Thyroidectomy for Graves' hyperthyroidism: retrospective study of patients' appreciation

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Introduction

Hyperthyroidism in Graves' disease can be managed with administration of radioiodine or pharmacologically with thionamides or surgically treated with subtotal or total thyroidectomy. The choice of therapy will depend on patient age and preferences, thyroid size, disease severity, presence of ophthalmopathy, and local resources and practices. Treatment policies vary considerably within and between countries and continents. Objective data such as functional results of therapy and morbidity rates have often been taken to evaluate the efficacy of surgical treatment, whereas the assessment of other variables, including improved quality of life of the patient, satisfaction of expectations and perception of processes of care, has generally been neglected. More and more, however, these aspects have received increasing attention, particularly in diseases that can be managed using different approaches. In this retrospective study on a series of surgical patients treated for hyperthyroidism in Graves' disease, we analyzed questionnaire responses to investigate how patients rated levels of quality of life before and after the operation and satisfaction with the processes of care received and treatment outcome.

Materials and methods

Patients

Of 108 patients surgically treated for hyperthyroidism in Graves' disease at our Institution between 1 January 1993 and 31 December 2003, 102 with a minimum follow-up of 12 months were included in the study. The series comprised 28 (27%) males and 74 females (age range, 16-74 years; mean, 40 years). A diagnosis of Graves' disease was based on the presence of characteristic clinical signs and symptoms and the results from confirmatory hormone and immunologic laboratory tests.
All patients had been followed up by one or more endocrinologists from the onset of disease to the time of surgery. A standard course of thionamide therapy (at least 18 months) was initiated to achieve lasting remission of disease; 19 patients chose to foreshorten pharmacological treatment and underwent surgery (range, 1-12 months; mean, 8 months); several of the 83 others continued pharmacological therapy considerably longer (range, 18 months to 17 years; median, 4 years); 2 patients had received subtotal thyroidectomy 36 and 5 years earlier, respectively.

SURGICAL TREATMENT
At the start of the study period, the standard surgical procedure was extensive subtotal thyroidectomy (EST), wherein a portion of the posterior capsule of the gland and <2 g of thyroid tissue were preserved from each side. During 1996, total thyroidectomy (TT) was introduced as an elective procedure, leaving the preferred option to the surgeon's discretion depending on the specific situation. For this reason, EST was still occasionally performed, in which unilateral or bilateral tissue residue (<2 g) was left to protect the recurrent laryngeal nerve and/or the parathyroid glands. Only during the last 3 years of the study period was EST fully replaced by TT. In our patient series, 33 (32%) received EST and 69 underwent TT.

All operations were performed under general anesthesia and with the conventional technique. The inferior laryngeal nerves were systematically identified and exposed. The external branch of the superior laryngeal nerves was not deliberately sought, but the surgeon attempted to protect it by accurately isolating the upper pole of each lobe and ligating the branches of the superior thyroid artery in contact with the thyroid capsule. The parathyroid glands were systematically looked for. When necessary, one or more parathyroids were transplanted into the sternocleidomastoid muscles. The operations were concluded with the placement of 1 or 2 suction drains which were usually removed the next day. The surgical wound was closed with an intradermal suture. The EST-treated patients were tested for thyroid-stimulating hormone (TSH) and thyroid hormone production 4 weeks after the operation. Those who received TT were prescribed levothyroxine replacement therapy at discharge. All patients were referred back to their endocrinologist for further follow-up.

OPERATIVE MORTALITY AND MORBIDITY
Surgical complications that occurred in these cases were analyzed in a previous study. Briefly, no surgery-related deaths were recorded. Unilateral transient recurrent nerve paralysis developed in 4 (4%) patients; transient hypocalcemia occurred in 12 (12%); permanent hypoparathyroidism developed in 1 (1%). Postoperative hemorrhage leading to compressive hematoma required reoperation in 4 (4%) patients.

EVALUATION OF EFFICACY OF SURGICAL TREATMENT
In our study, efficacy of surgical treatment was defined as the ability to respond positively to patient needs and expectations. To evaluate treatment efficacy from the patient's perspective, data were acquired from the responses to a questionnaire survey mailed to patients. The questionnaire was divided into 5 sections. The first section comprised 5 items pertaining to the pre-operative period and asked about the influence of the disease on the patient's physical and psychological status and social interactions, therapies received, any difficulties experienced with antithyroid drugs and periodic examinations.

The second part contained 5 items about the operation in reference to the reasons for choosing surgery and the degree of satisfaction with care processes, along with several specific aspects (quality of information received, efficiency of hospital facility, relationship with health care workers).

The third section (10 items) focused on the post-operative period. Some questions were devised to acquire data for objectively evaluating the result of therapy (post-operative thyroid function and therapies), while others focused on elements useful for outcome evaluation, including undesirable sequelae to the operation, any difficulties in antithyroid therapy, changes in health status, including physical and psychological status and social interactions versus the pre-operative period.

The fourth section (2 items) asked about the post-operative course of ophthalmopathy.

The fifth section (2 items) investigated the degree of satisfaction with the result of surgical treatment. The items asked for a global evaluation of quality of life before and after thyroidectomy, and whether the patient would recommend surgery to a friend with the same disease and in the same condition.

The questionnaire contained various types of responses to the items: yes/no; multiple choice on a continuous scale; scores on a scale from 0 (poor) to 10 (excellent). Open questions were included for expressing opinions and observations. The course of ophthalmopathy was self-assessed because no useful preoperative data were available for comparison.

STATISTICAL ANALYSIS
The chi-square test was applied to compare proportions; Student's t-test was used for comparing the means. A P value less than 5% was considered statistically significant.

Results
Of the 102 questionnaires mailed out, 83 (81%) were returned; 27 of 33 (82%) were received from the EST-treated patients and 56 of 69 (81%) from the TT-treated patients. Responses were received from the 4 patients...
who experienced transient recurrent vocal cord paralysis, from 10 of the 12 treated for transient hypocalcemia, and from 3 of the 4 reoperated for compressive hematoma. The mean time period since operation was 5 years, 9 months (range, 12 months to 11 years). One death related to neither surgery nor disease was ascertained (road accident); the reasons for the other missing responses were not further investigated.

Section 1. From onset of the disease to surgery
A severely impaired ability to carry out activities of daily living (ADL) or a severe impairment in affective and social relations were reported in 33% and 22% of cases (Table I).

The duration of pharmacological therapy varied widely (2 months to 17 years; mean, 4 years 3 months); 89% reported that antithyroid therapy and periodic examinations were not troublesome or only of minor inconvenience (Table I). Serious difficulties were reported by two patient categories, namely, those with pharmacologically difficult to control hyperthyroidism and those with methimazole intolerance. The former required frequent trials to adjust drug dosage, and subsequently repeated laboratory tests and medical examinations. The latter had the added expense of purchasing propylthiouracil which is currently not sold in Italy.

Section 2. Surgery
The most often stated reason for having selected surgical treatment was trust in the treating physician's advice (84%), followed by the wish to discontinue pharmacological therapy and follow-up examinations (41%); the hope of achieving an improvement in exophthalmos (29%); the presence of a large goiter (28%); the wish to become pregnant (14%). Alternative treatment with radioiodine was considered and rejected in 24% of cases. The majority of patients (84%) felt that the information they had received was adequate. Among those who responded that information had been rather superficial, some specified that they had not been adequately prepared for coping with the problems of replacement therapy or with a longer than expected period of convalescence. One item specifically investigated whether the information about possible treatment-related complications had been understood; 54 (65%) patients remembered having received pertinent information; 8 (10%) could not remember, and 21 (25%) stated they had not received specific information. Hospital function was judged generally adequate (Table II); less favorable judgments were primarily related to long waiting time or having to share hospital room and bath with other patients. Physician and nursing staff behavior was judged very positively by the majority of patients (Table II).

Table I – Responses to items pertaining to the pre-operative period.

<table>
<thead>
<tr>
<th>Item</th>
<th>No, or only slightly</th>
<th>Yes, but not significantly</th>
<th>Yes, greatly</th>
<th>No opinion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did the disease impair your ability to perform activities of daily living (work, school, sports, household activities, etc.)?</td>
<td>28 (34%)</td>
<td>27 (33%)</td>
<td>27 (33%)</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Did the disease impair your affective and social interactions (family, school or work environment, friends, partner)?</td>
<td>43 (52%)</td>
<td>20 (24%)</td>
<td>18 (22%)</td>
<td>2 (2%)</td>
</tr>
<tr>
<td>Did you have trouble following antithyroid therapy or returning for periodic examinations?</td>
<td>49 (59%)</td>
<td>25 (30%)</td>
<td>8 (10%)</td>
<td>1 (1%)</td>
</tr>
</tbody>
</table>

Table II – Responses to items about the efficiency of hospital facility and the relationship with health care workers.

<table>
<thead>
<tr>
<th>Item</th>
<th>On the whole, yes</th>
<th>No, barely adequate</th>
<th>No, fairly poor</th>
<th>No opinion</th>
</tr>
</thead>
<tbody>
<tr>
<td>While hospitalized for surgery, did the hospital give you the impression of working adequately?</td>
<td>74 (89%)</td>
<td>4 (5%)</td>
<td>5 (6%)</td>
<td>0</td>
</tr>
<tr>
<td>While hospitalized for surgery, did the medical and nursing staff respond adequately to your needs?</td>
<td>80 (96%)</td>
<td>1 (1%)</td>
<td>2 (2%)</td>
<td>0</td>
</tr>
</tbody>
</table>
Section 3. Post-operative period

Postoperative hypothyroidism developed in all patients, for which all received levothyroxine replacement therapy. Problems with replacement therapy were reported by 6% of patients, who had difficulty in achieving the right dosage (3 patients), or experienced discomfort from a feeling of dependence on therapy (2 patients). Some 63% of patients stated that their ability to perform ADL had improved after the operation, and 59% reported an improvement in affective and social interactions (Table III).

Items investigating the development of undesired sequelae revealed that 24 (29%) patients believed they had experienced a voice change. Specifically, symptoms included vocal cord fatigue (14 patients) and difficulty in reaching high notes when singing (20 patients). Seven (8%) patients complained of a persistent discomfort in the operated area; vague discomfort was reported by 3; a sense of strangulation or suffocation by 2; limited neck extension by 1 patient; local tenderness by 1 other patient. Judgment of the cosmetic appearance of the surgical scar was rated on an 11-point scale (0-10). The average score was 8; 70% of patients gave a high score (8-10), while 11% felt scar appearance was cosmetically unpleasant (score 0-5).

Section 4. Ophthalmopathy

According to the patients view of the eye problems, ophthalmopathy was present in 62 (75%) of patients at the time of surgery, of which 46 (55%) defined the condition as very pronounced or severe. At questionnaire administration, ophthalmopathy was present in 44 (53%) patients and considered very pronounced or severe by 10 (12%) (Table IV). The difference between the pre- and postoperative conditions was statistically significant (chi square, 36.236 with 3 degrees of freedom; P=0.000). Of the 46 patients with very noticeable or severe ophthalmopathy at surgery, 37 (80%) reported having experienced improvement, 3 (7%) worsening of the condition, and 6 (13%) no substantial change. Smoking habits of these patients did not result significantly related to the outcome.

Of the 16 patients who defined ophthalmopathy as barely noticeable at surgery, 1 (6%) reported worsening of the condition, 7 (44%) an improvement, and 8 (50%) no change.

Section 5. Global evaluation of Quality of Life

Evaluation of global quality of life (QoL) before versus after surgery as rated on a scale from 0 to 10 is shown in Figure 1. The preoperative QoL was rated as poor (scores of 0-5) by 47 (57%) patients and very poor (scores of 0-3) by 22 (27%) (mean score, 4.7). Postoperative QoL was rated poor (scores of 4 or 5) by 4 patients (5%) and highly satisfactory (scores of 8-10) by 52 (63%) (mean score, 7.9). The difference between the two means was statistically significant (t = -9.800 with 162 degrees of freedom; P=0.000).

Over half of patients (51 cases, 61%) increased their scores by 1-4 points. In 14 (17%) cases, the score improved by 5-8 points and in 6 (7%) by 10 points (from 0 to 10). In contrast, 11 (13%) patients rated their postoperative QoL as lower than or equal to their preoperative QoL. An analysis of these cases revealed that in 7 the pre- and postoperative scores (scores of 7-10) indicated a substantial well-being uninfluenced by the operation. The remaining 4 gave the postoperative QoL a score of 5 or 6; they reported no improvement in their ability to perform ADL or in affective and social interactions. One of these patients also had a severe ophthalmopathy which did not improve after thyroidectomy.

The degree of satisfaction with the choice of surgical treatment was measured by the item “Would you recommend surgery to a friend with the same disease and in the same situation?” A positive response was given by 90% of patients, none of which suggested having the operation at another medical center, whereas 4 patients (5%) gave a negative response and 4 (5%) did not express an opinion. An analysis of the 4 negative responses revealed various reasons for dissatisfaction with the surgical result: 3 patients cited persistent voice change, 2 cited frequent adjustments in replacement therapy dosages, 1 patient reported persistent scar discomfort judged cosmetically unpleasant, 1 reported no improvement in severe ophthalmopathy.

### Table III – Responses to items pertaining to the post-operative period.

<table>
<thead>
<tr>
<th>Item</th>
<th>Yes, slightly</th>
<th>Yes, sufficiently</th>
<th>Yes, greatly</th>
<th>No opinion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compared with the period before the operation, has your ability to perform activities of daily living improved (work, school, sports, household activities, etc.)?</td>
<td>28 (34%)</td>
<td>31 (37%)</td>
<td>21 (25%)</td>
<td>3 (4%)</td>
</tr>
<tr>
<td>Compared with the period before surgery, have your affective and social interactions (family, school or work environment, friends, partner) improved?</td>
<td>28 (34%)</td>
<td>33 (40%)</td>
<td>16 (19%)</td>
<td>8 (10%)</td>
</tr>
</tbody>
</table>
Discussion

Studies evaluating treatment for Graves' disease rarely include the patient's perspective or the impact therapy may have on the patient's quality of life (QoL). A Medline literature search produced only one reference to a Swedish study Ljunggren and co-workers conducted that was designed to capture this dimension of assessment. The study included a series of 174 patients randomly assigned to one of three treatment options: medical, radioiodine and surgical therapy. Like Ljunggren's study, ours too used a questionnaire mailed to a series of surgical patients treated at the same institution. The survey tool was designed to define from the patient's perspective various aspects of the disease and its treatment before, during and after surgery. The response rate (81%) was satisfactorily high.

The first section of the items investigating the preoperative period revealed that about 1 in 4 patients experienced the disease as a severe impairment to the ability to perform activities of daily living (ADL) and to maintain satisfying affective and social interactions. These data coincide with the final section, where, in response to the item asking for a brief judgment of the preoperative QoL as rated on a scale from 0 to 10, 27% of patients gave a score from 0 to 3. A significant deterioration in the QoL of patients with untreated Graves' disease was recently reported by Eberling and co-workers. Their study showed a negative impact on the patient's physical and psychological status and social life; however, with diagnosis and institution of treatment, a general improvement in variables was observed in most but not in all patients. Our questionnaire did not include an evaluation of the effect of antithyroid treatment. What we did find, however, was that pharmacological management and periodic examination were generally well accepted and did not pose significant problems in most cases.

The second section of the questionnaire focused on the operation. An analysis of the reasons for choice of surgical treatment revealed that most patients (84%) based their decision partly or fully on their trust in the physician's advice. In response to items on the adequacy of patient information, 84% of patients reported they had received from their treating physicians (endocrinologist, surgeon, etc.) clear and adequate information about the operation, yet a surprising 35% of patients stated they had not been informed at all about complications or could not remember whether the subject had been mentioned. This contradiction came unexpectedly. In our institution, standard practice is that information about possible complications of an operation are given orally at the first interview and then repeated on admission before signing the consent for surgery form. Evidently, adequate information was either not given or not always remembered as

<table>
<thead>
<tr>
<th>Evaluation</th>
<th>Before surgery</th>
<th>After surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Absent</td>
<td>20 (24%)</td>
<td>38 (46%)</td>
</tr>
<tr>
<td>Barely noticeable</td>
<td>16 (19%)</td>
<td>34 (41%)</td>
</tr>
<tr>
<td>Very noticeable</td>
<td>40 (48%)</td>
<td>7 (8%)</td>
</tr>
<tr>
<td>Severe (complicated)</td>
<td>6 (7%)</td>
<td>3 (4%)</td>
</tr>
<tr>
<td>No opinion</td>
<td>1 (1%)</td>
<td>1 (1%)</td>
</tr>
</tbody>
</table>

Table IV – Subjective evaluation of ophthalmopathy before and after surgery.

![Graph showing response to item: Rate your quality of life before with respect to after the operation on a scale from 0 (poor) to 10 (excellent).](image)
having been given. The questionnaire results hence shed light on an issue with implications for the surgeon’s professional responsibility to explain to the patient in clearly understandable fashion the risks of an elective surgical treatment.

The topic of information in thyroid surgery was recently examined in a French study 17, which showed that patients’ memory of orally provided information about complications prior to surgery is often weak. At hospital discharge, 69% of patients remembered only 1 or 2 of the possible complications mentioned, and 12% could not remember mention of any. The unanimous conclusion of the discussants (surgeon, internist, lawyer, judge) was that while the patient-surgeon interview is essential, providing the patient with additional written information is also important. In light of our study results we can only agree with this.

The degree of satisfaction with the processes of care is currently considered an important quality indicator 13. This derives from a host of factors which include interpersonal aspects of care, technical competence of clinicians, accessibility, and duration of waiting time. In our study, patients expressed a generally positive opinion of hospital function and a nearly unanimous appreciation of health care worker behavior. While some criticism was voiced mainly about waiting time, the degree of satisfaction with the processes of care was high in general. Our series comprised patients who had received extensive subtotal thyroidectomy (EST), with minimal unilateral or bilateral tissue residue, and others who had undergone total thyroidectomy (TT). The questionnaire responses indicated that both techniques were satisfactory in achieving the desired functional result, since at a mean postoperative interval of over 5 years no patients reported a relapse of hyperthyroidism. The EST procedures did not permit maintenance of even a normal range of thyroid hormone production. Very few (6%) patients reported problems with replacement therapy related to thyroid hormone production. In most cases evaluation of the cosmetic appearance of the scar was positive, while a not negligible 11% of patients felt scar unpleasant. A minimally invasive approach has been recently proposed also for Graves’ disease 19, 20; it could be better accepted and therefore it should be considered for selected cases.

A more or less marked improvement in the ability to perform ADL and in affective and social interactions was reported in 63% and 59% of responses, respectively. This finding coincides with the final section of the questionnaire that asked for a comparison between pre- and postoperative QoL rated on a scale from 0 to 10. The analysis of individual scores showed that nearly half (48%) of patients had experienced an improvement in their QoL of 3 to 10 points.

Responses to the fourth section on ophthalmopathy indicate that the number of patients who believed having or having had a visibly noticeable condition was considerably higher than the number documented in the medical records. Pronounced ophthalmopathy was reported in the medical charts of 24% of patients, whereas a very noticeable or severe ophthalmopathy in the preoperative period was claimed by 55% of patients. A similar discrepancy was found in Ljunggren’s study 15, which accounted for the difference by the fact the medical record very probably noted only cases with evident signs of infiltrative ophthalmopathy, whereas a certain number of patients probably experienced discomfort resulting from eyelid retraction or minor degrees of infiltrative ophthalmopathy. We believe that this explanation holds also for our series. The questionnaire responses showed a generally favorable course after thyroidectomy, with more or less marked improvement in 71% of patients who reported an ophthalmopathy prior to surgery. Postsurgical worsening of the condition was claimed by 6% of patients. The literature reports postthyroidectomy improvement rates of 64-74% 8, 10.

The final section showed that most patients felt that their QOL had generally improved after surgery, sometimes significantly so, and that they were satisfied with having had surgery. Some 90% of patients stated they would definitely recommend surgery to a friend with the same disease and in the same condition (and at the same institution), whereas only 5% would not advise surgery. Again, these results are in line with those of Ljunggren, who reported that of the patients assigned to surgical treatment, less than 5% would not recommend surgery to a friend with the same condition 15.

Conclusions

Our results strongly indicate surgical treatment is an efficacious option in the management of hyperthyroidism in Graves’ disease and can adequately respond to the needs and expectations of most patients. The small minority (5%) of patients who would not recommend

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surgical management should prompt reflection nevertheless. Their responses emphasized various possible reasons for dissatisfaction: undesirable sequelae to surgery, cosmetically unpleasant scars, unpredicted problems with replacement therapy, unimproved ophthalmopathy. These aspects many clinicians consider as secondary or partly inevitable or exaggerated by patients remain a cause of concern, and should therefore be mentioned whenever surgical treatment is recommended. It should be remembered that satisfaction is believed to be the relation between experience and expectations. In this interplay, guiding the patient toward having realistic expectations will increase the likelihood that they will be satisfied.

Riassunto

OBIETTIVO: Analizzare retrospettivamente le opinioni dei pazienti sul trattamento chirurgico del morbo di Basedow.

METODO: Lo studio comprende 102 pazienti sottoposti ad ampio tiroideectomia subtotal e o a tiroideectomia totale nel periodo 1993-2003. I dati sono stati acquisiti mediante un questionario, al quale hanno risposto 83 pazienti.

RISULTATI: Prima dell'intervento la capacità di lavoro/studio e le relazioni affettive/sociali erano deteriorate nel 20% e nel 22% dei casi. L'informazione ricevuta sull'operazione era adeguata per l'84% dei pazienti. L'efficienza dell'ospedale e le relazioni con medici/infermieri venivano giudicate positivamente nell'89% e nel 96% dei casi. Dopo l'intervento tutti i pazienti erano ipotiroidei in terapia con l-tiroxina; il 6% riferiva problemi inattesi con la terapia. Cambiamenti della voce o fastidi nel collo sono state più frequenti che non previste. Le complicanze chirurgiche, incluse lesioni vascolari, erano state meglio previste thanexpected by 13% dei pazienti. L'efficienza del servizio di assistenza e le relazioni affettive/sociali erano migliorate nel 63% e nel 59% dei casi. La qualità di vita, espressa con un punteggio da 0 a 10, era migliorata passando da una media di 4,7 a una media di 7,9 (P=0,000). Solo il 5% dei pazienti esiterebbe a raccomandare il trattamento.

CONCLUSIONI: La chirurgia rappresenta una soluzione effettiva per il trattamento del morbo di Basedow. Il 5% dei pazienti esiterebbe a raccomandare il trattamento preoperatorio di 4,7 a una media di 7,9 (P=0,000). Solo il 5% dei pazienti esiterebbe a raccomandare il trattamento. Le relazioni affettive/sociali erano migliorate nel 63% e nel 59% dei casi. La qualità di vita, espressa con un punteggio da 0 a 10, era migliorata passando da una media di 4,7 a una media di 7,9 (P=0,000). Solo il 5% dei pazienti esiterebbe a raccomandare il trattamento

References

