Original Article

# Psychosocial Characteristics of Parents of Children with Chronic Diseases and their Role in Primary Healthcare

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**Abstract**

**Introduction:** The increasing prevalence of chronic illnesses and disabilities during childhood represents a significant public health concern, with profound psychological and social implications for affected families. A condition is typically classified as chronic when it persists for more than three months and significantly impairs daily functioning or fulfillment of social roles. Chronic illness in children encompasses a wide range of conditions, including disabilities, autoimmune diseases, congenital syndromes, cardiac disorders, and neoplasms. When a child becomes chronically ill, the entire family system is affected—particularly parents, who bear the burden of caregiving while striving to maintain balance within the household.

**Aim:** The present study aimed to investigate the psychological impact of children's chronic illnesses or disabilities on their parents, with a focus on self-compassion, humor, and family functioning.

**Materials and Methods:** A cross-sectional quantitative design was employed. The sample consisted of 107 parents of children with chronic illness or disability. Validated instruments were used: the Connor–Davidson Resilience Scale (CD-RISC) for self-compassion, the Humor Styles Questionnaire (HSQ) for humor, the Family Crisis Oriented Personal Evaluation Scales (F-COPES) for family functioning, and the SF-36 Health Survey for perceived health status.

**Results:** No statistically significant gender differences were observed in self-compassion, humor, or family functioning. SF-36 data showed that 72.9% of participants rated their health as "good" or "very good," and 57.0% reported no change compared to the previous year. Physical limitations mainly affected vigorous activity, while social and emotional functioning remained relatively preserved. Despite some reports of fatigue and emotional distress, most participants did not experience frequent interference with daily or social activities.

**Conclusions:** The findings suggest no significant gender-based differences in self-compassion, humor, or family functioning among parents of children with chronic illness or disability. Overall perceived health was moderately positive, although some emotional strain was evident. These results contrast with existing literature, which often reports such differences. Study limitations—primarily the small and gender-imbalanced sample—may have influenced the findings. Further research with larger, more diverse samples is recommended.

**Keywords:** chronic disease, child, mental health of parents, spirituality, coping of chronic disease.

## Introduction

Advancements in early diagnosis and modern therapeutic interventions have transformed many once-fatal pediatric diseases into manageable conditions, contributing to increased survival rates. However, the prevalence of chronic illnesses in childhood is steadily rising, presenting significant psychosocial challenges not only for the affected child but for the entire family. This trend has raised concerns among healthcare professionals, as epidemiological studies document a notable increase in chronic pediatric conditions in recent years (Compas et al., 2012).

A condition is typically defined as chronic if it has a biological, psychological, or cognitive basis, persists for more than three months, and significantly interferes with daily functioning and role fulfillment. These limitations extend to the child's cognitive, emotional, and physical capacities, often necessitating ongoing medical, psychological, and educational support. It is estimated that approximately 30% of children worldwide are affected by a chronic illness. The most frequently diagnosed conditions include asthma, cystic fibrosis, congenital heart disease, type 1 diabetes mellitus, attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), depression, and cancer. These illnesses are generally categorized by severity: approximately 66% are mild, causing minimal activity restrictions; 29% are of moderate severity; and 5% are severe, leading to substantial limitations in daily life (Pop-Jordanova, 2023; Steinhausen, 1994).

Chronic illness during childhood is associated with medical complexities, frequent hospital visits, diagnostic burdens, and prolonged therapeutic interventions. These challenges are often compounded by uncertainty regarding prognosis, resulting in long-term psychological stress for both the child and the family. Moreover, children with chronic conditions frequently experience disruptions in daily routines, reduced school attendance, limited social engagement, and restrictions in diet, physical activity, and play—all of which vary according to the severity and progression of the illness (Steinhausen, 1994).

The impact of chronic illness extends beyond the individual child, deeply affecting family dynamics. Parents—often the primary caregivers—bear the brunt of this burden, with significant repercussions for their physical and mental health, financial stability, and professional and social lives. The child's siblings are similarly affected, often experiencing feelings of neglect, anxiety, or confusion. Parental attitudes play a central role in the family's adaptive capacity. The way in which parents interact with their ill child and the broader family unit, the degree to which they encourage or restrict participation in daily and social activities, and the availability of informal support systems can influence family functioning and overall well-being (Queen et al., 2016).

Importantly, spirituality has emerged as a critical coping mechanism. Evidence suggests that spiritual beliefs—both among children and their parents—enhance resilience, support acceptance of the condition, and promote psychological well-being (Reynolds et al., 2014). In this context, the need for comprehensive psychosocial support becomes paramount.

Children with chronic illness or disability—and by extension, their families—require sustained and multidisciplinary support. Access to accurate information, psychosocial guidance, and family-centered care is essential. Within the framework of Primary Health Care, nurses are strategically positioned to provide holistic support. They act as educators, coordinators, and advocates, offering guidance on the use of medical technologies and tools, facilitating communication with other health professionals, and addressing the emotional needs of the child and their family. The nurse's involvement is not only clinical but relational and supportive, fostering trust and promoting health literacy (Haktanir Abul et al., 2019).

## Materials and Methods

**Study Design:** The study is based on a quantitative, non-experimental, cross-sectional design, which involves collecting data from a sample of units at a specific point in time, aiming to gather quantitative data on two or more variables. These data are subsequently examined to identify patterns of association. A structured questionnaire was used to obtain data from an adequate sample while ensuring participant anonymity.

**Aim and Research Hypotheses:** The aim of the present study is to investigate the impact of children's chronic illnesses or disabilities on the psychology and daily lives of their parents, as well as to examine how parental psychosocial characteristics may influence their interaction with Primary Health Care services. The research hypotheses of this study are as follows: (1) mothers exhibit lower levels of self-compassion compared to fathers; (2) parents of children with chronic illness or disability demonstrate lower levels of humor compared to the average values of the Greek population, with mothers displaying higher humor levels than fathers; and (3) families of children with chronic illness or disability experience higher levels of dysfunction compared to national norms, with mothers reporting higher dysfunction levels than fathers.

**Population and Sample:** The study population consisted of parents who have a child with a chronic illness or disability. The final sample included 107 parents. Convenience sampling was deemed the most appropriate method for this research.

**Data Collection:** The questionnaire used in this study comprised four validated instruments and was structured into five thematic sections: (1) demographic characteristics of the sample, (2) the Family Crisis Oriented Personal Evaluation Scales (F-COPES), (3) the Connor–Davidson Resilience Scale (CD-RISC), (4) the Humor Styles Questionnaire (HSQ), and (5) the Short Form Health Survey (SF-36). Approval for the use of all instruments was obtained prior to the commencement of the study. The demographic section included items related to gender, age, marital status, place of residence, educational attainment, employment status, number of children, and self-reported mental health status. Data collection was conducted between May and August 2025. The printed version of the questionnaire was distributed to Daycare Centers for Children with Disabilities (KDAP-MEA) in the Municipality of Volos, as well as to local speech therapy centers and pediatric clinics. In parallel, an online version was created using Google Forms and disseminated via associations, organizations, websites, and social media platforms targeting parents of children with chronic illness or disability. Statistical analysis was performed using IBM SPSS Statistics version 29.0.1.0. Descriptive statistics included means and standard deviations for quantitative variables and frequencies and percentages for categorical variables. Inferential statistics included t-tests and Mann–Whitney U tests, depending on the normality of distributions.

**Ethical Considerations:** All responses were collected anonymously, and informed consent was obtained from all participants. Ethical approval was granted by the Ethics and Bioethics Committee of the Department of Medicine at the University of Thessaly.

## Results

A total of 107 parents participated in the study, of whom 89 were women (83.2%) and 18 were men (16.8%). The largest proportion of participants fell within the 41–50 age group (35.5%), followed by those aged 51–60 (29.0%), 31–40 (17.8%), over 60 (10.3%), and under 30 (2.8%). Five participants did not disclose their age. Regarding marital status, the majority of participants were married (n = 87, 81.3%), while 11 were divorced (10.3%), 5 single (4.7%), and 4 widowed (3.7%). In terms of place of residence, 51 participants (47.7%) lived in cities with populations over 150,000, 42 (39.3%) in cities with fewer than 150,000 residents, and 14 (13.1%) in villages or small towns. Regarding educational level, 45 participants (42.1%) held a university or technical education degree, 29 (27.1%) held a postgraduate or doctoral degree, 27 (25.2%) were high school graduates, and 3 (2.8%) each had completed middle school or primary school. In terms of employment status, 58 participants (54.2%) were public sector employees, 19 (17.8%) were self-employed, 17 (15.9%) worked in the private sector, 9 (8.4%) identified as homemakers, and 4 (3.7%) were unemployed.

With regard to sibling status, 93 participants (86.9%) reported having siblings, while 11 (10.3%) reported having none. Among those with siblings (n = 93), 51 (54.8%) had one sibling, 28 (30.1%) had two, 10 (10.8%) had three, and 2 participants (2.2%) reported having four, five, or six siblings each.

Regarding the number of children, 26 participants (24.3%) had one child, 46

(43.0%) had two, 24 (22.4%) had three, 9 (8.4%) had four, and 2 (1.9%) reported having either five or seven children.

When asked whether they had ever visited a psychologist or psychiatrist and whether they were currently receiving medication, 53 participants (49.5%) answered affirmatively. However, only 5 (4.7%) of them were currently taking psychiatric medication, while 54 participants (50.5%) reported no history of psychiatric consultation or medication use.Regarding somatic health, 84 participants reported not having any physical illness or taking medication, while 23 reported having a physical illness, of whom 22 were receiving medication. As for the child with the chronic illness or disability, 61 were boys (57.0%) and 46 were girls (43.0%). Concerning the time devoted daily to caregiving, 41 participants (38.3%) reported spending more than 13 hours per day caring for their child, followed by 31 (29.0%) who reported 1–3 hours, and 13 (12.1%) who reported 7–9 hours. Lower percentages were observed in the remaining caregiving time categories.

A total of 81 participants (75.7%) reported sharing caregiving responsibilities, with the majority, 59 (54.9%), sharing care with their spouse. Other forms of support included paid caregivers, grandparents, extended family, and school staff. In contrast, 26 participants (24.3%) reported receiving no help in caring for their child. Regarding the nature of the child's chronic condition or disability, the most frequently reported were autism spectrum disorder (n = 11, 10.3%), type 1 diabetes mellitus (n = 11, 10.3%), epilepsy (n = 9, 8.4%), cerebral palsy (n = 9, 8.4%), Down syndrome (n = 8, 7.5%), asthma (n = 7, 6.5%), and intellectual disability (n = 6, 5.6%). The remaining 46 participants (43.0%) reported other chronic conditions not falling into the aforementioned categories. In terms of psychometric instruments, the mean score on the Family Crisis Oriented Personal Evaluation Scales (F-COPES) was 3.2773. The Connor–Davidson Resilience Scale (CD-RISC) yielded a mean score of 2.9720. The Humor Styles Questionnaire (HSQ) showed a mean score of 3.9845.

The participants' self-perceptions of their health status, as measured by the SF-36 Health Survey, indicate a generally favorable assessment. Specifically, 40.2% (n = 43) of respondents rated their health as "very good" and 32.7% (n = 35) as "good", while only 1.9% (n = 2) characterized it as "poor". When asked to compare their current health to one year ago, 57.0% (n = 61) stated it was "about the same", with 21.5% (n = 23) reporting some level of improvement. Regarding physical functioning, limitations were most apparent in vigorous activities (e.g., running, lifting heavy objects), with 25.2% (n = 27) of respondents stating these were "severely limited", while basic activities such as walking one block or bathing were largely unaffected.

Physical health issues were found to impact work or daily activities for a significant portion of participants. Specifically, 28.0% (n = 30) reported being able to accomplish less than they would have liked due to physical health, and 24.3% (n = 26) reported having to modify the type of work they performed. Similarly, emotional problems such as anxiety or low mood were reported to affect work or daily functioning by 20.6% to 24.3% (n = 22–26) of participants. Nevertheless, 75.7% to 88.2% (n = 81–94) reported no such emotional hindrances in the past four weeks.

Pain was present in varying degrees among participants, with 27.1% (n = 29) describing it as "moderate" and 21.5% (n = 23) as "none". Notably, 37.4% (n = 40) stated that pain did not interfere at all with their daily tasks, while 11.2% (n = 12) reported considerable interference. Social functioning remained relatively preserved, as 63.5% (n = 68) reported "no" or only "mild" limitations in social engagement due to physical or emotional health.

Emotional well-being indicators suggested a mixed profile. While 31.8% (n = 34) reported feeling calm "most of the time" and 31.8% (n = 34) described themselves as "happy people", a substantial proportion also reported fatigue (26.2%, n = 28) and feeling "exhausted" (21.5%, n = 23) frequently. Feelings of melancholy or discouragement were present in 23.4% (n = 25) of respondents. Nonetheless, 30.8% (n = 33) reported that physical or emotional issues rarely interfered with their social activities, and only 2.8% (n = 3) stated that such interference occurred "always".

Finally, perceptions of overall health beliefs showed that most participants rejected the idea of becoming sick more easily than others (66.4%, n = 71), and 38.7% (n = 41) considered themselves to be as healthy as their peers. While 22.4% (n = 24) anticipated that their health would worsen, 50.5% (n = 54) expressed disagreement with that belief. Interestingly, 21.5% (n = 23) of participants stated that their health was "excellent".

### Inferential Statistics – Hypothesis Testing

### Research Hypothesis 1

***Mothers exhibit lower levels of self-compassion compared to fathers.***

To examine this hypothesis, an independent samples t-test was performed to compare the self-compassion scores of mothers and fathers. The results revealed no statistically significant difference between the two groups, indicating that gender did not influence self-compassion levels in this sample.

### Research Hypothesis 2

***Parents of children with chronic illness or disability demonstrate lower levels of humor compared to the Greek population average, and mothers exhibit higher humor levels than fathers.***

Due to non-normal distribution of the humor variable, a Mann–Whitney U test was employed to assess gender differences. The analysis showed no statistically significant difference in humor scores between mothers and fathers. The overall mean humor score for the sample was 3.98, which aligns with previously reported Greek normative values.

### Research Hypothesis 3

***Families of children with chronic illness or disability experience higher levels of dysfunction compared to Greek population norms, and mothers report higher levels than fathers.***

An independent samples t-test was conducted to compare family functioning scores by gender using the F-COPES scale. The analysis yielded no statistically significant difference. The average family functioning score in the sample was 3.28, which suggests moderate use of problem-solving coping strategies, but does not differ by parental gender. All statistical results related to the research hypotheses are summarized in Table 1.

**Table 1.** Hypothesis Testing Results

| Hypothesis | Variable | Test | Group Comparison | Mean (SD) | Test Value | p-value | Significance |
|---|---|---|---|---|---|---|---|
| H1: Mothers have lower self-compassion than fathers | Self-Compassion | Independent Samples t-test | Fathers (n = 18) vs Mothers (n = 89) | 3.03 (0.645) vs 2.96 (0.575) | t(105) = 0.434 | .666 | ns |
| H2: Mothers exhibit higher humor levels than fathers | Humor | Mann–Whitney U test | Fathers (n = 18) vs Mothers (n = 89) | Mean rank: 50.47 vs 54.71 | U = 737.5 | .597 | ns |
| H3: Mothers report higher family dysfunction than fathers | F-COPES | Independent Samples t-test | Fathers (n = 18) vs Mothers (n = 89) | 95.28 (18.90) vs 98.93 (12.62) | t(105) = – 1.023 | .309 | ns |

## Discussion

The purpose of the present study was to investigate the impact of children's chronic illnesses or disabilities on parental psychology and on family relationships. The study population comprised 107 parents of children with a chronic illness or disability. Parental self-compassion was assessed using the Connor–Davidson Resilience Scale, parental humor was measured with the Humor Styles Questionnaire, and levels of dysfunction in family relationships were evaluated with the Family Crisis Oriented Personal Evaluation Scales (F-COPES).

Analysis of the variables relating to the self-compassion of parents of children with chronic illness or disability showed that the level of self-compassion did not differ between mothers and fathers ($p = .666 > .05$). This result may be influenced by the large gender imbalance among participants, as 89 of the 107 parents were women (83.2%) and 18 were men (16.8%). This could be related to the fact that mothers typically devote more time to caring for their children and, in particular, to the care of chronically ill or disabled children, and in many studies mothers are described as the primary caregivers (Coughlin et al., 2017). According to the literature, studies have concluded that mothers of children with chronic illness or disability experience greater feelings of guilt, self-blame, depression, and anxiety compared with fathers, who tend to express their emotions less and adapt more easily to the difficult situations that arise within the family in order to address them (Compas et al., 2012; Scherer et al., 2019; Coughlin et al., 2017). Overall, both parents of children with chronic illness or disability report reduced psychological and physical quality of life. A study conducted in Canada found that caregivers of children with chronic illness or disability were more than twice as likely to exhibit depressive symptoms and limitations in daily life compared with parents of healthy children (Fairfax et al., 2018).

Thus, according to the literature, mothers' levels of self-compassion appear lower compared with fathers, although most studies support that both parents experience worse physical and mental health.

With regard to the second research hypothesis on the humor of parents of children with chronic illness or disability, correlations showed no statistically significant difference between mothers and fathers ($p = .597 > .05$). The mean score on the questionnaire was 3.9845. However, according to the literature, parents of children with chronic illness or disability display lower levels of humor compared with the average values of the Greek population, due to the intense stress and tension experienced on a daily basis as a result of the increased demands involved in caring for a child with chronic illness or disability. Humor is considered one of the healthiest factors for maintaining life balance and contributes to the development of physical, cognitive, and emotional skills. According to Bennett (2003) notes that humor provides benefits such as reducing social isolation, improving social relationships, limiting negative emotions, and relieving stress. Another study by Rew and Horner (2003) supports that humor not only produces laughter but also enhances self-confidence, optimistic thinking, and good mood, improves interpersonal relationships, and promotes emotional stability. The sample of the present study was limited, making it difficult to compare it with the general population or to compare humor levels between the two parental genders. One factor that could influence humor levels is whether parents receive assistance in caring for the child with chronic illness or disability. In this study, 59 of the 107 participants reported sharing care with their spouse, while 26 stated that they received no help from anyone in caring for their child. Therefore, parents who share the care of a chronically ill or disabled child may present higher humor levels, as they are not burdened psychologically and physically to the same extent as parents who undertake such care entirely on their own.

Regarding the final research hypothesis—that families of children with chronic illness or disability would experience higher levels of dysfunction compared to the average values of the Greek population and that mothers would exhibit higher levels than fathers—it was found that the degree of family relationship functioning did not differ between mothers and fathers ($p = .309 > .05$). The mean F-COPES score was 3.2773. This result may be influenced by the problem-solving strategies employed by parents, the presence or absence of a supportive social environment, the relationships among family members, and spirituality, which affects coping mechanisms. The difference between mothers and fathers could not be adequately distinguished due to the limited number of fathers compared to mothers in the sample. In the present study, no statistically significant differences were found in the levels of dysfunction among families of children with chronic illness or disability, either between mothers and fathers or compared with the average values of the Greek population. Studies have concluded that families of children with chronic illness or disability exhibit dysfunction due to the increased daily demands of child care alongside parents' occupational responsibilities, efforts to maintain balance among other family members, and social activities (Guz et al., 2020). Another study highlighted factors influencing the functioning of families with a chronically ill or disabled child, focusing on parental mental and spiritual overload, heightened anxiety, and limited time for professional work, resulting in financial constraints, problems in marital relationships, reduced time spent with the siblings of the affected child, and social restriction, ultimately leading to psychological problems and depressive symptoms (Kish et al., 2018).

Characteristics of a family experiencing high levels of dysfunction include lack of empathy, lack of communication and interaction among members, and the presence of fear and other negative emotions. However, research has shown that families of children with chronic illness or disability, once they recognize the situation and its severity, may decide to manage it as effectively as possible in order to maintain balanced family relationships, ensure the smooth functioning of the family, prevent members from withdrawing from their social roles, and promote stability within the family. Health professionals can teach family members the importance of empathy in achieving these goals (Pierce et al., 2019; Deavin et al., 2018).

The absence of significant findings across the tested hypotheses does not necessarily indicate a lack of psychosocial burden. Rather, it may reflect limitations in sample representativeness, self-report bias, or the need for more sensitive measures. Additionally, the findings could highlight a potential shift in family dynamics and resilience factors that warrant deeper qualitative exploration.Overall, while the study's results diverge from much of the existing literature, they contribute to the nuanced understanding of family adaptation and psychosocial functioning in the context of pediatric chronic illness. These findings underscore the importance of considering contextual variables, such as gender roles, support systems, and coping resources, when designing interventions for affected families.

**Limitations:** This study is subject to several limitations. First, the relatively small sample size and the overrepresentation of mothers may limit the generalizability of gender-related findings. Second, the reliance on self-report questionnaires introduces the possibility of social desirability bias and subjective misreporting. Finally, the cross-sectional design restricts any causal inferences regarding the relationships between self-compassion, humor, family functioning, and resilience.

**Future Research Directions:** Future research should seek to recruit larger and more demographically balanced samples, particularly with regard to parental gender, to better examine potential differences in self-compassion, humor, and family functioning. Employing longitudinal designs would allow for the exploration of causal relationships between psychosocial variables and parental well-being over time. Additionally, the inclusion of matched control groups from the general population would enhance the interpretability of comparisons with families of children with chronic illness or disability.

To gain deeper insights into the lived experiences of caregiving parents, qualitative or mixed-method approaches are recommended. Such methodologies can capture subjective meanings, contextual factors, and emotional nuances that are often missed by standardized quantitative instruments. Furthermore, future studies could assess additional psychosocial constructs—such as caregiver burden, coping flexibility, post-traumatic growth, or perceived stigma—to provide a more multidimensional understanding of parental adaptation and resilience.

Finally, the design and evaluation of tailored psychosocial interventions—such as compassion-based training programs, humor therapy modules, or structured family resilience interventions—may contribute to identifying effective strategies for strengthening the emotional well-being of parents caring for children with chronic health conditions or disabilities. Interdisciplinary collaboration with nursing professionals, psychologists, and primary health care providers will be essential in translating these research findings into practical applications.

**Conclusions:** The presence of a chronic illness or disability during childhood has profound implications not only for the affected child but for the entire family system. Parents are frequently confronted with elevated levels of anxiety, guilt, shame, and emotional exhaustion. These challenges often disrupt family dynamics and limit social engagement, while also contributing to role strain within the household.

The present study sought to examine the psychological burden experienced by parents of children with chronic illness or disability. Despite expectations drawn from the literature, no statistically significant differences were identified in levels of self-compassion, humor, or family dysfunction between mothers and fathers, or when compared to normative values from the general Greek population. These findings contrast with previous research that has documented significant gender-based differences and heightened psychosocial distress among parents of chronically ill children.

Regarding perceived health status, the majority of participants described their health as “good” or “very good,” and most reported no major deterioration compared to the previous year. Although physical and emotional health issues were reported to interfere with work or daily activities in a moderate proportion of participants, overall social functioning appeared relatively preserved. Emotional well-being indicators revealed a mixed picture, with many reporting fatigue and psychological strain, while others expressed satisfaction with their current state of health.

It is possible that these non-significant results reflect certain methodological limitations. Most notably, the relatively small sample size and the underrepresentation of male participants may have restricted statistical power and reduced the generalizability of the findings. Furthermore, a considerable number of potential participants declined involvement due to the questionnaire’s length or difficulty with online access—particularly among older respondents and those residing in rural areas.

Future studies should aim to recruit more diverse and balanced samples and include comparison groups comprising parents of healthy children. Exploring differences across specific diagnostic categories, as well as examining the perspectives of siblings, may also offer valuable insights into family dynamics and resilience. Special attention should be given to humor as a potential coping resource, an area that remains underexplored in Greek populations.

Finally, the psychosocial experiences of these parents merit further investigation in relation to Primary Health Care. Understanding how emotional burdens, coping strategies, and family functioning influence healthcare engagement can inform the development of tailored interventions. Nurses, in particular, are uniquely positioned to support these families—not only as caregivers, but also as educators, counselors, and advocates.

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