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Chapter 10

Discussion and future perspectives



Discussion

This thesis addresses dilemmas and consequences of the use of the minimally invasive repair of the pectus excavatum (MIRPE). Even after a century of experience with surgical and nonsurgical treatment of pectus excavatum, the decision on how and when to treat a patient with a pectus excavatum remains an area of debate. The same discussion continues about the reason for reconstruction: improved cosmesis or improved cardio-pulmonary function.

As a first step, this thesis starts with the assessment of the health information provided through the internet, which is commonly used by adolescents with PE to acquire information. The aim of this study was to evaluate the quality of the given information. Therefore we selected unique websites based on the most used internet search engines and measured their quality with the use of the DISCERN tool. We found a very low to moderate overall quality of the health information provided, with serious shortcomings. Especially adolescents with PE are a group which actively seeks information about their condition and possible treatment options. They are vulnerable to wrong interpretation of information and may have difficulties making informed decisions. Particularly hospital related sites and lay persons sites scored low on information quality, which fosters the need for medical societies to step in and provide unbiased high quality information instead. Particularly in the area of unexpected outcome and possible serious complications, information was predominantly lacking on the websites. This can negatively influence informed decision making later in the process if the patient opts for surgical correction of the PE.

A logical next step was to look at the daily surgical practice of pectus excavatum treatment in the Netherlands. Since international publications showed more and more cases of minimal invasive treated patients with PE, we assumed that to be the case in the Netherlands as well. Apart from one time registry of PE surgery in the UK during a 2-year period, no other registries exist around Europe. The numbers of the Dutch Hospital Registry were used to evaluate trends in surgical treatment over the years. An increase in total numbers of operations performed for PE was found and in addition an increase in MIRPE. Since the birth rate is quite stable over the last decades, this increase is more likely caused by factors other than increased incidence. A possible explanation could be found in the increased acceptability of cosmetic surgery in Dutch society in general. Next to that adolescents are subject to peer pressure and parents and adolescents alike

seem to be susceptible to forces in modern society who find cosmesis of great importance. A clear change with the society motto "what matters is beauty within" to the new motto "what matters is beauty to show". With respect to cosmesis are the scars from the MIRPE procedure easier to hide, compared to the scars created by open reconstruction of the PE.

Although the increased popularity of cosmetic surgery is mostly limited to local surgical corrections, the MIRPE procedure clearly is not. MIRPE can give raise to serious complications, which can result in an unsatisfactory cosmetic and cardio-pulmonary outcome. This makes reliable good quality information pre-operatively by the doctor and through the internet important, also from the perspective of expectation management. A different explanation for the increase in number of operation could be the underestimation of the complaints PE patients experience in daily live. Although many patients complain pre-operatively about localized pain, discomfort, and limited exercise capability, not many studies have tried or succeeded to objectify these complaints.

Pain seems to be an important complaint before surgery and certainly is of great importance after the MIRPE procedure. In general it is well established that surgery, specifically surgery to the thorax can be accompanied by severe pain. Pain experience is influenced by many factors, including anxiety, which could be of interest because it can be changed by counseling. We investigated the relationship between pre-operative STAI-state anxiety and late post-operative pain scores. In order to investigate the correlation a hierarchical linear regression analysis was performed, but no significant correlation was found with regard to anxiety and pain at rest after 6 weeks. Only pain during activity after 6 weeks showed a significant correlation, although this might be partly explained by the presence of a steel bar in situ in a still healing soft tissue area of the chest wall. Besides anxiety there are many other factors which might be of interest to further exploration such as additional use of hypnosis or cortisol levels testing to adapt pain medication.

Since post-operative pain after MIRPE seems to be of such great importance, this may have an impact on quality of life (QoL) after 6 weeks. Especially when considering that this group consist of mostly teenagers, during the period in their lives in which body image and general QoL are of great importance. More precisely when the person is establishing an independent identity, choosing a profession and starting sexual relations. Consequently the QoL questionnaires

from pre-operative and 6 weeks post-operative were investigated. Although the patient group was overall satisfied with their new appearance and had a clearly improved body image, pain was still a significant issue 6 weeks post-operatively. The measured self-esteem showed only small improvement. Therefore the question should be raised if the procedure, even if it leads to better cosmesis, but not much improvement in self-esteem, is worth the risk. A possible explanation for the limited changes in self-esteem, could be due to the short time interval of 6 weeks post-operative and the still present post-operative pain. Therefore we extended the post-operative period to 6 months and focused on self-esteem and QoL. Again a significant improved body image after MIRPE was established, as well as significant increased self-esteem, increased psychological resilience and lessening of emotional limitations after 6 months. Sub analysis showed that the largest shifts took place in the first 6 weeks period and to a lesser extend between 6 weeks and 6 months. Overall changes were too limited to lead to significant changes in general QoL or general health. The latter is disappointing because it leads to the question if the changes are so small that they do not lead to an increase in general QoL, is it then justified to perform MIRPE at all. To answer this question we should look at the important changes for teenagers. The change in body image and self-esteem could have an effect on their daily behavior, as well as on their social activities and recreational activities. These changes in selfesteem may increase coping capabilities and may be an important asset for the rest of their lives. The overall QoL measurement seems to be of lesser importance than the changes on sub-areas for the outcome after MIRPE procedure.

In the next part of the thesis, the outcome as measured with the Single Step Questionnaire (SSQ) was investigated. Of the available questionnaires after MIRPE, the SSQ is frequently used. It was developed and published in 2006 as a simple assessment tool to measure satisfaction in young adults after MIRPE procedure. Since the score contains areas as pain, body image, self-esteem, social activities and cosmetics, we believed that the score might fluctuate over time. However the claim is made that the SSQ score is time-independent. In this part of the study a group of patients completed the SSQ at 4 moments (6 weeks, 6 months, 12 months, 24 months post-operative). As hypothesized the SSQ score differed significantly over time, especially between 6 weeks and 6 months and was phase dependent. This is in accordance with the findings described in chapter 6 that the largest shifts in body image and self-esteem took place between 6 weeks and 6 months, as was the lessening of pain.

One of the items that is frequently assumed to be disturbed in patients with a PE is sport activity. The combination of appearance and physical complaints is thought to have a negative effect on the ability or the need to engage in sports. The results of measurements pre-operatively and 12 months post-operatively showed no increase of the percentage of patients engaged in sports activity, nor change in type of sport activity or team compared to individual sport activity after 12 months. However, there was a significant shift towards less perceived problems with physical exercise, decrease of complaints or difficulties during sports, and less avoidance. In the light of the discussion whether the deformity pectus excavatum is merely a cosmetic or a cardio-pulmonary problem, these results are interesting. The decrease in experienced complaints during sport activity and physical exercise seems to point towards an improvement in cardio-pulmonary function, next to the already established improvement in body image and self-esteem.

The last chapter of the thesis is dedicated towards health care costs of the MIRPE. The ever rising health care costs makes direction of limited resources necessary. One way to reach that is by cost utility analysis. So far there were no other cost-effectiveness studies done on PE treatment. To calculate the cost-utility a cohort was followed with a measurement of the SF-36 before and one year after surgery. From this the SF-6D was calculated and together with the calculation of the direct costs, a QALY calculation was performed. The estimated cost-utility ratio was € 293.500 per QALY gained, far above the max € 80.000 per QALY which is used in the Netherlands. Although one could argue that there is a longer lasting effect, improvement in SF-36 scores after one year will probably not be large enough for a substantially lowering of the ratio. However it is questionable if the system of measuring cost-effectiveness (QALY) in surgery like the MIRPE, which has at least a partial base in improvement of cosmetics, body image and self-esteem, is a suitable way to draw conclusions. The use of scores which incorporates psychosocial items next to functional items would be more appropriate.

Future perspectives

During the process of research for this thesis in combination with the existing literature cited in this thesis, a number of questions were raised which may be addressed in future studies. Evidence from our studies suggests that surgical intervention for pectus excavatum benefits the psychological functioning of many patients. However, the evidence for improvement after MIRPE on cardio-pulmonary function, although suggested by our study by better tolerance of sport activities, is still limited and needs more attention.

Pain is one of the factors that need clear attention. Our studies have shown that pain is not strongly correlated to pre-operative anxiety, but plays a negative role post-operatively longer than 6 weeks, while lessening between 6 weeks and 6 months. In the recent year, studies on new ways of limiting pain during and after the surgical procedure have been published. The use of intraoperative intercostal nerve cryoablation, paravertebral block and the erector spinae block (ESPB) look promising, but need more evaluation in this patients group and larger number of patients need to be assessed concerning effect on VAS score and QoL. Alternative ways to influence pain experience by patients after MIRPE procedure could be the use of distracting computer games, music, but also pre-operative structural counseling. In this patient group the effect of music is currently investigated.

To draw extensive conclusions on the outcome after use of the MIRPE, we need long term follow-up on the benefits and long term abilities or limitations of the patients. The follow up should be at least 4-5 years and have frequent measurement points. This period of time is needed, because the MIRPE procedure has a second stage after about 3 years when the metal bar is removed. Since this second operation can alter the earlier outcome, follow up should continue for several years after the last procedure. During the past decades there has been a shift from the open Ravitch procedure for patients with pectus excavatum towards the minimal invasive procedures. Since there is an ongoing discussion about which technique would be suitable for PE patients, especially in the group with a relative shallow pectus excavatum, it would be interesting to compare different operative strategies. The role of cardio-pulmonary limitations would be expected to increase with the depth of the pectus and should play a smaller role in shallow PE. The use of MIRPE technique versus silicon custom made prosthesis could also be explored, whereby both groups receive the same follow up. Another operative strategy which could be interesting to compare is MIRPE versus the minimal

access open repair of pectus excavatum (modified Robicsek procedure). A third technique for comparison with the MIRPE is the Pectus-Up, with its advantage to place the material outside the thoracic cavity. In all these studies the follow up should be the same in both intervention groups and should be continued at least 4-5 years, to include all aspects including long term changes of the different techniques in a standardized way.

Safety is an aspect of the MIRPE that also warrants further research attention. Unfortunately, serious complications do take place during MIRPE, as well during insertion as during removal of the bar. To limit these incidents, a study on the necessary learning curve of the surgeons and the development of a window of safety check before passing or removing the bar behind the sternum could be useful. Also an experimental study towards the minimal depth of the pectus excavatum that warrants the additional use of a crane technique or vacuum bell during operation to lower the chance of damage passing the pre-cardiac area seems worthwhile.

And last but not least the development or selection of a cost-effectiveness questionnaire is warranted. This makes it possible to measure the costs of procedures like the MIRPE on a rational basis with inclusion of the changes in important psychological variables. Such a questionnaire would provide a much needed base for transparency in health care costs and benefits of surgical procedures such as MIRPE not only aimed at functional improvement but also on psychosocial well-being.