Research in Developmental Disabilities 34 (2013) 1881–1885

Contents lists available at SciVerse ScienceDirect

Research in Developmental Disabilities

Incidence of dementia in older adults with intellectual disabilities

Andre Strydom [a,*], Trevor Chan [b], Michael King [a], Angela Hassiotis [a], Gill Livingston [a]

[a] UCL Mental Health Sciences Unit, Charles Bell House, 2nd Floor, 67-73 Riding House Street, London W1W 7EJ, United Kingdom
[b] Greenwich Community Learning Disability Team, Oxleas NHS Foundation Trust, Civic House, 20 Grand Depot Road, London SE18 6SJ, United Kingdom

ARTICLE INFO

Article history:
Received 22 November 2012
Received in revised form 15 February 2013
Accepted 15 February 2013
Available online 9 April 2013

Keywords:
Ageing
Intellectual disability
Mental retardation
Dementia
Alzheimer's disease
Incidence
Cohort study

ABSTRACT

Dementia may be more common in older adults with intellectual disability (ID) than in the general population. The increased risk for Alzheimer's disease in people with Down syndrome (DS) is well established, but much less is known about dementia in adults with ID who do not have DS. We estimated incidence rates from a longitudinal study of dementia in older adults with ID without DS and compared them to general population rates. 222 participants with ID without DS aged 60 years and older were followed up an average of 2.9 years later to identify those who had declined in functional or cognitive abilities. Those who screened positive had a comprehensive assessment for dementia, diagnosed using ICD 10 and DSM IV criteria. 134 participants who did not have dementia at initial assessment were alive and interviewed at follow up; 21 (15.7%) were diagnosed with dementia. Overall incidence rate for those aged ≥60 was 54.6/1000 person years (95% CI 34.1–82.3). The highest incidence rate (97.8/1000 person years) was in the age group 70–74. Standardised incidence ratio for those aged ≥65 was 4.98 (95% CI 1.62–11.67). Incidence of dementia in older people with intellectual disabilities are up to five times higher than older adults in the general population. Screening may be useful in this population given the high incident rates, particularly as more effective treatments become available. Studies to explore the underlying aetiological factors for dementia associated with intellectual disability could help to identify novel protective and risk factors.

1. Background

There have been several epidemiological studies of dementia in older adults with Down syndrome (DS) which is known to be associated with an increased risk for Alzheimer's disease (AD), but much less is known about dementia in the intellectual disability population who do not have Down syndrome (non-DS ID) (Strydom et al., 2010b).

Dementia may also be more common in adults with non-DS ID compared to the general population because of specific risk factors. ID is by definition associated with reduced brain reserve (i.e. smaller brain size, fewer neurons or synapse count) (Stern, 2002). The brain reserve hypothesis proposes that there is a critical threshold of reserve capacity that needs to be breached by pathological processes before clinical or functional symptoms will develop. Those with more reserve have been found to be less likely to develop dementia or cognitive decline (Valenzuela & Sachdev, 2006; Whalley, Deary, Appleton, & Starr, 2004). The brain reserve hypothesis therefore predicts that older adults with ID should have higher rates of dementia

* Corresponding author. Tel.: +44 0 2076799308; fax: +44 0 2076799426.
E-mail address: a.strydom@ucl.ac.uk (A. Strydom).

0891-4222/$ – see front matter © 2013 Elsevier Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.ridd.2013.02.021

than those with normal intelligence, and that dementia rates will be relatively high in younger age groups because those with progressive brain pathology will quickly reach a functional cut-off with early emergence of symptoms (Strydom, Hassiotis, King, & Livingston, 2009). Furthermore, several rare genetic ID syndromes are associated with progressive decline. However, older adults with ID may also be protected against dementia. For instance, they often have better cardiovascular risk profiles such as lower rates of smoking and ischaemic heart disease, which may reduce their risk for dementia, particularly vascular dementia (Haveman et al., 2010).

There have been a small number of dementia prevalence studies in the non-DS ID population, with several studies (Cooper, 1997; Shooshtari, Martens, Burchill, Dik, & Naghipur, 2011; Strydom, Livingston, King, & Hassiotis, 2007) showing an increased prevalence while some found rates similar to those in the general population (Zigman et al., 2004). We have previously shown that dementia prevalence varies by diagnostic criteria used, disability level and age (Strydom et al., 2007, 2009). Prevalence is also strongly influenced by mortality rates, and older adults with dementia have much higher mortality rates than those without dementia (Rait et al., 2010). Prevalence rates may therefore underestimate a population's risk for dementia.

The present study reports the annual incidence of dementia in older adults with non-DS ID and compares it with population rates (standardised incidence ratio, SIR).

2. Materials and method

This study reports on follow-up of the BOLD cohort which is described elsewhere (Strydom et al., 2007, 2009, 2010a). Appropriate ethics approval was obtained. Participants were any adults aged 60 years and older (mean age 68.8 years, SD 7.45; range 60–94) living in five London boroughs, who had ID of any aetiology except DS. ID was defined using ICD-10 criteria for mental retardation, and participants were identified by contacting all ID and ageing service providers within each borough. 222 participants participated in the baseline study (2004–2005), of whom 33.3% lived independently, in family homes or in settings without 24 h support; 51.8% lived in community settings with 24 h support, and 14.9% lived in hospitals or nursing homes. Informants were direct care staff, family or befrienders (73.9%), home managers (12.6%), nurses and other professionals (8.1%) or day care staff (4.5%). 28 met at least one of ICD-10, DSM-IV or DC-LD sets of dementia criteria. Participants were reassessed a mean of 2.9 years later (SD = 0.42; 34.2 months, range 25–45 months) using a screen for dementia or cognitive decline; interviewers were blind to baseline assessments. Informants needed to have known the individual for at least the previous two years. If this was not possible, then the informants were asked to consult with others or to refer to case notes and care plans before completing the rating.

Those screened positive had a full diagnostic assessment for dementia.

2.1. Screening and assessment

The dementia screening procedure was similar at both time points (T1 and T2). Screen positives were those who scored at or above the threshold for dementia for severe, mild-moderate and mild ID on the cognitive scale of the Dementia Questionnaire for Persons with Mental Retardation (DMR) (Evenhuis, 1996); decline in more than three aspects of activities of daily living on an adapted activities of daily living (ADL) schedule not accounted for by physical health issues; or a delayed recall after ten minutes of fewer than two items in a 3-item memory task based on the Shoe Box Test (Burt & Aylward, 2000). Those screening negative were presumed not to have dementia.

Informants completed a questionnaire based on the Cambridge Mental Disorders Examination (CAMDEX), in order to determine whether participants who screened positive had symptoms of dementia (Roth et al., 1986). Participants who were sufficiently able also completed cognitive assessments described elsewhere (Jamieson-Craig, Scior, Chan, Fenton, & Strydom, 2010; Strydom et al., 2007). These included the test for severe impairment (Albert & Cohen, 1992), mini mental state examination (Folstein, Robins, & Helzer, 1983) and the Tower of London test (Shallice, 1982). A structured physical examination was conducted to record neurological symptoms and signs associated with dementia and to identify thyroid disorder, stroke, Parkinson's disease and other physical disorders relevant to the differential diagnosis of dementia.

2.2. Diagnosis

Diagnostic procedures and reliability and validity of diagnoses are described in detail in other reports (Strydom et al., 2007, 2009, 2012). At baseline, independent diagnosis of dementia was made by two psychiatrists using an operationalised criteria tick list according to international operationalised dementia criteria. Disagreements were discussed with a third psychiatrist to reach a consensus decision. For the purpose of the incidence study, we defined dementia cases at baseline as all the participants who satisfied at least one of these criteria i.e. ICD-10 (World Health Organization, 1992), DSM-IV-TR (American Psychiatric Association, 2000), dementia with Lewy bodies (McKeith et al., 2005) and frontotemporal dementia criteria (McKhann et al., 2001). All baseline dementia cases were excluded from the incidence calculation.

At follow up, ICD10 and DSM IV dementia criteria were used to define cases. Independent diagnosis of dementia was once again made by two psychiatrists and disagreements were discussed with a third psychiatrist to reach a consensus decision.