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Vestibular Schwannoma Treatment : from quality of life towards quality of care

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Citation

Leeuwen, B. M. van. (2016, December 13). *Vestibular Schwannoma Treatment : from quality of life towards quality of care*. Retrieved from <https://hdl.handle.net/1887/44774>

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Title: Vestibular Schwannoma Treatment : from quality of life towards quality of care

Issue Date: 2016-12-13

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The art of perception: patients drawing their vestibular schwannoma

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ABSTRACT**Objectives/Hypothesis**

Drawings made by patients are an innovative way to assess the perceptions of patients on their illness. The objective of this study, at a university tertiary referral center, on patients who have recently been diagnosed with vestibular schwannoma, was to examine whether patients' illness perceptions can be assessed by drawings and are related to their quality of life.

Study Design

Cross-sectional study.

Methods

Patients diagnosed with vestibular schwannoma (mean age [range], 55.4 [17–85] years) between April 2011 and October 2012 were included (N5253). Sociodemographics, illness perceptions (Brief Illness Perception Questionnaire [B-IPQ]), and disease-specific quality of life (Penn Acoustic Neuroma Quality of Life [PANQOL] scale) were assessed to evaluate the impact of being diagnosed with vestibular schwannoma. Furthermore, patients' drawings of their tumor were analysed to explore the association between illness perceptions, drawings, and quality of life.

Results

Comparison of the B-IPQ scores of the current sample (N5139; response rate 54.9%) with other disease samples shows a significantly lower score for patients with vestibular schwannoma on the Coherence dimension, indicating a low understanding of the illness. Illustration of emotions (N512) in the drawings gave a negative association with quality of life. Intercorrelations indicate a positive association between a low amount of physical and emotional consequences of the illness and a higher score on the Balance, Hearing, and Energy dimensions of the PANQOL.

Conclusions

Patients' drawings give an insight into their perception of the tumor inside their head. Use of drawings may be helpful when developing and offering self-management programs. Quality of life appears to be significantly affected by the diagnosis.

INTRODUCTION

Vestibular schwannomas (VS) are benign, often slow-growing tumors of the vestibulocochlear (eighth cranial) nerve.¹ However, patients who are diagnosed with VS may not perceive their tumor as benign at all. They often suffer from a great deal of anxiety and uncertainty regarding the tumor growing in their head and the possibility of (aggravated) hearing loss, tinnitus, vertigo, facial paralysis, and death.²

All of these factors may have a serious impact on the patients' illness perceptions (IPs) and quality of life (QoL). In the common sense model of self-regulation (CSM),³ patients' responses to health threats determine how patients manage their illness.^{4,5}

IPs are based on the patients' cognitions and emotions in relation to complaints, symptoms, causes, consequences, and their future perspective with reference to their illness. Patients' IPs are significantly associated with physical, psychological, and social well-being and functioning.⁶ It seems that these perceptions play an important role in the variation of the severity of disease as experienced by the patients and therefore with their QoL.^{7,8} According to current literature, patients with VS experience reduced QoL from the moment of diagnosis.^{1,9-19} Recently, five studies have been published regarding QoL in patients with VS. All studies focused on (long-term) QoL after three different treatment options.¹⁹⁻²³ Recently, a systematic review was provided by Gauden et al.,²⁴ who advised further research using a disease-specific QoL measure. Until now, five study groups have used a disease-specific QoL questionnaire, the Penn Acoustic Neuroma Quality of Life (PANQOL) scale, to evaluate patients with VS.^{9,10,19,21,25,26}

Patients' QoL depends on many determinants. In the context of the CSM, sociodemographic, clinical, and psychological factors (i.e., illness perceptions) are the main determinants, not only in patients with VS, but in any illness category. Identified determinants of QoL in patients with VS before, during, and after treatment are male gender, balance disorders, vertigo, hearing loss, facial nerve or trigeminal nerve dysfunction, microsurgical resection, psychological factors (i.e., optimism, control), emotional intelligence, and IPs.^{18,27-33}

In the past decades, increased attention has been paid to patient reported outcome measures (PROM) when evaluating the effect of medical treatment, rather than physicians interpreting the patients' responses.^{34,35}

Patients' perceptions are crucial in determining their QoL.^{7,36} An innovative way in which the cognitive and emotional response of patients can be established is by asking them to make a drawing of their illness.^{2,37} The concept of the drawings started in 1961, when

Table 1. Characteristics of drawings according to the literature.

First author	Publication, country	Number of patients and type of illness	Characteristics of drawings
Gabriels ⁴¹	2000, USA	23 Asthma (children)	Drawn affect Verbalized affect Level of detail
Broadbent ⁴²	2004, New Zealand	74 Myocardial infarction	Size of drawing (area in percentages) Damage (yes/no) Size of damage (area in percentages) Number of blocked cardiac arteries (0/1/2/3) Expression of emotions (yes/no)
Guillemin ³⁷	2004, Australia	32 Heart disease	Exclusively heart or with other organs Correct anatomy of the heart or diptych Symptoms (yes/no) Expression of emotions Impact on society (yes/no) Use of colors (yes/no)
Reynolds ⁴⁰	2007, New Zealand	60 Heart failure	Size of drawing (area and height) Damage (yes/no)
Waweru ⁴³	2008, USA	6 HIV/AIDS (children)	Expression of emotions (Koppitz scoring)
Broadbent ⁴⁴	2009, New Zealand	27 Headache	Size of drawing (height and width) Location of pain, and number of places with pain Nature of pain (external/internal force) Expression of emotions (yes/no) Intensity of pen stroke
Daleboudt ⁴⁵	2011, The Netherlands	32 Systemic lupus erythematosus	Size of drawing (area) Number of kidneys (1/2) Size and distribution of damage (dots) Written explanation (yes/no)
Kaptein ²	2011, The Netherlands	13 Vestibular schwannoma	Size of drawing and tumor (area) Exclusively tumor or with surrounding tissue Shape of the tumor (line/round)
Wang ⁴⁶	2011, Australia	60 Cardiac abnormality (children)	Correct anatomy of the heart (scale 1-4) Correct description problem (scale 1-4)
Besser ⁴⁷	2012, United Kingdom	14 Osteoporosis	Size and shape of drawing Symptoms (spine curvature, loss of height, pain) Understanding of disease
Hoogerwerf ⁴⁸	2012, The Netherlands	12 Lung cancer	Size of drawing and tumor (area) Location of the tumor (correct/incorrect) Shape of the lung (correct/incorrect) Level of detail (high/low)
Lauche ⁴⁹	2012, Germany	6 Chronic neck pain	Position of the shoulders Completeness of drawing
LoK ⁵⁰	2012, Australia	12 Ventricular septal defect (children)	Size and site of defect Anatomy of heart (correct/incorrect)
Tiemensma ⁵¹	2012, The Netherlands	47 Cushing's syndrome	Size of drawing (height and width) Fat accumulation, skin lesions, changes in hair (yes/no) Expression of emotions (negative/positive/no)
Chong ⁵²	2013, New Zealand	52 Cerebral palsy (children)	Size of drawing and figure (height) Place of figure (inside/outside building)
Isla Pera ⁵³	2013, Spain	199 Diabetes mellitus (children)	Size of drawing (small/medium/large) Themselves / friends / family in drawing (yes/no) Health professionals / hospital in drawing (yes/no) Organs/elements/food related to diabetes/insulin (yes/no) Metaphoric / fantasy drawing (yes/no) Expression of emotions (sadness/worry/joy) Intensity of pen stroke and number of colors used
Luthy ⁵⁴	2013, Switzerland	32 Chronic obstructive pulmonary disease	Size of drawing (height and width) Body shape (partial/complete) Anatomical structures (yes/no) Obstruction of airflow (yes/no) Restriction of the lungs (yes/no) Dilatation of the lungs (yes/no)
Hatano ⁵⁵	2014, Japan	3 Cancer (children)	Size of drawing Place of drawing on the paper Level of detail (high/low) Expression of emotions (energy/anxiety/emptiness) Intensity of pen stroke, and use of colors (yes/no)

Craddick found that children's drawings of Santa Claus became larger as Christmas drew nearer.³⁸ Drawings made by patients have been successfully applied in a number of medical conditions and report that patients find it easier to illustrate their feelings more accurately by a drawing than they can express them with words.^{37,39,40} Previous studies on patients' drawings in which drawing characteristics were scored were identified by a PubMed search (March 20, 2015) and resulted in 18 studies (Table 1).^{2,37,40-55} These studies demonstrate that drawings made by patients reveal their perceptions on their illness.

Furthermore, positive patient perceptions of their medical condition represented in their drawing were found to be related to faster recovery, earlier return to work, and a higher QoL.^{40,42} No significant correlations between size of the drawing and psychological factors such as anxiety or depression were found.^{40,42}

With regard to patients with VS, a pilot study was done in 2011 to study their drawings before and after treatment. This study demonstrates that patients are willing and able to draw their tumors.² The authors hypothesized that drawings could be used as an outcome measure of patients' perceptions of their tumor, and that a comparison to objective measures could be made.^{2,12,56}

In this study, we aimed to investigate the use of drawings and explore their associations with IPs and QoL in patients who have recently been diagnosed with VS. To achieve this, we evaluated whether scores on the Brief Illness Perception Questionnaire (B-IPQ) dimensions, PANQOL scale dimensions, and drawing characteristics were associated. In addition, it was our aim to compare IPs of patients with VS with IPs of patients suffering from different chronic illnesses, reported in the literature.

MATERIALS AND METHODS

Participants

A cross-sectional study was performed in consecutive, newly diagnosed patients with VS in the period from April 2011 to October 2012. Patients were diagnosed in the Leiden University Medical Center, Department of Otorhinolaryngology and Head and Neck Surgery, or were referred to this tertiary center from all over the Netherlands. Patient characteristics were obtained from the patients' clinical charts and are summarized in Table 2. According to the international Kanzaki guidelines,⁵⁷ the tumor size was measured as the extracanalicular (longest cerebellopontine) dimension of the VS. Hearing was classified on the basis of the classification system of the Committee on Hearing and Equilibrium.⁵⁸ Class A is defined as normal hearing, Class B as moderate hearing loss, and

Class C and D as severe hearing loss. Patients who could not read Dutch or otherwise were unable to complete the questionnaire were not included. Patients with a diagnosis of neurofibromatosis type 2 or a cerebellopontine angle growth other than VS (i.e., meningioma) confirmed by radiologic examination were excluded from the study due to medical reasons.

Table 2. Patient characteristics and tumor characteristics of participating patients.

No. of participants	139
Age mean in years (range)	55.4 (17-85)
Gender, male - n (%)	68 (48.9)
Initial tumor size - n (%)	
Small (<11 mm)	85 (61.2)
Medium (11-20 mm)	32 (23.0)
Large (>20 mm)	22 (15.8)
Degree of hearing loss - n (%)	
Class A, normal hearing (<30 dB)	21 (15.1)
Class B, moderate hearing loss (30-50 dB)	47 (33.8)
Class C or D, severe hearing loss (>50 dB)	70 (50.4)
Unknown	1 (0.7)
Symptoms (patients could report > 1 symptom) - n (%)	
Tinnitus	107 (77.0)
Balance disorders	68 (48.9)
Vertigo	19 (13.7)
Cranial nerves dysfunction - n (%)	
Trigeminal nerve (N V) affected	15 (10.8)
Facial nerve (N VII) affected	4 (2.9)

Materials

B-IPQ

The B-IPQ⁵⁹ is a nine-item scale designed to assess the cognitive and emotional representations of illness: Consequences, Time Line, Personal Control, Treatment Control, Identity, Concern, Coherence, Emotional Response, and Possible Causes of the Disease. A higher score reflects a more threatening view of the illness. The B-IPQ is a valid and reliable measure of illness perceptions in patients with a variety of illnesses.⁶⁰ Further details can be found at <http://www.uib.no/ipq>

PANQOL scale—Dutch version

The PANQOL questionnaire is the first disease-specific QoL instrument for patients with VS. It has been developed and validated by Shaffer et al.⁹ and has been translated into Dutch by the current authors.¹⁰ The questionnaire consists of 26 multiple-choice questions on symptoms associated with VS. Participants are asked to rate each item on a Likert scale of 1 (strongly disagree) to 5 (strongly agree). The PANQOL scale consists of seven dimensions: Balance (six items), Hearing (three items), Anxiety (five items), Energy (six items), Pain (one item), Face (three items), and General Health (two items). A total score arises by calculating the average of all domain scores.

Procedure

Permission for this study was granted by the medical ethics committee of the Leiden University Medical Centre. Patients received a booklet that contained the B-IPQ, the PANQOL, and an empty page with a square of 14 x 17 cm and the following instruction: “Please draw a picture of what you imagine your tumor looks like. What other parts of your head are in close proximity to the tumor? This task is not about artistic ability; we are interested in your perception of the tumor and your own ideas about what has happened to your head ever since receiving the diagnosis.” The patients were asked to fill in the booklet at home, and send it back to the hospital in a stamped addressed envelope.

Statistical Analysis

B-IPQ

Means and standard deviations for the B-IPQ were calculated. Independent t tests were carried out to compare the B-IPQ dimension scores of the current sample to samples from previously published studies (Daleboudt et al.,⁴⁵ Husson et al.⁶¹ [patients without metastasis], Kaptein et al.,⁶² and Zivkovic et al.⁶³). Level of significance was calculated with a two-sided t test, with 95% confidence interval ($P < .05$).

Drawings

The drawings were scanned and analysed using the National Institutes of Health’s ImageJ software.⁶⁴ Two independent researchers (B.M.L., J.M.H.) measured the size of the tumor by following the drawn line that indicates the tumor. The ImageJ program enables accurate measuring and computing of the surface of the area that is measured. The same procedure was followed for the size of the total drawing by measuring the outer line of the drawing. The results of both researchers were averaged. In addition, the drawings in the current study were analysed for shape of the tumor (i.e., line or round shape), symptoms that are drawn (hearing, tinnitus, vertigo, unsteadiness), emotional expression

(yes or no), and level of details (high or low). Furthermore, a distinction was made between drawing the tumor exclusively or drawing the tumor including surrounding tissue. Three independent raters (B.M.L., A.G.L.M., A.A.K.) scored the drawings and reached consensus on each drawing characteristic.

PANQOL

Means and standard deviations for the PANQOL were calculated. Intercorrelations between the B-IPQ dimensions, drawing characteristics, and PANQOL dimensions were computed to explore associations between the IPs, drawings, and QoL. Data analysis was performed using the Statistical Package for the Social Sciences (SPSS version 20.0 for Windows; IBM, Armonk, NY).

RESULTS

Between April 2011 and October 2012, 253 patients presented with VS in the Leiden University Medical Center. One hundred thirty-nine patients (54.9%) completed and returned the questionnaires, including the drawing task, and were included in the study group. Baseline characteristics, which did not show significant differences compared to nonresponding patients, can be found in Table 2.

B-IPQ

The results of the comparison of the B-IPQ scores of the patients with VS and four other disease samples are given in Table 3. According to patients with VS, the illness does affect lives more than patients with colorectal carcinoma or melanoma think of their illness (Consequences dimension). Patients with lung cancer scored the highest on this dimension. The duration of the illness (Timeline dimension) is expected as longer by patients with VS than patients with colorectal carcinoma or melanoma expect of their illness, but shorter than patients with systemic lupus erythematosus (SLE) expect of their illness. The feeling of control over the illness (Personal Control dimension) in patients with VS is higher compared to patients with SLE or lung cancer, and lower compared to patients with melanoma. Patients with VS are more positive about the effect of treatment than patients with lung cancer or melanoma (Treatment Control dimension). Patients with SLE scored the lowest on this dimension. Patients with VS experience more symptoms than patients with colorectal carcinoma, lung cancer, or melanoma; however, patients with SLE experience the most symptoms from their illness (Identity dimension). On the Concern dimension, patients with VS scored lower than patients with SLE or lung cancer.

Table 3. Comparison of levels of illness Perceptions [mean and standard deviation] in the current study, compared to other illnesses using the B-IPQ.^{45;61-63}

B-IPQ dimensions	Current study		Daleboudt et al. ⁴⁵	Husson et al. ⁶¹	Kaptein et al. ⁶²	Zivkovic et al. ⁶³
	VS (N=139)	m (SD)	SLE (N=106)	Colorectal cancer (N=1020)	Lung cancer (N = 24)	Melanoma (N = 120)
Consequences	5.68 (2.85)	m (SD)	5.45 (2.58)	4.0 (2.5)**	7.50 (2.86)**	4.74 (3.00)**
Time line	7.07 (2.92)		8.44 (2.49)**	4.2 (3.3)**	6.13 (2.70)	5.78 (3.56)**
Personal control	5.85 (3.00)		4.88 (3.00)**	6.0 (3.1)	3.88 (3.60)**	6.61 (2.79)*
Treatment control	3.68 (2.74)		2.71 (2.23)**	3.5 (2.6)	6.82 (2.59)**	7.93 (2.12)**
Identity	5.24 (2.51)		6.14 (2.58)**	3.5 (2.6)**	3.70 (3.05)**	2.23 (2.62)**
Concern	6.02 (2.70)		6.90 (2.83)**	4.0 (2.5)**	7.83 (2.63)**	5.42 (3.21)
Coherence	2.64 (2.38)		3.29 (2.47)*	4.4 (3.0)**	5.58 (3.45)**	8.08 (2.21)**
Emotional response	5.28 (3.04)		5.50 (3.03)	3.6 (2.5)**	5.21 (3.09)	4.37 (2.91)*

Note: * p < .05; ** p < .01; NA: not applicable, VS: vestibular schwannoma, SLE: systemic lupus erythematosus, RA: rheumatoid arthritis. Higher B-IPQ scores reflect a more threatening view of the illness.



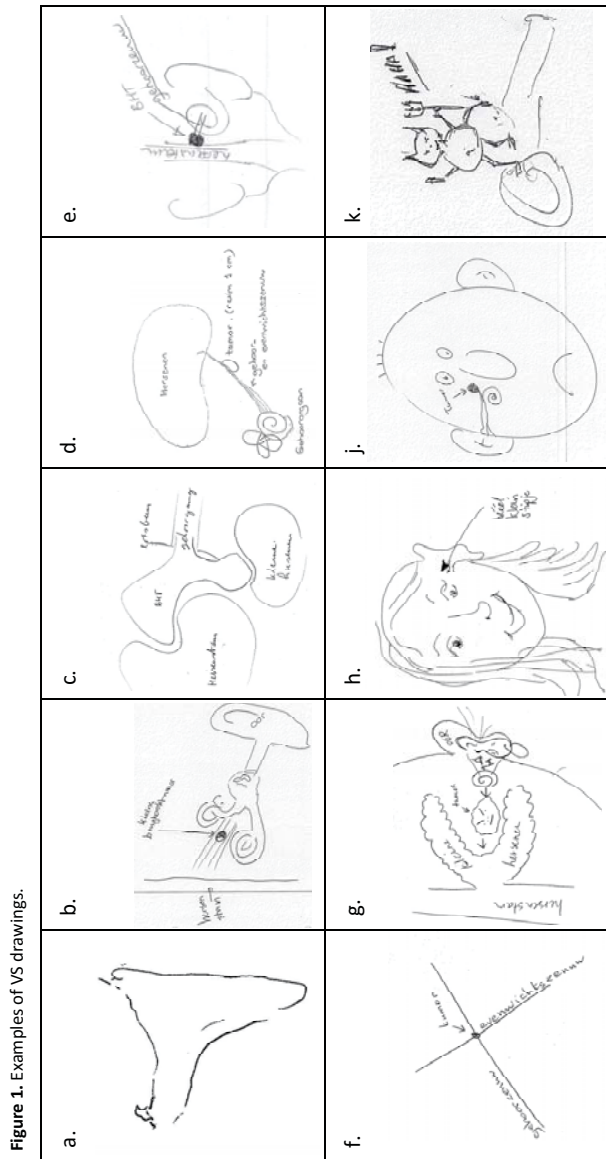


Figure 1. Examples of VS drawings.

Note: hersenstam (b,c,d,g) = brainstem; kleine brughoektumor (b) = small vestibular schwannoma; oor (b,g) = ear; BHT (c,d) = vestibular schwannoma; gehoorgang (c) = auditory canal; kleine hersenen (c,g) = cerebellum; rotsbeen (c) = petrosal bone; gehoorzenuw (d,e,f) = cochlear nerve; evenwichtszenuw (e,f) = vestibular nerve; gehoororgaan (e) = organ of hearing; heel klein stipje (h) = very tiny spot; tumor (e,f,g,i) = tumor; haha (k) = laughing loud.

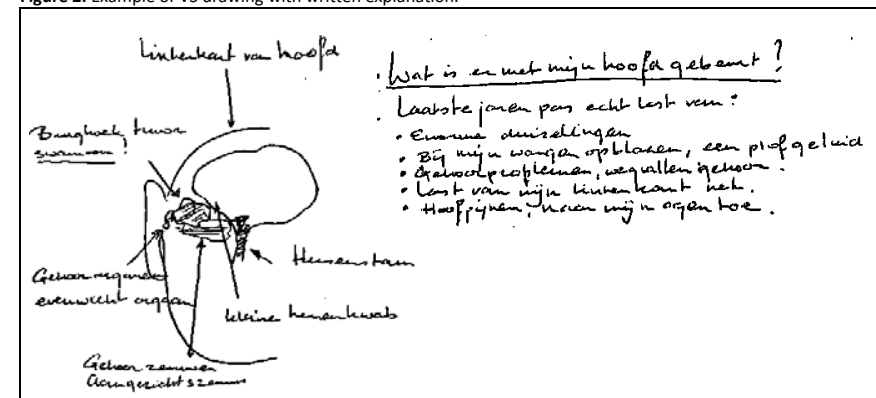
Patients with colorectal carcinoma scored the highest on this dimension. The most important significant differences were seen in the Coherence dimension (understanding of the illness), on which patients with VS scored significantly lower than patients in all the other disease samples. The score on the Emotional dimension response (fear response to an unknown health threat) is significantly higher than found in patients with colorectal carcinoma or melanoma.

What did the patients with VS draw?

A small number of patients (15.8%) made a drawing showing exclusively the tumor (Fig. 1a), whereas most patients (84.2%) drew the surrounding tissue as well (Fig. 1b,c). Most patients drew a tumor with a round shape (87%), other shapes (i.e., irregular, triangle) were rare. Forty-three patients (30.9%) drew the cochlear nerve (Fig. 1d–f). Thirty-three patients (23.7%) drew the vestibular nerve (Fig. 1e,f). Only five patients drew something pertaining to their tinnitus. The level of detail was low in the majority of the drawings (69.1%). Emotions were illustrated in only 12 (8.6%) drawings (Fig. 1g–k).

It is noteworthy that 73 patients placed written explanations on their drawing. An example is given in Figure 2.

Figure 2. Example of VS drawing with written explanation.



Note: brughoektumor = vestibular schwannoma; hersenstam = brainstem; gehoorsegment = organ of hearing; evenwichtsorgaan = organ of balance; kleine hersenkwab = cerebellum; gehoorzenuwen = cochlear nerve; aangezichtszenuw = vestibular nerve. Text: What has happened in my head? Only recently real problems: real dizziness, when inflating my cheeks a popping sound, hearing problems, hearing loss, pain on the left side of my neck, headaches towards my eyes.

PANQOL

The PANQOL scores of the current sample are given in Table 4. No statistically significant differences were found compared to previous published studies.^{8,9}

Table 4. Scores on the PANQOL dimensions [mean and standard deviation] in current sample of patients with VS (N=139)

PANQOL dimension	Current study (N=139) m (SD)
Balance	68.6 (29.3)
Hearing	41.7 (26.8)
Anxiety	73.2 (24.5)
Energy	69.7 (26.8)
Pain	71.6 (36.0)
Face	85.3 (19.9)
General	60.7 (21.8)
Total PANQOL score	67.5 (18.9)

Associations between drawing characteristics, IPs, and QoL

Intercorrelations between the B-IPQ dimensions and the PANQOL dimensions are given in Table 5. High significant negative correlations ($r > 0.50$; $P < .01$) were found between the B-IPQ dimensions Identity, Concern, and Emotional response and the PANQOL dimensions Balance, Hearing, and Energy, indicating an association between a low amount of physical and emotional consequences of the illness and a higher score on the Balance, Hearing, and Energy dimensions of QoL.

No significant correlations of at least a low strength ($r > 0.30$)⁶⁵ were found between the B-IPQ dimensions, PANQOL dimensions, and the drawing characteristics

Table 5. Intercorrelations of PANQOL dimensions and B-IPQ dimensions (N=139).

B-IPQ	PANQOL						
	Balance	Hearing	Anxiety	Energy	Pain	Face	General
Consequences	-.32*	-.46*	-.42*	-.48*	-.17†	-.24*	-.32*
Time-line	.06	.08	.09	.19†	.21†	.14	.03
Personal control	-.13	.01	.00	-.09	.21†	-.08	-.09
Treatment control	-.05	.09	.10	.03	.16	.06	-.01
Identity	-.54*	-.51*	-.37*	-.57*	-.27*	-.31*	-.38*
Concern	-.32*	-.32*	-.63*	-.46*	-.15	-.23*	-.38*
Coherence	-.23*	-.19†	-.33*	-.30*	-.26*	-.28*	-.27*
Emotional response	-.42*	-.45*	-.63*	-.53*	-.21*	-.39*	-.41*

** $p < .01$; † $p < .05$.

DISCUSSION

The aim of this study was to examine the relationship between IPs, characteristics of patients' drawings of their own tumor, and QoL of patients who have recently been diagnosed with VS.

There are some remarkable findings in the scores on the B-IPQ dimensions in patients with VS compared to patients with different chronic illnesses. First, the most striking finding is that patients with VS had the lowest score on the B-IPQ dimension Coherence. This indicates a lesser understanding of their illness in patients with VS than in patients with other chronic diseases or several types of cancer. Second, it is fascinating that patients with VS are more concerned about their illness than patients with colorectal carcinoma, whereas this severe disease is associated with high mortality. This might be related to the limited understanding of patients with VS of their own illness, inadequate provision of information by their physicians, and the uncertainty on their future treatment. Third, patients with VS experience, in general, more symptoms than patients with colorectal carcinoma, lung cancer, or melanoma, although not as much as patients with SLE. It is understandable that melanoma patients experience minimal symptoms given that most of these patients have an isolated tumor on their skin. This is in contrast to patients with VS,

who experience problems with their balance and hearing, with a strong influence on their daily activities and their social life. SLE patients experience a lot of symptoms throughout the body, with many inconveniences in daily life. It is hard to explain why patients with VS scored worse than the two groups of patients with cancer, although this may have to do with the feeling of a “time bomb in their head.”²

According to the analysis of the drawings, it is worth mentioning that the level of detail is low in most drawings. This may be explained by a low understanding of the illness or perhaps an inadequate explanation by the physicians. Furthermore, it is remarkable that only 12 patients (8.6%) illustrated their emotions in the drawing. This could be due to the study design, and perhaps we should have been clearer in our instructions and asked the patients explicitly to draw their emotions. Actually, 73 patients (52.5%) placed written explanations around their drawing, which indicates the ability and willingness to express their emotions about the illness.

Although only some weak significant correlations were found between the B-IPQ dimensions and the drawing characteristics, it seems worthwhile to pay attention to some of these trends. Positive correlations were found between the B-IPQ dimensions Consequences, Timeline, and Emotional response and the reflection of balance disorders or hearing in the drawings, which implies that if patients expect the illness to be more chronic in nature, and they experience a major impact of the tumor on their lives and mood, they are more inclined to represent balance disorders or hearing in their drawings. A possible explanation for this finding is that hearing and balance disorders have a major impact on daily life. This has already been established in previous research.^{17,33,66} Another remarkable finding was the correlation between the reflection of negative emotions in the drawings and QoL. Patients who drew negative emotions perceived a significantly lower level of QoL compared to patients who reflected positive emotions or no emotions at all. This could be helpful in clinical practice.

Associations between drawings and IPs were found in earlier studies concerning other illnesses.^{39,40,42,44,45} However, in this study we could not find strong evidence for the hypothesis that drawings could reflect IP. A possible explanation for our inability to find additional evidence supporting this association is the diversity of our patients. All of our patients had recently been diagnosed with VS, but the tumor size and clinical characteristics differed between patients. Some patients even had no symptoms at all. VS patients differ in this way from, for example, myocardial infarction and heart failure, where all patients suffer from an active state of their illness. Another explanation for

these results is the way we instructed our patients to draw. This left much to individual interpretation, resulting in a difficult comparison between the drawings.

Another limitation is that most patients had already seen the radiological examination of the tumor and were given a picture of the ear by their clinicians to explain the place of the tumor inside the head. This might have resulted in an altered illness perception of the patients.

Based on our findings, we suggest that adding a drawing task to the disease-specific QoL questionnaire (PANQOL) might be helpful for clinicians and patients. The nature of the drawing could give clinicians insight into patients' perceptions about their illness and the impact on their daily life. The drawings showed very clear patients' perceptions of their VS. Some patients know, very precisely, which structures are involved, compressed, or malfunctioning, whereas others just think of their tumor as a “tiny dot.” Furthermore, drawings are important to patients because it could be a way to express their emotions and feelings. If clinicians have an improved understanding of the perception of their patients (e.g., through drawings) it will help in providing information and encouraging self-management (e.g., awareness of the illness, knowledge about its treatment options, handling of symptoms caused by the illness, shared decision making by the patient and physicians). This form of self-management is important for daily care throughout the time the illness will last and will improve QoL in patients with chronic illness.⁶⁷⁻⁶⁹

CONCLUSION

Although VS is a benign, often slow-growing tumor, the symptoms patients experience can be very serious. Moreover, the knowledge of having a tumor in one's head on top of these symptoms can result in an enormous deterioration of QoL. Understanding of their illness can give patients coherence and support to cope with their illness. Drawings of patients could be an easy and fascinating way to gain insight into patients' perceptions about their illness at a glance. This will enable physicians the possibility of better understand the perceptions of their patients with VS. This knowledge will contribute in the overall care of patients with VS and may be helpful in self-management programs.

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