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Original Research Article

Association of dementia diagnosis, cognitive impairment levels, and their combination with care costs among publicly funded long-term care recipients

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Abstract

Background and objectives: Most people with dementia are undiagnosed and rely heavily on long-term care. Little is known about the relationship between dementia diagnosis and care costs, and inconsistent evidence exists on the cost implications of cognitive impairment severity. We examined how formal and informal care costs are associated with a dementia diagnosis and cognitive impairment levels across care settings.

Research design and methods: We used representative data from publicly funded long-term care recipients in residential care settings and community care settings in Hong Kong ($n = 1{,}603$). Staff time measurement was used to capture service utilization of both formal and informal care. Generalized linear model (log-link and gamma distribution) was used to estimate long-term care costs, controlling for covariates.

Results: A dementia diagnosis is associated with an additional 13% and 23% care costs in residential and community care settings, respectively. People with more severe cognitive impairment incur greater long-term care costs; the highest difference (a 189% increase) was found in informal care costs in community care settings among those with moderate-to-severe cognitive impairment. In community care settings, formal care costs were insensitive to cognition status but were consistently higher with a dementia diagnosis; in contrast, informal care costs were less associated with a diagnosis but increased with cognitive impairment severity.

Discussion and Implications: Having a diagnosis of dementia and poorer cognition are associated with higher long-term care costs in both residential and community care settings. A dementia diagnosis is potentially a more important driver of formal care costs than cognitive impairment levels within the current care system, in contrast to what is observed with informal care costs. Practitioners and policymakers need to ensure that individuals with cognitive impairment without a dementia diagnosis receive the appropriate level of care.

Keywords: Service utilization, Formal and informal care, Community care, Residential care, Care cost

Translational Significance: This study reveals how dementia diagnosis and cognitive impairment severity differentiate long-term care costs in residential and community care settings, addressing critical gaps in understanding care resource allocation. Both dementia diagnosis and cognitive impairment level increase total care costs. Specifically, in community care settings, formal care costs are associated with dementia diagnosis, while informal care costs are closely linked to cognitive impairment severity. These findings hold translational value for improving care systems by optimizing formal care allocation through early diagnosis, expanding support for informal caregivers, and ensuring equitable care access for undiagnosed individuals with cognitive decline.

The increasing number of people living with dementia poses significant social and economic challenges for individuals, families, the care system, and wider society (World Health Organization, 2021). Globally, the annual cost of dementia is estimated at US$1.3 trillion, over 80% of which is attributed to formal and informal long-term care (LTC) (Prince et al., 2015). Meanwhile, dementia and cognitive impairment are more prevalent among LTC recipients. An increasing number of countries has included cognitive status into care needs assessment for LTC service eligibility (Barber et al., 2020; Colombo et al., 2011). A formal clinical diagnosis for dementia is usually the gateway to available resources, supports, and information

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(Livingston et al., 2020). Improving the diagnostic rate for dementia has been widely recognized as a priority in the global action plan for dementia (World Health Organization, 2017) and national dementia strategies in most European countries (Wright & O'Connor, 2018). However, over 75% of people with dementia worldwide are without a formal diagnosis, a figure that can be up to 90% in some low- and middle-income countries (Gauthier et al., 2021). The primary reasons for underdiagnosis are stigma, lack of awareness, and insufficient diagnostic resources (Gauthier et al., 2021). Among LTC recipients, over two thirds of care home residents and 55% to 68% of community-dwelling older persons suspected of having dementia have not received a clinical diagnosis (Bartfay et al., 2013; Lang et al., 2017).

Previous studies on the determinants of care costs for dementia have mainly been conducted among people with a formal clinical diagnosis of dementia (Costa et al., 2018; Jutkowitz et al., 2017) or who were identified with a clinical protocol for dementia by healthcare professionals (Michalowsky et al., 2018; Zhu et al., 2020). However, the care costs for people with dementia without a diagnosis remain unknown, which is crucial for a comprehensive understanding of the economic burden associated with dementia and for better resource allocation and planning in care systems. Additionally, investigating the care costs of undiagnosed individuals can shed light on potential impacts with the detection and diagnosis of dementia, facilitating a better understanding of the importance of early identification and intervention.

To date, only two studies have explored the association between a formal diagnosis of dementia and care costs among people screened for dementia; their findings are inconclusive due to the heterogeneous components of care costs and care settings (Michalowsky et al., 2016; Romeo et al., 2017). Additionally, little research has explored the differential care costs due to a dementia diagnosis at different cognitive impairment levels. Seeking a diagnosis for dementia is commonly delayed; 60.5%-78.9% of people had been living with moderate-to-severe dementia at diagnosis (Gungabissoon et al., 2020; Thoits et al., 2018). Although most studies conducted among people with diagnosed dementia found that care costs for dementia increase with increasing severity of cognitive impairment (Khandker et al., 2020; Kongpakwattana et al., 2019; Ku et al., 2016), a few also found that cognitive impairment levels were not significantly associated with total care costs (Jutkowitz et al., 2017). Research considering both formal dementia diagnosis and cognitive impairment level for LTC costs across community care settings (CCS) and residential care settings (RCS) is lacking.

Meanwhile, informal caregivers—primarily family members, but also including friends, neighbors, and domestic helpers—play an essential role in supporting people living with dementia in daily activities (Michalowsky et al., 2016; Vandepitte et al., 2020), particularly where formal care services are inadequate. Frequently, informal caregivers also initiate help-seeking for a dementia diagnosis and other resources (Hill et al., 2021). However, it remains unclear how a dementia diagnosis and cognitive impairment level can differentiate the distribution of cost between formal and informal caregiving.

Resource utilization by people with dementia or cognitive impairment can be captured by multiple instruments (Yang et al., 2018). For example, questionnaires completed by service users or a family caregiver on the frequency of using a specific service have been employed to capture healthcare and formal care service utilization, while care time in the previous month has more frequently been used to measure informal caregiving. The staff time measurement (STM) approach can reduce recall bias and provide a more accurate comparison of the economic value of formal and informal care, as it collects information on the time spent on service users by different types of care staff over a certain period of time, e.g., a 24-hr time log over seven days, and care time can be costed based on the corresponding labor costs (Turcotte et al., 2019). However, limited research has used the STM approach to estimate the LTC costs for dementia and cognitive impairment.

A substantial proportion of people with dementia live in Chinese communities and face significant LTC needs (Feng et al., 2020; Prince et al., 2015), while most studies were conducted in Western countries. Compared with other Chinese communities, Hong Kong has the longest life expectancy, with a comprehensive LTC system providing community care and residential care services to frail older people (Lum et al., 2016; Lum et al., 2020). These services are mostly government-funded and provided to those assessed as having moderate to severe levels of care needs, regardless of their financial status. Dementia and cognitive impairment are common among these LTC recipients as they are very frail and have substantial care needs. Given the high prevalence of dementia and cognitive impairment among LTC recipients, studying the association between dementia diagnosis, cognitive impairment level, and service utilization is essential for optimizing resource allocation and meeting the complex care needs of this vulnerable population. This research has the potential to enhance the quality of care and maximize the value of public resources invested in LTC services.

This study used a dataset from a large-scale STM study among publicly funded LTC recipients in Hong Kong. It aimed to examine the relationship between formal and informal care costs with a dementia diagnosis and cognitive impairment level across residential and community care settings. Furthermore, we compared the LTC costs at different cognitive impairment levels between LTC recipients with and without a dementia diagnosis.

Method

Study subjects

This study used data from 1 603 subjects collected between May 2014 and December 2016. This included 601 users of government-funded community LTC services (CCS participants) and 1 002 residents living in government-subsidized nursing homes (RSC participants) in Hong Kong. The CCS participants were recruited from 23 adult daycare centers and 40 homecare services teams. The RCS participants were recruited from 26 residential care homes. During the study timeframe, the Hong Kong SAR government employed the Standardized Care Need Assessment Mechanism using Minimum Dataset for Home Care (MDS-HC) to determine eligibility for LTC services. Briefly, older adults assessed as having moderate-to-severe overall impairments (regardless of financial status) are eligible for receiving publicly funded community care services, while those assessed as having severe impairment are eligible for residential care services (Lum et al., 2016; Lum et al., 2020). Accredited assessors conduct face-to-face assessments to identify applicants' LTC service needs and match them with appropriate services. Eligible LTC recipients are only required to contribute a nominal copayment for additional services beyond the standard publicly funded care package. Direct payment or cash benefits for family caregivers were not available within our study timeframe.

Data collection

We used the Hong Kong Chinese Edition (version 9.3.0) of the interRAI Home Care (interRAI-HC) and the interRAI Long-term Care Facilities Assessment Form (interRAI-LTCF) assessment forms (interRAI, 2021a, 2021b) to collect clinical data about CCS and RCS participants, respectively. The interRAI system of assessments systematically collects sociodemographic information, clinical characteristics, cognition, and functioning data through observation and information provided by the care recipient and caregivers. All assessments were undertaken by appropriately trained full-time researchers.

Information on formal and informal LTC service utilization was collected through an STM survey starting within 1 month after our clinical assessments. The research team prepared a log sheet for each participant and trained the caregivers involved to record all services they provided to this participant within 1 day. The log sheet included service date, type of care (e.g., bathing, giving medication; see Supplementary Tables 1 and 2, see online supplementary material), duration (in minutes), the number of staff involved, and the staff designation (e.g., personal care attendant, registered nurse, and social worker). The STM survey for RCS residents took place over 7 days, recording data for 24 hr a day; that for CCS lasted for a month. All service utilization data were translated into annual care time for analysis.

The study was approved by the Human Research Ethics Committee of the University of Hong Kong (Reference No.: EA060114).

Service utilization

Formal care refers to care provided by paid professional staff (e.g., nurses, social workers, and physical therapists) and support staff (e.g., personal care workers), including both direct services (e.g., nursing care) and indirect services (e.g., meal preparation, laundry services). In RCS, direct care time was defined as the time spent on hands-on care for the residents. Indirect care that includes preparatory and follow-up work of care tasks such as meal preparation, pharmacy dispensing, and care planning may constitute a great portion of the total time cost. The RCS care workers reported their indirect care hours, which were compared to the average direct care time for each service type to create a ratio. The median of these ratios across all RCS facilities was used as the final estimate and applied to all units. Details of the staff type and care type are shown in Table 1 and Supplementary Tables 1 and 2 (see online supplementary material).

Informal care for CCS recipients refers to care provided by an informal caregiver (such as family members, friends, and domestic helpers) for service users for activities of daily living (ADL) and instrumental activities of daily living (IADL), including daily tasks (e.g., personal hygiene, bathing, managing medications, and feeding) and nondaily care (e.g., hospital escort and finance management), excluding household living tasks (e.g., household chores, shopping, and cooking). An informal care log sheet was used to collect CCS data. In RCS, care activities performed by informal caregivers but originally intended for formal caregivers were also recorded and, at the time of service, aggregated into formal care provision according to the service type. We assumed that formal caregivers would maintain the same level of care if the informal caregivers were unavailable. Meanwhile, we did not record any care provided by informal caregivers in RCS that was not on the predefined care checklist, such as routine companionship.

Care costs

Care costs for each participant during the STM period were estimated by multiplying the amount of service use (in terms of time or frequency) and unit costs based on the type of caregiver. We employed the hourly rate of each type of care staff as the unit costs from the official salary scale published by the government on April 1, 2016. The unit costs of informal care in CCS were equated to the hourly rate of a home helper. In CCS, the costs of meal services, routine transportation, and laundry services provided by formal care workers were directly calculated at HK$50 per meal, trip, and laundry service use, based on local practice. These costs were then converted to a wage-weighted unit. Details of the care definition and unit cost of each type of service are provided in Table 1.

Cognitive status and dementia

Cognitive status was measured by the Cognitive Performance Scale (CPS) as part of the interRAI assessment system (Foebel et al., 2016; Morris et al., 1999). The CPS is based on five interRAI items, including decision-making (ability to make daily decisions; score range 0-5), short-term memory (recall of recent events/information and delayed recall of three unrelated items; binary), ability to make oneself understood (verbal/nonverbal communication; 0–4), eating performance (independence in feeding; 0–6), and coma (binary). Accredited interRAI assessors (health and care professionals) rate these items based on multiple sources of information, including assessment (for short-term memory) and interview with the person, informants (informal caregivers and formal care providers), direct observation, and review of clinical records. The composite CPS algorithm (Hartmaier et al., 1995; Morris et al., 1994) maps these scores onto a hierarchical 7-level cognitive impairment classification (from *intact* to *very severe*), designed to reflect cognitive impairment stages, with higher scores indicating greater impairment (see Paquay et al., 2007) for the hierarchical scoring rules. It has been validated against the Mini-Mental State Examination (MMSE) (Hartmaier et al., 1995; Paquay et al., 2007) with scores linked with both MMSE and Montreal Cognitive Assessment (Andersson et al., 2021) available.

Dementia diagnosis (a binary variable) was determined based on the interRAI assessment information, indicating a medical diagnosis of Alzheimer's disease and other forms of dementia, irrespective of receiving treatment or not.

Covariates

We obtained covariate variables from the interRAI assessments. Participants' physical function was measured by the interRAI ADL Hierarchy Scale (ADL-HS, range 0–6) (Morris et al., 1999). We categorized participants into three functional groups, relatively independent (ADL-HS score 0–1), limited to extensive impairment (ADL-HS score 2–4), and dependent

Table 1. Care definition and unit costs (USD).

Care type	Definition	Valuing approach	Unit costs		
Formal care	Formal care was defined as care provided by formal care staff, including supportive staff and professional staff. Care costs were estimated by multiplying care time and unit costs of each type of care staff.	Unit costs were estimated using an hourly rate, which was equal to official monthly salary[a] multiplied by 12 months and divided by 52 weeks and 40/45 working hours. The weekly working hours for professional staff and supportive staff were 40 and 45, respectively.	Supportive staff		
			Workman	$8.7	per hour
			Programme assistant/Clerical assistant	$9.6	per hour
			Home helper	$10.3	per hour
			PCW/PTA/OTA/STA/RA	$10.9	per hour
			Clerical officer	$10.9	per hour
			Driver/Cook	$11.7	per hour
			Health worker	$14.9	per hour
			Welfare worker	$15.8	per hour
			Professional staff		
			Enrolled nurse/Dispenser	$20.8	per hour
			Physiotherapist/Occupational therapist	$25.3	per hour
			Registered nurse	$26.5	per hour
			SW/Dietitian/Speech therapist	$35	per hour
			Assistant superintendent	$42.1	per hour
			Superintendent	$54.8	per hour
			Medical officer	$62.6	per hour
			Activity coach[b]	$64.3	per hour
			Music therapist[b]	$128.6	per hour
	For care measured by frequency rather than time in CCS, we used direct care costs to reflect those care cost, which are equal to frequency of service use multiplied by unit costs of per type of service.	Unit costs of each type of service were estimated according to previous local research.	Meal service	$6.4	per meal
			Routine transportation	$6.4	per trip
			Laundry Services	$6.4	per time
Informal care	In CCS, informal care was defined as care for daily ADL and IADL and nondaily care (e.g., hospital escort and finance management), excluding household living tasks: household chores, shopping, and cooking. Care costs were equal to care time multiplied by unit costs of informal care.	Unit costs were estimated using replacement costs approach, same as unit costs of a home helper.	Informal caregiver (e.g., family members, friends and domestic helpers)	$10.3	per hour
	In RCS, informal care was captured as formal care according to service type.[c]	Using unit costs of formal care costs for various care staff.			

Note. All costs were converted to US dollar using the official average selling rate in April 2016 (1 USD = 7.7786 HKD). PCW = personal care worker; PTA = physiotherapist assistant; OTA = occupational therapist assistant; STA = speech therapist assistant; RA = rehabilitation assistant; SW = social worker; CCS = community care setting; RCS = residential care setting; ADL = activities of daily living; IADL = instrumental activities of daily living.

[a] The midpoint monthly salary of the Master Pay Scale (MPS) in the Salary Scale of Common Posts in the Non-government Organization released by the Department of Social Welfare in April 2016.

[b] Hourly rate of these categories not included in the MPS was estimated based on suggestions made by stakeholders in focus groups.

[c] Informal care time was aggregated into formal care time directly.

(ADL-HS score 5–6), as used in a previous study (Foebel et al., 2016). In addition, in our analysis, we controlled for participants' age (in years), gender, the number of comorbidities (i.e., previous diagnosis of diseases other than dementia), and care setting (CCS vs RCS).

Statistical methods

We first undertook a descriptive analysis of all participants, and by care settings, dementia diagnosis, using percentages for categorical variables and means and standard deviation for continuous variables. We then calculated the unadjusted annual costs by dementia diagnosis across cognitive impairment levels, care settings, and formal and informal care (only in CCS).

Given the right-skewed distribution of care costs, we used the generalized linear model (GLM) with the log link and gamma distribution to examine the association between LTC care costs and clinical diagnosis for dementia, controlling for levels of cognitive impairment, physical functioning, demographics, and the number of comorbidities. GLM analyses were conducted for all samples, the RCS, and CCS subsamples, and for formal care and informal care costs in CCS. Estimates of GLM were reported in the exponentiated form [Exp(b)], interpreted as the percentage change in estimated costs (=100×[Exp(b)−1]) for each unit change of a predictor (Knapp et al., 2016; Skoldunger et al., 2019). All models were adjusted for dementia diagnosis, CPS scores, ADL-HS scores, age (centered), gender, and the number of comorbidities other than dementia. We used the *glm* command to run GLM analysis (McCullagh & Nelder, 1989), reporting robust standard error, and *Margins* command to predict the adjusted average annual costs in Stata V16.0. We used listwise deletion to deal with missing values (1.6% of the total observations). Participants presenting intact cognition (CPS score = 0) but with a dementia diagnosis were excluded from the analyses as problematic data (*n* = 7).

Sensitivity analyses were performed to check the robustness of the results, controlling for behavioral and psychological symptoms of dementia (BPSD), treating CPS scores as a continuous variable, and including an interaction variable of dementia diagnosis and cognitive impairment level in GLM analyses, respectively. BPSD was measured by three binary variables: the presence of behavioral problems (i.e., wandering, verbal, abusive, physically abusive, socially inappropriate, disrobing in public, or resisting care), hallucinations, and delusions (Foebel et al., 2016). The interaction variable combined a binary variable indicating whether having a dementia diagnosis with a three-category variable indicating cognitive status. This cognitive status variable was recoded from CPS score and categorized as follows: borderline cognitive impairment (CPS score 0–1), mild-to-moderate cognitive impairment (CPS score 2–4), and severe cognitive impairment (CPS score 5–6), based on the classification in Foebel et al. (2016).

Results

The final sample comprised 579 community-dwelling LTC recipients and 991 care home residents, among whom 47.6% had a dementia diagnosis (CCS: 37%; RCS: 54%; Table 2). Among both CCS and RCS participants, those with a dementia diagnosis had higher CPS scores, worse ADL ability, were older, and comprised of more women than those without a dementia diagnosis. The sample was distributed unevenly across the seven levels of cognitive function in both RCS and CCS, while those without a dementia diagnosis had a better level of cognitive function (CPS mean score: CCS, 1.4; RCS, 2.2) than those with a dementia diagnosis. RCS participants with a dementia diagnosis were more likely to be older (mean age = 88.1 years), female (74.9%), and dependent for ADL tasks (69.7%) than other groups. On average, in all groups, participants had 3.4 comorbidities in addition to dementia.

Table 3 shows the unadjusted average annual formal and informal care costs (in USD) by cognitive level and a clinical dementia diagnosis in RCS and CCS. The overall average care costs of participants without a dementia diagnosis were lower than those with a diagnosis in both RCS ($22 194 vs $31 757; 43.1%) and CCS ($9 394 vs $17 232; 83.4%). This was also true for formal care costs ($5 194 vs $8 828; 70%) and informal care costs ($4 536 vs $9 319; 105.4%) in CCS. After disaggregating by CPS scores, participants with very severe cognitive impairment had the greatest costs if diagnosed with dementia in RCS ($36 806) and had the highest percentage difference due to a dementia diagnosis in CCS formal care (162.9%). Surprisingly, LTC recipients with a dementia diagnosis presenting moderate-to-very severe cognitive impairment had lower informal care costs than those without a dementia diagnosis, with a percentage difference ranging between −1.2% and −35.1%. Unweighted care time was shown in Supplementary Table 3 (see online supplementary material), basically reflecting a similar relationship pattern between service utilization and diagnosis and cognitive status.

Table 4 shows the results of the GLM analyses on LTC costs by care types and care settings. The associations are presented in the exponentiated form, suggesting the percentage change in estimated costs (=100×[Exp(b)−1]) for each unit change of a predictor. For instance, a dementia diagnosis had the strongest significant association with LTC costs by an additional 55% increase in CCS formal care costs, followed by a 23% increase in CCS total costs, and then a 13% increase in

Table 2. Characteristics of the analytic sample by whether having a clinical dementia diagnosis in residential care and community care settings.

		Residential care setting (*n* = 991, 63%)		Community care setting (*n* = 579, 37%)	
Variables	Total (*N* = 1570)	D−	D+	D−	D+
N (%)		458 (46)	534 (54)	365 (63)	214 (37)
Age, year, *M* (*SD*)	85.1 (8.2)	86.1 (8.1)	88.1 (7.1)	80.9 (8.1)	82.8 (7.7)
Female, %	67.9	70.30	74.90	55.90	65.40
Diagnosis of dementia, %	47.6				
Comorbidities other than dementia, number (*M*, *SD*)	3.4 (1.9)	3.8 (1.9)	3.3 (1.9)	3.2 (1.7)	3.3 (2.1)
CPS, score (*M*, *SD*)	3 (2.1)	2.2 (2.0)	4.3 (1.7)	1.4 (1.6)	3.8 (1.5)
0 Cognitive intact, %	12.4	15.8	0.0	32.5	0.0
1 Borderline cognitive intact, %	22.6	36.1	7.3	37.3	7.0
2 Mild cognitive impairment, %	18.5	17.1	16.7	16.7	29.0
3 Moderate cognitive impairment, %	12.5	10.1	16.1	5.8	20.9
4 Moderate-to-severe cognitive impairment, %	3.7	1.5	5.4	1.6	7.5
5 Severe cognitive impairment, %	11.5	8.1	17.2	2.2	20.1
6 Very severe cognitive impairment, %	19.2	11.4	37.3	4.4	16.4
ADL_HS					
0 Relatively independent, %	31.3	35.4	11.2	57.3	28.0
1 Limited to extensive impairment, %	21.8	19.9	19.1	18.4	38.8
2 Dependent, %	46.9	44.8	69.7	24.4	33.2

Note. Participants who had a diagnosis of dementia but presented cognitively intact (i.e., CPS score = 0) were excluded from the analysis (*n* = 7). D+ = with a dementia diagnosis; D− = without a dementia diagnosis; CPS = the InterRAI Cognitive Performance Scale; ADL_HS = the interRAI Activities of Daily Living Hierarchy Scale.

Table 3. Average annual formal and informal care costs (USD) by cognitive level and a clinical dementia diagnosis in residential care and community care settings.

	Residential care setting			Community care setting								
	Total residential care costs $ (*SD*)		% diff.	Total community care costs $ (*SD*)		% diff.	Formal care $ (*SD*)		% diff.	Informal care $ (*SD*)		% diff.
CPS score	D−	D+		D−	D+		D−	D+		D−	D+	
0 cognitive intact	13,412 (9,284)	/	/	6,363 (6,002)	/	/	4,087 (3,200)	/	/	2,398 (5,270)	/	/
1 Borderline cognitive intact	18,054 (12,511)	18,448 (10,030)	2.2%	8,162 (6,363)	9,807 (7,681)	20.2%	5,902 (4,849)	7,287 (6,551)	23.5%	2,401 (3,873)	2,700 (3,838)	12.5%
2 Mild cognitive impairment	24,006 (13,405)	26,105 (14,986)	8.7%	11,387 (8,647)	14,204 (8,055)	24.7%	5,773 (4,712)	8,411 (5,431)	45.7%	6,461 (7,687)	6,651 (8,039)	2.9%
3 Moderate cognitive impairment	26,275 (12,574)	29,086 (14,033)	10.7%	16,217 (11,324)	16,064 (10,475)	−0.9%	6,688 (5,499)	8,167 (8,763)	22.1%	11,117 (10,208)	8,707 (6,581)	−21.7%
4 Moderate to severe cognitive impairment	26,785 (11,520)	35,619 (13,627)	33.0%	17,355 (10,168)	18,770 (8,192)	8.2%	4,402 (4,295)	9,937 (4,802)	125.7%	15,543 (11,223)	10,094 (4,550)	−35.1%
5 Severe cognitive impairment	29,334 (7,944)	33,223 (13,284)	13.3%	15,868 (6,599)	20,220 (14,311)	27.4%	5,152 (3,075)	10,120 (9,541)	96.4%	10,717 (4,907)	10,592 (9,167)	−1.2%
6 Very severe cognitive impairment	35,459 (11,480)	36,806 (14,255)	3.8%	19,266 (10,727)	22,840 (10,706)	18.6%	3,403 (4,299)	8,945 (5,457)	162.9%	16,921 (10,361)	15,689 (8,307)	−7.3%
Total	22,194 (13,501)	31,757 (14,872)	43.1%	9,394 (8,124)	17,232 (11,021)	83.4%	5,194 (4,407)	8,828 (7,175)	70.0%	4,536 (7,156)	9,319 (8,325)	105.4%

Note. All costs were converted to US dollar using the official average selling rate in April 2016 (1 US$ = 7.7786 HK$); % diff. is the percentage increase of care costs for those with a dementia diagnosis from those without a diagnosis of dementia; Total $ included formal and informal care costs. D+ = with a dementia diagnosis; D− = without a dementia diagnosis; CPS = the interRAI Cognitive Performance Scale.

residential care costs. Informal care costs were not significantly associated with a formal dementia diagnosis in CCS. The LTC costs were significantly associated with cognitive impairment levels in most groups and generally increased with increasing cognitive impairment severity. Compared with the intact cognition group, the moderate-to-severe cognitive impairment group had the highest difference of a 189% increase in CCS informal care costs, and a 53% increase in residential care costs. Those with severe cognitive impairment had the highest difference of a 46% increase in CCS formal care cost; the very severe cognitive impairment group had the highest difference of a 120% increase in total community care costs.

After GLM adjustment, we estimated the average LTC costs in CCS and RCS at each level of cognitive performance for people who had received and not received a dementia diagnosis (Figure 1 and Supplementary Table 4, see online supplementary material). Figure 1 shows that both average total residential and community care costs increased along with cognitive impairment levels and were also elevated by a dementia diagnosis. Also, the average CCS formal care costs were insensitive to cognition status but were consistently higher if having a dementia diagnosis. By contrast, the adjusted average CCS informal care costs were less associated with a dementia diagnosis but increased with cognitive impairment severity and peaked at the moderate to severe cognitive impairment level. To complement the graphical presentation, Supplementary Table 4 (see online supplementary material) provides the corresponding numerical details of the adjusted LTC costs by dementia diagnosis status and cognitive impairment severity. It reveals that the cost increase rate associated with a dementia diagnosis consistently exceeded that associated with progressive cognitive impairment across most cost categories, except for CCS informal care costs, where dementia diagnosis was not significantly associated with care costs.

Other sensitivity analyses revealed similar patterns of associations between predictors and LTC costs after including BPSD variables (Supplementary Table 5, see online supplementary material) and regarding CPS scores as a continuous variable (Supplementary Table 6, see online supplementary material) in GLM analyses separately. To further understand the combined effect of diagnosis and cognitive impairment level, an interaction variable based on a dementia diagnosis variable and a three-level cognitive impairment variable was included in our main GLM models for different LTC costs. The results showed no significant association between the interaction term and any care costs (Supplementary Table 7, see online supplementary material). This suggested that the dementia diagnosis and

Table 4. Results of GLM analyses on formal and informal care costs by long-term care settings.

	Total residential care costs	Community care		
		Total community care costs	Formal care costs	Informal care costs
Variable	Exp(b)	Exp(b)	Exp(b)	Exp(b)
Diagnosis for dementia (ref.: = No diagnosis)	1.13***	1.23**	1.55***	1.13
	[1.06, 1.20]	[1.08, 1.41]	[1.29, 1.86]	[0.84, 1.53]
CPS (ref.: = 0 Cognitive intact)				
Borderline cognitive intact	1.20*	1.24*	1.44***	0.88
	[1.04, 1.38]	[1.03, 1.51]	[1.19, 1.74]	[0.52, 1.49]
Mild cognitive impairment	1.34***	1.50***	1.30*	1.78*
	[1.16, 1.55]	[1.21, 1.85]	[1.05, 1.61]	[1.04, 3.05]
Moderate cognitive impairment	1.38***	1.65***	1.32	2.12**
	[1.17, 1.62]	[1.27, 2.14]	[0.97, 1.80]	[1.28, 3.51]
Moderate-to-severe cognitive impairment	1.53***	1.93***	1.35	2.89***
	[1.26, 1.85]	[1.47, 2.54]	[0.98, 1.87]	[1.62, 5.17]
Severe cognitive impairment	1.44***	1.87***	1.46*	2.04**
	[1.24, 1.67]	[1.42, 2.46]	[1.05, 2.03]	[1.24, 3.35]
Very severe cognitive impairment	1.51***	2.20***	1.39	2.68***
	[1.30, 1.76]	[1.68, 2.88]	[0.98, 1.96]	[1.60, 4.51]
ADL-HS (ref.: 0 relatively independent)				
Limited to extensive impairment	1.72***	1.84***	1.33**	3.70***
	[1.53, 1.94]	[1.58, 2.13]	[1.11, 1.58]	[2.75, 4.99]
Dependent	2.20***	1.62***	0.92	4.45***
	[1.98, 2.45]	[1.36, 1.94]	[0.759, 1.11]	[3.16, 6.27]
N	991	579	579	531

Note. GLM = the generalized linear model with the log link and gamma distribution; controlling for age (centered), gender and the number of comorbidities other than dementia; Exp(b) = exponentiated coefficients, suggesting the percentage change in estimated costs (=100×[Exp(b)−1]) for each unit change of a predictor, 95% confidence intervals in brackets; CPS = the interRAI Cognitive Performance Scale, range 0-6; ADL_HS = the interRAI Activities of Daily Living Hierarchy Scale.
*$p < .05$, **$p < .01$, ***$p < .001$.

cognitive impairment levels are independently associated with LTC costs.

Discussion

This is the first study to investigate how formal and informal care costs can be associated with a clinical diagnosis for dementia and cognitive impairment levels across community and residential care settings. We used representative data for publicly funded LTC recipients and the STM approach to measure the time spent on each type of service utilization by different care staff. Cognitive and functional status were controlled in our analyses to ensure comparability among participants in terms of their dementia status (Bartfay et al., 2013, 2014). Our study revealed that total care costs in RCS and CCS were significantly associated with both dementia diagnosis and cognitive impairment level. In CCS specifically, the formal care costs were associated with dementia diagnosis, whereas informal care costs were associated with cognitive impairment level.

From a societal perspective on estimating LTC costs, we found that a dementia diagnosis was significantly associated with higher RCS total costs (13%), CCS total costs (23%), and CCS formal care costs (55%), but was not associated with CCS informal care costs. These findings contribute to existing literature by providing a more nuanced understanding of care cost dynamics. In contrast, two previous studies exploring the association between diagnosis of dementia and care costs among people screened for dementia reported divergent results. Michalowsky et al. (2016) compared costs among community-dwelling participants ($n = 240$) in Germany and found that a dementia diagnosis significantly triggers increased antidementia drug use but not total medical costs or formal care costs. The authors explained that this could be because antidementia drug use might reduce other medical service utilization, while postdiagnostic healthcare or formal care services for dementia were underprovided. The discrepancy in formal care cost associations may reflect differences in care systems and the specific services included in formal care across regions. Conversely, Romeo et al. (2017), analyzing data from 277 care home residents identified with dementia in England, found that a diagnosis was significantly associated with higher care costs. This suggested unidentified barriers to dementia diagnosis in residential care settings and unmet needs among undiagnosed residents. Together, these variations highlight the complexity of dementia diagnosis's interaction with care cost, emphasizing the need to account for care settings and service types.

The positive association of a dementia diagnosis with formal care costs might be the result of dementia-related interventions usually being delivered only following diagnosis. A dementia diagnosis may also alert caregivers to be more patient during caregiving and allow more preparation time to reduce care recipients' noncompliance, although a qualitative study found that knowledge of a formal dementia diagnosis had inconsistent effects, both helping formal caregivers to facilitate or hinder caregiving (Roelands et al., 2005). In Hong Kong, a Dementia Supplement policy has been introduced to encourage LTC providers to enhance care capacity for

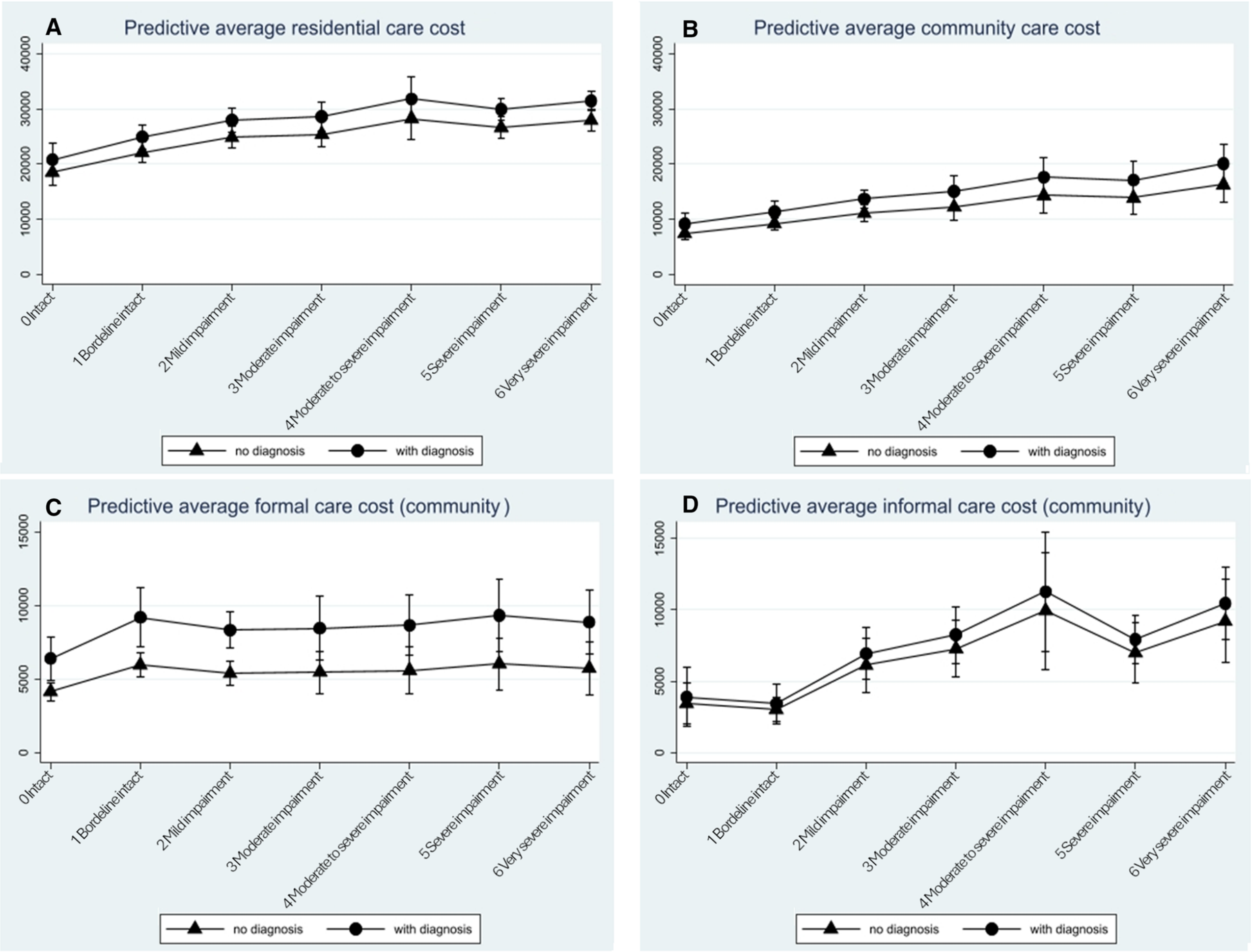

Figure 1. Predicted average residential care cost (A), community care cost (B), formal care cost (community, C), and informal care cost (community, D) at each level of cognitive performance between people who have received and not received a dementia diagnosis. 95% confidence intervals indicated by the whiskers. Expressed in US dollars at 2016 prices.

dementia. An additional budget based on the number of service users with a formal dementia diagnosis was allocated to strengthen the workforce in care homes and daycare centers (Department of Social Welfare, 2015; Legislative council, 2017). This policy design may partly explain the diagnosis-associated cost increase in total residential care and CCS formal care. As a result, LTC recipients without a dementia diagnosis very likely received fewer resources, even if they present the same level of cognitive and functional impairment as those with a diagnosis.

Unlike formal care provision, informal caregivers may find it difficult to adjust their caregiving capacity or increase the number of caregivers in response to a dementia diagnosis, as actual care needs are also less likely to be influenced by the diagnosis itself. This aligns with recent evidence showing that individuals with dementia are more likely to use formal care over informal care when both are available through a public system, compared to those without dementia (Shi et al., 2024). Especially in moderate-to-severe dementia, caregiving can be overwhelmingly time-consuming and stressful, often exceeding informal caregivers' capacity. In contrast, a dementia diagnosis can mobilize additional resources within the formal LTC system, leading to partial replacement of informal care with formal LTC service, particularly in later stages of dementia (Bremer et al., 2017).

A near-linear relationship was observed between cognitive impairment levels and all LTC costs, except for CCS formal care costs. This relationship is particularly pronounced for CCS informal care costs. These findings suggest that, to some extent, current service provisions by residential care staff and CCS informal caregivers reflected the changing needs due to cognitive impairment. A possible explanation is that current community care services, such as day centers and home care teams, may not be designed to accommodate the higher care needs of individuals with more severe dementia. Additionally, these services often lack the flexibility required to adjust to increasing care demands. For instance, increasing the number of days a patient can attend a day center is contingent upon service availability and may be constrained by the public budget and LTC waiting lists. This inflexibility in formal community care services may necessitate greater reliance on informal caregivers, thereby increasing informal care costs as cognitive impairment worsens. In the healthcare context, care costs may be more responsive to changes in cognitive impairment severity. For instance, a longitudinal study found an increase in health and social care costs in relation to Alzheimer's disease progression among people who had received a clinical diagnosis (Jetsonen et al., 2021). Similarly, a cross-sectional study using data from seven European countries reported that health care resource utilization escalates with increasing cognitive impairment (Khandker et al., 2020). By contrast, the US evidence (Jutkowitz et al., 2017) showed that poorer function rather than cognition was the key driver of increased Medicare expenditures. Our study provides more detailed observations on the association between LTC costs and cognitive impairment level.

Our findings showed that both dementia diagnosis and cognitive impairment level are associated with LTC costs, but they manifest these relationships differently. There is a stronger correlation between formal care and a dementia diagnosis, while informal care shows a greater correlation with the level of cognitive impairment. Additionally, the presence of a dementia diagnosis seems to be more closely related to an increase in total care costs compared to a single level of cognitive decline. We also assessed the interplay between dementia diagnosis and cognitive impairment level in relation to LTC costs by examining their joint effect. However, the inclusion of an interaction term in our analysis did not yield a significant correlation. Specifically, this indicates that having a dementia diagnosis does not modify the relationship between care costs and cognitive impairment level, and the cognitive impairment level does not moderate the relationship between LTC cost and having a dementia diagnosis. This suggests that the relationship between dementia diagnosis and cognitive impairment with LTC costs is distinct and operates on a separate trajectory.

We observed that average residential care costs exceed community care costs for individuals both with and without a dementia diagnosis at the same level of cognitive impairment. This likely occurs because care recipients in RCS typically exhibit higher levels of overall impairment, as eligibility criteria for RCS essentially require an overall severe impairment level, whereas CCS eligibility requires a moderate to severe overall impairment level. However, we also note that our methodology might have led to an underestimation of CCS informal care costs. This underestimation could be due to our conservative replacement approach, which values informal care hours at the home helper hourly rate. In contrast, we valued informal care time in RCS based on different care staff rates due to varying care tasks. If the societal perspective was consistently adopted in cost estimation cross care settings, CCS care costs can be more expensive than that in RCS when functional impairment is controlled for (König et al., 2014).

Our study also shed light on the prevalence of undiagnosed dementia among individuals in RCS and CCS. A widely used approach for detecting dementia involves assessing functional ability and cognitive impairment (Bartfay et al., 2013, 2014; McKhann et al., 2011). Given that our participants were all recipients of publicly funded LTC services, they would have undergone assessments indicating at least overall moderate impairment. It can be inferred that those presenting mild cognitive impairment (CPS score ≥2) were highly likely to have dementia. This definition could account for over 90% of our participants with dementia diagnosis. Among those without a dementia diagnosis, 48.2% of LTC recipients in RCS and 30.7% in CCS fell into this category. These findings indicate a higher rate of undiagnosed dementia in RCS compared to CCS. This contrasts with previous studies where over two thirds of care home residents and around 55% to 68% of community-dwelling older persons were considered highly likely to have dementia but had not received a clinical diagnosis (Bartfay et al., 2013; Lang et al., 2017).

Our findings have significant policy implications. First, the care needs of individuals with cognitive impairment and functional deficits may be overlooked within the formal LTC system, particularly in the CCS, if they lack a formal diagnosis. In contrast, those with a recognized diagnosis may receive greater attention and visibility. Improving the diagnosis rate for dementia requires collaboration between the healthcare and social care sectors (such as diagnosis task shifting) to ensure that LTC recipients receive timely and adequate services. Filling the service gaps for those with undetected dementia entails increased budgets for LTC. Those costs can be offset by the benefits of receiving cost-effective intervention and management to improve health-related outcomes and quality of life. In the long run, prompt intervention could reduce total care costs, such as delaying the need for institutionalization (Gauthier et al., 2021). Second, our study highlights the significance of resource allocation by identifying care needs beyond clinical diagnosis. Given the current number of people with undiagnosed dementia, a review of care planning is needed to deliver dementia-related services and interventions equally. It is vital to pay attention to publicly funded LTC recipients with undiagnosed dementia as they are more vulnerable and mostly have lower socioeconomic status. Third, our study also underscores the crucial role of family members in recognizing and addressing the care needs that arise from cognitive impairment. It also points out potential limitations in the ability of community care services to adapt to these needs. These insights are important for optimizing the design and delivery of care services to better meet the needs of individuals with cognitive impairment.

This study has the following limitations. First, there are concerns about the tasks that should be included to capture informal care time, such as supervision time and mealtime, although there is no golden rule for estimating informal care (König et al., 2014). In CCS, we did not include household chores, shopping, and cooking when calculating informal care time, as those may not be specific to the service users. Second, we aggregated informal care into formal care time according to service type in RCS, assuming that formal caregivers would maintain the same level of care if informal caregivers were unavailable to address this. This approach did not account for services exceeding the initial care package. However, this aggregation might underestimate the informal care burden in RCS, which is considerable for dementia patients residing in RCS (Li et al., 2024). Third, using those presenting cognitive impairment as the counterparts for participants with diagnosed dementia may bias the cost gaps between those with and without a dementia diagnosis. Therefore, we controlled the level of functioning ability (ADL-HS) and other covariates and compared the care cost differences due to the diagnosis among those presenting with different levels of cognitive impairment to deal with this issue. Although some differences with those who screened positively for dementia may remain, given the inadequacy of adequately qualified staff to assess dementia, our study used existing information to reduce potential bias in the comparison. Fourth, this study focused on the care provided within LTC fatalities, potentially limiting the comprehensive assessment of medical costs that are more directly related to the diagnosis. Future studies may further investigate the association between medical costs and a formal diagnosis of dementia, as well as its impact on overall costs. Another limitation of this study is the lack of available longitudinal data that could provide insights into the cost effectiveness of providing more intensive LTC to people with a dementia diagnosis and its potential impact on informal caregivers.

Supplementary material

Supplementary material is available at *Innovation in Aging* (https://academic.oup.com/innovateage).

Data availability

The data, analytic methods, or materials underlying this article will be available on reasonable request to the corresponding author. This study was not preregistered.

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Conflict of interest

None declared.

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