

The balancing act of living with symptoms

Patient-reported data and quality of care during and after treatment with proton beam therapy in patients with brain tumors

Akademisk avhandling

Som för avläggande av doktorsexamen vid Sahlgrenska akademien, Göteborgs universitet kommer att offentliggöras i hörsal Arvid Carlsson, Academicum Medicinaregatan 3, Göteborg den 14 februari, klockan 9.00

Av Ulrica Langegård

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Avhandlingen baseras på följande delarbeten

- I. Ulrica Langegård, MSc, RN, Karin Ahlberg, PhD, Assoc Prof, RN, Per Fransson, PhD, Assoc Prof, RN, Birgitta Johansson, PhD, Assoc Prof, RN, Katarina Sjövall PhD, RN, Thomas Bjork-Eriksson, PhD, Assoc Prof, MD, Emma Ohlsson-Nevo, PhD, RN. *Evaluation of quality of care in relation to health-related quality of life of patients diagnosed with brain tumor: A novel clinic for proton beam therapy.* Supportive Care of Cancer 2018; Nov 27
- II. Ulrica Langegård, MSc, RN, Birgitta Johansson, PhD, Assoc Prof, RN, Thomas Bjork-Eriksson, PhD, Assoc Prof, MD, Per Fransson, PhD, Assoc Prof, RN, Emma Ohlsson-Nevo, PhD, RN, Katarina Sjövall PhD, RN, Karin Ahlberg, PhD, Assoc Prof, RN. *Symptom Clusters in Patients With Brain Tumors Undergoing Proton Beam Therapy.* Oncology Nursing Forum 2019; May 1
- III. Ulrica Langegård, MSc, RN, Per Fransson, PhD, Assoc Prof, RN, Birgitta Johansson, PhD, Assoc Prof, RN, Thomas Bjork-Eriksson, PhD, Prof, MD, Emma Ohlsson-Nevo, PhD, RN, Katarina Sjövall PhD, RN, Karin Ahlberg, PhD, Assoc Prof, RN. *Protons or photons? Health-related quality of life in patients with brain tumors treated with proton beam therapy or conventional photon radiotherapy.* Submitted
- IV. Ulrica Langegård, MSc, RN; Karin Ahlberg, PhD, Assoc Prof, RN ; Thomas Bjork-Eriksson, PhD, Assoc Prof, MD; Per Fransson, PhD, Assoc Prof, RN; Birgitta Johansson, PhD, Assoc Prof, RN; Emma Ohlsson-Nevo, PhD, RN; Petra Witt-Nyström, PhD, MD; Katarina Sjövall PhD, RN. *The art of living with symptoms: A qualitative study in patients with primary brain tumors receiving proton beam therapy.* Cancer Nursing, 2019; Jan 25.

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Abstract

This thesis focuses on patients with primary brain tumors undergoing proton beam therapy (PBT) and the consequences of the treatment. Quality of care (QoC) in a recently established clinic in Sweden was also evaluated. Furthermore, this thesis describes the development of the first comprehensive, prospective health and care science research project assessing patient-reported data related to PBT.

Study I - QoC in relation to health-related quality of life (HRQoL) was evaluated in patients with primary brain tumors given proton therapy. A need for quality improvement was identified for several aspects of care. More negative symptom experience during the treatment period led to greater perceived importance of specific support.

Study II - Symptom clusters among patients with primary brain tumors given PBT were explored. Three clusters were identified: *Mood*, *Reduced Appetite* and *Reduced Energy*. Building knowledge about how these symptoms interact and are clustered can support healthcare professionals in more efficiently treating symptoms during and after PBT.

Study III - HRQoL, including acute side effects and associations between demographics and medical factors related to PBT, was investigated and compared with HRQoL related to conventional photon therapy (CRT). Global health/quality of life (QoL) deteriorated from baseline up to three months after treatment. The most pronounced symptom was fatigue.

Study IV - Grounded theory (GT) was applied and *The art of living with symptoms* emerged as the core concept in this qualitative study. It encompassed three interconnected symptom management processes expressed in the following concepts: *Adapting to limited ability*, *Learning about oneself* and *Creating new routines*. These concepts were summarized in a substantive theoretical model of symptom management.

The studies underlying this thesis revealed that patients with primary brain tumors experienced increased symptoms during the treatment period, and that they decreased gradually up to three months after the end of treatment. Healthcare professionals must clarify patients' needs for information and support related to symptoms and interventions and be aware that they change over time.

Keywords: brain tumor, proton beam therapy, conventional radiotherapy, illness, symptom experience, symptom cluster, health related quality of life, quality of care