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Beyond the individual: a contextual perspective on mental health in children with mild to borderline intellectual disabilities

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Chapter 5

Health problems in parents of children with mild to borderline intellectual disabilities in mental health care: A comparative study using linked databases

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Submitted

Abstract

Background: Little is known about health problems of parents whose children have mild intellectual disability or borderline intellectual functioning (MID-BIF) and mental health problems.

Objective: To quantify the presence and diversity of health problems among parents of children with MID-BIF and mental health problems.

Methods: This cross-sectional study uses linked data from Statistics Netherlands, mental health care providers, and general practices (GP). Parents were classified as group A ($n_{\text{mothers}}=565$, $n_{\text{fathers}}=436$; child with MID-BIF and mental health problems), group B ($n_{\text{mothers}}=3,830$, $n_{\text{fathers}}=3,137$; child with mental health problems only), or group C ($n_{\text{mothers}}=7,938$, $n_{\text{fathers}}=6,552$; general population). GP-reported ICPC-1 codes quantified health problems across body systems, into 1) presence of health problems, i.e., having at least one problem in a system, and 2) diversity, i.e., counting the number of systems with at least one problem. Analyses were adjusted for parental age and GP registration duration.

Results: Both groups A and B had a significantly higher presence of health problems than group C in several body systems. The largest group A differences were found in the endocrine/metabolic/nutritional, psychological, and digestive tracts, with ORs of 1.50–1.85 for mothers and 1.27–1.52 for fathers. Few group differences between A and B were significant. Both groups A and B had health problems in significantly more body systems than group C, indicating greater diversity.

Conclusions: Parents of children with mental health problems—regardless of MID-BIF—experience a higher presence and diversity of health problems than those whose children have no mental health problems, underscoring the need for integrated family care.

Introduction

Children with mild intellectual disability to borderline intellectual functioning (MID-BIF) have an increased risk of developing mental health problems (Bailey et al., 2019; Einfeld et al., 2011; Emerson, 2003). A growing body of research highlighted a bidirectional relationship between child mental health and parental well-being (Baker & Blacher, 2021; Gallagher & Whiteley, 2013), shaped by factors such as the demands of caregiving, shared environmental (socioeconomic) stressors, and shared genetic predispositions. Emerging evidence suggests that parents of children with intellectual disabilities (ID), across all severity levels, tend to have poorer physical and mental health (Chandravanshi et al., 2017; Staunton et al., 2020; Zhou et al., 2022). However, no studies have examined the health of parents of children with MID-BIF and mental health problems specifically. Importantly, unaddressed parental health problems are likely to exacerbate the child's mental health, reinforcing a cycle of intergenerational vulnerability (Campbell et al., 2021; Condon et al., 2020). Understanding the full scope of somatic and mental health problems among these parents could highlight unique health disparities within these families. This understanding may inform more integrated, family-oriented mental healthcare and facilitate early recognition.

More generally, parents of children with ID or mental health problems are known to experience high levels of psychological and physical health problems. Mental illness was significantly more common among parents of children with average intelligence in mental health services than in the general population (Campbell et al., 2021). A scoping review reported prevalence rates ranging from 16% to 79%, with higher estimates for mothers than for fathers. Additionally, elevated symptoms of depression and anxiety were consistently reported among parents of children with ID in the few available studies, particularly mothers and those whose child has additional mental health problems (Chandravanshi et al., 2017; Sharma et al., 2021; Tak et al., 2018). These findings suggested that the caregiving context may contribute to parental distress, especially when complicated by child cognitive challenges and mental health problems. Beyond psychological problems, parents also showed higher rates of somatic symptoms, fatigue, and sleep disturbances. Yet, these have received less empirical attention, despite their known bidirectional relationship with psychological distress as emphasized in the biopsychosocial model (Engel, 1977; Jansen et al., 2022). One recent

qualitative study highlighted broad mental and physical health burdens among parents of children with ID, including cumulative stress and exhaustion affecting daily life (Barratt et al., 2025). However, no studies have quantified the relative extent to which these problems occur and span multiple body systems (Arnold & McPherson, 2024).

Parents of children with MID-BIF may face distinct challenges, as suggested by a few studies (Dekker & Koot, 2003b; Embregts et al., 2010; Fenning et al., 2007; Kleefman et al., 2015; Riemersma et al., 2022). Unlike the more visible needs of children with severe ID, those of children with MID-BIF are often less apparent, involving more subtle cognitive difficulties (Kok et al., 2016; Nouwens et al., 2017; Snell et al., 2009). Nevertheless, children in this group also frequently experience emotional and behavioral problems (Dekker & Koot, 2003b), with studies estimating clinical levels up to 50% of cases (Dekker & Koot, 2003a; Kok et al., 2016). These child-related characteristics may be linked to increased parental stress (Kok et al., 2016), although empirical evidence on this connection remains limited. One study found that parents of children with MID and behavioral problems reported higher stress levels, lower perceived parenting competence, greater social isolation, and more dissatisfaction in relationships compared to parents of children with MID without such problems (Embregts et al., 2010). These difficulties were associated with increased vulnerability to psychological, as well as some somatic problems, although evidence for somatic conditions remains limited. Focusing on the children themselves, studies have shown that those with MID who also have a parent with mental health problems reported higher levels of social-emotional problems than children facing only one of these risk factors (Riemersma et al., 2022). Taken together, these findings point to a pattern of heightened, mutually reinforcing both somatic and psychological vulnerabilities in both these parents and children.

Guided by previous research, the overall aim of this study is to quantify and compare health problems of parents across three distinct groups: (1) parents of children with MID-BIF and mental health problems, (2) parents of children with mental health problems without MID-BIF, and (3) matched parents from the general population. We compared these groups in terms of the presence (i.e., any recorded health problem in a body system) and diversity (i.e., number of body systems with a problem) of somatic and mental health problems, using body systems from the International Classification of Primary Care (ICPC-1; Lamberts

& Hofmans-Okkes, 1996). We hypothesize that parents of children with MID-BIF and mental health problems experience both a higher presence and greater diversity of health problems, particularly mental health problems, compared to other parent groups. Our descriptive approach provides an empirical foundation for future research, as this is the first study to examine parental health differences in this population using general practice data.

Method

Sources of data

This study utilized data from the Extramural LUMC Academic Network, a regional population-based data infrastructure (Ardesch et al., 2023; Kist et al., 2024). Three data sources were analyzed: (1) non-public microdata from Statistics Netherlands (SN; results based on calculations by LUMC-Curium in project number 9269; Bakker et al., 2014); (2) patient records from multiple outpatient mental health centers for children with mental health problems; and (3) routinely collected GP electronic health records from ELAN-affiliated practices, covering a regional subset of practices.

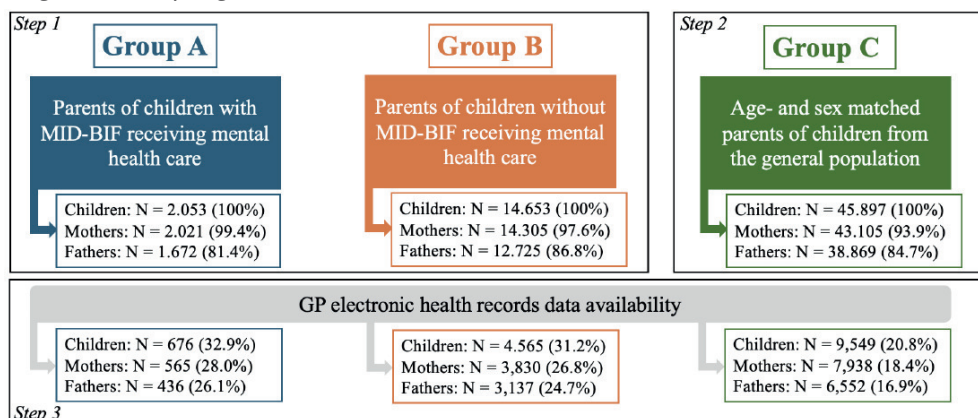
The SN microdata provided unique identifiers (record identification numbers, RINs), demographic variables, and parent–child linkages. Mental health patient records included age, sex, and mental health service registration dates, as well as diagnostic information. GP electronic health records contained information on health problems and care episodes.

Populations

The study population consisted of parents of children aged 17 or younger, divided into three groups. Group A included parents of children with MID-BIF (IQ 55–85 or similar functioning) who received outpatient mental health care between 2011 and 2020 at a specialized facility in the Hague. The children in this group had a mean age of 9.6 years ($SD = 4.2$, 63.8% male). Group B included parents of children with mental health problems without MID-BIF ($M_{age} = 11.0$, $SD = 4.5$, 54.8% male), identified through general child mental health centers. Group C served as a population-based reference group, matched on sex and approximately on age (± 1 year) to children in groups A and B combined ($M_{age} = 10.3$, $SD = 4.9$, 55.6% male). Although the aim was to select three reference individuals per child in groups A and B, the final number was slightly lower due

to a limited matching pool. After identifying children in groups A and B, matched children for group C were selected (see Figure 1 for flow chart). All parents in all three groups resided in The Hague or its surroundings.

Figure 1. Sampling flowchart



Ethical approval and data linkage

This study was exempted from review by the Medical Ethics Committee of Leiden-The Hague-Delft (CEP number: N22.048). For both mental health and GP data, information was securely stored and pseudonymized for researchers, with individuals given an opt-out option for data use. Confidential data linkage was performed using pseudonymized RINs. SN staff reviewed outputs to prevent identification risks. Further details on data linkage are available elsewhere (Ardesch et al., 2023).

Variables

Outpatient mental health care registration was used as a proxy to identify children with mental health problems. Parental demographic variables included age, birth country, family type (based on household composition at the parent's registered residential address), and household income in percentiles (see Table 1). Demographic characteristics were measured at the start of the child's treatment; for group C, values correspond to the matched child's reference year. Covariates were parental age and GP registration duration. Parental health problems were derived from their GP records coded using ICPC-1, which allows to group conditions into body system-based tracts to distinguish types of psychological and somatic problems (Lamberts & Hofmans-Okkes, 1996).

Of these, 16 tracts are relevant to females and 15 to males. Each tract, denoted by a letter (A to X or Y), covers a specific body system and includes codes for symptoms, complaints, and diagnoses commonly seen in primary care. Each ICPC chapter distinguishes between symptoms or complaints (codes 01–29) and formally diagnosed conditions (codes 70–99; Magnée et al., 2017; Pouls et al., 2023). For example, code P01 refers to “feeling anxious/nervous/tense”, whereas P76 denotes “depression”. In this study, we focused exclusively on codes 70 and above, as these reflect diagnosed somatic or mental health conditions. These codes were extracted from each parent’s episode list, reflecting all recorded diagnoses available during their period of registration. Tract Z (social problems) was excluded, leaving 15 tracts for females and 14 for males. Within these tracts, seven ICPC codes rated as non-problematic (score = 0) on the Cumulative Illness Rating Scale (CIRS; Linn et al., 1968) were excluded (e.g., A97 no disease, W78 confirmed pregnancy). To assess presence, we recorded whether each parent had at least one reported health problem within each tract. To assess health problem diversity, we added the number of tracts with at least one documented health problem per parent. A detailed overview of the ICPC tracts is provided in Appendix A.

Statistical analysis

Descriptive statistics were computed for parental age and the number of ICPC tracts per parent. Central to both analyses was the comparison among the three parent groups (see Figure 1).

In the first analysis, we examined the presence of health problems within each ICPC tract. Separate logistic regression models were conducted for mothers and fathers to estimate the odds of having at least one health problem in each tract across the three parent groups, adjusting for parental age and GP registration duration. Odds ratios (ORs) with 95% confidence intervals (CIs) were calculated for each ICPC tract, with OR > 1 indicating greater odds relative to the reference group.

In the second analysis, we assessed the number of ICPC tracts with at least one problem per parent separately for mothers and fathers and tested group differences using negative binomial regression, adjusting for parental age and GP registration duration. This model estimated incidence rate ratios (IRRs) and accounted for overdispersion in the count data.

Missing data (7.5% for GP registration duration) were handled using multiple imputation by chained equations under a missing-at-random assumption. For ICPC codes, the absence of a recorded diagnosis was interpreted as the absence of that condition. Analyses were conducted in RStudio (R v4.2.3; R Core Team, 2021) using *mice* for imputation and *stats* for generalized linear models. Logistic regressions were fitted with *glm*, and odds ratios (ORs), 95% confidence intervals, and p-values were reported ($\alpha = .05$).

Results

Study population

The study included 22,458 parents, 12,333 mothers and 10,125 fathers of 14,790 children ($M_{\text{age}} = 10.4$, $SD = 4.8$) registered with participating GPs (see Figure 1). Fathers were generally older than mothers at the year of mental health treatment onset of their child in groups A and B. Parents in group B were slightly older than those in group A. On average, parents were registered with their GP for approximately 9.6 years ($SD \approx 6.0$), with somewhat shorter durations observed in group C. Descriptive statistics are presented in Table 1.

Table 1. Parental characteristics at the time of child's mental health care onset

	Mothers			Fathers		
	Group A	Group B	Group C	Group A	Group B	Group C
<i>N</i>	565	3,830	7,938	436	3,137	6,552
Mean (and <i>SD</i>) age* in years	39.4 (7.1)	40.9 (7.4)	39.1 (7.3)	43.9 (8.4)	44.5 (8.2)	42.7 (7.9)
Mean (and <i>SD</i>) years registered with GP	9.65 (5.96)	9.92 (5.95)	8.28 (5.74)	10.23 (6.01)	10.08 (6.15)	8.69 (5.96)
Birth country (N, %)						
- The Netherlands	327 (57.9%)	2,344 (61.2%)	4,438 (55.9%)	246 (56.4%)	1,998 (63.7%)	3,869 (59.1%)
- Other European country	34 (6.0%)	263 (6.9%)	945 (11.9%)	13 (3.0%)	153 (4.9%)	641 (9.8%)
- Non-European country	204 (36.1%)	1223 (31.9%)	2,555 (32.2%)	177 (40.6%)	986 (31.4%)	2,042 (31.2%)
Family type* (N, %)						
- Dual parent household	329 (58.2%)	2,267 (59.2%)	4,585 (57.8%)	318 (72.9%)	2,155 (68.7%)	4,174 (63.7%)
- Single parents household	204 (36.1%)	1,377 (36.0%)	2,708 (34.1%)	27 (6.2%)	216 (6.9%)	661 (10.1%)
- Other	32 (5.7%)	186 (4.9%)	645 (8.1%)	91 (20.9%)	766 (24.4%)	1,717 (26.2%)
Mean (and <i>SD</i>) household income* (in percentiles)	31.61 (23.95)	41.57 (28.30)	44.64 (30.83)	39.41 (26.74)	50.36 (28.67)	54.75 (30.76)

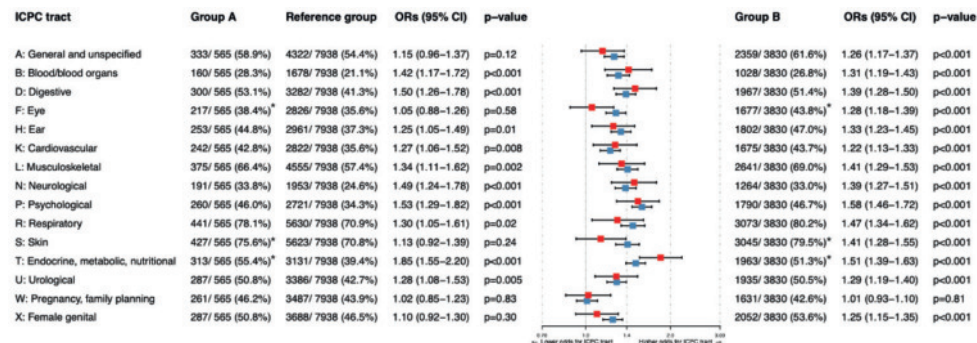
Note. *For groups A and B, values reflect the parental situation in the year the child started treatment; for group C, the matched child's year was used.

Presence of health problems per tract

Mothers

Figure 2 shows the proportion of mothers with at least one health problem per ICPC tract and corresponding ORs (groups A and B vs. reference), adjusted for age and GP registration duration. Both mothers of children with MID-BIF and mental health problems (group A) and those of children with mental health problems only (group B) had significantly higher odds of having at least one recorded health problem in several ICPC tracts. Higher odds were observed in 10 of 15 tracts for group A, and in 14 of 15 tracts for group B. The largest differences relative to the reference group were observed in the endocrine/metabolic/nutritional tract (T), with adjusted ORs of 1.85 for group A and 1.51 for group B; the psychological tract (P), with ORs of 1.53 (group A) and 1.58 (group B); and the digestive tract (D), with ORs of 1.50 (group A) and 1.39 (group B). Groups A and B differed significantly in the eye (F) and skin (S) tracts, with higher odds in group B, and in the endocrine/metabolic/nutritional tract (T), where group A showed higher odds.

Figure 2. Comparison of health problems among mother groups

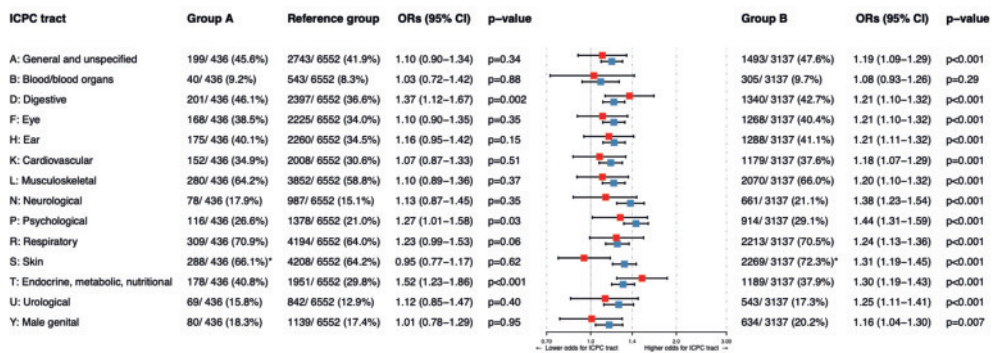


Note. Group A = Mothers of children with MID-BIF and mental health problems; Group B = Mothers of children with mental health problems without MID-BIF; Reference group = Mothers of children from the general population. ORs reflect the odds of having ≥ 1 health problem per ICPC tract (vs. reference), adjusted for maternal age and GP registration duration. Red boxes = group A vs. reference; Blue boxes = group B vs. reference; * = significant group A vs. B difference.

Fathers

Figure 3 shows the proportions of fathers with at least one health problem per ICPC tract and ORs (groups A and B vs. reference), adjusted for age and GP registration duration. A similar but less pronounced pattern than among mothers was observed. Compared to fathers in the reference group, significantly higher odds were found in 3 of 14 tracts for group A and in 13 of 14 tracts for group B. The largest differences were again observed in the endocrine/metabolic/nutritional tract (T), with adjusted ORs of 1.52 for group A and 1.30 for group B; the digestive tract (D), with ORs of 1.37 and 1.21, respectively; and the psychological tract (P), with ORs of 1.27 and 1.44. A significant difference between groups A and B was found only in the skin tract (S), with higher odds in group B.

Figure 3. Comparison of health problems among father groups

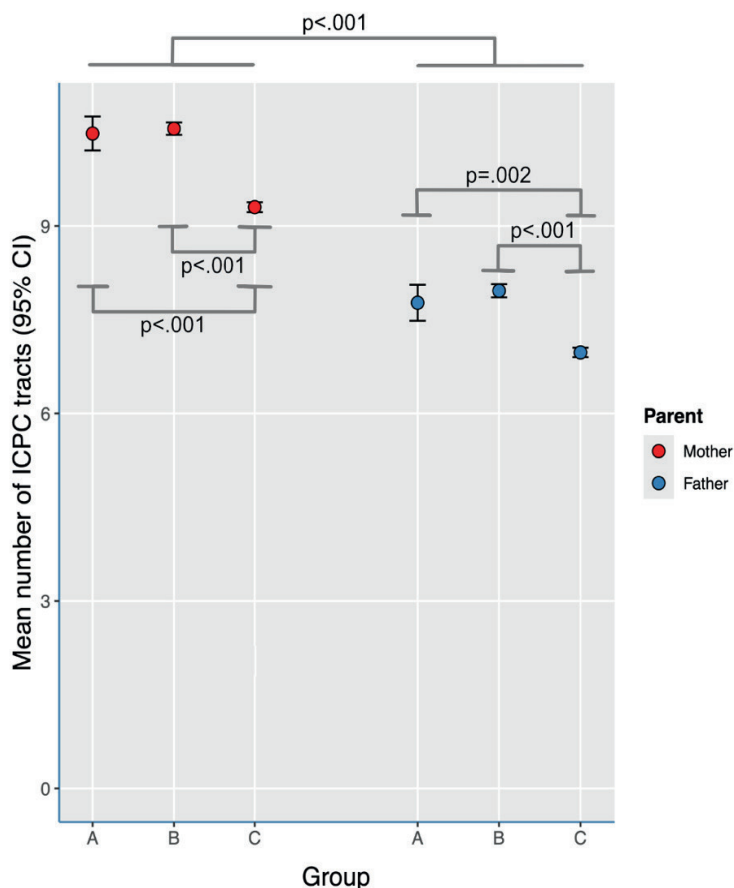


Note. Group A = Fathers of children with MID-BIF and mental health problems; Group B = Fathers of children with mental health problems without MID-BIF; Reference group = Fathers of children from the general population. ORs reflect the odds of having ≥ 1 health problem per ICPC tract (vs. reference), adjusted for paternal age and GP registration duration. Red boxes = group A vs. reference; Blue boxes = group B vs. reference; * = significant group A vs. B difference.

Diversity of health problems

As shown in Figure 4, mothers in groups A and B did not differ significantly ($p = .98$), but each had significantly more tracts than the reference group (IRR = 1.13, $p < .001$ for both). A similar pattern was observed among fathers, with no significant difference between groups A and B ($p = .27$), and both having significantly more tracts than the reference group C (group A: IRR = 1.07, $p = .002$; group B: IRR = 1.10, $p < .001$). Comparisons were adjusted for parental age and GP registration duration.

Figure 4. Mean number of ICPC tracts with ≥ 1 health problem



Note. Group A = parents of a child with MID-BIF and mental health problems; Group B = parents of a child with mental health problems; Group C = matched parents from the general population

Discussion

To our knowledge, this is the first study using GP-recorded data to quantify somatic and mental health problems in parents of children with MID-BIF and mental health problems, and compare them to health problems of parents of children with mental health problems only, and parents from the general population. Parents of children with MID-BIF and mental health problems showed a greater presence and diversity of health problems, including—but not limited to—psychological problems, compared to parents in the reference group.

However, largely similar patterns of health problems were found in parents of children with mental health problems only, suggesting that child mental health problems, rather than MID-BIF, may be the main factor driving the higher presence and greater diversity of health problems among parents.

Together, the combination of elevated presence and greater diversity of health problems across body systems could point to a wide-ranging health burden in line with the biopsychosocial model (Engel, 1977). This is particularly relevant given that several domains with higher presence—i.e., the psychological, endocrine/metabolic/nutritional, and digestive systems—are known to be especially sensitive to prolonged stress (Cohen et al., 2007; Leigh et al., 2023). Similar multi-systemic patterns have been reported in parents of children with autism, where chronic parenting stress was associated with both psychological symptoms and physiological dysregulation (Dijkstra-de Neijs et al., 2024; Van Der Lubbe et al., 2025).

Our findings address a critical gap in the literature, as evidence on the quantification of somatic and mental health problems in this parent population has been lacking. Previous studies have reported particularly elevated psychological and physical symptoms experienced by parents of children with ID (Chandravanshi et al., 2017; Sharma et al., 2021; Staunton et al., 2020; Tak et al., 2018; Zhou et al., 2022) and by parents of children receiving mental health care without ID (Campbell et al., 2021). Our study extends this work by focusing on parents of children with co-occurring MID-BIF and mental health problems—a group previously understudied—and by providing a comprehensive overview of their mental and somatic health problems across body systems. Altogether, this underscores the need to understand somatic and mental health as interconnected, especially within family systems.

Strengths and limitations

To contextualise our findings, it is important to consider both strengths and limitations. Relying on clinically recorded health data reduced the risk of recall and selection bias, which is especially valuable in research involving parents of children with complex needs. Additionally, the large sample size increased statistical power, and families in the sample reflect the region's ethnic and socioeconomic diversity. However, our database covers a subset of GPs (Ardesch et al., 2023). Second, the use of the nationally standardised ICPC

coding system supports consistent documentation across practices. Still, validity may vary with clinical judgment and recording practices, and routine care data may be subject to underreporting or misclassification. Third, by including both somatic and mental health problems in both parents, we provide a more comprehensive picture of parental health in line with the biopsychosocial model. The current cross-sectional design limits conclusions about the temporal order and bidirectionality of health problems, suggesting directions for future longitudinal research.

Conclusion and implications

Parents of children with mental health problems, with or without MID-BIF, show a higher presence and diversity of health problems, reflecting the complexity and vulnerability of their family systems. Given earlier evidence of associations between parental and child health (Baker & Blacher, 2021; Gallagher & Whiteley, 2013), our findings point to the importance of integrated, family-oriented care across mental health services, GPs, and youth care. Recent evidence increasingly supports the effectiveness of family-systems interventions in reducing parental stress and strengthening coping within families facing complex needs (Stolper et al., 2024; Sutherland et al., 2023). Beyond the family level, integrated care for both parents and children may also have favorable implications for broader societal costs, including healthcare use and labor participation (Trautmann et al., 2016; Venema et al., 2021). GPs are uniquely positioned to detect emerging problems in both generations, given their long-term involvement with families and their gatekeeping role in the healthcare system. Recognising family-level patterns of health problems can support timely referrals and coordination of multidisciplinary care.

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Appendix A. Overview of ICPC tracts

Letter	Tract	Examples
A	General and unspecified	Infectious mononucleosis, tuberculosis
B	Blood, blood-forming organs, immune mechanisms	Acute lymphadenitis, iron deficiency anaemia
D	Digestive	Ulcus ventriculi, disease of oesophagus, cholecystitis
F	Eye	Blepharitis, hypermetropia, myopia
H	Ear	Otitis externa, perforation tympanic membrane, deafness
K	Cardiovascular	Heart failure, atherosclerosis
L	Musculoskeletal	Infections of musculoskeletal system, osteoporosis
N	Neurological	Concussion, facial paralysis
P	Psychological	Anxiety disorder, depressive disorder
R	Respiratory	Asthma, chronic bronchitis, pneumonia
S	Skin	Eczema, psoriasis, urticaria
T	Endocrine, metabolic, nutritional	Diabetes, obesity, gout
U	Urological	Cystitis, urinary calculi
W	Pregnancy, childbearing, family planning	Abortion, toxemia
X	Female genital	Vaginitis, premenstrual tension syndrome
Y	Male genital	Balanitis, orchitis

