

## Abstract

### Unraveling Desmoid-Type Fibromatosis-specific Health-Related Quality of Life: Who Is at Risk for Poor Outcomes

**Authors:** Anne-Rose W. Schut <sup>1,2\*</sup>, Emma Lidington <sup>3</sup>, Milea J.M. Timbergen <sup>1,2</sup>, Eugenie Younger <sup>3</sup>, Winette T.A. van der Graaf <sup>1,4</sup>, Winan J. van Houdt <sup>5</sup>, Johannes J. Bonenkamp <sup>6</sup>, Robin L. Jones <sup>3,7</sup>, Dirk J. Grunhagen <sup>2</sup>, Stefan Sleijfer <sup>1</sup>, Cornelis Verhoef <sup>2</sup>, Spyridon Gennatas <sup>3,8</sup>, Olga Husson <sup>2,4</sup>

<sup>1</sup> Department of Medical Oncology, Erasmus MC Cancer Institute, Rotterdam, The Netherlands.

<sup>2</sup> Department of Surgical Oncology, Erasmus MC Cancer Institute, Rotterdam, The Netherlands.

<sup>3</sup> Sarcoma Unit, Royal Marsden NHS Foundation Trust, London, United Kingdom.

<sup>4</sup> Department of Medical Oncology, Netherlands Cancer Institute, Amsterdam, The Netherlands.

<sup>5</sup> Department of Surgical Oncology, Netherlands Cancer Institute, Amsterdam, The Netherlands.

<sup>6</sup> Department of Surgical Oncology, Radboud University Medical Center, Nijmegen, The Netherlands.

<sup>7</sup> Division of Clinical Studies, Institute of Cancer Research, Royal Marsden NHS Foundation Trust, London, United Kingdom

<sup>8</sup> Department of Medical Oncology, Guy's and St Thomas' NHS Foundation Trust, London, UK

**Background:** Desmoid-type fibromatosis (DTF) is a rare, soft tissue tumour. These tumours do not metastasize, but their local aggressive tumour growth and unpredictable behaviour can have significant impact on health-related quality of life (HRQoL). Little is known about which DTF patients are particularly affected by impaired HRQoL. The objectives of this study were to assess HRQoL among different groups of DTF patients and to investigate which socio-demographic and clinical characteristics were associated with DTF-specific HRQoL.

**Methods:** A cross-sectional study was conducted among DTF patients from the United Kingdom and the Netherlands. HRQoL was assessed using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30) accompanied by the DTF-QoL to assess DTF-specific HRQoL. Scores were compared amongst subgroups based on socio-demographic and clinical characteristics of DTF patients. Multiple linear regression analyses with backward elimination were conducted to identify factors associated with DTF-specific HRQoL.

**Results:** A total of 235 DTF patients completed the questionnaires. Female patients, patients with more than two comorbidities, or patients who received treatment other than only active surveillance (AS) or surgery scored significantly worse on subscales of both the EORTC QLQ-C30 and DTF-QoL. Patients  $\geq 40$  years scored significantly worse on the physical functioning scale of the EORTC QLQ-C30, while younger patients (18-39 years) scored significantly worse on several DTF-QoL subscales. Differences on the DTF-QoL subscales were found for tumour location, time since diagnosis and the presence of recurrent disease. Furthermore, treatments other than AS or surgery only, female sex, younger age and the presence of comorbidities were most frequently associated with worse scores on DTF-QoL subscales.

**Conclusion:** This study showed that (DTF-specific) HRQoL differs between groups of DTF patients. Awareness of these HRQoL differences could help to provide better personalised care tailored to the needs of a specific subgroup.