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# Six Major Challenges Faced by ALS Patients in China From an Ecological Systems Perspective

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## Abstract

# Introduction:

Amyotrophic Lateral Sclerosis is a progressive, neurodegenerative disorder that significantly impacts patients' quality of life. While current research has focused on the physical, psychological, and social intercourse challenges faced by ALS patients, the understanding of how these challenges manifest and interact in the Chinese context is limited. This study explores the multifaceted challenges experienced by ALS patients in China by using ecological systems theory to examine the interactions among micro, meso, and macro-level factors.

# Methods

A qualitative study was conducted with 18 ALS patients in China. Data were collected through semi-structured interviews, and the analysis was guided by grounded theory, focusing on open, axial, and selective coding. An ecological systems theory framework was employed to analyze the interaction of these challenges at various levels.

# Results

The study found that ALS patients face six major challenges: physical challenges and psychological challenges (at the micro level), family challenges and social intercourse challenges (at the meso level), and information challenges and healthcare access challenges (at the macro level). Furthermore, a strong link was found between physical and psychological challenges. Meanwhile, meso-level challenges exacerbated psychological distress, while micro-level challenges further intensified difficulties at the meso level. Additionally, macro-level challenges were found to have a structural impact on both micro and meso-level challenges. Finally, as ALS progresses, the primary challenges faced by patients also evolve.

# Discussion

The complex, multidimensional nature of ALS patients' struggles in China is highlighted, with ecological systems theory providing a comprehensive understanding of how these challenges interact across different levels. Practical implications emphasize the need for comprehensive care strategies that integrate psychological support, family respite care, and improved healthcare policies. Furthermore, there is a call for more systemic support for ALS patients, including better insurance coverage and increased public awareness.

# Conclusion

This study identifies the multifaceted challenges that ALS patients face in China, highlighting the interconnections across the physical, psychological, social, and healthcare domains. It emphasizes the need for a holistic approach to care, addressing these challenges at multiple levels to improve patient outcomes.

# 1. INTRODUCTION

Amyotrophic lateral sclerosis (ALS) is a fatal, progressive neurodegenerative disease that affects the upper and lower motor neurons in the spinal cord, brainstem, and motor cortex(Pasinelli & Brown, 2006). This results in gradual muscle wasting and weakness, which initially affects the limbs, bulbar muscles, and respiratory muscles, leading to loss of speech, swallowing difficulties, respiratory failure, and ultimately, complete paralysis(Robberecht & Philips, 2013). The incidence of ALS in Western countries is 2–3 cases per 100,000 individuals, with a lifetime risk of 1 in 400, and most patients die from respiratory failure within three years of symptom onset(Hardiman et al., 2011). Despite numerous studies, the pathogenesis of ALS remains poorly understood, complicating both diagnosis and treatment. Consequently, current treatment approaches focus primarily on improving and maintaining patients' quality of life (QoL)(Prell et al., 2019).

As one of the world's most populous developing nations, China faces unique challenges in addressing rare diseases such as ALS. According to a nationwide population-based study encompassing approximately 430 million people, the crude incidence rate of ALS in mainland China is 1.65 per 100,000 person-years, with a crude prevalence rate of 2.91 per 100,000 person-years(Xu et al., 2020). These figures suggest that the incidence and prevalence of ALS in China are lower than those in developed countries. However, the number of ALS patients in China is increasing, and current patients face immense pressure due to the increasing burden of the disease(Yuan et al., 2021). Therefore, it is imperative to study the current QoL status of ALS patients in China and explore effective strategies to improve their QoL.

Existing studies on the challenges faced by ALS patients serve as foundational research for enhancing QoL. Numerous studies have identified key challenges that impact the overall QoL of ALS patients. These include physical deterioration, such as muscle weakness and respiratory failure(Pagnini et al., 2015), which significantly reduces independence and daily functioning; mental health issues, such as depression(Körner et al., 2015), anxiety(Siciliano et al., 2019), and certain personality traits(Krampe et al., 2008); and social intercourse challenges, including social isolation(Sandstedt et al., 2016), and the burden of caregiving on families(Foley et al., 2016). These challenges indicate that QoL is influenced not only by physical strength and function but also by psychological and social factors(Simmons et al., 2000), underscoring the need for comprehensive care approaches that address multiple aspects of patients' well-being.

While existing research highlights the numerous challenges faced by ALS patients and emphasizes the importance of psychological, mental, and social support factors(Chio, 2004), there remains a significant

gap in the development of a comprehensive theoretical framework to explain the complexity of these challenges. Ecological systems theory provides a robust framework for addressing this gap by offering a multilevel perspective on patients' experience(Bronfenbrenner, 1981). This framework recognizes that patients' experiences and the challenges they encounter are shaped by factors operating at the micro, meso, and macro levels. At the micro level, individual factors such as physical health, psychological resilience, and coping mechanisms play critical roles in shaping patients' overall quality of life(van Groenestijn et al., 2016). At the meso level, the ecological systems theory emphasizes the importance of the patient's immediate social environment—family members, caregivers, and friends. These interactions can either alleviate or exacerbate a patient's suffering(Ilse et al., 2015). At the macro level, the ecological framework helps to analyze how systemic factors, such as healthcare access and sociopolitical conditions, influence ALS patients' quality of life on a larger scale(Jennum et al., 2013).

More importantly, ecological systems theory highlights the interactions between systems, such as how perceiving a family burden may contribute to psychological stress for the patient(Gentili et al., 2023), and receiving healthcare professional services can enhance individual well-being(Foley et al., 2007). By integrating these multilevel factors, ecological systems theory offers a comprehensive lens through which to understand and address the complex challenges faced by ALS patients, ultimately guiding more comprehensive and effective interventions and support strategies, such as improving individualized care plans, enhancing social support networks, and advocating for policy changes.

In China, research on ALS is increasing, but little attention has been given to understanding how patients experience the disease(Liu et al., 2018). Although some studies have focused on the QoL of ALS patients, they often examine isolated aspects rather than adopting a comprehensive, systematic approach. Moreover, qualitative research on this topic remains limited, despite it being recommended as the most appropriate method for assessing the psychological concerns of ALS patients(Thomas et al., 2018). Therefore, there is an urgent need for qualitative research from the perspective of ecological systems theory to explore the main challenges faced by ALS patients in China.

The primary objectives of this study are twofold: 1) What are the main challenges faced by ALS patients in China? and 2) How do these challenges interact and collectively impact the patients? Based on the analysis of the specific challenges faced by ALS patients in China and the exploration of the interactions among these challenges, this study aims to provide theoretical support for intervention strategies to improve patients' quality of life and overall well-being.

# 2. METHODS

## 2.1. Study Design

This study employed a qualitative exploratory design using grounded theory to explore the multidimensional challenges faced by patients with ALS. Grounded theory is well suited for exploratory research(Robrecht, 1995), as it allows for the generation of rich, theory-driven insights directly from

participants, capturing the complexities of their lived experiences. While some scholars argue that grounded theory should not be guided by preexisting theoretical frameworks, Goldkuhl Goran contend that integrating grounded theory with existing theories can enhance analytical depth and theoretical rigor(Goldkuhl & Cronholm, 2010). In this study, ecological systems theory served as a foundational framework for understanding the dilemmas arising from the dynamic interactions between individuals and their environments, thereby guiding the data analysis process.

This research was conducted by a multidisciplinary team, including professors specializing in neurology and social work who provided expert guidance, alongside psychiatrists, social workers, and hospital administrators, with four male and five female researchers. Reflexivity was maintained throughout the study, with all the researchers remaining critically aware of their professional backgrounds and potential biases. All the interviews were conducted as one-on-one personal interviews, ensuring that the interviewers had no prior relationships with the participants. To maintain rigor and consistency, all the interviewers underwent specialized training before data collection.

Our study was reported in strict accordance with the COREQ checklist, which helped ensure transparent, comprehensive, and systematic reporting of key methodological domains, including research team characteristics, study design, participant recruitment, data collection procedures, data analysis, and presentation of findings. The completed checklist available in Additional File 1.

## 2.2. Participants

A purposive sampling strategy was employed to recruit ALS patients who attended the specialist outpatient clinic at the Department of Neurology at Huashan Hospital, Fudan University, one of the top neurology departments in China, between June and September 2023. Following initial screening by neurology specialists during their daily outpatient consultations, potential participants were referred to social workers, who then conducted further eligibility assessments based on the study criteria and extended invitations for enrollment, ensuring informed consent and voluntary participation. The participants were required to meet the following inclusion criteria:1. ≥18 years old; 2. Clinically diagnosed with ALS;3. Able to communicate verbally and provide informed responses; 4. Provided informed consent after receiving a full explanation of the study. Patients were excluded if they:1. Lacked decision-making capacity; 2. Had a diagnosed psychiatric disorder that could interfere with participation.

A total of 18 patients (10 men and 8 women) were included, with a mean age of 57.7 years. Their occupations varied, including civil servants, farmers, and laborers, and they were from eight different provinces across China. The participants were covered by different types of medical insurance, including urban employee insurance, rural cooperative medical insurance, and self-pay. The detailed demographic characteristics are presented in Table 1.

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Insert Table 1

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## 2.3. Data Collection

Data were collected through in-depth, semi-structured interviews with ALS patients. In cases where patients had difficulty articulating their experiences, family members were invited to provide additional contextual insights. The interview guide was developed through a literature review and expert consultation, followed by pilot testing with three ALS patients to refine the questions. The final interview guide consisted of five thematic domains, covering:1. Disease experience;2. Daily living conditions;3. Family support;4. Access to information and healthcare services;5. Other relevant concerns. The interview guide is presented in Table 2.

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Insert Table 2

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The interviews were conducted in a quiet, undisturbed staff lounge at the hospital immediately after each patient's outpatient consultation, ensuring a distraction-free environment. The interviews were conducted by trained professional social workers and administrative staff. Each interview was audio-recorded and lasted approximately 60 minutes. Upon completion, all the recordings were transcribed verbatim. Data were managed and analyzed via Nvivo 11.0 software.

## 2.4. Data Analysis

The data were analyzed via grounded theory methods following the approach outlined by Anselm Strauss and Juliet Corbin(Corbin & Strauss, 2008). The analysis process consisted of three sequential coding stages:1.Open coding: Researchers conducted line-by-line coding of the transcripts, identifying initial concepts and subcategories.2.Axial coding: Concepts were further refined and grouped into core categories that captured key themes emerging from the data.3.Selective coding: A theoretical framework was developed to illustrate the interrelationships between core categories and the overarching themes of ALS patients' challenges. To ensure data saturation, an additional five participants were interviewed after the construction of the theoretical model on dilemmas. No new categories emerged, confirming that theoretical saturation had been achieved.

## 2.5. Ethics Approval and Consent to Participate

Ethical approval for this study was passed by the Ethics Committee of Huashan Hospital, Fudan University. Ethics Approval Number: 2025 Xueshen (0345), Huashan Hospital, Shanghai, China. All methods were performed in accordance with the World Medical Association Declaration of Helsinki Ethical Principles for Medical Research Involving Human Subjects and relevant local regulations. All participants provided written informed consent after receiving both verbal and written explanations regarding the study objectives, voluntary participation, and confidentiality assurances.

# 3. RESULTS

During open coding, interview data from 18 ALS patients were manually analyzed, yielding 149 initial codes. Through comparison and integration, these codes were consolidated into 42 distinct concepts (Table 3) and further categorized into 21 subcategories (Table 4). Axial coding refined the subcategories into six main categories (Table 5).

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Insert Table 3

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Using the ecological systems perspective, the main categories were classified into three levels: micro (physiological and psychological challenges), meso (family and social intercourse challenges), and macro (informational and healthcare access challenges).

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Insert Table 5

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# 3.1. Micro-Level Challenges

At the micro level, ALS patients face intertwined physiological and psychological challenges that exacerbate their overall burden, creating a vicious cycle of declining physical function and worsening mental health.

## 3.1.1. Physiological Challenges

The most immediate and noticeable challenge for ALS patients is progressive physical deterioration. Muscle weakness, particularly in the legs and hands, is among the earliest symptoms: *"I first noticed weakness in my legs" (A1)*; *"At first, it was just my hands that lacked strength" (A8)*. Some patients also experience muscle atrophy, further impairing their mobility: *"One of my hands seems to be shrinking" (A17)*. As muscle function declines, patients experience increasing difficulty walking, often requiring mobility aids such as canes or wheelchairs due to fatigue and frequent falls. In addition to motor impairment, many patients report pain, swelling, and muscle twitching, compounding their physical discomfort.

Sleep disturbances are also prevalent, with patients experiencing insomnia, frequent nighttime awakenings, and reduced sleep duration. Some rely on medication to improve sleep quality: *"I have trouble sleeping and have to take melatonin regularly"* (A12).

As the disease progresses, respiratory complications emerge, including reduced lung function, shortness of breath, and difficulty clearing secretions, leading some patients to require ventilatory support. Additionally, daily activities such as bathing, eating, and even tasting food become increasingly difficult, further limiting independence.

### 3.1.2. Psychological Challenges

In addition to physical decline, ALS patients experience significant psychological distress, particularly as they confront the incurable nature of their disease. Many reported experiencing anxiety, fear, and uncertainty about disease progression: *"I read an article about ALS, and my symptoms matched exactly. From that moment on, I started to feel extremely anxious" (A11)*. Some patients avoid discussing their illness or develop rigid behavioral routines, such as strictly adhering to medication schedules. In more severe cases, depression, hopelessness, and even suicidal thoughts arise. As the disease progresses, speech difficulties further isolate patients, worsening their emotional distress.

Patients also express guilt and distress over the burden placed on their families, intensifying their psychological struggles: *"I'm anxious because I will eventually lose all ability to care for myself. My family members are already busy with work, and I don't want to burden them further" (A9)*.

## 3.2. Meso-Level Challenges

At the meso level, the families of ALS patients serve as their primary support system but also experience substantial caregiving burdens. Meanwhile, patients face increasing social isolation, further limiting their participation in community life.

### 3.2.1 Family Challenges

As caregiving responsibilities intensify, family members' daily routines and social lives are significantly disrupted. Some caregivers are forced to retire early to provide full-time care: *"I had to retire early because someone needed to take care of my spouse" (A3)*. Others report reduced social interactions due to caregiving demands: *"My family used to go out together often, but now we rarely do" (A9)*.Patients' children, particularly only children, bear a heightened psychological and financial burden, struggling to balance work and caregiving responsibilities: *"Being an only child makes this even harder—I feel immense pressure" (A1)*; *"We all have jobs, so caregiving is a huge challenge" (A15)*.

Tensions within families also arise due to disagreements over care arrangements, leading to emotional strain: *"My family argues over how much care I need, and no one can agree on the best approach" (A4)*. Differences in illness perceptions further exacerbate conflicts: *"My wife insists this isn't a big deal and believes it can be cured, but I know the reality" (A12)*.Additionally, concerns about the future well-being of their children weigh heavily on some patients, especially with respect to the potential stigma their children might face due to their parent's condition*: "I worry that my child might struggle to find a partner because of my illness" (A16)*.

### 3.2.2. Social intercourse challenges

ALS patients experience progressive social withdrawal, as their diminished mobility and physical limitations hinder their participation in social activities: *"I used to be very social, but now I barely go out" (A4)*.

Some patients avoid leaving home due to fatigue and inconvenience, which also affects their families: *"Going out is exhausting—not just for me, but for my family too" (A9)*. This reluctance to engage socially leads to further isolation and emotional distress: *"I have lost interest in shopping or even buying clothes. Walking is already a struggle, so why bother?" (A13)*.

## 3.3. Macro-Level Challenges

At the macro level, ALS patients face systemic barriers in accessing reliable information and medical services, significantly impacting their ability to manage the disease effectively.

### 3.3.1. Information Challenges

Patients frequently report limited knowledge about ALS before diagnosis: *"I had heard of ALS before, but I didn't truly understand what it meant" (A4)*. Even after diagnosis, many struggle with incomplete or unreliable information: *"I know I have ALS, but I don't fully understand the implications" (A16)*.

Many rely on online sources for information, but the accuracy and reliability of such sources vary, leading to misconceptions and uncertainty: *"I primarily use search engines and medical forums to look up*

*information" (A1)*. Furthermore, a lack of awareness about medical reimbursement policies results in patients missing out on financial support: *"I had to pay everything out-of-pocket because I wasn't aware that certain costs could be reimbursed" (A1)*.

### 3.3.2. Healthcare Access Challenges

Navigating the healthcare system presents significant obstacles for ALS patients. Delays in diagnosis and misdiagnosis are common, leading to prolonged uncertainty: *"At first, doctors thought it was muscle weakness. It took two years to get an accurate diagnosis" (A1)*.

Financial burdens are another major concern, with high treatment and medication costs placing severe strain on families: *"The medications are expensive, and we have to pay for everything ourselves" (A10)*. Complicated disability assessment procedures create further barriers to obtaining necessary support: *"Getting a disability assessment is frustratingly difficult and time-consuming" (A14)*. Additionally, limited drug availability in local hospitals further complicates treatment access: *"Even major hospitals near me don't have the necessary medications" (A14)*.

Patients also struggle with appointment scheduling and long wait times, particularly for specialized care: *"I tried to book an appointment, but after a month and a half, I still couldn't get one" (A9)*. Those seeking treatment outside their home province face additional logistical and financial burdens, making healthcare access even more challenging: *"Traveling for medical care is the hardest part" (A3)*. Finally, patients express a strong need for psychological support, yet such resources remain scarce: *"Psychological counseling is just as important as medical treatment, but it's hard to find" (A1)*.

## 3.4. Interaction of Micro, Meso, and Macro-Level Challenges

Based on the assumption of intersystem interaction in ecological systems theory, this study further analyzes the relationships among the challenges faced by ALS patients, revealing that challenges at the micro, meso, and macro levels are interwoven and mutually influential.

### 3.4.1 The Strong Links Between Physical and Psychological Challenges

There is a strong connection between the physical and psychological states of ALS patients. Physical discomfort such as muscle pain and spasms not only causes bodily suffering but also imposes a significant psychological burden. Physical deterioration, such as the inability to express oneself freely and the increasing reliance on others for daily activities, directly impacts the psychological state of the patient, intensifying feelings of anxiety and fear: *"My mental state actually changes with my body" (A2)*. Changes in psychological status can also affect a patient's physical condition; negative emotions may

exacerbate physical symptoms, and a patient's cognitive beliefs and attitudes can influence their treatment adherence and effectiveness: *"Negative emotions have a huge impact on my body, for example, when I feel better emotionally one day, I immediately feel different physically compared to when I'm feeling down" (A1)*. Thus, the discomfort from physical symptoms triggers psychological distress, which in turn worsens the physical symptoms, creating a vicious cycle.

## 3.4.2 The Close Interconnection of Micro and Meso-Level Challenges

In the interaction between the micro and meso systems, micro-level challenges directly reflected in the patient's family and social life. Physical and psychological difficulties lead to greater dependence on family members for care and a reduction in social interactions, which in turn causes changes in the family's lifestyle and limits social activities. This intensifies both the economic and emotional burdens on the family. Additionally, changes in family dynamics and social interactions feed back into the patient's physical and psychological state, creating a micro-meso feedback loop.

## 3.4.3. The Structural Impact of Macro-Level Challenges on Micro and Meso-Level Challenges

Macro-level challenges such as difficulties in accessing healthcare and obtaining reliable information contribute to further deterioration of micro-level challenges, intensifying both physical discomfort and psychological stress. Inadequate medical resources and support make it more difficult for families to care for ALS patients, putting additional strain on family life, and potentially leading to internal family conflicts. Moreover, the lack of social awareness about ALS and the absence of supportive policies for ALS patients also expose patients and their families to social isolation and exclusion.

## 3.4.4. Temporal Analysis of Challenges Across Disease Progression

As ALS progresses, the main challenges faced by patients evolve, reflecting a temporal system shift. Initially, ALS patients experience physical difficulties, such as muscle weakness and fatigue. However, over time, psychological issues such as depression and anxiety intensify as their independence decreases. Early psychological distress often stems from fear of the future, but as the disease progresses, these emotional struggles are exacerbated not only by physical deterioration but also by increasing family and social intercourse challenges. The caregiving role within the family becomes more demanding, leading to heightened emotional and financial strain, while the patient's growing dependency intensifies social isolation and may contribute to family conflicts. Additionally, macro-level factors, including healthcare accessibility and sociopolitical conditions, influence patients' healthcare-seeking experience. Inadequate medical care, high treatment costs, and insufficient government support continue to exacerbate both the physical and emotional tolls. Furthermore, the lack of societal

awareness and comprehensive disability policies amplifies social isolation and stigma, particularly as patients become increasingly dependent on others.

# 4. DISCUSSION

## 4.1. The Urgent Need to Focus on Multidimensional Challenges

This study aimed to explore the multiple challenges faced by ALS patients in China, with a specific focus on the interaction between micro, meso, and macro-level challenges. The findings reveal that ALS patients in China face a complex array of interconnected challenges, categorized into physiological and psychological challenges at the micro level, family and social intercourse challenges at the meso level, and informational and healthcare access challenges at the macro level. The study also revealed that the interactions between these challenges amplify the patients' overall burden, creating a dynamic and multifaceted experience that worsens their quality of life (QoL). The study's findings emphasize the need for a comprehensive approach to ALS care that addresses these various challenges.

The findings of this study align with those of existing studies on ALS, particularly with respect to the physical and psychological challenges that patients face. Previous studies have consistently emphasized that ALS is not only a disease of physical degeneration but also a condition that strongly affects mental health(Vázquez Medrano et al., 2020). This study supports these findings by identifying the strong relationship between physical and psychological challenges in ALS patients in China. Furthermore, the burden placed on families, as highlighted in our study, aligns with previous research that emphasized how caregiving responsibilities can lead to emotional and financial strain on family members (Geng et al., 2017). Similarly, our finding that social isolation intensifies as the disease progresses is consistent with prior studies, which have noted the increasing social withdrawal experienced by ALS patients(Van Groenestijn et al., 2017).

Importantly, our study highlights the impact of macro-level factors in the Chinese context. One significant contribution is the identification of informational challenges as a distinct category. Many Chinese ALS patients in our sample expressed feelings of confusion and a lack of reliable information regarding their illness and available services. This may reflect disparities in health literacy and patient education infrastructure between China and some high-income countries. Furthermore, healthcare access challenges emerged as a prominent macro-level issue in our study. While ALS care is difficult everywhere, Chinese patients uniquely reported bureaucratic obstacles, limited availability of specialists outside major cities, and insufficient insurance coverage for expensive treatments or assistive devices. There is limited prior research explicitly examining these macro-level barriers in China, making our findings a valuable addition to the existing literature. They resonate with broader observations regarding rare diseases in developing healthcare systems: without robust insurance and support systems, families often bear catastrophic healthcare expenses and navigate care largely on their own.

## 4.2. Multidimensional Interventions for Multidimensional Challenges

This study offers valuable insights into the challenges faced by ALS patients in China through the application of ecological systems theory, which provides a comprehensive framework for examining the interdependencies between physical, psychological, social, and healthcare-related challenges. The findings emphasize that while attention must be given to the patient's individual physical and mental health, it is equally crucial to consider the impact of the patient's environment and broader societal factors. This approach enhances our understanding of ALS and emphasizes that addressing both individual and environmental factors is essential for improving patient care and outcomes.

Based on the findings of this study, a comprehensive strategy is essential to effectively address the multiple challenges faced by ALS patients at the micro, meso, and macro levels. At the micro level, strengthening multidisciplinary team collaboration is crucial for providing holistic and personalized treatment and care that addresses both the physical and psychological needs of ALS patients.(Hardy et al., 2022) Additionally, the introduction of respite care services for families will alleviate the long-term caregiving burden(Wu et al., 2022), offering relief to family caregivers. At the meso level, a focus should be placed on building strong social support networks for ALS patients, such as mutual aid groups both online and offline(Kazmer et al., 2014), and promoting the integration of ALS patients into their communities. The involvement of social charitable organizations is also critical in providing financial assistance and daily living resources to ALS patients' families. At the macro level, improving cooperation between treatment institutions, establishing information-sharing mechanisms, and increasing investment in ALS drug research are essential. Additionally, the government should expand healthcare insurance to cover ALS-related treatments and rehabilitation, reducing the financial burden on patients and their families.

## 4.3. Strengths and Limitations

This study possesses several key strengths that enhance its value and significance. Firstly, by employing ecological systems theory, the research provides a comprehensive, multi-level perspective on the challenges faced by ALS patients in China. This theoretical framework facilitates a nuanced understanding of how physical, psychological, familial, social, and healthcare-related challenges are interconnected, offering valuable insights that extend beyond isolated symptoms or issues. Secondly, the study employs a qualitative research design, which is particularly well-suited for exploring the lived experiences of ALS patients. By conducting in-depth interviews with 18 ALS patients, the research yields rich, detailed data that captures the complexity of their struggles. This approach facilitates a deeper exploration of the nuances of the disease's impact on patients' daily lives, providing insights that quantitative methods may overlook. Another strength of this study is its focus on the Chinese context, where research on the experiences of ALS patients has been limited. The study provides valuable insights into the unique challenges faced by ALS patients in China, particularly regarding healthcare

access and societal awareness, which may differ from the challenges encountered by patients in Western countries. This context-specific understanding is essential for developing tailored interventions and policy recommendations aimed at improving the quality of life for ALS patients in China.

While this study offers valuable insights, there are several limitations that must be acknowledged. First, the study relied on a small, purposive sample of 18 participants, which may not fully represent the diversity of ALS patients across China. Future studies should include a larger, more diverse sample to ensure that the findings are generalizable across different demographics, including various regions and socioeconomic statuses. Additionally, as the study is qualitative, the findings are based on subjective reports from patients and caregivers, which may be influenced by individual perceptions and biases. Longitudinal studies that track ALS patients over time would provide more in-depth insights into how challenges evolve throughout the course of the disease. Finally, while this study emphasizes the need for integrated care, the scope of intervention strategies suggested is broad. Future research should focus on specific intervention models that target both micro and macro-level challenges, particularly around healthcare access and family caregiving, to assess their efficacy in improving patient wellbeing.

# 5. CONCLUSION

This study provides a comprehensive understanding of the multifaceted challenges faced by ALS patients in China, highlighting the interplay between physical, psychological, social, and healthcare-related factors. By applying ecological systems theory, the research highlights the interconnectedness of these challenges and emphasizes the need for multi-level interventions. At the micro level, personalized care addressing both physical and psychological needs is essential, while at the meso and macro levels, improving family support systems and healthcare access are key to enhancing the overall quality of life for ALS patients. The findings contribute valuable insights to the existing literature on ALS care and offer practical recommendations for policymakers, healthcare providers, and researchers aiming to improve ALS patient outcomes in China. Future research should explore the long-term effects of these challenges and the efficacy of targeted interventions to address the evolving needs of ALS patients.

# Abbreviations

ALS: Amyotrophic Lateral Sclerosis; QoL: Quality of Life; COREQ: Consolidated Criteria for Reporting Qualitative Research;

# Declarations

**Ethics approval and consent to participate:** Ethical approval for this study was passed by the Ethics Committee of Huashan Hospital, Fudan University. Ethics Approval Number: 2025 Xueshen (0345),

Huashan Hospital, Shanghai, China. All participants provided written informed consent after receiving both verbal and written explanations regarding the study objectives, voluntary participation, and confidentiality assurances.

**Author Contributions Statement**:Pengfei Yan: Conceptualized the project and designed the interview guide; performed data coding and analysis. Zhihao Li: Drafted the initial manuscript. Jianing Zhao: Conducted participant interviews and collected data. Xiangjun Chen: Recruited patients and provided medical support. Yi Lin: Conducted participant interviews and coordinated the project. Yanfei Li: Conducted participant interviews and coordinated the project. Yuxiang Gu: Managed project resources and revised the final manuscript.Zixiao Liu: Designed project details, revised the initial manuscript, and optimized content.

**Availability of data and materials:** The datasets generated and analyzed during this study are not publicly available due to privacy restrictions but are available from the corresponding author upon reasonable request.

**Consent for publication:** We have obtained the participant's consent to publish individual patient data.

**Competing interests:** The authors confirm that they have no conflicts of interest.

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# Tables

Table 1: General Information of Participants (n=18)

| No. | Gender | Age | Occupation (Former) | Residence | Health Insurance Type |
|---|---|---|---|---|---|
| A1 | Male | 60 | Civil servant | Anhui | Employee insurance |
| A2 | Male | 75 | Farmer | Zhejiang | New rural cooperative insurance |
| A3 | Male | 61 | Civil servant | Jiangsu | Employee insurance |
| A4 | Male | 71 | Bus driver | Nanjing | Employee insurance |
| A5 | Female | 36 | Office clerk | Shanghai | Employee insurance |
| A6 | Male | 63 | Security guard | Shanghai | Employee insurance |
| A7 | Male | 49 | Farmer | Zhejiang | Self-paid |
| A8 | Female | 50 | Driver | Shanghai | Urban insurance |
| A9 | Female | 55 | Salesperson | Guizhou | Employee insurance |
| A10 | Female | 71 | Farmer | Jiangsu | New rural cooperative insurance |
| A11 | Male | 41 | Teacher | Zhejiang | Employee insurance |
| A12 | Female | 39 | Factory worker | Anhui | Employee insurance |
| A13 | Female | 60 | Accountant | Shanghai | Urban insurance |
| A14 | Male | 71 | Farmer | Hunan | New rural cooperative insurance |
| A15 | Male | 74 | Factory worker | Jiangsu | Self-paid |
| A16 | Male | 45 | Businessman | Fujian | Employee insurance |
| A17 | Female | 58 | Farmer | Jiangxi | New rural cooperative insurance |
| A18 | Female | 59 | Full-time homemaker | Jiangsu | Urban insurance |

Table 2: Semi-structured Interview Guide

| Set | Principal questions |
|---|---|
| Disease experience | Since being diagnosed with ALS, what physical changes have you experienced?<br><br>How have these physical challenges impacted your independence and quality of life?<br><br>Do you experience anxiety, depression, or other psychological distress? |
| Daily living conditions | Are there specific tasks you can no longer do on your own?<br><br>Have you received any psychological support?<br><br>Can you describe any specific challenges you face in your daily conditions |
| Family support and social intercourse | how has your family adapted to your illness?<br><br>What impact has this had on both you and your family members?<br><br>How has your interaction with friends and family changed? |
| Access to information and healthcare services | What sources of information about ALS have you relied on?<br><br>Have you encountered any challenges in accessing healthcare services or specialists for ALS treatment?<br><br>How satisfied are you with the healthcare services and support you have received for ALS? |
| Other relevant concerns | How has your experience with ALS influenced your perspective on the future<br><br>What are the most pressing challenges you anticipate as you move forward? |

Table 3: Examples of the Formation Process from Initial Codes to Distinct Concepts

| Original Statement | Initial Concept |
| --- | --- |
| (1) "It was in October 2021, when I first noticed weakness in my legs," (2) "I could already feel weakness in my legs when walking," (3) "I felt weak all over, just generally weak." | Weakness in limbs and body |
| (1) "Sometimes I have trouble falling asleep," (2) "I have poor sleep, always take medication, like melatonin." | Difficulty falling asleep |
| (1) "I used to socialize a lot, now it's less frequent, once every couple of weeks," (2) "I can't go out to eat anymore, it's just not possible," (3) "We used to be quite active before I got sick, but in the past two years, I haven't moved much." | Reduced social activity |
| (1) "I've been trying to get an appointment for a month and a half, but still couldn't," (2) "It's exhausting to book an appointment, especially if you need an extra slot at night, it's almost impossible," (3) "Couldn't book online, I had to ask a relative for help." | Inconvenient appointment scheduling |
| (1) "I mainly rely on Search engine for information about the disease," (2) "I also check on my phone," (3) "I just search on Baidu myself, even TikTok has information." | Reliance on the internet for disease knowledge |

Table 4: Concepts and Categories Formed by Open Coding

| No. | Subcategory | Initial Concept |
|---|---|---|
| p1 | Decline in physical function | Weakness in limbs and body, difficulty walking |
| p2 | Sleep disorders | Difficulty falling asleep, poor sleep quality |
| p3 | Breathing issues | Reduced lung function, difficulty breathing |
| p4 | Limited ability for daily activities | Difficulty bathing, difficulty eating, loss of taste |
| p5 | Pain and discomfort | Muscle twitching, lower limb swelling, pain, leg cramps |
| p6 | Poor mental state | Anxiety and fear, irrational emotions, withdrawal, low self-esteem, suicidal tendencies |
| p7 | Limited speech ability | Slow and difficult speech |
| p8 | High interrelation between psychological and physiological states | Psychological state changes with physical sensations, physical state affected by psychological state |
| p9 | Limited social interactions | Reduced social activities, inability to go out |
| p10 | Decreased willingness for social interaction | Unwillingness to go out |
| p11 | Change in family members' lifestyle | Living together, early retirement, limited social activities of family members |
| p12 | Increased family pressure | Increased pressure on children, pressure of raising children |
| p13 | Tension in family relationships | Conflicts in disease perception, disagreements in caregiving approaches |
| p14 | Unclear reimbursement policies | Insufficient understanding of reimbursement policies |
| p15 | Insufficient understanding of the disease | Lack of knowledge before diagnosis, insufficient understanding after diagnosis |
| p16 | Doubts about the accuracy and reliability of information | Dependence on the internet for disease knowledge |

Table 4 Continued: Concepts and Categories Formed by Open Coding

| No. | Subcategory | Initial Concept |
|---|---|---|
| p17 | Medical cost issues | High medication costs, limited understanding of reimbursement policies for out-of-town medical expenses |
| p18 | Issues with healthcare accessibility | Inconvenient appointment scheduling, difficulties for out-of-town patients seeking treatment |
| p19 | Difficulty in diagnosis | Long diagnosis period |
| p20 | Unclear treatment plan | Uncertainty in treatment options from doctors |
| p21 | Lack of psychological services | Need for psychological counseling |

Table 5: Main Categories Formed by Principal Axis Coding

| No. | Main Category | Subcategory |
|---|---|---|
| C1 | Physiological Challenges | p1 Decline in physical function, p2 Sleep disorders, p3 Breathing issues, p4 Limited ability for daily activities, p5 Pain and discomfort |
| C2 | Psychological Challenges | p6 Poor mental state, p7 Limited speech ability, p8 High interrelation between psychological and physiological states |
| C3 | Social intercourse challenges | p9 Limited social interactions, p10 Decreased willingness for social interaction |
| C4 | Family Challenges | p11 Change in family members' lifestyle, p12 Increased family pressure, p13 Tension in family relationships |
| C5 | Information Challenges | p14 Unclear reimbursement policies, p15 Insufficient understanding of the disease, p16 Doubts about the accuracy and reliability of information |
| C6 | Healthcare Access Challenges | p17 Medical cost issues, p18 Healthcare accessibility issues, p19 Difficulty in diagnosis, p20 Unclear treatment plan, p21 Lack of psychological services |

## Supplementary Files

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- AdditionalFile1ConsolidatedCriteriaforReportingQualitativeResearchChecklist.docx