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Patients' and caregivers' perspectives: assessing an intensive rehabilitation programme and outcomes in Huntington's disease

Paola Zinzi · Dario Salmaso · Marina Frontali · Gioia Jacopini

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Abstract

Aim To investigate the subjective evaluation of an intensive rehabilitation programme and outcomes by people with Huntington's disease (HD) and their caregivers.

Subjects and methods A written questionnaire was mailed to people with mild-moderate HD (n=40) who had completed at least one course of the intensive, inpatient rehabilitation protocol carried out at a facility of the Italian National Welfare System in the previous 3 years (on average 8.6 months before). Descriptive and inferential statistics were used. Thematic analyses were also conducted on written texts.

Results The response rate was 93%. A general improvement after discharge was perceived by all of the respondents.

Improvements were reported on gait, balance, motor control, and fall reduction. Duration of benefits was estimated to last from 1 to 3 months by 71% of informants with no carry over to the next admission, which occurred on average 5.7 months later. Ameliorations were also reported in speech and swallowing, and several psychosocial aspects: mood, apathy, familiar and social relationships (binomial test, $p < 0.05$). As far as organisational aspects of structure and programme are concerned, all respondents expressed a positive evaluation (binomial test, $p < 0.05$). The mean vote given to the whole rehabilitation experience by patients on a 10-point scale was 7.3, confirmed by caregivers' mean vote of 7.4. Additional free comments were added by the majority of respondents (n=35). From caregivers' and patient's perspectives, relevant themes emerged.

Conclusion An intensive rehabilitation programme in people with HD is perceived to produce relevant improvements beyond bodily motor and functional performance. Patients' and caregivers' evaluations are relevant in health-care research in order to assess the worth of a programme and to define new ones.

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Keywords Huntington's disease · Rehabilitation · Postal survey · Patient and caregiver perspective · Health-care research

Introduction

Huntington's disease (HD) is a degenerative, neuropsychiatric disease affecting the basal ganglia and widespread areas of the central nervous system. It is due to an aberrant gene, autosomal dominantly transmitted, and clinical features are a triad of emotional, cognitive, and motor disturbances. Symptoms gradually begin on average be-

tween the 3rd and 4th decades of life, though the onset may occur at any time, from childhood to old age.

Pharmacological treatments provide purely symptomatic benefits as the disease is still incurable (Quarrell 1999; Bates et al. 2002). Duration of the disease is about 15–20 years, with a progressive invalidating course. Gross assessment of the severity of the disease can be obtained through the Shoulson Rating Scale subdividing the disease progression into five stages based on patient's functional ability, from autonomous to totally impaired (Shoulson and Fahn 1979; Roseblatt et al. 1999).

Considering that there was some evidence derived from animal models (van Dellen et al. 2000; van Praag et al. 2000) and clinical practice (Binswanger 1980; Peacock 1987; Imbriglio and Peacock 1992) to support rehabilitation for people with HD, we started a pilot study in Italy in order to get a first reference of the effect of rehabilitation therapy on these patients. Participants were mainly recruited among the patients attending the outpatient clinic of the Neurosciences Department at the University Hospital A. Gemelli in Rome. Other patients were self referrals through the Italian HD Lay Association AICH-Roma Onlus website. Forty patients (17 males, 23 females) met the inclusion criteria:

- a definite clinical diagnosis of HD
- age >18 years;
- early to middle stage of disease (Shoulson Stage I–III);
- absence of concurrent severe psychiatric symptoms;
- no severe dementia: Mini Mental State Examination (MMSE) score >20 (Folstein et al 1975).

The patients were enrolled in the study and admitted to the Rehabilitation Home Care Nova Salus at Trasacco, in the Abruzzo region, for a standard 3-week period of intensive treatment, including physical, cognitive, and occupational therapy, respiratory rehabilitation, and speech therapy. The multidisciplinary treatment started for each subject at different time points, on the basis of the most suitable period, and could be repeated up to three times a year. This means that patients had the chance to repeat the treatment after 4 months. Within the time considered in our study, patients experienced a different number of admissions, which was most likely due to the different times of enrollment. All had the opportunity to continue with treatments after the conclusion of the pilot study.

At baseline, patients' medical history and basic information were collected; a clinical examination and full clinical and functional assessment were performed, including MMSE examination.

All patients enrolled were symptomatic and received a clinical diagnosis by an expert neurologist. The diagnosis of HD is based on the presence of typical neurological signs that are otherwise inexplicable and of a clear family history of HD. Imaging (MRI or CT scan) may be performed to

look for degeneration in the basal ganglia and cortex. A genetic test is available to confirm the clinical diagnosis. In our study, participants without a clear family history of the disease had their clinical diagnosis confirmed by genetic testing for the HD mutation.

Clinical variables, such as depression, cognition, and autonomy in daily life activities (ADL), were assessed at the beginning of each admission using widely known standardised tools (Zung 1965; Folstein et al 1975; Mahoney and Barthel 1965). Scales for balance and gait, and functional performance (Tinetti 1986; Reuben and Siu 1990) were administered both at the beginning and at the end of each admission to assess outcomes quantitatively.

In 2007 we published (Zinzi et al 2007) a study showing that each period of treatment resulted in highly significant improvements of motor (+16% on the Tinetti scale) and functional performance (+14% on the physical performance test). No carry over was detected from one admission to the next (occurring on average after 5.7 months), nor was any decline evident in motor, functional, emotional, and cognitive areas in the subsample with the longest analysable experience (11 subjects with 6 consecutive admissions over 2 years).

The success of a programme, however, is not only based on expert professionals' evaluation, but also on patients' personal experience and subjective perception, as rehabilitation is in itself a social interaction process whose outcomes are strongly dependent on patient attitudes and motivations regarding the treatment (Maclean and Pound 2000; Dixon et al. 2007).

Neurologic rehabilitation, in particular, is different from other treatments because it requires the active involvement of the patient and family, essential for the success of a programme. This pilot project was the first experience of rehabilitation for these patients all over the country, and we considered that knowing the way participants and caregivers evaluated, understood, and experienced rehabilitation could help to develop future programmes and improve HD patient management.

With this aim we planned a survey by means of a written questionnaire in order to obtain additional information and to gain deeper knowledge regarding rehabilitation.

Here, we report the evaluation of the programme and outcomes from a personal and family perspective as expressed by participants and caregivers through their answers.

Methods

We used a postal survey, carried out retrospectively, by an ad hoc questionnaire mailed to the people with HD (n=40) who had completed at least one course of the inpatient rehabilitation protocol within the pilot study in the previous 3 years.

The questionnaire was tailored to the rehabilitation experience and included all aspects of treatment and care provided by the professional staff (doctors and therapists as well as home care administrative personnel). It involved the subjective evaluation of the treatment and outcomes as well as the satisfaction with the stay in the inpatient rehabilitation setting.

The questionnaire included items that were structured as dichotomic, multiple choice, or open questions.

The first part covered patients' sociodemographics (gender, age, education, marital status, family size, and place of patient's living), self-referred medical information (age at symptom onset and disease duration), and respondent's characteristics (gender, age, and degree of kinship with the patient).

Subsequent items explored the following areas:

- source of information about the pilot project;
- attitude toward the rehabilitation programme (compliance with the protocol and admissions timing, intentions for the future).

The following items first explored whether a change was noticed after discharge, either positive or negative. Then the patients were asked for an evaluation of the rehabilitation outcomes. A list of possible motor, functional, and psychosocial changes was proposed, including: balance, gait, motor control, (drawn from motor/functional scales), falls, speech, swallowing, mood state, apathy, family relationship, and social relationship.

Further items were:

- evaluation of the duration of improvements (how long the amelioration lasted);
- vote concerning the rehabilitation experience on a 0-10-step scale (by both the patient and caregiver);
- evaluation of the residential structure's organisation, of therapists' professional competence and ability to meet patients' needs, and of social and relational aspects of the residential periods.

Each item gave respondents the opportunity to add any comments or detailed explanation they felt were relevant.

Contents of the items were arranged by the CNR research group on the basis of the scientific literature, of their long-lasting clinical experience on HD, and of informal talks with staff members and patients/families. Before mailing it, we tried the questionnaire in preliminary phone interviews in order to assess if the items were easily understandable and representative of all aspects of the rehabilitation experience. The questionnaire was then posted to all the subjects ($n=40$) who had undergone at least one rehabilitation admission during the 3 years of the study. Respondents were requested to sign an informed consent for the research on a separate

sheet and to fill in the questionnaire anonymously. It was clearly noted that the home care staff would not have access to personal answers in order to help informants feel free to express their evaluations and comments, either positively or negatively, without concern about being judged badly by home-care personnel or being excluded from the programme in the future. The ISTC/CNR Ethical Committee reviewed and approved the project's procedure.

Statistical analysis

Analyses were conducted using the SYSTAT statistical package (Systat 10 2000). Descriptive and inferential statistics (binomial and χ^2 tests) were used when appropriate. The level of significance was set at $P<0.05$. Thematic analyses based on grounded theory were conducted on written texts (Glaser and Strauss 1967).

Results

The response rate to the questionnaire was 93% (37/40)¹ without adopting any particular strategies to maximise it (such as providing return envelopes and stamps).

The socio-demographic and clinical characteristics of the patients enrolled in the study who returned the questionnaire ($n=37$) are reported in Table 1, including function, depression, and cognition scores from baseline clinical assessment.

The average age of the patients was 49.4 years, and 56.8% were female. Mean duration of the disease calculated since the self-reported time of symptom onset was 5.6 years, and all patients were in early to mid stages of disease (Shoulson stage I-III).

Patients' baseline characteristics assessed with standardised tools at the time of enrolment in the study clearly reflected the selection criteria for inclusion in the pilot project. Patients were not clinically depressed (mean score below the critical value of 40 on the Zung scale) or severely demented (MMSE average score 24.9). Mean score in ADL autonomy (Barthel index) was 87.2/100.

Fifty-six percent of patients had a long-term partner, and 83% had one or more children. Almost all the patients lived and were assisted at home (34/37; 91.9%); only one patient was assisted in a chronic facility. Two patients lived at

¹ Three questionnaires were missing for the following reasons: Patient 1 changed caregivers three times, so none was able to answer the questions; patient 2 changed residence with no forwarding address; patient 3 dropped out of the study after one single admission as her relatives felt she had "ameliorated too much", becoming more demanding in terms of attention and social needs. The main caregiver, her sister-in-law, did not fill in the questionnaire or bring her to the rehabilitation home care again.

Table 1 Socio-demographic and clinical characteristics of patients who participated in the survey (N=37/40)

Variable	N	(%)	(Mean $\pm$ SD)
Gender			
Males	16	43.2	
Females	21	56.8	
Education (years, mean $\pm$ SD)			10.2 $\pm$ 3.3
Shoulson stage			
I	11	29.7	
II	11	29.7	
III	15	40.5	
Marital status			
Married/stable partnership	21	56.8	
Single	7	18.9	
Divorced/separated	6	16.2	
Widow	3	8.1	
Children			
Yes	31	83.8	
No	6	16.2	
Patient lives:			
Alone	2	2.7	
Within family	34	91.9	
In chronic home care	1	5.4	
Mean age (in years)			49.4 $\pm$ 11.0
Mean duration of illness (in years)			5.6 $\pm$ 4.0
Mean age of illness onset (in years)			43.2 $\pm$ 10.7
CAG repeats (number)*			45.4 $\pm$ 3.5 (n=31)
Baseline scores on			
ADL/Barthel index			87.2 $\pm$ 18.1
Cognition/MMSE			25.2 $\pm$ 3.2
Depression/Zung scale			33.9 $\pm$ 7.7

*HD is often referred to as a trinucleotide repeat disorder because it results from having 40 or more CAG repeats in the IT15 gene on chromosome 4

Table 2 Socio-demographic characteristics of the respondents to the questionnaire (N=37)

Variable	N	(%)
Patients/caregivers	3/34	8.1/91.9
Gender		
Males	15	40.5
Females	22	59.5
Degree of kinship		
Spouse/partner	14	37.8
Children	8	21.6
Brothers/sisters	4	10.8
Healthy parent	5	13.5
Other relatives	3	8.1
Mean age ($\pm$ SD)	48.4 $\pm$ 13.2	

home alone, and one of them was assisted full time by a professional caregiver in charge of the family member who filled in the questionnaire. Families, the patient included, were mostly composed of two to four people living together (32/37, 86.5%); larger families (more than four people) were only reported in 13.5% of cases.

Table 2 reports the socio-demographic characteristics of the 37 respondents who completed the questionnaire. In three cases, the respondents were the patients themselves, whereas the majority were the main caregivers of the participants in the pilot study. The majority of them were females, and their mean age was 48.4 $\pm$ 13.2. All were family members; no one was a friend, a neighbour, or a professional caregiver.

Families had received information about the rehabilitation project from:

- The research group involved in the pilot study (CNR and the University Hospital A. Gemelli Outpatient Service, Rome): 24 (64.9%);
- The HD Lay Association Aich-Roma Onlus newsletter and website: 7 (18.9%);

- Word of mouth (relatives, friends, or other participants): 3 (8.1%);
- Other medical centre in contact with the research group: 3 (8.1%).

The majority of respondents (30, 81.1%) reported the patients' intention to continue with the rehabilitation programme in the future, as far as possible. Seven respondents, on the contrary, expressed the impossibility of continuing, mainly because of organisational difficulties (the distance of the home care from home or issues related to the disease itself). Regarding compliance with treatment and timing of admissions, 25 patients were described as "enthusiastic to participate in the programme and very compliant" (69.4%), while 6 were described as being "every time in need of being pushed to go to the rehabilitation home, but then compliant with the programme" (16.7%) and 5 as being "ambivalent about staying far from home for the 3-week inpatient programme" (13.9%).

As shown in Table 3, an overall positive effect of the rehabilitative treatment was reported by 100% of respondents. The main physical improvements were reported for body control (93.5%), speech (90.9%), balance (85.7%), swallowing (85.3%), and reduction of falls (73.1%). Relevant ameliorations were also reported for several psychosocial aspects, such as mood (90%), apathy (85.7%), and family (78%) as well social (74.4%) relationships. All frequency distributions were significant with the binomial test ($p < 0.05$).

When asked to evaluate the average carry over of the beneficial effects of the treatment (i.e., how long the amelioration lasted), the majority of respondents (71%) estimated that the benefits lasted from 1 to 3 months (Table 4). In the opinion of 16.1% of respondents, the duration of benefits was shorter (about 1 week after discharge).

Table 4 Duration of the benefits (n=31)

Duration estimated	N	%
More than 1 up to 3 months	14	45.2
About 1 month	8	25.8
About 1 week	5	16.1
Until next admission	2	6.4
Other	2	6.4
Total	31	100

Chi-square (df=4)=16.258, $p=0.003$

One item asked the participants who had completed more than one admission (n=30) to designate, among three sentences synthetically describing the rehabilitation effects, the sentence best expressing their own experience. The answers were distributed as shown in Table 5.

Subjective perceptions of medical treatment outcomes are usually considered to be less relevant than objectively measured outcomes. However, in our survey the perceived improvements in motor and functional performance fit the quantitative outcomes measured through objective clinical scales in the pilot study so that the subjective evaluation of benefits confirms that improvements had short- to medium-term duration (Zinzi et al. 2007). The sentence chosen by most respondents is a further confirmation of no specific carry-over effects.

As far as the organisational aspects of the caring home are concerned (Table 6), all respondents (100%) positively evaluated the inpatient facility, the arrangements of admission periods, and the staff attitude: therapists' professional competence and capacity to positively interact with the patient and the family were widely recognised (94.4% and 97.3%, respectively). Descriptions of the rehabilitation centre as "a second home" in the free comments suggest

Table 3 Perceived improvements after rehabilitation treatment

Improvements reported	Yes		No		Valid responses
	n	%	n	%	
General positive effect	36	100	-	-	36
Gait	28	84.8	5	15.2	33
Balance	30	85.7	5	14.3	35
Falls	19	73.1	7	26.9	26
Motor control	29	93.5	2	6.5	31
Speech	30	90.9	3	9.1	33
Swallowing	29	85.3	5	14.7	34
Mood state	27	90.0	3	10.0	30
Apathy reduction	30	85.7	5	14.3	35
Easing family relationships	26	78.8	7	21.2	33
Improving social relationships	26	74.3	9	25.7	35

All frequencies are statistically significant (binomial test, $p \leq 0.05$)

Table 5 The rehabilitation experience in one sentence by patients with >1 admission (n=29)

Sentence about the rehabilitation effects:	n	%
First admission gave the most striking effects, but also each subsequent admission added some improvements	8	27.6
First admission gave the most striking effects, and the subsequent admissions helped to recover what had been lost during the intermissions	17	58.6
First admission improved just the mood state, whereas the true physical improvements were obtained during the subsequent admissions	1	3.4
Above sentences don't match with our personal experience	3	10.3

Chi-square (df=3)=21.069, $p<0.001$

that it was an environment in which participants felt relaxed and at ease. The patient's view of the hospital stay has already been stressed as a relevant component of patient compliance with medical treatment (Jannsen et al. 2008). Moreover, quite often patients consider the good relationship with the therapist as a proof of the validity of the treatment (Donabedian 2003).

Regarding the social aspects of the experience: 89.2% of respondents reported the establishment of new friendships between patients and also relationships with other families. Sixty-seven percent reported they remained in touch with new friends after discharge during the intermission periods.

On a ten-point scale, participants' mean vote for the whole experience was 7.3 ± 1.9 , which was confirmed by the caregivers who voted 7.4 ± 1.9 (t -test=0.0, $df=72$, NS), describing a common shared positive evaluation.

Table 6 Evaluation of the rehabilitation experience: structure, professional staff, organisational and social aspects

Rehabilitation experience evaluation	Yes		No		Valid Responses
	n	%	n	%	
Structure pleasant and patient-friendly	37	100	-	-	37
Admission well arranged and scheduled	36	100	-	-	36
Kindness of the staff	36	100	-	-	36
Professional competence of the staff	34	94.4	2	5.6	36
Good relationship with patient and family	36	97.3	1	2.7	37
Establishment of new friendships	33	89.2	4	10.8	37
Keeping in touch with new friends either outside home care	25	67.6	12	32.4	37

All frequencies are statistically significant (binomial test, $p\leq 0.05$)

At the end of the questionnaire, the opportunity was given for additional comments, and 35/37 of respondents (95%) expressed their opinions by producing written texts analysed by two of the authors (P.Z. and G.J.) on the basis of grounded theory.

From the free comments of caregivers, relevant quotations were on the following positive effects of the experience: (1) better knowledge of HD; (2) better sense of control in patient management, which resulted in an overall better quality of life; (3) empowerment in the relationship with the neurologist and family doctor; (4) increased hope for the future of their children at risk.

From the patients' perspective, the "supportive" and "patient-centred" approach taken by the medical and therapist staff was deeply appreciated as it helped patients to feel "acknowledged as individuals". Patients' free comments demonstrated: improvement of self-esteem as they felt positively valued and appreciated; a strengthened sense of self-worth because of the personal satisfaction in their own improved cognitive and motor performance; decrease of depression and apathy linked to a strong sense of involvement in the programme, the emerging sense of community, and the establishment of new significant relationships.

Discussion

This survey examines how people with HD and their caregivers perceived and evaluated the inpatient, intensive rehabilitation treatment received within a pilot study carried out at a facility of the National Welfare System in Italy. All the participants felt that their inpatient stay produced improvements. Physical improvements in mobility and function, namely in gait, balance, motor control, fall reduction, speech, and swallowing. Physical improvements also appeared to affect other areas of the participants' lives and produce increased independence and enhanced psychological well-being: patients and caregivers reported amelioration of mood, apathy reduction, and improvements in family and social relationships.

The opportunity to participate in rehabilitation programmes and to maintain ongoing contact with the rehabilitation center was subjectively perceived as positive for their physical and psychosocial status. In connection with the rehabilitation treatments, participants experienced social support. The positive effect of social support connected with rehabilitation programmes has already been stressed in the literature (Nätterlund and Ahlström 1999).

The opportunity to meet other people with the same disease, to receive medical attention and physical training, and the good interactions with therapists were deeply appreciated and were quoted in the free comments as some of the reasons for the improvement in well-being.

Psychosocial well-being is not strictly determined only by illness-related factors, such as the stage of the disease and medical treatment efficacy, but it is largely dependent on psychosocial concomitants of the illness. This is in line with other studies in patients with Parkinson's disease, a similar chronic neurological condition, showing that doctors and patients have different concepts of factors impacting quality of life (Findley 2002). Experts' evaluations and expectations may diverge from those expressed by the people directly involved. This makes patients' and caregivers' perspectives very relevant and gives them a critical role in assessing any kind of health treatment and in the modeling of new ones.

Our findings also show that subjectively perceived success of a treatment outcome is not limited to professionals' opinions: patients' and caregivers' evaluations of rehabilitation programme effects, based on their personal experience, were as realistic as the scientific measures used in the pilot study to assess the treatment results. They correctly perceived the improvements in motor and functional performance as well as the short- to medium-term duration of the benefits. The lack of a significant carry-over effect can be explained in at least two ways: first, the time between admissions is too long, and the beneficial effect of the treatment is lost; second, the treatments are effective, but not to the point of contrasting the degenerative process of the disease. In both cases, shortening the time between admissions should better clarify the problem.

Given the highly positive impact of the improvements on patient and caregiver quality of life, even though partial and temporary, we plan to continue our study, exploring in a subsample of patients if continuing the physical therapy in outpatient service during the intermission periods would allow for a carry over of the beneficial effect. We also plan to study the effect of rehabilitation therapy in outpatient service, three times a week, in order to evaluate the effectiveness of different intensities of treatment in patients never assisted in a residential rehabilitation clinic.

When considering the results of this survey, one shortcoming should be considered: the period of time between the rehabilitation experience and the survey (on average 8.6 months) may have induced a recall bias.

A further limitation is the biased sample of the pilot study excluding patients in more advanced stages of diseases or with concurrent psychiatric symptomatology. Notwithstanding these shortcomings, the results show that various positive outcomes emerged from the rehabilitative process setting.

Future studies may be aimed at exploring the interaction of multiple outcomes with the rehabilitation treatment so as to identify the processes, either psychosocial or physiotherapeutic, that are particularly beneficial for enhancing quality of life of people with HD and their

caregivers. Offering rehabilitative therapies to individuals suffering from chronic neurologic conditions has already rendered promising results, yet this kind of therapy is not routinely provided to individuals with HD (Busse et al. 2008). This may be due to limited knowledge about how to treat these patients or to the incurability of the disease, which leads to a negative attitude of doctors toward the rehabilitation of patients who cannot be "restored to health". Whatever the reason—either the lack of a theoretical framework to guide the selection of rehabilitative treatments or the belief that patients with curable diseases seem more worthy of such economic efforts by welfare systems—our study stresses the multiple beneficial effects of these treatments on patients with HD. We hope it will contribute to outlining the rehabilitative plan that best fits these patients' needs.

Conclusion

Rehabilitative treatments are often underevaluated, but, for patients with illnesses with no cure, a caring approach must be the primary emphasis. Living with a progressive neurological condition, such as HD, represents an extreme emotional challenge. The severity of the motor, cognitive, and affective symptoms and the hereditary aspects of the disease pose a distinct burden on patients, children at risk, and spouses as the whole family has to be considered a "patient" needing care. Because of the wide variety of symptoms, managing people with HD requires a mix of clinical skills. As patients move through life with the disease, their functional abilities change, and so do their inner and social worlds. Medical care alone cannot provide the necessary support. Integrated care, combining pharmacological treatment and rehabilitative interventions, can help to modify the way patients and families cope with the disease. We cannot cure HD yet, but the rehabilitation treatment, helping patients to prevent injury and to preserve dignity, fostering independence and safety, and enhancing quality of life, is a way to achieve the best balance between the patients' expressions of their highest potentials based on residual capacities and the adaptation to the progressive decline of body and mind.

In clinical practice, attention should be given to the psychosocial well-being of HD patients as a goal of care extending beyond the alleviation of medical symptoms or simply prolonging survival. The results of our study suggest that intensive rehabilitation programmes in people with HD are perceived to produce relevant improvements beyond bodily motor and functional performance and that patients' and caregivers' perspectives seem realistic and can play a critical role in assessing the efficacy and the success of any kind of treatment.

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Conflict of interest The authors confirm that there are no relevant associations that might pose a conflict of interest.

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