

Construction of Essential Care Service Package for People Living with Dementia in Smoke-free Environment under Disease Pandemic in China

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Objectives: In recent years, the harm of smoking has attracted more and more public attention. Creating a healthy smoke-free environment has been widely favored and supported by the public. Smokeless environment has a certain positive effect on the rehabilitation of dementia patients. Sustained smoking cessation is associated with significantly decreased the future prevalence of dementia. Therefore, hospitals often establish a special organizational structure and management model for tobacco control, and carry out training and assessment for all staff. The nursing group also took it as the basic nursing standard. The 2019 disease pandemic has posed unique health threats to people living with dementia (PLWD). Therefore, a strict smoke-free environment is more necessary for the nursing group. One of the key challenges is scaling up long-term care services to meet the needs of the rapidly growing population of PLWD in developing countries. The aim of the study is to explore the care service needs, utilization and build an essential care service package (ECSP) for PLWD under the disease pandemic in China. **Methods:** From July 2018 to October 2019, a total of 1255 elderly with dementia in six cities in China by a cluster sampling were investigated with the self-designed questionnaire. Care service needs and utilization for PLWD with different levels of cognitive impairment were summarized. **Results:** The ECSP for PLWD was composed of 30 service items (7 for core care) in order to guarantee that all PLWD enjoy equal care services, basing on public financing and implementing strategies and taking China's situations into account. The selection plan for ECSP at different levels is designed as 'General Care Services + Selective Care Services', in which respective service items for low, mid, and high-level care for PLWD are 7+3, 7+6, and 7+10, and requires 151.41 hours, 201.88 hours, and 252.35 hours per

month, respectively. Conclusion: The present study provides the first large-scale data on care service needs and utilization for PLWD in mainland China. The ECSP for PLWD based on the needs advanced in the paper was a practicable and effective quantitative management means that deserves a large-scale application. Some safeguard mechanisms and operational implementing pathways of ECSP for PLWD during and after the disease pandemic in China are proposed.

Key words: smokeless environment; people living with dementia; essential care service package.

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It is an indisputable medical conclusion that tobacco smoke is harmful to health and is still one of the major preventable causes of morbidity and mortality worldwide¹. The number of deaths caused by smoking in the world is as high as 6 million per year, which exceeds the total number of deaths caused by AIDS, tuberculosis and malaria. Tobacco smoke consists of thousands of compounds including 69 carcinogens. There is ample evidence that smoking and secondhand smoke exposure (SHSe) can lead to various forms of cancer, such as lung cancer, esophageal cancer, gastric cancer, liver cancer, kidney cancer, bladder cancer and cervical cancer, colorectal cancer, breast cancer and acute leukemia². There is strong evidence that smoking and SHSe can lead to respiratory diseases and other chronic conditions, such as chronic obstructive pulmonary disease (COPD) and adolescent asthma, and increase the incidence of tuberculosis and other respiratory infections. Smoking impairs vascular endothelial function. There is sufficient evidence that smoking and SHSe can lead to coronary heart disease, stroke and peripheral artery disease². All tobacco products can lead to nicotine addiction and contain toxic, cancer-causing chemicals that can cause serious health impacts¹. Many epidemiological studies have shown that cigarette smoking and SHSe substantially increase the risk of Alzheimer's disease and all types of dementia. Evidence regarding the harmful effects of smoking on dementia is strong and shows a dose-response effect. Quitting

smoking, reduce and eliminate tobacco consumption and SHSe can significantly reduce the risk of morbidity and mortality of these diseases^{1,2}. Therefore, smoke-free environment is very important for patients in hospital nursing work.

The COVID-19 pandemic continues to pose a fearful public health threat to nations and around the world, especially has posed a great risk of people living with dementia (PLWD). Studies to date from China, Italy, Spain, India, and the United States have shown that a higher prevalence, morbidity and mortality of dementia among COVID-19 patients³. The usual care of PLWD is affected in several ways due to reducing availability of health services and diversion of public health restrictions to contain the pandemic. This has led to barriers to care service for PLWD in many countries. Most of PLWD and unpaid carers are vulnerable and have experienced high levels of unmet care service needs. The double hit of dementia and COVID-19 pandemic has caused major concerns about the management and care services for PLWD and their caregivers. It is very crucial to provide extra care support measures for PLWD and their caregivers during and after the COVID-19 pandemic⁴.

Dementia has turn into an important public health challenge all over the world. Across the globe, the prevalence of dementia has reached epidemic proportions worldwide, with 46.8 million individuals affected in 2015. This number

is projected to increase to 74.7 million by 2030 and to 131.5 million by 2050. The medical costs associated with dementia care were estimated at 818 billion USD and are expected to more than double in 10 years^{5,6}. In China, the prevalence of dementia among people aged ≥ 60 years has been projected to increase from 5.8% in 2020 to 6.7% in 2030, and to 23.29 million in 2030. The economic burden of dementia will reportedly increase from 167.74 billion USD in 2015 to 507.49 billion USD in 2030⁵⁻⁹. Given the enormous toll that dementia exerts on individuals, families and local and national governments, how to finance and deliver adequate care remains a public health and policy priority for developed and developing countries alike.

In response to the rapidly aging population and associated challenges to social security and pension system sustainability, the Chinese government began to establish a three-tiered universal long-term care (LTC) system as part of the 12th Five-Year Plan¹⁰. Financing and delivering dementia care has become a crucial component of LTC policy development, given the rapid increase in the number of people living with dementia (PLWD). In 2012 three cities in China—Shanghai, Qingdao and Nanjing—started implementing pilot projects to integrate health insurance, LTC insurance (LTCI), and a means-tested model¹¹⁻¹³. These pilot LTC projects were expanded to a total of 15 cities by 2016, with plans for further expansion to one urban in each province by 2020^{14,15}. All pilot sites have implemented policy and administrative procedures based on local, social and economic development levels^{13,16-17}.

Despite some impressive successes in the delivery of dementia care services, some challenges remain, including a lack of consistent client needs assessments and nursing standards, disconnect between service supply and the need for LTC

services, limited coverage dependence on local health insurance funds, and unavailability and inaccessibility of LTC services in some areas^{11-13,16-17}. Providing LTC is becoming more costly due to the growing population of PLWD. Only 8.2% of the eligible population has purchased LTC insurance in China, resulting in continued challenges in meeting the needs of a large segment of the population, particularly given the often protracted period of dementia progression and associated functional decline. Expanded LTC coverage is still limited to older adults with severe disability, and with the exception of six cities (Qingdao, Chengdu, Shanghai, Guangzhou, Suzhou and Nantong), it excludes PLWD^{11-13,16-18}. One of the key public policy challenges in LTC financing is balancing two opposing forces; the need for adequate coverage at the individual/family level versus the required sustainability of funding¹⁹.

An Essential Care Service Package (ECSP) is a concept borrowed from management science in which a collection of must-have services is deemed essential for coverage and payment decisions. Proponents argue that the ECSP can improve equity, efficiency and accountability in LTC financing. The ECSP concept has gained popularity in health and social insurance, especially in developing countries where value propositions for new policies are critically important. An ECSP recognizes and makes an explicit attempt to quantify the diverse needs of the population, which can help clarify the goals of providing adequate coverage while controlling cost increases, because few countries can afford publicly financed universal coverage of all health and social services for their older adult population^{11,16,17,19,20}.

How to scale up LTC services to meet the needs of the rapidly growing population of PLWD in China under

financial and personnel constraints has become an important area of research for LTC policy makers and researchers²¹. The objectives of the current study were to investigate care service needs and utilization for PLWD in China, develop a needs-based ECSP, and estimate the need for service provision by providers. The proposed ECSP can contribute to future research and policy development regarding the financing and delivery of health and social care for the growing population of PLWD by informing the design elements of universal healthcare coverage (UHC) of PLWD, and an equity-based approach in dementia care during and after the pandemic.

METHODS

Study Design, Setting and Population

In China, the PLWD population is served in a wide range of settings: home, community, LTC, rehabilitation, psychiatry hospitals, and a limited number of nursing homes funded by the civil service system. We conducted a multi-city cross-sectional survey study to describe the healthcare and social service needs and their utilization in institutional settings. A two-stage stratified random sampling design was used to select six cities of varying sizes and different levels of economic development from diverse geographic provinces/administrative regions (Shanghai/east, Qingdao/northeast, Ningbo/east, Changzhou/central south, Chengdu/southwest, and Zhengzhou/central north) to participate. Dementia care facilities (nursing homes, geriatric hospitals, psychiatric hospitals, and other institutions) from each city were then selected to participate in the study. Finally, eligible individuals in these sampling facilities were invited to complete the survey.

Inclusion Criteria

Residents were eligible for study inclusion if they (1) were ≥ 60 years, (2)

had a family caregiver willing to provide written informed consent, (3) cognitive impairment, (4) and met one of the following diagnostic criteria for Alzheimer's disease and related dementia: (1) "The International Statistical Classification of Diseases and Related Health Problems" (10th revision) (coded as G30 Alzheimer's disease, F00 AD dementia, F01 vascular dementia, F02 dementia caused by other diseases classified elsewhere, F03 unspecified dementia) from the World Health Organization²²; (2) "Diagnostic and Statistical Manual of Mental Disorders" from the American Psychiatric Association^{23,24}; or (3) Chinese Guidelines for Diagnosis and Treatment of Cognitive Impairment and Dementia^{25,26}. Those younger than 60 years old, undiagnosed, normal cognitive function, or unwilling to consent were excluded.

Procedures

All study personnel attended a 5-day training program in which mock interviews were used to train staff members on how to consistently collect information using the questionnaire. Six research staff teams then conducted the sampling and interviews between July 2018 and October 2019. All sampling was conducted by registered facilities licensed for dementia care based on local health service bureau and civil service administrative records. Upon selection into the sample, electronic medical record systems were queried to identify potentially eligible participants. Research staff then visited each facility and conducted face-to-face interviews with caregivers (professional and/or family) regarding the study subjects and their care. Each interview lasted between 30 min and 60 min.

Measures

The questionnaire and standard operating procedures were developed by reviewing the current literature and in consultation

with dementia research experts. A structured questionnaire was developed that incorporated validated instruments to assess the individual and family characteristics and dementia care needs of participants, including four domains: (1) demographics (age, gender, education, occupation, marital status, income, visit frequency, Barthel Index score, and mini-mental state exam [MMSE] score) (2) health and functional status (type of dementia, clinical symptoms, comorbidities, medication, rehabilitation), and (3) perceived service needs and use.

The Barthel Index was used to assess the activities of daily living (ADL) of PLWD; it consists of 10 items including bowels, bladder, grooming, toilet use, feeding, transfer, mobility, dressing, stairs, and bathing. The Barthel Index (0–100 points) was grouped into five levels: completely independent (100 points), mildly dependent (91–99 points), moderately dependent (61–90 points), severely dependent (21–60 points), and completely dependent (0–20 points)^{27,28}.

The MMSE was used to assess the cognitive dysfunction severity of PLWD. It consists of seven categories, each representing a different function: orientation to time, orientation to place, registration, attention and calculation, recall, language (naming, repetition, reading, and writing), and complex commands. The maximum score is 30 points. Two sets of cut-points were used to classify cognitive function based on education level. For those with ≤ 6 years (elementary school) of primary education (PE): severe (0–9 points), moderate (10–15 points), mild (16–19 points), and normal (20–30 points). For those with > 6 years of secondary education (SE): severe (0–10 points), moderate (11–17 points), mild (18–23 points), and normal (24–30 points)^{29,30}.

Essential Care Service Package

The ECSP is defined as a collection of health and social services necessary to

care for PLWD in home, community and institution settings, including the type of service and hours of care needed for each type. The guiding principle of ECSP development is to take person-centered care service needs as the orientation and universal care coverage on safeguarding vulnerable populations as the focus; this approach helps balance the basic services needs for PLWD with affordability, equity, feasibility, and sustainability in implementation by national and local governments^{13,31,32}. There were three major steps involved in the development process: (1) estimation of perceived needs based on the service use data obtained from the survey, (2) estimation of time needed to provide each type of service, and (3) comparison between perceived needs and actual utilization data to determine which services should be included in the ECSP.

Informed by the Australian model of care and essential service package (ESP) development for medical care, 80% of the health service needs were selected as the threshold for inclusion of the General Care Service of the ECSP³¹. Thus, any service perceived by $\geq 80\%$ of PLWD as being needed was included, as was any service with an actual utilization rate $\geq 60\%$ (e.g., basic care services for PLWD with low-level needs [mild cognitive impairment]). Services that did not meet these criteria were deemed as a Selective Care Service of ECSP for PLWD. That is, on the basis of the General Care Service, patients with mid-level (moderate cognitive impairment) and high-level (severe cognitive impairment) needs can choose additional service items. Based on the characteristics of special care services for PLWD, 30 basic service items were identified, including ADL (physical), medical/nursing/rehabilitation care, mental healthcare (psychological), and behavior management maintenance. The number of services and their frequency of need/use are expected to increase for PLWD at mild, moderate,

and severe stages of dementia and track disease progression with increasing needs over time.

Calculation of Perceived Demand, Utilization Rate, and Time Spent on Care Services

The formulas used for calculations are as follows:

$$\text{Perceived Needs} = \frac{\text{Number that responded YES to service demand (extremely+much+need)}}{\text{Total surveyed subjects}} \times 100\% \quad (1)$$

$$\text{Utilization Rate} = \frac{\text{Number that actually used the care service}}{\text{Total surveyed subjects}} \times 100\% \quad (2)$$

$$\text{Average Service Time} = \frac{\text{Total time spent for all subjects who used the care service}}{\text{Total subjects who used the care service}} \times 100\% \quad (3)$$

Estimation of the Monthly Service Hours by Care Level

Based on the principals outlined in the Nursing Subsidy Policy for Workers' Compensation^{33,34} and the Implementation Policy for Long-Term Care Insurance in Chengdu (Demonstration)³⁵, low, mid, and high levels were established to represent 30%, 40%, and 50%, respectively, of the average monthly wage of all urban employees in China in 2018. To facilitate interpretation and international

comparison, all wage rates were converted into US dollars using the average annual exchange rate (1 USD=6.6174 CNY)³⁶. The governmental payment rate for the ECSP was set at 70% of the monthly nursing subsidy standard base rate at each corresponding care service level^{14,33}.

(1) Calculation of the total monthly serviced hours of low-level care based on the average care time of the General Care Service items in the ECSP.

$$\text{Total Service Time Spent on Low – Level Care} = \sum_1^n (\text{Service time for a general care service item in ECSP}) \quad (4)$$

Where n is the number of the General Care Service items in the ECSP.

(2) Calculation of total monthly service hours for mid-level care

$$\text{Total Service Time Spent on Mid – Level Care} = \text{Total Service Time Spent on Low – Level Care} \times \left(\frac{\text{Monthly subsidy quota for mid-level}}{\text{Monthly subsidy quota for low-level}} \right) \quad (5)$$

(3) Calculation of total monthly service hours for high-level care

$$\frac{\text{Total Service Time Spent on High – Level Care}}{\text{Total Service Time Spent on Low – Level Care}} \times \left(\frac{\text{Monthly subsidy quota for high-level}}{\text{Monthly subsidy quota for low-level}} \right) \quad (6)$$

The total number of care service items was calculated from the total monthly service hours of each corresponding care level.

(1) Care service items with perceived need $\geq 80\%$ or utilization rate $\geq 60\%$

obtained from sampled dementia patients were selected as the General Care Service items in the ECSP (e.g., low-level care service).

(2) Calculation of the total number of mid-level care service items

$$\text{Total number of mid – level service items} = \text{Low – level service items} \times \left(\frac{\text{Total service time spent mid-level care}}{\text{Total service time spent low-level care}} \right) \quad (7)$$

(3) Calculation of the total number of high-level care service items

$$\text{Total number of high – level service items} = \text{Low – level service items} \times \left(\frac{\text{Total service time spent high-level care}}{\text{Total service time spent low-level care}} \right) \quad (8)$$

All survey data were entered into EpiData database software using a double-entry method for data validation. Statistical analysis was performed using SPSS software version 26 (IBM Inc.). Continuous variables are described as mean \pm standard deviation (SD), with t and F tests used for significance testing. Categorical variables are described by frequencies and percentages, and χ^2 tests were used for significance testing. Since the service hours were not normally distributed, natural logarithm transformation was performed before analyses to alleviate data skewness. Missing value in categorical and continuous variables were imputed using the last value carried forward and mean imputation methods, respectively. Two-tailed tests were used, with the significance level set at $\alpha=0.05$.

RESULTS

Participant Sociodemographic and Clinical Characteristics

A total of 1573 questionnaires were distributed; 1255 questionnaires were valid and included in the study, corresponding to a response rate of 79.8%. Table 1 shows that the average age was 80.9 years (SD=8.9, range: 60-105 years) and 59.1% were women. More than half (54.1%) of the respondents had <6 years of education. The majority of respondents were widowed (53.8%). Blue-collar workers, government officials, and farmers accounted for 32.7%, 21.8%, and 19.2%, respectively, of the population's employment before disease onset

Cognitive Impairment

Table 1 shows that 76.0% of PLWD were rated as having severe cognitive impairment, followed by moderate (17.0%), and mild (7.0%). Significant differences existed among age groups, types of dementia, and ADL (the Barthel Index) (all $P<0.01$). As age increased, moderate and severe cognitive

impairment ratios also appeared to increase. The proportion of severe cognitive impairment in vascular dementia (87.2%) and other types of dementia (77.0%) was higher than that of Alzheimer's disease (70.5%). Elders more dependent on others for ADL had a higher corresponding degree of cognitive impairment. The proportion of severe cognitive impairment gradually increased from 25.7% with complete independence to 91.7% with total dependence. There were no significant differences in gender, education level, occupation, marriage status, and numbers of comorbidities. (all $P > 0.05$).

Perceived Service Need

Table 2 shows that seven services were reported as essential for PLWD ($\geq 80\%$ of respondents): primary care visit (91.7%), medication management (88.0%), regular health evaluation (84.9%), medical records/care plan (84.2%), using the toilet (83.3%), grooming (81.6%), and housekeeping (81.5%). These services were included in the Essential Care Services for PLWD. Service needs in dining, grooming, using the toilet, expectoration care and housekeeping showed significant differences among cognitive impairment levels ($P < 0.05$).

Service Use

Table 3 shows 10 services with utilization rates $\geq 60\%$: primary care visit (84.0%), regular health evaluation (78.6%), medical records/care plan (77.2%), using the toilet

(76.9%), medication management (76.4%), dining (73.0%), dressing/grooming (73.0%), healthcare consultation and education (67.0%), housekeeping (66.5%), and pressure ulcer prevention (60.4%). Among them, the rates of the need of dining, healthcare consultation and education, and pressure ulcer prevention were $< 80\%$ (78.6%, 78.5%, and 67.9%, respectively), and the rates of the need for the other seven services were $> 80\%$ (Table 2). The above 10 service items were also included in the ECSP for PLWD with low-level care (mild cognitive impairment), and the remaining 20 items were included in the optional items of the ECSP for PLWD with medium- and high-level care (moderate and severe cognitive impairment). The utilization rates of dining, grooming, and using the toilet were significantly different among cognitive impairment levels ($P < 0.05$).

Time Spent on Care Services for Persons Living With Dementia

Table 4 shows the intensity of service (hours per week) for each type of care. The General Care Services (10 items) included in the ECSP for PLWD have a total care service time of 34.94 hours per week (151.41 hours per month). The service times for legal assistance, mental health counseling, community daycare, and emergency assistance had significant differences depending on the level of cognitive impairment ($P < 0.05$).

Table 1
Sociodemographic Characteristics of PLWD in Care Institutions

Variable	Number of cases (n,%)	Level of cognitive impairment			P-value
		Mild (n=88)	Moderate (n=213)	Severe (n=954)	
Age, years, Mean (SD)	1255 (100.0)	77.7±9.2	79.0±8.7	81.6±8.8	0.000
Gender					
Male	513 (40.9)	41 (8.0)	95 (18.5)	377 (73.5)	0.21
Female	742 (59.1)	47 (6.3)	118 (15.9)	577 (77.8)	
Total	1255 (100.0)	88 (7.0)	213 (17.0)	954 (76.0)	
Educational level					
PE	679 (54.1)	49 (7.2)	132 (19.4)	499 (73.5)	0.75
SE	576 (45.9)	47 (8.1)	104 (18.1)	425 (73.8)	
Occupation before retirement					
Blue-collar Worker	410 (32.7)	25 (6.2)	73 (17.9)	311 (75.9)	0.64
Farmer	241 (19.2)	22 (9.3)	49 (20.3)	170 (70.5)	
White-collar worker	137 (10.9)	15 (10.9)	21 (15.5)	101 (73.6)	
Government official	274 (21.8)	19 (7.0)	37 (13.6)	217 (79.4)	
Unemployed	38 (3.0)	1 (2.9)	8 (20.0)	29 (77.1)	
Other	122 (9.7)	6 (5.2)	23 (19.1)	92 (75.7)	
Marital status					
Partnered	497 (39.6)	35 (7.0)	100 (20.2)	361 (72.7)	0.12
Divorced	26 (2.1)	2 (7.7)	8 (30.8)	16 (61.5)	
Widowed	675 (53.8)	49 (7.2)	95 (14.0)	532 (78.7)	
Single	55 (4.4)	3 (5.6)	10 (18.6)	42 (75.8)	

Type of dementia					
AD	679 (54.1)	58 (8.6)	141 (20.8)	479 (70.5)	0.000
VD	417 (33.2)	12 (3.0)	41 (9.8)	363 (87.2)	
Other	159 (12.7)	13 (7.9)	24 (15.1)	123 (77.0)	
No. of comorbidities					
0	60 (4.8)	4 (6.7)	11 (18.3)	45 (75.0)	0.86
1	608 (48.4)	43 (7.1)	106 (17.4)	459 (75.5)	
2	306 (24.4)	19 (6.2)	42 (13.7)	245 (80.1)	
3	191 (15.2)	16 (8.4)	32 (16.8)	143 (74.9)	
4	68 (5.4)	5 (7.4)	18 (26.5)	45 (66.2)	
≥5	22 (1.8)	1 (4.5)	4 (18.2)	17 (77.3)	
The Barthel Index					
Complete independence	35 (2.8)	11 (31.4)	15 (42.9)	9 (25.7)	0.000
Mild dependence	33 (2.6)	14 (42.4)	11 (33.3)	8 (24.2)	
Moderate Dependence	177 (14.1)	26 (14.7)	58 (32.8)	93 (52.5)	
Heavy dependence	297 (23.7)	18 (6.1)	89 (30.0)	190 (64.0)	
Complete dependence	713 (56.8)	19 (2.7)	40 (5.6)	654 (91.7)	

Table 2
Institutions Perceived Service Needs of PLWD in Care Institutions (%)

Services	Level of cognitive impairment			Total (n=1255)	P- value
	Mild (n=88)	Moderate (n=213)	Severe (n=954)		
1. Housekeeping	74.7	86.4	81.0	81.5	0.050
2. Transportation	46.1	51.0	49.0	49.2	0.75
3. Dining	63.8	73.4	81.0	78.6	0.000
4. Dressing/grooming	58.8	76.6	84.7	81.6	0.000
5. Using the toilet	54.4	71.9	88.3	83.3	0.000
6. Home safety/modifications	58.2	66.3	68.3	67.3	0.18
7. Community day care	51.9	50.0	47.4	48.2	0.64

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8. Medical records/care plan	88.3	80.2	84.8	84.2	0.18
9. Primary care visit	85.7	92.3	92.1	91.7	0.12
10. Regular health evaluation	87.2	81.0	85.5	84.9	0.24
11. Medication management	87.7	89.8	87.7	88.0	0.71
12. Expectoration care	57.1	56.8	65.9	63.8	0.025
13. Oral care	62.5	62.6	66.9	65.9	0.42
14. Pain management	53.8	54.6	61.7	59.9	0.10
15. Emergency assistance	68.4	65.5	70.2	69.3	0.43
16. Specialty nursing care	75.0	68.4	71.6	71.3	0.50
17. Family guest beds	46.1	40.3	44.5	43.9	0.54
18. Companion	68.8	65.1	71.0	69.8	0.27
19. Life enrichment	62.5	61.1	66.0	64.9	0.40
20. Healthcare consultation and education	77.9	75.8	79.2	78.5	0.60
21. Mental health counseling	66.7	63.4	63.9	64.0	0.10
22. Hospice care	56.8	66.3	69.0	67.7	0.16
23. Caregiver training	66.2	66.5	65.8	65.9	0.99
24. Respite care	62.2	56.6	59.8	59.4	0.65
25. ADL training and lost prevention	64.1	65.5	62.5	63.1	0.71
26. Medical equipment purchase, rental, and usage guide	48.0	42.8	50.2	48.8	0.18
27. Hazard prevention and self-rescue	63.6	57.5	65.5	64.0	0.12
28. Legal inquiry assistance	45.3	46.3	52.2	50.7	0.23
29. Pressure ulcer prevention	65.4	64.5	68.9	67.9	0.42
30. Pairing assistance	44.2	43.5	44.6	44.4	0.96

Table 3
Service Utilization of PLWD in Care Institutions (%)

Services	Level of cognitive impairment				P-value
	Mild (n=88)	Moderate (n=213)	Severe (n=954)	Total (n=1255)	
1. Housekeeping	63.5	74.6	64.8	66.5	0.026
2. Transportation	29.2	37.6	27.9	29.7	0.034
3. Dining	56.8	68.9	75.4	73.0	0.001
4. Dressing/grooming	45.1	71.2	75.8	73.0	0
5. Using the toilet	50.7	67.4	81.2	76.9	0
6. Home safety/modifications	43.5	55.4	51.7	51.8	0.24
7. Community day care	37.5	36.2	30.5	32.0	0.19
8. Medical records/care plan	83.3	75.9	76.9	77.2	0.42
9. Primary care visit	78.7	87.9	83.6	84.0	0.14
10. Regular health evaluation	83.3	77.2	78.5	78.6	0.56

11. Medication management	76.3	81.3	75.2	76.4	0.19
12. Expectoration care	53.5	48.3	47.4	48.0	0.61
13. Oral care	57.1	55.8	58.4	57.9	0.82
14. Pain management	37.1	40.7	46.3	44.7	0.17
15. Emergency assistance	44.3	45.0	46.6	46.2	0.88
16. Specialty nursing care	58.3	53.8	52.1	52.8	0.57
17. Family guest beds	31.4	29.8	30.1	30.2	0.97
18. Companion	42.9	42.0	40.2	40.7	0.86
19. Life enrichment	40.6	39.3	34.6	35.8	0.39
20. Healthcare consultation and education	69.0	68.5	66.5	67.0	0.83
21. Mental health counseling	55.6	56.5	49.7	51.3	0.20
22. Hospice care	28.6	32.2	29.5	29.9	0.79
23. Caregiver training	43.3	43.9	38.6	39.8	0.40
24. Respite care	31.8	35.3	33.5	33.7	0.86
25. ADL training and lost prevention	49.3	55.9	49.7	50.8	0.31
26. Medical equipment purchase, rental, and usage guide	11.5	14.9	19.0	17.8	0.20
27. Hazard prevention and self-rescue	22.6	26.4	25.9	25.7	0.84
28. Legal inquiry assistance	20.3	23.3	23.2	23.0	0.87
29. Pressure ulcer prevention	58.6	60.2	60.5	60.4	0.95
30. Pairing assistance	30.9	32.9	26.0	27.9	0.17

Table 4
Intensity (Hours Per Week) of Services in Care Institutions, Mean (SD)

Services	Level of cognitive impairment				P-value
	Mild (n=88)	Moderate (n=213)	Severe (n=954)	Total (n=1255)	
1. Housekeeping	6.6 (2.5)	7.5 (2.7)	7.0 (2.7)	7.1 (2.6)	0.74
2. Transportation	7.5 (2.8)	4.8 (3.0)	4.7 (2.3)	4.8 (2.5)	0.18
3. Dining	7.2 (2.5)	6.0 (2.4)	6.1 (2.4)	6.1 (2.4)	0.58
4. Dressing/grooming	3.9 (2.0)	3.8 (2.2)	3.7 (2.1)	3.7 (2.1)	0.88
5. Using the toilet	4.1 (2.5)	4.5 (2.4)	4.3 (2.2)	4.3 (2.3)	0.82
6. Home safety/modifications	2.8 (2.3)	4.1 (2.0)	3.7 (2.0)	3.7 (2.0)	0.054
7. Community day care	31.7 (1.9)	28.7 (2.3)	14.3 (3.0)	18.1 (2.9)	0.000
8. Medical records/care plan	1.7 (2.6)	2.0 (2.3)	2.2 (2.3)	2.1 (2.3)	0.11
9. Primary care visit	2.0 (2.3)	1.9 (2.1)	2.1 (2.2)	2.0 (2.2)	0.38
10. Regular health evaluation	1.7 (2.6)	2.0 (2.4)	2.2 (2.3)	2.1 (2.3)	0.16
11. Medication management	1.8 (2.0)	1.7 (2.1)	1.9 (2.2)	1.9 (2.2)	0.15
12. Expectoration care	2.2 (2.5)	1.9 (2.1)	1.7 (2.1)	1.8 (2.2)	0.20
13. Oral care	1.8 (2.2)	1.9 (2.2)	2.0 (2.3)	2.0 (2.3)	0.52
14. Pain management	2.6 (2.3)	2.5 (2.2)	3.0 (2.5)	2.9 (2.5)	0.39
15. Emergency assistance	1.4 (2.1)	1.5 (2.1)	1.9 (2.1)	1.8 (2.1)	0.025
16. Specialty nursing care	3.8 (2.8)	3.5 (2.8)	3.5 (2.6)	3.5 (2.6)	0.93
17. Family guest beds	2.7 (3.2)	3.6 (2.9)	4.3 (2.9)	4.0 (2.9)	0.14
18. Companion	4.7 (2.4)	4.0 (2.7)	4.9 (2.5)	4.8 (2.5)	0.21
19. Life enrichment	5.3 (2.2)	4.4 (2.5)	4.3 (2.3)	4.3 (2.3)	0.44

20. Healthcare consultation and education	2.4 (2.6)	2.1 (2.4)	2.3 (2.3)	2.3 (2.4)	0.49
21. Mental health counseling	3.8 (2.5)	2.8 (2.4)	3.9 (2.3)	3.7 (2.3)	0.007
22. Hospice care	2.1 (2.1)	1.9 (1.9)	2.0 (1.7)	2.0 (1.8)	0.73
23. Caregiver training	3.0 (2.4)	2.6 (2.2)	2.9 (2.1)	2.9 (2.1)	0.43
24. Respite care	3.5 (2.8)	2.4 (2.4)	3.2 (2.3)	3.1 (2.4)	0.13
25. ADL training and lost prevention	6.5 (1.6)	5.9 (2.3)	5.5 (2.2)	5.6 (2.3)	0.55
26. Medical equipment purchase, rental, and usage guide	2.1 (2.4)	2.1 (2.6)	2.4 (2.2)	2.3 (2.3)	0.55
27. Hazard prevention and self-rescue	1.7 (2.2)	1.7 (1.9)	2.2 (2.2)	2.0 (2.2)	2.64
28. Legal inquiry assistance	1.9 (1.7)	1.6 (1.7)	2.3 (1.8)	2.1 (1.8)	0.016
29. Pressure ulcer prevention	2.6 (2.9)	2.8 (2.3)	3.5 (2.7)	3.3 (2.6)	0.057
30. Pairing assistance	4.2 (2.6)	3.1 (2.5)	3.3 (2.2)	3.3 (2.3)	0.44

Table 5. Selection plan for service items on different care levels

Services	Low	Medium	High
Total number of care service items	10	13	17
Number of general care service items	7	7	7
Number of selective care service items	3	6	10
Monthly care service time (hours/month)	151.41	201.88	252.35

The Monthly Standard Base Rate for the Essential Care Service Package

Based on 30%, 40%, and 50% of the average monthly wage (1037.83 USD) of all urban units in China in 2018 (National Bureau of Statistics of China 2019), the monthly standard base rates for ECSP nursing services at low, medium, and high levels in 2018 were calculated at 311.35 USD, 415.13 USD, and 518.92 USD per month, respectively.

Calculation of monthly service hours

(1) Total Service Time Spent on Low-Level Care: The total time of care service for General Care Services (10 items) was included in the ECSP for PLWD with low-level care was 151.41 hours per month.

(2) Total Service Time Spent on Mid-Level Care

$$= 151.41 \times \frac{415.13}{311.35} = 201.88 \text{ (hours per month)}$$

(3) Total Service Time Spent on High-Level Care:

$$= 151.41 \times \frac{518.92}{311.35} = 252.35 \text{ (hours per month)}$$

Calculation of total number of service items

(1) The number of basic care services for low-level PLWD: the numbers of General Care Services were included in the ECSP for PLWD, with a total of 10 items of basic care services.

(2) The total number of mid-level care service items:

$$= 10 \times \frac{201.88}{151.41} = 13.3 \approx 13 \text{ (items)}$$

(3) The total number of high-level care service items:

$$= 10 \times \frac{252.35}{151.41} = 16.7 \approx 17 \text{ (items)}$$

Selection of ECSP items at different care levels

The ECSP corresponds to the low, medium, and high levels of care for mild, moderate, and severe dementia, respectively. The ECSP selection plan at different levels is designed as “General Care Services + Elective Care Services,” in which the service items for low-, mid-, and high-level care with cognitive dysfunction severity of low, moderate, and severe for PLWD are 7+3, 7+6, and 7+10, respectively (Table 5).

DISCUSSION

The essential care service package for persons living with dementia is a practicable and effective approach to promote implementation of the long-term care insurance system.

There is a paucity of research into estimating levels of care and the ECSP for the growing PLWD population in mainland China. Given the rapidly changing demographics, meeting the challenges of financing and service provision for PLWD requires proactive planning and support from individuals, families, and national and local governments. Access to periodical primary healthcare services and continuity of essential care services for PLWD has worsened during the COVID-19 pandemic. PLWD are faced with serious double challenges³⁵. It is a corporate liability at all levels of stakeholders to meet the needs of PLWD, their caregivers and lessen their vulnerability, establish appropriate planned strategies for their care services during and post-pandemic^{3,38}.

Dementia is one of the most important variables in LTCI for the disabled elderly population. To the best of our knowledge, the present study was the first to quantify the substantial perceived needs and actual utilization from a survey of PLWD in six cities in central and eastern China. An ECSP of 30 care service items would be sufficient to ensure adequate service for this population. These findings are an important first step to inform clinicians

and policymakers regarding the design of LTCI coverage to finance and deliver PLWD care.

An essential service package (ESP) (or “basic” package) refers to a basket of health services for government programs to finance health services in low- and middle-income countries³⁹. Cost-benefit analysis of health benefit maximization was used as the gold standard for achieving UHC. Many developed countries have adopted such a framework in guiding their LTC financing, including that required for PLWD. For example, Australia developed home and community care service packages for the elderly at four care need levels (basic, low, moderate, and high); the corresponding government subsidy costs in July 2019 were 8,750 AUD, 15,250 AUD, 33,500 AUD, and 50,750 AUD, respectively⁴⁰. Japan has a seven-level care system based on ADL and the supportive care needs, with the government covering 50% of the total costs⁴¹. The US currently does not have an ECSP, but the development of a national plan for Alzheimer’s disease and other related dementia was enacted by the Alzheimer’s Disease Reporting Act of 2011 to improve care services and promote the use of the Toolkit of Dementia Friendly Community, which includes 4 stages (convene, engage, analyze, act) and 17 detailed implementation steps⁴².

Researchers in China have tried to address issues of the ESP in health services and public policy research^{43,44}. Chen et al. constructed a home care service package for the elderly with disabilities in Zhengzhou city and proposed 11, 19, and 20 items for those with mild, moderate, and severe disabilities, respectively⁴⁵. Shanghai stipulated 42 service items of community home care and care for the elderly and determined the payment standards for specific care services according to different evaluation levels⁴⁶. Chengdu clarified that developmentally disabled people who meet the conditions

of LTC insurance after assessment of dementia and disability can receive LTC insurance payments. The payment standard is determined by the corresponding care level of the disability. The monthly quota bases of the first, second and third levels of care are 50%, 40%, and 30% of the average monthly wage of the employed personnel in all units in Chengdu, respectively³⁵.

The ECSP for PLWD proposed in this study is based on the political, economic, social, cultural, and historical context of LTC in China. By using a public financing perspective and following the principles of public welfare, fairness, feasibility, and accessibility of basic care services, the resulting service estimates meet the national policy guidance aimed to ensure universal coverage of a core set of services for person-centered dementia care^{20,47}. It uses the monthly average wage of employees in all urban units in China to calculate the monthly subsidy quota standard of basic care services. It provides LTC services in the form of hierarchical care service packages that cover those who need a rate of care that is >80% of the UHC project (low-level care service project). In combination with the actual utilization of service items, those with a utilization rate >60% are also included in the General Care Services items of ECSP for PLWD with low-level care service, and the rest are included in the moderate- and high-level care service package options. The “General Care Services + Selective Care Services” is a modular combination of care service items that conforms to Maslow’s hierarchy of needs. On one hand, it considers the general requirements of the basic care services for most PLWD and guarantees fair and affordable accessibility at different levels; on the other hand, it also considers the personalized and diverse needs of PLWD with different care service levels, which enhances its applicability. With China’s continuous economic and social development and the government’s

financial investment, the content of ECSP should be monitored and revised as necessary. It will also play an important role in clarifying the responsibility of the government to equalize basic health and elderly care services³². Therefore, the ECSP is a practicable and effective quantitative management means to implement the LTCI system for PLWD; it is also a useful tool for holding the government, providers, and insurers accountable. It deserves application on a large scale.

A healthy lifestyle in the whole lifecycle has indicated to reasonably reduce the risk of dementia later in life. Sustained smoking cessation and reduce SHSe are associated with significantly decreased the future prevalence of dementia. It is never too late to quit smoking and clear off SHSe for the objective of reducing the risk of dementia. We strongly recommend that smoking cessation and reduce SHSe should be given a high public health priority among dementia prevention strategies for the elderly.

A professional evaluation system for assessing care service needs and classification services for PLWD should be established as an important part of the national LTCI program. This system will enable the linkage of care needs, service provisions, and payment functions that are standardized across the nation. Elderly people with mild, moderate, and severe dementia who have been professionally assessed are provided with corresponding levels of care by community health service centers, daycare centers, professional care institutions, tertiary specialized hospitals, and other institutions with personalized service offerings. Some safeguard mechanisms and operational pathways of the ECSP for PLWD during and after the COVID-19 pandemic in China are proposed, with the goals of making dementia a public health and social care priority; increasing greater investment in public infrastructure;

incorporating the ECSP into the LTCI system; strengthening the care integration of community resources and care network for dementia; constantly promoting the functions of professional care institutions, communities, and home care services; enhancing quality of care in healthcare facilities, and better continuity of care between primary and tertiary care; and improving the cost-effectiveness ratio and utilization efficiency⁴⁸.

Our study has several strengths including large-scale sample data on the service needs and utilization of the PLWD population in mainland China and the use of a well-validated electronic medical record system to diagnose and classify dementia. Data from the National Bureau of Statistics of China are the most authoritative sources for wages and were used to estimate care costs. This work provides a richer body of information on the ECSP and clearly describes what services will be available for every PLWD; such information is essential for health policy analysis and formulation and will serve as the basis for future planning of China's LTCI system.

Several limitations should also be acknowledged. In general, there are various care needs and utilization rates during different stages of dementia. Because of the greater disability and impaired functional status of institutionalized patients, they have more severe clinical features than patients living at home. As we mainly assessed institutionalized individuals in our study, the findings may not represent PLWD with mild to moderate dementia living at other locations. In addition, this study uses 2018-2019 surveyed data and not the real-time data collected amidst the COVID-19 outbreak. Future larger-scale studies of deeper understanding of lived experiences for PLWD covering more geographic locations during the COVID-19 pandemic should be conducted to improve estimate accuracy.

In conclusion, the present study represents one of the first large-scale efforts to develop a needs-based ECSP for PLWD in mainland China. The findings are expected to provide important information for policymakers, clinicians, and researchers to formulate new care standard guidelines for PLWD, to establish an effective LTCI for PLWD and develop a nationwide dementia action plan to implement an integrated health and social care system in China and other low to middle-income countries during the current COVID-19 pandemic, as well as any future pandemics.

Human Subjects Approval Statement

The study was conducted in accordance with the Declaration of Helsinki, and the study protocol was approved by the Ethics Committee of Ningbo College of Health Sciences, China (approval number NBWY-011).

Conflict of Interest Disclosure Statement

All authors of the study declare that they have no conflicts of interests. This research is not funded by any organization related to tobacco production.

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