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Development of a frailty index for older people with intellectual disabilities: Results from the HA-ID study

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ABSTRACT

Background: Although there is no strict definition of frailty, it is generally accepted as a state of high vulnerability for adverse health outcomes at older age. Associations between frailty and mortality, dependence, and hospitalization have been shown. We measured the frailty level of older people with intellectual disabilities (ID). Furthermore variation in gender, age, and level of ID were identified. Results were compared to a frailty study in the general European population.
Methods: This research elaborates on a large cross-sectional study: Healthy Ageing with Intellectual Disability (HA-ID). Nine hundred-eighty-two men and women (≥50 yr) with ID were included. Based on the collected data, we developed a frailty index with 51 health-related deficits, and calculated a frailty index score between 0 and 1 for each individual. Deficits included physical, social and psychological problems.
Results: The mean frailty index score was 0.27 (standard deviation .13). Frailty was positively correlated with age ($r = 0.297$, $p < .001$). More severe ID was associated with higher frailty scores ($\beta = 0.440$, $p < 001$). The upper limit of the FI was 0.69, which was consistent for all age categories.
Conclusion: As people with ID are getting older, the question whether additional years are spent in good health becomes salient. Here, people with ID over age 50 had frailty scores similar to most elderly people over 75 y. Future research is needed to confirm if frail elderly people with ID have an increased risk of adverse health outcomes.

1. Introduction

Although frailty, a state in which older persons are more vulnerable to negative health outcomes, has been extensively studied in the general population, little is known about frailty in people with intellectual disabilities (ID). Frailty in this population might be of major importance, given that people with ID have, in addition to general ageing problems, an increased risk of motor and sensory disabilities, chronic diseases (e.g. epilepsy), and mental health problems (Evenhuis, Henderson, Beange, & Chicoine, 2011; Meuwese-Jongejeugd et al., 2006; van Splunder, Stilma, Bernsen, & Evenhuis, 2006). It is therefore plausible that there is an early onset of frailty in this population compared to the general population.

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Furthermore, life expectancy of people with ID is approaching the general public's life expectancy (Bittles et al., 2002; Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000). To be able to prevent or delay frailty in this population, research on frailty in this population is urgently required.

The underlying mechanisms behind frailty are not yet fully understood. While it is well accepted that frailty is a useful construct, there is yet no consensus on how it should be operationalized, nor is there complete consensus on the definition, or on how it should be diagnosed (Rodriguez-Manas et al., 2013). The essential feature is that it is a state of increased risk for adverse health outcomes (Abellan van Kan et al., 2008). Gobbens et al. described frailty 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 increases the risk of adverse outcomes" (Gobbens, Luijkx, Wijnen-Sponselee, & Schols, 2010 (p. 342)) which is in line with prior conceptualizations (Buchner & Wagner, 1992; Rockwood, Fox, Stolee, Robertson, & Beattie, 1994). Associations between frailty and mortality, institutionalization, and dependence have been shown (Fried et al., 2001). Since frailty is a highly age-associated phenomenon (Fried et al., 2001; Mitnitski, Mogilner, & Rockwood, 2001) and the number of older adults increases across the globe (World Health Organisation, 2012), frailty becomes one of the major challenges for health care professionals (Levers, Estabrooks, & Ross Kerr, 2006).

Despite lacking complete consensus, two approaches are broadly accepted in the operational definition of frailty. The first defines frailty as a syndrome, with specific features; the second defines frailty from a multidimensional perspective. The frailty phenotype (Fried et al., 2001) proposes five features, using elements operationalized in the Cardiovascular Health Study (CHS). It classifies people as frail if 3 or more of the following features are present: slow walking speed, impaired grip strength, low activity levels, unintended weight loss, or exhaustion. The phenotypic approach has shown to correlate with adverse health outcomes in wide range of studies in different settings (Shamliyan, Talley, Ramakrishnan, & Kane, 2012). Our research group investigated frailty status of 848 clients of formal ID care, aged 50 years and over, according to these criteria and found that 13% was frail. Among the subgroup aged 50–64 years, the prevalence of frailty (11%) is comparable to that in the general population aged 65 years and over. Frailty in the subgroup aged 65 years and over was 18%, compared to 7–9% in the general population (Evenhuis, Hermans, Hilgenkamp, Bastiaanse, & Echteld, 2012). It has been suggested that frailty measured according to the CHS criteria is highly influenced by low mobility (Rothman, Leo-Summers, & Gill, 2008), which was also found in our study group with ID (Evenhuis et al., 2012). Due to the exclusively physical orientation of the criteria, longstanding motor disability may be misclassified as frailty. It could be that the second perspective to measure frailty, the multidimensional one, is more suitable for this population. This broader concept includes in addition to physiological health also social circumstances and mental health. There are several methods using such a multidimensional perspective, e.g. in the Netherlands, the Tilburg Frailty Indicator (Gobbens, van Assen, Luijkx, & Schols, 2012) and the Groningen Frailty Indicator (Peters, Boter, Buskens, & Slaets, 2012). However such methods based on self-report may be difficult to apply in this population because of limited understanding and communication problems, as well as unidentified health problems (Wilson & Haire, 1990).

Another multidimensional measure for frailty is the frailty index (FI) which is explicit in characterizing frailty not as a syndrome, but as a state. An FI is a quantitative measure based on a concept of non-specific accumulation of a broad spectrum of age-related impairments (deficits), including symptoms, signs, diseases, disabilities or laboratory measurements (Mitnitski et al., 2001; Rockwood & Mitnitski, 2007). A main advantage of the FI is the wide range of deficits which are not merely focused on physical health but also include social circumstances and mental health (Fisher, 2005). A systematic review taking into account 20 different frailty instruments concluded that the only instrument taking all frailty factors (nutritional status, physical activity, energy, strength, cognition, mood, social relations/social support) into account is the FI (de Vries et al., 2011). Frailty indices have been calculated for large older populations in Canada, Australia, Sweden (Mitnitski et al., 2005), China (Goggins, Woo, Sham, & Ho, 2005; Gu et al., 2009), Wales (Hubbard, O'Mahony, Savva, Calver, & Woodhouse, 2009), Mexico (Garcia-Gonzalez, Garcia-Pena, Franco-Marina, & Gutierrez-Robledo, 2009), United Kingdom (Collerton et al., 2012; Lang et al., 2009), Europe (Romero-Ortuno & Kenny, 2012), and the United States (Kulminski, Ukraintseva, Culminskaya, et al., 2008; Kulminski, Ukraintseva, Kulminskaya, et al., 2008; Yang, Rasmussen, & Friedman, 2002). Although these frailty indices were constructed using different datasets, different deficits, and different numbers of deficits (20–130), all were highly associated with early mortality (Mitnitski, Mogilner, MacKnight, & Rockwood, 2002b; Mitnitski et al., 2005; Rockwood & Mitnitski, 2011). High FI scores are related to institutionalization (Jones, Song, Mitnitski, & Rockwood, 2005; Rockwood, Mitnitski, Song, Steen, & Skoog, 2006) and to cognitive decline (Mitnitski, Fallah, Rockwood, & Rockwood, 2011). Frailty indices, designed for different countries, show the same characteristics: a skewed distribution concentrated to the right, a high correlation with age, and a consistent upper limit of the FI Score. Furthermore, Rockwood et al. showed that a random selection of deficits, within any given FI, yields comparable frailty estimates (Rockwood et al., 2006). Several researchers showed that FI-defined frailty predicts adverse health outcomes more precisely than phenotypic-defined frailty (Kulminski, Ukraintseva, Culminskaya, et al., 2008; Kulminski, Ukraintseva, Kulminskaya, et al., 2008; Mitnitski et al., 2011; Rockwood, Andrew, & Mitnitski, 2007). These results indicate a robust relation between deficit accumulation and frailty (Rockwood & Mitnitski, 2011).

For us, an advantage of this method is the relatively free choice of deficits, so an FI can be specified for older adults with ID. Furthermore, the broader approach might be a more valid perspective for this population. Constructing an FI for older people with ID may therefore help to provide insight into the onset and character of frailty and its associated factors in this group.

The main aim of this study was to provide first insight into the accumulation of deficits among older persons with ID. To achieve this objective the following questions needed to be answered.