

PECTUS EXCAVATUM

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The **aim of this chapter** is to describe the scientific and societal impact of the results of the present thesis.

Pectus excavatum, also known as funnel chest, is the most common anterior chest wall disorder. Symptoms can be of cosmetic, psychosocial, and physical nature. Consequences of pectus excavatum can be dramatic for patients, often resulting in body image disturbances, decreased self-esteem, and severe limitations in activity levels. Research on this subject is crucial to substantiate the seriousness of complaints and improve the quality of care. Moreover, it promotes awareness among patients and care givers and will eventually lead to a solid scientific evidence basis for health care insurance companies and governments.

Relevance for patients

Due to the relatively unknown character of pectus excavatum, many patients visit multiple care givers in different hospitals before final referral to a specialized pectus center. Internet and social media play a crucial role in the provision of specific information to patients, causing patients to be often better informed than their treating physician. Thus, from a patient's perspective, there is a strong need for advanced knowledge on chest wall deformities among health care professionals.

On patient level, pectus excavatum often elicits a significant burden. The majority of patients express that they are ashamed about their appearance and experience an unfavourable body image. Consequently, patients are being hindered in social interactions and have a declined social self-consciousness. By example, this may result in impediment to taking off clothes and thereby avoidance of public places such as beaches and swimming pools. Cardiac impression due to the depressed sternum frequently leads to exercise intolerance and inability to perform sports with peers. Surgical treatment of pectus excavatum significantly improves psychosocial and physical performance. However, in the interest of patients, there is still a lot to improve in terms of general knowledge on chest wall deformities and surgical care. Scientific research plays a crucial role in this. Therefore, pectus patients directly benefit from the results as described in this thesis as well as future studies.

Relevance for clinical practices

Raising awareness for chest wall deformities amongst care givers is of utter importance. A spectrum of doctors with different backgrounds can be confronted by patients who present with symptomatic pectus excavatum and their associated request for help. The more health care professionals are familiar with the disorder, the better they will be able to recognize the consequences and need for referral to a specialized center for further diagnostics and subsequent treatment. Currently, the tertiary referral centers in themselves should be challenged to unite and take care of establishing uniform definitions and care pathways. Development of new surgical techniques and improvement of perioperative care is strongly dependent on the effort of the small number of expert pectus surgeons worldwide. To facilitate further studies, a larger number of patients per center and thus further centralization of care is beneficial. By improving surgical techniques and perioperative care, recovery and patient reported outcomes will be enhanced. Research promotes knowledge sharing and accordingly enhances quality of care and outcome.

Relevance for pectus society

The medical field for chest wall deformities is very diverse. Globally, surgical treatment is in hands of different specialties and is being carried out by general thoracic, cardiothoracic, pediatric, general, and orthopedic surgeons. Solid anchorage in national or regional professional associations is lacking. Worldwide, only few interest groups on chest wall disorders exist. There is a strong need for development of (inter-)national networks in which pectus experts are brought together. A joint data registration could allow prospective multicenter and multinational research, therewith substantially increasing the number of participating patients and providing robust data. The latter is of importance to stress the relevance of adequate diagnostics and treatment in patients with pectus excavatum. Moreover, scientific substantiation plays a pivotal role in discussions with national health care insurance companies, such as currently in the United Kingdom where the NHS does no longer reimburses treatment.

Relevance for commercial parties

Since pectus excavatum is classified as specialized highly complex but low-volume care, the disorder is not a very attractive subject for medical industries. Development of new surgical instruments and implants is not prioritized, and such processes often take years. In contrast to other disorders, industry-facilitated research on chest wall disorders is almost non-

existent. In the interest of pectus patients and their care givers, an intensive cooperation with commercial parties would result in a substantial boost to quality. Extensive collaboration between tertiary referral centers for pectus surgery might increase the volume, therewith increasing the interest of commercial parties.

In conclusion, the present thesis contributes to increasing knowledge on pectus excavatum and its treatment. Furthermore, awareness amongst health care professionals is being expanded. As a result, this thesis contributes to the pursuit of perioperative care for patients suffering from pectus excavatum, thereby aiming to enhance their psychosocial and physical condition.