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Patient quality of life after vestibular schwannoma removal: possibilities and limits to measuring different domains of patients' wellbeing

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Abstract

Purpose Since the 1980s, health-related quality of life (HRQOL) has been recognized in the assessment of medical treatment. To determine the health-related quality of life (HRQOL) of vestibular schwannoma (VS) patients, a specific questionnaire that has been validated in different languages is essential.

Methods The Short Form-36 Health Survey (SF-36) and PANQOL questionnaires in German were evaluated in patients after removal of a VS via the translabyrinthine approach. Descriptive statistics of a comparison of the SF-36 results to those of a normal sample are illustrated. Criterion validity was investigated using Spearman's rank test to correlate the PANQOL domains with the SF-36 domains. A confirmatory factor analysis of the PANQOL was performed to determine the stability of the factor structure of the PANQOL questionnaire for our cohort.

Results The criterion validity of the German PANQOL questionnaire is comparable to that of the original English version. The SF-36 domains values ranged from 49.31/100 (role physical) to 66.46/100 (physical functioning). Compared to the normal population, patients who underwent surgical removal of a VS showed a significantly reduced quality of life, mainly in domains such as physical and social functioning, as well as psychological wellbeing.

Conclusion The German PANQOL has been validated and is now available. Post-surgical treatment should be focused not only on physiological rehabilitation but also on improving the quality of life, especially aspects of psychological and social wellbeing.

Keywords Health-related quality of life · Vestibular schwannoma · PANQOL · SF-36

Introduction

Since 1981, health-related quality of life (HRQOL) has been recognized as a parameter in the appraisal of medical treatments [1]. In addition to clinical indicators of disease activity, the patient's perception of their health status also affects the outcome assessment. The WHO states that "Quality of life is defined as an individual's perception of his/her position in life… affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment" [2]. Currently, evaluation of the HRQOL of patients with a vestibular schwannoma (VS) has moved into focus for skull base surgeons, radiotherapists, and other medical disciplines. Physician recommendation is the most commonly stated reason for choosing a treatment strategy, followed by "less invasive option than surgery" for stereotactic radiosurgery, "to avoid side-effects of treatment" for observation, and "do not want tumor in head" for microsurgery [3]. When comparing the decision for VS resection versus active surveillance, a significant association exists between psychological factors and patients pursuing surgery, including quality of life, depression, and self-esteem [4]. Quality of life has gained importance in medicine in recent years and has shifted the attention of physicians, with

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respect to treatment evaluation, from clinical and technical aspects toward a more patient-oriented focus on wellbeing. Currently, it is possible to evaluate the quality of the existing assessment tools and the benefits of including them in daily clinical practice.

In our preliminary work, our group translated the original English PANQOL into a German version [5] (Fig. 1) and evaluated the reliability and discriminative validity [6]. The test criteria in the given structure showed satisfactory, but not excellent results in some domains, possibly due to an unstable factorial structure of the questionnaire. Therefore, we examined criterion validity of the German PANQOL and investigated the factorial structure of the PANQOL in our patient cohort. Although the PANQOL questionnaire was shown to be an effective and specific tool for HRQOL measurement, it might have some limitations [6]. To determine the quality of life of VS patients, a specific questionnaire that has been validated in different languages is essential. Our data should enable a suitable application of the PANQOL questionnaire also in the German-speaking countries.

Materials and methods

Patients

The study was approved by the local research ethics committee. Among a homogeneous population of patients who had undergone microsurgery, we chose only patients who underwent translabyrinthine approaches. Patients with subtemporal or retrosigmoid approaches to the cerebellopontine angle, revision surgeries and surgeries after radiation were excluded. A total of 103 VS patients underwent microsurgical translabyrinthine tumor removal in our hospital between January 2007 and January 2017. Of these, 72 patients of legal age with fully completed PANQOL and SF-36 questionnaires were included. Additionally, a retrospective chart review was conducted to collect preoperative (sex, age, hearing impairment, tumor side, and size) and postoperative characteristics and symptoms (facial paresis and vertigo)[15].

Questionnaires

The general Short Form-36 Health Survey (SF-36) is an established, cross-disease measurement tool that quantifies the HRQOL and is used for validity verification of other questionnaires. The domains comprise vitality (VT), physical functioning (PF), body pain (BP), general health (GH), role limitations due to physical health (role physical, RP), role limitations due to emotional health (role emotional, RE), social functioning (SF), and mental health (MH). The results are comparable to other diseases or normal cohorts. The Penn Acoustic Neuroma Quality-of-Life Scale (PANQOL) is a questionnaire specifically for individuals with a VS. It covers the domains of hearing, balance, facial paralysis, pain, anxiety, energy, and general health.

Statistical analysis

Descriptive statistics were calculated for the SF-36 questionnaire results. A correlation matrix (Spearman's rank correlation coefficients) was generated between the PANQOL and SF-36 domains. A confirmatory factor analysis of the PANQOL was performed, and the model fit was tested, according to the criteria and two index recommendations of Hu and Bentler [7], to assess the factorial structure suggested by Shaffer et al. [8]. All statistical analyses were performed using the R language and environment for statistical computing and graphics, including the "psych" and "lavaan" packages for R [9, 10].

Results

Comparison of SF-36 scores of VS patients with the general population and patients with uni- or bilateral hearing impairment

The SF-36 scores of patients after translabyrinthine removal of VS were much lower than those of the general German population [11]. All eight domains were affected: PF, RP, BP, GH, VT, SF, RE, and MH. The differences between our cohort and the values for German patients with uni- or bilateral hearing impairment [11] were lower than those of the general German population (Table 1). The greatest differences compared to the general German population were found for the RP (− 31.9), SF (− 29.9), and RE (− 22.0) domains. When our cohort was compared to patients with uni- or bilateral hearing impairment, major differences were found for the SF (− 22.6), RP (− 14.8), and RE (− 9.6) domains. Almost no differences were found in the PF, GF, MH, and VT domains. Our cohort showed better values for the BP domain (+ 9.1).

Criterion validity—correlation matrix (Spearman)

Criterion validity was investigated using Spearman's rank test to correlate the PANQOL domains with the SF-36 domains (Table 2). Regarding criterion validity, it was assumed that the specific PANQOL domains would have a strong association with the SF-36 domains, which describe a more general construct of HRQOL but also represent aspects of quality of life that might be relevant to patients with impaired hearing and balance.

Regarding the PANQOL domains, "anxiety" was strongly correlated with the SF-36 domains VT, SF, and

Fragebogen: PANQOL – Lebensqualität bei Patienten mit Akustikusneurinom (Vestibularisschwannom)

Bitte beurteilen Sie, ob die Aussagen auf Sie zutreffen oder nicht.
1 = trifft gar nicht zu / 5 = trifft völlig zu

Kreisen Sie in jeder Zeile eine Zahl zwischen 1 und 5 ein.

	trifft gar nicht zu	trifft nicht zu	teils/teils	trifft zu	trifft völlig zu
1. Meine Hörminderung beeinträchtigt meine persönlichen Beziehungen.	1	2	3	4	5
2. Ich habe wegen der Hörminderung Schwierigkeiten, ein Gespräch zu führen.	1	2	3	4	5
3. Meine Konzentration wird durch Klingeln, Rauschen oder andere Geräusche im Ohr beeinträchtigt.	1	2	3	4	5
4. Ich habe erhebliche Probleme mit Schwindel.	1	2	3	4	5
5. Ich habe ein Unsicherheitsgefühl oder Gleichgewichtsstörungen.	1	2	3	4	5
6. Beim Stehen oder Gehen habe ich das Gefühl mich zu drehen oder zu fallen.	1	2	3	4	5
7. Richtungswechsel beim Gehen bereiten mir wegen des Schwindels und der Gleichgewichtsstörungen Schwierigkeiten.	1	2	3	4	5
8. Ich habe Schwierigkeiten, mich zu Hause im Dunkeln zu bewegen.	1	2	3	4	5
9. Ich befürchte, die Leute könnten wegen meiner Gleichgewichtsstörung denken, ich sei betrunken.	1	2	3	4	5
10. Ich verhalte mich in Gesellschaft von Menschen anders, weil ich Schwierigkeiten habe mein Gesicht zu bewegen.	1	2	3	4	5
11. Ich habe ein unangenehmes Gefühl, ein Jucken oder ein starkes Tränen in einem Auge.	1	2	3	4	5
12. Meine eingeschränkte Beweglichkeit im Gesicht hat sich auf meine Aussprache ausgewirkt.	1	2	3	4	5
13. Auf Grund meiner Erkrankung Akustikusneurinom (Vestibularisschwannom) schaffe ich weniger, als ich möchte.	1	2	3	4	5
14. Auf der Seite meines Akustikusneurinoms (Vestibularisschwannoms) habe ich Kopfschmerzen.	1	2	3	4	5
15. Manchmal bekomme ich Angst, dass etwas Schlimmes passieren wird.	1	2	3	4	5

Bitte beachten Sie die Rückseite !

Fig. 1 German version of the PANQOL

MH. "Facial paralysis" was not highly correlated with any SF-36 domain. "General health" was correlated with the SF-36 domains GH, VT, SF, and MH. Balance was highly correlated with the PF, RP, VT, and SF domains. Hearing was strongly correlated with the RP, VT, and SF domains. "Energy" was highly correlated with the RP, VT, SF, and

	trifft gar nicht zu	trifft nicht zu	teils/teils	trifft zu	trifft völlig zu
16. Ich mache mir oft Sorgen.	1	2	3	4	5
17. Ich fühle mich verlangsamt.	1	2	3	4	5
18. Manchmal bin ich ängstlich und habe ein flaues Gefühl im Magen.	1	2	3	4	5
19. Ich habe Panikattacken.	1	2	3	4	5
20. Aufgrund meiner Erkrankung Akustikusneurinom (Vestibularisschwannom) fühle ich mich oft isoliert.	1	2	3	4	5
21. Es fällt mir manchmal schwer, mich zu konzentrieren, z.B. beim Zeitunglesen oder beim Fernsehen.	1	2	3	4	5
22. Ich bin ungeduldiger geworden.	1	2	3	4	5
23. Ich habe kaum noch Energie oder Antrieb.	1	2	3	4	5
24. Ich habe Schwierigkeiten, mich an Dinge zu erinnern.	1	2	3	4	5
25. Ich bin kerngesund.	1	2	3	4	5
26. Ich erwarte, dass sich mein Gesundheitszustand im kommenden Jahr verschlechtern wird.	1	2	3	4	5

Herzlichen Dank für Ihre Teilnahme

Fig. 1 (continued)

Table 1 Descriptive statistics (SF-36) of patients who underwent translabyrinthine VS removal compared to a normal cohort (German population) and a cohort with uni- or bilateral hearing impairment (German population)

Domains	*n*	Mean (SD)	German norm Mean (SD)	Difference	Hearing impairment uni- or bilateral (German population)	Difference
Physical functioning	72	66.5 (28.0)	83.8 (23.6)	−17.3	66.22 (28.5)	+0.2
Role physical	72	49.3 (40.7)	81.2 (33.8)	−31.9	64.07 (40.0)	−14.8
Bodily pain	72	72.2 (28.3)	77.2 (28.5)	−5.0	63.05 (29.9)	+9.1
General health	72	54.9 (21.7)	66.2 (21.0)	−11.3	54.84 (22.1)	+0.1
Vitality	72	49.2 (19.7)	61.8 (19.2)	−12.6	53.10 (19.5)	−3.9
Social Functioning	72	57.8 (19.2)	87.7 (19.5)	−29.9	80.42 (22.0)	−22.6
Role emotional	72	66.2 (40.5)	88.2 (28.3)	−22.0	75.84 (38.6)	−9.6
Mental health	72	66.0 (17.7)	72.8 (17.3)	−6.8	67.85 (16.4)	−1.8

MH domains. Finally, the "pain" domain was remarkably correlated with the BP domain from the SF-36. The PANQOL "total" domain showed high coefficients for the RP, GH, VT, SF, and MH domains.

The correlation of the general health domain of the PANQOL versus the SF-36 was 0.78 ($p < 0.01$), but the reliability of the domain in the PANQOL questionnaire was poor (0.39) [6], indicating that this value has no impact. Specific problems such as facial paralysis did not show a satisfying correlation with the SF-36 domains. As the reliability of the pain domain is not calculable [6], the criterion validity values are not meaningful.

Confirmatory factor analysis

A confirmatory factor analysis of the PANQOL was performed to assess the factorial (domain) structure suggested by Shaffer et al. [8]. Model test criteria were chosen according the recommendations of Hu and Bentler

Table 2 Correlations (Spearman) between the PANQOL and SF-36 domains

SF-36 domains	PANQOL-domains							
	Anxiety	Facial paralysis	General health	Balance	Hearing	Energy	Pain	Total
Physical functioning	0.38**	0.21+	0.51**	**0.68****	0.41**	0.55**	0.29*	0.57**
Role physical	0.44**	0.30*	0.45**	**0.58****	**0.57****	**0.61****	0.38**	**0.64****
Body pain	0.35**	0.33**	0.38**	0.31**	0.38**	0.39**	**0.51****	0.50**
General health	0.58**	0.26*	**0.78****	0.56**	0.55**	0.55**	0.29*	**0.67****
Vitality	**0.59****	0.22+	**0.53****	**0.58****	**0.58****	**0.73****	0.38**	**0.70****
Social functioning	**0.64****	0.35**	**0.63****	**0.61****	**0.65****	**0.69****	0.36**	**0.74****
Role emotional	0.43**	0.19+	0.34**	0.49**	0.45**	0.50**	0.13+	0.49**
Mental health	**0.65****	0.25*	**0.55****	0.49**	0.47**	**0.61****	0.25*	**0.60****

*$p < 0.05$, **$p < 0.01$, + not significant (n.s.). High coefficients are printed bold

Table 3 Confirmatory factor analysis—PANQOL (factorial structure as explained by Shaffer et al. [8])

Number of observations	72
Estimator	ML
Minimum function test statistic	375.023
Degrees of freedom	279
p value (Chi-square)	0.000
User model versus baseline model	
Comparative fit index (CFI)	0.908
Root mean square error of approximation	
RMSEA	0.069
90 percent confidence interval	0.050 0.087
p value RMSEA ≤ 0.05	0.053
Standardized root mean square residual	
SRMR	0.075

[7], who suggested using a two index strategy to present model fit indices, including the maximum likelihood-based standardized root mean squared residual (SRMR), and supplementing it with a second fit index, for example, with the Tucker–Lewis index (TLI), comparative fit index (CFI), root mean square error of approximation (RMSEA) or other indices. However, decisions on model fits in general are difficult for conditions with a small sample size. In such cases, Hu and Bentler prefer to use combinations of the CFI and SRMR. Fit indices are shown in Table 3. According to the suggestions of Hu and Bentler, a CFI < 0.96 together with an SRMR > 0.09 are recommended as the cutoff criteria for model rejection if the sample size is ≤ 250. Our model showed fair-to-good fit with an SRMR = 0.075 but fair-to-poor fit for the CFI (0.0908). Additionally, the maximum likelihood Chi-square test (ML) showed a significant result, which indicates a reasonable deviation between the empirical and model-based covariance matrices. Therefore, the model fit does not seem to be appropriate (Table 3).

Discussion

Taking the minimal clinically important difference (MCID) of the quality-of-life assessment into account [12], our SF-36 scores of VS patients after translabyrinthine removal were still lower than those of the general German population (normal population), except for the BP and MH domains. Based on a comparison of our SF-36 results of quality of life after surgical removal of VS with those of other studies, our cohort seems to be affected in the same manner over most domains [13–15]. Carlson et al. [12] defined the MCID for VS to answer the question of whether a several-point disparity on a 100-point scale matters clinically, even when significantly different [16]. Knowing and including the specific MCIDs should be considered for interpreting the results of VS treatments using the SF-36 and PANQOL.

We also compared our postoperative values with the values of patients with uni- or bilateral hearing impairment (normal population), and the largest differences were found for the SF (− 22.6) and RP (− 14.8) domains. The PF, GH, MH, and VT domains showed no clinically important differences. In general, these results show that even though patients may be successfully treated from a technical point of view after the surgical intervention, many complain about a loss of quality of life in the long term, which may lead to depression or other psychological problems. Thus, early psychosomatic care could help reduce these symptoms. Comparable interventions in the context of psycho-oncological care have positive effects on emotional distress [17] and quality of life; therefore, a similar interventional concept for patients suffering from a VS could be successful.

Since the German version of the PANQOL [5] is used as an assessment tool, it is necessary to test and confirm its criterion validity. We chose the SF-36 questionnaire as external criterion because of its widespread use as established tool. We previously showed that the reliability and convergent validity were similar to the original [6]. The criterion validity is the correlation between an instrument and a valid gold

standard. The reliability of the individual domains should always be considered in the correlation matrix assessment. Using a correlation matrix (Spearman), we confirmed that appropriate correlations between the SF-36 and PANQOL were made (values > 0.5 were acceptable). The balance domain correlated well with different domains of the SF-36 but was not represented specifically. The SF-36 questionnaire provided valuable information for the global disease context, comparing the quality of life in VS patients to that in patients with other conditions. Based on our reliability [6] and validity results, we revised the factorial structure of the original questionnaire including seven domains (anxiety, facial dysfunction, general health, balance, hearing, energy, and pain). The model fit of the confirmatory factor analysis was not satisfying, possibly due to the relatively small sample size. Therefore, it is difficult to determine whether the original factorial structure of the PANQOL is also represented within German samples or patient populations. To provide an established instrument for daily clinical use, we recommend further work with the seven-factor structure. Furthermore, additional PANQOL data from other patients should be collected so that a confirmatory factor analysis can be conducted with a sufficient sample size. In the case of a poor model fit, exploratory analyses will be needed to investigate the sample-specific factorial structure.

The pain domain is represented by only a single item on the PANQOL and one of the limits to measure domains of patients' wellbeing. It is not possible to calculate the internal consistency as a measure of reliability (Cronbach's alpha), which also may affect the validity. Few studies have investigated the role of headache in vestibular schwannoma patients. Patients have reported a post-surgical headache as one of the most common presenting symptoms after unilateral hearing loss and balance disturbance and as one of the most difficult aspects of the vestibular schwannoma experience [18]. In addition to ongoing dizziness, headache seems to be the strongest predictor of long-term reduction in VS patient quality of life [19]. Regarding different surgical approaches, headaches resolved more often within 12 weeks after translabyrinthine approaches (48.4%) than after retrosigmoid approaches (23.4%) but had similar instances after 1 year [20]. In general, the translabyrinthine approach leads to a lower incidence (17.3%) of postoperative headache than the retrosigmoid approach (42.5%) [21]. In a long-term follow-up study (approximately 8 years after treatment), approximately half of VS patients still experienced headaches of varying frequency and severity [22]. Untreated VS patients are more than twice as likely to suffer from a severe headache disability than individuals without a VS. Patients with a small VS [20, 23, 24], age 40 years [18] and of female gender [20] seem more predisposed to headaches. It is important not to overlook providing sufficient analgesia for these patients while focusing on more obvious symptoms such as vertigo or facial palsy. To fully cover this domain, we recommend using a supplementary questionnaire, for example, the Headache Disability Inventory (HDI).

Goebel et al. [25] list a new aspect that has not yet been studied in detail: the influence of cognitive disorders, fatigue, and elevated mood symptoms on HRQOL in patients with untreated tumors of the cerebellopontine angle (VS and meningioma). The majority of their patients showed neurocognitive impairment, one-third clinically relevant depression/anxiety, and almost half of them high levels of fatigue. The symptoms significantly influenced the HRQOL of the patients examined. Hio et al. [26] were able to detect depression (SDS—Self-rating Depression Scale) in 26.7% of patients with untreated VS, where significantly more patients with hearing loss of the opposite side were affected. Investigations with the HADS score (Hospital Anxiety and Depression Scale) showed a non-increased rate of depression after microsurgery [27] compared to the general population. In the case of anomalies in the PANQOL questionnaire, this should be followed up further, if necessary by specific questionnaires or a targeted psychological examination. It is important that attending physicians assess the cumulative effects of multiple symptoms and comorbidities for VS patients.

Conclusion

After the translabyrinthine surgical removal of a VS, patients show a significantly reduced quality of life compared to the normal population. The criterion validity of the German PANQOL was tested and found to be comparable to that of the original questionnaire. Our results now enable the questionnaire to be used in German-speaking countries as well. In general, a more patient-centered perspective with a focus on individual physical and psychological impairment should be taken. As a solution, psychosomatic care should be considered if necessary.

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Compliance with ethical standards

Conflict of interest All authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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