Submission to Alberta Health Consultation on a Review of Continuing Care Regulations

Including:

Nursing Homes Operation Regulation
Nursing Home General Regulation
Co-ordinated Home Care Program Regulation

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Executive Summary

The College and Association of Registered Nurses of Alberta (CARNA) welcomes the opportunity to submit comments and make recommendations regarding the review and revision of the continuing care regulations (*Nursing Homes Operation Regulation*, *Nursing Home General Regulation*, and *Co-ordinated Home Care Program Regulation*).

We are pleased to see that these three regulations are being considered for revision together and understand that the Ministry is planning to review all continuing care legislation. CARNA fully supports this comprehensive approach to reviewing the legislation to allow an integrated approach to continuing care legislation. This approach makes possible a person-centred, primary care focused approach.

Evidence from across Canada indicates that "the needs of persons in long-term care are highly complex, resource allocations do not always correspond to needs, and quality varies substantially between and within provinces" (Hirdes, Mitchell, Maxwell & White, 2011). Not only that, but more people are dying in nursing homes, requiring specialty palliative care in these facilities. It is projected that as many as 39% of residents will die in a Canadian nursing home by 2020 (Fisher et al, 2000; Jayaraman & Joseph, 2013).

The review is an opportunity to ensure that the continuing care regulations provide a framework for accountability to the public. The revised continuing care regulations need to reflect public expectations of quality of care and services for themselves and their loved ones to provide good lives and good deaths. These expectations can then be embedded into the accountability framework of the legislation as standards. For the public, meeting a "standard" means achieving a level of quality or excellence. The same standards should apply to both public and private long-term care facilities as well as home care provided in clients' homes.

The current *Nursing Homes Operation Regulation (AR 258/1985)* stipulate minimum staffing requirements in Section 14. Staffing requirements must focus on best meeting the needs of the person in care. The minimum staffing requirements for nursing care currently in the regulation do not allow flexibility for patient needs and are not adequate to meet the health care needs of the population now living in long-term care facilities. Any specification regarding staffing levels in the regulations must be established using an evidence-based approach that is transparent and clearly reasoned.

When it comes to home care, hospital stays are shorter and patients are being discharged with increased expectation of more complex care delivery in the home. People are also living longer in the community with multiple chronic health conditions.

Registered nurses and nurse practitioners have the breadth and depth of knowledge to address the more complex, acutely ill health of long-term care residents and home care patients. For this reason, CARNA recommends that the regulations specify that directors of nursing must be registered nurses and that case managers across all settings, including long-term care and home care, should be registered nurses.

The regulations also need to ensure adequate primary care services in long-term care. References to "physicians" providing primary care should be changed to "primary care provider" and have that term defined as "physicians and nurse practitioners."

The role of the medical advisor (Nursing Homes Operation Regulation, Section 18) needs to be outlined in more detail, include deliverable expectations. We recommend that the regulations allow for this role to also be filled by a nurse practitioner.

CARNA also recommends uniform rules across home care/nursing homes/acute care settings so that people needing care are not penalized because of where they live. That means that people living in their own homes should not have to pay for prescription drugs or medical supplies that they would not have to pay for in the hospital. A systematic review of international literature reports that the cost of medicines is a crucial issue in compliance with treatment. When patients or residents do not fill prescriptions or take lower dosages to make the medication last longer, it results in poor outcomes for the patient and increased cost to society in increased and more acute hospitalizations and clinic visits, for example (Jin, Sklar, Min Sen Oh & Chuen Li, 2008).

The regulations should also be developed based on the concept of reasonable risk for residents of long-term care facilities and provision of a home-like living environment.

Finally, CARNA recommends that an electronic health record be available for every Albertan and be accessible by all health care providers.

Introduction

At CARNA, we recognize that the continuing care regulations are important pieces of legislation coming up for review prior to expiry in 2017. Registered nurses and nurse practitioners work in all areas of the healthcare system and provide care to Albertans across their entire span of life and we are pleased to offer some recommendations for the review.

We recognize that continuing care services are required by vulnerable client groups including, but not limited to, older adults. Our comments are made in this context and CARNA is a committed participant in the broader conversation about the increasing proportion of older adults within our population and their specific health needs. We have developed an *Older Adults Policy Pillar* (College and Association of Registered Nurses of Alberta, November 2013) to directly address and frame the best ways to approach the needs of this population. A thoughtful review and comprehensive revisions to these regulations and other continuing care legislation is an opportunity to shift the landscape for the future of healthcare for older adults and other vulnerable populations.

Principle-based

We were very pleased to see that a well-founded vision and principles have been developed by Alberta Health to underpin this review. The vision is: *Albertans are supported by a person-centred continuing care system that provides timely and appropriate care that enhances their quality of life and independence*. The principles include:

- *Continuing care is the person's home, not a health facility*
- *Providers understand and respect what is important to each person*
- *Health services support quality of life, but they are not the driver of quality of life*

In order to further integrate the priorities of registered nurses and Alberta Health, we recommend adding two principles in addition to those already mentioned:

- *The health care needs of older adults and all Albertans are best met through a person-centered primary health care model.*
- *The person in continuing care has the right to* ***maintain control of their lives and take risks****.*

These five principles will make transparent the assumptions and motives underlying the review, and can serve to govern both the review and subsequent revisions to support the best care for Albertans.

Recommendation:

1. Add two additional principles:

   The health care needs of older adults and all Albertans are best met through a person-centered primary health care model.

   The person in continuing care has the right to maintain control of their life and take risks.

Accountability Structure

We believe that Alberta Health's overarching vision and mission statement for the health system is sound and should be used to organize the review and revisions: *that Albertans receive the right care, at the right time, in the right place, by the right provider/team, with the right information, at the right value.* We have organized the text of our submission in the language of this vision.

For the public, meeting a "standard" means achieving a level of quality or excellence. CARNA recommends that the continuing care regulations be regarded as an accountability structure and provide an authoritative framework outlining the rules and details of what is expected in continuing care. The same standards should apply to both public and private long-term care facilities.

Recommendation:

2. The regulations should clearly define the accountability structure including the requirements for demonstrating and evaluating accountability and the consequences of not meeting the expected standard.

The Right Health Care at the Right Time

Too often we get the impression that home care and nursing home care is basic, or simple. In fact, the care provided to patients and clients in facilities and in their own homes has become increasingly complex (Hirdes, Mitchell, Maxwell & White, 2011). The complexity of care is related to chronic disease and co-morbidities and often requires increased vigilance in ways that are directly within the scope of registered nurse and nurse practitioner expertise.

The right care at the right time means timely access to primary health care services and should include the following:

- Access to appropriate care is **available** at all times
- **Regular** primary care provided by a physician or nurse practitioner
- Access to all services is **fair and equitable**. For example, clients in all continuing care settings must have access to palliative and end of life care or medical assistance in dying.

An example of the kind of collaborative and comprehensive care we refer to is being demonstrated in a partnership between the University of Alberta Faculty of Nursing and SAGE (Seniors Association of Greater Edmonton). This collaboration has led to the development of the largest NP-led clinic for seniors in Canada. The clinic includes a navigator to lead clients through all services they require including social services and housing, primary health provider, prescription refill or chronic disease management. The clinic is described in the latest issue of the *uAlberta Nursing Alumni Magazine*, which can be accessed here: https://issuu.com/ualbertanursing/docs/spring2016.

There is also evidence to support nurse practitioners as primary care providers in home care, with outcomes of less emergency department usage in Canada (Tung, Kaufman & Tanner, 2012). Referring especially to home care clients who cannot easily leave home to access primary care physicians, nurse practitioner care reduced hospital visits at initiation (recruitment) of home care services, 2-week and 4-week time points. There was no significant difference at 8-week time points, and this was in part related to policy requirements. For example, Alberta Health Services in Edmonton requires emergency department visitation for initiation of intravenous antibiotic administration. If nurse practitioner care becomes routine for home care clients, it is possible even more efficient care could be achieved by a general review of Alberta Health Services' policy related to home care.

The continuing care regulation should set requirements to meet standards of care that exist outside of the regulation itself such as best clinical practice guidelines.

The standards of care could be developed and then embedded in contracts with service providers such as Primary Care Networks. A standard of care may focus on transitions from one care setting to another including, for example, a medication reconciliation process to improve patient safety by preventing medication errors and adverse drug events (Fernandes & Shojania, 2012). This is particularly important during transitions from one care setting to another such as when a person is discharged from hospital back to a long-term care facility. Other examples where standards of care could contribute to improved consistency of care include annual medication review and vascular risk reduction, among many more.

In addition to standards related to medication reconciliation, a standard could be set requiring an annual review of medications for continuing care clients living with chronic disease. As well, existing resources such as Alberta Health Services' Vascular Risk Reduction Resources could be used to inform the development of evidence-based, best clinical practice guidelines.

Recommendations

3. The regulations should set out more efficient and improved care through a primary care model using teams comprised of family physicians, nurse practitioners and registered nurses working together with the recognition that this is a standard of care.

4. The role of the medical advisor should be more clearly outlined including deliverable expectations of this role. This role could be filled by a physician or nurse practitioner.

5. The regulations should set requirements to meet external standards of care such as best clinical practice guidelines.

In the Right Place

The place of care should not influence the access to services and people should not be penalized because of where they live. For example, medications are not publicly funded if a patient is in home care, but they are funded when the patient is in a facility such as a nursing home. The current perspective regarding where people live seems to be based on an acute care model of minimizing risk to the institution. This approach runs counter to the principles of patient-centered care and recognizing the right of persons in continuing care to maintain control of their lives and take risks. A long-term care facility is, after all, a home for its residents rather than an acute care hospital which means that the level of risk should be viewed differently. Standards should apply equally to public and private facilities.

Social determinants of health, such as housing and social inclusion, need to be forefront in decisions about care. We know that these determinants have more influence over an individual's health than the actual healthcare system, as discussed in the seminal article by Professor Michael Marmot (2005). Since the homes of residents and clients of the continuing care system are the settings for healthcare, these considerations need to become even more sophisticated. A systematic review highlights research evidence demonstrating the importance of evaluating social and economic policies that may have health consequences (Williams, Costa, Odunlami & Mohammed, 2008). These policies must be considered in light of providing quality health care in continuing care, home-based settings, whether in a private or facility-based home.

One of the recommended principles to be implemented during review of the continuing care regulations is that the person in continuing care has the right to maintain control of their lives and take risks. Research studies indicate that many health-care providers make assumptions about the physical frailty or mental capacity of older adults based on their age rather than their symptoms (Eymard & Douglas, 2012).

Even the mere activation of these negative stereotypes (when older adults start to believe these assumptions about themselves) about aging can lead to worse health outcomes, including lower levels of risk-taking (Coudin & Alexopoulos, 2010). This can result in older adults not receiving the care they need to maintain their health, dignity and independence (Stewart, 2015). That includes allowing people to live with reasonable risk.

The high standards of risk reduction used in hospitals take away from a home-like atmosphere when applied in long-term care facilities. People need to be able to live with reasonable risk. For example, models such as the Hogewey gated village in the Netherlands show how the normality of daily life can be maintained for people living with dementia. Residents live in settings related to their choice of lifestyle and are free to stroll through the village and visit the stores and cafes. The goal is to reduce the confusion and sadness that more clinical settings can create for people living with dementia ("Peace of Mind," 2015).

Recommendation

6. CARNA recommends uniform rules across home care/nursing homes/acute care settings so that people needing care are not penalized because of where they live. As one specific example, people living in their own homes should not have to pay (or co-pay) for prescription drugs they would not have to pay for in a healthcare facility.
7. Revisions must be made in the context of social and economic policies that may unintentionally undermine the focus of quality continuing care services.

The Right Provider/Team

Of course CARNA is especially aware of the strengths of registered nurse care and the quality patient outcomes that result from the empirical and tacit knowledge of registered nurses, as well as their skill and experience. Registered nurse care has been shown to reduce mortality and failure to rescue (instances where action could have prevented a negative patient outcome) rates as well as improvement in other nurse-sensitive patient outcomes. These results are particularly clear in a landmark study published in the *New England Journal of Medicine*, suggesting better care outcomes associated with both a greater number and higher proportion of care hours delivered by registered nurses (Needleman, Buerhaus, Mattke, Stewart & Zelevinsky, 2002). Current research is continuing to build on these findings (Chau et al, 2015). We fully recognize that other health care providers, including unregulated workers, have an important role to play in continuing care.

The focus of determining staffing needs has to remain on the overall complexity and health needs of the person in continuing care.

The current *Nursing Homes Operation Regulation (AR 258/1985)* stipulates minimum staffing requirements in Section 14. Staffing requirements must focus on best meeting the needs of the person in care. The minimum staffing requirements for nursing care currently in the Nursing Homes Operations Regulation (Section 14) do not allow flexibility for patient needs and are not adequate to meet the health care needs of the population now living in long-term care facilities.

Any specification regarding staffing levels in the regulations must be established using an evidence-based approach that is transparent and clearly reasoned.

For example, both those who determine staffing as well as the health care providers need to understand the unique presentation of symptoms of older adults and similarly vulnerable clients. Every plan of care made for each individual client must address physical, mental, emotional, social, intellectual and spiritual health needs.

The right provider/team should be determined based on a comprehensive assessment of the patient or client's needs. It is essential that individual accountability for the care of each patient is made crystal clear. Each member of the team, as well as the patient and family, must know what each person is accountable for in regards to resident or client care.

Here are two examples of how registered nurses may be most strategically placed to improve care outcomes leading to overall, long-term health care costs (by decreasing need for further treatment) as well as the consequent improvement in quality of life for the resident or client:

- Registered nurses are well-placed to not only be the Director of Nursing (as currently stated in the Nursing Homes Operation Regulation), but also to be case managers across all settings.

- The RN should be directly and clearly responsible for a caseload of patients, including the provision of some hands-on care when this is appropriate. This may occur across home care and facility settings. The RN would be responsible for a full initial assessment followed by regular assessments, a fully developed plan of care, assignment of care (may include hands-on care) and regular follow-up and monitoring of the patient/resident.

Recommendations

8. References in the regulations to "physicians" providing primary care should be changed to "primary care provider" and have the term defined as "physicians and nurse practitioners."

9. The regulations should define the Director of Nursing as a registered nurse.

10. The regulations should define case managers in long-term care facilities and in home care as registered nurses.

11. The role of the medical director needs to be outlined in more detail and include deliverable expectations. A nurse practitioner or physician can fill this role.

With the Right Information

The importance of the right information to support care in all sectors, including continuing care, cannot be overstated. We conceive of this in two parts:

Electronic Health Record. Albertans should each have an Electronic Health Record that is accessible to all health care providers (home care nurse, primary care provider, telehealth nurse, etc.) regardless of the health care setting. Current and accurate knowledge of the resident or client's needs, changes and treatment is critical to good primary care, including the management of multiple morbidities.

Data Mining. Canadian authors of a recent multi-source analysis of person-level clinical information demonstrate how analysis of information in databases can help to move to a new era of evidence-informed decision making about the role of nursing homes in Canada (Hirdes, Mitchell, Maxwell & White, 2011). Using Canada Census data, RAI assessments and locally available data (they use results from the Alberta Continuing Care Epidemiological Studies [ACCES] (Strain, Maxwell, Wanless, D. & Gilbart, 2011)), a more-informed understanding of the current performance and usage of services results in more flexible and appropriate system-level decision-making. University of Alberta professor, Dr. Carole Estabrooks developed a profile of residents in prairie nursing homes in Canada, using Hirdes et al (2011) data. Among other interesting findings, the Alberta researchers found that public facilities tended to care for residents "with more demanding characteristics: notably cognitive impairment, aggressive behaviours, and incontinence." Information such as this could underlie staffing, funding and family decision-making (Estabrooks et al., 2014).

Recommendation

12. Make development of an Electronic Health Record accessible by health providers in continuing care, home care, acute care and other health service delivery settings a priority.

13. The regulations must stipulate that care decisions (including staffing requirements) are based on a sound reasoning process, including a rigorous evidence-based process that includes both research evidence as well as patient-level data from national and local sources. Examples of these sources include CIHI and ACCES (as above).

At the Right Value

Alberta currently pays $6,966 per capita in health care costs, well above the national average and yet there is little to suggest that outcomes reflect this investment (Canadian Institute for Healthcare Information [CIHI], 2015). There are other models of care that are more risk tolerant at a lower cost that also have better outcomes. They allow older adults living in long-term care facilities to make more choices about their care and surroundings. For example, in the Netherlands, Hogewey costs about the same as other care facilities and is funded in part by the Dutch government with residents paying a portion of the expenses ("Peace of Mind," 2015).

Evidence shows that increasing the amount of care provided by registered nurses and nurse practitioners can prevent transfer to emergency departments and consequently, acute care

The principles imply that facilities and processes of continuing care will have access to resources they need to meet the public's expected standard of care.

Recommendation

14. Provide equal access to prescription drugs through a pharmacare plan that does not penalize older adults whether they live in long-term care facilities or in their own homes.

15. Develop regulation based on concept of reasonable risk for residents of long-term care facilities and provision of a home-like living environment.

Summary of Recommendations

1. Add two additional principles:
    - The health care needs of older adults and all Albertans are best met through a **person-centered primary health care** model.
    - The person in continuing care has the right to **maintain control of their lives and take risks**.
2. The regulations should clearly define the accountability structure including the requirements for demonstrating and evaluating accountability and the consequences of not meeting the expected standard.
3. The regulations should set out more efficient and improved care through a primary care model using teams comprised of family physicians, nurse practitioners and registered nurses working together with the recognition that this is a standard of care.
4. The role of the medical advisor should be more clearly outlined including deliverable expectations of this role.
5. The regulations should set requirements to meet external standards of care such as best clinical practice guidelines.
6. CARNA recommends uniform rules across home care/nursing homes/acute care settings so that people needing care are not penalized because of where they live. As one specific example, people living in their own homes should not have to pay for prescription drugs they would not have to pay for in a healthcare facility.
7. References in the regulations to "physicians" providing primary care should be changed to "primary care provider" and have the term defined as "physicians and nurse practitioners."
8. The regulations should define the Director of Nursing as a registered nurse.
9. The regulations should define case managers in long-term care facilities and in home care as registered nurses.
10. The role of the medical director needs to be outlined in more detail and include deliverable expectations. A nurse practitioner or physician can fill this role.
11. Make development of an Electronic Health Record accessible by health providers in continuing care, home care, acute care and other health service delivery settings a priority.
12. Research evidence is used to underlie staffing and treatment decisions.
13. Available data from national and local sources should be analyzed to better understand the continuing care population.
14. Provide equal access to prescription drugs through a pharmacare plan that does not penalize older adults whether they live in long-term care facilities or in their own homes.
15. Develop regulation based on concept of reasonable risk for residents of long-term care facilities and provision of a home-like living environment.

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