



Report of the Professional Issues Forum on
Rising Tide of Dementia in Canada”:
**Occupational therapists supporting people
living with dementia**
Quebec, QC CAOT Conference 2012

Introduction

The CAOT Professional Issue Forum on Addressing the “Rising Tide of Dementia in Canada”: Occupational therapists supporting people living with dementia was held June 8, 2012 at the CAOT National Conference in Quebec City from 8:30 a.m. to 11:30 a.m. The Forum was facilitated by Alison Douglas and panel presentations were done by Mr. Harvey Berger, Mary Shultz and Sylvia Davidson. Opening comments were done by Carrie-Lynne Comtois, occupational therapy student.

Rationale for implementing the initiative:

“Rising Tide: The Impact of Dementia on Canadian Society” (Alzheimer Society of Canada, 2009) outlines that approximately 500,000 Canadians are currently living with a form of dementia, 70,000 of whom are under the age of 65. By 2038, unless steps are taken to ‘stem this tide’, the number of Canadians with dementia is expected to grow to 1.1 million with the rate of incidence for those of 65+ years of age expected to increase to 250,000 new cases per year (2.5 times the current level). Family caregivers of people with dementia frequently experience psychological problems (40% to 75%) with the prevalence of clinical depression among caregivers estimated at 15 to 32% (Alzheimer's Disease International, 2010).

Living safely with dementia is an ongoing challenge due to the functional and cognitive changes that this disease brings, i.e. impairing judgement and problem-solving abilities. Consequently, creating safe environments is crucial to prevent stressful and dangerous situations. Finding the appropriate balance between safety and independence for each individual requires specific assessment and intervention strategies. Occupational therapists play an important role in working with individuals with dementia in supporting performance (e.g. enhancing self-esteem through reminiscence and maintaining functional mobility), facilitating meaningful occupations (e.g. teaching skills to caregivers to maintain independence in day to day functioning, such as bathing); supporting individuals with dementia in participating in meaningful leisure activities and in developing a safe and supportive environment (e.g. reducing safety risks for people with dementia who wander, assuring appropriate levels of sensory stimulation).

The Alzheimer Society is Canada’s leading source of support, information and education for people living with dementia, their families and caregivers, physicians and other health care professionals. Through a series of innovative programs, the Society helps connect people who are newly diagnosed to the information and support they need.

In the Fall of 2010, the Alzheimer Society of Canada (ASC) and the Canadian Association of Occupational Therapists (CAOT) established a collaborative venture to build the capacity of occupational therapists across the country and to provide reliable information and support to people living with dementia with a goal to ensure that these individuals live as safely as possible at home for as long as desired.

This collaboration has resulted in an extended session at CAOT Conference in Saskatoon, 2011 on how CAOT and the ASC can support occupational therapists in their work with people living with dementia (see Appendix 1), a national needs assessment survey (see Appendix 2), a series of webinars (see Appendix 3), the launch of the second edition of “Living at Home with Alzheimer’s Disease and Related Dementias” (see Appendix 4), Professional Issue Forum (PIF) at CAOT Conference in Quebec City, 2012.

Purpose

The purpose of this 2012 PIF was to seek information about how the complex needs of people with dementia and their families impact current occupational therapy practice, and how we can better equip occupational therapists to work more effectively with this increasingly numerous clientele, from a person-centred perspective.

The PIF objectives were:

- To learn about promising and leading practices which support excellence in the delivery of occupational therapy to individuals living with dementia and their family members.
- To understand which tools, strategies, partnerships and models of care would be most helpful in building occupational therapist’s capacity in this area of practice
- To inventory opportunities for occupational therapy engagement in the development of more effective, interprofessional, person-centred policy and practice.

Facilitator: Alison Douglas is an occupational therapist with clinical experience in acute care and home care. She recently completed a PhD at McMaster University and has research interests in older adults with cognitive deficits. In the past year, she has also helped CAOT with the development of the resource "Strategies to address elder abuse for occupational therapists".

Panelists:

Mr Harvey Berger lives with Alzheimer’s disease. He has experience speaking to large groups on ‘Living with Alzheimer’s’ and recounting his stories about his discovery, transition and coping with the disease.

Mary Schulz has been the Director, Information, Support Services and Education at the Alzheimer Society of Canada since 2006. Mary has spent her career in health care, providing individual and family counseling to clients facing crises associated with life-limiting illness, chronic disability and cognitive impairment. She has also helped to plan and implement programs and services in settings throughout the health care continuum. Mary obtained her Bachelor degree in Social Work from Ryerson University and holds a Masters degree in Social Work from York University.

Sylvia Davidson is currently the Professional Practice Chief for Occupational Therapy at Baycrest. She has spent over 20 years working with older adults, across the health care continuum, with a focus on dementia in her practice over the past 12 years. Sylvia has a Masters of Rehabilitation Science, a Bachelor's Degree in Occupational Therapy, a Bachelor's Degree in Anatomy and a Diploma in Gerontology. As well, she is a lecturer at the University of Toronto, teaching occupational therapy students about the art and the science of working with older adults.

Summary of Presentations:

For the full content of the presentations, please refer to Appendix 5 (Power Point Presentation). The following is a brief summary of the content each presentation.

Presentation by a consumer living with Alzheimer's disease: Mr. Harvey Berger spoke about challenges he faces in daily life and ways he has overcome them (coping strategies). Questions from the attendees included whether he faces stigma, what is his background and how that influences his ability to cope.

Presentation by a key partner: Mary Schulz, Director, Information, Support Services and Education at the Alzheimer Society of Canada

Mary briefly reviewed some of the vital statistics regarding the incidence and prevalence of dementia in Canada, both now and as forecast over the next thirty years. (ref: The Rising Tide of Dementia in Canada; www.alzheimer.ca) There is a compelling urgency for occupational therapists in Canada to continuously improve their skills and knowledge so as to meet the needs of the growing number of Canadians living with dementia and their families. As experts in improving individual function, including the ability to live as safely as possible with dementia, occupational therapists are in a unique position to work collaboratively with others to improve the quality of life of people with dementia regardless of the setting in which they live and the stage of the disease that they are experiencing.

Presentation by a clinical manager: Sylvia Davidson: Professional Practice Chief – Occupational Therapy. Baycrest, Toronto.

Sylvia presented highlights from what has been learned during previous CAOT, workshops and extended sessions and from the national survey conducted in 2011. While there are many challenges that occupational therapists face in their work with persons with dementia, their caregivers and families, there is a strong sense that our values and beliefs as occupational therapists (our person-centred approach to care, emphasis on strengths and abilities, recognition of the need to balance risk vs. autonomy) make us ideally suited to take on these challenges. Occupational therapists are ready to roll up their sleeves and start working together to share resources and build capacity.

SUMMARY OF SESSION FEEDBACK:

Overall, the PIF was well received and the full report of feedback can be found in Appendix 6. The majority of attendees reported that it met their expectations, it was informative, well organized, and that discussion was encouraged. Possible actions suggested in the roundtable discussion's for CAOT to undertake are listed in full in Appendix 6, salient points are summarized below.

Summary of Roundtable Discussion:

Small groups of 8-10 attendees discussed the four following questions. The salient points are summarized below. A full list of items generated can be found in Appendix 7.

1. What successes are out there for finding resources or building your capacity to deliver services in dementia care?

Successes that were noted by the attendees included online resources already developed, current partnership with ASC, and several specific successes at local sites such as a memory clinic, effective use of cognitive screening tools, presence of occupational therapist in a family health clinic where early detection was being done, and letters being sent to family physicians explaining the cognitive assessment results of their patients. Also noted was the presence of occupational therapists at national and provincial occupational therapy conferences, and topics related to dementia from an occupational therapy perspective at conferences. One success noted was a targeted curriculum for dementia within occupational therapy entry programs.

2. What opportunities are there for promoting involvement of occupational therapists to achieve best client outcomes in dementia care?

Important opportunities that were noted included the development of new curricula and new technologies (e.g mobile apps). Having forums about dementia, having occupational therapists involved in community support groups, bringing persons with dementia together for networking opportunities and having increased visibility with the public . A number of items that were mentioned related to changing attitudes about dementia and occupational therapy involvement, such as more than just screening, “maintain, not ‘do for’”, person-centred care, and change language to one of competence rather than one of deficits. Additionally, attendees discussed the different advocacy roles of occupational therapists: occupational therapists as consultants in Long Term Care, championing role in interprofessional teams, and expanding the role of rehabilitation assistants. The discussion of opportunities tended to overlap somewhat with actions or plans, and some opportunities noted were ideas for future development.

3. What actions/tools are needed to build capacity for occupational therapists to address dementia care in Canada?

A list of suggested actions was generated during the forum through brainstorming and discussion amongst attendees in roundtables and large-group format. These actions were then discussed by the professional issue forum team after the conference. The full list of generated actions at the roundtables can be found in Appendix 6. The list of actions for CAOT reported on

feedback forms after the session can be found in Appendix 7. Upon analysis of the forum input from both Appendix 6 and Appendix 7, the PIF team discussed that there were important themes emerging. These are summarized as:

- Need for sharing resources, and talking amongst practitioners and managers nationally about best practice with people with dementia
- Need for addressing issues with various stakeholder audiences
- Need for advocacy building in own organization and in broader system

In order to address these main issues, the first and most important action put forward by the team is to form a CAOT dementia practice networking group (i.e., a Community of Practice (CoP)). Sylvia Davidson has offered to chair the group as it starts. The overall aim is to provide a forum for knowledge exchange between occupational therapists who are working and interested in dementia care.(?). Functions of the working group include:

- capture/identify the needs of OTs currently not addressed with existing resources
- map out plan for putting resources in place/is resource allocation perhaps better understood?
- develop a knowledge translation group
- develop web resources
- develop additional resources, e.g. a primer on becoming connected in dementia practice
- enhance member knowledge of current tools and resources and involve them in the making of new ones

Identifying and addressing the needs for resources could lead to ongoing work between CAOT and the Alzheimer Society of Canada (ASC) and pursuit of funding to promote advances in dementia care. The ASC could be an honorary member of the CoP so as to provide a dementia-specific resource link.

This dementia practice working group would require resources typically provided to CAOT networking groups such as: teleconference line, web page, translation English and French, information dissemination to CAOT members with OT Weekly, and webinar support.

4. What kind of partnerships can be developed to enhance care?

Important partnerships could include community support groups both locally and nationally, researcher/clinician linkages, networking among occupational therapists (e.g. interest groups, OT Networker <https://www.caot.ca/ebusiness/source/members/otsearch.cfm>), and with family physicians, political representatives, and architects and vendors.

Summary of Overall Recommendations from PIF Discussions

This forum provided an opportunity to discuss promising and leading practices which support excellence in the delivery of occupational therapy to individuals living with dementia and their

family members, to understand which tools, strategies, partnerships and models of care would be most helpful in building occupational therapist’s capacity in this area of practice and to inventory opportunities for occupational therapy engagement in the development of more effective, interprofessional, person-centred policy and practice. However, there is much more action required to support occupational therapists to advance practices in dementia care. In particular there are a number of knowledge translation strategies that could be implemented to provide platforms for exchange of information and best practice, stimulate dialogue and to foster excellence in the delivery of occupational therapy to individuals living with dementia and their family members. CAOT can play a vital role by supporting a community of practice, web portal/platform, possible publication and on-going advocacy work to promote the role of occupational therapy to people living with dementia.

Summary of Knowledge translation strategies recommended for occupational therapists to address the “Rising Tide of Dementia in Canada”

Knowledge translation strategy	For CAOT to do/consider	For occupational therapist to do/consider
Develop Community of Practice for Dementia Care	Support this CoP through dissemination of meeting info, website, teleconference line, webinars	Host and participate in CoP
Develop Web resources: e.g. autonomy, safety, advocacy, technology aids	Provide networking between therapists and expertise to support development of resources, provide web space, explore future sources of funding for tool/resource development	Use current resources, share expertise, participate in resource development, participate in resource evaluation and dissemination: e.g. local educational sessions, posting information to colleagues
Develop a primer on becoming connected in dementia practice	Explore expertise for primer development, explore future sources of funding for resource development, link with other professions nationally	Participate in resource evaluation and dissemination
Advocacy/education about role of occupational therapy in dementia care	Continue partnership with ASC, support development of national strategy for dementia care, support CAOT visibility at formal conferences or meetings related to dementia care	Inform CAOT through surveys, email regarding relevant forums to attend

Appendix 1: Summary of feedback from extended session CAOT 2011

June 16, 2011 in Saskatoon, Saskatchewan

“Strengthening occupational therapists’ skills: Supporting people living safely with dementia”

How can CAOT and the Alzheimer Society support Occupational Therapists in their work with people living with dementia?

- Dementia-specific education for Occupational Therapist Assistants
- Share strategies on how to assess for competency in using power assisted equipment such as scooters. Discuss how to prepare individuals and families for the day when their safe use is no longer possible
- Develop/share an ethical framework to balance risk and independence
- Develop a companion tool for people with dementia and families on how to make decisions
- re balancing risk and independence
- Share samples of tools whereby a person's health information travels with them, making it easier to coordinate care across sectors
- Develop / share guidelines for care of people with dementia in acute care/emergency departments (e.g. follow falls prevention example)
- Create companion document for families re. how to prepare for acute care/emergency dept.
- visits
- Share tools re supporting people with dementia who have experienced trauma (e.g. war experiences/holocaust survivors) [e.g. Paula David's work]
- Help OTs distinguish between delirium, dementia, depression, medication interactions and include interventions for each
- Share consistent strategies for interventions with caregivers (e.g. dementia education)
- OTs need advanced training re dementia – don't focus on the basics – it's already available – needs to be OT specific wherever possible
- Focus on interprofessional practice – sharing strategies like "huddles" in long term care
- focus on common language
- Create local Alzheimer Society - Occupational Therapist education days on topics such as gentle persuasive approach
- Help OTs understand the importance of processing information via the senses (e.g. the value of things like weighted blankets and snoezelen rooms)
- Host Alzheimer Society meetings in acute care hospitals so people with dementia/caregivers and nursing staff can attend
- Teach primary health interventions for mild cognitive impairment (MCI)
- Showcase public awareness campaigns such as that developed for Advanced Care Planning
- Offer PIECES training for family caregivers in the home and for OTs
- Share innovations like Alzheimer Cafés and how to start one in your community

- Consider curriculum development to facilitate consistency of knowledge
- Education of health professionals re: caregiver stress & burnout
- Create companion document for caregivers themselves

Appendix 2: Report from national needs assessment survey

Note: questions 1-5 demographic information

Question 6 - What is/are the most challenging safety issue(s) you face as an occupational therapist when providing services in the home setting for people with dementia?

1. balancing rights vs risks
2. lack of tools
3. limitations in acute care to complete regular home visits - complete referrals for community follow up by other community OTs but do not receive feedback to ensure follow up has happened-- have sent referrals with plan made for assessments with family only to find out community declined to see patient (wanted other agency to see, etc)
4. wandering mobility impairments aggression using kitchen appliances
5. when a family member is present but doesn't want to be involved as a caregiver
6. various challenges for formal support options - mainly Home Care - services are more and more policy-driven, less client-centred. Lack of Adult Day Program services - these are terrific community supports to maintain physical and mental ability, which in turn promote continued safety. In at least the last 10 years I have seen no regional efforts towards developing, supporting or expanding these valuable programs. Driving - lack of consistent provincial approach - public education, process for both reporting and client obligations. Lack of effective and accessible alternative transportation options when driving is given up.
7. I work with the sub population of person who have dementia and developmental disabilities and the most challenging safety issues are actually: 1) the lack of the diagnosis of dementia by physicians 2) the lack of understanding and "buy in" by care providers
8. Dealing with families regarding least restraint interventions to prevent falls and promote safe wandering behaviours. It can be difficult to balance the independence/ autonomy of the individual with dementia with expectations of no risk of injury from the family.
9. Wandering/exit seeking behaviours -Home safety with appliances (taps, ovens) -Ability to cook/meal plan/eat adequately -How long is it safe to leave a person with dementia living at home independently before it is time to consider alternate living -Falls/poor insight regarding balance and need for mobility devices
10. not enough time to fully implement and monitor client coping and ability to implement suggestions and recommendations when client is discharged home
11. insight and awareness into declining functional abilities and balance; accessing funding to implement safety aids and equipment
12. Medication Mismanagement Difficulty with Meal Preparation Older people who are being financially abused by people they trust Wandering Falls Driving safety and Transportation concerns
13. Patients often have challenges following through with recommendations. This may be related to inability to see value in the recommendations secondary to cognitive challenges.

14. Forgetting to take meds regularly or forgetting that meds were taken, leading to overdose
Forgetting whether self care activities were completed
Remembering to turn off the stove after use
Forgetting to maintain surgical precautions related to their injury or surgery during ADLs and IADLs in the home
Wandering and forgetting directions
Forgetting important phone numbers in case of emergency
15. the most challenging is the unpredictable behaviors the person with dementia may have and the result to the caregiver.
16. Clients' lack of judgement and insight to allow strategies to be put in place to increase their safety
17. Helping family to prevent wandering. In this case, being client-centred in the traditional sense becomes challenging and more of a family-centred model is useful.
18. The most challenging issue that I face is having sufficient time to adequately assess, much less treat, people with dementia.
19. I do not provide services in the home setting. However, as a LTC therapist I am involved in the transition process from home to facility. Typically the factors that lead to a facility admission for a person with dementia are aggression towards caregivers, wandering/exit seeking behaviors or increasing care needs (typically associated with incontinence).
20. Getting them to understand that they have a problem and need to do something about it, especially if they have no family!
21. I am not currently, working with dementia clients, but did for many many years. I needed to learn, and work with these clients to gather the knowledge, skill and confidence to ensure they were safe in their living environment. Often, in my experience, the informal and formal caregiver lack of knowledge caused some of the greatest challenges to keeping the client safe. The therapist's lack of a tool kit of options when working with the families/caregivers, again in my experience, is the biggest challenge. Not all OTs have the understanding of the disease and therefore may not be able to address the safety issues appropriately. Challenges in the home can be use of appliances, stairs, going outside without supervision, going outside without being appropriately dressed for the weather, hot water, chemicals, cleaning supplies and the storage of them (they may not recognize them as cleaning supplies),
22. Potential for wandering. Elderly caregivers. Access to vehicle - wanting to drive. therefore managing behaviours. Patients whose primary roles was homemaker not accessing the stove etc. but still allowing rest of family to access these appliances.
23. Finding ways to have 24 hour supervision in the community without having to hire private help at high cost (most clients cannot afford it). Finding enough respite for caregivers so that they can maintain their quality of life.
24. Clients who are unsafe living alone but who do not have the insight to accept support services, or who confabulate stories which alienates their informal community supports. Driving against our recommendations/providing alternative transportation services when they can no longer drive (in rural areas).
25. The cooking or use of electrical appliances in the home. When they have home services we can have the meals done but there is not a cover of all meals. Some clients get up at night etc. for a variety of reasons. Supervision over 24/24 is not possible unless family does it or clients pays for private services.
26. Medication compliance and meals

27. Falls and stairwells
28. risk of falls safety in the kitchen - leaving the stove on
29. driving and using community transport, taking care of one's health (taking medication for example), self-neglect, cooking safely and getting good nutritional meals, preventing falls at home and outside, etc.
30. When client's cognitive impairment affects their insight and judgment resulting in their refusal of support services (either formal or informal support services). With supports we can often assist client's with dementia to remain in their home for much longer than if they refuse supports. This then becomes a competency issue. I am often involved in determining a client's competency in choosing to remain living in their own home, etc. It is challenging to come to determine degree of risk (to client and others) and client's capacity to make this decision to live at risk.
31. Availability of consistent caregiving support is a challenge in home settings to ensure general safety of the dementia client living at home. The dementia client often requires constant supervision for safety, thus eventually burning out family caregivers. It is difficult for family members (often an aging spouse) to schedule affordable, consistent staff. Some desirable modern architectural barriers are challenging (and often impossible) to modify cost-effectively for (dementia) clients developing mobility and transfer problems (e.g. sunken living areas posing unsafe steps, fiberglass shower units where grab bars cannot be installed easily, skylights affecting ease of pole lift installation, water-saving toilets of different shapes that will not fit raised toilet seats, pie-shaped stairs in condos that are narrow requiring expensive custom curved stair glide installations if even possible).
32. decreased ability to meet nutritional needs and higher fall risks associated with the cognitive and physical changes of dementia 2. declining physical activity and resulting declining physical health 3. Clients lack of insight into risk. for example there are clients who can not identify hazards (fire hazards, home security issues, etc) or can not come up with an effective response to ensure their own safety. However, these kind of hazards are high risk for injury but often low probability for occurring so sometimes it is the heightened concern or perception of these kind of risks by family/caregivers that prevents clients from remaining in the community.
33. Generally the Client is being cared for by an elderly spouse with their own health issues. Usually the caregivers are having to step into a role that was formerly played by the Client. It is difficult for them to adapt into the new role and even harder to make decisions around changes that will improve the Client's safety and well-being but may be more restrictive, e.g. adding a different lock to a door that will not allow the Client to go out on their own
34. behavior issues which can cause safety concerns for caregivers
35. Adequate supervision throughout the day
36. Clients potentially harming themselves (and others) e.g. preparing a meal (burns, causing fire to dwelling), falling down stairs etc. due to their cognitive impairment and not getting help in a timely manner Becoming more limited with their mobility because they lack initiation to care for themselves Skin break down, infections (UTIs) Clients being taken advantage of by others e.g. door to door sales people Elder abuse – financial, physical, emotional by their supports (family, friend, POAs, case workers)
37. Follow through of recommendations by family in a timely fashion. Fluctuating cognitive and functional abilities. Poor memory to incorporate the strategies.

Question 7 - What types of supports and/or resources are you, as an occupational therapist, currently using to address these home safety challenges?

1. communication with colleagues
2. recommendations to Alzheimer Society resources
3. TEST
4. Community resources used to assess in home after discharge: - geriatric program assessment team - geriatric mental health assessment team - community therapy services - day hospitals/ PRIME Resources recommended on discharge to help support clients: - lifeline - homecare - private care - community follow-up as listed above - community resources such as foot care, meal delivery, grocery delivery, etc
5. home safely Alzheimer's registry door or motion alarms ccac/ red cross/ silver cross for equip etc education to caregivers; liaise with team; caregiver relief programs education; booklets; day programs
6. Home Care, Alzheimer's Society, information, equipment, problem solving strategies
7. I work within a team that works with home care coordinators to validate and support recommendations. We refer to adult day programs consistently. We refer more challenged clients to a community care support program that has been recently opened (whose waiting list is now 9 months).
8. With the population of adults with developmental disabilities I try to advocate and provide education to both the physicians and care providers
9. A team approach involve many health disciplines to address safety concerns; Alzheimer's society information and support groups for families; research and evidence- based best practices.
10. Wander bracelets/door alarms/motion sensor systems -Home care services -Intervention from social work and physiotherapy -Education for client and caregivers -Regular contact with family, conferences between the family and health care team -Home visits and safety recommendations -Adaptive equipment -Suggesting modification of the interior home environment or adaptation to ADL routines
11. community care access centre, private OT services, education to caregivers
12. Family Education Functional Assessments to determine the persons abilities and limitations; determine environmental concerns impacting negatively; recommendations for aids and equipment to make the home safer; Referral to day care and community center programs; referral to vendors able to assist with equipment needs
13. Blister packing / VON Medication administration Meals on Wheels Continuing Care Alzheimer's' Society Services (i.e. Safely home program) Emergency Response Systems (i.e. Lifeline, In Touch) Accessible Buses
14. Contact family members or substitute decision makers as able to implement changes
15. CCAC Services Home At Last Services MOW (Meals on Wheels) Family support Client/Family education and recommendations Visual and verbal cues
16. Home care, Day programs, cognitive assessments, home safer tool, equipment, caregiver and client education.
17. Family, community CCAC case managers
18. Client's family, home support workers, paper resources - strategies ,etc.

19. I often, seek assistance from home care or a client's family for additional supports. I also refer clients that I am particularly concerned about to a geriatric outpatient unit for follow up.
20. N/A
21. Work on a Community Geriatric Team, so can use meds, Alz Soc, CCAC, my safety assessment, Public Trustees office, private homemaking services, etc to try and keep people safe at home
22. Working with the formal and informal caregivers to ensure they have a good understanding of the disease process, provide them with coping mechanisms, ways of redirecting the person with dementia, - this comes from education I have taken and have taught, reading, connecting with others to see what they have found works, trial and error. always respecting the client as a person. Alzheimer Society is also a good resource
23. Some support from Home Care Services. Very limited. Oftentimes in our health region a home discharge is not well supported. mindset that dementia = Long Term Care assessment
24. Home care respite services (in home and hospital admission) Adult day programs PRIME program Private companies that offer companion care/ respite care services
25. I work with the Family doctors, social workers and placement coordinators to find the best level of care for clients. If that is at home, there are referrals to Home Care services for medication administration, morning/evening care and bath help and Adult Day Support Programs, referral to community services for Meals on Wheels etc, and education of family members about the client's deficits and needs.
26. I'm often called upon when the family has noticed a problem with home functioning at home and talk about it to the doctor. Sometimes the client is hospitalized and before letting him out they request a home assessment to see how he functions in his environment. The extend of services need is then discussed with the family members.
27. MOW, frozen meals for family assist, blister packs or reminder phone calls, ensuring client. can ID to call 911 or pre-programmed family on phone in case of emergency, lifeline, disconnecting stove, facilitating calendar use, etc.
28. equipment and governmental programs
29. equipment recommendations for bathroom/tub transfers mobility aids emergency systems such as Lifeline recommending respite care for caregivers
30. references to community services (meals on wheels, reference to CLSC's services, references to a service like LifeLine, etc.), support of the family and caregivers, references to day programs, etc.
31. If client's cognitive status is such that they can learn to use compensatory strategies, then I work on developing a plan around such strategies (lists, calendars, memory aids - alarm clocks, computers, stove guard, blister packed meds, etc.). I also run a program for MCI or early dementia called Boost Your Brainpower that runs for 8weeks and addresses brain healthy lifestyle behaviors to help slow further decline. I have access to two rehab workers who I supervise to (typically)link up to community supports. If client's cognitive status is such that new learning is not possible, then external strategies, such as home support services (private or public depending on client and situation) are used - this is when the client cannot be expected to consistently care for themselves in a safe and effective manner.
32. local provincial health care resources (e.g. Vancouver Island Health Authority in Greater Victoria, federal benefits from Veterans Affairs Canada, local vendors and contractors

33. community meal delivery (private and Meals on Wheels) family assistance adaptive aids when learning is possible home and routine/habit modifications when possible community/recreational meal programs volunteer shopping day programs Community health worker assistance volunteer check in programs Life Line Alzheimer Society support groups and other education resources for family

34. Families, VAC if available, referral for adult day programmes to add structure and socialization to their day, encourage continued physical activity in a safe environment, referral to caregiver support program, etc.

35. homecare supports, day programs, teaching caregivers how to deal with behavior problems, promoting activity, Alz. Society Recreation therapist and supports .Home safety strategies/ adaptations to prevent wandering/other safety at home, equipment prescriptions,

36. CCAC PSW, Respite services, private options

37. Recommending personal alarms (lifeline etc.), meals on wheels, using automatic shut off devices, unplugging stoves/ removing knobs, linking clients and family to community services (e.g. day programs, volunteer visitors/calls), CCAC referrals for additional supports.

Recommending devices for ADL – bathroom aids, dressing aids Recommending engagement in a daily routine (consistent) Modifying the home to prevent falls – carpet, lighting, furniture etc.

Prescribing mobility devices Using memory strategies – timers, calendars, check lists, pre-programmed devices (phones, microwave)

38. Equipment vendors. Educational resources. Collaboration with other therapists.

Question 8 - Do you feel confident that these supports and/or resources enable you to meet the needs of this population in the best way possible? If no please elaborate Response Chart Percentage Count Yes 45% 17 No - if no please elaborate

Response	Chart	Percentage	Count
Yes		45%	17
No - if no please elaborate		55%	21
		Total Responses	38

1. Most of the time they are sufficient but they don't always meet the needs of complex cases

2. follow-up support for clients and caregivers and home care coordinators

3. The lack of support of physicians and the lack of credible research studies to quote etc

4. there is never enough that can be done, it would be a disservice to older adults to think we have done all that we can

5. At times changes will come at a monetary cost that supports such as family or friends are unable to provide the patient with.

6. Sometimes client's benefit from 24hour supervision, which is not always feasible for the family

7. lack evidence-based assessment tools

8. In Nunavut there are no long term care facilities for people who are unable to live at home. When people with dementia reach the point where it is too challenging for family for them to

remain at home, they must decide if they should send them to a Southern facility where they will rarely ever see their loved-one again or whether to struggle to keep them at home.

9. See Q 6, , dementia is the lowest rated service for our CCAC,

10. gaps in service for what the home care supports and community programs can provide for those that cannot afford private hire service.

11. clients and families do not always have the financial resources to purchase equipment and to put it in place so recommendations are not always followed

12. needs always exceed resources

13. It is my opinion that our team could use another 1FTE OT to better support our clients.

14. Much more research is needed for the growing dementia population as this group has not been a public focus group to date

15. access to community programs is variable, even when community and family support is limited funded support is also limited

16. there is an unmet need to provide the Client adequate socialization and activity to curb their restlessness and continue to provide some meaning to their days

17. often not enough supports, people may not be able to afford care needed, transportation issues, meal services

18. Not enough resources

19. Many recommendations are costly for the family. Patients often will require 24 hour caregiving. The people who provide the care may change often. Therefore, this reduces the opportunity for the strategies/recommendations to be utilized correctly.

Question 9 - Please tell us about the best or most promising occupational therapy practice (including models, assessment, interventions, etc) that you, as an occupational therapist, are currently using in your practice to address these home safety challenges

1. strong link with staff at Alzheimer Society

2. person hood theory

3. TEST

4. Most assessments are functional based in hospital. We have limited standardized assessments but use what we have including: - MMSE - MOCA - CCT - Cognistat I rely heavily on information from family & community resources when planning for discharge and determining care needs.

5. berg balance, Moca or cognistat New driver screening tool falls screen caregiver interview

6. I focus on helping the client and caregiver to come up with possible solutions to identified issues. I offer resources to help them. Sometimes in the case of a safety issue where the client doesn't want to change, I am a bit more directive, so that the caregiver doesn't have to take that role.

7. Home visit assessment Family conferences as appropriate Information about Community supports - eg Alzheimer's society wander registry Best? Promoting

© CAOT, 2012 Page 17

Multidisciplinary approach! Developing resources for family physicians!

8. therapeutic use of self

9. We have a falls management program that involves all disciplines, the resident and family. It uses MDS data to analyze patterns and risk factors to put in place an intervention plan to prevent falls and minimize injury in the resident with dementia while still allowing autonomy.
10. Regular contact between the client, caregivers, and the health care team to answer questions and provide ongoing education and support seems to help improve awareness of safety issues and willingness to accept interventions -Direct home visits with the client and caregivers
11. There is nothing specific that is being used. If we are able to, we pass care on to a rehab centre where they can have increased rehab and home visits to increase safety at home.
12. Functional Assessments of abilities and prescription of aids and equipment to enhance safety; education; referral to professionals for areas of concern outside the direct role of an OT
13. I work in a community based Seniors' Clinic where I partner very closely with physician consultants in geriatrics. We use comprehensive geriatric assessments to evaluate our clients and provide the most appropriate recommendations according to the results of the assessment.
14. Thorough OT environmental assessment along with a cognitive screen such as MMSE or MOCA to determine deficits.
15. Kitchen assessment and practice
16. Home Safer Tool. CMOP Caregiver Strain Index
17. Family conferences Aging in place (versus aging at home)
18. Sitting down with family members to figure out strategies together to deal with behaviours.
19. I find the AMPS to be the best assessment tool/process. Treatment is generally very limited due to time constraints.
20. N/A
21. So much depends on the level of cognitive impairment! we use the MoCa and the Folstein to screen, and do the rest by observation, discussion with all interested parties!
22. no longer practicing
23. Currently I often use a combination of a cognitive assessment and functional assessment. I am AMPS trained and will use this say combined with a Montreal cognitive assessment of cognitive assessment of Minnesota? Just to name an example. I am lucky that as an inpatient OT I am able to complete home assessments with my patients. These in situ assessments are very helpful.
24. Assessments using currently: -Cognitive Competency Test (CCT) -Home Visit (Including functional task assessments) -Caregiver report -Assessment of caregiver burden Interventions: - Having clients access community resources to support areas of dysfunction when rehab/ learning safer method is not possible -Having clients/ caregivers access Dementia specific community supports -Educating caregiver on current care needs and future needs of client - Referrals to Social Work re: future planning/ decision making/ end of life care planning This is not necessarily the most promising, but it is what we can do at this time.
25. The Allen Cognitive Levels assessment tool, with the related literature helps immensely with educating caregivers about the client's needs, whether it is the reason they cannot cope at work or that their function is what one might expect of a one-year-old. I use this with the Montreal Cognitive Assessment, and at times the Independent Living Scales (the latter if there are legal/guardianship issues).

26. The observation of the client in functional activities in his home , especially during the cooking and transfers gives me good information on the executive abilities and the problems. The informal approach seems to be less stressful and the client shows me more of what I want to see. Of course we use cognitive testing also. But with some clients this makes them anxious and often they refuse to complete the task.
27. home safety assessments - functional kitchen & med mgt. Assessments
28. Home safety evaluation developed at CLSC CDN and cognitive evaluations MOVCA MMS
29. assessment of safe tub transfers and recommendations of necessary equipment for safety
30. I always work in a interdisciplinary approach to address the complex needs of this population. I'm using family education. For assessment, I use mostly performance-based assessment (with tasks like cooking) and I analyse my observations with the PRPP approach.
31. psychosocial educational groups, Social groups for those who are isolated Assessments: ILS, BADS, competency assessment, BADS, MOCA and sometimes CCT although this is an old assessment and needs updated stats.
32. Maslow's Hierarchy of Needs - unlike many client groups who are involved in rehabilitation to achieve needs ascending this hierarchy, dementia clients generally regress and eventually require assistance with basic physical needs. Assessment tools used: MMSE, MoCA, Berg Balance, Geriatric Depression Scale
33. Home safety and falls prevention assessment in clients homes before falls or before injury from falls Concept of increasing physical activity in our frail home health clients - not quite as effective in practice as it could be Exercise programs in the community developed in conjunction with health care teams that lower functioning clients can participate in. Activity/exercise/fall prevention programs in assisted living sites
34. being there to answer caregiver/family questions and referral to programs when they are ready.
35. as in question 7
36. PEO
37. Following PEO model to guide practice e.g. able to identify behaviours and triggers Utilizing pre-discharge home safety assessments to assist with the transition from hospital to home Environmental modifications Compensatory strategies Engaging the client in daily routine/schedule Open communication with the client and their supports re: risks, benefits and options of returning home e.g. look into alternative discharge locations – retirement home, living with family. See answers to Q7
38. Interview with family. Updates from interprofessional staff. Observations of the patients skills/abilities/interests/behaviours etc. Home safety assessment.

Question 10 - What supports and/or resources do you wish you had to help you enhance home safety for older adults living with dementia?

1. More consistent resources across province. Recognition at Federal Level of need for support
2. more tools to support assessment
3. I wish I had more opportunity to assess clients in their home prior to discharge and meet with community resources to link up and provide more seamless transitions from hospital to

home. I wish there was someone to case manage these difficult cases and provide consistency in care plan no matter where the client is (hospital or home).

4. more caregiver relief in home

5. funding for some safety devices like bed alarms funding for necessary renovations to maintain the client at home more respite options for caregivers (or more availability in existing programs)

6. More accessible and developed Adult Day Programs. Options to maintain outside supported activity is physically and mentally beneficial. A little bit of personal care support in Adult Day Programs - if someone needs just a little help with toileting. Currently people who have a little bit of difficulty with incontinence have few options, and decline quicker. More caregiver supports/respite options. More home care flexibility - e.g. meal preparation. Or affordable meal support options.

7. For the sub population of person with developmental disabilities and dementia: -inclusion of this speciality population within the dementia pathways of health authorities

8. As I work in the LTC setting, in an older building, I wish we had more 1:1 attention for the Resident and the ability to redesign our environment to allow for more open space with more objects/ items for spontaneous sensory stimulation and reminiscence. A different environment would also inherently solve some of the safety concerns that arise from an older design.

9. Increase education and awareness to primary care physicians, so they would become aware of existing services and be able to refer newly diagnosed clients to these services. -Expanded home care services -Increased funding to day programs that focus on keeping people in their homes while providing inter-disciplinary health based services to allow this focus.

10. more time to complete further assessments as necessary. more time to use the home safety checklist and complete further defined recommendations for client safety.

11. Ease of access to funding; Earlier and routine education to increase awareness and insight into how dementia might impact functioning in later life Increase awareness of how to access resources available to older adults

12. More options for home support services as it is currently very limited what Continuing Care can provide.

13. More practical cognitive screens that relate directly to home safety in order to be able to more accurately predict patients performance in the home.

14. More community resources, day programs, activities/tools to assist with memory training or compensation

15. Some do not have much caregiver support and are in their homes by themselves. If that is the case, we need more day programs set up for this population or health care aids to provide services in the clients homes.

16. Evidenced-based assessment tools

17. Nunavut needs long-term care facilities to give families this option. For working with clients living at home, I would be interested in a course to improve my skills.

18. More time. A website dedicated to OTs working with people with dementia, where tools, info, and patient/family resources could be found quickly and easily.

19. N/A

20. 1. We need short stay assessment and Tx beds. We need more hospital beds, we need more nursing home beds, there needs to be more supportive living geared to income to include the

middle income people. There needs to be more homemaking available with specifically trained PSW's, who will work the hours they are needed, not when the agency can send them, ie 9-5! And we know they can do things...but will they? ie bathing!

21. More community support groups(for both caregiver and patient). Better access to respite for caregivers.

22. More ability to influence the number of hours of care a person could receive from home care, instead of just being able to make recommendations that may or may not be followed. More access to free overnight respite. More access to free "casual" respite for caregivers. (or at least something subsidized- like daycare is subsidized, how come we can't have for adults that need supervision?) More community programs with staff that are trained to work with people with dementia (different stages of disease process) In the various adult day programs: more trained staff and more client spaces. No wait times (or significantly shorter) wait times for community support programs (some clients wait months to get in to and Adult Day Program)

23. More funding for housecleaning, transportation services and respite care.

24. Greater support through CCAC with PSWs to assist in meals & meds; some clients are unable to mg. indep'ly & if no family support, ++ danger to clients

25. ras

26. funding for home equipment, particularly for seniors there is no public funding for this group in our province

27. A comprehensive and standardized (yet easy to use) assessment to help to quantify the risk of discharging a patient at home. Home services that are more universal and available.

28. better access to home support services (HSS). Our HSS system is not very good, the waitlist is too long, the lag time to get services in is poor, the training of staff is not optimal for dementia care.

29. improved equipment technology (eg 4-Wheel Walker seats that lock when sat on, Wheelchair footrests on basic models that swing under & do not have to be removed during transfers, coloured brake handles for easy recognition - research on exercise programs and walking programs for people with various levels of cognitive impairment - employer supported leaves for families trying to assist aging family member with dementia - better availability and affordability of respite care beds for community residents

30. Continued and better general information from reliable sources (ie not folks selling stuff) about improving safety with adaptive aids for mobility and function or with simple environmental changes so that potential clients can make changes before their cognitive losses prevent learning. Mobile falls clinics, community based falls prevention initiatives (not health care based but from municipal and provincial wellness/community safety programs) Home Support services that assisted clients more with nutritional needs - especially when the issues are decreased initiation and organization Home Support services that facilitate activation Outpatient services that provided rehabilitation for frail and demented seniors

31. more psycho-social training and resources

32. More respite hours. Transportation to day programs. Access to physician readily to assist with medications for behaviors/address deliriums.

33. List of resources that caregivers can use which are inexpensive

34. Validation that what we are doing is best practice for these clients. As an in-patient therapist we don't know what happens once the client is discharged back home. Ideally a smaller caseload and more time to work with clients and their supports

35. More time to help patient/family follow through with recommendations. More supports from the community (funding assistance, more outreach programs, day programs, support groups etc.)

Question 11 - Where do you feel the greatest gap in service delivery exists when addressing home safety in community-dwelling older adults living with dementia?

1. lack of consistency

2. lack of support for individuals being discharged back home

3. I feel family aren't educated on the services available so when clients come to the hospital it is often a "crisis". - I feel that different parts of the healthcare team (hospital vs community) are often working separately. I have had a patient in the past involved with: homecare, family MD, GPAT, SW from the city, family and still the patient was falling through the cracks and the case wasn't being managed by any one person. - I see government supporting housing options such as assisted living and supportive housing but find it frustrating when these options can't be utilized by lower income seniors.

4. same as above

5. early dementia-OT to assist with problem-solving for behaviours and changes that can cause stress within the family middle-people don't know that equipment would be helpful with mobility and transfers, prevent deconditioning, caregiver stress late-more respite and support from Home Care, home exercise programs to maintain mobility and transfers, caregiver stress

6. Much attention being given to assessment and diagnosis, setting up of clinics and retaining doctors.... yet not so much attention to establishing means of actual programs and interventions to maintain clients' physical health and safety, help caregivers, keep people out of hospital, connect them with resources along the dementia continuum. Inattention to formal community support programs to promote frailer seniors to be mentally and physically active and to age well in the community. The health care community is reactive when it should be proactive. That is the gap. Lack of education at the medical student level about dementia, aging issues, the important holistic, multidisciplinary non-medical issues. Over the years, our team has worked with medical residents who spent a rotation with our frail senior clientele. They used to be with us for 4-6 weeks. Now it is 2 hours, one time.

7. For the subpopulation of persons with developmental disabilities and dementia: 1) appropriate diagnoses

8. Caregiver education- whether that be the frontline worker or a family member caring for the individual at home.

9. Lack of resources to support caregivers in the process of caring for their loved ones...limited education, support groups, home care services, respite services, day programs, etc. Caregivers do not realize there are services that exist to support them...they are not referred to existing services.

10. The time between discharge from acute care to when the community services are able to get into their home to implement suggestions. Also, not being able to do follow-up from the

acute care setting to determine if they are implementing suggestions or are able to follow through with the suggestions.

11. Lack of awareness of what services are available to help More education
12. Inconsistency with Continuing Care and the home support workers they provide in people's homes.
13. Little to no follow through from patient and family after recommendations are given.
14. Lack of funding to support these individuals
15. The greatest gap may be the willingness of the person with dementia to make changes to their home. It is their home and once the OT is gone, the client may return to his/her way of doing things which may be unsafe.
16. Lack of support services and facilities to give families respite.
17. Insufficient staffing for OTs and support/personal care staff.
18. More hours allotted for home care support and more respite beds to help alleviate caregiver burden.
19. The understanding of the majority of people that an able bodied person may have cognitive impairment and not recognise it!!
20. The need to support and work with the formal and informal caregivers so they understand the disease, how to maximize the skills and abilities the person still retains, identify when these change and then how to accommodate. OTs should be instrumental in helping the client do this while they are able and then the caregiver as the client loses the ability to accommodate and adjust to the loses.
21. FUNDING!!! For those who can afford private care, there are so many more options than for those who must rely on what home care is willing to provide.
22. Affordable alternative transportation services.
23. The availability of homecare services and the possibility of cut-up hours to cover strategic periods of the day when the needs are identified as more important for service or supervision of the clients.
24. Can ID issues; however, ltd. cmtly services to address issues ID'd by OT
25. waiting lists and referrals
26. limited community occupational therapist's time with a large geographic area to cover
27. The accessibility to services is variable depending of where the patient live: each CLSC has different services and waiting list.
28. Poor home support services system. Poor transportation system to assist client's in getting to social programs that would keep them linked into community longer, particularly after they lose their Driver's license.
29. telling people that assistance is available when limited hours are funded overt time for people who require constant supervision (24 hrs daily at times) - establishing a more user-friendly method of admission to complex care homes that will be needed for many community-dwelling older adults when families can no longer cope
30. enough community based OT's to see clients in their homes
31. funding. So many adults living in their own homes are unwilling to spend anything on themselves to improve their situation and very few have alternate funding sources. Also the reluctance to ask for or accept assistance which leads to caregiver burnout and a faster

regression for the Client who is not challenged to use his/her remaining abilities in a functional manner

32. In home assistance to keep clients safe/ assist caregivers so person can stay home longer.

33. caregiver burden

34. Many clients are returning home to “wait at home” for long term care –there needs to be more supports in place (e.g. high needs day programs, PSW, respite, government programs to offset costs for caring for others in home etc.) for primary caregivers. We feel that we are sending mixed messages – e.g. client really isn’t safe to be alone at home, would need LTC, however the only place for these clients to wait is at home with limited community supports.

35. continued follow up with patient once discharged back home. Patients with dementia require longer f/u as behaviours/medical status may worsen, caregiving needs increase, cognition decreases.

Question 12 - If you could identify only two skills that you feel are the most important for occupational therapists working with this population to possess, what would they be and why?

1. flexibility & knowledge of constantly changing evidence re dementia care

2. ability to focus on meaningful occupation focus on person

3. TEST

4. creative-- able to creatively problem solve solutions to various problems - patience-- often need to try various options, work with family/ client longer term, etc

5. interviewing skills: to understand client's history, premorbid personality, triggers of behaviour flexibility and knowledge of resources: to work with caregivers, differing environments and differing levels of need

6. sense of humor / easy likeability (or they won't want you to come in) good negotiator (to convince them to accept changes or assistance that enhance safety)

7. Respect. Clients do make choices that carry risk. That does not always mean they make those choices from a fog of dementia. Sometimes the therapist's role is to clarify which. Patience. Clients can come to trust your opinion and input, but need to get their in their own time, in their own way. You may not always 'convince'. You may never make it better. But it is important at least to educate caregivers about supports and what they can do to help themselves.

8. Specifically for the sub-population of persons with Developmental Disabilities with dementia
1) advocacy 2) teaching

9. Creativity- use what the environment presents to make a safer living space. Compassion- you are dealing with a declining population and family members that are grieving losses of the person they once knew, while helping to care for the person that is left.

10. Clear ability to communicate and educate clients and caregivers. Need to be able to relay information specific to the level of the audience. You cannot address safety issues if you cannot clearly communicate why it is an issue and why it is important to change. -Ability to allow clients and caregivers to live at risk. Sometimes, despite your best attempts to educate all parties involved, people still choose a riskier behaviour and you have to be willing to work with those clients and caregivers despite their decisions.

11. patience rapport development

12. Ability to advocate for this population Ability to educate communities
13. Ability to be holistic and look at the whole picture - since seniors do not always present with clear concerns, you have to gather all of the information and be able to determine the most relevant clinical concerns. Active listening - you have to listen to your clients and their families, but you also have to be able to read everyone's body language to determine what is the most important to them.
14. Being able to anticipate the challenges a person may have in their home environment based on assessment.
15. Patience/understanding Compassion
16. 1. Home safety assessment and intervention as this population is remaining in their homes longer now. 2. Effective coaching and counselling for the caregiver to reduce caregiver stress and burnout.
17. assessment of cognitive competence good interpersonal skills
18. Time/patience to spend with families to work out effective solutions that will meet their needs and work in their home environment. personal skills to interact with client to re-direct behaviours, and build rapport.
19. Compassion. Holistic approach to assessment and treatment.
20. Individualized approach, as each person with dementia will respond to a different style (verbal, non-verbal communication etc.) Patience and compassion.
21. 1. Developing a rapport with these people, so they trust "you are not going to put them away" The ability to persuade CCAC that these people need time to adjust, and consistent homemakers!
22. Ability to assess that which remains and maximize it. Ability to "teach" the caregiver to "fish" - so they know how to see when the client is beginning to change and adapt to that change; and when they, the informal caregiver, is no longer coping effectively and help them navigate the system to ensure the support is there as required by the whole family.
23. Empathy and helpful hints for family in ensuring that they understand the realities of living with someone with dementia - instill the need to always plan ahead. Functionally based assessment tool kit
24. 1. Ability to assess the client's risk of harm in their home environment. Because: this will determine what interventions need to be in place to help keep the person and caregivers as safe as possible. 2. Ability to assess the client's and caregiver's readiness for change. Because: if the client is not ready for change, no intervention that changes the environment, support system etc. will work effectively. The focus of the intervention for support can then be on moving towards accepting change rather than making it, thus preventing failure of interventions and frustration.
25. 1. Cognitive assessments/interpretation of those, to help caregivers understand what they are capable of and what their needs are. 2. Compassion and caring approach, because families are dealing with huge stressors, and clients with dementia often cannot express their needs or frustrations.
26. The activity analysis process is very important because you can predict the required abilities and compare with the clients performance. With experience, you may be able to predict functioning in some abilities with what you observe in another because of the similar skill requirements for example. Using the activities to observe and assess the clients often gives me

more information than formal assessments. The communication skills are very important to be able to enter in the world that the client is living. You have to be able to listen and guide the discussion to try to get the client relaxed and open with the information he is willing to share with you.

27. 1. Communication - must be able to identify with client and family & liaise with all parties re: goals, plus work with clients to understand concerns 2. Problem-solving

28. empathy and ability to evaluate needs and match with resources

29. ability to perform cognitive assessments fall prevention strategies

30. Our holistic approach, because the situation is complex and involve the person and his environment. Our ability to link deficits to function, and then be able to explain to the family where are the person's difficulties and why she is acting like that.

31. Good assessment skills - thorough knowledge of brain function and how to assess each area of cognition Good treatment skills specific for in the area of dementia care. This is particularly important with client's with Dementia related BPSD.

32. ability to simplify communication and direction - ability to grade activities into very basic steps - ability to work quickly but calmly as dementia client can be anxious, agitated or aggressive

33. The ability to modify the environment that can be assimilated by clients with cognitive impairment. The knowledge and ability to inform families regarding the implications of cognitive losses and to modify their behaviour to support the client

34. empathy - the Client and caregiver need to feel comfortable talking about the situation and know that they can ask questions or for assistance at any time because the lines of communication are open knowledge of resources - if the opportunity presents we need to be able to provide the information requested on the spot, not several days later when the moment has passed

35. Knowledge about how to deal with behavior issues related to safety, physical adaptations to the home to deal with safety.

36. awareness of community resources -depending on severity the client may need as much resources & supports as possible liaise with family to identify client goals -since it is difficult to extract information directly from client's themselves depending on their severity

37. Patience – you will repeat yourself from one day to the next, it may take several sessions for the client learn what is being taught. Big picture thinking – having an understanding of where the client is (i.e. what level of cognitive impairment), what they want/need to do, where they are going to do it, who/what can help them and is this achievable.

38. knowledge regarding dementia caregiving needs/and caregiving burden effective strategies to reduce responsive behaviours

Question 13 - Please list any dementia-specific Continuing Education Workshops you have attended in the past 2 years

1. CCCD 2009

2. dementia workshop at McMaster university

3. These workshops have been offered through the health authority and have been approx 1 hour in length: - "Be Serious!!! No restraints? No alarms? No citations? Really!!!" By Diana

- Waugh, Inquisit - "Understanding behavioural and psychological symptoms of dementia" - "Dementia" by Jill Moats
4. can't recall the name- in service in company
 5. Capacity Assessor Workshop Montessori for Dementia (maybe more than 2 yrs ago?) I gave an inservice on the MoCA
 6. I did attend a Health and Wellbeing in Persons with Intellectual/Developmental Disabilities in Vancouver in Sept 2008 and I attended a session on "Aging in People with Developmental Disabilities" by Dr. Lillian Thorpe of Saskatchewan but it was not helpful--lack of clarification of functional changes and assessment and diagnoses.
 7. Safety Conference- Edmonton 2009 and 2010 People in Progress- Edmonton 2009 and 2010 Workshops on- site- Presentations by Alzheimer society, inservices on Dementia, Vascular dementia, Alzheimer's disease
 8. none
 9. Local dementia organizations info sessions at worksite offered in off work hours for families and caregivers
 10. Telehealth sessions (i.e. Mild Cognitive Impairment, Delirium/Depression/Dementia in the Elderly) CAOT in Halifax Primary Health Care Conference
 11. none
 12. Canadian Association on Gerontology annual scientific conference - many sessions relate to dementia Allies in Aging (annual education day through local chapter Alzheimer Society)
 13. None
 14. None.
 15. Pathways Dementia Training
 16. Local Alz workshops, plus many short audiovisual sessions by various providers across On. Live 1000km away from the hub of geriatrics! Travel is very expensive!
 17. Alzheimer conference March 2010 (Various presenters) -Personal Safety and fraud prevention March 2010 (Winnipeg Police Service)(some presentation material specifically related to dementia) -Cognition and driving September 2010 (CAOT webinar, reading various papers related to driving, dementia, driving retirement) -"Sunshiners" telehealth lecture October 2010 (Dr. Sloan)(some presentation material specifically related to dementia) - Protection for persons in care December 2010 (representative from the protection of person's in care office)(some presentation material specifically related to dementia) - variety of other inservices by service providers offering services to clients and their caregivers with dementia (Life Line, private support workers, meal management services, transportation services, etc.) - variety of papers, educational information to ready via MB Alzheimer society (I do not have my 2009 education record handy at this time)
 18. Shades of Grey, in Calgary.
 19. N/A
 20. Information workshops given by Canadian alzheimers society /QC
 21. presentations on cognition and cognitive testing, as well as capacity assessment at national conferences
 22. Graduate course on rehabilitation with aged population.

23. Differentiating dementia and delirium Depression, Dementia and Delirium workshop Competency Assessment with the older adult with Dementia Screening and Assessing driving ability in medically at risk drivers, including those with dementia
24. facility based mainly through Baptist Housing Ministry (BC) (As a Private OT, I work in community settings as well as LTC (more hours in latter setting).
25. none. I previously worked in a geriatric assessment and treatment program and participated in many education opportunities at that time.
26. Alz. Society annual conference, Alzheimer Knowledge Exchange Webinars, Psychogeriatric Team Exchange
27. N/A
28. montessori based dementia programming alzheimers symposium Total Responses 38

Appendix 3

Sampling of CAOT Lunch and learn webinars to build capacity (Oct 2011-Feb 2012)

1. Open for debate: Is technology now an essential component of good dementia care?
2. Simple pleasure: enabling persons with dementia and their care partners the most of the day
3. Safety, cognitive competence and dementia: What's missing in our assessment process?

Appendix 4

Living with Alzheimer's Disease and Related Dementias A Manual of Resources, References and Information SECOND EDITION

Edited by Sylvia Davidson

ISBN: 978-1-895437-85-0 | 192 pages

available at www.caot.ca

\$66.95/\$49.99 CAOT member

"The second edition of Living With Alzheimer Disease and Related Dementias gives OTs a thorough review of clinical issues and resources relevant to this area of practice. It discusses up and coming OT areas of practice, including assisting in the diagnosis of Mild Cognitive Impairment. I strongly recommend this book to all therapists working with people with dementia and their caregivers." "Living with Alzheimer's Disease and Related Dementias provides a useful reference about the disease and insights into the role of Occupational Therapists. I particularly appreciate chapters 4 and 14, and the numerous resources and references given." "Excellent resource for new and experienced clinicians working in the field of dementia care!"

"It is a rich resource that is excellent value for the money, introducing the clinician to new concepts and providing many references for further information."

Appendix 5:

Power Point presentation

http://www.caot.ca/pdfs/PIF/CAOT%20PIF%20PPT%20Rising%20Tide%20of%20Dementia%20in%20Canada_%202012.pdf

Appendix 6:

Summary of evaluation feedback

Number of responses: 30 English, 8 French
 Circle the number that reflects your opinion.

Circle the number that reflects your opinion.

1) The Forum met my expectations.

Strongly agree				Strongly disagree
1-24	2-9	3-0	4-5	5-0

2) The Forum was well-organized.

Strongly agree				Strongly disagree
1-27	2-7	3-0	4-2	5-2

3) Presentations were relevant and informative.

Strongly agree				Strongly disagree
1-28	2-6	3-0	4-2	5-2

4) Questions and participation were encouraged.

Strongly agree				Strongly disagree
1-29	2-5	3-0	4-2	5-2

5) Will the information offered assist you in your practice?

Strongly agree				Strongly disagree
1-19	2-13	3-3	4-1	5-1 n/a-1

6) What can CAOT do to advance occupational therapy practice in dementia care?

- Disseminate info
- Support practice groups
- Advocate @ govt level for early intervention and positions in primary care
- More best practice education on dementia in schools
- National interest groups
- Mobile apps for clients, caregivers, family and health care providers
- Support for caregivers
- Online resources- assessment templates, best practice..
- Enable us to learn from each other, share resources
- Continue to give us opportunity to network
- Encourage BPG, across continuum, risk management, ethical framework
- Canchild website- DCD workshop online- maybe we could do something similar for dementia on CAOT website
- Have presence at national level, network with other professional bodies

- Assist with learning to be advocates for OT
- Research grants and opportunities
- Encourage researchers to develop front line clinical tools to guide best practices in dementia care
- Advocate for social and economic benefits of OTs
- Consult national and provincially with OTS, across continuum of care to develop resources, frameworks
- Raise awareness of diversity of OT at national levels
- Continue to seek opportunities for key and innovative partnerships
- Best practice forum
- Partnership with community resources
- Political advocacy
- National plan for dementia
- Develop a working group to move forward on the development of the tools and resources discussed
- Advocate for national dementia strategy with other stakeholders
- Link with provinces to consider potentials for intercollaboration integrated provincial strategies to address health system policy in each jurisdiction
- Partnership with organizations (Alzheimer's society) and/or province ministers
- Develop communication tools (among OT's working with this population)
- Provide education on different methods of intervention

Additional Comments:

- It was wonderful to have the client experience then a group discussion
- It was absolutely wonderful to hear from a diverse group of OTs
- Thank you
- Need more time for discussion
- Exciting!!! Happy to help
- Excellent opportunity to discuss with colleagues from other provinces
- Personal stories are wonderful
- We need evidence of cost effectiveness to effectively advocate
- What an inspiring forum- thank you!!
- This session could have been longer- we would have loved the opportunity
- Super activity!!!!
- Bel enthonsasme des presentations, Bravo!!!
- Thanks to Harvey and his testimony.
- I work in Le Centre d'expertise en santé de Sherbrooke (<http://www.expertise-sante.com/accueil.htm>) and we are currently working in partnership with L'APPUI (Dr. Michel Boivin) (<http://www.expertise-sante.com/index.php?module=CMS&type=user&id=70>) = customized training targeted to caregivers in long-term care. Where people treated have cognitive deficits. Caregivers participating are invited to reflect on their actions, to question and to discover new avenues for intervention in these complex situations.

Appendix 7:

List of responses for each roundtable discussion

Successes- build on existing work

- online resources
- (CDRAKE, AITE study guides, Alzheimer knowledge exchange AKE, www.rgpeo.comRGP, www.caot.ca, Alzheimer's Society website, Algorithm for dementia screening (in French, University of Ottawa), link: <http://www.caot.ca/conference/Thursday.pdf> look at international strategies, www.fightdementia.org.au, Stephane Adam (Chargé de cours, responsable de l'Unité de Psychologie de la Sénescence chez University of Liège) <http://webcache.googleusercontent.com/search?q=cache:http://reflexions.ulg.ac.be/stephaneadam> He has developed a day hospital and a memory clinic to diagnose Alzheimer's disease (maison solale)
- Memory clinics (e.g. in FHT, OT role being advocated)
- Partnered with ASC
- Canadian Conference on Dementia- started building OT presence
- programming suggestions (day programs, maybe OT designs program, but does not 'staff it')
- targeted curriculum (expert speakers, personal stories)
- Provincial conferences- build on
- Processes in place within some settings: OT screen, MOCA, neuro referral, letter to family doc, early identification- family doc feedback on outcome of referral
- screening tools in French
- case studies- Belgium group
- Opportunities
- Continuing education Portfolio, or certificate programs in gerontology
- Having forums about the topic
- mobile apps, for client and caregiver, NICE, OT to contribute content, partnerships
- share success stories with administrators
- Stop offering just screening services- do interventions
- more than screening, change the idea of what rehabilitate means, untap the potential of OT
- OT involvement at onset, early intervention
- increase visibility with public
- bring persons with dementia together
- get OTs involved with support groups, agencies for people with dementia
- OT as consultants to those who provide care to people with dementia- focus on restorative care, through nursing and others, increase OT presence in LTC
- expand role for rehab assistants (Ryuta Kawashima research)
- Advocate for role in IP teams, find champions
- Educate/model best approaches- person centered, maintain not 'do for'
- OT on family health care teams- memory clinic
- Have a universal orientation

- change language cog competence instead of cog deficits
- Make 'OT' a "must have service"
- Actions/Plans needed

Actions:

- Announce/reveal results from success stories
- Advocacy training: advocacy skills from entry level to clinical, CAOT webinar, faculty partnerships for IPE, what needs do our partners have?
- Form Networks/interest groups- share views, beliefs; talk about maintaining independence vs compensation (e.g. OT Networker)
- age friendly community initiatives- partner with planners, ASC, clients
- build capacity with volunteers, informal caregivers, PSW, nursing aides
- look at AITA study guides
- OTs more access online tools/resources (listed above)
- examine our position re: risk, risk mgt tools, ethical decision making tools, algorithm for assessment and care, see BC, examine risk vs autonomy factors
- Dementia friendly design of transit, communities
- dementia passport
- Support research
- Support caregivers
- link with own political reps
- Tools
- National website- access to materials in EN/FR e.g. tools, best practice guidelines
- Best practice guidelines for dementia: Have more case studies (trying to understand dementia), discuss risk management (to manage risk vs. autonomy, to balance both and be client centered
- Screening tools website, screening tools resource in textbooks and papers noted in presentation
- Partnerships
- consult with architects when designing new buildings
- Researchers , admin and gvt- economic analysis of OT
- Community support groups, caregivers
- Vendors/manufacturers of assistive technology
- Link with political representatives
- ensure family doctors know outcome of OT referral

(Nos excuses. Les ressources ne sont pas disponibles présentement pour traduction.)