

Long-term socio-economic impact of vestibular schwannoma for patients under observation and after surgery

TINA TOS, M.D., PER CAYE-THOMASEN, M.D., D.M.Sc., SVEN-ERIC STANGERUP, M.D., MIRKO TOS, M.D., D.M.Sc., JENS THOMSEN, M.D., D.M.Sc.

Abstract

This study describes and compares the long-term socio-economic impact for patients diagnosed with a vestibular schwannoma and either operated on or observed.

A consecutive sample of patients diagnosed with vestibular schwannoma in Denmark and either operated on (748 patients) or observed by the wait-and-re-scan policy (272 patients) during the period 1976–2000 were studied retrospectively. The consequences of operation/diagnosis (and observation) on vocational status, ability to handle daily chores and some psycho-social aspects were studied by means of a prospective postal questionnaire. Ninety-six per cent of the operated and 83 per cent of the observed patients answered the questionnaire. Overall, 34 per cent of operated patients resumed their daily activities within one to two months, and 76 per cent within four to six months. Patients operated on for a large tumour resumed their daily activities later than patients with a small tumour. Regardless of tumour size, employment was unchanged for the majority of observed and operated patients. The vocational consequences were significantly worse for operated patients with a large tumour, than for observed patients. However, no difference existed between the observed group and operated patients with a tumour below 20 mm in size. A change in vocational status was most frequent for assisting spouses, unskilled manual workers and the self-employed. The majority of both observed and operated patients experienced no change in their ability to handle daily chores. The changed ability of operated patients was worse than that of observed patients. Among various changes in their psycho-social well-being, decrease in social ability was the most frequent complaint in both groups, followed by increased fatigue, decreased concentration, increased irritability, depression and headache, decreased intellect and libido. Regardless of tumour size, the change in social ability, concentration and fatigue was worse for operated patients. Concerning headache, patients operated on for a large tumour were better off than observed patients and patients operated on for a small tumour. There was no difference between the operated and observed groups concerning irritability, intellect and libido.

Deterioration of vocational status, ability to handle daily chores and several aspects of psycho-social well-being are reported both by patients operated on and observed for vestibular schwannoma. However, the negative changes were more frequent among the operated patients, although the differences were surprisingly modest, especially when comparing observed patients with patients operated on for a small tumour.

Key words: Neuroma, Acoustic; Quality of Life; Surgery; Observation

Introduction

Recently there has been an increased focus on quality of life issues, as well as on the views of the patient in general. Following the provision of information on the disease and available treatment modalities, the choice of treatment modality is made by the patient rather than the doctor with increasing frequency. This gradual sociological change emphasizes the importance of the information, provided by

the doctor on the natural history of the disease, as well as on the expected results, the impact on quality of life and on the socio-economic consequences of the various treatment modalities available. Three contemporary treatment modalities may be offered to a patient diagnosed with vestibular schwannoma: observation by the wait-and-re-scan policy, surgery or radiotherapy. As far as we know, only one previous study has attempted to compare the quality of life of patients operated on for a vestibular

schwannoma, with that of patients under observation for the same disease.¹ However, the socio-economic impact of diagnosis and observation was not described in this study.

The present study was performed in order to describe and compare the socio-economic impact and some aspects of psycho-social well-being in patients either operated on or observed by the wait-and-re-scan policy for a vestibular schwannoma. Such a description and comparison is essential, as it will provide us with highly valuable information for the patient facing the choice between surgery and observation. Thirty-eight per cent of our operated and 24 per cent of our observed patients are not satisfied with the information provided.² Thus, the procurement of hard data for improvement of patient information seems warranted, although it is impossible to prepare the patients intellectually, and especially emotionally, for all the eventual side-effects and consequences of their disease and/or operation.

Materials and methods

Patients

Nine hundred and forty-eight patients were operated on in Denmark for a sporadic, unilateral vestibular schwannoma during the 25-year period 1976–2000 (Table I). Ninety-five per cent of the patients were operated on by the translabyrinthine approach and the remaining five per cent either by the middle fossa or the sub-occipital approach. During the period May 2000 to January 2001, a questionnaire was mailed to 748 of the 948 operated patients (102 patients had died and 98 were foreigners, had emigrated, or could not be found). Two hundred and seventy-two of 316 patients had observed for the same disease by the wait-and-re-scan policy received a similar questionnaire (40 patients had died and 71 patients had emigrated or could not be found).

The median age at operation was 53 years (range 24.6–83.4). The patients answered the postal questionnaire at a median of 11.5 years after surgery (range 1.1–26.6). Seven hundred and sixteen (96 per cent) of 748 patients responded (Table I). The median age in the questionnaire was 64.3 years (range 25.7–94.6).

In the observed group 226 (83 per cent) of the 272 patients responded (Table I). The median age at diagnosis was 59.8 years (range 21.4–95.2). The patients answered the postal questionnaire at a

median of 3.7 years after diagnosis (range 1.1–18.1), and the median age at questionnaire was 64.1 years (range 26.9–100.7).

The questionnaire

The questionnaire contained a variety of questions concerning hearing, tinnitus, vertigo, facial function, socio-economy, some issues of psycho-social well-being and some typical difficulties patients may experience following vestibular schwannoma surgery or as a cause of the natural history of the disease. This paper focused entirely on the section of the questionnaire concerning socio-economy and some issues of psycho-social well-being (Appendix).

The patients were asked if the operation or diagnosis caused any changes in vocational status. The vocational impact was only considered for patients below 60 years of age (530 operated and 117 observed patients), as a higher age combined with significant disease almost without exception leads to some kind of retirement in Denmark. The median age at operation for the 530 patients was 49 years (range 24.6–59.9). The patients answered the postal questionnaire at a median of 10.2 years after surgery (range 1.1–20.5). The median age was 59.8 years (range 25.7–74.8). In the observed group of 117 patients below 60 years of age, the median age at diagnosis was 53.1 years (range 21.4–59.8). The patients answered the postal questionnaire at a median of 3.4 years after diagnosis (range 1.1–15.3), and their median age was 58.3 years (range 26.9–72.2).

Operated patients were asked if and when they resumed their daily activities after surgery. Further, the patients were asked to report on their occupation prior to treatment/diagnosis, as well as at the time of the questionnaire. The various jobs were categorized into specific employment groups, in order to be able to make comparisons. Changes in vocational status in the different employment groups were investigated. Further, the patients were asked if the operation/diagnosis had influenced their ability to handle daily chores. A part of the questionnaire dealt with headache and fatigue, as well as various aspects of psycho-social well-being, e.g. social ability and depression. The phrasing of each question implicitly emphasized that the patient had to consider whether the operation/disease was the true cause of a potential change in capabilities or psycho-social well-being.

Data analysis

Our centre recommends surgical intervention for three indications: cystic tumour, a tumour larger than 20 mm and documented tumour growth by repetitive magnetic resonance imaging (MRI). Accordingly, most observed patients had a tumour below 20 mm in size and a number of the operated patients had a tumour larger than 20 mm. In order to correct the data for this discrepancy, the operated patients were divided in two groups: tumour size below and above 20 mm. In order to compare groups, a score of the various issues of psycho-social well-being was

TABLE I

THE SERIES OF VESTIBULAR SCHWANNOMA, INCLUDING OPERATED AND OBSERVED PATIENTS IN DENMARK DURING THE PERIOD 1976–2000 (n = 1331)

	Operated (n = 948)		Observed (n = 383)	
	No	%	No	%
Died	102	11	40	10
Not contacted	98	10	71	19
Contacted	748	79	272	71
Responders	716	96	226	83

TABLE II

VOCATIONAL CONSEQUENCES IN PATIENTS 60 YEARS OR YOUNGER, AFTER OPERATION IN 530 PATIENTS, AND AFTER DIAGNOSIS AND OBSERVATION IN 117 PATIENTS WITH VESTIBULAR SCHWANNOMA

	Operated (n = 530)				Observed (n = 117)	
	Tumour size >20 mm (n = 301)		Tumour size ≤ 20 mm (n = 229)		No	%
	No	%	No	%		
No job consequences	176	61	149	69	85	75
Had to change work	21	7	12	6	5	4
Continue to work part-time	9	3	7	3	4	4
Had to stop working	81	28	48	22	20	18
Unanswered	14	5	13	6	3	3
Mann-Whitney test:	-----n.s.-----		-----n.s.-----		-----p<0.05-----	

produced (score 1 = better; score 0 = unchanged; score -1 = a little worse; score -2 = a lot worse).

Non parametric statistical analyses were performed, using the Mann-Whitney and Chi-square tests, with $p<0.05$ as the critical level of significance.

Results

Vocational consequences

The situation in regards to employment was unchanged for a majority of the patients, regardless of treatment modality (Table II). However, the group comparison showed that the vocational consequences were significantly worse for the operated patients with a large tumour size, than for the observed patients. There was no difference between the observed group and operated patients with a tumour size below 20 mm (Table II).

Figure 1 shows the percentage age of patients with unchanged employment in the various vocational groups. The group in which the operation had the least impact on vocational status was the upper level salaried employees. The most negatively affected was a small group of assisting spouses, as only 50 per cent had no change in employment. The second most affected were the unskilled manual workers, with no change in employment in 57 per cent of cases, followed by the self-employed (60 per cent with no change).

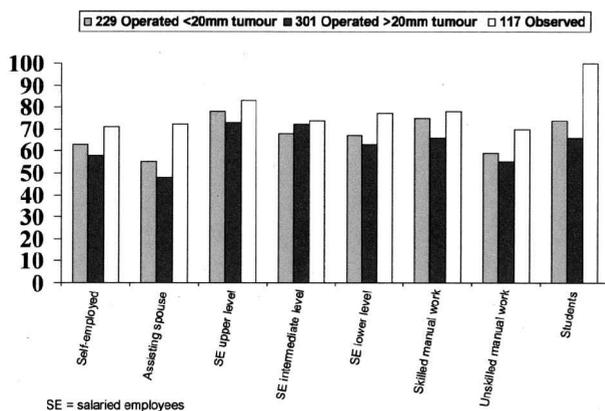


FIG. 1

Percent of various employment groups with no change in vocational status after surgery for vestibular schwannoma (patients ≤60 years; see Table II).

Regardless of tumour size in operated patients, the upper level salaried employees were significantly less affected on vocational status than the assisting spouses, the unskilled manual workers and the self-employed ($p<0.05$; Chi-square test). All other differences between operated patients were insignificant.

Although all of only four students had an unchanged vocational status following diagnosis, no significant differences were found in changes of vocational status between the various employment groups.

When comparing patients within the individual employment groups, significantly more observed than operated assisting spouses had unchanged employment, regardless of tumour size ($p<0.05$; Chi-square test). Further, the observed patients among the self-employed, the lower level salaried employees, the skilled manual workers and the unskilled manual workers were less affected than the operated patients with large tumours within the same employment group ($p<0.05$; Chi-square test).

Daily chores

The patients were asked if they had experienced any decrease in their ability to handle daily chores because of the operation or the diagnosis (observed patients) (Table III). The majority of patients in all groups experienced no change, although a few per cent were depending on the help of other people in handling daily chores. The change in the ability of operated patients with both small and large tumours was significantly worse than that of the observed patients, whereas no difference was found between patients operated on for a small or a large tumour (Table III).

The operated patients were further asked when they had resumed their daily activities (Table IV). Only 59 per cent of the patients answered this question. Of the patients who answered, 30–40 per cent had resumed their daily activities within one to two months, and 70–84 per cent within four to six months. Ten to 17 per cent had never returned to their daily activities. Patients operated on for a large tumour resumed their daily activities significantly later than patients operated on for a small tumour (Table IV).

TABLE III
CHANGES IN ABILITY TO HANDLE DAILY CHORES AFTER THE OPERATION/DIAGNOSIS

	Operated (n = 716)				Observed (n = 226)	
	Tumour size > 20 mm (n = 400)		Tumour size ≤ 20 mm (n = 316)		No	%
	No	%	No	%		
None	207	55	181	62	156	76
Decreased ability, but can manage daily chores without help	101	27	75	26	42	20
Decreased ability, but can manage daily chores with help	46	12	30	10	4	2
Decreased ability, depending on other peoples help	24	6	7	2	4	2
No answer	22	6	23	7	20	4
Mann-Whitney test:	n.s.		p<0.05		p<0.01	

Changes in aspects of psycho-social well-being

The patients were asked questions concerning their physical and psycho-social well-being (Appendix). Tables V–XII show changes in different aspects of physical and psycho-social well-being (social ability, concentration, fatigue, irritability, mental depression, headache, intellect and libido) after operation or diagnosis (observation). The results were summarized as mean scores in Figure 2 (see Materials and Methods). Decrease in social ability was overall the most frequent complaint, reported by 50–72 per cent of the patients, followed by increased fatigue, decreased concentration, increased irritability, depression and headache, decreased intellect and libido (Figure 2, Tables V–XII).

Regardless of tumour size, the change in social ability, concentration and fatigue was worse in the group of operated patients. No differences were found between patients operated on for either small or large tumours (Figure 2, Tables V–VII).

The patients operated on for a small tumour experienced worse depression than the observed patients. Strangely, there was no difference between observed patients and patients operated on for a large tumour (Figure 2, Table IX).

Concerning headache, there was no difference between observation and operation for a small tumour (Table X). However, patients operated on for a large tumour were relieved of their headache in 17 per cent of cases and were significantly better off than observed patients and patients operated on for a small tumour (Figure 2, Table X).

There was no difference between the operated and observed groups concerning irritability, intellect and libido (Figure 2, Tables VIII, XI, XII). Three per cent of patients operated on for a large tumour experienced an improvement in libido (Table XII).

Conclusion and discussion

It can be concluded that deterioration of vocational status, ability to handle daily chores and various aspects of physical and psycho-social well-being are experienced both by patients under observation and operated on for a vestibular schwannoma. However, negative changes of these issues were considerably

more frequent among operated patients, although the differences were found to be surprisingly small, especially when comparing operated and observed patients with the same tumour size.

Vocational consequences

During the 25-year period in Danish society in general, patients and the social security system have gradually changed. These factors may have influenced the post-operative vocational status of the patients and may accordingly explain some differences in relation to our previous study on 273 operated patients, representing the first part of this series (the period 1976–1990). In the first series of operated patients no vocational consequences were found in 74 per cent.³ In the extended series of this study, the figure is 61 per cent for large and 69 per cent for small tumours. In comparison, 75 per cent of the observed patients experienced no vocational consequences, which is significantly higher than the large, but not the small tumours.

In another Danish study, including 59 operated and 19 observed patients, 38 per cent of the operated patients ceased working after surgery.⁴ It should be noted however, that more than 50 per cent of these patients qualified for a disability pension. Changes among the observed patients were not described. A Swedish study by Mercke and co-workers included 146 patients and found that 24 per cent retired early

TABLE IV
TIME FROM OPERATION TO RETURN TO DAILY ACTIVITIES (716 PATIENTS)

	Return to daily activities			
	Tumour size > 20 mm (n = 400)		Tumour size ≤ 20 mm (n = 316)	
	No	%	No	%
1 to 2 months	75	31	69	38
2 to 4 months	69	29	55	30
4 to 6 months	25	10	29	16
6 to 12 months	28	12	8	4
12 months	4	2	2	1
Not at all	41	17	19	10
No answer	158	40	134	42

Mann-Whitney test: <0.05

TABLE V
CHANGES IN SOCIAL ABILITY CAUSED BY OPERATION OR DISEASE DIAGNOSIS IN 716 OPERATED AND 226 OBSERVED PATIENTS WITH VESTIBULAR SCHWANNOMA

Social ability	Score	Operated (n = 716)					
		Observed (n = 226)		Tumour size ≤ 20 mm (n = 316)		Tumour size > 20 mm (n = 400)	
		No	%	No	%	No	%
Better	1	–	–	1	0.4	10	3
Unchanged	2	101	50	85	30	99	28
A little worse	3	66	33	98	35	132	37
Much worse	4	35	17	95	34	117	33
No answer		24	11	37	12	42	11
Mean score		2.7		3.0		3.0	
Mann-Whitney test:		—————p<0.001—————		—————n.s.—————		—————	
		—————		p<0.001—————		—————	

TABLE VI
CHANGES IN CONCENTRATION CAUSED BY OPERATION OR DISEASE DIAGNOSIS IN 716 OPERATED AND 226 OBSERVED PATIENTS WITH VESTIBULAR SCHWANNOMA

Concentration	Score	Operated (n = 716)					
		Observed (n = 226)		Tumour size ≤ 20 mm (n = 316)		Tumour size > 20 mm (n = 400)	
		No	%	No	%	No	%
Better	1	–	–	1	0.4	15	4
Unchanged	2	132	66	132	48	170	48
A little worse	3	54	27	100	37	130	36
Much worse	4	14	7	40	15	42	12
No answer		26	12	43	14	43	11
Mean score		2.4		2.7		2.6	
Mann-Whitney test:		—————p<0.01—————		—————n.s.—————		—————	
		—————		p<0.01—————		—————	

TABLE VII
CHANGES IN FATIGUE CAUSED BY OPERATION OR DISEASE DIAGNOSIS IN 716 OPERATED AND 226 OBSERVED PATIENTS WITH VESTIBULAR SCHWANNOMA

Fatigue	Score	Operated (n = 716)					
		Observed (n = 225)		Tumour size ≤ 20 mm (n = 316)		Tumour size > 20 mm (n = 400)	
		No	%	No	%	No	%
Better	1	–	–	2	1	14	4
Unchanged	2	126	64	118	42	142	41
A little worse	3	47	24	93	33	119	34
Much worse	4	25	13	68	24	70	20
No answer		28	12	35	11	55	14
Mean score		2.5		2.8		2.7	
Mann-Whitney test:		—————p<0.01—————		—————n.s.—————		—————	
		—————		p<0.01—————		—————	

TABLE VIII
CHANGES IN IRRITABILITY CAUSED BY OPERATION OR DISEASE DIAGNOSIS IN 716 OPERATED AND 226 OBSERVED PATIENTS WITH VESTIBULAR SCHWANNOMA

Inability	Score	Operated (n = 716)					
		Observed (n = 226)		Tumour size ≤ 20 mm (n = 316)		Tumour size > 20 mm (n = 400)	
		No	%	No	%	No	%
Better	1	1	0.5	4	2	17	5
Unchanged	2	121	61	141	53	173	51
A little worse	3	59	30	79	30	107	32
Much worse	4	17	9	43	16	40	12
No answer		28	12	49	16	63	16
Mean score		2.5		2.6		2.5	
Mann-Whitney test:		—————n.s.—————		—————n.s.—————		—————	
		—————		n.s.—————		—————	

TABLE IX

CHANGES IN DEPRESSION CAUSED BY OPERATION OR DISEASE DIAGNOSIS IN 716 OPERATED AND 226 OBSERVED PATIENTS WITH VESTIBULAR SCHWANNOMA

Depression	Score	Operated (n = 716)					
		Observed (n = 226)		Tumour size ≤ 20 mm (n = 316)		Tumour size > 20 mm (n = 400)	
		No	%	No	%	No	%
Better	1	–	–	4	2	13	4
Unchanged	2	142	72	159	60	211	63
A little worse	3	42	21	65	25	81	24
Much worse	4	12	6	37	14	32	10
No answer		30	13	51	16	63	16
Mean score		2.3		2.5		2.4	
Mann-Whitney test:		————— <i>p</i> <0.05—————		————— <i>n.s.</i> —————		————— <i>n.s.</i> —————	

TABLE X

CHANGES IN HEADACHE CAUSED BY OPERATION OR DISEASE DIAGNOSIS IN 716 OPERATED AND 226 OBSERVED PATIENTS WITH VESTIBULAR SCHWANNOMA

Headache	Score	Operated (n = 716)					
		Observed (n = 226)		Tumour size ≤ 20 mm (n = 316)		Tumour size > 20 mm (n = 400)	
		No	%	No	%	No	%
Better	1	–	–	18	7	58	17
Unchanged	2	155	79	168	64	214	64
A little worse	3	30	15	35	13	40	12
Much worse	4	10	5	41	16	24	7
No answer		31	14	54	17	64	16
Mean score		2.3		2.4		2.1	
Mann-Whitney test:		————— <i>n.s.</i> —————		————— <i>p</i> <0.001—————		————— <i>p</i> <0.05—————	

TABLE XI

CHANGES IN INTELLECT CAUSED BY OPERATION OR DISEASE DIAGNOSIS IN 716 OPERATED AND 226 OBSERVED PATIENTS WITH VESTIBULAR SCHWANNOMA

Intellect	Score	Operated (n = 716)					
		Observed (n = 226)		Tumour size ≤ 20 mm (n = 316)		Tumour size > 20 mm (n = 400)	
		No	%	No	%	No	%
Better	1	–	–	2	0.8	11	3
Unchanged	2	168	87	199	80	240	73
A little worse	3	20	10	33	13	64	19
Much worse	4	6	3	16	6	16	5
No answer		32	14	66	21	69	17
Mean score		2.2		2.3		2.3	
Mann-Whitney		————— <i>n.s.</i> —————		————— <i>n.s.</i> —————		————— <i>n.s.</i> —————	

TABLE XII

CHANGES IN LIBIDO CAUSED BY OPERATION OR DISEASE DIAGNOSIS IN 716 OPERATED AND 226 OBSERVED PATIENTS WITH VESTIBULAR SCHWANNOMA

Libido	Score	Operated (n = 716)					
		Observed (n = 226)		Tumour size ≤ 20 mm (n = 316)		Tumour size > 20 mm (n = 400)	
		No	%	No	%	No	%
Better	1	–	–	–	–	11	3
Unchanged	2	175	90	206	81	250	75
A little worse	3	9	5	25	10	43	13
Much worse	4	11	6	24	9	28	8
No answer		31	14	61	19	68	17
Mean score		2.2		2.3		2.3	
Mann-Whitney test:		————— <i>n.s.</i> —————		————— <i>n.s.</i> —————		————— <i>n.s.</i> —————	

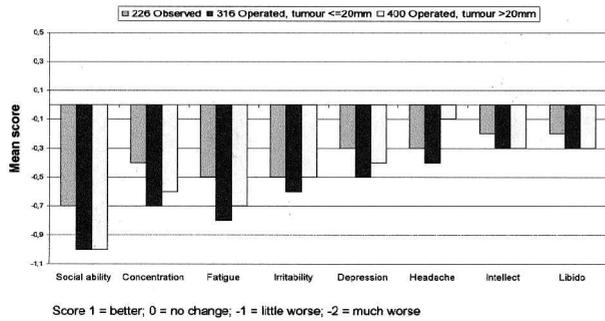


FIG. 2

Changes in various aspects of psycho-social well-being caused by operation or disease diagnosis in patients with vestibular schwannoma.

after surgery, whereas only 43 per cent resumed their former employment.⁵ The early retirement group and the group resuming their former employment was compared, and the study concluded that increasing age at operation and experience of the surgical team were risk factors. Tumour diameter did not correlate to early retirement, which equals our findings. Another Swedish study including 141 patients showed that surgery had no impact on the ability to work in 77 per cent of the patients. Nine per cent retired because of the operation (social security or disability pension) and three per cent were on sick leave. However, only 30 per cent of the patients were working full time.⁶

Thus, there seem to be no major differences of vocational consequences after surgery between the other Danish,⁴ the Swedish studies,^{5,6} and our findings, considering the age selection in our investigation (see Materials and Methods). It is difficult to compare the Nordic results with studies performed in a number of other countries, as it is fairly easy to obtain social security in Scandinavia in cases of early retirement due to illness or disability. A study from San Francisco included 130 patients and found a negative change in occupational status (unemployment or retirement) in only 14 per cent.⁷

It was found that the employment groups most affected by the operation were the assisting spouses and the unskilled manual workers. This is probably due to a looser connection to the labour market in these two groups. Surprisingly, the group with the third-most negative change was the self-employed. Beforehand, it was expected that the self-employed would have the highest level of employment, as this group is less prone to sick leave due to a high degree of self-financing. However, the answers of the open-ended questions of the questionnaire gave the impression that it was difficult for this employment group to change their line of work and that their job typically required outgoing client contact.

Recovery from surgery

Most patients like to have an idea of post-operative time required before returning to work and resuming daily activities. In our first study, including the

patients operated from 1976–90, 88 per cent returned to work within six months after surgery and nine per cent never resumed normal activities.³ These are better recovery figures than in the present study (76 per cent returning within six months and 14 per cent never resuming normal activities). As stated above, such changes may be due to a gradual change of Danish society in general, the patients and the social security system during the 25-year period. Another reason may be that as many as 292 (41 per cent) of the patients in the present series did not answer when they resumed daily activities, which may skew the results.

In a Dutch study of 176 patients, operated on mainly by the sub-occipital approach, 31 per cent of the patients were no longer able to work one year after surgery, whereas 15 per cent had resumed work part-time and 54 per cent had resumed work full time.⁸ The authors concluded that sub-occipital surgery and a large tumour size greatly influenced the patients working ability. In the study from San Francisco, 31 per cent of the patients returned to normal occupational activities after six weeks and 64 per cent had returned after three months.⁷ Only 16 per cent required more than six months to return to normal occupational activities. In the study by Wiegand and Fickel, including the members of the Acoustic Neuroma Association (ANA), only five per cent of the patients answered that they had never resumed their work.⁹ About 38 per cent could return to their work with no problems, 30 per cent of patients needed two to four months of adjustment and 15 per cent six to 12 months before fully resuming work. Ten per cent answered that they needed long-term adjustment.

Overall, the vocational consequences seem less common and less severe in the American,^{7,9} than in the European studies,^{3,6,8} including the present study. Varying tumour sizes between these studies, varying national social security systems and varying labour market legislation may explain such differences. This is in part illustrated by the present finding, that patients operated on for a large tumour resume their daily activities significantly later than patients operated on for a small tumour.

Daily chores

We found that most observed and operated patients experienced no change in their ability to handle daily chores and that only a few per cent depended on other peoples' help. The change in the ability of operated patients with both small and large tumours was significantly worse than that of the observed patients, whereas no difference was found between patients operated on for a small or a large tumour.

Aspects of psycho-social well-being

Among various changes in psycho-social well-being, a decrease in social ability was the most frequent complaint overall, reported by 50–72 per cent of the patients, followed by increased fatigue, decreased concentration, increased irritability, depression and headache, decreased intellect and libido.

- **This is a retrospective study of patients with vestibular schwannoma**
- **Quality of life issues were compared between those patients who had surgery and those who had watchful waiting**
- **Vocational status, ability to handle daily chores and psycho-social issues were compared**
- **Negative changes were more apparent in the operated group but the difference between the two groups were modest**

Regardless of tumour size, the change in social ability, concentration and fatigue was worse in the group of operated patients. No differences were found between patients operated on for small or large tumours. Forty-nine per cent of the operated and 37 per cent of the observed patients, compared to 26 per cent of the operated ANA members reported increased fatigue.⁹

It is interesting that 20 per cent of the observed patients had a worsening of headache after the diagnosis, whereas seven per cent of operated patients with a small tumour and 17 per cent of operated patients with a large tumour had relief from headache following surgery. This difference is significant, whereas no difference was found between the operated and observed groups concerning irritability and intellect.

Depression worsened in 30 per cent of the operated and 27 per cent of the observed patients. In the San Francisco study, the incidence of depression of different degrees was 51 per cent before and 48 per cent after surgery.⁷ In the ANA study, 38 per cent reported post-operative depression,⁹ and in the Jørgensen and Pedersen study 49 per cent.⁴ No pre-operative data on depression were provided in either of these two investigations. These differences seem considerable, but may at least in part be due to different phrasing of the questionnaire.

Only a few studies deal with sexual dysfunction after vestibular schwannoma surgery. It was found that a decrease in libido after diagnosis/operation is not rare, as reported by 20 per cent of the operated and 11 per cent of the observed patients (insignificant difference). Further, three per cent of patients operated on for a large tumour experienced an improvement in libido. In the ANA study, however, 10 per cent indicated that their operation resulted in significant sexual dysfunction.⁹

General considerations

We chose to design our own questionnaire, in order to be able to gather and analyse information on the specific and somewhat more general issues that are relevant for patients either observed or operated on for a vestibular schwannoma, in reference to clinical experience and contemporary knowledge on the natural history of the disease, as well as on typical

sequelae after translabyrinthine surgery.¹ It was possible, therefore, to address the main problems of our patients, in contrast to the more generalized quality of life issues addressed in some well-established questionnaires (e.g. the SF36). In the phrasing of the questions, it was emphasized that the patients should consider whether the event of the diagnosis (observation) or operation was the true reason for changes they may have experienced subsequently. By focusing on the specific event and the following period, the influence of a variable pre-morbidity of our patients is essentially reduced.

The observed patients have tumours of a size less than 20 mm. The operated patients were divided into groups with tumour sizes above and below 20 mm, in order to be able to compare operated and observed patients with the same tumour size. Some patients had growing tumours below 20 mm, leading to operation. These patients may be considered worse and with a more aggressive disease than patients with observed tumours, which have grown to a stationary size below 20 mm up to diagnosis (as registered by more than one MRI). This difference may have introduced some bias into these results, although we believe this to be modest.

The median age of the observed patients was higher than that of the operated patients (60 versus 53 years overall, and 53 versus 49 years in the groups analysed for change in vocational status). Further, the median follow-up from diagnosis/operation to questionnaire was 11.5 years for the operated and 3.7 years for the observed patients (10.2 versus 3.4 years in the groups analysed for change in vocational status). This may have influenced our results. Further, there are given limitations to the value of results from a questionnaire requesting some patients to recall conditions related to an operation dated up to more than 20 years ago.

It is imperative to be able to inform the patients on the socio-economic and quality of life changes they may expect after observation or operation for vestibular schwannoma, in order for them to ascertain realistic expectations concerning ability to continue their professional careers and return to their daily activities. We are convinced that many studies on quality of life issues with comparisons of surgical series, wait-and-re-scan series, as well as irradiated series of patients with vestibular schwannoma will appear in the literature during the coming years. They are urgently needed in order for us to be able to supply our patients with adequate information prior to their choice of treatment modality. It has to be realised that surgery of even small tumours has consequences worse than those of observation, concerning psycho-social well-being, ability to handle daily chores and vocational status. This clearly justifies a policy of observation and repetitive MRI of the increasing number of intra-meatal and small tumours,¹⁰ at least until growth is documented.

References

- 1 Tos M, Charabi S, Thomsen J. Clinical experience with vestibular schwannomas: epidemiology, symptomatology, diagnosis, and surgical results. *Eur Arch Otorhinolaryngol* 1998;**255**:1–6
- 2 Tos T, Caye-Thomasen P, Stangerup SE, Tos M, Thomsen J. Patients fears, expectations and satisfaction in relation to management of vestibular schwannoma. A comparison of surgery and observation. *Acta Otolaryngol (Stockh)* 2003;**123**:600–5
- 3 Parving A, Tos M, Thomsen J, Moller H, Buchwald C. Some aspects of life quality after surgery for acoustic neuroma. *Arch Otolaryngol Head Neck Surg* 1992;**118**:1061–4
- 4 Jørgensen BG, Pedersen CB. Acoustic neuroma. Follow-up of 78 patients. *Clin Otolaryngol* 1994;**19**:478–84
- 5 Mercke U, Magnusson M, Linderöth L. Long-term effect of translabyrinthine acoustic neuroma surgery on work capacity. In: Tos M, Thomsen J, eds. *Acoustic Neuroma. Proceedings of the First International Conference on Acoustic Neuroma, Copenhagen, Denmark, August 25-29, 1991*. Amsterdam: Kugler Publications, 1992: 877–80
- 6 Andersson G, Ekvall L, Kinnefors A, Nyberg G, Rask-Andersen H. Evaluation of quality of life and symptoms after translabyrinthine acoustic neuroma surgery. *Am J Otol* 1997;**18**:421–6
- 7 Chung JH, Rigby PL, Jackler RK, Shah SB, Cooke DD. Socioeconomic impact of acoustic neuroma surgery. *Am J Otol* 1997;**18**:436–43
- 8 van Leeuwen JP, Braspenning JC, Meijer H, Cremers CW. Quality of life after acoustic neuroma surgery. *Ann Otol Rhinol Laryngol* 1996;**105**:423–30
- 9 Wiegand DA, Fickel V. Acoustic neuroma – The patient's perspective: Subjective assessment of symptoms, diagnosis, therapy, and outcome in 541 patients. *Laryngoscope* 1989;**99**:179–87
- 10 Tos M, Stangerup SE, Caye-Thomasen P, Tos T, Thomsen J. What is the real incidence of vestibular schwannomas? (in press)

Address for correspondence:

Tina Tos, M.D.,
Duntzfelts Allé 7C,
DK-2900 Hellerup,
Denmark.

E-mail: tinatos@dadlnet.dk

Tina Tos, M.D. takes responsibility for the integrity of the content of the paper.

Competing interests: None declared

Appendix

The questionnaire

Which vocational consequences have the diagnosis/treatment of "a tumour on the hearing nerve" had for you:

- 1) None
 2) Continued part-time employment
 3) Had to change employment
 4) Had to cease employment
 Other (write)? _____

What was your occupation before the diagnosis/treatment? _____

What is your occupation now? _____

If you are still working, what was the period from operation to return to daily activities? (*Only operated patients were asked this question*).

- 1) 0 to 2 months
 2) 2 to 4 months
 3) 4 to 6 months
 4) 6 to 12 months
 5) Not returned

Has the tumour on the hearing nerve influenced your capability to handle daily chores?

- 1) No
 2) Yes, but I manage without help
 3) Yes, but I manage with some help
 4) Yes, I depend on help

How has the tumour on the hearing nerve influenced you in the following areas?
 Write one mark in each line.

	Unchanged	A little worse	Much worse	Better	Uncertain
Social ability					
Concentration					
Fatigue					
Irritability					
Depression					
Headache					
Intellect					
Libido					