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Assistive technology based on client-centered for occupational performance in neuromuscular conditions

Thais Pousada García, PhD*, Javier Pereira Loureiro, PhD, Betania Groba González, PhD,
Laura Nieto-Rivero, PhD

Abstract

Knowledge of the patient's own perception of functioning and dependence, and of environmental factors, is of significant value. The main goals of this study are (1) to obtain a general profile of the occupational performance of persons with neuromuscular disorders (NMD) and their needs related to that performance and (2) to determine the support resources (assistive technologies [AT], adjustment, and/or caregiver) required to improve or maintain their level of independence.

This cross-sectional study involved 24 persons with NMD. The functional independence measure (FIM), the checklist of a home's accessibility level, and a specific questionnaire were administered.

The sample included 14 women (58.3%) and 10 men (41.7%). A mean of 61.7 (standard deviation = 17.2) was obtained for FIM motor, over 91, indicating a moderate level of dependence. The AT most frequently used was a wheelchair (70.8%). Architectural barriers were detected in the majority of users' homes (87.5%).

Concise assessment of the independence needs of people with NMD, according to their occupational performance, and prescription of resources to meet those needs are required. This procedure should be implemented in healthcare programs, including care to a caregiver.

Abbreviations: ADL = activities of daily living, AT = assistive technology, FIM = functional independence measure, NGO = non-profit organization, NMD = neuromuscular disorders.

Keywords: activities of daily living, assistive technology, independence, neuromuscular disorders, occupational performance

1. Introduction

Neuromuscular disorders (NMD) constitute a heterogeneous group of pathologies, including motor neuron diseases, disorders of motor nerve roots or peripheral nerves, neuromuscular transmission disorders, and muscle diseases.[1,2] Despite the great variety of each one of them in terms of incidence, heredity, etiology, prognosis, and functional impairments, the 3 problems most frequently noted are muscle weakness, difficulty exercising, and fatigue, all of which lead to reduced physical activity and an increasingly sedentary existence.[1–3] NMD causes functional impairment that involves the loss of important abilities, since it impedes mobility, and so affects the ability to walk; causes other restrictions concerning occupational performance and the level of independence in various activities; and demands renewed adaptation on the part of the person afflicted.[4]

The progression of weakness is different for each person and each diagnosis, which leads to the person becoming dependent on the help and support of others or assistive technologies (AT). Most obvious is the deterioration over time in activities of daily living (ADL) that require finger and arm strength, and in personal mobility.[5,6] Therefore, as muscle weakness progresses, more caregiving assistance and the use of assistive devices and environmental adjustments are increasingly required to perform activities in occupational areas.[3,7–9] Although treatment focused on promoting physical skills and capabilities is an important aspect of the rehabilitation plan, the issues related to the environment, influenced by accessibility, and the use of AT to preserve functional independence are adequate resources for individuals with NMD.[10]

Although there are several studies related to functional independence or rehabilitation programs in persons with NMD,[4,5,11–13] most of them have not considered the role and importance of home adjustments, AT, and personal support from a caregiver in order to improve users' independence. Therefore, there is a need for a more comprehensive investigation into the role of different kinds of support that can improve the quality of life of persons with NMD, and thereby reduce healthcare costs and improve the efficiency of the social-health system.

According to the International Classification of Functioning, Disability and Health,[14] certain environmental factors, such as design and building products, can facilitate or restrict the capacity to engage occupational performance. For instance,

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Faculty of Health Science, University of A Coruña, Spain.

* Correspondence: Thais Pousada García, Universidade da Coruña, Faculty of Health Science, Campus de Oza,15074 A Coruña, Spain (e-mail: tpousada@udc.es).

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home and environmental arrangements, as well as the suitable prescription of and training in AT in order to achieve independence in performing ADL, are important facilitator factors.[8] In this study, we assume that the term "home adjustments/modifications" or "arrangements" refers to the conversion or adaptation of the environment in order to make the performance of tasks easier, reduce accidents, and support independent living.

It should be stated that, despite their high levels of dependency, many people with progressive NMD are able to live at home, thanks to so-called "informal caregivers," who are often relatives.[15] Caregiver is a generic term referring to a person, either paid or voluntary, who helps someone with different needs in his/her occupational performance. Thus, it is also important to provide family members who are caregivers with equipment options and information on available medical services.[10] Finally, the perspective of occupational therapy to empower people with NMD and their families through assessment of AT and environmental adjustments could be a great resource to improve their occupational performance and, therefore, their quality of life.

The main goals of this study are[1] to obtain a general profile of the occupational performance of persons with NMD and their needs related to that performance and[2] to determine the support resources (AT, adjustment, and/or caregiver) required to improve or maintain their level of independence.

2. Methods

2.1. Design

This study was cross-sectional in nature, because it intended to find the prevalence of the outcome of interest. Since there is no official and complete database on the incidence and prevalence of NMD in Galicia (region of Spain), nor at the national level, the work was carried out within the scope of a non-profit organization (NGO). Its collaboration has been counted, since it is the only source that aggregates, globally, the largest number of people with this condition in the region.

2.2. Ethical concerns

The research was conducted to meet the main ethical and legal concerns for studies that involve experiments on human. This study was conducted in Spain, so during its design and performance, the researchers had to consider not only international ethical guidelines, but also the specific Spanish laws regarding confidentiality, intimacy, and respect for the patient.

This research was approved by the Ethical Committee of Health, following the ethics code and criteria from this committee. The research also complied with the World Medical Association Declaration of Helsinki Ethical Principles. All participants in the study (affected person and caregivers) received an information sheet with all specifications regarding the research, and they could ask the researchers about any aspects they did not understand. Before starting the study, each participant read the information sheet and signed (voluntarily) an informed consent form.

2.3. Participant selection

Participant selection was made from the database of the NGO. The inclusion criteria were

(1) probable or definite NMD diagnosis according to the medical findings;
(2) residence in the province of A Coruña;
(3) age over 7 years[1];
(4) living at home, not in a specific center or hospice; and
(5) a condition associated with a moderate or high level of disability (minimum of 45%, according to legislation in the Spanish Act).[16]

From the database of the NGO, we found 72 patients with NMD living in Coruna. Based on the inclusion criteria, the number was reduced to 45 patients. The main reason for this reduction was the absence of the factor "moderate or high level of disability." Since 15 persons declined to participate in the study and 6 others did not respond when information was sent, 24 patients were included in the final sample.

2.4. Instruments and measurements

The variables fall into 3 categories:

(1) demographic and clinical characteristics,
(2) capacities of performance related to activity and participation, and
(3) environmental factors.

To collect the data, the following tools were used:

Functional independence measure (FIM): This tool was used to determine the level of independence in performing ADL.[17] The questionnaire assesses 6 areas of functional activity across 18 items: self-care, sphincter control, mobility, locomotion, communication, and social cognition. Those areas are grouped in 2 domains: motor (13 items) and cognitive (5 items). Each item is scored using a 7-point Likert scale from 1 (total assistance is needed) to 7 (performance without any support).[17] Validity, reliability, and sensitivity to changes have been well established.[18–20] The FIM validated the Spanish version used in this survey.[21] The FIM was applied through interviews and observations of ADL.

Hoffer classification: This tool was applied as a categorization method that allows determining the level in terms of non-ambulation (non-ambulatory and therapeutic ambulation) and functional ambulation (home ambulation or community ambulation).[22] Originally, the Hoffer classification was used to assess de-ambulation in people with myelomelingocele, but at present, it is applicable to different pathologies with a motor component, among them NMD.[23]

Checklist of home's accessibility level: The National Centre of Personal Autonomy and Assistive Technology in Spain (a member of the EASTIN project) developed this tool.[24] It is a checklist that helps professionals evaluate all of the important items in the people's home in order to improve the characteristics of accessibility. The tool is divided into 5 sections to assess the building's environment (parking and main entrance), the building's common characteristics (entry to building, corridors, stairs, and elevator), the home's main entrance (door and corridors), environmental control, and stairs, bathroom, and toilet characteristics. This resource was used as a checklist to gather information about the participants' home's characteristics, so visits to the homes were made in all cases.

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[1] This minimum age was established since the main evaluation tool, the FIM, is designed to be applied for people older than 7 years.

Specific questionnaire: To collect data about demographics, performance in other occupational areas (education, work, leisure, and social participation), and community life, the research group developed a questionnaire. Interviews with both the patient and the caregiver were conducted to complete it. As this questionnaire was made specifically for the present study, its psychometric properties are not available. Nevertheless, before applying this tool, testing was performed with 3 users who fulfilled all the criteria, except that of residing in A Coruna. This prior test allowed to establish the suitability of the questions and response options in the questionnaire. The tool was applied in the context of an interview with the participant, and if he/she could not respond adequately (eg, in minors), the caregiver was included in the interview. A sample of questions included in this questionnaire is shown in Table 1.

Data from all patients were collected by the same researcher.

2.5. Procedure

The intervention consisted in the elaboration of a plan for each participant, developed by an occupational therapist, which included 2 steps:

Assessment: An interview with each patient and his/her caregiver (in necessary cases) was conducted to collect the data, using the specific questionnaire and FIM. In order to determine characteristics of the architecture and/or possible barriers in the home environment, a checklist was applied. All interviews took place in the user's home. After conducting a personal interview with each patient, the occupational therapist established an occupational profile individually (based on the Occupational Therapy Practice Framework: Domain and Process).[25]

Data analysis: Quantitative variables were expressed using mean (standard deviation [SD]), median, and range values. Qualitative variables were expressed using absolute numbers and percentages. Nonparametric techniques were used, since we assumed that the sample does not respond to the normal distribution, after application of the Kolmogorov–Smirnov test. The level of significance was set to $P \leq .05$. The Mann–Whitney *U* test was used to compare differences between the 2 levels of ambulation in independence and support. To compare differences between the multiple variables, we used the Kruskal–Wallis test. To make the association between qualitative variables, an χ^2 measure was used. Correlations between quantitative variables were studied by means of the Spearman correlation coefficient for ranked data (rho) and the Pearson correlation coefficient (interval data).

Data were analyzed using the program SPSS v.22 for Windows.

3. Results

3.1. Profile of participants

The sample was comprised of 24 persons with NMD, including 14 women (58.3%) and 10 men (41.7%). The mean age of the sample was 28.4 years (range 7–54, SD 14.97). Only 1 person was working, while 37.5% participants in the sample population were unable to work (due to their level of disability). The most common level of studies achieved by participants (62.5%) was high school. Only 1 person lived alone, and the rest of the sample lived at home with relatives (with a partner, children, and/or parents). The most frequent diagnosis registered was limb–girdle muscular dystrophy (25%). The mean disability level was 71.21% (SD 18.2). Six persons were completely mobility independent, and the rest (75%) needed some level of support or AT for walking/locomotion.

Demographic and clinical data of the participants are shown in Table 2.

3.2. Occupational performance and functional independence

ADL: To determine the level of independence in ADL, the FIM was applied to the whole sample. The FIM scores ranged from 56 to 118 (maximum 126). The mean was 96.33 (SD = 17.2; motor FIM = 61.7; SD = 17.2; cognitive FIM = 33.9; SD = 3.2), and the median score was 97.5. The mean score of motor FIM was 61.7 (SD = 17.2) and of cognitive FIM was 33.9 (SD = 3.2).

On the other hand, we analyzed the FIM motor score in terms of both the type of ambulation (according to Hoffer classification) and the age of the sample. A Mann–Whitney U test was applied to determine any significant differences. Importantly, the

Table 1

Specific questionnaire (abbreviated).

1. Demographic and clinical data	Age, gender, driving license, level of studies, employment status, living conditions, diagnosis, level of disability, use of AT for mobility, level of ambulation
2. Performance in areas of occupation (level of independence and characteristics)	Activities of daily living: Level of independence (FIM), characteristics of performance, need for help (AT, caregiver, adjustments to environment)
	Household activities: Type of activities done, characteristics of performance, level of independence, need for help (AT, caregiver, adjustments to environment)
	Work: Participant is working? Characteristics of workplace, ways to go to work, level of independence, need for help in performing tasks
	Education: Type of schooling, adjustment done in school place, characteristics of accessibility at school, need for and use of personal assist
	Leisure: Activities more frequent, desired activities, difficulties participating in leisure activities
	Transport: Use of private car, adjustments made to their own car, use of public transport, type of public transport more used
3. Physical context	Home's characteristics Use of assistive devices Home arrangements
4. Social context	Persons living with patient at home Main caregiver Functions/task of main caregiver

AT = assistive technologies, FIM = functional independence measure.

Table 2

Characteristics of participants, performance of activities, and caregiving/supports.

Characteristics of sample demographics	N	%	Mean (SD)	Median
Gender:				
Male	10	41.7		
Female	14	58.3		
Level of studies:				
Primary studies or less	5	20.8		
Secondary studies/high school	15	62.5		
University	4	16.7		
Employment status:				
Employed	1	4.2		
Unemployed	2	8.3		
Homemaker	3	12.5		
Student	9	37.5		
Retired	0	0		
Unable to work	9	37.5		
Living conditions:				
Alone	1	4.2		
Cohabiting with parents	18	75		
Cohabiting with partner	1	4.2		
Cohabiting with partner and children	4	16.7		
Home's property:				
Own	24	100		
Rent	0	0		
Driving license:				
Yes	5	20.8		
No	19	79.2		
Level of disability:				
Moderate: 45% <level> 65%	10	41.7		
High: >65%	14	58.3		
Level of disability (over 100%)			71.21 (18.2)	75.5
Age			28.42 (14.97)	41
Health status				
Main diagnosis:				
Limb girdle muscular dystrophy	6	25		
Becker muscular dystrophy	4	16.7		
Spinal muscular atrophy (SMA)	4	16.7		
Duchenne muscular dystrophy	2	8.3		
Myotonic dystrophy (Steinert)	2	8.3		
Facioscapulohumeral MD	2	8.3		
Ullrich congenital muscular dystrophy	1	4.2		
Congenital muscular dystrophy	1	4.2		
Arthrogryposis multiplex congenital	1	4.2		
Unknown	1	4.2		
Use any support (AT) for ambulation:				
Ambulatory (without AT)	6	25		
Canes	3	12.5		
Walker	0	0		
Manual-assisted wheelchair	3	12.5		
Manual self-propelled wheelchair	3	12.5		
Electric wheelchair	9	37.5		
Level of ambulation				
Functional ambulation:	12	50		
Community ambulatory	9	37.5		
Home ambulatory	3	12.5		
Non-ambulation:	12	50		
Therapeutic ambulatory	3	12.5		
Non-ambulatory	9	37.5		
Perspective in areas of occupational performance			Mean (SD)	Median
Independence in ALD (assessed with FIM):				
Self-care (max 42)			28.12 (9.8)	
Sphincter control (max 14)			13.75 (0.9)	
Mobility (max 21)			13.08 (5.5)	
Locomotion (max 14)			7.67 (2.4)	

(*continued*)

Table 2

(continued).

Characteristics of sample demographics	N	%	Mean (SD)	Median
Communication (max 14)			13.62 (1.3)	
Social cognition (max 21)			20.25 (2.0)	
Independence in household activities:	N	%		
Cooking				
High dependence	11	45.8		
Moderate dependence	5	20.8		
Instruction/supervision	3	12.5		
Independence	5	20.8		
Washing/ironing clothes				
High dependence	14	58.3		
Moderate dependence	3	12.5		
Instruction/supervision	3	12.5		
Independence	4	16.7		
Sweeping/washing up				
High dependence	15	62.5		
Moderate dependence	3	12.5		
Instruction/supervision	5	20.8		
Independence	1	4.2		
General administration				
High dependence	2	8.2		
Moderate dependence	5	20.8		
Instruction/supervision	3	12.5		
Independence	14	58.3		
Education: (n = 9)				
Type of centre				
Ordinary	8			
Special	1			
Transport to go to the centre				
Student bus	1			
Car	3			
Public transport	1			
On foot	3			
Does the user need any caregiver during education time?				
Yes	5			
No	4			
Is the student's place adapted? (Yes/No)				
Yes	8			
No	1			
Leisure:				
Are the leisure places accessible for you?				
Yes	5	20.8		
No	19	79.2		
Have you had to modify your leisure activities?				
Yes	21	87.5		
No	3	12.5		
Transport:				
Car:	22	91.7		
Adapted driving	1	4.2		
Adapted access	4	4.2		
Both	1	4.2		
No adaptations	16	66.7		
No use of a car	2	8.3		
Bike:	3	12.5		
Public transport:	19	79.2		
Taxi	7	29.2		
Urban bus	9	37.5		
Train	2	8.3		
Airplane	1	4.2		
No use	5	20.8		
Caregiving and supports				
Support from caregiver:				
Yes (Relative):	21	83.3		

(*continued*)

Table 2

(continued).

Characteristics of sample demographics	N	%	Mean (SD)	Median
Mother	13	54.2		
Father	1	4.2		
Husband	3	13.5		
Wife	2	8.3		
Other relative	1	4.2		
Yes (Formal caregiver)	1	4.2		
No (I do not need a caregiver)	3	12.5		
Use of AT				
Yes (several options are possible):	20	83.3		
Medical treatment	2	8.3		
Training	1	4.2		
Orthoses-prostheses	1	4.2		
Care and protection	16	66.7		
Mobility	17	70.8		
Housekeeping	1	4.2		
Communication	2	8.3		
Handling	1	4.2		
Recreation	1	4.2		
No	4	16.7		
Home – Physical context:				
Previous home arrangements:				
Yes	18	75		
No	6	25		
Presence of barriers at home (Yes):	21	87.5		
Access	8	33.3		
Main entrance	10	41.7		
Corridors	13	54.2		
Communication between floors	4	16.7		
Kitchen	4	16.7		
Living/dining room	2	8.3		
Bedroom	4	16.7		
Bathroom	18	75		

AT = assistive technologies, FIM = functional independence measure, SMA = spinal muscular atrophy.

level of significance obtained ($P < .001$) indicates that there indeed is a significant difference between the types of ambulation (non-ambulators and functional ambulators) with respect to results from the FIM motor score. That is to say, people who still maintain ambulation reported a higher score for total FIM and, therefore, have a higher level of independence.

Finally, we performed different comparative analyses to determine possible significant differences between FIM results. The items evaluated and the associated results of this analysis are shown in Table 3.

Instrumental ADL: The specific questionnaire included different questions about performance in these tasks. As shown in Table 2, the participants' levels of independence in performing home management activities were quite low in general. Users need more help or support from the caregiver in activities with high physical demands, such as cooking or washing. On the other hand, tasks referring to general administration, such as paying bills, administering family finances, or making phone calls, are easier to perform for participants with NMD. Most of these patients (58.3%) have complete independence in performing these tasks.

Features related to education and/or work: Nine participants were studying when they were assessed. Participation at ordinary schools was the more frequent situation for the majority of them (n = 8). In this group, 62.5% (n = 5) needed personal assistance during learning activities, and in 88.9% their place of study was adapted. Regarding work-related activities, only 1 person was working during the development of this project. In this case, the work conditions consisted of full-time employment. Usually, this person went to the workplace by wheelchair, except during inclement weather (eg, in the presence of rain or strong wind), in which case she used a taxi. Few adjustments were made to her workplace before applying the interview in this research.

Leisure and social participation: Leisure activities were also recorded, because they are part of participation and community life and thus constitute an important area of performance. In this respect, several response options about the main activities of leisure were possible. The 3 most common leisure activities were using a computer,[21] reading,[19] and going out with friends.[18] In addition, participants were asked about the activities that they would like to do but could not perform due to their condition or the presence of barriers in the environment. The 3 desired activities mentioned with the highest frequency were playing sports,[22] traveling,[20] and going out or walking more.[20] The majority (87.5%) indicated that they had to modify their leisure activities due to their disease, and 20.8% said that the places to engage in leisure activities were not properly adapted with respect to mobility in the community. The obtained data are shown in Table 2.

Table 3

Results from bivariatal analysis from FIM, according to obtained means.

	Total FIM[*] Mean (SD)	Motor FIM[†] Mean (SD)	Cognitive FIM[‡] Mean (SD)
Age range:	$P=.840$	$P=.946$	$P=.288$
0–18 [13]	93 (19)	58 (19)	34.67 (1,61)
19–50 [3]	94 (16)	59 (16)	35 (0)
More than 50 yr [8]	102 (16)	69 (13)	33.12 (5, 3)
Level of ambulation	$P<.001$	$P<.001$	$P=.655$
Ambulants [12]	107 (12)	73 (10)	33.58 (4, 3)
Non-ambulants [12]	86 (15)	50 (15)	34.17 (1, 6)
Use of AT for personal mobility:	$P<.005$	$P<.001$	$P=.664$
Yes [17]	91 (15)	55 (16)	34.41 (1,4)
No [7]	110 (15)	77 (9)	32.57 (5,6)
Diagnosis group:	$P=.215$	$P=.108$	$P=.155$
Dystrophies [15]	93 (18)	57 (18)	34.67 (1,3)
Others [9]	101 (16)	69 (13)	32.56 (4,9)
Barriers at home	$P=.122$	$P=.145$	$P=.680$
Yes [21]	99 (15)	64 (16)	33.95 (3,3)
No [3]	79 (25)	46 (23)	33.33 (2,9)
Adjustments Before	$P=.331$	$P=.160$	$P=1.000$
Yes [19]	99 (15)	65 (14)	33.84 (3,5)
No [5]	87 (23)	49 (23)	34 (2,24)
Caregiver	$P=.122$	$P=.122$	$P=.561$
Yes [21]	112 (3)	77 (3)	35 (0)
No [3]	94 (17)	59 (17)	33,7 (3,4)

FIM=functional independence measure, SD=standard deviation.

[*] Maximum score in total FIM=126.

[†] Maximum score in motor FIM=91.

[‡] Maximum score in cognitive FIM=35.

Table 4

Influence of different variables on type of ambulation.

	Ambulants (N)	Non-ambulants (N)	*P*-value
Age range:			$P<.05$
0–18[13]	4	9	
19–50[3]	1	2	
More than 50 yr[8]	7	1	
Diagnosis group:			$P<.05$
Dystrophies[15]	5	10	
Others[9]	7	2	
Barriers at home			$P=.64$
Yes[21]	12	0	
No[3]	0	3	
Adjustments before			$P=.140$
Yes[19]	11	8	
No[5]	1	4	
Caregiver			$P=.546$
Yes[21]	10	11	
No[3]	2	1	
Use of AT			$P<.005$
Yes[20]	8	12	
No[4]	4	0	
Use of AT for mobility			$P<.001$
Yes[17]	5	12	
No[7]	7	0	

AT=assistive technologies.

3.3. Caregiving and assistive technology

In order to know the physical and personal support needed by participants, we analyzed environmental and social factors (Table 2). Only 3 participants did not need the help of a caregiver (eg, a relative or a personal assistant). With respect to the use of AT, the majority of participants in the sample (83.3%) used some device to support ADL. In these cases, the type of AT used most frequently for mobility was a wheelchair ($n=17$). The level of accessibility at home was analyzed using the checklist. It was deficient in almost all participants, and no barriers were found in the home environment in only 3 cases. The bathroom had the worst accessibility characteristics, while the living room was the space with fewer barriers. A large portion (75%) of sample participants made adjustments at home before participating in the present study, but due to prevailing inaccessibility, these were insufficient.

3.4. Ambulatory level and its relationships with other factors

Regarding the level of ambulation, patients were divided into 2 groups: those who had functional ambulation (community and home ambulation) and the others who were non-ambulators (therapeutic ambulation and non-ambulation), according to the Hoffer classification.[22] The main difference between the 2 groups was the level of independence, as shown by the results obtained through the FIM motor scale (Table 3). Importantly, the research group conducted several analyses to determine whether other differences or factors contributed to the findings. To this end, additional characteristics such as age, the type of diagnosis, the presence of barriers at home, the existence of previous environmental adjustments, the help of a caregiver, and/or use of AT were analyzed.

The results from these comparative analyses with respect to the level of ambulation – functional and non-ambulation – are shown in Table 4. They indicated that diagnosis (muscular dystrophy or another NMD) could have an influence on the level of ambulation. For instance, muscular dystrophy diagnosis could negatively affect the ability to walk in an affected person ($P<.05$).

In analyzing the age range, it seems that the disease could more greatly affect a patient's level of ambulation at earlier ages, as participants younger than 18 years of age exhibited nonfunctional ambulation more frequently in comparison with patients older than 50 years of age ($P<.05$). Finally, non-ambulatory participants use some type of AT (for mobility and other activities) more frequently than persons with functional ambulation ($P<.005$).

The following step consisted in the elaboration of a report to provide AT and to recommend home arrangements (products and technologies) and personal assistance (support and relationships). The occupational therapist took into account both the long-term and short-term needs of patients, considering the progressive nature of their disorders. The use of AT was recommended to 22 participants. For 87.5% of the sample, a plan was proposed to adapt their home. The role of the caregiver was also considered for 18 participants. In 15 of them, the level of attention provided by the caregiver increased, while for 50% of the participants, a close relative received counseling about ergonomics and suggestions about how to ideally perform transfers.

4. Discussion

With the progression of muscle weakness, more assistance from devices and caregivers is required for persons with NMD in order to maintain their level of independence in ADL.[8] This study conducted a global analysis of the characteristics associated with occupational performance in persons affected by NMD. In addition, the paper provides a general description of the types of AT and other support resources used by participants, evidencing the need to consider their important contribution from healthcare policies.

4.1. Factors to support independence in persons with NMD

Earlier studies have shown that people with any NMD have seen their independence in ADL reduced, and the majority of problems are caused by muscular weakness.[1,4,7] In this respect, a large number of difficulties in ADL, mainly in mobility, personal care, and transportation, were indicated in the research of Natterlund and Ahlström (2001). In the present study and in previous studies, a wheelchair represents the primary tool to support mobility in persons with some type of progressive, neurodegenerative disease such as NMD.[3,26,27] Rehabilitation for persons with NMD should have as a main goal to maintain their independence for as long as possible[28] and to include recurrent assessments regarding their ability to ambulate and participate in their work and home environments, as well as their need for AT. Therefore, Occupational Therapy plays an important role in the whole process, especially in counseling the affected person and caregiver.

The characteristics of the accessibility of the environment are one of the main conditioners for participation in the sample. An analysis of the profile of leisure activities undertaken by the participants demonstrates a similar pattern across these activities. They are predominantly undertaken inside the home and are routine and passive in nature. In fact, the most desired leisure activities are travel and participation in some sport, showing the difficulty that the participants encounter in public areas due to the presence of barriers. This finding is in agreement with the characteristics of the leisure activities desired by persons with disabilities referred to in previous studies.[29,30]

4.2. The importance of assistive technology and home adjustments as environmental factors

AT can provide persons with NMD with many benefits to functional independence, such as maintaining mobility, continuing or broadening community and social activities, conserving strength and energy, preventing falls, and enhancing their quality of life. The results obtained are difficult to compare with those obtained in other studies due to the lack of published literature on the subject. A relatively low use of devices labeled as "high tech" has been reported, which could be a result of the lack of awareness of the availability of such devices, the lack of information about them, and/or the rather high price of such devices. Therefore, correct assessment and counseling from an occupational therapist is important to meet the real needs of these persons.

In the case of NMD, when ordering any AT device, professionals must anticipate patients' future needs and the progression of the disease. However, this process may be stressful for both users and their families, because planning is itself a reminder of the progressive nature of the disease, and also because there is a natural tendency toward avoidance or denial of disease progression and the increasing complexity.[10] Making adjustments to the user's home is necessary in order for persons with NMD to maintain their independence in their own environment. The home tends to be a refuge for them. Thus, as has been suggested in other studies,[31–33] the absence of accessibility obstructs performing different maneuvers, including the movement of wheelchairs.

These barriers thus become a factor that limits the generalized use of AT within the user's home. In other words, the person has to adapt to the characteristics of the physical environment rather than the other way around. The presence of barriers at home for the majority of participants (N=21) indicates the need to consider these factors during the intervention with this population in order to facilitate their performance and to promote functional independence.

4.3. The importance of a caregiver/personal assistant

The presence of a family caregiver helps people with NMD remain in their home.[34] As reported in this work, other studies have similarly found that a caregiver provides a high level of support that increases as the disease affecting a user also progresses.[4,6]

Support in transferring individuals affected with NMD (ie, moving him/her from 1 place or position to another) is one of the main demands made of the caregiver. Thus, the use of any AT to assist in this task (eg, a hoist) could help improve and facilitate the tasks of the caregiver. To this end, various authors have determined the importance of monitoring the health of the caregiver with the goal of identifying problems that could have adverse effects on his/her overall well-being or on his/her ability to carry out the necessary tasks.[4,15,34]

In the present study, assessment and interventions for caregivers were performed in order to help them with their tasks and to integrate them actively in the whole process. The presence and integration of the caregiver in performance of ADL, personal mobility, and educational/work activities could have a positive influence on how the patient perceives the effect of AT. Therefore, the intervention process for people with NMD must take into account their family and caregiver, since the wellness and burden perceived by them could have an effect on the dispensing of care and, ultimately, on the quality of life of the patient.

4.4. The role of occupational therapy

One the most important approaches to promoting independence in people with NMD is occupational therapy. The professional assesses and gives advice related to the use of AT and making home modifications, while also proposing different strategies to develop ADL or to attend to caregivers' needs.[2] No guidelines or criteria currently exist for referring patients with NMD to occupational therapy support. As a result, referral practices seem arbitrary and show considerable variation. Moreover, there are no controlled clinical trials of occupational therapy in people with NMD.[2] The role of the occupational therapist is important for providing the best counseling and training regarding support that could have a positive effect on functional independence in people with NMD and, thus, on their quality of life and the well-being of caregivers.

Finally, knowledge of the user's perspective on his/her autonomy and the support that he/she needs is of fundamental importance for designing efficient and useful rehabilitation programs for persons with NMD. By obtaining information directly from patients, an occupational therapist will acquire firsthand knowledge about independence, performance, and the needs of users. These suggestions may help both patients and professionals make informed decisions during the AT device selection process, as well as during the counseling and follow-up stages.

4.5. Limitations of the study and future research

This research was limited by the small number of subjects. This may limit its statistical power, despite nonparametric testing. Nevertheless, the study provides firsthand information on the needs for support resources and the selection preferences in patients with NMD related to their occupational performance. An additional limitation is the lack of established psychometric properties for the specific questionnaire used in this study. This could hinder its application by other researchers. Moreover, there are certain variables that were not controlled or measured but that may act as confounding factors in the assessment of occupational performance. Examples of these factors include possible changes in the attitude or mood of the user, economic considerations, social resources, and the level of emotional support received. Another factor to consider is that this paper describes the characteristics and the recommendations about support resources, so the next step will be to determine the real effectiveness of this intervention after the follow-up phase. Taking into account the individual nature of occupational performance, making generalizations about the occupations of population is certainly difficult.

The need to expand the research on this topic is evident, which could be focused on examining the impact of these support resources in the lives of people with NMD through a longitudinal study, as well as their final influence on functional independence and occupational performance. Moreover, the incorporation of standards of outcome measures and the assessment of constructs related to quality of life would allow clinical professionals to better evaluate and prescribe AT for this population. This, in turn, could lead to better matching of persons and technology, contributing to increased efficiency and quality in social-health systems.

5. Conclusions

This study was conducted to offer an objective and general perspective on occupational performance, the profile of people with NMD, and the different kinds of support that can ideally promote their independence. Throughout this work, it was shown that an occupational therapist obtains an occupational profile about a patient, including his/her needs and priorities, and with this information, the professional can provide the best resources to help increase independence in the performance of areas of occupation.

(1) The type of ambulation of participants is influenced by factors such as age, diagnosis, and use of AT.
(2) AT and other kinds of support incorporated into a user's daily life will help him/her reach his/her objectives and expectations and would also help establish the social and personal benefits derived from the use of such support.
(3) The prescription and provision of these devices must be based on a complete evaluation of the person's needs, considering expectations and priorities and providing complete training.
(4) The heterogeneity of sample is a demonstration of that variability condition.
(5) It is vital not only to consider the support provided to the caregiver as a facilitating environmental factor, but also to take into account the caregiver's needs in the planning of rehabilitation programs in order to improve her/his wellness and the quality of care.

Author contributions

Conceptualization: Thais Pousada García.
Data curation: Laura Nieto-Riveiro.
Formal analysis: Thais Pousada García, Betania Groba, Laura Nieto-Riveiro.
Investigation: Thais Pousada García.
Methodology: Thais Pousada García, Betania Groba.
Visualization: Javier Pereira.
Writing – original draft: Thais Pousada García, Betania Groba, Laura Nieto-Riveiro.
Writing – review and editing: Javier Pereira.
Thais Pousada García orcid: 0000-0003-3356-0429.

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