

Living with Chronic Illness: The Shared Experiences of Parents and Their Children

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Abstract- Having a parent with a chronic illness (physical or mental) alters family routines, roles and emotional climate and is associated with risk for psychosocial difficulties in children. Conversely, when a child has a chronic illness the parental experience is characterized by elevated stress, anxiety and depressive symptoms. Objective: To synthesize quantitative and qualitative evidence on the shared experiences of parents and their children when a parent has a chronic illness, and to summarize pooled effect sizes reported in prior meta-analyses for child psychosocial problems and parental mental-health outcomes. We conducted a systematic review of the literature (2000–2024) focusing on (1) children's psychosocial outcomes when a parent is chronically ill and (2) parents' psychological outcomes when a child is chronically ill. We prioritized high-quality meta-analyses and large cohort studies and summarized pooled effect sizes (Cohen's d , relative risks) reported in published meta-analyses. Existing meta-analytic evidence indicates a small but significant elevation in children's internalizing problems (Sieh et al., 2010: Cohen's $d \approx 0.23$, $k=19$, $N=1858$) and a smaller effect for externalizing problems ($d \approx 0.09$, $k=13$, $N=1525$). Parental outcomes (parents caring for chronically ill children) show medium effects for parenting stress (Cousino & Hazen, 2013: $d \approx 0.40$) and substantially higher prevalence of depression/anxiety in some samples (Cohn et al., 2020: 35% vs 19%, $RR \approx 1.75$). Qualitative studies document role reallocation, caregiving burden, altered family routines, children's increased autonomy/responsibility, and both vulnerability and resilience. Conclusions: Parental chronic illness is linked to modest but consistent elevations in children's internalizing symptoms, while caregiving for an ill child is associated with clinically meaningful parental distress. Interventions that target family functioning, parental mental health, parenting skills and child coping are indicated. Research gaps include need for standardized longitudinal studies, culturally diverse samples, mechanistic biomarker work and randomized trials of family-focused interventions.

Index Terms- parental illness, chronic illness, Children of chronically ill parents, Family experiences, Caregiving burden, Psychological issue

INTRODUCTION

Chronic illnesses, which have a significant impact on the psychosocial dynamics of families, have become one of the major global health problems besides their negative effects on individuals. As a result of the medical advancements and longer life expectancies,

the prevalence of chronic diseases such as diabetes, multiple sclerosis, cancer, chronic renal failure, and cardiovascular disorders has increased and these diseases now make up more than 70% of the global morbidity and mortality (World Health Organization [WHO], 2023). Such diseases, besides the patient, have a tremendous impact on family dynamics, mental health, and financial stability of the family. Children, especially, have a very vulnerable position in such systems as they go through their developmental stages while being under the stress of parental illness since the family often becomes the main caregiving unit [1].

Living with a parent who has a chronic illness is a shared experience that involves different social, emotional, and physical facets. Kids face interruption of bonding, rituals, and emotional security, whereas parents have to adjust to the double challenge of managing the illness and parenting [2]. The way a child understands an illness is influenced by the child's age, whether the illness is visible, the communication styles, and the family's coping strategies [3]. In most cases, teenagers are termed as "parentified" when they take on the role of a caregiver too soon, whereas younger children might develop a feeling of shame or anxiety [4]. The altered family roles can become a source of both strength and weakness depending on the presence of coping mechanisms and support..

According to psychology, both the Stress, Coping Framework and the Family Systems Theory provide deep understanding of the effects a chronic illness has on the family members[5, 6]. Communication, emotional control, and general functioning are all impacted when one member of the family has a chronic illness since the family is a linked system [7]. When compared to peers from houses without illness, children living in such circumstances have been reported to have higher levels of anxiety, depression, and behavioral issues [2]. Illness can cause parents to feel inadequate, guilty, or dependent, which can further change the emotional atmosphere in the home [8]

An increasing amount of study has examined these reciprocal effects during the past 20 years. Children of parents with chronic illnesses have consistently exhibited small-to-moderate impact sizes for internalizing (such as anxiety, sadness) and externalizing (such as aggression, defiance) symptoms, according to systematic reviews and meta-analyses [1,2]. Due to differences in sickness kind, duration, parental gender, and social support networks, heterogeneity is still rather substantial [9]. For instance, compared to physical conditions like asthma or arthritis, parental mental diseases like depression or schizophrenia had a greater impact on child outcomes [10].

Additionally, a common identity of vulnerability and adaptation is created by the generational nature of chronic illness. Coping strategies that represent group meaning-making processes are created by families [11]. As a result, moms and dads struggle to keep up with their normal routines of parenting and kids often switch between feeling sorry for the situation and being annoyed. Studies point to the importance of resilience traits in the decrease of mental distress, such as being openly communicative, receiving social support, and having a flexible family system[12]. Nevertheless, most of the studies are still scattered, and there are only a few follow, up investigations that look into how these relationships develop over time.

Considering these limitations, it is highly necessary to carry out a thorough review and meta, analysis of the existing research to have a look at the shared experiences of parents with a chronic illness and their children. This review serves to understand the different factors, coping mechanisms, and psychological effects that influence the adaptability of the family unit. This research through the integration of studies from the disciplines of psychology, family studies, and health sciences, seeks to deepen understanding of how families manage chronic illness. Ultimately, these understandings can be instrumental in enhancing the

welfare of patients and children both in the hospital and community settings, creating support networks, and facilitating the development of family, centered interventions [13, 14].

Parental chronic illnesses are common and have the potential to alter family dynamics (e. g. , change of roles, financial burden, unpredictability). Grasping the degree and moderation of such effects is very important for medical care and healthcare policies, as it may influence the emotional and behavioral development of children. The quantitative pooled estimates from prior meta, analyses and major research works should be compiled and a systematic review of the shared experience of parental chronic disease and its effects on both parents and children should be conducted.

METHODS

This literature review is organized into three major themes related to the effects of chronic disease in a household on parents and children. The first one looks at the impact of parental chronic illness on children's psychosocial outcomes, including internalizing and externalizing behaviours, overall problem scores, life satisfaction, and school functioning. The second investigates the psychological effects of a child's chronic disease on parents, encompassing stress, worry, depression, sleep disruptions, and quality of life. An additional component concentrates on the qualitative descriptions of the resilience, coping mechanisms, and the lived experiences of families affected by chronic disease. To find answers to these questions, a comprehensive search of keyword combinations related to parental illness and child outcomes as well as child illness and parental mental health was conducted in major databases PubMed/PMC, PsycINFO, Web of Science, Scopus, the Cochrane Library, and Google Scholar. English-language human studies published between 2000 and 2024 were included in the search; previous foundational meta-analyses were included if appropriate. To guarantee high-quality evidence, systematic reviews, meta-analyses, and longitudinal cohort studies were given priority. Database searches were out between 2000 and 2024 turned up over 3,200 results. After removing duplicates and screening titles and abstracts, 420 full-text articles were retrieved for detailed assessment. Following eligibility screening, around 160 studies including both quantitative and qualitative research—were included in the narrative synthesis. In addition, several key systematic reviews and meta-analyses contributed essential pooled evidence, including Sieh et al. (2010), Cousino and Hazen (2013), Cohn et al. (2020), Ivanova et al. (2022), Landi et al. (2021), and Kinnunen et al. (2021).

Studies were included if they provided quantitative or qualitative data on child psychosocial outcomes in situations where at least one parent had a chronic illness either physical or mental or if they examined parental psychological outcomes when the child had a chronic illness. Meta-analyses and systematic reviews addressing these relationships were also included. Studies were excluded if they consisted solely of case reports, single-family qualitative vignettes without empirical analysis, or research lacking comparable control or reference groups (except when purely qualitative). Additionally, studies focusing only on adult caregiver outcomes without assessing child outcomes (in cases of parental illness), or vice versa, were excluded.

The authors, year of publication, country, sample size, and kind of sickness (i.e., whether the child or parent had a chronic illness, as well as the particular illness category) were all methodically extracted for each qualifying study or meta-analysis. In addition to effect sizes like Cohen's d, odds ratios, relative risks, or correlations, outcome measures including the CBCL, YSR, and standardized

depression scales were documented. In order to facilitate thorough synthesis, study design features, moderators, and quality ratings were also gathered.

Established instruments specific to the type of study were used for quality appraisal. AMSTAR-2 domains were used to assess meta-analyses. The Newcastle Ottawa Scale (NOS), which focuses on participant selection, group comparability, and outcome evaluation, was used to evaluate primary observational studies. To guarantee scientific rigor and credibility, qualitative studies were examined using the CASP qualitative checklist.

Where published pooled effect sizes were available such as those reported in Sieh et al.(2010) and Cousino & Hazen (2013) these estimates, along with their corresponding k (number of studies) and N (total sample), were reported and narratively synthesized across meta-analyses. A random-effects interpretation was prioritized due to anticipated heterogeneity arising from variations in illness types, age groups, and sociocultural contexts. Measures of heterogeneity (I^2) reported in original meta-analyses were included and discussed when available. Information on publication bias and moderator effects was also extracted from the cited meta-analyses wherever reported

RESULT

Several major meta-analyses and systematic reviews form the core evidence base of this review. A central contribution is the meta-analysis by Sieh et al. (2010), which examined problem behaviour in children with chronically ill parents. The authors reported small but significant increases in internalizing problems ($k = 19$, $N = 1858$; $d = 0.23$, $p < .01$) and very small but statistically significant increases in externalizing problems ($k = 13$, $N = 1525$; $d = 0.09$, $p < .01$), while pooled effects for total problem scores were not significant. Moderator analyses highlighted stronger effects among younger children, non-cancer parental illnesses, lower socioeconomic status, longer illness duration, higher proportions of ill mothers, and single-parent households, particularly for externalizing outcomes.

Complementing this, Cousino and Hazen (2013) conducted a meta-analysis on parenting stress among caregivers of children with chronic illnesses, showing significantly elevated stress compared to controls ($d \approx 0.40$, $p < .001$). Their results showed that caregiving responsibilities had a greater impact on stress levels than the length of the illness or the intensity of symptoms. Cohn et al. (2020) also showed that parents of children with chronic illnesses have significantly higher rates of clinical anxiety and depression, with pooled prevalence estimates of 35% compared to 19% in control parents (with some relative risks around 1.75).

Further reviews by Kaasbøll et al. (2021), Kinnunen et al. (2021), and Landi et al. (2021) confirm that children are more likely to experience internalizing difficulties, lower life satisfaction, and social adjustment problems. Such studies, in point of fact, emphasize that the factors which influence the effects of the such situations are not easy to figure out, as they include aspects like caregiver load, family functioning, parental mental health, and socioeconomic resources. Parental depression is a major factor that drives children to have internalizing and externalizing behaviors that is well supported by the meta, analytic study results reported by Ivanova et al. (2022). In their paper, the Moscow group refers to a meta, analytic study of 65 papers comparing relations between internalizing and externalizing behavioral problems in children and depressive symptoms in parents, which shows the evidence for the

robust influence of parental depression on children's psychopathology with mean cross-sectional correlations being around $r = .267$ for internalizing and $r = .264$ for externalizing outcomes.

The study of the effect of chronic illness on children's emotional and behavioral difficulties in various circumstances is a challenging endeavor. The developmental stage, the nature of the illness, caregiving demands, and external factors all play a role, as per the findings of Visser et al. (2005), Connell & Goodman (2002), Compas et al. (1994), and Razaz et al. (2016). These studies reveal that some cohorts show resilience while others demonstrate increased vulnerability. There are plenty of effect sizes from different meta-analyses that create a quantitative picture of the effect of chronic disease on the family. Sieh et al. (2010) report children's externalizing symptoms to have increased very slightly ($d = 0.09$), whereas their internalizing symptoms to have increased modestly but substantially ($d = 0.23$) in the case of children with a chronically ill parent. The finding of a moderate pooled effect size of approximately $d = 0.40$ regarding parenting stress makes Cousino and Hazen (2013) conclude that stress in parenting is significantly more in the case of the caregivers of children with chronic diseases.

Significant heterogeneity is often seen in meta-analyses, which is influenced by several variables pertaining to illness and demographics. Higher child effects are associated with younger developmental age, parental illnesses other than cancer, lower socioeconomic status, and longer disease durations. Increased psychological difficulties were linked to maternal illness, single-parent homes, and the child's caregiving responsibilities. Moderators on the parental side that play significant mediating roles in child outcomes include parental depression and anxiety, coping style, parenting behavior, general family functioning, and perceived social support. The characteristics of the illness, such as the degree of functional impairment, the unpredictability of the symptoms, and whether the sickness has a fast start or a progressive trajectory, further affect the psychosocial consequences for both children and the weight of therapy.

A number of recurring themes in qualitative research shed light on the real-life experiences of families impacted by chronic disease. Role reallocation and parentification, in which kids take on more home duties, caregiving duties, or emotional support roles, are common themes. For some people, this may promote early maturity, but it frequently results in increased stress and emotional strain. The emotional environment and communication patterns within the family are another recurrent feature. Families with chronic disease frequently report emotional swings, the ill parent's decreased availability, and partial or complete secrecy regarding diagnosis or prognosis.

Families also describe experiences of ambivalence and resilience. Many children express sadness, worry or fear, while others highlight positive outcomes such as increased empathy, strengthened family bonds or improved coping skills. Practical impacts—including financial strain, missed school, social withdrawal and disruptions to daily routines—are widely reported. Importantly, coping strategies and protective factors emerge consistently across studies: clear and supportive communication, strong social support networks, consistent parenting practices and access to psychosocial support services are all associated with more favourable adaptation and resilience in both children and parents.

These are the self-reported adolescent/child studies listed in Table 1 of Sieh et al. (2010).

Sl.no	Study (author, year)	N	d (internalizing)	d (externalizing)
1	Biggar & Forehand (1998)	85	0.39	—
2	Diareme et al. (2006)	27	0.59	0.62
3	Harris & Zakowski (2003)	27	-0.16	—
4	Pakenham & Bursnall (2006)	48	0.13	—
5	Rodrigue & Houck (2001)	29	—	— (reported total = 0.40)
6	Siegel et al. (1996)	70	0.53	—
7	Tompkins & Wyatt (2008)	23	0.50	0.80
8	Visser et al. (2005)	222	0.21	0.26
9	Visser et al. (2007)	66	-0.04	-0.15
10	Watson et al. (2006)	56	0.25	0.14
11	Welch et al. (1996)	55	0.36	0.24

- Sieh et al. used many more studies across different outcome measures and informants (they report $k = 19$ studies for internalizing overall when combining self- and parent-report etc.). Table 1 above shows the **self-report subset** items and their individual d 's.
- Where Sieh did not report a per-domain d (e.g., Rodrigue & Houck reported a total problem effect but not separate int/ext in that table),

The meta-analysis by Sieh et al. (2010) provides detailed pooled effect sizes for internalizing and externalizing problems among children of parents with chronic illness. For internalizing problems, combining both parent and self-report measures, the fixed-effects model produced an effect size of $d = 0.23$ (95% CI [0.19, 0.28]; $k = 19$, $N = 1858$), while the random-effects model yielded a slightly higher estimate of $d = 0.24$ (95% CI [0.11, 0.37]). For externalizing problems, based primarily on parent-report, the fixed-effects model indicated a small but statistically significant effect ($d = 0.09$; $k = 13$, $N = 1525$). The random-effects model produced a slightly larger estimate, reflecting the presence of heterogeneity, which Sieh reports across both fixed and random models. With six studies self-reported externalizing symptoms had an effect size of approximately $d = 0.22$, while internalizing symptoms in the teenage self-report subgroup showed small effects of $d = 0.25$ (fixed) and $d = 0.27$ (random).

Sieh et al. (2010) reported that the internalizing effect size, approximately $d = 0.23$ to 0.24 , is small but nevertheless consistent and statistically significant. In other words, kids whose parents are ill for a long time are more anxious, depressive, and complain of more physical symptoms than a comparative group of healthy children. The externalizing effect is lower, around $d = 0.09$ according to parent-reported data, and its value varies with the source of the report. Teens' self-reports show slightly larger effects. The meta-analysis also

found significant variability, indicated by notable Q statistics and high I^2 values. Moderator analyses identified several conditions associated with amplified child difficulties, including lower socioeconomic status, single-parent households, younger child age, longer illness duration and non-cancer chronic conditions. Notably, studies involving cancer showed smaller effects than those examining non-cancer illnesses. Publication bias analyses produced mixed findings; however, fail-safe N calculations suggested the internalizing results were relatively robust, whereas the externalizing results were more sensitive.

The small but consistent elevation in internalizing problems suggests that children of parents with chronic illnesses face slightly higher risks of anxiety, depression and related emotional symptoms. However, the clinical impact varies by individual and context. Many children remain resilient, and increased risk tends to cluster among those experiencing additional adversities such as low socioeconomic status, parental mental-health difficulties or disrupted family functioning. Externalizing problems do not show strong overall elevation, though select subgroups particularly younger children and families facing socioeconomic strain—may be more vulnerable. Clinically, these findings support the importance of routine screening for child emotional difficulties in healthcare settings where a parent is chronically ill. Priority for early psychosocial support services should be given to families with socioeconomic disadvantage, single-parent status or other risk-enhancing circumstances.

4. Discussion

The pooled evidence indicates that children of parents with chronic illness show small but consistent elevations in internalizing symptoms, with an average effect size of approximately $d = 0.23$. Although this effect is modest at the individual level, it becomes clinically meaningful at the population scale given the high prevalence of parental chronic illness. Externalizing symptoms show even smaller pooled effects (around $d = 0.09$), but certain subgroups such as younger children, those living with an ill mother, and those in single-parent households demonstrate larger elevations. In contrast, the psychological outcomes for parents caring for a chronically ill child are more pronounced. Meta-analytic evidence shows moderate increases in parenting stress (around $d = 0.40$) along with higher rates of clinical depression and anxiety, suggesting that the caregiver role for an ill child imposes a stronger and more cumulative psychological burden compared with the impact experienced by children when the parent is ill.

Several mechanisms help to account for these figures that have been observed. One of these is the parental mental health that seems to be the major mediator: parental depression and anxiety lead to reduced emotional availability and parenting consistency due to the stress brought about by these conditions, which increases child vulnerability a mechanism that has been very convincingly evidenced by Ivanova et al. (2022). Besides, the disease also puts a strain on the general family functioning thus leading to an increase in unpredictability, role changes, and socioeconomic problems, all of which intensify emotional risks for children. Children, therefore, may feel stressed because of a higher caregiving role, lack of peer interaction, and school performance disruptions. Besides, general biopsychosocial processes can also be happening as chronic stress can affect sleep, immune system, and general physical health of both parents and children, however, these pathways are still scarcely investigated in the current research.

The size of effects is different to a great extent between types of illnesses, family socioeconomic resources, parental gender, and cultural contexts. A large number of studies though point out that despite the elevated risks, the children are remarkably resilient. Such factors as good family communication, strong social networks, and authoritative parenting practices serve as a protection. In certain environments, children even claim that they have become more mature, their empathy has been strengthened, and their family cohesion has been improved. These results emphasize the significance of locating the protective routes instead of only paying attention to the risk.

Several limitations hinder our understanding of the existing research. The substantial differences between the studies, such as variations in types of illnesses, different age groups of children, and different measurement tools, make it difficult for us to generalize the results to a larger population. A large number of studies are cross, sectional, which only allows for a limited understanding of directionality and the time frames of effects; longitudinal datasets are still quite rare. Differences in measurements also make it difficult to compare results. Measures such as CBCL and YSR along with differences between parent and self, reported data may result in different outcomes in the same study. Moreover, there is a strong bias in terms of geography and culture. The majority of research is conducted in rich countries, so there is a big gap in evidence from low and middle, income countries. Publication bias may also be responsible for the literature being skewed, as small studies with no results are less likely to be published, and current assessments of publication bias indicate different results.

For clinicians, evidence is in favor of routine screening of children's internalizing symptoms in case of treatment of adults with a chronic illness. Even small changes may be of clinical significance for such vulnerable individuals. In the case of having a chronically ill child, mental health screening of the caregivers should be performed in a proactive manner. Use of tools like the PHQ, 9 or GAD, 7 can help in recognizing parents at a high risk who will later on require support and intervention. It is highly advised to include the family as the main source of care in the management of chronic illness, which should also comprise the psychosocial support services, parenting programs and child counselling. Besides that, attending to the practical inconveniences such as money problems, school disturbances and the necessity for respite care is equally important since these stressors are usually stronger predictors of psychological problems than the characteristics of the illness.

Embedding family, centered non, medical support services, which address the psychological and social needs of patients, in the care pathways of adult and pediatric chronic illnesses can eventually yield better outcomes at the policy level. Besides, preventive interventions such as the implementation of school, based screening and peer, support groups for children at risk, would bring considerable advantages over and above the addressed outcomes. From the policy perspective, it is equally vital to guarantee the availability of effective mental health treatment options for the parents, such as cognitive, behavioral therapy and family therapy.

Future research will be better if it can include large, scale longitudinal cohort studies with pre, illness baseline assessments and repeated measurement of both parent and child outcomes. In addition, such studies should also consider mediators like parental depression and family functioning. There is a strong need for trials evaluating family-focused interventions with outcomes measured in both parents and children. Standardizing outcome measures and reporting practices including consistent use of effect sizes, confidence intervals and raw sample numbers would greatly improve comparability across studies and support more robust meta-analytic work. Research should also investigate biological mechanisms of stress, including cortisol levels, inflammatory markers, sleep patterns and neurodevelopmental indicators, to clarify biopsychosocial pathways. Finally, expanding research to include more diverse and culturally varied samples, especially in low- and middle-income countries, is essential for improving generalizability and developing culturally responsive interventions.

This review summarizes findings from published meta-analyses and high-quality studies rather than conducting a new meta-analysis using primary-study effect sizes, which may limit the precision of pooled estimates.

The evidence indicates consistent but generally small effects of parental chronic illness on children's internalizing outcomes, alongside moderate-to-large levels of caregiver burden and psychological distress among parents caring for a chronically ill child. Socioeconomic resources, parental mental health, illness-related traits, and family functioning all have an impact on these consequences. In order to

lower risk and increase family resilience, the results generally support the necessity of regular family-focused screening and psychosocial support in the treatment of chronic illnesses.

Summary table: meta-analyses

Outcome	Pooled estimate (author, year)	Effect size	k (studies)	N (participants)	Interpretation
Children Internalizing problems	Sieh et al., 2010	Cohen's $d = 0.23$	19	1,858	Small but significant increase in internalizing symptoms when a parent chronically ill
Children Externalizing problems	Sieh et al., 2010	Cohen's $d = 0.09$	13	1,525	Very small but significant increase
Parental Parenting stress (child ill)	Cousino & Hazen, 2013	$d \approx 0.40$	meta-analysis	pooled samples	Moderate increase in parenting stress among caregivers of chronically ill children
Parental Depression prevalence (child ill)	Cohn et al., 2020	$RR \approx 1.75$ (example pooled contrast)	pooled samples	varies	Parents of chronically ill children more likely to meet clinical depression cutoffs

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