

# Visualization Analysis of Research Hotspots of Advance Care Planning for Dementia in Foreign Countries

Deng Can<sup>1,a</sup>, Hao Yuying<sup>1,b,\*</sup>, Wei Xinting<sup>1,c</sup>, Liu Jie<sup>1,d</sup>

<sup>1</sup>School of Nursing, Shaanxi University of Traditional Chinese Medicine, Xianyang, China  
<sup>a</sup>2416875461@qq.com, <sup>b</sup>hy8908@163.com, <sup>c</sup>1069374590@qq.com, <sup>d</sup>1424155464@qq.com  
\*Corresponding author

**Abstract:** This study analyzes the research status, hotspots and frontier progress of foreign advance care planning in dementia, and provides reference for domestic research. Retrieve the web of science literature on dementia advance care planning from inception to March 20, 2024. Use CiteSpace 6.2.R4 software to analyze the authors, institutional collaboration networks, and keyword co-occurrence networks of the included literature, and draw a visual graph. A total of 246 articles were included, and the overall number of articles was on the rise. There are 168 authors in the study of advance care planning for dementia, and a clear core team has been formed; The country with the highest number of publications is the United States; The research institutions are mainly higher education institutions, and there is close cooperation and exchange among them; Journal of the American Geriatrics Society is the magazine with the highest number of articles; Research hotspots include 'advanced care planning' and 'palliative care'. At present, the research on the advance care planning for dementia in foreign countries is relatively mature, with a wide range of research and strong correlation, which can provide reference for the research on the advance care planning for dementia in China.

**Keywords:** Dementia, Advance care planning, Advance directive, Visual analysis

## 1. Introduction

Dementia is a common clinical syndrome in the elderly, which affects memory, thinking, behavior and mood, and reduces people's ability to carry out daily activities<sup>[1]</sup>. Dementia has become a major global challenge for health and social care in the 21st century<sup>[2]</sup>. At present, there are more than 9.5 million people with dementia in China. Due to rapid aging, this number is expected to exceed 40 million by 2050, placing a heavy economic and nursing burden on the public and the health care system<sup>[3]</sup>. Advance care planning (ACP) is an important part of hospice care. It helps patients to confirm their preferences and willingness for medical care at the end of life. It can effectively promote communication among doctors, patients and family members, which can ensure that patients can still follow their personal wishes to take care measures in the future when they cannot participate in medical decision-making<sup>[4, 5]</sup>. In 2020, the National Health Commission issued the "13th Five-Year Plan for Healthy Aging" to propose the establishment of a palliative care service system suitable for the elderly in China<sup>[6]</sup>. Therefore, it is necessary to fully understand the research hotspots and future research trends of foreign countries on ACP for dementia. Therefore, this study adopts the method of visual analysis.

## 2. Data and Methods

### 2.1 Data

The core collection database of Web of Science was searched by computer from the establishment of the database to March 20, 2024. The search terms were (Dementia or Alzheimer disease And (advance care planning or advance\* care plan\* or advance health care plan\* or advance directive\* or advance medical plan\* or life-sustaining treatment preferences or end-of-life communication or end-of-life decision making or living will\* or medical power\* attorney or health care prox\* or durable power\* of attorney), The literature type selection of WOC was limited to 'Article' and 'Review Article', the language type selection was 'English', and the citation theme micro selection was 'Palliative Care', 'Dementia Caregivers', 'Dementia', 'Alzheimer's Disease'. A total of 2062 English-related literatures

were retrieved. By reading the title and abstract of the literature, reading the full text if necessary, excluding the literature inconsistent with this study, 246 articles were finally included in the literature.

## 2.2 Methods

The data was imported into CiteSpace software, and the time slicing was set to 2007-2024. The years per slice was set to 2, and the node types were selected as the author, institution, country and keyword. The g-index was selected as 25, and the Pathfinder method was selected to generate the map.

## 3. Results

### 3.1 Trend of Publication Volume

From 2007 to 2024, the annual number of publications showed an overall upward trend. From 2007 to 2017, the growth fluctuation was not significant. From 2017 to 2018, the growth rate was obvious, indicating that scholars' attention to the ACP for dementia increased significantly in this year. From 2018 to 2023, the fluctuation range was small, but the total number of publications was not less than 20, which was higher than that of previous years. In general, foreign research on advance care planning in dementia is on the rise. Figure 1.

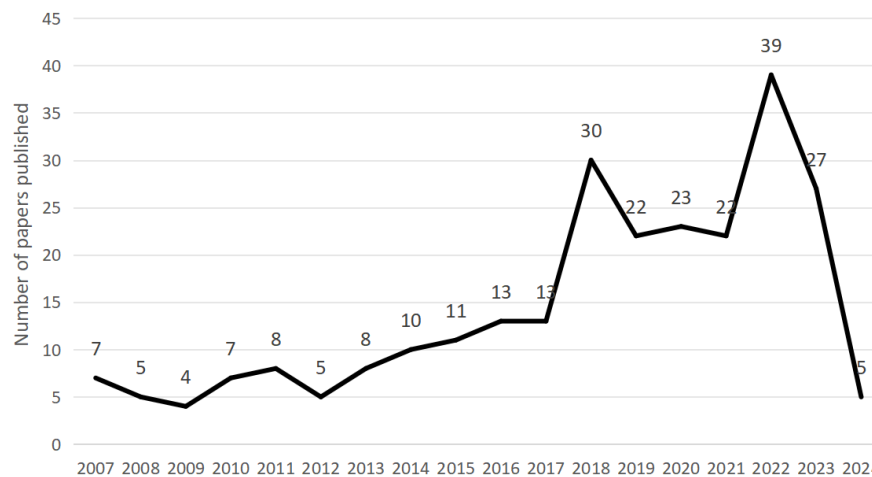


Figure 1: Total number of publications.

### 3.2 Authors Analysis

From the map, there are 168 nodes (  $N = 168$  ), that is, 168 authors. According to the formula of Price's law,

$$M \approx 0.749 (N_{\max})^{1/2} \quad (1)$$

$N_{\max}$  is the number of papers published by the most authors, and  $M$  is the minimum number of papers published by the core authors<sup>[7]</sup>. According to the analysis results, the author with the largest number of papers is Mitchell, Susan L, with a total of 14 papers in this field. Substituted into the formula, the number of core authors in this field is  $\geq 3$ . According to the statistical results, there are 37 core authors in the study of advance care planning for dementia in foreign countries, with a total number of 163 articles. Figure 2 shows a total of 168 nodes, 345 connections, and a density of 0.0246, which shows the relationship between the authors and the size of the font represents the number of articles published by the authors. According to the results of Figure 2, it can be analyzed that there are close links among most researchers, among which the most obvious is the cooperative group mainly composed of Mitchell, Susan L, van der steen, Jenny T, Hanson and Laura C, and from the map, it can be analyzed that there are close links and close cooperation among the three groups before.

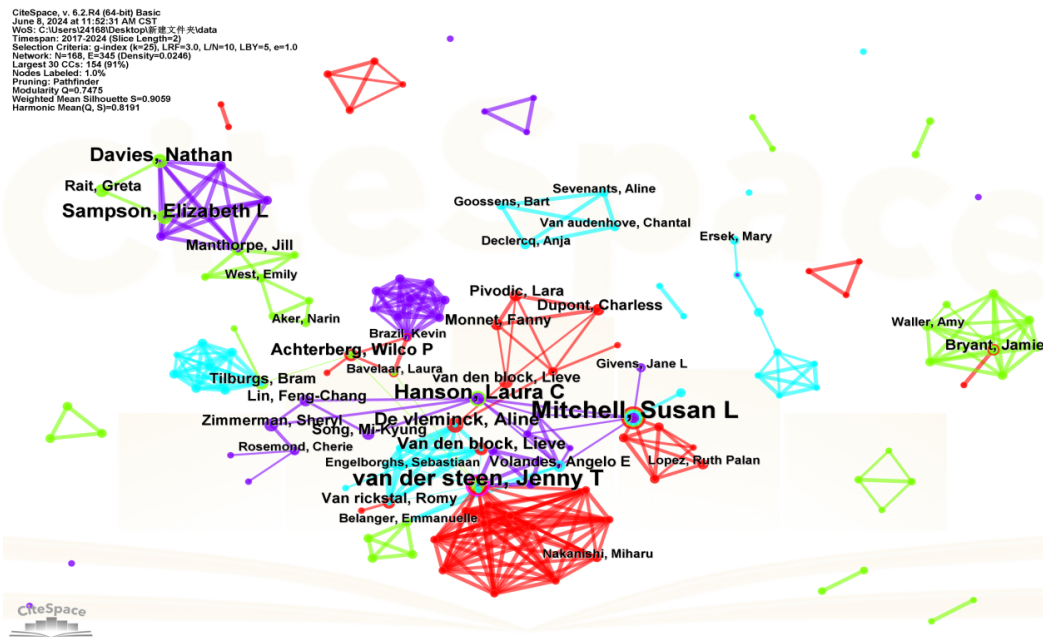


Figure 2: Analysis diagram of author cooperation network.

### 3.3 Country and Issue Agency

Import the data into Cite Space software to conduct a graph analysis of the countries and institutions that have published articles, in order to understand the countries and institutions that have conducted research on dementia advance care planning abroad. Select 'Country' and 'Institution' as the node types to obtain the distribution map of issuing countries shown in Figure 3 and the distribution map of issuing institutions shown in Figure 4. Conduct a graph analysis of the number of national publications, a total of 28 nodes and 44 connections were produced, with a density of 0.1164. It can be seen that most countries have close cooperation in this field. From the perspective of country distribution, high-yield institutions are mainly concentrated in USA, with 81 articles published, followed by NETHERLANDS(21 articles), ENGLAND(20 articles). A total of 141 nodes and 342 connections were generated, with a density of 0.0347. It can be seen that a relatively close cooperation network was formed among the institutions. Among them, Harvard University has the largest number of papers (19 articles), followed by Radboud University Nijmegen (14 articles), Vrije Universiteit Brussel (13 articles).



Figure 3: Analysis diagram of country cooperation network.

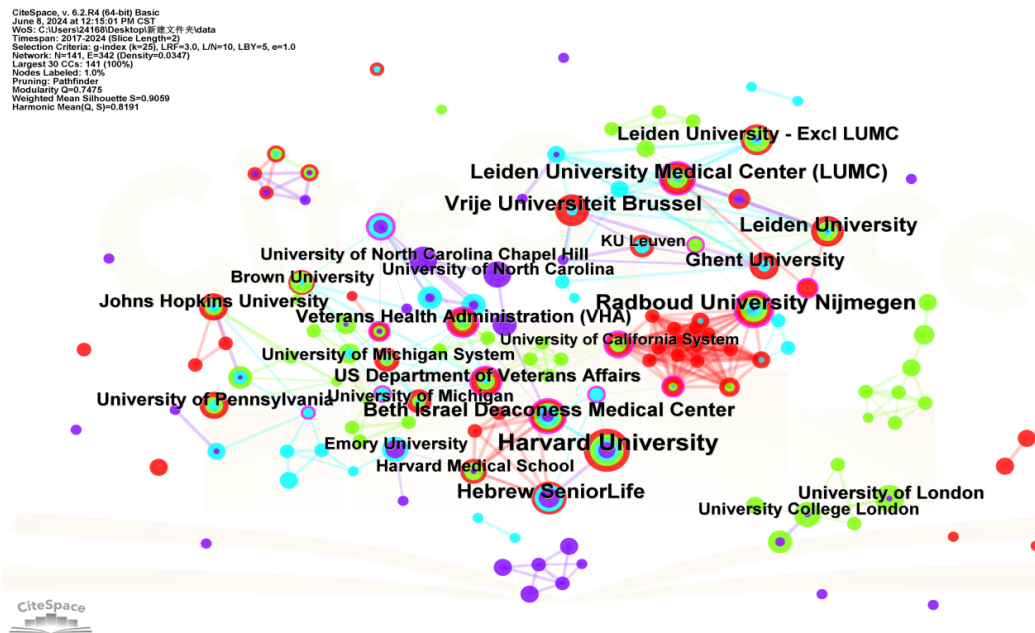


Figure 4: Analysis diagram of institution cooperation network.

#### 4. Analysis of Research Hotspots

##### 4.1 High-frequency Keyword Analysis

High-frequency keywords can reflect the hot issues in the research field. Figure 5 is the collinear analysis of keywords. The top 20 high-frequency keywords are shown in Table 1 for statistical analysis.

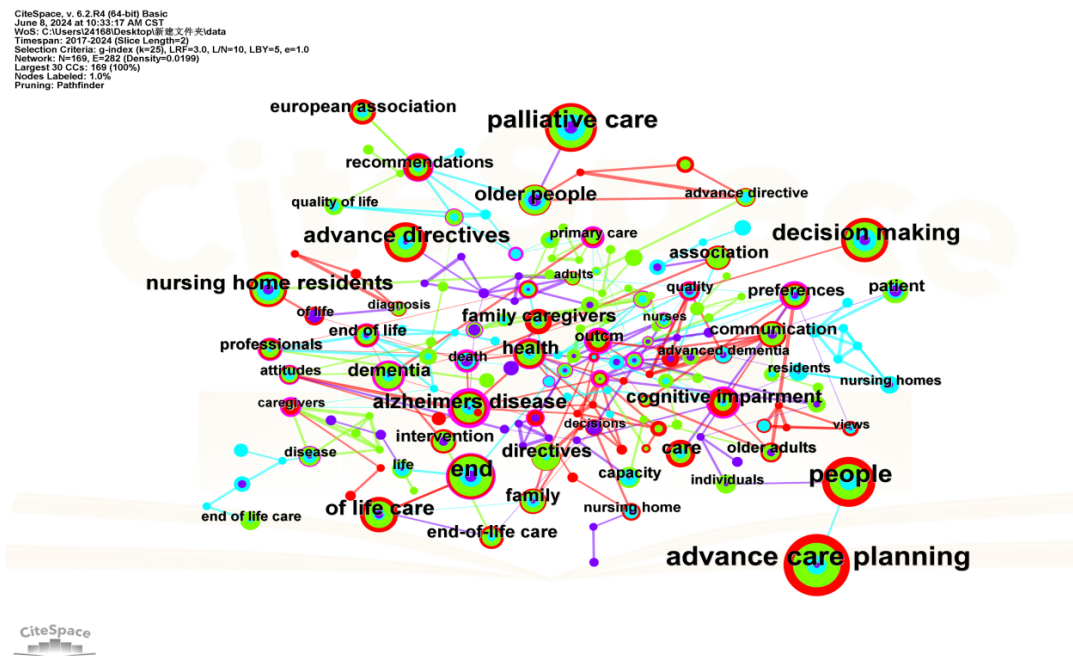


Figure 5: Analysis diagram of keywords.

*Table 1: ACP in dementia research high frequency words.*

Number	Keyword	Count
1	advance care planning	107
2	palliative care	81
3	people	73
4	end	68
5	decision making	65
6	advance directives	55
7	of life care	45
8	nursing home residents	45
9	alzheimers disease	41
10	directives	39
11	older people	36
12	cognitive impairment	35
13	care	33
14	end-of-life care	25
15	family	24
16	communication	23
17	end of life	23
18	life	23
19	attitudes	21
20	dementia	21

#### **4.2 Keyword Emergence Analysis**

Emergent words are keywords with significantly increased frequency of use in a short period of time, representing a research trend in a field. Using Cite Space software to extract burst words, a total of 25 high-frequency keywords were obtained, ranging from 2007 to 2024, as shown in Figure 6. Among them, ' decisions 2.11 ' had the highest intensity of emergence. Through the analysis of emergent words, the research hotspots in this field can be divided into the following stages : from 2017 to 2018, the research hotspots mainly focused on ' decision-making ', ' life ', ' health care ', ' death ', ' quality ', ' facilities ', ' alternative decision makers ' ; from 2019 to 2020, the research hotspots mainly focused on ' nursing homes ', ' satisfaction ', ' advanced dementia ', ' residents ', ' advance directives ', ' joint decision-making ', ' European Association ', etc; from 2021 to 2024, the research hotspots will only focus on ' hospice care ', ' long-term care ' and so on.

## Top 25 Keywords with the Strongest Citation Bursts

Keywords	Year	Strength	Begin	End	2017 - 2024
decisions	2017	2.11	2017	2018	
of life	2017	1.88	2017	2018	
health care	2017	1.86	2017	2018	
death	2017	1.65	2017	2018	
nursing homes	2017	1.64	2017	2020	
decision	2017	1.33	2017	2020	
satisfaction	2017	1.33	2017	2020	
advanced dementia	2018	1.22	2018	2020	
quality	2017	0.95	2017	2018	
facility	2017	0.93	2017	2018	
surrogate decision makers	2017	0.93	2017	2018	
residents	2017	1.69	2019	2020	
advance directive	2019	1.43	2019	2020	
shared decision-making	2019	1.32	2019	2020	
consent	2019	1.32	2019	2020	
european association	2019	1.29	2019	2020	
perceptions	2020	1.11	2020	2022	
definition	2019	1.06	2019	2020	
shared decision making	2020	0.93	2020	2022	
assisted suicide	2020	0.9	2020	2022	
terminal care	2021	1.79	2021	2022	
association	2017	1.54	2021	2022	
long-term care	2022	1.3	2022	2024	
end of life care	2019	1.12	2021	2022	
engagement	2021	1.07	2021	2022	

Figure 6: The top 25 emergent words cited in foreign literature.

## 5. Discussion

### 5.1 More and More Attention has been Paid to the Study of ACP in Dementia Abroad

The overall number of publications is in a rising state, especially in 2018 and 2022. The number of publications has increased rapidly, and a relatively stable core author group and core institutional group have been formed abroad, indicating that the study of advance medical care plan in dementia has received extensive attention from foreign scholars.

### 5.2 Research Hotspots Analysis

#### 5.2.1 Research Content

European scholars understand the attitudes of patients with dementia and their supporters towards ACP, and make recommendations for the revision of the definition. These recommendations better reflect the role of family or trust-based relationships, ensure that patients with dementia have the right to equal access to all aspects and equal access to care, and better address the social aspects of care<sup>[8]</sup>. In the study of young patients with onset dementia and their families' perceptions of ACP, scholars proposed the conceptualization of ACP as a holistic, flexible, and relevant process, and proposed planning recommendations on how to implement policies and practices for advance care. Their insights have laid a solid foundation for expanding the evidence base for palliative care internationally<sup>[9]</sup>. Advance medical care plan is the core content of high quality palliative care. With the rapid development of the times, more and more scholars pay attention to the importance of advance medical care plan itself. As an effective way of communication, it can improve the satisfaction of patients and their families to medical care and improve the quality of life of patients in the end stage<sup>[10]</sup>.

A addition to the patient's own research, foreign studies on ACP in patients with dementia have also investigated family caregivers, general practitioners and decision-making agents of patients with dementia. Taiwan scholars in China investigated the related factors of early dementia patients participating in ACP, and the results showed that the related factors were education level, marital status, and the agent signed the non-resuscitation consent<sup>[11]</sup>. A Japanese study<sup>[12]</sup> investigated the concerns of family caregivers about the implementation of ACP in patients with dementia at home. Six countries in Europe have used mySupport advance care plan to intervene with home caregivers to study whether this



has an impact on home caregivers' decision-making and care for elderly people in dementia nursing homes<sup>[13]</sup>. The current situation in the United States has investigated doctors' attitudes towards ACP in patients with dementia<sup>[14]</sup>. Australian scholar study<sup>[15]</sup> explored the barriers and drivers of ACP for Australian GPs caring for dementia patients. American scholars have studied how decision-making agents of dementia patients make treatment decisions for them, and the results show that they will choose their preferred decision-making when the patient is not clear<sup>[16]</sup>. It can be seen that the scope of foreign research on ACP in dementia has gradually expanded and is no longer limited to the patients themselves.

### 5.2.2 Research Direction

In recent years, foreign studies have mainly focused on ACP in long-term care and hospice care for dementia. Long-term care is an important strategy to deal with aging. The 2016 WHO Global Report on Ageing and Health states that long-term care should be redefined, a more proactive action agenda should be opened, and efforts should be made to empower older people wherever possible<sup>[17]</sup>. Long-term care encompasses a wide range of support services, from personal care, healthcare, social services to rehabilitation care<sup>[18]</sup>. Some scholars have found that previous studies on ACP in primary care are mainly aimed at the general population and will exclude dementia patients. Therefore, the study of 'shared choice' is carried out to allow families to actively participate in interaction and support ACP, and to improve communication with dementia patients in primary care. In this study, the ACP problem was solved for all subjects<sup>[19]</sup>.

Dementia patients will gradually become more serious over time. In the late stage, most dementia patients will have dysphagia, pain that cannot be expressed, psychological and behavioral symptoms. In the late stage of dementia, it is impossible to make decisions. Whether or not to take measures and what measures to take, it is impossible to accurately know the willingness of dementia patients themselves, so it is necessary to carry out ACP early. Analyst Wayne Shelton analyzed how ACP should be applied to key points in the progression of the disease, particularly in relation to food and nutritional care, from the diagnosis of dementia to death<sup>[20]</sup>. In addition, some scholars have discussed the relationship between the intensity of hospice care and ACP in patients with dementia, and found that the non-resuscitation order of patients with dementia and admission is related to the low intensity of hospice care<sup>[21]</sup>.

## 6. Summary

In this study, Citespace software was used to visually analyze the research on advance care planning for dementia patients in foreign countries, which provided hotspots and trends for future research in this field in China. This study also has limitations. It only conducts literature retrieval in the core database of Web of Science. Future research can expand the retrieval to other databases to show the trajectory and trends of research more comprehensively.

## References

- [1] Wong S L, Gilmour H, Ramage-Morin P L. *Alzheimer's disease and other dementias in Canada*[J]. *Health Rep*, 2016, 27(5):11-16.
- [2] Juul R I, Frikke-Schmidt R. *Modifiable cardiovascular risk factors and genetics for targeted prevention of dementia* [J]. *Eur Heart J*, 2023, 44(28):2526-2543.
- [3] Wang Y, Xiao L D, Yu Y, et al. *An individualized telephone-based care support program for rural family caregivers of people with dementia: study protocol for a cluster randomized controlled trial* [J]. *BMC Geriatr*, 2021, 21(1):629.
- [4] Curd P R. *Advance care planning reconsidered: toward an operational definition of outpatient advance care planning* [J]. *J Palliat Med*, 1999, 2(2):157-159.
- [5] Li Fang, Luo Lei, Guo Qin, et al. *Research progress on the influencing factors of the implementation of advance medical care plan in China* [J]. *Chinese Journal of Modern Nursing*, 2020 (No. 21) : 2954-2959.
- [6] National Health Commission Cadre Training Center [EB / OL]. [2024 / 5 / 30]. <https://www.otcmoh.org.cn/jlshow/103.html>.
- [7] Li Yuting, Yang Lin. *CiteSpace analysis of the research hotspots of hospice care in China in the past ten years* [J]. *Medicine and Philosophy (A)*, 2018 (No. 1) : 33-36.
- [8] van der Steen JT, Nakanishi M, Van den Block L, et al. *Consensus definition of advance care planning in dementia: A 33-country Delphi study*[J]. *Alzheimers Dement*, 2024, 20(2):1309-1320.
- [9] Van Rickstal R, Vleminck A, Engelborghs S, et al. *A qualitative study with people with young-onset*

*dementia and their family caregivers on advance care planning: A holistic, flexible, and relational approach is recommended*[J]. *Palliat Med*, 2022, 36(6):964-975.

[10] Harding A, Doherty J, Bavelaar L, et al. *A family carer decision support intervention for people with advanced dementia residing in a nursing home: a study protocol for an international advance care planning intervention (mySupport study)*[J]. *BMC Geriatr*, 2022, 22(1):822.

[11] Huang H L, Shyu Y L, Weng L C, et al. *Factors associated with the intention to engage in care planning among persons with mild cognitive impairment and dementia*[J]. *Geriatr Nurs*, 2023, 50:143-151.

[12] Nakanishi M, Nakashima T, Miyamoto Y, et al. *Family caregivers' concerns about advance care planning for home-dwelling people with dementia: a cross-sectional observational study in Japan*[J]. *BMC Palliat Care*, 2022, 21(1):114.

[13] Bavelaar L, Visser M, Walshe C, et al. *The impact of the mySupport advance care planning intervention on family caregivers' perceptions of decision-making and care for nursing home residents with dementia: pretest-posttest study in six countries*[J]. *Age Ageing*, 2023, 52(3).

[14] Tjia J, D'Arcangelo N, Carlston D, et al. *US clinicians' perspectives on advance care planning for persons with dementia: A qualitative study*[J]. *J Am Geriatr Soc*, 2023, 71(5):1473-1484.

[15] Alam A, Barton C, Prathivadi P, et al. *Advance care planning in dementia: a qualitative study of Australian general practitioners* [J]. *Aust J Prim Health*, 2022, 28(1):69-75.

[16] Nicholas L H, Langa K M, Halpern S D, et al. *How do surrogates make treatment decisions for patients with dementia: An experimental survey study*[J]. *Health Econ*, 2024, 33(6):1211-1228.

[17] Zhou Xuan, Zhou Lanshu. *Consideration on the current situation and future development of long-term care for the elderly in China* [J]. *Journal of Naval Military Medical University*, 2024 (No. 3) : 255-259.

[18] Yeung W J, Thang L L. *Long-Term Care for Older Adults in ASEAN Plus Three: The Roles of Family, Community, and the State in Addressing Unmet Eldercare Needs* [J]. *J Aging Health*, 2018, 30(10):1499-1515.

[19] Dy S M, Scerpella D L, Cotter V, et al. *SHARING Choices: Design and rationale for a pragmatic trial of an advance care planning intervention for older adults with and without dementia in primary care* [J]. *Contemp Clin Trials*, 2022, 119:106818.

[20] Shelton W, Geppert C. *Limits of advance directives in decision-making around food and nutrition in patients with dementia* [J]. *J Med Ethics*, 2024.

[21] Luth E A, Pan C X, Viola M, et al. *Dementia and Early Do-Not-Resuscitate Orders Associated With Less Intensive of End-of-Life Care: A Retrospective Cohort Study* [J]. *Am J Hosp Palliat Care*, 2021, 38(12): 1417-1425.