ORIGINAL ARTICLE

Mortality and health services utilisation among older people with advanced cognitive impairment living in residential care homes

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Objectives To study the demography, clinical characteristics, service utilisation, mortality, and predictors of mortality in older residential care home residents with advanced cognitive impairment.

Design Cohort longitudinal study.

Setting Residential care homes for the elderly in Hong Kong West.

Participants Residents of such homes aged 65 years or more with advanced cognitive impairment.

Results In all, 312 such residential care home residents (71 men and 241 women) were studied. Their mean age was 88 (standard deviation, 8) years and their mean Barthel Index 20 score was 1.5 (standard deviation, 2.0). In all, 164 (53%) were receiving enteral feeding. Nearly all of them had urinary and bowel incontinence. Apart from Community Geriatric Assessment Team clinics, 119 (38%) of the residents attended other clinics outside their residential care homes. In all, 107 (34%) died within 1 year; those who died within 1 year used significantly more emergency and hospital services (P<0.001), and utilised more services from community care nurses for wound care (P=0.001), enteral feeding tube care (P=0.018), and urinary catheter care (P<0.001). Independent risk factors for 1-year mortality were active pressure sores (P=0.0037), enteral feeding (P=0.008), having a urinary catheter (P=0.0036), and suffering from chronic obstructive pulmonary disease (P=0.011). A history of pneumococcal vaccination was protective with respect to 1-year mortality (P=0.004).

Conclusion Residents of residential care homes for the elderly with advanced cognitive impairment were frail, exhibited multiple co-morbidities and high mortality. They were frequent users of out-patient, emergency, and in-patient services. The development of end-of-life care services in residential care homes for the elderly is an important need for this group of elderly.

Key words
Cognition disorders; Frail elderly; Homes for the aged; Long-term care; Mortality

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New knowledge added by this study

- Knowledge about the demography and clinical characteristics of older residents of residential care homes for the elderly (RCHE) with advanced cognitive impairment was acquired.
- These residents had a high demand for community and hospital services (particularly those who died within 1 year), and exhibited a high mortality independent of other predictors of mortality.

Implications for clinical practice or policy

- Development of end-of-life care in RCHE is important, particularly for older residents with advanced cognitive impairment.
- More efforts to promote Advance Directives are warranted.

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Introduction

The rapid growth of the elderly population in Hong Kong has led to increased demand for residential care homes for the elderly (RCHE) to care for the functionally impaired older persons.[1] There are at present more than 78 800 RCHE places in Hong Kong.[2] Various community health services support such residents, including the Community Geriatric Assessment Team (CGAT), Community Visiting Medical Officers (CVMOs), Community

Care Nurses (CCNs), and Psycho-geriatric Team services. Also, there are Visiting Medical Officers (VMO) who are usually private doctors facilitating care of minor illnesses of these residents.

In Hong Kong RCHE residents, there is high prevalence of persons with cognitive impairment.[3] In a local study, cognitive impairment was an independent predictor for admission to RCHE after discharge from hospital.[4] Many older patients with advanced dementia have repeated hospital admissions and die during the course of such admissions.[5,6] Recent studies have shown that pneumonia, febrile episodes, and eating problems are frequent complications in such patients.[7] This group of older RCHE residents poses a major challenge for CGAT and other health care providers.[8]

Local studies exploring mortality, morbidity, and health care needs of older RCHE residents with advanced cognitive impairment are scarce. A better understanding of their needs can provide patients, families, RCHE staff, and health care providers more information on how to arrive at realistic expectations as the disease progresses.[9] In addition, as nearly all such older residents are sent to hospital if they deteriorate, virtually all deaths occur in hospitals rather than in RCHE.[10] This is in contrast to western societies where many older persons, particularly those with advanced dementia, die in RCHE.[11] This study could therefore serve to alert the government and the public that end-of-life (EOL) care should also be provided to older RCHE residents with advanced cognitive impairment, just as for cancer patients.

The objectives of this study were to examine the demography, co-morbidities, and clinical characteristics of the older RCHE residents with advanced cognitive impairment. We also set out to explore corresponding clinical service utilisation, mortality, and their predictors in this group of older people.

安老院舍中嚴重認知功能障礙患者的死亡率和醫護服務的使用率

目的 研究安老院舍中嚴重認知功能障礙患者的人口學、臨床特徵、醫護服務的使用率、死亡率和死亡預測因子。

設計 隊列縱向研究。

安排 香港港島西的安老院舍。

參與者 安老院舍中65歲或以上患有嚴重認知功能障礙的老人。

結果 共312名安老院舍的老人（71男及241女）被納入研究範圍。他們平均年齡為88歲（標準差8歲），Barthel指數20平均得分為1.5（標準差2.0）。其中164人（53%）接受腸哺入營養。幾乎所有參與者患有大小便失禁。除了社區老人評估小組的診所，119人（38%）也有到院舍以外的其他診所就診。共有107人（34%）在一年內死亡，他們均明顯地使用較多緊急醫護服務和醫院服務（P<0.001），需要更多社區護士作傷口護理（P=0.001）、餵食管護理（P=0.018）和尿導管護理（P<0.001）。一年死亡率的獨立危險因素為壓瘡（P=0.0037）、腸哺入營養（P=0.008）、使用尿導管（P=0.0036）和患有慢性阻塞性肺疾病（P=0.011）。根據一年死亡率，曾接受肺炎球菌疫苗接種有保護作用（P=0.004）。

結論 安老院舍中嚴重認知功能障礙患者均為體弱，並有多個共病和高死亡率。他們經常使用門診、急診和住院服務。於安老院舍發展臨終護理服務對於這些老人來說非常重要。

Methods

Design and setting

This longitudinal cohort study was conducted using convenience sampling in 66 RCHE facilities in Hong Kong West, of which 18 entailed subsidised care and attention homes and the rest were private. Cases were recruited between October 2010 and December 2010, and were followed up for 12 months (till December 2011), and data were collected at recruitment and in the following 12 months. The entire study protocol was approved by the Institutional Review Board of the University of Hong Kong/Hospital Authority Hong Kong West Cluster.

Subjects

Link CCNs serving these homes were responsible for case recruitment and data collection. Older patients (age ≥65 years) under the care of Hong Kong West CGAT were recruited. An Abbreviated Mental Test (AMT) was used to screen for advanced cognitive impairment[12]; to be included in the study, subjects had to have advanced cognitive impairment with an AMT score of 0/10, irrespective of the underlying cause. Older people who could not perform AMT due to language barrier, depression, severe deafness, and purely expressive aphasia were excluded.

Variables

We collected information including demographic data, Barthel Index (20) scores,[13] types and number of diagnoses, number of medications, active pressure sores, continence status, use of urinary catheter or an enteral feeding tube, tracheostomy care and suction. We also looked at whether the subjects received Comprehensive Social Security Assistance (CSSA) and had a Guardianship Order or Advance Directive.[14,15] Effective influenza vaccination (within 1 year) and a history of pneumococcal vaccination were also documented.

During the 12 months of follow-up, we documented the number of CGAT attendances, fast-track clinics attended, CVMO or VMO consultations, and allied health interventions. We recorded the number of acute and emergency department (AED) attendances, acute and convalescence hospital admissions, and the length of stay (LOS) in hospitals during the 1-year follow-up period.

Outcomes

The outcome in this study was mortality at or before 12 months of follow-up. For those who died, the chief diagnosis leading to death and the place of death were recorded.

Statistical analyses

The Statistical Package for Social Sciences (Windows version 16; SPSS Inc, Chicago [IL], US) was used in statistical analysis. Continuous valuables were expressed as mean ± standard deviation. As appropriate, paired and independent sample *t* tests were used to analyse continuous variables. The χ^2 test was employed to compare categorical variables. Statistical significance was inferred by a 2-tailed P value of <0.05. Univariate analysis was performed using mortality as the dependent variable. A multivariate analysis was performed and entailed stepwise binary logistic regression for factors with a P<0.1 in the univariate analysis, so as to discover independent predictors of mortality.

TABLE 1. Demographic and clinical characteristics of the studied subjects

Characteristic	Mean ± standard deviation or No. (%)			P value†
	All subjects (n=312)	Alive at 1-year follow-up (n=205)	Died within 1-year follow-up (n=107)	
Age (years)	88 ± 8	87 ± 8	89 ± 8	0.14
Men	71 (23)	40 (20)	31 (29)	0.06
Single/divorced/widowed	215 (69)	139 (68)	76 (71)	0.56
On CSSA*	233 (75)	153 (75)	80 (75)	0.98
On Guardianship Order	17 (5)	10 (5)	7 (7)	0.54
Had Advance Directive	0 (0)	0 (0)	0 (0)	-
Barthel Index (20)	1.5 ± 2.0	1.7 ± 2.2	1.1 ± 1.4	0.016
Norton score	10.0 ± 1.7	10.1 ± 1.9	9.9 ± 1.2	0.33
Urinary incontinence	309 (99)	203 (99)	106 (99)	0.97
Bowel incontinence	306 (98)	201 (98)	105 (98)	0.96
Active pressure sores	54 (17)	22 (11)	32 (30)	<0.001
Enteral feeding	164 (53)	93 (45)	71 (66)	<0.001
Indwelling urinary catheter	35 (11)	13 (6)	22 (21)	<0.001
Tracheostomy	2 (1)	2 (1)	0 (0)	0.55
Active influenza vaccination	249 (80)	168 (82)	81 (76)	0.19
History of pneumococcal vaccination	181 (58)	130 (63)	51 (48)	0.007
No. of diagnosis	5.9 ± 2.6	5.8 ± 2.5	6.0 ± 2.7	0.40
No. of medications	6.1 ± 2.6	5.9 ± 2.8	6.6 ± 3.4	0.04
Medical diagnosis				
Hypertension	188 (60)	125 (61)	63 (59)	0.72
Stroke	161 (52)	109 (53)	52 (49)	0.44
Diabetes mellitus	77 (25)	51 (25)	26 (24)	0.91
Hip fracture	66 (21)	37 (18)	29 (27)	0.06
Ischaemic heart disease	43 (14)	29 (14)	14 (13)	0.80
Heart failure	36 (12)	20 (10)	16 (15)	0.17
Parkinsonism	25 (8)	15 (7)	10 (9)	0.53
Depression	22 (7)	13 (6)	9 (8)	0.49
Chronic obstructive pulmonary disease	21 (7)	10 (5)	11 (10)	0.07
Chronic renal failure	6 (2)	3 (1)	3 (3)	0.42

* CSSA denotes Comprehensive Social Security Assistance

† χ^2 Test for proportions, independent *t* test for continuous variables

Results

During the recruitment period, there were 4800 residents living in the 66 relevant RCHE facilities under CGAT coverage. Among these, 2310 were under direct CGAT care, and AMTs were performed on all these residents; finally 312 older RCHE residents with an AMT score of 0/10 were included in this study. Among these, 71 (23%) were men and 241 (77%) were women. In all, 107 (34%) died within 1 year. Demographic variables and clinical characteristics of the subjects are shown in Table 1. A significantly higher proportion of subjects who died than survived within 1 year had active pressure sores (P<0.001). More of them were also on enteral feeding (P<0.001) and had a urinary catheter (P<0.001). In addition, those who died within 1 year were taking more medications (P=0.04) and had lower Barthel Index (20) scores (P=0.016). A greater proportion of survivors than those who died had received pneumococcal vaccination (P=0.007).

The Figure summarises the principal diagnoses of the subjects when they passed away. There were 12 patients in whom the diagnosis was unknown. Except for one subject, all the cases were labelled "dead before arrival" at the AED and referred to the coroner as the cause of death was "unknown".

Attendances at the AED, hospital admissions, and service utilisation (expressed as the number per 100 persons per month) and LOS in acute and convalescence hospitals (expressed as days per 100 persons per month) are shown in Table 2. Subjects who died within 1 year had significantly more AED visits, and received more acute and convalescent hospital services (all P<0.001). In particular, they used more services from CCNs, including wound care (P=0.001), enteral feeding tube care (P=0.018), and urinary catheter care (P<0.001). On average, those who survived 1 year had more frequent on-site CGAT consultation episodes (P=0.01) and occupational therapy interventions (P=0.001).

Although all our 312 subjects had partaken in CGAT services, 119 (38%) also attended out-patient clinics outside their RCHE. The five commonest out-patient clinics attended were surgical (n=37, 12%), ophthalmology (n=29, 9%), general medical (n=21, 7%), psychogeriatric (n=21, 7%), and orthopaedic (n=18, 6%).

Table 3 shows the results of multivariate analysis with odds ratios (ORs) and confidence intervals (CIs). Having urinary catheters, enteral feeding, chronic obstructive pulmonary disease (COPD), and active pressure sores were risk factors for 1-year mortality. A history of pneumococcal vaccination was an independent protective factor for 1-year mortality (OR=0.47, 95% CI, 0.28-0.78, P=0.004).

Discussion

In this study, most of the subjects (75%) were CSSA recipients and were highly dependent on financial support. The frailty of these RCHE residents was well demonstrated in that they had multiple pathologies, double incontinence, pressure sores, poor functional states and mobility, and endured polypharmacy. These findings concurred with those of many previous studies.[4,16]

The finding that none of our subjects had prepared any Advance Directive was not surprising,[17] as a person needs to be mentally sound to do so. To date, in Hong Kong recourse to Advance Directives has been meagre and it is only recently that the government has promulgated the concept. Advance Directive services were very likely unavailable to our subjects when they were still mentally sound.

We reported a high 1-year mortality of 34% in our study subjects, which was in keeping with previous studies reporting increased mortality in older people with moderate-to-severe cognitive impairment.[18,19] Among those who died within 1 year, the frequency of on-site CGAT consultations was lower than those who survived, possibly because the former were often in hospital and hence missed many scheduled CGAT clinics. Instead, they tended to see CVMOs more frequently and had more frequent fast-track clinic consultations. Those who survived 1 year had more frequent occupational therapist (OT) assessments and interventions. Conceivably, those who died within a year had less OT referrals as they were so dependent functionally that any OT intervention was considered futile. They also had less time to utilise OT services.

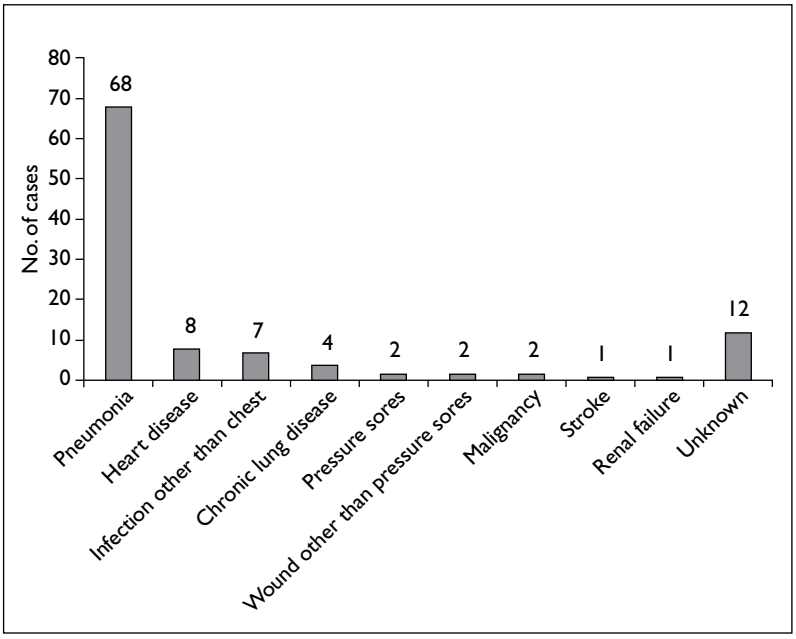

FIG. Principal diagnoses (cause of death) among the 107 cases who died within 1 year

TABLE 2. Hospital and community service utilisation of the subjects

Hospital and community service utilisation*	Mean No. ± standard deviation per 100 persons per month			P value†
	All subjects (n=312)	Alive at 1-year follow-up (n=205)	Died within 1-year follow-up (n=107)	
Hospital services				
AED attendance	26.1 ± 48.3	12.0 ± 18.1	53.0 ± 71.4	<0.001
Acute hospital admission	22.4 ± 44.0	11.1 ± 20.6	44.1 ± 64.4	<0.001
Acute hospital LOS (days/100 persons/month)	89.5 ± 157.3	46.5 ± 74.0	172.0 ± 228.0	<0.001
Convalescence hospital admission	9.3 ± 30.0	2.7 ± 6.5	22.0 ± 48.3	<0.001
Convalescence hospital LOS (days/100 persons/month)	93.6 ± 296.6	32.7 ± 93.4	210.5 ± 469.5	<0.001
Community services				
On-site CGAT consultation	30.4 ± 24.3	32.9 ± 24.4	25.5 ± 23.5	0.01
CGAT fast-track clinic	0.8 ± 7.0	0.3 ± 1.7	1.7 ± 11.8	0.09
CVMO consultation	33.9 ± 60.0	28.8 ± 35.4	41.0 ± 90.0	0.09
VMO consultation	4.7 ± 17.4	5.2 ± 18.4	3.9 ± 15.6	0.55
Psychogeriatric team consultation	1.4 ± 5.6	1.5 ± 5.6	1.2 ± 5.6	0.6
Speech therapist assessment	2.3 ± 8.0	1.9 ± 5.0	3.2 ± 11.7	0.18
Physiotherapist intervention	0.2 ± 2.2	0.2 ± 2.4	0.2 ± 1.7	0.9
Occupational therapist intervention	1.8 ± 5.9	2.6 ± 6.9	0.3 ± 2.6	0.001
Dietitian intervention	0.7 ± 3.0	0.9 ± 3.3	0.3 ± 2.0	0.09
Community Care Nursing Service				
Wound care	187.6 ± 417.6	130.0 ± 320.0	299.0 ± 543.0	0.001
Enteral feeding tube care	46.2 ± 58.1	40.6 ± 47.9	57.0 ± 73.0	0.018
Urinary catheter care	13.3 ± 45.9	6.6 ± 28.0	26.0 ± 66.0	<0.001
Injection of medicine service	1.4 ± 7.2	1.5 ± 6.6	1.3 ± 8.1	0.87

* AED denotes acute and emergency department, LOS length of stay, CGAT Community Geriatric Assessment Team, CVMO Community Visiting Medical Officer, and VMO Visiting Medical Officer

† Independent *t* test for continuous variables

TABLE 3. Results of the multivariate analysis

	Odds ratio	Confidence interval	P value
Urinary catheter use	3.2	1.46-7.2	0.0036
Chronic obstructive pulmonary disease	3.4	1.3-8.8	0.011
Pressure sores	2.7	1.37-5.1	0.0037
Enteral feeding	2.0	1.2-3.4	0.008
History of pneumococcal vaccine	0.47	0.28-0.78	0.004

Regarding AED visits, acute hospital admissions, and LOS in hospital, they were more than 4-fold greater in those who died within 1 year than in those who survived. Notably, 11 cases arriving in AED were labelled "dead before arrival". Not surprisingly, AED doctors who had not seen these older residents before were not able to sign death certificates, and usually referred the cases to the Coroner, with the bodies being transferred to the public mortuary. Those who died within 1 year also partook more frequently of CCN services (wound care, enteral feeding tube care, and urinary catheter care). It is increasingly recognised that good EOL care is imperative in the management of patients with irreversible diseases, such as advanced dementia.[20] As the EOL approaches, patients with advanced dementia experience distressing symptoms similar to those of others dying of terminal conditions.[21-24] Prior work in western countries suggests that older people with advanced dementia are under-recognised as

being at high risk of mortality and received little EOL care.[25-28] In Hong Kong, older RCHE patients with advanced cognitive impairment were sent to hospital if they deteriorated. It follows that nearly all treatments prior to EOL and death of RCHE older residents occurred in hospitals, and could explain why those who died had a 4-fold increase in AED visits and hospital utilisation rates. By way of contrast, in western societies many older people with advanced dementia die in RCHE facilities.[11] The development of EOL care in RCHE is important for this group of older people. Elements of EOL care could possibly be included for such patients, and not be restricted to those having Advance Care Planning and Advance Directives. Indeed, recourse to a palliative approach, intensive medical, nursing, spiritual and psychosocial support at the last phase of life should be offered to persons dying in RCHE, as they too may not want to spend their last few days in hospital.

The commonest cause of death in our subjects was pneumonia. Previous studies showed that pneumonia, febrile episodes, and eating problems are frequent complications in patients with advanced dementia.[7] We found that COPD, active pressure sores, urinary catheters, and enteral feeding were independent risk factors of 1-year mortality. Previous studies also reported that COPD was associated with increased mortality.[29] Active pressure sores can lead to infections and worsen the general condition of these patients.[30] The routine use of tube feeding in advanced dementia remains controversial, and there are no data to show that it improves survival.[31] Urinary catheterization is related to the development of urinary tract infection, and associated with greater mortality, especially in advanced age.[32] In this study, a history of pneumococcal vaccination was the only protector. Several recent studies looked at the effects of vaccination on long-term care in the Chinese.[33] They found that dual vaccination (against influenza and pneumococcus) provided additional protection to RCHE residents. However, influenza vaccination was less effective in reducing mortality in RCHE residents with poor functional capacity.[34] Our finding serves as further evidence that pneumococcal vaccination is important in reducing mortality in functionally poor older RCHE residents.

One limitation of our study was the use of an AMT score of 0 as an indicator for advanced cognitive impairment, because it is a screening tool rather than a diagnostic instrument for dementia. Nevertheless, we believe that most of the cases included in this report had advanced dementia, be it Alzheimer's disease, vascular cognitive impairment, or some other type. Second, we only included RCHE residents with advanced cognitive impairment under the care of CGAT. We tried to document all the workload of CCNs for our subjects in as much detail as possible, but some RCHE had their own nurses and health care workers; the workloads of these in-house staff were not recorded.

Conclusion

The RCHE residents with advanced cognitive impairment we studied utilised numerous services, including CGAT, CVMO, and out-patient facilities. They were frequent users of AEDs and in-patient services. The development of EOL care for RCHE is important and should meet the needs of this group of older people. Further promotion of Advance Directives and Advance Care Planning are needed for the local general public.

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