

# Improving Prediction of Risk of Admission to Long-Term Care or Mortality Among Home Care Users With IDD



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## ABSTRACT

### Background

Frailty is an established predictor of admission into long-term care (LTC) and mortality in the elderly population. Assessment of frailty among adults with intellectual and developmental disabilities (IDD) using a generic frailty marker may not be as predictive, as some lifelong disabilities associated with IDD may be interpreted as a sign of frailty. This study set out to determine if adding the Home Care-Intellectual and Developmental Disabilities Frailty Index (HC-IDD Frailty Index), developed for use in home care users with IDD, to a basic list of predictors (age, sex, rural status, and the Johns Hopkins Frailty Marker) increases the ability to predict admission to long-term care or death within one year.

### Methods

A retrospective cohort study was conducted using Residential Assessment Instrument for Home Care (RAI-HC) data for adult home care users with IDD who had a home care assessment between January 1, 2010 and December 31, 2013 (N = 6,169).

### Results

The HC-IDD Frailty Index was found to significantly improve prediction of transitions into LTC or death by explaining an additional 5.95% of the variance in such transitions among home care users with IDD ( $p$  value < .0001).

### Conclusions

We recommend the use of the HC-IDD Frailty Index in care planning and in further research related to the effectiveness of interventions to reduce or delay adverse age-related outcomes among adults with IDD.

### Key words:

intellectual disability; developmental disability; frailty; mortality; long-term care; home care; aging

## INTRODUCTION

The risks of health decline, admission to long-term care, and death associated with increasing age are well-known. Research has established that adults with intellectual and developmental disabilities (IDD) experience premature aging, as they exhibit age-related declines in health and functioning earlier than seen in the general population.<sup>(1)</sup> Persons with IDD present with significant limitations in intellectual functioning and adaptive skills that originate in the developmental years (i.e., before the age of 18).

Over 50 years ago, the works of Nirje<sup>(2)</sup> and Wolfensberger<sup>(3)</sup> introduced the normalization principle that incited governments worldwide to close institutions and establish community-based residential services and supports for adults with IDD. In many jurisdictions, however, deinstitutionalization remains incomplete.<sup>(4)</sup> There are also some countries, like the United States, where people with IDD are supported in institutions in some regions and in the community in other regions.<sup>(5)</sup> The situation is similar in Canada, where some provinces have closed all institutions for adults with IDD (e.g., Ontario) and others have not (e.g., Manitoba).

In Canada and elsewhere, there is concern that too many adults with IDD are living in long-term care homes instead of living and aging in the community. Recent work in Ontario (Canada) showed that admission to long-term care was five times higher among adults with IDD than in the general population.<sup>(6)</sup> In the field of IDD, admission to long-term care is seen as another form of institutionalization—re-institutionalization, for some—that should be avoided or delayed.

Though persons with IDD have seen gains in life expectancy,<sup>(7)</sup> they continue to experience premature mortality.<sup>(8)</sup> Reports on mortality in Germany, Australia, the United States, Ireland, England, and Canada revealed life expectancies

approximately 20 years shorter among persons with IDD than in the general population.<sup>(9,10,11,12)</sup> Age-adjusted mortality rates were approximately four times greater among persons with IDD.<sup>(11,13)</sup>

In the general population, life expectancy is higher among women<sup>(14)</sup> and mortality is associated with lower socioeconomic status.<sup>(15,16)</sup> Gender,<sup>(17)</sup> socioeconomic status,<sup>(18)</sup> as well as urban vs. rural living,<sup>(19)</sup> can also influence admission to long-term care among older adults. In terms of persons with IDD, several studies have noted gender differences in life expectancy/mortality,<sup>(9,10,11,13,20)</sup> but little is known about the impact of socioeconomic status and urban vs. rural living on this outcome in this population. Research into factors associated with admission to long-term care is emerging in the field of IDD with a focus on frailty.<sup>(21)</sup>

Frailty is seen as an indicator of age-related health decline.<sup>(22)</sup> In Ontario, the Johns Hopkins Frailty Marker has been used to measure frailty and predict related adverse outcomes.<sup>(23)</sup> It is derived using the Johns Hopkins Adjusted Clinical Group Algorithm (The Johns Hopkins ACG<sup>®</sup> System Ver 10); as such, it relies on diagnostic codes recorded in health administrative data for an individual over a period of time.<sup>(23)</sup> However, as adults with IDD experience many lifelong impairments and disabilities that are not necessarily age-related, the use of a static, diagnosis-based marker of frailty may not be appropriate for this population. The HC-IDD Frailty Index, developed and specifically validated for adults with IDD,<sup>(24)</sup> uses 42 deficits (see Additional File 1 of Reference #24) available in administrative home care data. The index, based on elements in the RAI-Home Care assessment instrument, assigns a frailty score between 0 and 1 to an individual; 0–0.21 is considered not frail and anything above 0.30 is considered frail.

## Study Objective

The objective of the study was to determine if adding an IDD-specific measure of frailty (the HC-IDD Frailty Index) to a basic list of predictors (age, sex, rural status, and the Johns Hopkins Frailty Marker) increases the ability to predict admission to long-term care or death within one year among adults with IDD receiving home care. Understanding the factors that are associated with admission to long-term care and with death may contribute to the development of targeted interventions to prevent or delay these age-related outcomes.

## METHODS

The study cohort was based on a previously defined cohort consisting of individuals with IDD between the ages of 18 and 99 years living in Ontario as of March 31, 2010.<sup>(25)</sup> Diagnoses of IDD<sup>(26)</sup> were identified by searching the Discharge Abstract Database, Same Day Surgery Database, Ontario Mental Health Reporting System, National Ambulatory Care Reporting System, Ontario Health Insurance Plan,

the Chronic Care Reporting System for Long-Term Care, and the Home Care Database. These datasets were linked using unique encoded identifiers, and analyzed at ICES ([www.ices.on.ca](http://www.ices.on.ca)) by the second author. The analysis was restricted to those individuals who had a home care assessment between January 1, 2010 and December 31, 2013 (N = 6,169). Data were further linked to the Office of the Registrar General Database and the Continuing Care Reporting System database to assess the two outcomes, death and admission to long-term care. If individuals had more than one home care assessment, the first assessment was used to derive the HC-IDD Frailty Index. All individuals were followed for one year from the home care assessment or until they experienced one of the two study outcomes.

The Rurality Index of Ontario (RIO)<sup>(27)</sup> combines information about population density and travel time to health referral centres to generate scores ranging from 0 (most urban) to 100 (most rural). A RIO score  $\geq 40$  (“the cut-off used to determine the eligibility of rural communities for physician recruitment incentives by the provincial government”<sup>(28)</sup>) was used to designate individuals as living in rural areas.

Integrated discrimination improvement (IDI)<sup>(29)</sup> was used to quantify how much the HC-IDD Frailty Index improved prediction of transitions into long-term care or death after one year beyond what was possible with a risk model built using standard predictors (age, sex, rurality, income, and the Johns Hopkins Frailty Marker). In other words, IDI quantified the increase in percentage of variance that could be explained by adding the HC-IDD Frailty Index to the standard risk model.<sup>(30)</sup> In order to calculate IDI, two regression models were built: one using only age, sex, rurality, income, and the Johns Hopkins Frailty Marker, and the second adding the HC-IDD Frailty Index. Both models were used to predict each individual’s probability of transitioning into long-term care or death within one year, and the difference between the predicted probabilities was calculated in order to determine the improved discriminating power due to the addition of the HC-IDD Frailty Index in the risk model.

The difference between the predicted probabilities of transitioning was averaged among those who died or were admitted to long-term care (where increased predicted probabilities of transitioning indicated the utility of the HC-IDD Frailty Index) and those who did not transition (where decreased predicted probabilities of transitioning indicated the utility of HC-IDD Frailty Index); the sum of the average discrimination improvement in these two groups is called the IDI. Pencina *et al.* refer to IDI as the “difference between improvement in average sensitivity and any potential increase in average ‘one minus specificity’” due to the inclusion of the new predictor.<sup>(29)</sup>

## RESULTS

The cohort was comprised of 3,217 women (52.1%) and 2,952 men (47.9%), with a mean age of 53.1 years. Nearly

half (49.7%) lived in the two lowest income quintile neighbourhoods and 18.2% lived in rural areas of the province. According to the Johns Hopkins Frailty Marker, 3,338 (54.1%) were classified as frail. However, the average HC-IDD Frailty Index score of 0.21 indicated a lower level of frailty in the cohort (a score  $> 0.21$  and  $< 0.3$  classifies individuals as pre-frail). Three hundred and thirty-six members of the cohort died (6.9%), and 1,269 (20.6%) were admitted to long-term care within a year of the index home care assessment. The integrated discrimination improvement (IDI) was significant, with a value of 0.0595 ( $p$  value of  $< .0001$ ).

## DISCUSSION/CONCLUSION

As predicted, the Johns Hopkins Frailty Marker lacks specificity among adults with IDD; therefore, using it to predict mortality or need for long-term care in this population is not appropriate. The addition of the HC-IDD Frailty Index improved the ability of the model to predict admission to long-term care or death within a year of a home care assessment by an additional 5.95%. As the aim is to identify individuals at risk, sensitivity is most relevant. Using the HC-IDD Frailty Index as a screening tool within home care would help identify individuals at risk of premature admission to long-term care or death who might otherwise not be recognized as potentially benefitting from adjustments to care planning. As the HC-IDD Frailty Index is derived from the RAI-HC, the data needed to compute it are readily available in home care settings which routinely use this assessment.

This study focused on the combined outcome of death or admission to long-term care. Future work should explore these outcomes separately or consider death as a competing risk. Future research should also examine screening for frailty among home care users with IDD, using a validated measure for use in this population, and evaluate the impact of subsequent modification of care planning on adverse outcomes (mortality/premature admission to long-term care). Research on frailty among adults with IDD not using home care is also warranted to identify potential unmet need for home care services.

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## CONFLICT OF INTEREST DISCLOSURES

The authors declare that no conflicts of interest exist.

## REFERENCES

1. Stax TE, Luciano L, Dunn AM, *et al.* Aging and developmental disability. *Phys Med Rehab Clin.* 2010;21(2):419–27.
2. Nirje B. The normalization principle and its human management implications. In Kugel RB, Wolfensberger W. editors. Changing patterns in residential services for the mentally retarded. Washington, DC: President's Committee on Mental Retardation (US); 1969. Chapter 7, p.179–95.
3. Wolfensberger W. The principle of normalization in human services. Toronto, ON: National Institute on Mental Retardation (CAN); 1972. Report available from [http://digitalcommons.unmc.edu/wolf\\_books/1/](http://digitalcommons.unmc.edu/wolf_books/1/)
4. Beadle-Brown J, Mansell J, Kozma A. Deinstitutionalization in intellectual disabilities. *Curr Opin Psychiatr.* 2007;20(5): 437–42.
5. Lakin KC, Larson SA, Salmi P, *et al.* Residential services for persons with developmental disabilities: status and trends through 2009. Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration (US); 2010. Report available at <https://rtc.umn.edu/docs/RISP2009.pdf>
6. Ouellette-Kuntz H, Martin L, McKenzie K. The risk of reinstitutionalization: examining rates of admission to long-term care among adults with intellectual and developmental disabilities over time. *J Policy Pract Intel.* 2017;14(4):293–97.
7. Patja K, Iivanainen M, Vesala H, *et al.* Life expectancy of people with intellectual disability: a 35-year follow-up study. *J Intell Disabil Res.* 2000;44(5):591–99.
8. Heslop P, Blair PS, Fleming P, *et al.* The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *Lancet.* 2014;383(9920):889–95.
9. Dieckmann F, Giovis C, Offergeld J. The life expectancy of people with intellectual disabilities in Germany. *J Appl Res Intell Disabil.* 2015;28(5):373–82.
10. Lauer E, McCallion P. Mortality of people with intellectual and developmental disabilities from select US state disability service systems and medical claims data. *JARID.* 2015;28(5):394–405.
11. McCarron M, Carroll R, Kelly C, *et al.* Mortality rates in the general Irish population compared to those with an intellectual disability from 2003 to 2012. *JARID.* 2015;28(5): 406–13.
12. Heslop P, Glover G. Mortality of people with intellectual disabilities in England: a comparison of data from existing sources. *JARID.* 2015;28(5):414–22.
13. Florio T, Trollor J. Mortality among a cohort of persons with an intellectual disability in New South Wales, Australia. *JARID.* 2015;28(5):383–93.
14. Lebel A, Hallman S. Mortality: overview 2012 and 2013. Report on the demographic situation in Canada. Ottawa, ON: Statistics Canada; 2017. Catalogue no. 91-209-x.

15. Van den Bosh K, Geerts J, Willemé P. Long-term care use and socio-economic status in Belgium: a survival analysis using health care insurance data. *Arch Public Health*. 2013;71:1–9. Available from: <http://www.archpublichealth.com/content/71/1/1>
16. Feder J, Komisar HL, Niefeld M. Long-term care in the United States: an overview. *Health Affairs*. 2000;19(3):40–56.
17. Gruneir A, Forrester J, Camacho X, et al. Gender differences in home care clients and admission to long-term care in Ontario, Canada: a population-based retrospective cohort study. *BMC Geriatr*. 2013;13:48. Available from: <http://www.biomedcentral.com/1471-2318/13/48>
18. Yang S, Hoshi T, Nakayama N, et al. The effects of socio-economic status and physical health on the long-term care needs of Japanese urban elderly: a chronological study. *Environ Health Prev Med*. 2012;18:287.
19. Lagergren M, Kurube N. Provision of long-term care in relation to needs in urban and rural municipalities in Japan and Sweden. *Geriatr Gerontol Int*. 2014;14(2):315–27.
20. Ouellette-Kuntz H, Shoostari S, Balogh R, et al. Understanding information about mortality among people with intellectual and developmental disabilities in Canada. *J Appl Res Intell Disabil*. 2015;28(5):423–35.
21. McKenzie K, Ouellette-Kuntz H, Martin L. Frailty as a predictor of institutionalization among adults with intellectual and developmental disabilities. *Intell Development Disabil*. 2016;54(2):123–15.
22. Rockwood K, Song X, MacKnight C, et al. A global clinical measure of fitness and frailty in elderly people. *Can Med Assoc J*. 2005;173(5):489–95.
23. Bronskill S, Carter MW, Costa AP, et al. Aging in Ontario: An ICES chartbook of health service use by older adults. Toronto, ON: Institute for Clinical Evaluative Sciences; 2010.
24. McKenzie K, Ouellette-Kuntz H, Martin L. Using an accumulation of deficits approach to measure frailty in a population of home care users with intellectual and developmental disabilities: an analytical descriptive study. *BMC Geriatr*. 2015;15:170.
25. Ouellette-Kuntz H, Martin L. Applied Health Research Question Report: Aging profiles of adults with and without developmental disabilities in Ontario. Toronto, ON: Health Care Access Research and Developmental Disabilities Program; 2014.
26. Lin E, Balogh R, Isaacs B, et al. Strengths and limitations of health and disability support administrative databases for population-based health research in intellectual and developmental disabilities. *J Policy Pract Intell Disabil*. 2014 Dec;11(4):235–44.
27. Kralj B. Measuring Rurality—RIO2008\_BASIC: methodology and results [Internet]. Toronto, ON: OMA; 2009. Accessed 2017 Sep 19. Available from: <https://www.oma.org/wp-content/uploads/2008rio-fulltechnicalpaper.pdf>
28. Tran C, Wijesundera HC, Qui F, et al. Comparing the ambulatory care and outcomes for rural and urban patients with chronic ischemic heart disease: a population-based cohort study. *Circ Cardiovasc Qual Outcomes*. 2014;7(6):835–43.
29. Pencina M, D'Agostino RB, D'Agostino RB, et al. Evaluating the added predictive ability of a new marker: from area under the ROC curve to reclassification and beyond. *Stat Med*. 2008;27(2):157–72.
30. Cook NR, Ridker PM. Advances in Measuring the Effect of Individual Predictors of Cardiovascular Risk: The Role of Reclassification Measures. *Ann Intern Med*. 2009;150(11):795–802.

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