Discontinuation or abandonment of mobility assistive technology among people with neurological conditions

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Introduction. Among other limitations, people with neurological conditions often experience problems with functional mobility. One of the intervention strategies employed to mitigate or compensate this limitation is the use of mobility assistive technology such as manual and electric wheelchairs, walkers, canes, crutches, etc. Although assistive technology is a commonly used intervention strategy among disabled people, the use of this technology is sometimes discontinued or abandoned due to a failure to meet the user's needs or a lack of training, among other reasons.

Patients and methods. The sample used in this study comprises 80 users of mobility assistive technology, 14 of whom have abandoned or discontinued their use of Assistive Technology. The study variables include the Psychosocial Impact of Assistive Devices Scale for outcome measurement, as well as specific sociodemographic variables relating to the sample and the assistive device used.

Results. Significant values were obtained in the three subscales of the Psychosocial Impact of Assistive Devices Scale. 50% of abandonments of assistive technology occurred among people diagnosed with stroke.

Conclusion. The Psychosocial Impact of Assistive Devices Scale can be a useful tool for assessing potential abandonment or non-use of Assistive Technology. More longitudinal studies are required to avoid this limitation on the use of assistive technology.

Key words. Abandonment. Assistive technology. Mobility. Neurological conditions. PIADS. Outcomes.

Introduction

The International Classification of Functioning, Disability and Health (henceforth, ICF) [1] includes mobility as a subcategory within the Activities and Participation component, covering aspects such as: changing and maintaining body position; carrying, moving and handling objects; walking and moving (including moving around using equipment) and moving around using transportation [1,2]. Impaired mobility can limit the execution and performance of daily living activities [2]; for many users, loss of mobility is the most significant loss of activity [3]. Therefore, one intervention strategy used to mitigate or compensate performance difficulties is the use of assistive technology (henceforth AT) to promote functional independence [4] and improve quality of life [5]. The use of mobility AT improves areas such as social interaction and overall health [6], while some types of mobility AT increase participation in activities among people with reduced mobility [2].

Within the heterogeneous group of people with neurological conditions and limited mobility, there are several pathologies that frequently give rise to mobility issues, such as neuromuscular diseases [7-9], acquired brain injury (ABI), stroke with severe hemiparesis and spasticity [10-12], neurodegenerative diseases such as multiple sclerosis [13] and amyotrophic lateral sclerosis [14]. A variety of assistive devices are prescribed for people with neurological conditions and limited mobility: electric wheelchairs [15-17], manual wheelchairs [18], canes and crutches [19], walkers, and other AT such as exoskeletons [20] and foot-ups [21]. Although AT is a common intervention strategy used with disabled people, it has a series of limitations including abandonment or discontinuation of its use [22]. Factors leading to the abandonment or discontinuation of use of AT can include: a) personal and psychosocial factors: loss of functional capacity in the user; acceptance of the disability [23]; gender [24]; age [25], including age at diagnosis [7,23] and perceived well-being [26]; b) contextual factors: loss of control over the occupational performance (5); social stigma associated with its use [23]; context of use of the AT [27] and the influence of different contexts upon its use [28], and c) factors relating to professional inter-

vention, policies and services: failure among suppliers to consider users' opinions or difficulty obtaining AT [29]; increased cost of care [30,31].

In this context, several models have emerged to minimise abandonment and non-use of AT. These include the ATOMS project model [22], which classifies possible factors influencing the abandonment or non-use of assistive devices into five categories: three containing negative factors relating to the person, the AT itself and the context; one containing positive factors and an others category covering neutral factors. No consensus has yet been reached in the literature as to the rate or proportion of abandonment, although most studies put the figure at around 30% [32]. The Psychosocial Impact of Assistive Devices Scale (PIADS) [33] is particularly useful and has been used in previous studies on AT, including specific mobility assistive devices such as wheelchairs (electric and manual) for patients with neuromuscular diseases [34] or specific pathologies such as multiple sclerosis [35] and different types of mobility AT for people with neurological conditions [36]. It has also proved capable of predicting retention and abandonment of AT [30].

Table I. Description of study variables by group.

Variable	Abandoning group		Non-abandoning group	
	n	%	*n*	%
Gender				
Male	8	57.1	36	54.5
Female	6	42.9	30	45.5
Education				
No education	-	-	2	3
Primary level	1	7.1	24	36.4
Secondary level	4	28.6	21	31.8
Higher education	9	64.3	19	28.8
Place of residence				
CDisability care home	-	-	9	13.6
Residential centre	-	-	7	10.6
Own home	14	100	50	75.8
Diagnosis				
BI	7	50	33	50
Neurodegenerative	3	21.4	18	27.3
Neuromuscular	3	21.4	7	10.6
Other	1	7.1	8	12.1

Objective

Therefore, the aim of this study was to identify possible sociodemographic variables relating to AT and influencing its abandonment or discontinuation, as well as to determine whether the PIADS and its subscales can be used as a tool to assess potential abandonment or discontinuation of AT.

Patients and methods

Sample

The sample comprises 80 participants: 82.5% (*n* = 66) continue to use AT and 17.5% (*n* = 14) have abandoned it. The sample was made up of 55% men and 45% women, with an average age of 59.44 years (16.6). With regard to education, 31.3% of the sample had completed primary education only, 31.3% had completed secondary level and 35% had graduated from university. All of the participants resided in urban areas, with 50% in Asturias, 7.6% in Andalusia, 26.6% in Castile and Leon and 15.1% in the rest of Spain.

The majority of the abandoning group had been diagnosed with stroke (50%), followed by neurodegenerative diseases and neuromuscular diseases (21,4%). Table I shows information about the sample for each study group. The average age of the abandoning group was 62 years old –standar deviation (SD) = 15.73–, while it stood at 58.8 years old (SD = 16.88) for the non-abandoning group. The diagnosis variable in this analysis is grouped, although the results of a differentiated analysis of the abandoning group by diagnosis revealed that the majority of abandonments occurred among people who had suffered ABI (*n* = 7; 50%).

A range of sociodemographic variables were included, such as gender, age, education, type of diagnosis, place of residence, time since diagnosis, degree of disability, degree of dependence and duration of use of AT, degree of disability (mode = 74.44%, *SD* = 14.95), degree of dependence (mode = 2), duration of use (years) (mode = 3.07) and time since diagnosis (days) (mode = 113).

Procedure

To avoid measurement errors, the data collection process was carried out by professional occupational therapists and figures on abandonment were gathered in two phases: an initial data collection phase

followed by a subsequent phase six months later, in which participants were asked about their ongoing use of AT. In six cases, it was not possible to complete the second phase for reasons unrelated to the study; in one case, the participant had passed away.

The following inclusion criteria were used to select the final sample: diagnosed with a known neurological disease; Minimental State Examination over 27; aged 18 years or over; owning or using a mobility assistive device for personal mobility. All participants provided written informed consent before being enrolled on the study. Data provided by participants were treated confidentially in compliance with the relevant legislation.

Instruments

The PIADS scale is a 26-item self-report survey which assesses the functional independence, well-being and quality of life linked to the use of assistive technology, which was adapted into Spanish by Quinteiro (2011) [37]. The scores in the PIADS are divided into three subscales: a) competency, which reflects perceptions of functional capacity, independence and performance; b) adaptability, which reflects inclination or motivation to participate socially and take risks, and c) self-esteem, which reflects confidence, self-esteem and emotional well-being. The PIADS scale requires respondents to assess how a specific assistive device affects their lives and makes them feel. In order to do this, they must respond to all items using a 7-point scale which extends from –3 (it has reduced) to +3 (it has increased). The middle point, zero, would indicate that no impact or change has been perceived to result from the use of the device.

Results

For the sociodemographic variables, the homogeneity of the variances was analysed using Levene's test and the Kolmogorov–Smirnov test for normality analysis. The result of the test confirmed that none of the items on the PIADS [33] or on the three subscales were significant, showing that the variables in the study groups have normal distribution and homogeneous variances, which allows parametric analyses to be performed.

In other words, these variables sociodemographic factors that can help to determine the profiles of the study groups. Significant relationships have been obtained in the chi-square independence statistic between the sociodemographic variables, use of AT and PIADS: city of residence; place of residence (urban or rural); type of building (for example, floor, house or chalet); level of studies; diagnosis; treatments received (occupational therapy, physiotherapy, speech therapy, psychological, neuropsychology and alternative therapies); AT (trekking, 4-point cane; foot-up; walker; manual wheelchair, electric wheelchair, crutch); family support, support from friends and caregivers; and PIADS variables (except those described above). An analysis of the type of diagnosis among users who discontinue their use of AT in terms of funding sources produced the following results: a) co-funded 14.24% (n = 2); b) funded by non-profit organisations 50% (n = 7) and c) self-funded 35.71% (n = 5). People diagnosed with stroke accounted for a total of 50% (n = 7) of those who abandoned/discontinued their use of AT, neurodegenerative illness 21.4% (n = 3); neuromuscular illness 21.4% (n = 3), other diagnosis 7.1% (n = 1). The most relevant results for these variables among the group that abandoned AT were: the time of use is mainly one or two years (64.3%), being the prescription of the AT by the rehabilitation doctor (28.6%) and the occupational therapist (21.4%), 71.4% have not received training and only 14.3% have been financed by social security. In summary, the people who abandoned the assistive technology were 14, 21.4% trekking canes (n = 3), 28.6% (n = 4) manual wheelchair, 21.4 % electric wheelchair (n = 3) and 28.6 % crutch (n = 4).

The PIADS was used to analyse the variables relating to the impact of assistive devices on users, encompassing the full scale and the three subscales: competency, self-esteem and adaptability. One group of variables was analysed, although in the preliminary comparative analyses, neither the Mann-Whitney U test nor the Kolmogorov-Smirnov test produced significant results, showing no differences between the group that abandoned AT and the group that did not. An initial analysis of the variables influencing abandonment was carried out by performing a one-factor ANOVA on all the study variables, as well as the full PIADS and its three subscales, allowing us to identify the variables relating to abandonment (Table II).

In order to fulfil the second objective, the possible differences between the study groups and the PIADS components were analysed using Student's t-test for independent samples. The Mann–Whitney U test was also used to analyse the sociodemographic variables due to their qualitative, ordinal nature.

Finally, in order to identify the profiles of each sample, an independence analysis of the χ^2 test

variables was carried out between abandonment and the study variables. With regard to the PIADS, the items that do not influence abandonment of AT are: confusion, efficacy, frustration, sense of power, ability to adapt to daily activities, and the full PIADS scale. However, the other items of the PIADS, AT and sociodemographic variables obtained significant values ($p < 0.05$) and were shown to influence the abandonment of AT. It is relevant to note that the non-abandoning group had higher average values in PIADS items. The quantitative variables that displayed a correlation with the abandonment factor were analysed using Student's *t*-test for comparing averages in independent samples (Tabla III).

The qualitative variables were analysed using the Mann–Whitney *U* test for comparing averages in independent (non-parametric) samples. In this test, education obtained a value of $p = 0.009$; this difference was particularly apparent in the abandoning group due to the high proportion of university graduates (68.3%).

Meanwhile, place of residence has a value of $p = 0.042$, because 100% of the abandoning group were living in their own homes. The remaining variables did not obtain significant values.

Subsequently, using the statistical of independence of the variables (χ^2), all variables are analyzed to establish their relationship with abandonment. The result obtained shows that they are the same variables that show significant differences in the Student's *t* comparison analysis. The variables that obtained significant results are independent and are not related to abandonment (Table III).

Finally, it is worth highlighting the ANOVA analysis of the PIADS variables, using dropout as an analysis factor, which shows a significant relationship in all the PIADS subscales (subscale competence: 10.564 $p = 0{,}002$; self-esteem 13.701 $p = 0.000$ and adaptability 16.773 $p = 0.001$), in other words, the scores of the subscales can be indicators to take into account in the abandonment behavior.

In order to establish profiles of abandonment and non-abandonment, it is important to note that five non-significant variables allowed the results to be adjusted: confusion, efficacy, frustration, sense of power and ability to adapt to daily activities (Table III).

Table II. Variables that obtained levels $p < 0.05$ in the one-factor ANOVA analysis.

	F	*p*
Sociodemographic		
Education	5.237	0.025
Place of residence	4.162	0.045
PIADS		
Competence	6.546	0.012
Happiness	16.25	0.027
Independence	7.177	0.009
Adequacy	4.843	0.031
Self-esteem	12.019	0.001
Productivity	18.698	0
Security	8.036	0.006
Usefulness	23.287	0.003
Self-confidence	14.919	0
Expertise	6.521	0.013
Skillfulness	8.899	0.004
Wellbeing	13.861	0
Capability	12.71	0.001
Quality of life	6.632	0.012
Performance	4.513	0.037
Sense of control	8.922	0.004
Embarrassment	4.997	0.028
Willingness to take chances	6.059	0.013
Ability to participate	11.823	0.001
Eagerness to try new things	11.378	0.001
Ability to take advantage of opportunities	5.991	0.017

PIADS: *Psychosocial Impact of Assistive Devices.*

Discussion and conclusions

AT plays an essential role in people with limited mobility. AT allows maintaining independence, improving quality of life as well as occupational performance [38]. The majority of existing studies report an abandonment rate of 30% following delivery of the AT [28-30], while others observe a rate of up to 80% [39]. However, this study established an abandonment rate of 17.5%, echoing other studies that identified a rate of 12% [40] or 12.61% to 24.26% [41]. Moreover, in this study the use rate was 82.5%; this is similar to the rate reported by Phillips et al [29], which ranged from 51 to 89.6% [42].

One interesting conclusion emerging from previous studies was that the non-use of AT is not always indicative of a problem [43]. In this study, 50% of AT was abandoned by users with stroke. This abandonment may be explained by the fact that, following rehabilitation, the mobility attained is maintained from 2-15 months following discharge. Other studies conclude that following a year of re-

Table III. Values for the variables that obtained significant differences in Student's *t*-test.

	t	gl	Sig.< 0.05
Competence	2.558	78	0.012
Happiness	2.254	78	0.027
Independence	2.679	78	0.009
Adequacy	2.201	78	0.031
Self-esteem	3.467	78	0.001
Productivity	4.324	78	0
Security	2.835	78	0.006
Usefulness	3.076	78	0.003
Self-confidence	3.862	78	0
Expertise	2.554	77	0.013
Skillfulness	2.983	77	0.004
Wellbeing	3.723	78	0
Capability	3.565	78	0.001
Quality of life	2.575	76	0.012
Performance	2.124	77	0.037
Sense of control	2.987	78	0.004
Embarrassment	–2.235	78	0.028
Willingness to take chances	2.551	78	0.013
Ability to participate	3.438	78	0.001
Eagerness to try new things	3.373	78	0.001
Ability to take advantage of opportunities	2.448	78	0.017
PIADS subscale: Competence	3.25	78	0.002
PIADS subscale: Self-esteem	3.369	78	0
PIADS subscale: Adaptability	3.533	78	0.001

PIADS: *Psychosocial Impact of Assistive Devices.*

habilitation, the acquired skills are maintained for 3 months after completing treatment. Even in geriatric rehabilitation, improved mobility is observed 10 months after suffering a stroke [44]. In this regard, Lauer, Longeneck and Smith [22] note that abandonment factors may be positive, such as improved function prompting stroke patients to abandon the use of AT. Meanwhile, Philips et al [29] conclude that the easiest AT to acquire is the first to be abandoned whereas this study shows that 50% of abandoned AT was self-funded.

Sociodemographic variables such as age and gender were not significant in this study [23], although previous studies have shown that women obtain greater satisfaction from wheelchairs than men [24]. In this study, gender was not a significant variable, although more men than women had abandoned the use of AT. With regard to the place of residence, an appropriate environment contributes to a greater sense of control, wellbeing and quality of life [45,46], which was a significant variable in this study. As for other variables such as the duration of use of AT or the time since diagnosis, these did not obtain significant values. Previous studies indicate that the PIADS can be less sensitive to change among users who are already expert in the use of AT [47,48]. The degree of disability or dependence also proved to be non-significant; other researchers have also concluded that the degree of dependence does not influence perceived quality of life [49]. Some scholars, such as Scherer (1998), advise that both therapist and user should be present throughout the entire process of assessment, adjustment and adaptation. In this study, variables such as the prescriber of the AT and training in its use were not significant; the latter is considered to be a negative factor relating to abandonment in the model established by Lauer, Longeneck and Smith [22].

Returning to our analysis of the items from the PIADS, all the PIADS subscales and items produced significant values, with the exception of efficacy, confusion, frustration and ability to adapt to daily activities. This indicates that the PIADS may be used as a tool to predict and evaluate abandonment or discontinuation of the use of AT [30]. Moreover, 23 of the items in the PIADS are linked to an ICF category [50]: this shared language suggests that the scale could be used clinically by neurorehabilitation teams, among others [1].

The limitations of the study include a small, non-representative sample and the fact that the results cannot be extrapolated to such a heterogeneous population. Several mobility assistive devices were also sampled. This research could be extended in several ways. In Spain, the literature on abandonment factors is currently limited. These factors are not necessarily negative and may even be positive, as Lauer, Longeneck and Smith [23] have shown in the case of improved function or replacement with a better device. Longitudinal studies are therefore required to ascertain the limitations of different types of AT.

Although mobility AT is necessary to improve quality of life among people with neurological conditions, there is a risk that its use may be abandoned or discontinued. In terms of the perceived impact of the use of AT, the differences between the abandoning and non-abandoning groups were significant as the PIADS test proved to be a tool that is able to provide relevant information in detecting potential abandonment. Twenty-one of the items on the scale reveal significant differences in which the abandoning group obtained lower results, including the re-

sults for the three subscales. Confusion, frustration, efficacy, sense of power and ability to adapt to daily activities do not appear to be differentiating characteristics in the abandonment of assistive devices in either group. The full PIADS scale does not yield significant results for predicting abandonment, but it could be suitable for adoption (or use) by rehabilitation clinics due to its links to the ICF. The ICF offers guidance to professionals and suppliers to assist their decision-making and it can be used to evaluate evidence-based outcome measures.

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Interrupción o abandono en el uso de productos de apoyo para la movilidad en personas con afectación neurológica

Introducción. Las personas con afectación neurológica suelen presentar, entre otras limitaciones, problemas en la movilidad funcional. Por ello, una estrategia de intervención para mitigar o compensar esta limitación es el uso de productos de apoyo para la movilidad, como sillas de ruedas tanto manuales como eléctricas, andadores, bastones, muletas, etc. Aunque los productos de apoyo son una estrategia habitual de intervención en personas con discapacidad, en ocasiones su uso es interrumpido o abandonado por no cubrir las necesidades del usuario o por falta de entrenamiento, entre otras causas.

Pacientes y métodos. La muestra del análisis está formada por 80 usuarios de productos de apoyo para la movilidad, de los cuales 14 abandonaron o interrumpieron el uso del producto de apoyo. Las variables del estudio incluyen la escala *Psychosocial Impact of Assistive Devices Scale* (PIADS) como medida de resultados, además de variables sociodemográficas específicas de la muestra y del producto de apoyo empleado.

Resultados. Se obtienen valores significativos en las tres subescalas de la PIADS. Un 50% de los productos de apoyo abandonados corresponde a personas con diagnóstico de ictus.

Conclusiones. La PIADS puede ser una herramienta adecuada para evaluar el posible abandono o la falta de uso de los productos de apoyo. Aunque los productos de apoyo son una correcta estrategia de intervención para mitigar las limitaciones en la movilidad, algunos usuarios abandonan o interrumpen su uso por diferentes factores. Es necesario realizar más estudios longitudinales para evitar esta limitación en el uso de productos de apoyo.

Palabras clave. Abandono. Condiciones neurológicas. Medidas de resultados. Movilidad. PIADS. Producto de apoyo.