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Pectus Carinatum Evaluation Questionnaire (PCEQ): a novel tool to improve the follow-up in patients treated with brace compression

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Abstract

OBJECTIVES: A questionnaire (Pectus Carinatum Evaluation Questionnaire, PCEQ) was developed to be applied in follow-up of patients with Pectus Carinatum (PC). After validation of the PCEQ, we aimed to quantify the compliance to brace compression and to assess factors that could influence this treatment in patients with PC.

METHODS: From July 2008 to July 2014, 56 patients with PC were treated with the Calgary Protocol of compressive bracing at Paediatric Surgery Department of Hospital São João. Forty patients (71%) completed the questionnaire. The PCEQ was divided into four sections: (i) compliance; (ii) symptoms; (iii) social influence; (iv) activities. For the validation process of the PCEQ, principal components analysis (PCA), orthogonal varimax or oblimin rotation and Cronbach's α coefficient were used. To evaluate the association between compliance and other sections of the questionnaire, we estimated the Pearson's correlation between compliance factor scores ('Compliance Days' and 'Compliance Hours') and the final score of each new questionnaire component identified by PCA ('Chest Pain', 'Dyspnoea', 'Back Pain', 'Parents' Influence', 'Friends' Influence', 'Activities', 'Time To Compliance'). For the sections 'Symptoms', 'Social Influence' and 'Activities', we estimated final scores as the sum of the questions that constitute each component. For the section 'Compliance', the factor scores were estimated by the regression method.

RESULTS: After PCA analysis, the PCEQ found nine different components with high reliability. When analysing the compliance of our study group, the final score for 'Activities' revealed a significant correlation with the factor score for 'Compliance Hours' ($r = 0.382$, $P = 0.015$). The final score for 'Time To Compliance' showed a significant correlation with both factor scores for 'Compliance Hours' ($r = -0.765$, $P < 0.001$) and 'Compliance Days' ($r = -0.345$, $P < 0.029$).

CONCLUSIONS: The PCEQ seems to be an important tool to follow up patients with PC treated by brace compression. Practical steps, such as developing a tight schedule in the early follow-up period or applying the PCEQ in first visits after initiating brace therapy, can be taken in order to increase compliance with brace therapy and improve the quality of life.

Keywords: Chest wall deformity • Sternal protrusion • Bracing • Chondrogladiolar type • Pectus

THORACIC

INTRODUCTION

Pectus carinatum (PC) is the second most common chest wall deformity [1]. Although a definitive aetiology has not been established, overgrowth of the costal cartilages with protrusion of the sternum is thought to be involved in the pathogenesis. A positive family history of chest wall deformity also suggests a genetic linkage; however, no specific mutation was identified [2]. Sternal protrusion may have origin in the gladiolus and inferior costal cartilages resulting in the chondrogladiolar (CG) type of PC, or in the sternal manubrium and superior costal cartilages resulting in the chondromanubrial (CM) type of PC. CG type is the most common and is classified as symmetric or asymmetric [3].

Classically, PC was treated by a modified Ravitch procedure. Recently, a minimally invasive surgery for PC was described by Abramson [4]. Nevertheless, a non-operative approach for the PC treatment using orthotic brace compression was described by Haje and Bowen [5]. This conservative approach gained popularity in the last two decades and is now the first-line therapy for CG type [5, 6]. Considering that the major complaint of these patients is body image, brace compression has the advantages of being non-invasive and more cost-effective, and avoids an operative scar [6–10]. Nevertheless, brace compression can be complicated by local pain and skin erosion, and may be an obstacle for physical activity and social life [3, 8, 11]. Since the results of brace therapy are related to the duration of compression, compliance is critical for

success [3, 7, 10]. It seems that patients use brace compression for less time than prescribed, which extends the correction phase [8].

External compression is an approach commonly used in other deforming conditions such as scoliosis. Since compliance was assumed as the main determinant of the success of the orthotic scoliosis brace, a questionnaire was developed and validated for this disease [12]. This questionnaire was proved to be a good method to identify problems perceived by patients during utilization of orthotic compression; the results of this study confirmed that the management of patients is crucial to identifying adaptation problems experienced by the patients. Changing this paradigm could be a main factor to increase compliance [12].

In the present study, we propose a questionnaire (Pectus Carinatum Evaluation Questionnaire, PCEQ, Supplementary material) to be applied during the follow-up of patients with PC. Using the PCEQ, we aimed to quantify the compliance to brace compression and to assess factors that could influence this treatment in patients with PC.

MATERIALS AND METHODS

Participants

For conservative treatment of PC, our institution adopted the Calgary Protocol. Briefly, this protocol recommends the use of external bracing for 23 h until the defect is flattened [13]. The manual compressive test evaluates the flexibility of costal cartilage by compressing the protrusion area with one hand and fixing the back of the patient with the other hand. All of the patients who started brace compression were considered to have a flexible deformity. Brace compression was used for a minimum of 3 months and a maximum of 2 years.

From July 2008 to July 2014, 56 patients with PC were treated with Calgary Protocol of compressive brace at Pediatric Surgery Department of Hospital São João. All patients were asked by phone to participate in the study to evaluate compliance by answering a multiple-choice questionnaire (Pectus Carinatum Evaluation Test, PCEQ, Supplementary material). Sixteen patients were excluded: 12 for not having answered the phone call after five attempts on different days during a period of 2 months, 2 for having refused to participate and another 2 for having CM type of PC (treated surgically).

The local ethics committee (São João Hospital/Faculty of Medicine, University of Porto) approved the study protocol. The data collected from the questionnaire were coded so that the anonymity of the patient was guaranteed. After obtaining appropriate informed consent, all the participants had the opportunity to choose the way they preferred to complete the questionnaire: 22 preferred a follow-up visit, 16 by telephone and 2 by letter. Participant characteristics are described in Table 1. Scoliosis was present in 8 patients (20%) and only 2 (5%) had symmetric PC.

Table 1: Participants' characteristics

	n (%)
Sex	
Female	7 (18%)
Male	33 (82%)
Scoliosis	
No	32 (80%)
Yes	8 (20%)
Pectus carinatum symmetry	
Symmetric	2 (5%)
Asymmetric	38 (95%)

Design of Pectus Carinatum Evaluation Questionnaire

Two experts on pectus carinatum independently collected questions from previous validated questionnaires used in other deformative diseases (pectus excavatum and scoliosis) and designed new questions to quantify the compliance with brace compression and to evaluate factors that could influence this treatment in patients with PC. To estimate the content validity of the PCEQ, we collected the main factors that could affect this treatment. Content validity was undertaken to ascertain whether the content of the questionnaire was appropriate and relevant to follow-up evaluation of patients with PC.

With this purpose, in a later consensus meeting, the experts decided to use 23 from 27 items and divide the questionnaire into four different sections. The goal was to measure: (i) 'compliance' (a sub-scale with two questions about the number of hours of compliance and another one with two questions about the number of the days of compliance); (ii) 'symptoms' (a sub-scale with two questions about chest pain, a sub-scale with two questions about back pain, another one with two questions about dyspnoea and just one question about the time needed to achieve the compliance); (iii) 'social influence' (a sub-scale with three questions about parents' influence and another one with three questions about friends' influence); and (iv) 'activities' (a sub-scale with six questions about the influence of brace compression on daily activities). The questions were Likert scale-type, visual analogue scale-type and quantitative in nature.

Principal components analysis (PCA) was used to convert a set of questions with possible correlated variables into a set of values of linearly uncorrelated variables (principal components). PCA is defined in such a way that the first principal component has the largest possible variance (i.e. accounts for as much as possible of the variability in the data), and each succeeding component has the higher variance in relation to the next one.

The scree plot criteria were used to identify the number of components suggested by the data, i.e. the number of sub-scales the data suggested for each section. The scree plot presents the percentage of variance explained by each component. The scree plot criteria (the elbow rule) delete all components from which the variance, explained by each component, stabilizes [14]. Orthogonal varimax or oblimin rotation was used to identify which questions belong to each component. We chose between a varimax or oblimin rotation considering if a simpler factor loading structured was showed assuming independent principal components or correlated principal components, respectively. It was considered that the association between questions and components was strong when the correlation (loading factor) was higher than 0.40 [15].

To assess the reliability (internal consistency) of the scale, i.e. the extent to which questions correlated with each other, the Cronbach's α coefficient was used. A high internal consistency was considered when Cronbach's α coefficient was higher than 0.70 [16].

The questionnaire was applied and validated in a Portuguese version and translated into English (Supplementary material).

Data analysis

To evaluate the association between compliance and other sections of the questionnaire, we estimated the Pearson correlation between compliance factor scores ('Compliance Days' and 'Compliance Hours') and the final score of each new questionnaire component identified by PCA ('Chest Pain', 'Dyspnoea', 'Back Pain', 'Parents' Influence', 'Friends' Influence', 'Activities', 'Time To Compliance'). In what concerns the sections 'Symptoms', 'Social Influence' and Activities, we estimated final scores as the sum of the questions that constitute each component. For the section Compliance, the factor scores were estimated by the regression method, a process for estimating factor score coefficients.

Qualitative variables were summarized in terms of frequency and percentage, while quantitative variables were summarized as the mean and standard deviation. Independent samples *t*-test was used to compare two independent samples, the age between participants and non-participants. The Fisher's exact test was used to compare the gender between participants and non-participants, considering that more than 20% of the expected values were lower than 5. All statistical analyses were performed with IBM Corp. Released 2013. IBM SPSS Statistics for windows, version 22.0 Armonk, NY: IBM Corp. For all statistics analyses, $P < 0.05$ was considered significant.

RESULTS

Validation of the Pectus Carinatum Evaluation Questionnaire

Internal consistency and the PCA of the different sections are described in Table 2.

PCA in section 'Compliance' found that two components explained 91.0% of total variance showing that this section was composed of two sub-scales. The first component showed high factor loadings with Questions 1 and 2, representing the sub-scale 'The number of days of brace use (Compliance Days)', while second component showed high factor loadings with Questions 3 and 4, representing the sub-scale 'The number of hours of the brace use (Compliance Hours)'. The component Compliance Days presented high internal consistency, while the component Compliance Hours presented a lower Cronbach's α.

Table 2: Factor loadings for the principal components analyses in sections Compliance, Symptoms, Social Influence and Activities and the respective scree plot values (variance explained and the cumulative variance by each component)

Components	Questions	Loading factor				% of explained variance	Cumulative % of explained variance	Cronbach's α
(A) Section I: Compliance[a,b]								
		1	2					
Compliance days	1	0.980	−0.019			61.674	61.674	0.899
	2	0.961	0.024					
Compliance hours	3	−0.061	0.960			29.291	90.965	0.468
	4	0.075	0.902					
(B) Section II: Symptoms[c]								
		1	2	3	4			
Chest pain	5	0.933	0.111	−0.001	−0.176	34.089	34.089	0.864
	6	0.927	0.146	0.0 65	0.110			
Dyspnoea	7	0.262	0.900	−0.303	0.087	24.660	58.749	0.846
	8	0.021	0.930	0.118	0.133			
Back pain	9	−0.058	0.061	0.923	0.100	20.621	79.370	0.835
	10	0.119	0.023	0.928	−0.001			
Time to compliance	11	−0.046	0.173	0.079	0.975	11.061	90.431	–
(C) Section III: Social influence[c]								
		1	2					
Parents' influence	12	0.888	0.043			37.545	37.545	0.697
	13	0.751	0.135					
	14	0.735	−0.078					
Friends' influence	15	0.066	0.785			26.068	63.613	0.620
	16	0.442	0.620					
	17	−0.169	0.817					
(D) Section IV: Activities[c]								
		1						
Activities	18	0.560				50.516	50.516	0.709
	19	0.767						
	20	0.805						
	21	0.675						
	22	0.538						
	23	0.858						

[a]Rotation method: Oblimin with Kaiser normalization.
[b]Component correlation matrix = 0.348.
[c]Rotation method: Varimax.

Table 3: Final scores and characteristics of the 'Compliance' characteristics

	Scale	Mean	SD	95% Confidence interval	
				Lower	Upper
Final scores					
Chest pain	(0–20)	7.95	4.60	6.48	9.42
Dyspnoea	(0–8)	2.08	2.23	1.36	2.79
Back pain	(0–20)	4.43	5.43	2.69	6.16
Parents influence	(0–12)	9.43	2.65	8.58	10.27
Friends influence	(0–12)	2.53	2.79	1.63	3.42
Activities	(0–20)	3.39	2.41	2.72	4.26
Time needed to compliance	(0–4)	2.30	1.90	1.69	2.91
Compliance questions					
How much do you fulfil the number of days of brace use prescribed?	(0–4)[a]	2.95	1.11	2.60	3.30
On average, how many days a week do you use the brace?	(0–7 days)	5.73	1.68	5.19	6.26
How much do you fulfil the number of hours of brace use prescribed?	(0–4)[a]	1.90	1.55	1.40	2.40
On average, how many hours a day do you use the brace?	(0–24 h)	12.05	7.20	9.75	14.35

[a]Scale (0, never; 1, few times; 2, sometimes; 3, many times; 4, always).

PCA in section Symptoms found that four components explained 90.4% of the total variance, pointing out that this section had four sub-scales. (i) The first component indicated high factor loadings with Questions 5 and 6, representing the sub-scale Chest Pain. (ii) The second component registered high factor loadings with Questions 7 and 8, representing the sub-scale Dyspnoea. (iii) The third component showed high factor loadings with Questions 9 and 10, expressing the sub-scale Back Pain. (iv) The last component is composed of Time To Compliance Question 11. All components (Chest Pain, Dyspnoea and Back Pain) presented a high internal consistency.

PCA in section Social Influence found that two components explained 63.6% of the total variance, indicating that this section consisted of two sub-scales. The first component showed high factor loadings with Questions 12, 13 and 14, representing the sub-scale 'Parents Influence' and second component showed high factor loadings with Questions 15, 16 and 17, constituting the sub-scale Friends' Influence. The component Parents' Influence presented high internal consistency, while the component Friends' Influence presented a lower Cronbach's α.

PCA in section Activities found a solution with just one component which explained 50.5% of the total variance. This sub-scale was composed of Questions 18–23 and presented high internal consistency.

Thus, the results of our PCA corresponded to the contents of the sections and sub-sections on the PCEQ.

Analysis of compliance

Forty patients (71%) were included in the present study. The studied population included 7 females (18%) and 33 males (82%) with a mean age of 15.1 (SD = 3.3) years at the time of questionnaire application (range, 4–21 years). In the non-participants' group, there were 2 females (13%) and 14 males (88%) with a mean age of 14.4 (SD = 4.9) years. There were no significant differences in the distribution of the two groups related to age ($P = 0.537$) or sex ($P = 1.000$) variables.

The characteristics of final scores and compliance section are described in Table 3. Parents' Influence and Time To Compliance final scores were those with higher values, with a mean of 9.43 (scale of 0–12) and 2.30 (scale of 0–4). On the other hand, Friends' Influence final score revealed to be a less important factor with a mean of 2.53 (in a scale of 0–12). Final scores Chest Pain, Dyspnoea, Back Pain and Activities presented mean values below the middle of the used scale. For example, the mean for Chest Pain is 7.95 and the middle scale is 10 (Table 3). On average, our group of PC patients admit to having fulfilled only 'sometimes' the number of hours of the brace use prescribed, corresponding to a mean of 1.90 (1 corresponds to 'few times' and 2 to 'sometimes'). Regarding the number of the days prescribed per week, patients admit to having used the brace 'many times', corresponding to a mean of 2.95 (2 corresponds to 'sometimes' and 3 to 'many times'). Quantitative questions regarding 'Compliance' showed a mean use of brace compression of 5.73 days per week and 12.05 h per day.

Table 4: Influence of PCEQ components in 'Compliance'

Score	Pearson's correlation[a] Factor score			
	Days	*P*	Hours	*P*
Chest pain	−0.050	0.758	0.129	0.429
Dyspnoea	−0.091	0.575	−0.199	0.219
Back pain	−0.141	0.384	−0.052	0.352
Parents' influence	−0.002	0.990	0.073	0.656
Friends' influence	−0.078	0.633	−0.119	0.463
Activities	−0.083	0.611	**0.382**	**0.015**
Time needed to compliance	**−0.345**	**0.029**	**−0.765**	**<0.001**

PCEQ: Pectus Carinatum Evaluation Questionnaire.
[a]Correlation between each domain and the days/hours of compliance with treatment.
Significant variables ($P < 0.05$) are in bold.

Subsequent to the creation of factor scores (Compliance Days, Compliance Hours) and final scores (Chest Pain, Dyspnoea, Back Pain, 'Parents Influence', 'Friends Influence', Activities and Time To Compliance), a correlation between factor scores and final scores

was achieved in order to identify factors with more influence on brace compression treatment (Table 4). The final score Activities revealed a significant correlation with the factor score Compliance Hours ($r = 0.382$, $P = 0.015$). The final score Time To Compliance pointed out a significant correlation with both factor scores: Compliance Hours ($r = -0.765$, $P < 0.001$) and Compliance Days ($r = -0.345$, $P = 0.029$).

Statistical analysis revealed no other significant correlations.

DISCUSSION

Brace compression therapy in PC provides an effective non-operative alternative with excellent patient satisfaction. Nevertheless, compliance is one of the major obstacles to the success of this treatment [9]. As previously reported, compliance to brace therapy may be compromised by local pain and skin erosion and impairment of physical activity and social life [3, 8, 11]. Adherence to a brace should be seen as an interaction between the treatment and the patient [12]. As far as we are concerned, ongoing monitoring by the treating team is crucial in follow-up. This should not only give support to the patient and the family, but also identify the main problems related to the treatment, in order to effectively increase compliance. A tool designed for periodic evaluation of PC patients may improve the compliance and the success of the treatment, allowing a closer follow-up whenever a problem is identified.

To the best of our knowledge, this is the first report presenting a validated questionnaire (PCEQ) for patients with PC. The PCEQ was divided into four different sections, allowing a thorough evaluation of compliance, symptoms, social influence and engagement with sports and daily activities. Compliance and Symptoms were the sections with higher loading factors, whereas Social Influence and Activities sections presented lower loading factors. The analysis of loading factors revealed that questions of each component are appropriated to evaluate the problem which is being tested. High reliability was found in the majority of components except for Compliance Hours and Friends' Influence, which might be explained by the low number of questions composing these two components.

As effectiveness of brace compression is correlated to the application length, compliance is critical for the success of this non-surgical option [3, 7, 10]. In our study, compliance was measured by the number of hours per day and number of days per week of brace use. In our group of patients, daily compliance was good once patients used the brace therapy on an average of 6 days per week. However, the number of hours per day of brace compression was, on average, 12 h per day, similar to the results of other studies [17]. Thus, compliance seems to be a problem of duration rather than frequency, which may jeopardize the outcome of brace compression because some previous studies showed that the best results are achieved whenever patients wear the brace for 23 h per day [3]. However, in a study by Martinez-Ferro et al., the authors obtained good to excellent results in 88.4% of patients with a mean length of 7.2 h per day [11].

In our study, we found a significant correlation between Time To Compliance and Compliance Days and Compliance Hours, i.e. patients who needed fewer days to achieve the number of hours prescribed for bracing were those with more compliance during the overall treatment period. Kang *et al.* demonstrated that the initial result of compression was the main predictor of compliance [18] and this may explain why more rapid adaptation to the brace is so strongly correlated with compliance. Therefore, the schedule of follow-up visits in the early period of treatment seems to be essential for adherence to bracing.

A strong correlation between engagement with sports and daily activities and the number of hours of brace use was found. PC patients with a high number of hours of use show significantly more limitations in sports and daily activities. This result may be related to the discomfort induced by brace compression that might be strong enough to interfere in patients' daily activities. Therefore, if the design and manufacture of orthoses cannot be improved, the team must work together with the patient to review the schedule of bracing in order to improve patients' quality of life.

In our group of PC patients, compliance was neither correlated with chest or back pain, dyspnoea nor with parents' and friends' influence. These might be related to the small sample size. However, in a recent study by Kang *et al.*, which evaluated factors affecting compliance, they found that pain, skin problems, confidence, shame and discomfort did not influence compliance [18].

As a conclusion, practical steps can be taken to increase compliance to brace therapy and improve quality of life, such as: (i) a tight schedule in the early follow-up period using a diary for the registry of brace use; (ii) application of the PCEQ in first visits after initiating brace therapy; (iii) a daily plan for brace utilization by the patient, taking into account daily and sports activities; (iv) a gradual compression for the first weeks of brace treatment; (v) regular discussion with the patient and parents about the impact of brace therapy on daily life. A multidisciplinary team is, therefore, crucial for successful conservative management of PC with brace compression.

SUPPLEMENTARY MATERIAL

Supplementary material is available at *EJCTS* online.

Conflict of interest: none declared.

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