18

Patient Experience Before and After Treatment: Psychological Effects and Patients' Personal Experience

Shyam K. Kolvekar, Natalie L. Simon,
and Trupti Kolvekar

Abstract

Pectus excavatum is the most frequent congenital anterior chest wall and sternal deformity. The NUSS procedure is a minimally-invasive surgical intervention carried out on patients with the anomaly. The procedure has an extremely high success rate and is proven to benefit the patient's respiratory and cardiac function. Pectus excavatum patients suffer frequent embarrassment over physical appearance and teasing- 22.8 % patients reported such teasing, with an expected 97.4 % majority of teasing coming from peers. Two patients were chosen, at either end of the age spectrum, and they shared an account of their own experiences.

Keywords

Chest wall deformity • Pectus Excavatum • Psychosocial Impact • Nuss Procedure • Pain Management

Pectus excavatum is the most frequent congenital anterior chest wall and sternal deformity. The NUSS procedure is the minimally invasive surgical intervention carried out on patients with the anomaly. The procedure has an extremely high success rate and is proven to benefit the patient's respiratory and cardiac function. Another less-documented benefit observed post-surgery is the considerable improvement in psychological welfare and social interaction. The negative psychological impact of pectus excavatum on patients has been proven to cause sufficient distress and induce constant self-scrutiny. Research undertaken on patients measuring psychosocial status prior-to and after treatment warrants the need for surgery. Non-surgical treatment methods are also proven to be effective at improving the patient's emotional condition and physical satisfaction.

S.K. Kolvekar, MS, MCh, FRCS, FRCSCTh (✉)
Department of Cardiothoracic Surgery,
University College London Hospitals, The Heart
Hospital and Barts Heart Center, London, UK
e-mail: kolvekar@yahoo.com

N.L. Simon, MBBS
Department of School of Medical Education,
Kings College London, London, UK

T. Kolvekar, BSc Biochemistry (Hon)
The Department of Structural Molecular Biology,
University College London, London, UK

© Springer International Publishing Switzerland 2016

S.K. Kolvekar, H.K. Pilegaard (eds.), *Chest Wall Deformities and Corrective Procedures*,
DOI 10.1007/978-3-319-23968-2_18

The majority of studies agree on the extent of poor psychological status amongst pectus excavatum patients. Eighty percent of patients observed in an n = 10 cohort study suffered psychological limitations, concerning *attractiveness*, *self-esteem and somatisation*. Eighty percent of the cohort was found to shy away from body presentation, for instance, when swimming or doing sports. The study found this to lead to insecurity, anxiety and denegation of the own body. Forty percent reported breathlessness, however, their lung-function tests were normal and there was no affirmed pulmonary limitation [1]. 74.8 % of patients in another study conducted to assess psychosocial functioning and its risk factors in children with pectus excavatum were found to have first perceived their deformity between 4 and 6 years of age. 58.8 % of patients in the study found the deformation by themselves and, comparatively less, (41.2 %) were informed of their deformation by people around them [2].

Pectus excavatum patients suffer frequent embarrassment over physical appearance and teasing- 22.8 % patients reported such teasing, with the expected 97.4 % majority of teasing coming from peers. This signals for information regarding pectus excavatum and other such chest deformities being implemented into the curriculum at educational establishments. Being teased about their chest deformity has proven to powerfully motivate patients to seek-out help regarding surgical and non-surgical treatment available. 37.1 % of patients actively sought help by asking their parents to take them to hospital [2]. Intermittent assiduity of the patient's physical appearance is said to cause a substantial lowering of one's self-esteem and extensive feelings of inferiority, depression, shyness and social anxiety. Poor body language is also discerned, such as a sloping posture with folded arms. Lifestyle restrictions often involve avoiding chest exposure when swimming, playing other sports, hugging and intimate relationships. In fact, 43.6 % of patients in the same cohort study admitted to finding chest exposure difficult and restraining from participation in such activities [2]. During puberty, the psychological strain due to pectus excavatum proved disadvantageous to development [1].

United Kingdom has a unique situation due to the National Health Service (NHS), which caters for the masses and is incredibly efficient at dealing with life-saving conditions. Often, in the past, when concerned parents approached their family General Practitioners with either funnel or pigeon chests, they were only reassured and not referred for any treatment. Some of these patients suffered in silence and it affected them in social environments. However, eventually patients started looking for answers; due to increased awareness of the condition, availability of treatment and the internet, leading to a large numbers of patients coming forward for first time to seek treatment. Treatment is available for early teens, depending on which region of the country the patient is from. There are a variety of reasons to why a patient would seek treatment from cosmetic, backaches to breathing issues, thus we see patients with either an unperturbed manner to extremely apprehensive and anxious attitude to their treatment (Table 18.1).

Patient Experience

AB: Male, 17 Years of Age

My experience of pectus excavatum and how I felt afterwards.

The main reason why I had the nuss technique surgery was cosmetic, although I was concerned that the condition might affect my lung capacity in the future even though I do not have respiratory problems now.

I first noticed when I was 13 years old in September 2011, my friends at school commented on it and I didn't really like that. We went away to Egypt that Christmas and my older brother pointed it out to me and I realised that it was quite severe. During the next 6 months it seemed to get worse. In summer 2012, I went to the doctor. I had looked it up by then and knew that I probably had a condition called 'pectus excavatum'. My GP said it was quite common but when I showed him my chest he did say that this was the worst case he had ever seen, and referred me to the hospital.

Table 18.1 Prevalence of psychosocial problems in patient group and control group

CBCL Scale	Patient group	Control group	x^2	*P*
	N = 337	N = 370		
Withdrawn	23 (6.82)	12 (3.24)	4.808	0.028[a]
Somatic complaints	15 (4.45)	8 (2.16)	2.692	0.087
Anxious/depressed	27 (8.01)	15 (4.05)	4.944	0.026[a]
Social problems	21 (6.23)	9 (2.43)	6.264	0.012[a]
Thought problems	17 (5.04)	12 (3.24)	1.455	0.228
Attention problems	16 (4.75)	13 (3.51)	0.683	0.409
Delinquent behavior	19 (5.64)	11 (2.97)	3.038	0.079
Aggressive behavior	21 (6.23)	13 (3.51)	2.846	0.092
Total problem	66 (19.58)	47 (12.70)	6.220	0.013[a]

From Ji et al. [2]. © 2011 Ji et al; licensee BioMed Central Ltd. This is an Open Access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/2.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited

Data are presented as number (%); CBCL: child behaviour checklist

[a] The differences are statistically significant if $P < 0.05$

That made me feel quite self conscious. Throughout the following year I was seen by a consultant a couple of time and had various photographs and tests. When I went on family holidays I did not like taking my t-shirt off which stopped me participating in some activities, for example swimming, that I would have done if it wasn't for my chest (Figs. 18.1, 18.2, and 18.3).

About a year after I had been diagnosed in summer 2013, I was expecting to have my operation, however my local hospital in Brighton does not do chest wall surgery on children so I had to wait for a place in London. My GSCE's intervened so I had to wait another year for my actual surgery.

The surgery went well although afterwards I was in a lot of pain, which is expected with this operation. I was on a morphine drip for a few days. The morphine made me very sick and also gave me hallucinations, which are common side effects. After I came off the morphine, I went onto oral pain relief. I recovered quite quickly after this and 3–4 weeks after surgery I was more or less off all pain relief. By this time I was also able to undertake light exercise, for example table tennis, going to the gym and riding my bike. About 2 months after surgery I started playing tennis, which is my favourite sport. For several weeks after the operation I was quite tired but within 5 or 6 weeks this stopped and I was able to carry on my normal routine (Figs. 18.4, 18.5, 18.6, and 18.7)

Overall I am very happy with the way my chest looks now, especially as I only had the operation a few months ago and I would recommend the operation to anyone. If I were in the same situation, I would definitely go through the process again. I feel much more confidant about taking my t-shirt off now, in fact I really like the way my chest looks now. There are still a couple of scars but these are already barely noticeable and I am not self-conscious about these at all.

I am planning a ski trip in February 2015.

AE: 48 Years of Age

I first became self-conscious about my pectus excavatum in my mid-teens. Prior to then, I had of course noticed that the shape of my rib-cage was different to that of most others, but had put this down to the fact that I was very skinny, and so the contours of my ribs were easier to see than most. My mother had often commented that my chest was just like that of her own father, my granddad.

Once I had realized that my ribcage was not "normal", life was never the same again.

Having never previously worried about clothes, I would now only wear loose-fitting tops, in dark colours, to better hide the dent and flared ribs. Swimming was a military-precise exercise, in which I would strive to get changed into trunks,

Fig. 18.1 Before: Front view

Fig. 18.2 Before: Right side view

and walk to the pool (arms crossed over my chest) without anyone seeing my chest, relaxing only once in the water. Girlfriends' hands were gently pushed away from by chest "because that tickles"; they would never see my naked chest, but instead plenty of dark coloured vests which became my trademark. At University, I remember buying two rolls of bandages in Freshers' Week, and trying to mummify my torso to improve its shape (it didn't work).

So, I was acutely aware and embarrassed by my chest's appearance. Of equal concern were the pains that would intermittently run down the inside of my left arm. I didn't know for sure, and still don't know, whether these were symptoms of my PE, but I assumed so, and this exacerbated my unhappiness and pre-occupation with the condition.

Over the years, it is true to say that my self-consciousness about my PE was never very far from the front of my mind. Before a social event, I would fret over the outfit that would least reveal my chest-shape. Going out in a tee shirt on a windy day was a no-no – the wind would blow the shirt to the contours of my chest. Sea- or pool-side holidays with friends were out of the question – it would be just too difficult to keep my "secret" hidden.

One might think that as someone with PE gets older, that the self-consciousness lessens, that he or she gets a sense of perspective – "worse things happen at sea". This was not my experience. I remained as acutely concerned about it in my 20s, 30s and 40s as I was in my mid-to-late teens. The routines which I put in place to hide the PE, particular clothes types, arms crossed where circumstances demanded it, remained in place.

Before marrying my wife, I had relationships with several other women, none of who were ever aware that I had PE (I'm still not quite sure how I managed to achieve this).

I first met my wife when she and I were both 18, although we didn't marry until we were 31 (and had spent most of the years in between apart, and with other partners). She was the one (non-family) person in whom I was able to confide, although I still was not able to relax without a top on even in her company. It never bothered her at

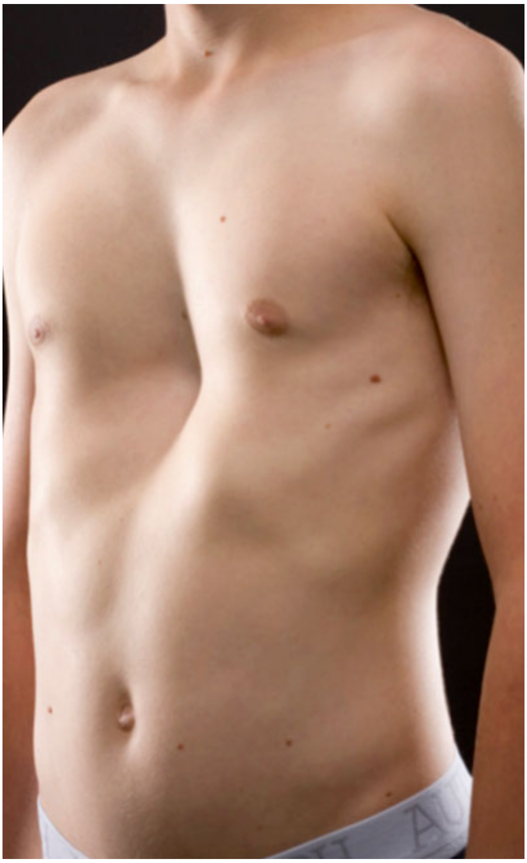

Fig. 18.3 After: Left side view

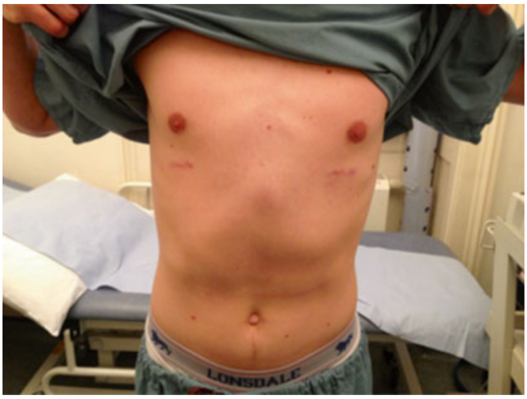

Fig. 18.4 After: Front view

Fig. 18.5 After: left side view

Fig. 18.6 After right side view

Fig. 18.7 The author and surgeon during work experience

Fig. 18.8 Before surgery for pectus excavatum

Fig. 18.9 After surgery for pectus excavatum

all; and she was always trying to reassure me that no-one would notice, which, whilst I appreciated the sentiment, didn't do anything to put my mind at rest.

Our first child, Daniel, was born on Valentine's Day 2000, our pride and joy. Within days I noticed a small hollow in his chest; I was distraught to see that I had passed on my condition to my first-born. We have since had a second son and a daughter, neither of who has PE; and, strangely enough, neither my younger sister nor my brother has PE.

I was 33 when Daniel was born, and had never considered that there might be a remedy for my condition. Indeed, at that time, I did not know that there was a medical name for the condition, that it was a condition shared by 1000s of others, and that indeed, there had been surgical procedures to address the condition for many years. It was Daniel having PE that eventually prompted me, in around 2007, to research the condition as much as possible, and I quickly found the wonderful website www.pectusinfo.com and the wealth of information available on its forums.

In 2010, I became aware that Dr. Hans Pilegaard, a world-renowned surgeon specializing in the correction of pectus deformities, was making regular visits to the London Heart Hospital to work with Dr. Shyam Kolvekar on UK cases. I started to fantasize about a solution to my own condition, without ever really believing it would happen. And then I send an email to Dr Kolvekar, who replied within minutes suggesting I contact his (wonderful) PA, Amy Gooding. Email exchanges with Amy, and an appointment was set up with Dr. Kolvekar in

London, within weeks. During my appointment with Dr. Kolvekar, he was warm, friendly, and immediately sympathetic to my condition. A subsequent appointment was scheduled for tests to gauge my suitability for the Nuss operation. A brief wait for a date when Dr. Pilegaard would next be at the London Heart Hospital, and then, so soon after my first email to Dr Kolvekar, a letter with the date of my operation.

I was ecstatic.

The staff at London Heart Hospital is fantastic, and my memories of my 3-day stay there for the Nuss operation are of being extremely well looked after. I remember Dr. Kolvekar and Dr. Pilegaard coming to see me the night before the operation, debating briefly whether it was a one- or two-bar fix, and putting my mind to rest on the natural concerns I had. I just knew I was in the best hands.

Post-operation, once I was back on the ward, I barely dared to take a look at my chest. For 45 years when I'd looked down at my chest, my heart sank (literally and metaphorically!) and it was very hard to believe I was dent-free. The result surpassed my wildest expectations – my chest was perfectly flat. It was a moment I will never forget (Figs. 18.8 and 18.9).

Only 2 days later, I was back home in the North East to continue my recovery. The day after getting home, I took a trip to town and bought a couple of tee shirts – they fitted properly (not big, baggy ones), and were yellow and white, colours I'd avoided for three decades. I remember walking down Grey Street wearing one of the shirts, with the wind blowing into me – and realizing that my arms were not crossed. Freedom!

My recovery went as smoothly as I could possibly have hoped. I barely felt any pain at all in my chest, but did struggle with a seriously aching back for a few days, which meant I had several literally sleepless nights. I was off all pain-killing medication within a couple of weeks after the operation, and back at work within 3 weeks. I didn't overdo the exercise, but took regular short walks to help me progress.

Almost 3 years to the day of the Nuss operation, I was back at London Heart Hospital to have my bars removed. Another smooth and fuss-free experience at the hands of the wonderful hospital staff, and I was back at home the next day. And the shape of my chest had improved again following bar removal, with my rib flare even less pronounced. I don't think I will ever look at my chest in the future, and not think: "Wow – what happened to the dent!"

So, is that the end of my pectus excavatum story? In one way, it's just the beginning. I've been through the journey now, and reflect on it with only great positivity. I have a tougher experience ahead, as I make that same journey with my son, Daniel. He has met Dr. Kolvekar, and, when the time is right, is hoping he can change his life beyond measure, as he changed mine…

References

1. Habelt S, Korn S, Berger A, Jozef Bielek J. Psychological distress in patients with pectus excavatum as an indication for therapy. IJCM. 2011;2(3): 295–300.
2. Ji Y, Liu W, Chen S, Xu B, Tang Y, Wang X, Yang G, Cao L. Assessment of psychosocial functioning and its risk factors in children with pectus excavatum. Health Qual Life Outcomes. 2011;9:1–8.