# The Quality of Life of Children and Adolescents with Anterior Chest Wall Deformity: A Systematic Review of the Literature.

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**ABSTRACT**

**Objective:** The aim of this study was to evaluate the current evidence regarding the Quality of life (QoL) of children and young people with Anterior Chest Wall Deformity (ACWD).

**Methods:** Using a defined search strategy, a systematic review of the literature was performed using PRISMA guidelines.

**Results:** The search identified 305 articles, after refinement, the full text of 51 studies were reviewed and 10 included in the review. A total of eight studies described QoL associated with the correction of ACWD, and two studies reported on QoL without correction. The surgical correction of ACWD was reported in six studies and non-surgical correction in two studies. A total of three disease specific and 24 generic QoL measures were used. The variation in QoL outcome measures, together with a lack of consistency in the time scales of data collection, did not allow for direct comparison between studies. However, the improvement in psychosocial QoL following correction of ACWD is clear. The impact of ACWD on physical QoL is less defined and the influence of age, gender, severity, and type of deformity is uncertain. The literature identified primarily surrounds QoL outcomes in relation to surgical correction and is therefore not representative of all children and young people with ACWD.

**Conclusions:** Correction of ACWD is associated with significant improvement in the psychosocial QoL of children and young people. Further work is required to standardise QoL data collection for all children with ACWD to achieve a greater understanding of the impact and guide future management.

**Key Words:** Anterior Chest Wall Deformity, Pectus Excavatum, Pectus Carinatum, Quality of life, Children, Adolescents

**INTRODUCTION**

Anterior chest wall deformity (ACWD) is an acquired or congenital structural abnormality of the chest wall occurring in 1 per 300-400 males with a 3-5:1 male dominance[1–3]. The most common presentation reported in the literature is pectus excavatum (PE), a depression of the sternum and associated cartilage ribs into the thoracic cavity[3]. The second most common presentation is pectus carinatum (PC), a protrusion of the sternum and / or cartilage ribs. More complex ACWD or mixed presentations of PE and PC are identified in a small number of cases[4].

PE presents at or soon after birth or, more commonly, during rapid skeletal growth in the peri-pubescent period. Most younger children with PE are asymptomatic due to their compliant, pliable chest wall and cardiac and pulmonary reserves[2,4,5]. In young adolescents, the PE deformity often rapidly increases and can become severe in as little as six to twelve months[2]. Commonly reported symptoms include shortness of breath, pain, reduced exercise tolerance and decreased endurance which leads to the inability to keep up with their peers and a cycle of inactivity, deconditioning and further reduced exercise capacity[2,4,5]. Although the mechanism for the onset of these symptoms is not clear, it is thought that the increase in PE severity causes the chest wall to become less mobile, adversely affecting the work of breathing. Cardiopulmonary symptoms are a consequence of reduced thoracic volume and direct cardiac compression[6]. In contrast, most children and adolescents with PC tend not to have significant symptoms, although in severe cases patients may report shortness of breath[2]. Discomfort over the anterior chest protrusion and musculoskeletal pain of the chest wall may be reported[2,4]. As both PE and PC deformities often become more apparent in early adolescence, this comes at a time of significant physical, emotional, and social changes[7]. The psychosocial consequences of ACWD surrounding body image, self-esteem and self-confidence can be severe causing patients to become socially withdrawn and display features of depression[8].

A proportion of patients with ACWD may not experience any psychosocial or physical impact and following reassurance from a healthcare professional they appropriately opt for no treatment. If correction of the ACWD is desired and indicated, the treatment options differ for PC and PE.

Historically, the correction of PE has been surgical with variations of the procedure first described by Mark Ravitch using an anterior incision to remove the affected costal cartilages[9]. Since the 1990s, the minimally invasive repair of pectus excavatum (MIRPE) described by Donald Nuss has largely replaced the Ravitch technique for patients with PE, using trans-thoracic bars to elevate the depressed sternum[10]. More recently, the vacuum bell as described by Eckart Klobe, has become a non-surgical alternative for correction of PE applying negative pressure to the anterior chest externally to lift the sternum[11].

The correction of PC is largely achieved using non-invasive bracing in which an antero-posterior force is applied to the chest wall using a dynamic chest brace[4]. Surgical correction should be reserved for those failing or unsuitable for bracing and is either by a modified Ravitch procedure[4], or by the minimally invasive repair of pectus carinatum (MIRPC)[12]. Overall, patients tolerate surgery well with minimal postoperative complications and recurrence of PC is rare[4].

It is recognised that certain young people are motivated to seek correction of their ACWD to achieve an improvement in physical and /or psychosocial symptoms. To help understand what motivates young people to seek correction, it is important to recognise the impact of ACWD on their quality of life (QoL). An individual’s QoL is their unique overall sense of well-being and satisfaction with life as a whole[15]. The concept of health-related quality of life (HRQOL) encompasses the aspects of QoL that affect the individual’s psychosocial and physical health[15]. Evaluation or measurement of HRQOL is used to enable health surveillance and is largely achieved through self-reported disease specific and generic QoL questionnaires.

The aim of this systematic review was to evaluate the current evidence available on the QoL of children and young people with ACWD.

# METHODS

**Literature Search Strategy**

In February 2023, a systematic literature review was undertaken according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis guidelines (PRISMA) Statement, under the guidance of an Academic Librarian (SH). The electronic databases appropriate to the research question (OVID MEDLINE, OVID EMBASE, OVID PsycINFO, EBSCO CINAHL) were searched separately with no language or time barriers placed on the search. Search terms used were ‘funnel chest’; ‘pectus excavatum’; ‘foveated chest’; ‘funnel breast’; ‘anterior chest’; ‘chest wall’; ‘pectus carinatum’; ‘pigeon chest’; ‘child\*’; ‘infan\*’; ‘pediatric\*’; ‘paediatri\*’; ‘adolescen\*’; teen\*’; and ‘quality of life’. Google Scholar was also used in addition to hand searching citations and references to identify additional relevant articles.

**Inclusion & Exclusion Criteria**

Articles were included if they met the following inclusion criteria. Participants in the study must be children with a diagnosis of ACWD either PE or PC, aged between 0 and 18 years when QoL was measured. The study must include a quantitative measure of psychosocial and /or physical QoL using either disease specific or generic QoL questionnaires. Articles were excluded if the full text was not in English, they were case studies, reviews, editorial opinions, testimonies, interviews, books, conference abstracts or posters, discussion papers or guidelines or an article developing a QoL outcome measure.

The literature search retrieved 305 articles as shown in the PRISMA flowchart (Fig. 1). After removal of duplicates, the remaining 211 titles and abstracts were screened by three reviewers (AJ, KS, NJR) excluding 160 articles. The full text of the remaining 51 articles were reviewed against the inclusion and exclusion criteria by AJ, KS and NJR, excluding a further 41 articles, resulting in 10 full text articles for review.

**Data Extraction and Quality Assessment**

A data extraction template was developed and the study selection, quality assessment and data extraction managed using Microsoft Excel. The study details extracted included: author, study design, country, type of deformity, participant characteristics, sample size, type of deformity, timing of intervention, QoL outcome measures and the main findings. Data extraction was performed by one reviewer (AJ) and double checked for accuracy by two reviewers (KS, NJR). A narrative synthesis approach was used to compare and describe the studies.

The quality and risk of bias was scored using the Institute of Heath Economics (IHE) Quality Appraisal of Case Series Checklist quality assessment tool[16]. Each study was independently scored by two reviewers (AJ, KS) and a third reviewer (NJR) consulted when agreement was not met. It was considered by the researcher that a score of over 50% was of good quality. No study was excluded on the grounds of quality.

**RESULTS**

**Study Characteristics**

The summary table (Table 1) presents the characteristics of the studies included. All 10 studies used a quantitative approach adopting a variety of study designs, quasi experimental (n= 1)[14], cohort studies (n= 5)[17-21], and case series (n= 4)[1,22-24]. There were six prospective studies[1,17,19-22] and four retrospective studies[14,18,23,24]. A control group was used in three studies[1,19,20], and one study used a comparison group[14]. The studies were undertaken in Europe (n=4)[1,20-22], North America (n=4)[14,17,18,24], and Asia(n=2)[19,23].

## **Population and Sampling**

There was large variation between sample size from n=10[22], to n=337[19] including one multi-centre cohort study[18]. There were six studies that described PE[1,14,18,19,22,23], two that described PC[17,24], and two that described both PE and PC[21,20]. Sampling techniques were mostly convenience (n=7)[1,14,17,19,20,23,24], two were purposive (n=2)[18,22] and one was unclear (n=1)[21].

## **Reasons for Intervention**

There were eight studies that evaluated the impact of ACWD correction on QoL[1,14,17,19,20,22-24], five of which did not comment on the rationale for undertaking correction[1,14,17,20,24]. Cosmetic reasons were stated in three studies [18,22,23], one of which also reported physical reasons[18] and another psychological distress[22].

## **The Type of Intervention for Correction of ACWD**

Surgical correction was reported in six studies[1,14,18,20,22,23] (Table 1). All six studies described the MIRPE procedure, one study also including a comparison group which used the Ravitch procedure[14]. A further study reported on the surgical correction of PC using the MIRPC procedure[20]. Three studies reported on non-surgical intervention, two of which reported on bracing for correction of PC[17,24] and one reported on the vacuum bell for correction of PE[22].

**QoL Outcome Measures**

To measure QoL, the authors of the studies used three different disease specific quality of life measures, the Pectus Excavatum Evaluation Questionnaire (PEEQ)[14,18,24] which was also modified and used for patients with PC[17], the Single Step Questionnaire (SSQ)[24], and the Modified Pectus Project Questionnaire (PPQ)[23]. A further 24 different generic QoL measures were used across the studies[1,14,19,20,21,22,24] (Table 2). Five studies reported on QoL before and after correction[1,17,20,22,23], three studies reported on QoL solely following correction[14,18,24], and two studies reported on QoL not in relation to correction[19,21].

## **Psychosocial QoL**

The studies measuring QoL independent of correction describe the detrimental impact of PE on psychosocial QoL[19,21]. A large study of 337 patients aged 6-16 years old compared patients with PE to control subjects. It was reported that those with PE had psychosocial symptoms of being ‘withdrawn’, ‘anxious or depressed’ and had ‘social’ problems[19]. In a more recent study, patients with PE aged 10-18 years old were found to have significantly lower scores for psychosocial QoL when compared to a control group[21]. No studies described the psychosocial QoL of patients with PC independent of correction.

An improvement in the psychosocial QoL of patients following correction of PE is described in four studies[1,18,22,23]. Despite variation in the outcome measures, key themes of general satisfaction[18,22-23], improved wellbeing[1,18,23], improved body image[22,23], improved self-esteem[1, 22,23], improved social belonging and social activity[1,22,23] were described and reported to contribute to improved psychosocial QoL. However, in a retrospective study using a comparative group to explore postoperative QoL, Lam et al.[14] reported on poorer HRQOL scores for patients who have undergone surgical correction of PE when compared to age-matched norms.

Two studies report an improvement of psychosocial QoL following the correction of PC with bracing. Improved satisfaction with appearance and self-esteem[24], and improved self-image[17] following bracing were described.

## **Physical QoL**

Physical QoL is reported in two studies[1,21]. A prospective study using the Pediatric Quality of Life Inventory, found patients with PE to have lower physical function than the control group, yet the same was not observed in patients with PC[21]. In a further prospective study of 107 children with PE using the Child Health Questionnaire, an improvement in physical and social activity was reported following the MIRPE[1]. The limited evidence surrounding physical QoL does not enable conclusions to be drawn.

**Other Influences on QoL**

The influence of age on QoL is not widely reported in the literature due to studies primarily recruiting children that are age appropriate for surgical correction. However, one study identified that children aged 12-16 years were at higher risk of psychosocial problems than those under 9 years[19]. It is notable that no study reports on the influence of gender on QoL. The relationship between the severity of ACWD and QoL in children and young people with PE is disputed. It was reported by Ji *et al.*[19] that increased severity of PE is more likely to be associated with psychosocial problems. However, a retrospetive study from the USA measuring QoL following MIRPE concluded that patients with a milder severity of PE experienced considerable improvement in QoL following correction[18]. Furthermore, the relationship between the type of ACWD and QoL is unclear with little comparison between PE and PC reported across the literature.

**DISCUSSION**

This systematic review set out to report on the QoL of children and young people with ACWD. There were ten articles included in this systematic review each of which used different methods and a variety of disease specific and generic outcome measures. Despite no uniform measure or consistency in the time scales of data collection, it is recognised that correction of ACWD is associated with improved psychosocial QoL of children and young people.

Prior to intervention, patients reported being withdrawn, anxious, depressed, and body conscious with most avoiding exposing their chest in public[19,22]. A significant improvement in psychosocial QoL following correction is widely described across the studies with improved general satisfaction, body image, self-esteem, and engagement in social activities of patients reported in patients with both PE and PC[1,17,18,22-24].

Despite limited evidence on physical QoL, patients with PE frequently report improved exercise tolerance after surgery[5]. The reason for this is unclear as the impact of PE on the cardiopulmonary system is disputed in both clinical practice and across the literature[13,14]. It has been proposed that an increase in the severity of PE causes the chest wall to become more rigid with cardiopulmonary symptoms occurring because of reduced thoracic volume and cardiac compression[6]. An alternative theory has suggested that improved physical activity and exercise tolerance in patients with PE following surgery is a consequence of the improved psychosocial QoL. This theory proposes that the increased satisfaction with appearance and consequent increased engagement in social activities improves physical QoL rather than there being a true physiological response[22]. No studies reported on physical QoL in patients with PC, therefore conclusions cannot be drawn.

A large proportion of studies undertaken relate to surgical intervention in early to mid-adolesence with some evidence to suggest the older the child, the lower their QoL[19]. The impact of age on the QoL of younger, pre-pubertal children with ACWD is unclear, furthermore, no studies have separated children who have PE from early childhood to those who first present in young adolescence. Conclusions cannot be drawn from the current literature whether gender of the child has an impact on their QoL however, it has been suggested that the development of breast tissue might result in females becoming less concerned regarding their appearance[21].

The relationship between the severity of the ACWD and QoL in children and young people with PE is unclear. Alaca *et al.*[21] proposed that the perceived appearance rather than the severity of the deformity is associated with physical function and psychosocial status. Similarly, a review by Han *et al*.[25] evaluating the QoL of children with adolescent idiopathic scoliosis described the requirement for greater attention to be placed on the child’s perception of their deformity rather than appraising surgical outcomes.

**Limitations of the review**

There is no defined core outcome dataset for children and young people with ACWD, a weakness that has limited the direct comparison of results. Furthermore, the research papers are only representative of the population that seek or have access to specialist services and are therefore potentially not a true reflection of all children with ACWD. As identified in this review, much of the current evidence base is focused on QoL in relation to surgical correction.

**CONCLUSION**

This review has shown that the correction of ACWD is associated with significant improvement of the QoL of children and young people. Despite this, it is unclear what influences the psychosocial and physical QoL of patients with PE and PC and how this may differ between presentations. It is not understood when ACWD starts to impact on the QoL of children and the relative contributions of the psychosocial and physical response. Furthermore, it is not clear what motivates some children and young people to pursue correction of their ACWD, yet others to opt for no intervention.

Future work is required to evaluate QoL from the initial presentation of ACWD to better understand both the psychosocial and physical impact and how QoL may vary between PE and PC presentations. Furthermore, we should look to establish the significance of the child’s age, gender and the severity of the ACWD, and explore the impact of the child’s perception of their deformity. With non-surgical treatment options increasingly available at a younger age, future work should establish the value of early intervention, the impact this may have on the QoL of children and young people and their long-term outcomes.

**What is already known on the topic?**

Children and young people with Anterior Chest Wall Deformity may experience issues surrounding body image, self-esteem, and self-confidence.

**What this study adds?**

Correction of Anterior Chest Wall Deformity is associated with significant improvement in the psychosocial QoL of children and young people.

**How might this study affect research, practice, or policy?**

The impact of Anterior Chest Wall Deformity on psychosocial quality of life must be considered in policy and practice. Future research should ensure an improved understanding of the impact of anterior chest wall deformity to shape future services.

**Conflicts of Interest Statement**

Competing interests: None declared.

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**Contributorship Statement**

Ashley Johnstone led on the study design, completed the literature search, the analysis of the literature, write up of the work and is responsible for the overall content as guarantor. Mr Carl Davis provided interpretation of the literature in addition to revision of the work and final approval and is agreement to be accountable for the work. Dr Kath Sharp and Dr Nicola Roberts both contributed to the study design in addition to being second and third reviewers for both inclusion and quality assessment. Both Kath Sharp and Nicola Roberts revised the work and provided final approval and agreed to be accountable for all aspects of the work. Mr James Andrews, Dr Neil Gibson and Dr Ross Langley each served as scientific advisors.

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| **Author** | **Year** | **Country** | **Deformity** | **Study Design** | **Multi-centre** | **Number of Participants** | **Age (years)** | **Reason(s) for Correction** | **Correction Type** |
| Alaca et al.[21] | 2021 | Turkey | PE &PC | Prospective Cohort Study | Unclear | 180 intervention, 90 control group | 10-18 | Not applicable | Not applicable |
| Bahadir *et al*.[20] | 2017 | Turkey | PE & PC | Prospective Cohort Study | No | 32 surgery, 31 no intervention | Mean age 14 | Not reported | MIRPE & MIRPC |
| Colozza *et al*. [24] | 2013 | Canada | PC | Retrospective Case Series | No | 25 | Mean age 14 | Not reported | Bracing |
| Gibreel *et al*. [18] | 2016 | USA | PE | Retrospective Cohort Study | Yes | 145 | Median age 15 | Cosmetic, physical, recurrence PE | MIRPE |
| Habelt *et al*. [22] | 2011 | Switzerland | PE | Prospective Case Series | No | 10, 7 completed follow up | 15-17, (median age 16) | Cosmetic, psychological distress | MIRPE & Vacuum Bell |
| Ji *et al.* [19] | 2011 | China | PE | Prospective Cohort Study | No | 337 intervention, 370 control | 6-16 | Not applicable | Not applicable |
| Kim *et al*. [23] | 2011 | Korea | PE | Retrospective Case Series | No | 39 | Mean age of surgery 6.8.  Mean age of survey 12 | Cosmetic | MIRPE |
| Lam *et al*. [14] | 2008 | Canada | PE | Retrospective Quasi Experimental | No | 23  (11 MIRPE, 12 Ravitch) | Mean age at surgery 15 | Not reported | MIRPE & Ravitch |
| Lomholt *et al*. [1] | 2016 | Denmark | PE | Prospective Case Series | No | 107 | Mean age males 15, Mean age females 13. | Not reported | MIRPE |
| Orrick *et al*.[17] | 2022 | USA | PC | Prospective Cohort Study | No | 97 | 11-17, Mean age 14 | Not reported | Bracing |

**Table 1** Characteristics of included studies

Abbreviations: PE – Pectus Excavatum; PC – Pectus Carinatum; MIRPE – Minimally Invasive Repair Pectus Excavatum; MIRPC – Minimally Invasive Repair Pectus Carinatum

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Author** | **Deformity** | **Clinic Appointment / Before Correction** | **After Correction (mean 0-12 months)** | **After Correction (mean> 12 months)** | **Summary of Findings** |
| Alaca *et al*. [21] | PC & PE | PAC; IPAQ-SF; BSI; BIS;  SAAS; SAS-A; PedsQL |  |  | PE group had lower scores for psychosocial conditions compared to control group.  Perceived appearance rather than severity is associated with physical function and psychosocial status. PE group had lower physical function compared to control group. |
| Bahadir *et al*. [20] | PC & PE | CDI; PHCSCS; CSPSCA;  SDQ (SR/PR); STAIC-T | CDI; PHCSCS; CSPSCA  SDQ (SR/PR); STAIC-T |  | No significant difference between operated and non-operated patient groups in psychiatric rating scales. |
| Colozza *et al*. [24] | PC |  |  | PEEQ; SSQ; SF-36 | Few patients are symptomatic before bracing although most avoid activities that show their chest. Patients very satisfied with appearance and self-esteem increased after bracing. |
| Gibreel *et al*. [18] | PE |  |  | PEEQ | Following surgical correction most patients (99%) were very happy or mostly happy with the way their chest looks with overall improved wellbeing.  Patients with Haller index <3.25 reported considerable improvement in QOL. |
| Habelt *et al*. [22] | PE | CBCL; FBeK; FBK-20;  ALS; YSR; SD Questionnaire |  | CBCL; FBeK; FBK-20;  ALS; YSR; SD Questionnaire | Prior to intervention, patients displayed psychological limitations concerning attractiveness, self-esteem, and somatisation. All patients showed good improvement following correction. |
| Ji *et al.* [19] | PE | CBCL |  |  | Compared with control group, children with PE displayed higher prevalence of psychosocial problems such as withdrawal, anxiety/depression, social problems, and total problems. |
| Kim *et al*. [23] | PE | Modified PPQ | Modified PPQ | Modified PPQ | Scores for satisfaction with appearance, social belonging, empowerment / self-confidence, and well-being increased following MIRPE. |
| Lam *et al*. [14] | PE |  |  | PEEQ; CHQ-CF87 | Patients undergoing PE correction by NUSS or Ravitch have similar HRQOL outcomes.  Patients with corrected PE showed worse scores for mental health, general health perceptions, change in health, pain, and self-esteem that age-matched norms. |
| Lomholt *et al*. [1] | PE | CHQ-CF87 | CHQ-CF87 / CHQ-PF50 |  | Patients had reduced physical function compared to controls prior to correction.  Patients and parents report improved emotional wellbeing and self-esteem and an increase in physical and social activities following correction. |
| Orrick *et al.* [17] | PC | Modified PEEQ | Modified PEEQ |  | Improvement in self-image following bracing for correction. |

**Table 2** The QoL outcome measures used in studies of patients with ACWD.

Abbreviations: PAC – Perception of the appearance of chest area; IPAQ-S-International Physical Activity Questionnaire – Short Form; BSI-Brief Symptoms Inventory; BIS-Body Image Scale; SAAS – Social Appearance Anxiety Scale; SAS-A- Social Anxiety Scale for Adolescents; PedsQL - Paediatric Quality of Life Inventory; CDI - The Children's Depression Inventory; PHCSCS - Piers-Harris Children's Self-Concept Scale; CSPSCA - Capa Social Phobia Scale for Children and Adolescents; SDQ-SR - Strengths and Difficulties Questionnaire - Self-Report Version; SDQ-PR - Strengths and Difficulties Questionnaire - Parent-Report Version; STAIC-T - State-Trait Anxiety Inventory for Children - Trait Version; SSQ- Single Step Questionnaire; PEEQ - Pectus Excavatum Evaluation Questionnaire; SF-36 – Short Form 36 Health Survey; CBCL - Achenbach Childhood Behaviour Checklist; FBeK - Body Appraisal Inventory; FBK-20 - Body Image Inventory; ALS - Manual for the self-esteem for children and youngsters; YSR – Youth Self Report; SD Questionnaire – Self Developed Questionnaire; PPQ - Pectus Project Questionnaire; CHQ-CF87 - Child Health Questionnaire – Child Form; CHQ-PF50 – Child Health Questionnaire - Parent Form; PPQ - Pectus Project Questionnaire.

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