Identification of User Requirements for Assistive Technology for Support of Upper Limb Daily Life Interactions from Stroke and Duchenne Muscular Dystrophy Patients

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***Abstract*— The uptake of assistive technology to improve the functionality of the upper limb in people with disorders affecting the neuromuscular system, such as stroke and Duchenne Muscular Dystrophy, is often limited by a gap between the users' needs and the design of the technology. This study aims to identify the technology-specific end-users' requirements for the development of upper limb assistive technology to support daily life activities, and thereby supporting self-management, in stroke and Duchenne Muscular Dystrophy, based on the results of disease-specific focus groups and specialist consultation. The focus group results showed that: unobtrusive support, intuitive use, and adaptiveness to an individual and disease progression are key for both stroke and Duchenne Muscular Dystrophy patients. The technology-specific end-user requirements identified in this study can be used to supplement general user requirements identified in the literature, in order to improve the design of assistive technology for support of upper limb daily activities.**

Keywords- DMD; Stroke; Assistive Technology; User Requirements; Upper Extremity.

I. INTRODUCTION

People with disorders that affect the neuromuscular system, such as Duchenne Muscular Dystrophy (DMD) and stroke, often suffer from difficulties in performing activities of daily living (ADL) due to reduced functionality of the upper limb (UL) [1]-[3]. Decreased functionality of the UL leads to a decrease in independence and impacts quality of life [4][5].

The demand for technological solutions, which can support or compensate for loss of functionality in motor function, increases with reduced level of independence and UL function [2][6][7]. Nowadays, numerous technological solutions are available ranging from simple assistive tools (e.g., adapted cutlery) to robots that entirely substitute human movements in very severe cases [7]-[9]. In theory, personal assistance or (in)formal care can be reduced by 30-42% through use of assistive technology [8][9]. Unfortunately, the preferences and needs of end-users and their environment are often not met in the technical design of the device which results in many users abandoning these devices [6][10]-[14]. In order to bridge the translational gap between the users' needs and the design of the technology, a user-centred design needs to be used in the development of the UL assistive technology [15]. Input from end-users from the beginning of the design, as done in a user-centred design, is regarded as effective to enhance the chance for uptake [16].

In the literature, focus is placed on general end-user perspectives for UL assistive technology. If assistive technologies are to be used to support independence during daily life activities, they need to be simple to apply [13]-[15][19], easy to use [11][12][17][18], safe [12], pleasurable [17][19][20], of reasonable cost [17][19][21][22], motivating and should be able to provide feedback [13]. The time taken to prepare, set up and maintain assistive devices are key issues for all stakeholders [11][12][17][19]. For stroke patients and carers the device needs to be easy to get on and off a weak, contracted hand/arm as well as intuitive in terms of correctly positioning the device [11][17]. Also, concerns about devices which are time consuming to clean and difficult to store are expressed [11][17]. The appearance of the device is not seen as important factor for either stroke patients nor healthcare professionals [12]. Conversely, for DMD patients, having a mobile device which is also attractive in appearance is an important issue because of the age related social needs. Thus, for self-management it is critical to incorporate the above mentioned features in the design of a device.

Nowadays, designers are focusing more and more on innovative and technically complex assistive technology, and a user-centred design is increasingly adopted. The People, Activities, Contexts and Technologies (PACT) framework was invented to cover all aspects of user-centred design including social and technological aspects. Although, eliciting end-user input through analysis of the PACT aspects is considered as a useful starting point for design

 ISBN: 978-1-61208-618-7

[23], the technological aspect is often neglected. In stroke and DMD populations, gathered end-user-input is often still targeted at rather generic information about the envisioned use of the assistive technology, for instance as reflected by the People, Activity and Context domains of the PACT framework [11][12][20][23]. There is little emphasis on end-users' views towards specific technical aspects, such as intention detection, options for support, and feedback.

The eNHANCE project aims to assist people with DMD and stroke in performing UL daily life activities with the environment. The focus of this project is on innovative aspects of the technology such as intention detection, performance assessment, and behavioural modelling. Therefore, the aim of this paper is to identify end-user requirements, specifically addressing the technical features, for the development of UL assistive technology. This project used questionnaires and focus groups in two target groups, namely stroke and DMD to determine these end-user requirements. The results are outlined in Section III and will be discussed in Section IV.

II. Methods

To elicit user input, the PACT framework [23] was used to design questions to be addressed during disease-specific questionnaires and focus groups with patients, carers and clinicians. To determine the starting point for the technology-specific questions to be discussed during the focus groups, a questionnaire addressing the People, Activity and Context domains of the PACT framework was set up.

A. Questionnaire

In order to develop the questionnaire, a literature survey was performed in stroke, to determine the existing body of knowledge regarding user input for UL supporting assistive technologies. The design of the questionnaire was based on published literature on questionnaire design [24][25]. Questions relating to the People (patient characteristics, technological affinity and hand function), Activity (Usage of hand, and which preferred activities) and Context (Table I) were addressed in the questionnaire. Although no paper-based questionnaire was performed in DMD, questions with regard to the People, Activity and Context domains were asked during the DMD focus group.

TABLE I. Questionnaire Statements, Answered on a 5-Point Likert Scale (From Strongly Disagree To Strongly Agree)

The device must be wearable
Storage of the device must be easy
The device must be lightweight
I want to don and doff the device myself
I would lack the confidence to use assistive technology at home
Support of my caregiver is important to use assistive technology
I want to wear the device under my clothes

In order to ensure consistency in the analysis of the user requirements, the design was kept as similar as possible for DMD as for stroke. Yet, the questions were modified for the DMD population, tailoring it to their specific pediatric needs. Further information was sourced from experience in previous related projects (e.g., FlexTension) and DMD healthcare professionals.

B. Focus Groups

Two focus groups, one with stroke survivors and carers, and the other with boys with DMD, aged between 15 and 16 years old, and their parents were held in July 2015. Stroke participants were recruited from the Roessingh Rehabilitation Centre, the Netherlands, and the focus group for DMD was publicised in the UK by the Action Duchenne DMD Advocacy group called "Taking Charge". During the focus groups more specific information with regard to the technology was represented by the following themes: support options, intention detection, personalization, feedback and motivational aspects (Table II). Several technical and biomedical experts were present to provide feedback about the use of the state of the art technology in the robotic arm.

TABLE II. Main Questions Discussed During Focus Groups

Introduction project, participants and focus group	
Support options	
- How would you like to be supported by the system? 1. System takes over entire movement 2. System compensates for gravity 3. System supports as needed	
Intention detection	
- Can you imagine in which way a system could detect your movement intention? Which of the following options would you find best, acceptable and unacceptable:	
A. Subconscious	**B. Conscious**
1. Eye-tracking	1. Voice recognition
2. Sensors (movement/pressure/force)	2. Joystick
3. Muscle activation	3. Pushing a button
Personalization	
- Would you like to have a system that can adapt itself to your personal preferences? - Can you imagine examples of how such a system could be personalized? - Would you like the system to detect the activity you are performing? - How much time is acceptable for the system to get used to your preferences?	
Feedback and motivation	
- Would you like to receive feedback from the system? If so, about 'how well' and/or 'how much' you performed? - What kind of feedback would you like to receive? Audio, visual, graphs and tables or vibrotactile? - Would you like to be encouraged by the system to use your upper limb?	

The focus group with DMD took place in the United Kingdom (UK), while the focus group with stroke survivors

 ISBN: 978-1-61208-618-7

took place in the Netherlands. Prior to the start of the study, written informed consent, and agreement for audio-recording of the focus group was obtained from all participants and if needed in case of DMD, their parents. The DMD focus group was conducted as part of a larger project run by the Action Duchenne DMD Advocacy group called “Taking Charge” which obtained consent for videoing and recording. No ethical approval was required for focus groups in this context. In the Netherlands, ethical clearance was obtained from the medical ethical committee Twente, Enschede, the Netherlands, in May 2015.

1) Stroke Focus Group

All topics were accompanied by examples (visual where possible) so that the participants could envisage the options more easily. Using an interactive presentation, those items were put up for discussion by asking the participants input via a variety of user interactions, such as voting and ranking, combined with plenary discussions between all participants about their thoughts, ideas, opinions, experiences and expectations.

2) DMD Focus Group

The format of the DMD focus group differed slightly from the stroke group, to accommodate expression of individual opinions in this group of younger participants. Following preliminary introductions and completion of a baseline questionnaire, an interactive presentation on the eNHANCE project was given. Once the presentation was completed, the end-users gathered together as a group to discuss the presented questions without the presence of the technical and medical experts. This was done to promote participation from young adults who may not voice opinions in the presence of adult experts. The group answers were then presented to the technical and medical attendees. Group ideas and suggestions were recorded by Dictaphone and video for later analysis.

C. User Requirement Identification

The qualitative data coming from audio-recordings and notes from the focus groups was elaborated. Transcripts were discussed between researchers and direct comments were subsequently grouped together. From this, common topics were identified to describe the user perspectives per predefined theme. Thereafter, user requirements were compiled according to preferences expressed by the majority of the participants in each focus group. Subsequently, user requirements were discussed between clinical experts for DMD and stroke separately, involving rehabilitation physicians, physiotherapists and clinical researchers. All requirements were independently prioritized by at least three clinical experts per target population using the MoSCoW method; Must have (M), Should have (S), Could have (C), Won’t have (W) [26]. The MoSCoW method is a technique used for prioritization of requirements with stakeholders to highlight the importance placed on each requirement. The final priority was based on most votes given for the corresponding user requirement.

III. RESULTS

In the result section, the findings from the questionnaire in stroke and the end-user requirements as derived from the focus groups in stroke and DMD are presented.

A. Findings from the Questionnaire in Stroke

Findings from the questionnaire in stroke from the People Activity and Context domains of the PACT framework are presented separately.

1) People Domain Findings from the Questionnaire

In total, seven stroke survivors filled out the questionnaire. Most of the questionnaire respondents were male, above the age of 60 and in the chronic phase after stroke (Table III). Main problems in functional use of the hand and arm were a lack of fine motor skills and control of the hand.

2) Activity Domain Findings from the Questionnaire

The majority of the respondents used their affected hand and arm at least sometimes. Dressing and undressing, biking and using the affected hand as supporting hand were the activities in which the most respondents used their affected hand and arm. With regard to activities in which they would like to use their affected arm; domestic chores, eating, drinking and cooking and dressing/grooming were reported most often. Personal hygiene, outdoor activities, mobility but also fine motor skill activities and hobbies were mentioned.

3) Context Domain Findings from the Questionnaire

Findings answering the questions of the ‘Context’ domain of the PACT framework are summarized in Figure 1. The majority of the respondents either agreed or strongly agreed that assistive technology should be easy to don and doff, wearable and light weight, and easy to store. All participants would be confident to use assistive technology independent at home. However, opinions about the amount of support needed from the caregiver and whether the device should be worn under the clothes or not were more diversified.

TABLE III. PRIMARY END-USER CHARACTERISTICS

Table Head	**Table Column Head**				
	Target population	***% Male***	***Mean age (range)***	***% Wheelchair user?***	***Stroke: Onset since disease in years (range)***
Questionnaire	Stroke (n=7)	71%	66 (45-78)	0%	3.4 (2.5-4.5)
Focus group	Stroke (n=3)	100%	70 (67-75)	0%	3.3 (2-4.5)
	DMD (n=6)	100%	15.2 (15-16)	100%	Not Applicable

 ISBN: 978-1-61208-618-7

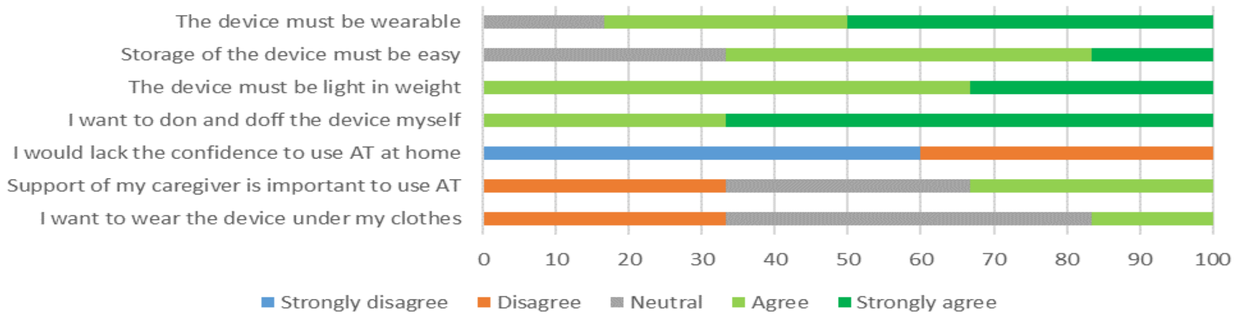

Figure 1. Perceptions of stroke survivors on contextual questions with regard to assistive technology, expressed in percentages

B. Focus Group Derived End-user Requirements Focused on Technological Aspects

Nine primary end-users (DMD boys and stroke survivors) and eleven secondary end-users (partners and parents) were included in the focus groups. Patient characteristics can be found in Table III.

TABLE IV. USER REQUIREMENTS WITH CORRESPONDING PROIRITY. M = MUST HAVE, S = SHOULD HAVE, AND '-'= NOT RRIORITIZED OR NOT APPLICABLE

User requirement	Priority	
	DMD	***Stroke***
Support options		
The system must allow the user to move actively without replacing human function	-	M
The amount of the support must consider the existing contractures on the upper limb	M	M
The system must support arm function during reaching and fine motor control of the hand	-	M
Intention detection		
The system must subconsciously detect the intention of the user	M	S
The system must have the possibility to switch to conscious control of the user	S	S
Personalization		
The system must be adaptable to personal limitations and needs	M	M
The system must be able to learn user preferences within one week	-	S
The system must be adaptable to different kind of movements in tasks related to activities of daily life	-	M
The system must consider the eventual users' deteriorating condition overuse, pain and muscle deterioration	M	-
Feedback and motivation		
The system must provide feedback during the daily tasks (quality and quantity of movement)	M	-
The system must not overproduce feedback	S	M
The system must keep track of performance based on personal capacity and should use that to motivate the user	-	M
The system must motivate the user to be active during the movements	S	M

In Table IV, a list of user requirements resulting from the translation of user expressions from end-users gathered during the focus groups can be found. In summary, both groups favoured assistance only as needed. The DMD group favoured subconscious control (e.g., eye-tracking, movement sensors, muscle activation) with an option to switch off the subconscious control. The stroke group was more divided with some favouring conscious (e.g., voice, joystick, button pressing) over subconscious control. Both groups wished for personalization of the system but differed with regard to individual characteristics, which should take into account mainly disease-specific aspects related to nature and severity of motor and/or cognitive limitations, as a basis for personalization.

IV. DISCUSSION

Reduced function of the upper limbs in both people with DMD and stroke impacts their functional independence and quality of life [1]. Although the use of assistive technology is promising, user-centred design methods are needed to include end-users in the design process and to enable development of devices that better suit the needs of the users [15]. Findings from the questionnaire and the user requirements gained from focus groups in the two selected target populations, DMD and stroke, provided useful and specific information on the technological features of assistive technologies for the UL from an end-users' perspective.

Remarkably, the themes and related topics identified by end-users as being essential requirements for the design of an intelligent UL supporting assistive technology were comparable between DMD and stroke participants. Despite these similarities, there were substantial differences between specific requirements between populations for each of those themes (see Table IV for examples) attributable to differences in the two populations (Table V). Unlike the DMD population, both men and women are affected by stroke, yet only men participated in the focus group. However based on findings of former focus groups including both women and men, no different outcomes are expected when women would have been included [15][27].

The functional benefit of a device must be balanced with its burden of use [7]. Minimization of the burden must result from including end-users in the design of the device. In addition to the end-user requirements about technological aspects of assistive technology gained from this study, there are a number of other aspects that are important for the adoption of assistive technology. In line with the findings from the questionnaire performed in this study, assistive technologies need to be: easy to use, portable, safe, and easy to don and doff during daily activities such as eating/drinking, preparing food, personal hygiene, as well as supporting hand in stroke in order to gain more independence and perform desirable activities [11][12][15][17][18][20][22][27].

As stroke survivors prefer to use assistive technology at home, storage of assistive technology must be easy. In DMD, assistive technology must be able to be attached to the wheelchair and to be used during the entire day [19], whereas in stroke an assistive technology can preferably be used several times a day depending on the easiness with which the system can be put on by the patient.

In stroke, accessibility or knowledge about the device is also identified as important factor for the uptake of UL assistive technology [28]. In general, the results of the questionnaire of this study and previous research incorporating input from both primary and secondary end-users are consistent with the 17 design and engineering criteria as set up by Batavia et al. [29]. Those criteria are applicable in both stroke and DMD.

TABLE V. PRIMARY DIFFERENCES BETWEEN TARGET POPULATIONS

Stroke	**DMD**
Static	Progressive
Male and female	Male
Unilateral involvement	Bilateral involvement
Predominantly older adults	Difficulties begin in early teens
Increased muscle tone (spasticity)	Spasticity not involved
Pain	Pain rarely present
Generally ambulant	Non-ambulant

Although previous research has identified a need for feedback, (mechanical) adjustment to patients and the ease of use, there has not been a specific focus on the technological aspects of assistive technology [11][12][22]. During the focus groups, almost every participant, both stroke and DMD, pointed out that it is important that their own existing power, movement and function must be enhanced, rather than replaced, by the system in order to be as independent as possible. Within both populations, highly individual aspects such as variety in disease severity, in addition to personal preferences and interests, needs to be taken into account during the personalization of interfaces. Furthermore, the differences between target populations as highlighted in Table V, resulted in different requirements. Whereas stroke survivors stated they always want to regain more functionality, regardless of the severity, in DMD, the primary concern is to fight deterioration at every stage of the disease. Therefore, it is of great importance that a system can be personalized not only to the personal preferences and interests of the user, but also to disease-specific needs in the motor and cognitive domains [28].

With regard to detection of the movement intention of the user, our participants predominantly preferred sub-conscious control, with the possibility to switch to or combine it with conscious control. In DMD, eye-tracking was favoured by all the boys and their parents. Although subconscious was most preferred in stroke, there was difference between participants in the preferred option (e.g., movement sensors, eye-tracking, muscle activation).

In order to reduce or reverse functional decline in motor function, active engagement during movement and intensive use of the arm of hand are crucial [30]. Although stroke survivors do not feel the urge to receive direct feedback from an assistive technology, boys with DMD would like to receive feedback about both quality and quantity of their movements. However, concerns were raised by the DMD group that the system needed regular reassessment in order to compensate for the deteriorating nature of the disease and the avoidance of overuse and pain.

In order to improve, people with stroke would like to be motivated by the system. In stroke, people can usually use their unaffected arm and hand unobtrusively to perform complex movements [31], which demotivates them to use their affected hand. Awareness of their movements and (possible) non-use of the affected side during daily life activities is important to them.

All patients, family caregivers and healthcare professionals were positive regarding the potential of assistive technologies to facilitate self-management and independence. Although the present study highlighted many similarities in essential topics to be covered in the design of an intelligent UL supporting assistive technology between DMD and stroke, interpretation of some of the specific requirements involved was different due to the differences in the target populations. Although differences in focus of the user perspectives may also be due to slight differences in information collection and participants between both groups, this study provides valuable information about users' views regarding technology aspects of an assistive technology, and relevant insights into the most population-specific topics. In this study, healthcare professionals were included in the prioritization of the user requirements afterwards, but they did not take part in the focus groups. Therefore, our findings as presented in this paper may be different if healthcare professionals were included earlier on in the process.

V. CONCLUSION AND FUTURE WORK

Actual use of a device can be related to the perceived usefulness and ease of use [32]. In order to improve the

 ISBN: 978-1-61208-618-7

chance of acceptance, specific attention needs to be paid to ease of use and usefulness as well as a high priority should be given to accessibility and personalization of both hardware and software aspects of assistive technology [27]. The user requirements from this study, focused on technical domains, can be used to complement the existing information on user perspectives identified as important barriers and facilitators for UL assistive technology. End-user input from this study has highlighted differences in end-user preferences and needs between and within populations, which have to be taken into account into the future design of an UL supporting assistive technology. Currently, the identified user requirements are being taken into account during the design of an intelligent, adaptive, unobtrusive UL supporting assistive technology within the eNHANCE project, aimed at assisting people with DMD or stroke in independently performing UL daily life activities.

ACKNOWLEDGEMENTS

This project has received funding from the *European Union's Horizon 2020 research and innovation programme* under grant agreement No 644000. This result reflects only the author's view and the Commission is not responsible for any use of the information in this result.

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