frontiers | Frontiers in Neurology

RETRACTED ON 30 JANUARY 2026

TYPE Original Research
PUBLISHED 21 January 2025
DOI 10.3389/fneur.2024.1393261

OPEN ACCESS

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RECEIVED 27 March 2024
ACCEPTED 30 December 2024
PUBLISHED 21 January 2025
RETRACTED 30 January 2026

CITATION
Hruška J, Bachmann P and Odei SA (2025) Enhancing ALS disease management: exploring integrated user value through online communities evidence.
Front. Neurol. 15:1393261.
doi: 10.3389/fneur.2024.1393261

RETRACTED: Enhancing ALS disease management: exploring integrated user value through online communities evidence

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Introduction: Assistive technologies (ATs) offer significant potential to improve the quality of life for individuals with Amyotrophic Lateral Sclerosis (ALS). This study explores the concept of integrated user value (IUV), focusing on five key aspects: quality, user experience, cost-effectiveness, safety, and accessibility. Understanding IUV is crucial for enhancing the development and deployment of ATs in ALS disease management.

Methods: A systematic search approach was utilized to collect data from Facebook ALS support groups, comprising posts from individuals with ALS and their caregivers. Using a predefined set of keywords, 416 posts were analyzed. The posts were categorized based on the five aspects of IUV, and an in-depth content analysis was conducted to explore patterns, challenges, and experiences associated with AT usage.

Results: The analysis revealed significant challenges across all aspects of IUV. Quality and user experience were interlinked, with users frequently citing inadequate designs and unmet customization needs. Cost-effectiveness was a key concern, with high costs and limited insurance coverage contributing to financial strain. Accessibility issues, including delays in acquiring devices and insufficient public facilities, further highlighted systemic challenges. Safety concerns emphasized the need for personalized and intuitive AT designs.

Discussion: The findings underscore the importance of a holistic approach to AT development, integrating all five aspects of IUV. Recommendations include enhancing product quality, ensuring affordability, prioritizing user-centered design, and addressing accessibility gaps. Collaboration between AT designers, healthcare providers, and policymakers is essential to optimize AT value and improve the quality of life for individuals with ALS and their caregivers.

KEYWORDS

assistive technology, ALS, integrated user value, disease management, support groups, online community

1 Introduction

In recent years, the development and integration of assistive technologies (ATs) have become pivotal in enhancing the lives of people with ALS (1), offering innovative solutions to overcome physical limitations and foster autonomy. This research explores the dynamic interplay between ATs and people with ALS, highlighting the transformative potential of online communities in facilitating support and knowledge exchange among people with ALS,

caregivers, and healthcare professionals (2). Facebook has become one of the world's largest social media platforms and has become a thriving hub for numerous online support groups catering to individuals with various medical conditions, including ALS (3). These networks have transcended geographical barriers, allowing people from various origins and locales to come together, share stories, and exchange critical information on managing ALS symptoms and seeking AT options (4). AT can play a crucial role in maintaining the quality of life for individuals with ALS (5, 6). As ALS steadily impairs one's capacity to communicate, move, and engage with the world, AT has emerged as a ray of hope for preserving independence and improving overall quality of life (7). ATs such as eye-tracking systems, speech-generating devices, and adaptive tools, have demonstrated encouraging results in enabling people with ALS to communicate effectively, navigate their environment, and perform daily tasks more easily (8).

Despite the potential benefits of AT, its implementation and incorporation into the lives of people with ALS can become complicated and stressful. Social media platforms and communities provide a safe and friendly environment for people with ALS, carers, and healthcare professionals to share personal experiences, debate AT difficulties, and collaborate to explore potential solutions (2, 9). Members of these Facebook groups can share first-hand experiences with various ATs that they have used or are now using. They can talk about their effectiveness, convenience of use, suitability for their specific demands, and any challenges they faced during the adoption process (10). Such first-hand accounts provide essential information for those choosing AT for the first time or wishing to improve their existing devices. Furthermore, Facebook support groups serve as a forum for networking with ALS and AT professionals. Manufacturers, researchers, and ALS-specialised healthcare professionals can actively participate in these forums, answering questions, offering their expertise, and making evidence-based solutions to solve the community's unique concerns. Despite the enumerated benefits social media platforms provide to people with ALS, they may face several challenges when using social media platforms. ALS often results in motor impairments, making it challenging for people with ALS to use traditional input devices such as keyboards that could allow them to stay connected. This could limit accessibility for certain group of people with ALS. People with ALS may also vary in terms of their level of technology literacy (11). Social media platforms that require some level of technical expertise can exclude people with ALS who are less familiar with the increasing digital tools.

These groups' cumulative expertise and experiences have the potential to generate novel ideas and advancements in AT (12). Real-world feedback can help engineers improve existing AT devices or create new ones that better meet the needs of people with ALS. Facebook support groups have developed as a major force in the ALS struggle, providing a sense of community, understanding, and empowerment among individuals impacted by the disease. These digital communities play an important role in uncovering the potential of AT to improve the lives of people with ALS by encouraging open discussions and sharing personal experiences (4). As technology advances and our understanding of ALS grows, the coordinated efforts of these groups give promise for a brighter future in which people with ALS could continue to improve their lives with the help of cutting-edge ATs.

While it's evident that Facebook support groups and digital communities in general are crucial in connecting people with ALS and elucidating their experiential challenges, their potential in delineating the attributed value of AT within ALS disease management remains underexplored. This study delves into the value aspects of AT from both the user and customer perspectives, specifically focusing on product's quality, experience, cost-effectiveness, safety, and accessibility. It is also indirectly addresses the challenges and potential solutions related to the use of AT among people with ALS.

2 Literature review

2.1 Amyotrophic lateral sclerosis

Over the past decade, significant progress has been made in our understanding of ALS, a neurodegenerative disease that affects the nerve cells responsible for controlling muscle movement (13). Research conducted in the last 10 years has shed light on various aspects of ALS, providing valuable insights into its causes, diagnosis, and treatment options (14).

In terms of treatment, while there is currently no cure for ALS, there have been significant advancements in managing the symptoms and improving the quality of life for patients (15, 16). Ongoing clinical trials and research are exploring new therapeutic approaches, including gene therapies and stem cell-based treatments, with the hope of finding more effective interventions in the future (17). Supportive care for people with ALS has also seen improvements, with multidisciplinary care teams addressing the diverse needs of individuals with the disease (18). ATs, such as communication devices and mobility aids, have enhanced independence and quality of life for people with ALS, while respiratory management strategies have helped address breathing difficulties associated with the disease (19).

2.2 The role of online support groups in ALS journey

In the journey of people with ALS and their carers, support plays a pivotal role in navigating the challenges posed by the disease (20). Facebook support groups have emerged as valuable platforms where individuals affected by ALS can find solace, share experiences, and access a wealth of information (21). Online communities play an important role in providing emotional support, fostering knowledge exchange, and empowering individuals on their ALS journey. ALS significantly impacts daily living activities, making simple tasks like eating, grooming, and dressing more challenging. In this context, adaptive aids such as specialised utensils, dressing assistance, and modified home equipment come to the rescue. Studies have shown that these aids contribute to improved functional independence and enhance the overall quality of life for people with ALS (22). Facebook support groups serve as platforms where members discuss and recommend adaptive aids, empowering individuals to maintain their independence and everyday routines. Beyond physical assistance, people with ALS face psychological and emotional challenges. Living with the disease can result in significant emotional distress, feelings of loneliness, and mental health concerns. Facebook support groups provide a lifeline, offering virtual support, telehealth programmes, and mental health applications that deliver emotional support, counselling, and therapy (23, 24). By sharing stories of resilience and coping

mechanisms, members of these groups promote mental wellbeing and help each other navigate the emotional journey of living with ALS. User experience is another vital aspect. By engaging in discussions about ease of use, customization options, and adaptability, group members share insights that help improve the design and development of ALS-specific ATs, optimising user experiences (25, 26). Facebook support groups have emerged as indispensable resources in the ALS journey (4). By fostering a sense of community, offering emotional support, and providing a platform for knowledge exchange, these groups empower individuals with ALS and their caregivers (27). They serve as virtual hubs of information, where discussions about respiratory ATs, adaptive aids, eye-tracking systems, and emotional support contribute to a richer understanding of ALS management. Ultimately, the collective wisdom shared within these groups has the potential to drive progress in the development and accessibility of ATs, enhancing the lives of those affected by ALS.

2.3 Assistive technologies in ALS disease management

ATs broadly denote the spectrum of devices, equipment, services, or systems that help people with ALS perform tasks, gain independence, and improve their overall wellbeing. These technologies strive to overcome the constraints and problems that people with impairments confront and to improve their functioning capacities (28). Assistive products can be physical, such as wheelchairs, eyeglasses, hearing aids, prostheses, walking aids, or continence pads, or non-physical (digital), such as software and apps that support interpersonal communication, access to information, daily time management, rehabilitation, learning, and training.

ATs play an important role in the treatment, management of symptoms, and care of people with ALS by improving their quality of life and preserving their independence (29). ATs have received enough scholarly attention because of their abilities to improve and enhance movement, communication, and house-environment management in people with ALS (29). ALS gradually impairs the capacity to speak, making communication difficult. Augmentative and alternate Communication (AAC) devices enable people with ALS to communicate more successfully by providing alternate modes of expression. These gadgets range in complexity from simple text boards to sophisticated eye-tracking systems. According to research, AAC devices dramatically increase communication and social interaction for people with ALS (30, 31). However, there is a necessity for early AAC intervention for people with ALS to enjoy the full impact of AAC devices on communication. ATs, or devices, are also known to enhance mobility among people with ALS. Individuals with ALS may encounter difficulty moving and muscle weakness as the disease develops. Wheelchairs, mobility scooters, and motorised exoskeletons are examples of ATs that can improve mobility, independence, and overall quality of life. Several studies have shown that assistive mobility devices improve functional independence and psychological wellbeing in people with ALS (32, 33).

Respiratory ATs could also help with ALS disease management (34). ALS frequently affects the respiratory system, causing breathing problems. Non-invasive ventilation (NIV) devices and ventilators, for example, aid individuals in managing respiratory insufficiency and improving respiratory function in people with ALS. These devices have the potential to increase survival, improve sleep quality, and reduce symptoms associated with respiratory distress (34, 35). ALS can impede an individual's ability to do activities of daily living (ADLs) such as eating, grooming, and dressing. People with ALS can keep their freedom and complete their daily routines more readily with adaptive aids such as specialised utensils, dressing assistance, and modified home equipment. Adaptive aids have been shown in studies to improve functional independence and quality of life of people with ALS [see, for instance, (22)]. Eye-Tracking systems is an example of an access method within the context of ATs that are widely used in ALS management and have received enough scholarly attention (36, 37). Individuals can use eye movements or brain impulses to control computers, communication devices, and environmental controls using eye tracking systems. These devices have shown promise in providing communication and environmental control for those suffering from ALS (37). People living with ALS may benefit from ATs or devices that provide psychological and emotional support (24). Living with ALS can have serious psychological and emotional consequences (38). Virtual support groups, telehealth programmes, and mental health applications are examples of AT that provide emotional support, counselling, and therapy (39). These technologies assist people in coping with the emotional issues of ALS, reducing feelings of loneliness, and promoting mental wellbeing (40). According to the relevant literature and the distribution utilised at the University of Cumbria, UK the ATs can be categorised into four primary categories: fixed AT (home adaptations), portable ATs (tools for daily living), electronic AT (sensory and functional support), and connected AT (remote assistance).

2.4 Integrated user value perspective

The understanding of the product (medical device) value received by people with ALS can encompass various perspectives, with the primary ones being related to technology value creation, user value, and customer value. In medical research, the concept of *technology value creation* is most frequently mentioned in the literature (41, 42). This perspective primarily focuses on the process through which technology brings value to organisations, individuals, or society as a whole. It also maps the gradual addition of value within the value/production chain (43, 44). *User value* specifically pertains to the value created for users of a product or service. It places more emphasis on user interfaces, satisfaction, and the user experience. Since it also deals with intangible services, it is a frequent healthcare concept (45, 46). Finally, the *customer value* perspective, discussed rarely in medicine oriented studies, deals with the overall value created for the customer, which includes both the product or service experience and the fulfilment of customer needs and expectations in relation to the price of the product (47, 48).

Given that this study aims to comprehensively assess the value of technological solutions (medical devices) on people with ALS' quality of life, we find it appropriate to combine both user and customer perspectives. People with ALS do not only use these devices but also make purchasing decisions, and they have their expectations regarding meeting their specific needs, considering the price. Moreover, the value understanding often incorporates not only the needs and experiences of people with ALS but also the overall impact and benefits for all involved parties, including family and informal caregivers, formal carers, healthcare providers, and others. This combined perspective is further referred to as "integrated user value" (IUV).

TABLE 1 Integrated user value creation concept.

IUV aspect	Definition	Expected value, benefits
Quality of the product/ device	Performance and reliability of the product/device used	Functionality and customization options, the level of the needs satisfaction, the level of comfort received and use of the latest technology
User experience	User satisfaction, and overall interaction between the product and its users	Overall satisfaction with the use and operation, quality of communication between the seller and user (manuals, support, training, feedback and improvement)
Cost-effectiveness	The value perceived in terms of its costs related to its benefits	High relative costs as a barrier of purchase, perceived value for money ratio, financial strain on people with ALS, caregivers and others, insurance compatibility (insurance plans and assistance)
Product safety	Concerns with the product's risk of causing harm to users (the value reduction)	Meeting of safety requirements or standards, perceived the reliability of monitoring (vital signs/symptoms), data privacy
Product accessibility	The ease of use related to physical and mental effort to purchase and operate the device	Ease of purchase of the device itself and parts, product availability on the market, intuitive interface and functionality, access to upgrades and innovations

For the purpose of IUV creation, a simplified conceptual framework (see Table 1) was developed. This framework incorporates aspects identified in study of Perotti (49), and other (50–52). It encompasses aspects, such as product quality, user experience, cost-effectiveness, product safety, and product accessibility.

First, high product quality is crucial in ensuring the reliability and effectiveness of ATs for individuals with ALS (7). This quality criteria encompasses the durability, functionality, and performance of the devices. Quality considerations involve factors such as the accuracy of communication devices, the responsiveness of mobility aids, and the reliability of respiratory support systems. It is essential to choose products from reputable manufacturers and ensure they meet industry standards and regulations. It is therefore imperative to ensure quality assurance for AT users by constantly supporting the aspect standards in product design (53, 54).

Second, user experience involves how people engage with AT as well as their general happiness with it (55). ALS specific AT should be built with user-centred approaches, considering the unique requirements and capacities of people with the disease. A positive user experience is closely interconnected with an accessibility aspect, as it is also influenced by factors such as ease of use, customization possibilities, and adaptability to changing needs (6). Therefore, end-user feedback and participation in the design and development process are important for optimising the user experience.

Third, when evaluating the value and usefulness of ATs for ALS management, cost-effectiveness is an essential factor to consider (56). These technologies might range from simple and inexpensive gadgets to more complicated and expensive solutions. Assessing cost-effectiveness entails considering the long-term advantages and potential savings linked to enhanced functionality, independence, and lower healthcare expenditures. The cost of these products is directly linked to accessibility because expensive prices may reduce access, while cheaper prices increase affordability, thereby improving access to these technologies (5). It is critical to weigh the cost of the technology against its potential influence on an individual's quality of life and overall disease management.

Fourth, when using ATs, safety is of the utmost importance, especially for people with ALS who may have impaired motor control and physical ability. Products should not pose additional hazards or harm to end-users; they should be rigorously tested and adhere to safety regulations. It is essential to strengthen and harmonise AT product standards to ensure their safety for end-users (57). Lack of proper enforcement of safety standards could make users ambivalent about using these devices, which could help improve their wellbeing (58).

Finally, product accessibility refers to the design and availability of products and services that can be freely accessed and utilised by people with disabilities (59, 60). It enables people with different abilities to participate in various activities, use products, and access information on an equal footing with others. Physical accessibility entails designing products and surroundings so that people with physical limitations can access and utilise them comfortably. Products should be not only built to accommodate a wide spectrum of people with ALS needs, but also ensuring fair access to technology (61). Additionally, the aspect of data privacy is playing an increasingly significant role, as it can alter the accessibility of a product, discourage its use, or harm the users themselves (62, 63).

3 Results

Predominant evidence on IUV of AT published in social support groups is presented in the structure of individual IUV aspects. Moreover, the posts identified the main issues (causes) and their effects for each technology aspect. These cause-effect relationships are also incorporated. Moreover, the analysis also provided content classified according to individual types of AT (from fixed to connected); for clarity, these results are provided in the Appendix.

3.1 Product quality

The analysis identified several challenges regarding the quality IUV aspect faced by people with ALS and, indirectly, also by caregivers. Issues such as inadequate quality, the necessity for device customization as the disease progresses, adapting to changing needs, and user-friendliness of design, among others, contribute significantly to user dissatisfaction. The issues highlight the urgent need for improved AT design, better home modifications, more comprehensive information, and an emphasis on user comfort. An in-depth exploration of the primary causes and their effects is presented in Table 2.

3.2 User experience

The user experience of people with ALS when interacting with ATs brings some significant challenges to light. These range from inadequate knowledge and understanding of ATs to practical usability issues,

information gaps, and quality concerns. These hurdles do not only hamper the independent operation of devices and delay the receipt of necessary support but also impact users' quality of life, financial situation, and overall independence. Further, the struggle to find suitable tools for daily tasks, dissatisfaction with device functionality, and concerns over the reliability and effectiveness of connected ATs contribute to user stress and frustration. An in-depth exploration of the primary causes and their effects is presented in Table 3.

3.3 Cost-effectiveness

Cost-effectiveness remains a paramount concern for people with ALS/caregivers of ALS selection and utilisation of ATs. High costs, limited insurance coverage, and the affordability versus quality dilemma impose financial strain on individuals and families. This often leads to increased efforts to find affordable alternatives, consider insurance changes, or even settle for low-quality devices, all of which could risk underutilization and impact overall quality of life and independence. Moreover, the information gap regarding cost-effective options and the suitability and logistics of various ATs adds to the difficulty in decision-making and potential stress. An in-depth exploration of the primary causes and their effects is presented in Table 4.

3.4 Product safety

The challenges associated with the product safety range from addressing ALS-specific symptoms and enhancing mobility within home environments to improving the operation and safety features of ATs, ensuring comfort and electrical safety, and providing user-specific, personalised solutions. The effects of these issues underline the necessity for safer, more intuitive, personalised, and integrated AT solutions that can enhance quality of life and independence for people with ALS. An in-depth exploration of the primary causes and their effects is presented in Table 5.

3.5 Product accessibility

The various accessibility challenges are derived from the qualitative analysis; these ones encompass issues with reliability and service, the need for effective product usage and optimisation, and concerns around home and public accessibility. The complexities involve selecting suitable ATs, modifying homes to increase mobility, addressing transport accessibility, managing misinformation, and handling delays in device delivery. Additionally, the struggle with financial constraints and the effectiveness of utilising ATs underscores the multifaceted nature of these accessibility problems. An in-depth exploration of the primary causes and their effects is presented in Table 6.

4 Discussion

4.1 The main findings

The study has revealed several critical insights into understanding the product value of AT used by people with ALS and their caregivers. These insights are interlinked across five main aspects of the technology's value: product quality, user experience, cost-effectiveness, product safety, and product accessibility.

4.1.1 Product quality and user experience

Product quality and user experience are closely intertwined. Issues related to inadequate quality, a lack of user-friendly designs, and the need for customization are found to contribute significantly to user dissatisfaction and practical usability difficulties. This does not only hamper the independent operation of devices, affecting the user experience, but also impacts people with ALS' overall quality of life and independence. As expected, if product quality is compromised, users will not derive maximum satisfaction from these devices, which will negatively impact their quality of life.

4.1.2 Cost-effectiveness

Cost-effectiveness emerges as a key concern interlinked with both product quality and user experience. The high costs and limited insurance coverage place a financial strain on people with ALS/caregivers. The struggle to balance affordability and quality often leads to a compromise on product quality or underutilization of ATs, which in turn negatively impacts the user experience. As suggested by Boot et al. (5), the cost of these AT devices is directly linked to accessibility because expensive prices may reduce access, while cheaper prices increase affordability, thereby improving access to these technologies. It is therefore not surprising that people with ALS/caregivers were critical about deciding to use these technologies based on the cost of the product and sought the experiences of other members of the group.

4.1.3 Product safety

Product safety is another crucial aspect connected to the user experience. ALS-specific symptoms and safety features of ATs necessitate the development of safer, more intuitive, personalised, and integrated solutions to not just enhance the safety quotient but also improve the overall user experience. This result signifies that users place a high priority on the safety of AT devices, and this was influential in their decision to use these products. Our result on product safety's role in influencing user experience corroborates the findings of research by Kenigsberg (28) and Kruse (65), which all identified increased safety as a facilitator to the adoption of AT for people with disabilities.

4.1.4 Product accessibility

Finally, product accessibility issues echo challenges seen in other aspects. Difficulties in reliability, service, effective product usage, misinformation, and delays in device delivery are all factors that could potentially deteriorate the user experience and reduce the perceived value of ATs. AT device accessibility is constrained by issues such as displeasure and failures in their operational parts. To ensure greater accessibility to ALS patients, products should be built to accommodate a wide spectrum of ALS users, ensuring fair access to technology (61, 66).

Overall, the key findings highlight the intricate interconnections between the different value aspects of ATs. Ensuring high product quality, enhancing user experience, optimising cost-effectiveness, improving product safety, and ensuring easy accessibility are all

TABLE 2 Product quality: the main causes and effects.

The main issue (cause)	Effects
Inadequate quality	Increased user frustration and dissatisfaction
	Inability to meet specific user needs (as diseases progress), leading to the requirement of customised equipment.
	Need to seek expert guidance or more reliable, high-quality product options.
Difficulty adapting to changing needs	Frequent need for device repair, replacement, and modification
	Requirement for ATs that are adaptable, flexible, and can react to changing needs.
	Increased effort in information seeking and decision-making regarding adequate transitions needed
Lack of user-friendly design in devices	User experience challenges in using the technology effectively.
	Foreign users need ways to adapt the product (language modification).
	A heightened emphasis on the user-friendliness aspect of the decision-making process.
Home modifications	Restriction of the user's mobility and independence, creating an urgent need for home modifications
	Users are forced to seek information about their specific needs and comprehensive knowledge about various products
Lack of information and overall complexity	Difficulty in understanding the functionalities, benefits, and limitations of ATs.
	The challenge of making informed decisions is due to lack of comprehensive, clear, and relevant information.
	Constantly seek guidelines on the effective use of ATs
Insufficient comfort provided by devices	Users often prefer other devices (wheelchair over a hospital bed) due to comfort.
	Need to focus on comfort when selecting and customising devices.
	Active search for advice and recommendations for more comfortable ATs

TABLE 3 User experience: the main causes and effects.

The main issue (cause)	Effects
Inadequate knowledge and understanding	Difficulty in making informed decisions about purchasing and using ATs.
	Increased reliance on peer experiences and suggestions, which may not always be applicable or beneficial for the individual.
	Possible delay in receiving necessary support due to the time taken to research and understand different technologies
Usability issues	Decreased independence due to difficulties in operating devices, which may also reduce the individual's confidence.
	Potential risks of injury or accidents when using devices that are hard to manage.
	Reduced quality of life if the discomfort or difficulty of using devices prevents the person from engaging in preferred activities
Information and findability gap	Prolonged struggle in carrying out daily tasks effectively due to not finding the right tool.
	Increased anxiety and stress associated with not knowing how to effectively use and adapt to their ATs
User experience gap	Dissatisfaction may lead to underutilization of purchased ATs, which can be a financial burden.
	Increased reliance on carers or support staff due to the inability to independently use ATs.
	Potential delay in transitioning to more appropriate devices, affecting mobility and independence
Challenges with electronic ATs	Frustration and stress due to difficulties in setting up and using electronic devices.
	Potential underutilization of features due to lack of understanding or perceived limited functionality
	Negative impact on communication and interaction if speech-supporting devices like Tobii are not used to their full potential
Quality concerns with connected ATs	Financial loss due to purchasing low-quality devices that require frequent replacements.
	Increased stress and uncertainty due to concerns about the reliability and effectiveness of these ATs.
	Potential risks to health and safety if the ATs fails at a crucial time, such as emergency alert systems.

imperative to enhancing the overall value of ATs and subsequently improving the quality of life for people with ALS and their caregivers.

4.1.5 Type of ATs specifics

In terms of differences among types of technologies used, fixed ATs primarily face issues around accessibility and adaptability, as well as difficulties in determining the best choice among available options. Research by Tinker and Lansley (67) found that fixed AT devices often come with challenges such as adaptation, without which they reduce their accessibility. On the other hand, portable ATs are plagued by issues of comfort, customization, service quality, and the need to adapt to changing physical needs. Electronic ATs have unique challenges in

TABLE 4 Cost-effectiveness: the main causes and effects.

The main issue (cause)	Effects
High-cost estimates for ATs	Increased financial stress on individuals and families affected by ALS.
	Search for more affordable alternatives or options for products
	Reduced accessibility due to the prohibitive costs of some advanced ATs
Information gap regarding available options	Increased difficulty in decision-making due to a lack of comprehensive guidance
	Increased interest in seeking advice on cost-effective ATs.
	Necessity for trial opportunities to avoid investment in unsuitable AT
Limited insurance coverage and funding	Concerns and confusion over whether certain AT, like wheelchairs, are covered by insurance.
	Frustration due to insurance only covering a portion of the total costs of AT.
	Significant out-of-pocket expenses burden individuals and families
	Consideration of insurance changes to better accommodate future AT needs.
	Barriers to accessing certain AT, like eye gaze machines, due to the lack of insurance coverage
Concerns of quality, suitability, and logistics	Dissatisfaction may lead to underutilization of purchased ATs, which can be a financial burden.
	Increased reliance on caregivers or support staff due to the inability to independently use ATs.
	Potential delay in transitioning to more appropriate devices, affecting mobility and independence.
High costs impacting buying decisions and usability	Frustration and stress due to difficulties in setting up and using electronic devices.
	Potential underutilization of features due to lack of understanding or perceived limited functionality
	Negative impact on communication and interaction if speech-supporting devices like Tobii are not used to their full potential
Affordability vs. quality dilemma	Financial loss due to purchasing low-quality devices that require frequent replacements.
	Increased stress and uncertainty due to concerns about the reliability and effectiveness of these ATs.
	Potential risks to health and safety if the AT fails at a crucial time, such as emergency alert systems.

terms of usability, setup complexity, and limited functionalities, whereas connected ATs face concerns mostly around quality and user satisfaction.

4.2 Research limitations

The presented research comes with inherent limitations that should be acknowledged. First, the research findings are primarily qualitative, thus lacking quantitative validation. This means that although we can glean valuable insights into the experiences and perceptions of people with ALS and their caregivers, we cannot quantify the prevalence of these experiences or statistically verify the associations and effects reported.

Secondly, the research is based on the analysis of social media communications conducted exclusively in the English language. While this offers a wealth of unfiltered, first-hand accounts of real-life experiences, it does come with limitations. Users on social media may attempt to receive appreciation or higher support from others by conforming their content of conversation to trendy topics or using exaggeration to look better in front of others (68–70). Moreover, they may more likely discuss significant or acute problems they face, while routine, everyday activities and issues may not get as much attention or discussion (71). Consequently, our understanding of the everyday use of ATs might be skewed towards more noticeable challenges and problems, potentially overlooking the mundane yet essential aspects of living with ALS.

Furthermore, the scope of the research is inherently limited to the demographic of people with ALS/caregivers who are active on social media and choose to share their experiences publicly. Therefore, it may not fully represent the experiences of all individuals with ALS, particularly those who are not active on social media or who prefer to keep their experiences private. These limitations should be considered when interpreting and generalising the findings.

Finally, because the analysis is based on the perceptions of members of a Facebook group dedicated to assisting people with ALS/caregivers, our findings should be interpreted with caution. The group members' perceptions of ATs are reflected in their posts and suggestions. They may not accurately reflect the current state of the advantages and downsides of ATs in the management of ALS disease since they may be influenced by group members' biases and disinformation, which may not always coincide with objective reality.

For future research, it would be optimal to analyse a greater number of Facebook groups, including those with participants from diverse linguistic backgrounds, to ensure broader audience coverage. Additionally, consideration should be given to incorporating other social media platforms, such as X (formerly Twitter) and Instagram, to expand the scope of the study. This approach would help address the potential bias inherent in relying on a limited number of groups or platforms, which may not fully capture the diversity of experiences and perspectives within the population under study. To mitigate these biases, researchers should aim to include groups and platforms that represent a variety of socio-economic, cultural, and geographic contexts. In addition, future studies could complement social media data with other sources, such as structured interviews, surveys, or clinical data, to triangulate findings and provide a more comprehensive understanding of the population's needs. Adopting mixed-methods approaches would not only reduce reliance on potentially skewed

TABLE 5 Product safety: the main causes and effects.

The main issue (cause)	Effects
ALS symptoms and disease transitions pose challenges for ATs safety	Inadequate fall prevention in ATs can lead to injuries such as fractures, sprains, or strains in people with ALS.
	People with ALS express frustrations due to falls and difficult transfers, such as from bed to a wheelchair, indicating AT might not fully address their needs.
	The fear of falling and discomfort during transitions can generate anxiety, reducing trust in these technologies and impacting people with ALS/caregivers of ALS emotional wellbeing.
	Dissatisfaction with how professional care teams handle transitions using AT can indicate the need for better training with these technologies and safer protocols
ATs may not fully support mobility within home environments	People with ALS may struggle with stairs and steps, even when using AT, causing difficulties in accessing different parts of their homes.
	Independence may be compromised due to insufficient support from AT, leading to increased reliance on caregivers and potentially reduced quality of life
Imposition of certain ATs without considering specific needs	People with ALS might feel that certain AT is imposed upon them without their specific needs being considered, potentially creating unsafe situations, like a wheelchair's height not allowing safe lifts.
	Unsuitable AT can lead to injury, falls, or non-compliance, indicating a need for individualised consultation and customization in AT selection.
	The lack of personalised AT can also lead to dissatisfaction and a lower perception of quality of life among people with ALS/caregivers.
Concerns with operation and safety features of ATs	Incidents, such as a foot being run over by a wheelchair, show that AT might need safer and more intuitive controls.
	Certain features of AT, like the wheelchair's tilt and recline, could pose safety issues, indicating potential design improvements to prevent accidents and injuries
ATs´ limitations in public facilities and during portability	Users express concerns about the safety of ATs in public spaces, hinting at a need for better integration of these technologies into public facilities and additional equipment.
	The portability and ease of access of devices significantly impact safety, leading to a preference for lightweight and easy-to-manoeuvre ATs
User discomfort and electrical safety concerns	ATs causing discomfort or pain can lead to non-compliance, highlighting the importance of ergonomics in the design of ATs.
	Electrical safety concerns when using multiple AT devices, such as overloading outlets, could pose risks of electrical fires or damage to the devices, underscoring the need for careful management and instruction for AT use.

social media datasets but also strengthen the validity and generalizability of the research outcomes.

5 Conclusions and implications

People with ALS and other stakeholders involved in ALS disease management encounter numerous challenges and considerations when selecting, purchasing, or using assistive technologies. By seeking information, sharing experiences, and expressing their needs, users aim to improve their overall quality of life and enhance their independence and mobility. For these reasons, the developed concept of integrated value is considered fundamental and important for research.

The findings of this study identify the individual aspects of IUV perceived by people with ALS and their caregivers. These aspects are deeply interconnected, influencing each other's outcomes, and ultimately impacting the overall value of ATs in ALS management. The study identified that product quality and user experience are closely intertwined. Inadequate quality and a lack of user-friendly designs contribute to user dissatisfaction, hindering independent device operation and affecting the overall quality of life and independence of people with ALS. Moreover, the issue of cost-effectiveness emerges as a significant concern, as high costs and limited insurance coverage create financial strain and lead to compromises on product quality and underutilization of ATs. Product safety also plays a vital role in the user experience. Specific ALS symptoms necessitate the development of safer and more intuitive solutions, ensuring not only enhanced safety but also improved overall user satisfaction.

The research also uncovered differences among the various types of ATs used. Fixed ATs faced issues of accessibility and adaptability, while portable ATs encountered challenges related to comfort, customization, and changing physical needs. Electronic ATs presented unique usability and setup complexities, while connected ATs were primarily associated with quality and user satisfaction concerns. Facebook support groups/forums provide unique opportunities to study vulnerable patient groups within the context of their home environments, this offers valuable insights into their daily challenges, behaviours, and care needs. These forums allow researchers and healthcare professionals to gain a more holistic understanding of these patients' lives, something that would be nearly impossible to achieve in traditional clinical settings due to the constraints and burdens imposed by their conditions. Through these forums, we can bridge critical gaps in knowledge and design interventions that are more aligned with the lived realities of people with ALS, ultimately improving their care outcomes and quality of life.

The findings emphasise the importance of focusing on the interconnected aspects of AT value to enhance the quality of life for people with ALS and their caregivers. Future research efforts should combine qualitative and quantitative methodologies to gain a more comprehensive understanding of AT usage and its impact on the ALS community. By addressing these challenges and collaborating with people with ALS, caregivers, and healthcare professionals, we can work towards optimising ATs and ultimately improving the lives of those living with ALS.

TABLE 6 Product accessibility: the main causes and effects.

The main issue (cause)	Effects
Concerns about reliability and quality of service	Users face challenges due to the inconsistent quality of support systems, which can lead to ineffective utilisation of AT. An example is when users struggle to operate a Hoyer sling optimally for tasks such as showering and toileting – or late or long service times.
Need for product information and customization	The lack of clear comparative information causes difficulties in deciding the most suitable ATs. For instance, users might struggle to choose between touch-screen-operated wheelchairs and motorised ones.
	There is a desire for ATs to be adaptable for their evolving needs as the disease progresses. For example, users might require control mechanisms that accommodate diminishing physical abilities.
Home adaptations for enhanced accessibility	Users need to adapt their homes, such as by building ramps or widening door frames, to accommodate AT like wheelchairs or walkers. Accessing and manoeuvring around a non-adapted kitchen with a wheelchair can be problematic.
	Full home remodels, like redesigning bathrooms and bedrooms, are required to optimise accessibility.
Challenges in public and transport accessibility and usability	Users experience difficulties accessing public spaces such as wheelchair-accessible bathrooms, signalling the need for improved equipment like Hoyer lifts for safe and easy use.
	Despite having access to certain devices, users face difficulties using them efficiently. For instance, some users find it hard to effectively use the Tobii device, suggesting the need for personalization and ongoing support.
Misleading information and delays in acquiring ATs	Misleading information about accessibility options for wheelchair users can create unnecessary challenges.
	Delays in receiving ordered devices, such as the Dynavox Tobii, highlight the necessity for more accessible and expedient distribution systems.
Financial barriers and demands of ATs	Users struggle to obtain AT like eye gaze machines due to financial barriers, including lack of insurance coverage, underscoring systemic accessibility issues.
	Donation, reuse, and gifting of ATs is important to increase their accessibility and affordability, helping more families in need.

The findings of this study could provide several practical recommendations for AT designers, healthcare providers, and policymakers to enhance the value and effectiveness of ATs for people with ALS and their caregivers. For AT designers, the study highlights the importance of prioritising user-friendly designs that are tailored to the specific needs of individuals with ALS. Devices should be customizable and intuitive, with interfaces that integrate seamlessly into users' daily lives, thereby promoting independence and improving quality of life. To address concerns about cost, designers should aim to develop cost-efficient solutions without compromising quality. This may involve exploring modular or scalable designs that allow users to select features based on their needs and budgets. Safety is another critical consideration, necessitating the inclusion of robust safety features such as emergency alerts, fail-safe mechanisms, and user-specific adjustments to mitigate risks. Additionally, accessibility should be a primary focus, with devices designed to accommodate a broad spectrum of physical and cognitive needs associated with ALS. Efforts to simplify setup processes and provide clear, comprehensive user manuals will further enhance accessibility. Different types of ATs also present unique challenges; fixed ATs should be designed for greater adaptability, portable ATs for improved comfort and durability, electronic ATs for simplified setup and usability, and connected ATs for improved reliability and user satisfaction.

Healthcare providers are essential in helping people with ALS and their caregivers maximise the benefits of ATs. They should offer personalised consultations to guide informed decisions, provide training on device operation and customization, and collaborate with designers to incorporate user feedback. Additionally, they should ensure timely device delivery and reliable maintenance services by coordinating with manufacturers. Policymakers play a vital role in improving AT accessibility and affordability. Expanding insurance coverage, offering subsidies, and providing tax incentives for manufacturers can reduce financial barriers. Funding research and fostering collaborations between stakeholders will drive innovation and safety improvements. Public awareness campaigns and streamlined regulatory processes are also critical for ensuring timely access, while universal design standards can promote inclusivity and adaptability.

Addressing product quality, user experience, cost-effectiveness, safety, and accessibility requires collaboration among AT designers, healthcare providers, and policymakers. Such efforts can enhance AT value and significantly improve the quality of life for people with ALS and their caregivers.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors without undue reservation.

Author contributions

JH: Conceptualization, Data curation, Formal analysis, Methodology, Writing – original draft, Writing – review & editing. PB: Conceptualization, Data curation, Formal analysis, Methodology, Writing – original draft, Writing – review & editing. SO: Data curation, Formal analysis, Methodology, Writing – original draft, Writing – review & editing.

Funding

The author(s) declare that financial support was received for the research, authorship, and/or publication of this article. This research was funded by Ministry of Education Youth and Sports:

Project ERDF No. CZ.02.1.01/0.0/0.0/18_069/0010054—IT4Neuro(degeneration).

Acknowledgments

We acknowledge the use of AI technology, specifically OpenAI´s ChatGPT-4 (version January 2024), for clarifying the meaning of certain posts, and assisting with English language corrections.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fneur.2024.1393261/full#supplementary-material

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