

Quality of life in couples living with Huntington's disease: the role of patients' and partners' illness perceptions

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Received: 13 June 2006 / Accepted: 13 February 2007 / Published online: 21 March 2007
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Abstract Research suggests that chronically ill patients and their partners perceive illness differently, and that these differences have a negative impact on patients' quality of life (QoL). This study assessed whether illness perceptions of patients with Huntington's disease (HD) differ from those of their partners, and examined whether spousal illness perceptions are important for the QoL of the couples ($n = 51$ couples). Partners reported that their HD-patient spouses suffered more symptoms and experienced less control than the patients themselves reported. Illness perceptions of patients and partners correlated significantly with patient QoL. Partners' beliefs in a long duration of the patients' illness and less belief in cure, were associated with patient vitality scores. Suggestions for future research emphasize the importance of qualitative research approaches in combination with cognitive-behavioural approaches.

Keywords Huntington's disease · Illness perceptions · Patient QoL · Partner QoL · Couples

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Quality of life research is increasingly being directed at both the impact of the social environment on the quality of life (QoL) of chronically ill individuals, and at the toll the illness exacts on the QoL of close family members [1]. One of the most influential members of the social network of chronically ill individuals is the spouse. Research conducted in chronically ill individuals and their healthy spouses revealed that the spouses' role problems [2, 3], their unsupportive behaviour [4–6], and the marital relationship itself [7] are some of the factors influencing patients' QoL.

Studies examining adaptation in caregivers have identified negative social support [8], patients' cognitive impairment [9, 10], and the caregivers' overestimation of the patient's functional disabilities [11] as some of the factors influencing the partners' QoL.

Recent findings suggest that patients' QoL is also dependent on beliefs fostered by the social environment regarding the patient's illness. Illness beliefs or illness perceptions can be subdivided into five components: identity (the label the patient places on the illness and the symptoms he/she experiences), cause (the personal ideas patients have about the cause of their illness), timeline (the duration of the illness according to the patient), consequences (the expected effects and outcome of the illness), and cure/control (the curability or controllability of the illness according to the patient) [12]. In the area of physical health problems, illness perceptions have been found to be related to the ways patients react and cope with their illness. A strong illness identity combined with a perceived long duration and perceived more severe consequences of the disease for daily life have been associated with poor physical and psychological well-being. Stronger beliefs regarding the curability or controllability of a disease have been found to have positive effects on patients' QoL [13, 14].

Research shows that illness beliefs of spouses significantly affect patients' beliefs, the coping mechanisms they adopt to deal with their disease, and ultimately their functioning and well-being [15, 16]. Heijmans and colleagues found that dissimilarities between the illness perceptions of chronically ill patients (patients with Addison's disease and patients with Chronic Fatigue Syndrome) and those of their healthy spouses were associated with higher impairments in predicted patients' adaptive outcome [15]. In another study, Figueiras and Weinman explored whether the degree of similarity in patients' and spouses' illness perceptions was related to recovery following myocardial infarction [16].

Few studies have focused on the role of illness perceptions for caregiver outcomes, and none have examined the role of patients' illness perceptions on the QoL of their healthy partners. Barrowclough et al. [17] and Fortune et al. [18] studied illness perceptions in carers of schizophrenia patients. Their findings suggest that carer perceptions about identity, consequences and control may have important implications for carer outcomes in schizophrenia. In this study we will focus on Huntington's disease (HD) which is an inherited neurodegenerative disorder, characterized by clearly defined clinical features such as involuntary movements and hypokinesia, dementia, and personality changes. The first symptoms of HD typically manifest between the ages of 35 and 45, and the disease has a mean duration of 16 years [19, 20]. At present, there is no cure for HD.

Little empirical data has been gathered on the psychosocial aspects of living with HD, but some research findings suggest that HD contributes to marital breakdown [21–23]. One of the most important reasons for this is believed to be the changes HD brings about in the relationship. Spouses of HD patients often consider their partners to be lost [23], particularly when dementia and changes in personality and behaviour develop [22, 24]. In addition, over time the spouse takes on an increasing nursing role, which creates a psychological distance between the patient and his/her spouse [22]. HD greatly impacts the patients' physical and psychosocial well-being [25, 26], and places a heavy burden on families [27–29]. Interestingly, some research has indicated that there is a discrepancy between the aspects of HD the patient finds most disturbing and those the spouse or partner finds most disturbing. Partners are most disturbed by mental and personality changes in the patients [30, 31].

In all studies examining the role of spousal illness perceptions for patient outcomes, researchers have concentrated on the degree of similarity / dissimilarity in patients' and spouses' illness perceptions as a predictor of patient outcome, thereby ignoring alternative possible relationship patterns between spouses' illness beliefs and patient out-

come. Results from Figueiras and Weinman [16] showed that not only similar positive perceptions in couples, but also conflicting representations were predictive of lower levels of disability (as compared to similar negative perceptions). This suggests that it might be more important that at least one member of a couple has positive perceptions. However, the results obtained in the Heijmans et al. [15] study show that better patient adjustment in Addison's Disease is related to spouses' *negative* perceptions about timeline, while better patient adjustment in Chronic Fatigue Syndrome is related to spouses' *positive* perceptions of a short illness duration. From these studies it seems that both contrasting and concordant perceptions in couples can be related to better patient adjustment, and further study is needed to evaluate the extent to which spouses' illness perceptions can influence outcomes which have been found to be related to the patient's own perceptions.

Thus, the first aim of this study was to examine if patients and partners hold similar views about HD. Our second aim was to compare the relationship patterns between patients' and partners' own illness perceptions and QoL. The third aim was to contribute to the understanding of the cognitive factors related to QoL in couples dealing with HD, by examining which spousal illness beliefs are important in both patients' and partners' quality of life.

Method

Sample and procedure

Participants in this study were 51 couples (HD patients and their partners) who were recruited from the outpatient clinic of the Department of Neurology of the Leiden University Medical Centre (LUMC; $n = 14$ couples), and the Dutch Huntington Association ($n = 37$ couples). HD patients from the LUMC were selected if they had received a clinical diagnosis of HD at least 1 year prior to commencement of the study, and if they were capable (mentally, emotionally, and physically) of participating in an interview lasting approximately 2 h. The selected patients ($n = 75$) and their spouses were invited by post to participate. A total of 36 patients and 19 spouses agreed to participate. The main reason for not participating were the verbal communication difficulties that patients were experiencing, and having participated in other research projects before. Non-participants did not differ from participants with respect to age, sex, or duration of HD. HD patients and their spouses recruited from the Dutch Huntington Association were invited to participate by means of a letter sent to all the members of the association ($n = 1,450$). The selection criteria for participation were the same as those applied to the patients selected from the

Department of Neurology of the LUMC. A total of 41 patients and 71 spouses agreed to participate. No information could be gathered on non-participants due to the fact that members of the Dutch Huntington Association are not registered on the basis of their patient status. Members include HD patients and their partners, as well as their family members, friends, and researchers in the field of HD. A total of 51 couples (married or living together) were identified. Patients and their partners were interviewed separately at their homes by a psychologist.

Measures

Demographic variables—HD patients and their partners were asked their age, sex, marital status, the duration of their relationship, number of children, their employment status, and the duration of HD.

Unified Huntington Disease Rating Scale [32]—We used the motor section of the UHDRS to assess HD patients' motor performance. The motor section is composed of 20 items rating ocular motor function, dysarthria, chorea, dystonia, gait, and postural stability. The Total Motor Score (TMS) is the sum of all the individual items, higher scores indicating worse motor performance (maximum score = 124).

Mini-Mental State [33]—We used this scale to assess HD patients' cognitive performance. It comprises 11 items covering a number of cognitive domains including: orientation, registration, attention, memory, language and visuo-constructional abilities. The maximum score is 30, lower scores indicating worse performance. Scores of 20 or less have been associated with dementia, delirium, schizophrenia or affective disorder [33].

The Illness Perception Questionnaire [34]—This questionnaire was used to assess the illness perceptions of HD patients and those of their partners (not yet validated in Dutch). The latter were interviewed by means of a partner-version of the IPQ [35]. The IPQ consists of the following five subscales: "Identity", "Timeline", "Cause", "Consequences", and "Cure/Control". In this study we divided the last subscale into "Cure" and "Control", thus creating a sixth scale. This is in line with current revisions of the IPQ in which these scales are generally separated [36]. The "identity" scale was composed of 24 items, each corresponding to a symptom commonly reported in HD. Patients are asked to rate whether or not they have experienced each symptom since their illness began, and if they believe the symptom to be specifically related to their illness (yes or no). Partners were asked whether or not their partner (the patient) had experienced each symptom since onset of their illness, and to report if they believed the symptom to be specifically related to their partners' illness (yes or no). The

summed yes-rated items on the second questions were divided by the number of items to form the illness identity scale, with higher scores indicating a stronger belief that the experienced symptoms are part of the patient's illness. Cronbach's alpha for patients and partners was 0.88 and 0.82, respectively.

For the remaining scales, patients and their partners were asked to indicate whether they agreed with statements on a five-point scale, ranging from "strongly agree" to "strongly disagree". The "Timeline" scale contained two statements about the perceived duration of the disease, with high scores indicating strong beliefs in a chronic long-term disease. Cronbach's alpha for patients and partners was 0.45 and 0.72, respectively. "Consequences" consisted of five items assessing beliefs about the impact of HD on everyday life. High scores indicate stronger beliefs in serious consequences of the disease. Cronbach's alpha for patients and partners was 0.69 and 0.61, respectively. High scores on the "Cure" scale (two items) indicate strong beliefs in the effectiveness of treatment. Cronbach's alpha for patients and partners was 0.77 and 0.66, respectively. "Control" contained two items pertaining to the degree to which patients and partners believe they have the ability to influence the course of illness. Cronbach's alpha for patients and partners was 0.85 and 0.83, respectively. The weight of all the items per scale were summed, and divided by the number of items, with the exception of those of the "Cause" subscale. Each item in this subscale was considered individually because each causal item represents a specific causal belief.

The Medical Outcome Study 36-item Short Form Health Survey [37]—We assessed the QoL of HD patients, and the QoL of partners by means of seven subscales of the MOS SF-36 ("Physical functioning", "Role functioning-physical", "General health", "Vitality", "Social functioning", "Role functioning-emotional", and "Mental health"). The raw scores are transformed in order to obtain a 0–100 scale, with higher scores indicating a better outcome.

Analysis plan

First, the samples of HD patients and partners from the outpatient clinic and the Dutch Huntington Association involved in this study were compared for demographic and illness related variables (age, sex, marital status, duration of the relationship, number of children, employment status, duration of HD, patients' TMS, and patients' scores on the MMS) by means of *t*-tests. To examine the extent of (dis)agreement that HD patients and their partners held with regard to their beliefs about HD, Pearson correlations and paired sample *t*-tests were computed.

To assess whether spousal illness perceptions are related to patients' and partners' QoL, we conducted hierarchical

regression analyses with scores on the MOS SF-36 as criteria. For patients, illness related variables (disease duration, TMS, and MMS scores) were entered as control variables, prior to the steps containing the patients' and partners' scores on the IPQ (step 2 and 3, respectively). For partners, parallel analyses were conducted, but no control variables were entered. The variables for the regression analyses were selected based on an examination of bivariate correlations between the illness perception dimensions and the QoL scales.

Results

Sample characteristics

Couples recruited from the Department of Neurology of the LUMC did not differ significantly in demographic or illness related variables from couples from the Dutch Huntington Association. Further analyses were thus conducted on the combined data.

In total, 51 HD patients (28 males, 23 females) and their partners (23 males, 28 females) were included in this study. The mean age of both patients and partners was 51 years ($SD = 10$). Forty-seven couples were married and four were living together. The mean duration of the relationship was 25 years (range: 2–48 years), and the mean number of children was 2 (range: 0–6). Eight couples did not have children. Thirty-nine patients (76.5%) were unemployed, of which 28 (54.9%; 19 males, 9 females) stopped working because of HD, whereas 10 (19.6%; 6 males, 4 females) were still working, and 2 (3.9%; males) were retired and receiving pension. Thirty-four partners (66.7%; 19 males, 15 females) were employed, 15 (29.4%) were unemployed (for different reasons including marriage and childbearing; 5 females had never had gainful employment), and 2 (3.9%; males) were retired and receiving a pension. The mean duration of HD was 7 years ($SD = 5$; range: 1–24). Patients' mean Total Motor Score (TMS) was 37.8 ($SD = 29.5$), and their mean score on the MMS was 23.5 ($SD = 3.9$).

Patient-partner differences in illness perceptions

HD patients and their partners did not differ significantly on the "Timeline", "Consequences", "Cure" or "Cause" subscales of the IPQ (see Table 1). Both groups of respondents reported perceiving HD as having a long duration and having many consequences for their daily lives, without either of them believing in a cure for HD. Patients and partners (with the exception of four patients and one partner) attributed HD to genetic causes. Six HD patients (11.8%) reported believing that stress was an important contributing factor to the development of the symptoms of HD they were experiencing.

Partners reported that the HD patients were suffering from significantly more symptoms (on the "Identity" subscale) of HD than the patients did themselves, and reported experiencing significantly less control over HD than the patients did.

Correlations between illness perceptions and QoL

Tables 2 and 3 display the bivariate correlations between the study variables. As expected, examination of the correlations between patients' and partners' illness perceptions and patients' QoL (presented in Table 2) shows that patients' QoL was most strongly associated with their own illness perceptions. A higher QoL correlated with a less strong illness identity, a longer perceived illness (and thus life) duration, less perceived consequences, more control, and less belief in treatment. With regard to partners' perceptions, the same associations (albeit fewer) were found, with the exception of partners' cure perceptions. Partner, but not patient, belief in cure through treatment was significantly related to patients' vitality and social functioning ratings. Also, partners' identity and consequences perceptions were not significantly related to patients' vitality, social functioning, and mental health ratings. Except for the MOS subscales "Role Functioning - emotional" and "Mental Health", illness perceptions of both patients and

Table 1 Means, standard deviations (SD), correlations and *t*-test statistics comparing Huntington's Disease (HD) patients and their partners on the Illness Perception Questionnaire (IPQ)

IPQ subscales	HD patients Mean (SD)	Partners Mean (SD)	Patient-partner correlation coefficient ^a	Patient-partner difference ^b <i>t</i>
Identity	.44 (.22)	.55 (.22)	.57***	-3.59***
Timeline	4.70 (.63)	4.50 (.81)	.10	1.44
Consequences	3.60 (1.19)	3.82 (1.01)	.29*	-1.16
Cure	1.72 (1.77)	1.69 (1.69)	.90***	.27
Control	3.11 (1.72)	2.36 (1.58)	.30*	2.73**

^a Pearson correlation. ^b Paired *t*-test

* $P < .05$; ** $P < .01$; *** $P < .001$

Table 2 Pearson correlations between Illness Perceptions (IPQ) and patients' QoL (MOS SF-36)

	<i>IPQ patients</i>					<i>IPQ partners</i>				
	Identity	Timeline	Consequences	Control	Cure	Identity	Timeline	Consequences	Control	Cure
<i>MOS subscales</i>										
Physical functioning	-.51***	.48***	-.31*	.37**	-.33*	-.43**	.28*	-.31*	.39**	-.39**
Role functioning (physical)					-.31*					-.29*
General health	-.39**		-.31*			-.31*				
Vitality	-.44**	.34*	-.35*				.33*			-.35*
Social functioning	-.32*		-.38**							-.31*
Role functioning (emotional)										
Mental health	-.40**		-.39**							

Note: Only significant correlations are depicted

* $P < .05$; ** $P < .01$; *** $P < .001$

Table 3 Pearson correlations between Partners' and Patients' Illness Perceptions (IPQ), and Partners' QoL (MOS SF-36)

	<i>IPQ partners</i>					<i>IPQ patients</i>				
	Identity	Timeline	Consequences	Control	Cure	Identity	Timeline	Consequences	Control	Cure
<i>MOS subscales</i>										
Physical functioning		.29*								
Role functioning (physical)			-.38**							
General health									.28*	
Vitality		.33*	-.29*						.30*	
Social functioning										
Role functioning (emotional)									.33*	
Mental health			-.40**					-.33*		

Note: Only significant correlations are depicted

* $P < .05$; ** $P < .01$; *** $P < .001$

partners correlated significantly with patient QoL. Thus, regression analyses were conducted on the remaining MOS subscales, including only the illness perceptions dimensions that correlated significantly with QoL.

Bivariate correlations between illness perceptions and partners' QoL are presented in Table 3. The quality of life of partners was associated with their own beliefs about the patients' illness, with a stronger belief in a long duration of the patients' illness being related to better physical functioning and more vitality, and less perceived consequences being related to better physical role functioning, more vitality, and to better mental health. Partners' vitality and mental health were also associated with illness perceptions of patients. Stronger patient beliefs in control over the illness, and less serious perceived consequences were related to better partner QoL. Interestingly, the only significant correlations between partners' ratings of general health and emotional role functioning, and illness perceptions were correlations with *patient* beliefs in control over the illness.

Importance of spousal illness perceptions for patients' QoL

To determine the relative extent that partners' illness perceptions are predictive of patients' QoL, hierarchical stepwise multiple regression analyses were conducted for patients' physical functioning, role functioning (physical), general health, vitality and social functioning. The results of the regressions are summarized in Table 4. After controlling for patients' illness related variables and their own scores on the IPQ, partners' IPQ scores added a significant amount of explained variance (13%) to patient scores on the "Vitality" subscale only. A stronger partner belief in a long duration of the patients' illness ($\beta .30$, $P < .05$), and less belief in cure through treatment ($\beta -.33$, $P < .05$) both added to the prediction of higher patient vitality.

The variance in patients' scores on the other subscales of the MOS SF-36 was explained mainly by patients' own IPQ scores, with the amount of added explained variance ranging from 9 to 20%. Less perceived consequences, a

Table 4 Hierarchical regressions examining if spousal illness perceptions explain additional variance in patients' QoL

Step and variables	Adj. R^2	R^2 change	F for R^2 change
<i>MOS physical functioning</i>			
1. Control variables ^a	.49	.52	17.05***
2. Illness perceptions (patient): identity, timeline, consequences, control, cure	.59	.14	3.29*
3. Illness perceptions (partner): identity, timeline, consequences, control, cure	.64	.08	2.06
<i>MOS role functioning (physical)</i>			
1. Control variables ^a	.01	.07	1.23
2. Illness perceptions (patient): cure	.11	.09	5.83*
3. Illness perceptions (partner): cure	.09	.00	0.01
<i>MOS general health</i>			
1. Control variables ^a	.10	.15	2.84*
2. Illness perceptions (patient): identity, consequences	.18	.11	3.24*
3. Illness perceptions (partner): identity	.16	.00	0.08
<i>MOS vitality</i>			
1. Control variables ^a	.12	.18	3.35*
2. Illness perceptions (patient): identity, timeline, consequences	.29	.20	4.65**
3. Illness perceptions (partner): timeline, cure	.41	.13	5.62**
<i>MOS social functioning</i>			
1. Control variables ^a	.01	.05	0.83
2. Illness perceptions (patient): identity, consequences	.11	.15	4.18*
3. Illness perceptions (partner): cure	.16	.06	3.51

^a Disease duration, TMS, and MMS scores

* $P < .05$; ** $P < .01$; *** $P < .001$

less strong illness identity, more control, and less belief in treatment contributed significantly to better QoL.

Importance of patients' illness perceptions for partners' QoL

To determine the relative extent that patients' illness perceptions are predictive of partners' QoL, hierarchical stepwise multiple regression analyses were conducted for partners' vitality and mental health. The results of the regressions are summarized in Table 5. Patients' IPQ scores added a significant amount of explained variance (8%) to partner scores on the "Vitality" subscale only.

Stronger patient beliefs in control over the illness (β .29, $P < .05$) added to the prediction of higher partner vitality.

Most variance was explained by partners' own IPQ scores, with amount of explained variance ranging from 16 to 21%. A longer perceived illness (and thus life) duration, and less perceived consequences contributed significantly to better QoL.

Discussion

Our results indicate that HD patients and their partners did not differ significantly in their beliefs regarding the dura-

Table 5 Hierarchical regressions examining if spousal illness perceptions explain additional variance in partners' QoL

Step and variables	Adj. R^2	R^2 change	F for R^2 change
<i>MOS vitality</i>			
1. Illness perceptions (partner): timeline, consequences	.17	.21	6.26**
2. Illness perceptions (patient): control	.24	.08	5.05*
<i>MOS mental health</i>			
1. Illness perceptions (partner): consequences	.14	.16	9.04**
2. Illness perceptions (patient): consequences	.17	.05	3.11

* $P < .05$; ** $P < .01$; *** $P < .001$

tion, consequences, causality, and curability of the disease. HD was attributed, in all but four HD patients and one partner, to a genetic cause. There were however, significant differences between the illness identity of HD patients and that of their partners. Partners attributed significantly more symptoms to HD than patients. In addition, HD patients and their partners differed significantly in the degree of control they believed they had over the disease process. HD patients perceived their disease as being more controllable than their partners. In general, as was the case in couples dealing with Addison's disease [15], patients held more positive beliefs about HD than their partners did.

Examining the relationships between spousal illness perceptions and patients' QoL, the results indicate that none of the partners' perceptions (whether consonant or dissimilar) are relevant in being associated with patients' quality of life in the areas of mental health and emotional role functioning. Partners' identity and consequences perceptions (whether consonant or dissimilar) are not associated with patients' quality of life in the areas of social functioning and vitality. Partners' consequences perceptions (whether consonant or dissimilar) are not relevant for patients' quality of life in the area of general health. Also, less partner (but not patient) belief in cure through treatment was related to higher patients' vitality and social functioning ratings. Thus, our results suggest that except for patients' physical functioning, it is of limited use to investigate (only) dissimilarities in illness perceptions of patients and partners as determinants of patient outcomes in HD.

With regard to the third aim of this study, although patients' and partners' own illness perceptions explained the largest amount of variance in QoL, spousal illness perceptions were related to patients' and partners' quality of life, but only to their vitality ratings. After controlling for patients' illness related variables and patients' own beliefs, a stronger partner belief in a long duration of the patients' illness and less belief in cure through treatment both added to the association with higher patient vitality. The results are in line with those of Heijmans et al. [15], who found positive relationships between spousal maximization of illness duration and patients' vitality ratings in Addison's disease. Stronger patient beliefs in control over the illness added to higher vitality scores in partners. From both our results and those of Heijmans et al., it appears that it is most beneficial to have a spouse who is realistic (albeit negative) about the possibilities for cure, and who expects the illness to be long-lasting. Research on how realistic optimism may impact on vitality in healthy persons and patient samples supports these findings [38, 39].

The results obtained in this study must be regarded in the light of some limitations. The lack of information on the non-response rate in the sample of members of the Dutch Huntington Association makes selection bias likely.

Also, the patients involved in this study were in the early to middle stages of HD, as shown by their scores on the UHDRS and MMS. This prevents extrapolation of our results to other samples of patients with Huntington's disease. On the other hand, our results indicate that the patients in our study did not differ significantly from those patients with Huntington's Disease involved in other studies with regard to important disease related characteristics such as motor and cognitive functioning [40]. Our results could, therefore, be instrumental in future research on quality of life in patients (and their partners) who are in these stages of HD. The relatively small number of couples included and the relatively large number of variables entered into the regression analyses must be taken into account as well.

More research is justified on the unique contributions of the spouses' perceptions of the illness that may be associated with outcome in chronically ill patients and their partners. Examining these associations further and studying which psychological mechanisms may be involved, for instance by interviewing pairs in whom these associations are clearly discernable, are areas for future research. From a clinical perspective, an understanding of the cognitive factors that are related to quality of life in couples dealing with chronic illness will help to guide family interventions. Given the relative paucity of research on biopsychosocial aspects of Huntington's disease, qualitative research on quality of life may be helpful in future research, e.g., in the work by Brouwer-Dudokde Wit et al. [41], where qualitative research in a case-study format that was carefully embedded in a theoretical framework helped explore quality of life issues in pre-symptomatic testing for HD. These researchers emphasize the relevance of adding an existential and/or spiritual approach in exploring quality of life issues in HD patients [42, 43]. Empirical studies in other neurological disorders support these suggestions: Hodgson et al. [44], for example, describe the lives of 10 couples living with Parkinson's disease, and outline how these couples preferred a multidisciplinary approach to their treatment and believed in taking an active role in their health care. Qualitative approaches to assessing QoL in Huntington's disease spousal carers are described in a recent paper by Aubeeluck & Buchanan [29], where visual representations of QoL were gathered by using 'Photo-voice': spousal carers photographed and described elements of their life. Finally, cognitive-behavioural approaches in patients with dementia and their caregivers were recently shown in a randomized controlled trial to result in improvements in patients' daily functioning and reduced burden in the caregiver. These studies and ours, illustrate possible directions for future research in patients (and their partners) who experience an extreme negative impact on quality of life [45].

References

1. Martire, L. M., Lustig, A. P., Schulz, R., Miller, G. E., Helgeson, V. S. (2004). Is it beneficial to involve a family member? A meta-analysis of psychosocial interventions for chronic illness. *Health Psychology, 23*, 599–611.
2. Manne, S. L., Zautra, A. J. (1989). Spouse criticism and support: Their association with coping and psychological adjustment among women with rheumatoid arthritis. *Journal of Personality and Social Psychology, 56*, 608–617.
3. Manne, S. L., Zautra, A. J. (1990). Couples coping with chronic illness: Women with rheumatoid arthritis and their healthy husbands. *Journal of Behavioral Medicine, 13*, 327–342.
4. Manne, S., Glassman, M. (2000). Perceived control, coping efficacy, and avoidance coping as mediators between spouses' unsupportive behaviors and cancer patients' psychological distress. *Health Psychology, 19*, 155–164.
5. Manne, S. L., Ostroff, J., Winkel, G., Grana, G., Fox, K. (2005). Partner unsupportive responses, avoidant coping, and distress among women with early stage breast cancer: Patient and partner perspectives. *Health Psychology, 24*, 635–641.
6. Norton, T. R., Manne, S. L., Rubin, S., Hernandez, E., Carlson, J., Bergman, C., Rosenblum, N. (2005). Ovarian cancer patients' psychological distress: The role of physical impairment, perceived unsupportive family and friend behaviors, perceived control, and self-esteem. *Health Psychology, 24*, 143–152.
7. Northouse, L. L., Mood, D., Templin, T., Mellon, S., George, T. (2000). Couples' patterns of adjustment to colon cancer. *Social Science & Medicine, 50*, 271–284.
8. Goldstein, L. H., Atkins, L., Landau, S., Brown, R., Leigh, P. N. (2006). Predictors of psychological distress in carers of people with amyotrophic lateral sclerosis: A longitudinal study. *Psychological Medicine, 36*, 865–875.
9. Ory, M. G., Hoffman, R. R. III, Yee, J. L., Tennstedt, S., Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *Gerontologist, 39*, 177–185.
10. Thommessen, B., Aarsland, D., Braekhus, A., Oksengaard, A. R., Engedal, K., Laake, K. (2002). The psychosocial burden on spouses of the elderly with stroke, dementia and Parkinson's disease. *International Journal of Geriatric Psychiatry, 17*, 78–84.
11. Riemsma, R. P., Taal, E., Rasker, J. J. (2000). Perceptions about perceived functional disabilities and pain of people with rheumatoid arthritis: Differences between patients and their spouses and correlates with well-being. *Arthritis Care Res, 13*, 255–261.
12. Leventhal, H., Nerenz, D. R., Steele, D. J. (1984). Illness representations and coping with health threats. In: A. Baum, S. E. Taylor & J. E. Singer (Eds.), *Handbook of Psychology and Health* (Vol. IV, pp. 219–252). Hillsdale, NJ: Erlbaum.
13. Fortune, D. G., Richards, H. L., Main, C. J., Griffiths, C. E. M. (2000). Pathological worrying, illness perceptions and disease severity in patients with psoriasis. *British Journal of Health Psychology, 5*, 71–82.
14. Hagger, M. S., Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology & Health, 18*, 141–184.
15. Heijmans, M., De Ridder, D., Bensing, J. (1999). Dissimilarity in patients' and spouses' representations of chronic illness. Explorations of relations to patient adaptation. *Psychology & Health, 14*, 451–466.
16. Figueiras, M. J., Weinman, J. (2003). Do similar patient and spouse perceptions of myocardial infarction predict recovery? *Psychology & Health, 18*, 201–216.
17. Barrowclough, C., Lobban, F. (2001). An investigation of models of illness in carers of schizophrenia patients using the Illness Perception Questionnaire. *British Journal of Clinical Psychology, 40*, 371–385.
18. Fortune, D. G., Smith, J. V., Garvey, K. (2005). Perceptions of psychosis, coping, appraisals, and psychological distress in the relatives of patients with schizophrenia: An exploration using self-regulation theory. *British Journal of Clinical Psychology, 44*, 319–331.
19. Conneally, P. M. (1984). Huntington disease: Genetics and epidemiology. *American Journal of Human Genetics, 36*, 506–526.
20. Roos, R. A., Hermans, J., Vegter-van der Vlis, M., van Ommen Bruyn, G. W. (1993). Duration of illness in Huntington's disease is not related to age at onset. *Journal of Neurology Neurosurgery and Psychiatry, 56*, 98–100.
21. Hans, M. B., Koeppen, A. H. (1980). Huntington's chorea. Its impact on the spouse. *The Journal Nervous and Mental Disease, 168*, 209–214.
22. Jarka M., Brosig B., Richter H. E. Psychosoziale Probleme bei Huntingtonscher Chorea: Teil 2. Ergebnisse und Erfahrungen aus einer fünfjährigen Projekt. *Psychiatrische Praxis* 196; 23, 121–125.
23. Korner, J., Fitzsimmons, J. S. (1985). The effect of Huntington's Chorea on family life. *British Journal of Social Work, 15*, 581–597.
24. Tyler, A. (1991). Social and psychological aspects of Huntington's Disease. In: Harper P (Ed.) *Huntington Disease* (pp. 179–203). London: WS Saunders.
25. Tyler, A., Harper, P. S., Davies, K., Newcome, R. G. (1983). Family break-down and stress in Huntington's chorea. *Journal of Biosocial Science, 15*, 127–138.
26. Anderson, K. E., Marshall, F. J. (2005). Behavioral symptoms associated with Huntington's disease. *Advances in Neurology, 96*, 197–208.
27. Helder, D. I., Kaptein, A. A., van Kempen, G. M., van Houwelingen, J. C., Roos, R. A. (2001). Impact of Huntington's disease on quality of life. *Movement Disorders, 16*, 325–330.
28. Kaptein, A. A., Helder, D. I., Scharloo, M., van Kempen, G. M. J., Weinman, J., van Houwelingen, J. C., Roos, R. A. C. (2006). Illness perceptions and coping explain well-being in patients with Huntington's disease. *Psychology & Health, 21*, 431–446.
29. Aubeeluck, A., Buchanan, H. (2006). Capturing the Huntington's disease spousal carer experience. *Dementia, 5*, 95–116.
30. Leimkühler, A. M. (1987). "Selbsthilfepotential der Familie" als Überforderung des Ehepartners: Bericht über eine Angehörigengruppe von Chorea-Huntington Patienten. *Psychiatrische Praxis, 14*, 78–83.
31. Stern, R., Eldridge, R. (1975). Attitudes of patients and their relatives to Huntington's disease. *Journal of Medical Genetics, 12*, 217–223.
32. Huntington Study Group (1996). Unified Huntington's Disease Rating Scale: Reliability and consistency. *Movement Disorders, 11*, 136–142.
33. Folstein, M. F., Folstein, S. E., McHugh, P. R. (1975). "Minimal state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12*, 189–198.
34. Weinman, J., Petrie, K. J., Moss-Morris, R., Horne, R. (1996). The Illness Perception Questionnaire: a new method for assessing the cognitive representation of illness. *Psychology & Health, 11*, 431–445.
35. Helder, D. I., Kaptein, A. A., Van Kempen, G. M., Weinman, J., Van Houwelingen, J. C., Roos, R. A. (2002). Living with Huntington's disease: Illness perceptions, coping mechanisms, and spouses' quality of life. *International Journal of Behavioral Medicine, 9*, 37–52.

36. Moss-Morris, R., Weinman, J., Petrie, K. J., Horne, R., Cameron, L. D., Buick, D. (2002). The revised Illness Perception Questionnaire (IPQ-R). *Psychology & Health, 17*, 1–16.
37. Ware, J. E. Jr, Sherbourne, C. D. (1992). The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Medical Care, 30*, 473–483.
38. Achat, H., Kawachi, I., Spiro, A., DeMolles, D. A., Sparrow, D. (2000). Optimism and depression as predictors of physical and mental health functioning: The normative aging study. *Annals of Behavioral Medicine, 22*, 127–130.
39. Brissette, I., Scheier, M. F., Carver, C. S. (2002). The role of optimism in social network development, coping, and psychological adjustment during a life transition. *Journal of Personality and Social Psychology, 82*, 102–111.
40. Siesling, S., Zwiderman, A. H., van Vught, J. P. P., Kiebertz, K., Roos, R. A. C. (1997). A shortened version of the motor section of the Unified Huntington's Disease Rating Scale. *Movement Disorders, 12*, 229–234.
41. Brouwer-DudokdeWit, A. C., Savenije, A., Zoetewij, M. W., Maat-Kievit, A., Tibben, A. (2002). A hereditary disorder in the family life cycle: Huntington disease as a paradigm. *Family Process, 41*, 677–692.
42. van der Meer, L., Timman, R., Trijsburg, W., Duisterhof, M., Erdman, R., van Elderen, T., Tibben, A. (2006). Attachment in families with Huntington's disease: A paradigm in clinical genetics. *Patient Education and Counseling, 63*, 246–254.
43. van Oostrom, I., Meijers-Heijboer, H., Duivenvoorden, H. J., Bröcker-Vriends, A. H. J. T., van Asperen, C. J., Sijmons, R. H., Seynaeve, C., van Gool, A. R., Klijn, J. G. M., Tibben, A. (2007). Comparison of individuals opting for BRCA1/2 or HNPCC genetic susceptibility testing with regard to coping, illness perceptions, illness experiences, family system characteristics and hereditary cancer distress. *Patient Education and Counseling, 65*, 58–68.
44. Hodgson, J. H., Garcia, K., Tyndall, L. (2004). Parkinson's disease and the couple relationship: A qualitative analysis. *Families, System & Health, 22*, 101–118.
45. Graff, M. J. L., Vernooij-Dassen, M. J. M., Thijssen, M., Dekker, J., Hoefnagels, W. H. L., Olde Rikkert, M. (2006). Community based occupational therapy for patients with dementia and their care givers: Randomised controlled trial. *British Medical Journal, 333*, 1196–1199.