Tools to Inform Policy
Chinese communities' Action in Response to Dementia
華人社會認知障礙症策略工具

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How does a diagnosis for dementia and cognitive impairment levels affect formal and informal care costs among publicly-funded long-term care recipients?

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Background

- Annual global dementia costs > US$1 trillion, **80%** of which are attributed to **formal and informal care** (ADI report 2015).
- Diagnosis: gateway to resources but **75%** people undiagnosed (>90% in in LMICs) (ADI report 2021).
- **Two-thirds** of care home residents and **55% to 68%** of community-dwelling older persons undiagnosed (Bartfay, Bartfay, & Gorey, 2013; Lang et al., 2017).
- Two studies on the effect of diagnosis on care costs , findings **inconclusive** (heterogeneous components of care costs and care settings)
  - In **Germany primary care**: diagnosis associated with **higher drug costs, lower** total medical care costs, but **not formal care costs** (Michalowsky, Eichler, et al., 2016).
  - In **England residential care**: diagnosis associated with **higher total healthcare and formal care costs** (Romeo et al., 2017).
- Evidence on the effects of having a formal diagnosis on formal and informal care costs across community and residential care settings lacking

Objectives

This study used a dataset from publicly-funded long-term care (LTC) recipients in Hong Kong to address two aims:

- (a) to examine the impact of a formal dementia diagnosis on formal and informal care costs across residential and community care settings, and
- (b) to compare the LTC costs at different cognitive impairment levels between LTC recipients having and not having a formal dementia diagnosis.

Long-term care system in Hong Kong

- Long-term care services in Hong Kong are mostly funded by the government and provided to applicants who are assessed as **moderate to severe** level of care needs regardless of their financial status.

Publicly-funded Long-term care services in Hong Kong

Community Care Services

- Enhanced Home and Community Care Service (EHCCS)
- Integrated Home Care Service – Frail case (IHCS – Frail)
- Day Care Centre / Unit for the Elderly (DE /DCU)

Residential Care Services

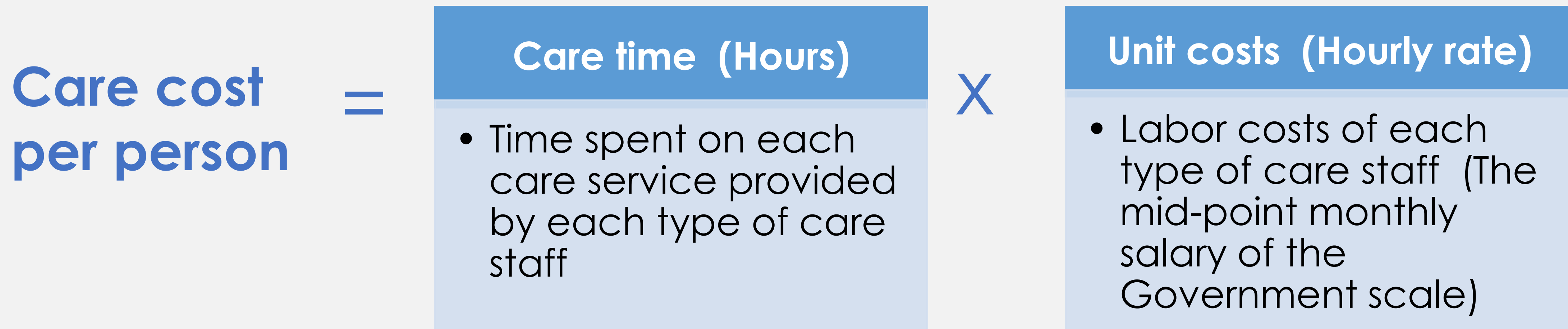
- Care and Attention Home (C&A)
  - Contract Homes
- Nursing Home (NH)

Data

- Collected in May 2014 and December 2016
- **Participants:** Publicly-funded long-term care recipients in Hong Kong

Community care setting (CCS)	Residential care setting (RCS)
• Participates were recruited from 20 Day Care Centers/Units and 40 home care teams;	• Participates were recruited 21 C&A, 3 Contract Homes and 2 Nursing Homes
• Sample size: n=601;	• Sample size: n=1002;

Care time and cost: Staff time measurement (STM)



- Individual-based **care time** recorded by involved care workers (a time-log sheet)
- **Formal care** services including medical, nursing, personal care, behavior management, other professional care, leisure activities, etc.
- **Informal care** including ADL and IADL tasks (excluding household living tasks: household chores, shopping, and cooking)

Unit costs

Table 1. Unit costs for each type of care staff

Notes: *The mid-point monthly salary of the Salary Scale of Common Posts in the Non-government Organisation released by the Department of Social Welfare in April 2016 ; **Hourly rate of these categories not included in the MPS was estimated based on suggestions made by stakeholders in focus groups; PCW = personal care worker; PTA = physiotherapist assistant; OTA = occupational therapist assistant; STA = speech therapist assistant; RA = rehabilitation assistant; EN = enrolled nurse; PT = physiotherapist; OT = occupational therapist; RN = registered nurse; SW = social worker; ST = speech therapist; All costs were converted to US dollar using the official average selling rate in April 2016 (1 USD=7.7786 HKD).

Care staff		Unit costs (Hourly rate, USD) *
Supportive staff	Workman	$8.7
	Programme assistant/Clerical assistant	$9.6
	Home helper	**$10.3**
	PCW / PTA / OTA / STA / RA	$10.9
	Clerical Officer	$10.9
	Driver / Cook	$11.7
	Health worker	$14.9
	Welfare worker	$15.8
Professional staff	EN / Dispenser	$20.8
	PT / OT	$25.3
	RN	$26.5
	SW / Dietitian / ST	$35
	Assistant superintendent	$42.1
	Superintendent	$54.8
	Medical officer	$62.6
	Activity coach**	$64.3
	Music therapist**	$128.6
Informal carer in the community		$10.3

Measures

Cognitive status and dementia

- **Cognition:** measured by InterRAI Cognitive Performance Scale (CPS), with a score ranging from 0 (cognition intact) to 6 (very severe impairment).
- **Dementia diagnosis**: identified from interRAI assessments, including Alzheimer's disease and dementia other than Alzheimer's disease, whether treated or not.

Covariates

- **Demographics**: age, gender
- **Clinical characteristics**: The number of diagnosed diseases other than dementia (continuous)
- **Functional status**: Activities of daily living hierarchy scale (ADL-HS, range 0-6), categorised as relatively independent (ADL-HS score 0-1) , limited to extensive impairment(ADL-HS score 2-4) and dependent(ADL-HS score 5-6).

Analytic Strategies

- Descriptive analyses
- **Generalised linear model (GLM)** with the log link and gamma distribution to examine the association with care costs

Results

47.6% of LTC recipients had a dementia diagnosis (**37%** in CCS; **54%** in RCS)

Table 2 Sample characteristics by long-term care settings and dementia diagnosis

	Total (n=1,570)	Residential care setting (n=991, 63%)		Community care setting (n=579, 37%)	
		D- (n=458, 46%)	D+ (n=534, 54%)	D- (n=365, 63%)	D+ (n=214, 37%)
Age, year (mean, 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 (mean, SD)	3.4(1.9)	3.8(1.9)	3.3(1.9)	3.2(1.7)	3.3(2.1)
CPS, score(mean, SD)	3(2.1)	2.2(2)	4.3(1.7)	1.4(1.6)	3.8(1.5)
0 Intact, %	12.4%	15.8%	0.0%	32.5%	0.0%
1 Borderline intact, %	22.6%	36.1%	7.3%	37.3%	7.0%
2 Mild impairment, %	18.5%	17.1%	16.7%	16.7%	29.0%
3 Moderate impairment, %	12.5%	10.1%	16.1%	5.8%	20.9%
4 Moderate to severe impairment, %	3.7%	1.5%	5.4%	1.6%	7.5%
5 Severe impairment, %	11.5%	8.1%	17.2%	2.2%	20.1%
6 Very severe 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: D= dementia diagnosis; CPS= the InterRAI Cognitive Performance Scale;

Results

- Average care costs with a dementia diagnosis:
  - RCS: **$31,757**
  - CCS: **$17,232**
- Average care costs without a dementia diagnosis:
  - RCS: **$22,195**
  - CCS: **$9,394**

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

CPS score	Residential care setting: Total $ (SD) D-	Residential care setting: Total $ (SD) D+	% Change	Community care setting: Total $ (SD) D-	Community care setting: Total $ (SD) D+	% Change	Formal care $ (SD) D-	Formal care $ (SD) D+	% Change	Informal care $ (SD) D-	Informal care $ (SD) D+	% Change
0 Intact	13,412 (9284)	/	/	6,363 (6002)	/	/	4,087 (3200)	/	/	2,398 (5270)	/	/
1 Borderline intact	18,054 (12511)	18,448 (10030)	2.2%	8,162 (6363)	9,807 (7681)	20.2%	5,902 (4849)	7,287 (6551)	23.5%	2,401 (3873)	2,700 (3838)	12.5%
2 Mild impairment	24,006 (13405)	26,105 (14986)	8.7%	11,387 (8647)	14,204 (8055)	24.7%	5,773 (4712)	8,411 (5431)	45.7%	6,461 (7687)	6,651 (8039)	2.9%
3 Moderate impairment	26,275 (12574)	29,086 (14033)	10.7%	16,217 (11324)	16,064 (10475)	-0.9%	**6,688** (5499)	8,167 (8763)	22.1%	11,117 (10208)	8,707 (6581)	-21.7%
4 Moderate to severe impairment	26,785 (11520)	35,619 (13627)	33.0%	17,355 (10168)	18,770 (8192)	8.2%	4,402 (4295)	9,937 (4802)	125.7%	15,543 (11223)	10,094 (4550)	-35.1%
5 Severe impairment	29,334 (7944)	33,223 (13284)	13.3%	15,868 (6599)	20,220 (14311)	27.4%	5,152 (3075)	**10,120** (9541)	96.4%	10,717 (4907)	10,592 (9167)	-1.2%
6 Very severe impairment	**35,459** (11480)	**36,806** (14255)	3.8%	**19,266** (10727)	**22,840** (10706)	18.6%	3,403 (4299)	8,945 (5457)	162.9%	**16,921** (10361)	**15,689** (8307)	-7.3%
Total	**22,194** (13501)	**31,757** (14872)	**43.1%**	**9,394** (8124)	**17,232** (11021)	**83.4%**	**5,194** (4407)	**8,828** (7175)	**70.0%**	**4,536** (7156)	**9,319** (8325)	**105.4%**

Notes: D, a clinical diagnosis for dementia; CPS, the InterRAI Cognitive Performance Scale; All costs were converted to US dollar using the official average selling rate in April 2016 (1 US$=7.7786 HK$); % Change 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.

Results (cont.)

- A **dementia diagnosis** was associated with **an additional 55% increase** in CCS formal care costs, followed by a **23%** increase in total community care costs and then a **13%** increase in residential care costs.
- The LTC costs were associated with **cognitive impairment levels** in most groups and generally **increased** with increasing cognitive impairment severity

Table 2 Association between LTC costs and cognitive status and dementia diagnosis (GLM analyses)

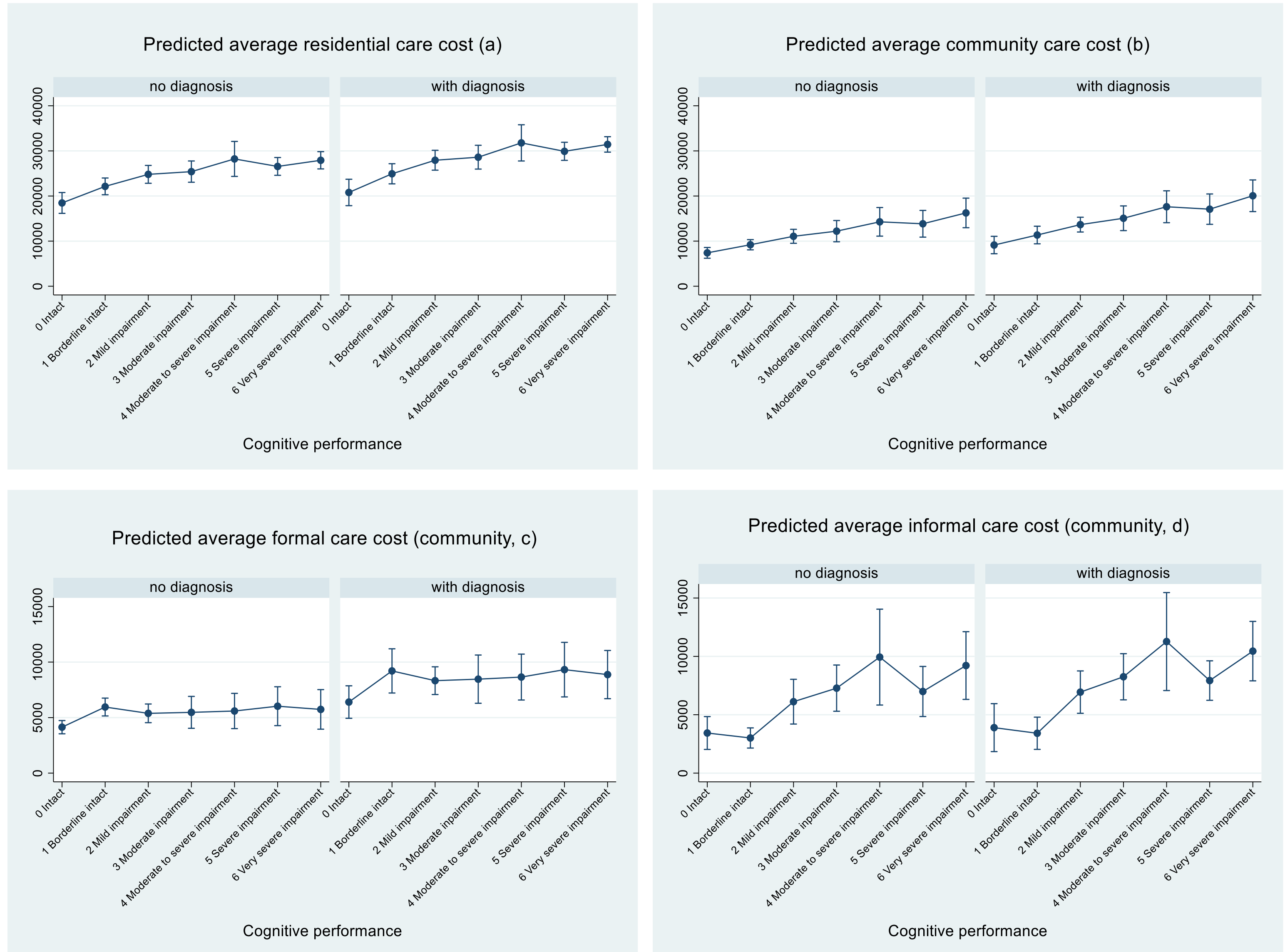
	Residential formal and informal care	Community are		
		Total	Formal care	Informal care
	Exp(b)	Exp(b)	Exp(b)	Exp(b)
Diagnosis for dementia (ref.:= No diagnosis)	1.13***	1.23**	1.55***	1.13
	[1.06, 1.20]	[1.08, 1.41]	[1.29, 1.86]	[0.84, 1.53]
CPS (ref.: = 0 Intact)				
1 Borderline intact	1.20*	1.24*	1.44***	0.88
	[1.04, 1.38]	[1.03, 1.51]	[1.19, 1.74]	[0.52, 1.49]
2 Mild 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]
3 Moderate 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]
4 Moderate to severe 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]
5 Severe 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]
6 Very severe 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]

Notes: cognitive status refers to the prevalence of cognitive impairment (i.e. CPS score>=2) and was also grouped by dementia diagnosis; Exp(Coeff)=exponentiated coefficients; Model were adjusted on age(centred), gender, the number of comorbidities other than dementia, and ADL_HS; * p<0.05, ** p<0.01, *** p<0.001; CPS= the InterRAI Cognitive Performance Scale;

Results (cont.)

- LTC costs **increased** along with having a formal diagnosis and cognitive impairment levels before moderate to severe impairment
- In **community care settings**, the formal care costs associated with a dementia diagnosis, while the informal care costs increased with cognitive impairment severity

Figure 1. Adjusted costs by care settings, diagnosis and cognitive impairment levels



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Discussion

- This study focuses on formal and informal care service utilisation of LTC recipients with/without a formal dementia diagnosis and at different levels of cognitive impairment.
- **Main findings:**
  - Higher LTC costs are associated with a formal dementia diagnosis and cognitive impairment severity in both community and residential care settings.
  - In the community, formal care costs are associated with a formal dementia diagnosis, while informal care costs are associated with cognitive impairment levels
- **Implications:**
  - **A formal dementia diagnosis** is a vital access of timely and adequate services in **long-term are settings.**
  - Care needs of those **without a formal diagnosis** but having cognitive impairment and functional deficit might be **neglected**.
  - Given the **high undiagnosed rate** of dementia, a review on care planning based on the cognitive and functional impairment level may be needed for **equally** delivering dementia-related services and interventions in long-term care settings.

Thank You

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