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Development and Validation of a Health-Related Quality-of-Life Measure in Older Children and Adolescents with Early-Onset Scoliosis. Early-Onset Scoliosis Self-Report Questionnaire (EOSQ-SELF) http://dx.doi.org/10.2106/JBJS.21.01508

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# **Appendix 1:** EOSQ-SELF Master List of Items

General Health

- 1. In general, you would say your health has been: (poor excellent)
- 2. How often have you been sick? (all of the time none of the time)

Pain/Discomfort

- 3. How often have you had pain/discomfort? (all the time none of the time)
- 4. How severe has your pain been? (very severe no pain)

Pulmonary Function

- 5. How difficult has it been for you to cry/speak without experiencing shortness of breath? (difficult easy)
- 6. How often have you experienced shortness of breath during activities? (all the time none of the time)

Transfer

- 7. How often has your health condition limited your access to places? (all of the time none of the time)
- 8. How difficult is it for you to keep up with your friends/peers when you get around? (difficult easy)

Physical Function

- 9. How difficult has it been for you to move/use your upper body? (difficult easy)
- 10. How difficult has it been for you to sit up on your own? (difficult easy)
- 11. How difficult has it been for you to keep your balance while sitting, walking, or running? (difficult easy)
- 12. How difficult is it for you to be active in athletic activities? (difficult easy)
- 13. How difficult is it for you to physically move your body at the speed you want? (difficult easy)
- 14. How difficult is it for you to physically move your body to keep up with your friends/peers' speed when walking together, playing games together, etc? (difficult easy)
- 15. \*\*\*How difficult has it been for you to move your head/neck to secure your field of vision? (difficult easy)

Daily Living-Merged to Physical Function

- 16. How difficult has it been for you to dress yourself? (examples: removing/putting on clothing, pushing arms and legs through shirts and pants, assisting with fasteners, zippers, buttons, Velcro) (difficult easy)
- 17. I need more time than my healthy peers to eat the same amount of food. (strongly agree strongly disagree)

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18. How difficult has it been for you to maintain good hygiene (make or keep yourself clean – taking a bath/shower, brushing teeth, washing face/hands, using the restroom)? (difficult – easy)

## **Participation**

- 19. How difficult is it for you to participate in routine physical activities at school/work? (difficult easy)
- 20. How difficult is it for you to participate in routine non-physical activities at school/work? (difficult easy)

Fatigue/Energy Level

- 21. How often have you had fatigue? (all the time none of the time)
- 22. How difficult has it been for you to keep up your energy all day? (difficult easy) Sleep
  - 23. How often do you get a bad night of sleep? (all of the time none of the time)
  - 24. How often has your breathing affected your sleep? (all of the time none of the time)
  - 25. \*\*\*How severely does your breathing disrupt your sleep? (very severe not at all)
  - 26. How often has your pain affected your sleep? (all of the time none of the time)
  - 27. How often have you had difficulty falling asleep? (all of the time none of the time)
  - 28. How difficult is it for you to fall asleep? (difficult easy)
  - 29. How difficult is it for you to change your positioning when sleeping? (difficult easy)

## Appearance

- 30. I don't like the way my clothes fit me due to my health condition. (strongly agree strongly disagree)
- 31. I don't like my height due to my health condition (strongly agree strongly disagree)
- 32. I like the way my back looks. (strongly agree strongly disagree)
- 33. I like the way my ribcage looks. (strongly agree strongly disagree)
- 34. I like the way my shoulders look. (strongly agree strongly disagree)
- 35. I like the way my body is tilted. (strongly agree strongly disagree)

#### Relationships

- 36. How often does your health condition create problems/issues between you and your parents? (all the time none of the time)
- 37. How often does your health condition create problems/issues between you and your siblings? (all the time none of the time)
- 38. How often does your health condition create problems/issues between you and your friends/peers? (all the time none of the time)
- 39. How often does your health condition create problems/issues between you and your girlfriend/boyfriend? (all the time none of the time)
- 40. How often does your health condition create problems/issues between you and your teachers/bosses? (all the time none of the time)
- 41. Due to my health condition, I am limited in my ability to make friends. (strongly agree strongly disagree)

## Family Dynamics

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- 42. How often does your health condition create problems/issues between your parents? (all the time none of the time)
- 43. How often does your health condition create problems/issues between your parents and your siblings? (all the time none of the time)
- 44. How often does your health condition create problems/issues between your parents/siblings and others? (all the time none of the time)

#### **Emotion**

- 45. How often have you felt anxious/nervous due to your health condition? (all the time none of the time)
- 46. How often have you felt sad/depressed due to your health condition? (all the time none of the time)
- 47. How often have you felt frustrated/angry due to your health condition? (all the time none of the time)
- 48. How often have you felt fearful due to your health condition? (all the time none of the time)
- 49. I have felt sad about something that someone has said about my health condition. (strongly agree strongly disagree)
- 50. How often does your health condition cause you to feel "left out?" (all of the time none of the time)
- 51. I have felt that my health condition is "unfair." (strongly agree strongly disagree)
- 52. How often does your health condition cause you to feel less confident? (all of the time none of the time)
- 53. How difficult is it for you to control your emotions due to your health condition? (all of the time none of the time)
- 54. How often do you experience a faster heartbeat, difficulty breathing, and/or racing thoughts when you think about your health condition? (all of the time none of the time)
- 55. I feel more sensitive to the needs of others as a result of my health condition. (strongly agree strongly disagree)
- 56. I feel more sensitive to the feelings of others as a result of my health condition. (strongly agree strongly disagree)

#### Satisfaction

- 57. How satisfied are you with your ability to do things? (very dissatisfied very satisfied)
- 58. How satisfied are your parents/caregivers with your ability to do things? (very dissatisfied very satisfied)
- 59. I can do the things I want to do despite my health condition. (strongly agree strongly disagree)