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Quality of life, functional ability and physical activity in children and adolescents after lower extremity bone tumour surgery

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Chapter 8

SUMMARY

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Improving survival rates in children and adolescents with malignant bone tumours, paved the way to the application of new surgical extremity-salvage techniques. For the surgical treatment of malignant bone tumours of the lower extremity, there are a number of resection options (amputation, limb sparing, and rotationplasty) available.

Each option has its own indication and after the surgery different advantages and disadvantages. The debate is whether limb-salvage or ablative surgery is advantageous for the individual patient.

Therefore, it is from importance to provide the surgeons and physicians as well as the patients and their parents with clear information about the consequences of the different surgical interventions.

Purpose of the studies presented in this thesis are evaluate and compare QoL, functional ability and physical activity levels among children and young adults in the first years after bone cancer surgery of the leg.

A cross sectional and a prospective study were conducted in the Dutch university bone cancer centres. Furthermore, a systematic review was done. The results of these studies are presented in six separate chapters.

Chapter 1 contains the general introduction of the thesis. The epidemiology as well as the treatment of malignant bone tumours in children and adolescents has been described in this chapter. Finally, the outline and aims of the thesis were explained.

In *Chapter 2* the results of a systematic review are presented, with a focus on differences in quality of life, functional ability or physical activity levels between surgical interventions for bone cancer of the leg.

The results show that outcomes are equivalent for those undergoing limb salvage or ablative surgery in regard to quality of life and physical activity. Small but inconsequent differences were reported in functional ability between limb-salvage and ablative surgery. Comparisons between studies are difficult, moderate quality, small numbers of patients, the use of varying research designs, methods and clustering of patients have limited research in this area.

In *Chapter 3* the results of a prospective study on QoL, functional ability and physical activity levels of children and adolescents after malignant bone cancer surgery of the leg showed that; survivors improve in the two years following resection of the bone tumour and the resulting limb-sparing or ablative surgery at all domains evaluated, with the exception of the mental QoL domains.

These improvements were most pronounced over the first year after surgery, in the second year these changes are far less pronounced.

In *Chapter 4* the quality of life scores from our young patients after bone tumour surgery around the knee joint were compared with healthy controls. Furthermore, we examined the impact of gender and type of surgical procedure on the QoL outcome in this nationwide cohort.

In general, patients had comparable levels of QoL within the social, emotional and cognitive domains as healthy controls. However, patients reported significantly worse scores than healthy controls within the physical function domains. This finding was seen with all

three questionnaires and in both younger and older age groups. The result of the patient interview endorses these findings, with the domain physical limitations and sports being most frequently mentioned as an area where limitations are perceived. With respect to the determinants of QoL, there appeared to be few significant differences between patients undergoing either limb sparing or ablative surgery or between female and male patients.

In *Chapter 5* the study aimed to investigate functional ability and physical ability in a nationwide cohort of children as well as young adults after different lower extremity bone cancer. With the help of questionnaires as well as objective measures for childhood and adolescence, a comparison was made between ablative and limb-salvage surgery and between allograft reconstruction, endoprosthetic replacement, amputation and rotationplasty.

The results of this study indicate small differences in functional ability and physical activity between children and adolescents who underwent limb-salvage or ablative surgery, these differences were in general not significant. Exceptions were better timed-up-and-down-stairs and various walking scores in the limb-salvage group.

In *Chapter 6* the development of a disease specific quality of life measure is presented. In a cross-sectional study among 72 patients with a malignant bone tumour of the lower extremity, it was found that a newly developed questionnaire; *DUX for lower extremity bone tumours in children and adolescents* (Bt-DUX), was practically applicable, had sufficient internal consistency and a good construct and discriminant validity.

In *Chapter 7* the results of the British version of the disease specific quality of life instrument; the Bt-DUX is described. Our study cross-culturally adapted and validated the Bt-DUX for use with English speaking patients.

The English translation of the Bt-DUX questionnaire demonstrated good internal consistency, construct and discriminant validity, comparable with the applicability of this instrument to Dutch-speaking patients.

