

# Determining Frailty in People With Intellectual Disabilities in the COVID-19 Pandemic

Dederieke A. M. Festen\* , Josje D. Schoufour† , Thessa I. M. Hilgenkamp\*<sup>‡</sup> , and Alyt Oppewal\* 

\*Erasmus MC University Medical Center Rotterdam, Rotterdam, the Netherlands; †Amsterdam University of Applied Sciences, Amsterdam, the Netherlands; and ‡University of Nevada, Las Vegas, Las Vegas, NV, USA

## Abstract

**Background:** Across the world, frailty is part of the guidelines that are being developed in the COVID-19 pandemic for triaging in crisis situations. The Clinical Frailty Scale (CFS) evaluates the ability to perform daily tasks to identify frail individuals, potentially excluding those from intensive care (IC) treatment. Individuals with intellectual disabilities (ID) experience varying degrees of dependence, distinct from age-related physical deterioration. Using the CFS for triage in crisis situations could potentially unjustifiably exclude individuals with ID from IC treatment. Our objective was to compare the classification of individuals with ID into different frailty categories based on the CFS and the well-studied ID-frailty index and to determine suitability of CFS for evaluation of frailty in individuals with ID during the COVID-19 pandemic.

**Methods:** This retrospective analysis of the observational healthy aging and intellectual disabilities (HA-ID) study included 982 individuals with ID of  $\geq 50$  years, who were classified according to the CFS and the ID-frailty index.

**Results:** Of the cohort of 982 older adults with ID, 626 (63.7%) would be classified as moderately frail (CFS score 6), but 92% of this group is not moderately frail according to the ID-frailty index. Furthermore, 199 (20.3%) would be classified as at least severely frail (CFS score 7–9), but 74.9% of this group is not severely frail according to the ID-frailty index. Overall, 730 out of 982 (74.9%) individuals would be incorrectly classified by the CFS as too frail to have a good probability of survival. The ID-frailty index predicts mortality better than the CFS in individuals with ID.

**Conclusions:** Our results show the CFS is not suitable to evaluate frailty in individuals with ID, with potential dramatic consequences for triage and decision-making during the COVID-19 pandemic. We strongly recommend using the ID-frailty index when assessing probability of survival for individuals with ID.

**Keywords:** COVID-19, frailty, intellectual disabilities, triage

## Background

For individuals with intellectual disabilities (ID), a referral to the hospital always involves careful weighing of the benefits and the costs of the referral and further treatment, before and during the COVID-19 pandemic. This process involves not just the patient, but his/her family members and the medical/health professionals involved in the patient's care. Across the world, various guidelines are being drafted and implemented in the COVID-19 pandemic to provide criteria for triaging in crisis situations when a lack of supplies, equipment, and/or personnel limits the ability to help everybody (White & Lo, 2020). Most of these frameworks include some type of estimation of the benefits of the treatment to the patient ("incremental probability of survival" defined as the "probability of survival with intensive care (IC) treatment" minus "probability of survival without IC treatment") as well as the life expectancy (Christian et al., 2014).

One of the criteria included to assess life expectancy is advanced age and/or frailty, with those being moderately or severely frail potentially being excluded from IC treatment in crisis situations. One of the measures often used to determine frailty is the Clinical Frailty Scale (CFS) (Rockwood et al., 2005), with a score of 7–9 for the severely frail and a score of 6 for the moderately frail. The classification of the CFS is largely dependent on the ability to independently perform activities in daily living, which is a precursor of morbidity and mortality in the general (aging) population. However, the CFS has not been investigated specifically in individuals with ID who often experience varying levels of lifelong dependence in activities of daily living due to their ID. This dependence is not related to physical deterioration and likely does not predict mortality in the same way it does in the general population. Measuring their frailty and their probability of survival with the CFS would therefore likely incorrectly classify them as being too frail to receive IC treatment.

As one of the largest epidemiological studies on health in aging adults with intellectual disabilities, the HA-ID study (Hilgenkamp et al., 2011) provided the necessary data to develop a Frailty Index specifically for this population (the ID-frailty index) (Schoufour, Mitnitski, Rockwood, Evenhuis, &

Received May 18, 2020; accepted December 2, 2020

Correspondence: Dederieke A. M. Festen, Department of General Practice, Erasmus MC University Medical Center Rotterdam, P.O. box 2040, 3000 CA Rotterdam, the Netherlands. Tel: +311107032123 (office)/+31610919132 (cell). E-mail: d.maes-festen@erasmusmc.nl

© 2021 The Authors. *Journal of Policy and Practice in Intellectual Disabilities* published by International Association for the Scientific Study of Intellectual and Developmental Disabilities and Wiley Periodicals LLC

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

Echteld, 2013). This ID-frailty index includes items across different domains of health that do predict morbidity and mortality in individuals with ID (Schoufour, Mitnitski, Rockwood, Evenhuis, & Echteld, 2015). A main advantage of the ID-frailty index is the wide range of deficits, which are not merely focused on physical health but also include social circumstances and mental health (Fisher, 2005). Frailty and predictive validity of the ID-frailty index was investigated in 982 older adults with ID following this cohort for 3 years. The ID-frailty index was predictive of a decline in daily functioning, mobility, increase in medication use, increased support needs and mortality (Schoufour et al., 2014; Schoufour, Echteld, Bastiaanse, & Evenhuis, 2015; Schoufour, Evenhuis, & Echteld, 2014; Schoufour, Mitnitski, et al., 2015).

The goal of this article was to compare the classification of individuals with ID into different frailty categories based on the CFS and the ID-frailty index and to investigate whether the CFS would incorrectly classify people with ID as being too frail as part of the evaluation of the “probability of survival” in individuals with ID during the COVID-19 pandemic. This is especially urgent for people with ID because of their high risk for infection due to difficulties with social distancing. They are depending on others for care and support in their daily lives, and frequently live together with other individuals with ID in larger homes or apartments. Additionally, it is harder for them to understand the situation and to follow the hygiene and distancing guidelines, which then increases the risk of infection for them and the people they live and work with.

**Methods**

In this retrospective analysis, we calculated frailty scores using the CFS (Rockwood et al., 2005) and the ID-frailty index (Schoufour et al., 2013) for the original cohort of 982 aging adults with ID (aged 50 years and over) of the HA-ID study (data collected during 2009–15, recruitment and participant characteristics described elsewhere (Hilgenkamp, Bastiaanse, et al., 2011, Schoufour et al., 2013)). We used the previously collected baseline data on the ability to perform activities of daily living in the sample to classify the individuals with ID according to the CFS (Hilgenkamp, van Wijck, & Evenhuis, 2011). This baseline data was collected with the Barthel Index for Activities

of Daily Living and the Lawton’s Instrumental Activities of Daily Living Scale, completed by the professional caregiver involved in the support of the individual with ID (Hilgenkamp, van Wijck, & Evenhuis, 2011). Scoring and classification were performed according to the published guidelines for the CFS (Rockwood et al., 2005). Information on psychometric properties of both instruments, including cut-off scores, sensitivity, specificity and Area Under the Curve to predict mortality in people with ID (ID-frailty index) and in the general population (CFS) has been reported previously (Rockwood et al., 2005; Schoufour, Mitnitski, et al., 2015). For the purposes of this investigation and the relevance to the decision-making about whether or not to provide IC treatment, we categorized the individuals in three groups: a CFS score lower than 6, a CFS score of 6 (considered moderately frail in the CFS) and a CFS of 7 or higher (considered severely frail in the CFS). To classify the individuals with ID according to the ID-frailty index, we divided our sample into relatively fit and prefrail (ID-frailty index score < 0.19 for relatively fit, and ID-frailty index score 0.2–0.29 for prefrail), mildly frail (ID-frailty index score 0.3–0.39), moderately frail (ID-frailty index score 0.4–0.49), and severely frail (ID-frailty index score ≥ 0.5). This categorization of scores on the ID-frailty index is related to an increasing mortality risk in aging adults with ID (as has been reported previously) (Schoufour, Mitnitski, et al., 2015). Since no data are available to determine whether the CFS is not suitable to evaluate the “probability of survival” in individuals with ID, we additionally assessed the predictive value for 5-year survival with Cox proportional hazard models, adjusted for age, sex, level of ID, and Down syndrome. Hazard ratios (HR) for mortality were calculated for the ID-frailty index and the CFS in separate models. We calculated HR using the Cox proportional hazard model. A HR of 1.93 can be interpreted as; the chance to die at any time point during the follow-up period (5 years) is almost two times as high for pre-frail elderly than for relatively fit elderly. Additionally, a comparative analysis was performed by including both instruments in one model.

**Results**

Of the total cohort of 982 older adults with ID, 626 (63.7%) would be classified as moderately frail (CFS 6) according to the

TABLE 1  
Comparison of the classification of older adults with intellectual disabilities with the Clinical Frailty Scale (CFS 6 and CFS 7–9) and the ID-frailty index in *n* (%)

		Clinical Frailty Scale			Total
		< CFS 6	CFS 6	≥CFS 7	
ID-Frailty index	Relatively fit	120 (76.4%)	<b>204 (32.6%)</b>	<b>1 (0.5%)</b>	325 (33.1%)
	Prefrail	32 (20.4%)	<b>242 (38.7%)</b>	<b>5 (2.5%)</b>	279 (28.4%)
	Mildly frail	4 (2.5%)	<b>135 (21.6%)</b>	<b>53 (26.6%)</b>	192 (19.6%)
	Moderately frail	1 (0.6%)	39 (6.2%)	<b>90 (45.2%)</b>	130 (13.2%)
	Severely frail	0	6 (1.0%)	50 (25.1%)	56 (5.7%)
	Total	157 (16.0%)	626 (63.7%)	199 (20.3%)	982 (100%)

TABLE 2

Hazard ratios for 5-year all-cause mortality according to the ID-frailty index and the Clinical Frailty Scale

Frailty measure	Status	n	Single frailty instrument		Both frailty instruments	
			HR (95% CI)	Wald	HR (95% CI)	Wald
CFS	<CFS 6	155	Reference		Reference	
	CFS 6	608	1.81 (0.97–3.38)	3.41	0.99 (0.51–1.95)	0.0
	≥CFS 7	198	8.71 (4.46–17.02)	40.07**	1.57 (0.72–3.45)	1.28
ID-Frailty index	Relatively fit	320	Reference		Reference	
	Prefrail	271	1.93 (1.08–3.45)	4.89*	1.96 (1.08–3.56)	4.84*
	Mildly frail	185	5.38 (3.06–9.46)	34.28**	4.96 (2.70–9.12)	26.65**
	Moderately frail	129	13.10 (7.46–23.0)	80.32**	10.23 (5.35–19.57)	49.37**
	Severely frail	56	22.85 (12.37–42.21)	99.89**	16.21 (7.87–33.37)	57.10**

All models were adjusted for age, sex, level of intellectual disability, and Down syndrome.

\* $p < 0.05$

\*\* $p < 0.001$

CFS, Clinical Frailty Scale; CI = confidence interval; HR = hazard ratio; n = number of participants per category.

CFS (see Table 1). Of this group, 32.6% are relatively fit according to the ID-frailty index, 38.7% are prefrail and 21.6% are only mildly frail. This means that 92% of this group would be incorrectly classified as moderately frail.

Of the total cohort of 982 older adults with ID, 199 (20.3%) would be classified as at least severely frail according to the CFS (CFS score 7–9). Of this group, only 25.1% is severely frail according to the ID-frailty index, which means that 74.9% would be incorrectly classified as severely frail.

Overall, 730 out of 982 (74.9%) individuals would be incorrectly classified as too frail to have a good probability of survival while they are in fact not moderately or severely frail (shown in bold in Table 1).

Table 2 presents the HR for 5-years all-cause mortality for individuals with ID classified according to the CFS and the ID-frailty index. These results show that the ID-frailty index predicts mortality more accurately than the CFS, and when both measures are combined in the same model to predict mortality, the CFS has no significant contribution in predicting mortality.

## Discussion

Our results show that the CFS is not suitable to evaluate frailty in individuals with ID, with potential dramatic consequences for triage and decision-making during the COVID-19 pandemic. The CFS, and other frailty measures that rely heavily on independence in daily functioning, dramatically overestimate frailty in individuals with ID, as their dependence in daily living skills is not related to physical deterioration and mortality. We propose the use of the ID-frailty index, developed specifically for (older) adults with ID. Individuals with mild, but especially moderate and severe frailty according to the ID-frailty index have a drastically increased risk of mortality in the next 5 years. Based on these results, and for the purpose of quick and efficient triage, we then shortened the ID-frailty index to a 17-item scale, which explains 89% of the variance of original 51-item version.

We are currently investigating its psychometric properties and are aiming to disseminate those results as quickly as possible. We strongly recommend the use of this ID-frailty index when calculating the probability of survival for individuals with ID during the COVID-19 pandemic.

## Acknowledgment

This study was carried out with the financial support of The Netherlands Organization for Health Research and Development (ZonMw) (nos. 57000003 and 314030302).

## Conflict of interest

None of the authors has any financial, personal, or potential conflict of interest.

## Author contributions

D.A.M.F.: initiated this investigation, oversaw the analyses, wrote parts of the paper and commented on drafts of the paper, J.D.S.: acquired the follow-up data, developed the Frailty Index, wrote parts of the paper and commented on drafts of the paper, T.I.M.H.: wrote the manuscript, commented on analyses, A.O.: performed analyses, wrote parts of the paper and commented on drafts of the paper.

## Ethics Statement

Ethical approval was obtained (MEC 2008-234 and MEC 2011-309) from the Ethics Committee of the Erasmus University Medical Center in Rotterdam. The study followed the guidelines of the Declaration of Helsinki.

## References

- Christian, M. D., Sprung, C. L., King, M. A., Dichter, J. R., Kissoon, N., Devereaux, A. V., Gomersall, C. D., Task Force for Mass Critical Care; (2014). Triage: Care of the critically ill and injured during pandemics and disasters: CHEST consensus statement. *Chest*, 146, e61S–e74S.
- Fisher, A. L. (2005). Just what defines frailty? *Journal of the American Geriatrics Society*, 53, 2229–2230.
- Hilgenkamp, T. I., Bastiaanse, L. P., Hermans, H., Penning, C., van Wijck, R., & Evenhuis, H. M. (2011). Study healthy ageing and intellectual disabilities: Recruitment and design. *Research in Developmental Disabilities*, 32, 1097–1106.
- Hilgenkamp, T. I., van Wijck, R., & Evenhuis, H. M. (2011). (Instrumental) activities of daily living in older adults with intellectual disabilities. *Research in Developmental Disabilities*, 32, 1977–1987.
- Rockwood, K., Song, X., MacKnight, C., Bergman, H., Hogan, D. B., McDowell, I., & Mitnitski, A. (2005). A global clinical measure of fitness and frailty in elderly people. *Canadian Medical Association Journal*, 173, 489–495.
- Schoufour, J. D., Echteld, M. A., Bastiaanse, L. P., & Evenhuis, H. M. (2015). The use of a frailty index to predict adverse health outcomes (falls, fractures, hospitalization, medication use, comorbid conditions) in people with intellectual disabilities. *Research in Developmental Disabilities*, 38C, 39–47.
- Schoufour, J. D., Evenhuis, H. M., & Echteld, M. A. (2014). The impact of frailty on care intensity in older people with intellectual disabilities. *Research in Developmental Disabilities*, 35, 3455–3461.
- Schoufour, J. D., Mitnitski, A., Rockwood, K., Evenhuis, H. M., & Echteld, M. A. (2013). Development of a frailty index for older people with intellectual disabilities: Results from the HA-ID study. *Research in Developmental Disabilities*, 34, 1541–1555.
- Schoufour, J. D., Mitnitski, A., Rockwood, K., Evenhuis, H. M., & Echteld, M. A. (2015). Predicting 3-year survival in older people with intellectual disabilities using a Frailty Index. *Journal of the American Geriatrics Society*, 63, 531–536.
- Schoufour, J. D., Mitnitski, A., Rockwood, K., Hilgenkamp, T. I., Evenhuis, H. M., & Echteld, M. A. (2014). Predicting disabilities in daily functioning in older people with intellectual disabilities using a frailty index. *Research in Developmental Disabilities*, 35, 2267–2277.
- White, D. B., & Lo, B. (2020). A framework for rationing ventilators and critical care beds during the COVID-19 pandemic. *Journal of the American Medical Association*, 323, 1773–1774.