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Advancing pectus deformity care: evaluation of current treatments, complications and future innovations

Braak, H. van

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CHAPTER 3

Improving quality of life with dynamic compression bracing in patients with pectus carinatum

Hendrik van Braak, Sjoerd A. de Beer, Jos W.R. Twisk, Sander Zwaveling, Matthijs W.N. Oomen, Justin R. de Jong, L.W. Ernest van Heurn

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ABSTRACT

Background

Patients with pectus carinatum have lower quality of life and self-esteem than their peers. We assessed the impact of dynamic compression system bracing on quality of life in patients with pectus carinatum.

Methods

We conducted a prospective cohort study on patients aged 10-21 years. We assessed quality of life using the Child Health Questionnaire-87, the State-Trait Anxiety Inventory-6, the World Health Organization Quality of Life-BREF, the 36-Item Short Form Survey, and the Single-Step Questionnaire adapted for pectus carinatum.

Results

Between March 2013 and March 2016, 225 patients treated with dynamic compression system bracing were included. Patients showed improvements across the overall scores of the 36-Item Short Form Survey ($\Delta 7.7$ (2.9-12.4)), Single-Step Questionnaire ($\Delta 4.1$ (2.0-6.3)) and three out of four World Health Organization Quality of Life-BREF domains (physical health ($\Delta 8.7$ (3.7-13.7)), psychological health ($\Delta 11.8$ (6.1-17.5)), environment ($\Delta 5.7$ (0.2-11.3))). No changes across the Child Health Questionnaire-87 overall score were observed ($\Delta 5.5$ (-0.5-11.5)). Most improvement occurred within six to twelve months after treatment initiation, stabilizing thereafter. Anxiety scores on the State-Trait Anxiety Inventory-6 did not improve ($\Delta 0.5$ (-0.1-1.2)). Scores on physical complaints, pain, psychological health and self-esteem/self-image improved across all questionnaires. In contrast to the successfully treated group, the unsuccessfully treated group showed no improvement on any of the questionnaires. Most patients (87.2%) would choose bracing again, 94.9% of patients were satisfied with the treatment.

Conclusions

Dynamic compression system bracing improves quality of life, reduces physical complaints and pain and boosts psychological health and self-esteem in patients with pectus carinatum.

INTRODUCTION

Pectus carinatum (PC) is a pediatric condition marked by abnormal overgrowth of costal cartilage which results in protrusion of the sternum. Incidence varies from 0.04-0.7% in the current literature.^{1,2} Almost 50% of the patients feel embarrassed about their chest and experience occasional bullying. This may lead them to avoid activities in which their chest is visible such as swimming. It may cause psychological distress, a disturbed body image and an overall reduced quality of life (QoL).²⁻⁴ Additionally, patients often report various physical complaints, primarily respiratory and cardiovascular, but also pain.^{5,6} Currently, dynamic compression system bracing (DCS-bracing) is the treatment option of first choice, with good results.² Despite these results, there is limited knowledge about the effect of DCS-bracing on improvements in QoL, self-esteem and psychological distress. Only three studies have addressed (facets of) QoL after treatment; however, they used different braces and bracing protocols.⁷⁻⁹ Two studies report on improvement of QoL after surgical correction of PC.^{10,11} The lack of studies on this topic is particularly surprising as a reduced quality of life is the primary reason for seeking treatment.

Therefore, we evaluate the changes in QoL in patients with PC treated using DCS-bracing, with emphasis on physical complaints, pain, psychological health and self-esteem/self-image.

PATIENTS AND METHODS

Patients and study design

We conducted a prospectively cohort study of patients who commenced DCS-bracing therapy between March 2013 and March 2016 at the Amsterdam Pectus Centre. Patients aged ten or older with sufficient knowledge of the Dutch language were included. A Medical Ethics Review Committee (METC) official waiver of ethical approval was granted by the METC of the Amsterdam Medical Center. Informed consent was obtained from all patients (or their parents) included in this study.

Treatment protocol

At the Amsterdam Pectus Centre, patients with pectus carinatum (PC) are treated using the FMF Dynamic Compression System brace (Pampamed). Pediatric surgeons handle both intake and follow-up appointments, following the treatment protocol outlined in Figure 1. Patients are advised to delay treatment until after the onset of their growth spurt. The pressure of initial correction is assessed using a pressure device that measures the average force required to correct the chest deformity. Patients are advised to wear the brace as much as possible, and we encourage them to wear the

brace at night to extend their treatment hours more comfortably. Treatment is deemed successful when a satisfactory outcome is achieved, as determined in consultation with the clinician.

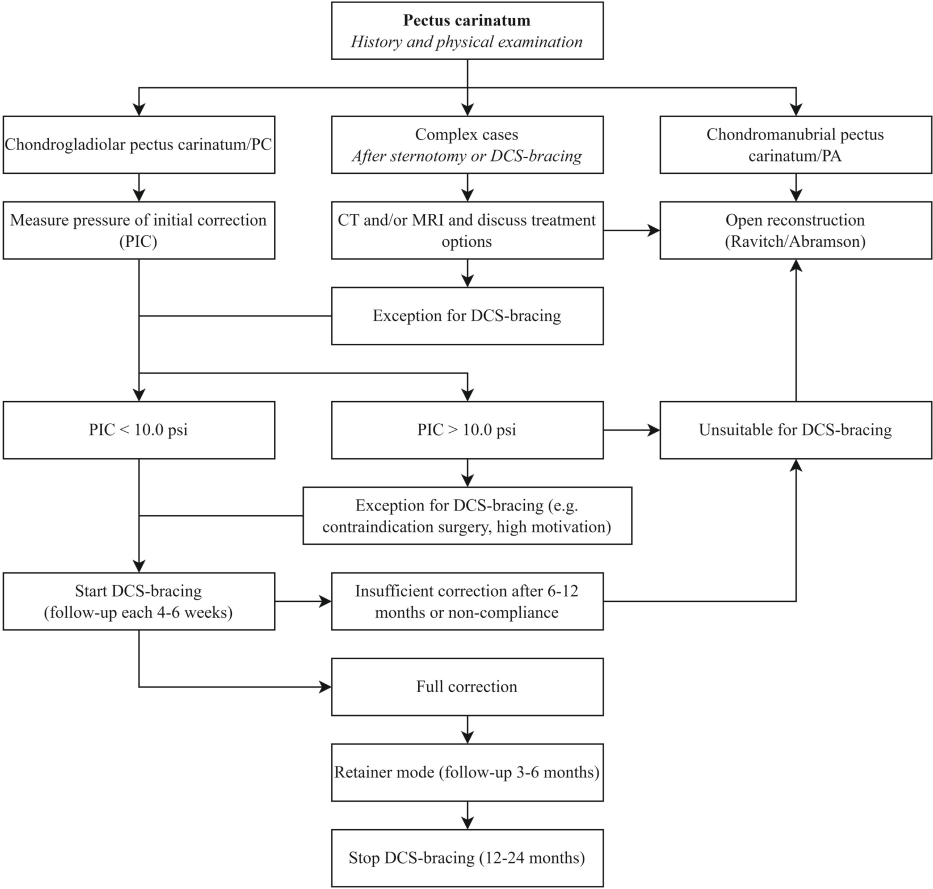


Figure 1 Treatment protocol DCS-bracing (CT = Computer Tomography, DCS = Dynamic Compression System, MRI = Magnetic Resonance Imaging, PA = Pectus Arcuatum, PC Pectus = Carinatum, PIC = Pressure of Initial Correction)

Questionnaires

Patients were divided into three age groups (10-16y, 16-18y and >18y), to meet the validation criteria for the various questionnaires, with distinct questionnaires administered to each age group. Patients younger than ten years were excluded. Questionnaires were administered at the start of treatment and at one, six, twelve, eighteen and 24 months thereafter.

The Single Step Questionnaire (SSQ) (Appendix A), originally developed to assess QoL in patients with PE after the Nuss procedure, was used to assess change in QoL and satisfaction during treatment.¹² The questionnaire was adapted in our center to fit PC patients and was used with all subjects. All items, except for three, were scored on a 5-point Likert scale.

Anxiety was assessed using the Six-item State-Trait Anxiety Inventory (STAI-6) (Appendix B).¹³ Items were scored on a 4-point Likert scale. The total score was displayed on a 0-24 scale.

The evaluation of QoL in the younger patients, aged ten to eighteen years, was done with the Child Health Questionnaire-87 (CHQ-87) (Appendix C). The CHQ-87 encompasses different domains, covering physical, emotional, and social well-being domains, including specific inquiries regarding self-esteem and self-image perception.¹⁴ Items were scored using a 4- or 5-point Likert scale. Domain scores were converted to a standardized 0-100 scale.

The World Health Organization Quality of Life Brief Version (WHOQOL-BREF) (Appendix D), a condensed version of the World Health Organization Quality of Life-100 (WHOQOL-100), was used to assess QoL in patients aged sixteen years and older across four key domains, being physical health, psychological health, social relationships and environment. Additionally, it assesses two overarching aspects (QoL and health satisfaction in general). To enhance our study's scope, we added the facet body image and facet pain of the WHOQOL-100. Items were scored on a 5-point Likert scale. Domain scores were converted to a standardized 0-100 scale.¹⁵

Besides the WHOQOL-BREF the Short Form Survey 36 (SF-36) (Appendix E), a 36-item questionnaire covering eight domains of health, was used for patients aged sixteen years and older. This questionnaire also focusses on the limitations in daily life due to physical health or emotional problems.¹⁶ We calculated the physical and mental component scores (PCS and MCS) besides the total score of the SF-36 to measure

QoL, as previously advised.^{17,18} Items were scored on a combination of Likert scales and binary scales. Domain scores were converted to a standardized 0-100 scale.

Scores of all items in the questionnaires were converted to positive scores to standardize the scoring. Higher scores indicated a better QoL.

Statistical analysis

Data were analyzed using IBM SPSS Statistics 28.0. Descriptive measurements were utilized to characterize the study population. Changes in QoL primary and secondary outcomes were analyzed using linear mixed models, given that this method is ideal for analyzing repeated measures with missing data.¹⁹ The linear mixed models only included time, which was treated as a categorical outcome variable represented by five dummy variables.

We used 95% Confidence Intervals (95% CI) to determine statistical significance. A 95% Confidence Interval that does not include the null value indicates that the result is statistically significant at the $P < .05$ level. The change in questionnaire scores is reported in the text as the absolute difference with 95% Confidence Intervals, formatted as (absolute difference (95% CI)), e.g., ($\Delta 5.5$ (-0.5-11.5)).

Outcomes

Primary outcomes were changes in QoL due to DCS-bracing. Secondary outcomes were changes in anxiety scores, changes in subdomains of the questionnaires, especially physical complains, pain, psychological health and self-esteem/self-image, and differences in outcomes between successfully and unsuccessfully treated patients.

RESULTS

Of all patients (N=260) treated in the study period 225 patients were included. Thirty-five patients were excluded either because of insufficient knowledge of the Dutch language, or they did not return any of the questionnaires. Baseline characteristics are listed in Table 1. Of all patients, 92.0% were male (207/225), median age was 15.0 (interquartile range (IQR) 13.0-16.0) years and median treatment time was 16.0 (IQR 12.0-23.0) months. All patients were diagnosed with PC, and none with pectus arcuatum (also known as Type 2 PC or Currarino-Silverman syndrome). None of the patients were still actively treated at the time of evaluation, 78.2% (176/225) finished treatment successfully, 13.3% (30/225) finished treatment unsuccessfully and 8.4% (19/225) were lost to follow-up. The number of respondents for each questionnaire at each time

point is detailed in Table 2. Initial response rates ranged from 62.7% to 77.3% at the zero-month mark, with a gradual decline over time.

CHQ-87

Table 3 shows the absolute and relative changes in overall scores of all questionnaires, while Figure 2 visually represents these changes in a graph to provide a clear overview. Total scores on the CHQ-87 did not change over the two years follow-up ($\Delta 5.5$ (-0.5-11.5)), although it increased from 76.1 to 81.6 points. More than half of this improvement occurred within the first six months of treatment. There were changes in the following subdomains: physical functioning ($\Delta 1.9$ (0.3-3.6)), role/social limitations due to behavior ($\Delta 2.2$ (0.6-3.8)), pain ($\Delta 6.3$ (1.1-11.6)), mental health ($\Delta 3.0$ (0.1-5.9)), and self-esteem ($\Delta 3.4$ (0.2-6.4)). There were no changes in the subdomains general health ($\Delta 3.9$ (-1.0-8.8)), role/social limitations due to physical health ($\Delta 1.9$ (-0.0-3.8)), role/social limitations due to emotional health ($\Delta 2.3$ (-0.4-5.0)), behavior ($\Delta 2.4$ (-0.1-4.9)), family cohesion ($\Delta 16.9$ (-1.5-35.2)), or family activities ($\Delta 0.9$ (-2.8-4.5)). The positive change in health increased over the two years from 3.2 to 7.1 points ($\Delta 4.0$ (2.3-5.6)).

Table 1 Baseline characteristics

	All patients (N=225)
Sex ^b	
Male	207 (92.0)
Female	18 (8.0)
Age (years) ^a	15.0 (13.0-16.0)
<16 years ^b	158 (70.2)
16-18 years ^b	60 (26.7)
>18 years ^b	7 (3.1)
Treatment time (months) ^a	16.0 (12.0-23.0)
Results ^b	
Treatment successful	176 (78.2)
Treatment not successful	30 (13.3)
Lost to follow-up	19 (8.4)

^a Nonparametric variables; expressed as median (IQR)

^b Data displayed as n (%)

Table 2 Responses per questionnaire

	0m ^a	1m ^a	6m ^a	12m ^a	18m ^a	24m ^a
CHQ-87 (N=223 ^b)	161	123	73	69	30	4
SF-36 (N=59 ^b)	38	26	20	6	8	12
WHOQOL-BREF (N=59 ^b)	37	31	23	15	8	15
STAI-6 (N=225 ^b)	174	127	85	76	43	52
SSQ (N=225 ^b)		127	97	68	43	75

^a n of responses

^b Number of patients eligible for this questionnaire at 0 months

CHQ-87 = Child Health Questionnaire-87, m = months, N/n = number, SF-36 = Short Form Survey 36, SSQ = Single Step Questionnaire, STAI-6 = Six-item State-Trait Anxiety Inventory, WHOQOL-BREF = World Health Organization Quality of Life Brief Version

SF-36

Total scores on the SF-36 did change over two years ($\Delta 7.7$ (2.9-12.4)), increasing from 83.4 to 91.0 points. QoL improved until six months after treatment initiation and then remained stable without decline. The PCS ($\Delta 0.5$ (-4.4-3.4)) and the MCS ($\Delta 1.3$ (-5.6-3.0)) did not change over the treatment period. There were changes in the subdomains physical functioning ($\Delta 4.4$ (1.2-7.6)), role of limitations due to physical health ($\Delta 11.2$ (3.1-19.4)), energy/fatigue ($\Delta 10.5$ (4.2-16.8)), emotional well-being ($\Delta 7.4$ (2.2-12.7)), social functioning ($\Delta 11.9$ (5.9-17.9)), pain ($\Delta 9.0$ (3.5-14.4)), and general health ($\Delta 10.5$ (3.1-18.0)). There were no changes in the subdomain role of limitations due to emotional problems ($\Delta 8.8$ (-1.0-16.5)). The positive change in health was stable during the two years and did not change ($\Delta 4.2$ (-3.1-11.5)).

WHOQOL-BREF

On all domains most improvement was made in the first six months after treatment initiation, after that it remained stable. There were changes in the subdomains physical health ($\Delta 8.7$ (3.7-13.7)), psychological health ($\Delta 11.8$ (6.1-17.5)), environment ($\Delta 5.7$ (0.2-11.3)), pain ($\Delta 13.1$ (3.2-23.0)), body image ($\Delta 37.7$ (29.5-45.8)). General QoL ($\Delta 10.9$ (5.5-16.3)) and health satisfaction ($\Delta 10.7$ (4.3-17.1)) did also improve. There was no change in the subdomain social relationships ($\Delta 1.2$ (-4.5-6.9)).

STAI-6

Total scores on the STAI-06 did not change over two years ($\Delta 0.5$ (-0.1-1.2)), although it increased from 21.0 to 21.5 points over two years. Most improvement was made in the first six months, with a slight decrease in total scores after six months.

Table 3 Absolute and relative change in (overall) scores of questionnaires

	0m	1m	6m	12m	18m	24m
CHQ-87						
Mean ^a	76.1 (6.8)	76.6 (6.9)	79.3 (4.4)	79.6 (4.2)	79.1 (4.3)	81.6 (7.1)
Difference from baseline ^b		0.5 (0.7)	3.2 (4.2)	3.5 (4.6)	3.0 (3.9)	5.5 (7.2)
SF-36						
Mean ^a	83.4 (13.7)	85.6 (13.2)	91.3 (7.5)	92.7 (5.3)	89.8 (8.0)	91.0 (10.5)
Difference from baseline ^b		2.2 (2.6)	7.9 (9.5)	9.3 (11.2)	6.4 (7.7)	7.7 (9.1)*
WHOQOL-BREF						
Physical health						
Mean ^a	78.4 (12.1)	79.4 (15.4)	87.1 (10.8)	87.4 (10.8)	86.8 (10.4)	87.1 (10.1)
Difference from baseline ^b		1.0 (1.3)	8.7 (11.1)	9.0 (11.5)	8.4 (10.7)	8.7 (11.1)*
Psychological health						
Mean ^a	71.7 (13.5)	77.1 (14.8)	82.5 (11.7)	83.3 (9.5)	81.9 (9.2)	83.5 (9.3)
Difference from baseline ^b		5.4 (7.5)	10.8 (15.1)	11.6 (16.2)	10.2 (14.2)	11.8 (16.5)*
Social relationships						
Mean ^a	79.8 (14.1)	78.2 (15.5)	82.2 (11.7)	81.4 (14.2)	83.9 (11.9)	81.0 (12.0)
Difference from baseline ^b		-1.6 (-2.0)	2.4 (3.0)	1.6 (2.0)	4.1 (5.1)	1.2 (1.5)
Environment						
Mean ^a	81.1 (10.3)	81.8 (13.0)	88.8 (10.6)	88.4 (8.9)	86.9 (11.6)	86.9 (9.3)
Difference from baseline ^b		0.7 (0.9)	7.7 (9.5)	7.3 (9.0)	5.7 (7.1)	5.7 (7.1)*

Table 3 Absolute and relative change in (overall) scores of questionnaires *Continued*.

	0m	1m	6m	12m	18m	24m
STAI-6						
Mean ^a	21.0 (2.7)	21.3 (2.6)	21.9 (1.7)	21.8 (2.2)	21.2 (2.3)	21.5 (2.4)
Difference from baseline ^b		0.3 (1.4)	1.0 (4.3)	0.8 (3.8)	0.3 (1.0)	0.5 (2.4)
SSQ						
Mean ^a		68.6 (7.3)	70.3 (7.3)	73.2 (7.4)	72.6 (7.9)	72.7 (4.1)
Difference from baseline ^b			1.7 (2.5)	4.6 (6.7)	4.0 (5.8)	4.1 (6.0)*

^a Mean (SD)

^b Absolute difference from baseline (percentage change relative to baseline)

* Statistically significant values

CHQ-87 = Child Health Questionnaire-87, m = months, SF-36 = Short Form Survey 36, SSQ = Single Step Questionnaire, STAI-6 = Six-item State-Trait Anxiety Inventory, WHOQOL-BREF = World Health Organization Quality of Life Brief Version

SSQ

Total scores on the SSQ did change over two years ($\Delta 4.1$ (2.0-6.3)), increasing from 68.6 to 72.7 points. QoL improved until twelve months after treatment initiation, after that it remained stable, without any significant decline. During treatment scores on exercise capacity ($\Delta 0.5$ (0.2-0.7)), satisfaction with body ($\Delta 0.3$ (0.1-0.5)), impact of DCS-bracing on social life ($\Delta 0.4$ (0.2-0.6)), limitations on social activity during bracing ($\Delta 0.5$ (0.1-0.8)), self-image after start of DCS-bracing ($\Delta 0.5$ (0.2-0.8)), pain in general ($\Delta 0.1$ (0.0-0.4)), and improvement of the thorax ($\Delta 0.2$ (0.0-0.4)) increased. Scores on general health ($\Delta 0.2$ (-0.0-0.4)), limitations on social activity before DCS-bracing ($\Delta 0.1$ (-0.2-0.4)), skin problems during treatment ($\Delta 0.1$ (-0.3-0.4)), self-image before start DCS-bracing ($\Delta 0.2$ (-0.3-0.7)), pain during the application of the DCS-brace ($\Delta 0.1$ (-0.2-0.4)), pain during daily activities ($\Delta 0.1$ (-0.1-0.4)), satisfaction with the DCS-brace ($\Delta 0.2$ (-0.0-0.4)), and awareness of the DCS-brace during wearing ($\Delta 0.3$ (-0.0-0.5)) did not change. Of all patients, 96.5% (192/199) was either satisfied (42.7%, 85/199), very satisfied (34.7%, 69/199) or extremely satisfied (19.1%, 38/199) with DCS-bracing at the conclusion of their treatment or at their last assessment before dropping out. Additionally, 85.0% (170/200) of patients would opt for DCS-bracing again if they had to make the decision anew, 12.5% (25/200) had doubts and 2.5% (5/200) would definitely not choose DCS-bracing again.

Improvement in QoL and success of treatment

Overall scores on the SF-36 ($\Delta 9.0$ (3.6-14.5)), scores on the subdomains physical health ($\Delta 9.4$ (3.7-15.0)), psychological health ($\Delta 11.9$ (5.5-18.3)) and environment ($\Delta 6.4$ (0.3-12.6)) of the WHOQOL-BREF, and overall scores on the SSQ ($\Delta 4.6$ (2.4-6.7)) did change in the successfully treated group. Scores on the subdomain social relationships ($\Delta -0.5$ (-6.7-5.7)) and scores on the CHQ-87 ($\Delta 5.0$ (-0.6-10.6)) and the STAI-6 ($\Delta 0.5$ (-0.2-1.2)) did not change. In contrast, the unsuccessfully treated group showed no improvement in the total scores of any of the questionnaires (CHQ-87 ($\Delta 5.9$ (-2.1-13.9)), SF-36 ($\Delta 1.5$ (-15.9-12.9)), subdomains physical health ($\Delta -0.5$ (-17.2-16.2)), psychological health ($\Delta 6.4$ (-14.3-27.2)), social relationships ($\Delta -2.9$ (-27.7-22.0)) and environment ($\Delta -4.0$ (-26.4-18.3)) of the WHOQOL-BREF, STAI-6 ($\Delta 0.3$ (-2.3-1.7)) and SSQ ($\Delta -4.7$ (-11.9-2.5))). This led to overall lower scores in QoL in the unsuccessfully treated group compared to the successfully treated group. Still, 65.8% (25/38) of the unsuccessfully treated group would opt for DCS-bracing again if they had to make the decision anew and 86.5% (32/37) was either satisfied or very satisfied with the treatment at their last assessment.

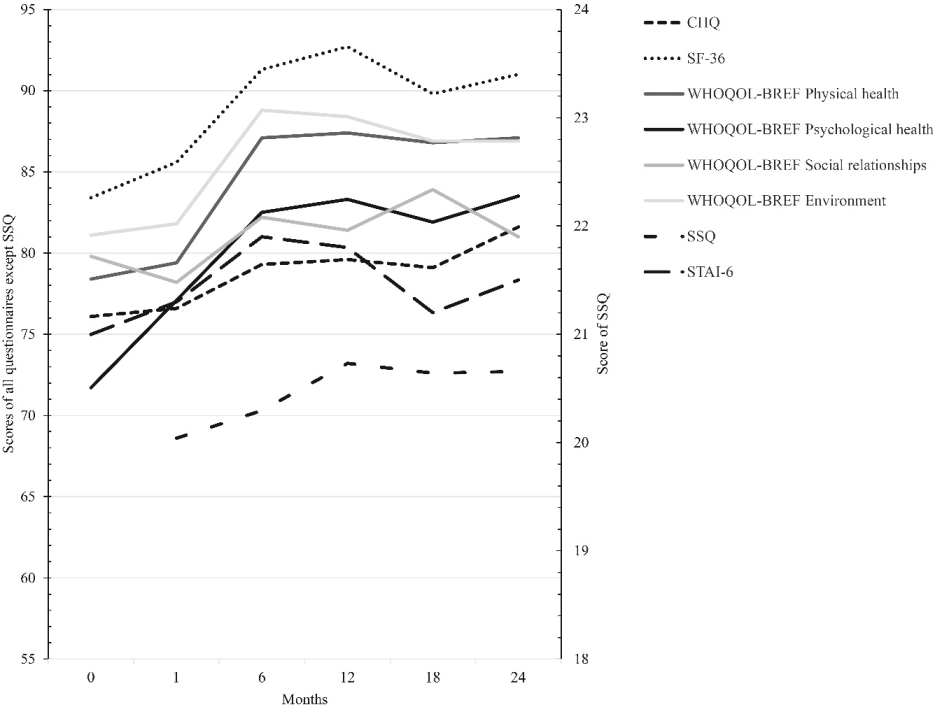


Figure 2 Change in (overall) scores of questionnaires (CHQ-87 = Child Health Questionnaire-87, SF-36 = Short Form Survey 36, SSQ = Single Step Questionnaire, STAI-6 = Six-item State-Trait Anxiety Inventory, WHOQOL-BREF = World Health Organization Quality of Life Brief Version

DISCUSSION

The overall QoL of patients treated with DCS-bracing for PC increased across the SF-36 and the WHOQOL-BREF, but not on the CHQ-87. The largest change in QoL took place in the first six to twelve months after treatment initiation, after this period QoL stabilized. There was no improvement in anxiety scores across the STAI-6. Scores on physical complains, pain, psychological health and self-esteem/self-image improved across all questionnaires. Most patients (87.2%) would choose DCS-bracing again and 94.9% were satisfied with the treatment.

In contrast to the successfully treated group, the unsuccessfully treated group showed no improvement on any of the questionnaires.

Change in QoL

The QoL measured by the CHQ-87, did not change. This may be due to the age difference between patients completing the CHQ-87 (aged 14.0 (13.0-15.0)) and those completing the SF-36 and WHOQOL-BREF (aged 17.0 (16.0-17.0)). Concerns about appearance typically begin around puberty, which tends to start later in boys. In our population, 92% of the patients are male. In a significant part of the younger group, it is likely that self-esteem concerns have not yet developed, and it is mainly the parents who are worried about the condition rather than the children themselves, often leading parents to initiate treatment decisions. In contrast, the other group consists of patients who are clearly going through puberty, resulting in increased self-awareness and self-esteem issues, prompting them to seek treatment independently. Consequently, the younger group may have a higher baseline QoL since their QoL is probably not affected, which could explain the lack of significant change in QoL observed in this group. However, assessing this difference in baseline QoL is challenging due to the use of different questionnaires across the groups.

This is one of the first studies to report on changes in QoL, making it difficult to compare our results to existing literature. The only study examining overall QoL in patients with PC reported no significant change in overall health over a follow-up period of 41 weeks.⁸ Nevertheless, literature is available on related topics such as anxiety, self-esteem, and treatment satisfaction

Anxiety, physical complaints, pain, psychological health and self-esteem/self-image

Earlier research suggested that PC affects patients the most on their psychological health, self-image and self-esteem but also causes physical complaints and pain.³⁻⁶ Every questionnaire showed improvement in the physical domain, with treatment leading to improvement of physical complaints, increased exercise capacity and energy. The same applies for pain, psychological health and self-esteem/self-image. There was no improvement on state anxiety scores.

These results are consistent with the scarcely available literature. Colozza et al. reports an improvement of both chest appearance and self-esteem (+17.8%) in a small group of patients (n=20) that were successfully treated with an external brace.⁷ Fraser et al. report changes on anxiety/depression (-4 on a 10-point Likert scale) and appearance/body confidence (+6 on a 10-point Likert scale) in a study with 159 patients.⁸ None of the studies reported on improvement of physical complaints or pain.

Treatment evaluation

In general, patients were very satisfied with the DCS-brace, 94.9% of the patients was satisfied and 87.2% of patients were confident that they would use the brace again. This is similar to another study, which reported a satisfaction rate of 94.8%.⁹ In another study the SSQ was also used, with a reported mean satisfaction of 3.7 (on a 5-point Likert-scale), comparable to our mean satisfaction of 3.8 after two years. They also reported that most patients would use the brace again.⁷ Other studies used a single 5- or 10-point Likert scale to assess patients satisfaction, reporting 4.7 out of 5 and 7-8 out of 10.^{8, 21}

Even when treatment fails, 65.8%% of patients would choose DCS-bracing as treatment again and 86.5% of these patients were satisfied with the treatment. This highlights the overall positive perception of DCS-bracing as a treatment for PC.

Treatment duration and results

In one of our earlier studies in the same patient population, we demonstrated improvement in self-assessment of the chest wall, with scores increasing from 4.0 to 7.8 on a 10-point Likert scale within the first six months.⁶ As seen in our QoL results, improvements stabilize after six months, suggesting that most progress occurs during this initial period, which patients can notably observe. This early improvement boosts their confidence, thereby enhancing QoL scores. Although the results on improvement of QoL suggest that after six months not much progress is made, the remaining months of treatment, with a median duration of sixteen months, are crucial for maintaining the chest wall's position to prevent relapse.

Limitations

A limitation of this study is the gradual decline in response rates over time, which is anticipated as some patients complete treatment early and are subsequently lost to follow-up. Despite this, such attrition may still influence the robustness of the reported outcomes. Although the use of different questionnaires was necessary for our different aims (CHQ-87 for younger patients, SF-36 and WHOQOL-BREF for older patients, STAI-6 for anxiety, and SSQ for treatment satisfaction), questionnaire fatigue may have contributed to the decline in responses.

Additionally, the lack of a control group for comparison limits our ability to assess whether the post-treatment QoL is comparable to that of healthy individuals. Incorporating a control group in future studies would provide a stronger basis for evaluating the true impact of treatment on QoL in these patients.

Another limitation relates to not using Minimal Clinically Important Differences (MCID). These values for the WHOQOL-BREF and SF-36 have been established for chronic and severe illnesses, such as cancer, but not for pectus deformities.²² Although some studies have cautiously applied these MCID values to less serious conditions, they typically involved populations of similar age to those in the original MCID studies and conditions more serious than pectus deformities.²³ In contrast, our study includes a significantly younger population with a much less severe condition, making the cautious application of these MCID values unsuitable in our opinion. Determining MCID values specifically for pectus deformities is necessary to accurately define what percentage increase in quality of life is clinically meaningful for this population.

Conclusions

DCS-bracing is a successful treatment in patients with PC, improving QoL in general and on different subdomains. DCS-bracing decreases physical complaints and pain and improves psychological health and self-esteem/self-image. The largest changes in QoL take place in the first six to twelve months after treatment initiation. Overall most patients are confident that they would choose DCS-bracing again and nearly all patients are satisfied with the treatment.

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APPENDIX A

SSQ

Circle the number that best matches how you felt about the question in the past week. For questions 8 and 9, you may write down a number, where 0 represents the worst self-image you can imagine and 10 represents the best self-image.

1	General health after brace therapy	5 much better now 4 slightly better 3 about the same 2 slightly worse now 1 much worse now
2	Exercise capacity after brace therapy	5 much better now 4 slightly better 3 about the same 2 slightly worse now 1 much worse now
3	Extent to which social activity is hindered by the appearance of the chest before starting brace therapy	5 extremely 4 quite a lot 3 moderately 2 a little 1 not at all
4	Extent to which social activity is hindered by the appearance of the chest after brace therapy	5 not at all 4 quite a lot 3 moderately 2 a little 1 extremely
5	Satisfaction with overall appearance after brace therapy	5 extremely satisfied 4 very satisfied 3 satisfied 2 dissatisfied 1 very dissatisfied
6	Problems with the skin under the pad	5 not at all 4 very little 3 little 2 a bit 1 a lot
7	Impact of the brace on social life	5 much better now 4 slightly better 3 about the same 2 slightly worse now 1 much worse now
8	Self-esteem before brace treatment	score 0-10
9	Self-esteem during or after brace treatment	score 0-10

10	Pain during the start of brace therapy	5 none 4 very little 3 little 2 a lot 1 very much
11	Pain interfering with day-to-day activity now	5 not at all 4 very little 3 little 2 a bit 1 a lot
12	Pain now	5 none 4 occasionally 3 moderate, no pain medication 2 moderate, with pain medication 1 a lot
13	Awareness of the brace while wearing it	5 not at all 4 little 3 moderate 2 a lot 1 extreme
14	Overall satisfaction with the final result	5 extremely satisfied 4 very satisfied 3 satisfied 2 dissatisfied 1 very dissatisfied
15	Chest looks different	5 much better now 4 slightly better 3 about the same 2 slightly worse now 1 much worse now
16	Going back, would have started the brace therapy again	10 yes 5 doubtful 0 no

APPENDIX B

STAI-state

Below you will find a number of statements that people have used to describe themselves. Read each statement and then circle the number on the right of the statement that best indicates how you feel right now, at this moment. There are no right or wrong answers. Don't think too long, and go with your first impression, as it is usually the best. The goal is to reflect how you feel at this moment.

		1 = NOT AT ALL	2 = A LITTLE	3 = QUITE A BIT	4 = VERY MUCH
1.	I feel calm	1	2	3	4
2.	I am tense	1	2	3	4
3.	I am confused	1	2	3	4
4.	I am relaxed	1	2	3	4
5.	I feel content	1	2	3	4
6.	I am worried	1	2	3	4

APPENDIX C

CHQ-87

Part 1: Your Health				
1.1 How would you describe your health?				
1 ☐ excellent	2 ☐ very good	3 ☐ good	4 ☐ fair	5 ☐ poor

Part 2: Your Physical Activities				
The following questions are about physical activities you can do on a normal day.				
2.1 In the past 4 weeks , has it been difficult for you to do the following activities because of your health?				
(Complete all questions)	Yes, very difficult 1	Yes, difficult 2	Yes, somewhat difficult 3	No, not difficult 4
a things that require <u>a lot</u> of effort, like playing football or running	☐	☐	☐	☐
b things that require <u>some</u> effort, like cycling or (roller) skating	☐	☐	☐	☐
c walking a long distance or climbing several flights of stairs	☐	☐	☐	☐
d walking around school or the neighborhood	☐	☐	☐	☐
e walking a short distance or climbing one flight of stairs	☐	☐	☐	☐
f doing your household chores	☐	☐	☐	☐
g bending, lifting, or stooping	☐	☐	☐	☐
h eating, dressing, washing, or going to the toilet by yourself	☐	☐	☐	☐
i getting in and out of bed or getting up from a chair	☐	☐	☐	☐

Part 3: Your Daily Activities

3.1 In the **past 4 weeks**, has it been difficult for you, due to feeling sad or worried, to:

(Complete all questions)		Yes, very difficult	Yes, difficult	Yes, somewhat difficult	No, not difficult
		1	2	3	4
a	do certain types of schoolwork or things with friends?	☐	☐	☐	☐
b	spend the normal amount of time on your schoolwork and friends?	☐	☐	☐	☐
c	finish your schoolwork or do anything with your friends?	☐	☐	☐	☐

3.2 In the **past 4 weeks**, due to problems with your behavior, has it been difficult for you to:

(Complete all questions)		Yes, very difficult	Yes, difficult	Yes, somewhat difficult	No, not difficult
		1	2	3	4
a	do certain types of schoolwork or things with friends?	☐	☐	☐	☐
b	spend the normal amount of time on your schoolwork and friends?	☐	☐	☐	☐
c	finish your schoolwork or do anything with your friends?	☐	☐	☐	☐

3.3 In the **past 4 weeks**, due to problems with your physical health, has it been difficult for you to:

(Complete all questions)		Yes, very difficult	Yes, difficult	Yes, somewhat difficult	No, not difficult
		1	2	3	4
a	do certain types of schoolwork or things with friends?	☐	☐	☐	☐
b	spend the normal amount of time on your schoolwork and friends?	☐	☐	☐	☐
c	finish your schoolwork or do anything with your friends?	☐	☐	☐	☐

Part 4: Pain

4.1 How much physical pain or discomfort have you had in the **past 4 weeks**?

- 1 ☐ none
- 2 ☐ a little bit
- 3 ☐ a bit
- 4 ☐ quite a lot
- 5 ☐ a lot
- 6 ☐ very much

4.2 How often have you experienced this physical pain or discomfort in the **past 4 weeks**?

- 1 ☐ never
- 2 ☐ once or twice
- 3 ☐ a few times
- 4 ☐ often
- 5 ☐ very often
- 6 ☐ (almost) every day

Part 5: Behavior

Below is a list of ways young people behave and the problems they sometimes have.

5.1 How often in the **past 4 weeks**:

(Complete all questions)		Very often	Often	Sometimes	Almost never	Never
		1	2	3	4	5
a	did you behave childishly?	☐	☐	☐	☐	☐
b	did you argue?	☐	☐	☐	☐	☐
c	did you find it difficult to concentrate on something?	☐	☐	☐	☐	☐
d	did you not do what your teacher or parents asked you to do?	☐	☐	☐	☐	☐
e	did you want to be alone?	☐	☐	☐	☐	☐
f	did you lie or deceive someone?	☐	☐	☐	☐	☐
g	did you struggle to be liked?	☐	☐	☐	☐	☐
h	did you feel awkward?	☐	☐	☐	☐	☐
i	did you run away from home?	☐	☐	☐	☐	☐
j	did you have speech problems, such as stuttering?	☐	☐	☐	☐	☐
k	did you steal something at home?	☐	☐	☐	☐	☐
l	did you steal something outside home?	☐	☐	☐	☐	☐
m	did you become cranky or moody when you didn't get your way?	☐	☐	☐	☐	☐
n	did you get very angry when you didn't get your way?	☐	☐	☐	☐	☐
o	did you find it difficult to do things with others?	☐	☐	☐	☐	☐
p	did you find it difficult to get along with others?	☐	☐	☐	☐	☐

5.2 How would you generally describe your behavior compared to other children your age?

1 ☐ excellent 2 ☐ very good 3 ☐ good 4 ☐ fair 5 ☐ poor

Part 6: Your Feelings**The following sentences are about moods and feelings that young people can have.****6.1 How often in the past 4 weeks:**

(Complete all questions)	Always	Usually	Sometimes	Almost never	Never
	1	2	3	4	5
a did you feel sad?	☐	☐	☐	☐	☐
b did you feel like crying?	☐	☐	☐	☐	☐
c did you feel anxious or scared?	☐	☐	☐	☐	☐
d did you worry about something?	☐	☐	☐	☐	☐
e did you feel lonely?	☐	☐	☐	☐	☐
f did you feel unhappy?	☐	☐	☐	☐	☐
g did you feel nervous?	☐	☐	☐	☐	☐
h did you feel upset?	☐	☐	☐	☐	☐
i did you feel happy?	☐	☐	☐	☐	☐
j did you feel cheerful?	☐	☐	☐	☐	☐
k did you enjoy the things you did?	☐	☐	☐	☐	☐
l did you have fun?	☐	☐	☐	☐	☐
m did you feel restless?	☐	☐	☐	☐	☐
n did you have trouble sleeping?	☐	☐	☐	☐	☐
o did you have a headache?	☐	☐	☐	☐	☐
p were you satisfied with yourself?	☐	☐	☐	☐	☐

Part 7: Self-Confidence

What do you think of yourself, your school, and others? It may help to think about what other children your age would think of these things.

7.1 How satisfied or dissatisfied have you been in the **past 4 weeks** with:

(Complete all questions)		Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied
		1	2	3	4	5
a	yourself	☐	☐	☐	☐	☐
b	your schoolwork	☐	☐	☐	☐	☐
c	how good you are at sports	☐	☐	☐	☐	☐
d	your friendships	☐	☐	☐	☐	☐
e	the things you are capable of	☐	☐	☐	☐	☐
f	how well you get along with others	☐	☐	☐	☐	☐
g	your body and appearance	☐	☐	☐	☐	☐
h	how you usually feel	☐	☐	☐	☐	☐
i	how well you get along with your family members	☐	☐	☐	☐	☐
j	how life is for you	☐	☐	☐	☐	☐
k	how good you are at being a friend to others	☐	☐	☐	☐	☐
l	what others think of you	☐	☐	☐	☐	☐
m	how you can talk with others	☐	☐	☐	☐	☐
n	your overall health	☐	☐	☐	☐	☐

Part 8: Your Health**Below are statements about health in general.****8.1** How true or not true is the statement for you?

(Complete all questions)		True	Usually true	Don't know	Usually not true	Not true
		1	2	3	4	5
a	my health is excellent	☐	☐	☐	☐	☐
b	I have been so sick once that I thought I would die	☐	☐	☐	☐	☐
c	I am never very sick	☐	☐	☐	☐	☐
d	I am less healthy than other young people	☐	☐	☐	☐	☐
e	I have never been very sick	☐	☐	☐	☐	☐
f	I seem to always get sick	☐	☐	☐	☐	☐
g	I think I will be less healthy later on	☐	☐	☐	☐	☐
h	I think I will be very healthy later on	☐	☐	☐	☐	☐
i	I never worry about my health	☐	☐	☐	☐	☐
j	I think I am healthy now	☐	☐	☐	☐	☐
k	I worry more about my health than my peers	☐	☐	☐	☐	☐

8.2 How would you describe your health now compared to one year ago?

1	☐ now much better than one year ago
2	☐ now slightly better than one year ago
3	☐ now about the same as one year ago
4	☐ now slightly worse than one year ago
5	☐ now much worse than one year ago

Part 9: You and Your Family

9.1 How often, in the **past 4 weeks**, has your health or behavior:

(Complete all questions)		Very often	Often	Sometimes	Almost never	Never
		1	2	3	4	5
a	limited the types of activities your family could do?	☐	☐	☐	☐	☐
b	disrupted everyday family activities (like eating or watching TV)?	☐	☐	☐	☐	☐
c	contributed to your family not being able to go out unexpectedly?	☐	☐	☐	☐	☐
d	led to tensions or conflicts at home?	☐	☐	☐	☐	☐
e	been a source of disagreement or bickering in your family?	☐	☐	☐	☐	☐
f	caused your family to cancel or change plans at the last moment?	☐	☐	☐	☐	☐

9.2 Sometimes family members don't get along very well. They don't always agree and can get angry. How well do you think your family gets along at home?

1 ☐ excellent	2 ☐ very good	3 ☐ good	4 ☐ fair	5 ☐ poor
--------------------------------------	--------------------------------------	---------------------------------	---------------------------------	---------------------------------

APPENDIX D

WHOQOL-Bref

We ask you to indicate in this questionnaire what you think of your quality of life, health, and other life areas. **Please answer all the questions.** If you are unsure about how to answer a question, **choose the response that seems most applicable**, often your first reaction. Keep your standards, hopes, pleasures, and concerns in mind. Think about your life in the **last two weeks**. For example, a question might be:

	Not at all	A little	Moderately	A lot	An extreme amount
Do you receive the kind of support you need from others?	1	2	3	4	5

You should circle the number that best matches the amount of support you have received from others in the past two weeks. For example, you would circle the number 4 if you received a lot of support from others, as shown below:

	Not at all	A little	Moderately	A lot	An extreme amount
Do you receive the kind of support you need from others?	1	2	3	4	5

Now the actual questionnaire begins:

	Very poor	Poor	Neither poor nor good	Good	Very good
1(G1) How would you rate your quality of life?	1	2	3	4	5

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2(G4) How satisfied are you with your health?	1	2	3	4	5

The following questions ask **to what extent (how much)** you have experienced certain things in the past two weeks.

		Not at all	A little	Moderately	A lot	An extreme amount
3(F1.2)	Do you worry about your pain or discomfort?	1	2	3	4	5
4(F1.3)	How difficult is it for you to deal with pain or discomfort?	1	2	3	4	5
5(F1.4)	To what extent do you feel that pain prevents you from doing what you need to do?	1	2	3	4	5
6(F11.3)	How much do you need medical treatment to function in your daily life?	1	2	3	4	5
7(F4.1)	How much do you enjoy life?	1	2	3	4	5
8(F24.2)	To what extent do you feel your life is meaningful?	1	2	3	4	5

The following questions ask **to what extent** you have experienced certain things or were able to do certain things in the past two weeks.

		Not at all	A little	Moderately	A lot	An extreme amount
9(F5.3)	How well are you able to concentrate?	1	2	3	4	5
10(F7.2)	Do you feel hindered by your appearance?	1	2	3	4	5
11(F7.3)	Is there anything about your appearance that makes you feel uncomfortable?	1	2	3	4	5
12(F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
13(F22.1)	How healthy is your environment?	1	2	3	4	5
14(F2.1)	Do you have enough energy for daily life?	1	2	3	4	5
15(F7.1)	Can you accept your physical appearance?	1	2	3	4	5

16(F18.1)	Do you have enough money to meet your needs?	1	2	3	4	5
17(F20.1)	How available to you is the information you need in your daily life?	1	2	3	4	5
18(F21.1)	Do you have opportunities for leisure activities?	1	2	3	4	5

The following questions ask how **satisfied or dissatisfied** you have been with various aspects of your life in the past two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
19(F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
20(F7.4)	How satisfied are you with your appearance?	1	2	3	4	5
21(F10.3)	Are you satisfied with your ability to perform daily activities?	1	2	3	4	5
22(F12.4)	Are you satisfied with your work capacity?	1	2	3	4	5
23(F6.3)	Are you satisfied with yourself?	1	2	3	4	5
24(F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
25(F15.3)	To what extent are you satisfied with your sex life?	1	2	3	4	5
26(F14.4)	How satisfied are you with the support you get from friends?	1	2	3	4	5
27(F17.3)	Are you satisfied with your living conditions?	1	2	3	4	5
28(F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
29(F23.3)	How satisfied are you with your transport?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
30(F9.1)	How well are you able to move around?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things, such as support from your family or friends, or negative experiences, like feeling unsafe.

		Never	Rarely	Sometimes	Fairly often	Always
31(F1.1)	How often have you experienced pain?	1	2	3	4	5
32 (F8.1)	How often have you experienced negative feelings such as depression or anxiety?	1	2	3	4	5

APPENDIX E

SF-36

This questionnaire is about your views on your health. These data can help track how you feel and how well you can perform your usual activities. Answer each question by marking the response as indicated. If you are unsure about how to answer a question, give the best possible answer.

1. How would you rate your general health? (circle one number)			
Excellent		1	
Very good		2	
Good		3	
Fair		4	
Poor		5	

2. How would you rate your health now compared to a year ago? (circle one number)			
Much better now than a year ago		1	
Somewhat better now than a year ago		2	
About the same as a year ago		3	
Somewhat worse now than a year ago		4	
Much worse now than a year ago		5	

3. The following questions are about activities you might do on a typical day. Are you limited in these activities because of your health? If so, how much?			
Activities	Yes, severely limited	Yes, slightly limited	No, not limited at all
a Vigorous activities such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b Moderate activities such as moving a table, vacuuming, swimming, or cycling	1	2	3
c Lifting or carrying groceries	1	2	3
d Climbing several flights of stairs	1	2	3
e Climbing one flight of stairs	1	2	3
f Bending, kneeling, or squatting	1	2	3
g Walking more than a kilometer	1	2	3
h Walking several hundred meters	1	2	3
i Walking about one hundred meters	1	2	3
j Bathing or dressing yourself	1	2	3

4. In the past 4 weeks, have you had any of the following problems at work or with other daily activities due to your physical health? (circle one number)

	Yes	No
a Spent less time on work or other activities	1	2
b Accomplished less than you would like	1	2
c Limited in the kind of work or other activities	1	2
d Had difficulty performing work or other activities (for example, it took extra effort)	1	2

5. In the past 4 weeks, have you had any of the following problems with your work or other daily activities due to emotional problems (such as feeling depressed or anxious)? (circle one number)

	Yes	No
a Spent less time on work or other activities	1	2
b Accomplished less than you would like	1	2
c Didn't do work or other activities as carefully as usual	1	2

6. To what extent have your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups during the past 4 weeks? (circle one number)

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

7. How much bodily pain have you had during the past 4 weeks? (circle one number)

None	1
Very mild	2
Mild	3
Moderate	4
Severe	5
Very severe	6

8. During the past 4 weeks, how much did pain interfere with your normal work (including work outside the home and housework)? (circle one number)

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

9. These questions are about how you feel and how things have been with you during the past 4 weeks. Please give the answer that comes closest to how you have felt. (circle one number)

	Always	Usually	Often	Sometimes	Rarely	Never
a Did you feel full of life?	1	2	3	4	5	6
b Were you very nervous?	1	2	3	4	5	6
c Did you feel so down that nothing could cheer you up?	1	2	3	4	5	6
d Did you feel calm and content?	1	2	3	4	5	6
e Did you have a lot of energy?	1	2	3	4	5	6
f Did you feel gloomy and downhearted?	1	2	3	4	5	6
g Did you feel exhausted?	1	2	3	4	5	6
h Were you a happy person?	1	2	3	4	5	6
i Did you feel tired?	1	2	3	4	5	6

10. How often during the past 4 weeks did your physical health or emotional problems interfere with your social activities (like visiting friends or relatives)? (circle one number)

Always	1
Usually	2
Sometimes	3
Rarely	4
Never	5

11. How TRUE or FALSE is each of the following statements for you? (circle one number)

		Absolutely true	Mostly true	Don't know	Mostly false	Absolutely false
a	I seem to get sick a little easier than other people	1	2	3	4	5
b	I am as healthy as anybody I know	1	2	3	4	5
c	I expect my health to get worse	1	2	3	4	5
d	My health is excellent	1	2	3	4	5
