental process. I don’t know how long transition is, but I know I am still in it.” (Informal Support - Long-Term Care 90)

Decline

Older adults experience moving into long-term care as a decline of their holistic health. Since older adults seek out long-term care services due to physical and cognitive impairments that cannot be cared for in the community, older residents connect this move with coming to terms with aspects of

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their lives that they will no longer live. Certainly, physiological and psychological aspects of health become more pronounced, leaving little time and energy for other aspects of their health that they once enjoyed.

“It’s a grieving process. You have to get use to a whole new life. I am not better in here. They keep saying I’m better in here. And they say I need to be here because of my health needs, but I don’t think so.”
(Older Adult - Long-Term Care 27)

Death

Moving into long-term care is connected with the processing of mortality. Certainly, older adults recognize the permanency of moving into long-term care and have difficulty processing that this will be their last move. Older adults reflect on their lives, their memories, their achievements and their regrets as they bereave their loss of life. While older populations fear that mortality is more eminent (Lockhart et al., 2001), palliative and bereavement services are only initiated at end stages of life, if they are initiated at all (Gallagher & Passmore, 2020).

“Who knows maybe in a couple of weeks I’ll feel better about it, but it’s hard to know and I keep coming back here, that I am here for good. I am here permanently. I’m too old. I am going to die here for sure. This is where you come to die.” (Older Adult - Long-Term Care 83)

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Increasing Choice to Decrease Aversions to Long-Term Care

Contemporary health care systems are designed based on linear algorithms of care. For example, once an older adult requires a set number of personal care hours, their only option (if they are not affluent) is to accept a bed in a communal long-term care facility. Certainly, moving into long-term care is experienced not as a ‘choice’, but as a threshold in which older adults’ care needs surpass what can be provided for in their community. Since older adults fear dependency and losing their autonomy, this lack of options deters them from accessing formal services until they have to. Even older adults with severe cognitive and physical impairments who are no longer capable of making the decision about moving into long-term care, have strong aversions to accessing these services. Since older populations and the general public link accessing long-term care services with health decline and mortality, these ‘dependency’ cultures are particularly difficult to redress. As a result, older adults and their families often delay applications to long-term care, which contributes to medical episodes (e.g. fractures, medication misuse etc.) being the major prompt to initiate long-term care applications. The limited long-term care options in Canada then fuels the on-going crisis nature of long-term care admissions by decreasing the ability of older adults to exercise their autonomy in later life.

“My mom would never have agreed to go into a home. There is no long-term care application. Never in a million years would she agree to go into long-term care.” (Informal Support - Community 56)

A patient-and-family-centred approach values the autonomy of patients and their families. Older adults and their loved ones must then be provided with more opportunities to actually make choices when accessing and while living in long-term care. These options will decrease older peoples’ aversions to living in long-term care settings by truly respecting the autonomy of residents and their families.

“It’s not fun getting older because you have to do what other people want you to do instead of what you want to do. I have no more home. He said this is my home and I said not in my brain.” (Older Adult - Long-Term Care 83)

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Consider this:

Long-term care facilities indicate that older adults have a right to smoke, yet residents are permitted to smoke only if they can get to the designated smoking area safely or if someone can assist them. The biomedical focus of formal care, however does not allow front-line staff to prioritize assisting residents outside to smoke even if the older resident indicates that smoking is an important aspect of their quality of life. This approach to care engrains ableism⁴ into front-line practice by taking away residents' choices due to physical and cognitive impairments.

“We have three gentlemen in here that smoke, but when they move in here we don't allow them to smoke unless family take them. (Front-Line Staff - Long-Term Care 40)”

Rural Reflection

Rural older adults are averse to moving into long-term care due to their crowded and fast-paced environments that starkly contrast their previous homes.

“It's getting use to living with so many people after living on your own for so long. It's hard. It's really hard and there's not support for that.”
(Informal Support - Long-Term Care 87)



⁴ Ableism is discrimination towards people with physical/cognitive impairments by favouring able bodied people.

Findings

Local Care is needed for Local Populations

Rural communities are unique with a diverse range of resources, supports, advantages and challenges, however these contextual facets are rarely considered in the care of older populations due to the macro focus of service provision. For example, rural health systems have potential to benefit from integrating their smaller rural health systems, however jurisdictional and funding divisions between health care sectors impede the ability of rural regions to fully embrace this best practice approach. These sectorized divisions make human resource deficits and service limitations in rural areas more pronounced by not allowing resources to be shared between health care services. Similarly, while rural communities can provide an intimate and supportive culture, public health services rarely collaborate with private, secular, non-secular and research entities that are dedicated to the on-going improvement of the local area. As such, macro driven care initiatives lead to inequities and access issues in rural regions due to the inability to leverage the strengths of local communities.

Rural Reflection

While Ontario has initiated a 'Home First' program to limit the adverse consequences of long hospital stays, the inadequacies of rural home care contributes to rural older adults being sent back to their residential homes without access to appropriate support while they wait for long-term care services.



Macro driven care models impact the use of long-term care services in rural regions. Since rural areas have few housing options for older adults in need of care (e.g. retirement homes, assisted living and supportive housing) and contemporary models of home care are not effective in rural environments, long-term care is utilized more often by rural older populations than their urban counterparts. Many rural residents also experience early entry into long-term care due to the biomedical focus of community services and the aging support networks that struggle to assist older

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adults in their community to age in place. These contextual features result in the number of provincially allocated long-term care beds in rural areas being disproportional to the needs of older adults in these regions. Many older adults must then access long-term care and/or assisted living outside of their communities, culminating in the displacement of older people and the requirement of additional resources (e.g. travel time, finances & transportation access). Consequentially, these barriers to accessing long-term care lead to the health decline of rural older populations.

“BSO was supposed to be put in place to combat wait-times for long-term care, but as someone pointed out BSO is not going to help with wait-times when there are no beds to go to. They can help stabilize a patient through interventions that work for behaviours, but if patients aren’t able to move out of hospital because there are no beds in long-term care, that’s the real problem.” (Front-Line Staff - Acute Care 45)

Macro initiatives also contribute to the inequitable care of rural older populations. Since long-term care is designed based on the provision of care in urban centres, these models rarely fit the needs of rural areas due to the lack of consideration of human resource deficits, limited services, large travel distances, socio-demographics and the high cost of living in rural areas. For instance, food costs in rural communities are significantly higher than urban centres, however these additional costs are not considered in the funding allocated to rural long-term care homes. Similarly, responsive behaviours are particularly problematic in rural communities where large catchment areas result in a lack of support from geriatric specialists and provincial interventions such as 1:1 staffing undermine regional human resource challenges.

“They [residents in long-term care] don’t get fresh fruit and veggies because we pay more for shipping up here.” (Administrator/Manager - Long-Term Care 78)

While the Behavioural Supports Ontario program in long-term care has been successful to reduce responsive behaviours throughout the province (Gutmanis et al., 2015), rural long-term care homes often share these support staff between facilities in their region due to the limited number of residents that they serve. This model generates inconsistent support for older adults exhibiting responsive behaviours, which counters best practice in caring for these vulnerable populations.

“The ministry does provide 1:1 for behavioural patients, but you have to have the staff to do 1:1 and it’s a process to fill out the application and it is a real challenge to fill those shifts. If those transfers came with extra resources it would be different.” (Front-Line Staff - Long-Term Care 37)

The ability to adapt long-term care provision to local contexts is then paramount to ensure patient-centred care that considers the diverse regions in Canada in which older adults live. Rural Reflections have been provided throughout this report to emphasize the importance of tailoring health care services to the needs and preferences of local populations.

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Valuing Older Peoples' Experiences of Health and Care Over Time and Place

Older adults experience health and care as a process over time that is not restricted by any one care setting. In contrast, health care services fixate on transfer events, such as admissions and discharges, which undervalues older adults' on-going experiences. Macro care structures reinforce this focus on transfer events through policies, procedures, funding allocation, quality management and provincial initiatives that prioritize patient flow through the health care system. This macro driven system fosters a utilitarian rather than an individualized approach to patient-centred care, which undervalues the experiences of older adults prior to, during and after transfer events. Specifically in long-term care, the admissions and discharges of residents are expedited to free up 'beds' in other areas of the health care system and to ensure that adequate operational funding for the home is maintained (as operational funding is directly linked with resident occupancy rates). As such, the move into long-term care is experienced as a hastened process with life altering decisions being made quickly to ensure the efficient turn-over of residents. Resident discharges after death, however, are also problematic, as families are expected to collect the residents' belongings quickly, undermining the bereavement experiences of family members who have just lost their loved one. The provision of task-based care is common during these transfer events, as health professionals try to attend to the long list of logistical requirements that are connected to resident transfers in and out of these facilities. This approach counters best practice in the provision of quality patient-centred care that stipulates that quick turn overs as well as task-based and fast-paced care environments are detrimental to older populations (Kelley et al., 2011). As such, older adults and their families are overwhelmed by admissions and discharges that are not adequately supported.

“My number came up so I had to move, otherwise someone else would take the bed and then you have to go on the bottom of the list if I didn't want to go. Then I don't know how long it would take to get in again, so there was a lot of pressure.” (Older Adult - Long-Term Care 27)

“Last Wednesday the LHIN called me and said there was a bed available and I had 24 hours to decide. 24 hours later she was at long-term care. It's all been so quick so you review and review in your mind all the things you have to do. You have to make all these decisions so quickly and set things up so fast.” (Informal Support - Long-Term Care 75)

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“Family has 48 hours to get out of the room, but when we are talking about funding there is a timeline.” (Administrator/Manager 78)

In contrast to this bed flow culture, patient-centred transitions occur when time and resources are dedicated to support the experiences of older adults and their families over time and place. Representing resident-and-family-centred care, this transitional support is required prior to the older adults’ decision to put their name on the wait-list for long-term care till after the resident has passed away. Allocating transition staff to accompany older adults and their families throughout their health and care experiences then leads to quality care by establishing a connection between care sectors, ensuring effective patient information transfer and providing support for the emotional overlay of these experiences.

“The staff knowing that she needed to have her [taken out to maintain anonymity] with her and the staff member going over to check on her the day of admission really helped. He was able to help with her transition. This helped to situate her, especially to have that staff that she knew. It didn’t feel like they were passing her off, it was just about the patient. It was very personal care and that’s the best. It was huge to have that person she knew there and help her settle.” (Informal Support - Long-Term Care 75)

Findings

Consider This: Information Relayed to Older Adults & Their Families about Long-Term Care

Older adults and their family members experience information overload during transfer events (such as admissions and discharges), but rarely retain this information due to the overwhelming nature of these experiences. To address this communication breakdown, health care services provide numerous pamphlets, however, the majority of this information is never read. On the other hand, older adults are given very limited information on what life will actually be like once they move into long-term care. This lack of information results in negative experiences of older adults as they transition into living in long-term care homes. While older adults and their families indicate that they do not need any more information prior to moving into long-term care, most residents and their families identify questions retrospectively that they would have asked only after they have already moved. The methods used to familiarize individuals with long-term care environments therefore need to change to support older adults to feel comfortable as they transition into and reside in long-term care.

3 Things Older Adults & Their Families Need to Know Prior to Moving into Long-Term Care

- 1) Bed allocation is based on availability rather than compatibility with roommates.
- 2) Some residents have significant cognitive impairments. As such, they may wander into other resident's rooms or take items that do not belong to them.
- 3) There is a limitation and type of personal belongings that can be brought into long-term care.

“At first when you start needing care there are so many people coming in giving you information and that’s confusing. It’s too much information and you don’t really understand how to access all the different kinds of supports and services and what’s available.”

(Informal Support - Long-Term Care 21)

“There needs to be support before they get here. A lot [of residents and family members] have only been given a pamphlet or talked briefly with CCAC, but not given support with the actual process.”

(Front-Line Staff - Long-Term Care 35)

Findings

The Social Stratification of Long-Term Care Services

Contemporary health care structures and processes engrain social stratification into practice through the establishment of macro initiatives that are not adaptable to the diverse needs of older populations. As such, older adults other than the dominant norm experience health care inequities and barriers to care access. While those with affluence can afford private care, have access to more care options and have the means to age in place, older adults with lower financial means regularly accept long-term care services prior to requiring 24 hour support and are more likely to be pressured into accepting long-term care beds outside of their home communities. Considering the admissions process into long-term care, social stratification contributes to access inequities of older adults with lower financial means through Ontario's prescribed ratio of private, semi-private and basic beds in long-term care homes. Specifically, older adults with lower financial means can only be placed on the basic bed waiting list, resulting in these individuals waiting longer for long-term care services or being pressured to move out-of-county to obtain timely access. Since older adults experience both physiological and psychological health decline due to extended hospital stays and displacement, the social stratification engrained in the admissions process of long-term care contributes to the health inequities of those older adults with lower financial means.

Rural Reflection

The high cost of living in rural areas (rent, food and transportation are proportionally more expensive in rural and remote regions when compared to the average household income) limits the amount and type of care that can be provided to those with lower financial means. For instance, the high cost of transportation results in older adults with lower financial means declining medical services that are not provided in long-term care settings.



Findings

Consider this: 2 Loopholes to Skip the Long-term Care Queue

To avoid the impact of extended wait-times for long-term care, two loopholes have been sought out by applicants to circumvent the social stratification of the admissions process. First, applicants can pay for a private room temporarily upon admission and then be placed on an internal transfer list for a basic room. Since the wait-list for private beds is typically less than the wait-list for semi-private and basic beds, this loophole helps older adults to gain entry into long-term care faster. Second, older adults can be placed on a crisis list which allows them to be prioritized entry into long-term care above others who are on the wait-list. Interestingly, those applicants who put their name on the wait-list for long-term care ahead of time wait longer in hospital as a result.

Long-term care practices favour the dominant norm and lead to the erasure of the needs and preferences of vulnerable populations (Chaze et al., 2019). In particular, inclusive care practices for older adults other than the dominant norm (e.g., Minoritised ethnic populations, LGBTQIA populations etc.) have been stipulated in some long-term care policies, yet these policies have not readily been translated into the front-line care models and/or the processes used to care for these residents. These factors lead to long-term care services that do not consider the diversity of long-term care populations, perpetuating the disadvantage of residents other than the dominant norm. Macro structures, models and processes of care thus require reform to ensure equitable access and the provision of holistic care within and when accessing long-term care services.

“In this particular case he was able to afford to live in his home and we were able to pay for a full-time caregiver. That meant that he had three square meals a day. She would bring him a newspaper. Check in on him. Do laundry, housekeeping. That allowed him to maintain his independence, but not everyone has that luxury.” (Informal Support - Community 73)

“Patients that are moving from hospital are the patients on the private list. This is an example of where money matters.” (Front-Line Staff - Acute Care 32)

Findings

Systemic Ageism in the Health Care System

Elderly friendly' models are emerging in health care; however, these initiatives are ineffective within broader systems that devalue older adults' needs and preferences (Karki et al., 2015). Specifically, the prioritization of biomedicine and patient flow internalizes ageism within the health care system. Bed flow culture in long-term care is particularly detrimental as it positions older patients as a barrier to systems efficiency rather than as a client to be served. This rhetoric is so engrained that older adults, themselves, are concerned about their strain on the system and experience deflation when they fail to fit the services provided (Banerjee, 2015). The consequences of ageism are then cyclical: older adults avoid reaching out for support until the point of crisis, which increases the cost of care (Clarke et al., 2017; Levy et al., 2020) and perpetuates the stigmatization of older populations.

A pressing example of systemic ageism in health care is the lack of long-term care beds available in Canada to adequately support the aging population. This lack of beds engrains ageism into front-line practice by insisting that older adults plan for their potential future care needs. Certainly, older adults put their names on long-term care wait-lists prior to needing 24 hour support in an attempt to avoid the 2-3 year wait to access these services. Planning for potential future losses, however, is not expected of any other age category and older adults and informal supports actively or passively reject this requirement. This approach to wait-lists results in older adult health decline either due to waiting for needed services or accepting a bed earlier than expected out of fear that another bed will not become available.

“There is something wrong with the way the wait-list to get into long-term care is done. It’s like patients put their name down because they know that the wait is so long, but then patients aren’t ready when their name comes up. A lot of times people come to long-term care earlier than they use to and this decreases their life span because they don’t know when the next bed will come available.” (Front-Line Staff - Long-Term Care 36)

Ageist language is used commonly in long-term care practice to describe older people (e.g. ‘bed’, ‘bed blocker’, ‘new admit’ and ‘ALCs’⁵). Other words such as ‘uninformed’, ‘live at risk’ and ‘refusal of care’ place judgments on older adults who do not prioritize biomedical definitions of health, who choose to exercise their autonomy or who are responsive to care practices that do not fit their needs or preferences. Interestingly, health professionals use this language not with the intention of discriminating against older people, but as a means to safeguard themselves from the divergence

⁵ Abbreviation used for Alternative Level of Care Patients

Findings

between macro system goals and the individualized needs of their patients. While this language is important to address, the systems and structures that engrain discrimination into practice and the limited care options available to older adults require reform to fully address systemic ageism within the health care system.

“As you age, you feel that you are being ignored and that your issues are not as important as those people who are 30-40 and that it’s expected that you will decline. It’s throughout the system, it starts with doctors and goes all throughout from nurses to care workers.” (Informal Support - Community 46)

“There is a pressure on older adults as the health system describes them as bed blockers.” (Informal Support - Community 54)

Consider This:

Current care practices in long-term care stipulate that older adults can consume solid food even if they have been prescribed a puree diet. This resident is said to be choosing to “live at risk”. This use of language, however places judgment on residents who prioritize other aspects of health above their physical health or who would rather choose death over losing their quality of life. In this case, health care practice defines these actions as a form of risk whereas residents connect these actions with life.

Findings

Considering All Informal Caregivers & Providing Them with Support

A plethora of health scholars have focused on the pivotal role of informal supports in caring for aging populations (Brigola et al., 2017; Powers & Buckner, 2018; Brigola et al., 2017). Specifically, informal supports perform many logistical tasks and provide the majority of social care, emotional support and recreational opportunities to counter the biomedical focus of contemporary care provision. Those older adults without informal supports are disadvantaged, since formal health services do not adequately attend to the holistic health of residents.

While the role of an informal caregiver is extensive, the legal designation of Power of Attorney (POA) and Substitute Decision Maker (SDM) places the majority of these responsibilities on a few individuals. Certainly, care processes in long-term care undermine the support that can be provided by other informal supports that does not impact patient confidentiality. Similarly, POAs/SDMs are not provided with education on the roles that other informal caregivers can play in the care of older residents. As a result, POAs/SDMs with health concerns, those with family commitments, those who are aging and those who are employed full-time struggle to support their loved ones.

**“Patients end up relying really heavily on neighbours, but when you aren’t the POA you aren’t part of the circle of care. I think we need to involve everyone in the plan including neighbours and friends.”
(Informal Support - Community 54)**

Although informal supports experience caregiver burn-out, they are also deeply impacted by the decline and uncertainty of their loved one’s health and grieve the former relationship they once shared. These circumstances contribute to informal supports experiencing extreme care giver guilt due to having to institutionalize their loved one when most promised that they never would. Despite the extent of these emotions, informal caregivers rarely share these experiences with formal health professionals and many informal supports indicate that they do not have the time or energy for the current formal support programs that have been made available to them.

“She never wanted to move into long-term care and it is the hardest thing knowing that we are going against what she wanted.” (Informal Support - Long-Term Care 87)

Findings

“He’s screaming in the middle of the night and calling me crying. It’s been incredibly stressful to manage.” (Informal Support - Long-Term Care 89)

The all-encompassing role of informal caregivers and the emotional strain that they experience results in the crisis nature of long-term care admissions. Generating processes to acknowledge the full extent of an older resident’s informal care network and generating new methods to support informal caregivers is then pivotal to generate patient-and-family-centred care.

Rural Reflection

In rural communities, the strain placed on rural caregivers is heightened due to aging populations and youth out-migration that leads to those in later life supporting others who are also aging. Since older caregivers rarely cope with these additional pressures, caregiver burn-out leads to early entry into long-term care as well as increased use of emergency and acute care services in rural communities.



A Plan of Action: 11 Recommendations to Enhance Long-Term Care Provision in Canada

In the same way that Canadians have come together to take action against the adversity caused by the COVID-19 pandemic, health care system reform in long-term care is possible to better align service provision with the needs and preferences of older people and the places that they live. These changes are necessary to redress the inequities faced both between and within older populations and to establish contextually sensitive front-line care that mimics the diverse regions of this country. Below are 11 recommendations that have been organized by the categories stipulated by Health Standards Organization who is tasked with developing the National Long-Term Care Services Standard in Canada. Laying the foundation to ensure high quality health services for all Canadians, these recommendations will act as a starting point to catalyze health care system transformation.

Resident-and-Family-Centred Long-Term Care Services

I. Best practices in long-term care will require embracing holistic models of care to align front-line practices with the ways in which residents define their health

Getting Started

To better align long-term care practices with the ways that older adults define their health, front-line care must be adapted to embrace holistic care models [(e.g., better attend to chronic conditions and co-morbidities as well as the 6 ways older adults define their health (p.5)]. This approach will require identifying and redressing the aspects of care that more readily reflect other priorities (e.g., biomedicine, bed flow culture, risk management/liability, professional obligations and sectorized divisions) that negatively impact the care experiences of older residents. Appreciating that physical and psychosocial aspects of health as well as quality of life cannot be cared for and/or treated separately, this method redresses the compartmentalization of health and care experiences to foster the provision of resident-and-family-centred care.

“Sometimes we get so caught up in care, we forget the human piece of things.” (Administrator/Manager 6)

Recommendations

2. Best practices in long-term care will require attending to the experiences of residents and their families as a process over time and place

Getting Started

Older adults experience health and care as a process over time and therefore support for these experiences cannot be confined to one particular care setting. For instance, information on long-term care should not be restricted to the admissions process, but rather should be provided through several opportunities for older adults and their families to engage with long-term care settings (e.g. respite services, tours, community seniors groups, volunteer opportunities, luncheons). This approach increases the exposure of older adults and their loved ones to what life is like in long-term care environments and fosters relationships between long-term care staff, residents and families. Facilitating a resident-and-family-centred approach to care then better supports patients across the care continuum by appreciating the on-going nature of health and care experiences.

“I think it would be great to have a case manager that follows patients and helps with these transitions and provides information on a client.” (Administrator/Manager 4)

“At first my mom was really against all these people coming into her home. It took her a long time to accept help and all the support, but when her mobility started to decline it became a lot harder for her to travel and she began to start to enjoy the visits from care staff. I would say it took her about 4-5 months before she actually started accepting care.” (Informal Support-Long - Term Care 91) *Best practices in long-term care will require supporting older adults and informal caregivers with the emotional overlay of health and care*

Getting Started

Since both older adults and their families experience complex emotions related to their on-going experiences, support for bereavement is paramount to ensure quality care provision. This support should attend to the 5 Ds: Displacement, Dispossession,

Recommendations

Dependency, Decline and Death (p.9) that have been identified in this report to comprehensively support older adults and their loved ones. The emotional overlay of health and care extends beyond long-term care settings and therefore support must start prior to an older adult putting their name on the wait-list for long-term, and for the family must extend after the resident has passed away. This emotional care is particularly critical to support admission and discharge events to assist with the difficult decisions and strong emotions evoked by these experiences. Since older adults and their families rarely access the formal emotional support available, new methods need to be sought out to facilitate effective care. Providing support for the emotional overlay of health and care then elicits a resident-and-family-centred approach that will enhance the provision of long-term care services.

“What the system doesn’t recognize is that this is a huge life change. They support you when you are having a baby, but don’t support you during this.” (Informal Support - Long-Term Care 26)

“It all built up, it was too much. I cried a lot, but I tried to stay strong. It was hard on both of us.” (Informal Support - Long-Term Care 89)

“Family often struggle more and need more emotional support that we can’t always provide. It is so hard for people and it’s full of hard decisions. For us it often becomes common place. These are important stories and we don’t always hear them.” (Administrator/Manager 6)

3. Best practices in long-term care will require respecting autonomy by aligning care provision with resident priorities and increasing opportunities for choice

Getting Started

While patient-centred models of care continue to highlight the need to respect patient autonomy, contemporary long-term care services do not provide residents with opportunities to make choices in their daily lives and formal care provision is not easily adapted to what individual residents identify as factors that contribute to their quality of

Recommendations

life. Front-line care must then incorporate flexibility to accommodate to individual wants and needs rather than insist that residents prioritize their physical health and personal care. Resident-and-family-centred care then values psychosocial aspects of health and asks each individual resident and family what aspects of service can contribute to them living their best life. Acknowledging that these priorities change over time, residents and families should be provided with on-going opportunities to tailor front-line care to their needs, wants and preferences. Fundamental to the establishment of resident-and-family-centred care, valuing patient priorities and providing opportunities to guide front-line care is pivotal to establishing a best practice approach.

“They need choices to be happy. The more choices you give the better their quality of life is.” (Front-Line Staff - Acute Care 22)

“We try to look at patient’s values and choices, but because we are an institution it’s really hard. Even when a patient is vegetarian we struggle to accommodate.” (Front-Line Staff - Long-Term Care 36)

“What can I do? It’s not like I can just move out. I have no choice.” (Older Adult - Long-Term Care 27)

Recommendations

Safe, Reliable, and High-Quality Care Based on Evidence-Informed Practices

- 4. Best practices in long-term care will require the continuous adaptation of care policies, structures and processes to ensure that front-line care provision is flexible to align with the ways that older adults define their health.**

Getting Started

Administrators/managers, front-line staff, ancillary staff, residents and informal caregivers are rich knowledge sources on the aspects of long-term care practices that do not align with the needs and preferences of residents. While there are many internal audits performed in long-term care and satisfaction surveys exist for residents and informal supports to provide general feedback, these approaches to quality improvement do not focus on the macro aspects of care that hinder effective practice. Thus, it is recommended that routine feedback be collected on macro systems of care to ensure that these broader elements align with the ways that older adults define their health. For example, quarterly reviews on specific topics such as data management, inter-sectoral communication, infection control, staffing ratios, admission/discharge processes, holistic care, support for bereavement etc. would assist provincial governments to identify and facilitate on-going improvements to the provision of long-term care services. By including all stakeholders in these audits (e.g. administrators/managers, front-line staff, residents and informal supports), a 360° analysis of long-term care can be conducted to avoid the compartmentalization of quality improvement initiatives. While this review will provide insight into needed improvements for all long-term care homes, these reviews will be particularly germane to provide rural communities with the opportunity to voice concerns about the inequities faced by residents in their local areas due to the added contextual challenges of service provision. Continually adjusting long-term care services to the ways that older adults define their health will then ensure that safe, reliable and high-quality care can be provided for all long-term care residents in Canada.

“They can’t see the social worker or the geriatric psychologist. We still can’t share those services because they are driven by the government and the different funding sources don’t allow for it.”
(Administrator/Manager 50)

Recommendations

A Healthy and Competent Workforce to Ensure Sustainable, Team-Based, Compassionate Care.

5. Best practices in long-term care will require addressing data management misalignments and communication breakdown within and between care sectors to establish collaborative care planning in practice

Getting Started

Health technology is underutilized in the Canadian health care system. While health technology has been leveraged in certain provinces and/or in certain sectors, these independent approaches compartmentalize older peoples' experiences of care.

Leveraging health technology to enhance collaborative care planning within and across care settings is then pivotal to foster information exchange between health professionals in all sectors that includes patients and informal caregivers. To minimize the impact of transfer events, care plans in long-term care should act as a continuation of the care plans that were established in previous sectors rather than initiating new care plans upon admission. This approach will generate process efficiencies by ensuring adequate information transfer between care settings and eliminating the fast-paced, task-based care provided during admission events. This team-based care is vital for front-line staff to have more time for other aspects of care provision and will improve the relations between agents within the health care system.

“The sentiment behind collaborative care planning is amazing to create a continuum of care, but most that exist do not benefit both health professionals and patients. It means that information on these care plans is not helpful for either the patient or the service provider and so they are shelved, but there can be joint care planning that could be effective for both.” (Administrator/Manager 4) *Best practices in long-term care will require the provision of staff training and the identification of staffing models that support holistic health, quality of life and the emotional overlay of health and care*

Recommendations

Getting Started

The education and training of long-term care staff is bio-medically focused, which results in a lack of competency in the facilitation of holistic care and geriatric practices. It is therefore recommended that all staff be trained to facilitate the Comprehensive Geriatric Assessment tool and P.I.E.C.E.S. approach that mark best practice in the care of older populations. In addition, it is recommended that staffing models in long-term care more readily reflect front-line staff beyond personal support workers, nurses and physicians to provide older adults and their families with holistic care. Although reconstructing staffing models to include recreation therapists, social workers, rehabilitation staff etc. represents best practice, this project reveals that rural communities struggle to recruit and retain specialized staff and large catchment areas contribute to access inequities of rural residents. These staffing models should then not stipulate specific education requirements for front-line staff, but allow local contexts to internally train their employees beyond their professional designations. This approach will ensure that front-line staff competencies align with the provision of holistic and geriatric best practices and ensure that quality care is provided to the residents that they serve.

“They [Front-Line Staff] aren’t trained for things like dementia; the things beyond medical training.” (Informal Support - Long-Term Care 82)

“A social worker would be great to better help with the guilt that families have.” (Front-Line Staff - Long-Term Care 61)

“I watch the bouncing ball of older adults with mental health and addictions and there is no psychogeriatric support because there are pieces missing in our care team.” (Administrator/Manager 6)

Recommendations

6. Best practices in long-term care will require the inclusion of local communities as essential team partners

Getting Started

Contemporary long-term care services must reflect and leverage the strengths of local communities to establish a team-based approach to the provision of long-term care. This method will require strategies and incentives to establish community partnerships (e.g., with private industry, other public services, research entities, secular as well as non-secular community organizations) that will enhance the care of residents and the connection residents have with their local communities. This approach will better attend to the holistic health of residents, while also increasing the time available for front-line staff to conduct other aspects of care provision. To relieve some of the pressures placed on informal caregivers, mechanisms to include informal supports other than the Power of Attorney/Substitute Decision Maker also need to be established. Facilitating community-based long-term care will then foster the collaborative team needed to produce a comprehensive circle of care for all long-term care residents.

“The local community has a positive impact on older adult health. I feel that community members are always willing to help. Neighbours helping neighbours.” (Front-Line Staff - Acute Care 7)

“Funding seems to always be the barrier to making partnerships with other community organizations.” (Administrator/Manager 50)

“The owners of the local businesses are really generous in giving their time. We wouldn’t have half the equipment if it wasn’t for the community raising money.” (Front-Line Staff - Long-Term Care 35)

Recommendations

An Organizational Culture that is Outcome-Focused and Strives towards the Safety and Well-Being of all Canadians

- 7. Best practices in long-term care will require establishing methods to evaluate holistic health outcomes, quality of life and the intangible aspects of care to prioritize them in front-line practice**

Getting Started

A welcoming and supportive culture where health professionals have the time to dedicate to holistic health and attend to the emotional overlay of care is the hallmark of effective health care service provision. Long-term care, however, prioritizes other elements of practice that can be more easily evaluated (e.g., physical health outcomes). Determining and encompassing methods to evaluate holistic health, quality of life and intangible aspects of care in practice is then necessary to establish organizational cultures that truly meet the needs and preferences of the populations that they serve. This approach will require the adaptation of target health outcomes, quality indicators, funding allocation as well as provincially and professionally driven initiatives to reflect holistic models of care rather than other priorities (e.g., biomedicine, bed flow, professional obligations, risk/liability etc.). This method ensures an outcome-focused culture that aligns with the ways that older adults define their health and care contributing the well-being of all Canadians in need of long-term care services.

“I know it sounds silly, but I won’t be able to cut my grapefruit in the morning. I like it just right and I am going to have to get someone to help me with it.” (Older Adult - Community 55)

“Supportive housing is able to get to know patients and those simple things like knowing that mom likes lemon meringue pie. It’s a simple thing. It’s hard to put your finger on, but it makes a difference.” (Informal Support - Community 57) *Best practices in long-term care will require increasing service options and access*

Recommendations

Getting Started

Current models of long-term care homogenize the older population, which results in access inequities that advantage the dominant norm. To redress this misalignment, long-term care provision must provide a wide range of long-term care services to fit the diversity of the aging population. Indeed, long-term care infrastructure, staffing, programs, care models, policies, procedures and living environments should not be universal, but be adapted to the local areas and the populations that they serve. This approach will decrease older adult and family members' aversions to long-term care, responsive behaviours and the decline of formal services ("care refusal").

In addition, the inaccessibility of long-term care services and the long waits endured by older populations leads to the health decline of residents and the oppression of the aging population. Redressing the number of long-term care beds available is then essential to ensure access to universal long-term care services for all Canadians.

To attend to the inequities created between older populations, the social stratification of the long-term care admissions process and front-line care practices must also be eliminated to ensure access and services that fit the needs and preferences of older populations other than the dominant norm. Establishing equitable care access and safety for all residents, this approach fosters an organizational culture in long-term care that is inclusive of all Canadians.

“It is hard when you have stayed in the same place for a while and then you go to a place where you don’t know anyone. Where you have to share a home with all these strangers.” (Informal Support - Long-Term Care 82)

“She was in hospital for 4 months. That’s a pretty long time to wait for long-term care...I don’t know if she would have deteriorated cognitively if she had been transferred sooner. It’s not really a great place for them.” (Informal Support - Long-Term Care 90)

Recommendations

8. Best practices in long-term care will require the recognition that large catchment areas, displacement and universal models of care foster inequitable services in rural areas

Getting Started

The provision of long-term care is dependent on the local context in which care is provided. Service provision that fosters large catchment areas, the displacement of rural residents and/or universal models of care that negate contextual features of local areas (e.g., cost of living, socio-demographics of local populations, resources etc.) generate inequities within older populations in Canada. To redress these facets of service provision, long-term care must be adaptable to the local areas in which care is provided. For example, establishing pooled funding models between sectors in rural areas, will assist long-term care homes to address human resource deficits in their regions. Similarly, local control over the designation of private, semi-private and basic beds can eliminate the social stratification of long-term care access. This approach encourages innovation and allows rural communities to tailor long-term care services to the rurality of local residents. Providing rural health systems with an opportunity to inform provincial governments of macro care structures, processes, quality indicators and funding allocation that act as a barrier to patient-centred service provision will be an essential element of this localized model. Striving toward the safety and well-being of all Canadians, localized care gives a voice to rural and remote areas in Canada that are not always represented in macro driven approaches to health and care.

“What we need in Haliburton County isn’t what we need in Toronto. We are grouped with places like Scarborough, but the needs here are different.” (Administrator/Manager 50)

“It’s hard that he’s far away [crying]. I am available to visit him only once a week because he’s out-of-county. I am able to talk to him every day on the phone, sometimes twice a day, but I miss him.” (Informal Support - Long-Term Care 26)

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