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Exploring amyotrophic lateral sclerosis patients' experiences of psychological distress during the disease course in China: a qualitative study

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ABSTRACT

Objective This study aims to explore the psychological distress course of Chinese amyotrophic lateral sclerosis (ALS) patients after the onset of the disease and to provide targeted nursing guidance.

Design The interview content was analysed qualitatively. We used seven steps of Colaizzi's method to analyse the participants' data.

Setting Wuhan, China, Traditional Chinese Medicine Hospital.

Participants A semistructured face-to-face interview were performed among 22 people with ALS from the motor neuron disease rehabilitation centre of a tertiary Chinese medicine hospital in China.

Result This study included a total of 22 participants, from whom three main themes regarding the psychological distress trajectory of ALS patients were extracted from the interview data: 'Time begins to run out' include tormented and restless waiting and shock and doubt in ALS disease confirmation, 'Family out of control' include the burden of stigma and function loss, the burden of missing family roles, the burden of marriage's emotional needs and the burden of offspring health, 'Way forward' include struggle between live and death and struggle between quality of life and the value of life.

Conclusion This study outlines the psychologically distressing journey of ALS patients. Studies have pointed out the need for targeted care to address patients' various sources of psychological distress to improve their quality of life and coping ability, increase their psychological resilience and reconstruct their life beliefs.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Qualitative research methods can delve deeply into and describe participants' experiences within their social, demographic and clinical backgrounds.
- ⇒ The diverse social backgrounds of amyotrophic lateral sclerosis (ALS) patients offer the broadest perspectives and experiences for research.
- ⇒ Understanding the psychological distress journey of ALS patients aids in providing targeted psychological guidance for them.
- ⇒ The study sample is limited to China, and the findings may not be applicable to other countries.
- ⇒ Due to considerations of disease survival period and research costs, longitudinal tracking was not conducted in the study.

INTRODUCTION

Amyotrophic lateral sclerosis (ALS) is a neurologically related disease characterised by respiratory complications postonset, eventually progressing to paralysis, with a median survival period of 3–5 years.[1–3] The global incidence of ALS stands at approximately 1–2.6 per 1 000 000 individuals, with a prevalence of 5–6 per 100 000.[4 5] Recent statistics indicate an annual incidence of 1.6 per 100 000 worldwide,[6] while in China, the annual incidence is reported at 1.24 per 100 000.[7] Despite being a rare disease, over 90% of ALS cases lack a family genetic history.[7 8] This condition not only compromises patients' physical functions and social interactions but also profoundly impacts their mental well-being.[9] ALS patients often report autonomic symptoms, heightened pain, sleep disturbances and gastrointestinal dysfunction, alongside increased fatigue resulting from decreased limb function and psychiatric symptoms.[10 11] Given the incurable nature of ALS, prioritising and enhancing the quality of life for affected individuals is of paramount importance.

Patients' mental well-being significantly influences their overall quality of life.[12] Individuals living with ALS commonly experience negative emotions such as anxiety, fear and depression throughout the course of the disease.[13] Studies have indicated that the prevalence of depression among ALS patients varies between 8% and 56%.[14–16] Moreover, there exists a direct correlation between a patient's psychological stress levels and their heightened risk of mortality.[17] Stressors such as loss of limb function and financial strain contribute to increased psychological burdens, reduced mobility and may even elevate the risk of suicide.[18 19] This psychological distress persists throughout the progression of ALS.[20]

Qualitative research related to ALS primarily delves into the lived experiences of ALS patients, caregivers and healthcare professionals. Studies depict the challenges faced by individual ALS patients, including physical limitations, psychological interventions and so forth.[21–24] They explore the experiences of ALS patient caregivers, revealing the economic, emotional and physical burdens they encounter.[25–27] Healthcare professionals often approach ALS from the perspectives of clinical treatment efficacy, personalised prognosis, rehabilitation therapy and feasibility of care plans.[28–30] However, there is a lack of research into the psychological distress experienced by ALS patients throughout the disease process. This study addresses this gap by understanding the disease-related suffering experienced by ALS patients. This understanding is beneficial for interpreting and comprehending the psychological barriers faced by ALS patients throughout the disease trajectory, which can significantly enhance knowledge on how to better cope with the psychological trauma caused by ALS.[8 20] Simultaneously, it provides theoretical and directional guidance for family caregivers and clinical professionals in providing psychological care for ALS patients.

METHOD

Design

This study employed a descriptive phenomenological approach using semistructured interviews, with the primary aim of exploring the psychological distress experiences of ALS patients. Purposive sampling and snowball sampling were utilised for participant selection. The study adhered to the Unified Standards of Qualitative Research Reporting checklist as a guideline.[31]

Participants

This study recruited those diagnosed with ALS and treated in the motor neuron disease rehabilitation centre of a tertiary Chinese medicine hospital in Wuhan, China, from April to May 2023. Inclusion criteria: (1) patients diagnosed with ALS according to the Gold Coast Principles;[32] (2) patients with basic communication skills or who are able to communicate using non-verbal methods such as using a communication board or typing on a computer and (3) agree to participate in this study and sign the informed consent form. Exclusion criteria: (1) severe mental disorders or organic diseases; (2) patients experiencing severe respiratory distress and speech impediments and (3) patients who explicitly declined to be interviewed.

Data collection

Based on the research objectives, a semistructured face-to-face interview guide was initially formulated, drawing from literature review and clinical consultations. Prior to the main study, three patients were interviewed, and based on expert feedback, the interview guide was revised and finalised (see online supplemental 1 for the ultimate interview guide).

The interviews were conducted by two nursing master's students who had received professional training. The entire interview process was documented, with the interview guide serving as the core framework. The sequence of questions was adjusted as necessary based on the actual interview circumstances, with repetitions, probes and summaries employed as needed. To ensure participants' comprehension of interview questions, explanations were provided by the interviewers based on the participants' cultural background and understanding. All interviews took place in a separate hospital room to safeguard patient privacy and ensure a quiet, undisturbed environment. No individuals other than the interviewer and participants were present during the interviews.

With patients' consent, all interviews were recorded and filmed, and the interview content was transcribed verbatim within 24 hours. Transcribed texts were organised and returned to patients for review to ensure accuracy. Interviews were conducted in Chinese and later translated into English, with all authors reviewing the translations. To maintain the authenticity of interview data, participants' viewpoints were evaluated and guided by the interviewers. To safeguard patient privacy, participants' names were replaced with 'p+number'.

A total of 24 patients were invited to participate in the interviews, with two refusing. Reasons for refusal included difficulty discussing feelings and unwillingness to spend time on research. Ultimately, 22 participants were included, comprising 14 males and 8 females. Each interview lasted approximately 20 to 40 min.

Data analysis

After the interviews, Yiqing Yu transcribed the audio into text within 24 hours and listened to it again for accuracy. Simultaneously, during the transcription process, Yiqing Yu watched the interview videos to observe changes in the interviewees' tone of voice and facial expressions, aiming to analyse their feelings more accurately. The transcribed text was then provided to the participants for feedback to ensure transcription accuracy.

This study employed Colaizzi's data analysis method.[33] The steps included: (1) transcribing and organising the raw interview data; (2) reading to extract significant statements related to the psychological distress experiences of ALS patients; (3) understanding the deep psychological meanings behind the extracted significant statements; (4) categorising meaningful common features or concepts, organising them into themes, thematic groups and categories for revealing experiences or viewpoints conveniently; (5) synthesising categorised results into exhaustive descriptions of psychological distress experiences; (6) framing exhaustive descriptions into descriptive expressions with identification and hierarchy and (7) providing descriptive expressions to participants for validation of accuracy and completeness. These steps were repeated to ensure complete understanding and saturation of statements and data.

Quality control

The research team, experienced in ALS-related studies, has established a robust foundation. Prior to commencement, detailed interview guidelines were crafted to ensure uniform questioning for all participants, thus guaranteeing data comparability and consistency. Interviewers received standardised training, demonstrating proficient communication skills. Interviews utilised a blend of written transcripts, audio and video recordings to precisely capture participant expressions, aiding subsequent analysis and validation. Periodic reviews of interview transcripts and notes were conducted throughout the data analysis process, employing diverse assessment methods to ensure data accuracy. The research report provides an honest and transparent account of the interview process, methodologies, and analysis procedures.

Ethical consideration

The study was reviewed and approved by the ethical review board of Hubei Provincial Hospital of Traditional Chinese Medicine (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 knew the right to withdraw consent without penalty. During data analysis, each participant was coded to ensure anonymity.

Patient and public involvement

During this study, participants and the public did not directly engage in the design of the interview guide and research process, nor did they assess the measurement of outcomes, but they were primary contributors to the research findings.

RESULTS

Sample characteristics

Twenty-two participants were interviewed in this study. They are indicated separately as P1–P22. The 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 collects the individual characteristics of the participants (the participant details table is provided in online supplemental 2)

Data from the interviews

Three themes and eight subthemes of ALS patients' experiences of psychological distress were obtained through qualitative research. These themes and subthemes are summarised in table 2 and illustrated by text and quotations below.

Table 1 Demographic information of the participants (n=22)

Subject	Category	Number (%)
Gender	Man	14 (64)
	Woman	8 (36)
Age (years)	≤40	4 (18)
	>40	18 (82)
Educational level	Primary school	1 (5)
	Technical secondary school	3 (14)
	Junior high school	1 (5)
	Junior college	6 (27)
	Undergraduate	7 (31)
	NA	4 (18)
Marital status	Married	21 (95)
	Single	1 (5)
Current work status	Unemployment	10 (45)
	On leave	10 (45)
	Retired	2 (10)
Family caregiver(s)	Spouse	10 (45)
	Others (children, parents, relatives, etc)	12 (55)
Time since symptom onset (months)	≤12	12 (55)
	>12	10 (45)
Time since diagnosis (months)	≤12	16 (73)
	>12	6 (27)
Symptoms of the disease	Sporadic	20 (90)
	Familial	2 (10)
Site of onset	Bulbar onset	4 (18)
	Limb onset	18 (82)

Time begins to run out—'I'm in the dark'.

Tormented and restless waiting

During the diagnosis process, patients undergo various tests to rule out other conditions, which can be time-consuming. While awaiting a diagnosis, they often feel anxious and uncertain about whether they have ALS and the extent of the illness, leading to distress and unease.

> This time of waiting really torture people, every second for me like a year so long. (P2)
>
> Every day I wait for the results is getting longer. I wish I knew. (P5)
>
> It took me a full 4 months from the time I had symptoms to the time I was diagnosed, and the thing I dreaded most every day during that time was seeing the doctor's diagnostic note. (P13)

Shock and doubt in ALS disease confirmation

The rarity of ALS often leads many patients to doubt the accuracy of their diagnosis. They are unwilling to believe that such a rare event could happen to them and therefore seek confirmation by visiting multiple hospitals.

Table 2 Identified themes and subthemes

Themes	Subthemes
Time begins to run out—'I'm in the dark'.	Tormented and restless waiting
	Shock and doubt in ALS disease confirmation
Family out of control— 'My family and I are facing a huge burden'.	The burden of stigma and function loss
	The burden of missing family roles
	The burden of marriage's emotional needs
	The burden of offspring health
Way forward——'I'm in for a long fight'.	Struggle between life and death
	Struggle between quality of life and the value of life

ALS, amyotrophic lateral sclerosis.

> I really went to three hospitals for tests. It wasn't until I finally went to Huaxi Hospital and completed the tests that I fully accepted it and resigned myself to it. (Tears well up in eyes) (P8)
>
> Initially, I had tests done in the provincial capital, and they said it was suspected to be ALS. I didn't believe it. Later, I went to the First Affiliated Hospital of Anhui Province and got the confirmed diagnosis. (P16)

When most patients learn of their diagnosis of ALS, they are usually shocked and unwilling to believe the news.

> I was shocked and confused at the time of diagnosis, and I was struggling to come to terms with this unfortunate reality.(P21)

Family out of control—'my family and I are facing a huge burden'

The burden of stigma and function loss

ALS patients often have muscle wasting in their limbs and speech problems, resulting in changes in walking, difficulty moving their hands, unclear speech, trouble communicating and excessive drooling. These functional impairments set them apart from the general population, increasing their psychological distress.

> I was ashamed because I couldn't control my body and my emotions, and I was very embarrassed about it. (P1)
>
> I don't even look like a healthy person anymore. Shame hangs over me because I feel like I've lost my dignity and autonomy. (P8)

Furthermore, their declining function necessitates reliance on others for assistance, leading to concerns about burdening their loved ones.

> The stigma made me feel very sad and depressed, and I felt that I had caused untold distress and pain to my family and friends. (P7)

The burden of missing family roles

The loss of physical function in ALS patients leads to difficulties in fulfilling their family roles, which often include roles as fathers, mothers or children. They are unable to support the older generation or provide support and care to the younger generation, not only failing to provide for their families but also becoming a burden on them.

> I'm sorry that my inability to take care of my children or my partner made me feel useless and powerless. (P17)
>
> I often feel guilty because I need to rely on my family to take care of my basic needs in daily life. (P9)
>
> I feel incredibly frustrated that I can't contribute to my family as much as I used to, and that I can't take on the housework and childcare responsibilities. (P12)

The burden of marriage's emotional needs

Among the interviewed patients, some are in their prime, with some having recently married. However, the disease's progression prevents them from fulfilling their partners' needs, including sexual intimacy, long-term companionship and emotional support.

> I sometimes feel helpless because I can't do the things I used to be able to do, which leads to me feeling like I can't give my wife enough support and love. (P18)
>
> I feel guilty because my illness has affected my marriage and prevented us from living a normal life. (P14)
>
> I feel sorry for my partner because he/she needs to take responsibility for caring for me and coping with my health problems. (P4)

The burden of offspring health

Following diagnosis, patients expressed concerns about the hereditary implications of their illness on the mental and physical well-being of future generations. The genetic nature of the disease heightened their psychological burden.

> I hope my children do not inherit my disease. I do not want to see them go through the same pain and suffering. (Cry) (P17)
>
> I don't want my son to feel anxious and low self-esteem because his father has ALS. (P12)

> I don’t know what I’d do if my children got sick because of me. (P3)
>
> I am afraid that my children will have bad psychological thoughts and excessive worries because of me. (P8)

Way forward—‘I’m in for a long fight’

Struggle between life and death

The treatment of ALS patients is expensive, lengthy and often painful. Facing these challenges, some patients may wish for relief through death, while the concern of their families and the hope offered by medicine keep them wavering between life and death.

> Because the disease makes me suffer so much, sometimes I don't want to live (Sign). But the thought that my children were too young and my family still needed me was painful inside me. (P12)
>
> My age has reached, a few years to live more than a few years of little difference, living instead of a drag on my son. But I just can't let go of my old mother, she is alone. (P11)
>
> I still believe in the progress of medicine, but in recent years, new treatment options have been slow to emerge. (P9)

Struggle between quality of life and the value of life

ALS patients dedicate significant time to rehabilitation and treatment activities to preserve a stable quality of life. However, this commitment often means sacrificing time for personal pursuits and potentially abandoning beloved activities. Many patients grapple with balancing their quality of life with finding meaning amid their illness.

> I often felt confused and lost because my quality of life was minimal, and I doubted whether I would be able to maintain a positive attitude and mood. (P22)
>
> I felt frustrated because I couldn't do what I used to love, and it made me question the meaning of my existence and the value of my life. (P17)
>
> I often struggle internally with my illness, trying to find meaning and purpose in my life that still has value. (P13)

DISCUSSION

Previous research has primarily focused on the disease experiences of ALS patients, aiming to construct a family self-help model and explore existential values from the patients’ perspective.[21] In contrast, our study specifically tracks the psychological distress arising during the course of ALS, aiming to delineate the psychological characteristics of patients. In this study, patients reported experiencing anxiety, unease, doubt and shock due to the disease, alongside the psychological burden of declining personal function, loss of family roles and emotional support and concerns about their children’s health. Ultimately, patients grapple with the balance between life and death, as well as between life quality and existential values. Our research provides insights into the psychological distress experienced by ALS patients within the context of existing studies.

As an incurable clinical condition, the uncertainty of disease prognosis and time left to live can significantly affect the mood of ALS patients.[34] During the diagnosis waiting period, patients may undergo a psychological process of breakdown, loss and self-denial.[35] Interviewees expressed feelings of hopelessness due to the disease’s incurable nature during this period, leading them to feel it pointless to plan for the future.[36] It is worth noting that the majority of interviewed ALS patients reported experiencing stigma associated with the disease, as highlighted in studies from Iran and the Netherlands, emphasising the psychological burden and negative emotions resulting from declining physical function, along with the impact of stigma on their quality of life.[22 25] Similar to previous research,[37] our study also documented how disease stigma influences the quality of life of ALS patients. As ALS advances, visible symptoms and reliance on assistive devices may increase stigma,[38 39] affecting social interactions and potentially leading to social isolation, distress, burden, and reluctance to seek help.[40 41]

Our study highlights family factors as the primary source of psychological burden for ALS patients. This burden mainly arises from the decline in physical function and resulting changes in family roles.[42] As physical abilities diminish, patients struggle to fulfil their usual household tasks and work obligations, often relying on caregivers for daily activities. Moreover, the physical fatigue caused by motor function loss can exacerbate psychological symptoms in ALS patients, impacting their overall quality of life.[43] The quality of life for ALS patients is positively associated with social support levels but negatively linked to feelings of despair, burden, distress and depressive symptoms.[44] As the disease progresses, patients increasingly depend on their families for additional assistance and support.[45] Research suggests that a lack of social support heightens psychological distress among patients, while caregiver burden decreases with higher levels of social support, emphasising the importance of societal support for ALS patients and their families.[22 45] Societal support typically encompasses strengthened policy protections and professional care, including long-term care insurance, medical investments, home visits, and community care.[46 47]

Additionally, interviewees expressed feelings of guilt and psychological burden towards their families. They attributed this to their inability to provide sufficient emotional support to their partners and concerns about their offspring. Typically, partners of ALS patients bear the primary responsibility for caregiving. Behavioural deficits in ALS patients and the time devoted to functional care are associated with caregivers’ depressive symptoms.[26 48] Particularly, younger partners not only face the challenge of balancing patient care with supporting family development but also find their needs unmet within the marriage. This has contributed to the rising mortality rates among partners of ALS patients in recent years.[49] Furthermore, ALS presents specific genetic characteristics,[50 51] prompting patients to worry about passing the disease to their offspring and causing them psychological distress. Compared with children from typical households, children of ALS patients are more prone to health and socioemotional issues, including somatic symptoms, social isolation, anxiety, depression, and low self-esteem.[52–56]

In comparison to Yuan *et al*'s study,[21] our participants were more inclined to discuss death. They perceived their care as a burden to their families, leading them to consider death as a means of alleviating this burden,[19] yet they grappled with the knowledge that their passing would bring irreparable sorrow to their loved ones. Furthermore, they struggled to find a balance between enhancing their quality of life through physical treatments, medications, rehabilitation and assistive devices and seeking meaning in life. Throughout the progression of the disease, patients may contemplate their existential significance, impact on others and future expectations.[57] This psychological struggle stems from the uncertainty faced by ALS patients,[34] who worry about their inability to contribute meaningfully or become a burden to their families and society.

Improving the psychological well-being of ALS patients involves several approaches. First, change coping techniques and strategies.[58 59] Patients can reduce psychological stress by either addressing the problems causing distress (problem-focused strategies) or managing emotional responses to stressors (emotion-focused strategies).[40] Second, increasing social awareness and understanding is crucial. Combating stigma against ALS patients involves openly discussing the condition, engaging in positive social interactions and rejecting negative attitudes.[60] Positive thinking interventions can also help reduce psychological distress caused by stigma.[61] Finally, prioritising the quality of life for ALS patients and their families is essential. This includes raising awareness through community activities, providing psychological support for family members and educating about attitudes towards death.[21 62]

Our study findings indicate that ALS patients experience a diverse range of psychological distress throughout the course of the disease. These distresses are pervasive throughout the entire progression of the illness and cannot be resolved with a quick fix. Healthcare professionals and relevant mental health intervention specialists need to develop targeted intervention measures based on the specific reasons for psychological distress in ALS patients. Additionally, attention should be paid to the psychological well-being of ALS patients' family members, particularly partners and children. In the future, establishing systematic psychological intervention programmes for ALS patients and their families would be meaningful, involving longitudinal tracking of their psychological changes and long-term monitoring and adjustment of their emotional states.

Several limitations of our work should be acknowledged. First, due to limited accessibility of the study population, all 22 participants in this study were from the same region in China, making it challenging to generalise their experiences to patients from other regions who may have different experiences. Second, due to factors such as varying lengths of hospital stays and high consultation rates, this study is cross-sectional, with participants being interviewed only once without longitudinal tracking. We believe this is necessary for future research. Additionally, some patients may have limited language expression due to the underlying disease, so we attempted to combine facial expressions and body movements or aids (such as writing boards and computer typing) to gain a more accurate understanding. Our study only included ALS patients themselves; future research could consider exploring the psychological distress experiences of ALS patients' caregivers.

CONCLUSION

This study outlines the psychological distress experienced by our ALS patients throughout their illness. Building on this, we conducted a detailed analysis of the factors contributing to psychological distress in ALS patients. The varied types and causes of psychological distress among different patients underscore the importance of tailored psychological interventions. Enhancing patient quality of life and providing social support are essential measures for improving patient psychological well-being. This research can inform the development of psychological intervention strategies and contingency plans for ALS patients and their families in the future, aiding mental health professionals and caregivers in establishing personalised psychological intervention plans to enhance the psychological resilience of ALS patients and their families.

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Competing interests None declared.

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Patient consent for publication Consent obtained directly from patient(s).

Ethics approval This study involves human participants. This study was approved by the Ethics Committee of Hubei Provincial Hospital of Traditional Chinese Medicine (HBZY2022-C42-01). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Data may be obtained from a third party and are not publicly available. The data sets generated and analysed during the current study are not publicly available for privacy and confidentiality reasons.

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Supplement 1：Interview outline used in this study

(1) What psychological feelings do you experience when you are diagnosed with amyotrophic lateral sclerosis (ALS)?

(2) Can you describe to us the psychological distress you experience during the diagnosis and treatment of the disease?

(3) What was your greatest psychological distress after being diagnosed with ALS?

(4) Tell us about your feelings and mental state during the most challenging time.

(5) Can you describe your psychological feelings and thoughts when you think about the future?

(6) Is there anything else you would like to share or any other experiences you'd like to talk about?

Supplement 2

Table 1 Demographic information of the participants (n=22)

Participants	Age	Gender	Educational level	Marital status	Current work status	Family Caregiver(s)	Time since symptom onset (months)	Time since diagnosis (months)	Symptoms of the Disease	Site of onset
P1	51	Male	Undergraduate	Married	Unemployment	Spouse	13	10	Sporadic	Bulbar onset
P2	57	Female	Junior college	Married	Unemployment	Spouse	12	11	Sporadic	Limb onset
P3	60	Male	NA	Married	Retired	Spouse	5	3	Sporadic	Limb onset
P4	56	Female	Junior High School	Married	Unemployment	Spouse	12	9	Sporadic	Bulbar onset
P5	45	Male	Undergraduate	Married	On leave	Elders	9	7	Sporadic	Limb onset
P6	54	Male	Junior college	Married	Unemployment	Son	9	8	Sporadic	Limb onset
P7	44	Female	Technical Secondary School	Married	On leave	Aunt	6	4	Sporadic	Limb onset
P8	35	Male	Undergraduate	Married	On leave	Father	12	10	Familial	Limb onset
P9	47	Male	NA	Married	On leave	Spouse	53	47	Sporadic	Bulbar onset
P10	45	Male	Undergraduate	Married	On leave	Brother	17	14	Sporadic	Limb onset
P11	54	Male	Junior college	Married	Unemployment	None	6	3	Sporadic	Limb onset
P12	35	Female	Undergraduate	Married	On leave	Spouse	9	8	Sporadic	Limb onset
P13	57	Male	Junior college	Married	Unemployment	None	10	5	Sporadic	Limb onset
P14	49	Male	NA	Married	On leave	Aunt	5	2	Sporadic	Limb onset
P15	47	Female	Technical	Married	On leave	Spouse	8	3	Sporadic	Limb onset

			Secondary School							
P16	33	Male	Junior college	Married	On leave	Mother	17	14	Sporadic	Limb onset
P17	55	Female	NA	Married	Retired	Spouse	6	2	Familial	Limb onset
P18	49	Male	Junior college	Married	On leave	Brother	25	20	Sporadic	Limb onset
P19	53	Male	primary school	Married	Unemployment	NA	5	1	Sporadic	Limb onset
P20	44	Male	Technical Secondary School	Married	Unemployment	Spouse	6	3	Sporadic	Limb onset
P21	30	Female	Undergraduate	Married	Unemployment	Spouse	27	23	Sporadic	Bulbar onset
P22	42	Female	Undergraduate	Single	Unemployment	Niece	24	18	Sporadic	Limb onset