

The Early Onset Scoliosis Questionnaire-24: Are Some Questions too Difficult?

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INTRODUCTION:

The Early Onset Scoliosis Questionnaire-24 (EOSQ-24) is a validated, caregiver-administered, health-related quality of life (HRQL) scale for children with Early-Onset Scoliosis (EOS). It has been our experience that a notable proportion of questions are given a non-standard response by caregivers, such as non-response, leaving comments, or selecting two options. Since these responses limit scoring of the survey, our goal was to describe and characterize such non-standard responses among filled EOSQ-24 surveys.

METHODS:

A sample of 240 filled EOSQ-24s from January 2022 to April 2023 were assessed at our center for occurrences of non-standard responses. Non-standard responses were defined as follows: no response (questions left blank or indicated as not applicable), comment left on a specific EOSQ domain or question, two options chosen (two separate responses chosen for a specific question), or a general comment left on the questionnaire unrelated to a specific domain or question. Surveys were analyzed according to overall frequency of non-standard responses and by domain and question.

RESULTS:

Sixty-seven surveys (27.5%) were found to include at least one non-standard response (Table 1). Of 1,608 total questions in the surveys, 286 (17.8%) had a non-standard response. Among the affected surveys, the most common type of non-standard response was a lack of response (22.1%), followed by comment left on question (12.1%). In most cases, each survey had approximately 1 to 3 (55.2%) or 4 to 7 (32.8%) non-standard responses. The domains that saw the most non-standard responses were daily living (11.5%), emotion (7.5%), and physical function (7.4%) (Figure 1). There were three specific questions within the top two domains that saw the highest rate for non-standard responses: questions 11 (41.8%), 10 (40.2%), and 12 (40.2%) (Figure 2). Question 10 falls under the Physical Function domain, and questions 11 and 12 under the Daily Living domain (Figure 3). These questions specifically ask about a child's ability to participate in activities related to self-care and daily life.

DISCUSSION AND CONCLUSION:

There was a 27.5% incidence of non-standard responses, especially in the "activities of daily living" questions. We hypothesize that this is caused by the wording of these questions, as they ask about the extent that children can perform certain activities, when some children are completely unable to perform the questioned activities (e.g., Q12 asks about the time needed to eat a certain amount of food when some children have feeding tubes). Since there are no "not applicable" options in the questionnaire, some caregivers face difficulties responding to these questions. When these questions are given non-standard responses, scoring is made extremely more difficult, and comparisons cannot be fully performed. This potentially leaves researchers with important data that is not able to be fully assessed.

We found a large proportion of non-standard responses in EOSQ-24 surveys, indicating that there are domains or questions that caregivers often face difficulties answering. Our findings urge simple updates to certain questions in the EOSQ-24 to address these limitations. At the very least, researchers should be aware of the presence of these limitations when

utilizing

the EOSQ-24

questionnaire.

Figure 1. Percentage of non-standard responses, by question domains, among 240 included surveys.

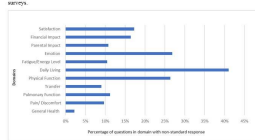


Figure 2. Number of non-standard responses, by question, among 1698 included questions.

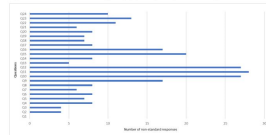


Figure 3. EOSQ-24 Questions and Domains with response options ranging on a 1-5 Likert scale. Bolded questions represent the 3 questions with the most non-standard responses.

- Domain: General Health: During the past 4 weeks
 - o 1. In general, you would say your child's health has been:
 - o 1. How often has your child been sick?
- Domain: Pain/Discomfort: During the past 4 weeks
 - o 3. How often has your child had pain/discomfort?
 - o 4. How severe has your child's pain/discomfort?
- Domain: Pulmonary Function: During the past 4 weeks
 - o 5. How difficult has it been for your child to breathe or talk/speak (age appropriate) without experiencing shortness of breath?
- Domain: Transfer: During the past 4 weeks
 - o 6. How often has your child's health condition limited his/her access to places?
- Domain: Physical Function: During the past 4 weeks
 - o 7. How often has it been for your child to move his/her upper body?
 - o 8. How difficult has it been for your child to sit up on his/her own?
 - o 9. How difficult has it been for your child to keep his/her balance while crawling, walking, or running?
- Domain: Daily Living: During the past 4 weeks
 - o 10. How difficult has it been for your child to dress him/herself or assist with dressing?
 - o 11. How often has your child had fatigue?
 - o 12. No child needs more time than a healthy child to eat the same amount of food.
 - o 13. My child needs more time than a healthy child to eat the same amount of food.
- Domain: Fatigue/Energy Level: During the past 4 weeks
 - o 14. How often has your child had fatigue?
 - o 15. How difficult has it been for your child to keep up his/her energy all day?
- Domain: Functioning: During the past 4 weeks
 - o 16. How often has your child felt frustrated due to his/her health condition?
 - o 17. How often has your child felt nervous about his/her health condition?
- Domain: Parental Impact: During the past 4 weeks
 - o 18. How often have you felt nervous/worried about his/her health condition?
 - o 19. How often has your child's health condition interfered with family activities?
 - o 20. How much has your child's health condition affected your energy level?
 - o 21. How often have you canceled or have you been late for work or social events due to your child's health condition?
 - o 22. How often have you spent enough time with your family/partner/spouse despite your child's health condition?
- Domain: Financial Impact: During the past 4 weeks
 - o 23. How often have you been able to spend enough time with your family/partner/spouse despite your child's health condition?
 - o 24. How much of a financial burden has your child's diagnosis of Early Onset Scoliosis been?
- Domain: Satisfaction: During the past 4 weeks
 - o 25. How satisfied are you with your child with his/her ability to do things?
 - o 26. How satisfied are you with your child's ability to do things?

Table 1. Number (%) of surveys and questions with various non-standard responses among total of 240 surveys and 1698 questions

Type of non-standard response among surveys	N (%)	Total = 240 Surveys
Any Non-standard Response	67 (27.5%)	
Any No Response	53 (22.1%)	
Any Comment	82 (33.3%)	
Any Two Options	16 (6.7%)	
Type of non-standard responses among questions		
Any Non-standard Response	286 (17.2%)	Total = 1698 questions
No Response	184 (11.1%)	
Comment	98 (5.8%)	
Two Options	10 (0.6%)	