

# SUMMARY



In general, patients with advanced-stage lung cancer have a limited prognosis and are prone to a decrease in Health Status, Health-Related Quality of Life, and Quality of Life due to disease and treatment-related symptoms. As such, the preservation of their well-being is an important treatment goal. In studies in lung cancer, the effect of treatment on Quality of Life is often analyzed next to the traditional endpoints of disease progression and survival. However, if the definition of Quality of Life as formulated by the World Health Organization is used, these studies merely describe Health Status and Health-Related Quality of Life and not Quality of Life. As a result, the interpretation of studies that use Health Status, Health-Related Quality of Life, and Quality of Life as outcome parameters is hampered by the lack of consensus about the definitions of these concepts.

The main objectives of this thesis are: 1) to enhance the knowledge of physicians, researchers, and other health care professionals about the conceptualization and application of some of the most frequently used patient reported outcomes in lung cancer, 2) to stimulate the use of Quality of Life measurement by testing the psychometric properties of the World Health Organization Quality of Life-BREF instrument (WHOQOL-BREF), 3) to identify clinical and sociodemographic variables that are related to (Health-Related) Quality of Life, 4) to investigate the association between patients' feelings about treatment and (Health-Related) Quality of Life, and 5) to explore the role of Quality of Life in the process of treatment decision making in patients with advanced-stage lung cancer.

In the **introduction** background information about lung cancer and the concepts of Health Status, Health-Related Quality of Life, and Quality of Life is provided. Although these concepts demonstrate some overlap, their focus differs. While Health Status describes at least physical, psychological and social functioning, Health-Related Quality of Life evaluates patients' perception about their functioning and well-being in the above mentioned areas. Quality of Life may also reflect domains like the environment or spirituality. Health-Related Quality of Life is Quality of Life, but focusses on health and is less broadly defined as Quality of Life. In addition, the role of patient reported outcomes in treatment and decision making is discussed. Their role seems to be underestimated given their limited use in clinical practice. This is unfortunate as patient reported outcomes may identify aspects of a patient's well-being that need extra attention during treatment and may provide information regarding the burden of adverse events.

Given that distress refers to a patient's unpleasant psychological (i.e., cognitive, emotional, and behavioral), social, and spiritual experiences, Health Status and Health-Related Quality of Life have some overlap with the items measured with the Distress Thermometer. Earlier it was demonstrated that Health Status and Health-Related Quality of Life are associated with survival. In **chapter 1**, the association between the Distress Thermometer and overall survival is investigated. The Distress Thermometer score does not appear to be a significant predictor for overall survival. We demonstrate, however, that patients with lung cancer experience less distress compared with patients diagnosed with other types

of cancer. This seems rather unexpected considering the limited prognosis in lung cancer and the severity and number of side effects of treatment these patients experience.

**Chapter 2** reports the results of a study in which we investigated the psychometric properties of a Quality of Life instrument, the WHOQOL-BREF. It is demonstrated that this instrument has satisfactory psychometric properties. Moreover, minimal clinically important differences (MCIDs) are calculated which facilitate not only the interpretation of results but also the use of this questionnaire in clinical practice and scientific studies in patients with advanced-stage lung cancer. The association of patient and disease-related factors with (Health-Related) Quality of Life is also investigated. Besides a low Eastern Cooperative Oncology Group performance status, high scores on depressive symptoms are associated with decreased (Health-Related) Quality of Life (**chapter 3**).

In this thesis three studies that have examined the association of treatment satisfaction with Quality of Life are reported. In the first study, we present results of a psychometric analysis of the Cancer Therapy Satisfaction Questionnaire (CTSQ; **chapter 4**). The CTSQ evaluates the expectations, feelings about side effects, and satisfaction of patients with their treatment. It is demonstrated that application of the CTSQ in patients with advanced-stage lung cancer is reliable and valid. **Chapter 5** describes the associations between CTSQ domains with (Health-Related) Quality of Life. Remarkably, not patients' satisfaction with treatment, but the domain that measures feelings about side effects (CTSQ) is most often associated with (Health-Related) Quality of Life. In addition, patients seem to be especially bothered by low-grade side effects (e.g., nausea, constipation, mucositis, anorexia, fatigue). This emphasizes the need for continuous screening and management of these side effects during treatment. Given the relation with (Health-Related) Quality of Life, the four CTSQ items that evaluate patients' feelings about side effects may be used to screen for decreases in (Health-Related) Quality of Life. Those patients that experience negative feelings about their side effects subsequently could complete a Health-Related Quality of Life and Quality of Life instrument to analyze which areas are affected or not. Knowledge of patients' satisfaction with treatment may provide important supplementary information for shared treatment decision making besides information about patients' treatment toxicities and (Health-Related) Quality of Life. In **chapter 6**, 86% of the patients reported that they probably or definitely will decide to undergo the same treatment again despite experienced side effects or decreases in their well-being. Moreover, it is demonstrated that satisfaction with therapy has a strong relation with the global Health Status/Quality of Life scale of the EORTC QLQ C-30 and the psychological health domain of the WHOQOL-BREF. Age, feelings about side effects, and tumor response appear to be related with satisfaction with therapy. In addition, patients that experienced increases in WHOQOL-BREF facet score (i.e., overall Quality of Life/general health) are more satisfied with treatment than those that reported no changes or decreases in Quality of Life. Considering the results of these two studies, it is proposed that CTSQ data may be used in a similar manor as survival

data of treatments in making shared treatment decisions. For instance, if a considerable proportion of patients who received chemotherapy were often hampered by side effects according to their CTSQ results, newly diagnosed patients with a limited prognosis could take knowledge of these results and make a more considered treatment decision.

**Chapter 7** discusses our findings in a study regarding shared decision making in patients with stage I or II lung cancer. It is observed that 81% of patients ideally will make a treatment decision together with their physician and that 74% thinks they are sufficiently involved in this process. About 40% of patients experiences decisional conflict. Feeling to be uninformed and uncertainty about their treatment choice contributes most to the experience of decisional conflict. We advocate that patients need to be adequately informed and that their involvement in treatment decision making is needed in order to improve patient knowledge and reduce decisional conflict.

In the **general discussion** the interpretation of our findings is presented and they are placed into context. Contemplating on our findings, suggestions for future research with patient reported outcomes in patients with lung cancer are provided. In addition, recommendations are made to enable their implementation in clinical practice.