

Surgical implications of sacrococcygeal teratoma and its consequences

Citation for published version (APA):

Kremer, M. E. B. (2017). *Surgical implications of sacrococcygeal teratoma and its consequences*. [Doctoral Thesis, Maastricht University]. Maastricht University. <https://doi.org/10.26481/dis.20170609mk>

Document status and date:

Published: 01/01/2017

DOI:

[10.26481/dis.20170609mk](https://doi.org/10.26481/dis.20170609mk)

Document Version:

Publisher's PDF, also known as Version of record

Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

[Link to publication](#)

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license above, please follow below link for the End User Agreement:

www.umlib.nl/taverne-license

Take down policy

If you believe that this document breaches copyright please contact us at:

repository@maastrichtuniversity.nl

providing details and we will investigate your claim.

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 midwives 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.