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Rate of deficit accumulation in home care users with intellectual and developmental disabilities

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ABSTRACT

Purpose: To identify factors associated with the rate of deficit accumulation in a population of adults with intellectual and developmental disabilities (IDD).

Methods: A longitudinal analysis of administratively held clinical data collected at routine home care assessments across Ontario (Canada) using the Resident Assessment Instrument for Home Care (RAI-HC) was conducted using a cohort comprised of 5074 adults with IDD 18–99 years of age who had at least two home care assessments between April 1, 2003 and March 31, 2015. Rates of deficit accumulation were calculated across variables of interest. Incidence rate ratios and 95% confidence intervals are presented. Negative binomial regression models using a generalized estimating equation (GEE) approach were developed.

Results: Increasing age, Down syndrome, and living in a group home were significant predictors of deficit accumulation. Rates of deficit accumulation tended to be higher among prefrail and frail individuals; however, impaired cognition and impairment in activities of daily living were associated with slower deficit accumulation. The relationship between provision of nursing and therapy services and deficit accumulation is unclear.

Conclusions: Frailty should be monitored among adults with IDD starting at age 40 years, those with Down syndrome, and those who live in group homes.

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Introduction

Population aging is associated with increases in disability and chronic conditions [1,2]. Adults with intellectual and developmental disabilities (IDD), who have lived with impaired cognition and adaptive functioning since childhood, show signs of physiological, social, and cognitive aging earlier than in the general population [3–5]. A recent literature review reported “almost a total lack of information about the aging process and its consequences” among persons with IDD (p.64) [6]. Although there has been attention to various age-related health conditions in this population, there is also recognition that few people will experience a single condition; hence, use of a measure that encompasses overall age-related decline is warranted.

Frailty is widely used to study health and aging. Although there is no consensus definition [7], it is generally accepted that frailty incorporates vulnerabilities within and across multiple domains (e.g., biological, social, psychological, environmental) [8]. The accumulation of deficits model proposes that individuals become increasingly frail based on the number of deficits present [9]. Here, deficits refer to any sign, symptom, disability, disease, or abnormal laboratory measurement—there is no set list of deficits. Instead, the emphasis is on the proportion of deficits present out of the total number measured. This approach reveals a limit to deficit accumulation around 0.7% or 70% of measured deficits [10,11], that is, the maximum number of deficits that can be tolerated (before death occurs).

Research to date suggests a stable average rate of deficit accumulation across the general population adult life span, with the number of deficits doubling every 15.4 years [12]. As such, someone with a frailty index of .35 at the age of 60 would be expected to reach the maximum at 75.4 years of age. It is not surprising, therefore, that deceleration in accumulation of deficits is seen at advanced ages (e.g., after 95+) and accelerated increase is seen before death irrespective of chronological age [13]. Differences in

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patterns of deficit accumulation over time among men and women have not been consistently found [13–16]. Kulminski et al., who have studied such sex differences extensively, suggest that findings may reflect the health dimensions included in the frailty index used [16]. They also report different sex patterns of deficit accumulation based on disability status; noting that among American adults aged 65 years and older with disability, males accumulate deficits faster whereas among those without disability, females accumulate deficits faster [15]. Finally, a faster accumulation of deficits was noted for elderly who at younger ages were less frail than for those who were more frail at younger ages. Age-related frailty patterns for low and high frailty groups tend to converge at advanced ages [15].

These findings from the general population are relevant to understand frailty and aging among adults with IDD. Studies using the accumulation of deficits approach to measure frailty in this group have reported rates of frailty 20–30 years earlier than what is observed in the general population [2,17]. This apparent earlier aging, is seen even earlier among the subgroup of adults with IDD who have Down syndrome among whom an elevated risk of Alzheimer's dementia is seen by the age of 40 [18]. As frailty is a multi-dimensional construct including environmental factors, the rate of accumulation of deficits among adults with IDD is likely to be different from that in the general population based on their experience of distinct support contexts. In particular, in most jurisdictions, the population of adults with IDD has been and continue to be supported through specialized services and supports including residential care arrangement such as group homes. There is a need to understand the rate of accumulation of deficit among adults with IDD including risk and protective factors.

Using a retrospective, longitudinal research design, this study aimed to determine the factors associated with the rate of deficit accumulation in a population of adults with IDD receiving home care services in Ontario, Canada.

Methods

Study population and design

This article presents a longitudinal analysis of administratively held clinical data collected at routine home care assessments across Ontario (Canada) using the Resident Assessment Instrument for Home Care (RAI-HC) [19]. The RAI-HC includes open-text diagnoses for assessors to indicate the presence of any “disease/infection[s] that [a] doctor has indicated is present and affects client's status, requires treatment, or symptom management ... [or a] disease [that] is monitored by a home care professional or is the reason for a hospitalization in last 90 days” [19]. The cohort comprised 7844 adults with IDD 18–99 years of age who had at least one home care assessment with an open-text diagnostic value indicating IDD [20] between April 1, 2003 and March 31, 2015; representing 0.92% of Ontario's overall home care population.

To determine the factors associated with the rate of deficit accumulation, a subset of the cohort was used. First, nine individuals were excluded with incorrect death dates. Next, assessments were deleted that were missing key information; 64 individuals were excluded as they had no assessments without missing characteristics of interest. Finally, 2697 individuals without at least two home care assessments completed were excluded, given the longitudinal nature of the study. A total of 5074 individuals contributed to the analyses.

Data

A data-sharing agreement between the Ontario Association of Community Care Access Centers (OACCAC) and interRAI

(a not-for-profit international research organization that develops assessments, including the RAI-HC), provides access to anonymized population-level data on the entire population of home care recipients in Ontario during the study period ($n = 856,905$). These data are held on a secure server at the University of Waterloo and available to the research team (as the second author is a Fellow of interRAI).

The variables from the RAI-HC used in the analyses include two values which remained constant throughout the follow-up: **sex** and presence of **Down syndrome**. An individual was coded as having Down syndrome if a record of Down syndrome or trisomy 21 was identified in an open-text diagnostic field at any assessment. The other variables were collected for each assessment. They included impaired cognition, impairment in activities of daily living, home care services received, whether the individual lived in a group home, frailty index score, and deficit accumulation. **Date of death** was also ascertained where applicable; it is recorded in data held by OACCAC and linked to home care data.

A score of ≥ 3 on the cognitive performance scale (CPS) was used to designate impaired **cognition**. This scale is embedded in the RAI-HC and is based on items related to decision-making, expression, and short-term memory. Scores range from 0 (intact cognition) to 6 (very severe impairment) [21].

The embedded activities of daily living hierarchy (ADLH) scale [22] uses four ADL items: personal hygiene, toilet use, locomotion, and eating. Scores range from 0 (independent) to 6 (total dependence); a cutoff of $ADLH \geq 3$ was used to indicate impairment in **self-care skills**.

Receipt of home care services at least once during the week before assessment was recorded in the RAI-HC. **Nursing and therapy** (i.e., physiotherapy, occupational therapy, or speech language therapy) services were coded as received or not received regardless of duration or intensity of services provided.

Individuals were identified as living in a **group home** if: (1) they lived in a board and care/assisted living/group home; (2) lived in a group setting with nonrelatives; and (3) did not live with their primary informal caregiver. This coding had good face validity with a group of experts in Ontario in the field of IDD who work in home care (meeting with the Ontario Partnership on Aging and Developmental Disabilities, June 8, 2016). In Ontario, group homes provide 24-hour care including support with activities of daily living (e.g., dressing, meal preparation, shopping) although it is expected that working age adults will engage in daily activities outside the home. Some group homes also provide support from allied health professionals.

The Home Care-Intellectual and Developmental Disabilities (HC-IDD) frailty index is a 42-item measure developed for the population of home care users with IDD [23,24] using a standard procedure [25]. It includes items related to physiological deficits (e.g., disease diagnoses), cognitive deficits (e.g., memory loss), psychological deficits (e.g., changes in behavior), social deficits (e.g., social isolation), and service use (e.g., changes in care needs). Each deficit is coded as “1” when the deficit is present at all, and “0” when absent, while some variables have intermediate coding (e.g., “0.5”). The deficit score is divided by the number of deficits available and rounded to the nearest integer. The resulting values are categorized into nonfrail (<0.21), prefrail (between 0.21 and 0.30) and frail (>0.30) [23,24]. The HC-IDD frailty index is predictive of admission to long-term care [23,26], mortality [23], and associated with living in a group home [20].

At the first assessment, every individual in the cohort had information available for coding of at least 39 deficits, and 93% had information for all 42 deficits. An increase in the HC-IDD frailty index score indicated an accumulation of deficits. Losing deficits

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