An evaluation of the Patient Education Program for Huntington's disease at six-month follow-up

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Submitted

Abstract

Objective: Living with Huntington's disease (HD) is often accompanied by many psychosocial challenges. The Patient Education Program for Huntington's disease (PEP-HD) is a standardized psychosocial education program of eight weekly sessions of 90 minutes. Patients and partners received education and self-management training to deal with psychosocial stressors due to HD. The aim of the present study is to assess the effectiveness of the program at six-month follow-up.

Methods: Forty HD patients, 19 premanifest HD gene carriers and 42 partners participated. Self-report questionnaires were used to assess depression and anxiety, psychosocial burden and need for help, quality of life, and coping style before the program, directly after participation and at six-month follow-up. Behavioral, motor and cognitive assessments were also performed.

Results: At six-month follow-up, HD patients experienced significantly less psychosocial burden. The initial short-term effects regarding reduction of behavioral problems and anxiety and improvements of coping in the HD patients, psychosocial burden in the caregivers and the improvement of coping in the premanifest group were no longer significant after six months. The program was evaluated as positive, most participants experienced benefit from participation. Helpful thinking was the coping strategy most often still used after six months. Most participants reported a need for a follow-up session.

Conclusions: Six months after participation in PEP-HD, patients with Huntington's disease still benefit from the program; they experience less psychosocial burden after participation. Short-term effects found in the premanifest carriers and partners were not sustained at six-month follow-up. Some form of follow-up session seems necessary.

Introduction

Huntington's disease (HD) is an autosomal dominant inherited neurodegenerative disorder with mean age of onset in middle age. The disease is characterized by progressive motor, psychiatric and cognitive symptoms.[1] With the discovery of the HD gene, premanifest testing became available. The premanifest stage is the stage before onset of apparent symptoms and signs when people have the knowledge that they will become ill. This may lead to anticipatory stress, anxiety, preoccupation with impending symptoms, suicidal ideation and feelings of hopelessness.[2,3] When symptoms become manifest, patients and caregivers have to deal with the emotional and social impact of progressive motor, psychiatric and cognitive dysfunction.

Many studies have reported beneficial effects of self-management interventions for patients with a chronic disease and/or their (informal) caregivers to help them managing the psychosocial impact of the disease.[4] The need for studies on psychological interventions in HD has been recommended often,[5-9] however no such study for HD has been described. Therefore, a standardized program was adapted from another neurodegenerative disease, namely Parkinson's disease. The Patient Education Program for Parkinson's disease (PEPP) is a fully standardized program.[10-13] Benefits for this program were found regarding PD patients' Qol and caregivers' psychosocial problems and need for help.[14,15] The HD adapted program was named: the Patient Education Program for Huntington's disease (PEP-HD). When evaluating a intervention of relatively short duration in a degenerative disease with accompanying cognitive decline, assessment of effects at long term follow-up is important. Therefore, the aim of the present study is to evaluate the effectiveness of the program in HD at six-month follow-up.

Methods

Participants

HD mutation carriers without manifest (premanifest) symptoms (PM carriers) and with known HD signs (HD patients) attending the outpatient neurological department of the Leiden University Medical Center (LUMC) or the outpatient department for Huntington's disease Nij Friesma Hiem (NFH) in Grou (northern part of the Netherlands), were selected from a database. Inclusion criteria were the following: 1) DNA confirmed diagnosis by expanded trinucleotide (CAG) repeat in the HD (*HTT*) gene; 2) a total functional score (TFC) $\geq$ 5); 3) a Mini Mental State Examination score (MMSE) $\geq$ 23); and 4) no current

psychotic symptoms or severe behavioral problems. Inclusion criteria were carried out by means of documentation in the medical file from the last visit at the hospital. If no recent data (of the previous year) were available, then data were obtained at the initial patient screening. An invitation letter was sent to 106 HD patients and 54 PM carriers to participate in the study with their partner. Participation without partner was possible. In this study, HD caregivers were considered as partners of manifest HD patients; and PM partners as partners of premanifest gene carriers. Patients, who were not able or willing to participate, were considered as non-participants, and participants who stopped during the study or missed more than two sessions were considered as drop-out. The study was approved by the Medical Ethics Committee of both departments and all participants gave their informed consent.

Procedure

A single group pre-post design was used. Groups of four to seven PM carriers or HD patients and groups of their partners subsequently entered the study. Participants received two baseline assessments at the hospital two months before and one week before participation in the PEP-HD. After eight weeks of intervention, they received post-assessment within two weeks afterwards and a six-month follow-up.

Intervention

Patients and partners participated in separate, but parallel groups of 4-7 members. Manifest and premanifest participants also participated in separate groups. The program consists of eight two-weekly sessions of 90 minutes duration: an overview of the PEP-HD program is presented in table 1. The program's content is standardized across groups. The intervention provided to the participants was adapted from the PEPP manual for Parkinson's disease and adjusted for HD.[10,11] The content of the PEPP manual was sustained. Video materials were made HD-specific, with a different focus per group (HD patients/PM carriers/HD caregivers/PM partners). The PEP-HD groups were trained by healthcare professionals who received two days of training to provide the standardized PEP-HD in a identical way.

Table 1 Thematic structure of PEP-HD

	Sessions	Structure	Main focus
1	Information	Introduction	The acquaintance of the participants and an overview of the program
		Active information	The importance of taking an active and central role in the health care system. Advantages of information about HD. Where to find information.
		Exercise	How to ask questions to health care professionals
		Homework	To draft questions for a visit to professionals
		Appetizer	Past experiences with keeping a diary/journal
2	Self-monitoring	Homework discussion	Homework discussion of session 1
		Active information	To learn about self-monitoring techniques, like a diary.
		Exercise	An exercise 'body awareness' focused on breathing and muscular tensions
		Homework	Option 1: Using a diary to record e.g. fluctuations in mood or HD symptoms Option 2: Performing the exercise 'body awareness'.
		Appetizer	Bringing something pleasant to the next session (e.g. an object or experience)
3	Health Promotion	Homework discussion	Homework discussion of session 2
		Active information	To improve wellbeing through pleasant activities
		Exercise	Exploring pleasant activities
		Homework	Performing a new pleasant activity every day
		Appetizer	Observing your own behavior in a stressful situation
4	Stress Management	Homework discussion	Homework discussion of session 3
		Active information	The role of unrealistic and unhelpful thoughts in stressful situations
		Exercise	Option 1: Learning to use alternative ways of thinking Option 2: Performing relaxation exercises to deal with stress
		Homework	Option 1: Trying out alternative ways of thinking Option 2: Relaxation training
		Appetizer	Observing changes of mood and causes of worry
5	Management of anxiety and depression (patients)/ Caregiver's challenge	Homework discussion	Homework discussion of session 4
		Active information	To teach about the difference between normal feelings of anxiety and sadness and when they turn into anxiety disorders or depression/caregiver overload. Second, learning about the role of unrealistic, unhelpful cognitions
		Exercise	Option 1: Positive thoughts Option 2: Maintaining healthy activities Discussion of a video clip of a HD patient/PM carrier/HD caregiver or PM partner telling about coping with the disease
		Homework	Option 1: Thinking of a positive event Option 2: Maintaining healthy activities
		Appetizer	Noticing situations in which you want to express your thoughts and feelings but not being able or having the confidence to do so
6	Social Competence	Homework discussion	Homework discussion of session 5
		Active information	Social skills like ways to communicate are discussed. Option 1: Unhelpful and helpful thoughts in communication Option 2: Ways of communication
		Exercise	Discussion of a video clip addressing communication problems (Patient/carrier group video: communication about having HD/being a HD gene carrier; caregiver/partner group video: communication about behavioral problems like aggression/communication about first symptoms)
		Homework	Option 1: Noting situations in which unhelpful thoughts contribute to a lack of socially competent behavior Option 2: Telling someone that you have HD
		Appetizer	To focus on the informal or formal support they would like to receive
7	Social Support	Homework discussion	Homework discussion of session 6
		Active information	To discuss the importance of and how to obtain social support
		Exercise	Role play/discussion
		Homework	Finding sources of support and asking for support
		Appetizer	Reflecting about the entire education program
8	Evaluation	Homework discussion	Homework discussion of session 7
		Active information	The group goes through the previous sessions and the program is evaluated. Expectations described in the first session and achievements are compared
		Exercise	Writing a postcard for each other and filling in a final evaluation questionnaire

Abbreviations: PEP-HD, Patient Education Program for Huntington's disease; HD, Huntington's disease; PM, premanifest.

Assessment

Demographics were administered. To assess disease signs, the Unified Huntington's Disease Rating Scale (UHDRS)[16] was administered, for a motor, functional (Total Functional Score, TFC) and behavioral score. General cognitive functioning was assessed with the Mini Mental Status Examination (MMSE).[17] Medication was recorded at every measurement. The following self-report questionnaires were administered at the hospital: 1) the Hospital Anxiety and Depression Scale (HADS)[18,19] measuring anxiety and depression. 2) Mental and physical quality of life was measured with the 36-item Short Form health survey questionnaire (SF-36).[20-22] 3) Psychosocial burden (bothered by and need for help) was assessed by an adapted version of the 'Belastungsfragebogen Parkinson kurzversion' (BELA-P-k)[23] with also a HD adpated partner version, the 'Belastungsfragebogen Parkinson Angehörigen kurzversion' (BELA-A-k).[24] Coping strategies were measured with the Utrecht Coping List (UCL).[25,26] At six-month follow-up, participants filled out an evaluation questionnaire.

Statistical analysis

The data were analyzed with the Statistical Package for the Social Sciences (SPSS 16.0). The significance level used was $p \leq 0.05$. Estimated age of symptom onset was calculated according to the equation of Langbehn.[27] The means of scores of measurement 1 and 2 were used as baseline scores to assess the changes from baseline to six-month follow-up. To assess changes in scores, dependent t-tests were performed in manifest patients and caregivers and Wilcoxon Rank tests were used in premanifest carriers and partners. Correlations were calculated for significant change scores with other variables. Results from the evaluation questionnaire were described descriptively.

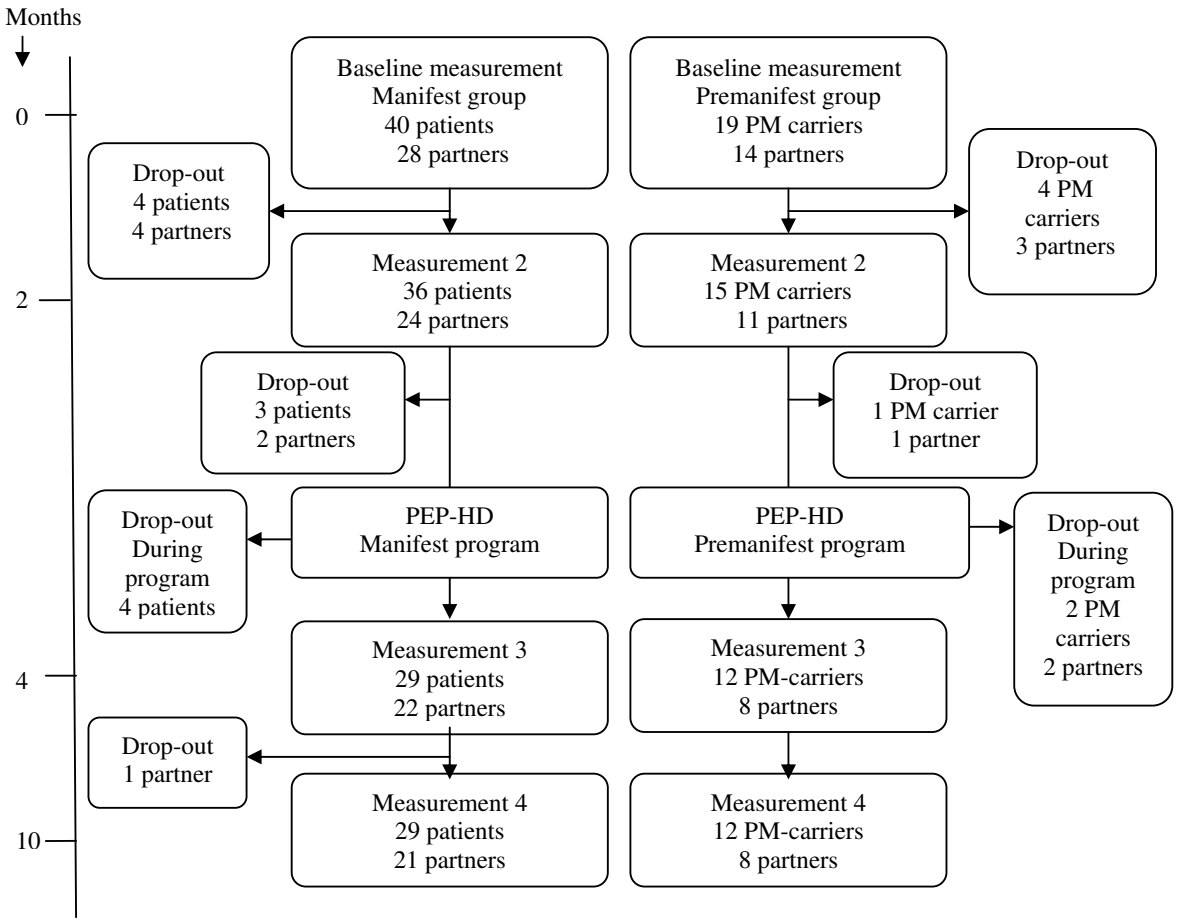
Results

Participants

Of the 106 HD patients and 54 PM carriers who were invited to participate with their partner, eventually, 40 HD patients, 19 PM carriers and 42 partners were interested and willing to participate in the study (Figure 1). The demographics and clinical characteristics of all participants are presented in table 2. Twenty-nine HD patients, 21 caregivers, 12 PM carriers and 8 PM partners completed the six-month follow-up assessment (Figure 1).

The HD patients who dropped out (n = 11) had significantly worse scores on the SF-36-physical measuring quality of life ($p < 0.01$) as compared to completers. No differences were found between participating HD caregivers and drop-outs (n = 7). Premanifest carriers who dropped out (n = 7) had significantly lower UHDRS-motor scores, indicating less motor symptoms ($p = 0.03$) than completers. Premanifest partners (n = 6) who dropped out had significantly higher BELA-A-k-need for help scores, indicating more psychosocial need for help ($p = 0.04$) as compared to completers. Reasons for drop-out during the study were: too burdensome (3 HD couples, 3 HD patients); participation in group not comfortable (1 HD patient and 1 PM carrier); personal circumstances (3 HD and 3 PM couples, 1 PM carrier, 1 PM caregiver); death of patient (1 HD couple); unknown (1 PM couple). Within the group of participants who dropped out (n = 31), 71% of the patients (n = 22) dropped out before start of the program (Figure 1).

Figure 1 Flowchart of subjects during the study with a time line for measurements



Abbreviations: PEP-HD, Patient Education Program for Huntington's disease; PM, premanifest.

Changes in scores at six-month follow-up

When baseline scores were compared with scores from six-month follow-up (Table 3), a significant positive effect for HD patients was found on BELA-P-k-bothered by scores, indicating a reduction of psychosocial burden six months after participation in the program ($p < 0.01$). This effect was not found directly after the program. Less reduction of psychosocial burden (on BELA-bothered by scale scores) was significantly correlated with the following baseline scores: more baseline depression (higher HADS-depression scores) ($p = 0.03$), more baseline psychosocial burden (higher BELA-P-k-bothered by and BELA-P-k-need for help scores) ($p < 0.001$), and more baseline palliative and avoidance coping strategies (higher UCL-palliative ($p = 0.01$) and UCL-avoidance scores ($p = 0.02$)). The effects on UHDRS-behavioral, HADS-anxiety, UCL-seeking social support and UCL-passive reaction, as found directly after the program, were no longer significant after six months. In HD caregivers, the short-term significant effect on BELA-A-k-bothered by (reduction of psychosocial burden) was not retained at six-month follow-up. Effects found in PM carriers and partners regarding increase of scores on UCL-seeking social support directly after participation were no longer significant at six-month follow-up.

Table 2 Demographics and clinical characteristics of all participants

	HD patients n = 40	PM carriers n = 19	HD caregivers n = 28	PM partners n = 14
Women, n	14	13	16	4
Age, years	53.4 (9.0)	41.3 (10.4)	55.6 (9.1)	44.9 (14.1)
Having a partner, n	30	16	28	14
Higher education level, n	16	3	11	7
Employed, n	9	15	14	12
Normal/Increased CAG, range	15-31/40-53[1]	15-25/38-51	-	-
Years since genetic test	7.0 (6.1)	5.7 (5.5)	-	-
Estimated age of onset	48.6 (8.3)	49.5 (13.1)	-	-
UHDRS				
- Motor scale	32.8 (17.0)	4.7 (3.5)*[2]	-	-
- Total Functioning Scale	9.2 (2.5)	12.6 (0.8)*[2]	-	-
- Behavioral scale	10.8 (9.1)	9.6 (9.5)	-	-
MMSE	27.8 (2.0)[2]	27.9 (1.3)	28.6 (1.2)	28.9 (1.4)
Medication use				
- Antidepressants, n	18	0	3	0
- Neuroleptics, n[3]	9	0	0	0
- Benzodiazepines, n	7	0	1	0
- Anti-epileptics, n[4]	2	0	0	0
- Other, n[5]	23	7	15	5
- No medication, n	6	12	11	9

Values are mean (SD) unless otherwise indicated. Abbreviations: HD, Huntington's disease; PM, premanifest; CAG, Cytosine-Adenine-Guanine repeat lengths; UHDRS, Unified Huntington's Disease Rating Scale; MMSE, Mini Mental State Examination.

* Significantly different from HD patients/HD caregivers. 1 In two HD patients, repeat lengths could not be verified, however DNA tests were performed; 2 one missing value; 3 Including Tiapride, primarily given as treatment for motor symptoms; 4 Primarily provided as mood stabilizers; 5 All other medication than psychotropic, like medication for coronary, lung or stomach diseases.

Table 3 Changes in scores from baseline to directly after the program to six-month follow-up

	HD patients		PM carriers		HD caregivers		PM partners	
	Directly after Δ n = 29	6-month-follow-up Δ n = 29	Directly after Δ n = 12	6-month-follow-up Δ n = 12	Directly after Δ n = 22	6-month-follow-up Δ n = 21	Directly after Δ n = 8	6-month-follow-up Δ n = 8
UHDRS-behavioral	-3.4 (8.8)*	-3.5 (10.7)	2.1 (6.7)	-1.6 (7.8)	-	-	-	-
HADS								
Anxiety	-0.8 (2.2)*	-0.9 (2.8)	-0.6 (1.4)	0.2 (2.6)	-0.4 (3.4)	0.4 (2.7)	-1.1 (2.8)	0.3 (4.9)
Depression	-0.6 (2.1)	-0.6 (2.0)	-0.3 (1.2)	0.7 (1.4)	-0.4 (1.9)	0.7 (2.4)	-0.6 (1.8)	-0.1 (2.1)
BELA-P/A-k								
Bothered By	-1.8 (6.3)	-3.7 (6.8)**	1.1 (4.9)	1.2 (5.4)	-1.9 (3.4)*	0.8 (4.7)	-0.1 (0.8)	0.4 (1.5)
Need for Help	0.2 (11.5)	-2.9 (13.2)	1.8 (5.5)	2.5 (8.8)	-2.1 (5.7)	-1.9 (6.5)	-0.1 (0.7)	-0.1 (2.5)
SF-36								
Mental	2.2 (8.0)	3.1 (9.3)	0.4 (3.3)	-2.6 (5.3)	-1.2 (5.8)	-3.6 (8.1)	1.8 (5.8)	0.2 (4.8)
Physical	- 0.4 (4.7)	-0.7 (5.5)	-0.4 (3.7)	0.3 (5.1)	0.7 (6.2)	1.9 (6.6)	1.0 (2.7)	1.8 (4.4)
UCL								
Active	0.5 (2.3)	0.9 (3.7)	0.6 (2.3)	0.6 (2.2)	0.3 (2.3)	-0.7 (3.3)	1.6 (2.2)	1.3 (3.3)
Palliative	0.1(2.8)	0.5 (3.0)	0.2 (2.7)	0.6 (2.1)	0.3 (2.6)	0.1 (2.5)	1.5 (2.8)	1.3 (1.9)
Avoidance	-0.6 (2.5)	-0.6 (2.7)	0.3(2.4)	0.8 (2.4)	0.2 (1.9)	-0.0 (3.3)	-0.3 (1.6)	-0.7 (1.5)
Seeking social support	0.6 (1.6)*	0.1(2.9)	0.9 (1.5)*	0.3 (2.1)	0.4 (2.1)	-0.2 (1.6)	1.9 (1.8)*	1.6 (2.6)
Passive reaction	-0.7 (1.6)*	-0.8 (2.3)	0.2 (1.7)	0.3 (1.3)	-0.2 (0.8)	0.1 (1.7)	-0.8 (1.4)	-0.6 (1.7)
Negative emotion expression	0.1 (1.2)	-0.3 (0.8)	-0.1 (1.1)	-0.1 (0.4)	0.3 (1.8)	0.2 (1.4)	-0.1 (0.5)	-0.4 (0.8)
Comforting cognitions	-0.1 (1.5)	-0.2 (2.3)	0.4 (2.1)	0.4 (2.2)	-0.2 (2.2)	0.0 (1.9)	0.9 (2.5)	0.9 (1.7)

Negative change scores reflect improvement on UHDRS, HADS and BELA-P/A-k, and worsening on SF-36; and less use of the particular coping strategy on UCL. Abbreviations: HD, Huntington's disease; PM, premanifest; UHDRS, Unified Huntington's Disease Rating Scale; HADS, Hospital Anxiety and Depression Scale; BELA-P-k, Belastungsfragebogen Parkinson/Angehörigen kurzversion; SF-36, 36-item Short Form health survey questionnaire; UCL, Utrecht Coping List. * $p \leq 0.05$, ** $p < 0.01$.

Medication changes

The following psychotropic medication changes were recorded in HD patients: end of antidepressant use (n = 1); change of antidepressant (n = 1); decrease of antidepressant dose (n = 2); start of antidepressant use (n = 2); start of benzodiazepine use (n = 2; increase of neuroleptics dose (n = 2). No changes were reported in HD caregivers' medication. In PM carriers: start of antidepressant use (n = 2, of which n = 1 had stopped usage again). Medication changes in PM partners were: start of AD use (n = 1).

Program evaluation

A summary of the results of the evaluation questionnaire is presented in table 4. Most patients reported benefit from participation in the PEP-HD, especially HD patients and their caregivers (83-92%). A positive effect of the program on the relationship was reported in most of the participants. Participants continued using the following coping strategies at six-month follow-up. Helpful thinking (derived from cognitive behavioral-therapy) was the most often used strategy learned in the program and used afterwards. PM

carriers used positive thinking most (67%). Careful planning of pleasant activities was the second most used strategy, especially in HD patients. Keeping a diary to record symptoms or mood was the least often used strategy in all groups (7-11%). About 70% of the HD patients and carriers and about half of the caregivers did report a need for a follow-up meeting.

Table 4 Evaluation of participation at six-month follow-up

	HD patients n = 40	PM carriers n = 19	HD caregivers n = 28	PM partners n = 14
Reporting benefits from participation in program	83%	92%	76%	67%
Program rating, mean*	8	8	8	8
Better dealing with the disease after participation	90%	57%	75%	55%
Positive influence of program on relationship	72%	57%	42%	56%
Need for follow-up meeting	69%	57%	66%	44%
Use of coping strategies since participation				
- Relaxation exercises	28%	24%	50%	44%
- Helpful thinking	41%	52%	67%	56%
- Writing down questions for professionals	39%	14%	42%	11%
- Pleasant activities	59%	48%	25%	22%
- Keeping a diary	7%	10%	8%	11%

Abbreviations: HD, Huntington's disease; PM, premanifest.

* 10 point scale with 0 as the most negative ranking and 10 as the most positive ranking.

Discussion

This study was the first to evaluate a psychosocial education program in Huntington's disease at six-month follow-up; results were compared with effects found directly after the program. Most participants evaluated the program as beneficial six months after participation.

We found an effect for the HD patients: they experienced less psychosocial burden six-months after the program. This effect needed time to appear, as it was not significant yet directly after the program. As most patients reported continued use of the coping strategies learned within the program, this may have reduced the psychosocial burden of the HD patients. Patients especially reported to have continued helpful thinking, a technique derived from the cognitive behavioral-therapy which has been proven to be beneficial for psychological wellbeing[4,28] Also, they reported to have continued careful planning of pleasant activities.

Remarkably, the short-term effects found directly after the program regarding reduced anxiety and reduced behavioral problems in HD patients were no longer significant after six-months. Looking at the difference scores of the HD patients, improvements in scores did not fade away. Change scores often even increased, indicating more improvement. However, larger standard deviations were found at six-month follow-up, indicating more variation in benefit after six months. It can be hypothesized that some patients incorporate the skills learned and improve even more, others are not able to retain or integrate the learned strategies in daily life. We found that more improvement of HD patients' psychosocial burden was related to more depression at baseline, more psychosocial problems and need for help and more palliative and avoidance coping strategies. These correlations with coping styles were not found at short-term assessment. So, especially patients with non-helpful coping strategies at baseline seem to benefit from the program several months after participation. This is in line with results from a meta-analysis on psychosocial interventions in cancer patients, in which it was concluded that the effectiveness of interventions increased when applied to patients with more psychological distress [29]. These patients may benefit most from learning new coping strategies as promoted in the program. However, we do not find significant effects regarding coping strategies at six-month follow-up. More research is needed to explore this finding. Compared to a study in which the program was evaluated at six-month follow-up in Parkinson's disease (PD),[14] a different result was found. In the PD study, the short-term effect on Qol directly after the program did not retain after six-month follow-up. In the present study, no effect was found on Qol. In contrast with the PEPP study in which a PD specific Qol questionnaire was used, we measured Qol in HD with a general Qol questionnaire. Development of a HD specific Qol instrument, also directed at premanifest carriers is important to obtain sensitive outcome measures for intervention studies in HD. The lack of outcome measurements sensitive for PM problems and improvements may have contributed to the lack of results for premanifest participants. Their improvements directly after the program regarding coping did not sustain. The lack of PM specific outcome measures together with the small PM sample are methodological limitations that impede conclusions about effectiveness in premanifest stages. However, important to consider are the positive evaluations of PM participants. They experienced benefit from the program, although somewhat less frequently than manifest participants.

As in the Parkinson's disease study,[14] short term effects regarding HD caregivers' psychosocial burden do not retain six months afterwards. In most studies on self-management interventions, effects tend to disappear at long-term follow-up.[4] In the clinical practice study of Lorig, improvements did sustain at one-year follow-up on various outcomes measures.[30] It is important for future research to find out what factors lead to long-term change. To sustain effects of the PEP-HD longer, a booster session for example after three months may be helpful to rehearse the knowledge and skills provided in the programme. This was also recommended in the PEPP study.[14] About 70% of the HD patients and carriers and about half of the caregivers did report a need for a follow-up meeting. The possible benefits of a booster session need further examination. In education in general, repetition is an important facilitator of learning [31]. Repetition may especially be important in Huntington's disease, because of impaired procedural learning due to the disease.[32]

Some limitations need to be addressed. First, the sample size was small, especially in the premanifest group, causing reduced power. However, this first study was important to evaluate the feasibility of the program in HD. It is important that the next step will be to assess the effectiveness of the program in a large randomized controlled trial. This can only be realized by means of an international multicenter study, as the HD population is relatively small. Even though such a study will have the challenge of language and culture differences. Another consideration for future research is to evaluate the effectiveness after a longer period of time than 6 months, as it is important to find out how long effects will sustain. A control group is important as Qol and psychosocial problems may change with disease progression. At last, drop-out rates were relatively high (drop-out rate of 28%), especially in premanifest HD (drop-out rate of 39%), when compared to our PEPP study [15] with PD participants (drop-out rate of 5%). Most participants (71%) dropped out before the start of the program, they may feel resistance to participate, and possibly they fear the confrontation of meeting other patients and/or talking about HD. High drop-out is a problem in psychological treatment[33] and strategies are needed to motivate patients, carriers an partners for participation, to support them in case of fear for participation.

In conclusion, it was found that six months after participation in PEP-HD, patients with Huntington's disease still benefit from the program; they experience less psychosocial burden after participation. Short-term effects found in the premanifest carriers and

partners, and HD caregivers did not sustain at six-month follow-up. Some form of follow-up session seems necessary.

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