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## Quality of life in children with functional constipation

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## Quality of life in children with functional constipation: Are child self-reports and parent proxy-reports interchangeable?



### To the Editor:

We thank Vriesman et al for providing an extensive overview of the health-related quality of life (HRQoL) of children with functional constipation.<sup>1</sup> HRQoL is identified as an important outcome when evaluating the effect of a treatment in both clinical trials and the doctor's office.<sup>2,3</sup> As mentioned by the authors, there is substantial debate who is the most appropriate respondent to assess children's HRQoL: the child itself or the parent(s).<sup>4</sup> To examine the parent-child agreement, the authors compared the total HRQoL scores on the Pediatric Quality of Life Inventory questionnaire reported by children and parents and suggested that the scores were quite similar, with a score of 62.03 (SD 11.46) and 64.95 (SD 12.99), respectively, so there seems to be good parent-child agreement on a group level. Therefore, they suggest that both parent proxy-reports as child self-reports can be used in a clinical setting, but they emphasize the need of large cohort studies.

We published a study investigating parent-child agreement on HRQoL in children with functional constipation ( $n = 56$ ), aged 8-17 years.<sup>5</sup> Just as Vriesman et al, we found a good parent-child agreement on a group level; intraclass correlation coefficient of 0.80 (95% CI 0.67-0.88) and 0.78 (95% CI 0.65-0.87) for the Defecation Disorder List and EuroQol-5-Dimension-Youth Visual Analogue Scale, respectively. However, we found considerable discordance on HRQoL between individual parent-child pairs. The limits of agreement of the Bland-Altman plots were  $-19.7$  and  $14.6$  for the Defecation Disorder List and  $-27.6$  and  $21.8$  for the EuroQol-5-Dimension-Youth Visual Analogue Scale, on a range of a 0 to 100 score on both questionnaires. Age and sex of the child were not associated with parent-child agreement. Therefore, we advise clinicians to pay attention to both the child's and parent's perception of the child's HRQoL.

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## References

1. Vriesman MH, Rajindrajith S, Koppen IJ, van Etten-Jamaludin FS, van Dijk M, Devanarayana NM, et al. Quality of life in children with func-

tional constipation: a systematic review and meta-analysis. *J Pediatr* 2019;214:141-50.

2. Tabbers MM, DiLorenzo C, Berger MY, Faure C, Langendam MW, Nurko S, et al. Evaluation and treatment of functional constipation in infants and children: evidence-based recommendations from ESPGHAN and NASPGHAN. *J Pediatr Gastroenterol Nutr* 2014;58:258-74.
3. Koppen IJN, Saps M, Lavigne JV, Nurko S, Taminiau AJM, Di Lorenzo C, et al. Recommendations for pharmacological clinical trials in children with functional constipation: the Rome foundation pediatric subcommittee on clinical trials. *Neurogastroenterol Motil* 2018;30:e13294.
4. Wallander JL, Koot HM. Quality of life in children: a critical examination of concepts, approaches, issues, and future directions. *Clin Psychol Rev* 2016;45:131-43.
5. van Summeren JJGT, Klunder JW, Holtman GA, Kollen BJ, Berger MY, Dekker JH. Parent-child agreement on health-related quality of life in children with functional constipation in primary care. *J Pediatr Gastroenterol Nutr* 2018;67:726-31.

## Reply



### To the Editor:

We thank van Summeren et al for their interest in our systematic review on health-related quality of life (HRQoL) in children with functional constipation. They expressed their concerns on the use of either self-report or parent proxy report to assess HRQoL of children with functional constipation, and stress that a combination of both reports should be used in current clinical practice. This notion is largely based on their study on HRQoL in children with functional constipation and their parents in primary care practices.<sup>1</sup> Although a good overall parent-child agreement of HRQoL as assessed by the EuroQol-5-dimension-Youth Visual Analogue Scale (EQ-5D-Y-VAS) and the Defecation Disorder List was reported in their study, they found considerable discordance between individual parent-child pairs. Therefore, they state that both methods should be used in the assessment of HRQoL of an individual child.

Van Summeren et al highlight a well-known and important challenge regarding the measurement of HRQoL in children with chronic health conditions. Patient report, in this case child report, is considered to provide a sound assessment of the impact of the disease on the patient, resulting in the development of several self-reported HRQoL instruments for children.<sup>2,3</sup> However, concerns have been raised regarding the insufficient language and cognitive skills of (young) children to fill out HRQoL questionnaires.<sup>4</sup> Moreover, it is increasingly recognized that parents may have a different perception of the symptoms of their child and have the tendency to underestimate their child's HRQoL, whereas children themselves may do the opposite.<sup>2</sup>

In our systematic review, 6 of 13 studies included in the meta-analysis reported on both self-report and parent proxy report of HRQoL as assessed by the Pediatric Quality of Life Inventory (PedsQL). Similar pooled HRQoL scores were found between children and their parents (64.95 and 62.03, respectively).<sup>5-10</sup> We stated that this finding could possibly