



Quality of life aspects in the management of thyroid cancer



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ARTICLE INFO

Article history:

Received 19 December 2014

Received in revised form 10 March 2015

Accepted 18 March 2015

Available online 25 April 2015

Keywords:

Thyroid cancer

Quality of life

Patient-reported outcomes

Cancer management

Meeting report

SUMMARY

While there is agreement that quality of life (QoL) is a central aim of medical treatment, the methods of its evaluation as well as its role in the patient's overall treatment experience are under continuous scrutiny. Different perspectives on patients' QoL have emerged; from the treating physician, from the psychologist, and naturally from the patient him/herself. This article provides insights into each of these views within the context of thyroid cancer where, as a consequence of increasing incidence and decreasing mortality rates, QoL aspects deserve close attention. Physicians often find themselves in situations where they perform a balancing act between what they know is best from a somatic point of view and learning about what is best for the individual patient. For psychologists in the field of oncology, a main area of interest is the incorporation of the patient's perspective into research by using patient-reported outcomes (PROs) which include QoL assessment. PROs can also be used in clinical practice as a way to start a conversation about symptoms and QoL aspects that perhaps patients might not volunteer, and this allows physicians to address QoL issues more directly. Patients usually appreciate being asked about all aspects of QoL, and need sound information about how their QoL might be affected by the disease and its treatment. By examining and understanding the different perspectives on QoL, and how QoL differs in patients with thyroid cancer compared with other cancers, it is hoped that the QoL can be enhanced in this particular patient group.

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Introduction

This paper summarises presentations and discussions from the *Quality of Life and Follow Up* session of a physician-only meeting held in Vienna, November 23, 2013 entitled *Thyroid cancer: from nodule to cure – the controversies*. The meeting was organised by the Austrian Society of Nuclear Medicine and Molecular Imaging and the Medical University of Vienna. The session presented three different perspectives on the QoL of thyroid cancer patients; those of the treating physician, the psychologist, and the patient. QoL is becoming an increasingly important issue but is difficult to define and address. Particularly in the case of thyroid cancer, the symptoms may have a broad range (from emotional to physical discomfort, depending on the thyroid hormone status), which can affect the patient severely. The patient does not know what kind of symptoms they may be facing and is often left alone with their diagnosis and fears. Time pressure and the reluctance to 'burden' the physician with 'emotional' symptoms may silence the patient, and the physician often only sees the favourable prognosis of

thyroid cancer compared with other cancer types and neglects to address QoL issues. A specific questionnaire may help to bridge these two perspectives and allow both sides to understand what and where the patient's discomforts are and what the physician can do to relieve them. Some symptoms may last for a specific time (e.g. hormonal withdrawal prior to ablative radioiodine treatment), and explaining this would help the patient to understand and accept the symptoms; or the situation could be avoided by using a different form of treatment (e.g. by using recombinant TSH stimulation). However, in Austria only a minority of patients receive this kind of preparation for radioiodine treatment and this is usually for thyroid remnant ablation. Therefore, the problems with symptoms caused by hormone withdrawal are less significant. In the majority of patients, if it is considered that subsequent therapeutic administration of radioiodine will not be required, exogenous stimulation by recombinant human thyrotropin (rhTSH) is used for diagnostic purposes. In cases where radioiodine treatment may be required, some centres still prefer endogenous stimulation for all patients. Additionally, some treatments e.g. TSH-suppressive therapy after radioiodine treatment, can lead to several symptoms such as palpitation, restlessness, and nervousness, which may last for the rest of the patient's life. Since thyroid

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hormone disorders may lead to emotional 'rollercoaster rides', a psychologist may be invaluable to help the patient cope with their symptoms. However, until the physician knows where the patient's discomforts are, they cannot be treated or managed.

The physician's view – Dr. Alexander Becherer

The physician's view of QoL in thyroid cancer patients can be explained and explored by examining case studies.

The first case presented was a 36 year-old female patient, with a slightly painful nodule in the anterior neck, and who had been showing symptoms for 1 month. Apart from a heart rate of 96 bpm, she was clinically euthyroid. On palpation, the nodule was moveable, rather dense, and likely situated in the isthmus on the left side. The physician's first assumption based on anamnesis and clinical findings was that this was most likely a cyst, and the patient was told that most of the nodules with this history are benign. The patient was relieved and very happy.

However, ultrasound showed that it was not a cyst, but a 17 mm hypoechoic nodule with irregular boundaries. As no TSH level was known, scintigraphy with Tc-99m pertechnetate demonstrated that the lesion was cold. Thus, fine needle aspiration cytology (FNAC) was indicated. The patient was given the updated news and was understandably very distressed.

The case illustrated that although it is better for patients (and improves the quality of their experience) to be given a firm diagnosis as soon as possible, particularly if the diagnosis is a benign one, this is often not possible based on statistical probabilities. The physician should wait for the results of the whole bundle of diagnostic tests because speculative diagnoses (even if statistically probable) can lead to great distress once a different diagnosis is made. However, in thyroid nodules scintigraphy can be done immediately and gives a result very quickly, which is much better for the patient than waiting for the thyrotropin result to determine whether a nodule is hyper- or hypofunctioning.

Given the results of sonography and scintigraphy, the physician's view was that the nodule had a significant chance of being a carcinoma. The patient was told that there was a 1 in 5 chance of the nodule being cancer (to make her aware of the possibility that she had a malignant disease, but without leaving her with a very pessimistic outlook). Finally, FNAC revealed papillary thyroid carcinoma. This highlighted the importance of not telling patients their results in detail if there is a possibility of changing the message. The patient underwent thyroidectomy a few days after receiving the FNAC result. She had a PTC pT1bN1a tumour, maximum diameter of 17 mm, BRAF V600E mutated, with 6 out of 39 metastatic lymph nodes. Her response to surgery and radioiodine ablation with 1850 MBq ¹³¹I under rhTSH stimulation was excellent, with a stimulated thyroglobulin (Tg) of 0.5 ng/ml (IMMULITE® 2000 XPi, Siemens Healthcare, Erlangen, Germany, analytic sensitivity, 0.2 ng/ml) two months after radioiodine ablation.

In terms of QoL issues, the patient was concerned about her small son, whether she would be able to see him grow up, and whether he would lose his mother. She was also concerned about her ability to have more children, and if the treatment for her cancer would mean that she would lose her hair. A key learning point from this interaction was the importance of remembering that although physicians may tell patients 'You have a carcinoma with an extremely favourable prognosis', and try to make the most memorable words for the patient 'an extremely favourable prognosis', in fact the words that the patient mainly hears are only 'you have a carcinoma' [1].

The second case concerned a 74 year old female patient with a 14 year history of follicular thyroid carcinoma, pT4N0Mx. She had 6 diagnostic scans over 6 years and was in complete remission. Then her Tg level started to rise, and the patient was treated with

radioiodine therapy. Following treatment the patient received 2 check-ups per year. No detectable lesions were found either by diagnostic scanning with ¹³¹Iodine, with ¹⁸F-FDG, or with ultrasound. However, her Tg levels continued to rise without any discernible clinical symptoms.

The QoL issues in this case centred around helping the patient to accept that her Tg level was a laboratory finding which necessitated more frequent check-up visits, but did not influence her wellbeing. The patient had tooth problems with softening of adamantine, caused by xerostomia (an adverse effect of radioiodine). Initially the patient did not want to spend any money on her teeth because she believed 'it's not worth while investing money on my teeth because I'm going to die soon.' However, the physician convinced her that the prognosis was good, and she had her teeth repaired and was very proud of them. The patient is currently in very good condition, is healthy, and enjoying life with her husband and grandchildren.

The third case report was of a 61 year-old male patient, with poorly differentiated follicular cancer pT4pT1Mx, that had relapsed locally twice already in the early course of the disease. Eventually he developed pulmonary metastases for which he underwent 3 operations on the right lung (first 9 years after his first diagnosis, then again 1 year later, and finally a further year later). The patient also underwent external radiotherapy for metastases in the left lung. He had been treated for the last 2 years with a tyrosine kinase inhibitor, which had slowed the progression of the cancer. The patient had no symptoms from the lesions, but treatment with sorafenib affected his QoL due to the development of severe hand-foot-syndrome, and subsequent mild diarrhoea when he switched his medication from sorafenib to pazopanib. However, the hand-foot-syndrome resolved and the patient controlled his diarrhoea during the day with other medication, and was able to continue to work as a travelling salesman. The patient was very, and would have not even attended his monthly check-ups if he had not needed a new prescription for pazopanib and on the insistence of his wife. She said that the main reason for her husband missing the check-ups was his fear of receiving bad news. His main complaints were diarrhoea, his hair becoming white, and a lack of compliance with his antihypertension medicine.

In summary, although this patient had a severe, progressive disease, he had an acceptable QoL. This is because he had different coping strategies than those of the patient in case study 2 – illustrated by the fact that he had bought a new sports car, showing that he saw his prognosis in a different way.

In general, it is important to remember that thyroid cancer is a disease with rising incidence but decreasing mortality in Austria and throughout the whole world [2,3], and this gap often leads us to believe that a patient should not be 'worried' by their thyroid cancer [1]. However, this is not very helpful, and physicians should avoid telling patients 'it could have been worse' because the patient is occupied with their own fate, asking why this happened specifically to them, even when they appear to be trying to make the best out of their situation.

Hypocalcaemia is an issue in QoL (even more than laryngeal nerve palsy, when it occurs unilaterally), and the side effects of radioiodine should be considered, although there is no risk of infertility or genetic changes [4,5]. Most patients live long enough to experience side effects and they can adversely affect QoL. For example, xerostomia occurs in 10–20% of patients [6,7]. There is a low risk of induction of a second malignant tumour by radioiodine, however, discussions centreing around this are controversial. Data on this issue are heterogeneous but there is a probable hazard ratio of 1.2 and females are more at risk than men.

Therefore, in summary, physicians should not give positive diagnoses too readily, even if the statistics are in favour of good news. It is easier to turn indifferent news into good news than vice

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