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Association of rurality, type of primary caregiver and place of death with end-of-life medical expenditures among the oldest-old population in China

Zhong Li^{1,2,3}, Peiyin Hung⁴, Kewei Shi⁵, You Fu^{6*} and Dongfu Qian^{1,2,3*}

Abstract

Background: Understanding whether the type of primary caregiver and end-of-life (EOL) care location are associated with EOL medical expenditures is crucial to inform global debates on policies for efficient and effective EOL care. This study aims to assess trends in the type of primary caregiver and place of death stratified by rural–urban status among the oldest-old population from 1998–2018 in China. A secondary objective is to determine the associations between rurality, the type of primary caregiver, place of death and EOL medical expenditures.

Methods: A total of 20,149 deaths of people aged 80 years or older were derived from the Chinese Longitudinal Health Longevity Survey (CLHLS). Cochran-Armitage tests and Cuzick's tests were used to test trends in the type of primary caregiver and place of death over time, respectively. Tobit models were used to estimate the marginal associations of rurality, type of primary caregiver, and place of death with EOL medical expenditures because CLHLS sets 100,000 Chinese yuan (approximately US\$15,286) as the upper limit of the outcome variable.

Results: Of the 20,149 oldest-old people, the median age at death was 97 years old, 12,490 (weighted, 58.6%, hereafter) were female, and 8,235 lived in urban areas. From 1998–2018, the prevalence of informal caregivers significantly increased from 94.3% to 96.2%, and home death significantly increased from 86.0% to 89.5%. The proportion of people receiving help from informal caregivers significantly *increased* in urban decedents (16.5%) but *decreased* in rural decedents (-4.0%), while home death rates significantly increased among both urban (15.3%) and rural (1.8%) decedents. In the adjusted models, rural decedents spent less than urban decedents did (marginal difference [95% CI]: \$-229 [\$-378, \$-80]). Those who died in hospitals spent more than those who died at home (\$798 [\$518, \$1077]). No difference in medical expenditures by type of primary caregiver was observed.

Conclusions: Over the past two decades, the increases in informal caregiver utilization and home deaths were unequal, leading to substantially higher EOL medical expenditures among urban decedents and deceased individuals who died at hospitals than among their counterparts who lived in rural areas and died at home.

Keywords: Primary Caregivers, Place of Death, End-of-life Care, Medical Expenditures, China

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Background

Health and social care systems for older adults are widely concerning worldwide due to aging populations and skyrocketing health care expenditures [1–4]. The World Health Organization projects a nearly doubled increase



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in the share of the world's population aged 60 years or older from 12% in 2015 to 22% in 2050 [5]. In China, the population over 65 years old grew rapidly from 8.9% in 2010 to 13.5% in 2020 and is estimated to reach 30% by 2050 [6, 7]. Many young people in rural China have been migrating to metropolitan areas, leaving many older adults behind in rural areas [8], and a recent decrease in family size and changes in attitudes toward kinship obligations have led to much greater needs for institutional caregiving services [9, 10]. Despite this increasing need, nursing home facilities and health care facilities are unevenly distributed across urban and rural communities, potentially exacerbating substantial rural–urban disparities in access to long-term care [11]. Caregivers play a significant role in the care of older adults with disabilities or serious illness or those in the end of life (EOL) period [12]. Comprehensive care has been proven to effectively meet the multidimensional needs of individuals with terminal illness and improve quality of life coupled with cost savings [13, 14]. Informal care may also reduce the utilization of health care services and related spending and improve discharge outcomes [15, 16]. Moreover, informal caregivers who engage in decision-making about transitioning to long-term care or hospices may pose unique opportunities to mitigate rising EOL expenditures [17, 18].

In China, patients with lower socioeconomic status (SES) rely more on informal care [19]. The long-term care insurance system has been piloted [20], but the limited capacity of the EOL care system has forced many patients with serious illnesses to seek help from and die in hospitals [21]. Disparities in access to care and SES have led to different patterns of EOL care utilization, expenditures, and places of death [22], which calls for the development of community-based EOL care [23]. Although national policies have been enacted to achieve the goals of healthy aging in China [24], only a few hospitals and nursing facilities have reported providing any hospice services due to workforce shortages and insufficient incentives, which results in a greater need for informal care [22]. The forgone time that results from informal caregiving has changed people's preferences to health care services rather than informal care by family members [25]. Moreover, continuity of care and financial arrangements for long-term care are inadequate [20]. Increased access to and affordability of medical service have made it easier for patients with serious illness and their families to seek help from hospitals, which might cause the overuse of hospital-based care and aggravate the financial burden for family members and the health care system [26]. A fragmented health care system leads to increased medical expenditures and other negative patient outcomes [27, 28]. Understanding the interplay between residential

rurality, the type of caregiver, and the place of death and their association with EOL medical expenditures is critical to inform policy enactment and implementation. However, previous studies on EOL care in China have focused on individuals with cancer and other serious illnesses, especially the aging population [21, 22]. To date, no research has investigated the associations of these three key factors and EOL medical expenditures with a sufficient sample size of the oldest-old cohorts. The purpose of this study was to demonstrate the trend of primary caregiver types and place of death stratified by rural–urban status among the oldest-old population in China from 1998–2018. A secondary objective was to determine the associations of rurality, the type of primary caregiver, and the place of death with EOL medical expenditures.

Methods

Study design and participant recruitment

The primary data were derived from the 1998–2018 Chinese Longitudinal Health Longevity Survey (CLHLS), a nationally representative, longitudinal survey administered by the Peking University Chinese Center for Disease Control and Prevention and the China Mainland Information Group. Via in-home proxy interviews with next of kin, family members or close friends, the CLHLS collected a range of health and health care information, including 1) mental health, cognitive function, social participation, nutritional status, family structure, and SES characteristics and 2) health condition, caregivers and medical expenditures during the last year of life among the deceased oldest-old population aged 80 years old or above [29].

The survey, which incorporates a multilevel, stratified, hierarchical sampling procedure across 23 provinces, is the longest dataset for older adult studies in China. Study samples from each wave were weighted using inverse probability weights to produce nationally representative estimates. For this study, seven waves of follow-up surveys among the deceased oldest-old population were conducted from 1998–2018. However, weight was not applied to respondents aged less than 80 or more than 106 years at their first interviews. Therefore, oldest-old individuals aged less than 80 or more than 106 years at their first interviews were excluded from the current study.

Measures

The key outcome variable was medical expenditures during the last year of life. Each respondent was asked about the *estimated total medical cost in the last year of the decedent's life*. Our primary independent variables were the deceased's primary caregivers during the last year of life and place of death. Primary caregivers were reported

by the next of kin in the post-death interview, including 1) spouse; 2) adult child(ren); 3) other family members; 4) social care; 5) friends; 6) nurse; 7) no caregiver; and 8) did not need a caregiver. A previous study defined formal care for older adults as paid care services provided by a health care institution or individuals for someone in need and informal care as unpaid care provided by family members, relatives, friends, and neighbors [30]. In this study, informal care consists of care delivered by a spouse, adult child(ren), other family members, and friends, while formal care includes care provided by social institutions and nurses. Place of death was categorized into home, hospitals, and nursing home facilities.

Based on previous studies, the following factors were included as covariates: 1) sociodemographic and socioeconomic characteristics: age at death, gender, ethnicity, years of schooling, number of children, annual per capita household income, primary income sources before dying, marital status, whether living with a spouse or not [2], and white-collar job before retirement [30]; 2) living arrangement during the last year of life: living alone, living in the nursing home, living with a spouse, living with other family members, and timely medical services [2, 17]; 3) health condition: self-rated health status, any disability in activities of daily living (being incontinent or needing assistance in performing one or more activities of bathing, transferring, dressing, eating and toileting) [31], bedridden before dying, and number of comorbidities [19] 4) health behaviors: exercise, drinking and smoking; 5) residential rurality and census region and year of death.

Statistical analysis

We first used person-level survey weights in the CLHLS dataset to adjust for sampling selection and potential nonresponse or coverage bias. All expenditures and household income were adjusted to the 2018 level according to the National Consumer Price Index. Second, we examined medical expenditures during the last year of life across different groups with Kruskal–Wallis tests. The Cochran–Armitage test and Cuzick’s test were used to assess trends in the type of primary caregiver and place of death, respectively. Third, given that expenditures of 100,000 Chinese yuan (approximately US\$15,286) are the upper limit of the outcome variable, we used Tobit regression models to examine the association of rurality, type of primary caregiver and place of death with EOL medical expenditures. Reported P values were 2-sided and considered statistically significant at $p < 0.05$. The analysis was conducted between July 1, 2021, and December 10, 2021. The data were managed and analyzed with Stata version 15.1 (College Station, TX). The Strengthening the Reporting of Observational Studies in

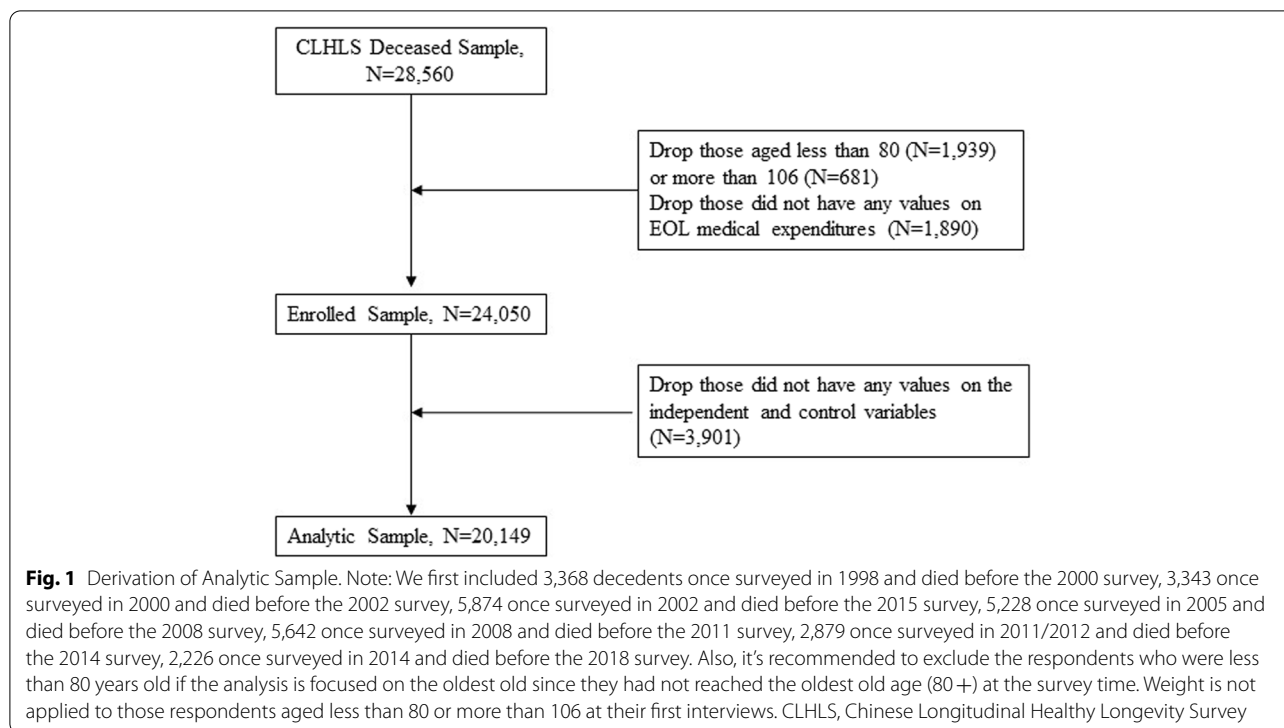
Epidemiology (STROBE) reporting guideline for prospective cohort studies was followed to report our findings [32]. This CLHLS study was approved by the institutional review board of Peking University and Duke University (IRB00001052-13,074), and each wave was independent of the different participants recruited. Written/oral informal consent was obtained from the respondents or the next of kin in the baseline and follow-up surveys. The current study was performed in accordance with the Declaration of Helsinki, and the Institutional Review Board of Nanjing Medical University considered the analysis of public and anonymous data to be exempt.

Sensitivity analysis

We used generalized linear regression models with a gamma distribution and log link function after dropping decedents who spent over 100,000 Chinese yuan during the last year of their life. We then examined the association between types of primary caregivers, place of death and medical expenditures stratified by residential rurality. All models were controlled for the aforementioned covariates.

Results

Of the 28,560 oldest-old people identified from 1998–2018, we excluded deceased individuals aged less than 80 ($N=1,939$) or more than 106 years ($N=681$), 1,890 decedents who did not have any values for EOL medical expenditures, and 3,901 individuals with missing values in any covariates (Fig. 1). The distribution of the oldest-old individuals included by year of death is presented in Supplementary Table 1. The final sample comprised 20,149 oldest-old people (8,235 [41%] urban and 11,914 [59%] rural) with a median age at death of 97 years (Table 1). After weighting using age-sex-rural/urban-specific sample weights, 95.0% of the deceased received help from informal caregivers and 87.5% died at home. Comparisons of weighted sample characteristics by rural–urban status among the oldest-old population are presented in Table 1. The included deceased had a median EOL medical expenditure of US\$ 188. Significant differences in the EOL medical expenditures by residential rurality, type of primary caregivers, place of death and other characteristics are presented in Supplementary Table 2. Figure 2 depicts overall (A1 and B1) trends in the type of primary caregiver and place of death among oldest-old deceased in China and trends by urban (A2 and B2) and rural status (A3 and B3). The prevalence of informal caregivers significantly increased from 94.3% in 1998 to 96.2% in 2018 ($p_{\text{trend}} < 0.001$), and the prevalence of home death significantly increased from 86.0% in 1998 to 89.5% in 2018 ($p_{\text{trend}} < 0.001$). After stratification by residential rurality, the prevalence of informal caregivers



among urban deceased increased from 80.2% in 1998 to 96.7% in 2018, while the prevalence of informal caregivers among rural deceased decreased significantly from 99.8% in 1998 to 95.8% in 2018 ($p_{\text{trend}} < 0.001$). The prevalence of home death among urban deceased increased from 65.5% in 1998 to 80.8% in 2018 ($p_{\text{trend}} < 0.001$), and the prevalence of home death among rural deceased increased from 94.0% in 1998 to 95.8% in 2018 ($p_{\text{trend}} < 0.001$). Detailed information on changes in the patterns of primary caregiver types and place of death are presented in Supplementary Table 3.

Adjusted models showed that deceased individuals who received informal care no longer differed from deceased individuals who received formal care in terms of EOL medical expenditure (marginal differences [95% confidence interval]: \$278 [\$-443 to \$1000]; Table 2). Rural deceased had less medical expenditures than urban deceased did (\$-229 [\$-378 to \$-80]). Compared to those who died at home, individuals who died at hospitals had greater medical expenditures (\$798 [\$518 to \$1,077]), while individuals who died at nursing home facilities did not (\$-440 [\$-1,055 to \$176]). Individuals older than 90 years old (\$-180 [\$-274, \$-86]) and centenarians (\$-424 [\$-546, \$-302]) spent less than deceased individuals younger than 90 years old. Individuals from the most affluent families (\$726 [\$452, \$999]) or who received retirement wages as their main financial source (\$551 [\$120, \$902]) had greater medical expenditures than their

counterparts did. Individuals who did not have timely medical services (\$-335 [\$-446, \$-223]) or who were not ill (\$-317 [\$-451, \$-183]) spent less than those who died with timely medical services. Individuals with any disabilities in activities of daily living (\$313 [\$178, \$448]) or those suffering from two or more chronic diseases had greater medical expenditures than their counterparts did.

The results of the generalized linear regression model remain consistent with our main findings in both direction and significance (Supplementary Table 4). After stratification by urban and rural status, the results remain similar to the main findings. Urban deceased who died at hospital spent more than those who died at home (\$967 [\$578 to \$1,357]). Rural deceased individuals who died at a hospital spent more than those who died at home (\$594 [\$243 to \$994]), which is far less than the results of our main findings (Supplementary Tables 5 and 6 in the Supplement).

Discussion

To the best of our knowledge, this study is the first to explore trends in the type of primary caregiver and place of death as well as their associations with EOL expenditures. This study provides vital information about the magnitude of the problem to enrich current research on EOL care, inform policy efforts to improve access to home and informal care, and reduce substantial disparities in EOL medical expenditures. Our data indicate that

Table 1 Weighted Sample Characteristics among Oldest-old, 1998–2018

Characteristic	All decedents (N = 20,149)	Urban (N = 8,235)	Rural (N = 11,914)	chi ²	P value
Informal Caregivers	19,436 (95.0)	7,724 (90.6)	11,712 (97.2)	35.6	<.001
Place of death				51.6	<.001
Home	18,285 (87.5)	6,820 (75.8)	11,465 (93.2)		
Hospital	1,389 (8.9)	1,086 (17.2)	303 (4.8)		
Nursing home facilities	475 (3.6)	329 (7.0)	146 (2.0)		
Age at death	97 (91,102)	96 (91,102)	97 (92,102)	38.3	<.001
80–89	3,757 (77.8)	1,666 (75.7)	2,091 (78.9)	10.2	0.001
90–99	8,216 (21.4)	3,420 (23.2)	4,796 (20.4)		
≥ 100	8,176 (0.8)	3,149 (1.1)	5,027 (0.7)		
Gender				0.3	0.59
Female	12,490 (58.6)	4,956 (58.0)	7,534 (59.0)		
Ethnicity				6.2	0.01
Han	18,752 (92.4)	7,777 (93.9)	10,975 (91.6)		
Being married during the last year of life	2,418 (20.4)	1,106 (24.1)	1,312 (18.6)	14.0	<.001
Years of schooling				39.7	<.001
0	14,738 (67.5)	5,496 (59.6)	9,242 (71.3)		
1–6	4,488 (27.2)	2,158 (31.0)	2,330 (25.4)		
≥ 7	923 (5.3)	581 (9.4)	342 (3.3)		
Number of children				4.7	0.003
0–2	4,145 (20.4)	1,887 (24.1)	2,258 (18.6)		
3–4	5,849 (29.0)	2,303 (27.0)	3,546 (29.9)		
5–6	5,792 (29.0)	2,293 (27.8)	3,499 (29.6)		
≥ 7	4,363 (21.6)	1,752 (21.1)	2,611 (21.9)		
Per capita household income annually				46.0	<.001
< 391	4,985 (35.4)	1,551 (25.6)	3,434 (40.1)		
391–942	5,159 (30.5)	1,950 (28.8)	3,209 (31.2)		
942–3,060	4,995 (20.1)	2,170 (24.8)	2,825 (17.9)		
> 3,060	5,010 (14.0)	2,564 (20.8)	2,446 (10.8)		
Main financial source					
Retirement wage	1,977 (11.2)	1,626 (25.7)	351 (4.1)	241.7	<.001
Family	16,845 (82.4)	5,965 (65.0)	10,880 (91.0)	281.9	<.001
White-collar jobs before retirement	816 (4.7)	596 (9.5)	220 (2.4)	83.0	<.001
Living arrangement					
living alone	2,007 (11.3)	735 (10.3)	1,272 (11.8)	2.0	0.16
living in the nursing home	486 (4.5)	344 (8.4)	142 (2.5)	31.1	<.001
living with spouse only	1,940 (12.6)	861 (15.5)	1,079 (11.2)	14.3	<.001
living with other family members	15,373 (70.3)	6,117 (64.2)	9,256 (73.3)	29.0	<.001
timely medical services				4.7	0.01
Yes	15,014 (81.6)	6,310 (83.8)	8,704 (80.5)		
No	1,322 (8.2)	572 (8.1)	750 (8.2)		
Was not ill	3,760 (10.2)	1,334 (8.1)	2,426 (11.3)		
Health Condition					
Self-rated health status				0.9	0.43
Very good or good	7,415 (41.2)	3,105 (40.3)	4,310 (41.6)		
So so	6,127 (32.4)	2,561 (34.2)	3,566 (31.6)		
Bad or very bad	3,152 (19.7)	1,215 (18.9)	1,937 (20.2)		
Not able to answer	3,455 (6.7)	1,354 (6.6)	2,101 (6.8)		
Any disability in ADLs	3,581 (25.6)	1,316 (21.7)	2,265 (27.5)	12.3	<.001
Bedridden before dying	14,947 (27.1)	6,143 (25.8)	8,804 (27.8)	1.5	0.23

Table 1 (continued)

Characteristic	All decedents (N = 20,149)	Urban (N = 8,235)	Rural (N = 11,914)	chi ²	P value
No of comorbidities				12.9	<.001
0	7,248 (33.1)	2,502 (27.7)	4,746 (35.6)		
1	6,466 (32.9)	2,538 (31.8)	3,928 (33.5)		
2	2,921 (15.1)	1,307 (16.7)	1,614 (14.4)		
≥ 3	3,514 (18.9)	1,888 (23.8)	1,626 (16.5)		
Health Behavior^a					
Physical exercise	3,920 (24.6)	2,011 (31.4)	1,909 (21.3)	38.6	<.001
Smoking	2,832 (18.6)	1,065 (15.9)	1,767 (20.0)	9.0	0.003
Drinking	3,233 (15.9)	1,242 (14.4)	1,991 (16.7)	3.4	0.07
Region				25.1	<.001
Eastern	7,714 (35.6)	3,347 (36.1)	4,367 (35.4)		
Central	4,688 (24.5)	1,430 (18.0)	3,258 (27.7)		
Western	6,161 (31.4)	2,471 (32.2)	3,690 (31.0)		
Northeast	1,586 (8.5)	987 (13.7)	599 (5.9)		

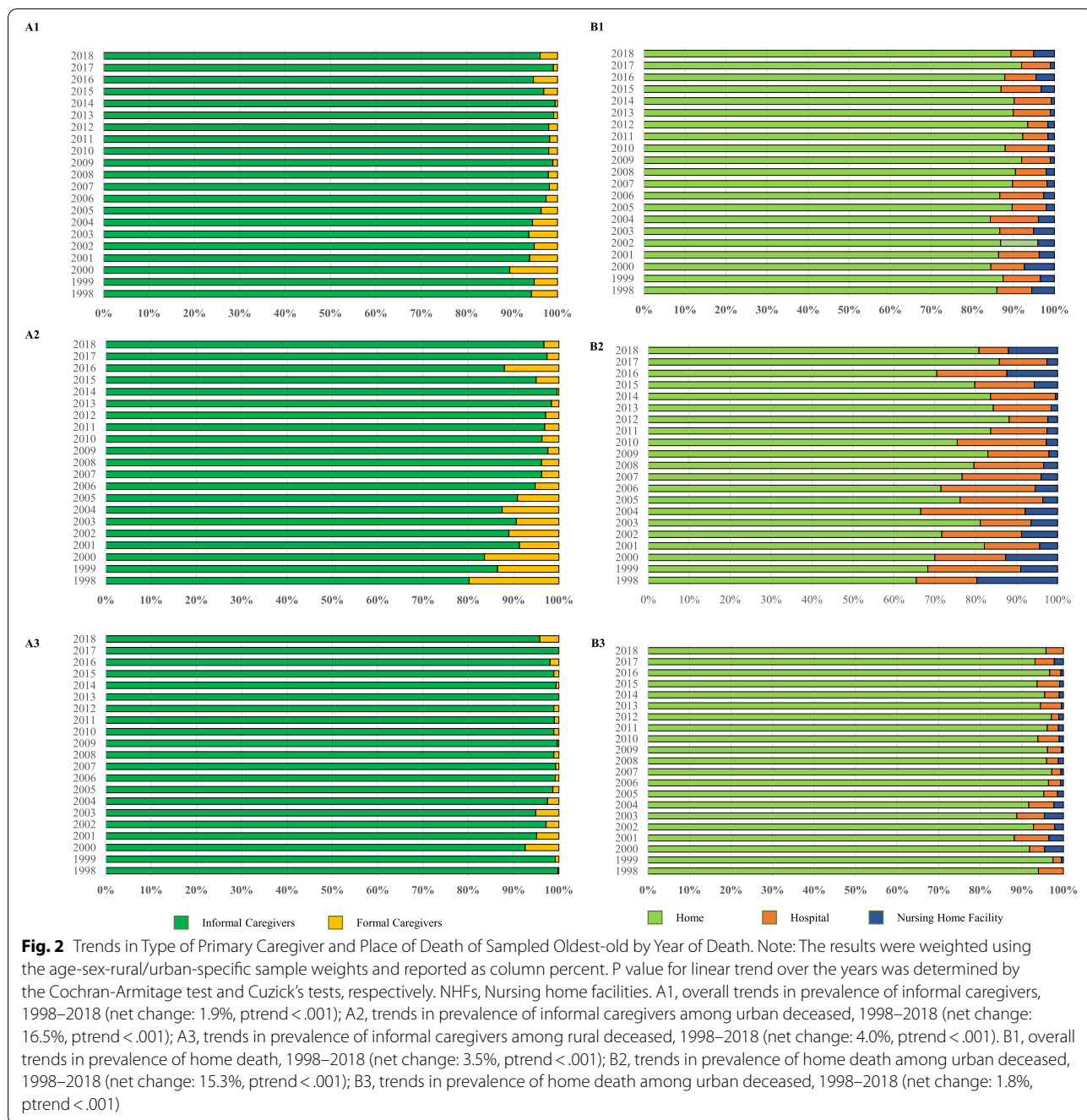
Note: Values were represented as No. (percentages) unless otherwise indicated. No. was calculated from study samples (unweighted). Percentages were calculated using the age-sex-rural/urban-specific sample weights; a, self-reported in the previous survey. ADLs, activities of daily living. All the currency was presented in the US dollars

more than 95% of oldest-old individuals received help from informal caregivers, and nearly 90% of them died at home as of 2018. Moreover, urban deceased spent much more than rural deceased did, and those who died in hospitals spent more than those who died at home. This suggests that persistent challenges remain for increasing access to out-of-hospital EOL care services among oldest-old individuals in China.

Currently, formal care is not routinely used to deliver health and social care among oldest-old individuals. Nursing home facilities are far less likely to be the place of death in China, with only approximately 5% of deaths occurring in nursing home facilities in 2018. Although formal care has long been advocated to improve access to care for older adults and to improve continuity of care between health care and social care providers, its use by oldest-old individuals is limited. Rates of informal care utilization among the oldest-old increased from 1998 to 2018, especially the prevalence of informal care among urban deceased. This result is similar to the findings of one study conducted in the US that showed that rates of informal home care use among older adults with disabilities increased from 2004 to 2016 despite 36.9% of formal home care use in 2016 [2]. However, many families face barriers to engaging in formal care, especially due to persistent cultural obstacles [10] and longstanding disconnects between hospitals and primary care facilities [33]. Differences in care continuity mean sizable differences in the utilization of services and costs [34]. More importantly, the prevalence of home death increased from 86.0% in 1998

to 89.5% in 2018, and similar trends were observed among the urban and rural deceased, suggesting that more intensive education, training and support for informal caregivers is warranted [33, 35–37]. Informal caregiving for elderly people with disabilities has been commonly used to provide services similar to those provided to paid formal caregivers in China [38]. However, with limited community-based care, family caregivers are unaware of what they do not know or should do. To meet the needs of oldest-old individuals during the last year of life, informal caregivers must receive expanded access to supportive services [39].

We found that urban–rural disparities in the EOL medical expenditure were especially pronounced among those who died in the hospitals. Different affordability and access to care, especially hospital-based care, mean disproportionate utilization of inpatient services among individuals with severe diseases. Moreover, the medical expenditures of individuals who primarily received formal care did not differ from those of deceased individuals who primarily received informal care. This finding may indicate potential opportunities to train formal caregivers to provide services comparable to services in hospital settings without increased medical expenditures [40]. In addition, unintentional incentives for caregivers to provide a longer length of stay might increase medical expenditures [41]. Therefore, continuity of care between hospitals and primary care facilities for oldest-old individuals who are discharged from hospitals is a major issue.



Given that EOL discussion is associated with less aggressive care near death and earlier hospice referrals [42, 43], it is concerning that EOL medical expenditures varied significantly by the age when death occurred, particularly in terms of greater expenditures among deceased individuals aged between 80 and 89 years. This study is similar to findings of a previous study showing that Medicare expenditures and the aggressiveness of medical care decreased in the

last year of life and decreased with age [44]. Previous studies also showed that individuals with multimorbidity had substantially greater medical expenditures [45], and individuals living in communities with a high SES were almost twice as likely to die in homes than individuals from low-SES communities [46]. Patients with advanced illnesses and their families often decide to use life-prolonging treatments [33]. Given that awareness of the terminal nature of life may reduce unnecessary

Table 2 Marginal differences of included characteristics on medical expenditure during the last year of life

Characteristics	Dy/dx	95% CI		P value
Rurality (Ref: Urban)				
Rural	-229	-378	-80	0.003
Primary Caregivers (Ref: Informal)				
Formal	278	-443	1,000	0.45
Place of death (Ref: Home)				
Hospital	798	518	1,077	<.001
Nursing home facilities	-440	-1,055	176	0.161
Age at death (Ref: 80–89)				
90–99	-180	-274	-86	<.001
≥ 100	-424	-546	-302	<.001
Per capita household income annually (Ref: < 391)				
391–942	4	-124	132	0.95
942–3,060	206	-26	438	0.08
> 3,060	726	452	999	<.001
Main financial source before dying				
Retirement wage (Ref: No)				
	511	120	902	0.01
Timely medical services (Ref: Yes)				
No	-335	-446	-223	<.001
Was not ill	-317	-451	-183	<.001
Health Condition				
Disabilities in ADLs (Ref: No)				
	313	178	448	<.001
Number of Comorbidities (Ref: 0)				
1	-4	-127	120	0.95
2	177	25	330	0.02
≥ 3	224	15	433	0.04
Region (Ref: Eastern)				
Central	-264	-425	-103	0.001
Western	-282	-436	-128	<.001
Northeast	-154	-419	111	0.26

Note: *Dy/dx* Average marginal effect, *CI* Confidence interval, *ADLs* activities of daily living. Only results of predictors of statistically significance were presented. Results of associations between gender, ethnicity, marital status, years of schooling, number of children ever born, family support as main financial source, once having white-collar jobs before retirement, living arrangement during the last year of life, self-rated health status, health behaviors and end-of-life medical expenditures were not presented. All the currency was presented in the US dollar

costs, educating caregivers may be an important part of advance care planning and related policy-making [47]. Because formal caregivers are not associated with EOL medical expenditures, purposive policies are urgently needed to address the increasing need for informal caregivers. This is particularly important for those who died at hospitals, urban and affluent deceased, and individuals with any disability in daily activities who are bedridden.

Our findings should be interpreted with the following potential limitations. Because the CLHLS data do not provide longitudinal weights, the application of

survey weights could cause biased estimates because of nonrandom losses of follow-up. First, we were limited to decedents without any missing values in any covariates. The excluded deceased were more likely to be cared for by informal care and to die at home, have lower income, receive financial support from their families, live alone, receive timely medical services, report having any disabilities in activities of daily living and being bedridden, and smoke and drink in the last year of life (Supplementary Table 7). Therefore, our results may not be generalizable to all oldest-old individuals. We were also not able to identify the cause of death. The type of insurance in which deceased individuals were enrolled also has a large proportion of missing values. We therefore took main financial support to represent the affordability of medical services. Although we used the number of chronic diseases as covariates, subgroups such as individuals with cancer or dementia were limited to capturing meaningful differences. Future studies should consider these groups with a greater need for EOL care. EOL medical expenditure may also be affected by the utilization of health services; however, in this dataset, there are no specific variables that indicate the number of inpatient and outpatient utilizations during the last year of life.

Conclusion

This study provides vital information about trends in the type of primary caregiver and place of death and their association with medical expenditures among the oldest-old population in China during the past two decades. The prevalence of informal caregivers significantly increased from 94.3% in 1998 to 96.2% in 2018, and the prevalence of home death significantly increased from 86.0% from 1996 to 89.5% in 2018. Significant regional and rural–urban disparities in EOL medical expenditures remain. Our study also found that place of death, SES and health conditions were significant predictors of EOL medical expenditures. Deceased from urban areas and those who died in hospitals, had higher SES, and had worse health conditions spent more than their counterparts. Given the well-documented benefits of informal and home care, policy-makers and health care professionals need to pay particular attention to these deceased and to incorporate their illness trajectory and goals of care to reduce disparities in EOL medical expenditures.

Abbreviations

EOL: End of Life; CLHLS: Chinese Longitudinal Health Longevity Survey; US: United States; SES: Socio-economics status; STROBE: The Strengthening the Reporting of Observational Studies in Epidemiology.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12939-022-01813-2>.

Additional file 1: Supplementary Table 1. Distribution of sampled oldest-old by year of death. **Supplementary Table 2.** Medical expenditures during the last year of life by sample characteristics. **Supplementary Table 3.** trends in type of primary caregiver and place of death of sampled oldest-old by year of death. **Supplementary Table 4.** Results of sensitivity analysis. **Supplementary Table 5.** Marginal differences of included characteristics on medical expenditure during the last year of life among urban deceased. **Supplementary Table 6.** Marginal differences of included characteristics on medical expenditure during the last year of life among rural deceased. **Supplementary Table 7.** Comparison of individual characteristics between deceased reported and not reported medical expenditure during the last year of life.

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Authors' contributions

Li and Qian, Fu had full access to all of the data in this study and takes responsibility for the integrity of the data and the accuracy of the data analysis. Li, and Qian, Fu led the conception and design of the study. Li, Hung, Qian, Shi did the statistical analysis and interpreted the data. Li and Fu drafted the manuscript, Hung, Shi, Fu and Qian critically revised the manuscript. All authors read and approved the final manuscript.

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Availability of data and materials

All the data were available from Peking University Open Research Data. Center for Healthy Aging and Development Studies, 2020, "The Chinese Longitudinal Healthy Longevity Survey (CLHLS)-Longitudinal Data (1998–2018)", <https://doi.org/10.18170/DVN/WB07LK>, Peking University Open Research Data Platform, V2.

Declarations

Ethics approval and consent to participate

This CLHLS study was approved by the institutional review board of the Peking University and Duke University (IRB00001052-13074), each wave is independent with different participants recruited. Written/Oral informal consent was obtained from the respondents or the next-of-kins in the baseline and follow-up surveys.

Consent for publication

Not applicable.

Competing interests

We declared no conflicts of interest.

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