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ARTICLE

# Validity and Reliability of a Chinese-Tailored Scale for the Evaluation of End-of-Life Care in Dementia Patients

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## Abstract

**Aims/Background** Highly valid and reliable instruments for evaluating end-of-life care for dementia patients and caregivers are lacking in clinical settings, hampering the progress of pertinent research on palliative care in China. Therefore, the present work focused on assessing the adaptability and reliability of the Chinese version of the End-of-Life Care in Dementia (EOLD) scale in evaluating nursing home caregivers who have cared for advanced dementia patients.

**Methods** A convenience sample of 170 caregivers was recruited from five nursing homes. The data collection instruments included a demographic form and the Chinese version of the EOLD scale. The Chinese version of the EOLD scale comprises three subscales: Satisfaction with Care at the End of Life in Dementia (SWC-EOLD); Symptom Management at the End of Life in Dementia (SM-EOLD), which includes further scales for psychological symptoms and physical symptoms; and the Comfort Assessment in Dying with Dementia (CAD-EOLD), which encompasses further evaluation scales for physical distress, dying symptoms, well-being, and emotional distress.

**Results** The reliability of all the scales ranged from satisfactory to good, with SWC-EOLD's $\alpha = 0.806$, SM-EOLD's $\alpha = 0.879$, and CAD-EOLD's $\alpha = 0.827$.

**Conclusion** In this study, a preliminary reliability assessment on the Chinese version of the EOLD scale was conducted, revealing that the three subscales exhibit strong internal consistency in reliability and structural validity. These results further confirm the applicability of the EOLD scale in dementia research within the context of palliative care.

**Key words: dementia; terminal care; nursing homes; caregivers**

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## Introduction

Dementia is a major factor that induces disability among people aged >65 years worldwide, including in China (Jia et al, 2020). Dementia has emerged as a significant public health issue worldwide (Gao et al, 2024). According to the "Global Status Report on the Public Health Response to Dementia" by the World Health Organization (WHO), dementia affected 55.2 million individuals worldwide in 2021, with 60% of cases occurring in low- and middle-income countries. The prevalence is projected to increase to 78 million in 2030 and 139 million by 2050 (WHO, 2021). In China, where approximately 25% of the global dementia population resides, around 15 million affected individuals are aged 60 and above, amounting to an overall prevalence rate of 5.6%. As the country with the highest number

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of dementia cases in the world, China has a reported dementia-attributed mortality rate of 34.8%, making it one of the most severely impacted countries (Yang et al, 2024). Dementia imposes tremendous economic and social burdens on the global public health system; however, the disproportionate provision of care services with respect to the growing number of dementia patients has aggravated this clinical and public health issue.

Dementia is a progressive and incurable disease, with Alzheimer's disease identified as a frequent causal factor (Liu et al, 2024). Advanced dementia (AD) refers to end-stage dementia, characterized by persistent impaired cognition resulting from cerebral dysfunction and marked decline in memory and functional capacity (Brown and Tolson, 2020). It is classified into seven stages based on the Global Deterioration Scale (GDS), with a greater stage suggesting more severe dementia, characterized by verbal ability loss, urinary incontinence, and the inability to walk, use toilet, or self-feed (Reisberg et al, 1982). Another scale, the Functional Assessment Staging Test (FAST), is also used to assess the stage of dementia; through this scale, AD can be classified into seven stages, with stage 7 classified as severe dementia. Stage 7 can be subclassified into stages 7a to 7f on the basis of the patient's ability, such as whether they can speak, even just one word, or lose the capability of walking, sitting upright or holding their heads up (Gupta and Patel, 2024; Sclan and Reisberg, 1992). It has been reported that AD lasts an average of two years (Browne et al, 2021).

Nursing homes are important sites of death for residents with advanced dementia (Akunor et al, 2022; Cross et al, 2020). Moreover, caregivers offer over 90% of the immediate care for their residents (Eaton et al, 2020). Residents with AD, who require comprehensive medical care and rely completely on support from registered nurses and caregivers for all aspects of daily living, are generally cared for in nursing homes, representing 15% of the total number in the UK (Haunch et al, 2022). In the USA, over half of individuals with dementia died in nursing homes (Cross et al, 2020). In Hong Kong, a significant number of AD patients pass away in hospitals, where training and facilities necessary to ensure a dignified end-of-life experience for elderly patients are unavailable (Luk and Chan, 2018). Recently, increasing attention has been given to end-of-life care for AD patients, with numerous studies being carried out to address issues related to interventions (Froggatt et al, 2020), pain management (El-Tallawy et al, 2023), tube feeding (Pullen et al, 2024), patient needs (Gupta and Patel, 2024), caregiver experiences and burdens (Armstrong et al, 2024), and ethical issues (Vaughan and Lesandrini, 2023). In China, however, the development of palliative care system, encompassing end-of-life or hospice care for individuals with AD, remains in its infancy stages. It has been reported that under 60% of patients with life-limiting conditions receive specialist palliative care in high-resource settings (Kochovska et al, 2024), yet no data exist on structured palliative care coverage for AD patients in China.

In 2001, Volicer et al (2001) developed the End-of-Life Care in Dementia scale (EOLD scale) for assessing the quality of life care for AD patients. The EOLD scale is currently employed in numerous research studies (Kroenke et al, 2022; Zumstein et al, 2022). Like the concept of quality of life, end-of-life care quality is a subjective metric measured based on patients' self-assessment. However, assessment may not be practical in patients with cognitive impairment. As a result, the quality of end-of-life care for patients with AD should be evaluated by caregivers through observing patients' condition using verbal and nonverbal cues. The EOLD scale was prioritized over generic palliative care instruments (e.g., Palliative Care Outcome Scale (POS) (Hodiamont et al, 2021); Quality of Dying and Death questionnaire (QODD) (Wang et al, 2021)) to uniquely capture dementia-specific trajectories, including progressive cognitive decline (using the Comfort Assessment in Dying with Dementia [CAD-EOLD] subscale) and caregiver-reported symptoms (Symptom Management at the End of Life in Dementia [SM-EOLD] subscale), which are absent in POS. Unlike QODD's focus on patient self-reporting, which is impractical in the AD contexts, EOLD scale is explicitly designed for caregiver proxy assessment.

Currently, no standardized evaluation criteria exist for assessing end-of-life care quality in AD patients in China. Therefore, the present work focused on evaluating the adaptability and reliability of the Chinese version of the EOLD scale in nursing home caregivers who cared for patients with AD meeting their demise in the last year. The findings offer a reference for researchers in selecting an appropriate evaluation tool.

# Methods

## Participants

According to sample size calculation principles, the sample size should be 5–10 times the number of items (Munro, 2005). In this study, a total of 170 study participants were recruited from May to July 2023 from five nursing homes in Guangxi and Guangdong Province, China. Nursing home caregivers who met the following criteria were included: (i) Having worked in a nursing home $\geq$1 year, (ii) Aged $\geq$18 years, (iii) Having spent a minimum of 6 months engaging with persistent caregiving, with $\geq$20 hours of direct care provision per week, (iv) Having cared for individuals with dementia who had passed away in the past year, and (v) Volunteering to participate in this study. Participants who had psychiatric disorders, were involved in other psychological intervention programs, had experienced other major negative life events in the last year, and could not use cell phones to complete the questionnaire, were excluded. A separate sample of 30 caregivers was chosen to evaluate the test–retest reliability with a two-week interval. This group of caregivers was not included in the 170 participants mentioned above.

## Cross-Cultural Adaptation

### *Scale Translation Process*

With the original author's permission, the scale was refined using the Brislin translation model (Jones et al, 2001). The process was conducted as follows: (1) Translation: two nurses with Master's degrees independently performed translation of the EOLD scale, resulting in two separate Chinese versions of the scale. The researcher then consolidated these versions into a single draft. The two translators reviewed the discrepancies in detail and collaboratively developed the first draft of the Chinese version of the EOLD scale by reaching a consensus on all items. (2) Back-translation: a physician with an M.D. degree who has studied overseas and a researcher with an M.A. specializing in medical English, both unfamiliar with the original scale, independently back-translated the first draft of the Chinese version. These translations were then reviewed and analyzed with an associate professor of medicine to ensure the items' meanings were consistent with the original scale. The back-translated version was then sent to the original developer of the scale. Subsequently, the researcher revised the Chinese EOLD scale based on feedback from the original scale developer, and an agreement was reached on the second draft of the Chinese version of the EOLD scale.

### *Cultural Debugging of the Scale*

A panel of six experts with extensive academic credentials or extensive experience in dementia care were invited to review the Chinese version of the EOLD scale. This panel included a geriatrician, an end-of-life care specialist, a psychologist, and three experts in geriatric nursing, with a minimum of 15 years of experience in clinical research on dementia care. These experts had professional experience ranging from 17 to 40 years (average 28.50 ± 7.20 years) and held either doctoral or master's degrees. Four held full senior titles, and two had deputy senior titles. The authority coefficients of the experts ranged from 0.70 to 1.00. Utilizing their clinical experience and professional knowledge, the experts evaluated the second draft of the Chinese version of the EOLD scale, assessing the accuracy of content, clarity of language, and alignment with China's cultural context. The cultural adaptation process involved expert evaluations using a 4-point Likert scale. Items scoring $\leq 2$ in any domain underwent revision. Modifications were made to the second edition based on the experts' feedback. The CAD-EOLD item "Peace" was revised to "The patient's final days were accompanied by family and free from unresolved conflicts", while the SM-EOLD item "Resistiveness to care" was rephrased as "Showed distress during caregiving activities". Upon incorporating these recommendations, the third draft of the Chinese version of the EOLD scale was completed.

### *Presurvey*

In April 2023, a convenience sampling method was used to select 30 caregivers from a nursing home in Dongguan City, Guangdong Province, who met the inclusion and exclusion criteria for a pre-survey. The aim was to determine whether the respondents accurately comprehended the meaning of each item on the questionnaire and to identify any discrepancies between their interpretation of the questions and the intended meaning of the items. If inconsistencies were detected, a review was conducted to revise the final version of the Chinese EOLD scale accordingly.

## Measures

### *Demographic Information Form*

Data pertaining to caregivers, including age, sex, educational background, religious affiliation, and marital status, were collected using a demographic information form. Additionally, data regarding the sex and age of the care recipient at the time of death were collected.

### *Chinese Version of the EOLD Scale*

The EOLD scale was proposed by Volicer et al (2001) to evaluate end-of-life care quality in AD individuals. It includes three subscales: the Satisfaction with Care at the End of Life in Dementia (SWC-EOLD), the Symptom Management at the End of Life in Dementia (SM-EOLD), and the Comfort Assessment in Dying with Dementia (CAD-EOLD). These subscales were initially developed on the basis of retrospective cross-sectional data collected from 156 family members of AD decedents (Kiely et al, 2006).

### *SWC-EOLD Subscale*

The SWC-EOLD subscale comprises 10 items that are rated with a 4-point Likert scale (Volicer et al, 2001), where 1–4 stand for strongly disagree, disagree, agree, and strongly agree, respectively (3 items are reverse-rated). The scale scores range from 10–40, with a greater score indicating greater satisfaction.

### *SM-EOLD Subscale*

The SM-EOLD subscale is used to evaluate nine symptoms of AD, including pain, fear, anxiety, depression, shortness of breath, agitation, skin breakdown, distress during caregiving activities, and calm (with the last one being reversely rated). The caregivers reported the symptom frequency on a 0–5 scale (every day, several days a week, once a week, 2 or 3 times a month, once a month, and never) within the previous 90 days. The scale scores range from 0 to 45, with a greater score indicating less severe symptoms.

### *CAD-EOLD Subscale*

The CAD-EOLD subscale is used to evaluate 14 conditions and symptoms of a patient within the final 7 days of life: pain, discomfort, shortness of breath, restlessness, choking, gurgling, difficulty swallowing, anxiety, fear, moaning, crying, serenity, calm, and being accompanied by family and free from unresolved conflicts. The symptoms were rated on a 1–3 scale, with the following options: not at all, somewhat, and a lot (with the final 3 items being reversely rated). The scale scores range from 14 to 42, with a greater score indicating superior symptom control and a higher level of comfort.

## Data Extraction

Data were extracted from questionnaires completed by the anonymous caregivers for individuals with dementia who died in the previous year. The survey was conducted on the internet using web-based questionnaires. The questionnaire was converted into an electronic format using a third-party online questionnaire

**Table 1. Summary of the caregivers' responses to the SWC-EOLD subscale (*n* = 170).**

| Item | Frequency (%) | | | | |
|---|---|---|---|---|---|
| | Strongly disagree, *n* (%) | Disagree, *n* (%) | Agree, *n* (%) | Strongly agree, *n* (%) | Item-total correlation |
| I felt fully involved in all decision making | 12 (7.1) | 49 (28.8) | 91 (53.5) | 18 (10.6) | 0.63 |
| I would probably have made different decisions if I had had more information* | 3 (1.8) | 29 (17.1) | 120 (70.6) | 18 (10.6) | 0.60 |
| All measures were taken to keep my care recipient comfortable | 0 (0) | 8 (4.7) | 94 (55.3) | 68 (40.0) | 0.48 |
| The health care team was sensitive to my needs and feelings | 6 (3.5) | 25 (14.7) | 115 (67.6) | 24 (14.1) | 0.56 |
| I did not really understand my care recipient's condition* | 27 (15.9) | 107 (62.9) | 25 (14.7) | 11 (6.5) | 0.18 |
| I always knew which doctor or nurse was in charge of my care recipient's care | 3 (1.8) | 13 (7.6) | 112 (65.9) | 42 (24.7) | 0.57 |
| I felt that my care recipient got all necessary nursing assistance | 3 (1.8) | 20 (11.8) | 116 (68.2) | 31 (18.2) | 0.63 |
| I felt that all medication issues were clearly explained to me | 6 (3.5) | 54 (31.8) | 93 (54.7) | 17 (10.0) | 0.63 |
| My care recipient received all treatments or interventions that he or she could have benefited from | 3 (1.8) | 27 (15.9) | 118 (69.4) | 22 (12.9) | 0.61 |
| I felt that my care recipient needed better medical care at the end of his or her life* | 4 (2.4) | 19 (11.2) | 101 (59.4) | 46 (27.1) | 0.61 |

*Reverse-coded for calculation of the total score. SWC-EOLD, Satisfaction with Care at the End of Life in Dementia.

**Table 2. Summary of care recipients' responses to the SM-EOLD subscale ($n = 170$).**

| Item | Frequency (%) | | | | | | Item-total correlation |
|---|---|---|---|---|---|---|---|
| | Never | Once a month | 2 or 3 days a month | Once a week | Several days a week | Every day | |
| Pain | 38 (22.4) | 13 (7.6) | 31 (18.2) | 29 (17.1) | 34 (20.0) | 25 (14.7) | 0.63 |
| Shortness of breath | 29 (17.1) | 18 (10.6) | 28 (16.5) | 29 (17.1) | 34 (20.0) | 32 (18.8) | 0.65 |
| Skin breakdown | 79 (46.5) | 28 (16.5) | 20 (11.8) | 17 (10.0) | 11 (6.5) | 15 (8.8) | 0.61 |
| Calm | 27 (15.9) | 11 (6.5) | 21 (12.4) | 27 (15.9) | 48 (28.2) | 36 (21.2) | 0.21 |
| Depression | 46 (27.1) | 21 (12.4) | 27 (15.9) | 25 (14.7) | 27 (15.9) | 24 (14.1) | 0.79 |
| Fear | 49 (28.8) | 21 (12.4) | 32 (18.8) | 26 (15.3) | 17 (10.0) | 25 (14.7) | 0.80 |
| Anxiety | 37 (21.8) | 20 (11.8) | 25 (14.7) | 30 (17.6) | 31 (18.2) | 27 (15.9) | 0.78 |
| Agitation | 27 (15.9) | 19 (11.2) | 33 (19.4) | 23 (13.5) | 36 (21.2) | 32 (18.8) | 0.78 |
| Distress during caregiving activities | 55 (32.4) | 17 (10.0) | 23 (13.5) | 25 (14.7) | 28 (16.5) | 22 (12.9) | 0.74 |

SM-EOLD, Symptom Management at the End of Life in Dementia.

survey platform. It is necessary to configure the settings such that each mobile device is used only once for completion.

### Statistical Analysis

Statistical data analyses were conducted using SPSS software (version 26.0; IBM Corporation, Armonk, NY, USA). Patient demographic data are summarized as descriptive data, such as percentages and frequencies. Measures of dispersion and central tendency of responses to every item were calculated, as were the item-total correlations. The item-total correlation was analyzed by Pearson or Spearman correlation. Items with item-total correlations $<0.3$ were excluded. Scale and subscale reliability were assessed with the coefficient $\alpha$. Structural validity was assessed using exploratory factor analysis (EFA) performed with a principal component and a varimax rotation. The Bartlett's test of sphericity and the Kaiser-Meyer-Olkin (KMO) test were used to assess the acceptability of the factor analysis. Factors with eigenvalues $>1.0$ were retrieved and selected based on a scree plot and the factor structure of the original scale. The value distribution of each scale was examined for normality by calculating the skewness and kurtosis coefficients. The skewness and kurtosis coefficients are between –1 and +1, indicating approximately normally distributed data. $p < 0.05$ indicated statistical significance.

## Results

### Demographic Characteristics

The sample comprised 170 caregivers, with no missing data post-imputation. The caregiver respondents were mostly females (85.3%). The age range was 18–67 years, and the average was 41.76 ± 13.71 years. The proportions of married, single, divorced, and widowed caregivers were 68.2%, 20.6%, 6.5%, and 4.7%, respectively. The educational levels of the caregivers were as follows: 8.2% elementary school and below, 37.1% secondary school, 22.4% high school, and 32.4% university and above. The majority of the caregivers (87.6%) had no religious beliefs. The average age of the care recipients at death was 84.41 ± 7.87 (range: 57–101) years. There were 77 (45.3%) males and 93 (54.7%) females in the care recipients.

### Analysis of SWC-EOLD Subscale Scores

The SWC-EOLD subscale was used to quantify care satisfaction among patients with AD within the previous 90 days. Table 1 displays the frequency of the 10 remaining items and their item-total correlations. The scores in our sample ranged from 15 to 40 (28.89 ± 3.94). The score distribution (Fig. 1) did significantly deviate from the normal distribution (skewness = –0.088 ± 0.186, kurtosis = 2.288 ± 0.370).

Scale items were subjected to factor analysis; as a result, this scale was composed of one factor, with a Cronbach's $\alpha$ coefficient of 0.806. The scale's test–retest reliability was 0.82.

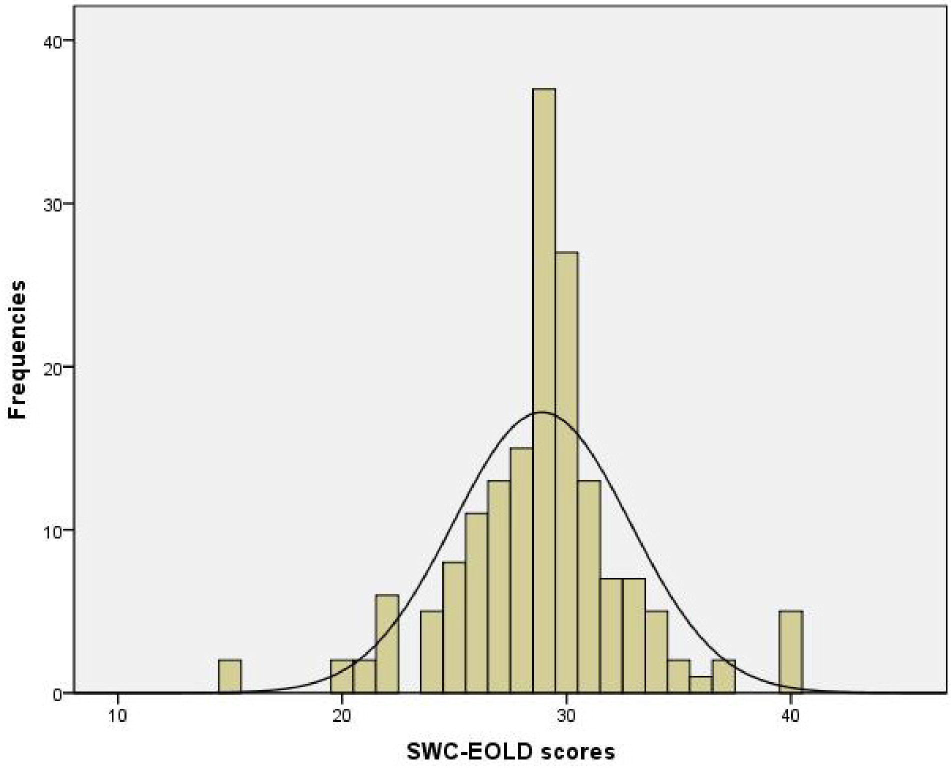

**Fig. 1. Distribution of SWC-EOLD scores.** SWC-EOLD, Satisfaction with Care at the End of Life in Dementia.

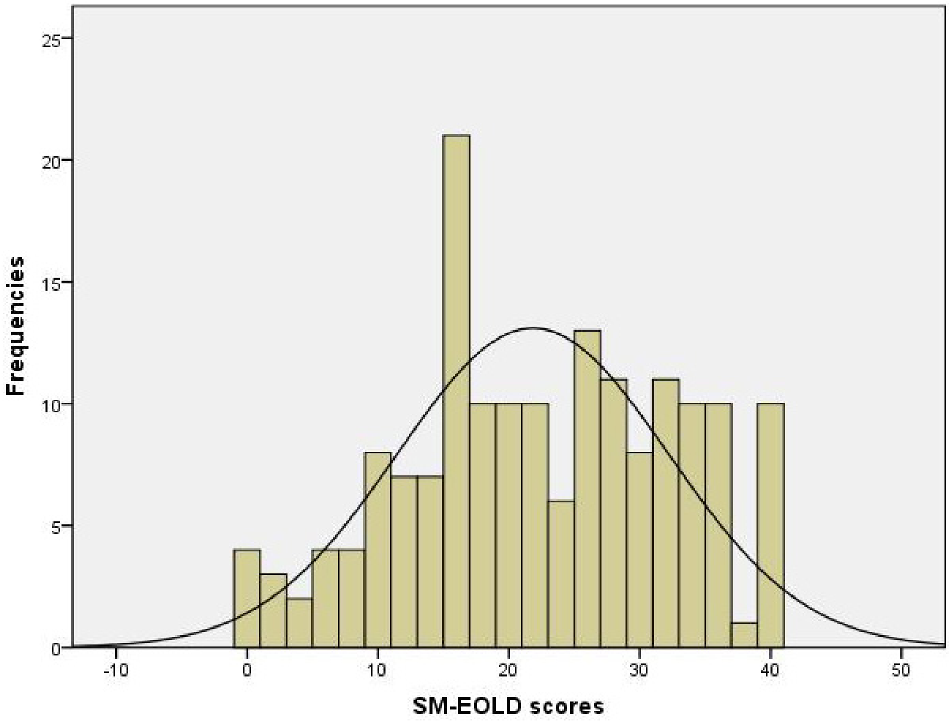

**Fig. 2. Distribution of SM-EOLD scores.** SM-EOLD, Symptom Management at the End of Life in Dementia.

**Table 3. Rotated factor structure of the SM-EOLD subscale.**

| Item | Factor loading | |
|---|---|---|
| | Factor 1 | Factor 2 |
| Pain | 0.191 | 0.800 |
| Shortness of breath | 0.262 | 0.731 |
| Skin breakdown | 0.235 | 0.694 |
| Depression | 0.734 | 0.360 |
| Fear | 0.815 | 0.299 |
| Anxiety | 0.857 | 0.197 |
| Agitation | 0.78 | 0.301 |
| Distress during caregiving activities | 0.817 | 0.168 |
| Eigenvalue | 3.373 | 2.034 |
| Percent variance | 42.167 | 25.420 |

The loadings utilized to identify the factors are underscored. SM-EOLD, Symptom Management at the End of Life in Dementia.

## Analysis of SM-EOLD Subscale Scores

The item responses on the scale reflected the care recipient's status in the final 90 days of his/her life. Table 2 presents frequencies of nine items, together with their item-total correlations. The item "Calm" was excluded from further analysis because the item-total correlation value was below the threshold of 0.3. The scores in the sample ranged from 0 to 40 (21.83 ± 10.35). The score distribution (Fig. 2) revealed no significant deviation from a normal distribution, as indicated by a skewness of –0.101 ± 0.186 and a kurtosis of –0.802 ± 0.370.

This study carried out principal component analysis using the varimax rotation approach with principal component extraction. Upon Bartlett's test of sphericity, the score was 671.134 ($p < 0.001$), whereas the KMO value was 0.866, indicating the presence of shared factors in SM-EOLD. Following the EFA, the scree plot indicated the presence of two factors whose eigenvalues were higher than 1.0. Factor 1, designated as "psychological symptoms and states" dimension, comprised five items. Factor 2, designated the "physical symptoms" dimension, comprised three items. Two factors were retained, cumulatively explaining 67.587% of the variance (Factor 1: 42.167%; Factor 2: 25.420%). All items loaded $>$0.50 on their respective factors (range: 0.694–0.857), with no cross-loadings $\geq$0.40 or items $<$0.30 (Table 3).

This subscale had a Cronbach's $\alpha$ coefficient of 0.879, whereas the two-factor Cronbach's $\alpha$ coefficients were 0.898 and 0.677, respectively. The scale's test–retest reliability was 0.79.

## Analysis of CAD-EOLD Subscale Scores

The responses to items in the CAD-EOLD subscale reflected the care recipient's state during death. The scores in our sample ranged from 16 to 42 (28.51 ± 5.09). Table 4 displays the frequency of the 14 remaining items. The score distri-

**Table 4. Summary of the care recipients' responses to the CAD-EOLD subscale ($n$ = 170).**

| Item | Frequency (%) | | | Corrected item-total correlation |
|---|---|---|---|---|
| | A lot | Somewhat | Not at all | |
| Discomfort | 50 (29.4) | 96 (56.5) | 24 (14.1) | 0.63 |
| Pain | 38 (22.4) | 101 (59.4) | 31 (18.2) | 0.58 |
| Restlessness | 55 (32.4) | 92 (54.1) | 23 (13.5) | 0.59 |
| Shortness of breath | 61 (35.9) | 94 (55.3) | 15 (8.8) | 0.56 |
| Choking | 30 (17.6) | 106 (62.4) | 34 (20.0) | 0.68 |
| Gurgling | 22 (12.9) | 97 (57.1) | 51 (30.0) | 0.61 |
| Difficulty swallowing | 84 (49.4) | 68 (40.0) | 18 (10.6) | 0.54 |
| Fear | 39 (22.9) | 87 (51.2) | 44 (25.9) | 0.73 |
| Anxiety | 39 (22.9) | 100 (58.8) | 31 (18.2) | 0.64 |
| Crying | 23 (13.5) | 81 (47.6) | 66 (38.8) | 0.53 |
| Moaning | 52 (30.6) | 96 (56.5) | 22 (12.9) | 0.63 |
| Serenity* | 27 (15.9) | 88 (51.8) | 55 (32.4) | 0.36 |
| Being accompanied by family and free from unresolved conflicts* | 35 (20.6) | 82 (48.2) | 53 (31.2) | 0.33 |
| Calm* | 36 (21.2) | 97 (57.1) | 37 (21.8) | 0.30 |

*Reverse coded for calculation of the total score. CAD-EOLD, Comfort Assessment in Dying with Dementia.

bution (Fig. 3) did not significantly deviate from the normal distribution (skewness = –0.072 ± 0.186, kurtosis = 0.097 ± 0.370).

The varimax rotation method was employed in principal component analysis with the extraction of principal components. The Bartlett's test of sphericity yielded a value of 1074.657 ($p < 0.001$) and a KMO measure of 0.817, indicating the presence of common factors within the scale. Following the EFA, the scree plot indicated three factors with eigenvalues greater than 1.0. Factor 1, termed the "physical distress and dying symptoms" dimension, encompassed seven items. Factor 2, named the "well-being" dimension, consisted of three items. Factor 3, referred to as the "emotional distress" dimension, included four items. Three factors were retained, cumulatively explaining 62.539% of the variance (Factor 1: 27.730%; Factor 2: 17.412%; Factor 3: 17.397%). All items loaded $>$0.50 on their respective factors (range: 0.564–0.904), with no cross-loadings $\geq$0.40 or items $<$0.30 (Table 5).

Cronbach's $\alpha$ coefficient of this subscale was 0.827, whereas those of the other three factors were 0.858, 0.857, and 0.770, respectively. The scale's test–retest reliability was 0.85.

## Discussion

To the best of our knowledge, EOLD scale is rarely used for assessing end-of-life care quality in AD patients in China. Our selection of EOLD over alternatives like the Dementia Quality of Life Scale (DEMQOL) was further justified by its multidimensional assessment of both care processes (SWC-EOLD) and patient

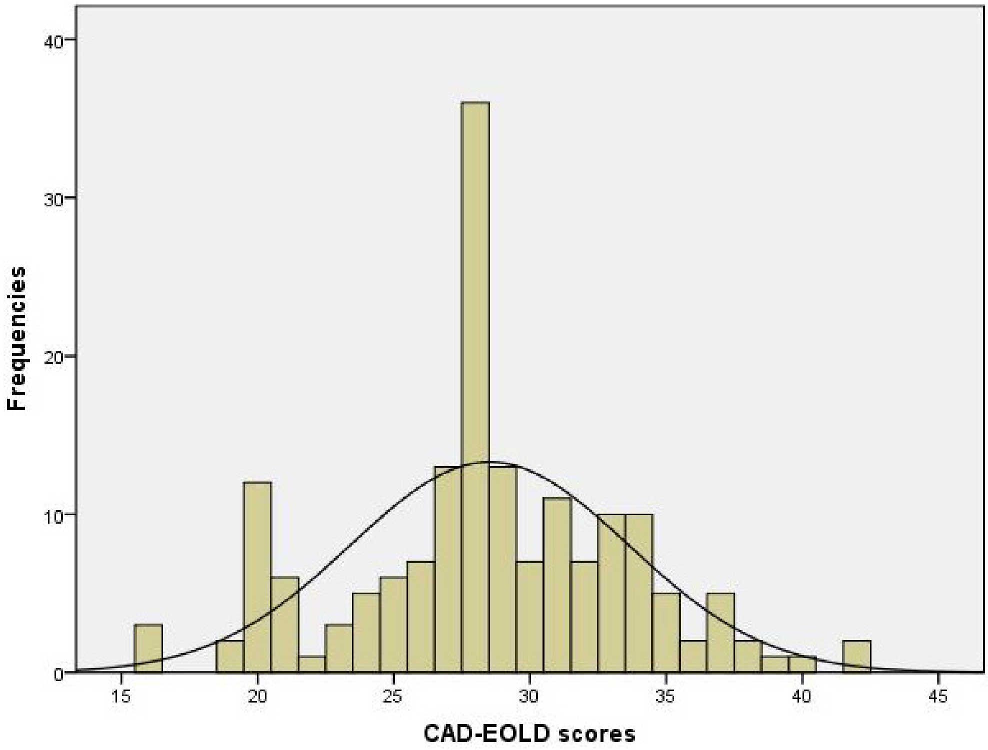

**Fig. 3. Distribution of CAD-EOLD scores.** CAD-EOLD, Comfort Assessment in Dying with Dementia.

outcomes (SM-EOLD/CAD-EOLD). While DEMQOL focuses solely on patient status, EOLD scale's dual perspective aligns with China's family-centered care model, where caregiver experiences are integral to care quality evaluation. This study supplements EOLD's application in China by empirically validating its psychometric robustness within a family-centered care context, demonstrating critical linkages between caregiver-reported processes and clinical outcomes while offering culturally-specific insights unattainable through patient-focused tools like DEMQOL. Evaluating end-of-life care for dementia patients may be complicated by their inability to convey messages about their comfort, distress or needs through speaking. Care assessment for such people relies on nonverbal communication and symptom assessment explained by their caregivers. Therefore, tools to assess the quality of end-of-life care are urgently needed. The present work showed that the Chinese version of the EOLD scale can serve as a valid tool tailored for the Chinese patients with AD.

In China, 16.99 million people with AD and associated dementia eventually need end-of-life care (Wang et al, 2024). Many of them are expected to spend the last phase of their lives in various palliative care settings, where issues of quality of care and satisfaction of patients and caregivers are critical points of concern (Aminoff et al, 2004). The SWC-EOLD subscale evaluates care satisfaction in the previous 90 days, covering aspects such as decision making, healthcare provider communication, understanding of patient condition, and medical and nursing care quality (Kroenke et al, 2022). On the basis of factor analysis of these scale items, this subscale included one factor, conforming to the original study (Volicer et al,

**Table 5. Rotated factor structure of the CAD-EOLD subscale.**

| Item | Factor loading | | |
|---|---|---|---|
| | Factor 1 | Factor 2 | Factor 3 |
| Discomfort | 0.736 | –0.031 | 0.187 |
| Pain | 0.581 | –0.022 | 0.288 |
| Restlessness | 0.238 | –0.086 | 0.777 |
| Shortness of breath | 0.788 | –0.197 | 0.115 |
| Choking | 0.774 | 0.042 | 0.199 |
| Gurgling | 0.683 | 0.14 | 0.129 |
| Difficulty swallowing | 0.787 | –0.179 | 0.050 |
| Fear | 0.492 | 0.149 | 0.576 |
| Anxiety | 0.241 | 0.166 | 0.719 |
| Crying | 0.068 | 0.115 | 0.760 |
| Moaning | 0.564 | –0.014 | 0.413 |
| Serenity | –0.012 | 0.904 | 0.078 |
| Peace | –0.129 | 0.904 | 0.078 |
| Calm | –0.129 | 0.857 | 0.193 |
| Eigenvalue | 3.882 | 2.438 | 2.436 |
| Percent variance | 27.73 | 17.412 | 17.397 |

The loadings utilized to identify the factors are underscored. CAD-EOLD, Comfort Assessment in Dying with Dementia.

2001). Our findings showed that this subscale had a Cronbach's $\alpha$ coefficient of 0.806, which was lower compared to those reported in other two studies (0.83 vs. 0.90) (Kiely et al, 2006; Volicer et al, 2001). Moreover, the average SWC-EOLD score of 28.89 ± 3.94 was lower than that reported in other studies (Kiely et al, 2006; Kroenke et al, 2022; Volicer et al, 2001). The distribution of scores on the SWC-EOLD subscale showed marked deviation from the normal distribution, indicating that non-parametric statistical approaches are more appropriate for analyzing these data. The lower SWC-EOLD scores among Chinese caregivers may reflect systemic and cultural disparities. First, China's palliative care policies lack standardized protocols for dementia-specific end-of-life care, unlike the UK's National Dementia Strategy or the USA's Hospice Care Act, resulting in fragmented service delivery. Second, familial decision-making norms inherent in the Chinese society, with end-of-life choices being largely family-driven rather than patient-centered, may reduce caregivers' satisfaction, as the type of care that can ensure familial harmony is commonly prioritized over individual preferences. Third, the 'filial piety' concept emphasized in the Confucian values may lead caregivers to perceive institutional care as a personal failure, exacerbating dissatisfaction despite comparable clinical outcomes.

The SM-EOLD subscale is a recommended tool for assessing AD residents in nursing homes by caregivers or nurses (Zumstein et al, 2022). We deleted the item "Calm", leaving eight items covering aspects such as pain, shortness of breath, and fear. EFA suggested that this subscale consists of two factors, similar to the original study (Volicer et al, 2001). This subscale had a Cronbach's $\alpha$ coefficient of 0.879, which was higher than that reported in other two studies (0.68 vs. 0.78) (Kiely et al, 2006; Volicer et al, 2001). The reliability coefficients of the SM-EOLD subscale are commonly known to be within an acceptable range. The mean SM-EOLD score was 21.83, which was lower than those reported in the studies of Kroenke et al (2022) and Kiely et al (2006)—measuring 29.3 and 36.4, respectively—and similar to that reported in the study by Volicer et al (2001). The variations in the mean score were attributed mainly to the differences in research participants, whereas the same value could be accounted for by the same data collection method used in Volicer et al's study (2001). The distributions of SM-EOLD scores were not significantly different from the normal distribution, indicating the feasibility of using potent parametric statistical tests in the SM-EOLD subscale analysis.

The CAD-EOLD subscale was developed for measuring symptoms frequently observed during death and is used following the death of AD patients (Sternberg et al, 2014). Exploratory factor analysis revealed three constructs in the sample of nursing home caregivers, labeled 'physical distress and dying symptoms', 'well-being', and 'emotional distress', whereas Volicer et al's research (2001) using an American convenience sample of family caregivers extracted four factors, which were labeled 'physical distress', 'dying symptoms', 'well-being' and 'emotional distress'. The composition of different participants, different cultures and the use of the CAD-EOLD subscale may influence the factor analysis results. The CAD-EOLD subscale had a Cronbach's $\alpha$ coefficient of 0.827, which was higher than those reported in studies using the original English version of the scale, measuring 0.82 in Volicer et al (2001) and 0.85 in Kiely et al (2006), respectively. These Cronbach's $\alpha$ coefficients are within the range of 0.770–0.858, indicating the acceptable internal consistency of the CAD-EOLD scores. The scale's test–retest reliability was 0.85, which indicated good stability over time. The mean CAD-EOLD score was 28.51 ± 5.09, which was lower than that reported by Sternberg et al (2014) (31.3 ± 6.7), Frey et al (2019) (37.21 ± 4.8), and Boyd et al (2019) (33.7 ± 5.2), indicating that the Chinese AD patients experienced poor comfort around the time of death. It is possible that variations in the data collection methods used in different studies have impacted the symptoms and signs reported by these patients. Similarly, the CAD-EOLD scale score distributions did not significantly differ from the normal distribution, suggesting that modifications in care delivery can improve end-of-life care in dementia patients.

Several limitations of this study should be highlighted. First, regional sampling (in Guangdong and Guangxi Province) limits generalizability of the findings obtained to rural or less economically developed areas in China. Future studies should adopt stratified sampling across China's northeast, central, and western zones. Second, data collected through retrospective reporting are vulnerable to recall bias; therefore, prospective longitudinal studies utilizing real-time symptom tracking approaches (e.g., caregiver diaries, wearables) are recommended. In addition to relying on caregiver proxy reports, which are praised for their practicality, triangulation with clinical indicators (e.g., pain biomarkers, agitation frequency logs) should be adopted to enhance validity of the scale score. Finally, policy-level interventions should be explored to address systemic barriers.

## Conclusion

This study demonstrated that the Chinese version of the EOLD scale is a valid and reliable instrument for assessing the quality of end-of-life care for dementia patients. Additional studies are required to validate the reliability and validity of this scale within the Chinese context. More data, such as outcome measures for end-of-life dementia care, are warranted to advance research in this area.

### Key Points

- The study successfully developed and tested a culturally adapted Chinese version of the End-of-Life Care in Dementia (EOLD) scale, addressing the lack of reliable instruments for assessing palliative care quality for patients with advanced dementia within China.
- The translated scale demonstrated robust internal consistency (Cronbach's $\alpha$: 0.806–0.879) and structural validity, consisting of subscales for effectively measuring satisfaction with care, symptom management, and comfort during end-of-life stages.
- The Chinese version of the EOLD scale was applicable for evaluating end-of-life care quality in the setting of Chinese nursing homes, lending support to advancing future research and devising interventions for improving dementia care outcomes for patients and caregivers.
- The study emphasized the necessity of culturally adapting Western-developed care tools—such as by redefining "Peace" as "being accompanied by family and free from unresolved conflicts"—so as to align the instruments with China's collectivist care paradigm and familial caregiving values, and underscored the significance of cultural sensitivity in cross-cultural implementation.

## Availability of Data and Materials

The data substantiating this study's findings are available from the corresponding authors upon reasonable request.

## Author Contributions

LPW, ZFC and LBC conceived and designed the study. ZFC, YOY, and CYC performed the literature research, data acquisition, and data analysis. LBC drafted the manuscript. LPW and ZFC reviewed the manuscript. All authors contributed to revising the manuscript critically for important intellectual content. All authors have read and approved the final version of the manuscript. All authors have participated sufficiently in the work and agreed to be accountable for all aspects of the work.

## Ethics Approval and Consent to Participate

The study was approved by the hospital ethics committee of the Affiliated Hospital of Guangdong Medical University (approval number: PJKT2024-153) and was conducted in accordance with the Declaration of Helsinki. Written informed consent was obtained from all participants.

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## Conflict of Interest

The authors declare no conflict of interest.

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