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Short Report: The influence of congregate setting on positive COVID-19 tests among a high-risk sample of adults with intellectual and developmental disability in Ontario

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A B S T R A C T

Background: For a number of reasons, persons with intellectual and developmental disability (IDD) are at increased risk of contracting COVID-19.

Aims: This study explored the influence of congregate setting on testing positive for COVID-19 among adults with IDD in Ontario.

Methods and procedures: 833 home care recipients with IDD were included, 204 were tested at least once for COVID-19. These data were linked to the homecare assessment data. The association between living in a congregate setting and receiving a positive COVID-19 test was explored using a logistic regression model among the total sample and those tested for COVID-19.

Outcomes and results: 77 individuals tested positive for COVID-19 (9.24%). Congregate setting, age, aggression, and mobility were significantly associated with receiving a positive COVID-19 test in the total sample. Among the subgroup, congregate setting and age were significant.

Conclusion and implications: Adults with IDD have an increased risk for positive COVID-19 tests at younger ages than other high-risk populations, such as elderly persons. These findings confirm the vulnerability of adults with IDD living in group settings to COVID-19. As such, they should be prioritized when COVID-19 prevention and public health strategies, including vaccination and boosters, are introduced.

What this paper adds?

Limited studies have explored COVID-19 outcomes among Canadians with IDD. Given that responses to COVID-19 varied across regions, COVID-19 outcomes must be explored quantitatively within Canada. The study confirms that older age and living in a congregate setting are independent risk factors for COVID-19 among adults with IDD. In this population, aggression, and mobility limitations also place individuals at higher risk of testing positive for COVID-19. Individuals with IDD may experience these risks at a younger age when compared to other high-risk populations, such as the elderly population residing in long-term care.

These findings could inform future policy and practice for older persons with IDD, and in particular those living in congregate settings. Given this population’s increased vulnerability, public health strategies must be prioritized among persons with IDD.

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Strategies should include prioritizing vaccinations and any future boosters required for this population. The Ontario government should also model their policy and practice after regions that successfully managed the spread of COVID-19 in congregate settings. Relevant plans to adopt could include increasing funding (e.g., hiring full-time staff), limiting the number of residents sharing spaces, and improving communication and coordination between group homes, public health, long-term care, and hospitals.

1. Introduction

The spread of COVID-19 in nursing homes has been described as the “Perfect Storm” due to the combination of residents with high levels of comorbidity, staffing shortages, inadequate testing, and insufficient personal protective equipment (Brown et al., 2021; Liu et al., 2021; Ouslander & Grabowski, 2020). The pandemic has, therefore, highlighted the susceptibility of vulnerablised populations, particularly those living in congregate settings.

Persons with intellectual and developmental disabilities (IDD) share many similarities with the older population that increase their susceptibility to COVID-19 diagnosis and mortality, such as high levels of multimorbidity and residence in congregate settings (Cooper et al., 2015; Ouslander & Grabowski, 2020). Social distancing measures can be challenging in such settings given that individuals may require direct support for activities of daily living and mobility (Landes, Turk, Formica, McDonald, & Stevens, 2020; Ouslander & Grabowski, 2020). Wearing masks for extended periods may also be difficult due to cognitive impairment and reduced understanding of their importance (Gleason et al., 2021; Ouslander & Grabowski, 2020). These factors, alone and in combination, lead to increased COVID-19 risk among persons with IDD.

In America, Gleason et al. (2021) found that IDD was one of the strongest independent risk factors for COVID-19 diagnosis and mortality. In Ontario (Canada), COVID-19 positivity rates, hospitalization, and mortality were higher among persons with IDD when compared to those without IDD (Lunsky et al., 2021). Regarding congregate setting specifically, Landes and colleagues (2020) reported that persons with IDD living in residential group homes were more likely to experience severe COVID-19 outcomes. These findings highlight that, similar to older adults in nursing homes, persons with IDD living in congregate settings are also susceptible to worse COVID-19 outcomes.

While individuals with IDD and older adults share similar COVID-19 risk, there are important differences. Most notably, individuals with IDD are at risk of worse COVID-19 outcomes at a much younger age (Lunsky et al., 2021; Turk, Landes, Formica, & Goss, 2020). This aligns with the knowledge that persons with IDD may show signs of premature aging, experience frailty and require increased care at a much younger age than the general population (Evenhuis, Hermans, Hilgenkamp, Bastiaanse, & Echteld, 2012). While overall COVID-19 case-fatality rates are similar across those with and without IDD, these are significantly higher at younger ages among those with IDD (Turk et al., 2020). Given all of this, exploring the impact of congregate settings on COVID-19 diagnoses among persons with IDD is critical. This study explores the influence of living in congregate settings on positive COVID-19 tests among a sample of adults with IDD receiving home care services in Ontario. These findings could inform our current understanding of pandemic preparedness and improve planning (e.g., vaccinations, hiring full-time staff, etc.) for future pandemics.

2. Methods

This study used an observational design, which consisted of secondary analysis of anonymized data. The Lakehead University Research Ethics Board granted exemption from ethical review for secondary analysis of anonymized data, as per the Tri-Council Policy Statement 2 (Canadian Institutes of Health Research, Natural Sciences & Engineering Research Council of Canada, & Council, S. S. a. H. R., 2018).

The study population included home care users with IDD (≥18 years old) in a large metropolitan region of Ontario. All had been assessed with the interRAI Home Care (HC) and the ID supplement as part of standard practice in the jurisdiction; all variables were obtained from these two assessments. The interRAI HC is a comprehensive assessment that includes demographics and information on key life domains (e.g., cognition, physical and mental health, behaviour, social relationships and support) that inform care planning (Morris et al., 2019). The ID supplement is based on the interRAI ID assessment (Martin, Hirdes, Fries, & Smith, 2007), and provides additional information on the nature of IDD. Though some assessments took place prior to the pandemic (i.e., n = 20 before March 11, 2020), the majority were done during the pandemic (n = 184). COVID-19 test results were linked to the most recent interRAI assessment.

The sample includes 833 home care users with IDD, where 204 had been tested at least once for COVID-19 between March 2020 and July 2021 (n = 629 were not tested). COVID-19 testing occurred if individuals exhibited relevant symptoms or had close contact with another person who tested positive. Among those with more than one COVID-19 test (n = 77), a single positive test resulted in the individual being considered as testing positive.

The exposure of interest was living in a congregate setting. Information on living settings was dichotomized into congregate (i.e., board and care, group home for physical disability, setting for persons with IDD) and private or assisted living (i.e., private home/apartment/rented room, assisted living/semi-independent living).

The following factors were also considered as covariates: age, sex, nature of IDD (available only for 519 with an ID supplement), receptive communication (usually/often understands vs never/sometimes understands), mobility (walking with or without assistive device vs uses mobile device or bed-bound), body mass index (BMI), and independence in ADLs (bathing, personal hygiene, dressing, toilet use, bed mobility, and eating). ADL items were evaluated based on a 7-point scale (0 = independent to 6 = total dependence), which was dichotomized into no physical contact (scores 0–2) and requires physical contact (scores 3–6). The score for dressing was created by using the most dependent among the two dressing items (upper body and lower body). Two embedded scales were also...
Table 1
Demographic and clinical characteristics of adults with IDD in the sample.

|                        | All (n = 833) | Positive test (n = 77) | Negative test (n = 127) | Not tested (n = 629) | Sig. |
|------------------------|--------------|------------------------|-------------------------|----------------------|------|
| **Age (years)**        |              |                        |                         |                      |      |
| <30 years              | 220 (26.41)  | 9 (11.69)              | 42 (33.07)              | 169 (26.87)          | 1, 2 |
| 30-<45 years           | 224 (26.89)  | 12 (15.58)             | 30 (23.62)              | 182 (28.93)          |      |
| 45-<60 years           | 206 (24.73)  | 21 (27.27)             | 26 (20.47)              | 159 (25.28)          |      |
| ≥60 years              | 183 (21.97)  | 35 (45.45)             | 29 (22.83)              | 119 (18.92)          |      |
| **Sex**                |              |                        |                         |                      |      |
| Male                   | 459 (55.10)  | 44 (57.14)             | 74 (58.27)              | 341 (54.21)          | NS   |
| Female                 | 374 (44.90)  | 33 (42.86)             | 53 (41.73)              | 288 (45.79)          |      |
| **Living setting**     |              |                        |                         |                      |      |
| Private                | 565 (67.83)  | 19 (24.68)             | 74 (58.27)              | 472 (75.04)          | 1, 2, 3 |
| Congregate             | 268 (32.17)  | 58 (75.32)             | 43 (33.86)              | 157 (24.96)          |      |
| **Nature of impairment (n = 519)** |          |                        |                         |                      |      |
| Unspecified            | 257 (49.52)  | 11 (20.37)             | 37 (40.66)              | 188 (50.27)          | NS   |
| Down syndrome          | 73 (14.07)   | 5 (9.26)               | 13 (14.29)              | 55 (14.71)           |      |
| Autism                 | 78 (15.03)   | 6 (11.11)              | 16 (17.58)              | 56 (14.97)           |      |
| Other                  | 111 (21.39)  | 32 (59.26)             | 25 (45.45)              | 251 (45.90)          |      |
| **Cognitive Performance Scale** |          |                        |                         |                      |      |
| Intact to mild         | 247 (29.65)  | 21 (27.27)             | 39 (30.71)              | 187 (29.73)          | NS   |
| Moderate               | 253 (30.37)  | 19 (24.68)             | 43 (33.86)              | 191 (30.37)          |      |
| Severe                 | 333 (39.98)  | 37 (45.45)             | 45 (35.43)              | 251 (39.90)          |      |
| **Receptive communication** |          |                        |                         |                      |      |
| Sometimes, rarely, or never understands | 364 (43.70) | 35 (45.45) | 54 (42.52) | 275 (43.72) | NS |
| Usually, often, or always understands | 469 (56.30) | 42 (54.55) | 73 (57.48) | 354 (56.28) |      |
| **Mobility**           |              |                        |                         |                      |      |
| Walking w/wo assistive device | 568 (68.19) | 38 (49.35) | 74 (58.27) | 456 (72.50) | 1, 3 |
| Mobility devices or bed-bound | 265 (31.81) | 39 (50.65) | 53 (41.73) | 173 (27.50) |      |
| **Aggression**         |              |                        |                         |                      |      |
| No aggression          | 498 (59.78)  | 35 (45.45)             | 65 (51.18)              | 398 (63.28)          | 1, 3 |
| Any aggression         | 335 (40.22)  | 42 (54.55)             | 62 (48.82)              | 231 (36.72)          |      |
| **Bathing**            |              |                        |                         |                      |      |
| No physical contact    | 84 (10.08)   | 7 (9.09)               | –                       | 73 (11.61)           | 3    |
| Physical contact       | 749 (89.92)  | 70 (90.91)             | –                       | 556 (88.39)          |      |
| **Personal hygiene**   |              |                        |                         |                      |      |
| No physical contact    | 146 (17.53)  | 14 (18.18)             | 14 (11.02)              | 118 (18.76)          | 3    |
| Physical contact       | 687 (82.47)  | 63 (81.82)             | 113 (88.98)             | 511 (81.24)          |      |
| **Dressing**           |              |                        |                         |                      |      |
| No physical contact    | 196 (23.53)  | 17 (22.08)             | 16 (12.60)              | 163 (25.91)          | 3    |
| Physical contact       | 637 (76.47)  | 60 (77.92)             | 111 (87.40)             | 466 (74.09)          |      |
| **Toilet use (n = 786)** |          |                        |                         |                      |      |
| No physical contact    | 253 (32.19)  | 19 (26.39)             | 26 (21.49)              | 208 (35.08)          | 3    |
| Physical contact       | 533 (67.81)  | 53 (73.61)             | 95 (78.51)              | 385 (64.92)          |      |
| **Bed mobility (n = 830)** |          |                        |                         |                      |      |
| No physical contact    | 561 (67.59)  | 45 (58.44)             | 73 (58.40)              | 443 (70.54)          | 1, 3 |
| Physical contact       | 269 (32.41)  | 32 (41.56)             | 52 (41.60)              | 185 (29.46)          |      |
| **Eating (n = 829)**   |              |                        |                         |                      |      |
| No physical contact    | 546 (65.86)  | 43 (56.58)             | 77 (60.63)              | 426 (68.05)          | 1    |
| Physical contact       | 283 (34.14)  | 33 (43.42)             | 50 (39.37)              | 200 (31.95)          |      |
| **BMI (n = 738)**      |              |                        |                         |                      |      |
| <25 kg/m²              | 305 (41.33)  | 36 (50.70)             | 53 (43.44)              | 216 (39.63)          | NS   |
| ≥25 kg/m²>30           | 199 (26.96)  | 14 (19.72)             | 35 (28.69)              | 150 (27.52)          |      |
| ≥30 kg/m²              | 234 (31.71)  | 21 (29.58)             | 34 (27.87)              | 179 (32.84)          |      |
1 = Positive different than untested (p < 0.05); 2 = Positive different than negative (p < 0.05); 3 = Negative different than untested (p < 0.05); NS = not significant (p > 0.05); – suppressed due to small cell count.

used. The Cognitive Performance Scale ranges from intact (0) to very severe impairment (6) (Morris et al., 1994); scores were delineated into three categories: intact to mild impairment (0–2), moderate impairment (3–4), and severe impairment (5–6). The Aggressive Behaviour Scale ranges from 0 (no aggression) to 12 (more severe aggression) (Perlman & Hirdes, 2008); and was dichotomized into no (0) and any signs of aggression (≥1). Both scales have been validated with individuals with IDD (Martin et al., 2007).

3. Calculation

Relevant demographic and clinical variables were explored across the total sample (n = 833), those who tested positive for COVID-19 (n = 77), those who tested negative for COVID-19 (n = 127), and those who were not tested for COVID-19 (n = 629). The three groups (untested, negative COVID-19 tests, and positive COVID-19 tests) were compared using Chi-square tests ($X^2$). Further chi-square tests were conducted to compare untested individuals to those who tested negative, those who tested negative to those who tested positive, as well as untested persons to those who tested positive.

A multivariate logistic regression model was conducted to determine the relationship between congregate setting and positive COVID-19 tests for the full sample (positive test n = 77; no positive test n = 756) using a manual backwards selection strategy with a liberal p-value of 0.25. Adjusted odds ratios (OR) with 95 % confidence intervals (CI) are reported. Effect modification was considered a priori, namely age and congregate setting, and tested using a log-likelihood ratio test. Outliers, goodness-of-fit, and multicollinearity were assessed.

A second logistic regression model with the same covariates explored the relationship between congregate setting and testing positive for COVID-19 among the tested subgroup (n = 204). Adjusted OR with 95 % CI are again reported. All analyses were conducted with SAS software.

4. Results

Table 1 displays the characteristics of the entire study sample, as well as by testing status and result. Overall, the average age was 44.36 years (SD = 16.73), and the mean BMI was 28.28 kg/m$^2$ (SD = 9.07). One quarter was under 30 years and another quarter was 60 years or older. There were more males and most lived in private settings. Among those with a completed ID supplement, the nature of the IDD was unspecified for about half; there were similar proportions of participants diagnosed with autism and Down syndrome, and the remaining quarter had other genetic disorders. Almost half of the sample had severe cognitive impairment, and less than half had challenges with comprehension. Most walked (with or without assistive devices), and over three quarters required assistance in bathing, personal hygiene, and dressing. Approximately two-thirds required support in toilet use. About 35 % of required assistance with bed mobility and eating, and just over 40 % exhibited aggressive behaviour.

Some significant differences (p < .05) were noted across the three subgroups (Table 1). Compared to both other groups, those who tested positive were older (positive vs not tested = p < .0001; positive vs negative = p = .0003) and more often lived in a congregate setting (p < .0001). Those who tested positive also had a higher proportion of mobility issues (p < .001) and aggression (p = .0024), as well as dependence in bed mobility (p = .0299) and eating (p = .0499) compared to the not tested group. Compared to those not tested, those who tested negative more often lived in a congregate setting (p < .0001) and were more dependent in all considered activities of daily living with the exception of eating (p = .1054).

In the multivariate logistic regression model, age, living setting, aggression, and mobility were significantly associated with a positive COVID-19 test result (Table 2). There was an increasing effect of age, and those living in congregate settings had almost five times the odds of testing positive than those in private settings. Increased odds for limited mobility and aggression were 2.3 and 1.7, respectively. The interaction between age and congregate setting was not significant based on the log-likelihood ratio test (p = 0.07). The final model demonstrated a good fit (Hosmer-Lemeshow test value; p = 0.34) and no concerns with residuals, outliers, or multicollinearity were identified.

Age group and congregate setting were still significantly associated with testing positive for COVID-19 in the model restricted to

| Variable | Full sample (n = 833) | Those tested (n = 204) |
|----------|----------------------|-----------------------|
|          | OR       | 95 % CI   | p       | OR       | 95 % CI   | p       |
| Age (30–<45 years vs. < 30 years) | 1.13 | 0.45, 2.83 | 0.7921 | 1.75 | 0.63, 4.87 | 0.2828 |
| Age (45–<60 years vs. < 30 years) | 1.70 | 0.72, 4.00 | 0.2279 | 2.91 | 1.11, 7.61 | 0.0295 |
| Age (≥60 years vs. < 30 years) | 2.81 | 1.22, 6.47 | 0.0150 | 3.62 | 1.44, 9.10 | 0.0063 |
| Congregate setting vs. private or assisted | 4.95 | 2.73, 8.98 | <.0001 | 3.01 | 1.49, 6.09 | 0.0022 |
| Limited mobility vs. mobile | 2.30 | 1.37, 3.85 | 0.0016 | 1.02 | 0.53, 1.94 | 0.9645 |
| Any aggression vs. none | 1.73 | 1.03, 2.89 | 0.0375 | 1.16 | 0.61, 2.21 | 0.6490 |

Note. All models adjusted for age group, congregate setting, limited mobility, and aggression.
those tested (Table 2), though mobility and aggression were not significant. The model fit was good (Hosmer and Lemeshow test p = 0.80), and no concerns with residuals, outliers, or multicollinearity were noted.

5. Discussion

In the overall model, congregate setting, age, aggression, and limited mobility were significantly associated with testing positive for COVID-19. That congregate setting was associated with COVID-19 aligns with previous studies (Landes et al., 2020; Landes, Turk, Damiani, Proctor, & Baier, 2021), demonstrating similarity in trends in Ontario and the USA. As seen in long-term care and nursing homes, it is difficult to maintain social distance when providing support with activities of daily living to multiple people living in close quarters (Landes et al., 2020; Ouslander & Grabowski, 2020) and distancing is further complicated by the need for mobility support. The presence of aggression may also have led to additional support and close contact with others, thereby further increasing COVID-19 exposure risk.

In examining the subset of those tested, only age and congregate setting were significant, and changes in the effect estimates were noted (OR was smaller for congregate setting and larger for older age). This suggests that including those not tested may have biased the measure of association for congregate setting upwards as those not tested are assumed to be negative and are disproportionately live in private settings. Conversely, including untested individuals resulted in a more equal distribution of age groups in those who were considered not to have the outcome. Only including those tested skewed the age distribution towards older individuals, which resulted in a stronger association with age. The lack of statistical significance for mobility and aggression in the restricted analysis is likely due to lack of power introduced by the smaller sample size.

That older adults living in congregate settings (long-term care/nursing homes) are at increased risk of COVID-19 is known. However, the average age in those settings tends to be 80 years or older (Brown et al., 2021; Liu et al., 2021), whereas it was 44 years in the current study. The increased risk of testing positive was present starting at age 45 among those with IDD, suggesting that they face heightened risk for COVID-19 at a much younger age than the general population.

This study was impactful as it is the first to explore the influence of congregate setting on COVID-19 positive tests in Ontario. Of the Canadian studies to date, the focus has been on positivity, hospitalization, and mortality rates rather than risk factors for testing positive for COVID-19 (Lunsky et al., 2021). Further, given the comprehensive nature of the interRAI HC and ID supplement, this study explored multiple demographic and clinical variables. However, some important factors could not be considered. For example, as the number of residents in each congregate setting was not reported, setting size, number of residents, and crowding (e.g., mean number of occupants per room and bathroom, etc.) could not be explored (Brown et al., 2021). The study is also limited as some participants’ most recent assessments had been conducted before the pandemic. While re-assessments are completed if there is a significant change in status, some modifiable factors may have changed during this time. Lastly, it is possible that considering untested individuals as negative for COVID-19 could introduce false negatives, potentially resulting in differential misclassification of the outcome.

Future studies will include ongoing monitoring of this group of home care clients with IDD to understand the long-term impacts of testing positive for COVID-19 on physical health, mental health, behaviour, social and recreational activities, and service utilization – all of which are available in the interRAI assessments. Pandemic preparedness across regions in Canada and the impact on COVID-19 outcomes should also be examined to help identify policies and practices that were effective in managing the spread of COVID-19 among adults with IDD.

Living in a congregate setting, older age, aggression, and mobility were independent risk factors for testing positive for COVID-19. Persons with IDD also have a greater risk of testing positive for COVID-19 at a younger age than other populations living in congregate settings, such as older adults in long-term care facilities. This is especially concerning given the increased multimorbidity that individuals with IDD face, in that they could also experience worse COVID-19 outcomes. Policies and practices should be adapted to ensure that this high-risk group is explicitly considered during pandemics. Policymakers and stakeholders should look to regions, like the province of British Columbia, that more successfully managed COVID-19 in congregate settings (Liu et al., 2021). Adults with IDD living in congregate settings should be prioritized for vaccinations and other emergency public health measures (e.g., increased funding, limiting the number of residents sharing spaces, limiting the number of homes in which staff work, etc.) to ensure they are appropriately supported during any future emerging “Perfect Storms”.

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Data availability

These data are available to the corresponding author for research use as a Fellow of interRAI, and may not be transmitted to third parties. Those interested in using home care data can apply to the Canadian Institute for Health Information for access. Requests to access these datasets should be directed to https://www.cihi.ca/en/access-data-and-reports/make-a-data-request.

CRediT authorship contribution statement

Rebecca Hansford: Methodology, Software, Formal analysis, Writing - original draft, Writing - review & editing, Visualization. Héïène Ouellette-Kuntz: Conceptualization, Methodology, Writing - review & editing, Supervision, Project administration. Lynn
Martin: Conceptualization, Data curation, Writing - review & editing, Supervision, Project administration.

Declaration of Competing Interest

The authors report no declarations of interest.

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