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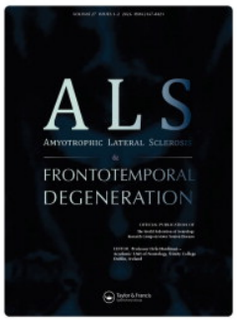

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REVIEW ARTICLE

Timing of communication and technology control support in ALS – a systematic review

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Abstract

Objective: To review evidence on the optimal timing of interventions that support communication and technology control for people living with Amyotrophic Lateral sclerosis (ALS). *Methods:* A systematic review was conducted following a pre-registered protocol. Databases were searched for studies involving people living with ALS that addressed timing of assistive technology interventions for communication or technology control. Screening and data extraction were completed in duplicate, findings were synthesized using a thematic analysis, and relevant findings presented as a descriptive summary. *Results:* Twenty-eight studies met the inclusion criteria. Evidence focused overwhelmingly on communication support rather than wider assistive technology interventions. Need for a communication aid typically occurs between one and five years from diagnosis and the timing of this varies significantly according to the site of onset of ALS. There are significant variations in the timing of changes for individuals within these groupings and there are likely a larger number of groupings that would be clinically useful. A significant correlation between changes in speaking rate and intelligibility has been shown. Once changes to speech do start to occur then the time to the loss of functional speech appears relatively consistent across the types of ALS. *Conclusion:* Current best practice guidelines are not reflective of the findings of this review and do not support professionals in identifying how to provide timely support. Monitoring speech changes systematically may support timely intervention. There is potential for individual level predictive modeling to help support people living with ALS to be proactive and prepared for changes.

Keywords: *Motor neuron disease, amyotrophic lateral sclerosis, assistive technology, augmentative and alternative communication, timing, intervention*

Introduction

Amyotrophic Lateral sclerosis (ALS) affects motor neuron function and consequently the control of muscles. This progressive process leads to a deterioration in the ability to carry out many daily life activities including speech and communication and controlling technology such as phones, computers, voice assistants, TVs or lights.

Assistive technology describes a wide range of technologies and associated interventions which support people living with disabilities to carry out everyday tasks (1). Electronic assistive technology such as communication aids, environmental controls, and computer access technologies are particularly pertinent to those living with ALS and can have a significant impact in improving quality of life and participation (2,3). Communication aids are part of a wider range of strategies known as Augmentative and Alternative Communication (AAC) that support those with complex communication needs. Communication aids are increasingly based on mainstream tablet or smartphone platforms and are used by individuals with a range of medical conditions, including ALS (4). Technologies such as personalized speech synthesis

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(voice banking) have supported individuals who lose speech due to conditions such as ALS to have an increased perception of identity in their use of the communication aid (5). Environmental controls were developed in the 1960s to support those with spinal cord injuries and their use has expanded to support people living with a wider range of conditions, including ALS. Control of a wider range of technologies, including computers and gaming devices is now possible and often a priority for people living with ALS. Alternative access methods are used as part of assistive technology systems and support those with physical disability affecting use of conventional controls such as touchscreens, keyboards or mice. Alternative access technologies allow individuals to control technology using other movements such as eye, head, finger or foot movement: eyegaze technology, speech recognition, alternative keyboards and mice, and switch or sensor controls are all well-established alternative access technologies used in practice (6).

Timing of communication and technology support is critical for optimal outcomes, yet the factors guiding referral and intervention remain unclear. At the point of diagnosis, an individual may likely be overwhelmed with information and the psychological burden of processing the information about their terminal disease (7). Providing information and support at or after the point of need risks the individual being left without support for a period, unable to practice and learn the use of the equipment, and/or dying before appropriate support is in place. The UK (8), USA (9–11), Canadian (12), and European (13) best practice guidelines for the management of ALS all recommend early assessment/offer of communication aids and/or environmental controls to those diagnosed with ALS. The UK and European guidelines use the phrase "without delay" but do not give guidance to clinicians about what should trigger a referral or intervention for support; the UK and European guidelines recommend regular, ongoing monitoring assessment and the US guidelines recommend an ongoing process.

People with ALS struggle to predict future changes and want to respond proactively (14) yet often receive assistive technology too late to be most effective (15,16). Late provision of assistive technology reduces intervention effectiveness, and acceptance depends on personal factors, environmental support, and professional training (17,18).

We carried out a review to identify literature that can inform the optimal timing of interventions supporting communication and technology control for people living with ALS.

Table 1. Communication and technology control synonyms.

Term	Synonyms
Communication	Augmentative and Alternative Communication (AAC): Communication aids Speech generating devices Voice output communication aids.
Control of technology	Electronic assistive technology: Environmental control (EC) Accessible home automation devices Alternative/accessible computer controls Alternative/accessible technology access devices, such as: switches, eye-gaze technology.

Materials and methods

This review used a mixed methods design with a convergent approach to analysis (19). Literature of any study design was systematically identified, findings of included papers related to the research question were extracted, and a thematic analysis of the included literature is presented below as a descriptive summary. The review was pre-registered on Open Science Framework (https://osf.io/9ekhb) and the JBI reporting standards for mixed methods systematic reviews were applied to reporting the findings (20).

Search strategy

The review encompassed interventions whose aim is support of communication and technology

Table 2. Search string construction.

Term	String	Notes
Participant	("MND" OR "ALS" OR "Motor Neurone Disease" OR "Motor Neuron Disease" OR "Amyotrophic lateral sclerosis")	Robust synonyms of ALS, MND
AND		
Intervention	("assistive" OR "augmentative" OR "Aided Communication" OR "AAC" OR "eyegaze" OR "communication aid" OR "VOCA" OR "SGD" OR "environmental control")	Assistive technology and Augmentative Communication specific terms, not including those which create significant inaccurate hits, such as AT – which is searched as "at."

All terms were included in block quotes in the search interfaces to ensure that any similar words algorithms in database interfaces were not used (as for example when applied to "assistive" this is then searched as assist*, assisting etc).
Search results can be found on the OSF registration project page (https://osf.io/9ekhb/files).

control. A search string was constructed based on the research question (Tables 1 and 2). Search terms for "timeliness" were not included because when tested terms such as "time*" produced many erroneous results and tests suggested that the scale of the literature would allow for hand searching at title and abstract review stage. The search string was applied to the databases listed in Table 3 on the 5th June 2025. Reference lists of included papers were also searched.

Inclusion and exclusion criteria

Inclusion and exclusion criteria (Table 4) were designed to capture the wide range of methodological approaches to considering timeliness of intervention. Studies were not restricted in terms of design, methodology, date or language of publication.

Screening

The search results were imported into the RAYAAN™ software which was used for:

- De-duplication: potential duplicates identified were manually reviewed and filtered by SJ.
- Title and Abstract review: SJ and KB reviewed, each blind to the other's review, queries or disagreement as to inclusion were then jointly discussed to consensus.
- Full text screening: SJ and KB reviewed the sourced full texts, each blind to the other's review; papers included by both reviewers were included, papers included by only one researcher were discussed to consensus, SB resolved any disagreement.

Table 3. Research databases and corresponding interfaces used for search.

Interface	Databases
EBSCOHost	CINAHL, MEDLINE
PubMed	PubMed (inc MEDLINE)
OVID	Embase, EmCare
ProQuest	PsychInfo, BNI, AMED
Web of Science	Core Collection

Either an academic or NHS account which provided full text access and search was used for access, depending on licensing.

Data extraction & analysis

Data were extracted by SJ and KB into a spreadsheet table (Table 5), data extracted were quoted text from the papers (i.e. not paraphrased).

As this was a descriptive mixed methods study no quality assessment of the included papers was planned. A thematic analysis of the extracted data was performed: for each paper a short descriptive

Table 5. Data extraction fields.

Category	Extracted information
Participant information	Number Diagnosis /diagnostic method; Assistive technology use; Phenotypes; Demographics.
Study Type	Intervention aim; Study Method; Study Period and data collection timing.
Measures	Timing/Timeliness measure; Definition of timely intervention; Variables recorded; Outcome measures.
Findings and Implications	Finding related to timeliness of assistive technology intervention; Barriers/facilitators to timely intervention identified; Implications for assistive technology practice.

Table 4. Review inclusion and exclusion criteria, organized by SPIDER terms (sample, phenomenon of interest, design, evaluation, research type).

Inclusion	Exclusion
(S) Participants with diagnosis of MND/ALS (any phenotype).	(S) Participants without diagnosis of MND (unless in control arm) (S) Participants are professionals working with people living with ALS. (S) Participants with *suspected* diagnosis of MND/ALS. (S) No participants.
(P) Use of communication or electronic assistive technology (as defined below). (P) Any aspect of timing of intervention/use of these assistive technologies.	(P) Does not address intervention/use of communication or electronic assistive technology (as defined below). (P) Studies detailing the development of novel technologies not used in clinical practice (P) Does not address timing of interventions.
(D) Any study design (with empirical data). (D) Any reporting language that a machine translation into English can be sourced for.	(D) No listed study design. (D) Reviews and opinion pieces.
(E) Any outcome related to communication or electronic assistive technology use, including device use or abandonment.	
(R) Any research type.	

Table 6. Summary of review screening process, reported as per PRISMA 2020 reporting standards.

Search results:	1984	Of which duplicate:	648
(from n = 5 databases, see Table 3)			
T&A screening:	1336	Of which excluded:	1272
Sought for screening:	64	Of which duplicate*:	1
Assessed for eligibility:	63	Of which excluded:	36
Included in review as eligible:	27		
Additionally identified from reference lists:	1		
Total studies included in review	28		

The data extraction file and full details of results are on the OSF site (https://osf.io/7j9e2/files/osfstorage).

summary of the extracted data relevant to the research question was created by SJ and reviewed by KB and SB; included papers were coded into themes based on these summaries; a single descriptive summary of the included literature was produced by SJ; and this was jointly edited and is presented in Results below.

Results

Table 6 summarizes the results of the review screening process. Twenty-eight papers were included in the final review (15,16,21–46). The third reviewer was not required to arbitrate. Of the 28 included papers: 10 were published since 2020 and 21 since 2010; 17 included information about site of onset of ALS; 20 involved less than 100 participants; 27 related to communication of which three additionally related to computer access, two additionally considered Environmental Control, and one related to nonspecific assistive devices.

Following data extraction the findings were coded into four main themes. A descriptive summary of the included papers is presented below organized by theme.

Timing of need: people living with ALS typically need a communication aid one to five years after diagnosis

Half of ALS patients were observed to need a communication aid after one year of first clinic appointment (21), and similarly 60% of participants, who had a mean time from bulbar symptoms of 10 months, needed a communication aid during the two years of the study carried out by Makkonen et al. (22). Almost half of the people living with ALS included in a subsequent study needed a communication aid between years two and three of ALS onset; and the vast majority reached what the authors' described as the "tollgate" of need for a communication aid by year four (23).

Significant differences were found in the time between symptom onset and use of a communication aid: varying from 15.5 months for a group classified as "quick" to 67 months for the group categorized as "slow" (24). Eshghi et al., using a speaking rate of 120 words per minute to indicate need for a communication aid, found a median time from symptom onset to this marker of 23 months for those with bulbar-onset ALS, and that 60% of participants with spinal-onset did not reach this rate over the 60 months of study follow-up (25).

Looking at a different aspect of timing, Ball et al. reported a mean communication aid use of 28 months (max 160), with 46% using aids in their final week and 13% on long-term ventilation (26). Doyle & Phillips noted "increased reliance on high-tech options during the middle stage and a return to low-tech approaches in the late stage" (27) and Peters et al. found communication modes increased as ALSFRS-R speech scores declined to one, then modes decreased at a score of zero (28). Only Gebrehiwet et al. examined timing for a form of alternative access, reporting eyegaze use ranging from 13 months (fast progression) to 74 months (slow progression) (24).

Variation in timing: the timing of need for communication support varies significantly based on the site of onset of ALS

Speech deterioration models show time and ALS type are key factors. Bulbar-onset ALS leads to faster decline, with functional speech lost on average seven months after first speech therapy, leaving only seven months to implement communication aids (29). Gebrehiwet et al. found bulbar-onset ALS significantly shortened time to communication aid use (but not eyegaze) (24), while Dalgıç et al. reported that patients without speech involvement at first clinic visit were unlikely to need communication aids within a year (21).

Two studies proposed a wider variety in phenotypes than site of onset (bulbar, spinal, mixed): Dalgıç et al. extracted phenotype combinations based on location of "affected functional body segment" and their analysis demonstrated variability in presentation across at least five sub-groups (21); Eshghi et al. also found individual cases of divergence in measures of speech decline in both spinal and bulbar groups suggesting that this "provides further evidence in support of motor phenotype heterogeneity" (25).

Ball et al. reported significant differences in time since diagnosis and speech intelligibility for all types of ALS and conclude that the speech of all people living with ALS will likely deteriorate as the ALS progresses (30). Modeling of changes in

speech rate and intelligibility suggests that for both slow and fast progressors "once bulbar disease develops enough to affect speech intelligibility and rate, the disease progresses rapidly regardless of the initial site of symptom" (31), a finding supported by Makkonen,et al. who found that for all types of ALS, after the onset of bulbar symptoms, communication remained functional for an average of 18 months (29).

Optimal timing: appropriate timing of support may be indicated by monitoring speech changes

Early referral before speech changes was considered very important by most people living with ALS (32), though some stressed the need to account for ALS variability. Judge & Hayton emphasized completing voice banking early, noting times ranged from 7–65 weeks (33). Londral et al. demonstrated an improvement in quality of life measures when introducing tablets with communication software early (ALSFRS-R speech score three or two) (34).

Elliott et al. identified substantial variation in the intervals of referral to speech and language therapists (SLT) for communication support, post diagnosis (35). Other studies looked at levels of late referrals: 12% of notes reviewed by Nordness et al. were classified as late, with reasons predominately being attributed to difficulty obtaining a referral (36); similarly 10% of respondents to a survey by Peters et al. reported meeting an SLT after their speech became difficult for others to understand (28); while 75% of participants in the study by McNaughton et al. reported having had an early referral, with 48% reporting that regular review was carried out (32).

The timing of assistive technology interventions is also influenced by provision and procurement systems. Provision data from Germany demonstrated a delay for communication aid procurement of 93 days and a substantial "failure rate" in procurement of 39% of communication aids, 23% of which related to delays meaning that the patient had died before provision (15). Interviewees in another study reported procurement had only been initiated when the need emerged leading to periods without assistive technology which participants described as "stressful and burdensome" (37). Similarly 48% of respondents to the survey by Palese et al. did not consider the provision period of assistive devices to be appropriate (38). Funke et al. suggest that the rate of failed procurement may relate to recommendations for assistive technology being made too late a stage in the ALS disease course (15), a finding echoed by participants in another study that also identified a lack of clinical review as contributing to this failure (37).

Changes in speech measures as a potential indicator of communication aid need was the focus of a number of included papers. Ball et al. first proposed using changes in intelligibility or speaking rate as clinical markers having found a significant correlation between speaking rate and intelligibility for all types of ALS and suggested 100 words per minute as a threshold rate (30), revising this in subsequent work to 120/122/125 wpm (25,26,36,39). Similarly, Rong et al. conclude from their analysis that for fast progressors, "the intermediate phase, in which speech remains intelligible and speaking rate drops from 150 wpm to 100 wpm in about 17 months, might afford speech-language clinicians the time to successfully transition patients to assistive communication devices" (31). Ball et al. subsequently provided a case example in a clinical setting of monitoring speech rate over the phone to indicate appropriate timing for a communication support evaluation (39); and Roman et al. also conclude that remote assessments of people living with ALS are feasible and may allow for timely communication support assessment that otherwise would be impossible because of travel or other constraints (40).

Acceptance of support: communication aids can be well accepted but factors such as changes in physical access are important in supporting adoption

In a clinic-based study where standard practice was to time carrying out a communication support assessment when participants dropped below 90% intelligibility or 100 wpm, Ball et al. found an acceptance rate of communication aids of 96% (90% immediate, 6% delayed) (41). Similarly, 91% of respondents to a survey with a self-rated ALSFRS-R speech rating of 1 or 0 reported using a powered communication aid of some form (28). These high reported acceptance rates contrast with the qualitative study by Murphy where all but one of the 15 participants abandoned their communication aids during the course of the study (42): difficulty in accessing the communication aid via hand was noted as one of the key reasons for this abandonment (all communication aids provided were hand operated). Physical access to communication aids was also suggested by Makkonen et al. as explaining variation in type of communication aids seen in their study by bulbar (low or high tech devices) and spinal (high tech devices only) groups (29).

Murphy noted other barriers to use of communication aids, including waits for provision of devices and individuals' resistance to try a communication aid whilst they had speech (42). Proactiveness of the individual living with ALS, knowledge of disease progression and the support available were identified as important to people living with ALS in accepting assistive technology, as were the timing of professionals' conversations about assistive technology (43). The desire to be "one step ahead of the disease progression, but not to have too much information

about expected future needs" and a reluctance to use assistive technology because of a "desire to manage on their own as long as possible" was linked with delays (44). Rolland et al. highlight rapid progression as a challenge (44) and most participants in Munan et al.'s study reported wanting information earlier (45). Nine of the 28 Veterans included in the study by Jang et al. received a device but delayed use of it (46), and similarly in another study participants reported avoiding seeking support or information "it is very early in my diagnosis so I have my head in the sand" (16).

Discussion

This review provides strong evidence that ALS site of onset is predictive of the timing of need for communication support, but that there is significant variation within groups and that other progression patterns that would impact on communication and technology control likely exist. Given this, it is perhaps not surprising that individuals and clinicians do not feel able to predict or preempt future changes.

Mapping and modeling of time to events in ALS is a current topic of investigation and large datasets are being used to this end. For example, analysis of the PRECISION-ALS data set has mapped time to events for onset of symptoms, diagnosis, noninvasive ventilation initiation, gastrostomy insertion, and death (47). This review identified modeling work that included proxies for communication support need as "milestone events" (21,23,24). It is not clear though that, beyond informing guidelines, group level modeling is useful for individuals in supporting preparation because there is significant variation within groups, and broad timings of potential changes may not support effective preparation.

The potential for making individual predictions about ALS progression and the need for assistive technology and communication aid use has been highlighted for some time (30) and more recently the potential to build individually predictive models of time to milestone events at or near the point of diagnosis has been demonstrated (48). These individually predictive models have not yet included the need for support in communication or technology control.

A number of studies have identified a lack of sensitivity in ALSFRS-R score change when considering speech/bulbar symptoms (25,31,49) and there is hence interest in the use of speech measures as diagnostic and prognostic tools (50). Speech measures have been shown to be effective for monitoring bulbar/speech function, classifying type of ALS, monitoring overall disease progression, and as a biomarker of progression for use in clinical trials (25,51–53). A significant correlation between speaking rate and intelligibility for all types of ALS was identified by work included in this review and a speaking rate threshold of less than around 120 wpm (for the North American speakers included in these studies) is proposed as indicating the need for communication support. Monitoring of speech rate as a method triggering the introduction of communication aids at the optimal time was identified is included in the 2012 version of the American Academy of Neurology ALS performance measures (54), but "ALS communication support referral" was dropped as a separate domain in the 2022 review (11) and is not included in other international guidelines. Intelligibility measures in the studies included in this review were human rated rather than analyzed computationally. Recently published work Bingham et al. has demonstrated that Quantitate Motor Speech analysis algorithms are effective in monitoring speech change in people living with ALS (51).

The loss of hand function is as inevitable as the loss of speech with the progression of ALS and Elliott et al. found 25% of people living with ALS using assistive technology were using an alternative access method (35). This review, however, identified no empirical evidence to support practitioners or people living with ALS in understanding how the need for access methods will change over time or ALS type, or how best to time the introduction of alternative access methods. Four of the papers included consideration of Environmental Control, Computer Access, or general assistive devices, however no data were able to be extracted from these papers related specifically to these wider assistive technology interventions. Whilst the search terms may have limited the inclusion of some papers, this is unlikely as the terms were very broad and a large number of results hand-searched at title and abstract stage. Measures of hand function that exist and that might be able to be used to model or predict assistive technology need are not reported in the literature and work looking at milestones in the progression of ALS exclude milestones related to physical accessibility – e.g. the ability to use a keyboard or touchscreen. The reviewed literature focuses almost entirely on timing of communication interventions and whilst maintaining communication is a priority for people with ALS, guidelines also emphasize the importance of controlling devices such as computers and phones (8,12). This is an area almost entirely overlooked by the research included in this review and this highlights that practice in this area must be based on clinical judgment or individual choice rather than research evidence.

Conclusions

This review provides information on the timing of communication changes caused by the progression

of ALS and demonstrates that the site of ALS onset influences the timing of need for communication support. There is, however, significant variation within groupings based on site of onset and this likely contributes to the perceptions of those living with ALS and professionals that future changes are difficult to anticipate. A wider number of phenotypic groupings are likely to be present and would be clinically useful in anticipating the need for communication support. It may also be possible to predict this need at an individual level based on initial presentation and progression. Monitoring changes in rate and intelligibility of speech may support timely communication support intervention but this is not adopted in best practice guidelines. Future research should: establish feasible indicators of communication support need; develop group and individually predictive models of communication change; and establish the efficacy of these indicators and models in supporting individuals to better prepare for communication changes.

Changes to physical ability that occur during the progression of ALS affect the control of a keyboard, mouse or touchscreen and are critical in individuals' use of technology, including communication aids. Despite its importance to individuals living with ALS, this review identified no literature that provided evidence that might inform the timing of alternative technology access methods nor other forms of assistive technology for control such as environmental controls. Further work investigating the optimal timing for provision of support related to technology control is urgently indicated.

Disclosure statement

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