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Characteristics of the least frail adults with intellectual disabilities: A positive biology perspective

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ABSTRACT

The current study focuses on the characteristics of older people with intellectual disabilities with the lowest frailty levels. Frailty is an increased risk of adverse health outcomes and dependency. Older adults with intellectual disabilities (ID) show more signs of early frailty than the general population. Knowledge of the least frail group characteristics may provide insight into possibilities to prevent early frailty in older people with intellectual disabilities. This study was part of the Healthy Aging and Intellectual Disability study (HA-ID) which incorporated 1050 adults aged 50 years and over with all levels of ID. Frailty was measured with a frailty index. The least frail group was selected based on a frailty index score $\leq$0.10. Odds ratios were used to compare the occurrence of health deficits in the least frail group to the remaining group. The least frail group consisted of 65 participants, corresponding with 6.6% of the study population. The least frail group was significantly younger, had less severe levels of ID, and less often Down syndrome than the remaining group. The lack of mobility and physical fitness limitations, dependence, no signs of depression/dementia, and little medical problems characterized the least frail group. The percentage of 50+ adults with intellectual disabilities within the least frail group is very low compared to that in the general aging population (>43%). Interventions to prevent or delay frailty in this population are highly recommended and can focus on health characteristics of the least frail group.

1. Introduction

Most of today's medical research is concentrated on the question: "What causes pathology?" focusing on the understanding of disease causes and the invention of new therapies is considered the so-called 'negative biology'. Controversially, 'positive biology' aims at understanding why some people age without the diseases and problems that many others suffer from. This perspective receives far less attention, although it could offer more insight in successful aging and generate a greater health benefit for the older adults than would eliminating one specific disease (Farrelly, 2012). A useful method for understanding the process of aging and healthy aging is frailty. Frailty is a state of increased

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risk of adverse health outcomes, which reflects multisystem physiological changes and is highly associated with age (Abellan van Kan et al., 2008). A recent study showed that very high levels of frailty (deficit accumulation) were found in older people with intellectual disabilities (ID; Schoufour, Mitnitski, Rockwood, Evenhuis, & Echteld, 2013). The current paper adopts a positive biology perspective by analysing the characteristics of older people with ID with the lowest frailty levels.

There are several methods for measuring frailty. One widely used approach is the frailty index (Mitnitski, Mogilner, & Rockwood, 2001). The frailty index is based on a non-specific accumulation of deficits in several health domains. Deficits are defined as diseases, symptoms, disabilities, laboratory results or health related questionnaires and must cover a range of systems. A frailty index score (FI-score) is calculated by dividing the sum of deficits present by the total number of deficits measured, resulting in a score between 0 and 1 (Searle, Mitnitski, Gahbauer, Gill, & Rockwood, 2008). The FI-score is highly associated with the risk of deterioration of health, dependence, and hospital admission, and frail people have decreased life expectancies (Rockwood & Mitnitski, 2007).

Recently, we developed a frailty index for older adults with ID (Schoufour et al., 2013) based on data collected in the Healthy Aging and Intellectual Disability study (HA-ID), a cross-sectional study performed in 1050 participants aged 50 years and over in The Netherlands (Hilgenkamp et al., 2011a; Hilgenkamp, van Wijck, & Evenhuis, 2011b). In addition to general aging problems adults with ID have an increased risk of motor and sensory disabilities, chronic diseases (e.g. epilepsy), and mental health problems (Evenhuis, Henderson, Beange, & Chicoine, 2001; Meuwese-Jongejeugd et al., 2006; Splunder van, Stilma, Bernsen, & Evenhuis, 2006). These factors could lead to increased frailty across the lifespan, and in this way to early frailty in older adults with ID. Although the frailty index developed for older adults with ID has not yet shown to be related to negative health outcomes, preliminary data show that average frailty levels are high, and that frailty levels in older adults with ID aged 50 are comparable to frailty levels of older people without ID aged 70 and above. Furthermore it was shown that more severe ID and higher age were associated with an increased frailty score. Frailty in this population is of growing interest, since life expectancy of adults with ID is approaching the general public's life expectancy (Bittles et al., 2002; Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000). The increased life expectancy and the high number of frail people make interventions to prevent or delay frailty urgently required.

In the perspective of positive biology, it would be interesting to know why some adults maintain very low frailty levels at high ages and remain in the so called zero-state – having no measured deficits – for a long time. Previous studies show that roughly 3% (70 years and above; Searle et al., 2008) and 9% (50 years and above; Romero-Ortuno & Kenny, 2012) of the general population can be classified in the zero state. Across the lifespan, these "fit" adults are far less likely to die within 12 years and stay relatively fit over time (Rockwood, Song, & Mitnitski, 2011). Positive biology would promote the use of health information of these fit older people for the prevention of future frailty (Farrelly, 2012). Among participants of the HA-ID study no one was classified in the zero state (Schoufour et al., 2013). However, there are older adults with ID who are relatively fit compared to others in the population. Therefore, in this study we investigated characteristics of the adults scoring lowest on the frailty index. More specifically: Which deficits are found significantly less often in older adults with ID with low FI-scores than in the remaining group?

2. Methods

2.1. Design and setting

In 2008, three Dutch care organizations and two academic departments (Intellectual Disability Medicine, Erasmus MC Rotterdam; Center for Human Movement Sciences, UMCG Groningen) started a large cross-sectional study titled 'Healthy Aging and Intellectual Disability' (HA-ID), to establish the general health status in older adults (50 years and over) with ID in the Netherlands. The present study is part of the secondary analysis of the HA-ID study. Three themes were chosen: physical activity and fitness, nutrition and nutritional state, and mood and anxiety. Within these themes a broad diagnostic assessment was conducted including physical fitness tests which were performed by physiotherapists, physical activity instructors or occupational therapists who were trained during a two-day course and all experienced in working with people with ID, and questionnaires, which were completed by the professional care givers or if applicable by self-report. IQ scores, Vineland scores and social emotional development were used to determine the level of ID by psychologists or test assistants. Data were collected between February 2009 and July 2010. Detailed information has been published elsewhere (Hilgenkamp et al., 2011a). 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.

2.2. Participants

The participating care organizations are located in the middle, southern and western part of the Netherlands. The three care organizations together had 2322 clients with borderline to profound ID aged 50 years and over, who were all invited to participate. The total number of people that actually participated was 1050. The study population is nearly representative for the Dutch population using formal care for adults with ID aged 50 and above, with a slight underrepresentation of men ($X^2(1, N = 2322) = 0.53$, $p = .03$), people aged 80 and above ($X^2(8, N = 2322) = 27.41$, $p = .001$), and people living independently ($X^2(3, N = 2237) = 50.55$, $p < .001$; Hilgenkamp et al., 2011b).