

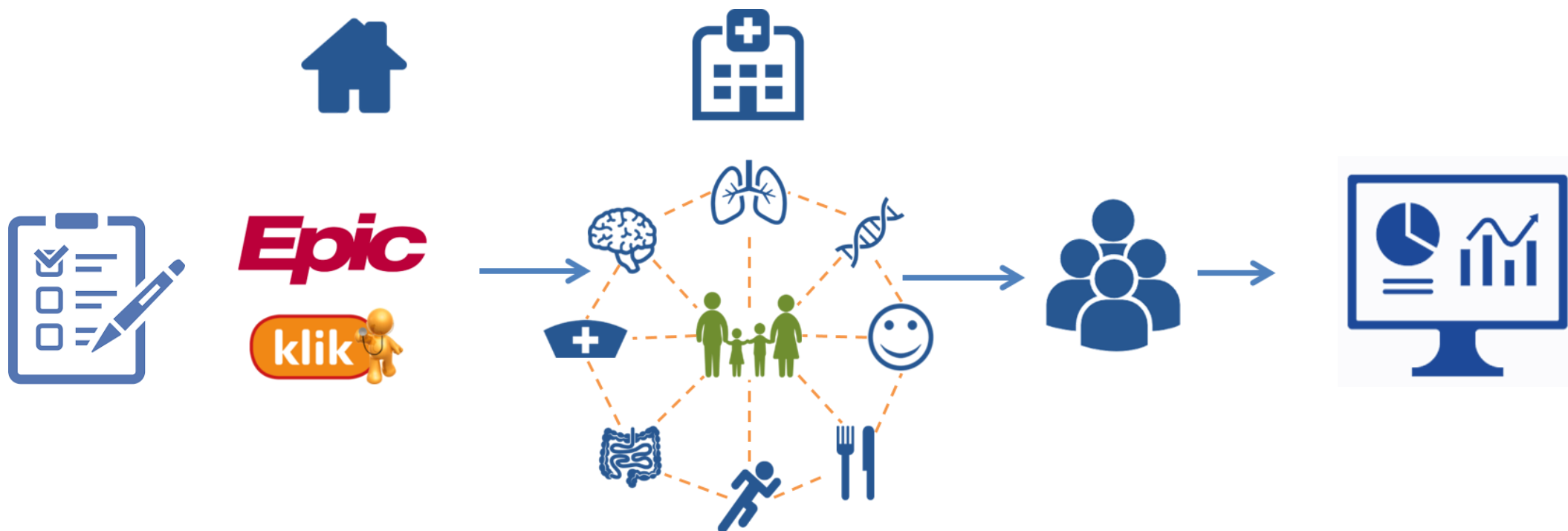
Parental distress and post-traumatic stress disorder in parents of patients with congenital gastrointestinal malformations

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Multidisciplinary follow-up program Amsterdam: Follow Me program





Introduction

- Parents of patients with congenital gastrointestinal malformations may come across various stress-inducing factors related to birth, diagnosis, treatment and admittance to the hospital ^{1,2}
- Previous evidence suggests an increased risk of post-traumatic stress disorder in mothers of patients with esophageal atresia ³
- Parents of patients with congenital malformations have a higher risk of emotional problems, anxiety and depression, financial problems and problems in parenting ⁴⁻⁶
- Repeated stress can lead to post-traumatic stress disorder and distress in daily life ⁷

1) Bronner et al, *ACTA Paediatr*, 2008, 2) Hinton et al, *BMJ open*, 2018, 3) Le Gouez et al, *PLOS one*, 2016, 4) Wigander et al, *J Pediatr Nurs*, 2018, 5) Ost et al, *Pediatr Surg Int*, 2017, 6) Figueroa et al, *Biomedica*, 2019, 7) Kazak et al, *J Pediatr Psychol*, 2006

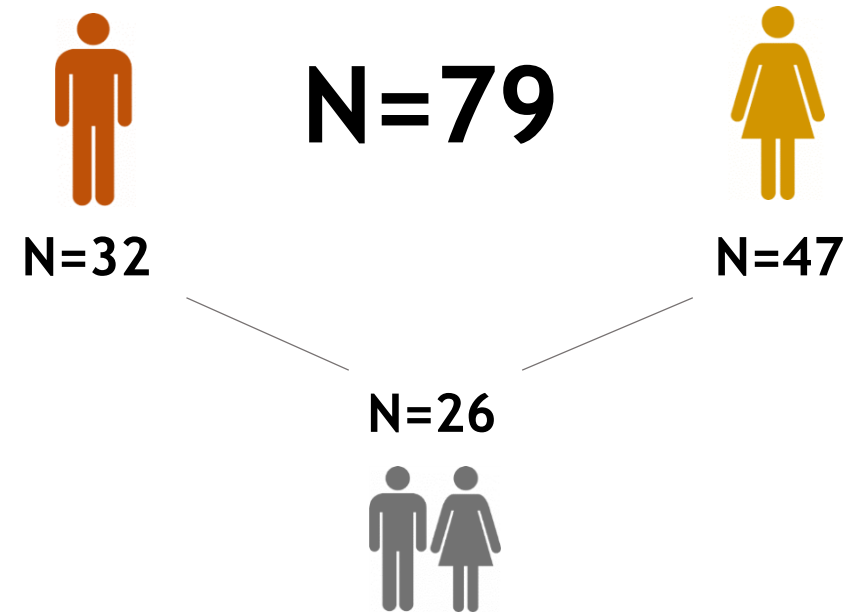


Sample characteristics

Inclusion criteria

- Child with congenital malformation
- Included in FMP follow-up (October 2017 - March 2020)
- Child's age at follow-up <3 yrs
- In case of multiple visits: first follow-up moment
- Adequate dutch language skills

Response Rate: 48%



Methods



DISTRESS



PTSD

Distress Thermometer for Parents (DT-P) ¹

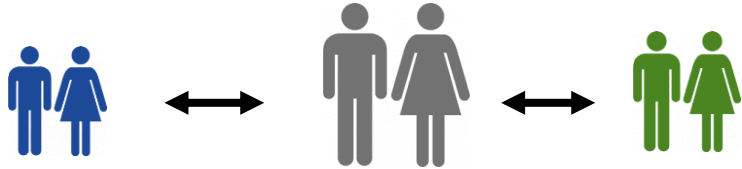
- 36 items
 - Clinical distress = overall score ≥ 4
 - Problems in various domains
- Dutch age-matched and sex-matched reference group available ²

- Self report Scale Post-traumatic stress Disorder (SRS-PTSD)
- 22 items based on DSM-IV diagnosis of PTSD
- Valid measure, comparable to clinical interview ³
- Dutch reference group available ⁴
- PTSD = positive score in 3 domains (Intrusion, Avoidance and Hyperarousal)

1) Haverman et al, *J Pediatr*, 2013 2) van Oers et al, *Qual Life Res*, 2017, 3) Carlier, et al., *Psychosom Med*, 1998, 4) Bronner et al., *J Trauma Stress*, 2009



Statistics

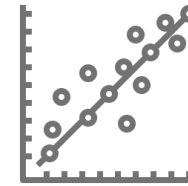


- Prevalence of clinical distress
- Severity of distress
- Problem domain scores
- Prevalence of PTSD



X^2 test

Mann Whitney U / Student's t-test



- Risk of clinical distress
- Risk of PTSD
- Severity of distress
- Severity of intrusions
- Severity of avoidance
- Severity of hyperarousal

BY

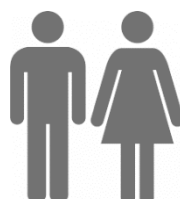
Male sex
Child age at follow-up
Type malformation
Length-of-hospital-stay
Educational level
Ethnic-cultural background



Mixed model logistic regression
Mixed model linear regression



Results: comparison to reference groups



46 %

$X^2=0.07, p=0.79$



34 %

$X^2=0.002, p=0.97$

48 % 5 %

35 % 2 %

$X^2= 26.45, p<0.001$ 23 %



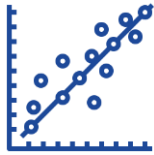
$X^2=2.00, p=0.157$ 6 %



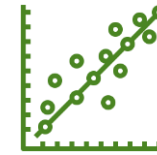
None of the domainscores was significantly different between groups, except parenting of infants (<2 yrs)



Results: risk factors for distress / PTSD



- None of the tested factors were associated with the risk of clinical distress and the severity of distress



- Male sex of parents was associated with lower risk of PTSD and with less severe symptoms of intrusions, avoidance and hyperarousal
- Longer length-of-hospital-stay was associated with more severe symptoms of intrusions, avoidance and hyperarousal
- Child's age at follow-up older was associated with less severe symptoms of intrusion



Discussion

- No higher risk of (clinical) distress in follow-up
- Higher risk of PTSD in mothers ^{1,2}
- The majority of parents (75%) showed symptoms of intrusion
- Severity of PTSD was correlated to child's age at follow-up and length-of-hospital-stay
- The nature of intrusions (experiences causing intrusions) could not be assessed in this study ³
- EMDR is an effective treatment for (even mild) symptoms of PTSD ⁴
- It is important to monitor psychological wellbeing of parents of patients with congenital malformations in follow-up



Take Home Message

Although parents experience **limited distress** in follow-up, **mothers are at risk of post-traumatic stress disorder**, emphasizing the **need to monitor post-traumatic stress disorder in parents** of patients with congenital malformations



Thank you for your attention!

Questions?

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