

When children undergo radiotherapy. Exploring care, developing and testing preparation procedures

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Radiotherapy (RT) is a repetitive treatment divided into daily fractions, scheduled five days a week from one up to several weeks depending upon the child's diagnosis. Although RT is painless and non-invasive, children experience anxiety. Depending on the child's age, anxiety or inability to comply, they may require sedation or general anaesthesia (GA), meaning that some children receive GA over 30 times during their RT, which may have a negative effect on the child's health. The overall aim of this thesis was to explore care, develop and test preparation procedures for children with cancer undergoing RT. Radiotherapy nurses' (RTN) perceptions of caring for children undergoing RT and parents' lived experiences while their child underwent RT was explored. Based on the findings, previous research and theoretical framework, age-appropriate information and preparation procedures for children undergoing RT were developed and tested for feasibility and effectiveness in terms of need for GA and anxiety. Furthermore, the impact of age-appropriate information and preparation procedures for children with cancer undergoing RT on parents' and family functioning, parents' anxiety and hospital costs compared to traditional care was evaluated.

Semi-structured interviews of RTNs were conducted and the interviews were analysed using a phenomenographical approach. Parents wrote a diary about their lived experience while their child underwent RT and the diaries were analysed with hermeneutic phenomenological methodology. A quasi-experimental controlled clinical trial was conducted. Seventeen children aged 3-18 years and 31 parents receiving age-appropriate preparation procedures were compared with 16 children and 32 parents in a control group. The children and parents in the control group received traditional care and in the intervention group, they received age-appropriate information and preparation procedures. The child's and parents' anxiety was measured and the child's emotional behaviour was observed during the first three fractions, then at every fifth fraction and the last fraction. Furthermore, the parents answered questionnaires about their sense of coherence, and their and the families' functioning.

The findings showed that the RTNs perceived that they provided holistic care, created a sense of security and became committed. The RTNs wished to meet the family and child before the treatment began. Continuity with healthcare professionals and routines was a priority and keeping the balance between care, technology and communication were important parts as well as broadening their competence regarding childcare. The analyses of the parents' diaries showed that the parents experienced their child's RT as a balancing act involving coercing and protecting their child, balancing despair and hope, and feelings of powerlessness and trying to gain control. Being close to their child, meeting the same healthcare professionals and finding routines and strategies during treatment was experienced as important. The whole family was in need of support and they wished for help to coordinate the care. To maintain normality in daily life it was important for the parents to gain control. The developed age-appropriate information and preparation procedures, including written information, in advance meeting the RTN, doll-models to play with, pay a visit to the treatment room, watch a movie or listen to music during RT and hold onto a "safety-string", were found feasible and acceptable. No statistically significant differences were found concerning the number of children receiving GA or their and the parents' anxiety. However, three children planned for GA in the intervention group completed their RT without GA, including 73 fractions awake. Children receiving GA, regardless of group, showed significantly higher negative emotional behaviour. Parents whose children received GA showed significantly increased anxiety. Parents of children in the intervention group showed significantly better communication at the first and last fraction and better social function at the child's last fraction. There were no significant differences between the groups concerning hospital costs. However, hospital costs for the three children not receiving GA in the intervention group were reduced by SEK 385 002.

In conclusion, this thesis has shown that age-appropriate information and preparation procedures for children with cancer undergoing RT are important for the children, parents and healthcare. If a child is able to undergo RT without receiving GA, it means fewer risks and restrictions for the individual child, and less anxiety for both the child and the parents. Furthermore, healthcare costs are reduced, which

makes it possible to prioritize other areas where anaesthetic professionals are needed. To demonstrate effectiveness, a larger study with a more homogeneous group of children is needed.