Expectations and Concerns Emerging from Experiences with Assistive Technology for ALS Patients

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Abstract. Amyotrophic lateral sclerosis (ALS) is a neurologic disease effecting a gradual loss of physical body functionalities with usually unaltered cognitive functionality. Due to the lack of autonomy, affected persons become dependent on the support of third parties, such as relatives, friends and informal and formal caregivers. Autonomy and self-determination play a crucial role in the lives of ALS patients and can partly be maintained by the implementation of assistive technologies and devices (ATD). In addition to life-supporting measures, ATD can support ALS patients in their mobility, communication and help them control their domestic environment, and thus foster social participation and autonomy. However, little is known about expectations and concerns of patients and their informal and formal caregivers regarding ATD. We therefore conducted semi-structured interviews as part of a mixed-methods requirements analysis to evaluate how ATD influences the lives and living spaces of patients with ALS as well as their family members and caregivers, and additionally their expectations and concerns raised by ATD. The presented study research was conducted as part of the research and development project "ROBINA - robot-assisted services for patients with ALS".

Keywords: Assistive technology and devices · ATD · Amyotrophic lateral sclerosis · Expectations and strengths · Concerns and weaknesses

1 Introduction

1.1 Amyotrophic Lateral Sclerosis – ALS

Amyotrophic lateral sclerosis (ALS) is a neurologic disease effecting a gradual loss of physical body functionalities with usually unaltered cognitive functionality. With the progression of the disease, affected persons have no longer control over their muscular

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movements up to the point that even respiratory muscles fail to work. Therefore, without assistive technologies and devices (ATD) such as feeding tubes and artificial ventilation systems, the disease ultimately leads to the death of the patients. Around 50% of all ALS patients die between two and four years after onset [1] and only 10% survive longer than 10 years [2]. With a prevalence between 1.44 and 6.25/100.000 inhabitants ALS is defined as a rare disease [3] but characterized by a high level of suffering for both patients and caregivers.

Decreasing body functionality in upper and lower extremities as well as impairments regarding speaking and swallowing adversely effects the performance of activities of daily living (ADL) and has negative effects on the quality of life of patients [4–6]. Persons with ALS experience a continuous decrease and ultimately loss of mobility, communicational skills, and nutrition intake, which is often followed by a restricted social participation, a feeling of worthlessness and frustration [7, 8]. Due to the lack of autonomy, affected persons become dependent on the support of third parties, such as relatives, friends and informal and formal caregivers. In turn, ALS not only affects the quality of life of patients, but also has a huge impact on their social environment.

These issues can partly be compensated by the implementation of a wide array of ATD. In addition to life-supporting measures, ATD can support ALS patients in their mobility, communication and help them control their domestic environment and thus foster social participation and autonomy.

1.2 ATD and ALS – Status Quo

Definition Assistive Technology

Assistive technologies comprise any devices with the purpose to support people with disabilities and help them compensate their impairments. The WHO defines assistive devices and technologies as “those whose primary purpose is to maintain or improve an individual’s functioning and independence to facilitate participation and to enhance overall well-being” [9]. The American Assistive Technology Act of 2004 offers a more comprehensive definition and refers to the term assistive technology device as “any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities” [10]. ATD includes, but is not limited to, hearing aids, visual aids, walkers and wheelchairs, devices for communication such as software with voice output or computers with gaze control and prostheses.

Types of ATD for ALS

As the ALS disease proceeds, patients experience the loss of mobility and speech and therefore lack of social engagement and communication. Apart from life-supporting measures, communication aids represent a crucial instrument to maintain the personal exchange of patients and their environment, not only for social purposes but also in order to inform about needs and issues.

Therefore, a broad variety of communication devices has been developed and is available on the market. With the progressive character of the disease, which is linked to a decrease of body functionalities, patients acquire a diverse variety of communication systems to meet their requirements. They range from electronic devices such as eye-gaze control

systems, which use eye-tracking software to select letters, words or pictures on a screen, to speech apps for smartphones or tablets, simpler writing tableaus and even brain computer interfaces that use a brain's electrical activities to control devices such as computers or prostheses.

ATD that is used to overcome mobility impairments comprise simple crutches or walkers, wheelchairs and power wheelchairs that can be controlled by joysticks, voice input or eye gaze and, related to that, wheelchair ramps to overcome height differences such as staircases. Restraints in mobility also affect transfer tasks such as changing the position for example from bed to chair or from wheelchair to toilet seat. There are several lifter systems available, each adapted to its purpose, with regard to installation position, control unit and extent of reach.

An important issue for persons with ALS is the control of their domestic environment, i.e. control of entertainment devices such as TV or radio, light control, telephone, and computer. Therefore, voice-control systems such as ALEXA or ECHO are from a certain value for people suffering from ALS who are still able to speak clearly. However, there are also alternatives available, that come integrated into one remote control and can for instance be attached on a wheelchair or next to the bed, helping to maintain the patient's independency and autonomy.

Facing breathing muscles affected by the disease, ALS patients must eventually consider respiratory aids. Non-invasive and invasive technologies are available to help patients breathe as well as to cough and to clear their respiratory passages.

There is much more life-supporting and assistive technology available and thoroughly studied. Please refer to [11–13] for more information.

Supply Situation with ATD in Germany

The considerations above show that the need for ATD among ALS patients is very high. However, the supply situation among persons affected by ALS varies widely. To understand the presented study results, it is necessary to look at the German health care system and to understand its strengths and weaknesses regarding ATD supply.

The German health care system consists of two types of health insurances – the statutory health insurance and the private health insurance, with 89.27% and 10.73% insured persons, respectively [14]. The statutory health insurances are financed by their members and employers as well as pension insurance institutes, contributions are income-related and benefit all members who are in need [15]. They conclude contracts with specific care providers such as health care supply stores. Private insurances are financed the same way, but contributions are dependent from age of entry, gender, scope of chosen health care services, and more. Another significant difference between the two insurance types is that private insured persons must pay health services directly to the service provider, the expenses are reimbursed afterwards, and medical doctors can charge up to three times the amount compared to statutory insured persons [15].

The provision of ATD is an essential service of the statutory health insurance. Statutory insurances fund ATD with an additional payment by the insured persons of 10% of the original price (between € 5 and € 10) or the difference between the original price and the price as contracted by the insurance [16]. There are some exceptions, depending on whether the ATD is intended for consumption or not. The insured person must fund additional services beyond the necessary supply as defined by the insurance.

Private insurances fund ATD according to the terms and conditions of the contracts with the insured persons. The contracts are individual for each insurance holder. Most of them are based on a deductible, which must first be exceeded by health services before the private health insurance takes over health care costs [16].

The German health insurance companies are obliged to verify the indicated need for the requested ATD. Thus, health insurances can either accept or reject applications to cover ATD costs, leaving the patients with the choice of objecting or applying again at a later a later stage, private funding or refusing to acquire the requested ATD at all.

A study from 2018 shows that there were failed ATD provisions in different domains such as walking aids, exercise devices and wheelchairs in Germany [17]. 26.3% of the requested ATD was rejected by the health insurance company, showing differences both between the various companies and ATD categories. The amount of rejected powered wheelchairs for example was double compared to orthoses. 9.8% of the requested ATD was rejected by the ALS patients themselves. Reasons for this were not documented but discussed to be a consequence of perceived stigmatization, missing infrastructure for the use of ATD or possibly of supply latency. Especially the delivery of motor-operated or electronic devices such as augmented and alternative communication (AAC) systems and electric wheelchairs lasted very long (96.11 $\pm$ 60.6 and 129.7 $\pm$ 84.6 days, respectively). This study showed the crucial weakness in the ATD rejection rates and the supply latency in patients with ALS in Germany.

2 Methodology

In order to obtain a detailed overview about experiences with, expectations and requirements of ALS patients to ATD, we conducted a mixed-methods requirements analysis within the research and development project "ROBINA – robot-supported services for an individual and resource-oriented care of patients with ALS".

The semi-structured interviews were conducted with five ALS patients, five informal caregiving relatives of ALS patients and a focus group of five professional ALS caregivers (Fig. 1). All interviews were performed according to a semi-structured guideline, developed by the researchers with experience in qualitative data collection and a medical doctor specialized in the treatment and healthcare provision, including ATD, of patients with ALS.

The semi-structured guideline contained questions related to the living and caregiver/support situation, expectations to and experience with technology, related problems and barriers, and requirements to assistive technology. All interviews were held at an ambulance clinic for ALS treatment. Two researchers were present during all interviews, one led the interviews, and the other researcher filled the relevant information in a standardized protocol form. Additionally, all interviews were recorded with an audio device. The interview guideline was pretested with one representative of each target group. All patients, relatives and professional caregivers received information material about the aim of the study, study process, data protection and gave their written consent prior to the study. The Ethics Committee of the Charité - Universitätsmedizin Berlin approved of the study (no. of approval: EA1/121/17).

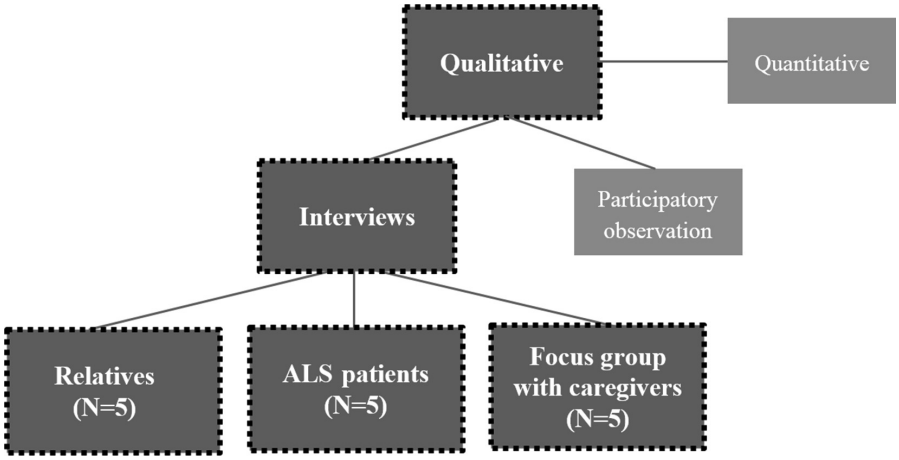

Fig. 1. Methodology of the mixed-methods study

The aim of the interviews was to identify strengths, weaknesses and barriers of assistive technology currently in use by the patients and their (formal and informal) caregivers and to evaluate the technology commitment of the patients and caregivers. Furthermore, to analyze the impact of assistive technology on the different user groups and to identify the requirements of a newly developed robotic system with regard to functionality, safety, operation modalities, positioning, hygiene and appearance. All interviews were transcribed and analyzed in accordance with Mayring [18].

3 Results

In the following paragraph, we present the results of the interviews. The five participating ALS patients were between 50 and 79 years old, four of them were male. The five participating relatives were between 50 and 83 years old, two of them were male, all of them were their partners and had experience in caregiving. The five professional caregivers of the focus group interview were between 50 and 65 years old, all of them were female and had experience with ALS patients.

3.1 Opportunities and Hopes Related to ATD

Due to the circumstances that ALS patients are dependent from ATD for life-supporting measures and for social participation and communication, ATD is expected to fulfill expectations for those purposes. The identified opportunities and hopes could be assigned to the categories of communication, social engagement, and autonomy.

As one of the main issues for ALS patients evident from the interviews is the loss of the ability to communicate with their social environment, depending on the progress of the disease via vocal, body language or both, ATD is anticipated to compensate these restrictions. Consequently, electronic communication operable via eye control or

minimal hand movement is important to enable ALS patients communicate their needs, support their involvement in social activities, and empower their relationship with relatives.

Social engagement comprises a lot more than communication with one's social environment. Beyond that, it involves a participation in social activities, interaction with others, and social exchange. An engagement in social activities is restricted in patients with ALS, mainly as their mobility and therefore activity radius decreases. Thus, technologies such as electric wheelchairs and transfer systems play a major role for the social engagement of ALS patients. This was stressed during the interviews by both patients and relatives. In relation to that, relatives explained situations in which ATD could help maintain the patient's privacy, for example when taking a shower or going to the toilet. "This is the same with taking a shower. She does not want me to look after her then or take over tasks or something like that." (Relative, A12). A different point of view was offered by a patient who was afraid to overburden his friends: "They [friends] pick me up and give me a lift back home again with the walker. The walker must be transported and not everyone is able to do that or wants to do that. […] Maybe at some point it becomes troublesome for them." (Patient, P02).

In this context, a central expectation of all groups was to maintain and retrieve autonomy specifically with regard to ADL. Hence, little activities such as scratching itchy skin or handing over something to drink, can empower patients, and at the same time relieve caregivers and lead to an improved patient-caregiver relationship. "It would be great if could also disburden somebody. Not to need somebody for every little thing, especially feeding." (Patient, P02). Especially iterative processes or activities were perceived as a burden for caregivers, but also for patients who wish not to become a burden to others. To mention an example, one of the interviewed relatives described the scenario that the patient requested a specific sweet several times per hour to support salivation. The relative explained it is very important for the patient but burdensome and tiring for both of them. Any ATD that could overtake this task would relieve not only the relative from iterative walks but also the patient from the requests and highly probable empower the patient's autonomy.

3.2 Concerns Related to ATD

ATD is usually rated positively, empowering patients and supporting their autonomy whilst disburdening formal and informal caregivers. Nevertheless, apart from benefits and strengths, ATD can also raise concerns and fears in affected persons. In our interviews, both patients and caregivers pointed out several situations that constituted or led to fearful or presumably dangerous circumstances. Compared to opportunities and hopes, concerns were mentioned a lot more in our interviews. Identified content could be assigned to the categories of safety, social engagement, handling, information, financing, living situation, stigmatization, and system adaptability.

A central concern ALS patients and relatives mentioned was regarding safety, frequently resulting from negative experiences with ATD. Concrete examples were a transfer system, which was used to transfer the patient from one room to another. The patient was afraid that if the system was installed above his head, it might fall off the ceiling and hit him due to is incapability to move away. Therefore, it was installed

further away from his bed, which effected a restriction in usage. Another example from the interviews was a professional caregiver who reported problems with an invasive ventilation system. She perceived this experience as very drastic, up to the point that she was afraid of experiencing similar problems with different ATD. Similar concerns related to technical failure were mentioned by patients and relatives, e.g. a low battery life of an electric wheelchairs and, therefore, getting stuck during transport. Even a little shift of the operating elements, e.g. due to an uneven ground, can become a major issue as this may result in the loss of control over ATD.

Furthermore, assistive technology can entail relevant worries if patients express or are believed to have suicidal thoughts. In one specific example, an electric wheelchair was used to commit suicide. This implied major consequences for the provider, the professional caregivers and the relatives, including interrogations and investigations for a legal reconditioning, causing insecurities and stress in addition to reputation risks. Even though the maintenance and regain of autonomy in patients with ALS is of a high priority, when it comes to self-harm or suicidal thoughts an ethical debate is inevitable.

In the worst case, concerns about safety might have an impact on the use and acquisition of ATD, including non-use, misuse or incorrect installation of the ATD in question, which might result in a reduced effectivity or usability.

Professional caregivers often experienced the handling of ATD as very time-intensive and pointed out worries in relation to correct handling. Since there is a huge variety of ATD available, even for the same purpose, a standardized operation is often impossible. Additionally, some ATD is according to the caregivers not necessarily intuitive in its operation. “Because new assistive technology arrives frequently. Additionally, the [program] language has been altered […]. I can switch on the light or operate a computer, four or five years that was impossible. We always learn something new.” (Professional caregiver, Pf04). Supplier companies offer introduction workshops, but in many cases professional caregivers or relatives cannot take part or would require more than one workshop, i.e. refresher courses on a regular basis. Thus, informal and formal caregivers face fear of incorrect handling and, on the other hand, often need to invest more time than estimated due to lack of training.

At the same time, professional caregivers also criticized the lack of informative catalogs listing assistive technologies specifically for ALS patients, which was reinforced by relatives of ALS patients. Often, a knowledge transfer about available ATD happens via word-of-mouth within self-aid groups or in internet platforms, and sometimes even ATD suppliers can apparently not provide the required information.

Another major concern was the financing of ATD. In many cases, health insurances would not take over the costs for prescribed ATD for several often incomprehensible reasons. I.e. patients had to either object to the rejection with legal support, which causes a lot of stress and is time- and cost-intensive, organize private funding, look for cheaper alternatives or they waived it. “I did it myself. I contacted the mayor, the senator, a representative for people with disabilities, I bugged everyone.” (Patient, P08). If the costs for expensive ATD are not covered by the health insurance and with rejections experienced, patients and relatives encounter a huge barrier for the acquisition of appropriate ATD. “We did not hand in the application for the ATD. We knew we would not get it funded anyway.” (Relative, A05).

In addition, ATD has lasting effects on the living situation of ALS patients and their family members. Some interviewees pointed out that a spatial separation of patient and the rest of the family can help to maintain a 'normal' life besides nursing aspects. The partners of two ALS patients lived on different floors, and another partner lived in a different flat. They still spent most of the time together but stressed their need for privacy especially in relation to the presence of professional caregivers and the installation of several ATD which makes the living environment look like a hospital environment. They explained that with a spatial separation they could relax from the nursing responsibilities and recuperate easier.

Another issue raised was the topic of stigmatization. Evidence of stigmatization due to a person's appearance or look can be found throughout the literature, throughout history and worldwide. Especially people with visible physical disabilities often suffer from stigma and the feeling to be different compared to most of the people surrounding them. Even though assistive technology can improve a person's quality of life and enhance their autonomy, some of the interviewed ALS patients stated that 'looking disabled' is not an option for them. One patient rejected the implementation of an emergency button because she did not want to look sick. Even after she had experienced a situation in which she could not get up after a fall anymore and had to make her assistant dog to fetch her phone and call help, she would still reject the emergency button. Other statements related to the appearance of ATD. Surprisingly, one patient criticized the lack of color within ATD and required a better quality of her wheelchair. According to this study participant the electric wheelchair was neither comfortable to sit in, nor was its fabric of good quality. The fabric was apparently black and linting everywhere, leaving the user frustrated.

Finally, the lack of adaptability of many systems was described as a huge usage barrier. Due to the progredient character of ALS, the resources and physical abilities of affected persons can decrease quickly. It became clear from the interviews that this fact makes the patients reliant on diverse operating options, ranging from very sensitive joysticks to voice control, eye gaze control or brain interfaces and many more. Since not all ATD are compatible with this range of control options, many devices become difficult to use up to the point of being totally useless for the patient.

One circumstance that additionally affects this issue is that the supply with assistive systems often takes long but is initiated not until the actual need is identified. Therefore, ALS patients do not only repeatedly experience long intervals of limited social participation or communicability, apart from a decline in performing ADL, frequently their body state worsens and thus cannot use the ATD anymore when it is finally being delivered. "And then I received an orthosis for my feet. I cannot use that anymore as I am not able to walk anymore now. Unfortunately, you often wait very long for these things and then when they are finally here, it is too late. This is really bad." (Patient, P08).

4 Discussion

The interviewed persons gave an important insight in their lives with ATD, related hopes and opportunities but also concerns and criticism. Some of the results have been discussed elsewhere with different or additional aspects.

According to the literature, safety concerns are not only related to physical pain or stress, but also to data misuse. It must be a priority to protect personal data and make sure it remains confidential. Computer technology, which often remains the last interaction possibility for ALS patients, constitutes a major issue. Especially privacy concerns take effect in monitoring ATD, such as feedback about movements or heart rates. The misuse of data could also be imaginable in the context of externally controlling ATD. Recent news about theft and purchase of data makes the concern even more concrete. Related to that, other studies argue that caregivers become more and more reliant on monitoring technology rather than focusing on the patient [23]. This constitutes an issue especially among patients whose communication skills are impaired, as technology failure may occur at any time. However, physical pain or stress have a very direct impact on the patients and therefore remain the main worries within safety concerns.

Suicidal thoughts and the use of ATD have not been studied extensively. From an ethical point of view, it is a very sensitive and controversial topic, often crossing social boundaries. Often, affected persons are left alone. Whether they are patients who wish to let got or relatives who miss support from third parties. Different stakeholders are usually involved, such as ATD supplier companies, professional caregivers, institutions such as caregiving facilities, legal representatives and many more. Each of them has their own needs, responsibilities and rights; therefore, a case-sensitive approach is necessary, especially for people in intensive and palliative care.

In the interviews, ATD was associated with an increase of quality of life, e.g. by social engagement. The literature confirms these results. According to several studies, communication technology for example can significantly improve the quality of life of persons with ALS, when implemented in time [19–22]. However, ATD was also linked to a possible loss of contact with other humans, as it is perceived to substitute the support from professional or informal caregivers. It is important to decide the best solution on an individual basis. Each person has different needs and requires different levels of support and autonomy. One must consider that it is not a matter of right or wrong but a matter of quality of life for the patients and their social environment.

The fact, that social engagement might be impeded by ATD as presented has to be considered from two sides. In the mentioned example, the affected ALS patient was afraid his friends would be overburdened with the transfer of patient and walker at some point. Even though that cannot be ruled out, it should be underlined that in this concrete example the walker enables the patient to take part in social activities in the first place. Therefore, such statements should be interpreted with caution und the reasons behind and a possible association with stigmatization should be examined.

The identified issues with the supply and financing of ATD in our study sample have been discussed and verified in several studies (compare also paragraph 1.2) [17, 24]. Nevertheless, results are not generalizable in an international context due to the different characters of health care systems worldwide. However, it raises the question whether the costs of ATD should be the determining factor for the care and supply of patients. Many public places have been adapted or re-built in order to enable a barrier-free access by people with disabilities; however, it is also the responsibility of a state and society to give them access to the means they need to benefit from the inclusion policies.

Appropriately, affected persons should be involved in the establishment of such policies, but also into the development of the means mentioned. The example of ALS shows very clearly, that technology which is not fully adaptable to the changing needs and preferences of its user group will become useless and miss its purpose. Even though the general understanding is that technology should, wherever possible, adapt to consumers [25], this is not always the fact [26, 27]. Reasons can be found both in the companies and in the customers. Personalized items or technology requires investment in innovative and flexible production and logistics, additionally to development time and expertise. This often happens at the cost of reasonable pricing. Apart from that, customer needs are very diverse and potentially not communicated clearly enough, which often constitutes a construction problem.

Related to that are the handling difficulties of formal and informal caregivers who struggle with a variety of non-standardized systems. This might also increase insecurities amongst both patients and caregivers to damage the system. Additionally, and correlating with safety concerns, the collection and processing of data for individual needs is questionable. Especially tracking technology data may reveal sensible information such as absence from home. Nevertheless, it remains a right for patients to receive individualized treatment and therefore module-based technology could represent a key approach for ALS patients.

However, even if assistive technology is perfectly adapted to the user's requirements, one issue may remain unsolved – the feeling of stigmatization. Stigmatization can be found in many groups, among children, older people, people born disabled and persons with acquired disabilities. Especially persons with acquired disabilities often abandon ATD, not wanting to show perceived weaknesses or to avoid social exclusion [28]. There is also the concern that other people might focus on a person's incapability instead of their resources. Even though this may have adverse effects, e.g. social exclusion due to immobility, for many people with ALS it is difficult to accept ATD. ATD is always present and notable for others, and shows a dependency in people who used to be independent and do not want to give up their independency.

Even though the sample size was small with five representatives of each of the three groups, the interviews gave new insights about hopes and concerns related to ATD in patients with ALS. The fact that due to the nature of the R&D project only persons affected by ALS where interviewed makes a generalization for other patient groups using ATD difficult. However, relevant information concerning ATD supply and financing could be derived from this study and will be investigated further using quantitative methods in a bigger sample size including different patient groups suffering from severe physical impairments.

5 Conclusion

The interviews gave an important insight into the lives of ALS patients and formal and informal caregivers using assistive technologies. Assistive technologies and devices offer relevant benefits for patients with ALS and can support their autonomy and social engagement. Nevertheless, the study revealed negative experiences of patients and formal and informal caregivers with ATD. Interview participants expressed several

concerns, doubts and fears, especially regarding safety and handling. Therefore, in order to ensure the empowerment of patients through technology, developers, suppliers and caregivers must involve patient needs into all steps of technology development and patient care. Additional attention should be devoted to the requirements from the groups involved in patient care in order to support a good care quality.

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