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Living with Amyotrophic Lateral Sclerosis (ALS): Navigating the Various Emotional and Psychosocial Challenges

Wang Dan [1,2,3], Sheilla M. Trajera [4,*] and Gregory S. Ching [5,*]
Graduate School, University of St. La Salle, Bacolod City 6100, Philippines; s0885420@usls.edu.ph
RN, Associate Chief Nurse, Department of Neurology, Henan Provincial Key Medicine Laboratory of Nursing, Henan Provincial People's Hospital, Zhengzhou, Henan 450003, China
Faculty, Zhengzhou University People's Hospital, Henan University People's Hospital, Zhengzhou, Henan, 450003, China
Faculty, BSN, MN, and PhD Programs in Nursing, University of St. La Salle, Bacolod City 6100, Philippines
Faculty, Graduate Institute of Educational Administration and Policy, National ChengChi University, Taipei City 116, Taiwan
Correspondence: s.trajera@usls.edu.ph; gching@nccu.edu.tw

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Abstract: ***Background/Objectives****: Amyotrophic Lateral Sclerosis (ALS) is a progressive neurodegenerative disorder with no known cure, leading to significant emotional and psychosocial challenges for both patients and their families. This study explored the lived experiences of ALS patients to deepen the understanding of their unique psychosocial needs, aiming to inform and improve patient-centered care approaches.* ***Methods****: Using a phenomenological approach, this qualitative study conducted in-depth interviews with 12 purposefully selected ALS patients from a general hospital in China. The collected data were analyzed to uncover key themes and sub-themes reflecting of the patients' lived experiences.* ***Results****: The analysis revealed four central themes with respective sub-themes: a) Embracing Adversities of Disease Progression – encompassing Physical Disorders, Cognitive Differences, and Psychological Distress; b) Adopting Differences of Cognitive Diversity – highlighting Self-Recognition Diversity, Role Adaptation Difficulty, and the Neglect of Privacy; c) Satisfying the Need for Support – including Social, Family, Financial, and Medical Support; and d) Coping Challenges and Strategies – such as Communication Barriers, Decision-Making Conflicts, Future Uncertainty, and Diversity of Resilience. These themes illustrate ALS patients' multidimensional challenges, particularly in end-of-life care contexts.* ***Conclusions****: The findings emphasize the necessity for comprehensive psychosocial support systems for ALS patients. A model for psychological intervention rooted in Multifaceted Comprehensive Cooperative Support is recommended to aid patients' adaptation and coping mechanisms throughout their ALS journey.*

Keywords: *Amyotrophic Lateral Sclerosis (ALS); Lived Experience; Psychosocial Support; Phenomenological Approach; Patient-Centered Care; End-of-Life Care; Emotional Well-being*

Introduction

Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease that significantly impacts patients' physical, communicative, and cognitive functioning [1,2]. Characterized by progressive muscle paralysis, loss of mobility, dysarthria, and dysphagia, ALS severely affects patients' quality of life [3]. Aside from a life expectancy of only three to five years following the onset of symptoms, ALS imposes a considerable physical, emotional, and psychological burden on both patients, caregivers, and their families

[4,5]. Understanding ALS patients' lived experiences is essential for informing healthcare practices, as it promotes a more patient-centered approach [6,7]. Thus, allowing healthcare providers to respond more effectively to ALS patients' emotional and spiritual needs.

Previous research underscores the foundational role of psychosocial support for ALS patients in finding meaning amid the challenges brought forth by the illness. This process lays a basis for comprehending the profound emotional effects of ALS on patients and their families [8]. Studies have showcased the unique challenges ALS patients encounter in seeking purpose, emphasizing the importance of patient-centered approaches that attend to the existential needs of this population [9,10]. Given the disease's extensive toll on both physical and mental health, examining how patients cope with their diagnosis can guide healthcare professionals in tailoring psychosocial support to meet individual needs [11,12].

Literature also highlights the importance of meaning-making for ALS patients. Researchers have found that ALS patients' search for meaning can be enhanced by social relationships, personal goals, and autonomy [13,14]. Identifying the meaning that patients with ALS find in their circumstances may inform interventions to improve their quality of life. Alternative psychotherapeutics can then be made available to ALS patients, providing valuable insights into options for improving their quality of life [15]. These studies emphasize that exploring meaning-making in ALS patients' lives can inform interventions that will enhance the quality of life and help maintain a sense of purpose and dignity. Findings from such research can also help shape advocacy and policy efforts, leading to the development of support systems that prioritize ALS patients' specific needs [16].

This study aims to investigate how individuals with ALS perceive the meaning they derive from their experiences with this progressive and life-limiting illness. Providing insight into the emotional, psychological, and social dimensions of ALS patients' journeys will assist healthcare providers and policymakers in improving the care provided to patients with ALS. Ultimately, this research seeks to provide a comprehensive understanding of ALS patients' psychosocial support needs and propose a model of psychological intervention through a Multifaceted Comprehensive Cooperative Support approach designed to assist patients in improving their adaptability and coping strategies.

Materials and Methods

Descriptive Phenomenological Research

This study utilized a qualitative research design grounded in descriptive phenomenology to explore the lived experiences of ALS patients [17]. Descriptive phenomenology is particularly suitable for capturing individuals' firsthand experiences and the meanings ascribed to them since it emphasizes the subjective nature of these experiences without imposing preconceived theories [18,19]. In healthcare and nursing, understanding the concept of finding meaning can provide vital insights into how individuals navigate their life experiences, even when faced with chronic illness or adversity [20]. The study utilized in-depth interviews and face-to-face video conversations via Zoom to gather rich, descriptive data, creating an environment where participants could openly share their experiences. In descriptive phenomenological research, such in-depth interviews are a fundamental data collection method, allowing researchers to access personal narratives and understand the core of a lived experience [21]. Through this approach, the study sought to uncover the essence of ALS as lived and perceived by individuals who directly confront the challenges of this condition.

Participants and Recruitment

The target population for this study consisted of ALS patients receiving treatment at a tertiary hospital in Henan Province, China, for at least one month. Participants were recruited through purposive sampling, with the researcher contacting ALS treatment centers to identify individuals who met the inclusion criteria [22]. In a lived experience study, purposeful sampling is essential since it allows researchers to select

participants with characteristics or experiences critical to the investigation's objectives [23,24]. Eligible participants were approached, provided with detailed information about the study, and asked to give their informed consent before participation. Before conducting the interview, the study protocol was first reviewed and approved by the panel of evaluators of the University of St. La Salle Graduate Program and the Institutional Review Board of Henan Provincial People's Hospital in Henan, China.

The participants included individuals diagnosed with ALS [25] who were willing to share their experiences. A total of 12 participants were included in the study, determined by data saturation, which ensured a comprehensive understanding of the phenomenon [26]. Data saturation was reached when further interviews or data collection no longer yielded new insights or themes [27]. With a sample size of 12, the researcher aimed to gather diverse experiences, ceasing recruitment once participants began to repeat points made by others [28]. To protect participant privacy, each individual was assigned a pseudonym: Anton, Bobby, Celia, Den, Elen, Felix, Green, Hellen, Iven, Jogger, Kendy, and Lin.

Inclusion criteria for participation were as follows: patients diagnosed with ALS, aged 18 years or older, currently undergoing or having undergone some form of therapeutic intervention related to ALS management. The exclusion criteria included individuals with cognitive impairments that hindered their ability to provide informed consent or participate effectively in interviews, and patients with severe communication difficulties that affected their capacity to express their experiences. Cognitive impairments were assessed by the Montreal Cognitive Assessment (MoCA) screening tool [29].

Table 1 presents the demographic and background details of the study participants, including age, gender, marital status, highest educational attainment, insurance type, original disease, and functional status. All participants were ALS patients receiving treatment at a certified tertiary hospital in Henan Province. The ages of the participants ranged from 22 to 68 years. Among the 12 participants, two were under 40 years old, two were between 40–50, two were between 51–60, three were 61–65, and two were 65–68. The youngest participant was a 22-year-old male diagnosed with ALS within the last 36 months.

Regarding gender, eight participants were male, and four were female. All but one participant was married; the remaining participant was divorced and primarily relied assistance from his parents. Those with stable marital support generally reported stronger social support networks. In addition, the participants exhibited diverse educational backgrounds: three completed middle school, three held high school diplomas, and six possessed bachelor's degrees. This variation in educational attainment influenced their access to healthcare resources. Insurance types among participants included city medical insurance, provincial medical insurance, commercial health insurance, and the New Rural Cooperative Medical Insurance. Notably, three participants were self-paying, indicating financial pressures due to non-fixed employment or lack of insurance. At the time of the interview, the functional states of the participants varied, reflecting the spectrum of ALS progression: three experienced paralyses in both legs or arms, five used crutches for mobility, three had breathing difficulties, and one had limited hand movement. The median duration since ALS diagnosis was approximately around 8.4 months, with six participants experiencing severe symptoms for over one year.

At a glance, younger patients faced career and family planning challenges, while older patients contended with issues related to retirement and independence. Economic factors significantly affected participants' access to healthcare and caregiving support, with those possessing better financial resources experiencing a reduced burden as compared to self-paying participants. Higher educational attainment correlated with increased awareness and adaptation to the challenges posed by ALS. Female participants generally received more family support, while some male participants incurred some emotional instability during the early stages of their diagnosis.

Table 1. Profile of the Participants.

Participants	Gender	Age	Marital Status	Occupation	Educational Level	Insurance Conditions	Original Disease	Months with ALS	Functional State
Anton	Male	48	Married	Employee	High School	Provincial Medical	Ocular	7	Both legs paralyzed
Bobby	Male	48	Married	Teacher	University	City Medical	Limb	11	Walking on crutches
Celia	Female	42	Married	Civil Servant	Middle School	City Medical	Bulbar	8	Breathing difficulties
Den	Male	52	Married	Self-employed	High School	Commercial Health	Respiratory	3	Both arms paralyzed
Elen	Male	44	Married	Employee	University	Provincial Medical	Limb	1	Breathing difficulties
Felix	Male	22	Married	Engineer	University	Self-payment	Limb	36	Both arms paralyzed
Green	Female	61	Married	Teacher	University	Provincial Medical	Respiratory	13	Breathing difficulties
Hellen	Female	62	Married	Salesman	University	Self-payment	Ocular	35	Walking on crutches
Iven	Male	66	Divorced	Self-employed	Middle School	Self-payment	Ocular	18	Walking on crutches
Jogger	Male	51	Married	Athlete	Middle School	City Medical	Respiratory	1	Walking on crutches
Kendy	Female	64	Married	Administrative Staff	University	City Medical	Ocular	17	Walking on crutches
Lin	Male	66	Married	Civil Servant	High School	Provincial Medical	Respiratory	28	Moves hands slightly

Setting

Participants for this study were recruited from the ALS wards at Henan Provincial People's Hospital and through ALS support groups. The list of ALS patients was obtained from the Neurology Department, and potential participants were screened based on the inclusion and exclusion criteria. The researcher approached those meeting the eligibility requirements with assistance from a trained research assistant who coordinated with ALS care centers, arranged the Zoom interviews, and facilitated informed consent procedures. Contact was typically made through face-to-face Zoom video interviews. Qualified patients were informed of the study's purpose, voluntary nature, and confidentiality measures. All eligible participants agreed to join, and informed consents were obtained before the start of the formal interview. Both the researcher and the assistant conducted interviews via Zoom. The research assistant, trained in qualitative research for over six months by the hospital, was equipped to handle patient interviews effectively, having developed rapport through their work in ALS care [21]. Additionally, to ensure the participants' well-being, a psychologist was available outside the interview setting to respond to any emergencies that may arise. Rapport with participants was further cultivated through strategies such as clear communication and respect for their experiences [20]. The researcher's pre-existing positive relationships with patients also contributed to a supportive interview environment.

Semi-structured interviews took place in a private and comfortable setting, with attention to participant autonomy. Participants were given written information beforehand, allowing time to reflect and ask questions. They were reassured that they could withdraw at any time without repercussions, ensuring that participation did not affect their care. Clear, detailed explanations were provided about confidentiality measures, participants' rights, and the voluntary nature of the study, thus creating an environment conducive to open expression [30]. Interviews were audio-recorded with participants' consent, supplemented by field notes to capture non-verbal cues. Probing questions encouraged participants to share their thoughts and emotions fully. Interviews continued until data saturation was achieved, wherein no new themes or insights emerged, ensuring a comprehensive understanding of the experiences under study [27].

Most interviews were conducted in the researcher's quiet, private office to ensure a conducive environment, with the research assistant on hand to manage logistical and technical details. Given that the principal researcher was based in the Philippines, the assistant also helped facilitate the local context, enhancing participants' sense of safety and comfort during the interviews. After each interview, audio recordings were transcribed, and NVivo software was used for qualitative data analysis. The research assistant further supported data accuracy by assisting with transcription and handling NVivo coding to ensure reliable, organized analysis of the gathered qualitative data.

Data Analysis

Data analysis followed Colaizzi's phenomenological thematic analysis approach, employing a structured, seven-step method to uncover the essence of participants' experiences with ALS [31]. Colaizzi's approach involves the following steps:

Familiarization: The researcher began by thoroughly reading and re-reading the participants' accounts of their experiences with ALS to gain an in-depth understanding.

Identifying Significant Statements: All statements directly relevant to the experience of living with ALS were extracted, capturing details that reflect the participants' perspectives.

Formulating Meanings: Meanings were formulated from these significant statements to represent each participant's experience of ALS.

Clustering Themes: Identified meanings were grouped into clusters of themes that recurred across participants' narratives.

Developing an Exhaustive Description: An inclusive description of the lived experiences with ALS was created, incorporating the clustered themes.

Producing the Fundamental Structure: The exhaustive description was condensed into a brief, essential statement that captured the core structure of ALS experiences.
Seeking Verification: The researcher returned the fundamental structure to the participants, seeking their feedback on whether it was able accurately reflected their experiences.

The NVivo software (on lease agreement from Hearne Software) was used to facilitate efficient coding, aiding in categorizing themes and sub-themes and offering a structured approach to thematic analysis [32]. The software enabled the researcher to identify patterns in the data and allowed for a systematic organization of qualitative data. Feedback from member checking—participants' validation of the results—was incorporated into the analysis. Any discrepancies or additional insights provided by participants were reviewed and integrated to refine the findings. To enhance credibility, an expert with experience in the psychosocial aspects of ALS reviewed the interview questions. This expert served as an inter-rater, evaluating the questions' clarity, relevance, and comprehensiveness, ensuring that they were well-suited to elicit meaningful responses [33].
A detailed audit trail documented every stage of the research process, from modifications to the interview protocol and recruitment challenges to decisions in data analysis, ensuring transparency [34,35]. The researcher also maintained reflexive notes to document personal reflections, thoughts, and biases after each interview and data analysis session, which helped cross-check findings for consistency and dependability [36]. Finally, triangulation was employed, incorporating data from interviews and reflective notes to enhance the study's rigor [37].

Results

Based on the thematic analysis, four central themes emerged, each with their respective sub-themes: a) Embracing Adversities of Disease Progression – encompassing Physical Disorders, Cognitive Differences, and Psychological Distress; b) Adopting Differences of Cognitive Diversity – highlighting Self-Recognition Diversity, Role Adaptation Difficulty, and the Neglect of Privacy; c) Satisfying the Need for Support – including Social, Family, Financial, and Medical Support; and d) Coping Challenges and Strategies – such as Communication Barriers, Decision-Making Conflicts, Future Uncertainty, and Diversity of Resilience.

Theme 1 - Embracing Adversities of Disease Progression

As ALS progresses, patients confront the harsh reality of living with a condition for which there is currently no effective treatment [38]. This awareness can foster feelings of helplessness, particularly as their physical capabilities decline. Many patients increasingly depend on caregivers for basic needs such as clothing, food, housing, and transportation, which can impose significant emotional burdens on patients and their families, ultimately impacting overall well-being [4]. The disruption of daily routines often leads to a diminished sense of control, resulting in heightened anxiety and self-pity [39].

Physical Disorders

ALS primarily affects motor neurons, leading to significant physical impairments as the disease progresses [40]. Patients experience a gradual loss of muscle function, manifesting as difficulty with movement, speech, swallowing, and breathing. These physical disorders profoundly affect daily life, increasing dependence on caregivers and assistive devices [12,41]. Additionally, physical symptoms can lead to secondary complications such as malnutrition from dysphagia, respiratory issues due to weakened diaphragm muscles, and mobility-related problems like pressure ulcers and joint contractures [42]. Managing these physical symptoms necessitates a multidisciplinary approach that includes physical therapy, respiratory support, nutritional interventions, and adaptive equipment to enhance quality of life [43]. Despite these efforts, ALS remains terminal, with most patients eventually succumbing to respiratory failure [44]. The management focus is on improving comfort and preserving as much functionality as possible [45].

Elen's refusal to use a wheelchair exemplifies a common emotional response to the loss of independence and dignity. "*I saw some people in wheelchairs being pushed away. I said that such a life is not interesting. I don't need to tell my family that if I end up in that situation, they should just let me lie in bed instead of giving me a wheelchair. Don't treat me as a patient. I can do it myself, and if it comes to that, it's better to let me die*." As physical abilities decline, patients must confront their limitations; often undergoing a challenging acceptance process [46]. Felix's rapid weight loss underscores the physical toll of ALS and the critical importance of nutritional support, such as feeding tubes, to enhance quality of life. "*Since my diagnosis, the disease has progressed rapidly. I could hardly swallow for three months and lost 25 kilograms. Insufficient nutritional intake has created significant problems for me.*" While, Anton's feelings of isolation due to losing the ability to speak and movement further highlight the emotional impact of ALS. *"From the beginning of the disease, I could not move my entire body. My heart wanted to, but I lacked the strength. I started having difficulty swallowing and would choke from time to time. I could not speak or express myself normally, and I felt abandoned by the world."* Communication barriers can intensify the feelings of loneliness, making consistent emotional support vital for psychological well-being of the patient [47]. These narratives emphasize the necessity of holistic care that addresses the emotional, social, and physical challenges faced by patients with degenerative diseases, underscoring the importance of feeling loved and understood.

Cognitive Differences

Cognitive diversity in ALS patients can be categorized based on the degree and type of cognitive impairment, which may include no cognitive impairment, mild cognitive impairment, frontotemporal dementia, executive dysfunction, language dysfunction, and behavioral changes [48]. This cognitive variability highlights how ALS differentially affects brain function, necessitating ongoing assessment and tailored support to meet individual patient needs [49]. The experiences of Anton and Den illustrate the varied cognitive challenges faced by ALS patients as the disease progresses. Anton describes difficulties with organization, decision-making, and multitasking. "…*I used to be organized, but now I forget appointments and struggle to keep things in order. My thoughts are scattered, and even small decisions feel overwhelming. I can't juggle tasks like I used to. …trying to do more than one thing at a time leaves me confused."* While Den notes a sense of slowed processing that complicates planning and adapting to unexpected changes. "*My mind feels slower; I need more time to process information or respond, especially in conversations or problem-solving. Simple tasks, like planning meals or adapting to changes, are now difficult, and unexpected events throw me off completely."* These cognitive burdens highlight the necessity for comprehensive care that addresses both physical symptoms and emotional and psychological needs [50]. By recognizing the full spectrum of cognitive diversity in ALS patients, caregivers and healthcare providers can create a more compassionate and effective support system that promotes dignity and quality of life.

Psychological Distress

ALS is a progressive neurodegenerative disorder that poses considerable psychological challenges for patients [15]. This distress is particularly pronounced in relation to medical uncertainty, attitudes toward death, and the stigma associated with the disease [51,52]. Through cognitive and behavioral strategies, ALS patients can learn to cope with feelings of helplessness and despair [53,54]. Engaging in open communication with healthcare providers, family members, and support groups also facilitates this process [49]. By addressing fears and uncertainties about the future, patients can begin to reconstruct a new sense of self that aligns with their current realities [55]. The experiences of Elen and Anton reveal the profound psychological distress and emotional burden associated with ALS, as well as the struggle to build resilience. Elen perceives herself as a burden to her family, withdrawing from social interaction and feeling overwhelmed by her loss of autonomy, which points to depression and emotional isolation. *"I feel like a burden to my family, and life feels miserable. I don't understand why I suddenly lost the ability to move. My symptoms started in my limbs and have spread, leaving me unable to care for myself. The psychological*

weight is immense, and even when my daughter offers to take me for a walk, I decline. Life feels dark, and when relatives visit, I avoid talking, sensing their pity."

Anton similarly expresses distress over his rapid decline, anxiety regarding financial strain, family burden, and dependence on assistive devices like ventilators, heightening his emotional distress. *"At the start of the year, I could still take my children to school. Now, only months later, I struggle to swallow and breathe, and the tubes make me feel like my body is no longer mine. I'm bedridden, worrying about bedsores and needing help to move. I can't read or speak easily, relying on my family to guess my needs. ...I used to love dancing and socializing, but now I feel disconnected. The diagnosis was long, and the financial burden of ventilators weighs on my family, which I resist. My deepest fears are losing loved ones and financial stability."* These accounts illustrate the complex interplay between physical decline and the quest for meaning in life. Feelings of being a burden to loved ones and the emotional isolation accompanying the loss of autonomy can lead to depression and withdrawal from social interactions [56]. The anxiety surrounding financial strain and dependence on assistive devices exacerbates this emotional suffering [50]. In reality, the internal conflict between needing support and fearing dependency underscores the importance of addressing both physical and emotional aspects of the disease. These narratives highlight the necessity for holistic care strategies that not only manage physical symptoms but also foster emotional resilience, enabling patients to navigate their challenges more effectively.

Theme 2 - Adopting Differences of Cognitive Diversity

Cognitive diversity in ALS patients encompasses a wide array of cognitive and psychological experiences as they navigate their illness [50]. This diversity reflects how patients perceive and adapt to changes in self-identity, evolving roles in personal and professional life, and privacy concerns [57,58].

Self-Recognition Diversity

The progressive decline in physical and cognitive abilities necessitates a redefinition of self-identity for ALS patients [59]. Self-recognition involves a psychological process through which patients reconcile with their changing condition, often resulting in cognitive dissonance between their past selves and present capabilities [60]. This dissonance can trigger a reevaluation of self-worth and identity, leading to emotional distress [61]. Research indicates that ALS patients frequently grapple with altered self-perception as the disease imposes limitations that starkly contrast with their pre-ALS identities [14,62,63]. Such confrontations can actually provoke psychological turmoil. Nonetheless, this period of self-recognition can also foster psychological resilience, as patients develop a redefined sense of self that accommodates their new reality [64].

The narratives of the participants reveal profound struggles with self-recognition as ALS disconnects patients from their former identities. Hellen's severe weight loss leaves her feeling like a "ghost" of her former self, undermining her sense of purpose. "*there is no dignity and life have no meaning. I have lost 35 pounds. I don't look like myself…so how can there be life meaning and dignity in the long run?"* Similarly, Bobby grapples with existential distress and isolation, fearing he is a burden to his loved ones. *"I felt like a burden to my family… I was afraid but couldn't stop worrying about my wife and son's future. The rapid progression of my disease makes psychological adjustment so difficult."* The rapid progression of ALS complicates efforts to reconcile current identities with past selves, creating a crisis of meaning [65]. Thus, psychological support is vital, helping patients maintain a sense of self and purpose amid these changes [66]. The existential distress varies; some find acceptance and meaning in life, while others face heightened anxiety and social stigma, which deepen isolation and lower self-esteem [63]. Addressing these complex psychological needs is crucial for supporting ALS patients in finding dignity and resilience amid overwhelming change.

Role Adaptation Difficulty

Maintaining involvement in various life roles can foster dignity and meaning [49]. However, as noted earlier, the progression of ALS often necessitates significant changes in personal and social roles, shifting from independence to increased reliance on caregivers. This transition can evoke feelings of lost purpose and autonomy, leading to helplessness and depression [56]. Conversely, successful role adaptation is linked to improved psychological well-being in ALS patients [47]. Those who adjust effectively to new roles, often with support from family and healthcare providers, report lower anxiety and depression levels [66]. Hence, finding new ways to contribute is essential for maintaining individual's self-worth.

The experiences of participants highlight the struggle with independence and changing family roles. Anton and Celia mourn their inability to fulfill former roles, heightening their sense of loss. Anton expresses, "*I used to be the breadwinner of the family, but now I am the one that needed support… It's really hard to let go of that sense of control. I worry that I'm no longer the partner they married."* Celia adds, "*it's not just the big things, such as giving up work… that are tough. It's the little things too… Every small loss feels like another piece of me is slipping away."* Conversely, Elen and Green exemplify how adapting to dependencies can foster resilience. Elen reframes accepting help as a strength. Reflects, "…*asking for help feels like admitting defeat. But I'm starting to realize that letting others in is a different kind of strength."* Green's focus on control empowers him amid decline. Green states, "…*every day is a battle between what I've lost and what I still have. I focus on what I can control, even if it's just my attitude."* These narratives underscore the need for supportive environments to help ALS patients maintain dignity and acceptance amid changing dynamics. In reality, ALS patients can find meaning through various values that help facilitates coping with the disease [8,13]. Spiritual values also help transcend physical limitations by finding peace through faith, while experiential values offer additional connection through relationships and meaningful moments [67]. Embracing these pathways can help ALS patients retain dignity, purpose, and fulfillment throughout their journey.

Neglect of Privacy

As ALS progresses, privacy concerns become increasingly salient. The reliance on others for personal care can evoke feelings of vulnerability and diminished privacy [68]. Additionally, the terminal nature of ALS amplifies emotional and cognitive challenges surrounding privacy [69]. Many patients engage in estate planning to ensure their wishes are respected, making privacy crucial for maintaining psychological well-being [45,70]. Studies suggest that creative activities can also foster emotional healing and agency, highlighting the importance of retaining control over personal information as the disease advances [71,72]. The experiences reveal significant concerns about privacy and the management of personal health information in ALS. Den recounts, "*when I was first diagnosed, it was like a bolt from the blue… I didn't want my mother to know, yet the doctor told my family without my consent."* Jogger shares, "*I have a little grandson… I could not believe I would one day be unable to help him, which made me question my life's meaning."* Consequently, the emotional distress resulting from the loss of privacy and autonomy compounds the psychological challenges faced by patients. Lin expresses discomfort, stating, "*I feel my value is diminished. The doctor revealed my illness without regard for my privacy, making me feel like a burden to my family."* Hellen adds, "…*I couldn't eat after my last examination, fearing death. The doctor didn't respect my wishes, leaving me feeling responsible for my family's future."* Addressing these issues is essential to supporting ALS patients in maintaining their dignity as they navigate their illness.

Theme 3 - Satisfying the Need for Support

Most ALS studies emphasize the importance of support in alleviating the patient's quality of life and well-being [73,74]. The majority of these supports are in the form of social, family, financial, and medical assistance. In addition to these supports, psychological counseling can play a crucial role in helping patients cope with the emotional challenges of the disease [70]. Access to adaptive technologies, such as communication devices, is also vital for maintaining independence and connection with others [75,76].

Moreover, creating a strong community network can provide a sense of belonging and reduce feelings of isolation [77].

Social Support

Social support from colleagues, neighbors, friends, parishioners, and patients is crucial in helping individuals maintain a sense of purpose in life [73]. While in the early days, many ALS patient express dissatisfaction with the level of social support available [78]. Currently, awareness of ALS has increased, leading to more visible social support over time [79]. The narratives of Iven, Jogger, and Lin emphasize the vital role of social support in the lives of ALS patients. Iven acknowledges the care he receives from his community, which sustains him during difficult times, demonstrating how strong social networks can enhance patient resilience. "*Talking with you makes me realize my progression seems slow, and I feel I can still maintain my current state and accomplish some things. I can still speak, and if that changes, I'll use a writing board. I manage household chores and feel deeply grateful for the care and love from everyone. Community lectures and painting workshops have lifted me through some of my darkest times. ...I have so many colleagues and friends who care for me. Their support motivates me; I realize that while the length of life is important, the quality of life matters even more."* Jogger's optimism regarding medical advancements reflects a widespread hope among ALS patients that research and community support may yield new treatments. His determination to find meaning in life, despite his challenges, illustrates how external support can inspire patients to overcome despair and seek purpose. "*With medical advances progressing fast, I hope to persist and live well each day, hoping for a future with new treatments. Even if they don't cure ALS, they may slow it down. The support I receive from society has been a true source of warmth, giving my life meaning and steering me away from despair. I aim to make the rest of my life count."* Lin noted that "*I have a family nearby that I usually visit, and although they used to be very polite, now they're less formal. I analyze their mindset—they probably think I'm going to die, which they find futile. However, I find comfort in visits from friends at my church. Sometimes, help comes from friends who truly understand me, rather than from those who cannot."*

From the perspective of social support, the search for meaning in life can be approached through spiritual, experiential, and creative values [67]. Spiritual values help patients connect with a higher purpose or belief system, offering comfort and acceptance during difficult times [80]. While, experiential values highlight the significance of relationships and shared moments, enabling patients to find joy in everyday interactions with loved ones [62]. For some, creative values allow patients to express themselves and contribute to their communities, reinforcing their identity beyond their illness [72]. All together, these values underscore how social support fosters hope, resilience, and a renewed sense of purpose for ALS patients, enhancing their overall well-being.

Family Support

The experiences of ALS patients reveal that the meaning of life is shaped by familial support, personal autonomy, and social expectations. Family understanding and respect provide essential emotional resilience, empowering patients to confront their disease with determination and an active approach in managing their condition [12]. However, societal norms and family expectations can also influence treatment decisions, with patients sometimes prioritizing the well-being and reputation of their families over their personal preferences [23,62]. This relationship dynamics can actually lead to patients following family advice, even when it contradicts their desires, highlighting the role of familial duty in shaping decisions [81]. Furthermore, a tension often exists between personal autonomy and the care provided by loved ones [82]. It is quite common that in the beginning patients may resist certain interventions, however, they eventually come to recognize and accept the care and love offered by their families.

The meaning of life for ALS patients is intricately tied to their familial relationships, where emotional support, care, and respect play pivotal roles. This interplay highlights the profound emotional and practical

assistance families provide, while also reflecting the compromises in autonomy that sometimes arise in the interest of maintaining family harmony. However, these relationships can introduce challenges, especially concerning autonomy and decision-making. As seen with Elen and Lin, "*I try to communicate my thoughts to my wife and children. They understand and respect my decisions, which provides the biggest support of my life. I believe in my ability to fight this disease and I want to make the best plans and preparations. …I strive to understand the disease and actively pursue treatment…"* stated Elen. Lin also noted "*I resisted seeing a doctor, but my family criticized my choice. They believed they are right, while I felt I was. Eventually, I lost that battle… I know, they meant well, wanting the best for me, and I recognize their love and care."* While family members provide essential care and emotional sustenance, they may also exert social and cultural pressures that shape patients' choices, as Celia demonstrated, "*I don't wish to treat this disease, but I think about my son's feelings and how others might perceive them. My son buys me a lot of supplements, but I already have lots of medicine, but since he already bought them, I end up eating them. I often remind myself, …I am old already, I should listen to my son."* Ultimately, the meaning of life for ALS patients often emerges from this complex dynamic between love, care, personal agency, and the expectations of their loved ones.

Financial Support

The financial burden of ALS can be overwhelming for patients and their families, leading to lost income, rising medical bills, and the need for costly adaptive equipment [83]. This financial strain exacerbates the emotional and psychological stress already associated in living with ALS [84]. The experiences of Felix, Kendy, Celia, Green, and Lin illustrate the multifaceted nature of support in the lives of individuals with ALS, showcasing how both emotional support and practical (financial) assistance is essential for managing the challenges of the disease. Felix embodies hope, drawing inspiration from ALS advocates who have raised awareness and funds for treatment, demonstrating the power of community support. "*I still hold hope. I've seen many advertisements showcasing the efforts of ALS advocates… and I want to learn from them. …What happens when we can't afford the care I need? The uncertainty about the future is daunting. I know my treatment is costly, and I feel guilty that my family must bear that burden. Knowing that my insurance covers some expenses eases my guilt slightly, and I hope for more public welfare funding to support ALS."* Kendy's encounters with distant relatives reveal that, despite feelings of awkwardness, emotional support can significantly enhance one's well-being. "*Some distant relatives have come to see me. Although it feels a bit awkward, but I guess their concern is genuine. They uplift my spirits without saying anything negative; if they do express anything sad, it makes me uncomfortable. They've donated considerable money and supplies, helping my family navigate practical challenges. I am very thankful for government support; my family was struggling financially at one point, and my child nearly dropped out of school."* Their encouragement and financial assistance during challenging times underscore the importance of having a supportive network to alleviate practical burdens. Meanwhile, Celia and Green express concern over the stress their illness imposes on their families, acknowledging the emotional toll that caregiving can take on loved ones. Celia states "*It hurts me to see my family is stressed because of me. They each have their own lives, yet they are always here taking care of me. I used to take care of everyone, and now I can't even manage on my own." While, Green noted, "I fear that my illness will wear down the people that I the love most. I'm always worried about straining our relationships. Financially, I'm stable now, but if I weren't, I doubt I'd feel as good*." This recognition highlights the need to balance patient needs with caregivers' well-being.

Lastly, Lin's insights about financial reimbursement expose the systemic challenges faced by ALS patients as he grapples with the potential challenges faced during his medical treatments. *"I underwent chemotherapy at another hospital that reimbursed 80% of the costs. Here, I must cover all the expense by myself. My son left work after I got sick, and when he returned, it reminded me that everyone must prioritize their lives first. I worry that my illness might leave my son in debt. If only I could get some funding… Yet, I recognize that every country faces its challenges; I'm not complaining—just expressing a bit of discomfort."*

In sum, family members are often the closest caregivers, creating deep emotional bonds; but at the same time, also leading to feelings of dependency and guilt. Patients may struggle with the shift in family dynamics, moving from independent to requiring substantial assistance [84]. This sub-theme also highlights the distinct differences between domestic and foreign healthcare systems; in China, patients bear part of the financial burden, which can be particularly challenging for those with limited means [7,85].

Medical Support

Many ALS patients place substantial trust in healthcare providers to help navigate their complex medical needs [86]. This reliance, though comforting, can sometimes create a sense of dependence that challenges patients' autonomy, highlighting a delicate balance between trust and the desire for informed, independent decision-making [68]. The experiences of the participants underscore the critical role of medical support for ALS patients, especially concerning privacy, dignity, and finding meaning amid illness. Patients rely on healthcare teams for symptom management, guidance, and emotional support [43], but they also express a strong need for autonomy and respect. Anton's wish for more involvement in his care reflects a desire for autonomy, "*I trust my doctors to guide me, but sometimes it feels like I'm just following orders. It's comforting to have a knowledgeable team, but I wish I can understand more of what they're telling me."* While, Green's reliance on compassionate care emphasizes the importance of understanding and connection. "*My doctors and nurses are my lifeline. Every visit brings anxiety about new symptoms, but they comfort me and provide clear guidance."*
Similarly, Celia's frustration with hospital procedures "…*Going to the hospital is difficult; there are long waits, and it's hard to feel dignified. It feels like patients are an afterthought.",* and Elen's concerns about privacy reveal how the medical environment can impact dignity and comfort. "*There are seven people per ward and one shared bathroom. I feel anxious using it, afraid others will judge me. The lack of privacy is tough."* Meanwhile, Iven's optimism and focus on palliative care illustrate how proactive, compassionate care can foster resilience and a sense of purpose. "*Holding out hope for new treatments keeps me going. With my doctors' help, palliative care has gradually improved my quality of life."* In essence, a patient-centered medical approach that respects privacy, promotes dignity, and supports patients emotionally can deeply affect ALS patients' coping and overall well-being [45]. Expressing gratitude for their medical team also helps ease some of the emotional burden [87], emphasizing the importance of compassionate care in meeting ALS patients' complex needs.

Theme 4 - Coping Challenges and Strategies

ALS presents profound challenges that remain primarily insurmountable in medical science [38]. The uncertainties surrounding the disease's development, prognosis, and treatment pose significant coping challenges for patients [65]. Key issues include communication barriers, decision-making conflicts, future uncertainties, and varied expressions of resilience [6]. Communication difficulties can lead to feelings of isolation; however, using augmentative devices and participation in support groups can help maintain vital connections [75,76]. To add, decision-making conflicts often arise due to uncertainties about treatment options and differing opinions among family and caregivers [68]. Treatment often involves multidisciplinary teams and fostering open discussions can help alleviate these conflicts [49]. In addition, future uncertainties can also trigger anxiety [65], but mindfulness practices and engaging in meaningful activities should be able to provide a renewed sense of purpose. Finally, the diversity of resilience among patients highlights various unique coping strategies, including spirituality and creativity that are often bolstered by strong support systems [64]. By addressing these challenges with tailored strategies, ALS patients can navigate their circumstances more effectively, thus maintaining a sense of meaning and connection.

Communication Barriers

As noted earlier in the other themes, patients with ALS frequently encounter severe communication challenges due to the progressive loss of speech capabilities [88]. These barriers can lead to frustration and isolation, exacerbated by the variability in patients' abilities to express their needs, which may result in misunderstandings with family members and caregivers [38]. Furthermore, although assistive communication devices can aid in communication, their complexity can present additional challenges [76]. More important, cultural differences in perspectives of disease progression and end-of-life care may further complicate communication [89].

The experiences shared illustrate the emotional toll that communication barriers impose on individuals with ALS. Anton mourns his transition from a lively conversationalist to someone struggling to express even basic sentiments, leading to isolation and frustration. "*I used to be outgoing, talking and laughing easily. Now, even forming a sentence is difficult. My family tries to be patient… it's awkward when they finish my sentences, leaving me feeling helpless. I speak less now, which is isolating, and saying simple things like 'I love you' takes so much effort. I never realized how much I valued communication until it became a struggle. …feeling trapped while the world moves on."* He emphasizes how his family's well-intentioned efforts, such as finishing his sentences, exacerbate his sense of helplessness. Felix echoes this sentiment, expressing the difficulty of typing and the resulting disconnection, which leaves him feeling perpetually behind in conversations, eroding his sense of identity and voice. "*It's hard for my family to understand how tough communication is now. Typing is slow… their impatience shows, even if they don't mean it. When they say, 'It's okay, don't worry about it,' the more it makes me feel like I shouldn't even try. Nodding or shaking my head is easier, but it's not the same. I feel like I've lost my voice."* Together, their narratives underscore the relational challenges posed by communication barriers in ALS, highlighting the necessity for caregivers to understand and have patience in maintaining meaningful human connections.

Decision-Making Conflicts

The process of medical decision-making for ALS patients is laden with complex emotions as they navigate the progression up until the end-of-life situation [46]. Multiple psychological and emotional factors influence these decisions, each significantly impacting the patient's overall well-being [90]. Patients and their families face emotionally charged decisions about treatment and care [91]. Decisions related to invasive procedures, such as tracheostomy or feeding tubes, often create conflict due to the uncertainty of the outcomes [71]. Some patients may prioritize quality of life, while others may wish to prolong life as much as possible. Family members sometimes act as surrogate decision-makers, leading to further conflict if their views are contrary with the patient's wishes [92]. Effective decision-making requires clear communication and a shared understanding among the patient, family members, and medical team [49]. Patients frequently grapple with profound fear and uncertainty when making medical decisions, particularly given the unpredictable nature of the disease's progression [65]. The prospect of choosing among various treatment options or end-of-life care plans can be overwhelming [88].

The narratives of ALS patients like Jogger, Helen, and Kendy highlight the profound impact of difficult decision-making on their sense of privacy, dignity, and overall meaning in life. These decisions often involve intimate aspects of their care, which can feel invasive and expose them to vulnerability. For instance, Jogger expresses a deep fear that every medical choice may lead to further deterioration of his health. "*Every medical choice feels like a gamble. Should I try new treatments or focus on comfort? I worry about burdening my family, but I'm not ready to give up. The unknown feels paralyzing …each decision feels like a weight I can't lift."* From the perspective of life meaning, these challenges push patients to reflect on their priorities and what truly matters in life [90]. Hellen's paralysis in decision-making illustrates a struggle not just with the choices themselves, but also with the fear of losing control over her own life, prompting her to search for deeper meaning amidst uncertainty. "*ALS feels like it's taking my choices away, leaving me trapped in fear that each decision could cost me more time. I used to be active, now even walking*

across a room is a struggle. I focus on what I can still do—spending time with my family, reading to my kids. It's not the life I pictured, but I'm finding ways to find joy." This journey can also be seen as a creative exploration of identity, where patients like Kendy negotiate between independence and dependence, grappling with the implications of accepting help. "*Deciding on a feeding tube was a struggle—I wanted to keep my independence, but watching my body fail is humbling; I was always independent, but now I rely on others. Learning to accept help has been hard but also meaningful. This isn't the life I wanted, but I'm learning to with live it."* The internal conflict between the need for privacy and the overwhelming support from family and healthcare providers highlights the complexities of navigating ALS [93]. These experiences underscore the importance of creating supportive environments that respect patient privacy while encouraging open communication about their needs, fostering resilience, and allowing ALS patients to find meaning in their struggles. Collectively, the difficulties in decision-making does not only reflect the challenges faced by ALS patients, but also point towards a broader conversation about autonomy, respect, and creating an intricate balance between personal privacy and the necessity of support in the face of a debilitating illness.

Future Uncertainty

Uncertainty about the future is a significant psychological burden for ALS patients. The unpredictability of ALS's progression leaves patients uncertain about how quickly they will lose physical abilities or how long they have left [65,70]. This uncertainty impacts decision-making, as patients often struggle to pursue treatments aggressively [41]. Additionally, uncertainty about care options and financial implications weigh heavily on both patients and their caregivers [6,68]. Developing strategies to communicate this uncertainty and plan for future care is essential in alleviating the stress associated with the unknown [10]. The experiences of ALS patients highlight the profound sense of future uncertainty that significantly impact their decision-making and emotional well-being. This uncertainty is closely linked to social relationships, as individuals who derive meaning from connections and engage in self-reflection tend to live life to the fullest. For instance, Lin's transition from meticulous planning to an inability to make short-term decisions underscores the anxiety of losing vital abilities. "*I used to plan everything—five-year goals, retirement dreams. Now, I can't even plan next week… for me, the future feels like a black hole, and it's terrifying! …all of a sudden I might not be able to speak or breathe on my own."*
Similarly, Kendy grapples with concerns about her family's future, "*The future is a constant worry. I think about my family—will they be okay without me? I try to prepare them, but it's painful knowing I won't always be there."* While Jogger likens his daily uncertainty to living with a ticking time bomb. These feelings illustrate the emotional paralysis that can accompany chronic illness. "*The worst part of ALS is the uncertainty. I wake up each day wondering what ability I'll lose next. It's like living with a ticking time bomb. I want to focus on the present, but it's hard when I don't know how much time I have left."* Conversely, Anton find purpose through simple things, focusing on what they can offer rather than their limitations. "*My family gives me purpose now. I may not be able to do everything, but I can still be there emotionally—listening, advising, supporting. That's where I find meaning."* Anton's emotional presence for his family highlights an adaptive coping strategy. This narrative illustrates that resilience and the search for meaning in the present can transform the experience of living with ALS from despair to hope. The emotional struggles associated with future uncertainty can be met with resilience and adaptive strategies [94]. Finding meaning in the present, nurturing social relationships, and embracing small joys can transform the experience of living with ALS from one of despair to one of hope and purpose [95]. This potential for individuals facing chronic illnesses to cultivate a fulfilling life, even amidst uncertainty, is a powerful testament to human resilience.

Diversity of Resilience

Resilience in ALS patients is influenced by a combination of psychological, social, and existential factors that enable them to cope with the significant challenges posed by the disease [64]. Strong social support

systems play a crucial role in alleviating emotional distress and providing practical assistance [66]. Psychological flexibility allows patients to adapt their mindsets and focus on what they can control, such as meaningful relationships and activities [10]. Furthermore, maintaining hope and a sense of purpose, even amidst the realities of an incurable condition, is essential for fostering resilience [8]. Many patients find strength in spiritual or existential beliefs that offer meaning and comfort as the disease progresses [80]. Additionally, access to adaptive technologies enhances their ability to maintain independence and connections with the world, further supporting their resilience [75]. Altogether, these factors enable ALS patients to confront their challenges with strength and adaptability.

The resilience of ALS patients is often defined by their ability to adapt to the over-whelming physical and emotional challenges posed by the disease [64]. Once an active person, Hellen now faces significant limitations in her mobility. "*Before ALS, I was an active person, always running, hiking… Now, I can barely walk across the room… I feel like I've lost so much of myself. But I try to focus on the things I can still do, like spending time with my family. I may not be able to run around with my kids, but I can still read to them and be present for them. It's a different kind of life than I imagined, but I'm doing my best to find joy in it."* Although this drastic change has been challenging, she focuses on spending time with her family and finding joy in what she can still do. Her resilience lies in her capacity to shift her focus from what she has lost to what she still cherishes.

Similarly, Bobby illustrates how ALS has transformed his priorities. "*ALS has taken a lot from me, but it has also given me a new perspective. I used to be intensely focused on work, but now I realize what matters most is the time I have with the people I love. It's a hard lesson to learn, yet in a way, I'm grateful for it."* He no longer pursues work-related achievements, but instead values the small, meaningful moments shared with loved ones. For him, resilience emerges from accepting his new reality and discovering purpose in the relationships that matters the most. Resilience for ALS patients is fundamentally about accepting the irreversible changes brought on by the disease while seeking new sources of meaning and purpose [96]. Support from family, psychological flexibility, hope, and spirituality are crucial in helping them navigate the emotional and physical challenges of ALS [80]. By embracing reality and employing adaptive strategies [82], patients can shift their focus from what they have lost to what remains possible, empowering them to face the future with strength.

Discussions

This study aimed to explore the lived experiences of ALS patients in China, focusing on how they find meaning amidst adversity. From data analysis, four main themes emerged Embracing Adversities of Disease Progression, Adopting Differences of Cognitive Diversity, Satisfying the Need for Support, and Coping Challenges and Strategies. The theme Embracing Adversities of Disease Progression highlights the patients' struggles with losing control over bodies and the resulting emotional impact. Patients reported feelings of desperation, fear, and guilt toward family members as they grappled with the progression of ALS, resonating with previous research on the psychological distress [10,15]. Sub-themes include Physical Disorders, Cognitive Differences, and Psychological Distress — each representing aspects of ALS that prompt individuals to seek meaning and reshape relationships with family members and their senses. Many participants, under the threat of death, shifted from negative emotions to a renewed focus on life priorities, reevaluating personal values, and strengthening connections with family members [12].

Adopting Differences of Cognitive Diversity describes challenges patients faced with self-recognition, role adaptation, and privacy issues. Patients often struggle with adapting to the changes ALS brings, which sometimes prompted a deeper exploration of identity, leading to resilience and acceptance [46]. Some patients, especially those with strong moral beliefs, even questioned their faith, potentially influenced by cultural beliefs, which associates good acts with positive outcomes [80]. Faith has been shown to provide comfort and meaning in challenging times [67], highlighting the need for healthcare providers to consider patients' emotional and spiritual conditions. In addition, dignity in care remains paramount, as patients often

report feeling stripped of autonomy and self-worth in crowded healthcare environments where basic needs, such as privacy, are unmet. Dignity therapy and compassionate medical environments are shown to improve mental well-being by reinforcing patients' self-worth, especially in palliative and long-term care [63].

Another aspect is the Satisfying the Need for Support emerged as a critical theme, with sub-themes Social, Family, Financial, and Medical Support, illustrates the complex interactions between these components. These reciprocal relationship reflects cultural values of interdependence, which is particularly emphasized in Chinese familial and societal structures, where solidarity and mutual support are paramount [10]. This mutual support creates an adaptive cycle, fostering resilience and purpose, though it also underscores challenges such as a lack of professional psychological support and difficulty accessing medical knowledge within family-based care systems [62]. However, too much reliance on family and social circles can strain relationships and introduce feelings of guilt and inadequacy, as patients are often acutely aware of the toll their care takes on loved ones. This dependence is exacerbated by gaps in healthcare systems, particularly in regions with limited resources for rare conditions like ALS, where professional caregiving is often insufficient.

The final theme, Coping Challenges and Strategies, encapsulates the core difficulties ALS patients encounter in managing communication barriers, decision-making conflicts, future uncertainty, and varied resilience levels. Integrating the experiences of ALS patients with insights on coping challenges and strategies highlights the profound difficulties they face while managing communication barriers, decision-making conflicts, and uncertainties about the future. The narratives reveal that ALS patients grapple with isolation and frustration due to impaired communication. Their experiences underscore the psychological burden of these barriers, compounded by cultural factors that influence how life and death are perceived.

Conclusion

From the themes, ALS presents unique and profound challenges for patients, not just physically but also emotionally, socially, and spiritually. As the disease progresses, patients experience a gradual loss of motor functions, significantly affecting their quality of life. In this context, life-meaning therapy becomes central, encouraging patients to find purpose even amidst adversity [97]. As noted within the literature, therapeutic approach should integrate multiple facets of support — emotional, psychological, and social — in order enhance the coping mechanisms of ALS patients, thus allowing them to navigate the complexities of their condition. The synthesis of the four key aspects of ALS care reveals a holistic approach. Embracing Adversities of Disease Progression focus on preserving patient autonomy and functionality, empowering them to engage in meaningful activities as their condition evolves. Adopting Differences of Cognitive Diversity highlights the mental toll of ALS, calling for enhanced psychological support through counseling, therapy, and adaptive technologies. Satisfying the Need for Support recognize the need for comprehensive interventions involving healthcare professionals, families, and communities, addressing not only physical symptoms but also the patient's emotional and spiritual health. Coping Challenges and Strategies emphasizes the importance of emotional well-being and psychological support, essential for managing fear, frustration, and uncertainty.

Overall, based from the results, the current study proposed the integration of life-meaning therapy across various domains, including empirical value, creative value, attitudinal value, and supportive elements. These should be able to significantly improve the life-meaning experiences of ALS patients, helping them to find disease attribution, feel loved and loved by others, and rediscover interests. In essence, ALS patients should be able to adjust their life attitude, find meaning in life, family support, social support, medical support, and resilience in their journey. Importantly, the comprehensive support model emphasizes the collective effort of healthcare professionals, family members, and communities in uplifting the patient's experience, ultimately promoting a sense of life meaning and purpose despite the progressive nature of ALS.

In conclusion, living with ALS is a complex and painful journey for both patients and their families. To effectively address these challenges, we propose a Multifaceted Comprehensive Cooperative Support Model that emphasizes the importance of mutual support between patients, families, and healthcare providers. This model facilitates a shift in focus from negative mental states to actively seeking meaning in life through four key dimensions: empirical value, creative value, attitudinal value, and supportive elements. The empirical value emphasizes disease attribution, helping patients understand the causes of their condition to enhance their sense of control. Creative value focuses on rediscovering interests and engaging in life reviews to foster a renewed sense of purpose. Attitudinal value encourages patients to adjust their mindset and find personal meaning amidst their struggles. Finally, supportive elements highlight the vital roles of family, social networks, and medical professionals in providing emotional, mental, and practical support (see Figure 1).

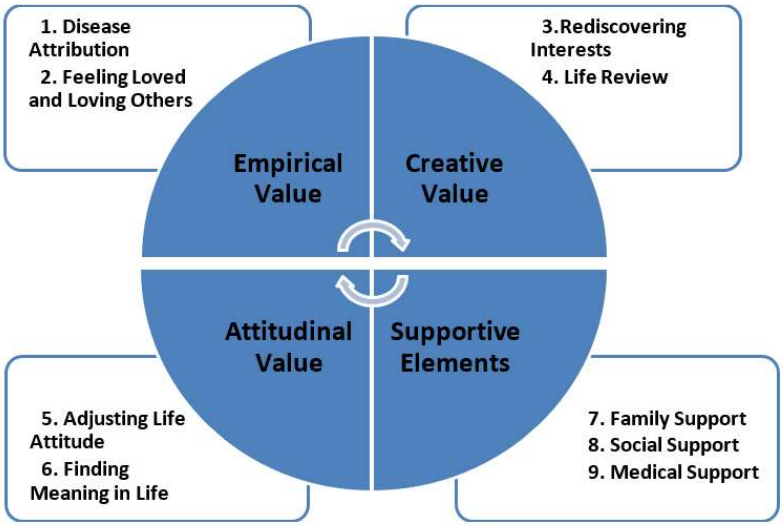

Figure 1. Multifaceted Comprehensive Cooperative Support Model.

The findings reveal key themes such as embracing the adversities of disease progression, recognizing cognitive diversity, fulfilling support needs, and developing coping strategies. These insights underscore the physical, cognitive, psychological, and social pressures faced by ALS patients, particularly at the end of life. Therefore, it is essential to adopt this comprehensive support model that integrates perspectives on life meaning, ensuring that interventions address individual patient needs while engaging broader social forces to aid in adapting to and managing the disease (please see Table 2).

Table 2. Detailed Multifaceted Comprehensive Cooperative Support Model.

Dimensions	Sub-themes	Explanation
Empirical Value	Disease attribution	Helping patients understand and attribute the cause of the disease rationally, which increases their sense of control over the illness and helps them face it better.
	Feeling loved and loving others	Enhancing patients' sense of life's meaning by fostering their experience of being loved and giving love, especially during the process of losing physical abilities.

Creative Value	Rediscovering interests	Encouraging patients to rediscover past hobbies or develop new ones, which can fill the void in their restricted life and provide motivation for living.
	Life review	Guiding patients through a life review to reflect on their accomplishments and life significance, which can help them find strength and a renewed sense of purpose.
Attitudinal Value	Adjusting life attitude	Helping patients cope with uncontrollable aspects of ALS by adjusting their mindset and accepting reality, enhancing their positivity towards life.
	Finding meaning in life	Assisting patients in finding their personal meaning in life through reflection and life review, which helps alleviate fear and anxiety about the end of life.
Supportive Elements	Family support	Family plays a vital role in providing emotional, mental, and material support to help patients maintain psychological balance while facing physical deterioration.
	Social support	Social support systems, including medical resources and community services, provide patients with necessary care and a sense of social participation, improving their quality of life.
	Medical support	Professional support from medical teams helps patients manage the physical and mental challenges of ALS, improving their quality of life and alleviating symptoms.

The study's limitations highlight several areas for improvement in understanding the experiences of ALS patients. Firstly, the sample size and diversity may not fully represent the broad spectrum of challenges faced by individuals with ALS, potentially limiting the generalizability of the findings. The qualitative nature of the interviews introduces a level of subjectivity, which could bias the results and may not capture the complexities of all patients' experiences. The implications of this research extend to healthcare policy, nursing practices, and personalized care for ALS patients. It is crucial to address not only the physical symptoms but also the psychosocial and existential challenges posed by ALS. By tailoring interventions to the unique needs and values of patients, healthcare professionals can enhance the overall quality of life and emotional well-being of those living with ALS. This study provides valuable insights for future research, potentially guiding the development of new therapies and holistic care models to improve life meaning and patient outcomes.

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