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Title: Development of a quality of life instrument for children with bronchopulmonary dysplasia

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Body: Background. Bronchopulmonary dysplasia (BPD) is a common complication of preterm birth. It is associated with prolonged hospitalization, long-term pulmonary morbidity and an increased risk for adverse neurodevelopmental outcome. The impact of these complications on health-related quality of life (HRQL) is not known because there is no disease-specific instrument to measure HRQL available. Aim. To develop a disease-specific questionnaire to measure HRQL in children with BPD aged 4 to 8 years old. Methods. Participants: children aged 4 to 8 years old with BPD. The first steps in the development of a HRQL instrument are item generation and item reduction. Sources for item generation were literature, expert opinion and parents of participants. For item reduction, parents indicated how much the items affected the HRQL of their child. The clinical impact method and item analysis were used to reduce items. Results. 51 children participated in the study; 20 in item generation and 31 in item reduction. 130 items were identified. With the clinical impact method 53 items with an overall importance (OI) >1.00 were selected. Three items with highest OI were 'easily distracted' (2.52), 'having a cold for longer period of time' (2.42) and 'coughing' (2.39). After item analysis, 47 items remained in the questionnaire. Items were linked to a variety of subjects such as pulmonary problems, growth/nutrition, exercise, school, behavior, social and emotional functioning. Conclusion. This is the first time the development of a disease-specific instrument to measure HRQL in BPD has been undertaken. The items in the developed questionnaire have clinical impact. The next step will be to determine validity of these items.