



“Dementia: The Common Thread in the IHSP-4 Fabric”
(First Draft)

Response to the Central LHIN DRAFT Integrated Health Service Plan 4

Presented at the CSS Sector Engagement Session, July 7, 2015

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Part I:

Response to the DRAFT IHSP-4

Preamble

The following report is provided by the Alzheimer Society in partnership with community stakeholders in response to the July 7, 2015 presentation by the Central LHIN of its DRAFT Integrated Health Service

Plan (IHSP) 4 to the CSS Network. Our comments attempt to build on the existing planning efforts of the Central LHIN and focus on further defining health system needs and strategies to improve health

outcomes and build a more integrated and sustainable health care system, with a focus on dementia.

Introduction

In Ontario, the coming years will be transformative for the health care system, as well as for society at-large. There will be new demands to be met, new services required, and a new way of organizing care so that it can remain sustainable. When considering the approach that must be taken to achieve this goal, it must be acknowledged that effective health care requires a holistic approach. It is as much about the connections and linkages between the identified priorities as it is about the priorities themselves. One of these underlying connections is dementia, a disease which mostly affects seniors. It is not difficult to predict the type of effect the population shift Ontario is

experiencing will have on our future health care system. In fact, change has already started to occur; from 2007 to 2012 Ontario saw a rise in the proportion of community-dwelling seniors diagnosed with dementia from 2.5% to 4.0%. This is an absolute increase from approximately 44,000 to 77,000 people.

In the Central LHIN (CLHIN) alone, the IHSP-4 planning report predicts that by 2016 this region will contain the most seniors, and this number will almost double in the 15 years that follow. This is corroborated by evidence from a recent investigation performed by the Institute of Clinical Evaluative Science (ICES),

commissioned by the Alzheimer Society of Ontario, which shows that CLHIN already had the most people with dementia among all LHINs, 10,206 to be precise, in 2012. As the population pyramid becomes more “top heavy” during this time, the burden of disease and the inadequacy of our current system must be considered.

Dementia is an underlying issue in many of the key priorities outlined in the CLHIN planning report; ***however there is no specific mention of dementia in the CLHIN strategy, despite growing recognition elsewhere in the province.***

Dementia Strategy in Ontario

The Ontario Ministry of Health and Long-Term Care is beginning activity to develop a comprehensive Ontario Dementia Strategy. Guided by the mandate given by Minister Hoskins, Parliamentary Assist Indira Naidoo-Harris and her team will begin consultations in the fall to inform the development of this strategy.

An initial scan of LHIN level dementia activity is underway, with LHINs being asked to provide a summary of services currently funded and available within each LHIN boundary. The level of activity varies across LHINs. The Champlain and South West LHINs have developed dementia specific models of care. The Waterloo Wellington and Mississauga Halton LHINs are in the process of developing seniors and dementia specific plans. In addition, a focus on seniors means

that across LHINs there is heightened recognition of the impact of dementia in their communities.

While current MOHLTC priorities include Seniors, Palliative Care and Mental Health, the mandate to develop an Ontario Dementia Strategy has centred on the overall prioritizing of dementia as a condition which has impacts across the health system. Because of dementia's cross-sector impact, the MOHLTC has begun work to learn how the health system as a whole can better respond to the challenges it currently faces when supporting people living with dementia and their circles of care.

While a strategy is being developed, the Alzheimer Society recommends that the LHINs look to the future when developing

their IHSPs. With implementation of an Ontario Dementia Strategy on the horizon, there are ways for the LHINs to respond to the current need they see in their communities.

This document illustrates the connection between the priorities in the IHSP-4 report and dementia, and uses data obtained from ICES (Project no. 2014 900 531 000) to illustrate dementia's place in the discussion of the future of health care in our region. This data set is only a first step in collaboration between the Alzheimer Society of Ontario and ICES; in the coming months the available data will continue to expand to provide further information about the status of dementia in Ontario.

Palliative Care Strategy

The definition of palliative care is evolving in the health community, with palliative care services becoming involved in patient care much sooner in the disease process, and often simultaneously to curative medical treatment. As the IHSP-4 framework states, the goal of palliative care is to help those with “progressive life-limiting illness, their families and their caregivers... live as they choose, and optimize their quality of life, comfort, dignity and security.” For dementia patients, instead of referring to these services as palliative, a term that often carries a negative connotation of being associated with near death, this could perhaps better be thought of as supportive or comfort care for persons with chronic disease.

There is no clearer case where the services of palliative care physicians would be valued than in the dementia population. This population is elderly, with an average age of 82. The population comprises some of the most complex patients: 71.5% of people with dementia have two or more comorbidities, and 23.8% have four or more

comorbidities. People with dementia are much more likely to be placed in long-term care at a younger age (48.7 people per thousand with dementia versus 1.6 people per thousand without, aged 66-84), and over 50% of all dementia patients utilize home care services. Of this home care population, pain has also been noted as a significant issue. 97.5% of dementia patients in home care experience multiple periods of pain daily, and 72% describe it as severe/excruciating. This indicates definite unmanaged needs which palliative care may be well positioned to assist with. Furthermore, seniors with dementia have a risk of mortality up to five times greater than the senior population without dementia. With this picture of the dementia population in mind, the value of palliative care to this population becomes apparent.

When accounting for the hub components of the palliative care initiative in the IHSP-4 report, the stated values correlate well with

Traditional Care Model



Integrated Care Model



<http://bestpractice.bmj.com/best-practice/monograph/1020.html>

the goals of dementia care. Advanced care planning, management of comorbidities, community and psychosocial support for patient and caregiver, as well as options for home care are already vital services provided to people with dementia. By providing these services through the lens of palliative care, the health care system can be better prepared to handle the current and future challenges of dementia care. Patients and their caregivers can be assured of more comprehensive and organized care delivery that maintains the stated goals of optimizing “quality of life, comfort, dignity and security.”

Mental Health

Dementia has often wavered in its description as being either a mental health concern or a physical disease process. With the health care community's increased understanding of the physical neurological aspects of mental health conditions however, the boundary between these categories grows increasingly blurry. As a result, trying to address dementia from a single angle is restricting, and leads to an incomplete model of care delivery for those suffering from it.

As a neuro-cognitive process, dementia frequently overlaps with what are considered to be classic psychiatric disorders. According to the ICES data from 2012, 22% of all seniors with dementia were depressed, and among the home care dementia community nearly 89% scored >3 on a depressive symptom scale (indicating a depressive disorder). In fact, these two conditions mimic each other to such a degree that clinicians often have difficulty distinguishing the symptoms of dementia and depression.

In addition to mood symptoms, people with dementia are also more prone to behavioural symptoms. Among the 2012 cohort home care population with dementia, 72% exhibited wandering behaviour, 78% were verbally abusive, 48% were physically abusive, 66% were socially inappropriate or disruptive, 84% resisted care, and 83% of these patients showed worsening symptoms over the previous three months. To say that dementia is not a mental health condition with these figures in mind would be a great disservice to the caregivers dealing with these behaviours on a daily basis.

It must be remembered that the majority of aid is delivered by family and friends of the person with dementia, rather than formal health care workers. Unless a person is in long-term care or acutely admitted to hospital, it is unlikely that they are receiving more than a minimum number of hours from service providers with much training to deal with behavioural symptoms. This health care inequity, which is likely a factor in the tremendous amount of stress faced by

caregivers, should be addressed as a priority in health service planning.

To combat these behavioural symptoms, there has been a high rate of use of antipsychotic medications. In the 2012 RAI assessed home care dementia population included in the ICES study, 88.5% of patients were taking these medications. In this same population, 97% of patients are using nine or more medications, often including other psychotropic drugs. In a time where health care resource use needs to be carefully monitored, prescription patterns such as these need to be scrutinized to ensure the benefits of these medications justify their continued use.

Though dementia may not classically be defined as a mental health condition, there is significant overlap in the effects and treatments of the disease. Including considerations for dementia in the mental health framework of IHSP-4, for this reason, will be a vital step towards more holistic care.

LTC Redevelopment and Capacity Planning

As the IHSP-4 report states, the Central LHIN has 7249 LTC beds in 46 LTC homes. Approximately 3% of the Ontario dementia population aged 66+ are placed in long-term care annually. This means that in 2012, 2,317 additional patients with dementia were placed in LTC in Ontario, 306 of which would have been in the Central LHIN. While this number represents a sizeable group of individuals who get the LTC services they require, it is a gross underestimate of actual need. For every LTC applicant that is placed,

there are approximately two individuals waiting for placement at home or in ALC beds. The fact that there is a roughly equal distribution of dementia patients in LTC aged 66-84 and 85+ leads to longer LTC stays versus the non dementia population. The net result is an LTC population where most residents are likely to have dementia. When planning for the future of LTC delivery, particular attention should be given to data pertaining to dementia.

Long-term care is costly, and it should be a goal to maintain care of people with dementia outside of long-term care settings; however with the growing dementia population and the increasing complexity of patients, there will continue to be an undeniable need for increasing capacity of LTC. Planning to increase supply of LTC beds and alternatives is a crucial component of capacity planning.

Seniors' Care

The Central LHIN is unique because of its large senior population. The IHSP-4 report projects that CLHIN will have the highest number of seniors of any LHIN by 2016, amounting to over 282,000 individuals 65 years or older living in the region. Based on projections of the total dementia population, it is expected that approximately 10% of these seniors will be affected by dementia. This amounts to nearly 28,000 people in 2016, increasing to nearly 53,000 people if the numbers stated in the IHSP-4 report follow through to 2031. Even if only 58% of these individuals are detected by the health care system (the estimated CLHIN dementia detection rate as of 2012), these remain large populations.

The complexity of these patients will be a major factor in their health care provision. From 2007 to 2012 the number of dementia patients with 4 or more comorbidities has increased from 19.1% to 23.8%, and will likely continue to rise. Apart from the

specific medical comorbidities that would be expected of any elderly population, people with dementia also face a higher than average risk of falls. In 2012, 9.8% of visits to emergency departments by people with dementia were fall related, and 11.9% of all ED visits by people with dementia were potentially preventable. Emotional distress is also a persistently increased risk in these populations, with 22% of people with dementia reported to be struggling with depression. This is not confined to patients however, as 92.7% of care givers involved with home care report distress as well.

Given the current budgetary constraints on health care infrastructure and personnel availability, the increasing senior population, and more specifically the complex dementia population, require preparations to be made to achieve adequate care in the future. The goal of providing care in the most cost effective manner possible is of primary importance with dementia patients. Home

care was already used by over 50% of people with dementia as of 2012, which is a great progression from 42% only five years before, however there is still further room for improvement.

Developing home care services may also impact the amount of ALC stays resulting from acute care hospital admissions by increasing the capacity for the type of care delivery required to get these patients out of hospital. In 2012, 28% of acute care hospital admissions for dementia patients in Ontario resulted in ALC stays, lasting an average of 9 days. This is compared to only 12% of acute care admissions for older patients without dementia. As the IHSP-4 report states, ALC is a symptom of a solvable problem. From the dementia care perspective, utilizing dementia data to improve home care capabilities is one way of addressing this symptom, and should not be overlooked in the IHSP-4 report.

Primary Care

The IHSP-4 report paints a promising picture for the future of primary care in the Central LHIN. It states that 93.4% of the population has a primary care provider. The strong presence of general or family physicians allows for more personalized long-term management of chronic disease, and is a crucial factor in reducing health care expenditures associated with preventable emergency room visits and other inefficiencies of the health care system.

Along with these traditional benefits of primary care providers, they are also invaluable in detecting disease early in its course, and ensuring that patients get the interventions they require before the window of opportunity has passed. Primary care is the solution to the 42% of dementia cases that go undiagnosed every year. With such a high proportion of the population

already seeing a family physician, the field is poised to close this gap, if they can be given the support in the form of screening tools and education that is required for this from their LHIN.

Primary care providers are by no means underperforming with dementia care, once cases are detected however. It is the most used service modality for people with dementia, with over 84% of Ontarians with dementia seeing their GP/FP at least once in 2012. The supports family physicians can offer patients and their caregivers are valuable, not only in terms of health care system dollars, but also in improvements to the lived experience of people with dementia.

The potential for health care system savings can be observed by comparing primary care to other service modalities. Looking at visits

to specialists, acute care admissions or emergency room visits, visiting the GP/FP showed the lowest relative cost burden to the health care system for patients with dementia in Ontario. Dementia detection and care can be challenging and costly, so an organized approach is crucial. Existing ministry strategies, such as Community Health Links and the coordinated care plans, are doing excellent work to provide a structure that may deal with these complex cases. Further support of primary care will only improve the efficacy of these systems and provide service improvements and cost saving opportunities. This aligns well with the goals of the ministry to increase access, effectiveness and sustainability of the health care system.

Conclusion

Despite the fact that dementia is not mentioned in the draft IHSP-4, it plays a central role in the identified health care priorities. We've shown with respect to the Palliative Care strategy, the services are most valued by the dementia population; in Mental Health, dementia frequently overlaps with what are considered to be classic psychiatric disorders; with LTC, dementia patients are prone to longer stays; with Seniors' Care, age is the most significant risk factor for developing

dementia; and with Primary Care, early diagnosis is one crucial way that the impact of dementia on IHSP 4 priorities can be mitigated. Because of dementia's cross-sector impact, the health care system as a whole must work to better respond to the challenges it currently faces when supporting people living with dementia and their circles of care.

Given that the mandate of the LHINs is to consider major trends and respond at a local level, we are urging the Central LHIN to

adopt an integrated care strategy in its IHSP-4 that formally recognizes the cumulative and pervasive impact of progressive, degenerative dementia on the health care system.

The Alzheimer Society of York Region is committed to supporting the Central LHIN's success by being a key partner in the advancement of the IHSP-4 system priorities and working with the Central LHIN and our community partners in developing solutions needed to achieve its goals.

Part II:

Illustrative Figures of the Impact of Dementia

The Rising Prevalence of Dementia

Key Findings

- Prevalence of physician-diagnosed dementia has increased from 2.6% to 4.1% between 2007 and 2012 in the Central LHIN, mirroring the province-wide increase over the same time period
- In absolute terms, there were 10,206 cases of physician-diagnosed dementia in CLHIN and 77,329 cases province-wide in 2012
- Projected rates of dementia have increased from 9% to 9.4% indicating that 42% of the dementia population had not been formally diagnosed in 2012
- Projections indicate that the prevalence of dementia will rise to 10% by 2021 and 10.4% by 2031

Considerations

- Can we alter the growth trajectory via health promotion?
- How can we reduce the “diagnostic gap” to provide earlier disease management to cases that have been missed?

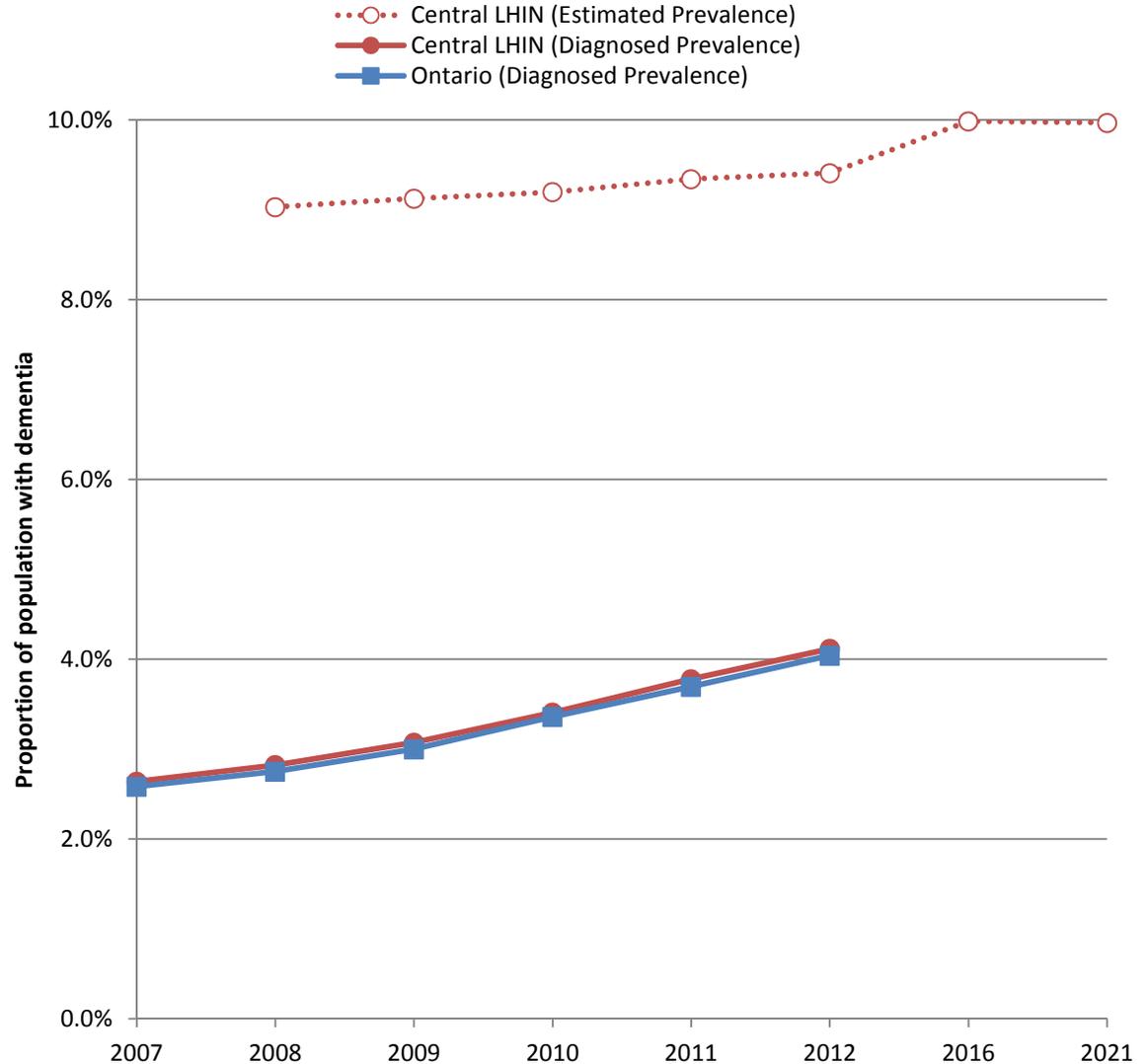


Figure 1. Prevalence of community dwelling older adults with physician-diagnosed dementia in Central LHIN and Ontario, and projected dementia cases in Central LHIN, as a proportion of population for each yearly cohort from 2007 to 2021.

Dementia is a Predictor of Health Outcomes

Key Findings

- Over a five year period, the annual rate of dementia diagnosis has doubled from 0.9% to 1.8%
- During this time, placement of people with dementia into LTC has slowed from 5.2% to 3.3% per year, while placement of individuals without dementia has remained stable but low at 0.2% of the non-dementia senior population
- People with dementia are at an increased risk of mortality, with mortality rates over the study period ranging from 8% to 12.2%, while the non-dementia population mortality rate remained stable at around 2.7%

Considerations

- What is the interaction between decreasing LTC placements and rise in home care service utilization? How are caregivers coping?
- How does palliative care adapt to a population where more older persons are dying while living in the community?
- Have changes in anti-psychotic prescription patterns affected health status over this time?

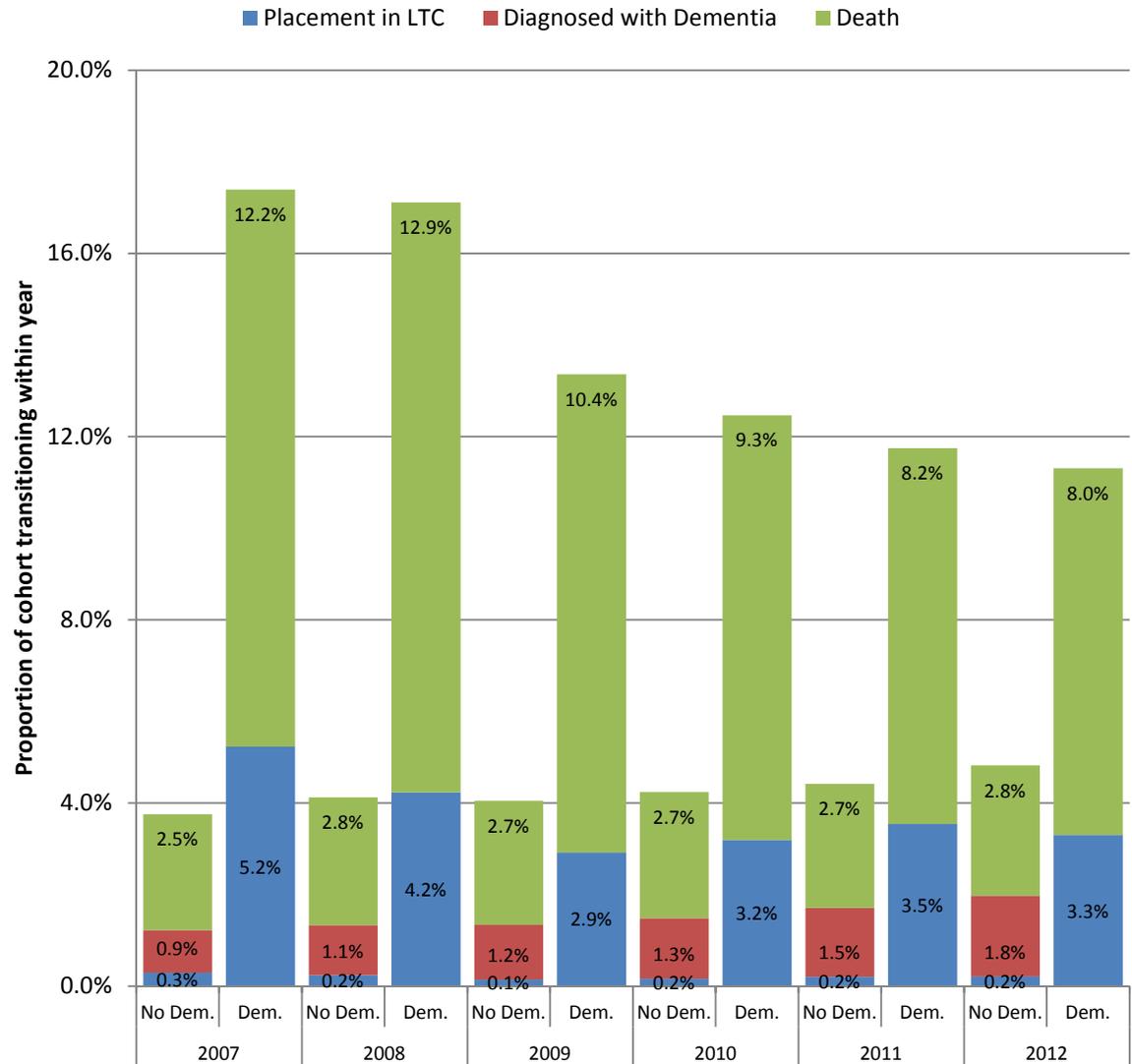


Figure 2. Transitions within-year among community-dwelling older adults in Ontario with and without physician-diagnosed dementia for the 2007 cohort over the study period from 2007 to 2012.

Advancing Age Suggests Higher Risk

Key Findings

- In 2012, 24% of people with dementia had four or more comorbidities, and 72% had two or more, indicating an increased likelihood that they will require complex care
- The proportion of people with dementia who are 85+ was 41% in 2012, versus 13% among people without dementia
- The rate of growth of the 85+ population has remained at approximately 10% per year for the non dementia population, but the dementia population has experienced a growth rate closer to 20% per year
- While individuals 65-74 years old are less likely to have dementia, they still made up 15% of the dementia population in 2012
- In both populations with and without dementia, the proportion of individuals with multiple comorbidities has been increasing steadily over time, mirroring changes in age

Considerations

- What are the implications for end of life care?
What is the caregiver profile for those 85+?



Figure 3. Age distribution (*top*) and prevalence of total number of comorbidities (*bottom*) as a proportion of community-dwelling older adults in Ontario for each yearly cohort from 2007 to 2012.

Alternatives are Required for LTC

Key Findings

- People with dementia are much more likely to apply for and be placed in long term care
- While the rate of placements for 85+ year olds greatly exceeded 66-84 year olds among the non-dementia population, the rate of placement was roughly equal between age groups in the dementia population
- Despite the increased ratio of LTC placements to applications among people with dementia, there is still a large proportion of individuals waiting for placement

Considerations

- How are the needs of individuals waiting for placements being met in the intervening time?
How does end of life care bridge this gap?

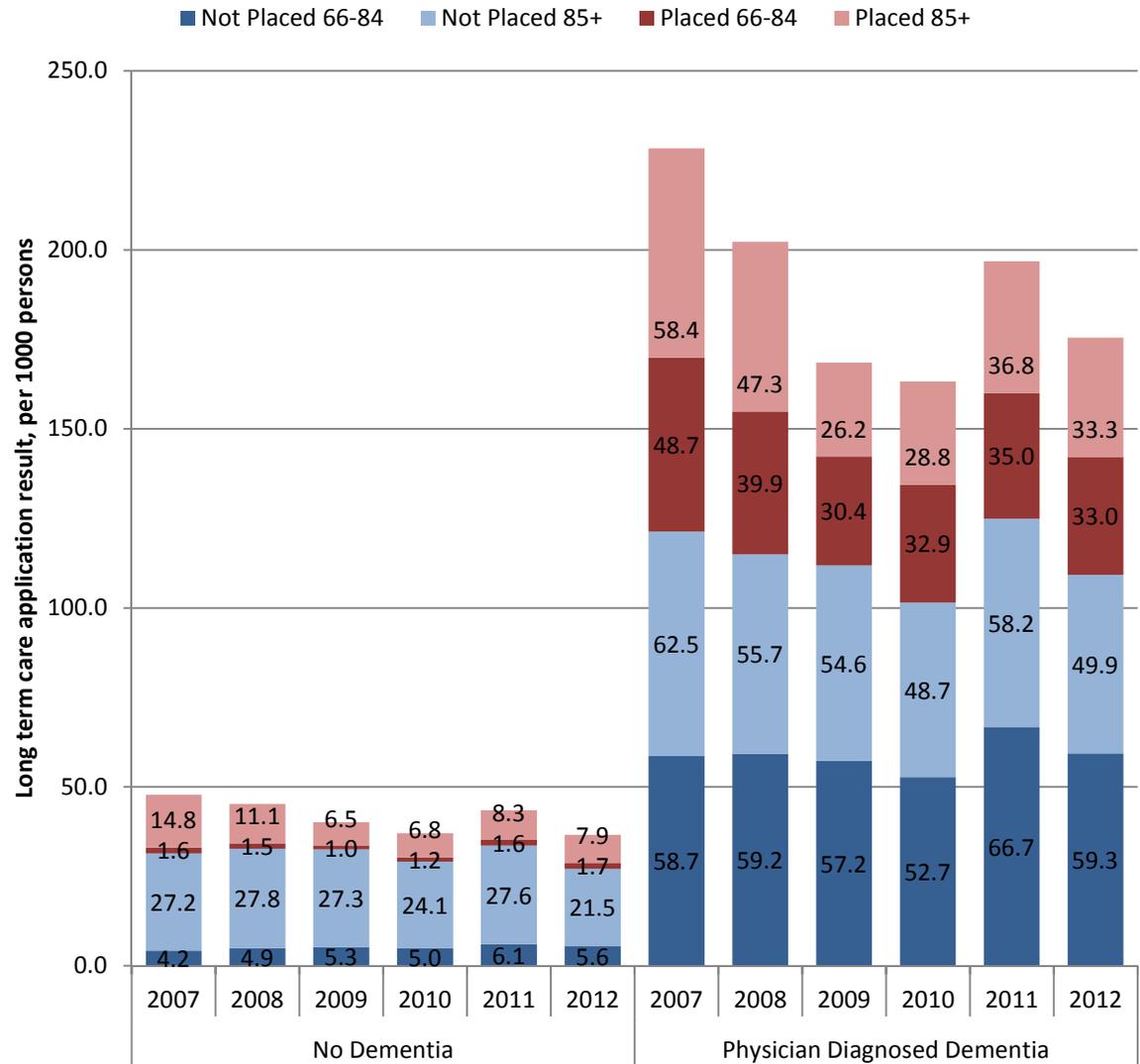


Figure 4. Long term care application results of community-dwelling older adults with and without physician-diagnosed dementia per 1000 persons as a proportion of total usage for 2007 cohort over study period from 2007 to 2012.

High Demand for Home Care

Key Findings

- 50.3% of the dementia population utilized home care services in 2012, increasing from 42% over the previous six years
- Home care utilization in the non dementia population has remained relatively stable at around 11 to 12%

Considerations

- How can home care services be made sustainable but remain sufficient with the increasing demand from people with dementia?
- How are caregivers coping with the increased burden of dealing with friends or relatives with dementia at home?
- How can the capacity be improved to serve older, frailer persons with dementia near the end-of-life?

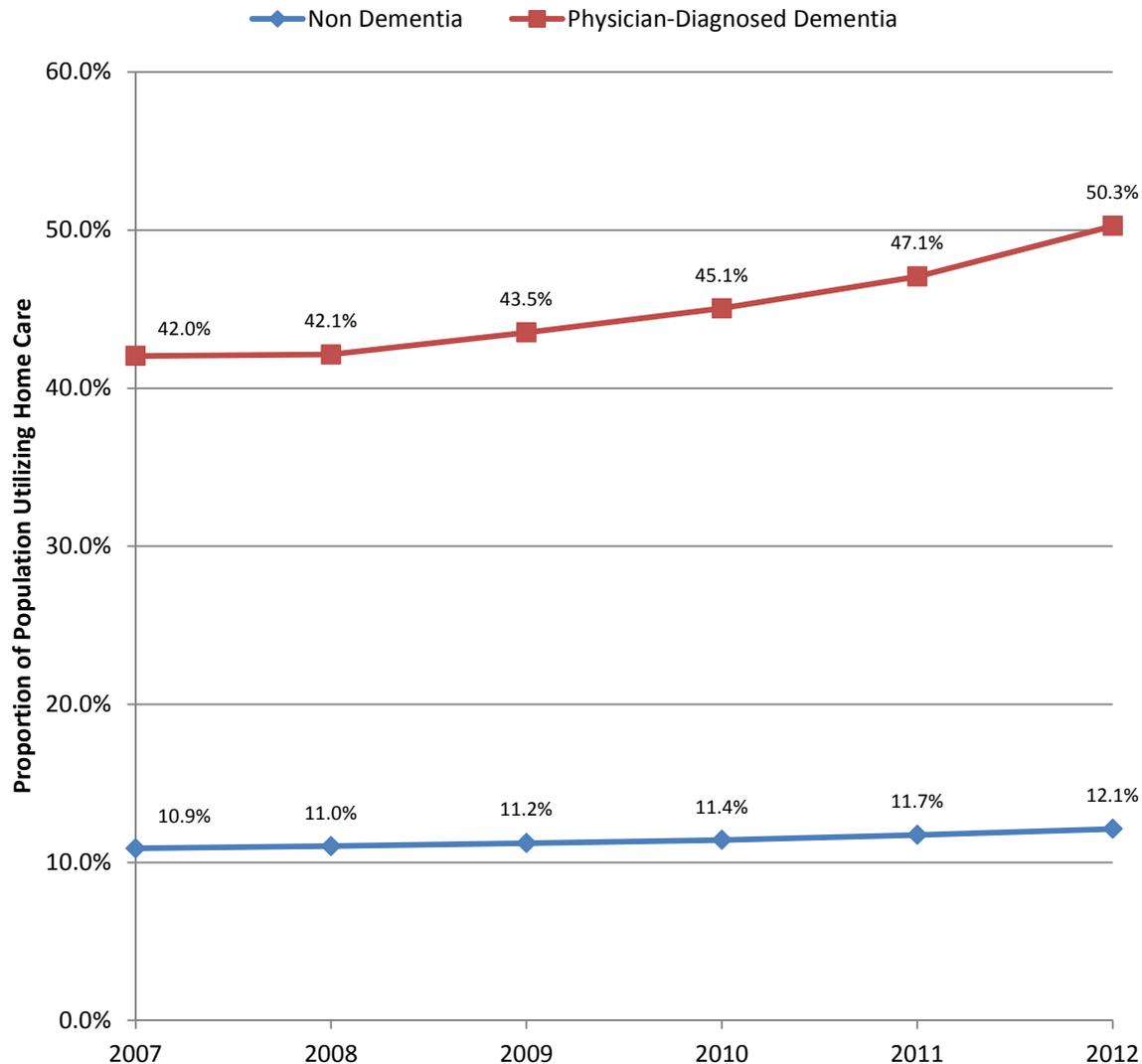


Figure 5. Home care service utilization among community-dwelling older adults with and without physician-diagnosed dementia as a proportion of population for yearly cohorts over study period from 2007 to 2012.

Dementia is a Costly Disease

Key Findings

- 26.6% of the dementia population are in the top 10% cost percentile ($\geq \$24,512$ per year), compared to 9.3% of the non-dementia senior population
- There is an overrepresentation of depression, stroke, falls, ALC stays and repeated emergency department visits among the physician-diagnosed dementia population in the top 10% cost percentile, compared to the non dementia population (deviation from 10.7% population baseline for dementia population)

Considerations

- How can the Health Links program and primary care be utilized to streamline care for high cost health outcomes, particularly with respect to the population with dementia?
- Is there a way to prevent cost inflation as the dementia population grows?

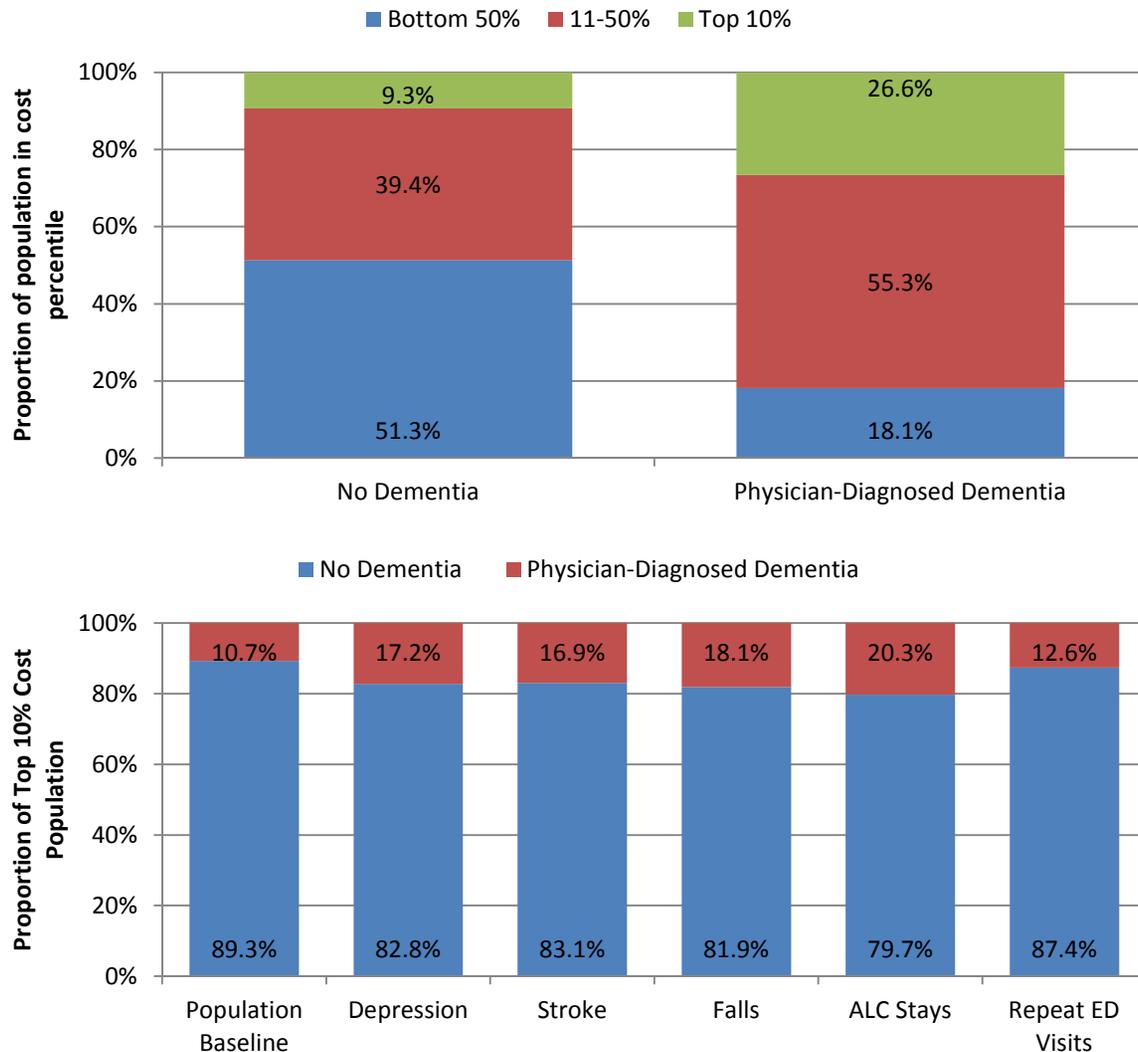


Figure 6. Distribution of cost percentiles by population (*top*) and representation of populations in top 10% cost percentile for select outcomes (*bottom*) as a proportion of the total subpopulation within community-dwelling senior populations for the 2012 cohort.

Pain Management without Self Advocacy

Key Findings

- Among home care patients assessed, 95.7% of those with dementia report multiple episodes of pain daily
- 72% of dementia patients from the same population report that the pain is horrible or excruciating
- This is slightly lower than the home care non-dementia population has reported, indicating a possibility that dementia patients may be less able to express their experienced condition

Considerations

- What is the connection between pain and behaviour symptoms?
- Is there an added level of complexity that would explain pain symptoms beyond multiple comorbidities? Does it correlate with age?
- How does palliative care address pain management when pain can be under-reported?

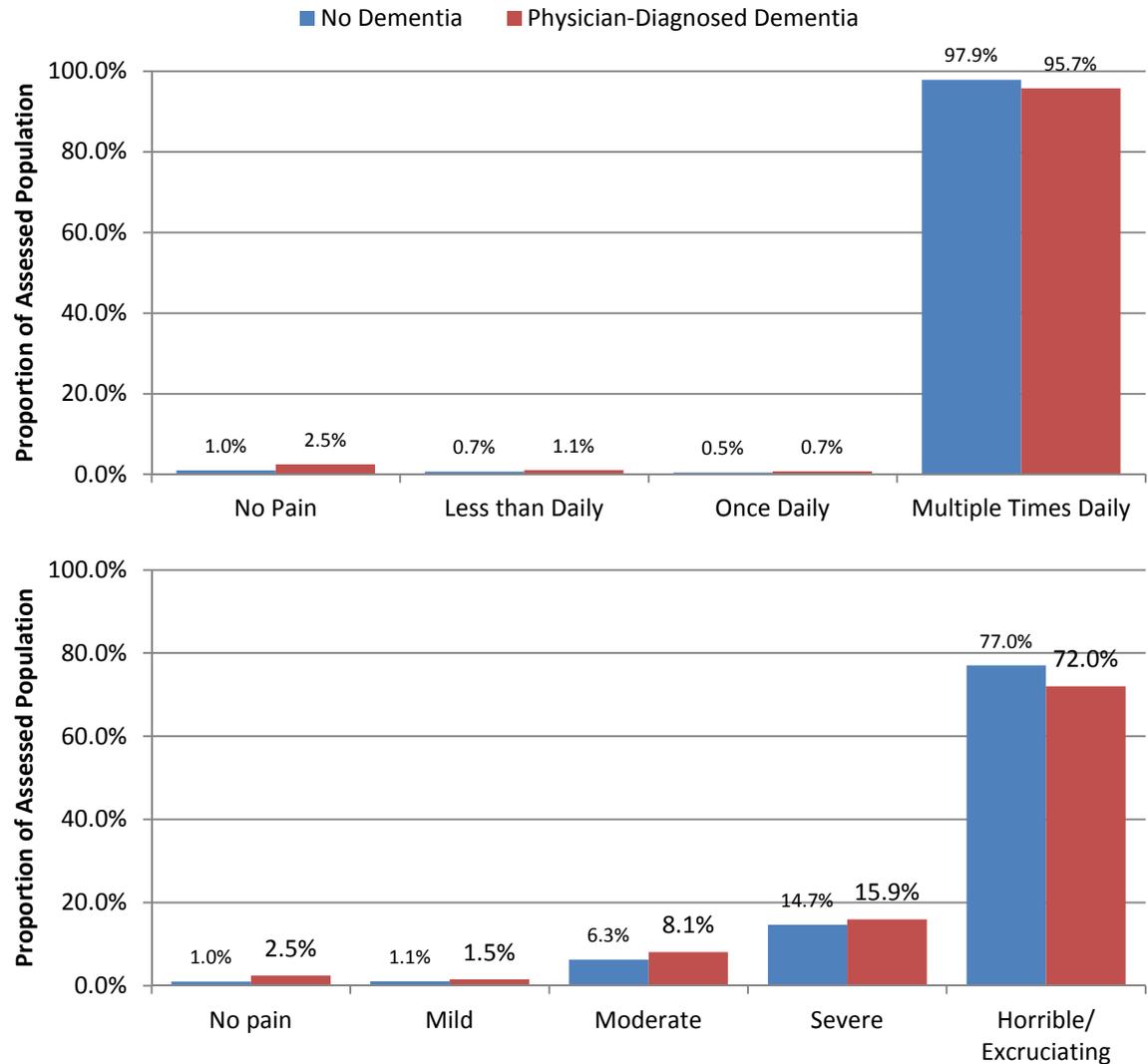


Figure 7. Pain frequency (*top*) and intensity (*bottom*) of RAI assessed home care populations in Ontario as a proportion of the total assessed population for the 2012 cohort.