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Workshop report

2nd Workshop on upper-extremity assistive technology for people with Duchenne: Effectiveness and usability of arm supports Irvine, USA, 22nd–23rd January 2018

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1. Introduction

1.1. Workshop theme, aims and participants

In 2015, the 1st workshop on Assistive Technology for People with Duchenne was held. The primary goal of that meeting was to bring individuals from different disciplines together and discuss opportunities to accelerate the development of upper-extremity assistive technology for enhancing the functional abilities of non-ambulant men with Duchenne Muscular Dystrophy (DMD). One of the conclusions of the meeting was that protocols to evaluate the efficacy and usability of arm supports in a laboratory and in a home-based setting were needed. To address this need, a 2nd workshop was held in Irvine (California, USA), on January 22nd–23rd 2018. Workshop participants were key stakeholders on the field of upper-extremity assistive technology from the Netherlands and USA, including experts in user requirements, engineers, movement scientists, rehabilitation scientists, physical therapists and clinicians. The aims of this workshop were (1) to provide an overview on the state-of-the-art related to the evaluation of upper extremity assistive devices, (2) to identify a set of outcome measures for upper-extremity assistive devices that can be used to evaluate the effectiveness of this technology and provide a ground for the development of a selection guideline. The meeting was initiated and supported by the Dutch Duchenne Parent Project.

1.2. DMD and arm supports

DMD is a progressive muscle disorder that is characterized by severe muscle weakness. The median survival of people with DMD increased in the last decades and it is currently estimated to be over 30 years [1,2]. Because of the prolonged life expectancy, the number of individuals living with DMD is increasing. This group of young men may live with impaired upper extremity function for more than 15 years, which severely limits the performance of basic activities of daily living (like self-feeding and personal care) and restricts social participation. There is evidence that suggests that assisted arm training can delay the progression of muscle weakness in the arms [3]. The use of assistive devices has the potential to improve the quality of life for people with DMD, by enabling them to continue performing activities of daily living

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and participating in social activities. In the last decades, several mobile arm supports that aim at compensating the loss of arm function in people with muscle weakness have been developed and are commercially available [4,5]. These devices are generally attached to the wheelchair and use springs to compensate the weight of the arm. In some cases, small actuators are used to adjust the weight compensation force and other device settings. Despite all the developmental efforts, few devices are commercially available [5,6] and only a small portion of the people who can potentially benefit from the use of an arm support actually uses one [5,7].

2. State-of-the-art

2.1. Outcome measures used in the evaluation of arm supports

Most of the studies that focus on the evaluation of arm supports examined only the effects under laboratory conditions or using questionnaires [6]. However, in order to assess advances in upper extremity care, including training programs and dynamic arm supports, better insight in arm use in daily life situations is required. This advocates the need for a home based assessment and a standardized set of outcome measures, as motor capacity (what someone does in a controlled environment) and motor performance (what someone does in their daily life) may only be partly related [8].

Dr. Tariq Rahman presented the results of a questionnaire-based study that evaluated the WREX. They found that 60% of 55 users included in the study continued to use the WREX at the time of the survey [9]. The study concluded that this device made a significant improvement in arm function for users while performing ADL. Reasons for abandonment included weight, interference with other activities, joint contractures, and imprecise gravity compensation. Users also reported more improvement of arm function with the wheelchair-mounted WREX than with the body-mounted version. Aesthetics, fitting, and reimbursement were identified as areas for improvement. The Canadian Occupational Performance Measure (COPM) [10] was used for quantitative evaluation of the WREX.

Prof. David Reinkensmeyer presented his early work with the T-WREX exoskeleton [11], which is a modified version of the WREX arm support that can provide arm rehabilitation therapy to subjects with neuromuscular disorders. Intervention studies showed that subjects with stroke that trained with the T-WREX had a greater decrease in arm impairment (i.e. measured with the Fugl-Meyer score) than participants that performed conventional therapy. This device has been commercialized by Hocoma A.H. as the Armeo Spring.

Dr. Mariska Janssen presented the results of the evaluation study conducted with the Passive A-Gear. This laboratory-based study measured kinematic data and surface electromyography while performing tasks of the Performance of Upper Limb scale [12]. In addition, she presented a biophysical model underlying to upper extremity limitations in DMD. This model is relevant for selection of appropriate interventions and design new arm support [13].

Additional evidence on effectiveness of arm supports. Kumar et al. conducted a user evaluation study with the Neater arm support and concluded that the use of the Neater arm support by adults and teenagers with neuromuscular disorders could greatly improve their independence, confidence, and ability to engage in social situations [14]. Hasegawa and Oura conducted a $N = 1$ user evaluation of the EMAS III. They found that the gravity compensation was not enough to support various activities of the upper arm since additional support force is necessary to lift the upper arm up for a hand to reach her face or head [15]. Koo et al. evaluated the active Gravity Neutral Orthosis (GNO) and found that the active GNO increased the range of motion and improved motor control in patients with neuromuscular disorders. Modest improvements in the quality of movement were noted, but functional movements were limited by the initial GNO design [16]. Kramer et al. designed the Dynamic Arm Support (DAS) and performed a qualitative user evaluation in four patients with neuromuscular disorders [17]. The DAS provides a compensation force that enables up/downward movement of the arm by small muscle force within the users range of motion. Errors in gravity compensation were caused by hysteresis and nonlinearity causing limited use of the DAS in users with very small muscle forces. Several papers have been published about the development and user evaluation of the ARMON [18]. Herder and co-workers concluded that even severely affected persons were able to perform elementary ADL activities using the ARMON and general appearance was highly appreciated [18,19], Lund et al. performed a user-centered evaluation of the ARMON and used the Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST) and Individually Prioritized Problem Assessment (IPPA) as their primary outcome measures [20]. They concluded that the Mobile Arm Support had a positive effect on the ability of the users to perform important tasks in their everyday lives independently. The users also reported an overall high level of content with the device whereas there were some remarks of discontent regarding the service and fitting process. Finally, a systematic review on the effect, effectiveness and usability of arm supports concluded from the results of 47 evaluation studies that there was an increased ability to perform activities of daily living and user satisfaction when using an arm support, but that their use at home was low [6].

2.2. Upcoming technologies: wearable sensing for monitoring arm activity

Wearable sensing technology provides the opportunity to quantitatively evaluate arm function and physical activity during daily life for extended periods of time. During the last decade, wearable sensing technology has proven useful for promoting health and fitness for the general public and athletes. Systematic reviews indicate that even a simple daily pedometer feedback is effective to increase walking activity

and thereby improve body mass index and blood pressure [21]. A plethora of wrist-worn sensors and phone apps for monitoring daily activity is nowadays marketed and have become a common gear on people exercising for physical fitness. Unfortunately, none of these products are tailored to people with movement impairments and thus have limited usefulness for them. Recently, few studies have been initiated to evaluate the effectiveness of providing feedback on arm activity [22,23].

Prof. Oresti Baños and Dr. Arjen Begsma presented advances in smartphone and smartwatch sensing, behavioral monitoring and virtual coaching systems. Smartphones have a variety of built-in sensors, like accelerometers, gyroscopes, heart rate sensors, GPS, etc. Smartphones enable experiments in every day environments, for large groups and across multiple dimensions. The University of Twente developed a mobile data collection and analysis platform, Holibehave, to enable researchers to monitor and analyze human behavior. Holibehave is largely based on an Android-based open-source context instrumentation framework called AWARE. This framework follows a client-server architecture that supports the collection of unobtrusive passive smartphone sensor data and is licensed under the Apache Software License 2.0, so it allows for performing changes and adding extensions to the main code. AWARE follows a modular approach: the AWARE client app abstracts the communication with the sensors and the acquisition of data; then, data is used to generate context through customizable code extensions named plugins. The Holibehave platform uses and extends this approach. The specialist sets on the server which sensors and plugins are going to be used, and once a user has joined the study—which is as simple as scanning a QR code through the AWARE client app–, plugins are automatically installed, when applicable, and the data acquisition begins. The data is obfuscated and encrypted using a one-way hashing of logged personal identifiers, such as phone numbers. Increased security is achieved with application permissions, certificates, user authentication, and the use of secure network connections to access and transfer the logged data between the client and the dashboard.

Prof. David Reinkensmeyer presented the development of the Manumeter device which is a wrist-worn sensor able to measure hand and arm movements using a magnetic ring [24,25]. This device is currently being used in a randomized controlled trial to evaluate the effect of providing feedback to subjects with stroke on the amount of hand use during the day.

Dr. Roxanna Bendixen presented an experimental protocol for an upcoming randomized home-based trial that will evaluate the effectiveness of the Armon Ayura and the WREX arm supports during daily life for 12 weeks [26]. The study participants will wear an ActiGraph activity monitor system on their wrist to quantitatively measure their arm movements. In addition, the study will evaluate upper extremity function using the Brooke UE scale, Activity of Daily Living Self-Report, Wolf-Motor Functional test, Goal Attainment scale and the Caregiver Time/Effort Report.

2.3. Upcoming technologies: new arm supports

Dr. Joan Lobo Prat presented his early work on the control of robotic arm supports for people with DMD using surface EMG and force signals [27,28]. In addition, he presented the development of MOVit, a novel, arm exercise-enabling driving interface for powered wheelchair users. MOVit consists of two custom-made, instrumented mobile arm supports that are mounted on the lateral sides of a powered wheelchair replacing the armrests. Instead of using a joystick to drive the wheelchair, the user moves the arm supports with his or her arms through a cyclical motion, while the software simulates a "virtual lever drive" chair [29].

Dr. Madeline Corrigan and Richard Foulds presented work on the benefits of amplifying the reduced forces produced by subjects' arms with the addition of small motors operating under admittance control [30]. Results have shown that users can make smooth arm trajectories over a larger range of motion than is allowed by passive arm supports [31]. They also discussed their Continuum Project based on a passive arm support that can be augmented with motorized modules for anti-gravity, horizontal and grasp assistance applied to maintain functional manipulation as muscle weakness progresses. The effectiveness of this approach is being studied in a translation project that is equipping 30 individuals with bilateral motorized exoskeletons for everyday use in the community [32].

3. Upper extremity outcome measures

Over the past decade several papers have been written in an attempt to identify the most feasible, valid and reliable outcome measures for measuring upper extremity function in people with DMD [33–36]. Based on the findings in these papers, new measurement instruments were developed for assessing upper extremity function in DMD [37,38]. However, none of these papers looked into the feasibility of outcome measures in relation with the use of arm supports. In addition, most of the papers focused on only assessment in a standardized clinical setting, while home based assessment using new technologies (i.e. wearable sensors) is not discussed. Therefore, the workshop aimed to identify outcome measures that are currently used for assessing the effectiveness of arm supports and to identify additional outcome measures that could be useful for this purpose in the future.

In order to do so, we categorized the outcome measures based on the International Classification of Functioning Disability and Health (ICF) [39]. In the ICF-model three different levels of human functioning are identified: 'the level of body function and structures', 'activity level', and 'participation'. In addition, we also categorized the outcome measures according to the methods used to assess the upper extremity: 'patient reported outcome measures', 'functional scales' and 'sensor-based (quantitative) assessments'. Table 1 shows a comprehensive overview of the outcome measures that were identified during the workshop and that could

Table 1
Outcome measures for assessment of arm supports.

	Body function and structure	Activity	Participation
Patient reported outcome measures	• Pain • Stiffness	• Abilhand • Activlim • Capabilities of Upper Extremity (CUE) questionnaire • DMD Upper Limb PROM • Fatigue (CIS, FFS, OMNI, NeuroPedQol) • Sense of effort (VAS)	• Quality of life (NeuroPedQol, PARS III, Kidscreen etc.) • Usage (diary) • Attitude (perception by others) • Canadian Occupational Performance Measure (COPM) • Goal Attainment Scale (GAS) • Psychosocial Impact of Assistive devices Scale (PIADS) • Quebec User Evaluation of Satisfaction with assistive Technology (QUEST)
Functional assessments	• Manual muscle testing (MMT) • Passive range of motion • Active range of motion	• Brooke scale • Performance of upper limb scale (PUL) • Wolf Motor Function Test (WMFT) • Jebsen hand function test (JHFT) • 9-hole peg test (9HPT) • Box and blocks test (BBT) • Action Research Arm test (ARAT)	• Video observation • Functional Independence measure (FIM)
Sensor-based (quantitative) assessments	• MRI • Electromyography (EMG) • Force (hand held dynamometer, myotools) • Active and passive range of motion • Near InfraRed Spectroscopy (NIRS) • Blood parameters (lactate, oxygen, NIRS etc.) as a measure for muscle damage.	• Fatigue (Electromyography) • Smoothness of movement • Reachable workspace (Kinect) • Functional workspace (Kinect)	• Activity sensors (Actigraph, GeneActiv, other smart watches) • Metabolic equivalent (MET)

potentially be used for assessing the effectiveness of arm supports.

We also considered the importance of taking some contextual factors into account when evaluating the effectiveness of arm supports in terms of the outcome measures mentioned in Table 1. These factors may include: ‘reimbursement by insurance’, ‘attitude towards arm supports’, ‘motivation’, ‘policy’, ‘the natural environment when doing home based evaluations’, ‘support from the environment’, ‘social interaction’, ‘(dis)comfort’, ‘self-esteem’ and ‘self-efficacy’.

In our opinion it is important to define a standardized set of outcome measures to evaluate the effectiveness of arm supports, as this would allow for a benchmarking and could improve the selection process of the most suitable arm support for a specific individual. For the selection of this standardized set of outcome measures we recommend to include at least one outcome measures in each ICF category. In addition, we recommend including both outcome measures that measure upper extremity capacity (in a standardized and laboratory-based environment) and outcome measures that measure upper extremity performance (in a natural/home based environment). In addition, the selection of outcome measures should take important aspects of arm supports into account, such as range of motion, comfort, aesthetics and functionality. An advantage on outcome measures for arm supports is that sensor technology can be integrated into the arm support without hindering the patient, which allows for unobtrusive measurements in the home environment. A disadvantage on outcome measures for arm support is that the arm support can interfere with the outcome measures, for example when using outcome measures that rely on visual information (optical 3D motion capture systems), or that need to be connected to the arm, such as activity monitors.

4. Conclusion

4.1. Outcome measures

During the workshop, participants shared their latest updates regarding research into arms supports and assistive technology for DMD. All participants agreed that a validated set of outcome measures is needed to evaluate arm supports and to optimize the clinical advice on arm support use. Future research should focus on gaining international consensus on the optimal set of outcome measures. All workshop participants, however, agreed that the set of outcome measures should not only focus on functional outcome measures, but it should also focus on experiences of arm support users. In addition, outcome measures should focus on both capacity (what can you do with an arm support) and performance (what do you do with an arm support in daily life). We should learn from earlier mistakes regarding the process of drug development, in which it was realized too late that feasible and validated outcome measures are needed.

4.2. Benchmarking and guidelines

During the workshop all participants agreed that the selection of an arm support should be made based on

its functionality in relation to the wishes of the user. An arm support that functions well for one person, might be useless for another person. So in order to make a good selection, it is very important to have sufficient information on the different arm supports available. In addition, it is important to have information about the users and their unique environment (school vs. special schooling, parents vs. different helpers vs. little help). Objective information on arm supports can be obtained by using the same, standardized set of outcome measures for all arm supports. In addition, subjective information on user experiences is equally as important. This combination of objective and subjective data on arm supports can provide a benchmark that current and future arm support users and clinicians can use to support their choice for a certain type of arm support. This benchmark in combination with individual patient characteristics might even be used for the development of a guideline for the selection of an arm support. Unfortunately, the selection of arm supports is currently not always based on functional improvement and wishes of its user, but for example on costs (and reimbursement options) and (limited) availability. Hopefully, sufficient benchmarking and evidence on the effectiveness of arm supports will increase our knowledge in this field, which can be useful for patients, caregivers, but also for reimbursement companies.

4.3. Future research topics

The workshop was concluded with a brainstorming session on the most important topics for future research related to arm supports. Three main topics for research were identified. The most important topic defined by the workshop participants was ‘User needs and wishes’. Within this topic it is important to identify essential issues for people with DMD in general. In addition, more information is needed on the justification for arm support use (benefits in relation to the burden). The second most important topic for future research was ‘Benefits of arm supports’. Within this topic investigations should focus on who can benefit from an arm support and what (therapeutic) improvements can be expected by using them. The third important research topic was ‘Outcome measures’. A standardized set of outcome measures is needed to define usability of arm supports in order to inform the selection criteria.

Finally, it is very important to create awareness for arm supports. Patients with DMD and the clinicians that treat them should be aware of the available arm supports and the potential benefits of arms supports. In order to create more awareness, the workshop participants came up with an idea for an international website which gives information on commercially available arm supports and includes an overview of scientific evidence on the effectiveness of arm supports. Therefore, one of the future aims of the workshop participants is to create this website.

Workshop participants

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Richard Foulds, New Jersey Institute of Technology, USA
Roxanna Bendixen, University of Pittsburgh, USA
Tariq Rahman, Nemours Biomedical Research, USA.

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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.nmd.2019.07.005.

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