4
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Assistive Technologies as Educational and Social Enablers in Rare Neuromuscular Conditions. A Systematic Literature Review[1]

Tecnologie assistive come strumenti educativi e sociali nelle malattie neuromuscolari rare. Una revisione sistematica della letteratura

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ABSTRACT

As part of a broader research project aimed at investigating and defining the contribution that assistive technologies (AT) can offer to improving the quality of life, self-determination, and

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autonomy of people with rare neuromuscular diseases (NMD), this paper presents the phases and findings of a systematic literature review. The review explores studies that examine how assistive technologies (AT), when properly designed and integrated into everyday life contexts, can function as enabling tools. Conducted according to the PRISMA protocol and covering the period 2015–2025, the systematic review identified and critically synthesized the main available evidence. The results highlight a positive impact of AT on individual well-being and autonomy, while also emphasizing the need for further investigation into aspects related to personalization, sustainability, and the training of users and caregivers.

Keywords: rare neuromuscular diseases, assistive technologies, quality of life, autonomy, self-determination, systematic literature review.

RIASSUNTO

Nell'ambito di un più ampio progetto di ricerca volto a indagare e definire il contributo che le tecnologie assistive (AT) possono offrire al miglioramento della qualità della vita, dell'autodeterminazione e dell'autonomia delle persone affette da malattie neuromuscolari rare (NMD), questo articolo presenta le fasi e i risultati di una revisione sistematica della letteratura. La revisione esplora gli studi che esaminano come le tecnologie assistive (AT), se progettate correttamente e integrate nei contesti della vita quotidiana, possano funzionare come strumenti abilitanti. Condotta secondo il protocollo PRISMA e relativa al periodo 2015-2025, la revisione sistematica ha identificato e sintetizzato criticamente le principali evidenze disponibili. I risultati evidenziano un impatto positivo delle AT sul benessere e sull'autonomia individuali, sottolineando al contempo la necessità di ulteriori indagini su aspetti relativi alla personalizzazione, alla sostenibilità e alla formazione degli utenti e dei caregiver.

Parole chiave: malattie neuromuscolari rare, tecnologie assistive, qualità della vita, autonomia, autodeterminazione, revisione sistematica della letteratura.

1. EMPOWERMENT THROUGH ASSISTIVE TECHNOLOGIES IN RARE NMDS

In recent years, research on quality of life and well-being has increasingly focused on individuals diagnosed with rare diseases, whose care needs extend beyond medical treatment to encompass a holistic, person-centered approach. Rare diseases, described as a *"complex mosaic of conditions"* (Stolk, Willemen & Leufkens, 2006), are characterized by diagnostic complexity, diverse clinical trajectories, and significant social invisibility. Among these conditions, rare neuromuscular diseases

(NMDs) represent a highly heterogeneous group affecting muscles, motor neurons, peripheral nerves, and neuromuscular junctions. More than 1,100 monogenic NMDs linked to 641 genes have been identified, including hereditary disorders such as SMA, DMD, myotonic dystrophy, and Charcot-Marie-Tooth disease, as well as acquired conditions like ALS and inflammatory myopathies (Benarroch *et al*., 2020).

Despite their diversity, people living with rare NMDs share similar challenges, including reduced independence, disruptions in family and relational life, and recurrent feelings of frustration linked to dependency on medical care and on others for daily activities (Pinnelli & Fiorucci, 2017, 2018; Von der Lippe *et al*., 2017). These experiences highlight the need for a shift from a strictly clinical understanding of disease toward a biopsychosocial perspective that recognizes the role of contextual factors, both facilitators and barriers, in shaping individual potential and quality of life.

While national and European policies increasingly acknowledge the importance of supporting vulnerable and rare-disease populations (EURO-NMD, UNIAMO, ORPHANET), pedagogical and educational research in this field remains scarce (Cohen & Biesecker, 2010; Coca *et al*., 2023). In this context, assistive technologies (AT) represent promising tools for enhancing autonomy, promoting social participation, and reducing the burden on health and social care systems. Beyond their functional benefits, AT can foster personal development, self-determination, and meaningful engagement in daily and community life (Pinnelli & Fiorucci, 2018; Pinnelli, 2022).

To fully realize these potentials, technological innovation must be guided by a clear conceptual framework that prioritizes individual needs and ensures an appropriate match between users and technologies. At the core of this process lie two essential elements: meaningful user involvement and a comprehensive understanding of the individual across biopsychosocial domains (Pinnelli, 2014).

These principles provide the conceptual basis for the ATA Process model, enabling multidisciplinary teams to identify the most suitable fit between the individual and the assistive technology (Scherer & Craddock, 2002; Corradi, Scherer & Lo Presti, 2013). However, current applications of the ATA Process remain limited to case studies, and the lack of structured training programs restricts its systematic use.

Addressing these gaps is essential for leveraging the full potential of assistive technologies to improve quality of life and support self-empowerment among individuals with rare neuromuscular diseases.

2. CURRENT STATE OF KNOWLEDGE

Understanding the contribution of Assistive Technologies (AT) to the lives of individuals with rare neuromuscular diseases (NMDs) requires first examining existing literature reviews and meta-analyses. To date, no systematic review has specifically assessed the role of AT in improving quality of life (QoL) among people with NMDs. Existing reviews have focused mainly on functional improvements linked to specific device categories, without adopting a holistic biopsychosocial perspective or integrating user-centered design principles. To address this gap, our analysis identified eight reviews published between 2015 and 2025 that examined AT use in the daily lives of individuals with NMDs (Table 1).

Although the search covered a decade, all reviews were published in the last five years, highlighting the scarcity of research on how AT supports QoL in this population. Most reviews examined NMDs broadly (Gondolla *et al.*, 2020; Beswick *et al.*, 2022; Bortolani *et al.*, 2022; Mijic *et al.*, 2024), while others focused on Amyotrophic Lateral Sclerosis (Fernandes *et al.*, 2021; Burke *et al.*, 2025), Muscular Dystrophies (Leone *et al.*, 2023), or Spinal Muscular Atrophy (Cumplido *et al.*, 2021). Seven reviews addressed mobility-related AT, including wearable devices (Gondolla *et al.*, 2020; Bortolani *et al.*, 2022; Burke *et al.*, 2025), robotics and exoskeletons (Gondolla *et al.*, 2020; Cumplido *et al.*, 2021; Burke *et al.*, 2025), and various gait-assistive technologies (Leone *et al.*, 2023; Mijic *et al.*, 2024). Others investigated monitoring tools such as accelerometers, activity trackers, and motion sensors (Beswick *et al.*, 2022). Psychosocial outcomes received limited attention: while several reviews reported improvements in strength, mobility, independence, or disease monitoring (Beswick *et al.*, 2022; Bortolani *et al.*, 2022; Mijic *et al.*, 2024), only Burke and his group (2025) also noted positive effects on Quality of Life in Amyotrophic Lateral Sclerosis, related to greater participation in daily activities.

Only one review (Bortolani *et al.*, 2022) employed a formal outcome measure for AT, the Technology Outcome Measure (TOM), to assess functional and health-related impacts (Espay *et al.*, 2016). Among the eight reviews, only Fernandes *et al.* (2021) focused on communication, showing that machine-learning approaches applied to biomedical signals can support diagnosis, communication and disease monitoring in Amyotrophic Lateral Sclerosis.

Overall, existing reviews remain limited by their focus on specific technologies or narrow NMD subgroups, as well as by the lack of a comprehensive, person-centered perspective that considers social participation, self-determination, and well-being. They also tend to overlook the essential role of user involvement in AT design and selection (Corradi *et al.*, 2013; Pinnelli, 2014) and seldom examine multidisciplinary evaluation models—such as the ATA Process—that aim to optimize the person–technology match (Scherer & Craddock, 2002; Fiorucci & Rossini, 2023). To address these gaps, the present systematic review offers an updated, biopsychosocially oriented synthesis of the literature, with a specific focus on how AT can be integrated into care models for individuals with rare NMDs. This approach seeks to identify emerging trends, methodological advances, and persistent knowledge gaps in order to inform future research and to guide clinical, educational, and pedagogical practices that promote well-being, autonomy, and empowerment across the lifespan.

References	**Review Objectives**	**No. of Included Studies**	**Method**	**Type of AT**	
Gandolla et al. (2020)	To analyse the effectiveness of wearable AT supporting upper-limb function during daily activities in people with NMDs	14	Systematic review and meta-analysis	Wearable devices, robotics, exoskeletons, orthotic devices	Mobility
Cumplido et al. (2021)	To evaluate the safety and efficacy of exoskeleton-assisted gait training and describe the main characteristics of clinical studies involving children with CP or SMA	21	Systematic review	Robotics, exoskeletons	Mobility

Fernandes et al. (2021)	To investigate machine-learning approaches combined with biomedical signals contributing to scientific and practical advances in ALS	18	Systematic review	Machine learning	Communication
Beswick et al. (2022)	To assess the usefulness and suitability of devices for evaluating motor function and disease progression in individuals with NMDs	20	Systematic review	Activity monitors, accelerometers, smartphone apps, gait tools, motion sensors, spirometers, electrical impedance myography, computerised microphones, dynamometry	Mobility
Bortolani et al. (2022)	To analyse the use of technological devices for assessing motor function in NMDs	100	Systematic review	Portable and wearable devices	Mobility
Leone et al. (2023)	To investigate the effectiveness of conservative non-pharmacological interventions for physical management in muscular dystrophies	39	Systematic review and meta-analysis	Assistive gait devices (AGD)	Mobility
Mijic et al. (2024)	To analyse the effectiveness of gait-assistive devices in daily activities	40	Systematic review and meta-analysis	Gait-assistive devices (AGD; exoskeletons for gait assistance, orthopedic footwear, knee/ankle–foot orthoses, non-invasive neuroprostheses)	Mobility
Burke et al. (2025)	To analyse the use of AT to improve the lives of people with ALS and compensate for upper- and lower-limb, trunk, and cervical muscle weakness	26	Scoping review	Portable and wearable devices, robotics, exoskeletons	Mobility

Tab.1: Summary of the Literature Reviews

AT = Assistive Technology; NMD = Neuromuscular Disorders (rare); CP = Cerebral Palsy; SMA = Spinal Muscular Atrophy; ALS = Amyotrophic Lateral Sclerosis; MD = Muscular Dystrophies

3. RESEARCH QUESTIONS AND STUDY OBJECTIVES

This review aims to systematically examine qualitative and quantitative studies that have explored the use of assistive technologies (AT) for individuals with rare neuromuscular diseases (NMDs), focusing on peer-reviewed articles published over the past decade (2015–2025).

The study forms part of a broader research project. Within the scope of this contribution and given the wide thematic focus of the overarching project, the analysis will concentrate specifically on the impact of assistive technologies on promoting well-being among individuals with rare neuromuscular conditions.

Building on evidence from the literature indicating that well-designed and personalized technologies can play a pivotal role in enhancing the quality of life of people with rare NMDs, this systematic review pursues the following objectives:

1. to analyze the available literature from the last decade to determine whether existing studies highlight the central role of assistive technologies in supporting individuals with rare NMDs and improving their quality of life.
2. to examine the models of assistive technology assignment employed in the selected studies, such as the HAAT model, the MPT model, or other structured approaches, and to assess their practical application for people with NMDs.

In accordance with these objectives, two research questions were formulated to guide the review:

- RQ1. Over the past ten years, have studies investigating the enhancement and assessment of quality of life among individuals with NMDs emphasized the centrality of assistive technologies?
- RQ2. Which assignment models (e.g., HAAT, MPT, etc.) inform the implementation of assistive technologies for individuals with rare neuromuscular diseases?

4. METHOD

4.1. Eligibility Criteria

The following eligibility criteria were applied for the selection of studies:

- *Design*: primary studies employing qualitative, quantitative, or mixed/multi-method designs; articles published in peer-reviewed journals;
- *Intervention*: studies examining the contribution of assistive technologies to the lives of individuals with NMDs, specifically those assessing or measuring improvements in quality of life;
- *Sample*: studies involving individuals with rare neuromuscular diseases (e.g., Duchenne muscular dystrophy, SMA, ALS, etc.);
- *Informants*: studies including, in addition to individuals with NMDs, informal or formal caregivers and/or healthcare professionals involved in their care;
- *Language*: studies published in English;
- *Publication period*: scientific articles published between January 2015 and May 2025;
- *Outcomes*: qualitative, quantitative, or mixed-method studies reporting observations, assessments, or measurements of the impact or effects of assistive technologies on the lives of individuals with rare neuromuscular diseases, particularly regarding quality-of-life enhancement.

4.2. Information Sources and Search Strategy

To identify relevant studies, a comprehensive bibliographic search was conducted across six major electronic databases: SCOPUS, ERIC, Web of Science, PubMed, EBSCOhost, and Wiley Online Library. A consistent combination of keywords was applied across all databases, using Boolean operators to structure the search. The keywords covered: main theme (“assistive technology” OR “human activity assistive technology” OR “adaptive devices” OR “rehabilitation technology” OR “wearable exoskeleton” OR “brain-computer interface”); context (“neuromuscular diseases” OR “rare neuromuscular disorders” OR “muscular dystrophy” OR “spinal muscular atrophy” OR “amyotrophic lateral sclerosis”); participant outcomes (“quality of life” OR “independent living” OR “functional mobility” OR “rehabilitation”).

Search strings were adapted to the indexing systems and thesauri specific to each database.

4.3. Study Selection Process

All studies identified through the database searches were exported into Rayyan, a web-based platform powered by artificial intelligence and specifically designed to support the management of systematic reviews. The platform proved useful for duplicate detection, collaborative screening, and blinded decision-making, thereby enhancing both the efficiency and the accuracy of the study selection process.

The initial import and duplicate removal were performed by one of the authors, who subsequently conducted a preliminary screening of titles and abstracts to exclude clearly irrelevant records. Thereafter, an independent full-text assessment was carried out for the remaining articles. Studies were excluded if they did not meet the predefined inclusion criteria, including inadequacies in methodology, aims, time frame, or study population.

Before the full-text screening phase, both reviewers participated in a calibration exercise to ensure a shared understanding and consistent application of the eligibility criteria. Any disagreements that arose during the selection process were resolved through discussion between the two authors. Reasons for study exclusion were systematically documented.

4.4. Data Extraction Process

Data from the included studies were independently extracted by the reviewers using a shared coding table. The table included the following categories: (a) bibliometric information (authors, title, year of publication, country of origin); (b) method (study design, research design, data collection tools, informants); (c) rare neuromuscular diseases (type of condition, characteristics of the sample); (d) assistive technologies (type, application domain, AT assessment or assignment model); (e) outcomes (quality of life, research instruments used, observations/measurements, and reported positive or negative effects).

After extraction, studies were categorized based on the results reported in each article.

5. RESULTS

5.1. Study Selection

A total of 2.567 records were initially identified through the database searches conducted using the predefined strategy. After removing duplicates (n = 347), 2.220 records remained for title and abstract screening. Of these, 2.111 records were excluded because they did not meet the established inclusion criteria. The full texts of the remaining 109 articles were assessed for eligibility. Following an in-depth evaluation, 50 studies were excluded for failing to meet one or more eligibility criteria. The remaining 59 articles underwent detailed examination using a predefined coding framework to assess their relevance to the research questions. A further 49 studies were excluded during this phase because they did not adequately address the key issues guiding the review. Ultimately, 10 studies met all inclusion criteria and were incorporated into the final synthesis (Figure 1).
The review process was conducted and reported in accordance with the PRISMA guidelines (Page *et al.*, 2020).

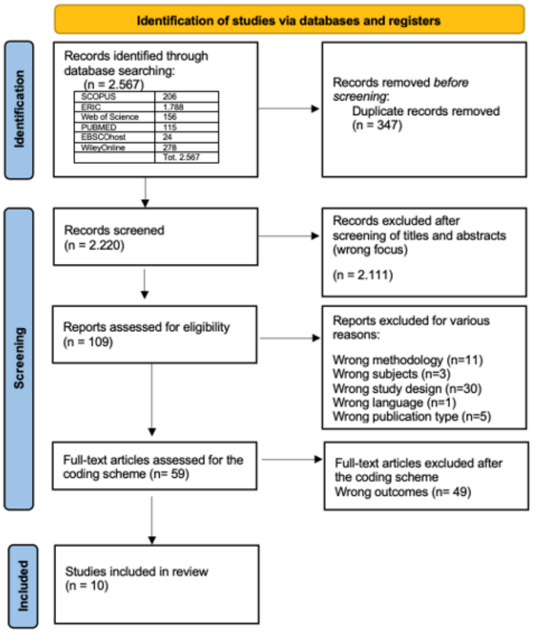

Fig.1: Study Selection Process

5.2. Overview of Study Characteristics

All included studies were published in international peer-reviewed journals, primarily within the medical and clinical fields.

Most of the studies were conducted in the United States (Ward *et al*., 2015; Wolpaw *et al*., 2018; Routhier *et al*., 2022), with additional contributions from Germany (Eicher *et al*., 2019), Brazil (Trevizan *et al*., 2018), Canada (Oldford *et al*., 2022), Spain (Pousada García *et al*., 2015) and Portugal (Tavares *et al*., 2024). One study involved an international collaboration across the United States, the Netherlands and Germany (Vansteensel *et al*., 2016), and another between Germany and Norway (Holz *et al*., 2015).

The selected studies showed substantial heterogeneity in research design, methodological approaches, sample sizes and measurement tools. Of the ten included studies, five employed multi-method designs (including two multi–mixed-methods studies, two cross-sectional studies, one survey and one prospective observational study). One study used a quantitative pre–post design and the remaining four adopted qualitative approaches (one qualitative study with systematic observations and three case studies).

Across studies, diverse methods were used to investigate the role of assistive technologies in individuals with rare neuromuscular diseases. Common data collection techniques included interviews, standardized assessments, and training sessions, while others relied on questionnaires, observations, or document analysis.

In terms of participants, five studies focused exclusively on individuals with rare NMDs (Holz *et al*., 2015; Pousada García *et al*., 2015; Ward *et al*., 2015; Vansteensel *et al*., 2016; Oldford *et al*., 2022). Three studies involved both individuals with NMDs and their caregivers (Wolpaw *et al*., 2018; Routhier *et al*., 2022; Tavares *et al*., 2024). One study included individuals with NMDs, caregivers, and healthcare professionals (Eicher *et al*., 2019), while one study compared people with NMDs to a control group without neurological diagnoses (Trevizan *et al*., 2018).

An analysis was conducted on the types of rare neuromuscular diseases included in the selected studies. Six studies focused on amyotrophic lateral sclerosis (ALS) (Holz *et al.,* 2015; Ward *et al*., 2015; Vansteensel *et al*., 2016; Trevizan *et al*., 2018; Wolpaw *et al.,* 2018; Eicher *et al*., 2019). Two studies examined Duchenne muscular dystrophy (DMD), and one study investigated spinal muscular atrophy (SMA) types II or III (Routhier *et al*., 2022; Tavares *et al*., 2024). The remaining two studies referred more broadly to heterogeneous groups of neuromuscular disorders (Pousada García *et al*., 2015; Oldford *et al*., 2022).

A closer examination of the types of assistive technologies (AT) included in the selected studies reveals notable diversity. Three studies focused on brain–computer interfaces (BCIs) (Holz *et al*., 2015; Vansteensel *et al*., 2016; Wolpaw et al., 2018). Three additional studies examined various categories of assistive technology devices (ATDs), including wheelchairs and home adaptations (Eicher *et al*., 2019), Internet of Things (IoT) solutions controlled through smart speakers (Tavares *et al*., 2024) and touchscreen-based devices (Trevizan *et al*., 2018). Two studies addressed the use of robotic technologies (Oldford *et al.,* 2022; Routhier *et al*., 2022), while the remaining two focused specifically on manual or powered wheelchairs (Pousada García *et al*., 2015; Ward *et al*., 2015).

Regarding the extent to which studies highlight the central role of AT in supporting individuals with NMDs, the authors employed a variety of instruments to assess quality of life. The Psychosocial Impact of Assistive Devices Scale (PIADS) was the most frequently used measure (Holz *et al*., 2015; Pousada García *et al*., 2015; Ward *et al*., 2015; Vansteensel *et al*., 2016; Oldford *et al*., 2022; Routhier *et al*., 2022). Other tools included study-specific interview questions (Eicher *et al*., 2019; Oldford *et* *al*., 2022) and standardized instruments such as the WHOQOL-BREF (Tavares *et al*., 2024), the Portuguese version of the ALS Assessment Questionnaire (ALSAQ-40/BR) (Trevizan *et al*., 2018), and the McGill Quality of Life Questionnaire (Wolpaw *et al.,* 2018).

With respect to the application and assignment of assistive technologies, only one of the ten studies explicitly reported the use of an assignment framework, referring to the Matching Person and Technology Model (MPTM) (Holz *et al*., 2015). In all other studies, the model or framework guiding AT assessment and assignment was not specified.

6. OUTCOME CATEGORIES

6.1. Impact of Assistive Technologies on Quality of Life in People with NMDs

The process of identifying and selecting scientific studies aimed at investigating the improvement of quality of life in individuals with rare neuromuscular diseases (NMDs) proved to be particularly challenging. This difficulty is primarily attributable to the scarcity of research that considers quality of life as a primary outcome, in contrast to the predominance of studies focused on strictly functional or clinical aspects, such as muscle strength, mobility, or respiratory capacity. Moreover, many studies provide fragmented descriptions of the assessment tools employed, making systematic comparison across different approaches difficult. This methodological heterogeneity partly reflects the absence of a shared theoretical framework that integrates biomedical and psychosocial dimensions in analyzing the impact of assistive technologies on the daily lives of individuals with NMDs.

In the included studies, authors employed a variety of instruments to measure the impact of assistive technologies on quality of life in individuals with NMDs.

References	**Type of NMD**	**Type of TA**	**Assessment Tools for Evaluating Quality of Life (RQ1)**
Tavares et al. (2024)	Duchenne Muscular Dystrophy	Internet of Things (IoT) devices controlled via smart speakers (SS)	World Health Organisation Quality of Life (WHOQOL-Bref)
Routhier et al. (2022)	Duchenne Muscular Dystrophy, Spinal Muscular Atrophy (Type II or III)	JACO robotic arm	Psychosocial Impact of Assistive Devices Scale (PIADS-10)
Oldford et al. (2022)	Neuromuscular Disorders	Robotics	Psychosocial Impact of Assistive Devices Scale (PIADS) Interviews
Eicher et al. (2019)	Amyotrophic Lateral Sclerosis	Assistive technologies and devices (ATD)	Interviews
Trevizan et al. (2018)	Amyotrophic Lateral Sclerosis	Touchscreen devices	Amyotrophic Lateral Sclerosis Assessment Questionnaire in the Portuguese Language (ALSAQ-40/BR)

Wolpaw et al. (2018)	Amyotrophic Lateral Sclerosis	Brain–computer interface (BCI)	McGuill Quality of Life questionnaire
Vansteensel et al. (2016)	Amyotrophic Lateral Sclerosis	Fully implanted brain–computer interface (BCI)	Psychosocial Impact of Assistive Devices Scale (PIADS)
Holz et al. (2015)	Amyotrophic Lateral Sclerosis	Brain–computer interface (BCI)	Psychosocial Impact of Assistive Devices Scale (PIADS)
Ward et al. (2015)	Amyotrophic Lateral Sclerosis	Powered wheelchair	Psychosocial Impact of Assistive Devices Scale (PIADS)
Pousada García et al. (2015)	Neuromuscular Disorders	Manual and powered wheelchair	Psychosocial Impact of Assistive Devices Scale (PIADS)

Tab. 2: Assessment Tools for Evaluating Quality of Life

Six of the ten included studies (Holz *et al*., 2015; Pousada García *et al*., 2015; Ward *et al*., 2015; Vansteensel *et al*., 2016; Oldford *et al*., 2022; Routhier *et al*., 2022) assessed the impact of assistive technologies on the quality of life of individuals with NMDs using the Psychosocial Impact of Assistive Devices Scale (PIADS). This standardized 26-item instrument measures the effects of assistive devices on quality of life, functional independence, and well-being (Day & Jutai, 1996).

Routhier *et al*. (2022) evaluated the impact of the JACO robotic arm among individuals with upper-limb limitations caused by neuromuscular disease, using a prospective pre–post design. In addition to observing functional performance in controlled settings, the authors explored everyday use over a two-month period and collected perceptions from users and informal caregivers. During the final assessment phase, they administered the PIADS-10, a shortened version of the scale (Jutai et al., 2007), capturing user-reported changes in happiness, independence, self-esteem, productivity, quality of life, sense of control, openness to new activities, and participation in daily life since adopting the device.

Similarly, Oldford *et al*. (2022) examined the psychosocial effects of a robotic device among adolescents with rare NMDs, who often face substantial barriers to recreational and social participation. Using the adult PIADS and a brief semi-structured interview, the authors explored participants’ perceptions of the device, its influence on daily activities, and its potential to expand social engagement.

Vansteensel *et al.* (2016) and Holz *et al*. (2015) also used the adult PIADS to assess satisfaction and psychosocial outcomes following the use of brain–computer interfaces (BCIs) for communication in individuals with ALS, fully implanted in the case study by Vansteensel *et al*. (2016).

Ward *et al*. (2015) and Pousada García *et al*. (2015) used PIADS to evaluate the impact of manual or powered wheelchairs on quality of life in people with ALS and other NMDs.

Another standardized instrument used to assess quality of life was the WHOQOL-BREF, adopted by Tavares *et al*. (2024) in a case study on the integration of IoT devices controlled by smart speakers in the home environment of an adolescent with Duchenne muscular dystrophy and his caregivers.

Trevizan *et al*. (2018) employed the ALSAQ-40/BR, the Brazilian Portuguese version of the ALS Assessment Questionnaire, which measures five domains: mobility, activities of daily living, eating and swallowing, communication, and emotional functioning.

Wolpaw *et al*. (2018) investigated in-home BCI use among individuals with ALS and provided caregiver training. Quarterly home visits assessed benefits, limitations, and quality of life using the McGill Quality of Life Questionnaire, a multidimensional 17-item scale measuring physical well-being, symptoms, psychological state, existential well-being, support, and global quality of life.

Finally, Eicher *et al*. (2019) used study-specific semi-structured interview questions to examine experiences with assistive technologies among individuals with ALS and their caregivers. Although the specific items were not reported, results were organized into thematic categories capturing perceived challenges, benefits, and overall quality-of-life implications.

6.2 Assessment Models for Assistive Technologies

Regarding the Assistive Technology Assessment (ATA) process, developed to identify the optimal procedures for improving the quality of assistive technologies provided and maximizing the benefits of their use, the findings emerging from the review are particularly noteworthy.

Although Bernd *et al*. (2009) argue that the International Classification of Functioning, Disability and Health (ICF) is a generic tool not specifically developed to assess AT-related needs, other scholars point to the ICF as a useful descriptive framework that can support professionals during the matching process (Karlsson, 2010). Indeed, the ICF captures the complex interactions between personal functioning, environmental factors, and technology use, allowing practitioners to consider the broader psychosocial impact of AT on the individual and their surroundings (Bernd *et al*., 2009). As such, it can serve as a conceptual foundation for the ATA process.

References	**Type of NMD**	**Type of TA**	**Assistive Technology Evaluation Models (RQ2)**
Tavares et al. (2024)	Duchenne Muscular Dystrophy	Internet of Things (IoT) devices controlled via smart speakers (SS)	Not specified
Routhier et al. (2022)	Duchenne Muscular Dystrophy, Spinal Muscular Atrophy (Type II or III)	JACO robotic arm	Not specified
Oldford et al. (2022)	Neuromuscular Disorders	Robotics	Not specified
Eicher et al. (2019)	Amyotrophic Lateral Sclerosis	Assistive technologies and devices (ATD)	Not specified
Trevizan et al. (2018)	Amyotrophic Lateral Sclerosis	Touchscreen devices	Not specified
Wolpaw et al. (2018)	Amyotrophic Lateral Sclerosis	Brain–computer interface (BCI)	Not specified
Vansteensel et al. (2016)	Amyotrophic Lateral Sclerosis	Fully implanted brain–computer interface (BCI)	Not specified
Holz et al. (2015)	Amyotrophic Lateral Sclerosis	Brain–computer interface (BCI)	Matching Person & Technology
Ward et al. (2015)	Amyotrophic Lateral Sclerosis	Powered wheelchair	Not specified

Pousada García et al. (2015)	Neuromuscular Disorders	Manual and powered wheelchair	Not specified

Tab.3: Assistive Technology Evaluation Models

However, in most of the studies included in this systematic review, authors did not employ a structured or validated AT assessment model when assigning assistive technologies to people with rare NMDs. Instead, they relied primarily on outcome-focused instruments, which evaluate satisfaction, performance, usability, or caregiver burden after the technology has been introduced. The tools most commonly used included *Quebec User Evaluation of Satisfaction with Assistive Technology* (QUEST 2.0) (Holz *et al.*, 2015; Vansteensel *et al.*, 2016; Routhier *et al.*, 2022); *System Usability Scale (SUS)* (Tavares *et al.*, 2024); *Questionnaire for the Assessment of Informal Carer Burden* (QASCI) (Tavares *et al.*, 2024); *Visual Analogue Scales for satisfaction, frustration, enjoyment, exhaustion, subjective BCI control, and loss of control* (Holz *et al.*, 2015); *NASA Task Load Index* (Holz *et al.*, 2015); *Canadian Occupational Performance Measure* (COPM) (Routhier *et al.*, 2022); *Upper Extremity Performance Test for the Elderly* (TEMPA 2.0) with and without AT (Routhier *et al.*, 2022); *Caregiver Assistive Technology Outcome Measure* (CATOM) (Routhier *et al.*, 2022).

While these instruments provide valuable insights into the effects of AT use, they do not provide a standardized or systematic basis for matching individuals with the most appropriate device. This gap underscores the need for more consistent application of validated assessment frameworks when selecting and assigning AT to individuals with rare neuromuscular disorders.

Among all included studies, only one (Holz *et al.*, 2015) explicitly applied a validated AT matching framework: the Matching Person and Technology (MPT) Model (Scherer, 1998). The MPT model was the first to emphasize active user involvement in the assistive technology selection process. It conceptualizes person, environment, and technology as interdependent and interactive components (Galvin & Scherer, 1996). In contrast to the traditional unidirectional medical model, where technology is prescribed by professionals, the MPT adopts a social model, recognizing the AT provider as part of the user's environmental context and as a factor influencing satisfaction and long-term use (Corradi, Scherer & LoPresti, 2013).

Holz and colleagues (2015) specifically employed the Assistive Technology Device Predisposition Assessment (ATD-PA), a component of the MPT model that evaluates an individual's predisposition to use a given device. This tool supports decision-making by identifying factors that may facilitate or inhibit AT adoption.

In their study, Holz et al. applied the ATD-PA to assess the readiness of a woman with advanced amyotrophic lateral sclerosis to use a brain–computer interface (BCI)-based painting system. The assessment revealed an excellent match between the user and the device, indicating a high likelihood of successful daily use. The participant, a 73-year-old woman with complete paralysis except for residual eye movements, mechanically ventilated and tube-fed, communicated through partner-scanning or an eye-tracking system. The ATD-PA results highlighted the appropriateness of the BCI system for her functional profile and personal preferences.

Overall, the findings of this review show that triangulation among user needs, functional impairments, and technological features is rarely conducted systematically. While outcome measures are widely used, validated matching models such as the ATA process and the MPT model remain largely absent from contemporary AT research involving people with rare NMDs. Future studies would benefit from adopting structured, biopsychosocially-oriented frameworks that ensure person–technology–environment alignment and promote sustainable, meaningful integration of assistive technologies into daily life.

7. DISCUSSION

The literature reviewed indicates that maintaining quality of life for individuals with neuromuscular diseases (NMDs) is not solely a clinical objective but a multidimensional process involving functional, psychosocial, relational, educational, and social domains. Within this framework, assistive technologies (AT) emerge not only as rehabilitative tools but as enabling technologies that support autonomy, expand opportunities for interaction, and foster processes of self-determination.

Experimental studies consistently show that the use of robotic arms, BCI systems, powered wheelchairs, touchscreen devices, and IoT solutions produces improvements in everyday functioning, participation, and various psychological dimensions. The use of the JACO robotic arm (Routhier *et al*., 2022) led to enhanced functional abilities and greater participation in daily routines, accompanied by increased perceived control and independence, as measured by the PIADS. Similar results were observed in studies of BCI-based communication systems (Holz *et al*., 2015; Vansteensel *et al*., 2016), where long-term home use was associated with improvements in quality of life, particularly in "adaptability", suggesting that these technologies can help individuals with advanced ALS face new activities and mitigate isolation when conventional communication tools are no longer viable.

Research on powered wheelchairs (Pousada García *et al*., 2015; Ward *et al*., 2015) similarly reports significant increases in competence, self-esteem, and participation. These findings highlight mobility not only as a functional need but as a key factor in identity construction, relational engagement, and active citizenship. Psychological benefits intertwine with educational and social ones: increased access to school and community settings, reduced caregiver dependence, and greater opportunities for choice and self-directed action.

Oldford *et al*. (2022) further emphasize the educational potential of robotic technologies, demonstrating how their use across home, school, rehabilitation, and outdoor contexts can support autonomy and self-efficacy. In this sense, AT functions as a pedagogical tool, enabling access to meaningful learning environments, sustaining motivation, fostering competence development, and promoting social inclusion.

Other studies reveal more heterogeneous outcomes. Tavares *et al*. (2024), using the WHOQOL-Bref in a case of DMD and IoT-based smart-speaker systems, reported improvements in physical well-being but fluctuations in other domains due to acute clinical events, highlighting the need to contextualize quantitative outcomes. Trevizan *et al*. (2024) found positive emotional effects of touchscreen devices in ALS, though differences compared to controls were limited. Wolpaw *et al*.

(2018) documented stable quality of life in long-term BCI use for communication, suggesting that training and sustained practice help consolidate benefits.

Finally, the qualitative work of Eicher *et al*. (2019) underscores the lived experiences of individuals with ALS and their caregivers, who perceive AT as essential for maintaining autonomy and meaningful activities while reducing dependence. Yet participants also reported challenges—complexity, bulkiness, insufficient customization, increased caregiver burden—highlighting the importance of timely device provision and ongoing educational support. These findings reinforce that AT becomes truly enabling only when accompanied by appropriate training, personalization, and relational scaffolding.

Overall, the studies reveal three core themes:

1. *educational and pedagogical dimension*: AT not only compensates for impairments but supports learning processes, active participation, decision-making, and identity development, playing a crucial role across the lifespan;
2. *social and participatory dimension*: AT enhances daily functioning, mobility, communication, and social interactions, enabling inclusion across home, school, community, and recreational environments;
3. *importance of personalization and support*: The effectiveness of AT depends on usability, individualized adaptation, caregiver involvement, and timely introduction, reinforcing the need for integrated, person-centered approaches in NMD management.

Taken together, assistive technologies emerge as powerful instruments of empowerment, bridging clinical care, educational practice, and social inclusion, and enabling individuals with NMDs to actively participate in shaping their life trajectories.

8. CONCLUSION

One of the most significant findings emerging from this study is that technologies—whether tools supporting communication or mobility—can bring about positive changes in the daily and social lives of individuals. However, the provision of technology must necessarily be integrated into a comprehensive intervention program that includes a thorough assessment of factors associated with effective device use, training on its operation, evaluation of the user's physical and social context, and careful monitoring to ensure that the device continues to meet the person's evolving needs. This approach relies on the coordinated delivery of health and social services to ensure continuity of care and the effectiveness of interventions.

As previously noted, during the final screening and coding phase, the majority of scientific articles were excluded because, although they focused on the role and impact of assistive technologies (AT) on improving the quality of life (QoL) of individuals with NMDs, they did not include clear measurement or observation tools for evaluating QoL. Instead, these studies primarily addressed the clinical and neuroscientific aspects of AT provision, emphasizing technology implementation, device feasibility, and functional improvements for the user.

The rapid advancement of technology, particularly assistive technology such as robotics, brain–computer interfaces (BCIs), and other innovations, has opened new opportunities to positively influence an individual's capacity to perform activities and participate in social life, thereby supporting people in vulnerable situations to develop or maintain independent living.

It is crucial to emphasize that, although the construct of QoL is highly complex and challenging to measure, it should not be neglected. The literature highlights that QoL encompasses all major dimensions of a person's existence, including not only health and physical functioning but also social, psychological, emotional, spiritual, and familial domains.

Nevertheless, QoL does not coincide strictly with health: while it is influenced by health status, it represents a broader concept that reflects the individual's overall perception of well-being (Ferrans & Powers, 1992). Adaptation theories provide a useful conceptual framework for understanding QoL, as they describe the processes through which individuals cope with and manage the implications of health-related threats, generating observable outcomes (Biesecker & Erby, 2008). From this perspective, QoL can be considered the result of an individual's adaptation to their condition, particularly in the context of chronic illness and disability (Stanton et al., 2001).

Another key aspect emerging from most studies is that, in addition to functional improvements and QoL, future research should address caregiver burden—defined as the physical, mental, social, and financial strain experienced by caregivers as a result of providing care to a family member (Zarit *et al.*, 1986). Most individuals with NMD require assistance, becoming entirely dependent on caregivers—usually family members—for daily activities, often resulting in caregiver overload. In this regard, studies that assessed caregiver burden using standardized instruments also highlight the extent to which assistive technology can alleviate this burden, thereby improving the well-being not only of the user but also of those providing care (Lanfeldt *et al.*, 2016; Wlpaw *et al.*, 2018; Eicher *et al.*, 2019; Lindsay, Cagliostro & McAdam, 2019; Routhier *et al.*, 2022; Tavares *et al.*, 2024).

9. LIMITATIONS

This systematic review presents several limitations that should be acknowledged. First, the considerable heterogeneity of neuromuscular diseases (NMDs) posed a significant challenge in defining the search string and selecting appropriate keywords. As a result, some rare NMDs may have been inadvertently excluded from the review. Moreover, relevant or emerging assistive technologies may not have been captured due to indexing limitations or the novelty of such interventions. Another key limitation concerns the inclusion criteria: by focusing specifically on studies assessing quality of life (QoL), the review excluded research evaluating the effectiveness of assistive technologies in improving functional outcomes among individuals with NMDs but not directly measuring QoL using validated or ad hoc instruments. This narrowing of scope may have led to the omission of potentially valuable evidence.

REFERENCES

Benarroch, L., Bonne, G., Rivier, F., & Hamroun, D. (2020). The 2021 version of the gene table of neuromuscular disorders (nuclear genome). *Neuromuscular Disorders*, *30*(12), 1008-1048.

Bernd, T., Van Der Pijl, D., & De Witte, L. P. (2009). Existing models and instruments for the selection of assistive technology in rehabilitation practice. *Scandinavian Journal of Occupational Therapy*, *16*(3), 146-158.

*Beswick, E., Fawcett, T., Hassan, Z., Forbes, D., Dakin, R., Newton, J., ... & Pal, S. (2022). A systematic review of digital technology to evaluate motor function and disease progression in motor neuron disease. *Journal of Neurology*, *269*(12), 6254-6268.

Biesecker, B. B., & Erby, L. H. (2008). *Adaptation to living with a genetic condition: The role of psychological adaptation*. *Clinical Genetics, 74*(5), 401–407.

Bologna, F., Perilongo, G., Mennini, F. S., Scarpa, M., & Silvano, G. (Eds.). (2024). *Malattie rare: una sfida tra passato e futuro*. Gius. Laterza & Figli Spa.

*Bortolani, S., Brusa, C., Rolle, E., Monforte, M., De Arcangelis, V., Ricci, E., ... & Tasca, G. (2022). Technology outcome measures in neuromuscular disorders: A systematic review. *European Journal of Neurology*, *29*(4), 1266-1278.

Bos, I., Stallinga, H. A., Middel, B., Kuks, J. B., & Wynia, K. (2013). Validation of the ICF core set for neuromuscular diseases. *Eur J Phys Rehabil Med*, *49*(2), 179-87.

*Burke, K. M., Arulanandam, V., Scirocco, E., Royse, T., Hall, S., Weber, H., ... & Paganoni, S. (2025). Assistive Technology in ALS: A Scoping Review of Devices for Limb, Trunk, and Neck Weakness. *American Journal of Physical Medicine & Rehabilitation*, 10-1097.

Coca, J. R., Gómez-Redondo, S., Soto-Sánchez, A., Lozano-Blasco, R., & Romero-Gonzalez, B. (2023). Perception of Social and Educational Quality of Life of Minors Diagnosed with Rare Diseases: A Systematic Review and Meta-Analysis. *International Journal of Environmental Research and Public Health,* 20(2), 933.

Coenen, M., Cieza, A., Freeman, J., Khan, F., Miller, D., Weise, A., ... & members of the Consensus Conference. (2011). The development of ICF Core Sets for multiple sclerosis: results of the International Consensus Conference. *Journal of neurology*, *258*(8), 1477-1488.

Cohen, J. S., & Biesecker, B. B. (2010). Quality of life in rare genetic conditions: a systematic review of the literature. *American Journal of Medical Genetics Part A*, *152*(5), 1136-1156.

Conway, K. M., Ciafaloni, E., Matthews, D., Westfield, C., James, K., Paramsothy, P., & Romitti, P. A. (2018). Application of the International Classification of Functioning, Disability and Health system to symptoms of the Duchenne and Becker muscular dystrophies. *Disability and rehabilitation*, *40*(15), 1773-1780.

Corradi, F., Scherer, M., & Lo Presti, A. (2013). *Misurare l'abbinamento delle tecnologie assistive. In Manuale di valutazione delle tecnologie assistive* (pp. 49-67). Italia: Pearson Italia.

*Cumplido, C., Delgado, E., Ramos, J., Puyuelo, G., Garcés, E., Destarac, M. A., ... & Garcia, E. (2021). Gait-assisted exoskeletons for children with cerebral palsy or spinal muscular atrophy: A systematic review. *NeuroRehabilitation*, *49*(3), 333-348.

Day, H., & Jutai, J. (1996). *Measuring the psychosocial impact of assistive devices: The PIADS. Canadian Journal of Rehabilitation*, 9(2), 159-168.

*Eicher, C., Kiselev, J., Brukamp, K., Kiemel, D., Spittel, S., Maier, A., ... & Greuèl, M. (2019). Experiences with assistive technologies and devices (ATD) in patients with amyotrophic lateral sclerosis (ALS) and their caregivers. *Technology and Disability*, *31*(4), 203-215.

Espay, A. J., Bonato, P., Nahab, F. B., Maetzler, W., Dean, J. M., Klucken, J., ... & Movement Disorders Society Task Force on Technology. (2016). Technology in Parkinson's disease: challenges and opportunities. *Movement Disorders*, *31*(9), 1272-1282.

*Fernandes, F., Barbalho, I., Barros, D., Valentim, R., Teixeira, C., Henriques, J., ... & Dourado Júnior, M. (2021). Biomedical signals and machine learning in amyotrophic lateral sclerosis: a systematic review. *Biomedical engineering online*, *20*(1), 61.

Ferrans, C. E., & Powers, M. J. (1992). Psychometric assessment of the Quality of Life Index. *Research in nursing & health*, *15*(1), 29-38.

Fiorucci, A., & Rossini, G. (2023). Le tecnologie assistive per la disabilità. Dall'assistenza protesica alla promozione delle abilità e dell'inclusione. Quale ruolo può svolgere il disability manager?, *QTimes webmagazine*, *15*, 82-93.

Galvin, J. C., & Scherer, M. J. (1996). *Evaluating, Selecting, and Using Appropriate Assistive Technology*. Aspen Publishers, 200 Orchard Ridge Dr., Suite 200, Gaithersburg, MD 20878; toll-free tele.

*Gandolla, M., Antonietti, A., Longatelli, V., & Pedrocchi, A. (2020). The effectiveness of wearable upper limb assistive devices in degenerative neuromuscular diseases: A systematic review and meta-analysis. *Frontiers in bioengineering and biotechnology*, *7*, 450.

Grob, R. (2013). The heart of patient-centered care. *J Health Polit Policy Law*, *38*(2), 457-465.

*Holz, E. M., Botrel, L., Kaufmann, T., & Kübler, A. (2015). Long-term independent brain-computer interface home use improves quality of life of a patient in the locked-in state: a case study. *Archives of physical medicine and rehabilitation*, *96*(3), S16-S26.

Karlsson, P. (2010). ICF: a guide to assistive technology decision-making. In *Proceedings of the ARATA 2010 National Conference*.

Landfeldt, E., Lindgren, P., Bell, C. F., Guglieri, M., Straub, V., Lochmüller, H., & Bushby, K. (2016). Quantifying the burden of caregiving in Duchenne muscular dystrophy. *Journal of neurology*, *263*(5), 906-915.

*Leone, E., Pandyan, A., Rogers, A., Kulshrestha, R., Hill, J., & Philp, F. (2024). Effectiveness of conservative non-pharmacological interventions in people with muscular dystrophies: a systematic review and meta-analysis. *Journal of Neurology, Neurosurgery & Psychiatry*, *95*(5), 442-453.

Lindsay, S., Cagliostro, E., & McAdam, L. (2019). Meaningful occupations of young adults with muscular dystrophy and other neuromuscular disorders. *Canadian Journal of Occupational Therapy*, *86*(4), 277-288.

*Mijic, M., Wirner-Piotrowski, C., Jung, A., Gutschmidt, K., Arndt, M., García-Angarita, N., ... & Schoser, B. (2024). The assistive gait devices and their implementation in activities of daily living for patients with neuromuscular disease: A systematic review and meta-analysis. *Journal of Neuromuscular Diseases*.

*Oldford, L., Hanson, N., Ross, I., Croken, E., & Bleau, L. (2022). Exploring the psychosocial impact of simple robotic assistive technology on adolescents with neuromuscular disease. *Journal of Rehabilitation and Assistive Technologies Engineering*, *9*.

OMS. Organizzazione Mondiale della Sanità (2001). *ICF Classificazione Internazionale del Funzionamento, della Disabilità e della Salute*. Trento: Erickson.

Page, M. J., Moher, D., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., ... & McKenzie, J. E. (2021). PRISMA 2020 explanation and elaboration: updated guidance and exemplars for reporting systematic reviews. *bmj*, *372*.

Pinnelli, S. (2014). Ambient assisted living, innovazione tecnologica e inclusione. *Media Education*, *5*(1), 1-13.

Pinnelli, S. (2022). ICT Solutions in the D-Sys-Com Research: Analysis of the Needs and Attitudes of the Frail Elderly Person. *Frontiers in Robotics and AI*, *9*.

Pinnelli, S., & Fiorucci, A. (2017). *Rari ma non troppo. Bisogni di cura e persona con malattia rara: risultati di indagine del progetto People with CIDP and Quality of life*.

Pinnelli, S., & Fiorucci, A. (2018). Progettazione e sviluppo di una Personal Care App per promuovere il monitoraggio delle attività centrate sul paziente nell'autogestione delle malattie rare. Il progetto RareBox. *MEDIC. METODOLOGIA DIDATTICA E INNOVAZIONE CLINICA*, *2*, 61-71.

*Pousada García, T., Groba González, B., Nieto Rivero, L., Pereira Loureiro, J., Díez Villoria, E., & Pazos Sierra, A. (2015). Exploring the psychosocial impact of wheelchair and contextual factors on quality of life of people with neuromuscular disorders. *Assistive technology*, *27*(4), 246-256.

*Routhier, F., Lettre, J., Bouffard, J., Archambault, P., Lemay, M., & Gélinas, I. (2022). Impacts of a robotic arm on people with upper-limb disabilities due to neuromuscular disorder. *JPO: Journal of Prosthetics and Orthotics*, *34*(3), 180-191.

Sagliaschi, S. (2010). L'ICF nei servizi socio-sanitari italiani. *L'integrazione scolastica e sociale*, 9(5), 509-515.

Scherer, M. J. (1998). *Matching Person & Technology (MPT) model manual*. The Institute for Matching Person & Technology, Inc.; versione italiana tradotta da Fondazione Don Carlo Gnocchi, 2002.

Scherer, M. J., & Craddock, G. (2002). Matching person & technology (MPT) assessment process. *Technology and Disability*, *14*(3), 125-131.

Stanton, A. L., Revenson, T. A., & Tennen, H. (2007). Health psychology: Psychological adjustment to chronic disease. *Annual Review of Psychology, 58*, 565–592.

Stolk P., Willemen M. J. C., Leufkens H. G. M. "Rare essentials: Drugs for rare diseases as essential medicines." *Bulletin of the World Health Organization*. 2006; 84(9): 745-751.

*Tavares, R., Inácio, A., Sousa, H., & Ribeiro, J. (2024). Smart Speakers as an Environmental Control Unit for Severe Motor Dependence: The Case of a Young Adult with Duchenne Muscular Dystrophy. *International Journal of Environmental Research and Public Health*, *21*(6), 778.

*Trevizan, I. L., Silva, T. D., Dawes, H., Massetti, T., Crocetta, T. B., Favero, F. M., ... & Monteiro, C. B. D. M. (2018). Efficacy of different interaction devices using non-immersive virtual tasks in individuals with Amyotrophic Lateral Sclerosis: a cross-sectional randomized trial. *BMC neurology*, *18*(1), 209.

*Vansteensel, M. J., Pels, E. G., Bleichner, M. G., Branco, M. P., Denison, T., Freudenburg, Z. V., ... & Ramsey, N. F. (2016). Fully implanted brain–computer interface in a locked-in patient with ALS. *New England Journal of Medicine*, *375*(21), 2060-2066.

Von der Lippe, C., Diesen, P. S., & Feragen, K. B. (2017). Living with a rare disorder: a systematic review of the qualitative literature. *Molecular genetics & genomic medicine*, *5*(6), 758-773.

*Ward, A. L., Hammond, S., Holsten, S., Bravver, E., & Brooks, B. R. (2015). Power wheelchair use in persons with amyotrophic lateral sclerosis: changes over time. *Assistive Technology*, *27*(4), 238-245.

*Wolpaw, J. R., Bedlack, R. S., Reda, D. J., Ringer, R. J., Banks, P. G., Vaughan, T. M., ... & Ruff, R. L. (2018). Independent home use of a brain-computer interface by people with amyotrophic lateral sclerosis. *Neurology*, *91*(3), e258-e267.

Zarit, S. H., Todd, P. A., & Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: a longitudinal study. *The Gerontologist*, *26*(3), 260-266.

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