Surgical implications of sacrococcygeal teratoma and its consequences

Valorization

Introduction and relevance of the scientific results

Sacrococcygeal teratoma (SCT) is a rare condition affecting merely six children annually in the Netherlands. This poses the question if it is worth to investigate long-term complaints and to set up a national follow-up guideline for children with SCT. If we widen our perspective from the national to the international situation, we see that worldwide approximately 133 million children are born annually, which potentially increases the number of children born with SCT to approximately 4,700 children annually. This calculation is based on the incidence of one in 27,000 live births in the Netherlands, which might even be an underestimation. Except for the oncological follow-up of these patients no guidelines are available that give recommendations on screening for associated anomalies or defining the long-term follow-up. However, as the majority of patients treated for SCT nowadays survive, attention must be shifted from achieving survival towards improving functional outcomes. Nationally and internationally there is a need for a standardized early screening program to detect associated anomalies and for an evidence based long-term follow-up program that can be implanted in clinical practice.

Target group

So far, little information concerning the long-term sequelae of SCT was available until now. Parents and patients suffering from SCT therefore could not be informed adequately about the expected sequelae resulting from treatment and the disease itself. Results and consequences of the present thesis are therefore relevant and applicable in daily life of patients with SCT and their parents. In addition, our results are relevant for a wide range of health professionals. Paediatric surgeons and neonatologists are obviously involved in the care of patients with SCT, but also more specialists in related fields might benefit from the present results. Obstetricians and gynaecologists play an important role in the prenatal diagnosis of SCT. They counsel affected parents during pregnancy and probably need to discuss abortion requests. Knowledge of pre- and postnatal complications as well as information on the long-term course of the disease is therefore essential. In

addition, obstetricians and midwifes possibly will be consulted by women previously treated for SCT who want to become pregnant or those previously treated for SCT needing medical assistance during pregnancy and delivery. Patients who suffer from buttock deformation might consult plastic surgeons. Urologists, nephrologists and gastroenterologists might be consulted because of functional sequelae at different ages. Beside the various specialists involved in the care of patients treated for SCT, our results are also relevant for general practitioners, who might be the first health professional contacted by patients who have been dismissed from outpatient follow-up.

Implementation and innovation

Centralization of care and standardization of treatment guidelines have shown to be the cornerstones of improvement care of patients with rare diseases. We showed in this thesis, that standardized care for patients born with SCT should also include preoperative preparations considering the laparoscopic clipping of blood supplying vessels in greater tumours or hemodynamic instable patients. In addition, focused screening for associated anomalies including hip dysplasia and hydronephrosis should be performed early. Furthermore special attention should be paid to oncological, functional and cosmetically long-term complaints. Implementation of all these aspects in a standardized care program for patients with SCT will be easy to apply in the Netherlands and also internationally.