Healthcare Needs of Older Autistic Adults:

A Review of the Literature

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Executive Summary

This review of the literature identifies health-related issues and care needs particular to older autistic adults, with a focus on their health, quality of life (QoL) and health care. A limited volume of studies examines aging in autism. The research generally indicates that older autistic adults are at greater risk for physical and mental health challenges, compared to older adults in the general population. Risk of earlier death, relative to the general population, is reported.

Medication use among older autistic adults is noted to be complicated, warranting research addressing medication efficacy for older autistic individuals. Research and practice advancement is needed to better address co-existing health concerns and treatment effectiveness, health monitoring, and the development of best practices for senior-based health care as well as other considerations in the lives of older autistic adults such as residential supports.

This review highlights the need for practice guidelines focused on health promotion and healthcare for older autistic adults. To that end, care guidance that does exist in the literature (for instance, guidance in care for children, and guidance in care for adults with development disability) offers instructive insight to this area of healthcare guideline development specific to older autistic adults. Additional recommendations comprise best practice advancement and sufficient resources to ensure generative support provision, as well as optimal primary and subspecialty care for this population. Also needed is evidence-informed interventional support, with attention to the Social Determinants of Health, to seek equitable and inclusive care and resources across our diverse Canadian population (e.g., sex and gender equity). The recruitment and training of researchers and health care providers within this field emerge as pivotal to capacity building, in the ultimate aim of quality healthcare for older autistic adults.

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This summary addresses health-related needs and issues among older autistic adults. Literature related to aging and health care in autism was reviewed, under the following sections: (1) *Health, Mental Health and Medication for Older Autistic Adults,* (2) *Quality of Life (QoL) for Older Autistic Adults,* (3) *Residential Care, (4) Common Causes/Risks related to the End-of-Life,* (5) *Toward Improved Health Supports,* (6) *Developing Clinical Practice Guidelines,* and (7) *Recommendations.*

1. Health, Mental Health, and Medication for Older Autistic Adults

There have been limited studies of co-occurring physical health conditions, mortality, and aging in autism, with the bulk of them being published in recent years. Many of the studies published looked at retrospective medical data or had a relatively smaller number of patients included. Despite the limited research in this area, recent trends have begun to emerge. Health conditions commonly associated with advanced age in the general population (e.g., cognitive disorders, heart disease, neurological diseases such as stroke) are noted to be significantly more common among autistic older adults, but the precise reason for the greater likelihood remains unclear (Braden et al., 2017; Croen et al., 2015; Powell et al., 2017; Wise et al., 2017). Croen et al. (2015) states that physical health conditions including epilepsy, Parkinson's disease, and gastrointestinal conditions are more common among autistic adults than non-autistic populations. Mental health conditions that are more common among autistic adults include schizophrenia, bipolar disorder, anxiety, depression, and suicidality or self-inflicted injury (Croen et al., 2015)

Hand et al. (2020) report that older autistic adults are more likely than an age-matched sample of the general population to experience: 1) physical health conditions of epilepsy, Parkinson's disease, and gastrointestinal issues, 2) mental health conditions of schizophrenia

and psychotic disorders, attention deficit disorders, personality disorders, and suicidality or self-inflicted injury, and 3) cognitive conditions such as delirium, dementia, and amnesia.

Mental health and psychological well-being of older autistic adults has been assessed in a limited number of studies, with relatively few studies focusing on older age groups specifically (Sonido et al., 2020). Elevated lifetime rates of depression, anxiety, social phobia, and obsessive-compulsive disorder are reported (Croen et al., 2015; Sonido et al., 2020). Also reported is a significantly higher proportion of autistic adults versus non-autistic adults who take at least one psychotropic medication even after adjusting for any psychiatric or neurologic diagnosis (Cvejic et al., 2018). Anxiety and psychotic disorders are the most common diagnoses for which antipsychotic medication is prescribed for older autistic adults (Nylander et al., 2018).

Although most studies report an association between age, physical, mental health and cognitive conditions in autistic individuals, some studies report mixed findings on the association between age, mental, and cognitive health conditions. Lever and Geurts (2016a) found that some cognitive strengths and difficulties may last throughout adulthood while others are reduced; further, typical age-related differences in cognition that you would expect to find in younger versus older adults in the general population were not increased in the autistic population, and may even be reduced. Lever and Geurts (2016b) also explore age relation in psychiatric conditions of autistic individuals, aged from 19 to 79 years, and report that autistic individuals show high levels of psychological distress through their lifespan, but the psychiatric challenges are less prevalent in older ages.

Limited studies have addressed autism and its impact on social competence, physical and mental health, cognitive changes, executive functioning, and neurological changes in older autistic adults (Hategan et al., 2017; Michael, 2016; Patra, 2016). According to Patra (2016), behavioural problems can be a challenge for some autistic adults. Diagnosis of these

problems is reportedly difficult due to their complex presentation; antipsychotic medications are often offered to manage them. A cross-sectional analysis of health care records found that the majority of older autistic adults required some support in activities of daily living (e.g., eating, bathing, dressing) (Fortuna et al., 2016). Patra (2016) reports high rates of fractures in elderly autistic people as compared to age matched controls, possibly due to lower bone mineral density that may be related to dietary limitations, low rate of physical activity, and the use of antiepileptics and antipsychotics.

The use of medications for autistic people is complicated as (1) certain classes of drugs are prescribed without much evidence of their efficacy in autistic individuals (Ballester et al., 2022), (2) some autistic individuals object to being 'over-medicated' and having their autistic traits 'pathologized' (Murray, 2020), and (3) the lack of rigorous studies on drug interactions and long-term adverse effects of these medications (Fieiras et al., 2023). For example, Smith DaWalt et al. (2019) found that health complications from medication side effects may cause death in some autistic people.

Neuroleptics, also known as antipsychotic medications, are frequently prescribed to address irritability, including severe aggression and self-injurious behaviours, in autistic individuals. Studies on drug-induced parkinsonism with non-autistic study participants highlight the risk of long-term exposure to neuroleptics (Erro et al., 2015; Shuaib et al., 2016). Some studies indicate that long-term use of neuroleptic medications in autistic individuals may increase the risk of developing Parkinson's disease later in life (Starkstein et al., 2015; Vohra et al., 2016). This could be particularly of concern, given that aripiprazole and risperidone are approved by the FDA to treat irritability in pediatric patients with autism, yet lack studies on long term efficacy and safety in this population (Fieiras et al., 2023).

Psychotropic medications, which include antidepressants, anxiety medications, stimulants, antipsychotics, and mood stabilizers, are also prescribed at high rates for autistic

individuals. One systematic review found that roughly 61% of autistic adults were currently being prescribed one or more of these drugs, with the likelihood of being prescribed one or more such medications increasing with age (Jobski et al., 2017).

An additional consideration regarding medication is the potential for drug interactions. 'Polypharmacy' is the use of more than one prescription medication at once to treat one or more health or mental health concerns. One study found that 35% of autistic children had evidence of taking two or more psychotropic drugs concurrently (Spencer et al., 2013). This is concerning as there have been few studies of drug interactions in autistic adults, and detecting adverse reactions can be challenging, especially in autistic individuals who also have an intellectual disability (Ballester et al., 2022).

These studies highlight the importance of considering the risk-benefit ratios of neuroleptic medication prescription, careful monitoring in the use of medication for autistic people, accountable clinical practice for autistic patients, improved systems of care, training, and proactive public and health policy.

2. Quality of Life (QoL) of Older Autistic Adults

Psychiatric co-occurrences are reported to have adverse impact on individuals' functional outcome, QoL, and long-term prognosis (Patra, 2016). Depression and anxiety negatively impact domains of physical, psychological, social, environmental, and autismspecific QoL of the older population, indicating that lower depression and anxiety ratings are associated with better QoL. Rates of depression and anxiety disorders are high in older autistic adults, and the level of psychological distress in autistic people is higher than among the typically developing comparison group (Lever & Geurts, 2016b). Lower QoL has been reported in autistic individuals who are (1) female, (2) have a concurrent mental health diagnosis, and (3) experience greater challenges associated with autism (Mason et al., 2018). Kamio and colleagues (2013) support the result of lower QoL among autistic females.

Bargiela et al. (2016) found that autistic females described challenges with health professionals recognizing and accepting their autism diagnosis and experienced high rates of sexual abuse. Future studies are recommended to further explore gender differences and other considerations in QoL.

The loss of families and caregivers (Happé & Charlton, 2012) and the loss of informal support (e.g., someone to talk to or someone to do things with) over time (Renty & Roeyers, 2006) are reported as a significant predictor of lower QoL. The effects of such life shifts are likely to be exacerbated among autistic individuals with higher support needs (Mason et al., 2018). Conversely, being in a relationship and receiving support are positive predictors of social QoL (Mason et al., 2018). Accordingly, social support may have a positive impact on the QoL and well-being of older autistic adults (Charlton et al., 2022).

A UK-based workshop brought together autistic people, relatives, clinicians, and researchers, among others, to establish priority research areas important to improving the physical health and well-being of autistic people. These priorities included calls for improved understanding of physical health concerns and treatment effectiveness, the development of a personalized annual health check program for autistic people, and investigations on best practices for residential facilities, healthcare accommodations, and service delivery (Warner et al., 2019).

Overall, it is difficult to draw definitive conclusions given the limited existing research. Specific investigation exploring correlates, causal factors as well as issues related to selfharm in older autistic adulthood is warranted. Accordingly, cross-sectional, longitudinal, and interventional studies are needed to inform service and health care providers in better supporting older autistic adults.

3. Residential Care

There is a dearth of research addressing residential care and offering residential care guidelines with a focus on autistic seniors with health conditions. Crompton et al. (2020a) note that residential care needs differ for older autistic adults relative to older adults in general. Their paper reports findings from three meetings with key stakeholders (i.e., older autistic adults, their families and caregivers, service providers, and researchers) in which individual experiences of older autistic adults were heard, existing practice guidelines were evaluated (including Alzheimer Scotland's *Getting to Know Me*, and the Alzheimer's Society's *This is Me*), and key priorities were identified (Crompton et al., 2020a). The following 10 elements were identified for improving residential care for older autistic adults: "(1) managing transitions into residential care, (2) autism training for residential care staff, (3) recognizing and respecting autistic differences, and understanding autistic well-being, (4) supporting physical health, (5) considering and attending to the sensory environment and sensory processing, (6) design principles, (7) creating community and belonging, (8) autonomy and choice, (9) advocacy, and (10) evaluating care quality" (Crompton et al., 2020a, p.121).

A separate study by the same group focused on co-creating a tool, the Autistic Satisfaction with Care Holistic Interview (ASCHI), that can be used to investigate the experiences of older autistic adults in residential care (Crompton et al., 2020b). They collaborated with people with lived experience and other experts in autism, aging, and residential care to identify key areas of interest for this population and generated questions based on those topics. The interview tool features questions pertaining to "Daily Life" (e.g., routines, interests, time spent with others), "Environment" (e.g., comfort and ease of movement, safety and privacy, sensory experiences), "Independence and Advocacy" (e.g., autonomy, control of everyday life, need for advocates), and "Physical Health and Well-

being" (e.g., physical health conditions, nutrition, fitness) of older autistic adults living in residential care (Crompton et al., 2020b, Supplementary Data).

4. Common Causes/Risks related to the End-of-Life

There are few studies on common causes of end-of-life within the autistic population. However, published mortality studies report reduced life expectancy in the autistic population compared to the general population (Hirvikoski et al., 2016; Hwang et al., 2019; Michael, 2016; Mouridsen, 2013; Smith DaWalt et al., 2019). The difficulty with comparing such studies is they may not be focusing on the same age range of people. For instance, accidents like drowning may be more common in younger autistic individuals, while cancer may be more common in older autistic adults. The following studies indicate a wide range of potential factors contributing to the earlier deaths in autistic people. Hirvikoski et al. (2016) report nervous system disorders and suicide as the two leading causes of death in autistic individuals. The authors also found higher mortality in autistic adults with a co-existing diagnosis of intellectual disability compared to autistic individuals without intellectual disability. The most common cause of death in autistic adults with and without intellectual disability were epilepsy and suicide, respectively (Hirvikoski et al., 2016). When separated by sex, nervous and circulatory system disorders were the leading causes of death in autistic males, while the risk of mortality due to endocrine system and congenital disorders as well as suicide was higher in females (Hirvikoski et al., 2016). Smith DaWalt et al. (2019) identify health issues as a major factor predicting death among autistic individuals, and indicate common causes of death to be chronic conditions such as cancer and heart disease, accidents such as choking on food and accidental poisoning, and health complications due to medication side effects are also reported. In examining a sample of 1,367 cause-of-death data files of autistic adults who had died between 1999 and 2014 in the United States, Guan and Li

(2017) found that the mean age at death was 36.2 years (median of 34 years) compared with 72.0 years (median of 77 years) in the general population, and note that 27.9% of the deaths in the autistic population are attributed to injury, including suffocation, asphyxiation and drowning.

In another paper with mortality numbers, Hirvikoski and colleagues (2016) state, "Individuals in the control group died at a mean age of 70.20 years (s.d. = 24.16, median = 80), whereas the corresponding figure for the entire [autistic] group was 53.87 years (s.d. = 24.78, median = 55), for [autistic individuals with high support needs] 39.50 years (s.d. = 21.55, median = 40) and [for autistic individuals with low support needs] 58.39 years (s.d. = 24.01, median = 63) respectively" (p. 235).

Hwang et al. (2019) indicate that rates of death are higher for autistic individuals with additional physical and mental health conditions, compared to those within the general population. They indicate nervous system and sense disorders (e.g., epilepsy) as the leading cause of death in autistic individuals with intellectual disability, and accidents, injury, self-harm, suicide, and poisoning as the main causes of death in autistic individuals without intellectual disability. Mouridsen (2013) further reports that epilepsy and being female are associated with decreased life expectancy. Bilder et al. (2013) indicate the most common causes of death to be respiratory, cardiac, and epileptic events.

Overall, common causes of deaths suggest heightened risk for autistic individuals. Smith DaWalt et al. (2019) identify the importance of social engagement, social support for daily living, and adequate access to health care to improve life expectancy and nurture a healthier lifestyle.

5. Toward Improved Health Supports

Various studies and reports stress the importance of, and advocate for, improved healthcare for aging autistic adults (Bennett, 2016; Bennett & Goodall, 2022; Edelson et al., 2021; Hand et al., 2020; Miot et al., 2022; Perkins & Friedman, 2012). However, there is yet a gap of evidence about healthcare training or practices specifically focused on older autistic adults. Patra (2016) notes a lack of expertise and the need for increased capacity in providing an autism diagnosis for older adults as well as greater understanding about the impact/role of autism relative to health care for these individuals.

Recent studies introduce assistive technologies (also termed: embodied assistive technology, assistive environments, and assistive robots) as effective tools to support older autistic individuals in healthcare (Martinez-Martin et al., 2020; Zheng et al., 2022). While studies of the use of assistive technologies for older autistic adults are still highly limited, these studies highlight ways in which they may offer promise for the aging population.

Unfortunately, our review did not yield formalized clinical practice guidelines specifically for the healthcare of older autistic adults; however, suggestions are offered to improve practice. Addressing autism within the context of health conditions (and vice versa) prevalent in older age, including attention to impacts of long-term medication use and agerelated care (e.g., Alzheimer's, arthritis, Parkinson's, osteoporosis, etc.), are anticipated to guide care for older autistic adults.

Although not specifically related to an older population, Nicolaidis et al. (2013) compare healthcare experiences of autistic and non-autistic adults. Their survey identifies lower satisfaction among autistic adults with patient-provider communication and health self-efficacy, and higher unmet healthcare needs related to physical health, mental health, and prescription medication. Nicolaidis et al. (2015) further identify several autism-related factors affecting healthcare for autistic adults, including: verbal and non-verbal communication skills, sensory sensitivities, difficulty identifying and communicating sources of pain, need

for consistency, need for additional time to process information, and challenges with organization such as scheduling and maintaining appointments.

Healthcare provider-level factors affecting health care experience are noted to intersect with patient-level factors and comprised: knowledge about autism in adulthood, assumptions about skills or needs, use or non-use of accessible language, provision of accommodations, and the incorporation of supporters into care (Nicolaidis et al., 2015). System-level factors are further identified in this study, including the availability of informal or formal supports, the complexities of the healthcare system, accessibility of healthcare facilities, stigma about autism, and societal issues (e.g., poverty and disparities in health insurance). Recommendations entail empowering autistic adults, training for service providers, and greater accessibility of the healthcare system to decrease discrimination in healthcare (Nicolaidis et al., 2015). This study also yielded the AASPIRE Healthcare Toolkit, a primary care resource for adults on the autism spectrum and their primary care providers (autismandhealth.org). Further exploring the factors identified in the study and developing these resources has the potential to improve healthcare training and practices for older (and other) autistic people.

Diagnosis in older life, healthcare practice review and improvement, and better understanding of the needs of older autistic individuals, are identified as important factors to improve healthcare practice guidelines. Studies about the effects of care service providers' responses to autistic individuals' needs in healthcare systems, diet, lifestyle, and medication use of autistic individuals will help us better understand the needs and support older autistic adults as they navigate the complexities of age-related health conditions such as Alzheimer's, Parkinson's, arthritis, and osteoporosis.

6. Need for the Development of Clinical Practice Guidelines

While our review did not find clinical practice guidelines specifically for autistic seniors in health care, the existing guidelines in pediatric care for autistic children and their caregivers, as well as the 2018 College of Family Physicians consensus guidelines for adults with intellectual and developmental disabilities, offer helpful guidance. Given substantial needs for healthcare in older years (Atella et al., 2019), the lack of care guidance specifically for older autistic adults warrants further guideline development/refinement.

Persistent Assessment

While the following recommendations were developed for children and adolescents, the implications of regular assessments for older autistic adults have the potential to reduce obstacles to adequate medical care. Ip et al. (2019) highlight the importance of surveillance and follow-up care on pending investigations, and initiating additional assessments, as required. Relatedly in an adult care context, Sullivan et al. (2018) noted the importance of periodic health assessments for adults with intellectual and developmental disabilities.

Older adults are due for assessments and screenings once they reach a certain age (e.g., colonoscopy, mammogram, prostate exam, etc.), but these screenings are being delayed or missed altogether by many autistic adults (Doherty et al., 2022). Follow-up investigation should include the wide range of potential co-existing conditions and considerations (e.g., dental/oral health issues, gastrointestinal conditions, nutrition gaps, sleep issues, anxiety, attention-deficit hyperactivity disorder, depression), challenges associated with autism (e.g., issues related to verbal, nonverbal, and social communication skills, psychological needs, gross and fine motor challenges, sensory processing conditions, and psychiatric co-morbidity), behavioural interventions, pharmacological management, and family support (Ip et al., 2019; Sullivan et al., 2018).

Recommendations for Pediatric Clinical Practice Guidelines

In a scoping review by Kouo and Kouo (2021), the following were employed at different health settings: an information collecting instrument (e.g., communication needs, social skills, safety, interests), supportive interventions or strategies (e.g., effective resources in past medical encounters and recommendations to reduce agitation and to communicate), involvement of relevant healthcare providers (e.g., nurses) or other supportive personnel, and education and resources for healthcare providers. Environmental modification, supportive communication strategies, behavioural interventions, and other best practices were also suggested (Kouo & Kouo, 2021). The Royal Children's Hospital Melbourne (2015) suggests environmental modification with pharmacological management, plans for medical procedures, investigation for causes of ongoing concerns in health, and follow-up addressing distress/agitation among autistic children and their families.

The Center for Autism & Related Disabilities (CARD, 2021, http://cardusf.fmhi.usf.edu/docs/resources/CARD_HospitalSupport.pdf.) offers practical guidance as well, including: decreasing wait time when possible, modifying the physical environment, modeling a caring attitude, and being prepared and proactive.

Adult Clinical Practice Guidelines

Our review further found clinical practice guidelines specifically for adults with intellectual and developmental disabilities (IDD). A group of leading Canadian researchers and physicians came together in 2018 to update the existing Canadian guidelines for the primary care of adults with IDD (Sullivan et al., 2018). These key leaders in the field reviewed evidence and synthesized expert knowledge and experiences to determine guidelines to improve standards of care, including the recommendation of specific clinical tools and practical resources. The guidelines emphasized the importance of ensuring the patient is at the center of communication, planning, and decisions regarding their care (Sullivan et al., 2018). It was noted that this may require physicians to schedule more time for

appointments and to familiarize themselves with the patient and use the patient's preferred communication methods (Sullivan et al. 2018; Guideline 2). It was also noted that while some individuals with IDD may not be able to make all decisions for their care, many patients with IDD do have some capacity for decision making, and should be provided with accommodation and support to ensure that they can participate in decisions for their own care as much as possible (Sullivan et al., 2018; Guideline 3). Physicians are encouraged to recognize that caregivers may struggle to meet the needs of the adult with IDD and may need access to support, respite, and other resources (Sullivan et al., 2018; Guideline 4). It is recommended that physicians perform periodic comprehensive assessments of physical health and mental health, and review whether the patient and their caregivers need access to financial or other community supports (Sullivan et al., 2018; Guideline 6). The guidelines further recommend that healthcare providers recognize that pain and distress can manifest atypically and that sensory experiences can impact the patient with IDD's perception of pain (Sullivan et al., 2018; Guideline 9). Physicians are cautioned to regularly review prescription medications and pay close attention to the impact of long-term use of certain medications and the interaction of multiple medications (Sullivan et al., 2018; Guideline 10). Physicians also are advised to assess the patient's risk for abuse, exploitation and neglect, and to refer alleged instances of victimization to appropriate local resources (Sullivan et al., 2018; Guideline 11). Finally, healthcare providers are advised to recognize that life transitions are often challenging for patients with IDD and their caregivers, and that proactive discussions, communication, and planning can reduce patient distress (Sullivan et al., 2018; Guideline 12).

Accordingly, a range of helpful clinical practice guidelines are suggested in health care for autistic children, adults, and their caregivers. Such guidelines likely will be informative in the development of clinical practice guidelines for older autistic adults and their caregivers. Guided by literature and research advancement such as that offered above, examination of healthcare approaches, communication strategies, environmental modification, collaborative support of professionals and social care, and community practice and treatment modification, is anticipated to inform clinical guidelines supporting care for older autistic adults. Such advancement is anticipated to optimize targeted care to this population in ultimately supporting well-being in later years.

7. Recommendations

Areas of needed advancement in this field are substantial. Emergent recommendations are as follows.

- 1. Further evidence about the physical and mental healthcare needs of older autistic adults is urgently needed.
- Practice guidelines would assist health care providers in relevant areas of care delivery common in older adulthood, i.e., autism relative to Alzheimer's disease, Parkinson's disease, etc.
- 3. There is need to develop housing resources that support optimal living arrangements and care in older age.
- 4. Development of interventional supports is needed, with attention to sex/gender and other Social Determinants of Health. Given relatively few studies to date, future work in addressing the intersectional and diverse needs of the aging autistic population needs to be a priority in research and practice.
- 5. Engagement, recruitment, and training of researchers and health care providers focused on autism and aging is warranted. This invites greater emphasis on interdisciplinary training and research focused on aging in autism. Accordingly, greater attention to this issue and advocacy is recommended.

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