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# Validation of the facial dysfunction domain of the Penn Acoustic Neuroma Quality-of-Life (PANQOL) Scale

Wouter L. Lodder<sup>1,2</sup> · Guleed H. Adan<sup>1</sup> · Chung S. Chean<sup>3</sup> · Tristram H. Lesser<sup>1</sup> · Samuel C. Leong<sup>1</sup>

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**Abstract** The objective of this study is to evaluate the strength of content validity within the facial dysfunction domain of the Penn Acoustic Neuroma Quality-of-Life (PANQOL) Scale and to compare how it correlates with a facial dysfunction-specific QOL instrument (Facial Clinical Evaluation, FaCE). The study design is online questionnaire survey. Members of the British Acoustic Neuroma Association received both PANQOL questionnaires and the FaCE scale. 158 respondents with self-identified facial paralysis or dysfunction had completed PANQOL and FaCE data sets for analysis. The mean composite PANQOL score was 53.5 (range 19.2–93.5), whilst the mean total FaCE score was 50.9 (range 10–95). The total scores of the PANQOL and FaCE correlated moderate ( $r = 0.48$ ). Strong correlation ( $r = 0.63$ ) was observed between the PANQOL's facial dysfunction domain and the FaCE total score. Of all the FaCE domains, social function was strongly correlated with the PANQOL facial dysfunction domain ( $r = 0.66$ ), whilst there was very weak-to-moderate correlation (range 0.01–0.43) to the other FaCE domains. The current study has demonstrated a strong correlation between the facial dysfunction domains of PANQOL with a facial paralysis-specific QOL instrument.

**Keywords** Quality of life · Acoustic Neuroma · Vestibular schwannoma · Facial palsy · United Kingdom

## Introduction

The Penn Acoustic Neuroma Quality-of-Life (PANQOL) scale is an acoustic neuroma (AN) specific quality-of-life (QOL) instrument validated for both English and Dutch-speaking patients [1, 2]. This 26-item survey assesses patient-perceived QOL in seven domains: hearing, balance, facial dysfunction, anxiety, energy, pain, and general health. The PANQOL was validated against the SF-36 where strongest correlations were found between the PANQOL's anxiety, energy, and general health domains and the Short Form-36's (SF-36) mental health, vitality, and general health domains, respectively. Whilst there was moderate ( $r = 0.52$ ) correlation with visual analogue scale assessment of facial appearance and function, the PANQOL facial dysfunction domain did not correlate significantly with any SF-36 domain [1]. According to the authors, this reflected facial weakness sequelae that the SF-36 could not capture. In contrast, van Leeuwen et al. [2] reported statistically significant ( $p < 0.01$ ) correlations between the facial dysfunction domain with the SF-36 domains, although the strength of correlation was weak, ranging between 0.30 and 0.44.

The PANQOL facial dysfunction domain comprises of three questions: “I act differently around people because of problems moving my face”, “I have discomfort, itching, or excessive tearing in one of my eyes” and “My speech has been affected by problems with my face”. As the PANQOL is the only patient-reported QOL instrument validated for AN patients at present, it is important that any health-related issue assessed by this instrument strongly relates to

✉ Samuel C. Leong  
lcheel@doctors.org.uk

<sup>1</sup> The Skull Base Unit, Department of Otorhinolaryngology-Head and Neck Surgery, University Hospital Aintree, Liverpool L9 7AL, UK

<sup>2</sup> Department of Otorhinolaryngology/Head and Neck Surgery, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

<sup>3</sup> Faculty of Medicine, University of Liverpool, Liverpool, UK

what patients actually perceive about their physical, functional, and psychological well-being.

Thus, the aim of this study was to evaluate the strength of content validity within the facial dysfunction domain of PANQOL and to compare how it correlates with a facial dysfunction-specific QOL instrument. It is envisaged that the results would enhance the overall utility of the PANQOL and in particular patients with facial dysfunction as a result of their AN and the impact of facial rehabilitation treatment.

## Materials and methods

Institutional review board approval was obtained (reference 3079). The British Acoustic Neuroma Association (BANA) board of trustees and the Liverpool AN patients support group were involved in the design of this cross-sectional, point-in-time observational survey.

The Facial Clinimetric Evaluation (FaCE) Scale was selected, after a review of the literature suggested that it was the most practical tool to specifically evaluate the impact of facial palsy on quality of life [3, 4]. The FaCE Scale was developed by researchers at the Baylor College of Medicine, Houston, Texas, to measure both facial impairment and disability [5]. This 15-item scale (consisting five-point Likert and visual analogue scales) covers six domains: facial movement, facial comfort, oral function, eye comfort, lacrimal control, and social function. Transformed total and domain scores were calculated on a scale from 0 to 100 (with higher scores indicating better QOL) using formulas provided by the authors (Table 1).

In contrast, questions on the PANQOL are answered on a scale from 1 to 5. The domain scores are then converted to a scale of 1–100 (also with higher scores indicating better QOL) for ease of reporting. A composite quality-of-life (cQOL) score is calculated from the averages of individual domain scores and is also reported on a scale of 1–100 [1, 2].

The online link to SurveyMonkey (<http://www.surveymonkey.com>) was e-mailed to members of BANA who were on the association e-mailing list and a reminder 4 weeks later. Respondents were asked if they had facial dysfunction as a result of their diagnosis or treatment received for their AN. Respondents who had facial dysfunction were asked to complete the FaCE and PANQOL questionnaires. In addition, the SurveyMonkey online questionnaire surveyed patient demographics (age range and gender), year of diagnosis, type of AN management, and when treatment started. No identifying information (such as name, date of birth, e-mail, or internet protocol address) was collected, and thus, the responses were completely anonymized. The forced responses to treatment received for AN were simplified to microsurgery, stereotactic radiosurgery, observation (with

interval MRI scanning), and a combination (microsurgery and radiotherapy). Information on tumour size and type of surgical approach (translabrynthine, middle cranial fossa, and retrosigmoid) was not collected as it was agreed with BANA that such data would not be routinely available from the majority of members.

The data collected on SurveyMonkey were exported to an Excel (Microsoft, Inc., CA, USA) spreadsheet where total and domain scores were calculated [1, 4]. Statistical analysis was performed using the SigmaPlot software package version 12 (Systat Software, Inc., CA, USA). Normality test (Shapiro–Wilk) was undertaken to determine the appropriate correlation coefficient ( $r$ ) analysis (Spearman, Pearson). A  $r$  value ( $\pm$ ) of 0.00–0.19 was considered as very weak, 0.20–0.39 as weak, 0.40–0.59 as moderate, 0.60–0.79 strong, and 0.80–1.00 very strong. A  $p$  value  $<0.05$  was considered statistically significant for all analysis.

## Results and analysis

The online SurveyMonkey link was e-mailed to 880 members of BANA. Of the 398 (45.2%) responses received, 178 (44.7%) respondents indicated that they had facial paralysis. Of these, 158 (89%) had complete PANQOL and FaCE data sets for analysis. There were 100 (63%) females and 58 males within this study cohort, of whom 67% were between the age of 51–70 years (Table 2). The majority (80%) of respondents had microsurgery; therefore, it was not possible to stratify the PANQOL and FaCE scores into treatment groups due to the small numbers within the other cohorts.

The mean composite PANQOL score was 53.5 (range 19.2–93.5), whilst the mean total FaCE score was 50.9 (range 10–95). Aspects on anxiety (mean 64.5, standard deviation (SD) 25.2) and pain (mean 66.2, SD 26.9) reported were the best PANQOL domain scores, whilst hearing (mean 45.7, SD 22.7) and energy (46.2, SD 25.2) domains returned worse scores (Table 3). The mean facial dysfunction PANQOL domain score was 47.8 (range 0–100). Both social function (mean 62.6, SD 25.7) and lacrimal control (mean 69.2, SD 25.7) were the better FaCE domain scores, whilst facial comfort (mean 36.8, SD 26.7) scored the worst.

Correlations between the PANQOL facial dysfunction domain and the FaCE domains are shown in Table 4. There was moderate correlation ( $r = 0.48$ ) between the total scores of the PANQOL questionnaire (mean 53.5, SD 15.9) and FaCE scale (mean 50.9, SD 18.4) (Fig. 1). Strong correlation ( $r = 0.63$ ) was observed between the PANQOL's facial dysfunction domain (mean QOL 47.8, SD 21.9) and the FaCE total score (mean 50.9, SD 18.4)

**Table 1** FaCE questionnaire [9]

The following are statements about how you might feel because of your face or facial problem

In the past week: (CIRCLE only ONE number on each line) Not at all = 1, Only if I concentrate = 2, A little = 3, Almost normally = 4, Normally = 5	
1. When I smile, the affected side of my mouth goes up	1 2 3 4 5
2. I can raise my eyebrow on the affected side	1 2 3 4 5
3. When I pucker my lips, the affected side of my mouth moves	1 2 3 4 5

Please rate how often each of the following statements applied to you during the PAST WEEK

(CIRCLE only ONE number on each line) All of the time = 1 Most of the time = 2 Some of the time = 3 A little of the time = 4 None of the time = 5	
4. Parts of my face feel tight, worn out, or uncomfortable	1 2 3 4 5
5. My affected eye feels dry, irritated, or scratchy	1 2 3 4 5
6. When I try to move my face, I feel tension, pain or spasm	1 2 3 4 5
7. I use eye drops or ointment in my affected eye	1 2 3 4 5
8. My affected eye is wet or has tears in it	1 2 3 4 5
9. I act differently around people because of my face or facial problems	1 2 3 4 5
10. People treat me differently because of my face or facial problem	1 2 3 4 5
11. I have problems moving food around in my mouth	1 2 3 4 5
12. I have problems with drooling or keeping food or drink in my mouth or off my chin and clothes	1 2 3 4 5

The following are statements about how you might have felt or been doing in the PAST WEEK because of your face or facial problem

Please rate how much you agree with each statement: (CIRCLE only ONE number on each line) Strongly agree = 1, Agree=2, Don't know = 3, Disagree = 4, Strongly disagree = 5	
13. My face feels tired or when I try to move my face, I feel tension, pain, or spasm	1 2 3 4 5
14. My appearance has affected my willingness to participate in social activities or to see family or friends	1 2 3 4 5
15. Because of difficulty with the way I eat, I have avoided eating in restaurants or in other people's homes	1 2 3 4 5

- Facial Movement Score  $((\text{Items } 1 + 2 + 3) - \# \text{ valid}) / 4 \_ (\# \text{ valid}) \_ 100$
- Facial comfort score  $((\text{Items } 4 + 6 + 13) - \# \text{ valid}) / 4 \_ (\# \text{ valid}) \_ 100$
- Oral function score  $((\text{Items } 11 + 12) - \# \text{ valid}) / 4 \_ (\# \text{ valid}) \_ 100$
- Eye comfort score  $((\text{Items } 5 + 7) - \# \text{ valid}) / 4 \_ (\# \text{ valid}) \_ 100$
- Lacrimal control score  $((\text{Item } 8) - \# \text{ valid}) / 4 \_ (\# \text{ valid}) \_ 100$
- Social function Score  $((\text{Items } 9 + 10 + 14 + 15) - \# \text{ valid}) / 4 \_ (\# \text{ valid}) \_ 100$
- Total Score  $((\text{Sum of all 15 items}) - \# \text{ valid}) / 4 \_ (\# \text{ valid}) \_ 100$

# valid = number of items within the domain for which an adequate response was given

(Fig. 2). Of all the FaCE domains, social function was also strongly correlated with the PANQOL facial dysfunction domain ( $r = 0.66$ ), whilst there was very weak-to-moderate correlation between the PANQOL facial dysfunction domain and the other FaCE domains. Next to the correlations, also the statistical significance was determined. In

Table 4, all the statistically significant outcomes are marked.

## Discussion

This is the first study showing the correlation between the AN-disease specific PANQOL questionnaire and FaCE scale. The results presented here show that composite PANQOL and FaCE scale scores correlate strong. Of all the FaCE domains, social function was strongly correlated with the PANQOL facial dysfunction domain ( $r = 0.66$ ), whilst there was very weak-to-moderate correlation (range 0.01–0.43) to the other FaCE domains.

The incidence of significant facial paralysis (i.e., House-Brackmann grade III or worse) following treatment for AN is uncommon. Long-term follow-up of large case series places this risk at below 10%; the incidence was dependant on a variety of factors including tumour size and surgeon experience [6–8].

A previous study by this group, utilising the FaCE instrument, had established the adverse impact of facial paralysis on the quality of life of AN patients in the United Kingdom [9]. This study also suggested that facial rehabilitation was not available to all patients and where it was offered, did not always result in significantly improved QOL scores. Furthermore, being diagnosed with AN resulted in poorer overall QOL, although some differences in PANQOL existed between the various treatment modalities and duration of follow-up.

At a mean of 2 year follow-up, the University of Pennsylvania research group reported that patients who had surgery returned lower mean facial dysfunction scores than

**Table 2** Summary of demographic and clinical data

	Number	Percentage
Gender		
Male	58	37
Female	100	63
Total	158	100
Age range		
<20	0	0
21–30	2	1
31–40	14	9
41–50	21	13
51–60	48	30
61–70	57	37
71–80	11	7
81–90	2	1
>91	3	2
Total	158	100
Treatment		
Microsurgery	126	80
Radiotherapy	10	6
Interval scan	11	7
Combination	11	7
Total	158	100

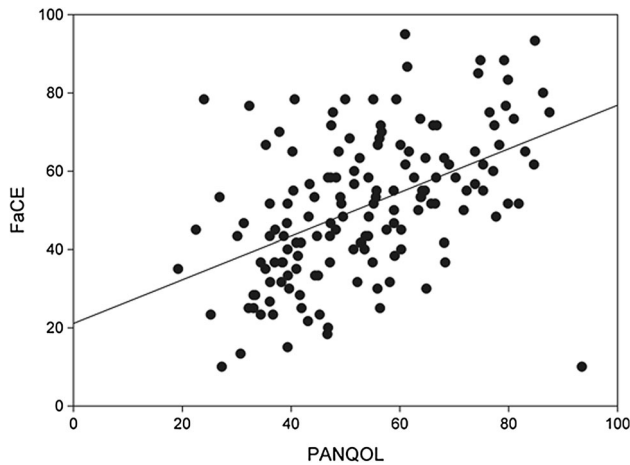
**Table 3** Total and domain scores (mean and standard deviation) of the Facial Clinimetric Evaluation Scale (FaCE) and the Penn Acoustic Neuroma Quality-of-Life Scale (PANQOL)

	FaCE		PANQOL	
	Mean	Standard deviation	Mean	Standard deviation
Total	50.9	18.4	53.5	15.9
Anxiety			64.5	25.2
Facial dysfunction			47.8	21.9
General health			57.5	13.5
Balance			46.7	21.0
Hearing loss			45.7	22.7
Energy			46.2	25.2
Pain			66.2	26.9
Social function	62.6	25.7		
Facial comfort	36.8	26.7		
Facial movement	50.4	26.9		
Oral function	53.8	30.7		
Eye comfort	37.7	30.2		
Lacrimal control	69.2	25.7		

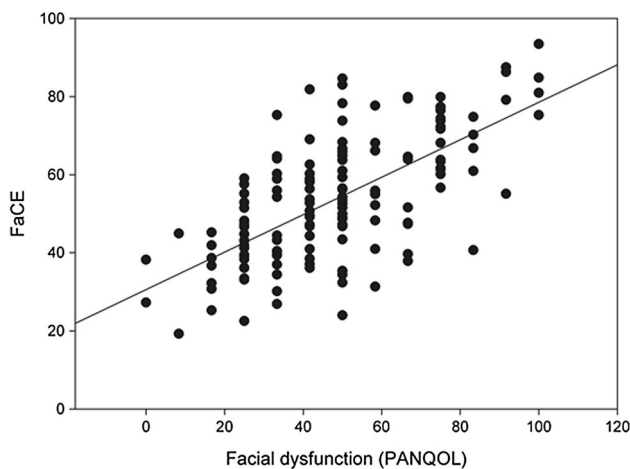
**Table 4** Correlation coefficient analysis of the Facial Clinimetric Evaluation Scale (FaCE) and Penn Acoustic Neuroma Quality-of-Life Scale (PANQOL) total and facial dysfunction domain scores

	FaCE QOL score						
	Total	Social function	Facial comfort	Facial movement	Oral function	Eye comfort	Lacrimal control
PANQOL total score	0.48*	0.54*	0.48*	0.01	0.39*	0.24*	0.02
PANQOL Facial dysfunction domain score	0.63*	0.66*	0.35*	0.30*	0.43*	0.35*	0.16

\*  $p < 0.05$



**Fig. 1** Scatter plot demonstrating distribution of PANQOL and FaCE total scores ( $r = 0.48$ )



**Fig. 2** Scatter plot demonstrating distribution of facial dysfunction domain of PANQOL and FaCE total score ( $r = 0.63$ )

the patients within the observation group [10]. Robinett et al. [11] reported that the PANQOL scores in their study were significantly worse in patients with facial paralysis, especially following microsurgery, and suggested the potential superiority of the PANQOL in measuring facial nerve-related QOL over other nonspecific instruments.

However, further prospective clinical studies would be required to ascertain whether the domain is sensitive to assess change following rehabilitation of facial paralysis. Demonstrating high correlation between post-intervention PANQOL domain and FaCE scores would validate veracity of this hypothesis.

The previous collaborative work with BANA suggested that those with facial paralysis have a greater degree of concerns and unmet needs [12]. This study utilized a novel questionnaire, the Patient Concerns Inventory (PCI), which is a checklist specifically for use in routine follow-up clinics to facilitate patient-directed consultation and ultimately empowers them to be actively involved in the management of their health. The PCI was originally developed for head and neck oncology, but now has numerous variants, including one for AN. The results of this study appear to dovetail with another which investigated the correlation between emotional intelligence (EI) and QOL in acoustic neuroma patients [13]. The authors reasoned that EI could be a determinant of QOL. How patients differ in the way that they are able to identify, express, utilize, and regulate their feelings and those of others may influence overall QOL. In their study, van Leeuwen et al. [13] reported moderate correlation between the PANQOL and Trait Emotional Intelligence Questionnaire-Short Form.

Some limitations of the current study should be addressed here. First, the membership of BANA is unlikely to be representative to the spectrum of AN patients in the U.K. It is unknown to what reasons patients joined the BANA; however, it can be expected that those who have a good treatment outcome do not remain engaged in support groups such as the BANA. Second, a group more biased toward a negative outcome such as those with facial paralysis is more likely to respond to a survey like this. Third, the respondent self-identified with facial paralysis or dysfunction; there was no information and, therefore, no option for further correlation between the severity of the facial paralysis and both the FaCE or PANQOL facial dysfunction domain and composite scores.

The current study has demonstrated a significant correlation between the facial dysfunction domains of PANQOL

with a facial paralysis-specific QOL instrument. This underscores the high content validity of this domain and reinforces prospective utility of the PANQOL in AN patients, especially those suffering with facial paralysis.

## Conclusion

The facial dysfunction domain of the PANQOL is significantly correlated with the FaCE, thus confirming the content validity of this particular domain. The overall utility of this tool as the QOL tool of choice in AN patients is greatly enhanced, especially in those with facial paralysis. It would be commendable to validate other functional disabilities assessed within the PANQOL such as the hearing and balance domains. For example, the latter could be assessed with Dizziness Handicap Inventory which is being undertaken by this research group. Further analytical work such as this would greatly enhance the overall utility of the questionnaire as the preferred QOL tool for skull base teams managing AN patients.

## Compliance with ethical standards

**Conflict of interest** The authors declare that they have no conflict of interest.

**Research involving human participants** 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** Patients consented their participation in the project by filling in the questionnaires after an invitation was sent by e-mail.

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