



QUALITY OF LIFE, QUALITY OF CARE, AND PATIENT SAFETY

HEALTH-RELATED QUALITY OF LIFE IN PATIENTS WITH MASTOCYTOSIS

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Introduction: Mastocytosis is a heterogeneous disease that is characterized by an increased number of clonal mast cells in the skin or other organs. Patients suffer from a variety of symptoms ranging from skin lesions to severe anaphylactic reactions. Some patients report psychological problems and impairments in social life. However, studies on impaired quality of life (QoL) in patients with mastocytosis have received limited attention so far and influencing factors are not specified.

Objective: To assess QoL in patients with mastocytosis and its influencing factors.

Materials and Methods: Clinical and diagnostic parameters of patients with mastocytosis were collected by interviewing the study participants and retrospective analysis of patient files. To evaluate health-related QoL impairment the disease specific Mastocytosis Quality of Life Questionnaire (MC-QoL) was used, which is a validated score based on a four-domain structure: skin, symptoms, emotions and social life/functioning.

Results: A total of 104 patients with different types of mastocytosis were included in this study. The MC-QoL scores showed a broad distribution. Statistical analysis of the total and domain scores revealed a significantly higher impairment of QoL for patients with indolent systemic mastocytosis with cutaneous involvement compared to mastocytosis in the skin except for the skin domain. Patients reporting food intolerance showed a significantly higher impairment in all domains. A serum tryptase level $\geq 100,0 \mu\text{g/l}$ was associated with a significantly higher social life/functioning related QoL impairment compared to normal tryptase levels. Patients suffering from symptoms for more than 25 years had a significantly higher impairment concerning the symptoms domain compared to a shorter duration of symptoms ≤ 5 years.

Conclusions: Quality of life in patients with mastocytosis varies a lot. Diagnosis, history of food intolerance and the duration of symptoms may have a significant impact on health-related quality of life. Tryptase level may be a biomarker for QoL impairment.

