Ontario Society of Occupational Therapists

Occupational Therapy and Behavioural Symptoms of Dementia

Introduction

Occupational therapy is a person-centered health profession concerned with promoting health and well-being through enabling participation and engagement in the activities of everyday life, across the lifespan. The role of occupational therapy in promoting the health and well-being of aging Ontarians, and individuals with dementia or other forms of cognitive impairment in particular, has been a growing interest among occupational therapists, researchers and policy makers alike.

The purpose of this paper is to review the current context of care for persons with behavioural symptoms of dementia, and the unique opportunities offered by the profession of Occupational Therapy to advance management of this challenging issue in long-term care homes in order to enable the quality of life of residents and to provide more effective support to address impacts of challenging behaviours on staff. The goal of the occupational therapist's assessment, treatment and leadership in this practice area is to;

- Identify underlying needs and issues that give rise to responsive behaviours in order to address these with a goal to supporting the resident's quality of life and preventing or minimizing the frequency of future disruptive behaviours.
- Support capacity building within the resident care team to address prevention/management of behavioural symptoms of dementia.
- Reduce consequences of responsive behaviours such as falls, ER visits, resident risk, resident on resident violence, etc.
- Support care team as a resource for behavioural issues, impacting workload by reducing time spent in addressing disruptive behaviours.

Population and environmental context

In 2012, older adults aged 65 and older represented 14.6 percent of Ontario's total population [1]. According to Dr. Samir Sinha, Provincial Lead for Ontario's Senior Strategy, this number is expected to double in the next twenty years. The estimated prevalence of dementia within this population of older adults is equally striking. The Alzheimer Society reports that, as of 2016, there are 564,000 Canadians living with dementia [2]. By 2023 this number is expected to rise 66%, to 937,000. Older adults with complex needs account for 60 percent of health care spending annually [1]. If left unaddressed, Dr.

Sinha writes, “our demographic challenge could bankrupt the province” [3].

Behavioural symptoms of dementia, or responsive behaviours, have been found to be present in between 56-90% of community dwelling individuals with dementia and from 91-96% of individuals in hospital and long term care settings[4]. The term responsive behaviour refers to any behaviour demonstrated by a person with dementia or other progressive neurocognitive disease[1] that occurs in response to a real or perceived internal or external stimulus. These behaviours, which include symptoms of restlessness, pacing, verbal and physical aggression are associated with poor quality of life, and can result in greater use of mechanical restraint and psychotropic drug use [4-6].

Further, behaviours in dementia have been associated with:

- Increased caregiver stress, illness and burnout [4, 7-9]
- Increased functional impairment [4]
- Faster progression of disease[4]
- Greater rates of institutionalization [4]
- Increased length of hospital stay[4] and days ALC [10, 11]
- Difficulties accessing Long-Term Care (LTC) and/or Rehabilitation Hospitals [11]
- Significant increase in direct costs of care [12]

Challenges in providing behaviour support exist across the health care system

The growing number of older adults with dementia has already started placing tremendous pressures on institutions, healthcare teams and families across hospital, long term care, and community settings. Over the last decade, the profile of residents in long term care has changed. Individuals with dementia are admitted to Long-Term Care Homes (LTCHs) later in their disease and have more complex medical comorbidities. Further, many homes in the province are physically set up for the profile of residents of former years - featuring three to four-person bedrooms similar to a hospital, shared washrooms and bathing facilities, crowded dining areas, and narrow hallways [13]. Health Quality Ontario has collected data on antipsychotic and restraint use as well as behavioural symptoms to inform new standards of care. The data suggest significant room for improvement in the care of persons with behaviours in the LTCH setting [14].

Regarding hospital pressures, a 2014 study found that the majority of patients in acute medicine units who were designated as ‘alternate level of care’ (ALC, meaning not requiring active medical treatment)

[1] The term responsive behaviours will be used in this paper, however there are number of terms used through the literature and clinical practice to describe behavioural symptoms of dementia to include neuropsychiatric symptoms of dementia and behavioural and psychological symptoms of dementia (BPSD). Each of these terms recognize the behavioural and psychological symptoms of dementia that are influenced by biological and disease factors as well as unmet psychosocial or physical needs that cannot be clearly communicated, or that are associated with something in the environment that is confusing or frightening to the person (Gutmanis et al, 2015). It is also important to consider that while the majority of literature on responsive behaviours focuses on individuals with Alzheimer’s and Related Dementias, health care providers are increasingly involved in caring for people with responsive behaviours for individuals with a variety of diagnoses including but not limited to acquired brain injury, delirium, and substance use.

had a diagnosis of dementia and had been waiting over one year for long term care placement [11]. Another 2012 study that explored the causes of long-term delayed discharge inpatients in acute care settings found that mood, behavioural symptoms, and psychiatric conditions were present in 12% to 25% of alternate level of care (ALC) patients, and that 65% of ALC patients waiting for nursing home admission were prescribed psychotropic medications. As well, they found that ALC patients that exhibited physically aggressive behaviors had significantly more ALC bed days relative to the average [10]. A research study in progress at St. Michael's Hospital in Toronto suggests that prior to the implementation of a comprehensive education and quality improvement initiative, many health care providers struggled to work collaboratively to prevent, assess, and create individualized care plans for responsive behaviours due to the multiple, complex and competing demands of the acute care setting. The data from this ongoing study also suggest that responsive behaviours present a concern to patient and provider safety alike. These concerns are echoed by the experience of many OSOT members, who observe significant gaps in health care provider knowledge of dementia and in formal processes of care to prevent and respond to behaviours in acute care environments. This is problematic as there is evidence to suggest that persons with responsive behaviours have longer hospital stays, are more likely to require ongoing institutionalization and have poorer outcomes [10, 11].

With respect to the pressures faced by both families and providers in the community, while aging at home is a priority of both of policy makers and many Ontarians, many OSOT members endorse the observations of caregivers of persons with dementia when they report that there are multiple challenges to caring for a person with responsive behaviours in their home [15].

"Home care is confusing. It was hard to know what we qualified for and it was always someone different which was confusing for me and my dad. We got really tired of telling our story. We need information on changing needs as the disease progresses. Next, we need help for the caregiver as long as client is at home - everything from a night's sleep, going for groceries and meeting a friend for tea."[15]

Caregivers are often older adults themselves, and are tasked with the responsibility of caring for someone full time, while acting as a system navigator and care coordinator. Access to respite (in-home or in group situations such as adult day programs), assistance for personal care, tertiary/specialty seniors mental healthcare providers varies across the province and may or may not meet the needs of a person with responsive behaviours and their family or caregiver. Often caregivers of people with the most challenging behaviours are left to manage their care at home, with a maximum of 10 hours/week of CCAC care (which may vary by LHIN). They struggle to keep their loved ones safe day and night, while attempting to maintain their own physical and mental health, which often suffers as a result.

Policy context

Creation of Behavioural Supports Ontario

In 2010, in recognition of the need for system transformation to meet the needs of individuals with dementia who demonstrate responsive behaviours, leaders from the Muskoka Local Health Integration

Network (LHIN), Health Quality Ontario (HQO), the Alzheimer Society of Ontario, and the Ministry of Health and Long Term Care (MOHLTC) came together to build a holistic, system-wide approach to caring for people with dementia and who exhibit responsive behaviours. The model of care was designed to be person-centered, health promotion focused, and was based on information gathered from clinical expertise, best-available evidence and caregiver lived experience. In 2012 the Behavioural Supports Ontario (BSO) framework was piloted in four early-adopting LHINs and rolled out across the remaining 10 LHINs. The principles guiding the development of this model include: system coordination and integration, accountability and sustainability, person-centered care, behaviour as communication, diversity, collaborative care, and safety[16]. In recognition of ongoing need for specialty services to support the complex needs of older adults who demonstrate responsive behaviours across community, hospital and long term care, in the fall of 2016 the Ontario government announced an increased 10 million dollars per year of funding for the BSO program [17]. The BSO initiative was developed to integrate with and leverage existing programs and services for people living with dementia and who demonstrate responsive behaviours. There is significant variation in terms of how and where BSO teams have been rolled out across the province; some have been rolled into specialized geriatric services, geriatric mental health outreach teams, community support services, or long term care settings, and others have close partnerships with inpatient geriatric assessment units, memory clinics, adult day programs, and the Alzheimer Society[18]. At this time, no BSO funding has been used to create specific positions for occupational therapists; however, there are some OTs who hold both clinical and leadership positions within this initiative. In addition, there are OTs who hold positions on Geriatric Mental Health Outreach teams as general clinicians or case managers. Initial BSO documents identified an "expert practitioner" as a core member on Mobile Interdisciplinary Seniors Behavioural Support Outreach Teams (SBSOT) [19]; however the Ontario Society of Occupational Therapists (OSOT) is not aware of any OTs employed in this regard.

Health Quality Ontario Standards on Behavioural Symptoms of Dementia

In 2016 Health Quality Ontario reviewed the data relating to the care of persons with dementia and found there are significant gaps in care for persons with dementia and knowledge among service providers. There are significant variations in use of restraint and psychotropic use between LTCHs in Ontario, with an average of 23% of LTCH residents receiving an antipsychotic *without* a diagnosis of psychosis[14]. Given the risks associated with pharmacological management of behaviour, this is highly concerning. At the end of 2016, HQO released new, evidence informed standards of practice suggest an interprofessional approach to assessment and care planning, using both non-pharm and pharm interventions, careful monitoring, and supported transitions for patients with dementia[20].

Concerns about current management practices for responsive behaviours

There is a growing concern about the risks associated with pharmacological treatments for responsive behaviour including but not limited to:

- Stroke
- Sedation
- Parkinsonism leading to functional or mobility impairment

- Falls
- Death [21-25]

At the present time, antipsychotic medications are the leading response of health care teams in the management of responsive behaviours. In 2014, 39.0% of seniors in long-term care (LTC) facilities were prescribed at least one antipsychotic medication for management of behaviour [26]. Despite high levels of antipsychotic use, only 12.4% of LTC residents experience improvement in behavioural symptoms with pharmacological treatment[14]. There is growing evidence to state that pharmacological management of BPSD is minimally effective, and the evidence that is available is based exclusively on short-term trials. Expert consensus suggests that pharmacological management of behaviour is not indicated for most persons with dementia, and should only be considered after careful consideration, where the risk of the behaviours outweigh risk of psychotropic use, after individualized care plans are trialed, and then, only when carefully titrated, and for the shortest possible duration [20, 27]. This type of assessment and ongoing evaluation requires a careful, collaborative, and coordinated approach between members of the health care team.

> *"When I started as a nurse practitioner in LTC, I was shocked to see how many residents were receiving long term antipsychotic or benzodiazapines to manage behaviour. Staff really seem to struggle with creating individualized care plans amongst the complex, multiple competing demands of providing care in the LTC home." J. Nurse Practitioner in a LTCH*

There is increased acknowledgement and consensus for the need to use non-pharmacological strategies as the first-line treatment. In recognition of the risks associated with this line of treatment for individuals demonstrating responsive behaviours, there have been a number of practice improvement initiatives and guidelines rolled out in recent years for prescribing medications for the management of responsive behaviours [20, 27]. Findings of interest include:

- Reducing antipsychotic use may reduce all-cause mortality [28]
- Reduction of psychotropic use reduces falls and unnecessary Emergency Department (ED) Visits [12]
- An estimate that 25 million antipsychotic prescriptions could be avoided by 2021, and 448 million prescriptions by 2046 [12]
- A multi-year care strategy focused on team-based, data driven approach to managing behaviours could see a significant opportunity for cost savings across the health care system by 2021:
    - 19% ↓ in antipsychotic prescription costs
    - 8% ↓ ED visit and hospital costs [12]

Room for change:

Health Quality Ontario reports that of residents with behavioural symptoms in LTCHs, only 12.4% experience improvement in their symptoms. The proportion of people *without* improvement in

behavioural symptoms has not improved in the last four year [14]. Further, researchers from the respected Murray Alzheimer Research and Education Program centred at the University of Waterloo, Ontario suggest that traditional understandings of behaviour relied solely on a biomedical lens. When behaviours are understood as pathological, not only are caregivers' abilities to manage behaviour considerably limited, there are significant negative implications for the quality of life of those receiving care [29]. ***Novel approaches are clearly indicated.***

Occupational Therapist as Leaders in the care of Persons with Responsive Behaviours

Alignment of behavioural and occupational therapy practice models and standards

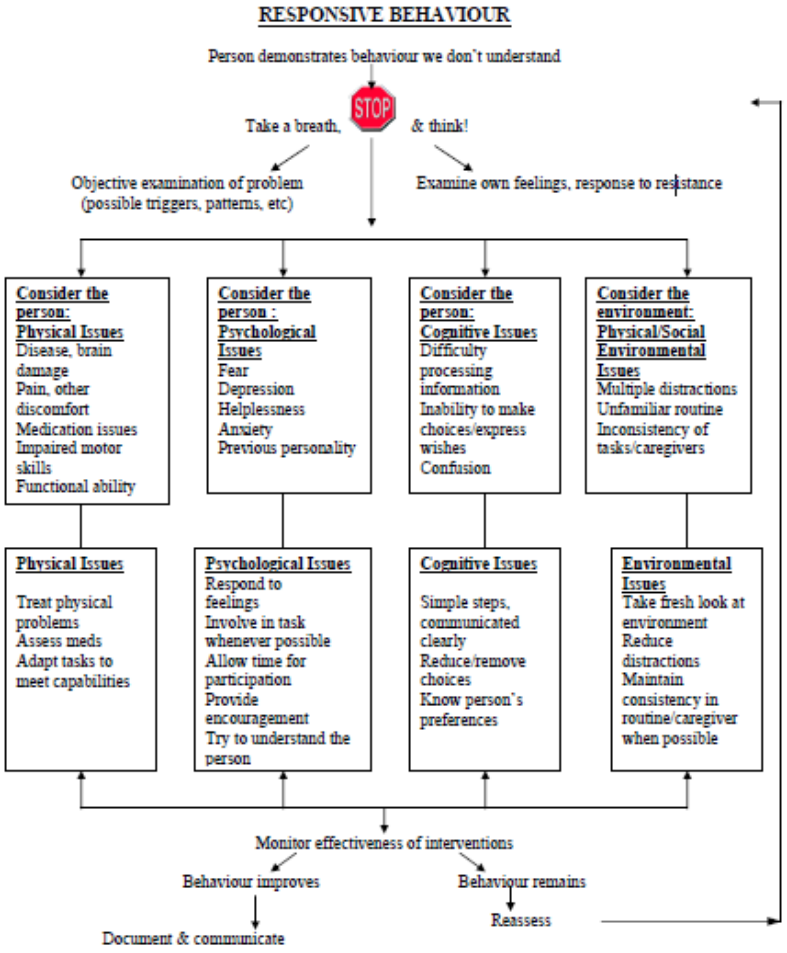
Occupational therapists (OTs) are trained to identify what matters most to their clients and to help them to overcome the barriers they face to engaging in their day-to-day lives in a way that is meaningful and health-promoting. OTs consider the fit between a person's physical, emotional, cognitive and spiritual health, the environment in which they live, and what it is they are striving to achieve[30]. For persons living with dementia, the confusion, fear and frustration that can result from a poor fit between what the person hopes to achieve, their abilities and their environment can be a significant contributor to responsive behaviour. The OT practice framework necessitates that interventions are rooted in the OT's assessment findings, and are monitored and modified as needed throughout implementation. Below, the theoretical and practice frameworks that underscore leading practice in behavioural assessment and non-pharmacological care planning are reviewed and the ways in which these align with practice models, skills and competences in occupational therapy are highlighted.

The dominant framework used by BSO clinical teams and other clinicians practising in a behavioural support capacity is the PIECES framework [31]. PIECES is an acronym which guides a holistic consideration of what may be contributing to or underlying an individual's presenting responsive behaviours – Physical, Intellectual (cognitive), Emotional, Capabilities (function), Environment, and Social/cultural – and which closely aligns with the occupational therapy theoretical model of P-E-O (Person-Environment-Occupation) [32]. The ABC (antecedent behaviour consequence) model, based in behavioural analysis, is also used as a model to guide assessment of responsive behaviours, particularly in terms of determining what may be "triggering" a behaviour [33]. The leading theoretical frameworks consider responsive behaviours to be a result of (1) an unmet need, and (2) a poor fit between the demands of the environment and the capabilities of the person.

What also must be considered when assessing the underlying cause(s) and possible triggers or antecedents for the responsive behaviour, is what function the behaviour serves for the individual. As occupational therapists, we may understand this as the "Occupation" in our PEO model, or the missing part of the PIECES model; what matters to this person, what are they aiming to achieve or what is their behaviour communicating about their needs? A 2012 Cochrane review has found promising evidence to support "Functional Analysis" based interventions for responsive behaviours [34]. This approach requires the clinician to systematically assess and strive to understand the meaning or function of the behaviour, and then use the information gathered through this process to guide the development of

hypothesis-driven, individually tailored strategies aimed to support both the individual with dementia as well as those caring for him. Findings from this review suggest that Functional-Analysis-based interventions can reduce the frequency of responsive behaviours and, through capacity building with caregivers, can improve caregivers' response to these behaviours. Due to constraints relating to scope of practice, defined role, and time, there are few professions that are able to lead the assessment, implementation and monitoring of non-pharmacological strategies in an evidence-informed and systematic way [35]. Occupational therapists have a depth and breadth of assessment skills that fill this gap [36]. It is worthy of note that while evidence-based interventions are growing in number, there is no universal, all-purpose intervention for treating this problem. Occupational therapists possess a variety of competencies to provide flexible, individualized, and comprehensive assessments in light of no one universally accepted framework for behavioural symptoms.

One such example of leveraging OT skills is a model proposed by Davidson [36], *The Behaviour Framework.* This presents a systematic approach that can be applied when dealing with any responsive behaviour.



Adapted from: "Dementia: A Systematic Approach to Understanding Behaviour ", S. Davidson, in Geriatrics & Aging, 2007, 10(2), pp. 104-107

The evidence for OT-led assessment in a model such as above aligns and supports the recently released HQO standards for the care of patients with behavioural symptoms of Dementia in Hospital and Long-Term Care settings [20]:

1.) Comprehensive Assessment
2.) Individualized Care Plans
3.) Individualized non-pharmacological interventions
4.) Indications for Psychotropic use*
5.) Monitoring and Titrating Psychotropic use*
6.) Switching Psychotropic Medication*
7.) Medication Review for Dosage Reduction*
8.) Mechanical restraint
9.) Informed Consent
10.) Specialized Interprofessional care team
11.) Provider Training and Education
12.) Caregiver training and Education
13.) Appropriate Care environment
14.) Transitions in care

*Although OTs are not involved directly in prescribing, they provide essential assessment and reasoning skills to help guide health care team discussions about risks and benefits as well as alternatives to psychotropic use.

Occupational therapists use a practice process that involves considering the social, practice context and the unique individual. As part of the comprehensive practice process OTs complete a comprehensive assessment, work collaboratively with stakeholders (the client, other care providers, family) to agree upon goals and priorities, then implement a plan while continually monitoring the progress against the expected outcomes and goals, and lastly using outcome measures to measure success [30].

Improvements in the care of persons with responsive behaviours will require a variety of skills and coordinated efforts. Occupational therapists are trained to use a variety of enablement skills to engage clients, families and other care providers including collaboration, consultation, coaching, advocacy, education[30]. These skills and professional values align closely with those of the BSO strategy and guiding frameworks, to include system coordination and management; integrated service delivery (intersectoral and interdisciplinary); knowledgeable care team and capacity building [16].

OT role and leadership in behavioural management

There are calls to maximize and expand scopes of practice of all health professionals to improve the sustainability, efficiency and quality of health care provision. Where all health care providers are practicing to their full extent of their knowledge and skill, client care is optimized [37]. Effective behaviour management strategies require astute assessment skills using a broad, multidimentional lens [29, 35]. There is good evidence to suggest that OTs have the necessary foundational knowledge, skill and judgement to fill this role.

"Our GMHOP clinician (who is an OT) helps us balance decisions about safety and risk when managing responsive behaviours and to provide us with novel strategies and approaches that expand our abilities to use non-pharmacological interventions. She brings a perspective and expertise not only in behaviours,

but in the care of people with significant mental health or trauma issues that our team does not have."
~ C. RN and Director of Care in a Long Term Care Home

Consider OTs in quite different practice settings and how each OT makes unique and vital contributions to advancing the care of persons with responsive behaviours:

- Joanne is an occupational therapist working in a LTC home. She is exceptionally skilled in providing seating and mobility devices, such as custom wheelchairs for clients. She assesses a person's physical and cognitive status as well as the demands of the environment. She has made very astute observations about residents' pain, positioning, pressure relief, ADL (ie. transfer, toileting and feeding), and functional mobility needs and implemented strategies to manage these issues, which have thereby reduced behavioural displays in persons with dementia.

- Elizabeth is an OT working on an Acute Medicine unit at a teaching hospital. She frequently receives referrals for inpatients who demonstrate behaviours that interfere with activities of daily living such as bathing, dressing, and dining, as well as seating concerns. Her skill set in assessment of the person and environment factors that interfere with the patient's abilities to engage in basic daily activities enables her to effectively identify and come up with creative strategies to address these barriers and maximize the patients' function and participation. Elizabeth has found that by promoting autonomy and engagement in basic daily activities, behaviours can be significantly reduced.

- Allison is an OT on a Trauma and Neurosurgery Unit at a Tertiary Hospital. She provided leadership and education for an initiative for a person-centered care approach to manage responsive behaviours in a busy, acute care setting. She recognized that patients who demonstrated behaviours required costly constant-care observers and were delayed in discharge and accessing rehabilitation. She identified a need for individualized care plans and team communication about the care plan. She leads weekly team rounds to implement, monitor and adapt the care plans as needed to help reduce behaviours in a more timely manner

- Sarah is an OT working in the community with specialized geriatric mental health services. She provides practical suggestions to informal and formal caregivers on how to maximize a person with dementia's ability to remain independent in their home and at the adult day program, minimizing their responsive behaviours and reducing caregiver stress. She identifies and initiates future planning, identifying when community resources have been exhausted and long term care placement application is appropriate. When the person moves to long term care, she provides information on strategies that work in the person's home to facilitate their transition into long term care.

With respect to treatment, OTs are well positioned to be experts in non-pharmacological interventions, as engaging people in purposeful activity is inherently non-pharmacological[36]. OTs have a rich education and experience in working with a variety of treatments to enhance quality of life of both

caregivers and people with Dementia[38], and have been acknowledged as a key partner in the care of people with Dementia (Mental Health Commission of Canada document). Interventions such as person-centered care [39], tailored behavioural plans [40], activity therapy [41], Montessori Methods for Dementia[42, 43], multi-sensory therapy and aromatherapy [34] are some of the interventions OTs may use to help a person with responsive behaviours.

There is a growing body of evidence and care standards that make the contributions of an occupational therapist essential to the management of behaviours [HQO]. Some of the leading interventions that are emerging in the literature align closely with OT practice, competence and enablement skills. There is high level evidence to support the following interventions:

- A study of community-dwelling individuals with dementia found the use of **individually-tailored activities based on an OT assessment in and intervention** can caregiver burden, preserve daily living and cognitive function and defer placement LTC[44]
- The use of **personalized pleasant activities -** either with or without social interaction- reduce agitation[45]
- **Experiencing pleasure is a skill that can be maintained through positive engagement in activity.** The ability to experience pleasure and positive interactions preserves not only a person's functional capacity, but also their ability to accept care without behaviours [46]
- **Environmental modifications can reduce behavioural displays** [47, 48]. OTs are experts in modifying environments to meet individual needs.

Occupational therapists in both general practice roles with older adults as well as in more specialized clinical roles focusing on behavioural assessment have an important role to play in supporting the management of responsive behaviours across practice settings.

Conclusion:

The pressures that are facing our healthcare system at this moment and time and which are expected to grow with the *rising tide* of Ontario's aging population require a multifaceted, collaborative, interprofessional approach to system transformation. Responsive behaviours are present in up to 96% of people with dementia and can have a significant impact on quality of life, health outcomes, eligibility for long term care, length of hospital stay, and caregiver health. With growing evidence that pharmacological treatments are not a catch-all solution to this problem, important initiatives such as Behavioural Supports Ontario (BSO) and the new Health Quality Ontario (HQO) standards are helping to pave the way for a new approach to understanding and working collaboratively to manage behavioural symptoms in our patients, clients and residents with dementia.

When we review the current, leading approaches to behavioural assessment and treatment, it is apparent that occupational therapists possess a unique and invaluable lens through which responsive behaviours can be understood, interpreted and managed. Our practice process and leading practice

models align seamlessly with leading behavioural approaches and guide us through a holistic assessment process to understand the meaning or function behind the behaviour and consideration of the combination of cognitive, physical, emotional, spiritual, environmental and function-related factors impeding a person from living meaningfully and fully. Occupational therapists possess key assessment, enablement, treatment, and evaluation skills that align with current best practices with this population. Our strong skills in interprofessional collaboration and leadership position us to be leaders in this unique practice area.

As our health care system looks to develop new and innovative ways to manage the growing number of people with dementia, many of whom will demonstrate behaviours that pose a barrier to the safe delivery of care and prevent safe and smooth transitions across the continuum of care, we advocate for occupational therapists to be recognized and supported for the important role they can play in both leadership and clinical roles to advance system transformation, reduce the health care costs related to consequences of responsive behaviours (falls, ER admissions, staff turnover, etc.), and, most importantly, enrich the quality of life of residents of Ontario long-term care homes for as long as possible.

February 2017

References:

1. Sinha, S.K., *Living longer, living well.* Report submitted to the Minister of Health and long-term care and the minister responsible for seniors on recommendations to Inform a Senior Strategy for Ontario, 2012.
2. Alziemer's Society of Canada, *Report summary Prevalence and monetary costs of dementia in Canada (2016): a report by the Alzheimer Society of Canada.* Health Promot Chronic Dis Prev Can, 2016. 36(10): p. 231-232.
3. Dudgeon, S., *Rising Tide: The Impact of Dementia on Canadian Society: a Study*. 2010: Alzheimer Society of Canada.
4. Cerejeira, J., L. Lagarto, and E. Mukaetova-Ladinska, *Behavioral and Psychological Symptoms of Dementia.* Frontiers in Neurology, 2012. 3(73).
5. Cooper, C., et al., *Systematic review of the effectiveness of pharmacologic interventions to improve quality of life and well-being in people with dementia.* American Journal of Geriatric Psychiatry, 2013. 21(2): p. 173-183.
6. Cooper, C., et al., *Systematic review of the effectiveness of non-pharmacological interventions to improve quality of life of people with dementia.* International Psychogeriatrics, 2012. 24(6): p. 856-870.
7. Matsumoto, N., et al., *Caregiver burden associated with behavioral and psychological symptoms of dementia in elderly people in the local community.* Dementia & Geriatric Cognitive Disorders, 2007. 23(4): p. 219-224.
8. Chan, D., et al., *Grief reactions in dementia carers: a systematic review.* International Journal of Geriatric Psychiatry, 2013. 28(1): p. 1-17.

9. Clyburn, L.D., et al., *Predicting caregiver burden and depression in Alzheimer's disease.* Journals of Gerontology Series B: Psychological Sciences & Social Sciences, 2000. 55B(1): p. S2-13.
10. Costa, A.P., et al., *Acute care inpatients with long-term delayed-discharge: evidence from a Canadian health region.* BMC health services research, 2012. 12(1): p. 172.
11. McCloskey, R., et al., *Alternate level of care patients in hospitals: what does dementia have to do with this?* Canadian Geriatrics Journal, 2014. 17(3): p. 88-94.
12. Murman, D.L., et al., *Comparison of healthcare utilization and direct costs in three degenerative dementias.* Am J Geriatr Psychiatry, 2002. 10(3): p. 328-336.
13. Canadian Association for Long Term Care. *Caring for Canada's Seniors: Recommendations for meeting the needs of an aging population.* 2017.
14. Health Quality Ontario, *Information and Data Brief: Behavioural Symptoms of Dementia Care for patients in Hospitals and Long-Term Care Homes,* 2016.
15. Lived Experience Cafe Dementiacrossroads.ca, in *October/November 2016 Lived Experience Advisory Conversations*. 2016.
16. Behaviour Supports Ontario. *Provincial Framework of Care*. [cited 2017 January 20]; Available from: http://www.behavioursupportsontario.ca/25/Provincial_Framework_of_Care/.
17. Ministry of Health and Long Term Care. *News Release: Ontario Investing Additional $10 Million to Enhance Behavioural Supports Program*. August 18, 2016.
18. Gutmanis, I., et al., *Health Care Redesign for Responsive Behaviours-The Behavioural Supports Ontario Experience: Lessons Learned and Keys to Success.* Canadian Journal of Community Mental Health, 2015. 34(1): p. 45-63.
19. Dundgeon, S.R., Patti, *Appendix C Proposed Behavioural Support System Model: Detailed Working Document*, Behaviour Supports Ontario, 2010: http://brainxchange.ca/Public/Files/BSO/BSS_Appendices_to_Report_Full_document.aspx.
20. Health Quality Ontario, *Behavioural Symptoms of Dementia: Care for Patients in Hospitals and Residents in Long-Term Care Homes*, 2016.
21. Gauthier, S., et al., *Recommendations of the 4th Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCDTD4).* Canadian Geriatrics Journal, 2012. 15(4): p. 120-126.
22. Conn, D., et al., *Guidelines for the assessment and treatment of mental health issues in LTC: focus on mood and behaviour symptoms.* Canadian Nursing Home, 2008. 19(1): p. 24-31.
23. Sink, K.M., K.F. Holden, and K. Yaffe, *Pharmacological treatment of neuropsychiatric symptoms of dementia: A review of the evidence.* JAMA, 2005. 293(5): p. 596-608.
24. Huybrechts, K.F., et al., *Differential risk of death in older residents in nursing homes prescribed specific antipsychotic drugs: population based cohort study.* BMJ, 2012. 344, e977.
25. Kales, H.C., et al., *Risk of mortality among individual antipsychotics in patients with dementia.* American Journal of Psychiatry, 2012. 169(1): p. 71-79.
26. Canadian Institute for Health Information, *Use of Antipsychotics Among Seniors Living in Long-Term Care Facilities, 2014.* 2016.
27. Kales, H.C., et al., *Management of neuropsychiatric symptoms of dementia in clinical settings: recommendations from a multidisciplinary expert panel.* J Am Geriatr Soc, 2014. 62(4): p. 762-9.
28. Ballard, C., et al., *Top cited papers in International Psychogeriatrics: 6a. Quality of life for people with dementia living in residential and nursing home care: the impact of performance on activities of daily living, behavioral and psychological symptoms, language skills, and psychotropic drugs.* Int Psychogeriatr, 2009. 21(6): p. 1026-30.
29. Dupuis, S.L., E. Wiersma, and L. Loiselle, *Pathologizing behavior: Meanings of behaviors in dementia care.* Journal of Aging Studies, 2012. 26(2): p. 162-173.

30. Townsend, E.A. and H.J. Polatajko, *Advancing an occupational therapy vision for health, well-being, and justice through occupation.* Ottawa, ON: CAOT Publications ACE. 2007.
31. Pieces Canada. *PIECES Framework. 2005*
32. Law, M., et al., *The Person-Environment-Occupational Model: a transactive approach to occupational performance.* Canadian Journal of Occupational Therapy, 1996. 63(1): p. 9-23.
33. Bird, M. and E. Moniz-Cook, *Challenging behaviour in dementia: A psychosocial approach to intervention.* Handbook of the Clinical Psychology of Ageing, Second Edition, 2008: p. 571-594.
34. Moniz Cook, E.D., et al., *Functional analysis-based interventions for challenging behaviour in dementia.* Cochrane Database of Systematic Reviews, 2012(2): p. 283–90.
35. Kales, H.C., L.N. Gitlin, and C.G. Lyketsos, *Management of Neuropsychiatric Symptoms of Dementia in Clinical Settings: Recommendations from a Multidisciplinary Expert Panel.* Journal of the American Geriatrics Society, 2014. 62(4): p. 762-769.
36. Davidson, S., *Dementia: A systematic approach to understanding behaviour.* Geriatrics & Aging, 2007. 10(2): 104-107.
37. Nelson, S., et al., *Optimizing scopes of practice.* New models of care for a new health care system. Ottawa, Canadá: Canadian Academy of Health Sciences. 2014.
38. Gitlin, L.N., et al., *Tailored activities to manage neuropsychiatric behaviors in persons with dementia and reduce caregiver burden: a randomized pilot study.* American Journal of Geriatric Psychiatry, 2008. 16(3): p. 229-239.
39. Konno, R., H.S. Kang, and K. Makimoto, *A best-evidence review of intervention studies for minimizing resistance-to-care behaviours for older adults with dementia in nursing homes.* Journal of Advanced Nursing, 2014. 70(10): p. 2167-2180.
40. Livingston, G., et al., *A systematic review of the clinical effectiveness and cost-effectiveness of sensory, psychological and behavioural interventions for managing agitation in older adults with dementia.* Health Technology Assessment, 2014. 18(8): p. 1-226.
41. Douglas, S., I. James, and C. Ballard, *Non-pharmacological interventions in dementia.* Advances in Psychiatric Treatment, 2004. 10(3): p. 171-177.
42. Ducak, K., M. Denton, and G. Elliot, *Implementing Montessori Methods for Dementia™ in Ontario long-term care homes: Recreation staff and multidisciplinary consultants' perceptions of policy and practice issues.* Dementia, 2016.
43. Elliot, G., Montessori Methods for Dementia*.* McMaster University, 2011.
44. O'Connor, C.M., et al., *Use of the Tailored Activities Program to reduce neuropsychiatric behaviors in dementia: an Australian protocol for a randomized trial to evaluate its effectiveness.* International Psychogeriatrics, 2014. 26(5): p. 857-869.
45. Testad, I., et al., *The value of personalized psychosocial interventions to address behavioral and psychological symptoms in people with dementia living in care home settings: a systematic review.* Int Psychogeriatr, 2014. 26(7): p. 1083-1098.
46. Cohen-Mansfield, J., et al., *What affects pleasure in persons with advanced stage dementia?* J Psychiatr Res, 2012. 46(3): p. 402-406.
47. Zuidema, S.U., et al., *Environmental correlates of neuropsychiatric symptoms in nursing home patients with dementia.* Int J Geriatr Psychiatry, 2010. 25(1): p. 14-22.
48. Smit, D., et al., *Wellbeing-enhancing occupation and organizational and environmental contributors in long-term dementia care facilities: an explorative study.* Int Psychogeriatr, 2014. 26(1): p. 69-80.