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Original article

COVID-19 precautions experienced by a sample of adults with intellectual and developmental disabilities

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ABSTRACT

Purpose: This study describes factors associated with COVID-19 precautions (i.e., self-isolation and the use of personal protective equipment) among a sample of adults with intellectual and developmental disabilities (IDD) in Ontario, Canada.

Methods: The sample included 756 home care recipients with IDD who did not test positive for COVID-19 between March 2020 and July 2021. Among these, some received COVID-19 precautions. Precaution data were obtained from a large metropolitan organization serving persons with IDD in Ontario, and linked to home care assessment data. Unadjusted and adjusted odds ratios with 95% confidence intervals were calculated using logistic regression models to examine the association between COVID-19 cautions and demographic and clinical factors. Effect modification and interactions were explored.

Results: One hundred twenty-seven (16.8%) home care clients experienced precautions. After adjustment, congregate setting, aggression, and limited mobility were significantly associated with COVID-19 precautions. Age modified the relationship between congregate setting and precautions.

Conclusions: Pandemic responses need to recognize the impact on subgroups of adults with IDD, such as those living in congregate settings (including younger individuals) or engaging in responsive behaviors. How these precautions impacted individuals—in the short and long term—warrants further investigation.

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Introduction

The COVID-19 pandemic has had a significant impact on persons with intellectual and developmental disabilities (IDD). Multiple studies have reported an increased risk of COVID-19 diagnosis and mortality among those with IDD [1–5], and IDD status was one of the most significant predictors of COVID-19 mortality

Abbreviations: COVID-19, severe acute respiratory syndrome coronavirus 2; IDD, Intellectual and developmental disability; interRAI HC, inter Resident Assessment Instrument Home Care; ID supplement, Intellectual disability supplement; CPS, Cognitive Performance Scale; ABS, Aggressive Behaviour Scale; ADL, Activities of daily living; OR, Odds ratio; CI, Confidence intervals; SAS, Statistical Analysis System; MCAR, Missing Completely at Random; FET, Fisher's Exact Test; RERI, Relative Excess Risk due to Interaction; RERIOR, Relative Excess Risk due to Interaction (calculated with odds ratios).

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in the United States [1]. Increased age (OR = 1.04 per year; 95% CI, 1.02–1.06), Down syndrome (OR = 2.91; 95% CI, 1.49–5.69), chronic kidney disease (OR = 4.17; 95% CI, 1.90–9.15) [3], living in a congregate setting (OR = 3.01; 95% CI 1.49–6.09) [2], and living in settings with a higher number of residents (OR = 1.07; 95% CI, 1.0–1.14) [3] have been associated with COVID-19 diagnosis among adults with IDD. Heart disease (OR = 6.59, 95% CI 4.51, 9.62) and Down syndrome (OR = 10.60, 95% CI, 2.68–41.90) were also risk factors for COVID-19 mortality [3]. While these studies have helped to understand COVID-19 diagnosis, risk factors, and outcomes among adults with IDD, the experience of COVID-19-related precautions and quarantine has yet to be fully explored.

Isolation and precaution-related challenges among persons with IDD have been reported, including increased mental stress from restricting usual activities and missing social contact and closeness with others [6–9]. The restriction of usual activities may also lead to responsive behaviors and subsequent overreliance on psychotropic medication, and placement breakdowns [7]. Studies have

also reported on how COVID-19 precautions present challenges to families and providers who support adults with IDD [6,7,10]. Overall, these studies emphasize the importance of understanding the impact of COVID-19 precautions on individuals with IDD and the increased demands and subsequent stress that could arise for those supporting them. However, to date, no studies have reported on the proportion of adults with IDD who experience COVID-19 precautions, or on who is most likely to be affected. Given the heterogeneity of persons with IDD and their living arrangements, understanding potential interactions among risk factors is critical to inform risk identification and development of effective interventions.

While precautions play an important role in reducing the impacts of COVID-19, there is a sense that adults with IDD may have been at higher risk of experiencing precautions than other groups even when not testing positive for the infection. This study describes the demographic and clinical profiles of adults with IDD who did not test positive for COVID-19, and assesses the proportion of those who were still placed under COVID-19-related precautions (i.e., self-isolation and personal protective equipment (PPE) use requirements). It also identifies factors associated with precautions and explores their interaction.

Materials and methods

An observational cross-sectional design analyzing secondary anonymized data was used. Exemption from ethical review for secondary analysis of anonymized data was granted by the Research Ethics Board, as per the Tri-Council Policy Statement [11]. Data were linked and anonymized by the organization, and made available to the researchers.

Study population

The study population is based on a sample of home care users with IDD (≥ 18 years of age) within a large metropolitan area in Ontario (Canada) ($n = 756$). In Ontario, and elsewhere in Canada, home care services are provided to both people living in their own homes (alone, or with others), as well as in community-based residences (such as group homes) (Canadian Institute for Health Information (CIHI), 2022 [12]). Services provided include those over the short term (e.g., post-surgical recovery) or the longer-term (e.g., personal support and health care services to help people remain in the community; end-of-life care) [12]. A recent study found that home care users with IDD received a variety of services—from homemaking and meal support to therapies and nursing care [13].

Home care users were tested for COVID-19 between March 2020 and July 2021 if they exhibited relevant symptoms or had close contact with another person who tested positive. For the purposes of this study, those who tested positive for COVID-19 were ineligible. As such, the sample includes 756 home care users with IDD who had not received a COVID-19 diagnosis (tested = 127; not tested = 629).

Data and variables

All demographic and clinical variables used in this study came from two assessments conducted as part of regular practice: the interRAI Home Care (HC) instrument and the Intellectual Disability (ID) supplement. The interRAI HC is a comprehensive assessment used to plan home care services and supports, and contains over 200 items that includes demographic and clinical information related to key life domains (e.g., cognition, functioning, physical health, mental health, and service use) [14]. The ID supplement is based on the interRAI ID assessment [15] and provides key information specific to individuals with IDD (e.g., nature and severity of IDD). The assessments are conducted by clinicians (e.g., nurse,

social worker) who rely on interviews with the person, family, and other professionals involved in the person's care, as well as medical records and their own observations. The information from the assessment is then used to support care planning. Note that 141 HC assessments pre-dated the start of the pandemic (March 11, 2020), and ID supplement data were not available for 291 individuals.

Basic demographic variables included: age (<30 years; $30 \leq 45$ years; $45 \leq 60$ years; >60 years), sex (male, female), and living setting (congregate; private or assisted living). Functioning is described using items related to receptive communication (usually and/or often understands; never and/or sometimes understands), mobility (walking with or without assistive device; mobile device or bed-bound), and independence in activities of daily living (ADLs) (i.e., bathing, personal hygiene, dressing, toilet use, bed mobility, and eating). Two categories were created that reflected whether physical contact was needed to help the individual complete the ADL tasks (no physical contact = independent, set-up, or supervision; physical contact = limited physical assistance to total dependence). Note that the "dressing" variable combines two items on dressing (upper and lower body), and used the most dependent score. Scores on the Cognitive Performance Scale (CPS) were categorized into: intact to mild impairment (0–2), moderate impairment (3–4), and severe impairment (5–6) [16]. The Aggressive Behavior Scale (ABS) is based on four items (verbal abuse, physical abuse, resistance to care, and socially inappropriate disruptive behavior), with scores ranging from 0 (no signs of aggression) to 12 (more severe aggression) [17]. A LOESS curve was used to assess the linearity of ABS with COVID-19 precautions [18]. Based on the LOESS curve, a viable cut-off score at one was used (no aggression: 0; any signs of aggression: ≥ 1). Both the CPS and ABS have been validated in individuals with IDD [15]. The ID supplement provided details regarding the nature of IDD (e.g., Down syndrome, autism).

Precautions were assigned to individuals by the organization using standard coding rules. Here, "C19 caution" resulted in notification for self-isolation and use of PPE.

Analyses

Descriptive statistics were used to inform on the characteristics of the total sample ($n = 756$), and by receipt of COVID-19 precautions (yes vs. no). Associations with precautions were explored using Chi-Square tests (χ^2). Logistic regression models were conducted to determine the adjusted influence of relevant demographic and clinical variables on precautions. The nature of the missing data was examined with Little's MCAR Test resulting in the use of complete case analysis and reporting of the extent of missing data [19,20]. Unadjusted and adjusted odds ratios (OR) with 95% confidence intervals (CI) are reported. Manual backwards selection with a liberal P -value of .25 was used to calculate the adjusted ORs (in addition to the inclusion of age and sex). Residuals and outliers, goodness-of-fit, and multicollinearity were assessed.

Effect modification and interaction were considered in separate terms; effect modification considered the causal effect of one exposure within the strata of another exposure, while interaction examined the causal effects of the two exposures together [21]. Potential effect modifiers and interactions were identified a priori (effect modifiers = age*congregate setting; sex*aggression; interaction = congregate*aggression). Log likelihood-ratio tests were used to test for interaction and effect modification. The $-2 \log L$ for models with and without the interaction terms were compared, with $\alpha = 0.05$ set as the significance level. For interactions and effect modifiers with a significant p -value, multiplicative and additive effects were explored. Multiplicative effects were considered based on stratum-specific ORs. The relative excess risk due to interaction (RERI) and 95% CI were also calculated [22–24]. As the OR was found to approximate the RR in this sample (Supplemen-

tary file), the following formula was used to calculate the $RERI_{OR}$ [22,24]:

$$RERI_{OR} = OR(AB) - OR(A\bar{B}) - OR(\bar{A}B) + 1$$

Where:

$OR(AB)$ = Odds ratio of the outcome if both factors A and B are present

$OR(A\bar{B})$ = Odds ratio if factor A is present but not B

$OR(\bar{A}B)$ = Odds ratio if factor B is present but not A

Coding for the $RERI_{OR}$ and 95% CI were conducted using Appendix 1 in VanderWeele and Knol [23]. As age had multiple categories, the $RERI_{OR}$ was only calculated for the youngest and oldest age groups. Analyses were completed using SAS (SAS, 2013) [25].

Results

Table 1 displays the characteristics of the full sample, as well as by receipt of precautions. The mean age of the sample was 43.36 years (SD = 16.46), there were more males, and most lived in private or assisted living settings. Among those with an ID Supplement, about half had an unspecified nature of intellectual impairment, about 15% had an autism or Down syndrome diagnosis, and the remainder had other genetic diagnoses. Just under a third had no or mild cognitive impairment, whereas approximately 30% and 40% had moderate or severe impairment, respectively; fewer than half had severely impaired receptive communication. Just over two-thirds of individuals walked (with or without assistive devices), and over one third exhibited aggression. Over 80% of the sample required physical assistance in bathing and personal hygiene, whereas this was true for about three quarters for dressing and two-thirds for toilet use. The majority of the sample did not require physical assistance for bed mobility and eating. Approximately 17% of the sample received precautions.

Factors that differed significantly based on receipt of COVID-19 precautions were further examined in bivariate and multivariate models (Table 2). Before adjustment, all factors included in Table 2 were significantly associated with receipt of precautions (in addition to dependence in hygiene, OR = 1.86; 95% CI 1.03, 3.36; toilet use, OR = 1.97; 95% CI 1.24, 3.14; and bed mobility, OR = 1.71, 95% CI 1.15, 2.53). Following adjustment, age, sex, congregate setting, aggression, limited mobility, and dependence in bathing and dressing remained in the model. Congregate setting, aggression, and limited mobility were found to be significantly associated with precautions in the adjusted model. These estimates were also similar across the unadjusted and adjusted models. No issues were identified with model fit (Hosmer-Lemeshow test; $P = .051$), residuals, outliers, or multicollinearity.

Effect modification was explored for age and congregate setting, sex and congregate setting, and sex and aggression. The interaction between aggression and congregate setting was also considered. The log-likelihood ratio test was significant for age and congregate setting ($P = .04$). Further, the pseudo R^2 for the model with age*congregate setting was higher than the model without the product term (With product term: pseudo $R^2 = 0.073$; Without product term: pseudo $R^2 = 0.067$). Non-significant tests were identified for congregate setting and sex ($P = .32$), aggression and sex ($P = .051$), and congregate setting and aggression ($P = .15$). As such, only the influence of age on congregate setting was explored further.

Table 3 provides the single and joint effects, along with the distribution of persons with precautions and no precautions across the various age groups and living settings. For the single effects, those living in congregate settings had 2.13 increased odds of experiencing a precaution, while ORs were not significant across age. When considering joint effects, the combined risk for precautions

varied but was only significant and the highest for those residing in congregate settings and under 30 years of age compared to individuals living in private settings and over the age of 60 years (OR = 3.44; 95% CI 1.18, 10.08).

To explore effect modification on the multiplicative scale, age-specific ORs comparing congregate and private settings are reported (Table 4). There were increased odds of experiencing precautions associated with congregate setting for those under the age of 30 (OR = 4.64; 95% CI 1.84, 11.69); similar to joint effects, other ORs were not significant.

Effect modification was also explored on the additive scale. Table 5 displays the ORs for a logistic regression with only the youngest and oldest age groups ($n = 359$), as well as the $RERI_{OR}$ and 95% CIs. Since $RERI_{OR} > 1$, a positive additive interaction was demonstrated. However, this finding was not significant (95% CI -0.79, 6.03), and thus cannot confirm that the combined impact is greater than the addition of the individual effects of age and setting. It is rather a multiplicative effect, as demonstrated by the age-specific ORs.

Discussion

Living in a congregate setting, aggression, and limited mobility were significantly associated with experiencing COVID-19 precautions in the sample of home care users with IDD who did not have a COVID-19 diagnosis. Our study suggests that the increased risk of living in congregate setting applies not only to COVID-19 diagnoses and mortality, but also to precautions. Factors potentially resulting in increased contact with others were associated with COVID-19 precautions. Those living in congregate settings, engaging in aggression, and with limited mobility may have increased contact with others due to environmental, behavioral, and adaptive functioning factors, respectively. Similarly, those who require physical assistance with bathing and dressing may also be at increased risk for experiencing precautions, though these findings were not significant in the adjusted model. Attention should be paid to aggression, limited mobility, and residence in congregate settings as they were associated with precautions.

Age modified the relationship between congregate setting and COVID-19 precautions on the multiplicative scale. It was hypothesized that older individuals would be at an increased risk compared to those younger living in congregate settings. However, the opposite effect was observed. Younger individuals residing in congregate settings may have higher odds of receiving precautions than older individuals living in congregate settings for various reasons, including responsive behaviors that subsequently lead to increased physical contact with others and potential need for precautions. In addition, most individuals under 30 years of age do not reside in congregate settings. As such, younger adults in congregate settings may have more complex medical and behavioral profiles that require increased interaction and proximity with support workers. Lastly, those who tested positive for COVID-19 were not eligible, in order to focus on those experiencing precautions without a COVID-19 diagnosis. An earlier study identified that older age was associated with testing positive for COVID-19 [2]. It is possible that most of the older home care clients residing in congregate settings tested positive for COVID-19 and thus not included in this study. These findings emphasize that certain age groups residing in congregate settings may be at risk for different COVID-19 impacts. Such factors speak to the complexity of this population and should be considered when exploring the effect of COVID-19 precautions on adults with IDD residing in congregate settings.

Considering the impact of COVID-19 precautions is essential when supporting individuals with IDD during the pandemic. Courtenay and Perera (2021) emphasized that social distancing, quarantine requirements, and precautions including restrictions to

Table 1
Demographic and clinical characteristics of adults with IDD in the sample

	All (n = 756)		C-19 precautions (n = 127)		No C-19 precautions (n = 629)		X ² (P)
	n	%	n	%	n	%	
Age (years)							
<30 years	211	27.91	42	33.07	169	26.87	0.2265
30≤45 years	212	28.04	30	23.62	182	28.93	
45≤60 years	185	24.47	26	20.47	159	25.28	
≥ 60 years	148	19.58	29	22.83	119	18.92	
Sex							
Male	415	54.89	74	58.27	341	54.21	0.4022
Female	341	45.11	53	41.73	288	45.79	
Living setting							
Private or assisted	546	72.22	74	58.27	472	75.04	0.0001
Congregate	210	27.78	53	41.73	157	24.96	
Nature of impairment*							
Cause unspecified	225	29.76	37	29.13	188	29.89	0.308
Down syndrome	68	8.99	13	10.24	55	8.74	
Autism	72	9.52	16	12.6	56	8.9	
Other	100	13.23	25	19.69	75	11.92	
Missing	291	38.49	36	28.35	255	40.54	
Cognitive Performance Scale							
Intact to mild	226	29.89	39	30.71	187	29.73	0.6096
Moderate	234	30.95	43	33.86	191	30.37	
Severe	296	39.15	45	35.43	251	39.9	
Receptive communication							
Never or rarely understands	329	43.52	54	42.52	275	43.72	0.8034
Usually, often, or always understands	427	56.48	73	57.48	354	56.28	
Mobility							
Walking w/wo assistive device	530	70.11	74	58.27	456	72.5	0.0014
Mobility devices or bed-bound	226	29.89	53	41.73	173	27.5	
Aggressive behavior							
No aggression	463	61.24	65	51.18	398	63.28	0.0107
Any aggression	293	38.76	62	48.82	231	36.72	
Bathing							
Supervision or independent	77	10.19	–	–	–	–	0.0021
Assistance to total dependence	679	89.81	–	–	–	–	
Personal hygiene							
Supervision or independent	132	17.46	14	11.02	118	18.76	0.0362
Assistance to total dependence	624	82.54	113	88.98	511	81.24	
Dressing (combined)							
Supervision or independent	179	23.68	16	12.6	163	25.91	0.0013
Assistance to total dependence	577	76.32	111	87.4	466	74.09	
Toilet use†							
Supervision or independent	234	30.95	26	20.47	208	33.07	0.0037
Assistance to total dependence	480	63.49	95	74.8	385	61.21	
Missing	42	5.56	6	4.72	36	5.72	
Bed mobility†							
Supervision or independent	516	68.25	73	57.48	443	70.43	0.0076
Assistance to total dependence	237	31.35	52	40.94	185	29.41	
Missing	3	0.4	2	1.57	1	0.16	
Eating†							
Supervision or independent	503	66.53	77	60.63	426	67.73	0.1054
Assistance to total dependence	250	33.07	50	39.37	200	31.8	
Missing	3	0.4	0	0	3	0.48	

* Not available for n = 291 (n = 36 for those tested; n = 255 for those not tested).

† Missing data: n = 42 for toilet use, n = 3 for bed mobility and eating– Suppressed due to small cell count.

Table 2
Association between independent variables and COVID-19 precautions: unadjusted and adjusted odds ratios (OR) with 95% confidence intervals (CI)

Variable vs. Reference	Unadjusted*			Adjusted†		
	OR	95% CIs	P	OR	95% CIs	P
Congregate vs. private	2.15	1.45, 3.20	0.0001	2.13	1.36, 3.34	0.001
Any aggression vs. none	1.64	1.12, 2.41	0.011	1.76	1.16, 2.68	0.008
Limited mobility vs. mobile	1.89	1.27, 2.80	0.002	1.64	1.06, 2.55	0.028
Dependence in bathing vs. independent	4.04	1.45, 11.26	0.008	2.47	0.77, 7.98	0.13
Dependence in dressing vs. independent	2.43	1.40, 4.22	0.002	1.67	0.89, 3.24	0.13

* All models n = 756.

† Final model also adjusted for age and sex; n = 756.

Table 3
Descriptive summary across age groups and settings and ORs for single and joint effects

	Precautions (n)	No precautions (n)	Estimate	95% CI
ORs for single effects				
Private	74	472	1.0 (reference)	
Congregate	53	157	2.13	1.36, 3.34
≥60 years	29	119	1.0 (reference)	
45≤60 years	26	159	0.69	0.37, 1.26
30≤45 years	30	182	0.75	0.41, 1.37
<30 years	42	169	1.10	0.61, 1.99
ORs for joint effects				
Private and ≥60 years	11	63	1.0 (reference)	
Congregate and ≥60 years	18	56	1.41	0.59, 3.36
Private and 45≤60 years	13	105	0.63	0.26, 1.53
Congregate and 45≤60 years	13	54	0.95	0.38, 2.38
Private and 30≤45years	19	147	0.57	0.25, 1.29
Congregate and 30≤45years	11	35	1.28	0.49, 3.37
Private and <30 years	31	157	0.74	0.34, 1.61
Congregate and <30 years	11	12	3.44	1.18, 10.08

Note. Adjusted for sex, aggression, limited mobility, dependence in bathing, and dressing.

Table 4
Effect modification via multiplicative effects: Strata specific ORs for congregate versus private at each age group

Congregate vs. private by strata	OR	95% CIs
Congregate vs. private at <30 years	4.64	1.84, 11.69
Congregate vs. private at 30≤45	2.26	0.97, 5.26
Congregate vs. private at 45≤60	1.51	0.64, 3.56
Congregate vs. private at ≥60	1.41	0.59, 3.36

Note. Adjusted for sex, aggression, limited mobility, dependence in bathing, and dressing.

Table 5
Examining only the oldest and youngest age group to obtain RERI_{OR}

	Private		Congregate	
	OR	95% CIs	OR	95% CIs
≥60 years	1 (reference)	NA	1.30	0.52, 3.24
<30 years	0.66	0.30, 1.48	3.58	1.17, 10.96

Note. Measure for RERI_{OR} = 2.62 (95% CI–0.79, 6.03). Calculated using coding by VanderWeele and Knol [23]. Model adjusted for sex, aggression, limited mobility, dependence in bathing and dressing; n = 359.

usual activities may impact mental health and that such precautions may trigger responsive behaviors, which could have long-term consequences, including the use of psychotropic medications [7,8]. Given the potential for increased aggression among those who already display this type of behavior, the addition of precautions could potentially lead to staff burnout or other problems, such as placement breakdowns [7]. Overall, our study reveals the complexity inherent in supporting a diverse population and should be used to inform COVID-19-related planning moving forward (e.g., vaccination and booster prioritization; behavioral and mental health supports, etc.).

A strength of this study is that it provides an in-depth examination of potential effect modification present in social relationships and considers both additive and multiplicative effects. Studies exploring individuals with IDD tend to focus on risk factors and not explore potential effect modification, which could be pivotal to include given the heterogeneity of this population for required supports, and living situations. While the use of routinely collected home care assessment data allowed for examining a wide array of personal, functional, and clinical characteristics, missing ID supplement data and the timing of interRAI HC assessments present potential limitations. First, only a subset of home care clients had an ID supplement, meaning that there were limited data to inform on

the relationship between precautions and the nature of IDD. Second, specific information regarding the number of residents living in each setting was not available; therefore, the difference between private and congregate settings could not be characterized by the number of residents. Some individuals also had their interRAI HC and ID supplement assessments before the start of the pandemic, and so modifiable variables (such as the presence of aggression) may have changed between the assessment and COVID-19 testing or timing of the precautions.

Future studies will include ongoing monitoring of this group, which will be essential for understanding longitudinal changes in COVID-19 precautions among adults with IDD in Ontario. Over time, a larger sample and longer follow-up will be possible and could consider the impact of precautions on mental health, aggression, and the use of psychotropic medication, for example. As the interRAI HC also includes items related to the distress of informal caregivers, the mental health and capacity of such supports to continue supporting home care users with IDD in private settings over time could be examined. It would also be important to consider studies examining distress among paid caregivers supporting adults in congregate settings to fully understand the impact of the precautions on caregivers.

Conclusion

The large number of home care clients who experienced COVID-19-related precautions despite not receiving a COVID-19 diagnosis are concerning. While precautions, including self-isolation and PPE, are beneficial in decreasing the spread of COVID-19, they should be used judiciously given that individuals with IDD already face decreased opportunities to interact with others. These findings could be used to inform strategies to reduce the risk of precautions—for example, prioritizing individuals with IDD living in congregate settings, including younger individuals, for vaccinations and other health mental health, and behavioral supports.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:[10.1016/j.annepidem.2022.08.041](https://doi.org/10.1016/j.annepidem.2022.08.041).

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