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Validating the Penn Acoustic Neuroma Quality of Life Scale in a Sample of Dutch Patients Recently Diagnosed With Vestibular Schwannoma

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Objective: To examine the validity of the Penn Acoustic Neuroma Quality-of-Life Scale (PANQOL) in a sample of Dutch patients recently diagnosed with vestibular schwannoma.

Study Design and Setting: Cross-sectional study in a university tertiary referral center.

Methods: Between April 2011 and March 2012 consecutive patients (mean age, 56.4; range, 17–85 yr) diagnosed with vestibular schwannoma (n = 155) were included. The PANQOL was translated into Dutch according to the accepted rules of forward-backward translation. Quality of life at diagnosis was measured with the generic SF-36 and the disease-specific PANQOL. Factor analysis was used to explore the factor structure of the PANQOL. The scores of the patients in the current study were compared with those of patients from the United States of America. Correlations between SF-36 and PANQOL were examined to study psychometric characteristics of the PANQOL.

Results: One hundred nineteen patients (76.8%) completed the questionnaires. SF-36 scores are comparable to previously published studies measuring Quality of Life at diagnosis. Factor analysis on our data has confirmed the original 7-dimensional structure of the PANQOL. The PANQOL scores from the Dutch and the USA patients are comparable. Correlations between PANQOL and SF-36 dimensions corroborate the validity of the Dutch PANQOL version.

Conclusion: Vestibular schwannoma patients experience a reduced quality of life immediately after the diagnostic process. The PANQOL seems to be a valid disease-specific measure of quality of life in Dutch patients who have recently been diagnosed with vestibular schwannoma. **Key Words:** Penn Acoustic Neuroma Quality-of-Life Scale—Psychometrics—Quality of life—Short Form-36 Health Survey—Vestibular schwannoma.

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Quality of Life (QoL) has evolved into an important outcome by which the effect of medical treatment is determined in modern medicine. As a consequence of this development, the multidimensional nature of disease is emphasized, which is particularly visible in patients with chronic somatic illness. These patients have to deal with the emotional, cognitive, behavioral, and social consequences of their illness and its medical management. The consequences translate into QoL, defined as “the functional effect of an illness and its consequent therapy upon a patient, as perceived by the patient” (1).

Patients with vestibular schwannoma (VS) often present with unilateral sensorineural hearing loss and associated tinnitus, vertigo, or imbalance (2). As a result of the slow-growing behavior and benign character of the tumor, VS is a chronic illness, which is irreversible, has a long duration, and implies a significant burden on the health system. In small- and medium-sized tumors, for elderly patients, and for those with coexisting morbidities that preclude invasive treatment, watchful waiting (wait-and-scan) has proved to be an evidence-based treatment strategy (2–4). However, vestibular schwannoma can cause brainstem compression, and microsurgical resection or irradiation therapy can have serious consequences as well (5,6). Each of the 3 modalities has its impact on patients’ QoL. In fact, VS patients experience diminished QoL from the moment of diagnosis. Studies have shown that the QoL of patients with VS is lower than that found in patients with other chronic illness (3,7–16), such as head and neck cancer (2,17). Only a few studies focus on QoL in

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VS patients before (proposal of) treatment (5,17–24). This current study contributes to the body of literature on disease-specific QoL in patients recently diagnosed with VS.

Several studies assessing QoL in VS patients have used the Short Form-36 Health Survey (SF-36). This is the most widely used generic questionnaire that assesses QoL. However, as a generic instrument used for VS patients, the SF-36 has, by definition, limitations concerning auditory and vestibular function and surgical interventions because these factors are disease-specific problems in VS patients (18). Recently, the Penn Acoustic Neuroma Quality-Of-Life Scale (PANQOL) was developed and validated for American (USA) patients. This is the first disease-specific QoL instrument for patients with VS (23). Shaffer et al. (25) reported data that seem to corroborate its validity and reliability.

QoL research conventionally aims at assessing QoL with generic and disease-specific measures (1). Therefore, the aim of this study has been to translate and to validate the disease-specific PANQOL to assess disease-specific QoL in a sample of Dutch patients recently diagnosed with VS. The advantage of a disease-specific questionnaire is the inclusion of symptoms caused by VS in the determination of the QoL. Factors associated with VS are instrumental in decision making, informing patients, and on the choice of treatment.

MATERIALS AND METHODS

Patients

During the period of April 2011 and March 2012, a cross-sectional study was performed on 155 consecutive new patients who were diagnosed with VS in the Leiden University Medical Center, Department of Otorhinolaryngology and Head and Neck Surgery. Patients with a cerebellopontine angle growth other than a vestibular schwannoma (i.e., meningioma) that was confirmed by radiologic examination or patients with a diagnosis of neurofibromatosis Type II were excluded for medical reasons. Patients who could not read Dutch or who were otherwise unable to complete a written questionnaire were also excluded. Patient characteristics and tumor characteristics were obtained from the patients' clinical charts and are summarized in Table 1. The tumor size was measured according to common consensus (26) as the longest cerebellopontine, also called extracanalicular, dimension of the vestibular schwannoma. The intracanalicular component was not included in the tumor size. Hearing was classified according to the classification system of the Committee on Hearing and Equilibrium (27). Class A was defined as normal hearing, Class B as moderate hearing loss, and Classes C and D as severe hearing loss.

MATERIALS

The Short Form-36 Health Survey

The SF-36 consists of 36 multiple choice questions that assess 8 dimensions: physical functioning (PF), social functioning (SF), physical role limitations (PR), emotional role limitations (ER), mental health (MH), vitality (VT), bodily pain (BP), and general health (GH). A higher score on the SF-36

TABLE 1. Demographic and medical characteristics of the patients

No. of participants	119
Age mean in years (range)	56.4 (17–85)
Sex, male, no. (%)	58 (48.7)
Initial extracanalicular tumor size, no. (%)	
Small (<11 mm)	72 (60.5)
Medium (11–20 mm)	25 (21.0)
Large (>20 mm)	21 (17.6)
Unknown	1 (0.8)
Degree of hearing loss, no. (%)	
Class A, normal hearing (<30 dB)	15 (12.6)
Class B, moderate hearing loss (30–50 dB)	33 (27.7)
Class C or D, severe hearing loss (>50 dB)	69 (58.0)
Unknown	2 (1.7)
Symptoms (patients could report > 1 symptom), no. (%)	
Tinnitus	87 (73.1)
Balance disorders	64 (53.8)
Vertigo	14 (11.8)
Cranial nerves dysfunction, no. (%)	
Trigeminal nerve (N V) affected	11 (9.2)
Facial nerve (N VII) affected	2 (1.7)

indicates a status of better health. Dutch population norms are available for referential purposes (28,29).

The Penn Acoustic Neuroma Quality-of-Life Scale

The PANQOL consists of 26 multiple choice questions on signs and symptoms associated with vestibular schwannoma. Participants are asked to rate each item from 1 (strongly disagree) to 5 (strongly agree). The PANQOL has 7 dimensions: balance (6 items), hearing (4 items), anxiety (4 items), energy (6 items), pain (1 item), face (3 items), and general health (2 items) (25).

Procedure

The Medical Ethics Committee of the Leiden University Medical Center granted permission for the study. Patients received a package with the SF-36, PANQOL, and questions on sociodemographic characteristics. They were asked to return their completed questionnaires in a prepaid envelope.

The PANQOL questionnaire was translated into Dutch according to the accepted rules of forward-backward translation (30). No divergence between the original and translated items was found, so this was used as the questionnaire in this study.

To compare our study to previously published studies, scores on the SF-36 dimensions at baseline in our study were compared with the results of Godefroy et al. (18), Pollock et al. (5), and Vogel et al. (17), all in patients with VS. This comparison was performed because the same inclusion criteria were used in these studies, and the scores of the SF-36 dimensions at baseline were clearly reported. Other studies with SF-36 results at baseline in this patient category used other inclusion criteria (21) and/or did not report detailed scores on the SF-36 (19,20,22–24).

Statistical Analyses

Data analysis was performed with the Statistical Package for the Social Sciences (SPSS version 17.0 for Windows). Means and standard deviations for the SF-36 and PANQOL were calculated. SF-36 scores were compared with previously published studies using independent *t* tests. Level of significance was calculated with a 99% confidence interval ($p < 0.01$). Exploratory factor analysis was performed using a varimax rotation on principal components. Loadings with a minimum

of 0.40 were considered relevant. Factor analysis is a statistical method used to describe variability among observed and correlated variables in terms of a potentially lower number of unobserved variables called factors or dimensions. There are 2 types of factor analysis: confirmatory and exploratory. Confirmatory factor analysis is a method of determining whether the dimensions confirm to what is expected on the basis of previous studies. Exploratory factor analysis is a method used to explore the underlying structure between measured variables. It reduces a large set of variables to a limited number of underlying dimensions. In this article, exploratory factor analysis was performed to examine whether the underlying structure as published by Shaffer et al. (25) could also be identified in the current sample of patients (31,32). Reliabilities of the PANQOL dimensions were calculated with Cronbach's alpha. Cronbach's alpha is a measure of the internal consistency of questionnaire items. The value of alpha is an indication of the extent to which a number of items in a test measure the same concept. A commonly accepted interpretation of Cronbach's alpha is excellent (≥ 0.9), good (0.8–0.9), acceptable (0.7–0.8), questionable (0.6–0.7), poor (0.5–0.6), or unacceptable (<0.5) (32).

The PANQOL dimensions in our sample were compared with the PANQOL scores of the USA patients by independent *t* tests. Correlations between scores on SF-36 dimensions and PANQOL dimensions were analyzed using Pearson's correlation coefficients.

RESULTS

The 155 patients who were diagnosed with VS between April 2011 and March 2012 were included in the study group. One hundred nineteen of these patients completed and returned the questionnaires (76.8%). Seven patients refused because of personal problems (4.5%), and 29 did not respond at all (18.7%). The baseline characteristics are shown in Table 1. Patient characteristics of nonresponders were not significantly different from responding patients.

The means and standard deviations of the SF-36 dimensions at baseline in the current study and in the 3 comparable samples are given in Table 2 (5,17,18). The current study has shown significant differences with all studies on the domain of Social Functioning and with 2 studies on the domain of Bodily Pain (5,18). Both the current study and the studies of Godefroy et al. (18) and Pollock et al. (5) have shown significant differences to the study of Vogel et al. (17) on the domains Physical

Functioning, Physical Role Limitations, Emotional Role Limitations, Mental Health, and Vitality as shown in Table 2. On the other SF-36 dimensions, no major differences were observed.

Figure 1 shows the SF-36 dimensions in the current study (black line) and the three comparable samples (5,17,18). F1

Exploratory factor analysis was performed on the PANQOL data, using a varimax rotation on principal components based on a fixed number of 7 factors to maintain the 7-dimensional scale, as published by Shaffer et al. (25). All the 6 Balance items contribute to the same dimension. The Energy items and the Face items form their own dimensions in our sample similarly to the findings of Shaffer et al. (25). Three of 4 Hearing items contribute to 1 dimension. The fourth Hearing item ("I often feel isolated as a result of my diagnosis of acoustic neuroma") contributes with all 4 Anxiety items on another dimension. We decided to include this Hearing item in the Anxiety dimension because this question can be explained as an Anxiety item. The first General item ("My health is excellent") contributes as a single item on a dimension. The second General item ("I expect my health to get worse the coming year") contributes, together with the Pain item, on a subsequent dimension. For these 3 questions, we decided to maintain the structure as Shaffer et al. (25) with the 2 General items in 1 dimension and the single Pain item in another dimension. This was decided because in this way, the factor structure of the PANQOL established by Shaffer et al. (25) is maintained in the Dutch version.

Figure 2 shows a comparison of the PANQOL-scores of our sample and the PANQOL sample, described in the original PANQOL study (25). In the figure, the mean scores on the dimensions are shown for the USA PANQOL population and for our sample. Significant differences were found in the Hearing and General dimension, with our sample scoring lower than the USA sample. F2

The scores of VS patients in the current sample on the PANQOL dimensions are shown in Table 3. The means, the standard deviations, and the reliabilities of the 7 dimensions in our sample and the USA sample were calculated using the dimensions as described previously. T3

Correlations between SF-36 dimensions and PANQOL dimensions are shown in Table 4. The strongest correlations (given bold) were found between the PANQOL dimensions Balance, Hearing, Anxiety, Energy, Pain and T4

TABLE 2. Comparison of SF-36 scores in the current study with three comparable samples (5,17,18)

Mean (standard deviation)				
SF-36 domains	Current study n = 119	Godefroy et al. (18) n = 70	Pollock et al. (5) n = 82	Vogel et al. (17) n = 80
Physical functioning (PF)	84.2 (20.7)	81.0 (23.9)^a	89.9 (16.6)^a	78.3 (26.1)^a
Social functioning (SF)	75.4 (25.5)	74.3 (28.3)	83.3 (17.3)	56.1 (19.5)^a
Physical role limitations (PR)	71.2 (36.8)	73.6 (39.7)	81.1 (36.4)	31.9 (40.4)^a
Emotional role limitations (ER)	73.7 (37.2)	82.4 (31.0)	81.3 (32.8)	25.4 (39.4)^a
Mental health (MH)	69.9 (15.3)	70.0 (15.7)	75.3 (21.8)	63.5 (13.2)^a
Vitality (VT)	63.2 (18.8)	66.8 (15.8)	62.3 (18.2)	53.8 (13.7)^a
Bodily pain (BP)	62.2 (16.6)	86.3 (18.8)^a	84.4 (19.0)^a	62.4 (38.4)
General health (GH)	60.8 (18.5)	57.4 (18.3)	75.6 (20.8)^a	54.5 (15.6)

^a*p* < 0.01 compared with current study (in bold).

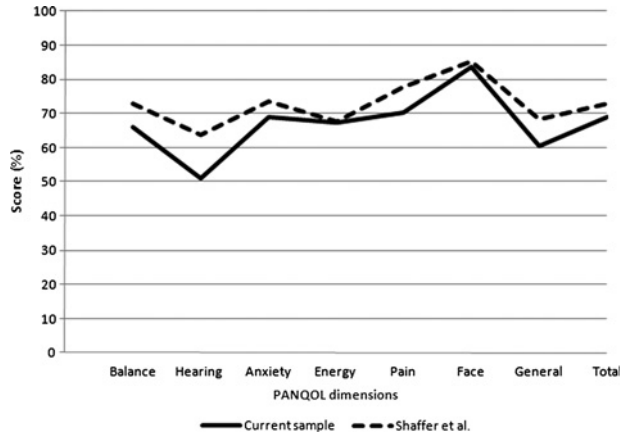


FIG. 1. Comparison of SF-36 scores in the current study compared with 3 other VS samples (5,17,18). PF indicates physical functioning; SF, social functioning; PR, physical role limitations; ER, emotional role limitations; MH, mental health; VT, vitality; BP, bodily pain; GH: general health.

General, and the SF-36 dimensions Physical Functioning, Social Functioning, Mental Health, Vitality, Bodily Pain and General Health, respectively. The PANQOL domain Face did not correlate strongly with any SF-36 domain.

DISCUSSION

Patients diagnosed with VS have shown an impaired QoL from the moment of diagnosis, measured with the generic SF-36 and the disease-specific PANQOL. Factor analysis has shown a 7-dimensional structure as published in the original USA PANQOL sample (25). This finding is a substantiation of the validity of this questionnaire.

For almost all PANQOL dimensions, we found significant correlations with the SF-36 domains (Table 4). Overall, the PANQOL seems to be a valid and relevant QoL questionnaire for VS patients.

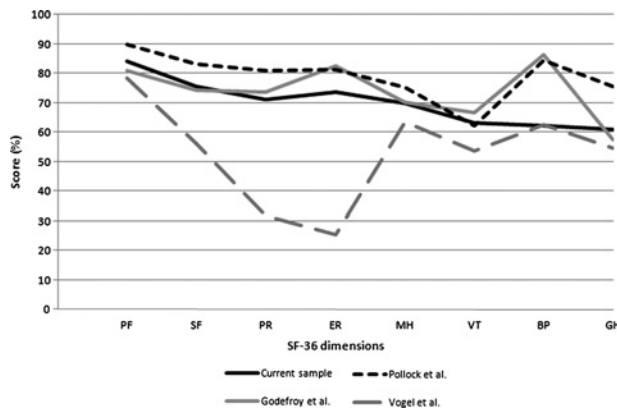


FIG. 2. Comparison of PANQOL scores in current sample and USA sample (25). *Significant difference, $p < 0.01$, compared with the current study.

TABLE 3. Means and standard deviations, and internal consistency (Cronbach's alpha) of Penn Acoustic Neuroma Quality of Life Scale dimensions of vestibular schwannoma patients (N = 119) in the current study and those in the original USA Penn Acoustic Neuroma Quality of Life Scale study (25)

PANQOL dimension	Mean (SD), current study	Mean (SD), Shaffer et al. (25)	Internal consistency, current study	Internal consistency, Shaffer et al. study (25)
Balance	66.0 (29.4)	72.9 (20.5)	0.94	0.87
Hearing	41.3 (27.3)	63.8 (22.2)	0.75	0.77
Anxiety	71.3 (25.2)	73.5 (20.4)	0.88	0.81
Energy	66.2 (28.9)	67.6 (23.0)	0.91	0.88
Pain	70.4 (35.9)	77.7 (28.7)	NA	NA
Face	83.6 (21.3)	85.4 (18.9)	0.65	0.71
General	60.4 (22.1)	68.3 (21.3)	0.31	0.73

NA indicates not applicable because only one item is included in this dimension.

Because strong correlations between the SF-36 and the PANQOL were found in this study, one may wonder about the advantages of the PANQOL. The SF-36 as a generic QoL measurement has, by definition, limitations concerning disease-specific problems, such as sensorineural hearing loss, associated tinnitus, vertigo, or imbalance. The PANQOL focuses on these disease-specific life-limiting aspects and measures specifically VS-induced QoL. As a result, we obtain a QoL related to VS, not influenced by coexisting morbidity and factors that are not associated with VS. Because of this, the PANQOL is clinically more relevant than the SF-36 in patients with VS when one wants to assess disease specific QoL in patients with VS.

In this study, SF-36 scores of patients recently diagnosed with VS are comparable to previously published studies measuring QoL at diagnosis before treatment, indicating a severely reduced QoL (5,17,18). We compared the results from the current study with those of the

TABLE 4. Intercorrelations between dimensions on SF-36 and Penn Acoustic Neuroma Quality of Life Scale in the current study (N = 119).

Penn Acoustic Neuroma Quality of Life Scale dimensions	SF-36 dimensions							
	PF	SF	PR	ER	MH	VT	BP	GH
Balance	0.64	0.39	0.45	0.43	0.38	0.52	0.27	0.47
Hearing	0.32	0.54	0.45	0.42	0.43	0.51	0.30	0.34
Anxiety	0.36	0.41	0.31	0.36	0.61	0.42	0.31	0.43
Energy	0.54	0.56	0.62	0.56	0.59	0.70	0.46	0.43
Pain	0.42	0.44	0.31	0.21	0.32	0.38	0.58	NS
Face	0.40	0.44	0.30	0.35	0.41	0.43	0.37	0.37
General	0.39	0.44	0.41	0.43	0.41	0.46	0.24	0.53

PF indicates physical functioning; SF, social functioning; PR, physical role limitations; ER, emotional role limitations; MH, mental health; VT, vitality; BP, bodily pain; GH, general health; only statistically significant correlations (p 0.01 or lower), are given. The strongest correlations are given bold. NS, not significant. The correlations are Pearson's product-moment correlation coefficients.

PANQOL study sample by Shaffer et al. (25). When the exploratory factor analysis was applied to our results, we found some differences compared with Shaffer et al. (25). The factor analysis implies that most questions point to specific dimensions. One item of the hearing dimension (“I often feel isolated as a result of my diagnosis of acoustic neuroma”) showed a (high) load on the anxiety dimension. It is probable that anxiety, rather than hearing loss, is influential in the feelings of isolation.

Measuring QoL becomes increasingly important in modern medicine as a factor in determining the effects of medical treatment. Perhaps QoL is just as meaningful to people as being healthy. Yet it remains striking that QoL in VS patients is worse than patients with other chronic illnesses, even those with head and neck cancer (17). Most physicians anticipate that the diagnosis of head and neck cancer in patients will have a much larger impact as this condition will (most likely) require major surgery and patients will face possible death. Patients with any choice of treatment (i.e., watchful waiting, microsurgical removal or stereotactic irradiation therapy) may have difficulty in making such a decision. Another explanation is that VS patients feel misunderstood; physicians have diagnosed them with a tumor inside their head, and the vast majority follows a watchful waiting policy. A wait-and-scan policy may make people feel uncomfortable or scared because they feel they have a “time bomb” in their head, and physicians just wait and do not remove it. It seems important to know what impact our approach has on the QoL of patients, as well as when and how we should measure QoL. Identifying QoL is essential because once we know the factors which are relevant, then we can anticipate the effects of treatment and make adjustments to that treatment. QoL should be taken into consideration during decision making and in the proposal of treatment.

QoL is about a person’s sense of well-being, arising from satisfaction or dissatisfaction with the domains of life that he or she considers important. Therefore, QoL inventory will be interpreted from a personal point of view (i.e., subjective) (1,33). The question remaining is whether patients are influenced by either conversations with their physician or nurse practitioners on their tumor, or whether they are influenced by more widely available information (e.g., internet).

A drawback of the PANQOL is the reliability of the dimension. General, which is psychometrically unacceptable (Cronbach’s alpha value of 0.31). This is explained by the fact that there are only 2 questions about general health in this questionnaire. Another drawback is that the Pain dimension consists of only 1 item.

Studies examining factors that influence the QoL in VS patients show that illness perceptions and coping are major determinants (17). Therefore, the key question in further VS research is how patients cope with their disease and which factors contribute to this coping mechanism. If these factors are known, we can address them in the proposal for treatment and in optimizing decision making and in information provision for patients. QoL

may be used as a warning tool for proactive anticipation of needs of the patient and on whether reconsidering treatment or the need for physical, physiologic, or social support. In recent literature, a wealth of publications is available on self-management education programs for patients with chronic illnesses that improve patients QoL (33–35).

Our research group will use the PANQOL in further studies to evaluate factors contributing to the QoL of VS patients. In addition, we aim at developing interventions that focus on changing illness perceptions and assessing the effect of these interventions on QoL. In similar studies, encouraging results have already been achieved (36).

CONCLUSION

This study is the first in which the PANQOL is used to measure QoL of VS patients in patients outside the USA at the moment of diagnosis. A significantly impaired QoL was found in patients recently diagnosed with VS, both when using the PANQOL as the SF-36. In our sample, evidence to confirm the 7-dimensional structure of the original PANQOL was found.

The PANQOL seems to be a valid measure of QoL in our sample of VS patients and correlates with all the dimensions of the SF-36. The issue of which determinants contribute to the reduced QoL in these patients needs further exploration. QoL should be included in any study in patients with vestibular schwannoma, both as a descriptive measure and in intervention studies as an outcome variable.

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