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Multimorbidity in older adults with intellectual disabilities

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ABSTRACT

Multimorbidity may be related to the supposed early aging of people with intellectual disabilities (ID). This group may suffer more often from multimorbidity, because of ID-related physical health conditions, unhealthy lifestyle and metabolic effects of antipsychotic drug use. Multimorbidity has been defined as two or more chronic conditions. Data on chronic conditions have been collected through physical assessment, questionnaires, and medical files. Prevalence, associated factors and clusters of multimorbidity have been studied in 1047 older adults (≥50 years) with ID. Multimorbidity was prevalent in 79.8% and associated with age and severe/profound ID. Four or more conditions were prevalent in 46.8% and associated with age, severe/profound ID and Down syndrome. Factor analyses did not reveal a model for disease-clusters with good fit. Multimorbidity is highly prevalent in older adults with ID. Multimorbidity should receive more attention in research and clinical practice for targeted pro-active prevention and treatment.

1. Introduction

It has long been a common understanding, that people with intellectual disabilities (ID) 'are old from the age of 50 years onwards' (Perkins & Moran, 2010; Roth, Sun, Greensite, Lott, & Dietrich, 1996). Nevertheless, apart from people with Down syndrome (Roth et al., 1996), premature aging has never been scientifically confirmed for this group. Geriatric frailty occurs early in the population with ID (Evenhuis, Hermans, Hilgenkamp, Bastiaanse, & Echteld, 2012) and is considered to be a risk factor for subsequent deterioration of health and independence (Fried et al., 2001), occurs early in the population with ID. Their mean frailty index scores at age 50–59 years are comparable to those in the general population aged 70–79 years (Schoufour, Mitnitski, Rockwood, Evenhuis, & Echteld, 2013). This early occurrence of frailty might be an explanation for the perceived early aging.

Frailty might be partly caused by multimorbidity, which refers to the occurrence of two or more chronic conditions. The prevalence of multimorbidity has been extensively studied in older people with normal intelligence (Glynn et al., 2011; Schram et al., 2008; Van Oostrom et al., 2011). The results of these studies imply that prevalence increases with age and is related to female gender, lower education and low social-economic status (Marengoni, Winblad, Karp, & Fratiglioni, 2008; Salisbury, Johnson, Purdy, Valderas, & Montgomery, 2011; Tucker-Seeley, Li, Sorensen, & Subramanian, 2011; Uijen & van de Lisdonk, 2008). Despite the numerous studies, treatment options are still vague. Physicians seem to treat each disease

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separately and show little attention for the synergy between different diseases (Bower et al., 2012), whereas lack of good treatment causes ongoing functional decline, impaired quality of life and early death (Drewes et al., 2011; Fortin et al., 2006; Hunger et al., 2011; Landi et al., 2010).

People with ID seem to have an increased risk of chronic multimorbidity (McCarron et al., 2013) for several reasons. Multimorbidity may start at a young age, with conditions related to brain damage, impaired brain development, and etiologic syndromes. For example, people with cerebral palsy often have motor impairment, epilepsy and other neurologic problems (Arvio & Sillanpaa, 2003). What is more, risks to develop age-related conditions may be different because of superpositioning on childhood conditions and other unfavorable factors (De Winter, Bastiaanse, Hilgenkamp, Evenhuis, & Echteld, 2012). For instance, an increased risk of cardiovascular risk factors is found both in young and older adults with ID (De Winter et al., 2012; Emerson, 2005; Haveman et al., 2011). This may not only be attributable to an unhealthy lifestyle, but also to metabolic effects of antipsychotic drug use (De Kuijper et al., 2013) and fragmented sleep–wake rhythms (Maaskant, van de Wouw, van Wijck, Evenhuis, & Echteld, 2013).

Nevertheless, medical care for this group is primarily reactive, i.e. if complaints or observed symptoms are brought to the attention of the physician (Lennox, Diggens, & Ugoni, 1997). Multimorbidity and frail unhealthy life-years may be delayed by treating conditions that are to be expected during early and later adulthood, as well as anticipating healthcare, aimed at prevention and pro-active diagnosis. Consequently, healthcare costs will decrease because of less dependency caused by additional diseases.

To improve healthcare for people with ID, more knowledge on multimorbidity is necessary (McCarron et al., 2013). Therefore, we studied the prevalence and associated factors of chronic multimorbidity in the broad client population, aged 50 years and over, of Dutch intellectual disability service providers. We have also studied the presence of meaningful clusters of multimorbidity, as a basis for anticipating healthcare.

2. Method

2.1. Design and study population

This study was part of the cross-sectional 'Healthy Ageing and Intellectual Disabilities' (HA-ID) study. This study has been performed in a consort of three large formal ID service providers in the south and west of the Netherlands in both rural and urban environments. These service providers provide care (e.g. washing, nursing) and support (e.g. helping with finances, housekeeping) to a broad spectrum of clients. They cover different levels of support needs: centralized residential accommodations (mainly care), community-based homes (mainly support), day activity centers and supported independent living. The distribution of clients primarily receiving care (35%) and clients primarily receiving support (65%) is similar as in the total Dutch population using formal ID services (Hilgenkamp et al., 2011). People with ID unknown to formal ID services are not part of our study population.

For the HA-ID study, all clients aged 50 years or over were invited to participate ($n = 2322$). The age-limit of 50 years was chosen, because it was generally accepted, though not proven, that people with ID, and not only people with Down syndrome, show signs of premature aging (Patel, Goldberg, & Moss, 1993; Perkins & Moran, 2010). Of the general Dutch population aged $\geq$50 years, 0.5% is known to formal ID services (Woittiez & Crone, 2005) of which 10% receives care or support from one of the services participating in this study. Recruitment and the informed consent-procedure have been described in detail elsewhere (Hilgenkamp et al., 2011). In short, all clients receiving care or support from one of the three participating ID service providers on the 1st of September 2008 have been invited to participate in the HA-ID study. Except for age $\geq$50 years, no exclusion criteria have been used. Of the total number invited, 49.7% of the clients or their legal representatives gave informed consent to participate of whom 98.2% ($n = 1050$) actually participated.

This study has been approved by the Medical Ethical Testing Committee of the Erasmus University Medical Centre at Rotterdam, the Netherlands (MEC nr: 2008-234).

2.2. Definition of multimorbidity and rationale of included diseases

In most studies multimorbidity is defined as two or more chronic conditions, including diseases and risk factors (e.g. hypertension). In the current study, multimorbidity has been defined as two or more chronic conditions which may negatively influence daily functioning. A selection based on included diseases in other multimorbidity studies and included diseases in the HA-ID study has resulted in a list of 20 conditions (Table 1). Conditions with subjective symptoms (e.g. migraine, lower back pain) have not been included, because these conditions are hard to diagnose in people with more severe ID due to their limited abilities to report symptoms.

Dysphagia, motor impairment, epilepsy, hearing impairment, visual impairment, gastro-esophageal reflux disease, and autism have been added to the multimorbidity list, because the prevalence rates of these diseases are found to be higher in people with ID because of their association with brain damage of brain dysfunction (Bohmer et al., 1999; De Bildt, Sytema, Kraijer, & Minderaa, 2005; Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001; Kennedy, McCombie, Dawes, McConnell, & Dunnigan, 1997; Oppewal, Hilgenkamp, van Wijck, & Evenhuis, 2013; Ring, Zia, Lindeman, & Himlok, 2007; Splunder, Stilma, Bernsen, & Evenhuis, 2006). Depression has been added because recent research has found that major depression is five times more prevalent in older people with ID than in the general older population (Hermans, Beekman, &