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Seating and Mobility Concerns of Adults with Duchenne Muscular Dystrophy

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Abstract: *Background*: Appropriate wheelchair and seating systems are key to allow for the participation of people with Duchenne Muscular Dystrophy. There is little research that focuses on their long-term seating issues and what topics they want studied. *Methods***:** This mixed-method study with adults with Duchenne used an Internet-based survey about wheelchair mobility and discomfort, followed by in-depth interviews. Unanticipated remarks in the interviews led to a second survey regarding the effects of cold weather on wheelchair driving. Descriptive and qualitative analyses were performed. *Results*: Thirty-seven individuals completed the original survey: 78% used a powered wheelchair, 58% were uncomfortable in their wheelchair, and 94% felt the need to change their seating position. In-depth interviews ($N = 9$) revealed three themes: seating and pain management, caregiver cooperation, and temperature sensitivity. Almost all (8/9) interviewees explained that cold was a barrier to their participation. In the second survey ($N = 13$), 11 reported that cold affected their driving, with 10 remarking that it prevented them from participating in daily life activities and 11 stating that the effects of cold on wheelchair driving should be studied. *Conclusions***:** It is essential to ask end-users to identify key issues to ensure the relevance of research to people with disabilities.

Keywords: disabilities; mobility; participatory research

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1. Introduction

Duchenne Muscular Dystrophy is a rare X-linked disease, affecting males almost exclusively, that has a characteristic progressive pattern of muscle degeneration [1]. It includes muscle weakness, postural compensation, risk of contractures, and functional loss, with a prevalence of 4.8 per 1000 [2]. Optimal management and intervention are needed across the lifespan, as people with Duchenne live longer [3]. A recent meta-analysis shows that people with Duchenne who use ventilators can now live to their fourth decade, a significant increase from the median of 19 years without a ventilator [4]. Another study of men with Duchenne over 40 years old adds that individual disease management, including hospitalization when needed, is also important for increased longevity [5]. People with Duchenne typically require a wheelchair in their early teenage years [2]. An appropriate wheelchair and seating system is important for allowing for an active life role and participation [6,7], since it enables freedom, independence, quality of life, as well as mental wellbeing; users feel their wheelchair is part of their identity [6].

Seating and mobility are part of the rehabilitation management for people with Duchenne and should emphasize self-advocacy and client participation in decision-making [8]. A qualitative study of three adults and one adolescent with muscular dystrophy highlighted the importance of understanding the user's experience when evaluating seating [9]. Themes included the users' desire to be active participants in the process, as well as the importance of supporting and encouraging self-advocacy of people with Duchenne in their wheelchair provision process. Consumer engagement is extremely important to ensure that research is relevant, meaningful, and prioritizes the needs of people with Duchenne and other rare diseases [10,11]. Research that collaborates with those affected by the issue being explored, with the goal of action or change [12], highlights the value of end-users' inputs and respects that they are experts on their own lives [13], ensuring that the results will be significant and have an impact on their lives [14].

There is little research that focuses on the consequences of long-term seating and wheelchair mobility on people with Duchenne or asks them what should be studied. Studies have found that comfort and prevention of pain, as well as stability, pressure management, and joystick access, are key issues for adults with neuromuscular diseases [15,16]. This led to the notion that adults with Duchenne might choose research that focuses on issues related to comfort, cushions or re-positioning. The aims of this research were as follows: (1) to ask people with Duchenne what specific concerns they have about their comfort, seating, and mobility needs; (2) to gain insight into their lived experience on the subject; and (3) to choose a research topic that would benefit them.

2. Materials and Methods

2.1. Methods

This sequential explanatory mixed-method study [17] had three stages: (1) an Internet and telephone survey that was quantitively analyzed; (2) individual interviews that were qualitatively analyzed through a deductive/inductive method; and (3) a second survey that was quantitively analyzed.

After receiving approval from the ALYN Hospital Ethics Committee (Approval No. 064-22; ALYN being a Hebrew acronym for a pediatric rehabilitation hospital in Jerusalem, Israel), an online survey was distributed. The survey, containing the Tool for Assessing Wheelchair Comfort (TAWC) and the Functional Mobility Assessment (FMA), was sent to individuals with Duchenne muscular dystrophy registered in ALYN's electronic medical records, and the Little Steps, a family-led organization supporting individuals with Duchenne. All surveys started with informed consent, and responses were anonymous. Respondents were invited to participate in an in-depth interview, and were instructed to contact the authors if interested. Participants who opted into the interview provided written consent by signing informed consent forms for this additional stage. The in-depth interviews (see Supplementary Material for guidelines) were conducted by both authors with respondents via individual Zoom meetings (both are females and expert clinicians in assistive technology and have doctoral degrees in occupational therapy). During the interviews, the authors clarified that the participants were part of a study that would choose a topic of research and presented the results of the survey. The participants discussed their opinions about the results and which topics they felt would be relevant for future studies on adults with Duchenne. Parents were present for two of the interviews. There was no need for repeat interviews. Interviews were recorded and transcribed verbatim and then coded to draw themes. A phenomenological approach was used to gain insight into the participants' lived experiences [18]. A deductive/inductive hybrid thematic analysis was used that began with the results of the first survey (deductive), but generated new themes (inductive) [19]. Two researchers coded the data, then discussed and created themes and adjusted them until agreement was reached. Following agreement, interviews were re-read and quotes for themes were retrieved, and sub-themes were identified. Figure 1 shows the audit trail. The themes were not shared with the interviewees. However, a second survey with four questions (see Supplementary Material for questions) was sent to original participants to further understand the themes raised in the interviews due to the unanticipated issues raised during the interviews. The results of both surveys were analyzed through descriptive statistics. The COREQ (COnsolidated criteria for REporting Qualitative research) checklist [20] was followed.

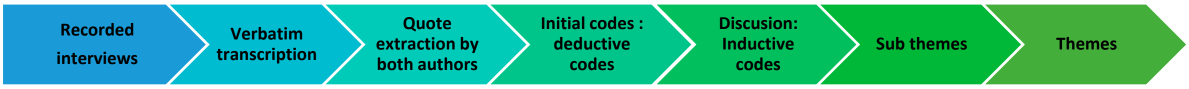

Figure 1. Audit trail.

2.2. Participants

For the first stage, an explanation of the study with a link to the survey was posted on the Internet site of Little Steps and sent via email to all people on the ALYN Hospital registrar who answered the inclusion criteria: (1) a diagnosis of Duchenne Muscular Dystrophy; (2) 14 years of age or more; (3) agreed to participate in the study. Exclusion criteria: Individuals who did not speak either Hebrew, Arabic, or English. All people who fit the inclusion and exclusion criteria were included. After 2 weeks, a telephone reminder call was made, followed by another call where help was offered to complete the survey together with the participant. The participants for the second stage were chosen by convenience sampling amongst the participants of the survey who wrote that they would be interested in being interviewed and spoke either Hebrew or English. Code saturation was reached after nine interviews, as similar codes were presented through the interviews [21], and, therefore, no additional participants were needed. Finally, a second survey was sent to all respondents of the first survey.

2.3. Tools

Questionnaires were used in the first survey to collect information about seating experiences, the challenges of positioning, and areas that participants felt should be assessed in research. It contained questions translated from the TAWC and the FMA. The questionnaire was available in Hebrew or Arabic according to the respondent's preference.

The TAWC [22] consists of three sections: eight statements to gather general information about factors that might cause discomfort, thirteen statements relating to comfort and discomfort rated on a seven-point Likert scale (the General Discomfort Score, GDS), and rating degree of discomfort on seven areas of the body (Discomfort Intensity Score-DIS). The TAWC is a tool with adequate reliability and concurrent validity, as well as good stability and responsiveness to change [23,24].

The FMA Beta version 1.0 [25] consists of ten statements about personal mobility while using current mobility aid (manual wheelchair, power wheelchair, or scooter etc.). The respondent chose the appropriate level of agreement on a seven-point Likert scale (from completely agree to completely disagree). The FMA beta has very high intraclass correlation coefficient (ICC), as well as test–retest and inter-rater reliability and validity [26].

REDCap, an electronic data capture tool, was used to collect, manage, and store the data (in the ALYN hospital's secure computer system.

Semi-structured interviews started by presenting the results of the first survey and continued with an open discussion about the participants' opinions on the results and subjects they wanted to be studied (see Supplementary Material).

3. Results

3.1. First Survey

The first survey was sent to 130 people with Duchenne, and after telephone reminders, 37 people completed the survey. The median age of respondents was 21 years (ranging from 14 to 48 years) and 19 (51%) attended school or worked. Figure 2 shows a breakdown of their occupation. Twenty-nine of the participants (78%) used a powered wheelchair every day, and the rest used a manual wheelchair. Most (29 of the 33 who answered this question; 88%) reported that their wheelchair allowed them independence in mobility, though 9 (24%) of the respondents answered only "somewhat agree". Just over half of the participants (18/31; 58%) reported that they were not comfortable in their wheelchair, and the same percentage reported that they changed their position by themselves. Most participants (29/31; 94%) responded that they needed to move or change position. Discomfort in their feet (7.5/10) and legs (7.4/10) were greater than in their the neck, buttocks, or arms, as seen in Figure 3.

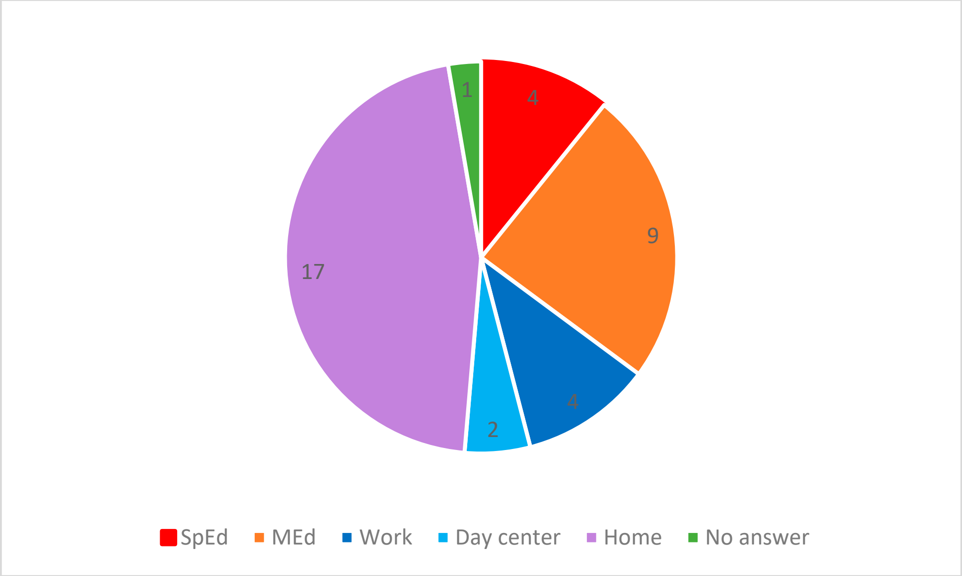

Figure 2. Occupations of the participants, as reported in the first survey. SpEd—special education; MEd—mainstream education.

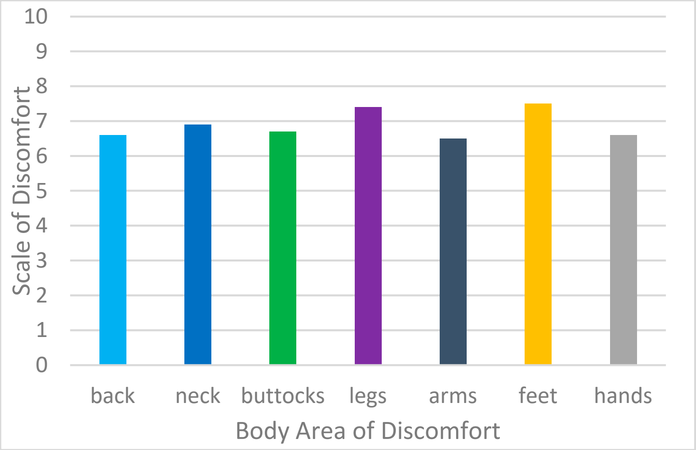

Figure 3. Area of discomfort (rated from 0–10).

3.2. *Interviews*

In-depth 30–45 min interviews were conducted with nine participants who expressed interest in sharing their opinions, to better understand the results of the survey. The median age of the interviewees was 26 years old (range 17–42 years old). Pseudonyms are used to protect privacy. The three main themes that arose were seating and pain management, caregiver cooperation, and temperature sensitivity (as shown in Table 1).

Table 1. Interview themes and sub-themes.

Seating and Pain Management	**Caregiver Cooperation**	**Temperature Sensitivity**
Seating over extended time We are experts, but need professional help Strategies for discomfort	Knows my needs Easy to explain	Cold all year Home-made solutions Participation

3.2.1. Seating and Pain Management Included Three Sub-Themes

Seating over Extended Time

The participants remarked that the length of time they sat was problematic, rather than the seating system itself. Most of them said that the chair was comfortable.

> *"If I sit for more than 10 h a couple of days, then the pain becomes permanent. Then I need to go to bed at 20:00 and get up at 10:00."* (Sean)

> *"Sitting on the chair is comfortable, it's just the, like, the never-ending sitting. . .(that's) not comfortable."* (Ron)

> *"Most of the day it doesn't hurt but after a long time it, like, bothers me."* (Eli)

We Are Experts, but Need Professional Help

Although the interviewees felt confident in understanding their seating requirements, due to the complexity of their seating needs, they needed professional help that was not always accessible.

> *"In our situations it's pretty hard (for health care professionals) to come for one meeting. . . it's a process that requires investment of time."* (Owen)

> *"They tried to adjust my footrests, and nothing was perfect. . . my feet are really problematic. It's really not simple...I don't have professional help."* (Henry)

Strategies for Discomfort

The interviewees all had developed strategies that helped them alleviate discomfort. The strategies were varied, and problems were also discussed.

> *"I do it (change positions) proactively before it is very severe pain."* (Elton)

> *"To use tilt, I need to ask somebody (to help). So yes, a few times a day I do tilt to lean back to straighten out a bit."* (Owen)

> *"I sometimes use tilt to rest a bit or somehow change position a bit. . ..sometimes you're busy and, like, forget."* (Eli)

> *"I tried tilt, from a practical side it helped to relieve pressure but in my case the price (of sitting higher and then difficulties at work on the computer) was too high."* (David)

> *"It's relatively comfortable for me to sit. . .most of the day. . .sometimes I move (to the side), I sort of jump in place like this because of the pressure of sitting."* (Hugh)

3.2.2. Caregiver Cooperation Also Included Two Sub-Themes

The participants described a form of symbiosis with their caregivers, who either knew what to do or easily understood the participant, and, therefore, as a dyad, they could solve the seating issues. The participants felt that changing positions was not a priority issue for research.

Knows My Needs

> *"She (my mother) already really knows me. We are used to adding cushions and, like, managing with what we have."* (Owen)

> *"When they seat you, they already know you really well, so they know how to seat you."* (Elton)

> *"My caregiver does all the position (changes) I want."* (Sean)

Easy to Explain

> *"It's pretty easy (to explain to the caregiver how to move me), it's not a problem."* (David)

> *"It's easy to explain, it's a matter of a minute."* (Eli)

3.2.3. Temperature Sensitivity Included Three Sub-Themes

The participants spontaneously raised their concern about the difficulty they had driving in cold weather, despite that this topic was not included in the first survey and therefore is not part of the summary presented. The interviewees reported trying many solutions to allow them to continue to participate in daily life tasks despite the cold.

Cold All Year

The participants' definition of cold was surprising, and not necessarily related to winter, especially given the Mediterranean climate in which the study took place.

> *"Not only in the winter (the cold interferes with hand control), also in the summer...below 20, 23 or 24 degrees."* (Sean)
>
> *"It doesn't have to be significantly cold for my hand to freeze and it can't do anything."* (Owen)
>
> *"It's hard for me when my hand is cold."* (Mo)
>
> *"For me 24 degrees (Celsius) outside is, like, the minimum that I can do."* (Elton)

Home-Made Solutions

The participants showed initiative (as befitting people who felt they were experts on their seating issues) and had tried many do-it-yourself solutions such as convector heater gloves and a caregiver massaging the cold hand. However, they were not satisfied with the results.

> *"I made a heating solution, but it's still sometimes hard to drive.... it's clumsy and interferes with my hand position."* (Sean)
>
> *"(The home-made handwarmer) is something I'd like to keep working on, but because of lack of time we don't manage to advance with it to the end."* (Owen)
>
> *"I warm my hand. . .someone moves my hand for me."* (Mo)
>
> *"I use a glove but it's hard with the fingers and all."* (David)

Participation

Many interviewees remarked that cold temperatures prevented them from participating in events that were important to them.

> *"There are days, I must admit, that I give up on work (because of cold weather)."* (David)
>
> *"Everything has gotten complicated.... Someone is always with me. I don't go out alone."* (Sean)
>
> *"So, I try, like, things that are indoor."* (Elton)

3.2.4. Additional Themes

Two other themes were mentioned by a few participants, including joystick control and universal health coverage.

> *"[The joystick adjustment] gave me back the ability to use the joystick myself."* (Owen)
>
> *"It's a smaller movement. It [the acceleration] scares me."* (Sean)
>
> *"At the end of the day it's a matter of money. It's not about what can be done."* (Sean)

Even though the survey results indicated a need for research on ways in which seated positions can be changed to increase comfort, the great majority of the interviewees did not agree that this was a priority topic. They reported that their caregiver understood their discomfort and could change their position or that they could change positions themselves. Eight of the nine interviewees said that cold affects their mobility, and described not leaving their homes when it was cool as they could not drive independently.

3.3. Second Survey

The unanticipated results of the interviews led to the second survey, which was sent to the 37 participants who responded to the first survey; 13 people completed the second survey. Most (11/13 participants; 85%) agreed or strongly agreed that cold affected their driving, and 10/13 participants (77%) agreed or strongly agreed that cold prevented them from participation, as displayed in Figure 4. Most (11/13; 85%) strongly agreed or very strongly agreed that the subject of driving in cold weather should be studied.

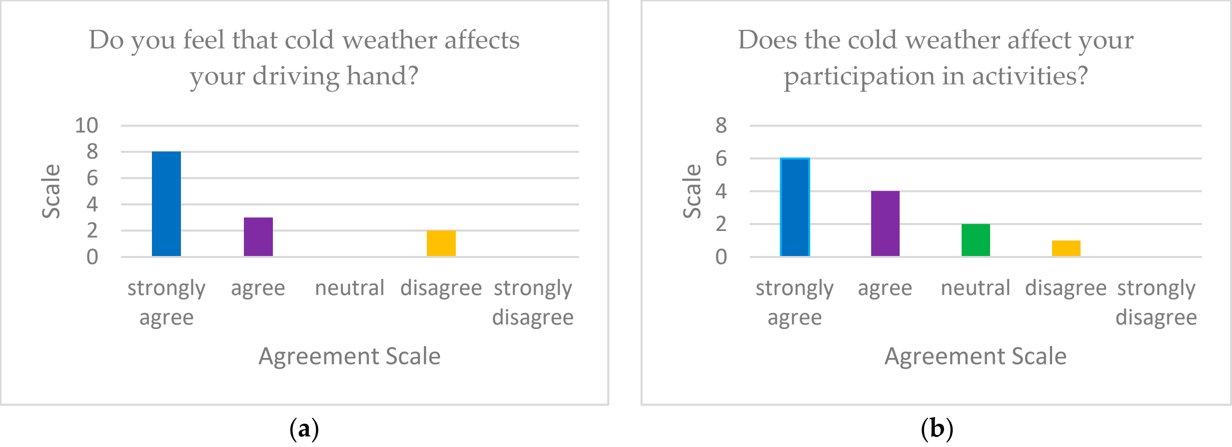

Figure 4. Effects of cold weather from the second survey: (**a**) Do you feel that cold weather affects your driving hand? (**b**) Does the cold weather affect your participation in activities?

4. Discussion

Understanding experiential knowledge, which academic research might not even be aware of, is crucial to increase applicability of the results [14], which can lead to results that researchers did not envision, as occurred in this study. A participatory study with older adults showed a similar phenomenon, when participants, in contrast to the researchers' hypotheses, indicated that they wanted to use assistive technology but had difficulties because it was not properly adapted to their abilities [27]. The current results highlight the importance of asking end-users to identify topics of importance to them, as the researchers did not notice the issue that they chose in the literature, nor observed it clinically. In order to increase the applicability of the results, this study used a three-phase methodology that allowed for the researchers' initial misconceptions to surface. That is, our original premise was that adults with Duchenne experience discomfort in seating and, therefore, would be interested in research which relates to issues of comfort, cushioning, or re-positioning. This premise was validated in the first survey that asked questions about mobility and discomfort, but was not supported in the subsequent interviews. Without the voice of the interviewed participants, the remaining analysis would have focused on the less relevant topic of seating adjustments. In contrast, the issue of cold, which greatly impacts their participation, would have been missed. This demonstrates the importance of involving end-users in research where they share their life experience to generate research that is significant to them and to other users, rather than being driven primarily by theory [13].

An interesting finding, based on the results of the first survey, was that just over half of the participants are not comfortable in their wheelchair. This roughly fits with previous research showing that 41–49% of people with Duchenne who sit in wheelchairs report pain [16,28], but is much lower than Pellegrini's findings [29] that 88% of people with Duchenne report pain. The large discrepancy in results may be due to the ages of the participants in the different studies, as pain seems to worsen with age and disease progression, and in the first two studies the median age was 14.5 and 15.9 years [16,28], but the last study does not report age. In the current study, participants cited their legs and feet as the area of most discomfort, more than their buttocks and more than their neck. This differs from a study where pain in the legs was reported by ambulatory people with Duchenne [30], and wheelchair users with Duchenne cited the lumbosacral as the painful area [28]. The current participants, who all used wheelchairs, did report pain in their buttocks, but less than in their legs and feet. This may have been due to their use of pressure-relief cushions, as well as strategies to reduce discomfort (e.g., tilt and/or caregiver's help to change their position).

The interviews highlighted that prolonged sitting over the course of the day was one of the key reasons for pain. Liu et al. and Kim et al. cite sitting as the central cause of pain for late-stage non-ambulatory people with Duchenne, and that changing sitting position was the main relief method [16,28]. This supports the theme of seating and pain management, with two of the sub-themes: seating over extended time and strategies for discomfort. That is, prolonged sitting, rather than sitting itself, is the main issue. Although there is research about monitoring pressure over time for people with spinal cord lesions [31] or people in manual wheelchairs [32,33], there is much less research on pain over time for powered wheelchair users. In a study that identified wheelchair sitting issues for adults with neuromuscular diseases, pain prevention reached 100% consensus by the health care professionals, although the end-users with Duchenne do not specifically discuss pain prevention, but rather cushion provision to avoid buttocks pain [15].

Joystick access is mentioned in the additional themes. Three interviewees mentioned difficulties controlling the joystick, as Sean's quote exemplifies. The other six either had no difficulties or already had a sensitive joystick, which allowed for them to regain control. This fits with findings from Pellegrini et al., who show that sensitive joysticks can provide a solution for adults with Duchenne, allowing for them to return to participation [34], as Owen expressed.

A further result of this study was that the need to change positions for comfort was solved with their caregivers and did not merit further investigation. In the sharing model, a caregiver can be seen almost as an extension of a person with a severe physical disability [35], which is echoed in this study. Since the first survey raised concerns about discomfort and the need to change positions, it was interesting to find that the interviewees had already solved this issue with their caregivers. Interestingly, in the study to identify wheelchair sitting issues, end-users with Duchenne came to a consensus about the provision of tilt in space and reclining backrests [15]. The end-users in this study mentioned powered seating strategies, such as tilting in space, as a strategy they used. The ministry of health in Israel rarely funds powered recliners, which may explain why they were not aware of its benefits and did not raise this seating strategy.

The key unanticipated outcome was the effect of cold on driving and participation, which was especially remarkable, as the Mediterranean climate where the research was conducted is relatively warm. The participants said that below 24 degrees Celsius was considered "cold" for them, which may explain why the issue of cold was raised despite living in a relatively warm region. In a Canadian study, 85% of wheelchair users responded that cold weather affects their hand function and therefore their ability to drive, and 42% go out less in the winter [36]. This fits with the theme of cold and the subtheme of participation from the current study's interviews. Using gloves did not help driving in winter, as the gloves restricted movement [37], or, as David said, "I use a glove but it's hard with the fingers and all". The topic of winter mobility does appear in the literature; however, in a scoping review of the subject, only 4 out of 23 studies were related to powered mobility, and the studies focused on barriers such as snow and ice rather than the effects of cold [38]. The studies covered diverse diagnoses, but none related to Duchenne [38], where hand function is known to decrease with the progression of the disease [39].

There were several limitations in this study. The response rate to the survey was low, despite the reminders. The research was conducted in a small country, with limited cultural diversity. Although the study sought the opinions and perspectives of end-users, it would have been better to have a person with lived experience in all stages of the research from planning through data analysis and writing the result, as is conducted in participatory research. Future research directions should include a larger sample so that the results may be analyzed by age (as Duchenne is a progressive disease), hand function, and geographical location. It would also be interesting to learn if issues of cold affect people with other diagnosis, and in which conditions. The results of this research have led to an ongoing subsequent study that is exploring the effectiveness of a hand-warming device on powered mobility for adults with Duchenne.

5. Conclusions

The study results show that most people with Duchenne suffer discomfort in their wheelchairs, and almost all need to change their position to obtain relief. Three themes arose: seating and pain management, caregiver cooperation, and temperature sensitivity. An unexpected subject, the effects of cold on driving a wheelchair and on participation, was raised. This study highlights the importance understanding end-users' lived experiences and ensuring that the results are relevant. Although people with Duchenne do have discomfort from sitting, especially after prolonged periods, they are able to apply their expertise to alleviate the pain with help from caregivers. Cold weather prevents participation, not only in the winter, and was chosen as the topic for future research.

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/disabilities4040066/s1, File S1: Surveys and interview guide.

Author Contributions: Conceptualization, methodology validation, formal analysis, investigation, resources, data curation, writing—review and editing, visualization, supervision: all carried out by both authors; writing—original draft preparation: L.R.; project administration and funding acquisition: N.G. All authors have read and agreed to the published version of the manuscript.

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Institutional Review Board Statement: This study was conducted in accordance with the Declaration of Helsinki and approved by the Institutional Review Board of ALYN Hospital (064-22, 7 July 2022).

Informed Consent Statement: Informed consent was obtained from all participants involved in the study.

Data Availability Statement: Data are stored in the secure repository at ALYN Hospital. For details, please contact the corresponding author.

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Conflicts of Interest: The authors declare no conflicts of interest.

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