Journal on Developmental Disabilities
Le journal sur les handicaps du développement
JoDD
Volume 24, Number 2, 2019

Applying the HC-IDD Frailty Index to Developmental Services Agency Chart Data

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Keywords

frailty,
intellectual and developmental disabilities,
developmental services

Abstract

Frailty is a common geriatric syndrome experienced by adults with intellectual and developmental disabilities (IDD) earlier than those without IDD. Measurement of frailty in this population is crucial to inform care planning aimed at preventing adverse outcomes. This study sought to determine whether frailty could be measured based on information documented in developmental services agency charts and how chart-derived scores performed compared to a validated frailty measure developed for adults with IDD who receive home care. Records from a developmental services agency were reviewed for the presence of deficits indicated in the Home Care – Intellectual and Developmental Disabilities Frailty Index (HC-IDD FI). Only 13 of the 42 HC-IDD FI deficits met the inclusion criteria to create a chart-derived score. In the developmental services sample (n = 170), the chart-derived score was associated with age, level of IDD, living arrangement, and hospitalization in the subsequent year, but not with sex. Poor agreement between the HC-IDD FI and scores derived from items captured in charts was observed in a sample of 106 home care recipients with IDD. Assessing frailty among aging adults with IDD using developmental services agency records requires the systematic recording of changes in function to account for the dynamic nature of frailty.

Frailty is an age-associated clinical syndrome characterized by elevated risk of adverse health outcomes, such as disability, institutionalization, morbidity and mortality (Evenhuis, Schoufour, & Echteld, 2013), increased care intensity, and health care costs (Schoufour, Evenhuis, & Echteld, 2014). There are two main approaches to measuring frailty: the phenotype approach (Fried et al., 2001) and the accumulation of deficits approach (Rockwood & Mitnitski, 2007). The phenotype approach identifies frailty as the presence of at least three of the following characteristics: weight loss, weakness, exhaustion, low physical activity, and slowness, while the accumulation of deficits approach considers the proportion of deficits (e.g., decline in function, medical diagnoses, social isolation) present, rather than specific symptoms. Regardless of the measurement approach, frailty has been shown to develop significantly earlier on average in individuals with intellectual and developmental disabilities (IDD) compared to the general population (Evenhuis et al., 2013; McKenzie, Ouellette-Kuntz, & Martin, 2017; Schoufour, Mitnitski, Rockwood, Evenhuis, & Echteld, 2013). As a result of the increasing life expectancy among individuals with IDD (Thorpe, Davidson, & Janicki, 2000), frailty is predicted to become a major healthcare challenge in this population.

Thus far, four groups of researchers have developed frailty measures specifically for adults with IDD (McKenzie, Martin, & Ouellette-Kuntz, 2016). The Home Care-IDD Frailty Index (HC-IDD FI) was developed by McKenzie, Ouellette-Kuntz and Martin (2015) using an accumulation of deficits approach based on items reported in the RAI-Home Care assessment instrument (Morris et al., 2009), which is used as part of regular clinical practice across Ontario's home care sector. The HC-IDD FI includes 42 deficits that span five domains (i.e., physiological, psychological, cognitive, social, and service use), and is associated with age, health status (McKenzie et al., 2015), and admission to long-term care (McKenzie, Ouellette-Kuntz, & Martin, 2016). The score is calculated by dividing the number of deficits present by the number of deficits measured, and then categorized into non-frail (score < 0.21), pre-frail (score = 0.21–0.30), and frail (score > 0.30). Additional details on the development of the HC-IDD FI and categories is provided in McKenzie et al. (2015). The HC-IDD FI has also been shown to improve the ability to predict admission to long-term care or death among home care users with IDD (Ouellette-Kuntz, Stankiewicz, McIsaac, & Martin, 2018).

In Ontario, responsibility for supporting adults with IDD in the community (for example, through residential services, day programs, and employment supports) lies with the developmental services sector, not the health care sector. However, just as in the general population, adults with IDD may experience health conditions or health events that have an impact on their ability to remain in the community. In Ontario and elsewhere, a focus on aging in place has meant that home care services are used to assist individuals in their home through provision of nursing care, homemaking support, meal support, and therapies. Ontarians with IDD, whether they live in their own home, family home, or group home, are also eligible to receive home care services. As use of the RAI-HC assessment is restricted to those in home care, information on frailty calculated through the HC-IDD FI is available only for a subset of adults with IDD – those assessed for home care services. As assessment of frailty in the developmental services sector could contribute to enhanced care planning and better outcomes in this population, there is a need to measure frailty outside of the home care system. This study aims to do that by: (1) determining if the items from the HC-IDD FI are captured in developmental services sector agency files and produce a chart-derived score; (2) assessing the relationship between the resulting chart-derived score with sociodemographic factors known to be associated with frailty in this population (e.g., age, sex, level of IDD), as well as with hospital admission; and (3) testing the validity of the chart-derived measure through comparison with the HC-IDD FI score in a sample of home care users with IDD.

Method

Ethics approval for this study was provided by the Queen's University Health Sciences & Affiliated Teaching Hospitals Research Ethics Board. All analyses were conducted using SPSS.

Samples

The study is based on a sample of 170 adults with IDD supported by a developmental services agency who were registered residential clients from 2016 to 2017 (i.e., to ensure hospitalization data was available for the subsequent year), and a sample of 106 home care recipients with IDD in Ontario assessed with the RAI-HC. The home care data are held on a secure server at the University of Waterloo and made available to the research team through a data-sharing agreement between the Ontario Ministry of Health and interRAI (i.e., through Dr. Lynn Martin as interRAI Fellow).

Presence of HC-IDD FI Items in Developmental Services Sector Agency Files

A chart review was conducted to identify the presence of the 42 deficits in the HC-IDD FI. Generally, if an item was not present in the chart, it was coded as "missing." Given the participating agency's reporting requirements and policies, missing items related to diagnoses, prescribed medications, hospitalizations, and falls were instead coded as "not present." More specifically, absence of the following were considered to be "not present" rather

than "missing": hospital admission, dementia/Alzheimer Disease, diabetes, arthritis, hypertension, respiratory disease, fall frequency, osteoporosis, hearing impairment, cataract, antidepressant, medications, delirium, coronary artery disease, specific infection, stroke, and circulatory diseases. It was assumed that the absence of health conditions in chart data indicate that the individual was not diagnosed or reported to have the deficit.

As in the development of the HC-IDD FI, deficits had to meet the following inclusion criteria to be retained in the chart-derived measure: no more than 30% of the client files were missing information regarding the deficit, and the deficit was neither too prevalent (i.e., present in more than 80% of clients) nor too rare (present in less than 5% of clients) (Schoufour et al., 2013). A score was then calculated using deficits that met the inclusion criteria (see McKenzie et al., 2015).

Relationship Between the Chart-Derived Score, Sociodemographic Factors, and Hospital Admission

Using a cross-sectional study design, the chart-derived score was tested for its association with age (Spearman's rank correlation coefficient), sex (Mann Whitney U Test), living arrangement (i.e., group home vs. host family; Mann Whitney U Test), and level of IDD (Spearman's rank correlation coefficient and Kruskal Wallis Test).

A retrospective cohort approach was used to test the association between the chart-derived score and hospitalization in the subsequent year (Mann Whitney U Test).

Validity of the Chart-Derived Measure in a Sample of Home Care Users with IDD

The HC-IDD FI and chart-derived scores were both computed in the home care sample to determine the convergent validity (i.e., correlation) between the two scores, using the concordance correlation coefficient (Lin, 1989).

Results

Sample Characteristics

Of the 170 clients from the developmental services agency, the majority lived in a group home (77.6%) while the others lived with a host family. Clients' ages ranged between 19.8 and 86.4 years (M = 51.9 years), and 51.2% were men. Approximately a third had a mild to moderate level of IDD (32.9%) and 40.6% had a severe to profound level of IDD; the level of IDD was not indicated in 26.5% of the charts reviewed. Although not statistically significant, those living in host family settings were slightly younger (M = 48.8 years vs. 52.8 years in group homes, p = .13). There was an association between the type of living arrangement and level of IDD (p < .001) with half of adults living in group homes (50.8%) having a severe to profound level of IDD compared to only 5.3% of those living with a host family.

Presence of HC-IDD FI Items in Developmental Services Sector Agency Files

Only 13 of the 42 deficits in the HC-IDD FI met the inclusion criteria: hospital admission, dementia/Alzheimer disease, diabetes, arthritis, hypertension, respiratory disease, fall frequency, osteoporosis, hearing impairment, cataract, stamina, antidepressant use, and medication use (see Table 1 on the following page). Twenty-two deficits were excluded based on missing data, and seven were excluded as they were too rare (see Table 2 on p. 47). The scores derived from these 13 items, shown in Table 1, ranged from 0 to 0.58 (M = 0.19).

Relationship Between the Chart-Derived Score, Sociodemographic Factors, and Hospital Admission

There was a moderate positive correlation between the chart-derived score and age, $r(168) = 0.43$, p < .001, and a weak positive correlation with level of IDD, $r(168) = 0.22$, p = .002. Specifically, individuals with a severe/profound level of IDD had a significantly higher score compared to those with an unknown level of IDD (Mdn = 0.19 vs. Mdn = 0.12,

Table 1. Breakdown of Chart Abstraction Results for 13 Included Deficits in the Developmental Services Agency Sample (n = 170)

Included Deficits	*Present (percent)*
Medications (4 or more within the last 7 days)	70.6
Osteoporosis	29.4
Cataract	23.5
Antidepressant (use within the last 7 days)	18.8
Hearing Impairment	17.0
Hypertension	15.3
Arthritis	12.4
Fall Frequency (more than 1 fall in the last 90 days)	9.4
Diabetes	8.8
Respiratory Disease	7.6
Dementia/Alzheimer Disease	5.3
Hospital Admission (within the last 90 days)	5.3
Stamina (leaving the house less than 6 days a week)	5.3*

**Note: 5.9% of information was missing in the stamina category*

respectively; $p = 0.004$). Living in a group home (*Mdn = 0.19)* was associated with higher scores than living with a host family (*Mdn* = 0.12), $U = 1215.50$, $p < .001$). Scores did not differ by sex ($U = 3165.00$, $p = .163$).

Approximately 18.8% ($n = 32$) of the sample was hospitalized within the year following the measurement of the chart-derived frailty score, with a total of 48 recorded hospitalizations. Higher scores were significantly associated with hospitalization (*Mdn* = 0.19 vs. *Mdn* = 0.15 for not hospitalized, $p = .026$).

Validity of the Chart-Derived Measure in a Sample of Home Care Users With IDD

The sample of 106 home care recipients with IDD were on average 32.1 years old (with ages ranging from 20 to 63 years), which is almost 20 years younger than the average age for the agency sample reported above. As with the agency sample, the majority in the home care sample were men (59.4%). This sample consisted of individuals with varying levels of IDD, however, the level of severity was not reported in the RAI-HC instrument. The HC-IDD FI scores ranged from 0.02 to 0.52 ($M = 0.12$) and the chart-derived scores ranged from 0.00 to 0.37 ($M = 0.11$). There was poor agreement between scores ($r_c = 0.43$) (see Figure 1 on p. 48).

Discussion

This study revealed that most items in the HC-IDD FI were not systematically captured in developmental services agency records. Items excluded due to missing data mostly related to changes in function. Although attention to change in function is likely, there was no systematic approach to ensuring changes or stability in functioning (e.g., dressing ability) are documented in client charts. In the context of frailty assessment, it is important to capture and record small changes.

The deficits that were excluded because of rarity included diseases often associated with increasing age (e.g., delirium, coronary artery disease, stroke, and circulatory diseases). The relative rarity of these deficits could be explained by the fact that the study sample

Table 2. Breakdown of Chart Abstraction Results for 29 Excluded Deficits in the Developmental Services Agency Sample (n = 170)

Excluded Deficits	*Criteria for Exclusion*	
	> 30% Missing	Rare (< 5%)
Changes (Decline/Worsening)	(Percent)	(Percent)
Social Activity (participation)		1.8
Continence	98.2	
Decision Making	97.1	
Communication	94.1	
Mood	91.2	
Overall Care Needs	88.8	
Hygiene/Bathing	82.4	
Toilet Use	79.4	
Dressing	78.8	
Eating	74.7	
Behaviour	68.2	
Unsteady Gait	48.8	
Mobility in Bed	44.1	
Stair Climbing	38.2	
Transfers	35.3	
Locomotion out of Home	32.4	
Diagnoses		
Circulatory Diseases		2.9
Stroke		0.6
Specific Infection		0.6
Coronary Artery Disease		0.4
Delirium		0.0
Other issues/symptoms		
Social Isolation (alone for long periods of time or all of the time)		0.6
Loneliness	100	
Fear of Falling	99.4	
Shortness of Breath	98.8	
Short-term Memory Problem	98.2	
Edema	95.3	
Pain Disruption (disrupts usual activities)	91.2	
Pain Frequency (any pain)	36.5	

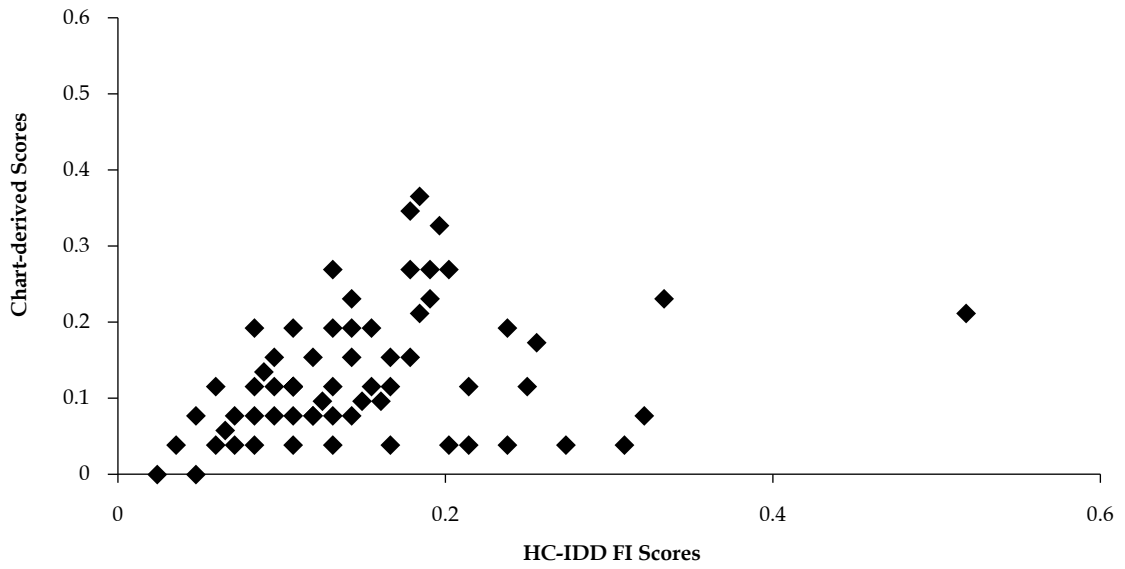

*Figure 1. HC-IDD FI and chart-derived scores concordance plot in the home care sample (n = 106)**

**Note: The chart-derived and HC-IDD FI scores are likely not concordant due in part to the insufficient number of deficits included in the chart-derived score and to the differing demographics in the developmental services and home care sample.*

was younger than the home care cohort used to develop the HC-IDD FI (mean age of 51.9 years compared to 56.2 years in home care) (McKenzie et al., 2015). Social isolation and changes in social activity were also rarely recorded in the charts; this may be unique to the sample where living arrangements (group home and host family) promote group activities and opportunities for socialization.

Despite the limited number of items that met the inclusion criteria, the resulting chart-derived score was associated with age, level of IDD, and living arrangement in the developmental services agency sample, but not with sex. These associations have been previously reported in the literature. Frailty has consistently been shown to increase with age (see, for example, Evenhuis Hermans, Hilgenkamp, Bastiaanse, & Echfeld, 2012), and to be more prevalent among those with more severe levels of IDD (Schoufour et al., 2013). For 26.5% of the developmental services agency sample, however, the level of IDD was not available through the chart review. The extent to which this information may be missing from client charts across the developmental services sector is unknown and the reason for missingness is unclear. A review of the documentation of level of IDD in developmental services agencies may be warranted. The lack of difference in frailty scores by sex has been previously reported by Schoufour and colleagues (2013). However, future research should continue to examine this sex difference and attempt to understand it. While the relationship between frailty and living arrangement has not been extensively explored, an Ontario study found that among a sample of home care users with IDD, those living in group homes were older, more frail, and had more severe levels of IDD than those living elsewhere in the community (Martin, Ouellette-Kuntz, & McKenzie, 2018). In the agency sample, half of the individuals living in group homes had a severe/profound level of IDD compared to around 5% in host family settings; it is therefore not surprising that those in group homes had higher scores. That said, there is a need to further investigate the cause and effect relationship between frailty, level of IDD, and living arrangement.

In the agency sample, the chart-derived score was predictive of hospitalization in the subsequent year. The limited literature in this area has produced contradictory results: some have reported that frailty is a significant predictor of hospitalization, with frail and pre-frail indi-

viduals having a higher risk of hospitalization (Kojima, 2016), though others have reported no significant relationship (Schoufour, Echteld, Bastiaanse, & Evenhuis, 2015).

The poor agreement between the chart-derived and HC-IDD FI scores in the home care sample can be mainly attributed to the paucity of deficits included in the chart-derived score. Previous research has recommended a minimum of 30 to 40 items for a reliable frailty index (Searle, Mitnitski, Gahbauer, Gill, & Rockwood, 2008); relying on only 13 items to measure frailty is therefore not recommended. Most retained deficits related to diagnoses rather than everyday function – as such, the 13-items may not be sensitive to change in status or capture the dynamic nature of frailty.

This study has a number of strengths including the evaluation of all residential clients within a developmental services agency, consisting of a diverse group of clients with a wide age range, and use of a validated frailty measure. Agency charts also had designated areas for documenting diagnoses and incidents (ex. falls and hospitalizations), which helped to clarify that the missingness of certain deficits indicated that they were not present rather than truly missing.

However, this study is not without limitations. The study was limited to a single agency, and additionally restricted to residential clients as they were thought to have more complete files (for example, compared to individuals supported in day programs only). Consequently, the chart-derived measure may not be generalizable to other agencies or other types of clients. Other agencies may also have different record keeping practices, which may result in identification of more or fewer frailty deficits. While it is thought that the discordance between the chart-derived and HC-IDD FI scores is mainly attributable to the small number of deficits contributing to the chart-derived score, inherent differences between the two samples may have also played a role. In particular, the home care sample had a younger mean age, and a greater proportion of males compared to the developmental services agency sample. It also was not possible to evaluate the level of IDD severity and living arrangements in the home care sample.

Based on the findings from this and previous studies (e.g., Searle et al., 2008), reliance on 13 items to measure frailty is not recommended. The dynamic nature of frailty necessitates the recording of deficits across multiple frailty domains, especially those related to functional changes. In order to understand the generalizability of the current study findings, the application of the HC-IDD FI to charts from other agencies is needed to ensure the HC-IDD FI is a measure of frailty that developmental services agencies can use. Other outcomes associated with frailty (for example, admission to long-term care, falls, and mortality) should also be considered when determining the predictive ability of the chart-derived measure in future studies.

Key Messages From This Article

People with disabilities. Many changes occur as you get older, especially in your health and abilities. Noting the smallest change in everyday ability can help others support you.

Professionals. Frailty predicts adverse outcomes and is more prevalent among adults with intellectual and developmental disabilities. Client charts should capture key information needed to measure frailty as knowledge of frailty status could improve care planning and facilitate personalized care.

Policymakers. Implementation of a frailty measure in developmental services requires detailed chart-data and will help support well-being and aging care among individuals with intellectual and developmental disabilities.

Acknowledgements

Ongwanada and inter-RAI made this project possible by allowing access to their data. The authors wish to thank Shelley Gelineau, Manager of Client Information Services at Ongwanada,for her assistance with accessing clinical records and Jonathan Chen at the University of Waterloo for his support with the access and analysis of interRAI data.

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