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Wijnen, Marc H. W. A.; Hulscher, Jan B. F.

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Karl Storz Lecture

Centralization of pediatric surgical care in the Netherlands: Lessons learned

Marc HWA Wijnen^{a,*}, Jan BF Hulscher^b

^a Department of Surgery, Princess Maxima Center, Heidelberglaan 25, Utrecht 3584 CS, the Netherland

^b President of the Netherlands Society of Pediatric Surgeons, UMC Groningen, Groningen, the Netherland



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ABSTRACT

Centralization of care is a difficult process, as there are several stakeholders that are involved and should be heard. What can be the best option for a small group of patients may be detrimental to a larger group of patients that cannot be adequately treated close to home. The weighing of these factors is different in every environment.

One universal rule however is: if you don't do it yourselves, others will do it for you. In the Netherlands, pediatric oncology, including surgery, is centralized in one center (Utrecht) with the help of several shared care centers scattered throughout the country for things that can be managed close to home.

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1. Introduction

Centralization of care is always a sensitive topic, because it usually involves the loss of patients in one center in favor of another center. However, I think that we can all see the same questions before us, be it from patients, parents, society or even ourselves. For full disclosure I should mention that I am of the group that thinks that when you do things more often you get better at it. I am saying this because I encounter many surgeons who think that this is not the case for pediatric surgeons, unless patients are sent to his or her own hospital.

Many years ago, before the word Brexit had any meaning, the UK took the lead by centralizing and restricting the care and treatment of infants with biliary atresia to three English centers [1]. This strategy has inspired many ever since. In this light, I will describe the road we went down in The Netherlands to try and increase numbers and improve outcome for the children entrusted to us.

2. The Netherlands

Firstly, it is important to present some key facts about the Netherlands in order to understand the context and the change in surgical practice that will be described.

There are 17 million people in the Netherlands, with 180,000 births per annum. It is also one of the most densely populated countries in the world at 416/km². There are six neonatal pediatric surgical centers with each no more than one or two hours away

from each other and indeed the whole country can be crossed within 3 h.

The six pediatric surgical units are evenly distributed geographically (Fig. 1) and are all attached to a co located university hospital. Each unit has about 4–6 full time pediatric surgeons with a total of about 30–35 surgeons in all. This excludes five pediatric oncology surgeons. In an average year we would expect to see oesophageal atresia ($n = 30$), anorectal malformation (ARM) ($n = 30$), Hirschsprung's disease ($n = 30$), congenital diaphragmatic hernia (CDH) ($n = 30$) and biliary atresia ($n = 10$).

All oncological surgery, except for retinoblastoma is centralized in a different hospital in Utrecht which is more central in the country and is not part of these six units. This will be considered latter as centralization of oncology services is a different story altogether.

3. Centralization in neonatal pediatric surgery

The Netherlands Society of Surgery started a mechanism of adult surgical audit in 2009 that enabled hospitals to record their numbers and measure their outcome in several major areas such as surgery of the carotid artery, the esophagus and pancreatic resections. [2–5] This allowed intra hospital comparison and somewhere to references one's own results, anonymously, and without insurance companies or other hospitals being able to see your full results.

A bar was also set for the minimum number of procedures that were required to continue with this operations. The numbers were averaged over 2 or 3 years and were checked by both the Association and eventually the insurance companies after a further 3 years. This all led to an enormous shift in where patients were

* Corresponding author.

E-mail address: M.H.W.Wijnen-5@prinsesmaximacentrum.nl (M.H. Wijnen).



Fig. 1. Map of The Netherlands, 6 surgical centers with green circles.

being treated and did improve results in these areas dramatically, both with regard to morbidity and also mortality.

Pediatric surgeons began to embark on the same audit journey, knowing this experience in adult surgery, although many thought that this was not applicable or even needed by pediatric surgeons, the Kings and Queens of rare diseases.

So how, apart from pressure from the association of surgery and to a lesser extend insurance companies, did we go about this.

Firstly, the Board of the Dutch Association of Pediatric Surgeons board, brought in two well known chief inspectors, formerly of the Department of Health, as consultants to identify the direction of travel, and what would be the level of agreement we could expect to reach amongst ourselves, as surgeons and maybe more importantly with the various Heads of pediatric departments and other stakeholders. They came up with two scenarios both requiring centers to open up and share their results, caseload and with an agreement to enter their data in an open registry with mandatory auditing. This was the European Pediatric Surgical Audit or EPSA.

The disease(s)/operation(s) we chose were more or less semi elective, at least allowing for transfer to another hospital for surgery without compromising the health of the baby. These included: oesophageal atresia, ARM, Hirschsprung's disease, CDH (though this was already almost exclusively done in the two Dutch ECMO centers in Rotterdam and Nijmegen), biliary atresia, omphalocele and gastroschisis (albeit requiring a prenatal referral).

Two scenarios were suggested. Scenario one, which was to centralize all neonatal surgery into two centers, both doing all but the rarest (e.g. bladder exstrophy) cases occurring less than ten/ year. Scenario two, which was to let all centers do a few anomalies but keep all the centers as they are, so shuffling diagnosis.

After extensive and exhausting discussions our group of pediatric surgeons decided on the second option. This was mainly because it was feared that it would be impossible for the remaining centers to recruit staff, given that no congenital anomalies were no longer to be operated upon. Potentially this might lead to a deskilling and spiral with collateral damage to basic surgical services.

The criteria we chose for this re shuffling of cases within the six centers could be divided into two elements:

- Firstly, it was proposed that there should be at least 10 cases of the disease per year.
- Secondly, a number of softer requirements were proposed. Such as the presence of multi disciplinary teams, pediatric intensive care units (PICU), the availability of ECMO and neonatal intensive care (NICU), 24 h availability of gastroenterologists, ENT specialists, radiologists etc.

This plan was finally agreed on by the Dutch Association of Pediatric Surgeons and in 2016 confirmed by the Netherlands Association of Surgery. The pediatric audit system (EPSA) was officially started at the beginning of 2017.

Three years were taken to see what each center would produce and, if needed, change. After three years a first audit, by an independent auditor, was planned and this was done in 2020.

In these three years several things happened that brought centralization closer. Bilateral agreements between centers were made to refer cases, for example oesophageal atresia to one center and ARMs to the other. Also, some centers decided to stop doing certain operations all together without any kind of reciprocity. Biliary atresia was centralized quickly with localization to the only pediatric liver transplant center in the country (Groningen) and in fact their 30 day clearance of jaundice after Kasai portoenterostomy has dramatically improved [6,7].

Infants with CDH were also now fully centralized in the two ECMO centers (Rotterdam and Nijmegen). Some centers that were aiming to continue certain procedures also tried to collaborate outside of the Netherlands by joining the European Reference Network system and many succeeded.

The first pediatric surgical audit took place in 2020 and the results are now being discussed with the following steps planned.

4. Centralization in pediatric oncology

From the beginning it was felt that centralization here should be complete with only a single hospital as the best option. There was an initial consultation process in 2008 involving seven Heads of Department of the existing pediatric oncology centers. They asked themselves the key question: where would I treat my child if he or she had a form of cancer, and why if this was not their own center would they treat children with the same disease? Also why should we spend money for research in seven places for very often the same disease.

There was already a functioning national registration system in place and a centralized laboratory for haemato oncology, but it was felt that more centralization could improve outcome and decrease morbidity. There was also a degree of pressure from a patients' association that had seen no real improvement in survival rates in many types of pediatric cancer.

Both oncologists and parents supported each other which resulted in real plans to centralize care for pediatric oncology patients. Very early in this process the surgeons joined them in this effort and finally administrators and politicians entered the stage. Some idea of the heightened tensions at the time can be gleaned from one of the author's experience (MW), who received letters from three hospitals where he was employed, threatening expulsion and loss of employment if he joined this initiative. By the end, three of the seven Heads of Department did lose their jobs, before centralization became a fact.

It then took a further seven years before the first stone was laid (Fig. 2) and most of this time consisted of fighting the university hospitals that had hosted the other seven pediatric oncology centers. Some arguments against centralization suggested that parents didn't want to travel, and that there would be collateral damage for the hospitals losing these patients, e.g. loss of intensive care.

INTRA-OPERATIVE COMPLICATIONS

Major



POST-OPERATIVE COMPLICATIONS <30 DAYS

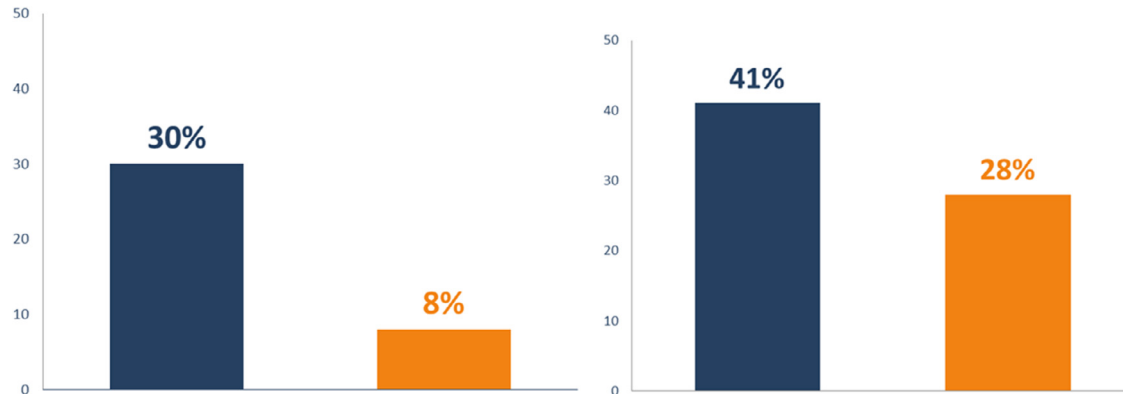


Fig. 2. Prinses Máxima Centrum, Utrecht.

However, the case for centralizing the surgery part was never disputed that much.

The overriding aim of the new Princess Maxima Center for Pediatric Oncology is to increase the survival rate for oncology patients while at the same time improving quality of life for the survivors and it was probably quite arrogant that centralization care would be enough. We therefore realized that the new hospital had to be a research hospital as well and this was what we built. Clinical care is delivered in the same building as we conduct research and all research is driven or directed rather by teams consisting of basic and clinical researchers and clinicians. In simple surgeons' language, we as clinicians tell the researchers what the problem is and often they come up with solutions that we had not even thought of. By now we have about 500 basic and clinical researchers working in the building and most of the national funding goes either to or through us.

We must realize that we are working with parent organizations as partners in this venture and parents/patients can be considered as co owners of the hospital. Indeed some of the things that we as clinicians would not think of or prioritize become important in the building itself and the day to day running of the hospital. Our rooms are all single and are divided between a parents' part and a children's part. Two parents are able to stay overnight and all rooms have a parent's facility and a balcony. Silent infusion pumps preserve sleep and snack and food service is available at any hour with 74 different snacks chosen by the kids who named it as their number one priority.

On the surgical side, we have chosen a model where we don't "own" patients, but all are managed by the group as a whole. There is no separate outpatient time for surgeons, but one of us is always available to join the outpatient appointment with the oncologist. This way the patient very rarely comes to only see the surgeon.

From June 2018 the center opened in a new building. Surgery itself and any PICU support takes place in the adjacent children's hospital which is linked by a 150 yard bridge.

To get an idea of our workload here are some numbers. We opened originally in 2014, with only three surgeons for solid tumors but only those occurring in the chest and abdomen. Since April 2018, there have been five pediatric surgeons, three with experience in pediatric oncology and now two in training. In addition,

there are three part time orthopedic surgeons, and one part time ENT surgeon. Adult oncology surgeons, cardiothoracic pediatric surgeons, plastic surgeons and urologists etc. are shared with the children's hospital. Surgery happens in two operating theatres daily and there are an additional 1,2 rooms for procedures just requiring sedation.

Every year, the surgery deals with: tumor resections ($n = 130$), neurosurgical cases ($n = 120$), renal tumors ($n = 35$), neuroblastoma resections ($n = 25$), bone tumors ($n = 20$), other sarcomas ($n = 20$), germ cell tumors ($n = 25$), and liver tumors ($n = 7$). The center works closely with the National Liver Referral center in Groningen, the only pediatric transplant center, where small children and children at risk for transplant will be operated. More than 700 lines and other forms of vascular access were undertaken.

Clarity of results after centralization is an important part of the whole equation in order to convince the sceptics. For this a benchmark is needed and we reviewed retrospectively the outcomes of all Wilms, liver and neuroblastoma surgery in the Netherlands in the previous 10 years and in the 4 original centers. Complications, mortality and morbidity were all assessed and after 3 years we were able to do the first analysis comparing pre and post centralization, reported this in the Washington SIOP in 2018 (Fig. 3).

We are now in the process of updating this dataset for the first five years and essentially this looks the same. So, blood loss, operating time, renal tumor rupture, unplanned nephrectomies and other per operative complications (but not postoperative complications such as adhesions) went down significantly. Local recurrence is another good benchmarking tool, but owing to its infrequent nature we have no solid data on this, so far it seems at least equal to the situation before, but with different therapies such as radiation therapy strategies, now standard in Stage 4 and Immunotherapy with anti Gd2.

What else has changed? We feel that one of the most important changes is the ability to focus entirely on oncology, both in the clinic and in research. The whole center is geared towards cancer and this has enabled basic research in this field, really for the first time.

Are there downsides to centralization for patients? Well, even in a country that is as small as the Netherlands traveling is not ideal and we still make use of about 20 shared care hospitals scat-



Fig. 3. Complications after neuroblastoma surgery assessed Pre (Blue bar) and Post (Orange bar) Centralization. Rate of intraoperative (major hemorrhage) complications (A) and post operative complication rate (< 30 days) (B). Data presented during S.I.O.P. Washington 2017.

tered throughout the country. Our philosophy behind this concept is to “do central what is needed, and do close to home what we can”. We try to minimize travel and hospitalization and use the shared care centers as much as possible. For surgery this is difficult but with the use of chemotherapy at home, one stop shop for most examinations and out patient appointments to try and diminish this burden.

A further argument against concentration in a single center is that there is a lack of competition and no chance for a second opinion in the country. Our counter to this is that our competition is not in our country but in the world as a whole, and we gladly refer patients to any facility when there is a treatment or operating procedure available that we do not have. The most important factor in this is open communication with parents and other institutions. Open about results, complications and numbers.

Are there disadvantages for the surgeon? Perhaps, as neonatal surgery all but vanishes and one cannot look forward to a quiet day of day surgery hernias every now and again.

What does it change for research? That is probably the most visible change. Diseases such as ARM or Hirschsprung’s disease have very little funding available, but this is not the case for oncology. This means that a research group can be formed relatively easily to implement and innovate surgical research. Some of the newer projects which have been started include validation of the use of 3D printing and imaging and whether it is helpful in the preoperative planning and helps to translate 2D images to 3D reality. Augmented reality opens a door to quick high definition images through the Microsoft HoloLens™ and we are currently working on using this application in patients per operatively e.g. in partial resection of the kidney.

Fluorescence guided surgery is also another new area of interest. Currently, we use different types of fluorescent agents in surgery. So, Indocyanine Green (ICG) can be used as marker dye where formerly we would have used IV methylene blue in, for example, sentinel node biopsies. We couple the ICG with the radioisotope technetium to try and improve efficacy. The main advantage seems to be that when lymph vessels are cut the whole area does not turn blue. ICG also appears to have a role in assessing the increased vascular permeability of tumor vessels. This is seen in this in various tumors, such as primary liver tumors, and liver and bone metastases. Finally, we have been assessing the use of tumor specific fluorescence, for example a GD2 antibody can be linked with a fluorophore to detect remaining neuroblastoma tissue during the resection (Fig. 4).

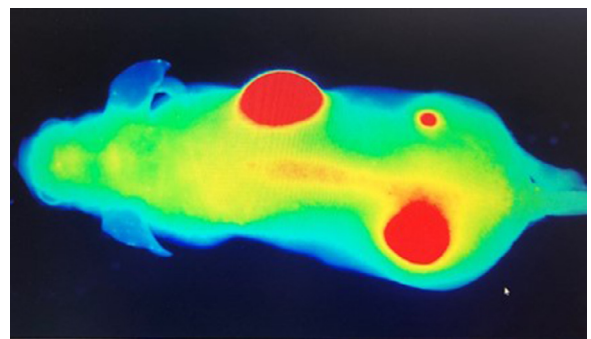


Fig. 4. Subcutaneous locations of neuroblastoma implants in a mouse made fluorescent with Anti Gd2 linked with fluorophore.

In conclusion, we have come a long way but are not there yet. Some things appear important such as asking for independent advice, opening up the data for all centers as a prerequisite, involving specialist societies and insurance companies and finally involving all the stakeholders particularly including parents and even patients. This might seem tedious and sometimes exhausting, but it is worth it in the end. Most of all and this bears repeating if you don’t do it do it yourselves, others will do it for you.

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