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Original Study

# Social Engagement and Distress Among Home Care Recipients During the COVID-19 Pandemic in Ontario, Canada: A Retrospective Cohort Study

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## ABSTRACT

*Objectives*: To examine factors associated with distressing social decline and withdrawal during the COVID-19 pandemic for home care recipients.

Design: Retrospective cohort.

*Setting and participants:* Home care recipients age 18 years or older in Ontario, Canada without severe cognitive impairment with an assessment and follow-up between September 1, 2018 and August 31, 2020.

*Methods:* Data were collected using the interRAI home care. Outcomes of interest were distressing decline in social participation and social withdrawal. Independent variables were entered into multivariable longitudinal generalized estimating equations. Interaction terms with the pandemic were tested. Those significant at P < .01 were retained in final models and reported as odds ratios (ORs), 95% confidence intervals (CIs).

*Results:* We compared 26,492 and 19,126 home care recipients before and during the pandemic, respectively. The pandemic was associated with greater odds of experiencing distressing social decline (OR 1.28, 95% CI 1.22–1.34) and withdrawal (OR 1.09, 95% CI 1.04–1.15). Living alone (OR 1.13, 95% CI 1.05–1.22), frailty (OR 3.21, 95% CI 2.76–3.73), health instability (OR 2.22, 95% CI 2.02–2.44), and depression (OR 2.14, 95% CI 2.01–2.29) increased the odds of distressing social decline. Older age (OR 0.71, 95% CI 0.65–0.77), functional impairment (OR 0.58, 95% CI 0.51–0.67), and receiving caregiving (OR 0.73, 95% CI 0.67–0.79) decreased the odds. Home care recipients with mild/moderate dementia were less likely to experience distressing social decline during the pandemic. Those who lived alone were more likely. Frailty (OR 9.49, 95% CI 7.69–11.71) and depression (OR 2.76, 95% CI 0.25–3.00) increased the odds of social withdrawal. Functional impairment (OR 0.32, 95% CI 0.27–0.39), congestive heart failure (OR 0.77, 95% CI 0.70–0.84), and receiving caregiving (OR 0.50, 95% CI 0.46–0.55) decreased the odds. Home care recipients age 18–64 years and older than 75 years were less likely to experience social withdrawal during the pandemic.

*Conclusions and implications:* Social support interventions should focus on supporting those living alone, with frailty, health instability, or depression.

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The COVID-19 pandemic was declared by the World Health Organization on March 11, 2020. Public health measures to reduce disease

transmission were quickly implemented around the world, including

closure of nonessential businesses, stay-at-home orders, and physical

distancing. COVID-19 proved to be especially dangerous for vulnerable

populations and older adults, such as those receiving home care

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(home care), with an increased risk of long-term morbidity and mortality.<sup>1</sup> Subsequently, public health measures have been especially strict for this group.

Older adults have reported increased social isolation and loneliness during the pandemic.<sup>2</sup> Social isolation can be detrimental to mental and physical health. Social isolation, loneliness, and living alone have been reported to increase the risk for mortality by 29%, 26%, and 32% respectively.<sup>3</sup> Further, those who are socially isolated are more likely to experience disturbed sleep,<sup>4</sup> engage in less physical activity, have more sedentary time,<sup>5</sup> and develop depression and psychological distress.<sup>6</sup> The pandemic has further catalyzed an increase in psychological distress related to social isolation.<sup>7</sup> Indeed, adults in Canada had twice the odds of experiencing depressive symptoms during the pandemic compared with prepandemic.<sup>8</sup>

According to the Person-Environment Fit model,<sup>9</sup> psychological adjustment to stress is a function of the degree of fit between aspects of the social or physical environment and an individual traits. Viewing the pandemic through this model suggests that people receiving home care may have faced heightened vulnerability to stressors. Home care recipients have complex health conditions, including multimorbidity, mobility issues, cognitive impairment, recent hospitalizations, and need for assistance with instrumental and basic activities of daily living.<sup>10,11</sup> At the environmental level, home care recipients, particularly those with complex health conditions, rely on external sources of support to manage their health and wellness. Caregiving support often comes from both formal/paid sources (eg, nurses, therapists, personal support workers) and informal/unpaid sources (eg, family, friends, neighbors, and others with whom they have a social relationship).<sup>12</sup> The pandemic disrupted formal home care services as well as adult day programs and other community support services supporting home care recipients and caregivers. The pandemic also may have reduced contact with informal caregivers, especially in situations where the care recipient and caregiver do not live together. Taken together, the Person-Environment Fit model posits that vulnerable persons may have insufficient resources and support to adjust to major stressors such as a global pandemic.<sup>9</sup>

The purpose of our study is to examine the individual and environmental factors associated with distressing decline in social participation and social withdrawal as a measure of poor psychological adjustment to stress during the first wave of the COVID-19 pandemic for home care recipients in Ontario, Canada. Factors identified in this study will be used to develop a profile of who is at risk and suggest strategies that can proactively mitigate the risks associated with social isolation.

# Methods

### Study Design and Data Sources

Data for this retrospective study were obtained from the interRAI home care. In Ontario, Canada, the interRAI home care is used as part of routine clinical practice to gather person-level data on home care recipients who are expected to require home care services for at least 2 months. The interRAI home care is a standardized comprehensive assessment that covers physical functioning, cognition, mood, behavior, social functioning, disease and health conditions, health service, and medication utilization.<sup>13</sup> The interRAI home care is completed upon on home care admission and every 6 to 12 months thereafter, or earlier if there is a significant change in health status. It is completed by trained assessors who gather information from home care recipients, their family members, caregivers, and healthcare providers, and through chart review. It has been shown to be valid and reliable.<sup>13</sup> Assessments are typically completed in-person; however, in April 2020, Ontario temporarily changed methods of assessment to

minimize close contacts, including completing the assessments virtually.<sup>14</sup>

## Population

The comparison sample included all home care recipients with an interRAI home care assessment completed in the community between September 1, 2018 and February 28, 2019 and a second interRAI home care assessment completed in any setting (ie, community or hospital) between March 1, 2019 and August 31, 2019. We constructed the pandemic sample in a similar way, but between September 1, 2019 and August 31, 2020. We chose to have the baseline assessment for the pandemic sample prior to March 2020 to be able to describe change that resulted between baseline and follow-up because of the onset of the pandemic. We calculated the time between assessments as the number of days between the two assessments in each sample. We restricted the first assessment to the community as the characteristics of people receiving an assessment in hospital are different than those living at home (eg, to determine long-term care placement). We excluded all assessments completed in the Ontario Health West region since they chose to suspend use of the interRAI home care assessment during the first wave of the pandemic. Because our dependent variables required accurate self-report of response to a subjective change, we also excluded home care recipients with severe cognitive impairment defined as having a Cognitive Performance Scale score at their first assessment of 4 or higher. Sample preparation is described in Figure 1.

# Variables of Interest

The first dependent variable examined was a decline in level of participation in social activities in the last 90 days at their follow-up assessment which the home care recipient was distressed about.<sup>15–19</sup> The distressing social decline variable asks if there were changes in social activities in the last 90 days (or since the last assessment if less than 90 days ago) and is scored by assessors as 0 no decline, 1 – decline, not distressed, and 2 – decline, distressed. Social activities were defined as social, religious, occupational, or other preferred activities, and distress was self-reported by the home care recipient. For our study, we dichotomized this variable as the home care recipient experienced distressing social decline (score of 2) or not (score of 0 or 1). The second dependent variable was withdrawal from social activities.<sup>20</sup> The social withdrawal variable asks if person has withdrawn from activities of interest such as long-standing activities or being with friends and family is scored by assessors as 0 not present, 1- present but not exhibited in last 3 days, 2 - exhibited on 1-2 of last 3 days, and 3 - exhibited daily in last 3 days. For our study, we dichotomized this variable as the home care recipient exhibited social withdrawal on at least 1 of the last 3 days (score of 2 or 3) or not (score of 0 or 1). All items in the interRAI home care are based on the clinician's judgement of the most accurate response category using all sources of information available, including the person's self-report and responses provided by informal and formal caregivers. The first source of information is to ask the home care recipient. If they are unable to respond they will ask informal and formal caregivers to provide information to answer the question.

The independent variables were chosen based on items and scales available in the interRAI home care related to the person and environment constructs of the Person-Environment Fit Model and that demonstrated a relationship with social distress and withdrawal in previous literature. Within the person construct, we chose age,<sup>21,22</sup> sex,<sup>23</sup> frailty,<sup>3,24–26</sup> health instability,<sup>3,24–26</sup> hearing and vision,<sup>27</sup> functional abilities,<sup>23,28</sup> cognition,<sup>29–31</sup> depression,<sup>22</sup> and selected health conditions that affect cognition, physical, and mental health (ie, dementia,<sup>29–31</sup> congestive heart failure,<sup>32</sup> Parkinson disease,<sup>33</sup> and

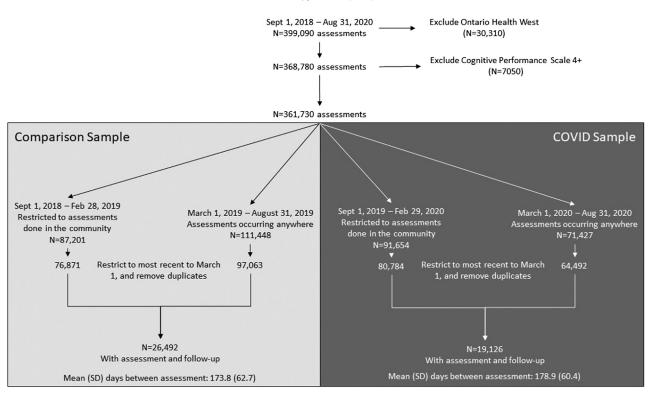


Fig. 1. Sample creation.

bipolar disorder<sup>34</sup>). Frailty was defined using the interRAI home care Frailty Scale which is 29-item scale that was developed from crossnational home care data and demonstrated criterion-related validity.<sup>35</sup> It is scored from zero or no frailty markers to a maximum of 29. Within the newer version of the interRAI home care there are no variables for 2 of the original scale items: "renal failure" and "loss of appetite." Thus, we constructed the scale to have 27 items and determined that the relationship between the 29 and 27 item scale was sufficient (r = 0.989). Healthy instability was defined with Changes in End-Stage Signs and Symptoms Scale, which is scored from 0 to 5 where 0 represents no health instability and 5 represents severe health instability.<sup>36–38</sup> Hearing and vision were defined with the Deafblind Severity Index, which is scored from 0 to 6, where 0 represents no impairment in either sense and 6 represents severe impairment in both senses.<sup>39,40</sup> The Functional Hierarchy Scale was used to describe functional abilities. It is scored from 0 to 11, where 0 indicates no basic or instrument activity of daily living impairment and 11 indicates severe impairment in all basic and instrumental activities of daily living.<sup>41</sup> Cognition was defined with the Cognitive Performance Scale, which is scored from 0 to 6 where 0 indicates no impairment and 6 indicates severe impairment.<sup>42</sup> As previously described, we excluded those with a Cognitive Performance Scale score of 4 or higher. Finally, depression was described with the Depression Rating Scale which is scored from 0 to 14, where 0 indicates no depressive symptoms and a score of 3 or above is associated with depression diagnoses.<sup>43,44</sup> Within the environment construct, we chose variables describing whether the person lives alone,<sup>45,46</sup> and their reported amount of time spent with other people through informal (eg, family and friends) and formal (eg, healthcare providers) care.<sup>47,48</sup> Informal care was defined as the total number of hours of care provided for instrumental and basic activities of daily living by a family, friend, or neighbour in the past 3 days. Formal care was the total number of minutes of care provided by personal support worker/home health aide, home nurse, homemaking services, physical therapy, occupational therapy, speech-language pathology and audiology services, and psychological therapy by any licensed mental health professional in the past 7 days.

# Data Analysis

Characteristics of the comparison and pandemic samples were expressed in count and percent and the  $\chi^2$  statistic was used to examine differences between the samples. All selected independent variables were entered into univariate longitudinal generalized estimating equations for each outcome of interest. Next, all independent variables were entered in an interaction with the pandemic variable for each outcome of interest. Final multivariate models were constructed by adding all variables and significant interaction terms to the model and retaining those significant at *P* < .01. All statistical analyses were completed in SAS v 9.4 (SAS Institute). This study was reviewed by and received research ethics board approval from the University of Waterloo and Dalhousie University.

# Results

There were 26,492 and 19,126 home care recipients in the comparison and pandemic samples, respectively. The time between assessment was on average 5 days longer in the pandemic sample, with a mean (standard deviation) of 178.9 (60.4) vs 173.8 (62.7) days in the comparison sample (Figure 1). There were small differences between the 2 samples in age, frailty, health instability, and cognition with the pandemic sample having a slightly lower proportion of home care recipients over the age of 85 years, and with no to mild frailty, health instability, or cognitive impairment (Table 1). A higher proportion of the pandemic sample declined in their social activities and were distressed about it [n (%): pandemic 3986 (15.0); comparison 3549 (18.6), P < .001] and withdrew from social activities [n (%):

#### Table 1

Baseline Descriptive Statistics of Home Care Recipients in Comparison and Pandemic Sample

Comparison Sample $n = 26,492$ (%)	Pandemic Sample $n = 19,126$ (%)	χ <sup>2</sup> P Value
3214 (12.1)	2541 (13.3)	
4273 (16.1)	3148 (16.5)	
8660 (32.7)	6172 (32.3)	
10,345 (39.1)	7265 (38.0)	.001
16,497 (62.3)	11,851 (62.0)	.502
2560 (9.7)	1727 (9.0)	
4862 (18.4)	3711 (19.4)	
7017 (26.5)	5172 (27.0)	
4805 (18.1)	3243 (17.0)	
3683 (13.9)	2670 (14.0)	
3565 (13.5)	2603 (13.6)	.001
4653 (17.6)	2912 (15.2)	
14,959 (56.5)	10,886 (56.9)	
6880 (26.0)	5328 (27.9)	<.001
8496 (32.1)	6000 (31.4)	
10,573 (39.9)	7784 (40.7)	
		.178
2432 (9.2)	1718 (9.0)	
5404 (20.4)	4025 (21.0)	
14,948 (56.4)	10,723 (56.1)	
		.386
7318 (27.6)	4958 (25.9)	
	. ,	<.001
12.872 (48.6)	9269 (48.5)	
	. ,	
		.004
		.009
	. ,	.986
	. ,	.018
	. ,	.181
		.468
,		
15 929 (60 1)	11 609 (60 7)	
	. ,	.276
3322 (19.7)		.270
8674 (32.7)	6155 (32.2	
. ,		
	. ,	.417
	. ,	<.001
		.002
	4273 (16.1) 8660 (32.7) 10,345 (39.1) 16,497 (62.3) 2560 (9.7) 4862 (18.4) 7017 (26.5) 4805 (18.1) 3683 (13.9) 3565 (13.5) 4653 (17.6) 14,959 (56.5) 6880 (26.0) 8496 (32.1) 10,573 (39.9) 7423 (28.0) 2432 (9.2)	$\begin{array}{ccccc} 4273 (16.1) & 3148 (16.5) \\ 8660 (32.7) & 6172 (32.3) \\ 10.345 (39.1) & 7265 (38.0) \\ 16.497 (62.3) & 11.851 (62.0) \\ \hline \\ 2560 (9.7) & 1727 (9.0) \\ 4862 (18.4) & 3711 (19.4) \\ 7017 (26.5) & 5172 (27.0) \\ 4805 (18.1) & 3243 (17.0) \\ 3683 (13.9) & 2670 (14.0) \\ 3565 (13.5) & 2603 (13.6) \\ \hline \\ 4653 (17.6) & 2912 (15.2) \\ 14.959 (56.5) & 10.886 (56.9) \\ 6880 (26.0) & 5328 (27.9) \\ \hline \\ 8496 (32.1) & 6000 (31.4) \\ 10.573 (39.9) & 7784 (40.7) \\ 7423 (28.0) & 5342 (27.9) \\ \hline \\ 2432 (9.2) & 1718 (9.0) \\ 5404 (20.4) & 4025 (21.0) \\ 14.948 (56.4) & 10.723 (56.1) \\ 3708 (13.0) & 2660 (13.9) \\ \hline \\ 7318 (27.6) & 4958 (25.9) \\ 19.174 (72.4) & 14.168 (74.1) \\ \hline \\ 12.872 (48.6) & 9269 (48.5) \\ 7376 (27.8) & 5555 (29.0) \\ 6244 (23.6) & 4302 (22.5) \\ 7495 (28.3) & 5197 (27.2) \\ 3668 (13.9) & 2647 (13.8) \\ 1694 (6.4) & 1120 (5.9) \\ 474 (1.8) & 375 (2.0) \\ 9380 (35.4) & 6835 (35.7) \\ \hline \\ 15.929 (60.1) & 11.609 (60.7) \\ 6941 (26.2) & 4995 (26.1) \\ 3622 (13.7) & 2522 (13.2) \\ \hline \\ 8674 (32.7) & 6155 (32.2 \\ 12.818 (48.4) & 9358 (48.9) \\ 3963 (15.0) & 3549 (18.6) \\ \hline \end{array}$

pandemic 2983 (11.3), comparison 2336 (12.2), P = .002] than in the comparison sample.

Table 2 shows the results of the bivariate analyses for both outcomes. The pandemic was associated with greater odds of experiencing social decline and being distressed and social withdrawal. Those with frailty, health instability, depression, Parkinson disease, bipolar disorder, or who lived alone were more likely to experience social decline and be distressed. However, those who were older, male, had functional or cognitive impairment, dementia, and received informal or formal care were less likely to have those outcomes. Frailty, health instability, vision and hearing impairment, functional or cognitive impairment, depression, dementia, Parkinson disease, bipolar disorder, living alone, and receiving informal care increased the odds of social withdrawal while being in an older age group (compared with those 18–64 years old) and receiving formal care decreased the odds.

Table 2 shows the final multivariate models for the 2 dependent variables. Home care recipients living with frailty, health instability,

or depression had higher odds of experiencing social decline that was distressing while those who were older, had functional impairment, and received informal or formal care had lower odds. For the outcome of distressing social decline there was a significant interaction between the pandemic and dementia: home care recipients with dementia during the pandemic were less likely to experience social decline and report being distressed than those without (Figure 2). In contrast, home care recipients who lived alone were more likely to experience social decline and report being distressed during the pandemic (Figure 2). Home care recipients who were frail, depressed, and lived alone were more likely to experience social withdrawal while those who had functional impairment, dementia, congestive heart failure, and received informal or formal care were less likely. There was also a significant interaction between the pandemic and age for the outcome of social withdrawal where home care recipients age 18-64 years and older than 75 years were less likely to experience social withdrawal during the pandemic (Figure 2).

Results of Bivariate and Multivariable Models Examining the Association between Distressing Social Decline and Social Withdrawal and the Independent Variables

	Social Decline, Distressed		Social Withdrawal	
	Bivariate	Multivariable	Bivariate	Multivariable
Characteristics	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
Pandemic (REF = no pandemic)	1.28 (1.22-1.34)	1.09 (1.02-1.17)	1.09 (1.04-1.15)	0.86 (0.74-1.00)
Age, y				
18-64	REF	REF	REF	REF
65-74	0.90(0.83 - 0.99)	0.93 (0.85-1.02)	1.09(0.98 - 1.22)	0.93 (0.81-1.07)
75-84	0.76 (0.71-0.83)	0.83 (0.76-0.90)	0.94(0.85 - 1.03)	0.73 (0.64-0.83)
85+	0.64 (0.59-0.69)	0.71 (0.65-0.77)	0.85 (0.78-0.94)	0.67 (0.59-0.76)
Sex (REF = female)	0.91 (0.87-0.96)	=	1.06(1.00-1.13)	(
InterRAI Home Care Frailty Scale				
0-6 (no to mild frailty)	REF	REF	REF	REF
7–9	1.18 (1.06–1.32)	1.34 (1.19–1.51)	1.45(1.22 - 1.73)	1.88 (1.55-2.28)
10-12	1.29 (1.16–1.43)	1.67 (1.48–1.90)	2.00 (1.70–2.35)	3.23 (2.66–3.93)
13-14	1.41 (1.26–1.57)	1.98 (1.73–2.27)	3.07 (2.61–3.62)	5.82 (4.74-7.15)
15-16	1.62 (1.45–1.82)	2.33 (2.02-2.69)	4.55 (3.86-5.36)	9.49 (7.69–11.71)
17–27 (severe frailty)	2.27 (2.03-2.53)	3.21 (2.76-3.73)	8.85 (7.53–10.38)	20.88 (16.87-25.84
Changes in End-Stage Signs and Symptoms Scale	2.27 (2.05-2.55)	5.21 (2.76-5.75)	8.85 (7.55-10.58)	20.88 (10.87-23.84
0 (no instability)	REF	REF	REF	
1-2 (mild instability)		1.52 (1.40–1.66)		_
	1.78 (1.64–1.94)	. ,	1.46 (1.32–1.60)	-
3+ (moderate to severe instability)	3.12 (2.85-3.41)	2.22 (2.02-2.44)	2.69 (2.44-2.97)	-
Deafblind Severity Index	DEE		DEE	
0 (none)	REF	-	REF	-
1–2 (mild)	0.96 (0.90-1.02)	-	1.11 (1.03–1.19)	-
3+ (moderate to severe)	1.01 (0.95-1.08)	-	1.37 (1.27-1.48)	-
Functional Hierarchy Scale				
0-2 (minimal impairment)	REF	REF	REF	REF
3-4 (mild impairment)	0.88 (0.80-0.97)	0.76 (0.68-0.85)	1.16 (1.02–1.32)	0.69 (0.59-0.81)
5-8 (moderate impairment)	0.85 (0.78-0.93)	0.61 (0.54-0.68)	1.34 (1.134–1.69)	0.49 (0.42-0.57)
9–11 (severe impairment)	1.06 (0.96-1.18)	0.58 (0.51-0.67)	1.73 (1.52–1.97)	0.32 (0.27-0.39)
Cognitive Performance Scale				
0–1 (no to mild impairment)	REF	-	REF	-
2-3 (mild to moderate impairment)	0.80 (0.74-0.83)	-	1.29 (1.21-1.39)	-
Depression Rating Scale				
0 (none)	REF	REF	REF	REF
1-2 (mild)	1.68(1.58 - 1.79)	1.50 (1.41-1.60)	2.10 (1.95-2.27)	1.68 (1.55-1.82)
3+ (moderate)	2.64 (2.48-2.81)	2.14 (2.01-2.29)	4.13 (3.84-4.44)	2.76 (2.55-3.00)
Dementia ( $REF = no dementia$ )	0.61(0.57 - 0.65)	0.46(0.42 - 0.51)	1.26 (1.18-1.34)	0.81 (0.75-0.87)
Congestive heart failure (REF = no heart failure)	1.03 (0.96–1.11)	0.84 (0.77-0.90)	1.07 (0.98–1.16)	0.77 (0.70–0.84)
Parkinson disease (REF = no Parkinson)	1.11 (1.00–1.23)	-	1.25 (1.12–1.41)	-
Bipolar disorder (REF = no bipolar disorder)	1.24 (1.04–1.49)	_	1.60 (1.33–1.93)	_
Lives alone (REF = does not live alone)	1.22 (1.16–1.28)	1.13 (1.05-1.22)	0.96 (0.90-1.02)	1.23 (1.15-1.32)
Informal care	1.22 (1.10 1.20)	1.15 (1.05 1.22)	0.30 (0.30 1.02)	1.25 (1.15 1.52)
0–10 h	REF	REF	REF	REF
10–20 h	0.89(0.84 - 0.94)	0.87 (0.81-0.93)	1.13 (1.05–1.21)	0.81 (0.75–0.87)
20+h	0.89(0.84-0.94) 0.95(0.88-1.03)	0.87(0.81-0.93) 0.84(0.77-0.92)	1.13(1.03-1.21) 1.32(1.22-1.44)	0.81(0.75-0.87) 0.76(0.69-0.84)
Formal h	0.95 (0.88-1.03)	0.84 (0.77-0.92)	1.32 (1.22–1.44)	0.76 (0.69-0.84)
	DEC	DEE	DEE	DEE
0–100 min	REF	REF	REF	REF
100-500 min	0.94 (0.89-1.00)	0.84 (0.79-0.89)	0.94 (0.88-1.00)	0.73 (0.68-0.78)
500+ min	0.94 (0.87-1.01)	0.73 (0.67-0.79)	0.94 (0.87-1.03)	0.50 (0.46-0.55)
Interaction terms				
Pandemic*dementia	n/a	1.35 (1.20–1.52)	n/a	-
Pandemic*lives alone	n/a	1.24 (1.13-1.38)	n/a	-
Pandemic*age group, y	n/a	-	n/a	-
18-64	n/a	-	n/a	REF
65-74	n/a	-	n/a	1.27 (1.04-1.55)
75-84	n/a	-	n/a	1.33 (1.11-1.59)
85+	n/a	_	n/a	1.35 (1.13-1.61)

CI, confidence interval; n/a, not applicable.

Asterisk (\*) signifies an interaction term.

## Discussion

Our study found that the pandemic was independently associated with distressing social decline and social withdrawal, and there were significant interactions between the pandemic and dementia, living alone, and age. Increased time with informal or formal caregivers may be protective against social decline and withdrawal. Social support interventions should focus on supporting home care recipients living alone, with frailty, health instability, or depression, particularly during public health crises like the COVID-19 pandemic. Although some independent variables had a small effect on the odds of experiencing distressing social decline and withdrawal (eg, living alone, informal care), others had a large effect (eg, frailty, functional impairment) indicating that some factors may have had a more potent effect.

During the pandemic, home care recipients with dementia were less likely to experience social decline and report being distressed than those without. Typically, as dementia progresses more help is required from social networks that could increase their contact with network members, which may have been especially true during the pandemic. Previous work has found that social isolation may decrease

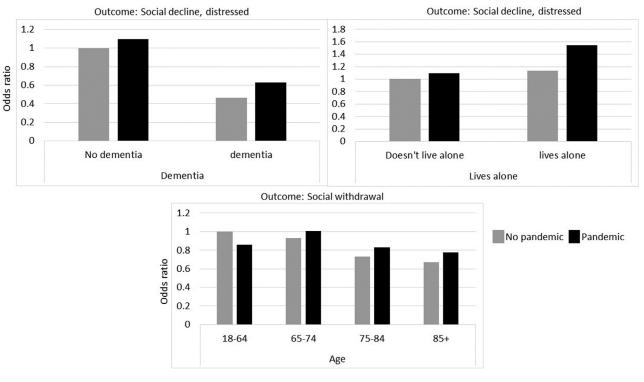


Fig. 2. ORs for interactions terms in final multivariate models.

as dementia severity increases<sup>29</sup> and suggests this may be because older adults with dementia have more extensive caregiving networks than those without.<sup>30</sup> A study examining the perceived impact of physical distancing measures for older adults with dementia receiving home care during the pandemic found that those with mild dementia were coping relatively well emotionally because of good support systems, though experiencing physical declines because of decreased physical activity.<sup>31</sup>

A second interaction was found between the pandemic and living alone, the pandemic magnified the odds that home care recipients who lived alone would experience social decline. Although this risk was present among those who lived alone prior to the pandemic, the strength of the association was magnified in the context of the first 2 waves of the pandemic. Limited social interactions such as living alone can lead to maladaptation to stress such as avoidance and withdrawal, which were likely exacerbated by physical distancing measures.<sup>45,46</sup> The OR for living alone was small, indicating that living alone does not strongly predict distressing social decline or withdrawal. Previous work has found similar results with living alone contributing to a small extent to the development of new-onset psychiatric disorders throughout the pandemic.<sup>49</sup> For some, living alone is not seen as a problem as they are resilient and maintain satisfactory social relations with family and peers, while for others living alone is more problematic.<sup>50</sup> Individual variation in coping strategies for living alone through the pandemic could explain our small OR.

Finally, home care recipients who are younger than 65 years or older than 75 years were less likely to experience social withdrawal during the pandemic. The observed pattern is likely because younger people who are receiving home care have extremely complex health conditions and live with their family or other caregivers. During the pandemic, their social interactions likely did not change substantially, and their social networks remained robust in comparison to other home care recipients who decreased their social contacts to prevent disease transmission. On the other end of the age spectrum, previous work has found that older age is associated with decreased rates of isolation and loneliness.<sup>21</sup> Those who are older may also live with more health conditions requiring increased hours of informal and formal support, increasing their social contacts. These hypotheses warrant further investigation in future studies.

Within the environment construct of the Person-Environment Fit model, factors in our study significantly associated with distressing social decline and social withdrawal were living alone and receiving informal and formal care. In accordance with our results, previous work has found that social connections that include family members, friends, or healthcare workers protect against depression by buffering the effects of stress and enhancing coping abilities.<sup>47,48</sup> home care recipients with limited social resources would likely benefit from strategies to prevent further decline in mood. A study by Wu et al<sup>51</sup> found that writing to friends and increasing in-person family time were 2 social interventions that showed promise for mitigating low mood for older adults with limited social resources.

At the person level, frailty and depression were associated with increased risk for social decline and withdrawal. Previous work has also found greater frailty is associated with increased risk of experiencing more social isolation<sup>24</sup> and loneliness.<sup>25</sup> Our results indicate that increasing levels of frailty were associated with increased odds of distressing social decline and withdrawal, particularly for those living with severe frailty. The relationship between frailty and social isolation appears to be bidirectional: frail older adults are more likely to have fewer and smaller social networks<sup>26</sup> but social functioning has also been associated with poor health outcomes like frailty.<sup>3</sup> Regardless, the public health measures intended to decrease the spread of COVID-19 throughout the pandemic have decreased social interaction. For those who are frail with already small social networks this decrease may have been especially distressing. For those living with depression, social support is associated with the presence, severity, and outcome of depression.<sup>22</sup> Adults over the age of 70 years are especially vulnerable to losing social support when they are experiencing psychological distress and being distressed when they lose support.<sup>22</sup> Physical distancing measures imposed by the pandemic caused many people to lose in-person support out of fear of spreading the virus to vulnerable populations such as like those receiving home care. For those already experiencing psychological distress, the loss of social contacts likely resulted in increased distress and withdrawal. Although many older adults transitioned to virtual modes (eg, phone calls, video chat, email) of social connection during the pandemic,<sup>52,53</sup> some found it challenging and not as fulfilling as in-person interactions.<sup>54</sup>

### Strengths and Limitations

A strength of study is we had a comparison sample that captured 1 year of data for home care recipients in Ontario prior to the pandemic, allowing us to explore the effect of the pandemic separate from the average rate of decline occurring in home care in addition to individual and environmental traits on our outcomes. However, there are limitations with our data. Although there was a shift to complete assessments virtually after March 2020, many home care services were also suspended to limit contact with people outside the household resulting in fewer overall assessments completed. The number of comprehensive interRAI home care assessments decreased by 44% while nursing and occupational and physical therapy services decreased by 8.5% and 40.2%, respectively in April 2020.<sup>14,55</sup> Decreased volumes did eventually rebound, for example, volumes of services provided reached more than 90% of prepandemic averages by September 2020.<sup>55</sup> A previous study by our group confirmed that home care recipients assessed during the first wave of the pandemic had worse health instability, communication impairment, and cognitive impairment compared with the previous year.<sup>55</sup> The differences we observed in our comparison and pandemic samples were small, and statistical differences may have been due to our large sample size. However, similar to our previous work we cannot determine whether the differences are related to prioritization of complex home care recipients or real change in health status of the population.

## **Conclusions and Implications**

In our study, the pandemic was independently associated with distressing social decline and social withdrawal and there were significant interactions between the pandemic and dementia, living alone, and age. Increased time with informal or formal caregivers may be protective against social decline and withdrawal. Social support interventions should focus on home care recipients living alone, with frailty, health instability, or depression to reduce social decline and withdrawal, particularly during public health crises like the COVID-19 pandemic.

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