

# Chapter 18

## Quality of Life Issues

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### Typical Quality of Life Concerns in Head and Neck Cancer Patients

Keeping quality of life (QoL) as good as possible is very important for patients being treated for cancer. Head and neck cancer patients suffer frequently from problems with swallowing, a changed ability to smell and taste something, from sticky saliva, dry mouth, coughing, problems with teeth, inability to open the mouth wide, or difficulties speaking [1–7].

It depends on the individual patient what QoL issues are most important to him. This should be elucidated during the patient-doctor consultation. However, for developing treatments and supportive care measures, it is helpful to find out what QoL issues are of importance to many patients. In a recent international study [8], the majority of head and neck cancer patients rated the following QoL issues as most relevant for them: swallowing, anxiety, eating, talking, dry mouth, pain and skin problems.

### Mental Health as a Predictor of Quality of Life

Psychological morbidity is an important associate of poor quality of life [9–11]. It is important to note that head and neck cancer patients suffer more frequently than other cancer patients from psychosocial problems, especially some time after their diagnosis [12]. This fact goes often unnoticed by the doctors and nurses in charge for the patients:

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Only about half of the patients with severe emotional problems such as a clinical depression are identified as emotionally distressed by the medical team [13, 14].

Reasons for this underdiagnosis are manifold. One is that doctors have usually little time for conversations with their patients. Talking with patients is unfortunately paid worse than prescribing medicines. Another reason is that some colleagues may feel poorly trained in how to talk to patients and, probably more important, how to deal with their emotional concerns. A third reason is that some patients tend to conceal their emotional concerns. This happens, inter alia, because they do not want to bother their oncologists or surgeons with their problems, realising that the doctors have already very little time and so much work to do, and they do not want to disturb them with their – as they may feel it – minor or ridiculous problems. Some patients may find it easier to open up to their general practitioner than to their surgeon.

Head and neck cancer occurs more often in men than in women, and men find it, on average, harder to talk about their emotional problems, simply because they were brought up with the slogan “boys don’t cry,” and hence, they feel as a looser or “sissy” when they do. It takes patience and an active approach from the doctor to learn from the patients where he is suffering from. Men may find it difficult to be in need for help in the first place, and needing help for emotional problems may be even harder.

In an Australian study [15], about 1,100 general practitioners were interviewed about their experience with men talking about their emotional concerns. The doctors said, for example: “*Men find it hard to open up, you have to be very alert to notice warning signs. Often first impressions. A good history usually makes diagnosis relatively easy, but men don’t generally volunteer as much information .... Reluctant to come to the doctor in the first place and when they do, they focus on physical symptoms rather than their state of mind.*”

Even relatives may underestimate the patients’ emotional problems because the patients feel unable to confide in them. An illustrative example was published by Gibson and McCombe [9]. They interviewed patients who had been treated with total laryngectomy along with their partners after discharge from the hospital. The following passage illustrates the despair of the patients and their inability to open up even to their partners: “*The patient’s partner felt that the patient’s mood was unchanged following the operation. The only difference she felt was that he was more willing to walk the dog. When interviewing the patient later that afternoon he graphically explained how when walking the dog he would stand for hours by the railway line, staring at the track, trying to build up the courage to jump in front of the speeding trains.*” (p. 351).

## Stigma and Social Withdrawal

A specific problem in head and neck cancer is that the consequences of the disease and its treatment can not be concealed – other people can see, hear and sometimes even smell that these patients had cancer. This may result in stigmatisation [16]. In

general, a stigma is an unwanted individual characteristic that differentiates one person from the others and that leads to social withdrawal of these “others” [17]. The extent of withdrawal depends on the type of the stigma: A disease that is visible and severe evokes more social distance than a disease that is visible but not serious. The withdrawal is lowest if the disease is invisible [18]. Research into stigmatisation has shown that the reasons for such a social withdrawal are insecurity in social interactions, fear that the own wellbeing may suffer, assuming moral weakness in the stigmatised person, feeling guilty to be healthy, and disgust [18].

However, not only the others may withdraw from the patient. Head and neck cancer patients also withdraw from their social environment [19–22]. Why do they do this? It can again be explained by stigmatisation which is a two-sided process. If people are stigmatised by others, they receive negative reactions more frequently. This can result in a negative self-concept, especially when the stigma is accepted as being a part of the self. Avoiding contact with other people alleviates negative feelings (of being unwanted, ugly, disabled, etc.) and makes the patient feel more in control. On the downside, it prevents him from making positive experiences in the social contact with other people which can result in a vicious circle [21].

## How to Measure Distress and Quality of Life

Distress and quality of life issues can be identified in the doctor-patient consultation simply by asking “How do you feel?” if this is accompanied with showing the patient that we have the time and willingness to listen to him.

Another option, optimally in addition to the individual consultation, is to use validated questionnaires. They provide reliable data and are easy to use in the daily routine and in clinical studies. Frequently used tools to screen for distress are the Hospital Anxiety and Depression Scale (HADS) [23], the Patient-Health-Questionnaire Short Form (PHQ-9) [24], and the Distress Thermometer (DT) [25]. All of them are reliable, validated for cancer patients, translated into several languages and brief [26–28].

Good instruments to measure quality of life in cancer patients are the Functional Assessment of Cancer Therapy (FACT-G) [29] and the European Organisation for Research and Treatment of Cancer Quality of Life Core Questionnaire (EORTC QLQ-C30) [30]. For patients in palliative care, the shortened version EORTC QLQ-C15 can be recommended.

Specific for head and neck cancer are, for example, the Functional Assessment of Cancer Therapy, Head and Neck Module (FACT-HN) [31], the University of Washington Quality-of-Life Instrument (UW-QOL-R) [32], the MD Anderson Symptom Inventory – Head and Neck Module (MDASI-HN) [33], and the head and neck module of the EORTC (QLQ-H&N35) [4]. The latter is currently being revised and updated to cover side effects of modern treatment schemes [8]. All these instruments are well accepted by patients [34–36].

## How to Talk About Emotional Distress and Quality of Life

As outlined above, head and neck cancer patients might find it difficult to approach the doctor actively and talk about their emotional concerns. This is not only related to the fact that they are frequently men who are socialised not to show weakness or despair, they also often had less education than the doctor whom they are speaking to which may make them feel intimidated and shy. The best way to cope with this situation is to actively and repeatedly ask the patient about his quality of life, with interest and concern. When patients realise their doctor really cares, they open up more freely. This is not only in the interest of the patient but also helpful for tailoring supportive care and increasing adherence to treatment [37].

The following advices can guide doctor-patient consultations:

- Don't wait until your patient says something.
- Ask actively how he/she feels.
- Ask repeatedly.
- You do not need a lot of time for this, just be present in the moment and show that you really care.
- If professional psychological help is needed, offer it as something normal. Make it a "prescription" that the patient should use.
- Provide addresses of social workers, psychologists, self-help groups, etc.
- Patients want to talk to you in the first place. Do not simply send them away to the psychosocial experts. Instead, offer your time and *additionally* the help of the experts.

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