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Care Systems for People with Parkinson's Disease and Their Interaction with Clothing: Case Study in Portugal

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ABSTRACT

Clothing products can be stigmatizing when they do not include the users' needs in their technical-functional and aesthetic characteristics. People with Parkinson's disease may have difficulties and an inability to dress. As a result, they may need assistance from caregivers and professionals to perform the activity. This article investigated how assisting care can help to promote independence in dress/undress activity for people with Parkinson's disease in Portugal. The results indicated that the patient's functional symptoms, the care place, the type of assistance they receive as a stimulus to independence, and the access of products in this system influenced the independence in dress/undress activity. The responsibility and opportunity to discuss non-stigmatizing clothing, that offer viable alternatives to promoting well-being, is important for the discussion about inclusive clothing. Future studies should investigate the usability approach with users to outline relevant guidelines to the inclusive and ergonomics clothing development.

Keywords: Inclusive fashion, Ergonomics design, Usability, Parkinson's disease

INTRODUCTION

Clothing like any other consumer product is an artifact that aggregates history, identity, and individuality (Monteiro, 1999). There are clothing segments for occasions, based on social activities, and segments for needs, based on functional issues. But, in both situations, stylists must project favorable aesthetic-symbolic-functionality in ergonomics products to satisfy the users, evoking good emotions. Linked with fashion design, inclusive clothing products belong to a segment that still carries many stereotypes for producing bad emotions, due to the lack of design attributes. In which the characteristics of inclusive products are still mostly with a basic design, without fashion attributes and this lack of diverse styles can cause stigmatization and exclusion (Molenbroek et al. 2011). Research (Komatsu et al. 2005; Mady et al. 2015; Neves et al. 2018) on inclusive clothing related to the usability of dressing/undressing in elderly daily life has been explored to provide clothing strategies that are more appropriate for the aging process. Once, this activity can be difficult, or even impossible to be performed by those who have motor restrictions (Who 2001; Marteli et al. 2021). Parkinson's disease (PD) affects the mobility and motricity of at least 6.1 million people worldwide (Dorsey et al. 2019), with older people being the most representative of this group. As a result, such disease affects the individuals' interaction in their place/social context (Rahman et al. 2008), and it can result in the dependence of professional caregivers and or family members to perform Activities of Daily Living (ADLs) (Dorsey et al. 2019). Guiding more appropriate clothing to promote independence, can be attributed to occupational therapists who work in the rehabilitation of people with PD. But for this to happen, it is necessary for stylists to allow not only ergonomics functions that facilitate interaction, but also bring satisfaction in an attractive style, respecting cultural differentiation (Molenbroek et al. 2011). It is when the product was expressed as a fashion object, desired by everyone - designed for everyone. Thus, this paper is an excerpt of a doctoral investigation in design, aimed to understand the multidisciplinary cares' actions in people with PD, for promoting independence in clothing usability, especially the perspectives of care and assistance in the interaction with clothes and shoes, from the perspective of caregivers and rehabilitation professionals. Within the results, it can be possible to discuss project demands, through sociocultural parameters about consumption, identity, difficulties and needs, regarding dressing activity and clothing manipulation (Neves et al. 2018). This investigation started with caregivers and professionals, it was possible to understand the different profiles of people with PD and possible scenarios for future studies to be carried out directly with users. The paper presents the results of the research developed in Portugal, between September 2020 and September 2021.

METHODS

Participants

Through a Research Survey based on Google Forms, the reach of 33 participants was obtained. We had to exclude 12 participants, for not presenting clear answers and/or content with contribution to the theme. After that, for the participants who accepted to be contacted for the interview, an appointment by phone call or by virtual platforms was made, being the conversation deepened based on the answers previously provided. The results presented should not be generalized, but understood as broad problems identified on care experiences reports. The characterization of the sampling was given by: 9.5% Informal Caregiver, 38.1% Formal Caregiver, and 52.3% Rehabilitation Professionals, being 85.7% female and 14.3% male. Characterized by being: 33.3% occupational therapist, 33.33% health assistance, 23.8%

nurse, 4.7% psychomotrician, 4.7% physiotherapist, and 9.5% also working as professor. Having experience in 38.1% LTCFs, 33.3% at home, 28.6% in clinics and 28.6% in hospital. Taking care of: 9.5% family members, 4.7% friends; 14.3% until 5 patients, 19% until 10 patients, 28.6% until 30 patients, 14.3% until 50 patients and 14.3% not specified. The time of care experience was 19% less than one year, 4.7% in 1-2 years, 19% in 3-5 years, 9.5% in 6-10 years, 19% in 11-20 years, and 28.6% more than 20 years.

Procedures

The methodological procedures were based on a descriptive and exploratory approach, which was approved by a Research Ethics Committee (UNESP-Brazil, number 40707620.4.0000.5663). An Informed Consent Form was present in the Survey, as questions about the participants' characterization and general information about care and assistance experiences. Preliminary results about the assistance and rehabilitation in PD and the Assistive Devices (ADs) used for dressing/undressing were already previously published (Marteli et al. 2022). To understand the relationship with the products, questions about the activity involving ADs uses and about the experiences related to dressing/undressing clothes and shoes were included in the Survey. All the entire description of the procedures and analysis (which was based on the process of coding responses by the Atlas.ti software) were previously published in Marteli et al. (2022). The coding has been done and the percentage of responses was shown.

RESULTS AND DISCUSSION

Procedures Perception About the Clothing Usability

Through the participants' experience of caring for people with PD, all reported assisting in the treatment of those who had difficulties and/or incapacities in the usability of dressing. The abilities that involve dressing/undressing were an indicator of functional independence (Rahman et al. 2008). It means that people who have difficulty or inability to dress are subject to dependence on care and assistance for interaction with this activity. Also, participants mentioned that patients need help in part or all phases of dressing activity. Moreover, 28.5% reported that there are cases in which people could not perform it, being dependent. These conditions lead patients to search for rehabilitation services (Prados Fernández et al. 2022). Rehabilitation allows the relearning of the activity and with that a positive interaction involving clothing and its different forms of use. For the participants, not only aspects related to the disease can make it difficult to perform the tasks, as all the types of products can interfere in the independence. These factors are connected and interfere with clothing usability. Participants associated the difficulties and limitations in the product's interaction with the symptoms caused by PD, and the literature (Rahman et al. 2008) also indicates this fact. The results showed that 33.3% of participants reported that motor symptoms influenced usability and were reported in both upper limbs (shoulders, arms, hands, and fingers) (Neves et al. 2018), lower limbs (legs and feet), and trunk (neck, chest, and abdomen). Furthermore, Prados Fernández et al. (2022) investigated 196 patients with PD and described that 53% of the sample had trunk impairment due to involuntary movements during the dressing - but the authors did not present the characteristics and the kind of the evaluated products, which makes it difficult for the subject discussion with the results. In addition, 14.3% of participants mentioned the difficulty of short and rigid movements. These movements are essential, for example, for manipulating a t-shirt that has no open/close fastenings. 38.1% cited difficulties in performing fine movements and 23.8% in gripping, which are essential movements to hold generally small parts of the products. 19% of the participants already reported hand tremor, an involuntary movement that is characteristic of PD. The participants also cited the relationship of loss of spatial perception of the body, in which 19% of the participants pointed out as a frequent cause in some patients they assist. This loss of spatial perception can be linked to the non-motor symptoms, like the fear of performing the activity, pointed out by 9.5% of the sample, for fearing and predicting the risk of falls (Bloem et al. 2001).

Relation of Care in Difficulties of the Dressing Activity

In ADLs, the care and assistance universe may cause a dependence occurrence on support and/or “substitution”. Some professionals explain that this substitution was common even if the people with PD were still able to perform some movement of the dressing activity, they preferred that a caregiver does it. Among the factors listed by the participants, fear of falls, as mentioned above, can influence dependence and the care environment, which requires different care logistics. The care service provided in homes and rehabilitation clinics is more focused on the individuality and needs of each patient. In institutional spaces such as Long-term Care Facilities (LTCFs) and hospitals, all participants who had experiences in working there reported that the individual stimulus needed more time for assistance. The demand for care did not allow to encourage patients to do, train and/or relearn the activity to minimize the effects of functional losses. Gil (2020), during qualitative research in Portugal, reported a relation between a few professionals for LTCFs different scenarios and great care demands. According to the author, this lack of personalized care can cause “harmful consequences” in quality of care and, consequently, the patients’ quality of life. Still, the author discusses that such basic care becomes mechanized and not individualized for patients. In this sense, in the logistics of care, the activity is faster being performed by the professional than by the patient. The professional ends up not having the necessary time for adequate assistance/training. Regardless of the place the patient is in the activity involving clothing, dressing/undressing, putting on and taking off shoes, a participants’ difficulty in facing clinical evaluations and reports from their patients, especially regarding: buttoning, tying, pulling, pressing, and putting, was identified by 80.9%. Through the discussions generated during the interviews, the participants gave examples of activities involving the products and difficulties experienced by the patients. Buttoning, an activity reported as a difficulty by Mady et al. (2015) and

Marteli et al. (2021), especially shirt buttons, was discussed by the participants that fine motor skill is needed to perform the holding movement and put the button in the opening. For tying pants or shoes with laces, manual coordination and torso control are required for flexibility and stability. The participants mentioned other activities that can also be difficult for the patients, such as putting the feet in shoes, head in the t-shirt collar, and arms and legs in parts and openings of the garment. These are the main causes that lead patients and/or family members to search for rehabilitation assistance. However, in the rehabilitation sections, it was reported that there are some patients who, during the process, are not interested in relearning the activity, having a significant loss of independence. The disinterest was reported as influenced by feelings of frustration (57.1%), impatience (23.8%), lack of motivation (23.8%), and anxiety (14.3%). Participants commented that this can occur in any disease or condition and the non-motor symptoms influence the performance of ADLs. This disinterest scenario was only possible to be reversed or softened through specialized treatment, adding medication, physical activity, and mainly the acceptance of the new condition. According to reports, it was common for some patients to stop wearing clothes that caused difficulty and replace, for example, social pants and jeans for sweatpants. This fact can mischaracterize the users' individuality and negatively influence self-esteem. This fact can happen when they do not identify themselves with that product and use it because they have no other option easier and attractive. 28.5% of the participants mention that most of their patients were concerned with appearance and being well dressed, with clothes whose segment was part of their style and identity.

Appearance, Disease and Clothing x Problematic Relationship

People increasingly seek to take care of their appearance, which is related to the attributes that clothing can offer. Some clothing, when aesthetically pleasing to users, can improve self-esteem, as these products represent an extension of the body itself (Monteiro, 1999). About this, a participant reported that: "There is low self-esteem at the beginning [when the patients start rehabilitation], but after sessions, they return to having this concern and desire to care themself. But as the disease progresses, they end up not caring about all the clothing, they want to feel comfort and independence more than anything, so it is common to see them in social shirts and sweatpants, for example (Report 1)". It was mentioned that rehabilitation supports physical recovery and self-esteem. But, over time, the comfort prioritization and independence in dressing cause acceptance of an "unusual garment" or fashion trend. The products' design can also interfere with self-esteem and the mode to use them. To understand these perspectives, the participants answered about the type of clothing segments their patients could wear or would like to wear on ADLs. Four clothing segments used in everyday life were mentioned: 90.5% sportswear, 42.3% casualwear, 33.3% classic/social wear, and 14.3% sleepwear. But casual wear and classic/social were styles more cited by participants because they would like to use them more, but with difficulties, they tend not to wear them. Despite the casual and classic/social styles being the dearest segment to patients, professionals usually advise the patients to use sportswear in rehabilitation activities, as its characteristics (fabric and molding) allows for a better expansion of movements. With this targeted use, patients ended up incorporating the clothes into other daily activities. Mainly because this segment has characteristics that can make dressing/undressing easier. About sportswear, it is known that there is an acceptance and preference of use in other ADLs, mainly by younger age groups, as observed by Houser (2016). This phenomenon is seen in current fashion and was emphasized by one of the participants: "Some patients did not like the 'new' style [sportswear], referring to the grandchildren as users of this style, mainly because they are accustomed to a specific 'dress code' used throughout their lives. So, they do not identify with this style, as it is not their liking. But they do not always manifest themselves, as the guarantee of their autonomy is far from being obtained. These clothes are easier for caregivers to put on and take off" (Report 2). Even not liking very much to wear it, 54.4% of the participants pointed out that they perceive the use of the sportswear style as a new consumption habit - as an option for practicality (42.8%) and comfort (14.3%). This is because it is not linked to the sportive function, but the characteristics of the product that make the act of dressing easier. Other situations were reported, like the clothing adaptation and the non-acceptance of changes. Regarding the clothing adaptation, it was noticed that it is not common to make repairs and modifications, as this can be an expensive service compared to the purchase of a new one. However, 33.3% of the participants still report that their patients adapt their clothing and 14.3% cite the use of Velcro as a replacement fastener. About this, a participant said: "When there is an adaptation, it is even possible to improve the incapacity and frustration feelings. When they do, it is very interesting the change of perspective [regarding ease of use]" (Report 3). The non-acceptance of changes related to new ways of using their clothing and sportswear were also pointed as factors that favored dressing dependence.

CONCLUSION

The results showed the experience of 21 participants who rehabilitated and assisted in ADLs people with PD regarding clothing usability and dressing/undressing activities. This usability was pointed to as a difficulty, being a marker of independence. So, the products need to be functional and stylish to make users feel comfortable. About the clothing products, it was found that the models that were easy to manipulate were usually sportswear models, and users did not like to wear them. Its use was mainly linked to the practicality of possible independence, which was no guarantee that will result in a good performance. External aspects also as pointed as influence the clothing usability were scored, as the patients' functional status, the care environment, the kind of assistance they receive as a stimulus to independence, and the product access in this system. There is a demand for changes in the clothing sector to promote inclusive products development. This development must be based on ergonomic principles, including as many users as possible, and components such as style and identity, like modular clothing that appears as a technical alternative to the possibility of transforming, replacing, and customizing parts of the product. About this subject, it is not possible to generalize about "clothing for people with PD", but this topic can be used as part of the discussion to cover many other groups of people with movement difficulties in the dressing/undressing activities. Thus, future studies should attend to these needs, creating conditions to introduce inclusive products that promote the well-being of users. With this, it is expected that the investigation of the theme will be extended to users, addressing such factors to identify how clothing design can improve aspects of usability of products. The limitation of this study was the sample size because in the period investigated, Portugal was in lockdown due to the Covid-19 pandemic.

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