The impact of frailty on care intensity in older people with intellectual disabilities

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A R T I C L E   I N F O

A B S T R A C T

Frailty appears to develop earlier and is more severe in people with intellectual disabilities compared to the general population. The high prevalence of frailty may lead to an increase in care intensity and associated health care costs. Therefore a longitudinal observational study was conducted to determine the effect of frailty on care intensity. The association between frailty and care intensity at baseline and follow-up (3 years later) was assessed. Furthermore, the ability of the frailty index to predict an increase in care intensity after 3 years was evaluated. This study was part of the Dutch 'Healthy aging and intellectual disabilities' (HA-ID) study. Frailty was measured at baseline with a frailty index that included 51 health-and age-related deficits. For all participants information on care intensity in seven steps was available, based on long term care indications under the Act on Exceptional Medical Expenses (AWBZ) – a law that finances specialized long-term care. 676 participants (50 years and over) with ID were included in the final analysis. In 26% of the participants, care intensity had increased during the follow-up period. Increased care during the follow-up was related to a high frailty index score at baseline, independent of gender, age, level of ID and the presence of Down syndrome ($p = 0.003$). After exclusion of ADL and IADL items, the frailty index remained significantly related with increasing care intensity during follow-up ($p = 0.007$). Our results underline that screening instruments for early detection of frailty and effective interventions are required to limit the burden of frailty for individuals and caregivers, but also to limit health care utilization.

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1. Introduction

Improved quality of residential and healthcare has increased the life expectancy of people with intellectual disabilities (ID) (Bittles et al., 2002; Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000). Much is still unknown about the effects of aging on health and health care needs in this older population. In recent years, the Healthy Aging and Intellectual Disability (HA-ID) study provided information on a broad spectrum of health aspects and quality of life in older people with ID (Hilgenkamp et al., 2011). Among many results, it was observed that frailty develops earlier and is more severe compared to the general population (Evenhuis, Hermans, Hilgenkamp, Bastiaanse, & Echteld, 2012; Schoufour, Mitnitski, Rockwood, Evenhuis, & Echteld, 2013). The high prevalence of frailty may lead to an increase in care intensity, which was evaluated in this study.

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The operationalization of frailty remains controversial and various models for measuring frailty have been reported (Clegg, Young, Iliffe, Rikkert, & Rockwood, 2013). In general, researchers agree that frailty is a state in which older people are more vulnerable to negative health outcomes compared to others of the same age (Rodriguez-Manas et al., 2013). One frequently used operationalization is the frailty index, which is based on the non-specific accumulation of deficits (Mitnitski, Mogilner, & Rockwood, 2001). Deficits can be symptoms, signs, diseases, disabilities or laboratory measurements as long as they fulfill certain criteria (e.g. health and age related) (Searle, Mitnitski, Gahbauer, Gill, & Rockwood, 2008). The frailty index is a robust method, showing validity across diverse clinical and community dwelling populations, and has been adapted as a useful measure to evaluate health status in older people (Clegg et al., 2013; Rockwood & Mitnitski, 2007). We have argued that the frailty index is a suitable measure for the ID population (Evenhuis, Schoufour, & Echteld, 2013; Schoufour et al., 2013) and we have confirmed its ability to predict adverse health outcome in an older ID population (Schoufour, Mitnitski, Rockwood, Evenhuis, & Echteld, 2014; Schoufour, Mitnitski, Rockwood, Hilgenkamp, et al., 2014).

In the general population, it has been shown that frailty predicts the transition to long-term or higher care facilities (Drubbel et al., 2013; Gobbens, van Assen, Luijkx, & Schols, 2012; Hogan et al., 2012). In people with ID, this relation has not yet been evaluated. Increase of care intensity is associated with care costs, and insight into the financial consequences of frailty can help to raise awareness toward policy makers. Our main objective was to study the predictive value of frailty for increase of intensity of care during a 3-year follow-up period. Furthermore, we provided an overview of the characteristics that are associated with intensity of care (e.g. multimorbidity, level of dependence, behavioral problems).

2. Methods

2.1. Study design and participants

The HA-ID study is a longitudinal study of older adults (50 years and over) with ID (Hilgenkamp et al., 2011), executed in a consortium of three large formal ID service providers in the Netherlands. These service providers offered low to high level of care and support to people with ID. The HA-ID aimed to study the health status of people with ID within three themes: (1) physical activity and fitness, (2) nutrition and nutritional state, and (3) mood and anxiety. Baseline data collection took place between February 2009 and July 2010. Ethical clearance was provided by the Medical Ethics Committee of the Erasmus Medical Center Rotterdam (MEC 2008-234) and by the ethics committees of the participating care organizations. All clients aged 50 years and over who received care from one of the participating care organizations were invited ($N = 2322$) to participate. Eventually 1050 clients, or their legal representatives, provided informed consent, 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. A full description of the design, recruitment, representativeness, and diagnostic methods has been published elsewhere (Hilgenkamp et al., 2011). A second wave of measurements was collected 3 years after baseline (between February 2012 and August 2013). 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. The participants, or their legal representatives, who still received care from one of the care organizations, were asked again to provide written informed consent for the follow-up study.

2.2. Outcome measures

2.2.1. Client characteristics

Information on age, gender and residential status was collected through the care provider services. Residential status was categorized as centralized setting, community-based setting and living independently with ambulatory support. Level of ID was obtained from the scores of psychologists or test assistants, who determined level of ID from available IQ tests, Vineland scores and social emotional development. The presence of Down syndrome was retrieved from the medical files.

Care intensity was based on a strictly standardized professional estimation of the required level of care and support and, if necessary, on behavioral problems (see Section 2.2.2). Information on care and support related items were therefore also provided. Multimorbidity was defined using a list of 20 chronic conditions, assessed through physical assessment or obtained from medical files (Hermans & Evenhuis, 2014). To enable comparison with other studies, multimorbidity was defined as the presence of ≥ 2 and ≥ 4 comorbid conditions. Severe behavioral problems were defined as the presence of automutilation and/or aggressive behavior (verbal or physical). To determine the levels of dependence, questionnaires on activities of daily living (ADL) and instrumental activities of daily living (IADL) were completed by professional caregivers. ADL was assessed with the Barthel Index (Mahoney & Barthel, 1965). It consisted of 10 items (feeding, bathing, grooming, dressing, bowels, bladder, toilet use, transfers (bed to chair and back), mobility on level surfaces, and mobility on stairs) with two to four answer categories. The total ADL score ranged from 0 (completely dependent) to 20 (completely independent). The Lawton scale was used to measure IADL (Lawton & Brody, 1969). The Lawton scale consisted of eight items (telephone use, groceries, food preparation, housekeeping, laundry, transportation, medication and finances) with three answer categories (not able, able with support, independent). The total score ranged from 8 (completely dependent) to 24 (completely independent).