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The use of a frailty index to predict adverse health outcomes (falls, fractures, hospitalization, medication use, comorbid conditions) in people with intellectual disabilities



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ABSTRACT

Frailty in older people can be seen as the increased likelihood of future negative health outcomes. Lifelong disabilities in people with intellectual disabilities (ID) may not only influence their frailty status but also the consequences. Here, we report the relation between frailty and adverse health outcomes in older people with ID (50 years and over). In a prospective population based study, frailty was measured at baseline with a frailty index in 982 older adults with ID (≥ 50 yr). Information on negative health outcomes (falls, fractures, hospitalization, increased medication use, and comorbid conditions) was collected at baseline and after a three-year follow-up period. Odds ratios or regression coefficients for negative health outcomes were estimated with the frailty index, adjusted for gender, age, level of ID, Down syndrome and baseline adverse health condition. The frailty index was related to an increased risk of higher medication use and several comorbid conditions, but not to falls, fractures and hospitalization. Frailty at baseline was related to negative health outcomes three years later in older people with ID, but to a lesser extent than found in the general population.

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1. Introduction

As the life span of people with intellectual disabilities (ID) increases (Long & Kavarian, 2008; Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000), age-related frailty will likely become a major problem for individuals, caregivers and health care facilities, as has been seen in the general population (Clegg, Young, Iliffe, Rikkert, & Rockwood, 2013). Nevertheless, there is no information on the causes, development and consequences of frailty in people with ID (Evenhuis, Schoufour, & Echteld, 2013).

Frailty has been described as “a dynamic state affecting an individual who experiences losses in one or more domains of human functioning (physical, psychological, social), which is caused by the influence of a range of variables and which

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increases the risk of adverse outcomes” (Gobbens, Luijkx, Wijnen-Sponselee, & Schols, 2010) (p. 342). Frailty can be measured with different instruments, based on different operationalizations. Previously, we measured frailty in people with ID using a frailty index (Schoufour, Mitnitski, Rockwood, Evenhuis, & Echteld, 2013). A frailty index is a method that focuses on the quantity, rather than on the nature of health problems: the more problems are present in an individual, the more frail he or she is (Mitnitski, Mogilner, & Rockwood, 2001; Rockwood & Mitnitski, 2011). It captures physical, psychological and social health and has been shown to predict negative health outcomes in several clinical and community-dwelling populations (Clegg et al., 2013; Mitnitski et al., 2001; Rockwood & Mitnitski, 2007). People with ID showed high frailty index scores compared to the general population of the same age (Schoufour et al., 2013; Schoufour, van Wijngaarden, et al., 2014).

Frail individuals in the general population are more likely to fall, have fractures, get admitted to a hospital, and develop more chronic diseases including osteoarthritis, depressive symptoms, coronary heart disease, diabetes mellitus and chronic lower respiratory tract disease (Gobbens, van Assen, Luijkx, Wijnen-Sponselee, & Schols, 2010; Hogan et al., 2012; Macklai, Spagnoli, Junod, & Santos-Eggimann, 2013; Tang et al., 2013; Weiss, 2011). These consequences may be different for older people with ID due to their lifelong disabilities. For example, lifelong mobility limitations and low bone quality (Bastiaanse, Mergler, Evenhuis, & Echteld, 2014) may influence the relation between frailty and falls and fractures. The high levels of comorbidity (Hermans & Evenhuis, 2014) may lead to an increased risk of hospital admission. Contrary, the care and support provided at the care organizations may limit the necessity of hospitalization, specifically for those with severe behavioral problems or profound levels of ID. Also, gastrointestinal, neurological, sleep, and musculoskeletal problems, epilepsy, and visual and hearing impairments can be lifelong, start at a younger age, or are more prevalent compared to the general population, leading to early interventions and possibly habituation (Evenhuis, Henderson, Beange, Lennox, & Chicoine, 2001; Meuwese-Jongheugd et al., 2006; Sinai, Bohnen, & Strydom, 2012; van de Wouw, Evenhuis, & Echteld, 2012; van Splunder, Stilma, Bernsen, & Evenhuis, 2006). As a result, the relation between frailty and morbid conditions may be less strong than found in the general public. To explore how frailty is related with health problems, we used prospective data from the Healthy Aging and Intellectual Disability study (HA-ID) (Hilgenkamp et al., 2011). The main aim of our study was to analyze the ability of the frailty index to predict the occurrence of falls, fractures, hospitalization, chronic medication use, and comorbid conditions over three years.

2. Methods

2.1. Study design and participants

This study was part of the ‘Healthy aging and intellectual disabilities’ study (HA-ID) (Hilgenkamp et al., 2011). This observational study collected information on the general health status of older people with ID using formal care in the Netherlands. All clients of the care organizations aged 50 years and over were invited to participate ($N = 2322$). Those capable of understanding the available information signed the consent form themselves. Legal representatives were approached for those who were not able to make this decision. Written informed consent was provided for 1050 clients, forming a nearly representative study population for the Dutch population of older adults (aged 50 and above) with ID who use formal care, albeit with a slight underrepresentation of men, people aged 80 and over, and people living independently. Baseline data collection took place between February 2009 and July 2010. The Medical Ethics Committee of the Erasmus Medical Center Rotterdam (MEC-2008-234) and the ethics committees of the participating care organizations approved this study. Details about recruitment, design, inclusion criteria, and representativeness of the HA-ID study have been published elsewhere (Hilgenkamp et al., 2011). Three years after baseline, follow-up data were collected between February 2012 and August 2013. The participants, or their legal representatives, who still received care of the care organizations were asked again to provide written informed consent for the follow-up study. The follow-up study was approved by the Medical Ethics Committee of the Erasmus Medical Center Rotterdam (MEC-2011-309) and the ethics committees of the participating care organizations.

2.2. Data collection

Details about the baseline data collection have been described elsewhere (Hilgenkamp et al., 2011). In short, baseline characteristics were retrieved from the administrative systems of the care organizations. Measurements were conducted within three main themes (1) physical activity and fitness, (2) nutrition and nutritional state, and (3) mood and anxiety. The broad spectrum of data collection included anthropometric measurements, physical fitness tests, psychiatric assessment, and laboratory tests in addition to file records (e.g. medical file). Level of ID was obtained from the records of behavioral therapists and psychologists. The presence of Down syndrome was obtained from medical files. Mobility limitations were categorized as no help, walking-aid or wheelchair use. Follow-up data were collected three years after baseline without client interference.

2.2.1. Falls and fractures

At baseline and follow-up, professional caregivers provided information on how often the participants fell in the past three months (not fallen, 1–2 falls, 3–5 falls, 6–10 falls, 11 falls or more). At baseline, data on fractures having

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