

Parental Narrative Coherence Following Rapid Genomic Testing in Childhood: Implications for Identifying Ongoing Support Needs

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Abstract

Rapid genome sequencing in critically ill infants and children enables early genetic diagnosis, with potential for improving long-term family outcomes. However, the impact of these diagnoses on parent-child relationships and family dynamics are poorly understood. To investigate parental perceptions and affective meaning-making after a genomic result, this study applied Five-Minute Speech Samples (FMSS), a narrative method in which parents are invited to speak freely about their thoughts and feelings regarding their child and their relationship. These narratives were collected on average 3.5 years ($SD = 1.0$) after genomic testing and transcripts were rated for coherence – indexed by believable, clear, and succinct narratives, a marker of parent-child relationship quality. FMSS-Coherence was compared (1) among mothers ($n = 53$) of children with complex health conditions with and without a genomic diagnosis in the PEREGRIN study, using ANCOVA, and (2) between PEREGRIN parents and parents of gender- and aged-matched typically developing children in the NewFAMS study (total $n = 100$, 50 mothers and 50 fathers), using a mixed-effects model. Narrative coherence did not differ significantly by genomic diagnosis status or by health condition / typical development. In both cohorts, nearly half of parents scored low in coherence (48% PEREGRIN, 46% NewFAMS), reflecting ongoing parental concerns and difficulty forming balanced narratives about their child and relationship, regardless of aetiology. These findings suggest psychosocial adjustment difficulties are common among parents of children with complex health needs, supporting early psychosocial assessment within genomic and paediatric care pathways.

INTRODUCTION

Serious child illness brings substantial practical and psychological challenges that may influence how parents perceive their child (1). Rapid genomic sequencing has increased the number of families receiving rare and ultra-rare diagnoses early in parenting, often during periods of considerable uncertainty (2). Understanding how parents think and feel about their child following genomic testing may help identify families who need additional psychosocial support (3,4).

One useful tool for gaining this understanding is the Five-Minute Speech Sample (FMSS) paradigm, designed to assess expressed emotion (5) and now widely adopted in parenting research (6). Here, we applied Sher-Censor's (7) system for coding narrative coherence, which captures the extent to which parents can describe their child openly and flexibly, including both positive and negative characteristics within descriptions marked by warmth and acceptance. Challenging experiences, such as serious illness or developmental uncertainty may constrain parents' capacity to form a coherent representation of their child. Drawing on two samples: (i) parents of children with complex health conditions (PEREGRIN cohort), and (ii) parents of typically developing children (NewFAMS cohort), we compared narrative coherence for mothers of children with complex health conditions with or without genomic diagnosis and for parents of children with or without complex health conditions.

Parental Narratives and the Parent-Child Relationship

Decades of developmental research suggest that the quality of parent-child relationships hinges on how a parent thinks and feels about their child (8). Warm, accepting and sensitive parenting fosters children's development (9), and is inversely associated with child anxiety and depressive symptoms (10), while emotional neglect and overprotection increase the risk of such symptoms (11). Parents who view their child as incapable of change invest less warmth in the relationship and show greater punitive / disengaged parenting (12). Understanding the predictors of variation in how parents think about their child is therefore important.

Parental Narratives of Children With and Without a Genomic Diagnosis

Studies of diverse families report associations between FMSS coherence and both parenting quality and child socio-emotional adjustment (13–15), with studies involving parents of children with autism spectrum disorder (ASD) demonstrating that diagnostic experiences may shape parental representations (16,17). Families of children with complex health conditions report highly variable experiences, but parenting stress, less effective parenting practices and reduced relationship quality are common (18). Chronic health conditions may alter parental expectations, increase perceptions of child vulnerability, and create ongoing uncertainty, contributing to parents' stress, with consequences for child development and mental health (19). Moreover, having a critically unwell child in Neonatal or Paediatric Intensive Care Unit (NICU/PICU) is inherently traumatic (20). Technological advances have led to earlier genomic testing (21), which is now expanding into neonatal screening (22). Although genomic diagnoses are typically reported as having transitory psychosocial effects and evoking low parental decisional regret, variability exists (23,24).

Clinical and personal benefits of early genomic testing include personalised treatments, psychological relief, reproductive autonomy, and access to peer and professional support (25,26). However, results can also lead to "diagnostic shock", by revealing life-threatening conditions and forecast developmental trajectories that would otherwise emerge gradually (3). Receiving a diagnosis can both elevate and reduce parental anxiety (27), altering perceptions of the child and evoking distress or guilt (28). Decline rates for genetic testing vary widely (12-93%) and reflect parental concerns about privacy and bonding (29). Early disclosure of genomic information may disrupt parent-child bonding, parental wellbeing and family dynamics (30). Understanding how children's health status shapes parental perceptions is clinically important, as emerging evidence suggests that interventions can improve aspects of narrative coherence (e.g., concern, acceptance, and complexity), with positive impacts on parenting (16,31).

Narratives from Mothers versus Fathers

Three studies have compared mothers' and fathers' narrative coherence, with findings indicating similar average levels, but gender-specific correlates (15,17,32). Two studies (15,32) were framed within the longitudinal New Fathers and Mothers Study (NewFAMS), which included participants from the UK, USA and Netherlands. For the 200 British couples, actor-partner interdependence modelling showed that narrative coherence was only related to couple-relationship quality and life satisfaction in fathers (32). Likewise, for the Dutch 105 couples, FMSS coherence ratings were only related to direct observational ratings of sensitivity in fathers (15). The third study (17) involved parents of 82 autistic children and indicated that emotional availability was associated with narrative coherence for fathers, but with resolution to child's diagnosis and positive comments for mothers. Yet despite being more involved in childcare than in previous generations (33) fathers remain an understudied group.

The Current Study

Narrative coherence has yet to be explored in the context of child's genomic diagnosis. In a sample of parents of children with complex health needs who underwent rapid genomic testing (rGS), we first examine whether parental views of the child vary with diagnostic status and then compare clinical and non-clinical samples to examine whether reduced narrative coherence reflects health-related adversity specifically or broader processes of family adaptation.

Narrative coherence provides a useful lens for examining parental adaptation as it indicates whether, despite challenging experiences such as serious child illness, parents have a balanced, organised, and emotionally coherent view of their child. Whereas previous studies have focused on acute reactions to genomic testing (e.g., 3,34), the present study examines parental representations after families have had time to incorporate diagnostic information into everyday life.

Our first aim was to build on previous work (35) suggesting that genomic diagnosis may adversely affect narrative coherence in mothers of children with complex health conditions (Study 1, PEREGRIN mothers). However, as genomic diagnoses can facilitate adaptation, we did not specify the direction of group differences.

Our second aim was to compare narrative coherence among parents of children with or without complex health conditions (Study 2, PEREGRIN *cf.* NewFAMS). Given the challenges associated with caring for a child with health needs, we expected the clinical sample to show parental lower narrative coherence than the community sample. We also compared mothers and fathers, but given limited prior research, did not form an a priori hypothesis.

MATERIALS AND METHODS

Participants

The samples in this study are derived from two cohorts (PEREGRIN and NewFAMS) recruited in the East and Southeast of England, UK, described in detail elsewhere (32,35).

PEREGRIN Cohort

Study 1 design was preregistered; see (<https://doi.org/10.17605/OSF.IO/E7HPJ>). The data reported here comes from a larger mixed-methods study of 96 parents of seriously ill children who received rapid trio genome sequencing (rGS) in NICU/PICU or whilst under the care of Paediatric Neurologists or Geneticists (36,37). PEREGRIN (Parental Experiences of Rapid Early Genomic Results in Infancy) participants were recruited via NIHR Rare Disease Bioresource. Eligibility criteria included: (i) prior participation in the Next Generation Children project (NGC) and having received rGS, (ii) being a parent of either an infant (≤ 2 years at rGS) with or without a genomic diagnosis, or a child (> 2 years at rGS), with a genomic diagnosis. Eligible parents whose child had died > 12 months previously were eligible. Genomic diagnoses included mitochondrial, neuromuscular, neurodevelopmental, and epilepsy syndromes. Clinical diagnoses included congenital anomalies, hypoxic ischaemic encephalopathy, neonatal stroke, neurodevelopmental conditions, cerebral palsy, seizures, and cardiac anomalies. All children lived at home, with a mean of 2.14 children per household (range 1–5).

85 parents (53 mothers and 32 fathers) from 56 families completed the FMSS within a detailed interview about impact of rGS, conducted 1 to 5 years after rGS (*mean* 3.5 years, *SD* = 1.0), which resulted in a genomic diagnosis for 32 children in Study 1 (60.3% of families). Study 1 analyses were restricted to one parent per family ($n = 53$). At interviews, mothers' mean age was 39.71 years (*SD* = 5.75 years), children's (56.6% female) 5.87 years (*SD* = 3.09 years). Reflecting the local population, 58.5% of mothers had a degree. Most mothers (84.9%, $n = 45$) were married or cohabiting, 13.2% ($n = 7$) were single, and 1.9% ($n = 1$) divorced. Most (86.8%) reported White ethnicity ($n = 46$), 3.8% ($n = 2$) Asian, 1% ($n = 1$) Latina, and 7.9% ($n = 4$) other.

NewFAMS Cohort

Study 2 (**Table 1**) was not preregistered. It uses data from 25 PEREGRIN couples with full FMSS and questionnaire data, matched by child gender, and as closely as possible by child age and parent education with 25 NewFAMS couples. NewFAMS study (ref. 38) included 221 cohabiting couples expecting their first baby, recruited from antenatal clinics. Eligibility criteria included: delivery of a healthy singleton baby, English as a primary home language, and no history of severe mental illness/substance misuse. The current study uses data collected when children were 48 to 64 months old (ages 4 and 5). At birth, mothers' mean age was 32.21 (*SD* = 2.51), fathers' mean age was 32.79 (*SD* = 2.80). Slightly higher percentage of parents than in PEREGRIN cohort had a bachelor's degree or above (72%, $n = 36$). Most (88%) reported White ethnicity ($n = 44$), 6% Asian ($n = 3$), 2% Black ($n = 1$), and 4% other ($n = 2$).

Procedure

All parents provided written informed consent and independently completed online demographic / mental health questionnaires and the FMSS paradigm (adapted from ref. 39). Recordings were transcribed, de-identified, and checked for accuracy.

Measures

FMSS-Coherence

The current study employed the FMSS-Coherence coding scheme (40), which has six 1- to 7-point subscales: Focus, Elaboration, Separateness, Concern, Acceptance, and Complexity. For overall coherence, scores of 5 to 7 are rated as 'coherent' and indicate a consistent, elaborated, complex and believable picture of the child, without overwhelming concern or substantial problems in separateness. Lower scores (1 to 4) indicate contradictory, confused narratives, with poor acceptance or separateness, high levels of concern, or unrealistically positive or negative portrayal of the child (ref. 7). The first two authors were trained by the coding manual author and then trained two final-year undergraduates. All four researchers coded the first 20 PEREGRIN transcripts; all remaining transcripts were double coded. Three of these coders also coded NewFAMS transcripts, allocating mothers and fathers in the same family to separate coders. Inter-rater reliability was high: the mean interclass correlation coefficient (ICC) was 0.86 overall, and $> .73$ for all subscales. All discrepancies were resolved by discussion.

Parental Mental Health

In Study 1, parental anxiety and depression was assessed using the Hospital Anxiety and Depression Scale (HADS) (ref. 41), which comprises two 7-item subscales for anxiety and depression, scored from 0-21 each: scores < 7 indicate non-cases, 8-10 mild, 11-14 moderate, and 15-21 severe levels of anxiety/depression. Both subscales had excellent internal reliability in this cohort (Cronbach's alpha for Anxiety = 0.85, for Depression = 0.82).

Child's Health-Related Quality of Life

In Study 1, the developmentally appropriate Paediatric Quality of Life Inventory (PedsQL™ V4.0 Generic Core Scales) that measures parental perception of child's health-related quality of life (HRQL) (ref. 42) was used as a covariate. All 23 items have 5-point Likert scales (0 = "never a problem", 4 = "almost always a problem"). PedsQL™ items are reversed scored and transformed to a 0 to 100 scale, with higher scores representing better HRQL. Across diverse samples, parent-proxy-report of PedsQL™ provide a

valid and reliable measure (ref. 43), which had good internal reliability for all sub-scales in this cohort, Cronbach's alpha = 0.73 to 0.95.

Data Analysis

Statistical analyses were conducted in IBM SPSS Statistics (Version 30.0) and included a one-way analysis of covariance (ANCOVA) to compare mothers' narrative coherence (continuous scores) between diagnostic groups (Genomic Diagnosis vs No Genomic Diagnosis) in the PEREGRIN cohort, controlling for theoretically and empirically relevant variables. A sensitivity power analysis using G*Power 3.1 indicated that with the current sample size ($n = 53$), $\alpha = .05$, and two covariates gave 80% power to detect large effects ($f = .39$ (partial $\eta^2 = .13$) or larger), with pairwise deletion of missing data.

Second, we estimated a mixed effects model to examine whether narrative coherence differed across parents of children with complex diagnoses ($n = 25$ couples) and a community sample of parents of typically developing children ($n = 25$ couples). This approach accounts for non-independence of parents within families (44). We used a two-level model with parents (Level 1, $N = 100$) nested within families (Level 2, $N = 50$). Fixed effects included parent gender (Level 1, 0 = mothers, 1 = fathers) and cohort (Level 2, 0 = PEREGRIN, 1 = NewFAMS). We estimated random intercepts for families to account for non-independence of mothers' and fathers' responses within dyads. The model was estimated using the Restricted Maximum Likelihood method. Based on simulations, a sample size of 50 mother-father dyads provides adequate power to detect medium-to-large effects for between-family predictors (ref. 45), but is not sufficient to examine cross-level interactions.

RESULTS

Maternal Narrative Coherence in the Context of Child's Genomic Diagnosis

Descriptive Statistics and Bivariate Correlations (see Table 1).

Maternal age at interview ($r = -.30, p = .014$) and child health-related quality of life (HRQL) scores ($r = .29, p = .017$) were related to mothers' narrative coherence scores and so included as covariates in the main model. 40.0% of mothers of children without a genomic diagnosis (8/20), and 63.6% of mothers of children with a genomic diagnosis (21/33) scored in the "low coherence" range (dichotomized score).

Supplemental Table 1 shows proportions of low scores for subscales.

Main Model Testing Differences by Child Genomic Diagnosis

A one-way ANCOVA was conducted to compare diagnostic groups (with / without genomic diagnosis) for mothers' narrative coherence (continuous scores). Assumptions of homogeneity of regression slopes, homogeneity of variance, and normality of residuals were met. Coherence scores were higher for

mothers in the no-diagnosis group ($M = 5.30$, $SD = 1.42$) than in the genomic diagnosis group ($M = 4.66$, $SD = 1.31$), a mean difference of .64 (95% $CI [-0.13, 1.42]$) in the hypothesized direction (Cohen's $d = .48$, Hedge's correction = .47). However, after adjusting for maternal age and child HRQL, this difference was substantially attenuated, such that the adjusted means did not differ between the no-diagnosis ($M = 5.04$, $SE = .32$) and genomic diagnosis ($M = 4.82$, $SE = .24$) groups: $F(1, 48) = .251$, $p = .619$, partial $\eta^2 = .005$. Maternal age was statistically significant as a predictor in the final model: $F(1, 48) = 6.61$, $p = .013$, partial $\eta^2 = .121$, whereas child HRQL was not: $F(1, 48) = 2.56$, $p = .116$, partial $\eta^2 = .051$.

Parental Narrative Coherence Across Clinical and Community Samples

Descriptive Statistics by Sample

Table 2 presents demographic characteristics for PEREGRIN and NewFAMS cohorts. **Supplemental Figure 1** shows means and 95% CI s for Coherence total scores and subscales by cohort and parent gender. **Supplemental Table 2** shows descriptive frequencies of low scores (and high concern). For Total Coherence, when dichotomised, 48% of parents in the PEREGRIN (44.0% of mothers, and 52.0% of fathers) and 46% of parents in the NewFAMS (56.0% of mothers, and 36.0% of fathers) scored in low coherence range (scores 1 – 4).

Main Model Testing Differences by Cohort

Against expectations, PEREGRIN and NewFAMS parents in did not differ significantly in narrative coherence (**Figure 1**; $b = -.18$, $SE = .28$, 95% $CI [-0.75, 0.39]$ $t(48) = -.64$, $p = .526$). Similarly, narrative coherence did not differ significantly between mothers and fathers overall ($b = -.10$, $SE = .21$, 95% $CI [-0.52, 0.32]$, $t(49) = -.48$, $p = .637$). The residual variance was $\sigma^2 = 1.11$, and the family-level intercept variance was $\tau_{00} = 0.44$. The intraclass correlation coefficient indicated that 28.5% of variance in coherence was attributable to between-family differences. Fixed effects accounted for less than 1% of variation in narrative coherence (marginal $R^2 = .007$), whereas the full model including family-level clustering accounted for 29% of the variance in narrative coherence scores (conditional $R^2 = .290$). Pearson correlations showed the overall pooled within-couple association ($n = 50$ couples) to match the ICC: $r = .279$, $p = .049$.

DISCUSSION

In minor ways we differ, in major we're the same – Maya Angelou, Human Family

With expanding availability of genomic testing, more families are receiving genetic diagnoses early in their child's life. These diagnoses have potential to reduce invasive investigations and inform clinical care, thereby improving the quality of life for both child and family. However, they can also introduce

treatment burden, diagnostic shock/trauma, and parental distress. Here, we explored parents' thoughts and feelings about their child after a period of adjustment to their child's diagnosis, comparing mothers' narrative coherence for children with health conditions with/without a genomic diagnosis (Study 1), and between mothers and fathers of clinical and community cohorts (Study 2). Neither comparison showed a significant mean difference.

These findings are reassuring, as developmental research suggest that how parents think and feel about their children influences the quality of parent-child relationships (8,46). That is, parents who attribute child's (mis)behaviour to permanent traits (*"this is just who they are"*) invest less warmth in the relationship and show higher levels of both punitive and disengaged parenting (12). FMSS instructions are open-ended, making this paradigm accessible to individuals of all educational and socio-economic backgrounds; it has been utilised across a range of developmental periods and contexts, including clinical and nonclinical settings (47). Our null results are a testament to parental resilience: caring for a child with complex health needs has been described as 'extreme parenting', yet our findings suggest considerable common ground in how parents of children with typical and atypical development think about their parent-child relationship.

Maternal Narrative Coherence Does Not Differ by Genomic Diagnostic Status

Study 1 compared narrative coherence (1-5 years post rGS testing) for mothers whose children had or had not received a genomic diagnosis for an early life critical illness. At interview, although several genomically undiagnosed children also experienced substantial ongoing challenges, parents of children with a diagnosis reported greater overall impact on child functioning (HRQL). Mothers in this group showed lower narrative coherence, but this contrast fell below significance after adjusting for maternal age and child's HRQL. As maternal age was unrelated to diagnostic status, this attenuation is likely explained by child HRQL. That is, differences in coherence are attributable to differences in parent-rated child development and functioning, rather than diagnostic status, suggesting that parental narrative coherence is tied to the lived, day-to-day realities of a child's condition and individual parental adjustment, rather than to the diagnostic category itself. Likewise, in studies with parents of children with cancer and rare diseases, parental reports of relief from guilt after exome / genome sequencing do not hinge on whether a causal result is returned (48,49), suggesting that the psychological significance of testing is independent from the diagnostic result. Note, however, that interviews were conducted 1-5 years after rGS testing, which limits the detection of acute effects of genetic testing on parental perceptions and narrative coherence. Supporting this view, the framing qualitative study (50) showed that parents reported temporally dynamic impacts on family relationships.

Narrative coherence was negatively related to maternal age, a finding that contrasts with findings from studies of prenatal narratives (15), and narratives from parents of autistic children (16). Likewise, narrative coherence in Study 1 was unrelated to maternal education, and parent-reported depression /

anxiety symptoms, characteristics reported to relate to coherence in previous studies (13,16,51). Notably, however, as in previous studies, difficulties in narrative organisation appeared relatively common among the PEREGRIN mothers – regardless of aetiology, where just over half (54.7%) showed low coherence.

Parental Narrative Coherence Does Not Differ Across Clinical and Community Groups

Surprisingly, we did not find evidence that parents of children with complex diagnoses (PEREGRIN) showed lower levels of narrative coherence than parents of typically developing children (NewFAMS). Descriptive statistics highlight both commonalities in parental narratives and a relatively high overall prevalence of narrative difficulties (48% in PEREGRIN couples, 46% in NewFAMS). Similar proportions of low coherence scores have been reported for mothers of preschoolers with behaviour problems (52, $n = 212$ dyads), and in parents of autistic children (16 $n = 81$ dyads). Much higher rate of 78.18% of low coherence has been reported in a community sample of mothers of toddlers (53). These findings highlight the widespread need for parental support.

Mothers and Fathers Do Not Differ in Their Levels of Narrative Coherence

Only a handful of studies have assessed FMSS coherence in both mothers and fathers. Study 2 showed no significant effect of parent gender, echoing findings from primiparous expectant couples (15,32), and parents of children with autism (17), although some studies (54,55) have reported subtle differences in mothers' and fathers' narrative content, focus, or style. Interestingly, Sher-Censor et al. (17) found fathers' coherence to be associated with their emotional availability (EA, i.e., they exhibited more sensitive, attuned interactions with their child). By contrast, mothers' coherence was unrelated to EA but was associated with positive comments about their child and with their resolution of child's autism diagnosis (measured by Reaction to Diagnosis Questionnaire). Thus, narrative coherence may reflect different relational aspects for fathers and mothers. As highlighted in a review of 22 studies relating FMSS measures (assessed via four distinct coding systems) to directly observed parent-child dynamics (47), fathers remain under-represented in research and so more work with larger samples is needed to explore whether expressed attitudes and representations show similar or contrasting links with parent-child relationship quality for fathers and mothers.

Narrative coherence ratings in our study showed small-to-moderate within-couple similarity ($ICC = 28.5\%$), suggesting that narratives about the child may be co-constructed and reflect wider family relationship functioning (56). Parents of children with complex needs are especially reliant on practical and emotional support from extended family, and so an interesting avenue for future research would be to identify factors that strengthen or weaken within-family similarities in narrative coherence. For

example, might post-diagnostic support for parents lead to improved coherence in narratives provided by grandparents? However, our findings also highlight the importance of focusing on individual parenting experiences within couples, to tailor support accordingly. For example, concern and acceptance subscales may shed light on parental representations and be amenable to interventional support.

Strengths and Limitations

Including both mothers and fathers, comparing across matched clinical and non-clinical cohorts, and the timing of assessment are all methodological strengths of this study. Conducting interviews 1–5 years after rGS captures a period of relative adjustment rather than acute distress, complementing findings from acute post-diagnostic studies and providing a more ecologically stable picture of parental representations.

Study limitations include: (i) the lack of power needed to examine cross-level interactions (e.g., between parent gender and group status); (ii) the cross-sectional design, which precluded investigation of how parental representations shift with evolving clinical or family circumstances; and (iii) the lack of direct observational ratings of parent-child interactions that could help evaluate how closely parental narratives correspond to everyday caregiving behaviour.

Conclusion

After a period of adjustment to rGS results, parents of children with complex health conditions (with/without a genomic diagnosis), showed similarities in their narrative coherence. Contrary to our expectations, parents in clinical and community samples did not differ in their narrative coherence. Notably, nearly half of parents in both groups struggled to provide a multidimensional, realistic, and consistent narrative of their child and their relationship. While these null results are partially reassuring, there is a need to identify and provide support to families who express high levels of concern, low acceptance, or find it difficult to make meaning of their parenting experiences. As rGS becomes more widely used in early infancy, both the short and long-term effects of genomic test results on child-caregiver bonding and relationships should be examined. When combined with measures of family functioning and wellbeing, FMSS-based examination of narrative coherence may be a useful method for investigating relational strengths and difficulties.

Declarations

Data Availability

Deidentified data are available upon request. Data requests should be addressed to the corresponding author.

Ethical Approval

The PEREGRIN study was approved by the local research ethics committee (REC reference: 21/EE/0154, HVS/2020/3264, IRAS: 300380), by the NIHR Bioresource (NBR133), and by the Cambridge University Hospitals NHS Foundation Trust institutional review board (A095947). The NewFAMS study received ethical approval from the local NHS Research and Ethics Committee (London Bloomsbury REC: 14/LO/1113). The studies adhered to the principles set out in the Declaration of Helsinki.

Competing Interests:

The authors declare no competing interests.

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Author Contributions:

Conceptualisation: H.D., C.H., M.M.; Data Curation and Project Administration: H.D., C.H.; Funding Acquisition: C.H., H.D.; Formal Analysis: H.D., M.M.; Resources: H.D., M.M., S.C., I.C., M.F.; Supervision: C.H.; Writing-original draft: H.D., M.M.; Writing-review and editing: H.D., M.M., C.H.

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Tables

Table 1 Zero-Order Pearson Correlations Within the PEREGRIN Sample

	1.	2.	3.	4.	5.	6.	7.	8.	9.
1. Maternal age	–								
2. Maternal education	-.076	–							
3. Child age at interview	-.035	-.192	–						
4. Child sex	.027	.181	-.032	–					
5. Maternal anxiety ¹	.052	-.007	.004	-.044	–				
6. Maternal depression ¹	.158	-.052	.113	-.146	.713***	–			
7. Child HRQL	-.017	.282*	-.412**	.053	-.370**	-.415**	–		
8. Child diagnosis	.034	-.422***	.453***	-.126	-.085	.051	-.549***	–	
9. Maternal coherence	-.300*	.215	-.158	.084	.041	-.062	.294*	-.245*	–
<i>M</i>	39.71	-	5.87	-	8.25	5.10	56.84	-	4.87
<i>SD</i>	5.75	-	3.09	-	4.23	3.82	24.03	-	1.39
Min	30.42	1	2.37	0	2	0	9.09	0	3
Max	55.87	7	15.20	1	18	18	96.74	1	7

* $p < .05$, ** $p < .01$, *** $p < .001$

Note. N = 53. ¹ Data is missing for one participant (N = 52). child sex: 0 = female, 1 = male; child diagnosis: 0 = no genomic diagnosis, 1 = genomic diagnosis. HRQL = health-related quality of life, measured by PedsQL™; Maternal education: 1 = Lower secondary or less, 7 = Doctorate.

Table 2 Demographic Characteristics of PEREGRIN and NewFAMS

Variables	PEREGRIN		NewFAMS	
	Mothers	Fathers	Mothers	Fathers
Age (years) – M (SD)	32.17 (3.79)	35.28 (5.30)	32.21 (2.51)	32.79 (2.80)
Highest education (n)				
Lower-secondary	0	3	0	0
Upper-secondary	4	3	1	0
Post-secondary	4	6	4	5
Short-cycle tertiary	1	2	1	3
Bachelor's degree	11	3	12	9
Master's degree	3	8	6	4
Doctorate	2	1	1	4
Ethnicity (n)				
White	23	24	22	22
Asian	1	1	0	3
Black	0	0	1	0
Latinx	1	0	0	0
Other	0	0	2	0
Child age (years)	4.95 (1.63)		4.63 (.62)	
Child sex	14 female (56%)		14 female (56%)	

Figures

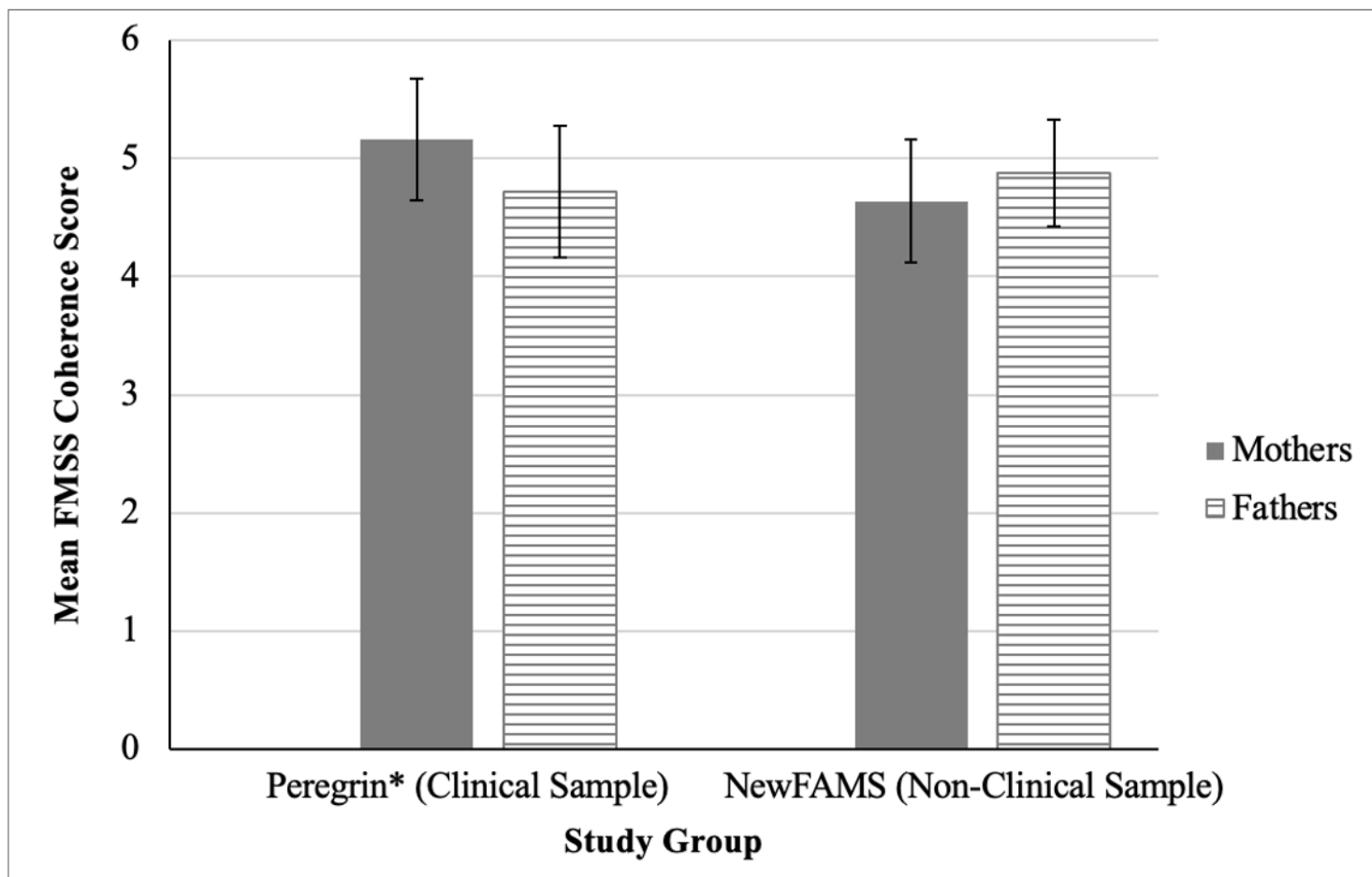


Figure 1

Mean Differences in Total Coherence Scores in PEREGRIN and NewFAMS Samples

Supplementary Files

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