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RESEARCH ARTICLE

Provision of assistive technology devices among people with ALS in Germany: a platform-case management approach

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Abstract

Objective: The procurement of assistive technology devices (ATD) is an essential component of managed care in ALS. The objective was to analyze the standards of care for ATD and to identify challenges in the provision process. *Methods*: A cohort study design was used. We investigated the provision of 11,364 ATD in 1494 patients with ALS at 12 ALS centers in Germany over four years. Participants were patients that entered a case management program for ATD including systematic assessment of ATD on a digital management platform. *Results*: Wheelchairs (requested in 65% of patients), orthoses (52%), bathroom adaptations (49%), and communication devices (46%) were the most needed ATD. There was a wide range in the number of indicated ATD per patient: 1 to 4 ATD per patient in 45% of patients, 5 to 20 ATD in 48%, and >20 ATD in 7% of patients. Seventy percent of all requested ATD were effectively delivered. However, an alarming failure rate during procurement was found in ATD that are crucial for ALS patients such as powered wheelchairs (52%), communication devices (39%), or orthoses (21%). Leading causes for not providing ATD were the refusal by health insurances, the decision by patients, and the death of the patient before delivery of the device. *Conclusions*: The need for ATD was highly prevalent among ALS patients. Failed or protracted provision posed substantial barriers to ATD procurement. Targeted national strategies and the incorporation of ATD indication criteria in international ALS treatment guidelines are urgently needed to overcome these barriers.

Keywords: *Amyotrophic lateral sclerosis*, *motor neuron disease*, *assistive technology devices*, *electric-powered wheelchairs*, *augmentative and alternative communication devices*, *platform*, *case management*, *provision*

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Introduction

In ALS, assistive technology devices (ATD) are used to support the patients' motor capacity and to compensate mobility and communication deficits. ATD are crucial to social participation for patients with ALS (1–5). Although the provision of ATD constitutes an important health care intervention, few systematic investigations of ATD procurement in ALS have been reported so far. However, some studies have indicated that the provision process of ATD can be problematic for patients and their caregivers. Limited availability, inadequate provision of ATD, and a high administrative burden during the procurement process have been reported as common barriers in different health care systems (6–10). More detailed information on ATD must be obtained to determine the current standards of care and to identify potential gaps in the ATD procurement process. Thus, the aims of the present study were to (i) evaluate the frequency of ATD among ALS patients, (ii) elicit the failure rate in ATD provision, (iii) analyze the causes of failed procurement, and (iv) identify the latencies in ATD provision. We hypothesized that frequency of ATD request, failure rates as well as the time to delivery vary among the ATD in ALS. Furthermore, we hypothesized that causes of failed provision of ATD vary among distinct domains of ATD.

Methods

Study design

A cohort study was performed and reported consistent with STROBE guidelines for observational studies (11). Data on the procurement process of ATD were prospectively collected as part of a multicenter case management procedure. Data capture was realized from June 2013 to May 2017. Data were retrospectively analyzed.

Participants

Patients with the diagnosis of ALS according to revised El-Escorial criteria and the clinical variants of progressive muscle atrophy (PMA) and primary lateral sclerosis (PLS) were included in the cohort study. The documented request for one or more medically needed ATD was mandatory inclusion criterion for this observational study.

Setting

Case management

Data on the procurement of ATD were collected in ALS patients that were treated in one of 12 specialized ALS centers in Germany. All contributing centers were collaborating within a multi-center case management network. The medical indication for ATD was defined by ALS-trained neurologists and followed by a shared decision-making process involving the patient, caregivers, and next of kin. After obtaining informed consent, the request for an ATD was sent to a case manager specialized in ATD provision. The need for ATD was documented on an ATD request form including 35 menu items of frequently used ATD domains and a free-text option for any other ATD. The case manager matched the specific ATD requirements with the fitting ATD provider. Matching criteria for providers comprised the supply profile, qualification, specialization on ALS, proximity to place of residence and ratings of previous provisions. Prescriptions, evaluation reports, medical statements and other required documentation along the procurement process were coordinated by the case manager and documented on a digital management platform.

Data management

Case management of ATD provision was facilitated on a digital management platform (https://www.ambulanzpartner.de/). The platform encompasses an electronic health record including the medical data required for ATD provision. Furthermore, the platform comprises of the patient-specific medical and technical requirements for ATD provision and digitally enables the multi-step workflow of ATD procurement. The platform links all participating ALS centers, coordinators, and ATD providers. Coordinators and, respectively, providers of ATD, entered the data into the platform. The data capture was controlled by trained data managers. By that means, data assessment was performed in a structured and well-defined manner. The patients and their caregivers were granted optional access to the platform.

Protocol approvals and registrations

The study protocol was approved by the Medical Ethics Committee of the Charité – Uni-ver-si-täts-me-di-zin Berlin, Germany. A signed patient information and informed consent form was obtained from all participating patients.

Variables and data sources

For all participants, a data set of sociodemographic data was captured: diagnosis of ALS (and its variants), age, gender, place of residence, insurance company, ALS center, and ATD providers. Provision characteristics were collected: domain and specification of required ATD, date of request for ATD, date of delivery or rejection of requested ATD. The assessment of ATD was based on drop-down lists that were generated from the complete database of certified and registered assistive devices available within the German health care system (https://hilfsmittel.gkv-spitzenverband.de). The duration of the procurement process was defined as

time interval (in days) between the request and delivery for any ATD processed on the platform. Causes of failed provision were assessed using a shortlist including the following items: rejection by health insurance, refusal by patient, death of patient before provision, and other causes of not providing ATD.

Statistical methods

Descriptive analyses (frequency, mean, median, percentage) were used to (i) compare the frequency of ATD provision in distinct domains of ATD; (ii) investigate the frequency and causes of failed procurement processes; (iii) calculate the latency of ATD provision. Difference of frequencies between two groups was assessed by Fisher's exact test or Chi-square test. The latencies in ATD provision were analyzed using the Shapiro–Wilk test, Kruskal–Wallis test and Mann–Whitney *U*-test. Data analysis was performed using SPSS (Version 24.0).

Results

Participants

A cohort of 1,494 ALS patients was recruited. The mean age of patients was 62 years (SD 11.7 years). More male (59.6%) than female (40.4%) patients were included in the study. The optional use of the case management program (and recruitment for this study) was handled differently among the study sites. In some centers, study participation was proposed to the majority (>90%) of eligible patients whereas in other centers, the case management was offered to a subgroup of patients (to <50% of eligible patients). In the result, the 12 participating study sites contributed in a variable extent to the recruitment of this study. The ALS centers were categorized in large (>500 recruited patients), mid-sized (>100, but less than 500 recruited patients), and small (<100 recruited patients) recruitment sites. The data were captured at two large sites (Berlin, Essen), four mid-sized sites (Jena, Hannover, Bochum, Ulm), and six small sites (Leipzig, Bonn, Münster, Halle, Dresden, Mannheim).

Descriptive data

Data sets of 11,364 ATD procurement processes were captured. In a subset of ATD data, the items for "time to delivery" and "causes of failed provision" were missing – leading to incomplete ATD data sets ($n = 988$). Furthermore, there were patients with loss of follow-up of ATD provision ($n = 1304$). Both, incomplete ATD data sets and loss of follow-up were excluded from analysis (remaining $n = 9072$ complete data sets). All analyses involving causes of failed provision processes and the latency to delivery of ATD were limited to the subset of electric-powered wheelchairs, orthoses, and augmentative and alternative communication (AAC) devices.

Main results

Requested ATD

An overview of requested ATD is summarized in Table 1 and Figure 1. Requested ATD encompassed all ATD that were medically indicated and coordinated on the platform. However, not all requested ATD were actually delivered to the patient (see below). Therefore, the indicated ATD reflected the medical need for ATD rather than the ATD actually provided. There is a high need for ATD with prominence of complex and individualized devices. Most patients were in need of wheelchairs, orthoses, and AAC devices. Among AAC devices, eye and head control systems – paradigmatically provided for patients in advanced stages of the disease – were requested in 13% of the patients ($n = 195$).

Number of ATD per patient

The number of indicted ATD per patient is shown in Figure 2. There was a wide range in the number of ATD indicated per patient. The mean number of ATD per patient was 7.6 (SD 7.6). 54.8% of patients were in need of five or more ATD. In 6.5% of patients, the indication for more than 20 ATD per patient was found.

Failed procurement processes

The rate of failed procurement processes was analyzed for the main ATD domains and summarized in Figure 3. Dropout during the provision process was identified in all ATD domains. The overall failure rate of all ATD analyzed was 29.8% ($n = 2699$). Effectively, 70.2% ($n = 6374$) of requested ATD were provided. Failure rates varied largely among individual ATD. The lowest failed procurement rate referred to bathroom and daily activity adaptations (23.3%), orthoses (20.9%), and walking aids (20.4%). Remarkably, high-failure rates were revealed for more complex and costly ATD such as motor-operated cycling exercise devices (46.7%), transfer devices including lift systems and ramps (40.3%), AAC devices (38.8%) and wheelchairs (38.5%). For the provision of wheelchairs, a more detailed analysis was performed and summarized in Figure 4. A substantial failure rate of 52.0% was found for electric-powered wheelchairs whereas the rejection of manual wheelchairs (25.9%) was significant lower (Chi-square test: $p < 0.001$).

Causes of failed procurement

For powered wheelchairs, AAC devices and orthoses, the causes for failed ATD procurement

Table 1. Indication of assistive technology devices (ATD).

	Number of ATD in cohort		Patients with indicated ATD[a]	
Assistive technology device	*n*	%	*n*	%
Bathroom and daily activity adaptations (total)	1786	15.7	732	49.0
Bath and shower devices	680	6.0	442	29.6
Toilet devices	869	7.6	546	36.5
Assistive devices for daily living[b]	237	2.1	161	10.8
Beds, bedframes, and anti-decubitus devices (total)	1547	13.6	713	47.7
Beds and bedframes	595	5.2	511	34.2
Raising beds	58	0.5	55	3.7
Anti-decubitus devices	894	7.9	475	31.8
Orthoses (total)	1609	14.2	783	52.4
Orthoses, lower extremities	629	5.5	443	29.7
Orthoses, upper extremities	466	4.1	304	20.3
Orthoses, cervical	301	2.6	238	15.9
Orthoses, body, and spine	50	0.4	45	3.0
Orthopedic shoes and inlays	117	1.0	82	5.5
Electric stimulation orthoses	46	0.4	35	2.3
Walking aids	422	3.7	332	22.2
Motor-operated cycling exercise devices	445	3.9	381	25.5
Wheelchairs (total)	1909	16.8	966	64.7
Manual wheelchairs[c]	715	6.3	620	41.5
Positioning wheelchairs	248	2.2	219	14.7
Electric wheelchairs	720	6.3	605	40.5
Electric drive for manual wheelchairs	226	2.0	197	13.2
Transfer aids (total)	1314	11.6	610	40.8
Electric transfer aids, lifter	344	3.0	254	17.0
Mechanical transfer aids	374	3.3	236	15.8
Motorized stair climbers	204	1.8	179	12.0
Stair lift systems	81	0.7	78	5.2
Ramps	311	2.7	218	14.6
Augmented and alternative communication devices (total)	1066	9.4	682	45.6
Communication devices, complex	421	3.7	398	26.6
Communication devices, other	215	1.9	201	13.5
Eye and head control systems	276	2.4	195	13.1
Signalling systems	154	1.4	131	8.8
Other ATD	1266	11.1	517	34.6
Total ATD	11,364	100	1494	100

[a]Number of patients with one or more ATD per domain; number of ATD aggregated per patient;
[b]Aids for dressing, eating, drinking, reading and writing;
[c]Standard wheelchairs and sport wheelchairs.

processes were analyzed and summarized in Table 2. Rejection of ATD provision by the health insurance was the leading cause of failed procurement in all the ATD domains studied (50.9%). ATD were classified "rejected by insurance" when the decision by the insurance company was final. Outgoing or completed appeals of the patient to overturn the refusal of the insurance were not included. A second main factor for dropout of the procurement process was the patient's wish to refrain from using ATD, which again was attributable to various reasons (29.5%). Finally, some patients had died before the requested device could be delivered (19.6%).

Latency of provision

The latency in the procurement process was analyzed for powered electric wheelchairs, orthoses, motor-operated cycling exercise devices, and AAC as summarized in Figure 5. Significant differences were found in the latency of the procurement processes. While the delivery of orthoses occurred in a rather short delay (65.5 days, SD 72.5), the procurement of powered wheelchairs (135.7 days, SD 84.6), motor-operated cycling exercise devices (109.9 days, SD 71.8), and AAC (93.3 days, SD 62.8) had protracted substantially.

Discussion

In this study, ATD provision was analyzed at specialized ALS centers in Germany collaborating on managed care for ATD. Systematic data assessment was facilitated by the common use of a digital management platform. Currently, more than 1200 ALS patients are registered on the platform representing about 15% of the ALS population in Germany (10). The digitalization of the ATD provision process allowed a tracking and systematic analysis of the multi-step ATD procurement process. Despite the advantages of the platform-based registry and substantial number of recruited patients, several limitations have to be addressed. All participating study sites represented specialized ALS centers experienced in ATD provision.

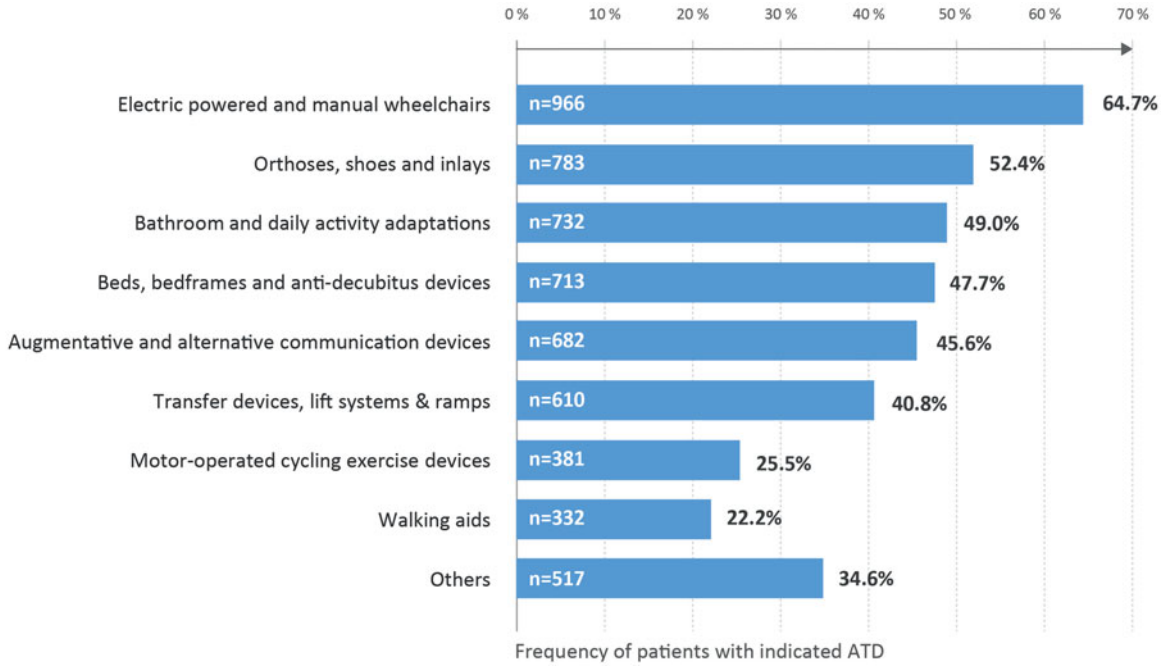

Figure 1. Need for assistive technology devices in ALS. The frequency of requested ATD is depicted for the main domains of ATD procurement. The percentage (and total number) of patients, that have a medical indication for ATD, is shown. ATD: assistive technology devices; n: number of patients.

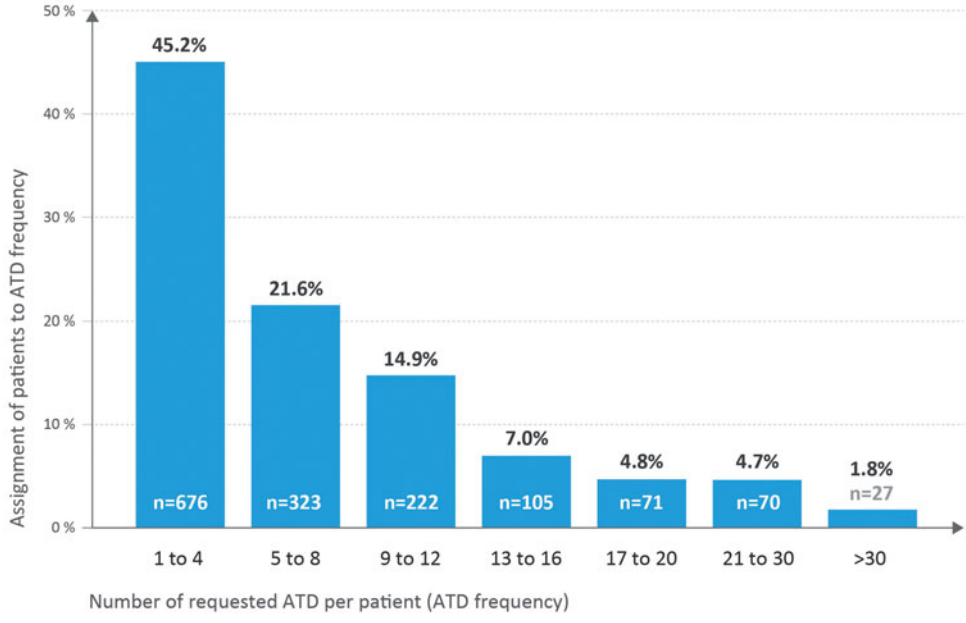

Figure 2. Frequency distribution for assistive technology devices (ATD) in ALS. ATD: assistive technology devices; n: number of patients.

Thus, we cannot exclude that key figures of ALS-related ATD procurement may deviate offside specialized ALS centers. The generalizability of our results was furthermore limited by the diverging extent of how ATD case management was utilized. In fact, some participating centers used the case management (and platform) for most of the eligible patients while other study sites utilized this option for a small number of patients only (9). Therefore, the variable use of the platform may have created some observation bias. It is conceivable that the more complex and intensive ATD provision may be overrepresented while less complex procurement processes were provided independently from the platform, i.e. outside the analyzed data set.

The prominent items in ATD procurement are wheelchair mobility, AAC devices, orthoses, and transfer devices. These devices are complex and highly personalized. Paradigmatically, eye and head controlled communication systems are among the most sophisticated ATD and were found in 13% ($n = 195$) of patients – a substantial subgroup of

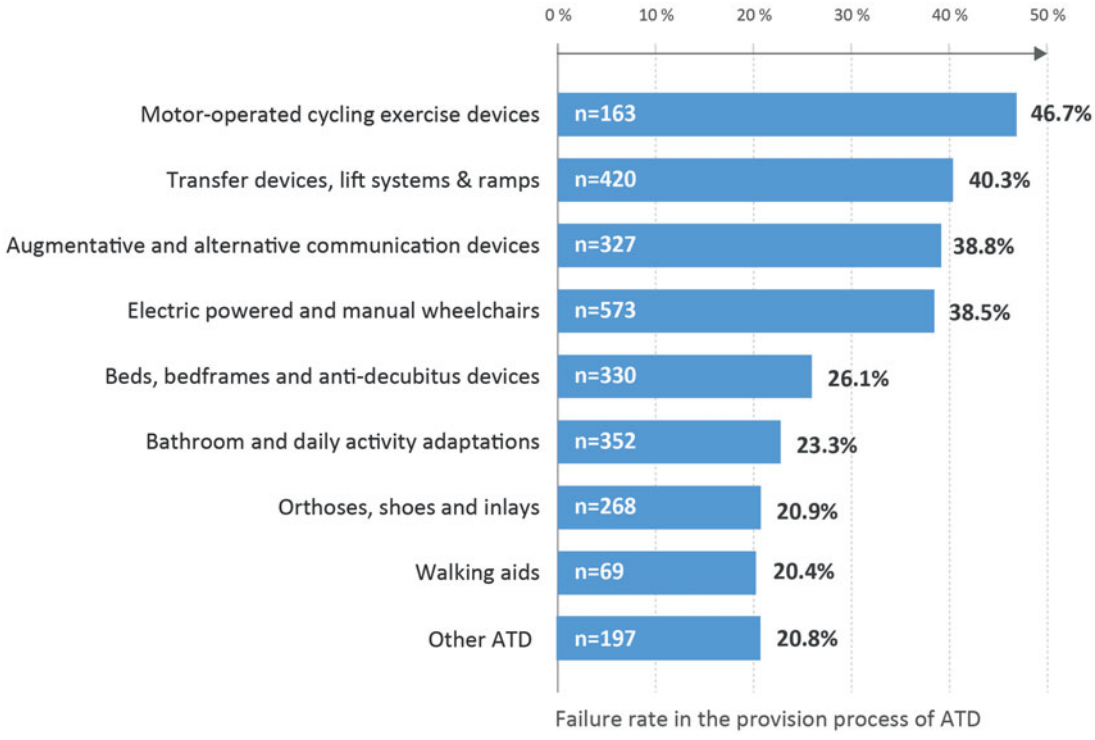

Figure 3. Failure rate in the procurement process for assistive technology devices in ALS. The frequency of failed ATD provision processes is depicted for the main domains of ATD procurement. The percentage (and total number) of ATD is shown, that were medically indicated but not provided. ATD: assistive technology devices; n: number of patients.

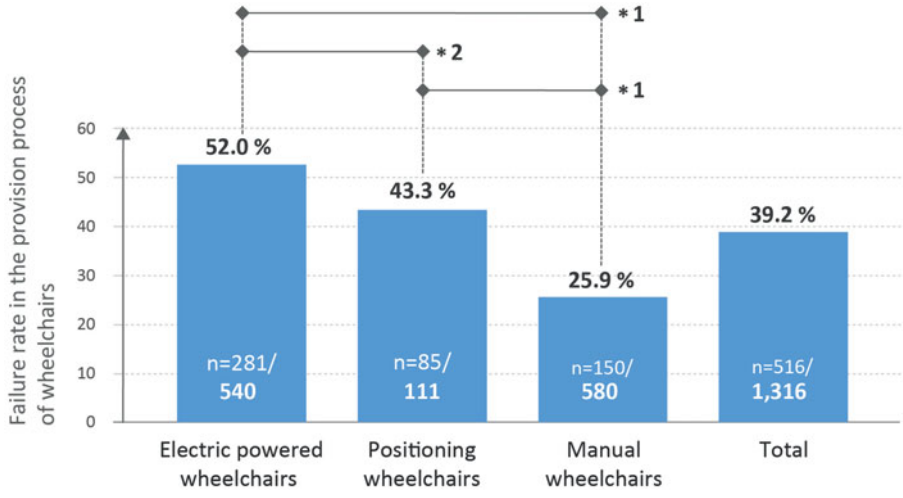

Figure 4. Failure rate in the procurement process for various specifications of wheelchairs. The frequency of failed ATD provision processes is depicted for the procurement of three main specifications of wheelchairs in ALS. The percentage (and total number) of wheelchairs is shown, that were medically indicated but not provided. ATD: assistive technology devices; n: number of patients; $^{*1}p<0.001$; $^{*2}p<0.05$.

ALS patients that had not been quantified before (12,13). For adequate procurement of complex ATD, on-site consulting, testing, and customization of the ATD are mandatory (14,15). Data on the most relevant and frequent devices – as provided by this study – will support neurologists and other professions within multidisciplinary ALS care teams in their role as consultants and managers on ATD. Given the shown frequency and complexity of ATD, continued qualification on ATD is desirable for all professionals engaged in the care of ALS patients. This training on ATD in conjunction with a tight collaboration of neurologists, physical therapists, speech therapists and occupational therapists, nutritionists, social workers, case managers, and providers might at least minimize some of the healthcare system limitations that ALS patients encounter when attempting to secure ATD.

In the cohort studied, patients were provided with a mean number of eight assistive

Table 2. Causes for failed procurement processes of assistive technology devices (ATD).

	All ATD; $n = 2.699$		Electric powered wheelchairs; $n = 281$		Orthoses; $n = 233$		AAC devices; $n = 327$	
Causes for failed procurement process	Failed (total)	Failure Rate	Failed (total)	Failure Rate	Failed (total)	Failure Rate	Failed (total)	Failure Rate
Decline by health insurance	1374	50.9%	110	39.1%	104	44.6%	156	47.7%
Decline by patient	795	29.5%	121	43.1%	96	41.2%	95	29.1%
Patient died before delivery	530	19.6%	50	17.8%	33	14.2%	76	23.2%

AAC: Augmentative and alternative communication devices.

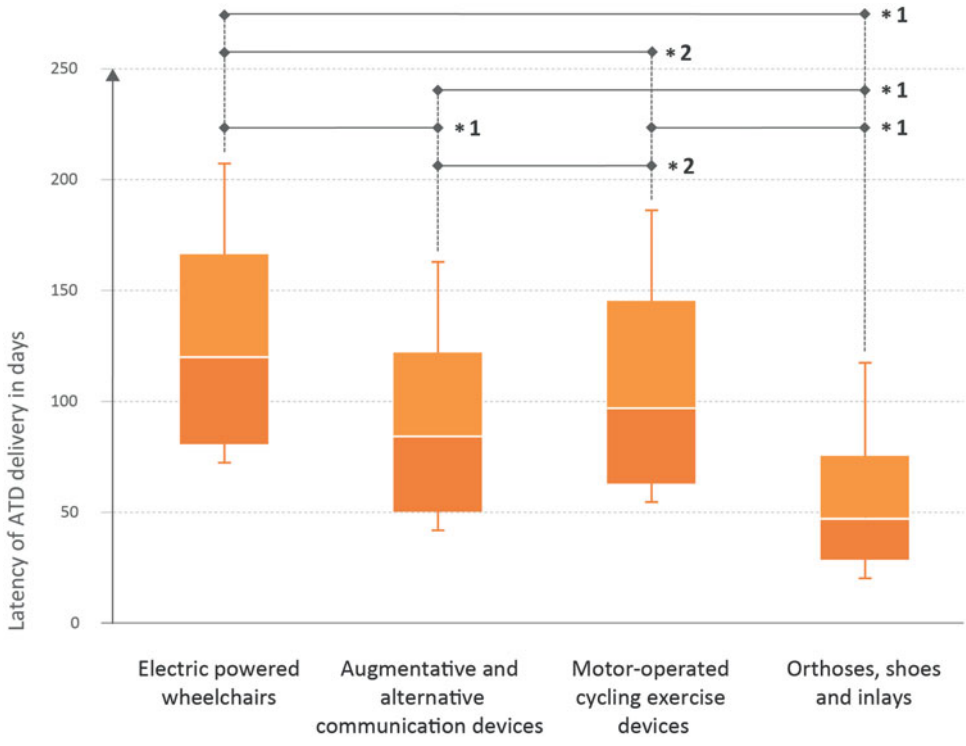

Figure 5. Latency of provision of assistive technology devices in ALS. The latency in the procurement process of ATD is defined as time interval (in days) between indication and delivery of the device. ATD: assistive technology devices; $^{*1}p < 0.001$; $^{*2}p < 0.05$.

devices (SD 7.6). The high number of requested ATD per patient underlines the relevance of ATD-related treatment options – being a key component of managed care in ALS. A subgroup of 25% of patients requested more than 10 devices. However, there was a wide range in the number of requested ATD per patient. The variability in the number of requested ATD may refer to the clinical spectrum and different stages of ALS covered in this cohort. Furthermore, different priorities of ALS centers concerning ATD have to be discussed. Moreover, some ATD are likely to have been managed outside the management platform. Therefore, the factual frequency of ATD was probably underestimated.

Seventy percent of the requested ATD were in fact delivered to the patient. An alarming failure rate was found for those ATD that are of particular importance to patients' autonomy and quality of life (1–5) including wheeled mobility or AAC devices. Our results point to a major challenge in ALS care and correspond with previous reports on barriers in ATD provision (5,6,8,9). Further studies are required to investigate the yet unexplored impact on quality of life and patient autonomy resulting from failed ATD provision. Besides the patients' perspective, a substantial waste of human resources of care teams – due to futile consulting and administrative processes – have to be discussed.

Refusal by health insurance companies was the main reason for failed ATD procurement. Costly ATD (electric wheelchairs, stair lifts, AAC devices, motor-operated cycling exercise devices) were more frequently refused than less expensive devices (e.g. manual wheelchairs, walking aids, bathroom adaptations; Figure 3). We speculate that financial considerations may guide the decisions taken by

insurances with regard to ATD. However, the internal decision criteria of insurances for the approval or rejection of ATD requests are not transparent. Adversely, ALS treatment guidelines currently do not provide precise indication criteria for ATD (16–18). Thus, consensus criteria for ALS-related devices are urgently needed.

A second main cause of failed ATD provision were factors related to the patient. Rather surprisingly, the relevance of patient-related factors had rarely been reported before (5,9,19). The interpretation of our data is limited because many patient-related factors (e.g. disease severity, progression rate, educational status, neuropsychological deficits) were not assessed systematically and beyond the scope of this study. Furthermore, various yet unexplored factors of feasibility have to be considered. Thus, with regard to powered wheelchairs, space, and transportation limitations (e.g. lack of stair lifts) are restrictive to successful provision. In more complex ATD such as AAC devices reduced acceptance has to be discussed. Improving the patient's imagination of how they might be able to use the ATD in the early stages of decision-making will prevent some failure of procurement. The referral to highly specialized providers as well as the personal try-out and customization of ATD in the home environment are of major importance for reducing the failure rate in ATD provision (20,21). Of major relevance are psychological challenges that people with ALS can confront when faced with the need to use ATD because of the multiple losses (including physical loss) they encounter. It is recognized that people with ALS may in some cases, exert control over how they engage with services to accommodate to loss (22).

A third reason for not providing ATD was the death of the patient before delivery of the device. In this context, different causes have to be considered. The indication for the ATD might have been made at too late a stage during the course of disease or the provision process had protracted. To address all of these constellations, a timely and effective ATD procurement process is warranted.

The delay of procurement processes was found as a principle challenge in ATD provision. Substantial latencies in ATD delivery were identified in the provision of selected ATD domains such as electric wheelchairs, AAC devices, and motor-operated cycling exercise devices. Interestingly, the delivery of less costly orthoses was realized within significantly shorter periods of time. Similar to the discussion on the refusal rate for ATD, the latencies in the procurement of costly devices may contribute to the notion that the health insurance companies' financial considerations may delay the decision-making process. Given the expected delay of ATD provision, establishing an early indication for the most crucial ATD is advisable.

The procurement of ATD is determined by standards of care in any given healthcare system. Our study was limited to a specific cohort of ALS patients in Germany. Comparative investigations in other countries are sparse (5–8). Therefore, head-to-head studies in different healthcare systems are of major interest. In conjunction with approaches at national level, this will contribute to overcoming barriers in the procurement process of ATD in ALS.

In conclusion, ATD provision was a frequent and ongoing healthcare intervention in the studied cohort. Complex and individualized devices such as wheelchairs, orthoses, bathroom adaptations, and communication devices were identified as the dominating needs for ATD in ALS. However, an alarming number of requested ATD were eventually not provided to the patient. The causes are heterogeneous and related to a – not yet well understood – decision making process of insurance companies and patients. Furthermore, a substantial latency in ATD procurement was found for devices that are crucial for patient autonomy and social inclusion. Our findings of failure and latencies in the procurement process were in accordance with previous reports showing barriers to adequate ATD provision in different healthcare systems. Despite its pivotal importance for ALS care, the provision with ATD has not been in the focus of clinical ALS research so far. Further studies are needed to develop medical indication criteria for ATD and to incorporate them in national and European ALS treatment guidelines.

Declaration of interest

TM received consultancy fees from Cytokinetics, GSK and Desitin Arzneimittel GmbH; serves on scientific advisory boards for Cytokinetics, GSK and TEVA. TM and CM are founders of the internet platform Ambulanzpartner and hold shares of Ambulanzpartner Soziotechnologie APST GmbH.

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