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**Psychometric Validation of the Traditional Chinese Version of the Early Onset Scoliosis-24 Item Questionnaire (EOSQ-24)**

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27

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30 (reference number: UW 15-596).

31

32 **Introduction**

33 Early Onset Scoliosis (EOS) can be defined as an abnormal lateral curvature of the spine  
34 that presents before 10 years of age.<sup>1</sup> Possible causes include congenital vertebral anomalies,  
35 neuromuscular, syndromic or idiopathic. Due to the large growth potential, the earlier the  
36 onset of scoliosis, the worse the final curvature will be.<sup>2</sup> Hence, if left untreated, the natural  
37 course of EOS include severe spinal deformity, compromised respiratory function and  
38 pulmonary failure<sup>3,4</sup>, cardiac disease, and increased mortality.<sup>2,5</sup> EOS should thus be managed  
39 early once diagnosis has been made. Unsatisfactory treatment can undoubtedly impose  
40 significant mental, physical and financial burdens on patients as well as their parents or  
41 caretakers.<sup>6</sup>

42 In order to properly assess the impact of the disease process and treatment provided, it is  
43 desirable to not only monitor by clinical and radiographic parameters, but to consider the  
44 importance of quality of life as a measure of treatment outcome. A disease specific instrument  
45 for assessment of the EOS patients will be useful to assess patients' functional and emotional  
46 status, and equally important the effect on parents and caretakers. The Early-Onset Scoliosis  
47 Questionnaire (EOSQ) was developed <sup>7</sup> to reflect the important issues of EOS patients and  
48 their caregivers, and it was found to be capable of measuring the quality of life of EOS  
49 children<sup>6</sup> with construct validity showing unique domains measuring intended issues of  
50 interest. The more commonly used version, Early-onset Scoliosis 24-Item Questionnaire

51 (EOSQ-24), was shown to be able to demonstrate differences in quality of life of EOS  
52 patients pre- and post-operatively, and it appears to be an appropriate outcome measure for  
53 comparing treatment options.<sup>8</sup>

54 Different ethnicities have variable presentations with regards to spine pathologies<sup>9</sup> and  
55 may also have an effect on symptom severity, treatment indications and outcomes.  
56 Management decisions should thus be tailored towards the respective population group.  
57 Given the size of China's population, there are hundreds and thousands of EOS patients who  
58 do not yet have any objective assessment scale to measure treatment outcomes. It is necessary  
59 to have a standardized method of assessment of patient or care-taker-perceived outcomes to  
60 compare treatment modalities and determine the best management option for patients with  
61 regards to health-related quality of life. This helps clinicians decide on interventions that are  
62 evidence-based rather than based upon clinician belief. This provides EOS patients with the  
63 best quality of care. Hence, the aim of this study is to translate the EOSQ-24 questionnaire  
64 from its original English version to traditional Chinese, as well as to maintain the  
65 characteristics of the original property of EOSQ to facilitate quality of life assessments of  
66 Chinese EOS patients.

67

## 68 **Materials and Methods**

### 69 *Subjects and Setting*

70 A convenience sampling of Southern Chinese patients diagnosed with EOS were  
71 recruited at the Duchess of Kent Children's Hospital in Hong Kong during the months of  
72 November 2015 to January 2016. Those who were excluded from recruitment included  
73 patients diagnosed with scoliosis at the age of 10 or over, non-Chinese, and those parents or  
74 caregivers who were illiterate and could not understand traditional Chinese. Ethics approval  
75 was obtained from the institutional review board of the University of Hong Kong/Hospital  
76 Authority Hong Kong West Cluster (reference number: UW 15-596).

77 Subjects' parents/caretakers were approached by research personnel, and those who  
78 consented answered a structured questionnaire which consisted of the translated, traditional  
79 Chinese (Hong Kong) version of EOSQ-24 questionnaire (**Appendix A**), followed by a  
80 Likert scale for assessing the ability of understanding the just completed EOSQ-24  
81 (traditional Chinese Hong Kong) by the parents/caregivers. The traditional Chinese version of  
82 the Child Health Questionnaire – Parent Form 50 (CHQ-PF50) was then administered for  
83 validation.

84 Demographic and clinical data at the time of visit were collected. The type of EOS  
85 diagnosed was indicated as congenital, neuromuscular, neurofibromatosis, syndromic, spinal  
86 cord anomaly and idiopathic. The age at diagnosis of EOS, the age at recruitment and gender  
87 of patients were recorded. Without prior knowledge of the conduction of questionnaires, a  
88 spine surgeon performed the consultation and radiographic measurement as usual. Cobb

89 angle measurements were performed on whole spine posteroanterior radiographs taken in  
90 either standing or erect in sitting posture. The curve magnitude (classified as either  $\leq 30^\circ$  or  
91  $>30^\circ$ ) and location of the curvatures were recorded. This curve magnitude was chosen  
92 because it was likely the threshold where clinicians intervened with brace treatment. Other  
93 clinical parameters also included the type of treatment modalities: under observation only,  
94 having bracing, completed bracing, post-operative, with planned surgery, and undergoing  
95 growing rod distractions. Whether the patients could walk without aids, required walking aids  
96 like crutches, or was non-ambulatory were noted.

97

#### 98 *Translation and Cross-culture Adaptation*

99 The original version of EOSQ-24 is in American English. It was translated into  
100 traditional Chinese (Hong Kong) following one of the internationally accepted translation  
101 techniques<sup>10</sup>, which consisted of a double forward translation and a single back translation.  
102 The translations were performed by independent professional non-physician translators to  
103 make as suitable to lay-persons as possible. After the first forward translation, the translated  
104 traditional Chinese version of EOSQ-24 was reviewed by a panel of health-related  
105 professionals (consisting of at least one spine specialist) who were from the local Hong Kong  
106 population. It was then back translated into English by a professional non-physician translator  
107 who had no access to the original questionnaire. The final forward translation was carried out

108 by an independent professional non-physician translator, and the final version of the  
109 translated and culturally-adapted EOSQ-24 in traditional Chinese (Hong Kong) was finalized  
110 and approved by the review panel.

111

## 112 *Study Instruments*

### 113 EOSQ-24

114 The EOSQ-24 is a disease- specific questionnaire with 24 questions with 11 separate  
115 sub-domains and 3 domains. The sub-domains were general health, pain, pulmonary function,  
116 mobility, physical function, daily living, fatigue, emotion, parental burden, financial burden,  
117 and satisfaction. The domains were patients' quality of life, burden, and satisfaction. There  
118 were five responses from point 1 to 5 per item in a ranking style with relevance to the  
119 questions. All 11 sub-domains scores were calculated as (average points of items for  
120 sub-domains – 1)/4\*100, rescaling the score metric from 1-5 to 0-100. All 5 domain scores  
121 were calculated in the same matter. The EOSQ-24 total score was the average of 11  
122 sub-domain scores. There was also a five-point Likert scale for parents/caregivers to rate  
123 regarding the clarity and understanding the translated EOSQ-24.

124

### 125 CHQ-PF50

126 The CHQ-PF50 was designed to assess the functional status and psychosocial



127 well-being of children 5 years and older and relative burden of care on parents.<sup>11</sup> The  
128 CHQ-PF50 included 13 domains and 2 summary scores with 50 items. The domains were  
129 Global Health, Physical Functioning, Role/Social Limitations-Emotional/Behavioural,  
130 Role/Social Limitations-Physical, Bodily Pain/Discomfort, Behaviour, Mental Health,  
131 Self-Esteem, General Health Perceptions, Parent Impact-Emotion, Parent Impact-Time,  
132 Family Activities, and Family Cohesion. According to CHQ-50PF scoring manual<sup>12</sup>, 10  
133 selected domains score were aggregated into two summary scores: Physical Summary Score  
134 and Psychosocial Summary Score. In brief, each selected domain score was standardized  
135 using a z-score transformation which the difference between domain score and general  
136 population mean was divided by standard deviation of general population. Computation of  
137 Physical Summary Score was obtained by multiplying each selected CHQ-PF50 scale z-score  
138 by its respective physical factor score coefficient and summing the ten products. All domains  
139 and summary scores ranged from 0 to 100.

140

#### 141 *Statistical Analysis*

142 Descriptive statistics including mean, standard deviation (SD) and percentage of floor  
143 and ceiling of domain and total scores were calculated. At least 15% of patients achieving the  
144 lowest or highest possible score was considered as present for floor or ceiling effect,  
145 respectively.<sup>13</sup> By using Pearson's correlation test, the construct validity of the EOSQ-24

146 domain was assessed against the CHQ-PF50 domain scores holding similar constructs.

147 The internal consistency was assessed by Cronbach's alpha using a value  $>0.7$  to  
148 indicate adequate internal consistency and reliability.<sup>13,14</sup> The sensitivity of the EOSQ-24  
149 score was determined by performing known group comparisons by effect size, independent  
150 t-test and analysis of variance, where appropriate. Cohen's effect size was calculated as the  
151 difference between mean scores, divided by pooled SD. Comparisons of known clinical  
152 groups were: (i) Observation treatment versus bracing or surgery; (ii) Observation treatment  
153 versus bracing only; (iii) Bracing versus surgery; (iv) Curve magnitude: Cobb angle  $\leq 30^\circ$   
154 versus  $>30^\circ$ ; (v) Ambulatory versus non-ambulatory; and (vi) Various types of EOS-  
155 Congenital versus neuromuscular versus syndromic vs idiopathic. As EOS of  
156 neurofibromatosis (2%) and spinal cord anomaly (3%) nature were of such small proportion  
157 of the study population, they were excluded in the analysis of **clinical diagnosis** group  
158 comparisons.

159 Data analyses were conducted using SPSS Windows 23.0 (IBM SPSS Inc., Chicago, IL,  
160 USA). P-value $<0.05$  was considered statistically significant.

161

## 162 **Results**

163 A total of 100 patients (60 females, 40 males) who were diagnosed with EOS were  
164 recruited, and their parents/ primary caregivers were asked to fill in the translated EOSQ-24

165 and CHQ-PF50. The response rate was 100% and all questionnaires were filled in the clinic  
166 without any missing responses. This studied population was heterogeneous, consisting of  
167 various aetiologies for EOS, spinal curvature of different magnitudes (Cobb angles),  
168 undergoing different stages of treatment and ambulatory status (**Table 1**).

169

#### 170 *Understanding of translated EOSQ-24*

171 A 5-point Likert scale was used to assess the understanding of the Chinese EOSQ-24 from  
172 the parents/caregivers who filled the translated questionnaire, giving an indication of its clarity.  
173 There were 66% and 10% of the parents/caregivers who answered ‘Agree’ and ‘Strongly  
174 Agree’ respectively on their ability to understand the EOSQ-24 questionnaire. Only 15%  
175 answered ‘Neither Agree/Disagree’, and 9% for ‘Disagree’. No subjects chose ‘Strongly  
176 Disagree’.

177

#### 178 *Internal Consistency*

179 **Table 2** presented the mean, standard deviations, floor and ceiling effects of the  
180 EOSQ-24 item, sub-domain, domain and total scores. The Cronbach’s coefficient was  
181 calculated for the analysis of reliability (**Table 2**). The Cronbach’s coefficient of the total  
182 EOSQ-24 score was 0.896, indicating a very good reliability. The internal consistency of the  
183 three domains of EOSQ-24, namely Patient Quality of Life, Family burden and Satisfaction,

184 was excellent (Cronbach's  $\alpha$ : 0.829-0.919). The range across all sub-domains was 0.589 to  
185 0.930.

186

### 187 *Ceiling and Floor effects*

188 For the study population, the mean sub-domain scores of EOSQ-24 ranged from 57.9  
189 (General Health) to 84.4 (Pulmonary Function), and the mean scores of individual items  
190 ranged from 2.9 (Q1 of General Health) to 4.4 (both Q5 & 6 of Pulmonary Function). A total  
191 of 10 items were not skewed, since Item 1, 12, 13, 14, 17, 18, 19, 23 and 24 had a median  
192 score of 3 and the median for Item 10 was 3.5 (50<sup>th</sup> and 51<sup>st</sup> response values were 3 and 4  
193 respectively). The rest of the items were left-skewed, with Item 5, 6, 7, 8 and 9 being highly  
194 left-skewed, indicating responses pointing towards normal mobility, physical and pulmonary  
195 function of this study population. With the absence of any right-skewed items, a floor effect  
196 was found in 0% to 26% of patients and a ceiling effect in 0% to 71% of patients (**Table 2**).

197

### 198 *Validity*

199 As summarized in **Table 3**, the total score of EOSQ-24 had significant correlations  
200 ( $p < 0.001$ ) with all domains of CHQ-PF50. Also, the three individual EOSQ-24 domains  
201 correlated significantly with all CHQ-PF50 domains. The sub-domain scores of EOSQ-24  
202 correlated significantly ( $p < 0.001$ ) with those of CHQ-PF50, particularly strong correlation in

203 the sub-domains of Pain, Physical Function and medium strength of correlation in General  
204 Health, Mobility, Parental Burden and Emotion. The Satisfaction domain of EOSQ-24 had  
205 strong significant correlation with the domain of Self-esteem of CHQ-PF50. A good construct  
206 validity was demonstrated and depicted in **Table 3**.

207 The discriminative validity could be indicated by the sensitivity of the EOSQ-24 in  
208 differentiating known clinical groups as displayed in **Table 4**. The EOSQ-24 was able to detect  
209 statistical differences in its total score between patients who were ambulatory versus  
210 non-ambulatory, as well as between EOS patients of various etiologies. There was statistical  
211 significant differences in the domain Family Burden and sub-domain Emotion and Financial  
212 Burden for patients undergoing bracing as compared to those who had surgery, despite the total  
213 score difference being not statistically significant ( $p=0.092$ ). Other clinical groups could not be  
214 differentiated by EOSQ-24 based on the statistical value, however, there were sub-domain  
215 scores which could be suggestive of being important when comparing various stages of  
216 treatment and the magnitude of the spinal curvature.

217

## 218 **Discussion**

219 This is the first study to translate and culturally adapt the EOSQ-24 for the Chinese  
220 population. This is a necessary first step to provide a standardized outcome questionnaire for  
221 Chinese EOS patients to allow for outcome comparisons and for determining the best

222 treatment options based on health-related quality of life assessment. Our results show that this  
223 translated questionnaire is well accepted by the study subjects and have demonstrated good  
224 construct validity and excellent reliability for comparing different diagnoses, ambulatory  
225 status and treatment modalities. We were also able to determine significant differences  
226 between domains of Emotion, Family Burden and Satisfaction among different EOS  
227 diagnoses.

228 Patients who are diagnosed with EOS require early treatment. Outcome assessment does  
229 not only include monitoring severity of spinal curvature, but also quality of life assessments  
230 of patients and their primary caretakers. It is demonstrated that scoliosis and resultant  
231 thoracic insufficiency may have a profound impact on patient's quality of life.<sup>15</sup> In fact,  
232 unlike adolescent idiopathic scoliosis, at a young age, EOS patients face the risk of poor  
233 thoracic development leading to associated pulmonary morbidity and early mortality.<sup>3,4</sup>  
234 Patients with EOS may have an equally poor quality of life as children with severe asthma or  
235 cardiac disease.<sup>6,16</sup>

236 Previous analysis of the generic instrument CHQ alone in patients with thoracic  
237 insufficiency syndrome (TIS) is unable to reveal a moderate or large degree of change of  
238 quality of life before and after vertical expandable prosthetic titanium rib (VEPTR) surgery.<sup>16</sup>  
239 Despite the lower physical domain score, the scores in psychosocial domains in patients with  
240 TIS are shown to be similar to those in healthy children.<sup>16</sup> This raises the question of whether a

241 generic instrument like CHQ has the adequate responsiveness and sensitivity to detect specific  
242 changes in quality of life found in this particular population of patients.

243 For EOS patients, EOSQ appears to be a more appropriate and reliable instrument, as it  
244 is a patient-based quality of life measure. Every step of its development involved the primary  
245 caregivers of patients, as well as input from health professionals.<sup>6</sup> Item and domain creation  
246 were driven by patient-based issues of concern that reflect quality of life and caregiver  
247 burden, through various stages of treatment and clinical severity.<sup>6</sup> The EOSQ-24 is shown to  
248 demonstrate differences in quality of life before and 6 months after surgery (VEPTR,  
249 traditional growing rods and Shilla) and can be an appropriate measure of outcome in  
250 comparing treatment options for EOS patients.<sup>17</sup> Hence, for the Chinese population, it is  
251 necessary to translate the EOSQ-24 into Chinese and validate it using the CHQ-PF50, in  
252 order to project the quality of life of these young patients from their parents/caregivers' point  
253 of view.

254 This study has found good internal consistency and thus reliability for the total score and  
255 domain scores for the translated EOSQ-24. The internal consistency of the Chinese EOSQ-24  
256 (Cronbach's  $\alpha$ : 0.896) is found to be comparable with other translated EOSQ-24, namely the  
257 Turkish (Cronbach's  $\alpha$ : 0.909) and the Spanish (Cronbach's  $\alpha$ : 0.897) versions.<sup>18,19</sup> The  
258 Chinese EOSQ-24 is also found to good construct validity, with strong correlation of scores  
259 with all domains of CHQ-PF50. Moreover, the translated EOSQ-24 demonstrates sensitivity

260 in detecting differences between subjects who have different diagnosis and ambulatory status.  
261 It is interesting to recognize that the differences are significant in the domain Satisfaction  
262 ( $p < 0.001$ ) as well as Family Burden ( $p = 0.014$ ) among various diagnosis groups, together with  
263 multiple sub-domains. Among patients undergoing different treatment, EOSQ-24 is sensitive  
264 in differentiating between patients undergoing bracing as compared to those who undergo  
265 surgery by the domain of Family Burden, accounted by the Emotion and Financial Burden  
266 sub-domain. Even though the EOSQ-24 does not capture a statistical significant difference  
267 between patients under observation versus other treatment modalities, nor differentiating  
268 patients with different severity of curvature magnitude, the instrument still detects the relevant  
269 sub-domains which play a strong role suggestive of differentiating among the groups. For  
270 instance, for patients with different magnitude of curvature (Cobb angle  $\leq 30^\circ$  versus  $> 30^\circ$ ),  
271 sub-domain Pulmonary Function has a p-value of 0.067 (effect size=0.367), whereas patients  
272 with bracing versus those with surgery done, sub-domain Pain has a p-value of 0.082 (effect  
273 size=0.408).

274 One limitation of the study is that it was performed in a single tertiary center in Hong  
275 Kong. Its generalizability to the entire Chinese population is unknown. It is fortunate that there  
276 is only one common written language that is shared by all Chinese populations, with the  
277 traditionally written characters used in Hong Kong, Macau and Taiwan, and simplified  
278 characters used in Mainland China. The traditional Chinese version can be converted to



279 simplified Chinese characters for application to the rest of Mainland China, but some minor  
280 modification may be necessary to suit the local linguistic preferences on certain terminologies.  
281 The modification is expected to be minimal since there are no cultural differences between  
282 these populations. Nevertheless, both character versions are usually understandable for those  
283 who read Chinese.

284 This is thus the first study to translate and culturally adapt the EOSQ-24 for the Chinese  
285 population by native health-related professionals. The translated questionnaire is well  
286 accepted by the parents/caregivers and demonstrates good construct validity, excellent  
287 reliability, and also sensitive for discriminating subjects with different diagnosis, ambulatory  
288 status and treatment modalities. This EOSQ-24 questionnaire is successful in capturing  
289 significant differences in the aspects of Emotion, Family Burden and Satisfaction among  
290 different diagnoses under EOS. These are domains which cannot be effectively measured by  
291 clinical parameters alone and are often difficult to gauge by clinicians. Yet, they are  
292 important contributing factors towards the quality of life of EOS patients and burden of  
293 caregivers. In addition, it can be an important disease-specific instrument for measuring  
294 outcomes of treatment specific for Chinese EOS patients. It will be ideal as the next step to  
295 test the responsiveness of the Chinese EOSQ, and with a much larger sample size to reveal  
296 more effective domains successfully.