

TRISMUS

Incidence, Effects on Health-Related Quality of Life and Development of the Gothenburg Trismus Questionnaire

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This thesis is based on the following studies, referred to in the text by their roman numerals.

- I. Johnson J, van As-Brooks CJ, Fagerberg-Mohlin B, Finizia C.
Trismus in head and neck cancer patients in Sweden: Incidence and risk factors.
Medical Science Monitor 2010;16:CR278-282.
- II. Pauli N, Johnson J, Finizia C, Andréll P.
The incidence of trismus and long-term impact on health-related quality of life in
patients with head and neck cancer. Acta Oncol. 2013 Aug; 52(6):1137-1145.
- III. Johnson J, Carlsson S, Johansson M, Pauli N, Ryden A, Fagerberg-Mohlin B, Finizia C.
Development and validation of the Gothenburg Trismus Questionnaire (GTQ).
Oral Oncology 2012 Aug; 48(8):730-736.
- IV. Johnson J, Johansson M, Ryden A, Houltz E, Finizia C.
The impact of trismus on Health-Related Quality of life and mental health.
In manuscript

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UNIVERSITY OF GOTHENBURG

TRISMUS

Incidence, Effects on Health-Related Quality of Life and Development of the Gothenburg Trismus
Questionnaire

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ABSTRACT

The word trismus is modern latin, derived from the greek word "trismos" meaning "grinding" or "rasping". Trismus is defined as a limitation in the mouth/jaw-opening ability due to a reduced mandible mobility. A Maximum Interincisal Opening (MIO) ≤ 35 mm is often used as the cut-off point for trismus. It can occur as a result of tumor growth, and more importantly, as a side-effect to head and neck (H&N) oncology treatment, especially radiotherapy and surgery. Trismus can also result from benign jaw related conditions, often referred to as temporomandibular disorders (TMD). The aim of this thesis was to investigate how trismus affects the quality of life and mental health in patients with H&N cancer and TMD, examine the incidence of trismus and ultimately to improve the management and care of patients with trismus.

Aims & Methods:

Study I; A retrospective study including 69 patients aiming to investigate trismus incidence in relation to different H&N cancer diagnoses and treatment regimens.

In *Study II* the incidence of trismus after oncology treatment was prospectively examined in 75 patients as well as the impact of trismus on Health Related Quality of Life (HRQL). We used Patient reported outcome (PRO) instruments, including the European Organization for Research and Treatment of Cancer Quality of Life Questionnaires, the Gothenburg Trismus Questionnaire (GTQ) and measurements of MIO.

In *Study III* we developed and validated a trismus specific instrument, the Gothenburg Trismus Questionnaire (GTQ). Patients with H&N cancer and with TMD participated in the study. We used empirical evidence, a pilot study and a "gold standard" validation procedure.

The aim of *Study IV* was to measure the impact of trismus on HRQL and mental health in patients with H&N cancer and TMD, using the PRO instruments Short-Form 36 Health Survey, the Hospital Anxiety and Depression scales and the GTQ.

Results:

The results showed that trismus is a common sequela after H&N cancer treatment. In the retrospective study 42% of the patients had post-treatment trismus and in the prospective material 38% had trismus 6 months following treatment. The latter study also highlighted that trismus severely impacts HRQL. The GTQ showed good psychometric properties and was well accepted by the patients and the results in study IV demonstrated that trismus significantly affects HRQL and mental health and that the GTQ has a clear clinical relevance.

Conclusions:

Our main findings demonstrate that trismus has a significantly negative impact on HRQL and mental health in both H&N cancer and TMD patients and that it is a common and sometimes excruciating sequela after H&N cancer treatment. We suggest that the GTQ is used in clinical practice and in research, employed as a screening tool as well as an endpoint in intervention and rehabilitation studies. Other implications are that patients with trismus should now be approached in a holistic way with respect for the underlying cause, treating not only the physical aspects of trismus but also addressing the patients' mental health. Further research is needed, especially addressing trismus rehabilitation, prevention and training.

Key words: Trismus, Cancer, Head and Neck, Radiation therapy, TMD, Oncology, PRO, HRQL, Questionnaire, Instrument.

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