



The Vienna Frailty Questionnaire for Persons with Intellectual Disabilities—Revised



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ABSTRACT

Frailty is a theoretical concept used to track individual age-related declines. Persons with intellectual disabilities (ID) often present with pre-existing deficits that would be considered frailty markers in the general population. The previously developed Vienna Frailty Questionnaire for Persons with ID (VFQ-ID) was aimed at assessing frailty in this specific population. However, findings of the initial frailty study in 2007 revealed some weaknesses. This paper reports on the development of the Vienna Frailty Questionnaire for Persons with ID – Revised (VFQ-ID-R) as well as its first application and psychometric evaluation. The authors re-administered the VFQ-ID-R to participants with ID who had been assessed with the VFQ-ID in 2007. The goal was to study the factor structure and reliability of the revised test. Internal consistency of the VFQ-ID-R was found to be very good for the entire scale and was moderate for the four domains of the scale. Inter-rater reliability and retest reliability were found to be good. The revisions made to the VFQ-ID will be useful in assessing and supporting ageing individuals with ID.

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1. Introduction

Frailty is an evolving concept in gerontology research. It is especially useful to track age-related declines on an individual level and to predict adverse health outcomes (Lacas & Rockwood, 2012). Different theoretical approaches to frailty exist. There is neither an official definition nor an agreed-upon way of measuring it (Hogan, MacKnight, & Bergman, 2003; Lacas & Rockwood, 2012; Rockwood, 2005). Most theories of frailty focus primarily on physical deficits (Ferrucci et al., 2004; Fried et al., 2001; Romero-Ortuno, Walsh, Lawlor, & Kenny, 2010), while others include broader aspects like mood or social contact (e.g. Ravaglia et al., 2008). One well-known theory is the Frailty Index (FI, Mitnitski, Mogilner, & Rockwood, 2001), which assesses frailty by mere accumulation of different deficits. Although methods for creating an FI were proposed (Searle, Mitnitski, Gahbauer, Gill, & Rockwood, 2008), the deficits chosen for the computation of an FI are not relevant for predicting adverse health outcomes (Mitnitski, Song, & Rockwood, 2004). They can even be chosen randomly (Rockwood, Andrew, & Mitnitski, 2007).

Persons with ID often present pre-existing deficits, which are in turn considered frailty markers in the general population (e.g., deficits in the *Activities of Daily Living*, ADL). Thus, the premorbid level of frailty-related deficits in persons with ID differs compared to the general population. This can bias the measurement of frailty, e.g., the computation of an FI in persons

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with ID. Using methods that were designed for the general population in persons with ID can lead to flawed results. This argumentation is comparable to the discussion on diagnosing dementia in persons with ID. There it is widely accepted that instruments for the general population are not suitable for persons with ID due to their differing premorbid level (e.g. Nieuwenhuis-Mark, 2009; Prasher, Farooq, & Holder, 2004). Just like diagnostic tools for dementia, frailty instruments need to be specially designed in order to gain accurate results.

The issue of adapting existing frailty measurement tools has already been addressed (Brehmer & Weber, 2010) and consequently an instrument to assess frailty in the ID population was designed; the *Vienna Frailty Questionnaire for Persons with ID* (VFQ-ID). This questionnaire focuses on changes in specific aspects and not on the mere existence of deficits, which makes it applicable for all persons with or without ID, irrespective of their premorbid level of frailty-related deficits.

The VFQ-ID was first used 2007 on 190 persons with ID and its psychometric properties were examined (Brehmer & Weber, 2010). Some weaknesses related to its content and to the method of conduction were revealed in the process. The aim of the present study was to redefine and improve the VFQ-ID by describing and reflecting on these encountered weaknesses and to introduce the VFQ-ID-Revised (VFQ-ID-R). This paper reports on the first application of the VFQ-ID-R and its psychometric evaluation. We report on structural validity and reliability measures of the new instrument. Furthermore, this study will give an example to demonstrate the use of the VFQ-ID-R in practice as a useful instrument to track age-related decline in persons with ID.

2. Material and methods

2.1. Participants

All persons ($n = 190$), who had participated in the first frailty study (Brehmer & Weber, 2010), were contacted and invited to the follow up study. Out of these, 43 persons denied participation due to the following reasons: (a) 24 persons did not want to be interviewed again, (b) ten persons could not be contacted for various reasons (e.g. moved to another province of Austria), (c) four persons could not participate due to their deteriorated health status, (d) the caregivers of three respondents with ID decided not to take part without giving any reasons, (e) one person died, and (f) one interview set was not returned by the informant. The final sample of this follow-up consisted of 147 persons with ID, including 69 women (46.9%; see Table 1).

The age range was 20–72 years ($M = 43$). Regarding living arrangements, 61.9% ($n = 91$) lived in an institution or group home and 38.1% ($n = 56$) either lived alone or with their family. Nearly two thirds (64.6%; $n = 95$) of the sample was living in an urbanised area and 35.4% ($n = 52$) in a rural area. With respect to support required, 108 persons with ID (73.5%) were able to speak for themselves during the interview. Only 39 caregivers (26.5%) had to speak for their clients, who could not communicate verbally. Following the recommendation of the ethics committee for the first frailty study, once again we did not objectively measure the level of ID to keep the respondents load low and the conduction rather simple, but asked for records on previous ID testing. This information on ID diagnosis in addition to the main carer's appraisal of the intensity of support needed by the participant with ID in the ADLs was used to estimate the participant's ID level. The coding of mild and moderate ID equals low intensity of support in the ADLs, whereas severe and profound ID equals high intensity of support and a respective diagnosis (see Table 1). The sample parameters (age, living conditions, level of ID and sex) are similarly distributed compared to the original study by Brehmer and Weber (2010).

To assess *inter-rater reliability*, 17 persons with ID (nine men and eight women) were voluntarily questioned a second time by another interviewer. The mean age of this group was 48 years. 70.6% ($n = 12$) lived in an institution or group home and 29.4% ($n = 5$) either lived alone or with their family. The majority (82.4%; $n = 14$) were living in an urbanised area and only three persons (17.6%) in a rural area. All persons were able to speak for themselves.

To explore *retest reliability* of the final VFQ-ID-R, another 17 persons, including ten women, were questioned again four weeks after the first interview. The mean age of this sample was 41 years. A total of 76.5% ($n = 13$) resided in an institution or group home and 23.6% ($n = 4$) either lived alone or with their family. 82.4% ($n = 14$) were living in an urbanised area and 17.6%

Table 1
Sample characteristics.

| Age | Mild/moderate ID ($n = 114$) | | | | Severe/profound ID ($n = 33$) | | | |
|-------|--------------------------------|---------------------|--------------------|---------------------|---------------------------------|--------------------|--------------------|--------------------|
| | Urban ($n = 72$) | | Rural ($n = 42$) | | Urban ($n = 23$) | | Rural ($n = 10$) | |
| | IS ($n = 44$) | Non IS ($n = 28$) | IS ($n = 23$) | Non IS ($n = 19$) | IS ($n = 21$) | Non IS ($n = 2$) | IS ($n = 3$) | Non IS ($n = 7$) |
| 20–29 | 7 | 8 | 2 | 2 | 4 | 2 | – | 5 |
| 30–39 | 12 | 6 | 1 | 3 | 5 | – | 1 | 1 |
| 40–49 | 13 | 11 | 6 | 7 | 6 | – | 1 | 1 |
| 50–59 | 5 | – | 8 | 4 | 5 | – | – | – |
| 60+ | 7 | 3 | 6 | 3 | 1 | – | 1 | – |

Note. Mild/moderate ID equals low intensity of support. Severe/profound ID equals high intensity of support. IS illustrating figures for persons living in institutional settings (e.g. group homes) and Non IS illustrating figures for persons in non-institutionalised settings (e.g. living with family members or independently).

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