


Occupational performance in Huntington's disease: A cross-sectional study

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Abstract

Introduction: Huntington's disease (HD) is an autosomal dominant neurodegenerative disorder characterized by motor dysfunction, cognitive impairment, and psychiatric disorders. These symptoms cause functional limitations in occupational performance. This study aimed to describe the difficulties in self-care, productivity, and leisure activities and to analyze the patients' own perception and satisfaction and the association with sex, age, disability, HD severity, and quality of life.

Method: We conducted an observational, retrospective study in 38 patients with HD without cognitive impairment at the Burgos University Hospital. We assessed occupational performance, quality of life, and HD severity with the Canadian Occupational Performance Measure, Short-Form Health Survey 12, Unified Huntington's Disease Rating Scale, Total Functional Capacity, and the Problems Behavior Assessment.

Results: One hundred sixty-five occupations (median 4, range 2–7) were categorized as self-care (50.90%), leisure (30.30%), and productivity (18.79%). Patients reported a higher degree of satisfaction with the activities prioritized than with the degree of performance. Elderly HD patients reported more satisfaction in leisure and women in self-care. Self-ratings of satisfaction in productivity were associated with higher levels of mental wellbeing.

Conclusions: HD patients have problems with their daily life occupations, particularly with self-care. This underlines the need for assessment tools that capture the complexity of occupations.

Keywords

Activities of daily living, rehabilitation, patient-centered care, occupational therapy, self-concept

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Introduction

Huntington's disease (HD) is an autosomal dominant neurodegenerative disorder that usually appears in adulthood. HD is caused by a mutation in the *HTT* located on chromosome four, where an abnormal repetition of the cytosine–adenine–guanine (CAG) nucleotide is produced. HD is characterized by motor dysfunction, predominantly chorea, cognitive impairment, and psychiatric disturbances such as anxiety or depression (Kumar et al., 2020). HD symptoms produce functional limitations and difficulties in performing activities of daily living (ADL). It is relevant to know the priorities of patients with manifest HD to identify the problems that they have in their daily lives. This will allow occupational therapists to implement a patient-centered practice and serve as a basis to set goals and priorities in the intervention (Law et al., 2004; Vyslysel et al., 2021).

People suffering from neurological conditions endure situations in their daily lives that cause severe disability and

restrict participation in meaningful activities (Cuesta-García and Alegre-Ayala, 2022; Josman et al., 2020). Occupational performance is a holistic and integrated way of life that a person defines as valuable and relevant, so occupational performance is achieved through active participation in carrying out routines, roles, tasks, and subtasks in his/her own integration of self-care, leisure, and productivity (Blain and Townsend, 1993; Nott et al., 2021).

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The active participation of patients with manifest HD is a key aspect of the quality of rehabilitation processes, facilitating clinical decision-making and allowing monitoring of functional progress (Enemark et al., 2018). Occupational therapists believe that engaging in meaningful occupations helps people maintain and organize a daily routine and consequently achieve greater wellbeing and improve their health and quality of life (Boop et al., 2020; Hammell, 2004; Johanson et al., 2017).

The Canadian Occupational Performance Measure (COPM) is one of the most used assessment tools in occupational therapy and rehabilitation to capture a patient's self-perception of occupational performance (Caire et al., 2022; Law et al., 1990). It is an individualized measure designed to identify individual difficulties in the performance of ADL (Kielhofner, 2006), which shows good sensitivity for determining clinically significant improvements and changes after interventions in the total self-rated performance of patients (Doig et al., 2010). This measure has been validated in various clinical settings with different populations, and it has been translated into 35 languages supporting the validity of the COPM as a measure of occupational performance (Berardi et al., 2019; Ohno et al., 2021; Thyer et al., 2018; Tuntland et al., 2016).

Several studies reported that the COPM is also used as an outcome measure in different pathologies such as Fibromyalgia Syndrome (Pérez-de-Heredia-Torres et al., 2016), Multiple Sclerosis (Pérez-de-Heredia-Torres et al., 2020), or Parkinson's disease (PD; Kobayashi et al., 2022). Nevertheless, few investigations have explored the everyday experiences of patients with HD, addressing their satisfaction level and occupational performance. It should be crucial to identify the factors that may support or restrict their performance in tasks and activities using the COPM. Therefore, this study aimed to describe which occupations HD patients perceived as difficult to perform, which occupational area the activities were related to (self-care, productivity, and leisure), and then to describe the priority or importance that the activity has in the life of the patient, the self-assessment of their current performance in the activity, and the self-evaluation of their satisfaction with their current performance. In addition, we evaluated the relationship between occupational performance and age, sex, quality of life, cognitive states, psychiatric symptoms, and mobility.

Method

Design

We conducted an observational, retrospective study including patients with HD from the Neurology Department of the Burgos University Hospital.

Ethics

This study was approved by the Research Ethics Committee of the University Hospital of Burgos and Soria. All the

procedures were conducted in accordance with Good Clinical Practice standards (European Medicines Agency, 2002) and following the ethical principles established in the Declaration of Helsinki (Helsinki Declaration, 2013). Participants gave their written consent and were assigned a study code to anonymize their data. Information and data were stored in a secure folder in a secure location dedicated to this study. (Certificate number: CEIM-2535, May 25th, 2021).

Participants

A total of 38 patients with manifest HD were included in this study. The participants were ambulatory patients with a clinically confirmed genetic diagnostic of HD (>36 CAG repeats in the HTT gene). We excluded patients with significant cognitive impairment with a mini-mental state examination (MMSE) score <23, with significant comorbidity according to the investigator's judgment (sensory deficit, sequelae, and/or neurological diseases, that is, stroke, head injuries, epilepsy, and other systemic pathologies such as cancer or cardiovascular pathology) that could interfere with their occupational performance.

Procedure

The study procedure was the same for all participants: they were informed of the study protocol; they accepted the informed consent, and they were familiarized with the interviewer before the onset of the data collection. This study was conducted during one single visit to the Neurology Department of the Burgos University Hospital. We used semi-structured questionnaires to collect sociodemographic data and their main occupations.

Assessments

Canadian Occupational Performance Measure (COPM): the COPM is a semi-structured, patient-centered, easy-to-administer, and change-sensitive interview that helps people to identify those tasks that present difficulties in their occupational performance. It is designed to detect changes in the patient's self-perception of their occupational performance over time, both in the way it is carried out the activity and in their degree of satisfaction (Gaudet, 2002; Law et al., 2014). This measure shows a satisfactory test-retest reliability with different neurological diseases such as stroke (0.88–0.89) (Yang et al., 2017). When using the COPM, the first thing to do is to ask the patients to describe those activities that they are expected or want to carry out, or those they need to do, in which their execution they have difficulties in their daily lives. Then, patients are asked about three areas that are also subdivided into these subgroups: *self-care* is subdivided into personal care (dressing, taking a shower, shaving, etc.), functional mobility (moving from one place to another), and community management (transportation, shopping, finances,

etc.). The area *productivity* is subdivided into paid/unpaid work (volunteering, finding/keeping a job, etc.), household management (cooking, cleaning the house, etc.), and play/school (homework, play skills, etc.), and finally, the area of *leisure* is subdivided into quiet recreation (listening to music, watching TV, reading books, newspapers, or magazines, knitting, sewing, etc.), active recreation (playing sports, taking care of a pet, going to the movies, having meals outside of the home, going to the park, etc.), and socialization (phone calls, visiting, parties correspondence, etc.). After that, the patient is asked to score from 1 (not important) to 10 (very important) the activities mentioned above, according to the priority or importance that each activity has in his/her life. According to this, the occupational therapist shows the patient the five activities to which he/she has given the most importance, and then, the therapist asks him/her to score in a scale from 1 (I cannot do it at all) to 10 (I can do it very well) his/her performance. The patient is also asked to score his/her degree of satisfaction, from 1 (I am not at all satisfied) to 10 (I am very satisfied) (Law et al., 1990).

Short-Form Health Survey 12 (SF-12): SF-12 is a shortened form of the SF-36, which measures the quality of life and assesses the degree of wellbeing and functional capacity using 12 items. It is a questionnaire administered by the researcher or self-administered. This assessment has very good test-retest reliability (ICC=0.78) (Cheak-Zamora et al., 2009).

Mini-Mental State Examination (MMSE): the MMSE is a brief test to examine orientation, immediate and short-term memory, attention, calculation, language, and praxis using 11 simple questions grouped into seven domains. The maximum score is 30 points, with a cutoff for cognitive impairment of an MMSE score <24 (Ringkøbing et al., 2020). We used this scale to screen cognitive impairment of the patients.

Unified Huntington's Disease Rating Scale (UHDRS) total motor subscore (TMS): the TMS is a measure of the UHDRS, which assesses Total Motor Score function with 31 items using a 5-point ordinal scale ranging from 0 to 4, meaning the highest score inability to perform the motor task. Total scores range from 0 to 124, with higher scores indicating the greatest motor impairment. This measure shows excellent reliability for TMS (ICC=0.94; Youssov et al., 2013).

Total Functional Capacity (TFC): the TFC is a standardized scale that assesses current functional status in five functional areas: occupation, finances, domestic chores, ADL, and care level. Each item score can range from 0 to 2–3, being 0=unable and 3=normal. Total score ranges from 0 to 13, with greater scores indicating higher functioning (Beglinger et al., 2010). This scale shows a high degree of internal consistency (Marder et al., 2000).

Problems Behavior Assessment (PBA): the PBA is a semi-structured interview that measures behavioral problems that patients have had in the last 4 weeks. They rate the severity and the frequency of behavioral abnormalities using the scores 0 (absent), 1 (questionable), 2 (mild), 3 (moderate),

and 4 (severe) (Kingma et al., 2008). It shows good internal validity, intra-rater and inter-rater reliability, and strong correlations with other psychopathological rating scales (Ruiz-Idiago et al., 2017).

Statistical analysis

The prioritized occupations were categorized for each COPM subcategory. The mean \pm SD and median (25th–75th percentile) were calculated from the patients' scores concerning the importance, performance, and satisfaction with the occupations. We used nonparametric tests due to our data were not normally distributed.

The Mann–Whitney *U*-test was used to evaluate differences in the total number of reported occupations and the degree of performance and satisfaction in each of the three COPM occupational areas: (i) men and women, (ii) young and old individuals (below or above the median age of 62 years), (iii) cognitive state, (iv) quality of life, (v) mobility, and (vi) function. Finally, Spearman's correlation test was used to determine the association between age, quality of life, cognitive states, psychiatric symptoms, years of education, and mobility with satisfaction and perceived performance. To categorize the level of Spearman's correlation coefficient (*r*), we adopted the following scores: $r < 0.40$ corresponded to low correlation, $r = 0.40–0.75$ corresponded to moderate correlation, and $r > 0.75$ corresponded to high correlation (Fleiss et al., 1999). Statistical significant value was considered with a two-tailed *p*-value <5%. All statistical analyses were performed with IBM-SPSS version 28.

Results

Thirty-eight patients with manifest HD with a mean age of 58.63 ± 11.43 years participated in the study, being men 60.5%. The time since onset of symptoms was 9.38 ± 4.96 years with a mean \pm SD TFC score of 8.34 ± 3.26 , 81.58% of the patients were unemployed, and 78.9% were married (Table 1).

Number and ratings of reported occupations

Of the 38 patients with HD who participated in the study, 11 patients (28.9%) identified with no problems during their daily activities.

The participants reported 165 problems in their everyday occupations in all the main areas and subareas. The most frequently experienced problems were related to the main area of self-care (50.91%), followed by leisure (30.30%) and productivity (18.79%). Each participant rated an average of four problems, being the subcategories of personal care (36.36%), household management (18.78%), and quiet recreation, the activities in which patients had more difficulties in their performance (15.75%; Table 2).

Table 1. Sociodemographic and clinical characteristics.

Characteristics	Total HD sample = 38
Sex (%)	
Men	23 (60.5)
Women	15 (39.5)
Age (years), mean (SD)	58.63 ± 11.43
Median (range)	62 (33–75)
Main occupation (%)	
Employed	18.42
Unemployed	81.58
Marital status (%)	
Married	30 (78.9)
Partnership	1 (2.6)
Single	5 (13.2)
Divorced	2 (5.3)
MMSE, mean (SD)	25.89 (5.94)
TMS, mean (SD)	34.11 (19.98)
SF-12, mean (SD)	
Physical component	47.46 (9.14)
Mental component	49.64 (12.52)
TFC, mean (SD)	8.34 (3.26)

SD: standard deviation; MMSE: mini-mental state examination; TMS: total motor score; SF-12: Short-Form Health Survey 12; TFC: total functional capacity.

A total of 104 occupational problems were prioritized and rated as important to change by the patients, and they rated their performance and satisfaction of them. The results showed that the participants consequently rated their satisfaction with occupational performance lower than their performance in these occupations. The lowest performance average was in the subarea of functional mobility, and the highest was in quiet recreation. For satisfaction, the lowest mean rate was in the subareas of socialization and household management (Table 3).

Description of reported occupations within the COPM occupational areas and subareas

Difficulties in ADL measured by the COPM were divided into three main areas: self-care, productivity, and leisure.

Self-care. Self-care includes occupations aimed at getting ready for the day and getting around. It is subdivided into personal care, functional mobility, and community management.

Personal care. The subarea personal care refers to activities such as dressing, taking a shower, shaving, and feeding. It is the subarea in which patients have more difficulties in their day-to-day activities. Participants reported that the majority of their problems were related to the ADL of dressing, in particular, they found difficulties in tying shoelaces and shirt buttons. Other problems mentioned were fastening the

bra and putting on the socks. In total, 27% of personal care problems were related to the personal hygiene and grooming, the most mentioned were brushing teeth and shaving. Moreover, they reported problems showering, specifically soaping with a sponge or drying the body with a towel. They also reported difficulty standing for prolonged periods (longer than 10 minutes).

Functional mobility. This subarea is related to the ability to move independently in a variety of environments in order to accomplish functional activities and participate in ADL at work, at home and in the community.

Many patients reported that their biggest problem was making transfers, especially getting in and out of the car and getting in and out of the shower. Some participants also mentioned that they had difficulties both during the stance phase when the body initially makes contact with the ground, and in the swing phase, when the weight-bearing leg swings forward and back down to the ground. They also experienced a decrease in speed and stride length during walking.

Community management. Community management is a subarea that may include driving, grocery shopping, taking public transportation, managing one's finances, and completing community errands.

Participants reported problems managing their household economy and home expenses (keeping track of consumption and expenses). They also experienced problems when shopping at the supermarket; specifically, they mentioned forgetting what to buy, finding it difficult to concentrate on reading a product's label, and choosing what to take.

Productivity. This area is related to an individual's contributions to society through paid and unpaid work. It includes occupations that produce goods or services and provide a sense of belonging to a community. This area is subdivided into paid/unpaid work and household management.

Paid/unpaid work. Only one person of 38 reported having problems in paid work, specifically with stress management and the lack of energy and fatigue. Because of this, they had difficulties getting the job done and carrying out its responsibilities. About 73% of the total sample were of working age, and 25% were employed.

Household management. This subarea includes those activities usually performed by a housekeeper to maintain a home's essential services, including meal planning, shopping, cleaning, etc.

After the subarea of personal care, household management is the second subarea in which participants found more

Table 2. Occupational performance problems per area and subarea.

Area n problems	Subarea n problems	Occupational performance problems	n	
Self-care n = 84	Personal care n = 60	Dressing	29	
		Grooming	16	
		Showering	9	
		Feeding	5	
		Toileting	1	
	Functional mobility n = 17	Transferring	7	
		Walking in general	5	
		Getting into the shower	4	
		Walking on stairs	1	
		Shopping	5	
	Community management n = 7	Banking	2	
		Cooking	10	
	Productivity n = 31	Household management n = 31	Cleaning in general	7
Laying table			5	
Hanging laundry			3	
Doing dishes			3	
Making bed			2	
Put the washing machine			1	
Reading			11	
Watching TV			9	
Writing/drawing/painting/making handicrafts			2	
Using the internet/computer			2	
Leisure n = 50	Quiet recreation n = 26	Listening to music	1	
		Paying cards	1	
		Walking	10	
		Doing sports in general	3	
		Traveling	1	
		Meeting friends	7	
		Start a conversation/communicating with other people	3	
	Active recreation n = 14	Socialization n = 10		

Table 3. The ratings of performance of everyday occupations and satisfaction with the occupational performance.

Areas	Number of prioritized occupations	Performance	Satisfaction with performance
In total	104		
Self-care			
Personal care	35	6.34 ± 1.84	6 (5–8) 6.22 ± 2.93 6 (3.5–9)
Functional mobility	11	4.63 ± 2.23	6 (3–6) 4.27 ± 2.53 5 (2.5–5.5)
Community management	4	6.25 ± 3.34	7 (4.75–8.5) 5.5 ± 3.64 5.5 (2.5–8.5)
Productivity			
Household management	18	5.22 ± 2.15	5 (4–8) 4.06 ± 2.7 3.5 (1.25–6)
Leisure			
Quiet recreation	18	6.39 ± 3.08	7.5 (3.5–9) 5.53 ± 3.22 6 (2.5–8)
Active recreation	11	5.45 ± 2.06	5 (5–6) 4.36 ± 2.38 5 (2–6)
Socialization	7	5.63 ± 2.34	5.5 (4.75–7.25) 4 ± 3.24 3 (1–5.75)

Values of importance, performance, and satisfaction are presented as mean ± SD and median (25th–75th percentile).

difficulties. They reported a total of 31 problems associated with taking care of their homes. The main difficulty for them was cooking meals, in particular, such as holding on vegetables while peeling them, cutting food with the knife, planning meals, and following the recipes.

They also reported having difficulties with cleaning. These included vacuuming, tidying up, and dusting. They mentioned laying the table as problematic for them because objects easily fall out of their hands. The participants experienced difficulties in washing the dishes, and they were not

Table 4. Spearman’s correlation.

COPM	Age	TMS	PBA	SF-12 Physical health	SF-12 Mental health	MMSE	Years of education
Performance							
Self-care	0.122	-0.243	-0.305	0.262	0.156	-0.016	0.169
Productivity	0.061	-0.071	0.050	-0.480	0.033	0.007	0.527
Leisure	0.186	-0.179	-0.219	0.056	0.016	0.118	0.417
Total	0.083	-0.371	-0.311	0.008	0.242	0.090	0.529*
Satisfaction							
Self-care	0.025	0.044	0.001	0.063	-0.070	-0.452*	-0.097
Productivity	0.141	0.118	-0.509	-0.348	0.580*	0.032	0.376
Leisure	0.382	0.205	-0.174	-0.268	0.067	-0.221	0.290
Total	0.162	0.097	-0.294	-0.153	0.094	-0.492*	0.133

COPM: Canadian occupational performance measure; TMS: total motor score; PBA: problems behaviors assessment; SF-12: Short-Form Health Survey 12; MMSE: mini-mental state examination.

* $p < 0.05$.

satisfied with the result of it in relation to their effort. They mentioned that their partner or family member had to rewash the dishes.

Leisure. Patients are asked about their difficulties in performance in the leisure area, which is the last area patients are asked about. It refers to nonobligatory activities that are intrinsically motivated and engaged in during their free time. This area is subdivided into quiet leisure, active leisure, and socialization.

Quiet leisure. Quiet leisure subarea refers to recreation activities that do not involve physical activity, such as reading, painting, listening to music, or playing cards.

After the subarea of household management, quiet leisure is the third subarea in which participants found more difficulties. In particular, they expressed problems when reading a book because of the lack of concentration, the difficulty in remembering what they had just read, and the sense of apathy. These same problems were reported when watching television. They also experienced difficulties while writing, drawing, and using the computer.

Active leisure. Active leisure is the subarea related to all those activities that involve action, such as playing sports, traveling, community outings, etc. Many participants experienced problems performing physical activities, particularly going for a walk, due to the loss of balance and gait instability.

Socialization. The subarea of socialization refers to the involvement of individuals in community spaces and/or in social groups and activities such as visiting friends and family, talking on the phone, going to parties.

The participants reported problems when participating in social contexts. In particular, they mentioned having problems when meeting friends due to a lack of desire and to a

sense of apathy. They also referred to difficulties when they started a conversation or introduced a topic.

Reported occupations and degree of satisfaction and performance in relation to age, sex, quality of life, function, cognitive states, psychiatric symptoms, and mobility.

There was a significant difference between the quality of life and the number of reported occupations in self-care ($p=0.022$)—people with lower scores in the SF-12 reported more difficulties in performing occupations. There was no significant difference between the sexes for the number of reported occupations in relation to self-care, productivity, or leisure. There was no difference in age, cognitive state, the severity of psychiatric symptoms, or mobility.

Nevertheless, there was a significant difference between the age and the degree of satisfaction in leisure ($p=0.023$)—people older than 62 years reported more satisfaction in leisure but no significant differences in self-care and productivity. Concerning sexes, there was a significant difference in the degree of satisfaction in self-care ($p=0.037$)—women reported significantly more satisfaction than men in self-care.

The associations between COPM performance and satisfaction self-ratings with different variables are presented in Table 4. A moderate positive correlation was found between self-ratings of satisfaction in productivity and quality of life (mental health) ($r=0.580, p=0.048$), indicating that higher self-ratings of satisfaction were associated with higher levels of mental wellbeing. Furthermore, the results indicated that satisfaction in self-care correlates in a statistically significant and negative way with the cognitive state ($r=-0.452, p=0.030$), indicating that lower self-ratings of satisfaction in self-care were associated with higher levels of cognitive function. The COPM global satisfaction score was significantly correlated with cognition, indicating that lower self-ratings of satisfaction were associated with higher levels of cognitive function ($r=-0.492, p=0.014$). There was a significant positive correlation between the years of education

and performance, indicating that people with more years of education perceived better performance in their occupations ($r=0.529, p=0.005$).

Discussion

The present study aimed to describe which self-care, productivity, and leisure occupations patients with manifest HD perceive as difficult to perform and the individual's perception of the importance of performance and satisfaction with these occupations. We also investigated the interactions between occupational performance and age, sex, quality of life, cognitive states, psychiatric symptoms, and mobility. Our results revealed that patients with HD experience most of their difficulties in occupations related to the area of self-care, followed by the areas of leisure and productivity.

Nine subgroups were analyzed with the COPM, and among them, the largest amount of difficult occupations was found in the subarea of personal care, confirming previous studies that described the consequences of HD for daily occupations using standardized assessment tools such as the UHDRS TFC (Beglinger et al., 2010). Another study that was also conducted with patients with HD revealed that more than half of the problems mentioned by the patients were related to self-care, confirming our results (Clemens and Achterberg, 2014). At the same time, a guide developed by occupational therapists who worked with patients with HD concluded that one of the most frequent problems of these patients was related to activities that involved manual tasks such as eating, fastening buttons, and writing. This is due to reduced manual dexterity, poor coordination, and reduced grip (Cook et al., 2012). Other studies based on the COPM have also identified self-care as the category, including most occupational difficulties (McColl et al., 2006).

About 30% of the occupational performance problems mentioned by the patients were concerned with leisure, which means when a person does activities that he/she enjoys. This is in line with a review on social withdrawal in HD patients, which showed that patients with HD tend to reduce their leisure activities. In particular, they reduce their participation in social activities outside the home, decide not to socialize anymore, interrupt their work activity, and finally decrease their participation in family activities (Gibson and Springer, 2022).

Similarly, other authors found that social problems, such as going out for social events or complications in family and friendship relations, existed before they were in an advanced stage of the disease (Ho and Hocaoglu, 2011). Difficulties with communication abilities and social impact were also mentioned (Victorson et al., 2014). The study conducted by Cruickshank et al. (2020) reported that patients with HD with a mean of 13 in the TFC assessment (13 points maximum possible) had fewer social contacts and were embedded in fewer social networks than controls.

Regarding productivity, the participants mentioned difficulties in house management, specifically when cooking. Other authors have studied the impact of chorea on productivity, concluding that one of the most common problems experienced by HD patients is difficulties in cooking or preparing meals (Claassen et al., 2021). A study that compared the performance of people with mild PD and HD using a virtual reality tool that simulated a kitchen concluded that all participants had significant difficulties in timely completing tasks in which executive functions were required. These results suggested that patients with HD had higher executive impairment compared with patients with PD (Júlio et al., 2022).

Patients with manifest HD commonly report problems at work, and the unemployment rate has been found in 47.5% of the patients with TFC scores ranging from 11 to 13, and in 99% of HD patients with a TFC score <7 . These results indicated that work abilities are affected within a few years since clinical diagnosis and from the early stages of the disease (Ko et al., 2020).

The participants rated a lower degree of satisfaction with their occupational performance. This dissatisfaction could be due to depression and anxiety, very frequently related to HD (Maltby et al., 2021), and for that, they feel a lack of pleasure when performing occupations, which at the same time could influence their experience of satisfaction. A previous study reported that sadness and depressed mood were early symptoms of HD (Paoli et al., 2017). Depression in HD is associated with motivational anhedonia, and it has been reported in approximately half of gene-positive HD family members (Gubert et al., 2020; Mclauchlan et al., 2022; Paulsen et al., 2001).

The lower satisfaction ratings in their occupational performances revealed the importance of considering a patient's subjective experience when setting rehabilitation goals based on a client-centered occupational therapy context (Townsend and Stanton, 2002). Occupational therapists who follow a client-centered practice believe that it is essential that the patients are involved in their own therapeutic relationship. This practice assumes a holistic view of the human being as a person composed of mind, body, and spirit who decides which tasks he/she would like to improve (Blain and Townsend, 1993; Polatajko et al., 2013). Patients' participation and engagement in everyday occupations are relevant to their quality of life and mental health (Johanson et al., 2017).

Quality of life was associated with the number of occupational problems reported, where patients with lower scores in the SF-12 reported more difficulties in the performance of occupations. These results support evidence of the positive impact that self-perception has on personal self-efficacy and perceived quality of life (Fritz et al., 2018). Self-perception of their illness affects patients' beliefs and consequently their functioning and wellbeing (Kaptein et al., 2007).

Limitations and strengths

A limitation of this study was the small sample size, which limits the possibility of extrapolating these findings to the HD community. On the other hand, our results support that the use of self-assessment tools that identify the underlying factors that impact occupational performance contributes to a multidimensional understanding of the disease. Studies show that self-perception of the problems that patients with HD present in their occupational performance facilitates clinical decision-making, allows functional progress to be monitored, and improves patients' motivation.

Future research efforts should be directed to apply the COPM as an outcome measure to show the efficacy of occupational therapy intervention in patients with HD.

In conclusion, this study shows that patients with manifest HD report a variety of occupations that they perceive as challenging to perform. Using the COPM to identify problems presented by patients with HD enables the design of personalized health care and a patient-centered practice that will positively impact the patient and his/her families.

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Research ethics

Approved by the Research Ethics Committee of the University Hospital of Burgos and Soria. (Certificate number: CEIM-2535, May 25th, 2021).

Consent

Participants gave their written consent and were assigned a study code to anonymize their data.

Patient and public involvement data

During the development, progress, and reporting of the submitted research, Patient and Public Involvement in the research was included in planning and progress of the research.

Declaration of conflicting interests

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Contributorship

LS-V researched literature and conceived the study. LS-V, MS-R, and JR-P involved in data analysis. EC, LA, LS-V, DP, and IM-S contributed to the protocol development, IM-P and NM helped in patient recruitment, and CC-G and AG-B gained ethical approval. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

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