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Provision and financing of assistive technology devices in Germany: A bureaucratic odyssey? The case of amyotrophic lateral sclerosis and Duchenne muscular dystrophy

Cornelia Henschke*

Department of Health Care Management, Technische Universität Berlin, Germany

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ABSTRACT

Objective: The regulations for financing assistive technology devices (ATDs) are complex and fragmented and, thus, might influence adequate provision of these devices to people who need multiple ATDs. This study aims to explore and analyze patients' problems with the provision and financing of ATDs for the following two rare diseases: amyotrophic lateral sclerosis (ALS) and Duchenne muscular dystrophy (DMD).

Methods: A survey was conducted by means of semi-standardized questionnaires addressing the issues of coverage decisions for ATDs and problems with provision of ATDs. Information was retrieved from ALS ($n = 19$) and DMD ($n = 14$) patients. Conducted interviews were transcribed verbatim and analyzed using qualitative content analysis.

Results: Respondents experienced difficulties with the provision and financing of ATDs. They underlined problems such as long approval processes and a serious bureaucratic burden, which induced inadequate provision of ATDs. Experiences of ALS and DMD respondents frequently were similar, especially regarding financing decisions and the process of decision making by sickness funds.

Conclusion: The results suggest that difficulties in receiving and financing ATDs are common problems among ALS and DMD patients. There is a need for an interdisciplinary approach in the provision of ATDs and their financing, which should be coordinated by case managers.

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1. Introduction

The use of assistive technology devices (ATDs) is one strategy to mitigate or eliminate barriers to independence in individuals with disabilities. These devices assist people with functional deficits in performing daily activities. In Germany, a multitude of ATDs, which includes products used directly by patients, is available (e.g. mobility aids or communication devices). For many disabled people, the provision of ATDs is crucial for functional independence,

maintenance of physical and mental health, and self care. Moreover, quality of life in people could be enhanced with the use of assistive technology capable of ameliorating mobility, communication and house-environment management [1–3].

Adequate provision and financing of ATDs is particularly important for people suffering from diseases with a high and ongoing need for these devices. Amyotrophic lateral sclerosis (ALS) and Duchenne muscular dystrophy (DMD) require a high and ongoing need for ATDs. Due to the rarity of these diseases, the availability of special care providers with expert knowledge is limited. Therefore, a well-coordinated, multidisciplinary approach for provision of ATDs is relevant for these patients. ALS – a neurodegenerative disorder of unknown etiology, excluding some familial cases – is characterized by rapidly progressive

* Correspondence address: FG Management im Gesundheitswesen, Technische Universität Berlin, Strasse des 17. Juni 135 (H80), D-10623 Berlin, Germany. Tel.: +49 30 314 28703; fax: +49 30 314 28433.

E-mail address: cornelia.henschke.1@tu-berlin.de

muscular paralysis, which leads to death within 3–5 years of symptom onset. The crude incidence rates for the 45- to 74-year-old age brackets range between 0.6 and 2.4 per 100,000 in European and North American populations [4,5]. DMD is a chromosome-linked recessive disorder and is one of the most frequent muscular degenerative diseases. The absence or defect of dystrophin – a cytoskeletal protein – leads to loss of independent ambulation in the early teenage years, with subsequent respiratory insufficiency and dilatative cardiomyopathy in the second decade of life for most patients. The mean age of death without key interventions, such as the use of corticosteroids to improve muscle strength and function as well as surveillance for respiratory and cardiac complications, was about 19 years, whereas currently more patients reach adulthood due to the use of non-invasive ventilation [6,7]. With an incidence of 1 per 3600–6000 live male births, DMD is the most common neuromuscular disorder during childhood [8].

Neither of these rare diseases can be cured nor can their progression be reversed or stopped [8,9]. Therefore, adequate provision of ATDs as one essential symptomatic therapy that mitigates or compensates disabilities and optimizes quality of life for ALS and DMD patients is fundamental for prophylaxis of orthopedic complications and for improving motor skills [7,9,10]. People suffering from ALS and DMD are included among those with both immediate and ongoing needs for assistive technologies, which can be costly and often require substantial customization. Thus, an insurer's refusal to cover an expensive device might prevent a patient from obtaining the device, thereby restricting the patient's ability to participate in normal daily activities. Due to the fast progression of these diseases, adequate and timely provision and financing of assistive technologies are essential for patients.

However, the increase in health expenditures in Germany from €124,000 billion in 2000 to €161,000 billion in 2009 [11] has affected the field of medical devices, which includes ATDs. In Germany and many other European countries, these developments resulted in a considerable number of regulatory interventions in the markets for medical devices [12] (e.g. the introduction of a reference price system or essential changes in the instruments of contract management of sickness funds). In Germany, changes in contract management should promote competition between diverse stakeholders such as manufacturers of ATDs to achieve cost savings. The structures and regulations for financing of ATDs are complex and fragmented and, thus, might influence adequate provision of these devices to people who need a multitude of ATDs. Literature concerning the management of ALS and DMD mention the importance of ATDs for patients with ALS and DMD [6,13]. However, nothing is known about problems in providing and financing ATDs for people with these diseases. Therefore, the primary contribution of the paper is to identify deficiencies in the provision and financing of ATDs. The study aims to explore and analyze patients' problems with the provision and financing of ATDs for these two rare diseases: ALS and DMD. This paper reports the findings of the qualitative study conducted with ALS and DMD patients to provide policy recommendations for well-coordinated provision and financing of ATDs. As 85% of the German

population is covered by the statutory health insurance (SHI) system [14], the study focuses on problems in provision and financing of ATDs for persons covered by social health insurance. To understand difficulties in supplying ATDs to patients with ALS and DMD, the regulatory framework for provision and financing of ATDs in Germany is first described.

2. Assistive technology devices

2.1. Defining the benefit catalog

The basic entitlements of SHI-insured to receive ATDs are defined in the Social Code Book V (SGBV), which is the most relevant health care scheme in Germany. The SGB V, among other aspects, regulates rules for providing and financing social services at the federal level. Additionally, the Federal Joint Committee (*Gemeinsamer Bundesausschuss, G-BA*), the supreme decision-making body that determines the benefit package, issues directives on ATDs with regard to adequate, expedient and cost-effective care for the insureds [15]. The directive on ATDs broadly defines the situation in which patients are entitled to ATD benefits and limits the prescription of ATDs to the following cases: ensuring the success of medical treatment, preventing threatened health damage, preventing the health endangerment of a child, and avoiding or reducing the risk of long-term care. Furthermore, the fundamentals of the ATD benefit catalog are established in this directive. This catalog includes a list of ATDs subdivided into 33 categories and lists individual products provided at SHI expense [16]. The Federal Association of Sickness Funds administers this quasi-positive list. Nonetheless, the Federal Ministry of Health can exclude from the SHI benefits package any ATDs with a small or disputed therapeutic benefit or a low selling price. If a certain ATD is not included in the SHI benefit package, sickness funds decide on a case-by-case basis whether to provide the ATD.

2.2. Provision and financing of ATDs

In Germany, a pre-condition for provision of ATDs is a medical provider's prescription. A patient who receives an ATD prescription first has to pay a co-payment of a quarterly surcharge of €10 for outpatient treatment by the medical provider. In a second step, the patient must submit to the sickness fund an application for the provision of an ATD along with the prescription, which must attest the medical need for the device. In addition, the ATD provider (i.e. persons or institutions authorized to supply assistive technologies, e.g. medical supply stores or orthopedic workshops) must submit a general cost calculation. Sickness funds must decide whether to approve the application within 3 weeks. However, the funds can obtain expert advice concerning a patient's application, which prolongs the time limit for the funds' decision. In this case, the SHI Medical Review Boards monitor the applicant's medical need for an ATD. Finally, sickness funds must approve the application to guarantee the ATD provider receives remuneration according to the contracts, agreements or reference prices.

However, the regulations for cost coverage of ATDs are complex and fragmented. Cost coverage of six out of 33 ATD categories is regulated by using a nationwide reference price system. Patients have to pay the difference between the reimbursement cap, as determined by the Federal Association of Sickness Funds, and the selling price of the device. Since April 2007, contract management of sickness funds has been based on three types of contracts, which should be applicable for almost all 33 categories of ATDs, regardless of the existence of a reference group: (1) Sickness funds and their associations are authorized to issue tenders for contracts with ATD providers or their established associations, subject to the condition that economic efficiency and quality of care are ensured (e.g. incontinence pads). (2) If no tenders are issued, the contract partners conclude contracts according to the specific details of ATD care. Sickness funds have to announce publicly their intention to enter into a contract with providers (e.g. wheelchairs). (3) If contracts that meet the previously described models do not exist, or if care cannot be provided in a reasonable way (e.g. in the case of specifically customized ATDs or ATDs, which require a high provision of services) sickness funds and the ATD provider are permitted to conclude individual agreements on a case-by-case basis (e.g. specifically customized sitting aid). A condition precedent to the three types of contracts is a lower price than the existing reference price [12]. This patchwork of contracts and agreements between insurers and providers, both at the federal and at the state levels, illustrates a lack of uniform regulation of the financing of assistive technologies in Germany. Moreover, according to existing contracts and agreements, sickness funds can restrict their patients' choice of provider and ATD manufacturer, i.e. patients are provided with ATDs by the contractual partner of their sickness fund.

Fig. 1 illustrates the payment flow and supply chain activities of the various actors involved in the production, provision and payment of assistive technologies.

In Germany, patients have to pay different types of payments for the provision of ATDs. (1) Patients have to pay a maximum co-payment of €10 per ATD to the provider of ATDs. In the case of consumable ATDs, patients have to pay a maximum copayment of 10€ per month. (2) An additional payment – more precisely the differential between the reference price and the actual price – has to be paid by patients who choose a product with a higher price than the reference price or the price of an existing contract (e.g. patients who expect a higher-product quality). Exemptions from co-payments are granted either to specific population sub-groups (e.g. children up to the age of 18 years, the poor or people with substantial health care needs) [16]. However, these exemptions do not apply to the additional payment.

3. Methods

3.1. Design and participants

Complex organizational phenomena are best studied with qualitative research methods [17]. The process related to the provision and financing of assistive technologies includes different actors, more precisely organizations

such as sickness funds or providers of ATDs who are involved in a complex and time-consuming care process. Therefore, the author decided for qualitative content analyses as one of the research methods to analyze text data. Qualitative content analysis was employed to investigate patients' experiences [18] with the provision and financing of their ATDs. Patients diagnosed with ALS and DMD who participated in the survey were identified by ACHSE (*Allianz Chronischer Seltener Erkrankungen*), a non-profit association for the needs of people with rare diseases. This association contacted the executive committees of support groups for these diseases, who in turn contacted their members and provided the fundamentals of the project. Thirty-four ALS patients and 28 DMD patients were contacted, of whom 22 and 16, respectively, agreed to participate and 19 and 14, respectively were finally interviewed. The survey included patients from all regions of Germany.

3.2. Data collection

Semi-structured one-to-one phone interviews were conducted with ALS and DMD patients between November 2010 and March 2011. Prior to the interview, participants received an information leaflet explaining the study objectives and a quantitative survey aimed at revealing patients' satisfaction with various health care providers. This survey did not include questions concerning the provision of assistive technologies. However, patients were asked if they would like to participate in a telephone interview that focused on ATDs.

In some cases, family members were integrated in the interviews (e.g. for patients who could not communicate). In the first part of the interview, patients were asked to name all assistive technologies they used. Second, the following final interview questions were asked: (1) report your satisfaction with the provision of assistive technologies, with special regard to the quality of products and service; (2) list barriers or obstacles in the context of the health insurance's decision whether to provide ATDs. Prior to the interview, these questions were reviewed by a researcher with regard to their clarity. The interviews were conducted by the author and one other researcher. With the permission of the ALS and DMD patients, all interviews were audio-taped with a digital recording device. The patients' anonymity was guaranteed by assigning continuous numbers (e.g. ALS_01). All interviews, which lasted between 30 and 44 min, were transcribed by an authorized external person. The transcripts provided the basis for a computer-based qualitative analysis.

3.3. Data analysis

Since analytical software used for coding interview transcripts contributes to a more systematic analysis of qualitative data and prevents information-processing bias [19], the transcripts were coded and analyzed using Atlas.ti version 6.2 (Scientific Software Development GmbH, Berlin, Germany), a qualitative data analysis software package. After coding of the text passages, which facilitates comparison across interviews, a coding scheme was

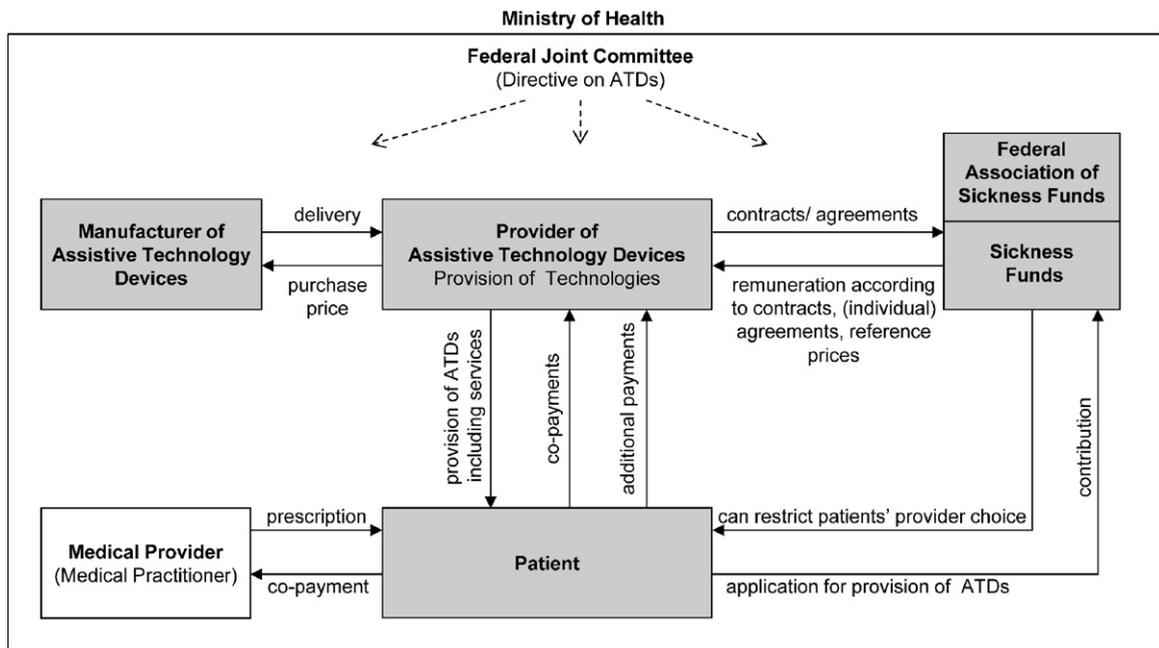


Fig. 1. The provision of assistive technology devices: Payment flows and supply chain activities.

developed using qualitative content analysis [20]. According to Mayring [20] inductive category development was used, i.e. categories derived inductively from the text that is analyzed. With the help of the software package, text passages (from a single word to more than a sentence) were coded and grouped into categories, which emerged from the data. The categories are based on study questions that were determined a priori: (1) problems regarding provision of ATDs and (2) problems concerning the financing of ATDs from patients' viewpoints. The derived subcategories were further reduced to main categories, e.g. emerged categories related to problems concerning the provision of ATDs were reduced to main categories by distinguishing between problems related to different stakeholders (e.g. ATD providers, physicians) or to the product.

New themes that arose were patients' reactions to problems with provision and financing of ATDs. Therefore, extra codes were added to the coding list during the coding process to structure the subcategories and main categories in detail. Both study questions, the patients' perception of problems concerning (1) the provision of assistive technologies and (2) the financing of assistive technologies, were extended by including categories concerning the reaction of patients to these problems. After conducting and analyzing 33 interviews, no fundamentally new information or arguments emerged. This indicates that the point of saturation was reached. No additional information, which is of prime importance for the development of new categories, was expected from further interviews. Fig. 2a and b provides a more-detailed view of the established categories.

The semi-structured interview methodology allowed respondents to discuss several topics in one response. As expected some responses include statements from two categories. These elements were coded in both relevant

categories. As statements were coded by one person, the coding process was repeated a second time after 2 months to ensure intrarater reliability [21]. The agreement rate of 94% was calculated as the proportion of agreement from coding to recoding.

4. Results

A total of 33 interviews, which included patients suffering from ALS and DMD were conducted, transcribed and analyzed. Characteristics of the participants were gathered by means of a quantitative survey (Table 1).

4.1. Application areas of assistive technology devices

Table 2 provides an indication of the demand for assistive technologies by patients with ALS and DMD. A number of 205 ATDs were listed by the 33 interviewees. Table 2 presents the absolute frequency of the number of ATDs actually used by patients. Four categories were established to systemize application areas of assistive technologies. Thus, every patient reported on average 6.2 ATDs. All 33 patients needed technologies to improve mobility or prevent a decline in their current level of medical function. Based on the number of quotations in the transcripts pooled for both rare diseases, every patient reported on average 5.4 assistive technologies for the application area *mobility and functional decline*. These technologies include tailored assistive devices (e.g. orthoses, walking frame, crutches, manual and electronic wheelchairs) and home adaptations (e.g. higher toilet seats, bath tub lifts). The other three areas of application – *respiratory insufficiency, communication and nutrition* – also play an important role in the provision of assistive technologies, but mainly in advanced stages of ALS and DMD. Respiratory failures are the most common cause

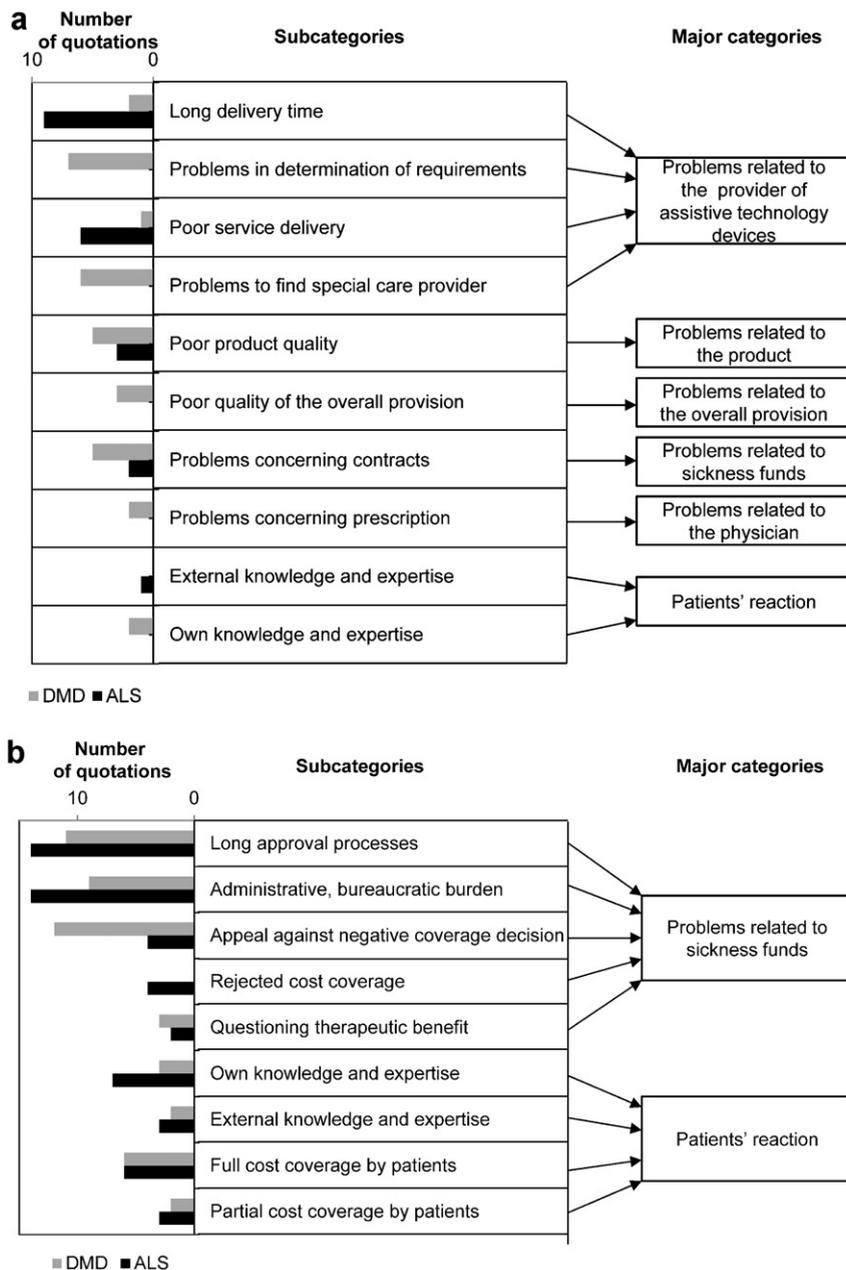


Fig. 2. Problems regarding the (a) provision of assistive technologies from patients' view and (b) financing of assistive technologies from patients' view.

Table 1

Characteristics of participants included in the study.

Variable	Participants suffering from	
	ALS – total (n = 19)	DMD – total (n = 14)
Age in years: mean (S.D.); min.–max.	60.2 (11.9); 31–88	15.9 (9.0); 4–37
Sex		
Male	16 (84%)	14 (100%)
Female	3 (16%)	–
Employment status		
Employed – full time	1 (5%)	–
Employed – part time	1 (5%)	–
Retired	11 (58%)	–
Disabled	6 (32%)	3 (21%)
Day-care center, schooling	–	11 (79%)

Table 2

Application areas for assistive technologies.

Application area	Number of quotations, presenting the use of an assistive technology	
	ALS (n = 19)	DMD (n = 14)
Mobility and functional decline	94	85
Respiratory insufficiency	9	6
Communication	8	0
Nutrition	2	1

of death in ALS patients [13]. Patients reported the use of pulse oximetry, assisted ventilation and cough assistance devices. Disease progression makes verbal communication increasingly difficult. The loss of the ability to communicate can have serious psychological and social consequences. Therefore, augmentative and alternative communication can be used (e.g. letter boards). In the case of very limited communicative capability, electronic devices such as gaze communication systems are used [9].

4.2. Problems associated with the provision of assistive technologies

Although Fig. 2a summarizes difficulties concerning the actual provision of assistive technologies, approximately one half of the respondents stated that they were satisfied with the actual provision of assistive technologies. However, 16 of 33 respondents stated difficulties with the provision of ATDs. The established categories are demonstrated in Fig. 2a. These categories are further assigned to problems related to the ATD provider, physicians (medical provider), contracts between sickness funds and ATD providers, or to the product. Difficulties related to overall provision include quotations, in which patients were not able to distinguish between problems with the ATD provider or the product.

The most frequently mentioned problem related to the ATD provider was *long delivery time*. "...We had to wait more than 8 weeks for the orthoses..." (DMD.14), "...Because of the long waiting time, the electronic wheelchair could not be used due to the fast progression of disease..." (ALS.16); "...I had to wait more than 3 months for stair-climber..." (ALS.01). DMD respondents further underlined *problems with the determination of a requirement for assistive technologies and problems in finding a special provider of assistive technology devices*. "...it was difficult to find a provider of ATDs, who is familiar with wheelchairs for children..." (DMD.13); "...Providers of assistive technologies often do not know which kind of an ATD is really needed for children, e.g. a provider of ATDs supplied my child with an inappropriate anti-bedsore cushion..." (DMD.01). Moreover, seven quotations referred to *poor advisory service*, including poor service delivery. "...The device operation was not explained to me..." (ALS.03). *Contracts between sickness funds and an ATD provider* are problematic for patients if they have to travel long distances to receive care or if they are limited in their choice of assistive technologies. *Problems concerning the prescription of assistive technologies* include cases such as "...the medical doctor prescribed a cough assisting device only due to

my enquiry..." (DMD.01). Problems concerning contracts between sickness funds and an ATD provider are stated in seven quotations. "...Contracts between sickness funds and provider of assistive technologies only include products featuring a poor product quality..." (DMD.09).

Patients reacted to the described problems by actively collecting information about appropriate assistive technologies and putting pressure on sickness funds by e-mailing, phoning or writing letters or they make use of support provided by patient organizations such as the German Society for Muscular Disorders.

4.3. Problems associated with the financing of assistive technologies

Fig. 2b summarizes the main issues that negatively influence patients' satisfaction with the financing of assistive technologies. A total of seven respondents declared that they have had no difficulties with sickness funds regarding assistive technology coverage. However, the vast majority of respondents (26 of 33 respondents) specified problems related to the financing of ATDs. The following categories emerged from the data: *long approval processes*, *administrative bureaucratic burden*, *appealing against negative coverage decision*, *rejected cost coverage*, and *questioning therapeutic benefit*.

The most frequently mentioned difficulties were the *long approval processes* and the high *administrative bureaucratic burden* for patients. "...For the first time financing of assistive technologies was no problem. However, this only applies to low priced assistive technologies..." (ALS.01); "...I felt left alone with the application for ATDs..." (ALS.02). Nonetheless, *appealing against coverage decisions* and *repeated rejection of cost coverage* of assistive technologies was mentioned to be a serious problem as well. "...Every time cost coverage decisions are a hard fight..." (DMD.08). "...The application for a wheelchair was declined. We appealed against this decision. Proceedings have taken more than a half year..." (DMD.06). Additionally, patients denounced *repeated rejections* of cost coverage. Respondents also mentioned the fact that *therapeutic benefits were questioned*. "...There is no therapeutic benefit for this voice recognition program..." (AL.05). To respond to these developments, patients often partially or fully bear the cost of assistive technologies that were rejected by sickness funds. "...I partly paid the costs for a therapy bike..." (DMD.13). In addition, they use *external* or *their own knowledge* and expertise to fight decisions concerning cost coverage. "...Support by my physiotherapist

was very helpful in appealing against sickness fund's cost coverage decision. . ." (DMD_08).

5. Discussion and policy implications

5.1. The provision of assistive technologies

Problems with patients' receipt of assistive technologies concern almost all stakeholders involved in the provisioning process. Approximately half of the respondents mentioned difficulties arising from ATD providers. The main difficulties are long delivery times and problems in the determination of requirements. Because of the fast progression of ALS and DMD, it is highly important for patients to be provided with adequate assistive technologies immediately. If respiratory care, which includes the use of cough assistance and nocturnal ventilation, was structured and managed proactively, patients' survival time was prolonged [22,23]. Resting ankle-foot orthoses are instrumental in preventing or minimizing equinus contractures. Additionally, they are appropriate throughout the patients' life [24,25]. Long delivery times also result in patients being unable to use the assistive technologies when received. Consequently, delayed delivery of assistive technologies may result in higher cost for sickness funds due to an application for a renewed provision.

Poor advisory services resulting in incorrect use of assistive technologies are associated with damage to health and could lead to follow-up costs. DMD patients referred to difficulties in finding providers of special ATDs. This may result from the fact that DMD patients are younger than ALS patients and that ATD providers supply more devices for elderly patients than for children. Another challenge arises from the complexity of different contracts in the provision of assistive technologies. Contracts between sickness funds and care providers limit a patients' access to care providers or to specific assistive technologies. This is a problem especially for people living in rural areas, who are unable to travel additional distances.

Assistive technologies are important to either prevent or compensate for the effects of physical injury. Therefore, the provision of assistive technologies has to be centered on the individual needs of patients. An individual assessment of disorders that includes possible use of ATDs should be established by qualified medical practitioners in consideration with physiotherapists [26] as a basis for prescription of and explicit provision of ATDs. ATD providers have to continue these assessments by documenting the explicit provision of ATDs. The necessary cooperation of all stakeholders participating in the process of providing ATDs to patients could be accomplished in this way.

5.2. Financing assistive technologies

The study showed that both long approval processes of sickness funds and patients' administrative bureaucratic burden are hurdles most often experienced by patients when seeking financial coverage of the technology. Applications for ATDs must thoroughly explain the need for an ATD. In some cases, especially in the context of expensive assistive technologies, the Medical Review Board must

ensure that the assistive technology in question is required for the patient's care. This is, indeed, a necessary process. However, due to the fast progression of ALS and DMD this process should be expedited. Without the issuance of a positive coverage decision, ATD providers will not be willing to provide the patient with assistive technologies. Therefore, these hurdles affect the provision of assistive technologies by prolonging the time to actual use of ATDs. Furthermore, patients often have to appeal a negative coverage decision, which is an additional bureaucratic effort for both patients and sickness funds. Patients often react by acquiring specific knowledge or calling an expert. In the worst case scenario, they have to bear the cost partially or fully, which possibly constitutes a large economic burden for them. The application procedure must be disburdened for all stakeholders involved in the provision and financing of ATDs. Precise guidelines for patients, prescribing physicians, providers of ATDs, and sickness funds should be introduced.

The fast progression of ALS and DMD requires timely and adequate provision and financing of assistive technologies. Long decision-making processes have a negative impact on adequate provision of assistive technologies. Undertreatment and inappropriate treatment might be the consequence. Time-consuming processes occur at diverse levels of the provision and financing process (e.g. decision of sickness funds to cover the assistive technologies or long delivery times by ATD providers). The assignment of case managers to coordinate care seems to be a possible solution to overcome these difficulties. Case managers as "system agents" should coordinate system resources for patients and are still accountable for successful patient movement through the system. Therefore, case management should focus on coordinating complex, fragmented services to meet the needs of patients with the simultaneous consideration of controlling cost [27]. Specific groups for case management are patients with specialized health problems such as HIV, mental illness, and high-cost and/or catastrophic illnesses [28] such as ALS and DMD.

Case management was originally developed for the purpose of cost savings and the improvement of patients' access to care. However, studies show that case management can be expensive and produces high service costs [28]. The literature contains diverse effectiveness and cost-effectiveness studies of case management versus routine care for different diseases, such as for mental illnesses. However, their results differ widely [29–33]. As cost constraints do not allow health care systems to make use of all treatment alternatives, results from cost-effectiveness analysis should be used as one of the measures to make decisions on allocation of health care resources [34]. Despite the different results of cost-effectiveness studies of case management for different diseases, this strategy seems to be suitable for delivering high-quality health care to ALS and DMD patients whilst ensuring effective use of resources. Therefore, effectiveness and cost-effectiveness studies of case management programs for ALS and DMD are needed.

In fact, the effect of case management depends on how the service is being provided and the case manager's ability. In the literature, different approaches to case management

were identified over time. Within the “brokerage model”, case managers primarily act as enablers, system coordinators and brokers of services. Their primary functions include (1) the assessment of patient need, (2) the development of individual health care plans for patients, (3) the arrangement of service delivery, (4) the monitoring and assessment of services and (5) evaluation and follow-up. Those case managers typically have large case loads, with a volume of 50 or more patients, and are office based [35]. Due to the low incidence of ALS and DMD, case management should be adopted for patient groups taking into account a range of diseases that have a high need for ATDs such as neurodegeneration with brain iron accumulation. The inclusion of those patients in case management might be necessary with a view to the service costs caused by case management.

Case management for ALS and DMD patients requires a detailed determination of the primary functions of the case manager (e.g. to assist patients in the management of the (bureaucratic) process of the provision of ATDs). Their special qualifications have to include an in-depth knowledge of clinical care, and organizational and financial resources and processes [36]. The appointment of case managers might provide the following advantages: (1) Patients are actively involved in their health care, which might result in an increase of quality of life. (2) A coordinated provision and financing of assistive technologies could reduce time-consuming processes at diverse levels of the provision and financing process, which otherwise could induce additional cost due to inappropriate treatments. (3) Case managers could facilitate the working relationship between the prescribing medical practitioner, provider of assistive technologies and sickness funds to improve the health care of people suffering from ALS and DMD.

5.3. Strengths and weaknesses

To my knowledge, this is the first study in Germany to describe problems in provision and financing of assistive technologies from a patient’s point of view. A total of 33 patients suffering from ALS and DMD provided information on a range of experiences. The use of a qualitative approach was an appropriate method to explore problems in the provision and financing of ATDs. It allowed a detailed exploration of a complex area, making feasible the identification of difficulties in the provision of assistive technologies and providing the base for solutions to these problems. However, some methodological limitations should be mentioned. The study relied on the reported experiences of patients. Perceptions of sickness funds might differ, especially in the context of therapeutic benefits for patients. Moreover, the number of quotations gives only a global indication of the relative importance that respondents attached to different concepts. Quantitative interpretations (e.g. in terms of percentages) should not be derived from these quotations. Furthermore, the intensity of the use of ATDs differs according to the severity within both diseases. Additionally, a very early stage of disease does not require the number of different ATDs needed in an advanced stage of disease. It was not possible to control for disease severity.

6. Conclusion

This qualitative study outlines patients’ problematic experiences with the provision and financing of assistive technologies. An in-depth understanding might help to improve provisioning and financing aspects for the patients as well as for the other stakeholders (e.g. sickness funds). Sickness funds and ATD providers should keep in mind that the need for ATDs is highly complex in people suffering from ALS and DMD. Due to the fast progression of ALS and DMD, patients must be provided with assistive technologies immediately. Precise guidelines for the application procedure of ATDs for patients, prescribing physicians, providers of ATDs, and sickness funds can help to simplify and expedite the application process and therefore facilitate a more immediate provision of ATDs for patients. In addition, diseases whose requirements for ATDs differ from standard care (i.e. require multiple ATDs, especially customized products) need an interdisciplinary management approach, which should be coordinated by case managers. Currently, only a few sickness funds in Germany offer special advisory services concerning the provision of ATDs. However, a well-coordinated, multidisciplinary approach for provision of ATDs could provide patients with a better quality of life and avoid inappropriate services, which often cause additional costs for sickness funds. A possible solution for existing problems may be the provision and financing of assistive technologies coordinated by case managers to reduce time-consuming processes at diverse levels of the provision and financing process and prevent additional cost due to inappropriate treatments. Nonetheless, cost-effectiveness of case management programs has to be evaluated.

The study provides first findings of problems in providing and financing ATDs for people diagnosed with ALS and DMD, who have a high and ongoing need for ATDs. One can assume that similar problems might exist in other European countries. According to directive 2011/24/EU on the application of patients’ rights in cross-border healthcare, the commission shall support member states in cooperating in the development of diagnosis and treatment capacity. Especially in the case of rare diseases, member states should also consider reference networks as focal points for medical training and research, information dissemination and evaluation. As a first step, this requires that countries are aware of the way patients are diagnosed and treated. As care for patients with rare diseases is often not standardized, the necessary information needs to be collected by other means. This study provides a useful example of how such stocktaking can be done on the level of a member state.

Conflict of interest

The author declares no conflict of interest.

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