

Factors associated with caregiver distress among home care clients in New Zealand: Evidence based on data from interRAI Home Care Assessment

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Abstract: (Limit 150 words)

Objective(s): To identify factors associated with caregiver distress among home care clients in New Zealand.

Methods: The cohort consisted of 105,978 community-dwelling people aged 65 years or older requiring home care services in New Zealand who had at least one informal caregiver. Bivariate and multivariable logistic regressions were used to identify factors associated with caregiver distress.

Results: Variables associated with risk of caregiver distress included Depression Rating Scale, Aggressive Behaviour Symptoms, Primary informal caregiver relationship to patient, Cognitive Performance Scale, Changes in Health, End stage disease, Signs and Symptoms scale, informal care time, secondary informal caregiver relationship to care recipient, Activities of Daily Living hierarchy scale, and any hospitalisation.

Conclusion: The study has identified important characteristics that are associated with caregiver stress. These results suggest that caregiver distress can be relieved by promoting protective factors and aiming to reduce risk factors among home care clients in New Zealand.

Keywords: Caregiver distress, Geriatric Assessment, older adults, interRAI, Home Care

Introduction

The majority of support received by home care clients comes from informal rather than formal sources¹. Informal caregivers are often untrained and under supported while taking on roles as case managers, paramedics, and patient advocates, filling the gaps in systems that are often depersonalised, fragmented and bureaucratic². Informal caregiving is often associated with significant physical, emotional, and financial cost to the caregiver. Informal caregivers provide unpaid care and support for families or friends who may otherwise be unable to stay at home³. It is estimated, that approximately 480,000 people in New Zealand provide informal care on a regular basis for someone who is ill or disabled⁴. According to a 2014 report, in New Zealand, informal carers provide between \$7.3 and \$23.3 billion New Zealand dollars' worth of support per year⁴. Given the large amount of time and resources informal carers spend on unpaid care it is in our best interests to provide care and support the wellbeing of informal caregivers.

Caring for a person with chronic and complex care needs may result in caregiver distress^{5,6}. Caregiver distress is one of the key components of caregiver burden. In the majority of the literature 'caregiver burden' and 'caregiver distress' are used interchangeably. However, caregiver burden can be operationalized using both objective measures (e.g. the number of hours of care provided) and subjective measures (i.e. self-reported questions on the caregivers' level of stress and anxiety). In this research paper, we focus on the caregivers' (subjective) feelings of distress due to providing informal care^{7,8}. The emotional well-being of the person receiving care can also influence the emotional well-being of caregivers⁹. Caregivers of older adults in New Zealand have elevated levels of distress^{10,11}. The amount and intensity of a client's depressive symptoms may correlate with a caregiver's depression. The duration, amount and type of care that is provided by a family caregiver is linked with a higher amount of caregiver stress^{1,5,6}. Having the care recipient live with the caregiver is

also an important contributor to caregiver distress. Caregiver distress has been found to decrease if a care recipient moved from living with the primary caregiver to another location⁵. Spousal caregivers have a higher likelihood of caregiver distress than when the caregiver is a son, daughter or other family member¹².

New Zealand has an ageing population-based, care for people with health conditions and disabilities has shifted towards community-based settings rather than institutions¹³. Deinstitutionalisation and the focus on ageing-in-place have been translated into policies that encourage and promote people to stay in their homes. Anyone requiring home care services must undergo a needs assessment. Home care services include household support, assistance with bathing, and caregiver support¹³. The interRAI Home Care assessment is mandatorily used to assess the needs of people in New Zealand and determine eligibility for government-funded services.

Due to a growing population of older adults, there is need for informal caregivers¹⁴. Growing caregiver distress is putting increasing strain on informal care, prompting much attention from scholars and policy makers alike. Caregiver distress is not a new issue, with researchers noting in 2010 that “There does seem to be a contradiction between the value we place on caregivers and what we provide to support them, both materially and psychosocially”¹¹. Little has changed in this respect since the paper by Jorgensen *et al.*^{10,9}. To alleviate some of the burden on the caregiver, identification of the factors that may lead to increased risk of caregiver distress is necessary.

Previous studies have identified factors associated with caregiver distress for the interRAI Palliative care and Home care assessment instruments^{1,5}. There has been one study conducted on New Zealand interRAI-HC data identifying caregiver burnout. In our study we use a different definition of caregiver distress and explores additional clinical factors that

may be associated with caregiver distress¹⁵ to identify characteristics associated with caregiver distress. Specifically, we aim to determine the prevalence of caregiver distress among older people receiving home care in New Zealand, examine care recipient and caregiver characteristics, and health services variables that may contribute to caregiver distress among home care clients.

Methods

Study design and participants

This study uses cross-sectional data among home care clients in New Zealand. Participants were aged 65 years and over, lived in a home-based setting, and had a primary informal caregiver. All participants underwent an interRAI-HC assessment between 5 July 2012 and 1 June 2018 and consented to their data being used for planning and research purposes. Where multiple home care assessments were available for an individual, only the first assessment was used. Individuals who were reported as having no primary informal caregiver were excluded from the analysis (N=6,691).

Instruments/variables

The interRAI-HC version 9.1 (©interRAI corporation, Washington, D. C., 1994-2009) assessment tool is a comprehensive geriatric assessment across 20 domains including mood and behaviour, social supports, cognitive and physical function, and psychosocial wellbeing¹⁶. The home care assessment is used for all older people in New Zealand requiring publicly funded formal care services. Assessors interview the client, their family, and rely on medical records to complete the interRAI assessment. All data are entered into an electronic database, which are collected and maintained by New Zealand's Technical Advisory Services (TAS). Participants who consented for their data to be used for research (approximately 93% of all

assessments undertaken) are released for research and planning purposes, with the approval of the Ministry of Health ¹⁷.

Variables of interest were identified from previous literature on caregiver distress and recorded within the interRAI dataset, ¹ and included demographics, caregiver characteristics, clinical indicators, and health service use. Caregiver distress was defined as answering 'yes' to one or more indicators of informal care: "Informal helper(s) is unable to continue caring activities"; "Primary informal helper expresses feelings of distress, anger, or depression"; and "Family or close friends report feeling overwhelmed by person's illness". This definition has been used in other previously published papers ^{1, 18, 19}. Despite previously published papers not including the item "Family or close friends report feeling overwhelmed by person's illness", we chose to include this question because it is considered important for identifying the reserves of the informal caregiver support system ^{5, 6, 15, 19}. Informal caregivers were identified as a family member, friend, or neighbour who provides unpaid care to an individual ²⁰. While this study focused on predictors of caregiver distress, all items used to identify caregiver distress were based on the care recipient as there are no questions about the caregiver themselves in the interRAI-HC assessment.

The interRAI-HC assessment has outcome scales which use information taken from multiple questions to calculate a person's risk of a specific event. Scales used in this analysis include Activities of Daily Living (ADL) hierarchy scale, the Cognitive Performance Scale (CPS), the Depression Rating Scale (DRS), the Aggressive Behaviour Scale (ABS), and the Changes in Health, End-stage disease, Signs, and Symptoms scale (CHESS). The ADL hierarchy scale is a scale grouping activities of daily living according to the stage of the disablement process in which they occur²¹. Early loss ADLs are assigned lower scores than late loss ADLs. Higher scores indicate greater decline (progressive loss) in ADL performance²¹. The scores range from 0 to 6 ²¹. The items included in the ADL hierarchy scale are personal hygiene,

toilet use, locomotion, and eating²¹. The CPS is a measure of an individual's cognitive impairment, and uses the items on memory impairment, decision making ability, and level of consciousness^{22,23}. Scores in the CPS range from 0 to 6²². The DRS is a screening tool for depression, the scale uses a number of questions relating to mood such as making negative statements, repetitive anxious behaviours, and persistent anger with self or others. The scores range from 0 to 14²³. The ABS is a measure of frequency and diversity of aggressive behaviours. Items included in the ABS include questions about verbal abuse, physical abuse, resistance of care, and socially disruptive behaviour²⁴. Scores in the ABS range from 0 to 12²⁴. For each of the above scores, a high score indicates a stronger clinical indicator. The CHESS scale is used to identify those with higher levels of medical complexity and at risk of serious decline in health. Scoring of the scale ranges from 0 – No health instability to 5 – Very high health instability²⁵. Items included in the CHESS scale are changes in decision making, changes in ADL status, health conditions, end-stage disease, and nutritional issues²⁵.

Statistical analysis

Variables of interest were grouped by sociodemographic, care recipient, and caregiver characteristics and are presented as percentages for caregiver distress. Multicollinearity was checked by using the variance inflation factor, and multicollinearity was not present. Bivariate logistic regression models were grouped by sociodemographic, client, and caregiver characteristics. A multivariable model included all variables of interest. Odds ratios (ORs) and 95 per cent confidence intervals were reported for each variable of interest. All analyses were conducted using SPSS version 25. A $p < 0.01$ was used to define statistical significance rather than $p < 0.05$ due to the large size of the sample, to reduce the number of significant variables. Ethics approval was obtained from the New Zealand Ministry of Health and Disability Ethics Committee (14/STH/140). The reporting of the results for this study followed STROBE guidelines (www.strobe-statement.org).

Results

The cohort consisted of 105,978 care recipients with a mean age of 82.2 (Standard Deviation 7.5) and 59.9 per cent were female (Table 1). Approximately 39.6 per cent of caregivers experienced distress, where 19.7 per cent answered “yes” to the question “Informal helper(s) is unable to continue caring activities;” 19.5 per cent of people answered “yes” to the question “Primary informal helper expresses feelings of distress, anger, or depression;” and 24.9 per cent of people answered “yes” to “Family or close friends report feeling overwhelmed by person’s illness.” A minority (5.6%) of care recipients received >36 hours and 7.3 per cent received 18-35 hours of informal care per week. Table 1 displays the characteristic information stratified by presence or absence of caregiver distress.

< Insert Table 1 Here >

Table 2 displays bivariate associations and odds ratios of caregiver distress for care recipient demographics, and caregiver characteristics, clinical indicators, and health service use indicators, and the final logistic regression model. Multivariable analyses identified DRS, ABS, Primary informal caregiver relationship to patient, CPS, CHESS scale, informal care time, secondary informal caregiver relationship to care recipient, ADL hierarchy scale, any nutritional problems, end-stage disease, sex, marital status, days with home care nurse visits per week, bowel incontinence, inadequate pain control, gastrointestinal problems, dyspnoea, bladder incontinence, and any hospitalisations as being associated with caregiver distress.

Individuals who were in a relationship had higher rates of caregiver distress than those who were not in a relationship. Primary caregivers who were a spouse of the care recipient were more likely to experience distress than if the primary caregiver was a child, other relative, or friend. The caregivers of those receiving 18 or more hours of informal care had higher odds of experiencing distress.

Several clinical factors were also associated with caregiver distress. For care recipients with a prognosis of six months or less to live, the caregiver had a higher odds ratio of distress. Having inadequate pain control also increased the odds of caregiver distress. Care recipient factors associated with caregiver distress included higher levels of cognitive impairment (as measured by the CPS), depressive symptoms (as measured by the DRS), and aggressive behaviour (as measured by the ABS). Caregivers of persons who were dependent in ADLs were more likely to be distressed than if the person was independent in ADLs. The presence of either bowel or bladder incontinence increased the odds of the caregiver experiencing distress. Care recipients with gastrointestinal or nutritional problems had increased odds of having a distressed caregiver.

Both healthcare service factors were significantly associated with caregiver distress. However, when the care recipient had been hospitalised in the last 90 days, it decreased the odds of having a distressed caregiver relative to those not hospitalised in the last 90 days. When there were greater than or equal to three days with home care nurse visits, the odds of the caregiver being distressed increased.

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Discussion

The prevalence of caregiver distress among home care clients in New Zealand was nearly 40 per cent, which is higher than a previously published New Zealand study (32.4%)¹⁸.

Additional studies have reported the prevalence of caregiver distress amongst home care (21%) and palliative care clients (22%) in Ontario, Canada,^{5, 1} Hong Kong (15.5%)¹⁵, New Zealand (13.9%)^{15, 18} and Belgium (57%)⁶. However, not all of these studies includes the additional item of “Family or close friends report feeling overwhelmed by person’s illness”.

The addition of this item is likely to increase the estimate of distress therefore comparisons to previous reports based on the older instruments should be made with that caveat in mind.

In our study, caregiver distress was observed when care recipients exhibited aggressive behaviour. This finding is in agreement with studies included in a systematic review²⁶ and in a study identifying caregiver burnout in Hong Kong and New Zealand¹⁵. Another study suggested that family caregivers could tolerate physical limitations and cognitive deficits better than aggressive behaviour of their care recipient²⁷. A previous study found that level care recipient aggression could predict the decision to discontinue home care, where those who were more aggressive towards their carer frequently would move into residential care facilities²⁸.

Higher odds of caregiver distress were observed when a primary caregiver was a spouse rather than a child or another relative of the individual. In other studies, spouses who are the primary caregivers experience distress which leads to poorer health outcomes for themselves^{15,29}. This can be a stressful time for the spouse as they must adjust to any changes that arise from needing to take care of their significant other.

Adult children who were primary caregivers were also likely to experience caregiver distress. Within the literature female caregivers are found to provide more informal care, and consequently have a higher likelihood of caregiver distress than male caregivers²⁵. They can be considered as a “sandwich generation caregiver” or “women in the middle” who are defined as an adult caregiver providing care for their elderly parents and children simultaneously²⁶. These caregivers may be struggling with competing demands in their multiple roles which may include being a parent, wage earner, household manager, primary emotional supporter, and caregiver²⁶. The positive association between competing demands and caregiver distress was previously found in Caucasians with two or more children and a

lower annual income^{26,30}. To alleviate the caregiver distress among sandwich generation caregivers, research suggests using family leisure time as therapeutic recreation to reconcile family transition^{27,31}. Besides the caregiver factors investigated in this study, such as relationship to care recipient and number of hours of informal care, other factors such as the age of the caregiver have been shown to increase the likelihood of caregiver distress. Young caregivers are shown to have higher rates of distress²⁸ due to their competing demands of work, childrearing, and eldercare.

Our study found that, where care recipients had greater than two days a week of home care nurse visits compared with those who had between zero and two visits per week, the likelihood of caregiver distress increased. A similar association was found among Canadian palliative home care clients¹. It was also noted that having any home nursing visits in a week was associated with an increase in caregiver burnout in Hong Kong and New Zealand¹⁵. It is possible that weekly nursing visits may indicate the care recipient's higher levels of need. Additionally, we found that the odds of caregiver distress were reduced where care recipients had been admitted to hospital within the 90 days prior to assessment compared with those who had no hospitalisation. The hospitalisation may have been a form of respite for the caregiver⁵. Conversely, Bull and co-workers³² found that with the recent trend of shorter hospital stays, care recipients admitted to hospital tend to return home before their recovery is complete, in turn requiring overwhelming assistance from caregivers as the client may lose their self-care abilities during the hospital stay.

People of Asian and European ethnicities were associated with having an increased risk of caregiver distress compared to Māori individuals. A Canadian study found that Chinese and Korean Canadians were more likely to experience caregiver distress than others³³. This was possibly due to increased health care needs in the Korean Canadian group, and the issues

around language barriers³³. Pacific people and Other ethnicities were not significantly associated with caregiver distress in our model.

This study identified items within the interRAI-HC that may lead to caregiver distress. The items we have identified in this assessment may help to identify specific areas of support that may benefit from alleviation of some of the caregiver distress. For example, to prevent or alleviate distress in caregivers, individuals who require 36+ hours of informal care time per week, may benefit from additional support. A self-assessment instrument for an informal caregiver, i.e. an assessment completed by the informal caregiver of the client would allow the services involved to gain an insight into the different aspects of the caregiver burden. In turn, these services could suggest targeted respite support and service options provided by the Ministry of Health in New Zealand^{3, 34, 35}.

The current study has several limitations that could have affected the study results. First, these results are based on cross-sectional data, and do not imply causality. Second, the data lack important information related to caregiver characteristics that could be important for understanding the associations with caregiver distress. When a caregiver signals distress, a supplement to the interRAI assessment may be helpful for identifying and addressing which areas the caregiver is having the most problems with, and to help target support in those areas. Additionally, this study was developed for a New Zealand interRAI-HC cohort and reflects the New Zealand health care setting, thus, may not be generalisable to other settings. It must be noted that, given the large cohort, some characteristics, while found to be significantly associated with caregiver distress, have a small effect size and therefore may not truly impact on distress. There may be a small number of people who answered 'yes' to the question about informal helper(s) being unable to continue caring activities who may not necessarily be experiencing distress, they may simply have moved away and are no longer able to continue providing care for their family member.

Conclusions

The study has identified important characteristics that are associated with caregiver stress. Knowing what these items are may help with providing support and relief where possible. The World Health Organization recognizes this challenge and recommended a collaboration between formal and informal caregivers to facilitate the continuity of care and the participation of patients, families and communities in the care process through people-centred and integrated health services³⁶. This combination should be the basis of primary care for older adults. Future work is needed to investigate whether caregiver distress can be relieved by promoting identified protective factors and reducing risk factors among home care clients in New Zealand.

Policy Impact Statement

Proactive and systemic policies can identify types and severity of caregiver stress among home care clients. These could potentially help better address the avoidable stress among caregivers and improve quality of care among care recipients.

Practice Impact Statement

There is an opportunity to follow up with informal caregivers about common issues that lead to them becoming stressed. This may include, introducing a caregiver supplement to the current interRAI to help understand which areas of need an informal caregiver is struggling with.

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Table 1 Characteristics of care recipients in the study cohort totals and stratified by presence or absence of caregiver distress (n=105 978)

Variable	Total Number (%)	Number (%) with distressed caregiver	Number (%) with no distressed caregiver
Sociodemographic characteristics			
Age Group			
65-74	21 498 (20.3)	9 021 (21.5)	12 477 (19.5)
75-84	45 987 (43.4)	18 503 (44.1)	27 484 (43.0)
85+	38 493 (36.3)	14 464 (34.4)	24 029 (37.6)
Sex^a			
Female	63 522 (59.9)	22 457 (53.5)	41 065 (64.2)
Male	42 389 (40.0)	19 490 (46.4)	22 899 (35.8)
Ethnicity			
Māori	6 095 (5.8)	2 273 (5.4)	3 822 (6.0)
Pacific	3 428 (3.2)	1 238 (2.9)	2 190 (3.4)
Asian	2 863 (2.7)	1 367 (3.3)	1 496 (2.3)
European	92 581 (87.4)	36 677 (87.4)	55 904 (87.4)
Other Ethnicity	1 011 (1.0)	433 (1.0)	578 (0.9)
Marital status			
Not in a relationship	62 070 (58.6)	19 759 (47.1)	42 311 (66.1)
In a relationship	43 908 (41.4)	22 229 (52.9)	21 679 (33.9)
Primary informal caregiver relationship to care recipient			
Spouse	34 811 (32.8)	18 976 (45.2)	15 835 (24.7)
Child ^b	54 896 (51.8)	18 512 (44.1)	36 384 (56.9)
Other ^c	16 271 (15.4)	4 500 (10.7)	11 771 (18.4)
Secondary informal caregiver relationship to care recipient^d			
Spouse	1 293 (1.2)	650 (1.5)	643 (1.0)
Child	51 989 (49.1)	21 586 (51.4)	30 403 (47.5)
Other [†]	19 070 (18.0)	6 186 (14.7)	12 884 (20.1)
No secondary caregiver	33 616 (31.7)	13 566 (32.3)	20 050 (31.3)
Informal care time (Last 3 days)			
<18 hours	92 314 (87.1)	34 200 (81.5)	58 114 (90.8)
18-35 hours	7 691 (7.3)	4 097 (9.8)	3 594 (5.6)
36+ hours	5 962 (5.6)	3 691 (8.8)	2 271 (3.5)
Clinical Characteristics			
Prognosis (End-stage disease)			
No	101 782 (96.0)	39 540 (94.2)	62 242 (97.3)
Yes	4 192 (4.0)	2 448 (5.8)	1 744 (2.7)
Pain scale^e			
0	42 250 (39.9)	17 316 (41.2)	24 934 (39.0)
1	22 840 (21.6)	9 067 (21.6)	13 773 (21.5)
2	27 379 (25.8)	10 077 (24.0)	17 302 (27.0)
3	10 030 (9.5)	4 021 (9.6)	6 009 (9.4)
4	3 475 (3.3)	1 506 (3.6)	1 969 (3.1)
Inadequate pain control^f			
No	95 767 (90.4)	37 713 (89.8)	58 054 (90.7)

Yes	10 207 (9.6)	4 275 (10.2)	5 932 (9.3)
ADL hierarchy scale^c			
0-1	76 486 (72.2)	26 511 (63.1)	49 975 (78.1)
2-4	23 987 (22.6)	12 400 (29.5)	11 587 (18.1)
5-6	5 501 (5.2)	3 076 (7.3)	2 425 (3.8)
Cognitive performance scale^f			
0-1	53 438 (50.4)	15 075 (35.9)	38 363 (60.0)
2-4	48 216 (45.5)	24 086 (57.4)	24 130 (37.7)
5-6	4 322 (4.1)	2 826 (6.7)	1 496 (2.3)
CHESS scale			
0-1	46 604 (44.0)	14 190 (33.8)	32 414 (50.7)
2-3	49 387 (46.6)	21 481 (51.2)	27 906 (43.6)
4-5	9 986 (9.4)	6 317 (15.0)	3 669 (5.7)
Bowel incontinence			
No	95 654 (90.3)	36 208 (86.2)	59 446 (92.9)
Yes	10 324 (9.7)	5 780 (13.8)	4 544 (7.1)
Bladder incontinence			
No	76 706 (72.4)	28 645 (68.2)	48 061 (75.1)
Yes	29 272 (27.6)	13 343 (31.8)	15 929 (24.9)
Any current gastrointestinal problems			
No	65 355 (61.7)	24 533 (58.4)	40 822 (63.8)
Yes	40 623 (38.3)	17 455 (41.6)	23 168 (36.2)
Any nutritional problems			
No	77 094 (72.7)	27 278 (65.0)	49 816 (77.8)
Yes	28 884 (27.3)	14 710 (35.0)	14 174 (22.2)
Dyspnoea at rest^e			
No dyspnoea at rest	97 913 (92.4)	38 354 (91.3)	59 559 (93.1)
Dyspnoea at rest	8 061 (7.6)	3 634 (8.7)	4 427 (6.9)
Depression rating scale^e			
0	63 611 (60.0)	19 770 (47.1)	43 841 (68.5)
1-2	26 614 (25.1)	12 651 (30.1)	13 963 (21.8)
3-5	12 116 (11.4)	7 057 (16.8)	5 059 (7.9)
6-14	3 633 (3.4)	2 509 (6.0)	1 124 (1.8)
Aggressive behaviour symptoms			
0	95 163 (89.8)	34 560 (82.3)	60 603 (94.7)
1-4	9 562 (9.0)	6 422 (15.3)	3 140 (4.9)
5+	1 250 (1.2)	1 005 (2.4)	245 (0.4)
Healthcare Service Indicators			
Any hospitalisation (last 90 days)			
No	56 754 (53.6)	20 475 (48.8)	36 279 (56.7)
Yes	49 224 (46.4)	21 513 (51.2)	27 711 (43.3)
Days with home care nurse visits per week			
0-2	19 279 (18.2)	8 176 (19.5)	11 103 (17.4)
3+	86 699 (81.8)	33 812 (80.5)	52 887 (82.4)

^a67 values missing, ^bChild includes child-in-law as an informal caregiver ^cOther informal caregiver includes parent/guardian, sibling, other relative or whānau, friend, and neighbour, ^d10 values missing, ^e4 values missing, ^f2 values missing, ^g3 values missing

Table 2 Unadjusted and Adjusted Odds Ratios for caregiver distress variables (n=105 978).

Variable	Unadjusted odds ratio (95% CI)	Adjusted odds ratio (95% CI)
Sociodemographic Characteristics		
Age Group		
65-74	Reference	Reference
75-84	0.929 (0.90 to 0.96)	1.01 (0.97 to 1.04)
85+	0.831 (0.80 to 0.86)	1.08 (1.03 to 1.12)
Sex^a		
Female	Reference	Reference
Male	1.56 (1.52 to 1.60)	1.18 (1.14 to 1.21)
Ethnicity		
Māori	Reference	Reference
Pacific	0.96 (0.88 to 1.04)	0.93 (0.85 to 1.03)
Asian	1.55 (1.41 to 1.69)	1.42 (1.28 to 1.56)
European	1.11 (1.05 to 1.45)	1.09 (1.02 to 1.15)
Other Ethnicity	1.26 (1.10, 1.45)	1.16 (0.99, 1.34)
Marital status^a		
Not in a relationship	Reference	Reference
In a relationship	2.21 (2.15 to 2.26)	1.17 (1.12 to 1.23)
Primary informal caregiver relationship to care recipient^a		
Spouse	3.15 (3.02 to 3.28)	2.42 (2.27 to 2.57)
Child	1.33 (1.28 to 1.38)	1.29 (1.23 to 1.35)
Other ^b	Reference	Reference
Secondary informal caregiver relationship to care recipient^a		
Spouse	1.49 (1.33 to 1.66)	1.48 (1.30 to 1.68)
Child	1.05 (1.02 to 1.08)	0.92 (0.89 to 0.95)
Other	0.71 (0.68 to 0.73)	0.88 (0.84 to 0.91)
No secondary caregiver	Reference	Reference
Informal care time (Last 3 days)^a		
<18 hours	Reference	Reference
18-35 hours	1.95 (1.86 to 2.05)	1.29 (1.22 to 1.35)
36+ hours	2.79 (2.65 to 2.95)	1.54 (1.45 to 1.63)
Clinical Characteristics		
Prognosis (End-Stage Disease)^a		
No	Reference	Reference
Yes	2.22 (2.08 to 2.36)	1.23 (1.14 to 1.33)
Pain scale^a		
0	Reference	Reference
1	0.95 (0.92 to 0.98)	1.00 (0.97 to 1.04)
2	0.84 (0.81 to 0.86)	0.90 (0.87 to 0.93)
3	0.96 (0.92 to 1.01)	1.00 (0.94 to 1.05)
4	1.10 (1.03 to 1.18)	1.05 (0.97 to 1.14)
Inadequate pain control^a		
No	Reference	Reference
Yes	1.11 (1.06 to 1.16)	1.10 (1.04 to 1.16)
ADL hierarchy scale^a		

Variable	Unadjusted odds ratio (95% CI)	Adjusted odds ratio (95% CI)
0-1	Reference	Reference
2-4	2.03 (1.97 to 2.09)	1.32 (1.28 to 1.37)
5-6	2.42 (2.29 to 2.56)	1.28 (1.20 to 1.37)
Cognitive performance scale^a		
0-1	Reference	Reference
2-4	2.55 (2.48 to 2.62)	1.94 (1.89 to 2.00)
5-6	4.91 (4.59 to 5.24)	2.08 (1.93 to 2.25)
CHESS scale^a		
0-1	Reference	Reference
2-3	1.76 (1.71 to 1.80)	1.40 (1.35 to 1.44)
4-5	3.96 (3.78 to 4.14)	1.87 (1.75 to 1.98)
Bowel incontinence^a		
No	Reference	Reference
Yes	2.10 (2.01 to 2.19)	1.14 (1.08 to 1.20)
Bladder incontinence^a		
No	Reference	Reference
Yes ^a	1.41 (1.37 to 1.45)	1.05 (1.02 to 1.09)
Any current gastrointestinal problems^a		
No	Reference	Reference
Yes	1.25 (1.22 to 1.28)	1.07 (1.04 to 1.10)
Any nutritional problems^a		
No	Reference	Reference
Yes	1.90 (1.85 to 1.95)	1.27 (1.23 to 1.32)
Dyspnoea at rest^a		
No dyspnoea at rest	Reference	Reference
Dyspnoea at rest	1.28 (1.22 to 1.34)	1.07 (1.02 to 1.31)
Depression rating scale^a		
0	Reference	Reference
1-2	2.02 (1.96 to 2.08)	1.62 (1.57 to 1.67)
3-5	3.11 (2.99 to 3.24)	2.25 (2.15 to 2.35)
6-14	5.01 (4.65 to 5.38)	3.13 (2.89 to 3.39)
Aggressive behaviour symptoms^a		
0	Reference	Reference
1-4	3.61 (3.45 to 3.78)	1.98 (1.89 to 2.09)
5+	7.43 (6.44 to 8.56)	2.70 (2.32 to 3.14)
Healthcare Service Indicators		
Any hospitalisation (last 90 days)^a		
No	Reference	Reference
Yes	1.38 (1.34 to 1.41)	0.88 (0.85 to 0.90)
Days with home care nurse visits per week		
0-2	Reference	Reference
3+	1.15 (1.11 to 1.19)	1.16 (1.12 to 1.20)

^aStatistically significant as $p < 0.01$, ^bOther informal caregiver includes parent/guardian, sibling, other relative or whānau, friend, and neighbour

List of Abbreviations

ABS – Aggressive Behaviour Scale

ADL – Activities of Daily Living

ARC – Aged Residential Care

CGD – Caregiver Distress

CHESS – Changes in Health, End-stage disease, Signs, and Symptoms

CPS – Cognitive Performance Scale

DRS – Depression Rating Scale

OR – Odds Ratio

SD – Standard Deviation

Statement of data availability

The data that support the findings of this study are available on request from Technical Advisory Services. The data are not publicly available due to privacy or ethical restrictions.