JAMDA

Brief Report

Impact of the COVID-19 Pandemic on Home Care Services Among Community-Dwelling Adults With Dementia

Aaron Jones PhD [a,b,*], Laura C. Maclagan MSc [a], Connie Schumacher RN, PhD [c], Xuesong Wang MSc [a], R. Liisa Jaakkimainen MD, MSc [a,d,e], Jun Guan MSc [a], Richard H. Swartz MD, PhD [a,d,f], Susan E. Bronskill PhD [a,d,g]

[a] ICES, Toronto, Ontario, Canada
[b] Department of Health Research Methods, Evidence, and Impact, McMaster University, Hamilton, Ontario, Canada
[c] Department of Nursing, Brock University, St Catharines, Ontario, Canada
[d] Sunnybrook Research Institute, Sunnybrook Health Sciences Centre, Toronto, Ontario, Canada
[e] Department of Family and Community Medicine, University of Toronto, Ontario, Canada
[f] Department of Medicine (Neurology), University of Toronto, Toronto, Ontario, Canada
[g] Dalla Lana School of Public Health, University of Toronto, Ontario, Canada

ABSTRACT

Keywords:
Dementia
COVID-19
home care services
time series analysis

Objective: To examine how the COVID-19 pandemic impacted use of home care services for individuals with dementia across service types and sociodemographic strata.
Design: Population-based time series analysis.
Setting and Participants: Community-dwelling adults with dementia in Ontario, Canada, from January 2019 to September 2020.
Methods: We used health administrative databases (Ontario Registered Persons Database and Home Care Database) to measure home care services used by participants. Poisson regression models were fit to compare weekly rates of home care services during the pandemic to historical trends with rate ratios (RRs) and 95% confidence intervals (CIs) stratified by service type (nursing, personal care, therapy), sex, rurality, and neighborhood income quintile.
Results: During the first wave of the pandemic, personal care fell by 16% compared to historical levels (RR 0.84, 95% CI 0.84, 0.85) and therapies fell by 50% (RR 0.50, 95% CI 0.48, 0.52), whereas nursing did not significantly decline (RR 1.02, 95% CI 1.00, 1.04). All rates had recovered by September 2020, with nursing and therapies higher than historical levels. Changes in services were largely consistent across sociodemographic strata, although the rural population experienced a larger decline in personal care and smaller rebound in nursing.
Conclusions and Implications: Personal care and therapies for individuals with dementia were interrupted during the early months of the pandemic, whereas nursing was only minimally impacted. Pandemic responses with the potential to disrupt home care for individuals living with dementia must balance the impacts on individuals with dementia, caregivers, and providers.

© 2021 AMDA − The Society for Post-Acute and Long-Term Care Medicine.

The COVID-19 pandemic disrupted health service delivery across health systems, particularly during the first months of local community transmission.[1] Significant drops in the volume of ambulatory care occurred as services were canceled, delayed, or shifted to virtual settings to reduce the risk of COVID-19 transmission.[2,3] Although some North American studies have shown that a number of the services that fell in the spring of 2020 had recovered by late summer and early fall, the recoveries were not necessarily equivalent across demographic and geographic groups.[4,5]

The disruption of health services can be particularly challenging for people living with dementia in the community, many of whom receive essential care from a variety of health care providers.[6] Individuals with dementia in Ontario access a variety of different publicly provided home care services, including personal care, nursing, and various professional services such as physiotherapy and occupational therapy.[7] Differences in the typical urgency of these services may have led to them being differentially affected by the pandemic. In addition, given evidence that the pandemic is exacerbating existing inequalities,[8,9] it is important to examine whether the impact of the pandemic was distributed equally across sociodemographic dimensions.

The objective of this study was to investigate how the rates of home care services provided to community-dwelling adults living with dementia changed during the initial phases of the COVID-19 pandemic. Specifically, we examined rates of use across service types of personal care, nursing, and therapies and additionally examined whether the changes in rates were equivalent across strata defined by rurality, sex, and neighborhood income.

Methods

Study Design and Setting

We performed a population-based time series analysis of home care service use among community-dwelling adults with dementia in Ontario, Canada. Ontario is Canada's most populous province with a population of nearly 15 million individuals.

Data Sources

Population-based health administrative databases were linked using unique encoded identifiers and analyzed at ICES. Databases used include the Ontario Registered Persons Database, used to identify participant demographics, and the Home Care Database, used to identify publicly funded home care services. The use of data in this project is authorized under section 45 of Ontario's Personal Health Information Protection Act and does not require review by a Research Ethics Board.

Participants

We included all community-dwelling adults with dementia in Ontario aged 40 years and older who were eligible for Ontario's publicly funded health insurance at the start of each week between January and September 2019 (historical period) and 2020 (pandemic period). Individuals with dementia were identified using a validated health data administrative algorithm.[10] Eligibility was determined on a week-by-week basis, meaning that the participants were not a fixed cohort but could vary over time.

Measures

Home care services included personal care, nursing, and therapies (physiotherapy, occupational therapy, speech language therapy, nutritional therapy, and social work). Rates of weekly home care visits were calculated across 3 strata: sex, rurality (rural/urban), and neighborhood income quintile (Q1, lowest; Q5, highest). Rurality was defined by the Rurality Index of Ontario,[11] with values higher than 40 considered rural, and neighborhood income quintile was defined using Statistics Canada census data.[12] Sex, rurality, and income quintile were chosen as strata as they have been previously tied to inequalities in access to care that could be exacerbated by the pandemic.[13,14]

Analysis

We plotted the weekly rate of home care visits per 100 individuals, stratified by service type, sex, rurality, and neighborhood income quintile during both time periods. We used Poisson regression models with year as the sole independent variable to calculate rate ratios (RRs) and 95% confidence intervals (CIs) for each weekly rate in the pandemic period (2020) compared to the corresponding historical week (2019). Models were run overall and stratified by the selected sociodemographic variables. We reported RRs for the week with the lowest home care service rate in 2020 per strata, as well as the latest week in the analysis (end of September). Analyses were performed with SAS, version 9.4 (SAS Institute, Inc, Cary, NC).

Results

The number of community-dwelling adults with dementia was 131,466 as of the first week of March 2020 (and varied slightly from week to week across the time series). Persons with dementia had a median age of 80 years, 57.5% were female, and 9.2% resided in rural regions. The average rate of home care services per 100 individuals per week in 2019 was 13.1 for nursing, 179.7 for personal care, and 4.1 for therapies. Previous work indicates that individuals receiving nursing and therapies tend to be younger, have fewer functional and cognitive impairments, and more likely to be post-acute compared with patients receiving personal support.[15]

Time series plots indicate significant declines in personal care visits beginning in mid-March 2020 (Figure 1). At the lowest point, this corresponded to a 16% reduction (RR 0.84, 95% CI 0.84, 0.95) compared with the same week in 2019 (Table 1). By the end of September, the rate had recovered to the 2019 level (RR 0.99, 95% CI 0.99, 1.00) (Table 2). For reference, Ontario declared a state of emergency due to the COVID-19 pandemic on March 17, 2020,[16] and nonessential businesses and workplaces were closed on March 24, 2020.[17] A regional, graduated reopening began on June 12, 2020, and stretched across the summer.[18] Individuals in rural areas experienced a slightly larger decline (RR 0.77, 95% CI 0.75, 0.79, vs urban 0.84, 95% CI 0.84, 0.85) but similar recovery. Those living in areas with the highest income (Q5) also experience larger initial declines.

The trend for nursing visits appeared to dip slightly at the start of the pandemic but the lowest weekly rate in April 2020 was similar to that in 2019 (RR 1.02, 95% CI 1.00, 1.04). By the end of September 2020, the rate of nursing visits was 14% higher than 2019 (RR 1.14, 95% CI 1.11, 1.16). However, the rural population did not experience an increase in nursing visits in 2020 vs 2019 (RR 0.99, 95% CI 0.92, 1.07).

The rate of therapies declined dramatically through March and April 2020, reaching half of the level of 2019 (RR 0.50, 95% CI 0.48, 0.52). By the end of the September 2020, the overall rate was somewhat higher than that of 2019 (RR 1.11, 95% CI 1.07, 1.15). A full set of model results is available in Supplementary Table 1.

Discussion

Public home care services provided to community-dwelling adults living with dementia were interrupted during the first few months of the COVID-19 pandemic (March and April 2020) but recovered
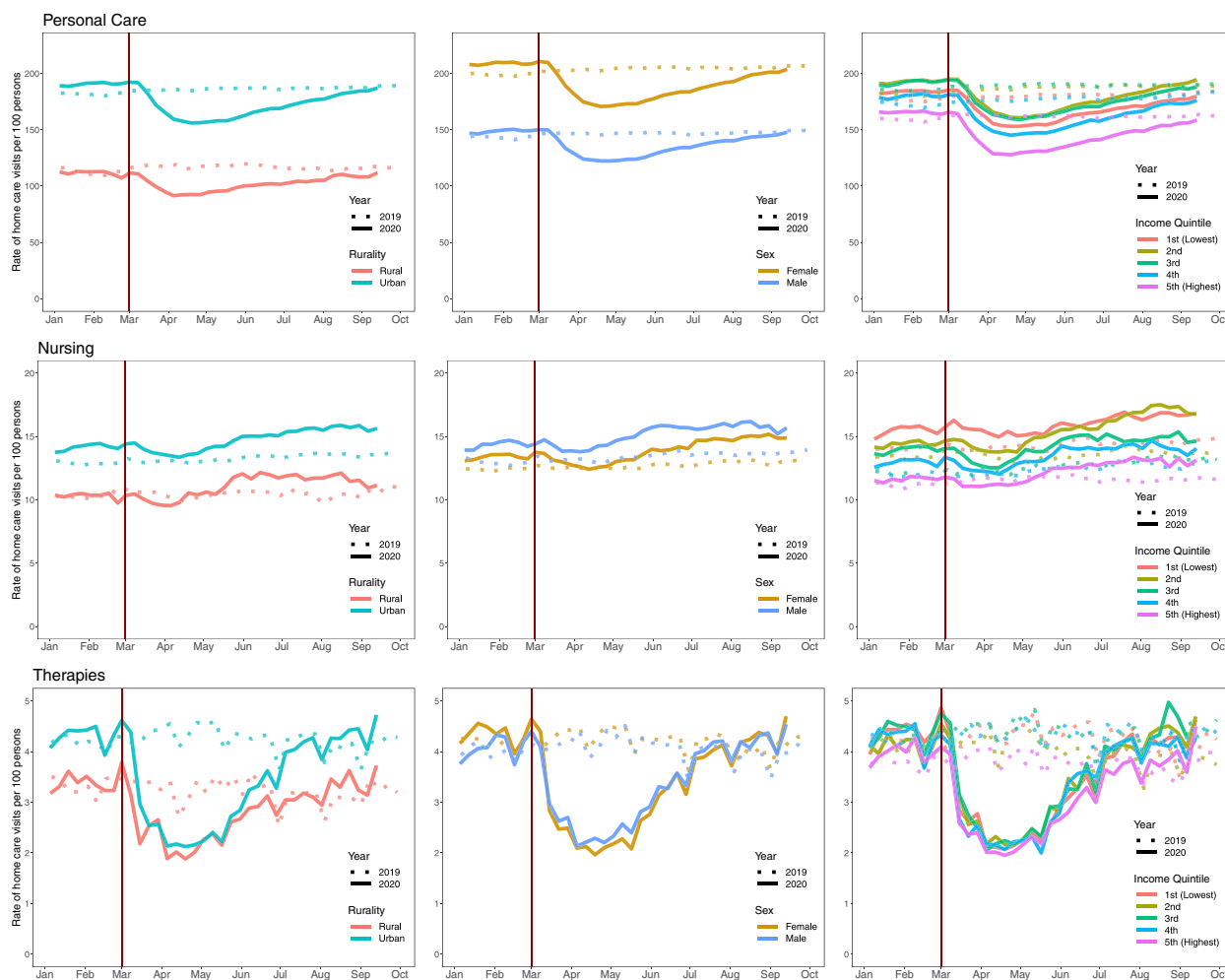
Fig. 1. Time series of home care visits for individuals living with dementia in the community, Ontario, Canada, January 2019 to September 2020.

through the summer months and regained or exceeded historical levels by the end of September 2020. The degree of disruption varied by service type, with nursing declining only slightly, personal care declining by a moderate degree, and therapies declining by a larger degree. The disruptions were largely similar across strata defined by rurality, sex, and neighborhood income quintile, though individuals in rural areas experienced a larger decline in personal care and smaller

rebound in nursing, and individuals in the highest income quintile experienced a larger initial decline in personal care.

Home care services are a critical component of the support system for adults with dementia in the community. Across Canada, home care services were restricted or reduced during the early months of the pandemic, particularly if they were deemed less essential.[19] Home nursing in particular provides necessary care that would otherwise

Table 1
Poisson Model Estimates of Home Care Service Rates in 2020 Compared to 2019 at Week of Lowest 2020 Rate Among Community-Dwelling Persons With Dementia in Ontario, Canada

Sociodemographic Strata	At Week of Lowest Rate*		
	Personal Care, RR (95% CI)	Nursing, RR (95% CI)	Therapies, RR (95% CI)
Overall	0.84 (0.84, 0.85)	1.02 (1.00, 1.04)	0.50 (0.48, 0.52)
Rurality			
Urban	0.84 (0.84, 0.85)	1.02 (1.00, 1.05)	0.49 (0.47, 0.52)
Rural	0.77 (0.75, 0.79)	0.94 (0.87, 1.02)	0.62 (0.52, 0.73)
Sex			
Female	0.84 (0.84, 0.85)	0.99 (0.96, 1.02)	0.45 (0.43, 0.48)
Male	0.83 (0.82, 0.84)	1.04 (1.01, 1.07)	0.48 (0.45, 0.52)
Income quintile			
First (lowest)	0.85 (0.84, 0.86)	1.05 (1.01, 1.10)	0.50 (0.45, 0.55)
Second	0.85 (0.84, 0.86)	1.06 (1.02, 1.11)	0.48 (0.44, 0.53)
Third	0.84 (0.82, 0.85)	1.02 (0.97, 1.07)	0.45 (0.41, 0.50)
Fourth	0.83 (0.82, 0.84)	1.00 (0.95, 1.06)	0.50 (0.44, 0.56)
Fifth (highest)	0.79 (0.78, 0.81)	0.94 (0.89, 0.99)	0.51 (0.45, 0.57)

*Week of lowest rate in 2020 by strata compared to corresponding week in 2019.

Table 2
Poisson Model Estimates of Home Care Service Rates in 2020 Compared With 2019 at Latest Week of Analysis Among Community-Dwelling Persons With Dementia in Ontario, Canada

Sociodemographic Strata	At Latest Week[*]		
	Personal Support, RR (95% CI)	Nursing, RR (95% CI)	Therapies, RR (95% CI)
Overall	0.99 (0.99, 1.00)	1.14 (1.11, 1.16)	1.11 (1.07, 1.15)
Rurality			
Urban	0.99 (0.99, 1.00)	1.15 (1.12, 1.17)	1.11 (1.06, 1.15)
Rural	0.97 (0.95, 0.99)	0.99 (0.92, 1.07)	1.10 (0.96, 1.26)
Sex			
Female	0.99 (0.98, 1.00)	1.13 (1.10, 1.16)	1.11 (1.06, 1.16)
Male	0.99 (0.98, 1.00)	1.14 (1.11, 1.18)	1.10 (1.04, 1.16)
Income quintile			
First (lowest)	0.98 (0.97, 0.99)	1.15 (1.10, 1.19)	1.09 (1.01, 1.17)
Second	1.03 (1.02, 1.05)	1.21 (1.16, 1.26)	1.18 (1.09, 1.28)
Third	0.99 (0.98, 1.00)	1.13 (1.08, 1.18)	1.11 (1.02, 1.20)
Fourth	0.96 (0.95, 0.98)	1.06 (1.00, 1.11)	1.00 (0.91, 1.09)
Fifth (highest)	0.98 (0.97, 0.99)	1.13 (1.07, 1.19)	1.15 (1.05, 1.25)

[*]Week of September 20, 2020, vs week of September 22, 2019.

need to be received in other ambulatory care settings. Thus, nursing may have been considered more essential than personal care or therapies based on provincial guidelines that prioritized reducing direct impacts on safety and minimizing harms,[20] explaining the differences we observed in our study. Services may also have been canceled directly by home care recipients or their caregivers over concerns regarding risk of COVID transmission.[21] In addition, early in the pandemic, home care workers faced unsafe working conditions because of a lack of personal protective equipment and infection control guidance, which also may have led to cancelation of service.[22,23]

Regardless of the cause, any interruption to home care places additional burden on individuals with dementia and their caregivers. Personal care services assist an individual in the activities such as dressing, toileting, and transferring and if not provided by a home care worker would need to be provided by an unpaid caregiver. Increasing caregiver burden has been observed during the pandemic and linked to rising rates of distress and burnout.[24,25] Although it may not be considered as essential as nursing, the loss of personal care can impact the safety of those needing care, increasing the risk of falls and injury. Additionally, loss of services may increase social isolation, which has been linked to new and worsening neuropsychiatric symptoms among individuals with dementia during the pandemic.[26] Any policy or directive with the potential to disrupt home care services needs to consider the risks incurred by people with dementia, caregivers, and home care workers, all of whom may face additional burden and/or risk.

Although the impact of the pandemic across sociodemographic strata was generally consistent, rural areas experienced a greater decline in personal care and smaller rebound in nursing services. Residents in the wealthiest areas also had a larger initial decrease in personal care, which may be related to having additional options or resources to secure the necessary care. Equitable access to home care in rural areas has been previously identified as a challenge and any policy or directive that would disrupt home care services needs to ensure it will not exacerbate extant access issues.[27] Future research should further examine the impact of the pandemic on individuals with dementia, including whether the interruption of home care services resulted in a downstream increase in emergency department visits or hospital admissions.

Limitations

Our data sources capture all publicly funded home care services in Ontario, but we do not have data on home care that is paid for privately. Also, we do not have information on the specific reasons why home care services were canceled or delayed. Finally, our study did not include a comparison group of older adults without dementia.

Conclusions and Implications

Home care services are an essential component of the support systems for adults living with dementia in the community. Although nursing care was largely uninterrupted during the COVID-19 pandemic, personal care and therapies declined dramatically during the early months, although service levels recovered by the end of September 2020. Pandemic responses that may interrupt home care services need to carefully consider the risks incurred by individuals with dementia, caregivers, and home care workers while not exacerbating existing inequities in access to care.

References

1. Canadian Institute for Health Information. Impact of COVID-19 on Canada's health care systems. Available at: https://www.cihi.ca/en/covid-19-resources/impact-of-covid-19-on-canadas-health-care-systems. Accessed April 15, 2021.
2. Glazier RH, Green ME, Wu FC, et al. Shifts in office and virtual primary care during the early COVID-19 pandemic in Ontario, Canada. CMAJ 2021;193:E200–E210.
3. Whaley CM, Pera MF, Cantor J, et al. Changes in health services use among commercially insured US populations during the COVID-19 pandemic. JAMA Netw Open 2020;3:e2024984.
4. Birkmeyer JD, Barnato A, Birkmeyer N, et al. The impact of the COVID-19 pandemic on hospital admissions in the United States. Health Aff (Millwood) 2020;39:2010–2017.
5. Chatterji P, Li Y. Effects of the COVID-19 pandemic on outpatient providers in the United States. Med Care 2021;59:58–61.
6. Bronskill SE, Maclagan LC, Walker JD, et al. Trajectories of health system use and survival for community-dwelling persons with dementia: A cohort study. BMJ Open 2020;10:e037485.
7. Government of Ontario. Home and community care. Ontario.ca. Available at: https://www.ontario.ca/page/homecare-seniors#section-3. Accessed May 4, 2021.
8. Topriceanu CC, Wong A, Moon JC, et al. Evaluating access to health and care services during lockdown by the COVID-19 survey in five UK national longitudinal studies. BMJ Open 2021;11:e045813.
9. Dorn A van, Cooney RE, Sabin ML. COVID-19 exacerbating inequalities in the US. Lancet 2020;395:1243–1244.
10. Jaakkimainen RL, Bronskill SE, Tierney MC, et al. Identification of physician-diagnosed Alzheimer's disease and related dementias in population-based administrative data: A validation study using family physicians' electronic medical records. J Alzheimers Dis 2016;54:337–349.
11. Kralj B. Measuring Rurality - RIO2008_BASIC: Methodology and Results. Toronto: Ontario Medical Association. Available at: https://docplayer.net/91599736-Measuring-rurality-rio2008_basic-methodology-and-results.html. Published 2009. Accessed April 20, 2021.
12. Statistics Canada. Postal Code Conversion File Plus (PCCF+) Version 6C, Reference Guide. Available at: https://mdl.library.utoronto.ca/sites/default/public/mdldata/open/canada/national/statcan/postalcodes/pccfplus/2011/2015aug/82-F0086-XDB-2016v6c-eng.pdf. Published 2016. Accessed May 4, 2021.
13. Sourial N, Arsenault-Lapierre G, Margo-Dermer E, et al. Sex differences in the management of persons with dementia following a subnational primary care policy intervention. Int J Equity Health 2020;19:175.

14. Bainbridge D, Seow H, Sussman J, et al. Factors associated with not receiving homecare, end-of-life homecare, or early homecare referral among cancer decedents: A population-based cohort study. Health Policy 2015;119: 831–839.
15. Jones A, Schumacher C, Bronskill SE, et al. The association between home care visits and same-day emergency department use: A case–crossover study. CMAJ 2018;190:E525–E531.
16. Government of Ontario. Archived - COVID-19: Government service changes and public closures. Available at: https://www.ontario.ca/page/covid-19-government-service-changes-and-public-closures. Accessed August 9, 2021.
17. Ontario orders the mandatory closure of all non-essential workplaces to fight spread of COVID-19. news.ontario.ca. Available at: https://news.ontario.ca/en/release/56435/ontario-orders-the-mandatory-closure-of-all-non-essential-workplaces-to-fight-spread-of-covid-19. Accessed August 9, 2021.
18. Ontario permits more businesses and services to reopen in the coming days. news.ontario.ca. Available at: https://news.ontario.ca/en/release/57132/ontario-permits-more-businesses-and-services-to-reopen-in-the-coming-days. Accessed August 9, 2021.
19. Bielska IA, Embrett M, Jewett L, et al. Canada's multi-jurisdictional COVID-19 Public Health response – January to May 2020. Zdr Publiczne Zarządzanie 2020;2020:88–105.
20. Chief Medical Officer of Health. Directive #2 for health care providers (regulated health professionals or persons who operate a group practice of regulated health professionals). Toronto, Canada. Available at: https://www.crpo.ca/wp-content/uploads/2020/03/CMOH-Directive-2-RHPA-professionals-2020-03-19.pdf. Accessed March 19, 2020.
21. Giebel C, Hanna K, Cannon J, et al. Decision-making for receiving paid home care for dementia in the time of COVID-19: a qualitative study. BMC Geriatr 2020;20:333.
22. Rowe TA, Patel M, O'Conor R, et al. COVID-19 exposures and infection control among home care agencies. Arch Gerontol Geriatr 2020;91:104214.
23. Sterling MR, Tseng E, Poon A, et al. Experiences of home health care workers in New York City during the coronavirus disease 2019 pandemic: A qualitative analysis. JAMA Intern Med 2020;180:1453–1459.
24. Budnick A, Hering C, Eggert S, et al. Informal caregivers during the COVID-19 pandemic perceive additional burden: Findings from an ad-hoc survey in Germany. BMC Health Serv Res 2021;21:353.
25. Cohen SA, Kunicki ZJ, Drohan MM, et al. Exploring changes in caregiver burden and caregiving intensity due to COVID-19. Gerontol Geriatr Med 2021 Feb 26; 7:2333721421999279. [Epub ahead of print].
26. Manca R, De Marco M, Venneri A. The impact of COVID-19 infection and enforced prolonged social isolation on neuropsychiatric symptoms in older adults with and without dementia: A review. Front Psychiatry 2020;11: 585540.
27. Forbes DA, Edge DS. Canadian home care policy and practice in rural and remote settings: Challenges and solutions. J Agromed 2009;14:119–124.

Supplementary Table 1
Full Poisson Model Results

	Rate Ratios (95% CIs) Comparing 2020 vs. 2019			
	At Week of Lowest Rate Between Mar 1 and Sep 20, 2020		At Latest Week (Week of Sep 20, 2020)	
	B (95% CI)	P	B (95% CI)	P
Overall				
Home care visits: nursing	0.020 (0.000, 0.039)	.047	0.131 (0.104, 0.148)	<.001
Home care visits: personal support	−0.174 (−0.174, −0.163)	<.001	−0.010 (−0.010, 0.000)	.004
Home care visits: therapy	−0.693 (−0.734, −0.654)	<.001	0.104 (0.068, 0.140)	<.001
Strata: female				
Home care visits: nursing	−0.010 (−0.041, 0.020)	.47	0.122 (0.095, 0.148)	<.001
Home care visits: personal support	−0.174 (−0.174, −0.163)	<.001	−0.010 (−0.020, 0.000)	.006
Home care visits: therapy	−0.799 (−0.844, −0.734)	<.001	0.104 (0.058, 0.148)	<.001
Strata: male				
Home care visits: nursing	0.039 (0.010, 0.068)	.014	0.131 (0.104, 0.166)	<.001
Home care visits: personal support	−0.186 (−0.198, −0.174)	<.001	−0.010 (−0.020, 0.000)	.10
Home care visits: therapy	−0.734 (−0.799, −0.654)	<.001	0.095 (0.039, 0.148)	.001
Strata: income quintile 1 (lowest)				
Home care visits: nursing	0.049 (0.010, 0.095)	.018	0.140 (0.095, 0.174)	<.001
Home care visits: personal support	−0.163 (−0.174, −0.151)	<.001	−0.020 (−0.030, −0.010)	.003
Home care visits: therapy	−0.693 (−0.799, −0.598)	<.001	0.086 (0.010, 0.157)	.024
Strata: income quintile 2				
Home care visits: nursing	0.058 (0.020, 0.104)	.007	0.191 (0.148, 0.231)	<.001
Home care visits: personal support	−0.163 (−0.174, −0.151)	<.001	0.030 (0.020, 0.049)	<.001
Home care visits: therapy	−0.734 (−0.821, −0.635)	<.001	0.166 (0.086, 0.247)	<.001
Strata: income quintile 3				
Home care visits: nursing	0.020 (−0.030, 0.068)	.51	0.122 (0.077, 0.166)	<.001
Home care visits: personal support	−0.174 (−0.198, −0.163)	<.001	−0.010 (−0.020, 0.000)	.07
Home care visits: therapy	−0.799 (−0.892, −0.693)	<.001	0.104 (0.020, 0.182)	.011
Strata: income quintile 4				
Home care visits: nursing	0.000 (−0.051, 0.058)	.96	0.058 (0.000, 0.104)	.034
Home care visits: personal support	−0.186 (−0.198, −0.174)	<.001	−0.041 (−0.051, −0.020)	<.001
Home care visits: therapy	−0.693 (−0.821, −0.580)	<.001	0.000 (−0.094, 0.086)	.94
Strata: income quintile 5 (highest)				
Home care visits: nursing	−0.062 (−0.117, −0.010)	.014	0.122 (0.068, 0.174)	<.001
Home care visits: personal support	−0.236 (−0.248, −0.211)	<.001	−0.020 (−0.030, −0.010)	.007
Home care visits: therapy	−0.673 (−0.799, −0.562)	<.001	0.140 (0.049, 0.223)	.002
Strata: urban				
Home care visits: nursing	0.020 (0.000, 0.049)	.032	0.140 (0.113, 0.157)	<.001
Home care visits: personal support	−0.174 (−0.174, −0.163)	<.001	−0.010 (−0.010, 0.000)	.015
Home care visits: therapy	−0.713 (−0.755, −0.654)	<.001	0.104 (0.058, 0.140)	<.001
Strata: rural				
Home care visits: nursing	−0.062 (−0.139, 0.020)	.13	−0.010 (−0.083, 0.068)	.87
Home care visits: personal support	−0.261 (−0.288, −0.236)	<.001	−0.030 (−0.051, −0.010)	.010
Home care visits: therapy	−0.478 (−0.654, −0.315)	<.001	0.095 (−0.041, 0.231)	.15