Vestibular schwannoma treatment : patients' perceptions and outcomes

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Chapter 2

Illness perceptions, coping, and quality of life in vestibular schwannoma patients at diagnosis

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Abstract

Objective: To evaluate illness perceptions, coping behavior, and quality of life in patients with vestibular schwannoma at diagnosis.

Study design: Prospective patient analysis.

Setting: University Teaching Hospital, tertiary care clinic.

Patients: Consecutive patients with vestibular schwannoma (n = 79) completed a set of questionnaires at diagnosis in order to assess psychological characteristics and quality of life.

Intervention: Diagnostic and rehabilitative.

Main outcome measures: Psychological characteristics and quality of life, measured via questionnaires focusing on illness perceptions (Illness Perception Questionnaire Revised), coping (Utrecht Coping List), and quality of life (SF-36), were compared to normative data for the general Dutch population and to data concerning patients with other illnesses.

Results: The SF-36 scores of vestibular schwannoma patients at diagnosis were significantly decreased when compared to healthy controls, patients with head and neck cancer, benign prostate hypertrophy (BPH), chronic obstructive pulmonary disease (COPD), and deaf patients. Scores for illness perceptions were in between those of patients with acute pain and chronic pain for most subscales, except illness identity, emotional representations, and illness coherence. In their coping behavior, vestibular schwannoma patients scored lower on the subscale active coping, sought less social support, and expressed their emotions less, but also showed less passive coping compared to reference values.

Conclusions: Vestibular schwannoma patients experience impaired quality of life compared to healthy controls and reference groups. Their illness perceptions are in between those of patients with acute and chronic pain, and their coping behavior is less active in general. This may have implications for clinical decision making and for optimizing interaction with patients. Changing illness perceptions and coping by means of an intervention and encouraging social support by means of patient support groups may improve quality of life in vestibular schwannoma patients.

Introduction

In modern medicine, patient-reported outcomes are increasingly viewed as central in evaluating medical care. Quality of life (QoL) is an operationalization of patient-reported outcomes and is defined as "the functional effects of an illness and its treatment, as perceived by the patient" (1). There is overwhelming evidence for the finding that objective characteristics of an illness are hardly associated with QoL. QoL seems to be analyzed mainly via social, psychological, and patient-health care provider characteristics.

The idea of illness perceptions is one such psychological characteristic (2). Illness perceptions pertain to the idiosyncratic ideas (cognitions) of patients (and physicians) regarding complaints and symptoms. They seem to play a role in the variation in QoL experienced by patients. Illness perceptions include the beliefs and attributions patients have regarding their illness and specifically regarding symptoms, causes, consequences, and the time the illness will last. This information is most often not directly asked for in a clinical setting. However, research shows that illness perceptions partly analyze the severity of disease experienced by the patient (QoL) and outcome (3,4).

Coping behavior is the behavior one shows in reaction to adversity in life, whether it is coping with illness or with something simpler such as, for example, a flat tire. It is thought that this coping behavior may affect the perception of QoL. An active coping style is associated with better QoL and better outcome, whereas a general passive coping style is associated with worse QoL and outcome. Seeking social support and expressing emotions, also part of coping behavior, have been shown to be important in achieving good QoL (5).

In current literature, an increasing amount of studies concerning other illnesses in different medical fields focus on QoL issues. Of these illnesses, several QoL reference groups were chosen on the basis of both clinical relevance and availability. In clinical practice, otorhinolaryngologists are familiar with head and neck cancer patients as well as deaf patients. Therefore, it may be interesting to see whether vestibular schwannoma (VS) patients have better or worse QoL than these 2 other patient groups. Furthermore, patients who have benign prostate hypertrophy (BPH) are similar to VS patients in that they both have a benign, slow-growing tumor that may cause quite bothersome symptoms. Chronic obstructive pulmonary disease (COPD) patients were chosen because they have a chronic disease causing many limitations and handicaps in daily life.

For the Utrecht Coping List (UCL), reference groups were chosen based on availability and comparability, apart from population norms. Patients with chronic pain were chosen because of the chronic character of their medical condition, which may be considered more chronic and thus less acute than recently diagnosed VS. Patients undergoing bone marrow transplantation were chosen because they have a serious life-threatening condition. Utrecht Coping List scores for head and neck cancer patients; deaf patients; or patients with BPH, COPD, or acute pain were not available.

As in other fields, QoL is a much studied topic in VS patients. Most studies are retrospective, and they consistently report QoL to be lower than in specified norm groups, usually posttreatment (6-16). In some of these studies, vertigo is found to be the major symptom affecting QoL (17,18). No study to date has evaluated illness perceptions or coping in VS patients (19). Very few studies have evaluated QoL in VS patients before treatment or before proposal to treatment (18,19). Therefore, the aim of this study was to evaluate QoL, illness perceptions, and coping behavior in patients with VS at diagnosis before proposal to treatment.

Materials and Methods

Patients

Between January and October 2005, 90 consecutive patients were newly diagnosed with VS. All these patients received a set of questionnaires accompanied by a letter informing them of the purpose of the study and instructions on how to complete the questionnaires. Patients were included before treatment and treatment proposal. Seventy-nine patients completed and returned the set of questionnaires (87.8%). Six refused due to personal problems, 4 did not respond, and 1 responded anonymously.

Thirty-six patients were men (45.6%), and mean age was 57.7 years (25.8-78.7 yr). According to the hearing classification system of the Committee on Hearing and Equilibrium (20), hearing was 20.5% Class A, 30.8% Class B, 23.1% Class C, and 25.6% Class D. Tinnitus was experienced by 64.6% of patients, and 38% experienced unsteadiness, defined as balance disorder. Eight of these patients and 2 others (total of 12.7%) experienced vertigo, defined as a paroxysmal spinning sensation, often with nausea and vomiting. The average duration of symptoms was 1 to 5 years. The trigeminal nerve was intact in 92.4% of patients, and all patients but 1 (98.7%) had House-Brackmann Grade I of the facial nerve. Thirty-eight percent of tumors were strictly intracanalicular, and mean extracanalicular tumor size was 14.62 mm measured with MRI (Table 1).

Table 1. Characteristics of patients with VS.

	Responding patients (%) n = 79	**Non-responding patients (%) n = 11**
Sex, men	**36 (45.6)**	5 (45.5)
Age, yr (mean, (range))	**57.7 (25.8-78.7)**	56.9 (29.9-78.5)
Hearing		
Class A	**16 (20.5)**	2 (20)
Class B	**24 (30.8)**	3 (30)
Class C	**18 (23.1)**	4 (40)
Class D	**20 (25.6)**	1 (10)
Symptoms		
Tinnitus	**51 (64.6)**	9 (81.8)
Unsteadiness	**30 (38)**	5 (45.5)
Vertigo	**10 (12.7)**	1 (9.1)
Headache	**5 (6.3)**	0 (0.0)
Earache	**3 (3.8)**	0 (0.0)
Duration of symptoms		
0-6 mo	**15 (19.0)**	1 (9.1)
7-12 mo	**17 (21.5)**	1 (9.1)
1-2 yr	**9 (11.4)**	1 (9.1)
2-5 yr	**21 (26.6)**	5 (45.5)
5-10 yr	**7 (8.9)**	2 (18.2)
>10 yr	**10 (12.7)**	1 (9.1)
Status of cranial nerves		
N V unaffected	**73 (92.4)**	10 (90.9)
N VII unaffected (H-B I)	**78 (98.7)**	11 (100)
Unaffected	**71 (89.9)**	10 (90.9)
Tumor characteristics		
Intracanalicular	**30 (38.0)**	3 (27.3)
Size (extracanalicular), mean (SD)	**14.62 (8.36)**	14.88 (8.01)
Cystic component	**6 (7.5)**	2 (18.2)

Patient characteristics of responding and non-responding patients were similar. H-B I indicates House-Brackmann Grade I; N V, trigeminal nerve; N VII, facial nerve; SD, standard deviation.

Methods

The Medical Outcomes Study 36-Item Short Form Health Survey

The SF-36 is the most widely used questionnaire to assess QoL and has been validated and proven to be a reliable instrument to measure QoL in general (21). It consists of 36 items comprising 8 subscales of QoL. These subscales are 1) physical functioning and 2) social functioning, that is, the degree of limitations experienced in daily life physically and socially, respectively; 3) physical role limitations and 4) emotional role limitations, that is, limitations in work or other daily activities due to physical and emotional problems, respectively; 5) mental health, the degree of depression and anxiety; 6) vitality, the degree of energy and exhaustion; and 7) bodily pain and 8) general health quantify the subjective evaluation of the patient's own health status and pain. Higher scores indicate better perceived QoL. Data on patients' responses were scored according to the instructions on scoring syntax in the SF-36 manual (22). Dutch population norms are available for reference.

The Illness Perception Questionnaire Revised

The Illness Perception Questionnaire Revised (IPQ-R) consists of 3 parts measuring 1) illness identity, 2) cognitive and emotional representations, and 3) causal attributions (i.e., causes patients hold responsible for their illness), with the parts containing 28, 38, and 18 items, respectively. Answers are to be chosen from a 5-point Likert scale (strongly disagree to strongly agree) or from a yes-no scale. Scores are calculated over 8 dimensions of illness perception. These 8 dimensions are 1) illness identity, concerning the number of symptoms attributed to the illness; 2) timeline acute/chronic and 3) timeline cyclical concern strongly held beliefs regarding the chronicity or cyclical nature of the condition; 4) consequences concern the negative consequences of the condition, where higher scores represent negative beliefs; high scores on 5) personal control and 6) treatment control, reflecting the perceived controllability of the illness, and 7) illness coherence, representing personal understanding of the condition; indicate positive beliefs; high scores for 8) emotional representations correspond with a greater likelihood to seek medical care. Causal attributions are evaluated by category: psychological, risk factor, immunologic, accident, or chance. These causal attributions indicate which factors patients hold responsible for causing their illness: psychological factors, risk factors that is smoking, immunologic factors, or merely bad luck (accident or chance). Mean values for patients with various medical disorders, including chronic pain and acute pain, for patients with head and neck cancer, and for patients with COPD are available for comparison (23-25). For deaf patients or BPH patients, IPQ-R scores were not available. Because the general population is not assumed to have an illness, there are no IPQ-R norm values for the general population. Scores of patients with chronic pain and acute pain may be used instead.

Utrecht Coping List

The UCL consists of statements concerning 7 different coping styles: active coping (disentangling the situation and purposefully working to solve the problem), seeking distraction (seeking distraction not to have to think regarding the problem), avoidance (leaving the problem to what it is or running away from it), seeking social support (seeking comfort and understanding from others), passive coping (being completely overwhelmed by the problem), expressing emotions (showing irritation and anger regarding the problem), and fostering reassuring thoughts (optimism). Of 47 statements, patients indicate whether they find these applicable to themselves on a 4-point scale ranging from “seldom or never” to “very often”. Higher scores indicate greater affinity with specific coping styles. Dutch population norms are available for the general population aged 19 to 65 years, as well as for patients with chronic pain and for patients undergoing bone marrow transplantation (5,26,27).

Reference Populations

For the SF-36, reference populations consisted of patients with head and neck cancer, BPH, COPD, and deaf patients. In the reference study by Funk et al. (28), 180 head and neck cancer patients were included with a mean age of 58.9 years. Exclusion criteria were recurrent disease, cutaneous cancers, lymphomas, sarcomas, and thyroid or parathyroid tumors. Sex distribution was not mentioned, clinical American Joint Committee on Cancer stage at diagnosis was Stage I (13%), Stage II (17%), Stage III (18%), Stage IV (50%), or unknown (2%).

The study by Salinas Sanchez et al. focused on BPH in 181 men with a mean age of 68.8 years and undergoing surgery for prostate-related symptoms (29). Of these patients, 103 had objective symptoms such as urine retention.

Geijer et al. (30) conducted a study on COPD patients. The study population consisted of 395 male smokers with a mean age of 55.4 years due to a higher prevalence of COPD in men and limited study resources. Disease severity in COPD is measured with the Global Initiative for Chronic Obstructive Lung Disease (GOLD) classification. In the study population, 69.7% did not have any airflow limitation, 29.6% had mild disease (GOLD I), and 10.6% had moderate disease (GOLD II).

The SF-36 scores of 27 deaf patients were analyzed by Mo et al. (31). Postlingually deafened adult cochlear implant candidates were included, of which there were 12 men and 15 women. In 14 of these patients, the cause of deafness was unknown. The other patients had hereditary deafness, otosclerosis, meningitis, Ménière disease, trauma, or rubella.

For the IPQ-R, reference populations consisted of patients with head and neck cancer or COPD. Scharloo et al. (24) included 68 patients with head and neck cancer with a mean age of 60 years, of which 70% were men. Patients were excluded if they were mentally retarded or demented, or unable to fill in the questionnaires for other reasons. American Joint Committee on Cancer staging was I (11 patients), II (15 patients), III (12 patients), or IV (30 patients). The IPQ-R scores of 171 COPD patients were evaluated in another study by Scharloo et al. (25). Mean age of this population was 66 years, with 112 men and 59 women. Patients were excluded if they had other significant disabling diseases that would confound symptom reporting and QoL scoring. Disease severity of COPD was moderate (GOLD II) in 84 patients and severe (GOLD III) in 87 patients.

The first UCL reference population was studied by Hopman-Rock et al. (26) and consisted of 59 patients with chronic pain aged 63.7 years on average. Twenty-five percent of patients were men. Patients were excluded if they participated in another substudy of the Rotterdam study, had cognitive impairments, or were living in a home for the elderly. The second reference population consisted of 123 bone marrow transplant patients studied by Broers et al. (27). Mean age at bone marrow transplantation was 35.4 years. Of these patients, 74 were men and 49 were women. Patients were excluded if their IQ was too low or if their data were incomplete. Indications for treatment were acute leukemia (52%), chronic myelogenous leukemia (17.1%), or lymphoma (30.9%).

Statistical Analysis

Means were calculated for subscales of all questionnaires and compared with available Dutch population norms by Student’s t-tests. If available, means were also compared with means of patients with comparable illnesses. Significance was calculated with a 99% confidence interval. A significance level of 0.01 was used to adjust for multiple testing. Analyses were performed with the Statistical Package for the Social Sciences (SPSS 14.0 for Windows).

Results

In summary, when compared with patients with other illnesses, VS patients showed significantly lower QoL scores for almost all subscales except physical functioning. Mental health was only better in deaf patients and patients with COPD, whereas perceived general health was better for all patient groups except for men with BPH (Table 2).

Compared with patients with acute pain, VS patients scored significantly higher on the timeline (acute/chronic) subscale of the IPQ-R, indicating that they considered their illness to be more chronic than patients with acute pain. However, VS patients had a significantly lower sense of personal control and treatment control. They did not differ significantly in illness identity, in the belief in a cyclical character of their illness, or in emotional representations. Compared with patients with chronic pain, VS patients scored significantly lower on the timeline (acute/chronic) subscale, indicating that they considered their illness to be more acute than patients with chronic pain. Moreover, they had a significantly higher sense of treatment control and a significantly more coherent view regarding their illness. For personal control and psychological attributions, there were no significant differences in scores.

VS patients significantly thought of their illness as a more chronic problem and had a significantly greater sense of illness coherence compared with patients with recently diagnosed head and neck cancer. VS patients had significantly lower scores for emotional representations and expected their illness to have significantly less consequences to their lives compared with patients with head and neck cancer.

Patients with COPD attributed more symptoms to their illness (illness identity) and thought that their illness would be chronic and cyclical significantly more than VS patients. They considered their illness to have greater consequences to their lives and had a higher sense of personal control, whereas they had a lower sense of treatment control compared with VS patients. Higher scores on the first 5 subscales may be associated with less favorable outcomes compared with higher scores on the last 3 subscales. Regarding the cause of their illness, 23.8% of VS patients reported chance or bad luck was the cause of their illness. Most patients (52.5%) could not point out 1 specific item as a possible cause of their illness (Table 3).

Table 2. Comparison of SF-36 scores in VS patients to other populations.

SF-36	VS n = 78	DN n = 1139	HN n = 180	D n = 27	VS ♂ n = 36	BPH ♂ n = 181	COPD ♂ n = 395
PF	**78.3 (26.1)**	81.9 (23.2)	71.99 (29.22)	80.8 (18.7)	**84.2 (25.2)**	74.1 (21.6)*	86.3 (17.7)
SF	**56.1 (19.5)**	86.9 (20.5)*	70.48 (28.28)*	73.1 (26.1)*	**58.7 (20.2)**	80.5 (22.8)*	87.9 (18.4)*
PR	**31.9 (40.4)**	79.4 (35.5)*	52.22 (43.45)*	71 (40)*	**27.8 (39.1)**	57.9 (40.6)*	85.9 (29.5)*
ER	**25.4 (39.4)**	84.1 (32.3)*	60.65 (41.69)*	78.7 (34.5)*	**13 (29)**	77.4 (35.7)*	88.9 (26.9)*
MH	**63.5 (13.2)**	76.8 (18.4)*	64.69 (20.49)	76.2 (18.2)*	**65.4 (13.4)**	73.1 (21.3)	78.4 (16.4)*
VT	**53.8 (13.7)**	67.4 (19.9)*	51.58 (24.26)	58.8 (21.8)	**56.3 (14.9)**	68.9 (23.5)*	68.3 (19.2)*
BP	**62.4 (38.4)**	79.5 (25.6)*	59.38 (26.05)	75.1 (26.8)	**62.4 (40.1)**	69.8 (28.5)	83.3 (22.5)*
GH	**54.5 (15.6)**	72.7 (22.7)*	63.01 (20.71)*	72.6 (21.6)*	**52.6 (16.7)**	60.1 (19.4)	66.1 (18.8)*

Mean (standard deviation). Differences between means were tested with Student's t-tests.

*$p < 0.01$ compared with VS patients.

BP indicates bodily pain; BPH ♂, male patients with benign prostate hypertrophy (29); COPD ♂, male patients with chronic obstructive pulmonary disease (30); D, deaf patients (31); DN, Dutch population norms (22); ER, emotional role limitations; GH, general health; HN, head and neck cancer patients (28), MH, mental health; PF indicates physical functioning; PR, physical role limitations; SF, social functioning; SF-36, 36-Item Short Form Health Survey; VS, vestibular schwannoma patients; VS ♂, male VS patients; VT, vitality.

Coping styles of VS patients differed significantly from coping behavior of the average Dutch population. VS patients showed less active coping, but also less passive coping; they sought less social support; and expressed their emotions, that is, showed irritation and anger regarding problems, less compared with population norms. Compared with patients with chronic pain, VS patients were less avoiding toward problems, sought more social support, showed less passive coping, and fostered fewer reassuring thoughts. Patients undergoing bone marrow transplantation expressed their emotions significantly more than VS patients but fostered less reassuring thoughts (Table 4).

Table 3. Comparison of IPQ-R scores in VS patients to other populations.

IPQ-R	**VS** **n = 80**	**AP** **n = 35**	**CP** **n = 63**	**HN** **n = 68**	**COPD** **n = 171**
Illness identity	**2.21 (2.44)**	2.81 (1.73)	6.19 (2.81)*	2.32 (2.49)	5.62 (2.86)*
Timeline (acute/chronic)	**20.62 (3.99)**	13.4 (5.38)*	23.12 (4.41)*	17.12 (4.35)*	26.66 (4.41)*
Timeline (cyclical)	**10.59 (3.78)**	9.37 (2.58)	12.87 (3.89)*	9.92 (3.06)	12.13 (4.88)*
Consequences	**16.41 (2.05)**	14.23 (4.44)*	23.45 (3.89)*	19.43 (4.28)*	19.25 (6.05)*
Emotional representations	**15.33 (3.93)**	16.12 (4.03)	19.75 (4.15)*	19.21 (5.54)*	14.13 (7.03)
Personal control	**19.08 (2.62)**	22.94 (3.52)*	18.42 (4.01)	18.77 (3.78)	22.44 (5.89)*
Treatment control	**16.92 (2.96)**	19.43 (3.28)*	14.22 (3.36)*	17.46 (2.86)	14.29 (3.74)*
Illness coherence	**18.1 (3.6)**	9.31 (3)*	13.37 (4.78)*	15.79 (3.78)*	

Mean (standard deviation). Differences between means were tested with Student's t-tests. Higher scores on the first 5 subscales may be associated with less favorable outcomes compared with higher scores on the last 3 subscales.

*p < 0.01 compared with VS patients.

AP indicates patients with acute pain (23); COPD, patients with chronic obstructive pulmonary disease (25); CP, patients with chronic pain (23); HN, head and neck cancer patients (24); IPQ-R indicates Illness Perception Questionnaire Revised; VS, vestibular schwannoma patients.

Table 4. Comparison of VS UCL scores to other populations.

UCL	VS n = 79	DN n = 55	CP n = 299	BM n = 21
Active coping	**17.4 (3.9)**	19.2 (3.7)*	16.4 (4.2)	17.5 (3.3)
Seeking distraction	**16.9 (3.6)**	18.3 (3.1)	16.8 (3.9)	16 (3.7)
Avoiding	**15 (2.9)**	15.8 (3.5)	16 (3.1)*	15.3 (2.1)
Seeking social support	**12 (2.9)**	14.9 (4.2)*	10.2 (2.9)*	12.7 (3.2)
Passive coping	**9.9 (2.5)**	12.5 (2.7)*	11.7 (3.8)*	9.2 (2.4)
Expressing emotions	**4.9 (1.5)**	7 (1.8)*	5.3 (1.7)	6.1 (1.7)*
Fostering reassuring thoughts	**12.4 (2.3)**	13.2 (2.7)	13.3 (3.2)*	10.7 (1.9)*

Mean (standard deviation). Differences between means were tested with Student's t-tests.
*p < 0.01 compared with VS patients. CP indicates patients with chronic pain (26); DN, Dutch population norms (5); BM, bone marrow transplant patients (27); UCL, Utrecht Coping List; VS, vestibular schwannoma patients.

Discussion

As expected, on the basis of previous studies, QoL in Dutch VS patients before treatment was decreased compared with Dutch population norms (19). Because patients were included consecutively before treatment and treatment proposal, treatment modality did not induce bias in QoL, and apparently, QoL is reduced independently of treatment: microsurgery, radiosurgery, or wait and scan policy.

Surprisingly, VS patients were shown to perceive a lower QoL than all other patient groups. Even patients with recently diagnosed head and neck cancer had higher scores for QoL, whereas their life expectancy may be much shorter than that of VS patients. Keeping in mind that most VS patients (79.5%) did not have Class A hearing, it was striking that their QoL was still significantly lower than that of deaf patients before cochlear implant. Quality of life of men with another benign yet bothersome “tumor”, BPH, was not similar to QoL of male VS patients. Coping with breathlessness (COPD) apparently does not decrease QoL as much as coping with VS. Apparently, VS patients are a group of patients that suffer from the moment of diagnosis.

The observation that illness perceptions of VS patients were in between those of patients with acute and chronic pain was not unexpected. Shortly after diagnosis, patients may have experienced their illness as acute in one way, whereas they may have realized that the tumor in their head would influence their daily lives for some time. In that sense, they may have viewed their illness, albeit recently diagnosed, as chronic. Patients with head and neck cancer considered their illness less chronic, but they expected more consequences to their lives, which could possibly be explained by their altered life expectancy. Among other factors, patients with COPD differed from VS patients in a stronger illness identity and a greater sense of personal control. This could be explained by the symptoms of COPD that may be more easily related to the illness than symptoms to VS, and that behavior such as smoking or physical activity may have a direct influence on the symptoms experienced.

The most striking difference in coping behavior compared with reference values was the decrease in seeking social support and expressing emotions. This may cause a decrease in QoL because seeking less social support may probably result in receiving less social support. It was obvious that VS patients showed a more active and, thus, hopefully, more effective way of coping than patients with chronic pain. This may be explained by the duration of illness, which is much shorter in patients with newly diagnosed VS. Therefore, it may be important to ensure that coping behavior of VS patients does not diminish to the level of patients with chronic pain.

Putting this all together, VS patients experienced a decreased QoL with illness perceptions and coping behavior that could be expected with their type of illness. However, in general, the perceived QoL of VS patients was significantly lower than QoL of patients we compared it to. This demonstrates the need for a method to improve QoL in VS patients.

In patients who had myocardial infarction, it was found that interventions aimed at changing illness perceptions positively influenced outcome (32). The intervention consisted of 3 sessions. The first focused on providing information regarding the illness and explaining symptoms and terminology, as well as exploring the patients' beliefs regarding it. The second session focused on these beliefs to create a plan to decrease future symptoms and to create a greater sense of control. In the third session, this plan was evaluated, and symptoms and fears concerning recovery were discussed. Patients reported fewer symptoms 3 months after this intervention and returned to work earlier than controls.

Similar interventions may be beneficial to other groups of patients as well, such as VS patients. It is important to realize that recently diagnosed VS patients in a way experience their illness as acute probably because they have just been diagnosed with a new illness. However, in another way, they experience their illness as chronic perhaps because they realize that it will not be cured within a short period of time. This may call for a different approach to the VS patient than to the patient who has acute myocardial infarction when implementing a change in ilness perceptions.

Because of the previously observed relationship between QoL and coping, that is, seeking social support, it may be expected that stimulating patients to join patient support groups and patient societies may be beneficial to VS patients, especially those lacking social support. Sharing concerns and experiences may ameliorate QoL and perhaps change illness perceptions in such a way that patients exhibit more optimism and develop more problem-focused coping and seek social support.

Questionnaires may be helpful to the clinician in pinpointing a more-than-average decreased QoL, adverse illness perceptions, and suboptimal coping behavior. The clinician may be able to intervene and anticipate on this decreased QoL even before treatment by means of adjustment of treatment proposal, and both pretreatment and posttreatment, by offering extra care and attention when needed, for example, in the form of social workers. Assessing QoL via a concise questionnaire adds significantly to the quality of medical care. It does take a few minutes to fill out questionnaires. However, it takes (much) more time to do a blood test, let alone a more invasive biomedical diagnostic test, which not always adds any relevant extra knowledge.

Finally, this study confirms previous knowledge on diminished QoL in VS patients and adds information regarding illness perceptions and coping behavior. Our study provides clinicians with knowledge concerning the psychological factors that possibly influence QoL and, thus, outcome in VS patients. With awareness regarding this topic, we can try to improve QoL in VS patients.

Conclusion

QoL of our sample of VS patients at diagnosis, measured with SF-36, is less than that of the general population, and for most subscales, also less than the QoL of patients with head and neck cancer, deaf patients, patients with BPH, and patients with COPD. Illness perceptions are in between those of patients with acute and chronic pain and slightly more positive than those of patients with head and neck cancer and COPD.

VS patients distinguish themselves from the general Dutch population by being less active in their coping behavior. Patients undergoing bone marrow transplantation show slightly more active behavior, whereas patients who have chronic pain show significantly less active coping behavior.

Because illness perceptions and coping, but especially QoL in VS patients, are not as good as reference values, it is worth investigating possibilities for improvement. It is important for all those taking care of VS patients, both clinically and nonclinically, to be aware of this decrease in QoL at diagnosis. According to the study of Petrie et al. (32), we may be able to improve outcome by an intervention in the field of illness perceptions. Keeping this in mind, it would be valuable to investigate the role of illness perceptions, coping, and symptoms on QoL in VS patients in a future study to evaluate the possibilities for improvement of QoL in this group of patients.

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