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# ORIGINAL ARTICLE

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# The illness experience for people with amyotrophic lateral sclerosis: A qualitative study

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# Abstract

**Aims and objectives:** This study aims to gain a comprehensive understanding of the illness experience of amyotrophic lateral sclerosis (ALS) patients in China and the meaning they attach to those experiences.

**Background:** ALS is a progressive and fatal neurodegenerative disorder that significantly impacts individuals and families. There is a large number of patients with ALS in China. However, little is known about how they live with ALS.

**Design:** Phenomenological qualitative research was performed among twenty people with ALS from the neurology department of a tertiary hospital in China. Colaizzi's method was used to analyse the participants' data. The Consolidated Criteria for Reporting Qualitative Research (COREQ) was used as a guideline to secure accurate and complete reporting of the study.

**Results:** We proposed three themes and eight subthemes on the illness experience of participants: (1) life countdown: 'my body was frozen' (body out of control and inward suffering); (2) family self-help: 'we kept an eye on each other' (family warmth and hardship, and supporting the supporter); and (3) reconstruction of life: 'what was the meaning of my life' (learning to accept, rebuilding self-worth, resetting the priority list and living in the moment).

**Conclusions:** In the family self-help model, patients are prompted to turn from negative mentalities to search for meaning in life actively. Healthcare providers need to attach importance to the family self-help model to alleviate the pressure on medical resources.

**Relevance to clinical practice:** Healthcare providers should encourage patients to play a supportive role in the family and provide more care support and professional care knowledge guidance to caregivers, to promote the formation of the family self-help model which might help to improve the experience of patients and families.

#### KEYWORDS amyotrophic lateral sclerosis, culture, illness experience, qualitative study

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# 1 | INTRODUCTION

Living with Amyotrophic lateral sclerosis (ALS) incurs physical, psychosocial and existential issues (Ozanne et al., 2013). Chinese patients with ALS face even more daunting challenges. Patients and their families are under greater economic pressure than other countries due to China's inadequate financial support for health and social services (Gong et al., 2016). Only the 'Riluzole Tablets' is included in the medical insurance reimbursement list. Meanwhile, the multidisciplinary clinic, the standard of care for patients with ALS in developed countries (Stephens et al., 2016), is so few in China. Hence the chance of accessing the available treatment and palliative care is limited. A cross-cultural study has also reported that the different attitudes of patients with ALS towards therapeutic decisions, the acceptance of death and the use of life support are grounded in cultural and historical traditions (Andersen et al., 2018). Chinese unique cultural philosophy might impact patients' perception of physical and emotional states and how they make sense of disease (Thomas et al., 2018). These aspects make Chinese patients with ALS different from those in other countries. Therefore, it is essential to understand Chinese patients' lived experiences to guide care provision.

# 1.1 | Background

Amyotrophic lateral sclerosis (ALS) is a progressive and fatal neurodegenerative disease that predominantly involves upper and lower motor neurons (Morris, 2015). ALS is rare and has an incidence of about 1–7 in 100,000 population in developed countries (Thomas et al., 2018). The disease clinically manifests itself as muscle weakness, atrophy and spasticity in the limb or bulbar muscles and hastily progresses to more body regions with no remission period (Robberecht & Philips 2013). In the late stages of the disease, people with ALS develop into a 'totally locked-in' state (TLS) where only residual muscular movement is possible, with the intellect and the personality usually remaining unimpaired. A majority of them die of respiratory failure within 3–5 years from symptoms onset (Hardiman et al., 2011).

Since ALS is incurable, its treatments mainly focus on improving and sustaining the quality of life (QoL) (Prell et al., 2019). Previous studies have revealed that psychological well-being plays a prominent role in determining the QoL of people with ALS (Neudert et al., 2004). Patients with ALS develop a number of emotional issues, especially anxiety, fear and depression (Unglik et al., 2018). Physical disability and imminent death increase the likelihood of hopelessness and desire for physician-assisted suicide (Paganoni et al., 2017). They are also more likely to feel burdensome, resulting in a discredited definition of themselves and a diminished will to live (Foley et al., 2016). Of note, most research on the psychological well-being of people with ALS was quantitative. However, these studies were limited in identifying specific psychological difficulties with ALS because the measures they used were not specifically designed for ALS (Mistry & Simpson, 2013).

# What does this paper contribute to the wider global clinical community?

- Demonstrates that suffering from ALS is a painful journey with physical, psychosocial and existential issues. The findings enhance healthcare providers' understanding of patients' concerns and needs, even in different cultural settings.
- Healthcare providers need to attach importance to the family self-help model, especially for countries with insufficient medical resources. Professional care and knowledge support should be provided to alleviate the burden of families.
- Policies support with resource and care provision need to be strengthened to meet the needs of patients and families.

Available qualitative research to date is limited, although it has been recommended as the most appropriate way of assessing mental concerns in ALS (Thomas et al., 2018). Some research into patients' narratives with ALS indicated shared experiences such as loss and forced change (Foley et al., 2014; Locock et al., 2009; Mistry & Simpson, 2013). Studies have qualitatively explored the relationship between patients and significant others, especially with family caregivers (Cipolletta & Amicucci, 2015; Locock & Brown, 2010). Interpersonal relationships may either threaten or help establish patients' existential meaning (Ando et al., 2019).

There is growing evidence of ALS in China, but little attention has been directed to how they experience the illness (Liu et al., 2018). Our aim with this study was to take the first step in trying to investigate the lived and managed experience of patients with ALS in mainland China.

# 2 | METHOD

# 2.1 | Study design

A phenomenological qualitative research design involving indepth semi-structured interviews was chosen. It is particularly suitable to explore the complex phenomenon and the essence and meaning to those who experience it (Holloway & Galvin, 2016). Colaizzi's method was employed for data analysis, which provides detailed and sequential steps that increase the results' reliability and dependability (Wirihana et al., 2018). The Consolidated Criteria for Reporting Qualitative Research (COREQ), a 32-item checklist, was used as a guideline to secure accurate and complete reporting of the study (Tong et al., 2007), see Supplementary File 1.

# 2.2 | Participant

This study recruited those diagnosed with ALS and treated in the Neurology Department of a tertiary hospital in Wuhan, China, from February to July 2018. Patients with severe respiratory insufficiency or impairments in verbal communication were excluded. A purposive sampling method was conducted to ensure the sample diversity in age, gender, function state and course of ALS. The principle for determining the sample size was practised as follows: after data saturation was reached, two more patients were interviewed. If there were no new topic emerging, further recruitment would be terminated.

The second author of this study was an experienced nurse in charge of clinical nursing education in the neurology department currently. For potential participants, she told them about the purpose and methods for this research and invited them to participate. If they were interested in participating, they would receive written materials with details of the study and additional verbal information before the interviews. In total, 24 patients were invited for an interview, and four refused to participate. Two patients did not want to spend time on this study. One said it was hard for him to talk about feelings, and one did not report a reason for the refusal. Finally, 20 participants were recruited for the study.

# 2.3 | Data collection

Data were collected by in-depth semi-structured interviews. Prior to the interviews, participants were required to sign informed consent. Those who agreed to participate were interviewed face to face in a private room of the neurology department. Interviews were conducted by the second author of this study, who had been trained in conducting interviews. The researcher was not known to the participants before interviewing. A semi-structured outline was developed with several open-ended questions exploring informative answers containing the situations, thoughts and emotions on ALS experience (See supplementary File 2). Each participant was interviewed once. All conversations began with the same question: 'Could you please talk about your experience after diagnosis of ALS?'. Their responses were clarified with questions like 'what do you mean by saying that?'. Considering the decline of communication ability, participants could express themselves with paper or caregivers' help. Noting the impact caregivers may have on an open conversation with a participant, their presence was recorded in the finding section. Each interview lasted 30 to 60 min. At the end of the interviews, each participant would receive a little gift as a reward.

All interviews were audio-recorded with patients' consent and transcribed verbatim within 24 h by the second author. The transcripts were then sent back to the interviewees to affirm accuracy. The interviews were in Chinese, and the quotes in this paper were translated into English by the first author and checked by all authors.

# 2.4 | Data analysis

Colaizzi's method was used to analyse the data with seven steps: (1) Read the transcript to be familiar with the data; (2) Identify and extract significant statements and phrases; (3) Formulate meanings; (4) Group all formulated meanings into categories, clusters of themes and themes; (5) Define all emergent themes into an exhaustive description; (6) Describe the fundamental structure of the phenomenon; (7) Return the findings to participants to seek verification (Wirihana et al., 2018). All data and field notes obtained during the interviews were entered into NVivo 10 to support qualitative data analysis.

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The first author and the second author performed the initial analysis independently. After that, all co-researchers discussed whether the analysis results were appropriate according to the transcripts and note-comparing. If the authors had different opinions, the discussion continued until all authors achieved consensus.

# 2.5 | Ethical consideration

This study received approval from the Local Ethics Committee prior to the commencement of the research. 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 rights to withdraw their consent at any time without any penalty. The researchers promised not to use any personal identifier in research reports or publications. During data analysis, each participant was coded to assure anonymity. Any information that might potentially identify individuals, third parties or institutions was masked.

# 3 | RESULTS

In total, twenty participants, thirteen men and seven women were interviewed in this study. The age of participants ranged between 28-72 years of age (median = 51 years) and had been diagnosed with ALS in the previous 6-60 months (median = 14 months). The personal characteristics of the participants are listed in Table 1.

Three themes and eight subthemes were obtained through the phenomenological qualitative study regarding the patients' living experience with ALS. These themes and subthemes are summarised in Table 2 and illustrated by text and quotations below.

#### 3.1 | Life countdown: 'My body was frozen'

After being first diagnosed with ALS, the countdown of life began. Impacts of ALS on patients were grouped into two subthemes: 'body out of control' and 'inward suffering'. TABLE 1 Interview information and characteristics of the participants

Participant	Age (years)	Gender	Educational level	Marital status	Occupation before diagnosis	Family- Caregiver(s)	Months since ALS	Functional state at the time of interview
P1	51	Male	Junior High School	Married	Farmer	Spouse	12	Paralysed in both arms
P2	33	Male	Undergraduate	Married	Teacher	Spouse	6	Walking with crutches
P3	55	Male	Undergraduate	Married	Civil servant	Spouse	10	Paralysed in both legs
P4	51	Male	Junior High School	Married	Workman	Spouse	24	Paralysed in both legs. Moves his hands a little bit
P5	64	Male	Undergraduate	Married	Administration staff	Spouse	36	Paralysed in all four limbs, has breathing difficulties
P6	44	Female	Junior High School	Married	Self-employer	Spouse	14	Paralysed in all four limbs
P7	65	Male	Undergraduate	Married	Teacher	Spouse	6	Walking with crutches
P8	43	Female	Junior High School	Married	Workman	Spouse	10	Paralysed in both arms
P9	44	Male	Undergraduate	Married	Teacher	Spouse	12	Paralysed in both arms
P10	28	Female	Senior High School	Single	Freelancer	Mother	8	Paralysed in both legs
P11	53	Male	Postgraduate	Married	Engineer	Spouse	60	Paralysed in all four limbs, has breathing difficulties
P12	72	Female	Uneducated	Married	Farmer	Daughter(s)	24	Paralysed in all four limbs and ventilated
P13	38	Male	Undergraduate	Married	Unemployed	Spouse	12	Paralysed in both legs
P14	52	Male	Junior High School	Married	Farmer	Daughter(s)	17	Paralysed in both arms
P15	56	Female	Junior High School	Married	Workman	Spouse	14	Paralysed in both legs and one arm.
P16	35	Male	Undergraduate	Single	Salesman	Mother	18	Paralysed in both legs
P17	32	Female	Technical Secondary School	Single	Self-employer	Mother	32	Paralysed in all four limbs, has breathing difficulties
P18	39	Male	Senior High School	Married	Engineer	Spouse	8	Walking with crutches
P19	68	Male	Undergraduate	Married	Administration staff	Spouse	14	Walking with crutches
P20	59	Female	Undergraduate	Married	Teacher	Spouse	16	Paralysed in both legs

# 3.1.1 | Body out of control

Participants perceived their bodies started to get out of control after suffering from the illness. They walked strangely, got thinner or drooled unconsciously. These changes had a profound impact on their overall self-perception. They felt embarrassed and ashamed to communicate with others. Some tried to estrange themselves from circles of relationships.

> "Being sick always makes me drool like a baby. Every day, I have to wipe off my saliva. When people came to my home, I often wondered if they thought I looked like a freak. I only wanted to stay alone. It is embarrassing."

> > (P8)

As muscle weakness and stiffness kept progressing, participants felt as if their bodies were frozen. Since most of them were clear in mind, some described that they could do nothing but watch themselves die.

> "My fingers stiffen up. My body seems to be frozen. The feeling is hard to express in words. I feel like I'm a robot rusting slowly and destroyed by illness and pain." (P4)

# 3.1.2 | Inward suffering

It is too hard for individuals to accept the diagnosis of ALS. They went into denial and believed they were misdiagnosed to make themselves feel better. Some started to question their beliefs as they felt they had done well in life.

"I have never heard of this [ALS] before. How could I get such a strange disease? I hope my doctor is wrong.

TABLE 2 Identified themes and subthemes

Themes	Subthemes
Life Countdown: 'My body was frozen'.	Body out of control
	Inward suffering
Family self-help: 'we kept an eye on each other'.	Family warmth and hardship
	Supporting the supporter
Reconstruction of life: 'What was the meaning of my life?'	Learning to accept
	Rebuilding self-worth
	Resetting the priority list
	Living in the moment

Doctors are not gods. There must be some moments when they make a mistake."

(P1)

"Since I was a child, my parents always taught me that virtue has its reward, evil has its retribution. I had never done anything bad, but why did this happen to me? I don't know what to believe anymore [Silence]."

(P17)

Patients invariably associated ALS with death and dying. As a result, words such as 'fear', 'desperate' and 'hopeless'' were most frequently mentioned during the interviews. Some participants described themselves in a state of ambivalence. While desiring to be cured, they often had suicidal thoughts as the disease progresses.

> "I always dreamed that I was cured. But when I woke up, I found myself still in bed with stiff limbs. It is so desperate...... Sometimes I want to end it all." (Accompanied)

> > (P12)

# 3.2 | Family self-help: 'We look after each other's back'

Family as an independent system plays a crucial supportive role. Facing the plight, the patients and their family members depended on each other to help themselves.  $^{Journal of}$  Clinical Nursing $^{-}$ WILEY $^{\perp}$ 

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# 3.2.1 | Family warmth and hardship

The family provided the greatest support to patients. All the participants' caregivers were their spouses or parents. They shouldered more responsibilities, such as caring for the patients, raising children and earning money to support the family. Due to the illness, patients and their families spent more time with each other than before. Some patients stated that their families got closer together. The family warmth encouraged patients to be stronger to face the disease and actively involved in their treatment.

> "When my grandchildren kept themselves by my side, I always felt very happy. Their smiles act like a magic potion that soothes me a lot." (Accompanied)

(P12)

"With the support of my family, I became braver. No matter what the final result is. I think my life is meaningful."

(P10)

However, many patients described that there is a lack of communication between them and their families. They kept the internal suffering to themselves and avoided talking about the disease with families to reduce caregivers' psychological pressure.

> "She[wife] cried a lot even when I didn't say anything. How dare I tell her my feelings? I had to keep those to myself."

> > (P8)

Besides, being cared for by family members caused emotional problems. Many participants lived with a pervasive sense of guilt, as they perceived themselves as incurring a massive burden on their family, especially those cared for by their elderly parents. Some described a sense of anxiety and helplessness since they worried about whether they have been properly cared for.

> "My mom is 70 now. She had a wea`k heart but still had to take care of me. I am such an unfilial son." (P16)

# 3.2.2 | Supporting the supporter

In our study, patients converted the feelings of guilt into strong senses of family responsibility. They did their part within their power to buttress their families physically and psychologically. On the one hand, strategies were employed to reduce the physical burden on caregivers, for instance, minimising needs and striving to do things they were capable of in daily life. Meanwhile, participants showed emotional support to their families. They reassured the family and

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became sensitive enough to capture slight emotional fluctuations in caregivers.

"I'm afraid she [wife] cannot handle this, and I worry about her health. So, I do whatever I can do, like wiping the table, to ease her burden."

(P3)

"My wife took care of me all the time. Sometimes, even though she was laughing, I could feel she was under great pressure. I also wanted to take care of her emotional health."

(P13)

# 3.3 | Reconstruction of life: 'What was the meaning of my life?'

Under the threat of illness and death, patients started to pursue the meaning of life and reconstruct their lives messed up by the disease.

# 3.3.1 | Learning to accept

Learning to accept reality and death was the most crucial first step that patients had to take to embark on a journey of meaning-making. By confronting reality and death, patients stated that they could reconsider their value and rediscover the meaning of life.

Many patients took a downward comparison approach to accept reality. Participants compared themselves with those in worse circumstances, thus shifting their identities from 'victims' to 'survivors'.

> "I felt better when I saw some young patients in the hospital. I am 68 years old now, much older than them. If I want to live to age 70, there are only two years ahead. However, if a 20-year-old patient wanted to make it to age 70, it would be much harder."

> > (P19)

Influenced by Chinese traditional culture, some patients believed that thinking about life was more meaningful than death.

"It is useless to think about death now. What is more important now is living a good life for the rest of the day, and not disappointing those I love." (Accompanied)

(P17)

#### 3.3.2 | Rebuilding self-worth

Participants rebuilt their self-worth to make the meaning of life. They invested their energies in activities to feel valued and needed. Many

patients kept going to work or tried to do easy housework. Some expressed a strong desire to get involved in helping others. One participant shared his experience with ALS in social software, hoping to inspire and encourage those in the same plight as them. Another participant longed for organ donation as a continuation of life.

> "Last year, an old woman told me to look after myself. I think she is right. I can walk without any aid. Why should I bother others? Do some little things, I will feel more valuable."

> > (P8)

### 3.3.3 | Resetting the priority list

The meaning of life can be found by resetting the priority list. Having to live with the disease, the patients saw significant changes in their views of money and fame. Individuals once spent a great deal of time on making money. But now, spending time with family has become the most important thing for them.

> "I started to recognize how important life is. I used to be busy saving money for children's education. Now we [He and his wife] can just sit and talk, heart to heart. Her [wife] support motivated me to receive treatment."

> > (P13)

For some younger participants involved in child-rearing, their children's growth and future became the things they were concerned about most. Their children were spiritual support for them to struggle to live longer.

"My little girl is only three years old. I want to be alive and watch her grow up. So, take every remaining day seriously, and my life could be more meaningful."

(P18)

#### 3.3.4 | Living in the moment

Living in the moment was a crucial aspect of individuals in pursuing the meaning of their life. It meant narrowing the attention to the present and making the most of the days remaining. Patients chose to live in the moment to liberate themselves from the disease temporarily and reduce worries to a manageable level. They enjoyed things more sensitively and embraced every little moment of happiness.

> "Instead of being sad all the time, it is better to look at the scenery outside. Listen to the birds sing, feel the leaves rustling in the wind, and watch the rose blossoms. All of these make me happy."

# 4 | DISCUSSION

This study aimed to investigate the lived and managed experience of patients with ALS in China. Our result demonstrated that the initial experience after diagnosis of ALS was characterised by feeling out of control for the body, desperation for prognosis and guilt to family. Under the threat of death, those negative feelings transformed into an active exploration of the relationship between self and others. Individuals became highly dependent on the family and also played a supportive role in the family. Moreover, their perspective of life was transferred from a more external view to a more in-depth view, such positive conduct as resetting priorities in life, re-evaluation of personal values and seeking the meaning in life took place (Helgeson et al., 2006).

Participants lost control of their bodies and experienced many emotional issues, such as depression, fear and guilt reported in previous research. (Averill et al., 2007; Benbrika et al., 2019; Unglik et al., 2018). It was worth noting that suffering from ALS led to a questioning of faith, especially for those who were morally strict with themselves and eliminated immoral behaviour. It might be because most people in China believe in Karma, emphasising that good acts will have positive consequences, whereas evil deeds will produce negative results (Xu, 2018). Previous research has revealed that personal faith helps people avoid despair and make sense of what is happening to them (O"Brien & Clark, 2015). Therefore, healthcare providers should pay attention to the emotional condition of patients, especially their faith and spiritual needs, in addition to their physical condition.

We found a family self-help model formed, that is family members cared for patients, and patients supported supporters. In this study, family support for patients helped them face reality and actively seek the meaning of life, and the patients provided physiological and psychological support to their families to alleviate their sense of guilt and the family burden. Studies on family caregiving in other life-limiting illnesses (e.g., HIV and multiple sclerosis) indicated similar family relationships (Payne & McPherson, 2010; Uphold et al., 2012). Notably, the family self-help model was reported in all participants' families, which might arise due to the inadequacy of the Chinese Medical Insurance System and limited existing medical facilities for the rare disease. Moreover, the Chinese cultural concept of familism stressing solidarity and interdependence might also promote the universality of family self-help. Nevertheless, our study reported some limitations of this family care model, such as poor communication between patients and families, a strong sense of self-burden of patients and family caregivers' lack of professional care knowledge (Ando et al., 2019; Foley et al., 2016). Healthcare providers, especially in regions with imperfect healthcare systems, could attach importance to the family self-help model to support patients. Interventions tailor-made to patient and family's needs may improve the experience of patients and families with ALS.

Interestingly, our result reported some differences in patients' feelings of being cared for by family caregivers. The aged patients reported higher subjective well-being, while those cared for by Journal of Clinical Nursing-WILEY

aged parents exhibited stronger guilt, anxiety and out of control. Filial piety, seen as 'the top of all virtues' in Chinese traditional culture, may contribute to the difference. The elderly had little psychologically burdened of being cared for, as it was conventional for children to look after their parents. Moreover, they showed high happiness since spending more time with their families (Lee, 2009). On the contrary, adult patients showed more guilt, as being cared for by their parents physically and financially was not consistent with traditional Chinese social expectations(Chen et al., 2016). Besides, they feel anxious about not being adequately cared for because of their elderly parents' lack of physical strength and professional care knowledge. It suggests that attention should be paid to the inner experience of patients of different ages, which could provide healthcare providers with guidance in personalised care.

Under the threats of death, patients were motivated to reappraise their self-value and pursue the meaning of life. Research has emphasised that meaning is the purpose of life, and it can be found even in the worst situations (Metz, 2013). In this study, individuals' meaning of life was sought by learning to accept, rebuilding selfworth, resetting priority list and living in the moment. The result is supported by numerous previous research (Boston et al., 2011; Foley et al., 2016; Ozanne et al., 2013). Meaning's positive influence on experience indicates that it is vital for healthcare providers to help people with ALS find an element of meaning and purpose in their lives, which may improve their experience with ALS.

Notably, participants seldom talked about death. Lin (Lin, 2003) believed that the Chinese avoiding thinking of death was a phenomenon of culture. In China, people's view of life and death is the most affected by Confucianism, which attaches great importance to human life. Nevertheless, as some scholars raised, Confucianism lacked attention to death (Chen et al., 2017). It is verified in this study. Participants considered living a meaningful life in the remaining days but avoided talking about death. Despite the optimistic life attitude of participants being beneficial for patients to pursue life's meaning, their neglect of death resulted in lacking sufficient understanding of the content and significance of 'good death'. Furthermore, the phenomenon is more severe since the slow and lack of systematic development of death education in China(Haishan et al., 2015). Therefore, healthcare providers should strengthen death education among Chinese patients with ALS, guide them to think about 'good death' and establish a correct attitude towards death so that they can face death fearlessly.

Several limitations of our work should be noted. Firstly, twenty 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 gain a comprehensive appreciation of 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 recognised that their presence could potentially influence participants' narratives.

# 5 | CONCLUSION

In conclusion, since living with ALS was a painful journey, patients and their families strived to form a family self-help model. In this model, mutual support between patients and their families has a positive impact on their experience, and patients are prompted to turn from negative mentalities to search for meaning in life actively. Healthcare providers should pay attention to and utilise this model in providing health services and actively promote the formation of family self-help models to alleviate pressure on medical resources. In addition, this study also emphasises the need to support patients to live well until they die and plan for elements that contribute to enabling a good death.

# 6 | RELEVANCE TO CLINICAL PRACTICE

Families play an important role in supporting patients with ALS. Healthcare providers should actively promote the formation of family self-help model. For patients with ALS, healthcare providers need to encourage them to play a supportive role in the family; For family caregivers, more care support and professional care knowledge guidance need to be provided to relieve their burden. In addition, social welfare systems and community healthcare systems should be strengthened to meet the needs of patients and caregivers. It is also indispensable to strengthen death education and encourage patients and their families to communicate about the disease and death actively.

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#### CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

### AUTHOR CONTRIBUTIONS

Conceptualisation, formal analysis and writing – original draft: M-MY. Methodology and Investigation: XP. Supervision: T-YZ. Validation and data curation: M-L-YW. Formal analysis: YC. Writing – review and editing: KZ. Writing – review and editing: X-JW.

#### DATA AVAILABILITY STATEMENT

Some or all data, models, or code generated or used during the study are available from the corresponding author by request.

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### SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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