Online Resource 2: description of questionnaires

Gastroschisis at school age: what do parents report?

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Annelieke Hijkoop,[1] André B. Rietman, René M.H. Wijnen, Dick Tibboel, Titia E. Cohen-Overbeek, Joost van Rosmalen, Hanneke IJsselstijn.

[1] Department of Pediatric Surgery and Intensive Care, Erasmus MC – Sophia Children's Hospital, Rotterdam, the Netherlands; a.hijkoop@erasmusmc.nl.

Description of questionnaires

We used Dutch versions of all questionnaires. All questionnaires were parent-reported. If two answers were selected for one question, we documented the most unfavorable score.

Background

Description: We asked caregivers to report the following background information: child's living situation (e.g. with biological parents or in a foster family, presence of two caregivers, number of children), maternal and paternal education levels (based on the International Standard Classification of Education 2011) [1], medical (use of medication, hospital admissions, use of medical aids such as a wheelchair or parenteral nutrition), educational (e.g. regular or special, grade repetition, learning difficulties, need of extra help at school), social-emotional functioning (presence of behavioral or emotional problems), and main language spoken at home.

Child vulnerability

Child Vulnerability Scale (CVS) [2,3]

Description: The CVS is an 8-item questionnaire on parental perceptions of their child's vulnerability. Each item states a problem, for example 'my child gets more colds than other children I know'. Answers vary from strongly disagree (=0) to strongly agree (=3) on a 4-point Likert scale. Total scores range from 0-24; higher scores reflect higher perceived vulnerability. We used a cut-off of ≥10 for high perception of vulnerability.

Validated: This questionnaire has been validated for Dutch children aged 5-18 years [2].

Motor function

Movement Assessment Battery for Children- Second Edition (MABC-2) Checklist [4-6]

Description: The M-ABC 2 Checklist is aimed at evaluating motor problems in daily life. Section A measures movement in a static (or predictable) environment; section B measures movement in a dynamic (or unpredictable) environment. Both sections consist of 15 items. Each of the 30 items states a skill, for

example 'rides a bicycle without stabilizers'. The parent indicates to what extent the child is able to do this, varying from very well (=0) to not close (=3). Scores are reported using a Traffic Light color system, corrected for age, with high scores representing poor performance. 'Green zone' indicates a score within the normal range (< 85th centile); 'amber zone' means that the child is at risk for motor problems (85th-94th centile), and a score in the 'red zone' indicates a high possibility of serious motor problems (≥ 95th centile).

Validated: This questionnaire has been validated for Dutch children aged 3-16 years [6]. As no Dutch reference norms exist for 17-year old children, these children were scored according to reference norms for 16-year olds.

Cognition

Pediatric Perceived Cognitive Function (PedsPCF) questionnaire [7]

Description: The PedsPCF assesses the child's cognitive functioning as perceived by the parent, referring to the past four weeks. Each item reflects a problem, for example 'forgets things easily'. Answers vary from very much/all of the time (=1) to not at all/none of the time (=5) on a 5-point Likert scale. Based on preliminary results of the collection of Dutch reference data, we used only the first 30 items of the PedsPCF rather than the full-length PedsPCF (which counts 43 items), and we used the following cut-offs of ≤-1 standard deviation (SD): 102 (7-12 years), 104 (13-18 years). Total scores range from 30-150; higher scores reflect better cognitive functioning.

Validated: This questionnaire has been validated for Dutch children aged 7-18 years [8].

Health status

Pediatric Quality of Life Inventory (PedsQL) [9]

Description: The PedsQL is an instrument for measuring health status in children and adolescents. It consists of four subscales: physical (8 items), emotional (5 items), social (5 items) and school functioning (5 items). Each item reflects a problem, for example 'problems with running'. Answers vary from never (=0) to almost always (=4) on a 5-point Likert scale. Each answer is reversed scored and rescaled to a 0-100 scale

(0=100, 4=0). Total scores range from 0-100; higher scores reflect better quality of life. We used the version that referred to the past month.

Validated: This questionnaire has been validated for Dutch children aged 5-18 years [10].

Quality of life

DUX-25

Description: The DUX-25 is a visual health-related quality of life questionnaire. Each question evaluates the child's feelings in daily life, for example 'your child often feels …'. It consists of four subscales: physical (6 items), emotional (7 items), social (7 items) and home functioning (5 items). Answers are scored on a happy-to-sad faces scale by use of smileys. These smileys visualize a 5-point Likert scale, ranging from sad (=0) to happy (=100). Total scores range from 0-100; higher scores reflect better quality of life.

Validated: Dutch reference data are currently being analysed (age 8-17 years).

Behavior

Strengths and Difficulties Questionnaire (SDQ) [11]

Description: The SDQ covers the most important domains of child psychopathology and personal strengths. It consists of five subscales: emotional symptoms, conduct problems, hyperactivity-inattention, peer problems, and prosocial behavior. Each item is scored on a 3-point Likert scale; answer vary from not true (=0) to certainly true (=2). Higher scores reflect more difficulties, except for the prosocial scale where higher scores reflect strengths. All but the prosocial behavior subscale scores are summed to generate a total difficulties score. Total scores range from 0-40. The total difficulties score was categorized into 'normal' or 'abnormal' using age-dependent cut-off values [11].

Validated: This questionnaire has been validated for Dutch children aged 2-18 years [11]. In children aged <6 years, no SD scores or cut-off values were available for 'conduct problems' and 'peer problems' due to insufficient internal consistency of these subscales in this age group.

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