

Toward a Research Agenda on the Impact of Dementia upon Carers of Adults with Intellectual Disability

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Abstract

The World Health Organization's report, *Dementia: A Public Health Priority*, noted that the number of people affected by dementia will continue to increase and called for nations to address the impact of dementia upon their populations. This included considering the impact on carers providing for adults with intellectual disability affected by Alzheimer's disease and related dementias. Within the context of the USA's dementia plan, a national group has advocated that the needs and interests of adults with dementia and their carers be taken into account when dementia-related research is undertaken. In preparation for the second national summit on caregiving and dementia to be held in the USA in 2020, this article describes an effort undertaken by this national group to identify needed research related to carers of adults with intellectual disability. The group identified three focal areas for the summit to consider: the effect of behavioral and psychological symptoms of dementia on carers, challenges for carers of adults with intellectual disability when dementia becomes evident, and barriers that carers face when accessing supports. A list of recommended topics to be researched is provided.

Key words: *Alzheimer's disease, carers, dementia, Down syndrome, intellectual disability, national plans*

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Introduction

Dementia is an age-associated condition that affects brain health, general functioning, and self-direction that leads to a diminished quality of life and eventual death. The World Health Organization (WHO, 2012) in its report, *Dementia: A Public Health Priority*, noted that prevalence and incidence projections indicated the number of adults with dementia will continue to grow, particularly among the oldest old. The WHO (2019) also noted that approximately 50 million adults worldwide have dementia and an additional 10 million adults will be identified in each forthcoming year. Dementia, according to the WHO (2017a), is a major cause of disability and dependency for older-aged adults and has a marked impact on both the individuals with dementia and their carers.

Many countries now have national plans on how to address the impact of dementia stemming from Alzheimer's disease or other causes (Chow et al., 2019; Wortmann, 2013). These national plans typically are directed toward the general population and often omit mention or understate plans to address the special needs of groups, such as individuals with lifelong intellectual disability¹ who may be at higher risk of dementia (Watchman & Janicki, 2019). The WHO (2012) noted this oversight and called for national plans to subsume people with special needs within their plans. Special mention was made regarding people with intellectual disability, including those adults with Down syndrome who manifest high risk for Alzheimer's disease and its outcome early-onset dementia.

These national plans address a range of issues, such as encouraging research regarding the causes and eventual prevention of dementia, identifying viable support of treatment strategies and managing supports for carers, setting up public education programs, and enhancing the capabilities of workers to care and support adults

affected by dementia (Wortman, 2013). Additionally, the plans focus on the social care aspects of support for people with dementia. With respect to persons with lifelong disabilities, the WHO (2012) recognized that some adults are particularly vulnerable to the genesis of Alzheimer's disease and other causes of dementia. In particular, the WHO noted that adults with Down syndrome, an intellectual disability, are among adults who are at significant risk for developing Alzheimer's disease. Studies suggest that more than 70% of adults with Down syndrome will be affected by dementia after the age of 60 years – many of whom may manifest early-onset dementia (Janicki & Dalton, 1999).

The WHO (2012) noted the need to target people with intellectual disability in national dementia plans. Gardner (2016) reported that of 28 plans she studied which addressed intellectual disability and dementia in various ways, most presented information about this issue while a smaller group described actions they are undertaking. In this vein, the recently issued Dementia Strategy for Canada (Public Health Agency of Canada, 2019) has included a notation of the special needs of adults with intellectual disability affected by dementia, with an expectation that actions will follow. In contrast, a national group in the USA concerned with adults with an intellectual disability affected by dementia undertook an effort to make this issue prominent (Janicki & Keller, 2014). This group, the National Task Group on Intellectual Disability and Dementia Practices (the NTG), issued a comprehensive report that included recommendations for addressing detection, care, and support for this population (NTG, 2012).

In the United States, the National Institute of Health (NIH) has been charged under the USA national plan to be the lead entity organizing and supporting research on the effects of dementia, including issues concerning adults with intellectual disability (ASPE, 2012). As part of this charge, the NIH holds a rotating triennial research summit on Alzheimer's disease, related causes of dementia, and dementia caregiving. In 2019, the NIH began planning for the 2020 summit and issued a call for information on topics to be covered at the Second National Research Summit on Care, Services, & Supports for

¹ For practical purposes we are using the WHO (2017b) definition of intellectual disability, which is a condition with "... a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence) [which] results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development."

Persons with Dementia and their Caregivers (National Institute on Aging, 2019). In response to this call, the NTG organized a submission on several select issues that were important to incorporate into an expanded dementia caregiving research agenda. In this paper, we report on three issues of relevance to the upcoming summit and cite recommendations for targeting research funding. Its relevance to an international audience is that these issues resonate irrespective of national conditions and can serve to help stimulate research with respect to a variety of issues faced by carers.

Methodology

To obtain input into the development of a formal document outlining topic areas for an expanded research agenda, the NTG held an open forum at the May 2019 annual conference of the American Academy of Developmental Medicine and Dentistry (Open Forum, 2019). The forum attracted a cross section of disciplines and interests, including families. The information obtained at the open forum from commentary provided by the attendees was combined with other input drawn from discussions with associated parent-based organizations and intellectual disability service providers. The issues gleaned from these various sources were then parsed into those most relevant to the charge of the NIH research summit and of consequence for research considerations on caregiving and supports (see National Institute on Aging, 2019). Based on the information obtained from this process, a working group then organized the suggestions and recommendations into three related topics that reflected the main concerns raised. A summative report was produced and submitted to the NIH (NTG, 2019). The three areas derived were:

(1) research into the prevalence of responsive behaviors, including the behavioral and psychological symptoms of dementia (BPSD) and their nature, frequency, and degree of adverse impact on continued home-based care;

(2) research exploring key environmental factors that facilitate, mitigate, or aggravate extended caregiving at home or other community settings, with parsing on the nature

of dementia, its stages, site design aspects, and beneficial interventions; and

(3) research into problems experienced by families and other carers in seeking assistance for care and supports in community settings and the basis for those problems.

Research Focal Areas

Impact of responsive behaviors alongside behavioral and psychological symptoms of dementia. One of the areas identified warranting further investigation was the effect and impact of responsive behavior including behavioral and psychological symptoms of dementia (BPSD) upon carers of adults with intellectual disability affected by dementia and caregiving sustenance. This issue was discussed as part of the topic of post-diagnostic supports at the *International Summit on Intellectual Disability and Dementia* held in Glasgow, Scotland in 2016 (Watchman & Janicki, 2017). The presence of responsive behaviors/BPSD was noted as a challenging factor (see Dodd et al., 2018). As responsive behaviors/BPSD include a range of behaviors (e.g., agitation, aberrant motor behavior, anxiety, elation, irritability, depression, apathy, disinhibition, delusions, hallucinations, and sleep or appetite changes) that are present at one time or another in the majority of adults affected by dementia, their nature and magnitude can adversely affect caregiving sustainability (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012). Thus, determining if such challenging behaviors – upon dementia diagnosis – are more exacting expressions of chronic behavior present earlier in the lifespan, but masked or overshadowed by other mitigating health or behavioral factors, or are new expressions of dementia symptoms can help with plotting trajectories of treatment and behavioral interventions. Epidemiological research on the prevalence of responsive behaviors/BPSD among older-aged adults with intellectual disability is needed, as is research that can discern whether these behavioral expressions are linked to dementia or represent aggravations of pre-existing behaviors.

Accurate recognition of responsive behaviors/BPSD should increase awareness and understanding of underlying behavioral and

psychological issues, thus enabling adaptive caregiving and provision of appropriate interventions. Although closely associated with progressive dementia, some responsive behaviors or BPSD may be caused by factors other than dementia-related pathologies (Prasher & Janicki, 2019). Some symptoms may have their genesis in lifelong ‘maladaptive’ behaviors linked to the etiology of the intellectual disability that are aggravated by age, the environmental situation, or sensory/cognitive losses. Adults with intellectual disability affected by dementia may also have a range of comorbid conditions that are overlooked due to ‘diagnostic overshadowing’ (British Psychological Society, 2015). Some adults aging with intellectual disability and dementia may also experience sleep disturbance, hyperactivity (including agitation and aggression), affective symptoms (such as anxiety and depression), and delusions and hallucinations that may be related to other causes. Additionally, for adults with Down syndrome experiencing dementia, high rates of comorbid conditions (e.g., depression, hearing/vision impairments, hypothyroidism, epilepsy, anemia, and weight loss) (Bayen et al., 2018; McCarron et al., 2017) may confound diagnosis and/or identification of responsive behaviors/BPSD.

Dodd et al. (2018) noted that family carers and support staff may fail to recognize that some adults with intellectual disability and dementia experience pain or sensory confusion, and thus not offer timely treatment of symptoms or confuse the behavior resulting from pain or sensory losses as a responsive behavior or BPSD. Given that various stimuli may set-off an incident of changed behavior, continuing to assess all physical and psychological causes is important. Thus, research to examine the nature and incidence of such presentations and application of interventions is warranted.

Of concern is that while long-term caregiving is often compromised by the existence of chronic ‘challenging behaviors’ (Heller et al., 2018), it may be further compromised more specifically by new or increased intensity of behaviors generally recognized as responsive behaviors/BPSD linked to the presentation of dementia. Responsive behaviors or BPSD can affect the quality of life of both individuals affected by dementia as well as

carers and be compromising factors in caregiving duration and carer health (Oristein et al., 2013). How these specifically may affect caregiving or compromise or shorten the capacity of dementia care management among families of adults with intellectual disability is unknown. Research to ascertain the prevalence of responsive behaviors/BPSD, their type and intensity, and their interactions with lifelong ‘challenging behaviors’ would be beneficial. Research findings would help to formulate strategies for non-pharmacological interventions and for assisting carers with daily care management.

Impact and effect of situational factors that mitigate or aggravate extended community-based caregiving.

While responsive behaviors/BPSD are related in great part to the behavior of the affected adult, other factors also contribute to carer sustainability. In 2012, the NTG issued a report, ‘*My Thinker’s Not Working*’: *A National Strategy for Enabling Adults with Intellectual Disability Affected by Dementia to Remain in Their Community and Receive Quality Supports*,’ noting that lifelong caregiving may create ‘double jeopardy’ (NTG, 2012). This is manifested when parents are the primary lifetime carers² for adults with an intellectual disability and as Alzheimer’s disease or other brain diseases or conditions become evident, these families may be adversely affected and require new supports. Such situations may involve not only family carers who are parents, but also siblings and other relatives (see as examples narratives in Jokenin et al., 2018). After adapting successfully to the day-to-day challenges of oversight and supports for a dependent adult, many family carers may be overwhelmed by having to provide continued extensive care at home once dementia becomes pronounced and

² Carers in this paper are defined as “individuals, related or unrelated to the adult with an intellectual disability, who are providing dementia supports and supervision, looking after the adult’s interests, and involved in significant decisions about supports and care, or acting as advocates on their behalf.” (see Jokenin et al., 2017, p.412)

Jokenin et al. (2017) explain that “Caregiving takes on various forms and carers may be defined by roles and responsibilities assumed or ascribed to them. Thus, . . . the term “carer” quite broadly reflects the range of different contexts globally and the situations in which people with intellectual disability live.” (p. 416)

care demands change. The home environment is an important contextual component of care and requires adjustments and modifications to meet the functional changes brought on by dementia (Soilemezi, Drahota, Crossland, & Stores, 2017). Dealing with the progression of dementia also involves continually adapting care to address new challenges that often relate to increased time demands addressing a range of new needs and expanding caregiving responsibilities, which some families may not be able to provide.

In the USA, it has been estimated that some 75% of older-aged adults with an intellectual or developmental disability reside with their families (Braddock et al., 2017). With increasing age, age-associated impairments and pathologies begin to take prominence and result in challenges for both family carers and their adult relative with an intellectual disability (Heller et al., 2018). The recognizable impact on older carers is evident when considering the average age of onset of dementia (about 52 years for adults with Down syndrome and about 67 years for adults with other intellectual disability).

Further, estimates are that in excess of 5% of adults currently living at home with older family carers may be affected by mild cognitive impairment (MCI) or dementia. In many cases, family carers are a generation removed and are aging themselves and may be experiencing their own decline. The impact of any challenges associated with dementia-caregiving can significantly affect continued in-home care (NTG, 2012). When caregiving for individuals with intellectual disability, many families experience and adapt to a lifetime level of care that is functional. However, challenges for providing the add-on care needed for coping with dementia as it progresses can become problematic and may often exceed existing family capacities (see as an example, Frizell, 2017; see also Jokenin et al., 2018).

Various trends or patterns have been observed regarding what help family carers need when coping with dementia care. In many situations, carers' physical and emotional health, as well as family finances, can often be compromised and stretched beyond capacities to continue to cope and care for someone affected by dementia at home. One construct for examining the nuances

of dementia-related caregiving is using the staging schema provided by Jokenin et al. (2017) in a paper on family caregiving that emanated from the 2016 International Summit on Intellectual Disabilities and Dementia in Glasgow, Scotland. The staging schema recognizes the complexity of caregiving progression once dementia becomes a factor in lifelong caregiving and offers a framework for studies. This schema categorized dementia-related caregiving into four phases that could be applied to each issue or concern encountered during the progression of the disease: (a) a "diagnostic phase" [i.e., seeking validation as to the cause of change in function early on with an assessment for dementia as well as later with the onset of other causes that change behavior]; (b) an "explorative phase" [i.e., accepting the diagnosis and exploring dementia capable interventions and support options as they apply to conditions that arise]; (c) an "adaptive phase" [i.e., coping, adapting and managing the symptoms that arise in each phase of dementia]; and (d) a "closure phase" [i.e., resolving caregiving issues or a relief from responsibilities following end-of-life (where "decompression" occurs) or adapting to the loss and rebuilding lives and focus (where "reconstruction" occurs) – depending on the degree or nature of interpersonal investment of the carers]. The phases are not necessarily precise and discrete nor followed in a linear fashion and depend in part on carer situations.

This construct helps explain to some degree the nature of caregiving challenges and responses within a life-long caregiving context when dementia becomes evident. It warrants further exploration with respect to how caregiving is affected and if challenges and practices are universal. It would be highly beneficial to support targeted research to examine this construct and test its applications to resilience, durability, coping, and care practices and outcomes.

Thus, research directed toward exploring key factors that facilitate, mitigate, or aggravate extended caregiving at home or in other community settings, while considering the nature of dementia, its stages, home design aspects, and beneficial interventions, would have a constructive purpose. Finding out more about what situational factors facilitate or compromise efficient in-home care can help determine what

can be done to aid carers, whether by offering targeted training, extending home modifications, or providing respite or other relief sustaining strategies and introducing helpful interventions.

Impact of barriers to obtaining extra-familial assistance for home-based caregiving. Another carer factor is how families access and manage intra- and extra-familial resources and assistance to meet the demands that dementia care imposes. As noted above, the numbers of older family carers still providing home-based supports and supervision of an adult with an intellectual disability are significant. These numbers serve to provide a relief for the staggering costs of long-term care that would otherwise be borne by governments and NGOs³. With the onset of dementia these carers are often taxed to continue to provide home-based care. Like their peers in the general population caring for a spouse or parent (without an intellectual disability) affected by dementia, these carers look for ways to continue to provide care while seeking needed outside assistance and support. Family carers living separately from their relative with an intellectual disability, who is beginning to be affected by dementia and who lives in an out-of-home care setting, also struggle to understand the disease, maintain their relationships, and ensure that appropriate quality supports are provided in a timely fashion (Jokenin et al., 2017). Research designed to produce more information about these carers and their challenges as advocates and overseers of services being provided would be most beneficial.

Historically, family carers have either borne the costs of care for a relative with intellectual disability or turned to government-based disability departments or ministries or third sector/NGOs for assistance. Having access to this resource differentiates lifelong carers from late-life carers (e.g., of persons with dementia in the general population). However, the nature and demands of caregiving for a person with dementia presents with new and unanticipated challenges for many of these families who have witnessed a lifetime of development, growth in skills, and movement toward autonomy in many adults with an intellectual disability (Heller et al., 2017).

Dementia, as it does with adults in the general population, leads to losses of function, compromises normal expectations of self-direction and self-care, and introduces new challenges associated not with under-developed social and personal skills, but with behaviors that may compromise hard-won established routines, shared household responsibilities, pace, peace at home, and quality of life.

Questions arise as to what degree can adaptations take place and what outside resources, services, and supports might be accessed to help with adapting to the new and changing reality, including care practices and the creation of a dementia-capable environment. Policy studies determine as to whether this will come from the system that has provided many years of support for developmental progression (i.e., the governmental disability authorities and their associated private provider network) or from a heretofore unknown and unfamiliar network to these families that supports dementia caregiving. Research into aspects of these care systems (and how to blend the best aspects of each) would benefit both carers and the systems in place to sustain and aid them to meet needs.

Some localities have initiated special efforts to address the growing numbers of clientele in both public and private sector services affected by dementia. Some have authorized and are funding specialized group homes or other housing that is 'dementia capable' (Janicki, 2016). Others have instituted family support programs to help carers facing home-based dementia-related care demands and have instituted training and education programs for provider agencies and families (Watchman, 2014). However, these are not wholesale efforts and much that is needed by the provider sector in terms of additional financial and programmatic supports remains elusive. The reality is that many carers' physical and emotional health as well as family finances are often compromised and stretched beyond capacities to continue to cope and care at home for someone affected by dementia. The challenges faced by families of adults with intellectual disability affected by dementia when entering a new system of care that may offer supports can be overwhelming, particularly if faced with age-of-eligibility barriers (as many adults with Down

³ Non-governmental organizations.

syndrome have early-onset dementia). Research studying these factors and deriving recommendations for extra-familial supports for dementia care is warranted and can translate not only to the disability care community but also to the greater community of caregiving when dementia is involved.

Thus, research into problems experienced by families and other carers in seeking assistance for care and supports in community settings and the identification of both barriers and facilitators for those problems is important and can benefit public policy and practices. If supported with evidence, governments can use these findings to frame their community dementia care policies and use the information to expand constructive and cost-effective efforts to aid carers.

Commentary and Research Recommendations

Research into what works best with helping carers is one of the aspects of the framework raised by the WHO (2012) report and other research agendas that have been proposed by various sources (e.g., Pickett et al., 2018). In this vein, the effort that the NTG undertook resulted in a proposal for targeting and underwriting research that would both expand knowledge and provide the basis for public policy initiatives and programs affecting the carers of aging individuals with intellectual disability with neuropathologies. Even through visualizing this through the lens of the situation in the USA, where there are some 1.7 million aging carers of adults with intellectual disability, the translational aspects of these areas of enquiry can be beneficial to a greater pool of carers universally and is not limited to only those involved with caregiving of adults with intellectual disability and dementia. The three areas we raised are areas for some the nub of concerns that will either make or break continued caregiving in home situations or in-service provision and are of utmost import when assigning research to caregiving and intellectual disability and dementia.

There are other equally relevant issues that warrant attention via research efforts. Among them are the recent efforts to identify biomarkers of Alzheimer's disease in people with Down syndrome (Lee, Chien, & Hwu, 2017). The

finding of one or more relevant biomarkers has the potential of creating an 'early warning system' for neuropathologies which may present in later age and one that can help carers plan and progressively adapt to changing cognitive functioning. Other issues warranting research include the impact on carers of regression in younger adults with Down syndrome (Chicoine & Capone, 2019) and psychiatric presentations that mirror dementia earlier in life (Stein et al., 2013). These raise questions about their genesis and warrant undertaking research to measure their impact on caregiving.

In the NTG report submitted to the NIH summit planning group, it was proposed that the following listing of enquiry areas be included within a comprehensive research agenda examining carers and caregiving:

- Epidemiological research on the prevalence of responsive behaviors and BPSD among adults with intellectual disability and research discerning to what extent behavioral expressions are linked to dementia or aggravations of pre-existing behaviors or comorbid conditions.
- Research on the type and intensity of responsive behaviors and BPSDs and their interactions with lifelong 'challenging behaviors' and the relation to formulating strategies for non-pharmacological interventions and for community care management.
- Research exploring key factors that facilitate, mitigate, or aggravate extended caregiving at home or in other community settings, with parsing on the nature of dementia, its stages, site design aspects, and beneficial interventions.
- Research about what situational factors facilitate or compromise efficient in-home care (such as targeted training, extending home modifications, providing respite, or other relief sustaining strategies).
- Research examining the application of the dementia caregiving staging construct to test its applications relative to resilience, durability, coping, and care outcomes.
- Research to produce information about effective carers functioning as advocates and overseers of services provided.

- Research examining best models for national care systems most beneficial to carers and facilitating collaborations among systems.
- Research on beneficial methods of enabling support services for home-based community caregiving of adults with intellectual disability.
- Research deriving recommendations for effective and beneficial governmental policies and supports for dementia care for adults with intellectual disability.
- Research examining which families, carers, and organizations can best prepare for eventualities of Alzheimer's disease or for using biomarker research findings to develop new strategies for prophylactic approaches.

Conflicts of interests

Authors declare no conflict of interests.

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