

Health-related quality of life after stem cell transplantation – The first year

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av
Inger Andersson

Fakultetsopponent är Professor Karin Nordin
Institutionen för folkhälso- och vårdvetenskap, BMC, Uppsala Universitet

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- I Andersson I, Hjermstad M, Stockelberg D, Persson LO. Health-Related Quality of Life in stem cell transplantation. Clinical and psychometric validation of the questionnaire module, High Dose Chemotherapy (HDC-19). *Acta Oncol.* 2008;47:275-85.
- II Andersson I, Ahlberg K, Stockelberg D, Brune M, Persson LO. Health-related quality of life in patients undergoing allogeneic stem cell transplantation following reduced intensity conditioning versus myeloablative conditioning. *Cancer Nurs.* 2009;32:325-34.
- III Andersson I, Ahlberg K, Stockelberg D, Persson LO. Patients' perception of health related quality of life during the first year after autologous and allogeneic stem cell transplantation. *Eur J Cancer Care.* Epub 2010 Mar 23.
- IV Life after stem cell transplantation – patient's perception of symptom, function and quality of life. (Submitted for publication)

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UNIVERSITY OF GOTHENBURG

Health-related quality of life after stem cell transplantation – The first year

Inger Andersson

Institute of Health and Care Sciences at Sahlgrenska Academy, University of Gothenburg,
Gothenburg, Sweden

Abstract

High-Dose Chemotherapy (HDC) followed by Stem Cell Transplantation (SCT) has been proven to be beneficial for a variety of haematological diseases, solid tumours and immune disorders. Despite improved care and treatment, SCT continues to produce significant long-term complications with impaired functioning and distressing symptoms. In this thesis the overall aim was to improve our knowledge about how SCT patients experience different types of transplantations and the effect it may have on their Health-Related Quality of Life (HRQoL) during the first year after SCT. Semi structured interviews were performed and two questionnaires, the European Organization for Research and Treatment of Cancer Quality of Life questionnaire (EORTC QLQ-C30) and the module, High-Dose-Chemotherapy (HDC-19), were administered. Health-related quality of life after allogeneic SCT following Reduced Intensity Conditioning (RIC) and MyeloAblative Conditioning (MAC) were compared. Both groups showed a similar pattern of development over time in functioning and symptoms, albeit more severe in the MAC group. One year after SCT there were no significant differences between the groups in global Quality of Life (QoL). However, RIC patients improved in global QoL back to baseline earlier compared to MAC patients. When allogeneic and autologous patients were compared, RIC patients seemed to recover in the same way as autologous patients and these two groups were closer in their scoring compared to MAC patients. The results emphasize the need to separate the two allogeneic groups when evaluating HRQoL after SCT. Symptoms related to the digestive system like; dry mouth, sore mouth, appetite loss and change of taste together with fatigue were among the most frequent reported symptoms throughout the SCT period for all three groups. In the MAC group, symptoms of dry mouth and change of taste even increased, and one year after SCT these symptoms were more pronounced compared to baseline. Four themes emerged from the data analysis of the interviews and illustrate how the participants described their life from discharge until one year after SCT; *obstacles on the road to normality, to be part of a normal life, the chance to be cured overshadow everything and new values in life*. The patients described that they felt restricted in life and had problems to manage the response from family and friends. Stem cell transplantation had changed their opportunities in life, meaning that plans for the future had to be altered, sometimes in a negative way. Stem cell transplantation is a demanding procedure that affects the patients HRQoL over a long period of time. Alleviation and management of distressing symptoms and impaired functioning are some of the most important tasks for the health care providers in order to contribute to a better health and life situation for SCT survivors.

Keywords: health-related quality of life, stem cell transplantation, myeloablative conditioning, reduced intensity conditioning, symptoms, functioning

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