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Patient experiences of the radiotherapy process and treatment

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Akademisk avhandling

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Abstract

Background: Most cancer patients undergo external radiotherapy (RT) at some stage during their treatment trajectory. RT is often associated with unfamiliar procedures where the technical environment, side effects and interaction with staff seem to play a major role in the patient's treatment experience. These experiences could sometimes lead to disruption of the treatment which may have negative consequences for the outcome. The overall aim of this thesis was to gain further knowledge about how patients experience RT and the related processes. Such knowledge is of vital importance when developing and improving care within a high-tech RT environment.

Methods: To gain further knowledge and understanding about patients experience of RT – both quantitative (I, II, III) and qualitative (III, IV) methodology were used. The data in the thesis focused on patients undergoing external RT at different RT units in Sweden. Study I and II, focused on two regions, the northern region of Sweden and the region of Stockholm and Gotland. Study III and IV were performed at eight different RT units in Sweden.

Results: In Study I, two types of topical agents (Calendula Weleda cream vs. Essex cream) were compared regarding reducing the risk of severe acute radiation skin reactions (ARSR). No difference in severe ARSR was found between the groups and the patients reported low levels of ARSR. In Study II, the influence of an RT unit's psychosocial climate and treatment environment on cancer patients' anxiety during external RT was evaluated. Data was collected (questionnaire) from 892 patients. The results showed that both the treatment environment and the psychosocial climate of the RT unit significantly impacted cancer patient anxiety levels. In Study III & IV, a questionnaire to measure the patient´s experience during external RT was developed and tested. The results showed that the RT Experience Questionnaire (RTEQ), with 23 items, was a tentatively valid and reliable instrument to measure how patients experience the RT process and the environment in the treatment room. In Study IV, written comments from the open-ended question "Is there anything else you want us to know?" in the preliminary RTEQ was analysed with qualitative content analysis. This data was abstracted into the following four major categories reflecting the experience of the RT process: Experiences in the high tech RT environment; Understanding the RT procedures and side effects; Dealing with daily life during RT and The nurses' role and performance.

Conclusion: The RT environment and the RT related processes seem to impact cancer patients, both physically and psychologically. A person-centered care approach, as well as attention to the design, both of the treatment process and the physical environment could significantly improve the patient experience and patient involvement. The results also highlight the importance of taking patient experiences into account when introducing new RT methods and techniques.

Keywords: Cancer, radiotherapy, radiation skin reactions, patient experience, treatment environment, anxiety, person-centred care, questionnaire.

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