RESEARCH



Actual needs of patients with amyotrophic lateral sclerosis: a qualitative study from Wuhan, China

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Abstract

Background Amyotrophic Lateral Sclerosis (ALS) is a progressive and fatal neurodegenerative disorder that significantly impacts individuals and families. Previous research on ALS has predominantly focused on its pathophysiology, genetic factors, and potential therapeutic interventions. While these aspects are essential for understanding and treating the disease, there has been a growing recognition of the importance of studying patients' actual needs. Understanding these needs is vital for developing patient-centered care models that can enhance the well-being of ALS patients. However, existing studies on patients' needs are often limited in scope. Many are conducted in Western countries, and the results may not be directly applicable to patients in other cultural and socioeconomic contexts. China, with its large population and diverse cultural, economic, and healthcare landscapes, presents a unique setting for studying ALS patients' needs. At the same time, traditional Chinese medicine (TCM) practices are deeply ingrained in their healthcare system and may affect the way people with ALS seek treatment and manage their condition. Therefore, these differences may lead to differences in the actual needs of ALS patients in China. In conclusion, this qualitative study on the actual needs of ALS patients in China aims to bridge the gap in the existing research. By exploring these needs, it can provide valuable insights for healthcare providers, policymakers, and researchers, ultimately contributing to the improvement of care and quality of life for ALS patients in China.

Method We carried out a qualitative study using an empirical phenomenological approach. Individual in-depth interviews were performed among 22 people with ALS from the motor neuron disease rehabilitation center of a tertiary Chinese medicine hospital in China, and the interview content was analyzed qualitatively. Interview recordings were converted to text content by NVivo 11.0 software and analyzed using Colaizzi's phenomenological method.

Result Three main themes were identified in this study: (1) Demand for healthcare services, (2) Emotional requirements, (3) Functional requirements. In addition, 8 sub-themes were extracted as the actual needs of ALS patients.

Conclusion This study is based on the real experience of ALS patients after diagnosis, and a deep understanding of these experiences can explore the actual needs of patients from many aspects and give reasonable advice and help. Given the particularity of the disease and the uncertainty of treatment, patients will have practical needs

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for relevant medical support, emotional requirements, physical functions, and other aspects during the period of illness, and the corresponding support is an effective measure to reduce the burden on patients.

Keywords Amyotrophic lateral sclerosis, Actual needs, Qualitative study, Supportive needs

Introduction

Amyotrophic Lateral Sclerosis (ALS), a fatal neurodegenerative disease [1], has been called "the fifth most fatal disease in the world" [2]. Previously, the prevalence of ALS was estimated to be 1-11.2/100,000 population [3, 4]. In the United States alone, there are 100 cases of ALS per 40,000 people [5], and there are about 5,000 new cases of ALS per year [6]. However, due to the large population base in China, the number of patients cannot be ignored [7]. According to statistical data, the annual incidence of ALS is 1.24/100,000 in China [7, 8], and more than 90% of ALS patients are sporadic diseases without a clear family history [9, 10], which are rare diseases. The main clinical manifestations are muscle weakness [9], muscle atrophy, drinking bucking, dysphagia, respiratory dysfunction, etc. [11], eventually resulting in voice, swallowing disorders, and even respiratory failure. Patients are paralyzed or even die within 2-5 years after onset [6, 12, 13]. In addition to serious physical burdens and psychological problems caused by the disease, patients are also faced with the current situation that their actual needs cannot be met [14-19]. Although ALS has been extensively studied in clinical practice, there is still a limited understanding of the actual needs of patients.

Throughout the course of the disease, patients endure numerous daily life challenges in addition to the physical illness. These include difficulties such as being unable to eat, dress, and bathe independently [20-23]. Furthermore, they face issues with ambiguity in treatment [24, 25], emotional requirements [26-28], and a lack of support for various functional needs [29, 30]. ALS patients experience more real-world problems than other patients and may experience varying degrees of financial difficulties [31, 32], social isolation [33, 34], and other practical problems even after treatment and discharge from the hospital. This highlights the need to address practical difficulties without losing sight of the practical needs of this patient population. Through an in-depth analysis of the actual needs of ALS patients, this study could help to improve the medical and support services, improve the quality of life of ALS patients, promote the improvement of social-related policies, and meet their expectations for future treatment.

The first practical step in achieving the above goals is to clearly understand patients' actual needs. By explaining and understanding the actual needs of ALS patients throughout the disease, one can very effectively extend what ALS patients need by gaining insight into the current situation. Therefore, this study aimed to investigate the actual needs of ALS patients.

Method

Study design

A phenomenological qualitative research design involving in-depth interviews was chosen. Colaizzi's data analysis method was used to inductively determine themes and formulate meanings [35], which increased the results' reliability and dependability. This study used the Consolidated Criteria for Reporting Qualitative Research (COREQ) as a guide for writing [36].

Participant

This study recruited those diagnosed by Gold Coast Criteria with ALS and treated in the motor neuron disease rehabilitation center of a tertiary Chinese medicine hospital in Wuhan, China, from April to May 2023 [37]. Inclusion criteria: (1) Patients diagnosed with ALS according to the Gold Coast Principles; (2) Good language skills and communication skills; (3) Agree to participate in this study and sign the informed consent form. Exclusion criteria: (1) Patients who, as determined by the PHQ-9, have a mental disorder or emotional instability that prevents them from cooperating with the interview; (2) Patients with cognitive impairments or speech difficulties; (3) Patients who explicitly declined to be interviewed.

According to grounded theory, theoretical saturation is considered to be reached when new data no longer provide new contributions or challenges to the established theoretical framework [38]. Participants were sent a written informed consent form in advance of the survey and the consent form was further read to them upon request. All participants gave their informed consent before commencing the baseline survey. In total, 24 patients were invited for an interview, and two refused to participate. Reasons for rejection were difficulty in talking about feelings and not wanting to spend time on the study. Finally, 22 subjects were included, including 14 males and 8 females. Each interview lasted approximately 20 to 40 min, and each interviewee is interviewed only once. Confidentiality is ensured by using numbers instead of names (e.g., P1, P2, etc.) and deleting identifiable information from the transcript. All audio and text records are kept on a password-protected computer. Throughout the

study, we followed the standard guidelines for qualitative research reports. Confidentiality and anonymity were guaranteed.

Data collection

Data were collected through in-depth interviews. Before the interviews, participants were required to sign informed consent. The researcher was not known to the participants before interviewing. The interview was conducted in a meeting room of the ward. The environment was quiet and undisturbed.

The descriptive phenomenological method of qualitative research was used, and a semi-structured face-toface interview outline was preliminarily formulated based on a literature review and consultation with clinicians according to the purpose of the research. Three patients were interviewed before the start of the main study, but they were not included in the data of this study because the preliminary interview was mainly used for adjustment interview outline, and the outline was significantly modified after the preliminary interview. Finally, the revised interview outline is as follows: (1) What difficulties have you had to deal with since the onset of the disease? How to solve and cope? (2) Can you tell me about any support you've received? (3) What support do you think would be most helpful to you? (4) What specific help do you need?

Data analysis

The researchers transcribed, organized, and repeatedly read the interview recordings within 24 h of the interviews using NVivo 11.0 software. Then, Colaizzi's sevenstep analysis method was used to analyze the collated textual material [36]. First, two researchers carefully read the interview transcripts, parsed out significant statements, and coded recurring, meaningful ideas. The coded ideas were then collated to write detailed, omission-free descriptions, identify similar ideas and sublimated thematic concepts, and returned them to interviewees for verification. Finally, all researchers on the research team discussed and revised the preliminary results to ensure the accuracy of the results.

Ethical consideration

This study was approved by the Ethics Committee of Hubei Provincial Hospital of Traditional Chinese Medicine and was registered on the clinical research website under the registration number HBZY2022-C42-01. Participants received oral and written information about the study and were assured of legal data storage and anonymity. All participants signed informed consent and were aware of the right to withdraw their consent at any time without any penalty. During data analysis, each participant was coded to assure anonymity.

Results

Sample characteristics

In total, twenty-two participants, fourteen men, and eight women were interviewed in this study. They are indicated separately as P1-P22. The age of participants ranged between 30 and 60 years of age (median=48 years) and had been diagnosed with ALS in the previous 5–53 months (median=9.5 months). Table 1 lists the individual characteristics of the participants.

Data from the interviews

Three themes and eight sub-themes of the actual needs of ALS patients were obtained through qualitative research. These themes and subthemes are summarized in Table 2 and illustrated by text and quotes below.

Demand for healthcare services

Support from the healthcare system was an issue that each patient raised during the interview, and they showed a strong need for systemic therapy, as well as uncertainty about treatment and the future.

(1) More effective treatments

There is no definitive treatment for ALS, and treatment options are very limited. Patients may need to undergo experimental treatments, etc., which leads to uncertainty and risk

"I tried everything, but it didn't work. Now therapy is just a psychological comfort, but beyond that, I don't know what to do." (P4)

"I have tried both Traditional Chinese Medicine (TCM) and Western medicine, with little effect. But there is no cure for this disease, and I understand that. I plan to go to relevant institutions for drug testing later." (P5)

"There is no definitive answer for the treatment of ALS. Everyone's situation is different, so the effect of the treatment can also vary greatly. It made me feel very confused and helpless." (P18)

(2) Support from the healthcare system

Due to the specific nature of ALS, the healthcare system may face diagnostic, therapeutic, and supportive challenges. Patients may need to spend a lot of time and

Participants	Age group	Gender	Educational level	Marital status	Family- Caregiver(s)	Months since ALS diagnosis	Site of onset	ALSFRS-R
P1	50-55	Male	Undergraduate	Married	Spouse	13	Bulbar onset	25
P2	55-60	Female	Junior college	Married	Spouse	12	Limb onset	30
Р3	60-65	Male	NA	Married	Spouse	5	Limb onset	44
P4	55-60	Female	Junior High School	Married	Spouse	12	Bulbar onset	NA
P5	40-45	Male	Undergraduate	Married	Elders	9	Limb onset	35
P6	50-55	Male	Junior college	Married	Son	9	Limb onset	31
P7	40-45	Female	Technical Secondary School	Married	Aunt	6	Limb onset	40
P8	35-40	Male	Undergraduate	Married	Father	12	Limb onset	43
Р9	45-50	Male	NA	Married	Spouse	53	Bulbar onset	NA
P10	45-50	Male	Undergraduate	Married	Brother	17	Limb onset	38
P11	50-55	Male	Junior college	Married	None	6	Limb onset	48
P12	35-40	Female	Undergraduate	Married	Spouse	9	Limb onset	31
P13	55-60	Male	Junior college	Married	None	10	Limb onset	NA
P14	45-50	Male	NA	Married	Aunt	5	Limb onset	29
P15	45-50	Female	Technical Secondary School	Married	Spouse	8	Limb onset	30
P16	30-35	Male	Junior college	Married	Mother	17	Limb onset	20
P17	55-60	Female	NA	Married	Spouse	6	Limb onset	46
P18	45-50	Male	Junior college	Married	Brother	25	Limb onset	25
P19	50-55	Male	primary school	Married	NA	5	Limb onset	NA
P20	40-45	Male	Technical Secondary School	Married	Spouse	6	Limb onset	NA
P21	30-35	Female	Undergraduate	Married	Spouse	27	Bulbar onset	11
P22	40-45	Female	Undergraduate	Single	Niece	24	Limb onset	33

Table 1 Interview information and characteristics of the participants (n = 22)

Abbreviations: NA Not Available

Table 2 Identified themes and subthemes

Themes	Sub-themes				
Demand for healthcare services	More effective treatments				
	Support from the health care system				
Emotional requirements	Intimate companionship				
	Depth understanding				
	Positive encouragement				
Functional requirements	Daily needs				
	Communication needs				
	Mobility and transportation needs				

effort to find the right physician and professional body to coordinate cooperation between multiple medical teams.

"I found a private massage parlor for treatment firstly, the price is very expensive, but the effect is general. After that, it took us a long time to communicate with doctors before we came to the TCM hospital for systematic treatment." (P1)

"I was also recommended other treatments, but I refused because choosing a new treatment would

require time to adjust, and I probably didn't have that much time." (P10)

Emotional requirements

Due to the progressive and debilitating nature of ALS, patients grapple with a host of physical and psychological changes that give rise to distinct emotional needs.

(1) Intimate companionship

The physical condition of ALS patients deteriorates continuously, and their daily activities are severely restricted. Simple tasks like dressing and washing often require assistance from others. This situation makes them feel extremely lonely, and their longing for intimate companionship becomes even more intense. They wish their family members could always be by their side, not only to provide daily care but also to offer warm physical contact, such as hugs and hand - holding, so that patients can truly feel loved. During their free time, they hope to watch TV and chat with their families, sharing the trifles of life, which can relieve their fear of the disease and anxiety about the future. "Every time I see my family members busying around but having no time to sit down and talk with me, I feel empty inside. I especially hope that we can sit around and chat like we used to." (P5)

"Every night I find it hard to sleep, and I wish I had someone to talk to instead of facing the darkness alone." (P1)

(2) Depth understanding

Moreover, the unique emotional toll of ALS, which is often difficult for others to fully comprehend, has patients clamoring for emotional understanding. They express frustration when well-meaning family, friends, or even medical staff seem unable to grasp the depth of their emotional distress. The combination of physical pain and the psychological burden of facing a terminal illness requires a level of empathy and insight that is frequently lacking. Thus, patients long for others to recognize and validate their complex emotional experiences, providing a sense of being seen and heard.

"I told my family that I'm very scared and that I won't be able to do anything in the future, but they always say it will get better. However, they simply don't understand how I feel now." (P10)

"I told my friend that I felt like an invalid, that I couldn't do anything, but he just said don't think about it, he had no idea how bad I felt." (P2)

(3) Positive encouragement

In addition, the arduous journey of living with ALS is fraught with setbacks and challenges, leaving patients in a constant battle against feelings of hopelessness. Consequently, they have an urgent need for emotional encouragement. Words of affirmation, expressions of faith in their strength, and gestures of support can serve as powerful motivators, enabling them to find the courage to persevere in the face of seemingly insurmountable odds.

"I could hardly carry on until the doctors told me that I was doing well, which gave me the courage to continue the treatment." (P16)

"The training was so painful that I wanted to give up several times, but it was only when my fellow patients and doctors kept encouraging me that I was doing well and making great progress that I persevered." (P8) Patients have different needs for specific functions/activities due to diseases or changes in physical conditions. Some patients indicated that they experienced generalized pain, progressive speech loss, and loss of control of their bodies.

(1) Daily needs

Because of the progression of the disease, there are many actual needs in the life of ALS patients, such as how to eat independently, dress and undress, and personal cleaning.

Everything I eat has to be pureed to be swallowed, and even medication must be taken this way. My swallowing function is very weak, and I need assistance with dressing, washing, and using the toilet. (P4)

"Now I need help from others to get dressed and take a bath at home. I really feel like a failure because I can't even handle these small tasks. But I don't know what I should do, nor who can help me. (covering his face and crying) (P8)

(2) Communication needs

Individuals with ALS frequently develop speech and communication problems in the course of their disease. However, there is no other way to deal with it except speech therapy. Therefore, they urgently need equipment or methods that can increase and replace communication.

"It's always been what I tell them to do. But now my tongue is not flexible and I speak very slowly. If I cannot speak in the future, my family will not be able to take good care of me." (P15)

"I have a hard time talking now, and sometimes I have to repeat myself several times before people understand me. This makes me tired, hope there is a way to help me solve this problem." (P18)

(3) Mobility and transportation needs

As the disease progresses, patients with ALS have reduced muscle strength and may face difficulty in daily mobility activities such as walking, standing, and stair climbing. As a result, their travel requirements have increased

"I need to find transportation that works for me,

such as accessible cars or customized transportation services that meet my travel needs and help me stay connected to the outside world." (P5)

"Within a year I could no longer walk. I couldn't get out of the house, and even getting across the province to seek medical treatment was extremely difficult. If only there were special transportation to solve this problem." (P10)

"I don't know how to choose the appropriate assistive devices to help me get around. If only health care providers or organizations could provide similar information and travel services." (P16)

Discussion

Previous studies have mainly focused on the pathophysiology, genetic factors, and potential therapeutic interventions of ALS, aiming to find major breakthroughs in the disease [39–41]. In contrast, our study is centered on the Wuhan region of China, with the aim of depicting the actual needs of local patients. In this study, patients reported specific needs that have emerged as a result of the disease, such as demand for healthcare services, emotional requirements, and functional requirements. Against the backdrop of existing research, our study provides insights into the actual needs of ALS patients in the Wuhan region of China, which are distinct from those in other countries and regions.

As a rare disease, patients exhibited a pressing need for more effective treatments. The dearth of curative options for ALS has led them to explore various approaches, including Western and Traditional Chinese Medicine (TCM), often with underwhelming results [42–45]. This unmet need for better treatments underscores the urgency of research and innovation in the field. Moreover, the call for enhanced support from the healthcare system was palpable. Patients grappled with challenges in navigating the intricate healthcare network, from identifying suitable physicians to coordinating among multiple medical teams. This reveals a gap in the healthcare system's ability to provide seamless, patient -centered care for ALS patients.

One of the novel aspects of this study is its focus on the unique context of Wuhan, China. The integration of TCM and Western medicine in the local healthcare system offers a distinct perspective on ALS treatment. While previous research has touched on treatment options, our study delves into how patients in Wuhan navigate and combine these two medical systems in their pursuit of treatment. This provides valuable insights for healthcare providers and researchers looking to optimize treatment strategies in regions with similar healthcare settings. Page 6 of 9

The family-centered care model, deeply ingrained in Chinese culture, also plays a pivotal role in how ALS patients' needs are addressed. Our study reveals how this cultural aspect influences patients' emotional and functional needs, such as the role of family in providing intimate companionship and daily care. This understanding is crucial for developing culturally appropriate care plans and support systems.

The sub-themes of intimate companionship, depth understanding, and positive encouragement within emotional requirements illuminated the profound emotional impact of ALS on patients. The progressive nature of the disease, accompanied by physical decline and social isolation, intensifies the longing for intimate companionship. Family and society must recognize and respond to this need more effectively. The yearning for depth understanding reflects the complexity of patients' emotional experiences, which often elude the comprehension of those around them. Healthcare providers, in particular, need to be better equipped to offer empathetic and holistic care. Positive encouragement emerged as a crucial need, as patients constantly battle feelings of despair and hopelessness in the face of the disease's relentless progression. Compared to existing literature, our study offers a more nuanced understanding of ALS patients' emotional needs [46-48]. We not only confirm the importance of emotional support but also identify specific types of support that are most crucial for patients in the Wuhan context. For example, the emphasis on depth understanding highlights the need for healthcare providers and family members to engage more deeply with patients' emotional experiences, going beyond surface-level comfort. This new perspective can guide the development of targeted emotional support interventions.

Additionally, the interviewees provided more specific descriptions of their functional needs. These needs can be broadly categorized into three areas: daily living needs, communication needs, and mobility needs. Particularly regarding daily living needs, most interviewees mentioned that they were unable to perform very simple actions (such as eating, drinking, and dressing), which increased their desire for practical assistive devices. Examples of such devices include adaptive utensils, specially designed clothing, shower chairs, and bathtub lifts [49]. Patient with limited communication, while doing good speech therapy, can also use Automatic Speech Recognition (ASR) technology to alleviate the existing symptoms and actively manage their health [50]. As a result of reduced physical control, it is difficult for them to drive a vehicle alone and therefore rely on other people or specialized transportation for travel and transportation needs [50].

Compared to Miriam et al.'s study, our participants are more inclined to express their personal needs directly and explicitly state what they want and need, seeking practical solutions [51]. They believe that only tangible items that directly impact their daily lives and treatment are the most useful to them. For example, they want to know which medications are most effective, which hospitals provide the best treatments, and which devices can alleviate their suffering. They hope their actual needs will be addressed, enabling them to live independently rather than being dependent on others.

Meeting the actual needs of patients involves a wide range of considerations. Firstly, every hospital should make efficient use of medical resources by establishing a multidisciplinary team. This team should include neurologists, respiratory specialists, physical therapists, speech therapists, nutritionists, and psychologists to provide comprehensive care services. Secondly, to access practical and useful information, a dedicated online platform or website should be created. This platform should offer comprehensive, up-to-date, and reliable information about ALS, including disease progression, treatment options, care techniques, and support resources, with regular updates. Simple and easy-to-understand guides, manuals, and videos should be produced and distributed, introducing the basic knowledge of ALS, daily care techniques, and coping strategies to ensure that patients and their families can easily understand and apply them. Finally, training should be provided for the use of specific equipment to enable individuals to adapt independently. This includes adaptive dressing aids, lifting devices, and non-invasive ventilation equipment.

Conclusion

This study outlined the actual needs of ALS patients in China. Although the actual needs are highly individual, our study highlights the need to focus on the needs of medical service care, providing emotional requirements as well as meeting their functional needs. Giving corresponding practical support is an effective measure to reduce the burden on patients.

Limitation

Several limitations of our work should be noted. Firstly, twenty-two participants were recruited solely from a hospital located in central China and could hardly represent patients from other regions, who may experience things differently. Secondly, we only interviewed each participant once and failed to capture their experiences over time. Consequently, additional longitudinal research is needed to comprehensively appreciate patients' lived experiences from different regions and during various stages of ALS. Thirdly, some participants attended the interviews with their caregivers. Even though caregivers could help the participants understand the interviews, it was recognized that their presence could potentially influence participants' narratives. Therefore, we would consider the real thoughts of the participants from the aspects of movement and attitude to further understand their real opinions. Fourth, due to the specific nature of the interviews, our participant group primarily consisted of young and middle-aged individuals (median 48 years), and therefore, we did not investigate other age groups. Thus, we recommend including a broader range of age groups in future studies. Finally, since most of the participants were limb-onset ALS patients, future research should also include more patients with other sites of onset.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12904-025-01684-8.

Supplementary Material 1.

Acknowledgements

Authors would like to profusely thank all individuals who supported and helped them to conduct this study.

Authors' contributions

LZ designed and developed the study analyzed and interpreted the data and drafted the manuscript. FY, DX, JZ and GQ were involved in the development of the research question. MW and CL assisted with the analysis, and interpretation of data, and YY was involved in the acquisition and interpretation of data. LZ, YQ and JL contributed to the analysis and interpretation of data. All authors reviewed and approved the final draft.

Funding

This research was supported by funding from the Joint supported by Hubei Provincial Natural Science Foundation and Traditional Chinese Medicine Innovation and Development Joint Fund. (Grant number: 2023AFD160). The project was also funded by the 2024 Provincial Nature Joint Fund Program. (Grant number :2024AFD279).

Data availability

The datasets generated and analyzed during the current study are not publicly available for reasons of privacy and confidentiality.

Declarations

Ethics approval and consent to participate

This study was approved by the Ethics Committee of Hubei Provincial Hospital of Traditional Chinese Medicine (HBZY2022-C42-01). The research was performed in accordance with the Declaration of Helsinki. Participants were sent a written informed consent form in advance of the baseline survey and the consent form was further read to them upon request. All participants gave their informed consent before commencing the baseline survey.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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Received: 14 July 2023 Accepted: 7 February 2025 Published online: 22 February 2025

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