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COMMENTARY

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Cognitive reserve and dementia risk management in people with an intellectual disability

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Key Points

- Dementia risk is elevated in people with intellectual disability, particularly for those with Down syndrome
- Differences in lifestyle factors have been cited as factors that exacerbate dementia risk in people with intellectual disability
- Lifestyle factors can be targeted to enhance cognitive reserve and reduce dementia risk for people with intellectual disability

1 | INTRODUCTION

Over the 20th century, and into the 21st, the longevity of people with an intellectual disability has shown a remarkable, although not always sustained, increase from an average of 30 years in the past to over 60 years today.[1,2] Longer life also means vulnerability to some negative health developments and disorders associated with ageing, including dementia; a longitudinal study of people with Down syndrome (the most common genetic cause of intellectual disability) estimated the cumulative risk to be 88% by age 65[3] with mean age of diagnosis of 55 years.[3,4] Onset age for people with intellectual disability without Down syndrome is closer to ages for the general population, but incidence is estimated to be as much as five times higher than the general population.[5] In addition to heightened dependency, people with Down syndrome who develop dementia have also been found to have a higher number of comorbid health conditions[3,6] and increased mortality rates.[7] However, there remains large variation in the clinical presentation and confirmed diagnosis of Alzheimer's disease, with rate of disease progression and related decline often unclear and poorly understood in people with intellectual disability.

Dementia is challenging to detect or diagnose in this population,[8] as clinicians cannot simply use the same assessments employed with the general population, which depend on an assumed minimum

baseline level of cognitive or functional performance against which progressive decline can be demonstrated. The challenge for instrumentation is compounded by a reliance on verbal performance in many instruments and a relative lack of research on what constitutes normative cognitive ageing in the population with intellectual disabilities.[9] There are a number of specialised tests for persons with intellectual disability, for example, the CAMDEX-DS,[10] but here there are barriers in access to specialised services with staff who are trained in using such assessments.[11] Even for functional decline, changes in performance may be dismissed as 'just a part of' intellectual disability.[12] A lack of screening for or detection of dementia in people with intellectual disability will result in harm; for example, in such circumstances, people with intellectual disability have less timely access to post-diagnostic supports for dementia; these include interventions, therapies and environmental supports.[13] This in turn can have negative effects on families and caregivers of people with intellectual disabilities, and on health and social care systems.

The higher incidence and prevalence rates of dementia noted are motivating continuing work on assessment. In the meantime, understanding why dementia is so prevalent in this population, and what steps may potentially slow onset and progression, mean that, as for the general population, we also need a better understanding of the ability of people with an intellectual disability to maintain cognitive performance in the presence of neural pathology. We also need a better understanding of the modifiable risk factors likely to be of influence. A current paucity of evidence on dementia risk in people with intellectual disability renders it more difficult to target intervention for this population. A better evidence base will help to refine strategies and prioritise requirements for reducing dementia risk and thereby improve quality of life in this population, and so discussion of this topic is timely and important.

The objectives of this commentary article are to outline possible modifiable risk factors for dementia that may differ between people with intellectual disability and the general population, outline existing knowledge on cognitive reserve proxies and dementia risk in people with intellectual disability, and propose strategies for reducing dementia risk in people with intellectual disability.

2 | MODIFIABLE RISK FACTORS FOR DEMENTIA

In a recent publication targeting the general population, it is estimated that 12 modifiable risk factors may prevent or delay approximately 40% of cases of dementia.[14] Livingston et al.[14] quantified a number of these modifiable risk factors for dementia, based on research in the general population. In early life (age <45 years); they highlighted as a general risk factor less education (7%); for mid-life (age 45–65 years), hearing loss (8%), traumatic brain injury (3%), hypertension (2%), alcohol (1%), and obesity (1%); and for later life (>66 years), smoking (5%), depression (4%), social isolation (4%), physical inactivity (2%), air pollution (2%), and diabetes (1%).

Being more able to depend on someone to listen to one, based on a question from the Berkman-Syme Social Network Index,[15] was found to be associated with better cognitive performance than would be estimated from total cerebral volume in participants from the general population.[16] A meta-analysis of research in the general population also demonstrated an association between incident dementia and less frequent social contact, as well as with lower social participation.[17] Indeed, it has been posited that social engagement may act as a means for accessing cognitive reserve, by allowing people to use social and environmental resources.[18]

For people with intellectual disability, longitudinal follow-up and reviews of medical databases have confirmed that, as compared to the general population, there are lower levels of hypertension and diabetes, and less smoking and alcohol use, low levels of education and higher levels of traumatic brain injury, physical inactivity and depression. In the literature on people with intellectual disability, the consequences of obesity and hearing loss are poorly followed up on and there is little attention to exposure to air pollution and social isolation.[3,19–21]

There has been some research interest in associations between these lifestyle factors and dementia in people with intellectual disability. There was no association found between physical activity, diet, weight, or cognitive activity between people with Down syndrome with dementia compared to people with Down syndrome without dementia, although these lifestyle factors were assessed using quite broad ordinal scales (for example, diet was coded as either 'good diet' or 'bad diet';[22]).

Time spent in sedentary behaviour was associated with lower cognitive functioning, while time in moderate-to-vigorous activity was associated with higher functioning, in adults with Down syndrome without dementia.[23] These findings were in spite of there being a lack of association between sedentary behaviour or moderate-vigorous activity with beta amyloid or tau. Moderate and high intensity exercise have been associated with lower risk of CAMDEX-DS-assessed skills decline or decline in personality and behaviour for people with Down syndrome.[24] Similar to Kenshole et al.,[22] exercise was measured at a broad ordinal level ('high', 'moderate', or 'low').

Multiple modifiable risk factors for dementia have therefore been shown to differ between people with intellectual disability and the general population, although further research is required on the interaction between these risk factors and cognitive function/dementia in people with intellectual disability. Opportunities for prevention and management of dementia symptoms in people with intellectual disability need to be addressed, including further research on the role of cognitive reserve.

3 | COGNITIVE RESERVE

In the general population, although there is evidence of Alzheimer-related (amyloid) pathology in one-third of older people in the absence of cognitive symptoms of dementia, there is evidence of declining incidence of dementia in Europe and North America.[25] The declining incidence in the context of an ageing population suggests

that dementia risk is modifiable, and there may be protective mechanisms that buffer cognition against the impact of brain insult. In a white paper,[26] Stern et al. discuss several different concepts that could account for resilience to age- and disease-related changes in brain and cognition, including brain maintenance and cognitive reserve. They have defined cognitive reserve as 'the adaptability of cognitive processes that helps to explain differential susceptibility of cognitive abilities or day-to-day function to brain ageing, pathology, or insult' (p. 1306), and emphasise cognitive reserve as active and dynamic, with cognitive processes coping with brain changes.

Others have highlighted that, as compared to the general population, there is a relatively low level of engagement in healthy lifestyle factors relating to cognitive reserve in people with an intellectual disability, that provides an ability to maintain cognitive performance in the presence of a dementing disease.[27] This viewpoint suggests that lower levels of cognitive reserve in people with an intellectual disability leads to more vulnerability and more rapidly experienced and worsening cognitive symptoms in the context of dementia.[28] Conversely, there is also the possibility that by targeting factors associated with cognitive reserve in people with intellectual disability, dementia risk and severity may be reduced for this cohort. With this article, we wish to draw more attention to the potential of enhancing cognitive reserve in people with intellectual disability.

3.1 | Assessment of cognitive reserve and association between proxies and dementia risk

Cognitive reserve is difficult to assess directly, so proxy variables and latent variable models are used to operationalise this concept, which acts as a moderator between risk (brain insult/pathology) and outcome (clinically significant decline in cognition or function).[29] A wide variety of proxies for cognitive reserve may be used, and sociobehavioural proxies 'include education, IQ, occupational complexity, leisure and physical activity, and other protective factors that have been identified, most often in epidemiologic research' (page 1306).[26] The factors mentioned by Livingston et al., based on previous research in the general population,[14] could also be considered cognitive reserve proxies, and represent an opportunity for dementia prevention.

Amount of education alone has often been used as a proxy measure of cognitive reserve.[30] Other measures combine multiple proxy measures. For example, the Cognitive Reserve Index questionnaire[31] includes education, work experience and leisure activities to form a general index. Intelligence quotient (IQ) is often used as a proxy measure of cognitive reserve. Although there has been a lack of research looking directly at IQ and dementia risk in people with intellectual disability, severity of intellectual disability is linked with IQ (particularly under ICD criteria). A systematic review found that, for people with severe to profound intellectual disabilities, very few studies have reported symptoms ascribed to dementia, although this could be related to difficulty in administering neuropsychological tests or gaining reliable longitudinal informant reports.[32] Habitual participation in cognitively stimulating activities contributed to performance on crystallised and fluid cognitive assessments in adults with intellectual disability,[33] suggesting that performance on IQ tests may be correlated with habitual levels of these activities.

A prevalent belief that there is lower cognitive reserve for people with intellectual disabilities reflects that cognitive reserve in the general population has generally been reported as associated with level of education[34] and employment.[35] Although people with an intellectual disability are increasingly participating in education and employment, they are not doing so to the same extent as the general population; for example, in 2002, school participation rates in adolescents in Ireland aged 15–19 were 10% lower for people with an intellectual disability compared to figures for those of a similar age without a disability; rates of third level education for people with intellectual disability are much less, with estimated levels in Ireland of lower than 1%.[36] Regarding employment, in a nationally representative study in Ireland of people with intellectual disability over the age of 40 years, only 6.6% reported being in regular paid employment.[37] Finally, for people with an intellectual disability, education, work experiences and leisure activities are all likely to differ from the general population in terms of cognitive demand. The cautiousness of findings and conclusions on the potential for people with intellectual disabilities to build cognitive reserve should not preclude further exploration of the potential of interventions to improve cognitive reserve and thereby address the modifiable risk factors such as education.

In a study involving 40 people with Down syndrome aged 40–59, the mean score on the Cognitive Reserve Index questionnaire was 85, indicating a medium level of cognitive reserve, with similar scores across the education, working activity and leisure activity domains.[38] Another study of people with Down syndrome assessed leisure activities, education and employment.[39] Level of schooling and employment accounted for a large degree of the variance in cognitive performance (assessed by a battery of neuropsychological tests assessing aspects of cognition such as reading, verbal fluency, orientation, memory). However, level of schooling did not directly correlate with dementia rating on the Dementia Scale for Down syndrome.[40] Level of cognitive functioning was associated with dementia rating, and although there was no direct association between education and employment and dementia rating, there was an association with cognitive function, potentially suggesting initial level of cognitive functioning may mediate the effect of schooling and employment on cognitive decline. The fact that a battery of cognitive tests was used would suggest that schooling and employment do not necessarily affect reserve for only one aspect of cognition, although further research is required on the generalisability of cognitive reserve in people with intellectual disability to aspects of cognitive performance that are not directly used on an ongoing basis while building reserve.

Several studies involving people with Down syndrome in particular, have shown that cognitive reserve is present in people with intellectual disability, may be measured in ways similar to the general population, and that levels of reserve may be modifiable.

Further research is required on people with intellectual disability of other aetiologies, to better understand if the role of cognitive reserve in incidence and progression of dementia differs in this population compared to people with Down syndrome.

3.2 | Interventions to enhance cognitive reserve

A study conducted in the general population found that people with lower cognitive reserve appeared to benefit more from cognitive training than those with higher reserve.[41] A study examining the effects of computerised cognitive training in adults with Down syndrome found that training was feasible. While the sample was small (n = 40), results suggested that cognitive training had a positive effect on some objective measures of executive functioning, including Stroop and Tower of London tasks.[42] However, level of cognitive reserve as measured by the Cognitive Reserve Index questionnaire did not appear to influence changes in scores on executive function post-training.

4 | REDUCING DEMENTIA RISK IN PEOPLE WITH AN INTELLECTUAL DISABILITY

The current evidence for people with intellectual disability indicates that participation in cognitively stimulating activities is associated with higher cognitive performance,[39] but has not yet been directly linked with dementia rating. More evidence on the role of cognitive reserve in the presentation and management of dementia symptoms among people with intellectual disability is required.

Where there is reduced access to lifelong learning opportunities, less opportunities for work, or fewer stimulating leisure activities that are of interest to the individual, the scope for fostering cognitive reserve is greatly limited. Notwithstanding the need for further research, there is still value in encouraging people with an intellectual disability, as adults, to continue in education or return to education later in life, and to find meaningful employment. Services working with people with an intellectual disability can further help by encouraging and making available cognitive stimulating activities that appeal to those individuals. In particular, research is needed to examine the applicability of theories on modifiable risk factors and cognitive reserve in relation to a population with a genetic risk for Alzheimer's disease.

There are also opportunities in encouraging interventions such as group based cognitive stimulation therapy, tailored to person-specific and enjoyable activities that stimulate thinking, memory and concentration. Such interventions have been found effective for the general population with/at risk for dementia.[43–45] A feasibility trial found that a 20-week individual cognitive stimulation therapy was feasible and acceptable for people with an intellectual disability and dementia, and quality of life was higher in those who received the therapy compared to a waitlist control, although there was not an effect on cognition in this trial.[46] It is possible that benefits may be more difficult to achieve in people with an intellectual disability who have progressed to dementia, but further research may offer more guidance.

Reminiscence has been shown to preserve autobiographical memories in ageing adults.[47] In addition to oral reminiscence, there is long-standing evidence that approaches such as compiling a scrapbook of photos related to life events and favoured memories are effective[48] in the general population, and for people with intellectual disability.[49]

Physical activity programmes can increase activity levels for people with intellectual disability.[50] A moderate-to-vigorous physical activity intervention for adults with Down syndrome was well-attended when delivered remotely, increasing physical activity and cognitive function.[51] Group-based physical activity has been shown to be feasible and well-accepted by people ageing with intellectual disability.[52] A recent programme, PPALS-2, has been designed to promote adults with intellectual disability as physical activity leaders amongst their peers (https://www.tcd.ie/tcaid/research/Project5.php). A 12-week exercise intervention improved performance on a paired associate learning memory in adults with Down syndrome, although the intervention did not affect other cognitive assessments.[53]

A community-based approach to helping people with intellectual disability overcome social isolation may help to reduce the demands of individual caregivers in this area.[54] A social group aiming to foster friendships was developed by staff and group members at a disability employment service, and participants reported in interviews that participation improved health and well-being, increased physical activity and led to new social networks.[55]

5 | DISCUSSION AND CONCLUSIONS

The impact of dementia in the general population in terms of economic and broader societal cost has generated great interest in finding how to minimise dementia risk.[56] At the same time, further and continuing research is required to build a more detailed understanding of both dementia risk in people with an intellectual disability, and strategies for minimising such risk, but the existing evidence supports providing more opportunities for people with intellectual disability to engage in education and cognitively stimulating work and pastimes. Dementia risk factors identified for the general population[14] can be targeted by interventions tailored to people with intellectual disability, such as increasing physical activity, reducing social isolation, minimising alcohol and cigarette consumption, and treating/managing diabetes, depression, hypertension and obesity. The efficacy of lifestyle interventions in general among people with intellectual disabilities deserves further investigation as they have the potential to contribute to cognitive reserve and offer additional beneficial effects as persons age. Cognitive and functional performance should be assessed from the age of 35 upwards, to detect early signs of cognitive or functional impairment. A lack of detection of cognitive decline can result in harm for people with intellectual disability, as it will delay their access to timely support. An example

of good practice in the area of assessment and support is the National Intellectual Disability Memory Service in Ireland (https://www.tcd.ie/tcaid/research/NIDMS.php), which offers baseline cognitive screening as well as individualised plans targeting modifiable dementia risk factors.

Further research is needed that combines assessment of cognition, lifestyle factors and neuroimaging of biological markers of dementia pathology within the same cohort of people with intellectual disability, particularly amyloid pathology in people with Down syndrome. Such research allows for clearer assessment of the preservation of cognitive function in the presence of neural pathology. Some research has also used relatively broad measures of lifestyle factors such as diet and physical activity, whereas more detailed assessments and those with more continuous outputs (as opposed to ordinal, 'low-medium-high'-type outputs), as well as cognitive assessments with sufficient sensitivity to detect subtle changes, could allow for a more nuanced understanding of lifestyle and dementia risk.

Most research conducted thus far in people with intellectual disability has been cross-sectional. Further longitudinal tracking of the impact of level of relevant lifestyle factors on cognitive decline will create a better evidence base on the role of cognitive reserve in people with an intellectual disability, including the potential that fostering cognitive reserve within individuals with intellectual disability may enhance quality of life. There are some promising findings but as yet there is too little research tackling this question directly, and we still do not know which approaches are best for supporting cognitive function in people with an intellectual disability as they age. It is important to include the voices of people with intellectual disability in this research, for example, by recruiting research team members with intellectual disability as well as having research participants with intellectual disability. Until more empirical work is completed and applied to develop evidence-based best practices for supporting cognition and minimising dementia risk in people with intellectual disability, this population will receive suboptimal care in this area, which is critical for maximising the quality of life of adults ageing with an intellectual disability.

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CONFLICT OF INTEREST STATEMENT

No authors have any conflicts of interest to declare.

DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

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