

The psychological aspects of parents who take care of children with chronic illnesses: A Review of the literature

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World Journal of Advanced Research and Reviews, 2023, 19(02), 1136–1176

Publication history: Received on 30 June 2023; revised on 10 August 2023; accepted on 13 August 2023

Article DOI: <https://doi.org/10.30574/wjarr.2023.19.2.1612>

Abstract

Introduction: Nowadays, chronic diseases in children are constantly increasing. Parents have a crucial role in taking care of their children as they are responsible to fulfill their needs. This situation aggravates their psychological state.

Purpose: To study the psychological effects of parents who take care of children-adolescents with chronic diseases which don't belong to the category of rare diseases or psychiatric disorders.

Methods: This literature review was conducted with data retrieved from two electronic databases, "Pubmed" and "Google Scholar". The research lasted from December 2021 to September 2022.

Results: For this literature review 1433 studies were retrieved while after further analysis 32 studies were used. As a result, parents of children with chronic illness experienced the feeling of anxiety, fear, depression and emotional burden, affecting their quality of life to a large extent.

Conclusions: Families caring for a child with a chronic disease were characterized by a burdened psychological state and a low quality of life, which was influenced by socio-demographic, economic and psychological factors. It was deemed necessary to provide more effective support to these families as well as to develop tools for the treatment of chronic disease.

Keywords: Psychological effects; Caring parents; Children with chronic illness; Psychological effects; Chronic illness; Childhood cancer; Parents; Diabetes; Asthma; Children; Parental anxiety; Adolescents; Disability; Renal failure; Pandemic; Covid-19

1. Introduction

The diagnosis of a child with a chronic disease has an impact on the mental health of the family of the affected children, especially on the parents, who have taken on the role of caregiver. Caring for these children is a process that takes years and requires effort and consistency. It is a holistic and individualized process that, combined with the intense emotions that arise due to the difficulty of the situation, considerably affects the mental health of the parents. Moreover, the consequences of this situation can also affect other aspects of the parents' lives such as their professional career, social relationships, as well as their financial status [1].

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Generally, when the disease is announced, both the parents and the affected member experience the so-called "stages of mourning": diagnosis, anger, withdrawal, negotiation, and acceptance. Caregivers before reaching the final stage of this process might be affected by several factors, such as the age of onset of the disease, the severity, the existence of a diagnosed psychological disorder in the family members, the existence of other healthy children, the financial situation of the family, as well as the type of the disease, i.e. whether it is congenital or acquired.

In these cases, the relationship between the parents and the chronic patients is very important, as the condition affects the psychology of children and adolescents, which is reflected in the transitions of the psychological mood of the parents. [2] Consequently, these families have an urgent need for psychological and financial support to be able to provide meaningful support to the affected child.

Unfavorable financial conditions might burden the psychology of parents even more, being unable to meet the financial demands that coexist with chronic diseases, due to long-term medication regimens, diagnostic tests, as well as repeated hospitalizations. Frequently, parents do not prioritize their own needs, as they tend to become overprotective of the affected member. This fact results in the physical and mental exhaustion of the parents, as well as the neglect of healthy family members. Parents are forced to be constantly alerted to efficiently deal with emergencies due to chronic illness, such as a seizure or a hypoglycemic episode. The vast majority of the parents in similar situations present symptoms of depression, anger and anxiety at the initial announcement of the disease, consequently often creating socio-behavioral and mental health problems in the pediatric patients, resulting in the creation of a vicious cycle that affects the mental balance of both children and parents. [2] Literature suggests that mothers of children with chronic diseases have higher rates of parental stress, as well as more intense symptoms of emotional instability, than fathers who seem more often to refuse the new reality. Having a sick child might shake the parents' relationship, as physical and psychological fatigue impacts the relationship between them. During health crises within the family, caregivers often have to face social stigma as well, which is related to worsening self-esteem, mental health and financial conditions of the family [3].

Furthermore, the Covid-19 pandemic seemed to affect all aspects of human activity, significantly burdening the psychology of the Greek population. Under these conditions, it would be interesting to examine the way the pandemic affects the psychological state of parents who care for a child with a chronic illness.

This literature review aims to study the psychological effects of the care of children and adolescents with chronic diseases to parents, who do not belong to the category of rare diseases and psychiatric disorders. More specifically, the literature review aims to analyze the psychological state of parents so that the negative effects resulting from their children's illnesses to be communicated and addressed more effectively. In addition, we refer to tools and methods for improving the mental health of parents. Finally, this study focuses on the effect of the Covid-19 pandemic on the psychological state of parents.

2. Material and methods

For the conduction of this literature review, the electronic databases «PubMed» and "Google Scholar» were searched for relevant articles from December 2021 to September 2022. The search was conducted with the use of the following keywords/phrases: "psychological effect", "parenting caring", "children with chronic illness", "psychological impact", "chronic disease", "pediatric cancer", "parents", "cancer of childhood", "diabetes mellitus", "asthma", "children", "parenting stress", "adolescents", "teenagers", "disability", "treatment", "therapy", "renal failure", "pandemic", "Covid-19". PubMed search revealed 1117 results, while from the Google Scholar database we found 316 results. The primary research questions of our study are «what are the psychological effects of parents having children with a chronic disease?", "how do the chronic diseases of pediatric patients affect their parents?" and "how did the pandemic affect the psychological state of parents who took care of a child with a chronic disease?".

The selection of the scientific articles was based on specific eligibility criteria. For the selection of the articles, we used the following inclusion criteria: Articles must have been published between 2017 and 2022, in Greek or English language. They must refer to the psychological effects of parents of children and adolescents aged 0-18 years, and the chronic disease of the children should not belong to the category of rare diseases and psychiatric disorders. We excluded studies that were literature reviews, case studies, clinical trials, and meta-analyses, as well as duplicate articles.

In terms of the characteristics of the articles, we extracted data such as the study's population, tools, aim, and type of research, as well as the results and conclusions, which are presented in detail in Table 1. The articles search and selection were carried out by two independent researchers based on the PRISMA method. The studies were then reviewed and selected first based on their title, followed by their abstract and finally based on their full text. The final number of studies included in this literature review was 32.

Table 1. Study characteristics

Authors - scientific journal	Population sample - tools	Objective -type of research study	Results	Conclusions
Albani, 2017, PhD dissertation [2]	<p>Sample: 285 parents of children with T1DM.</p> <p>Tools: 1) Family Environment Scale, Form R-FES, 2) Hostility and Direction of Hostility Questionnaire - HDHQ, 3) Symptom Checklist 90-R - SCL-90, 4) State - Trait Anxiety Inventory - STAI, 5) Other As Shamer Scale-OAS, 6) Experience of Shame Scale-ESS 7) Socio-demographic sample registration form.</p>	<p>Aim: The assessment of the socio-demographic characteristics that affected the psychology of parents who cared for children with Type 1 Diabetes Mellitus.</p> <p>Type of research study: Empirical research</p>	<p>Gradual acceptance of the disease by the parents, as well as the changes that occurred due to it both at the family and personal level.</p> <ul style="list-style-type: none"> •Somatization of psychological changes and external shame differed according to parental age. <p>The demographic characteristics of the sick children were associated with the psychopathology of their parents.</p>	<p>Awareness of the impact of the socio-demographic factors on parents' psychology improved the way the management of the disease and strengthened the support offered by parents to children with Type 1 Diabetes Mellitus.</p>
Baek et al., 2017, Pediatric Nephrology [4]	<p>Population Sample: 79 parents of children with end-stage renal disease, including 47 children receiving dialysis and 32 children who underwent a renal transplant.</p> <p>Tools: 1) Pediatric Patient Quality of Life Questionnaire: Impact on the Family, 2) Pediatric Patient Quality of Life Questionnaire: End-Stage Renal Disease</p>	<p>Aim: Evaluating the impact of pediatric end-stage renal disease on parents.</p> <p>Type of research study: Cross-sectional study.</p>	<p>Families with children on hemodialysis were more affected in terms of social, physical, emotional functioning, stress, communication level, social relationships, daily activities and the health level of the parents compared to the parents of children who faced the disease with peritoneal dialysis or grafting.</p> <p>Family relationships were negatively affected by the duration of the disease.</p> <p>The level of family communication was influenced by the mother's age.</p> <p>Cohabitation affected the families.</p> <p>Parents' health level was affected by general fatigue and peer interaction.</p>	<p>The type of treatment followed for renal disease seemed to affect the families. The parents of children who went through hemodialysis rather than peritoneal dialysis or transplantation had a bigger impact on their daily routine. Also, these parents reported more emotional burden which affected their quality of life due to the disadvantages and difficulties accompanying hemodialysis.</p>

<p>Lagercrantz et al., 2017, The Journal of Asthma [15]</p>	<p>Population Sample: 18 parents of children with severe allergic episodes</p> <p>Tools: Four focus group interviews</p>	<p>Aim: The assessment of the quality of life of families who cared for a child with severe allergic episodes (Asthma, Eczema, Food Allergy, High Fever)</p> <p>Type of research study: Qualitative study</p>	<p>Parents reported experiencing limitations and the need for planning in their daily lives due to their child's illness.</p> <p>Outside the family environment, parents reported feeling fear and anxiety about their child's physical and psychological health.</p> <p>Parents felt dependent on the doctor and were concerned that their child was having difficulties integrating smoothly into the school environment due to the allergy.</p> <p>Lack of information about the disease was observed both in the family and in the social environment.</p>	<p>Allergic episodes restricted the life of the whole family and emotionally burdened the parents who felt the need for continuous and comprehensive information about their child's respective allergy. Therefore, the provision of psychological support and information to families through Health Services is necessary.</p>
<p>Nightingale et al., 2017, Journal of Pediatric Nursing [31]</p>	<p>Population Sample: 23 parents and 22 health professionals from 6 artificial kidney units in UK.</p> <p>Tools: Interview.</p>	<p>Aim: The design of a tool that would identify the learning needs of parents regarding the provision of clinical care to a child with chronic diseases in the family environment.</p> <p>Type of research study: Mixed methods, two-phased design study</p>	<p>Health professionals recognized the need for parents to be properly informed about their children's disease, as well as its outcome.</p>	<p>The evidence of the study suggests that asking parents directly about their learning needs seems the most reliable option for health professionals to better support individual parents' learning regarding the management of their child's chronic condition.</p>
<p>Brodwall et al., 2018, BMJ Open [32]</p>	<p>Population Sample: 14 parents of children with abdominal pain aged 5-15 years.</p> <p>Tools: Interview</p>	<p>Aim: The analysis of the experiences of parents of children with chronic abdominal pain.</p> <p>Type of research study: Qualitative research study</p>	<p>Family functioning was affected by the intensity and duration of the pain.</p> <p>Parents felt unable to meet their children's needs.</p> <p>Parents believed that health professionals would be indifferent to their children's symptoms.</p>	<p>Evidence showed that parents of children with undiagnosed abdominal pain felt confused as they did not know the cause and how to treat their child's illness and sought professional help to treat chronic pain and improve family functioning.</p>

<p>Carmassi et al., 2018, Neuropsychiatric Research and Treatment [11]</p>	<p>Population Sample: 134 mothers and 65 fathers of children with Idiopathic Epilepsy (IE) or symptomatic epilepsy (SE)</p> <p>Tools: 1) Depression Assessment Questionnaire (HAM-D), 2) Posttraumatic Stress Assessment Tool (TALS-SR), 3) Semi-Structured Clinical Interview (SCID-5)</p>	<p>Aim: The assessment of Depressive Disorder and Posttraumatic Stress Disorder in parents of children with Epilepsy</p> <p>Type of research study: Qualitative study</p>	<p>15.7% of participants were diagnosed with PTSD and 18.4% were diagnosed with partial PTSD.</p> <p>7.5% of participants reported moderate levels of depression.</p> <p>In the Depression Assessment Questionnaire, a statistically significant difference emerged between mothers and fathers regarding Physical Anxiety and IE.</p> <p>Depressive Disorder was associated with female gender, PTSD, and type of child crisis.</p>	<p>Parents of children with Epilepsy were psychologically affected by their children's illness, however, mothers more often experienced PTSD and Depression than fathers.</p>
<p>Iversen et al., 2018, International Journal of Qualitative Studies on Health and Well-being [5]</p>	<p>Population Sample: 7 couples and 1 mother with a child with Type 1 Diabetes Mellitus (T1DM)</p> <p>Tools: Interview</p>	<p>Aim: The assessment of the experience of parents of children with Type 1 Diabetes Mellitus</p> <p>Type of research study: Interpretative phenomenological analysis</p>	<p>Parents were trying to combine normal life with the need to be constantly alert to cope with their child's needs.</p> <p>Parents reported feeling anxious, sad, hopeless and tired.</p> <p>Parents sought socialization with other families and their support.</p>	<p>The diagnosis of T1DM greatly affected the life of the family and the psychological state of the parents who were trying to cope with the urgent and non-urgent needs of their child.</p>
<p>Kub et al., 2018, Western Journal of Nursing Research [14]</p>	<p>Population Sample: 276 low-income mothers who cared for a child with high-risk asthma</p> <p>Tools: 1) Participant monitoring, 2) Demographic data recording form, 3) National Asthma Education and Prevention Program (NAEPP) guidelines 4) Interview, 5) Likert scale, 6) Visual Analogue Scale for Anxiety (VAS), 7) Depression Scale (CES-D)</p>	<p>Aim: To assess the chronicity of depressive symptoms in a sample of inner-city mothers of children with high-risk asthma.</p> <p>Type of research study: Longitudinal study. (Secondary data analysis of a prospective randomized controlled trial)</p>	<p>The Depression Scale showed a decline in the level of depression over time.</p> <p>The occurrence of depression in mothers was related to a high level of stress due to the mothers' daily professional obligations and their child's illness.</p> <p>Social support reduced the level of depression in mothers.</p>	<p>30% of mothers who cared for a child with asthma reported depressive symptoms which did not change over time. Family support to the mothers coming from the social environment, as well as comprehensive information, contributed to the decrease in depression.</p>

<p>Woolf-King et al., 2018, Journal of Clinical Nursing [24]</p>	<p>Population Sample: 10 parents and 15 caregivers of children with congenital heart disease (CHD)</p> <p>Tools: Semi structured interview</p>	<p>Aim: The evaluation of the psychological effects on parents and caregivers who cared for a child with CHD and the role of providing psychological support in a Cardiology Unit</p> <p>Type of research study: Qualitative study</p>	<p>Parents reported disbelief, despair, feelings of sadness and surprise when their child was diagnosed with MS.</p> <p>Three factors influenced the parents' psychology: the distance of the main residence from the ICU, the existence of a second child and the lack of communication with the health professionals who had taken care of the child in the ICU.</p>	<p>The data showed that the diagnosis of a child with CHD took an emotional toll on the family. The parents and caregivers considered their psychological support essential from the stage of diagnosis until the child's return home, an event that is impossible to carry out due to a lack of infrastructure and specialized staff.</p>
<p>Irie et al., 2021, Cancer Nursing [23]</p>	<p>Population Sample: 78 parents of childhood cancer survivors and 44 parents of children with chronic illnesses</p> <p>Tools: Tools: 1) Parent Development after Traumatic Experience Questionnaire, 2) Event Impact Rating Scale, 3) Core Beliefs Questionnaire, 4) Event Reflection Questionnaire</p>	<p>Aim: The correlation of parents' development after the traumatic experience (diagnosis of children with cancer) and post-traumatic symptoms and the comparison of the above with parents of children diagnosed with another chronic illness.</p> <p>Type of research study: Cross sectional study</p>	<p>Results indicate that the parents of children who had been diagnosed with cancer did not show a statistically significant difference regarding their progress after the diagnosis, the effect the diagnosis had on them and the symptoms they experienced after the diagnosis compared to the parents of children who had been diagnosed with another chronic disease.</p>	<p>Parents of children who survived childhood cancer appeared to develop and transform the illness into a positive experience when they re-examined their core beliefs relative to parents of children diagnosed with another chronic condition.</p>
<p>Makara-Studzinska et al., 2019, BioMed Research International [7]</p>	<p>Population Sample: 60 mothers of healthy children and 60 mothers of children with T1DM</p> <p>Tools: 1) Demographic data recording form, 2) Antonovsky Sense of Cohesion Scale (SOC-29), 3) Schwarzer and Schultz-Berlin Social Support Scale (BSSS), 4) Rosenberg Self-Esteem Scale (SES), 5) Zigmond and Snaith Anxiety and Depression Scale (HADS)</p>	<p>Aim: The assessment of the psychological state of mothers of children with T1DM compared to mothers of healthy children</p> <p>Type of research study: Quantitative study</p>	<p>The greater the self-confidence, the greater the sense of coherence (sense of understanding, resourcefulness, logic) reported by mothers in both groups.</p> <p>Maternal anxiety and depression affected mothers' sense of coherence and self-confidence in both groups.</p> <p>In mothers of children with T1DM, it was found that levels of Depression increased with the provision of protective support. Among mothers of healthy children emerged that depression levels were reduced by providing support.</p>	<p>The diagnosis of a child with DM1 significantly affected the psychological state of the mothers, specifically the self-confidence and the sense of coherence, which improved by providing psychological support to both them and their children. Support from the social environment also contributed to the treatment of type 1 diabetes.</p>

			In both groups, the greater the support provided, the greater the self-confidence and sense of coherence mothers reported.	
Loades et al., 2019, Child Care Health Development [16]	<p>Population Sample: 100 mothers and 65 fathers of 115 children diagnosed with chronic fatigue syndrome.</p> <p>Tools: 1) Physical Functioning Rating Scale (SF-36), 2) Vocational and Social Adjustment Scale, 3) Anxiety Inventory (STAI), 4) Child Depression Rating Questionnaire (CDI), 5) Parental Fatigue Rating Questionnaire (PFQ) , 6) Hospital Anxiety and Depression Scale (HADS), 7) Family Functioning Questionnaire (Systemic CORE)</p>	<p>Aim: The correlation between the fatigue of children diagnosed with chronic fatigue syndrome and the fatigue of the parents who had taken care of them.</p> <p>Type of research study: Cross sectional study</p>	<p>Regarding parents, the occurrence of fatigue was associated with the occurrence of anxiety and depression, as well as with the partner's fatigue, and not with the occurrence of fatigue in their child.</p> <p>Parental stress and depression were associated with the presence of obstacles that hindered the smooth functioning of the family.</p> <p>Child depression appeared to be impacted by the mothers' emotional burden due to difficulties, reduced resilience and adaptability subscales.</p> <p>Children's physical functioning, social relationships and fatigue were associated with mothers' reduced endurance and adaptability subscale.</p>	<p>Parents reported that fatigue was due to stress, depression, family difficulties and the partner's emotional state. A positive association was found between fathers' depression and the onset of depression in children. The occurrence of depression in children was associated with the overwhelmed emotional state of the mothers and the difficulties they faced regarding their adaptation to their child's illness.</p>
Rani et al., 2019, Neurological Sciences [12]	<p>Population Sample: Parents of 60 children with Epilepsy</p> <p>Tools: 1) Parental Stress Questionnaire, 2) Parental Stress Scale</p>	<p>Aim: Understanding the anxiety and stigma experienced by parents of children with Epilepsy</p> <p>Type of research study: Quantitative research</p>	<p>The majority of parents reported communication problems both within the family environment and with the health professionals who cared for their child as well as changes in their marital relationship.</p> <p>A big proportion of parents reported sadness, anxiety, despair, loneliness, and changes in their emotional state related to the difficulties encountered during their child's treatment.</p> <p>Parents reported that their child received special treatment because of epilepsy.</p> <p>Child's comorbidity increased parental anxiety</p>	<p>Parental stress and the emotional state of the parents depended on the degree of control of the crises, comorbidity, demographic characteristics of the parents, the way the child was treated by the school environment and the social environment, as well as the relationship with the health professionals.</p> <p>The stigma experienced by these families was more intense, in cases of comorbidity. The support of families of children with</p>

				epilepsy by health professionals is essential.
Rennick et al., 2019, BMC Pediatric [28]	Population Sample: 17 parents who cared for 14 children with chronic conditions who were hospitalized in the Intensive Care Unit (ICU) Tools: Semi-structured interviews	Aim: The evaluation of the experience of parents of children with a chronic condition during their admission to the ICU. Type of research study: Descriptive study	The parents reported emotional, psychological difficulties, the feeling of uncertainty and concern regarding the decisions they had to make about their child's health when he was admitted to the ICU. The parents provided the child with specialized care within the context of the family environment. Parents were constantly alert during their child's stay in the ICU and reported that they felt more secure when they had developed personal relationships with the health professionals who had taken care of their child.	Parents of children with a chronic condition treated in the ICU acquired specialized knowledge and skills to be able to care for the child at home. A decisive role in the development of the child's illness was played by the cooperation with the ICU health professionals, who were supposed to provide psychological support to the family.
Vlachou et al., 2020, Thesis [25]	Population Sample: 8 families having a child with cancer. Tools: Semi-structured interview	Aim: The evaluation of the experience of parents who cared for a child with cancer Type of research study: Qualitative study	At the diagnosis of the disease, parents reported psychological shock and emotional burden During the treatment stage, parents reported mixed feelings that depended on how the child managed the illness. The majority of families did not seek professional psychological support outside the hospital during treatment. Half of the families reported that they were not satisfied with government support.	The diagnosis of a child with cancer took an emotional toll on all family members and financially burdened the parents. It also affected the family's relations with the friendly and social environment. The psychological support of the above families by health professionals and the strengthening of state support was deemed essential.

<p>Al Qadire et al., 2020, Cancer Nursing [17]</p>	<p>Population Sample: 264 parents of children with cancer Tools: 1) Scale Hospital Anxiety and Depression Scale, 2) Zarit Burden Scale</p>	<p>Aim: The assessment of the level and factors of burden in parents caring for children with cancer Type of research study: Cross sectional study</p>	<p>The largest percentage of parents reported a moderate level of psychological burden. The presence of a chronic illness in the parents, the stage of the child's cancer, the appearance of symptoms by the child, financial difficulties, anxiety and depression were associated with a greater level of psychological burden.</p>	<p>Levels of psychological burden varied among families caring for a child with cancer and depended on both child- and parent-related factors. Health professionals should be aware of these factors to help families comprehensively through interventions.</p>
<p>Benveniste et al., 2020, Qualitative Health Research [26]</p>	<p>Population Sample: 12 parents of children (9 mothers and 3 fathers) with end-stage renal disease Tools: Semi structured interview</p>	<p>Aim: The analysis of the experience of parents caring for children with kidney disease from the first to the end stage of the disease. Type of research study: Qualitative study</p>	<p>At the diagnosis stage, parents felt vulnerable and experienced the chaos that accompanied the feeling of fear. At the onset of the first symptoms, the parents experienced the stage of denial, but then they became familiar with the nature and treatment of the disease. The illness affected the personality of the child and his family and became part of their identity. The absence of a possibility of recovery for the child caused disordered feelings in the family.</p>	<p>The experience of a family with a child with a chronic condition depended on the type of narrative chosen. The first type of narrative refers to the cases where complete recovery was possible and focused on medical interventions, while the second type of narrative referred to the cases where the child's full recovery was not possible and focused on the child and the family.</p>
<p>Celik et al., 2021, European Neurology [13]</p>	<p>Population Sample: 116 mothers of children with epilepsy Tools: 1) Interview, 2) Beck's Anxiety Questionnaire</p>	<p>Aim: The assessment of the stress of mothers having children with epilepsy during the Covid-19 Pandemic Type of research study: Quantitative study</p>	<p>Stress levels did not differ between mothers who visited their child's doctor and those who performed the review by telephone during the Pandemic. Mothers' stress levels depended on the frequency of seizures and the mothers' educational level. Mothers' likelihood of contracting the virus was influenced by frequency of visits and length of hospital stay.</p>	<p>Throughout the pandemic, mothers' stress levels were positively affected by their children's seizure frequency. Treatment adherence, striving for a normal life and keeping parents fully informed contributed to the elimination of anxiety.</p>

<p>Commissariat et al., 2020, Pediatric Diabetes [30]</p>	<p>Population Sample: 79 parents of children with T1DM Tools: Semi-structured interview</p>	<p>Aim: The analysis of the emotional burden of parents of children with T1DM Type of research study: Qualitative study</p>	<p>Parents felt emotionally burdened by having to educate their child and the school environment about the special needs of 1DM. The inability to find an appropriately trained and trusted caregiver for the child also resulted in an additional emotional burden for the parents. Parents wanted continued education about T1DM to feel safe.</p>	<p>The recognition of the causes of the emotional burden of parents of children with DM1 contributed to the improvement of the quality of life of such families. This was achieved through the provision of support and training, focused on the family's, child's and social environment's smooth adaption to the new life conditions due to DM1.</p>
<p>Continisio et al., 2020, Italian Journal of Pediatrics [21]</p>	<p>Population Sample: 47 parents of children with Cystic Fibrosis (CF) Tools: Abidin's Parental Stress Questionnaire</p>	<p>Aim: The assessment of the anxiety of parents of children with Cystic Fibrosis Type of research study: Quantitative research</p>	<p>Most parents reported normal levels of stress. Parental stress levels were positively related to CF severity, number of children in the family, and parent-child interaction.</p>	<p>The diagnosis of a child with Cystic Fibrosis was related to the appearance of stress in parents, however, the creation of a plan that approached the family holistically and offered psychological support to family members could contribute to the elimination of parental stress.</p>
<p>Khorsandi et al., 2020, BMC Nephrology [1]</p>	<p>Population Sample: 17 parents of children with chronic kidney disease. Tools: Semi-structured interview with physical presence.</p>	<p>Aim: The identification of factors influencing parents regarding the care of children with kidney disease. Type of research study: Qualitative study</p>	<p>Two categories of factors emerged. Religious beliefs, family and social support belonged to the 1st category of factors, which made it easier for parents to take care of their children. Stress, duration of the disease and unfavourable treatment conditions belonged to the 2nd category, which included factors that made the children's care difficult.</p>	<p>The health workers' mapping of the factors contributed to the implementation of the necessary interventions to support the parents. Specifically, parents' access to information and financial and emotional support could improve the quality of care for them, in parallel with the elimination of factors that made it difficult to care for their children.</p>

<p>Van Gampelaere et al., 2020, Pediatric Diabetes [8]</p>	<p>Population Sample: 105 families of children with TDM1 and 416 families of healthy children</p> <p>Tools: 1) Pediatric Patient Quality of Life (PedsQL) Questionnaire, 2) Strengths and Weaknesses Questionnaire (SDQ), 3) Parental Stress Rating Scale (PSS), 4) Anxiety and Depression Rating System (PROMIS), 5) Protective Behavior Rating System, 6) Parental Autonomy Scale (POPS), 7) Parental Control Scale (PCS-YSR), 8) Report of Parenting Behavior Questionnaire (RPBI)</p>	<p>Aim: The comparison of families with a child with type 1 diabetes to families which are not confronted with chronic illness, with regard to children's well-being, parental distress, and parenting behavior. Additional aim was the exploration of differences between families whose child has optimal vs suboptimal glycemic control.</p> <p>Type of research study: Cross sectional study</p>	<p>Families of children with T1DM reported a lower quality of life of their children compared to families of healthy children. Mothers of children with T1DM reported higher levels of anxiety, depression and worry compared to mothers of healthy children.</p> <p>Regarding Parental Behavior, fathers of children with DM1 reported lower levels of protective behavior than fathers of healthy children, while parents of children with DM1 reported lower levels of autonomy and responsibility than parents of healthy children.</p> <p>Regarding children with insufficient control of T1DM, a lower level of quality of life was obtained. Their mothers reported higher levels of anxiety and depression and lower levels of responsibility compared to mothers of healthy children.</p>	<p>Children's quality of life, parental distress and parenting behavior were affected by T1DM and further by the degree of T1DM regulation. Under these circumstances, psychological support for the families of children with T1DM and the provision of quality care to children with T1DM are deemed necessary.</p>
<p>Kapiri et al., 2021, Archives of Greek Medicine [33]</p>	<p>Population Sample: 123 parents of autistic children</p> <p>Tools: 1) FAS scale to assess perceived fatigue, 2) MSPSS scale to assess perceived social support, and 3) FACIT-SP-12 scale to assess spirituality</p>	<p>Aim: The evaluation of fatigue, in parents with children on the autistic spectrum, as well as the impact of spirituality and the support of the social environment on the fatigue.</p> <p>Type of research study: Quantitative study</p>	<p>Fathers showed a lower level of mental fatigue than mothers.</p> <p>Family support from their environment reduced levels of mental fatigue.</p> <p>Mental fatigue was highly dependent on physical fatigue.</p>	<p>Parents of children with autism spectrum disorder were characterized by moderate levels of fatigue which was influenced by social support, spirituality and the gender of the caregiver.</p>
<p>Kosmidou, 2021, Thesis [9]</p>	<p>Population Sample: 130 parents of children with Type 1 Diabetes Mellitus.</p>	<p>Aim: The identification of the causes that burden the parents of children with diabetes mellitus and the assessment of</p>	<p>Parental stress was associated with children's self-care ability and parents' social status.</p> <p>Chronic fatigue is related to chronic stress.</p>	<p>The stress of parents of children with type 1 diabetes was associated with the parents' mental resilience, their time, their children's level of self-care, their age, as</p>

	Tools: 1) Demographic Data Record Form, 2) Parent Family Impact Acute Questionnaire, 3) Resilience Scale Questionnaire, 4) Perceived Stress Questionnaire.	mental resilience and stress. Type of research study: Cross sectional study	The age of the children with diabetes mellitus was associated with the social relations of the parents. Parents' socialization improved their mental health.	well as their financial situation. The burdened mental state of the parents affected their quality of life. Support and guidance groups were essential.
Kostopoulou et al., 2021, Swiss Medical Weekly [19]	Population Sample: 1106 parents of children with and/or without chronic diseases Tools: Questionnaires 1) Demographics, 2) Pediatric Patient Medical History, 3) Anxiety Rating Scale (PSS), 4) Impact of Event Scale (IES-R)	Aim: The assessment of Parental Stress during the Covid-19 Pandemic, in Greece. Type of research study: Cross sectional study	Parents of children with chronic diseases reported higher levels of stress compared to parents of children without chronic diseases. Higher levels of stress were observed in parents of children with heart, respiratory and immunodeficiency diseases. Mothers reported higher levels of stress compared to fathers. 51.7% of parents of children with chronic illnesses reported high rates on the Impact of Event Scale, 51.7% of parents of children with chronic illnesses reported an increased level of impact since their child's diagnosis.	Parental Stress levels increased during the Covid-19 Pandemic and in particular higher levels of stress were observed in parents who cared for a child with a chronic illness.
Mpalaskas, 2021, Thesis [10]	Population Sample: 110 caregivers of children with Type 1 Diabetes Mellitus. Tools: 1) Parent-DDS Questionnaire, 2) Spielberger Questionnaire (STAI)	Aim: The assessment of the level of perception of parents of children with Type 1 Diabetes, regarding their quality of life, as well as their psychological state. Type of research study: Cross sectional study	<ul style="list-style-type: none"> • High levels of general discomfort and temporary anxiety were found in 2/3 of the parents. • The factors that influenced the occurrence of parental anxiety were the financial situation, the age of the parents and the therapeutic regimens applied to their children. • General parental distress was associated with complications of diabetes mellitus. 	Parents of children with type 1 diabetes were characterized by high levels of stress and general discomfort, which were associated with their socio-demographic characteristics, as well as the progress of their children's disease.
Lagoudaki, 2021, Master's Thesis [6]	Population Sample: 192 parents-caregivers of children with Type 1 Diabetes Mellitus (T1D)	Aim: The assessment of the difficulties faced by the parents of children with T1D	On the Temporal Anxiety Scale, most parents reported nervousness and worry. On the Persistent Anxiety Scale, parents reported anxiety, low level of calmness	The data supported that T1DM affected the daily life of the family, which had to respond to the needs of the affected member regarding prevention and treatment.

	<p>Tools: 1) Demographic data recording form, 2) Questionnaire for the Evaluation of the Quality of Life of Pediatric Patients with T1DM, 3) Spielberger's State-Trait Anxiety Inventory, 4) Spielberger Anxiety Scale</p>	<p>Type of research study: Quantitative study</p>	<p>and security, moderate level of overstress. Parental stress was related to the child's age and the child's age of diagnosis.</p>	<p>The children's parents reported moderate levels of temporary and permanent stress that did not appear to be affected by the pandemic.</p>
<p>Terzi, 2021, Thesis [20]</p>	<p>Population Sample: 1487 parents of children without chronic or serious illness and 216 parents of children with serious or chronic illness. The participants were identified from the patient lists of 19 pediatricians in Greece.</p> <p>Tools: A Google Forms questionnaire with four sections (introduction page, general information section, children's medical history, psychometric scales).</p>	<p>Aim: The assessment of the psychological state of parents who cared for a child with a chronic disease, in relation to the Covid-19 pandemic, as well as the assessment of the stress of children with a chronic disease, as perceived by the parents.</p> <p>Type of research study: Cross sectional study</p>	<p>Increased stress was observed in parents caring for children with immunodeficiency. Female and young participants were associated with increased stress. Complete vaccination against the Covid-19 infection reduced the stress on parents and children. There was a positive correlation between children's age and anxiety</p>	<p>Over time, parents' levels of anxiety about Covid-19 infection decreased as their knowledge about the virus increased. Parents' stress did not depend on the pandemic but on the type of chronic disease. Mainly, high levels of stress were observed in parents caring for children with immunodeficiency. On the other hand, the children's anxiety depended on their age and whether or not their parents had been vaccinated.</p>
<p>Belov et al., 2021, WLek [22]</p>	<p>Population Sample: 104 parents (40 fathers and 64 mothers) of children with chronic musculoskeletal problems.</p> <p>Tools: 1) Hamilton Depression and Anxiety Scale, 2) Buss Durkee Hostility Questionnaire</p>	<p>Aim: The analysis of the psychopathological condition of parents of children with chronic musculoskeletal problems.</p> <p>Type of research study: Quantitative study</p>	<p>Psychopathological effects between mothers and fathers differed and depended on the duration of chronic illness. Mothers showed higher anxiety, depression and emotional instability and reported more frequent sleep disturbance than fathers. Both mothers and fathers reported feeling tired. Mothers experienced high mental stress while fathers experienced higher physical stress.</p>	<p>A chronic musculoskeletal condition in children seemed to affect parents differently. Mothers appeared to experience more unpleasant emotions than fathers, whose psychological state was expressed through aggression.</p>

			Fathers showed higher levels of aggression than mothers.	
Chan Sun et al., 2021, Journal of Pediatric Nursing [29]	Population Sample: 11 mothers of children with T1DM Tools: Journal	Aim: The analysis of experiences of mothers of children with DM1 Type of research study: Phenomenological study	Mothers reported that both themselves and the social environment were surprised at the announcement of T1DM Mothers noticed changes in all areas of their daily lives. Guilt, fear for their child's future and psychological fatigue were representative symptoms of the mothers. Mothers reported difficulty adjusting to the demands of DM1 and physical fatigue due to the need for constant vigilance. Mothers reported that any support was instrumental in improving adaptation to the demands of DM1.	The diagnosis of a child with T1DM significantly affected the daily life of the mothers, who experienced a multitude of mixed emotions. The professionals' support and the social environment contributed to mothers' easier acceptance of their new everyday life.
Mariyana et al., 2021, Journal of Pediatric Nursing [27]	Population Sample: 11 parents and caregiver of children with a chronic disease Tools: Interview	Aim: The description of the experience of parents and caregivers of children with chronic diseases. Type of research study: Descriptive qualitative study	Parents' first reaction to the announcement of their children's chronic illness included crying, denial and guilt. Parents expressed fear regarding the possible death of their child due to the chronic disease. Caregivers tried alternative and traditional ways of treating their children's chronic illnesses and followed health professionals' instructions precisely. Parents felt pressure as they tried to meet their children's needs and cope with the role of parent. Caregivers turned to religion for psychological support.	Parents experienced strong emotions when they were first informed about their child's illness, however, they adjusted to the new reality over time while experiencing the five stages of grief. In addition, the parents tried to take care of their children comprehensively, while spiritual support played a decisive role in the psychology and motivation of the caregivers when taking care of the children.
Wauters et al., 2021,	Population Sample: 599 parents of children with chronic diseases (sample for the first objective) 507	Aim: The assessment of the level of anxiety and depression of parents of	Parents of children with chronic illnesses reported more intense stress compared to parents of children without chronic	The Covid19 pandemic has affected the parents of children with chronic

<p>Journal of Pediatric Psychology [18]</p>	<p>parents with chronic diseases (sample for the second objective) and 417 parents of healthy children</p> <p>Tools: 1) Demographic Record Form, 2) Parent Information and Outcome Reporting System (PROMIS), 3) Insomnia Index (ISI), 4) Impact Factor Questionnaire, 5) Parental Burnout Assessment Tool</p>	<p>children with chronic diseases.</p> <p>The analysis of the factors that hinder the quality of life and the psychological state of the parents.</p> <p>Type of research study: Cross sectional study</p>	<p>diseases. Specifically, stress was more common among mothers and young parents. Parents who took care of their children alone showed depression.</p> <p>Parental stress was associated with the quality of care provided, the number of children in the family, the parent's responsibilities, burnout, and the family's financial situation.</p> <p>Parents' depression was affected by their age, the quality of care provided, their responsibilities, burnout and the family's financial situation.</p> <p>Parental sleep problems were associated with burnout, financial hardship, ethnicity, and quality of care provided.</p>	<p>diseases. These parents experienced burnout due to obligations, which burdened their psychological state.</p>
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3. Results

Of the total number of studies found (1433), those that were not primary research and duplicates were rejected. After screening for title, abstract and content, a total of 32 studies that met the criteria for this literature review remained.

Among the 32 studies selected at the final step of our study, 1 was a doctoral dissertation, 5 were master's theses, and 1 was graduate thesis. Nineteen studies were held in Europe, four in America (Boston, California, Canada) and three in Asia. The parents' population within the selected studies accounted for 3452. All the studies included had been published throughout the period 2017-2022. In all of them a permission was given prior to the participation.

Among the thirty-six studies, we found that nine were related to Type 1 Diabetes Mellitus-T1DM, five referred to unspecified chronic diseases, three were related to childhood cancer, four to end-stage renal disease, three to epilepsy, while one studied asthma, allergies, chronic abdominal pain, congenital heart disease, chronic fatigue, cystic fibrosis, autism, and musculoskeletal disorders. The most examined variable among the studies was anxiety (13), followed by depression (7), quality of life (3) and fatigue (3). Additionally other factors studied were aggression (2), social support (2), shame (1), post-traumatic stress (1), parental autonomy (1), parenting behavior (1) and insomnia (1). Twelve studies were qualitative and data collection conducted through interview, while the rest were quantitative and used forms of measurement tools.

4. Discussion

In the present literature review, the psychological effects experienced by parents of children with chronic diseases were analyzed, except for rare diseases and psychiatric disorders. Specifically, the children in the studies we included in our review suffered from respiratory system disorders, cardiovascular diseases, kidney diseases, diabetes mellitus, autism spectrum disorders, cystic fibrosis, cancer, musculoskeletal problems, epilepsy, abdominal pain, allergic episodes, and chronic fatigue syndrome. These diseases resulted in increased rates of stress; however, the general psychological state of the parents was affected by external and internal factors. The main finding was that parents of children with chronic diseases experienced a great deal of anxiety, fear, depression, and emotional burden, resulting in the deterioration of their quality of life.

Parents experienced or reported high levels of stress as shown by Baek et al., (2017), which studied parents who cared for children with end-stage renal disease. Stress level depended on how the disease was treated, for example, hemodialysis was associated with higher anxiety levels than peritoneal dialysis and transplantation. [4] Also, the studies of Iversen et al., (2018), Lagoudaki (2019), Makara-Studzinska (2019), Van Grampelaere et al., (2020), Kosmidou (2021) and Balaska (2021) referred to the association of parental stress with pediatric T1DM. [5-10] In Lagoudaki's (2019) study, parents reported moderate levels of temporary and permanent stress related to the child's age and specifically to the child's age at T1D diagnosis. [6] Furthermore, high anxiety was recorded in the studies of Carmassi et al., (2018), Rani et al., (2019) and Celik et al., (2021), among parents of children with epilepsy. [11-13] Carmassi et al., (2018), referred that 15.7% of the sample showed Post-Traumatic Stress Disorder (PTSD) while 18.4% reported partial Post-Traumatic Stress Disorder (PTSD) related to the occurrence of depressive symptoms. [11] High levels of anxiety were also observed in Kub et al., (2018) and Lagercrantz et al., (2017) studies, that focused on pediatric patients with asthma and allergic episodes. [14, 15] Loades et al., (2019) came to the same conclusion, that parents of children with chronic fatigue syndrome experienced a high degree of stress. [16] Also, Al Qadire et al., (2020) pointed out that parents of children with cancer are affected severely psychologically. [17] Wauters et al., (2021), Kostopoulos and Terzi (2021) studied parents of children with severe chronic disease and reported that higher levels of stress were observed in parents who cared for a child with immunodeficiency, cardiac and respiratory diseases, while younger mothers seemed to suffer from higher levels of stress. [18-20] Finally, Continisio et al., (2020) and Belov et al., (2021) documented high levels of stress in parents of children with cystic fibrosis and musculoskeletal problems respectively, with the latter indicating that mothers reported higher levels of psychological stress while the fathers of physical stress. [21, 22]

In terms of depression, Kub et al. (2017) assessed the psychological state of parents caring for children with asthma and concluded that over time and specifically after one year, parents showed lower levels of depression. However, the level of depression was increased by the occupational activities of the parents. [14] In the same conclusion ended up also Wauters et al., (2021), assessed the psychological state of parents with chronic diseases. The latter reported that depression was influenced by parents' economic status and age, burnout, and the quality of care provided. [18]

Carnassi et al., (2018) and Belov et al., (2021) supported that mothers tend to have higher levels of depression than fathers. [11, 22] Also, Makara StudziNska et al., (2019) and Van Gamprelaere et al., (2020) reported a high level of

depression among parents of children caring for a child with T1DM. [7, 8] Literature also suggested that parental depression of parents with a child suffering from diabetes mellitus was related to the origin of the name and the presence of siblings in the family. [2] Last, Loades et al., (2019), assessed the psychology of parents who cared for a child with chronic fatigue syndrome, and supported that depression was related to parental fatigue. [16]

Emotional burden constitutes another significant issue for parents of children with chronic diseases, as reported by Irie et al., (2019), Iversen et al., (2018), and Baek et al., (2017). [4, 5, 23] The latter attributed the emotional burden to the choice of hemodialysis, as kidney disease treatment, over peritoneal dialysis and transplantation. [23] Albani's (2017) that focused on parents of children with T1DM, highlighted the somatization of the psychological effects on parents. [2] Data also suggest that the emotional burden of the parents was intense during the stage of diagnosis of the disease. [19, 24-27] Benveniste et al. al., (2020) and Mariyana et al., (2021) correlated the emotional burden of the parents with the absence of the possibility of recovery from the chronic disease. [26, 27] Rani et al., (2019), Rennick et al., (2019) and Balaskas (2021), indicated that the emotional burden of parents was more intense during the treatment stage of the child's chronic disease and depended on the outcome of the disease. [10, 12, 28] Belov et al., (2021) and Chan Sun et al., (2021), that assessed parents of children with chronic musculoskeletal problems and T1DM, showed that mothers presented a higher level of emotional distress compared to fathers. [22, 29] Last, Commisariat et al., (2020) and Al Qadire et al., (2020) correlated the emotional burden of parents with the insufficient quality of care provided to their child, financial difficulties, the child's symptoms and an inability to find a qualified and responsible caregiver for their child. [17, 30]

A significant part of the literature indicates the deterioration of the quality of life of the parents of children who cared for a child with a chronic disease. Lagoudaki (2019), Commissariat et al., (2020) and Van Grampelaere et al., (2020), studied the psychological profile of parents of children with T1DM and correlated the deterioration of the family's quality of life with changes in daily habits brought about by diabetes and with the increased obligations that parents assume in order to meet the physical and psychological needs of their child. [6, 8, 30] Balaskas (2021) found similar findings to the aforementioned and they also correlated quality of life with the degree of diabetes control. Specifically, poor diabetes control was associated with reduced quality of life. [10] Baek et al., (2017) assessed the parents' quality of life with another child's coexistence, while Wauters et al., (2021) supported that the quality of life was influenced by economic factors, from the quality of care provided to the child, the severity of symptoms, anxiety and depression of parents. [4, 18] This finding is also confirmed by Lagercrantz et al., (2017) which assessed the psychological effects of parents who cared for a child with an allergy. [15]

Nightingale et al., (2017) aimed to create a tool to assess the learning needs of parents regarding their children's chronic illness. They associated the parents' lack of information about the child's condition, the psychological needs and the outcome of the chronic illness, with symptoms of anxiety and fear in the parents. Furthermore, parents seemed to prefer having a structured questionnaire tool that provided feedback. [31] Terzi (2021), suggested the strengthening of state agencies and the establishment of safe environments that provide information and psychological support for citizens and especially for parents who had a child with chronic diseases, especially during the pandemic caused by the SARS virus Covid-19. [20] They also supported that parental stress decreased over time and was associated with the likelihood of the chronically ill child contracting the virus. Full vaccination appeared to further reduce parental stress. [6, 13] However, Kostopoulou et al., (2021) and Wauters et al., (2021) showed a positive correlation between the pandemic and parental stress, depressive symptoms and parental burnout. [18, 19]

Limitations of the study

Throughout this study, several limitations appeared. First, only studies published in Greek and English throughout the last 6 years (2017-2022) were included in the review. The selected studies emerged after searching across only two databases (PubMed and Google Scholar). Studies that were literature reviews, case studies, clinical trials and meta-analyses were excluded. Additionally, we excluded studies that assessed the psychological effects of rare chronic illnesses and psychiatric diseases, in the parents of a pediatric patient. Future studies are needed to determine if our findings could be generalized. Further limitations constitute the lack of evaluation of the quality of the studies and their screening in terms of their title, abstract and content conducted by two researchers.

5. Conclusion

Our findings suggest that families caring for a child with a chronic illness experience a different reality compared to normal families. More specifically, the special characteristics of chronic disease, such as the severity of the disease, chronicity, costs, complex treatment regimens and regular visits to nursing institutions affect severely the lifestyle of the family, especially the parents. Parents often feel to blame for their children's condition and psychologically

burdened, as they were called upon to face dilemmas and meet the increased needs of their children, having assumed a primary and decisive role in their care. Therefore, the increased obligations affect their psychological state, as they greatly experience the feeling of anxiety (temporary or permanent), depression, shame, social isolation, and rejection. Parents are forced to modify their daily routines and be constantly alert to deal with possible emergencies due to their children's chronic illnesses. Also, their life is determined by high rates of mental and physical fatigue. Mothers appeared to be more emotionally charged than fathers, as they assume more responsibilities regarding the care of the sick child. In addition, the child's characteristics (age, sex, presence of siblings, etc.) and the child's age at the time of the diagnosis also influence the psychological state of the parents. The psychological burden on the parents results in the deterioration of their quality of life both individually and as family members. This affects the function, communication, family ties and companionship of the parents. In this way, a relationship of interdependence emerges between the psychology of parents and children, which is quite often reinforced by social exclusion, due to the nature of the disease, and the lack of information in the social environment about the special characteristics of the chronic disease and its management. Therefore, it is considered necessary to provide psychological, financial and social support to these families, as well as education, regarding the pathophysiology of chronic diseases, so that parents can apply documented mechanisms to manage the disease. Furthermore, our findings highlight the importance of creating and staffing Primary Health Care services for information provision and advisory support to families who have children with chronic diseases. Last, regarding the effect of the pandemic on the psychology of parents, it appeared that there are not enough studies to adequately assess the degree of burden on the psychological state of parents.

Compliance with ethical standards

Disclosure of conflict of interest

None to declare.

Statement of ethical approval

The present research work does not contain any studies performed on animals/humans subjects by any of the authors.

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AUTHORS – SCIENTIFIC JOURNAL	POPULATION SAMPLE - TOOLS	OBJECTIVE -TYPE OF RESEARCH STYDY	RESULTS	CONCUSIONS
<p>Albani, 2017, PhD dissertation [2]</p>	<p>Sample: 285 parents of children with T1DM.</p> <p>Tools: 1) Family Environment Scale, Form R-FES, 2) Hostility and Direction of Hostility Questionnaire - HDHQ, 3) Symptom Checklist 90-R - SCL-90, 4) State - Trait Anxiety Inventory - STAI, 5) Other As Shamer Scale-OAS, 6) Experience of Shame Scale-ESS 7) Socio-demographic sample registration form.</p>	<p>Aim: The assessment of the socio-demographic characteristics that affected the psychology of parents who cared for children with Type 1 Diabetes Mellitus.</p> <p>Type of research study: Empirical research</p>	<ul style="list-style-type: none"> • Gradual acceptance of the disease by the parents, as well as the changes that occurred due to it both at the family and personal level. • Somatization of psychological changes and external shame differed according to parental age. • The demographic characteristics of the sick children were associated with the psychopathology of their parents. 	<p>Awareness of the impact of the socio-demographic factors on parents' psychology improved the way the management of the disease and strengthened the support offered by parents to children with Type 1 Diabetes Mellitus.</p>
<p>Baek et al., 2017, Pediatric Nephrology [4]</p>	<p>Population Sample: 79 parents of children with end-stage renal disease, including 47 children receiving dialysis and 32 children who underwent a renal transplant.</p>	<p>Aim: Evaluating the impact of pediatric end-stage renal disease on parents.</p> <p>Type of research study: Cross-sectional study.</p>	<ul style="list-style-type: none"> • Families with children on hemodialyses were more affected in terms of social, physical, emotional functioning, stress, communication level, social relationships, daily activities and the health level of the parents compared to the 	<p>The type of treatment followed for renal disease seemed to affect the families. The parents of children who went through hemodialysis rather than peritoneal dialysis or transplantation had a bigger impact on their</p>

	<p>Tools: 1) Pediatric Patient Quality of Life Questionnaire: Impact on the Family, 2) Pediatric Patient Quality of Life Questionnaire: End-Stage Renal Disease</p>		<p>parents of children who faced the disease with peritoneal dialysis or grafting.</p> <ul style="list-style-type: none"> • Family relationships were negatively affected by the duration of the disease. • The level of family communication was influenced by the mother's age. • Cohabitation affected the families. • Parents' health level was affected by general fatigue and peer interaction. 	<p>daily routine. Also, these parents reported more emotional burden which affected their quality of life due to the disadvantages and difficulties accompanying hemodialysis.</p>
<p>Lagercrantz et al., 2017, The Journal of Asthma [15]</p>	<p>Population Sample: 18 parents of children with severe allergic episodes</p> <p>Tools: Four focus group interviews</p>	<p>Aim: The assessment of the quality of life of families who cared for a child with severe allergic episodes (Asthma, Eczema, Food Allergy, High Fever)</p> <p>Type of research study: Qualitative study</p>	<ul style="list-style-type: none"> • Parents reported experiencing limitations and the need for planning in their daily lives due to their child's illness. • Outside the family environment, parents reported feeling fear and anxiety about their child's physical and psychological health. • Parents felt dependent on the doctor and were concerned that their child was having difficulties integrating smoothly 	<p>Allergic episodes restricted the life of the whole family and emotionally burdened the parents who felt the need for continuous and comprehensive information about their child's respective allergy. Therefore, the provision of psychological support and information to families through Health Services is necessary.</p>

			<p>into the school environment due to the allergy.</p> <ul style="list-style-type: none"> • Lack of information about the disease was observed both in the family and in the social environment. 	
<p>Nightingale et al., 2017, Journal of Pediatric Nursing [31]</p>	<p>Population Sample: 23 parents and 22 health professionals from 6 artificial kidney units in UK.</p> <p>Tools: Interview.</p>	<p>Aim: The design of a tool that would identify the learning needs of parents regarding the provision of clinical care to a child with chronic diseases in the family environment.</p> <p>Type of research study: Mixed methods, two-phased design study</p>	<ul style="list-style-type: none"> • Health professionals recognized the need for parents to be properly informed about their children's disease, as well as its outcome. 	<p>The evidence of the study suggests that asking parents directly about their learning needs seems the most reliable option for health professionals to better support individual parents' learning regarding the management of their child's chronic condition.</p>
<p>Brodwall et al., 2018, BMJ Open [32]</p>	<p>Population Sample: 14 parents of children with abdominal pain aged 5-15 years.</p> <p>Tools: Interview</p>	<p>Aim: The analysis of the experiences of parents of children with chronic abdominal pain.</p> <p>Type of research study: Qualitative research study</p>	<ul style="list-style-type: none"> • Family functioning was affected by the intensity and duration of the pain. • Parents felt unable to meet their children's needs. • Parents believed that health professionals would be 	<p>Evidence showed that parents of children with undiagnosed abdominal pain felt confused as they did not know the cause and how to treat their child's illness and sought professional help to</p>

			indifferent to their children's symptoms.	treat chronic pain and improve family functioning.
Carmassi et al., 2018, Neuropsychiatric Research and Treatment [11]	<p>Population Sample: 134 mothers and 65 fathers of children with Idiopathic Epilepsy (IE) or symptomatic epilepsy (SE)</p> <p>Tools: 1)Depression Assessment Questionnaire (HAM-D), 2)Posttraumatic Stress Assessment Tool (TALS-SR), 3)Semi-Structured Clinical Interview (SCID-5)</p>	<p>Aim: The assessment of Depressive Disorder and Posttraumatic Stress Disorder in parents of children with Epilepsy</p> <p>Type of research study: Qualitative study</p>	<ul style="list-style-type: none"> • 15.7% of participants were diagnosed with PTSD and 18.4% were diagnosed with partial PTSD. • 7.5% of participants reported moderate levels of depression. • In the Depression Assessment Questionnaire, a statistically significant difference emerged between mothers and fathers regarding Physical Anxiety and IE. • Depressive Disorder was associated with female gender, PTSD, and type of child crisis. 	Parents of children with Epilepsy were psychologically affected by their children's illness, however, mothers more often experienced PTSD and Depression than fathers.

<p>Iversen et al., 2018, International Journal of Qualitative Studies on Health and Well-being [5]</p>	<p>Population Sample: 7 couples and 1 mother with a child with Type 1 Diabetes Mellitus (T1DM)</p> <p>Tools: Interview</p>	<p>Aim: The assessment of the experience of parents of children with Type 1 Diabetes Mellitus</p> <p>Type of research study: Interpretative phenomenological analysis</p>	<ul style="list-style-type: none"> • Parents were trying to combine normal life with the need to be constantly alert to cope with their child's needs. • Parents reported feeling anxious, sad, hopeless and tired. • Parents sought socialization with other families and their support. 	<p>The diagnosis of T1DM greatly affected the life of the family and the psychological state of the parents who were trying to cope with the urgent and non-urgent needs of their child.</p>
<p>Kub et al., 2018, Western Journal of Nursing Research [14]</p>	<p>Population Sample: 276 low-income mothers who cared for a child with high-risk asthma</p> <p>Tools: 1) Participant monitoring, 2) Demographic data recording form, 3) National Asthma Education and Prevention Program (NAEPP) guidelines 4) Interview, 5) Likert scale, 6) Visual Analogue Scale for Anxiety (VAS), 7) Depression Scale (CES-D)</p>	<p>Aim: To assess the chronicity of depressive symptoms in a sample of inner-city mothers of children with high-risk asthma.</p> <p>Type of research study: Longitudinal study. (Secondary data analysis of a prospective randomized controlled trial)</p>	<ul style="list-style-type: none"> • The Depression Scale showed a decline in the level of depression over time. • The occurrence of depression in mothers was related to a high level of stress due to the mothers' daily professional obligations and their child's illness. • Social support reduced the level of depression in mothers. 	<p>30% of mothers who cared for a child with asthma reported depressive symptoms which did not change over time. Family support to the mothers coming from the social environment, as well as comprehensive information, contributed to the decrease in depression.</p>

<p>Woolf-King et al., 2018, Journal of Clinical Nursing [24]</p>	<p>Population Sample: 10 parents and 15 caregivers of children with congenital heart disease (CHD)</p> <p>Tools: Semi structured interview</p>	<p>Aim: The evaluation of the psychological effects on parents and caregivers who cared for a child with CHD and the role of providing psychological support in a Cardiology Unit</p> <p>Type of research study: Qualitative study</p>	<ul style="list-style-type: none"> • Parents reported disbelief, despair, feelings of sadness and surprise when their child was diagnosed with MS. • Three factors influenced the parents' psychology: the distance of the main residence from the ICU, the existence of a second child and the lack of communication with the health professionals who had taken care of the child in the ICU. 	<p>The data showed that the diagnosis of a child with CHD took an emotional toll on the family. The parents and caregivers considered their psychological support essential from the stage of diagnosis until the child's return home, an event that is impossible to carry out due to a lack of infrastructure and specialized staff.</p>
<p>Irie et al., 2021, Cancer Nursing [23]</p>	<p>Population Sample: 78 parents of childhood cancer survivors and 44 parents of children with chronic illnesses</p> <p>Tools: Tools: 1) Parent Development after Traumatic Experience Questionnaire, 2) Event Impact Rating Scale, 3) Core Beliefs Questionnaire, 4) Event Reflection Questionnaire</p>	<p>Aim: The correlation of parents' development after the traumatic experience (diagnosis of children with cancer) and post-traumatic symptoms and the comparison of the above with parents of children diagnosed with another chronic illness.</p> <p>Type of research study: Cross sectional study</p>	<p>Results indicate that the parents of children who had been diagnosed with cancer did not show a statistically significant difference regarding their progress after the diagnosis, the effect the diagnosis had on them and the symptoms they experienced after the diagnosis compared to the parents of children who had been diagnosed with another chronic disease.</p>	<p>Parents of children who survived childhood cancer appeared to develop and transform the illness into a positive experience when they reexamined their core beliefs relative to parents of children diagnosed with another chronic condition.</p>

<p>Makara-Studzińska et al., 2019, BioMed Research International [7]</p>	<p>Population Sample: 60 mothers of healthy children and 60 mothers of children with T1DM</p> <p>Tools: 1) Demographic data recording form, 2) Antonovsky Sense of Cohesion Scale (SOC-29), 3) Schwarzer and Schultz-Berlin Social Support Scale (BSSS), 4) Rosenberg Self-Esteem Scale (SES), 5) Zigmond and Snaith Anxiety and Depression Scale (HADS)</p>	<p>Aim: The assessment of the psychological state of mothers of children with T1DM compared to mothers of healthy children</p> <p>Type of research study: Quantitative study</p>	<ul style="list-style-type: none"> • The greater the self-confidence, the greater the sense of coherence (sense of understanding, resourcefulness, logic) reported by mothers in both groups. • Maternal anxiety and depression affected mothers' sense of coherence and self-confidence in both groups. • In mothers of children with T1DM, it was found that levels of Depression increased with the provision of protective support. • Among mothers of healthy children emerged that depression levels were reduced by providing support. • In both groups, the greater the support provided, the greater the self-confidence and sense of coherence mothers reported. 	<p>The diagnosis of a child with DM1 significantly affected the psychological state of the mothers, specifically the self-confidence and the sense of coherence, which improved by providing psychological support to both them and their children. Support from the social environment also contributed to the treatment of type 1 diabetes.</p>
<p>Loades et al., 2019, Child Care Health Development [16]</p>	<p>Population Sample: 100 mothers and 65 fathers of 115 children diagnosed with chronic fatigue syndrome.</p>	<p>Aim: The correlation between the fatigue of children diagnosed with chronic fatigue syndrome</p>	<ul style="list-style-type: none"> • Regarding parents, the occurrence of fatigue was associated with the occurrence of anxiety and depression, as well as with the partner's 	<p>Parents reported that fatigue was due to stress, depression, family difficulties and the partner's emotional state. A positive association was</p>

	<p>Tools:1) Physical Functioning Rating Scale (SF-36), 2) Vocational and Social Adjustment Scale, 3) Anxiety Inventory (STAI), 4) Child Depression Rating Questionnaire (CDI), 5) Parental Fatigue Rating Questionnaire (PFQ) , 6) Hospital Anxiety and Depression Scale (HADS), 7) Family Functioning Questionnaire (Systemic CORE)</p>	<p>and the fatigue of the parents who had taken care of them.</p> <p>Type of research study: Cross sectional study</p>	<p>fatigue, and not with the occurrence of fatigue in their child.</p> <ul style="list-style-type: none"> • Parental stress and depression were associated with the presence of obstacles that hindered the smooth functioning of the family. • Child depression appeared to be impacted by the mothers' emotional burden due to difficulties, reduced resilience and adaptability subscales. • Children's physical functioning, social relationships and fatigue were associated with mothers' reduced endurance and adaptability subscale. 	<p>found between fathers' depression and the onset of depression in children. The occurrence of depression in children was associated with the overwhelmed emotional state of the mothers and the difficulties they faced regarding their adaptation to their child's illness.</p>
<p>Rani et al., 2019, Neurological Sciences [12]</p>	<p>Population Sample: Parents of 60 children with Epilepsy</p> <p>Tools: 1) Parental Stress Questionnaire, 2) Parental Stress Scale</p>	<p>Aim: Understanding the anxiety and stigma experienced by parents of children with Epilepsy</p> <p>Type of research study: Quantitative research</p>	<ul style="list-style-type: none"> • The majority of parents reported communication problems both within the family environment and with the health professionals who cared for their child as well as changes in their marital relationship. • A big proportion of parents reported sadness, anxiety, 	<p>Parental stress and the emotional state of the parents depended on the degree of control of the crises, comorbidity, demographic characteristics of the parents, the way the child was treated by the school environment and the</p>

			<p>despair, loneliness, and changes in their emotional state related to the difficulties encountered during their child's treatment.</p> <ul style="list-style-type: none"> • Parents reported that their child received special treatment because of epilepsy. • Child's comorbidity increased parental anxiety 	<p>social environment, as well as the relationship with the health professionals. The stigma experienced by these families was more intense, in cases of comorbidity. The support of families of children with epilepsy by health professionals is essential.</p>
<p>Rennick et al., 2019, BMC Pediatric [28]</p>	<p>Population Sample: 17 parents who cared for 14 children with chronic conditions who were hospitalized in the Intensive Care Unit (ICU)</p> <p>Tools: Semi-structured interviews</p>	<p>Aim: The evaluation of the experience of parents of children with a chronic condition during their admission to the ICU.</p> <p>Type of research study: Descriptive study</p>	<ul style="list-style-type: none"> • The parents reported emotional, psychological difficulties, the feeling of uncertainty and concern regarding the decisions they had to make about their child's health when he was admitted to the ICU. • The parents provided the child with specialized care within the context of the family environment. • Parents were constantly alert during their child's stay in the ICU and reported that they felt more secure when they had developed personal relationships with the health 	<p>Parents of children with a chronic condition treated in the ICU acquired specialized knowledge and skills to be able to care for the child at home. A decisive role in the development of the child's illness was played by the cooperation with the ICU health professionals, who were supposed to provide psychological support to the family.</p>

			professionals who had taken care of their child.	
Vlachou et al., 2020, Thesis [25]	<p>Population Sample: 8 families having a child with cancer.</p> <p>Tools: Semi- structured interview</p>	<p>Aim: The evaluation of the experience of parents who cared for a child with cancer</p> <p>Type of research study: Qualitative study</p>	<ul style="list-style-type: none"> • At the diagnosis of the disease, parents reported psychological shock and emotional burden • During the treatment stage, parents reported mixed feelings that depended on how the child managed the illness. • The majority of families did not seek professional psychological support outside the hospital during treatment. • Half of the families reported that they were not satisfied with government support. 	<p>The diagnosis of a child with cancer took an emotional toll on all family members and financially burdened the parents. It also affected the family's relations with the friendly and social environment. The psychological support of the above families by health professionals and the strengthening of state support was deemed essential.</p>

<p>Al Qadire et al., 2020, Cancer Nursing [17]</p>	<p>Population Sample: 264 parents of children with cancer</p> <p>Tools: 1) Scale Hospital Anxiety and Depression Scale, 2) Zarit Burden Scale</p>	<p>Aim: The assessment of the level and factors of burden in parents caring for children with cancer</p> <p>Type of research study: Cross sectional study</p>	<ul style="list-style-type: none"> • The largest percentage of parents reported a moderate level of psychological burden. • The presence of a chronic illness in the parents, the stage of the child's cancer, the appearance of symptoms by the child, financial difficulties, anxiety and depression were associated with a greater level of psychological burden. 	<p>Levels of psychological burden varied among families caring for a child with cancer and depended on both child- and parent-related factors. Health professionals should be aware of these factors to help families comprehensively through interventions.</p>
<p>Benveniste et al., 2020, Qualitative Health Research [26]</p>	<p>Population Sample: 12 parents of children (9 mothers and 3 fathers) with end-stage renal disease</p> <p>Tools: Semi structured interview</p>	<p>Aim: The analysis of the experience of parents caring for children with kidney disease from the first to the end stage of the disease.</p> <p>Type of research study: Qualitative study</p>	<ul style="list-style-type: none"> • At the diagnosis stage, parents felt vulnerable and experienced the chaos that accompanied the feeling of fear. • At the onset of the first symptoms, the parents experienced the stage of denial, but then they became familiar with the nature and treatment of the disease. • The illness affected the personality of the child and his family and became part of their identity. 	<p>The experience of a family with a child with a chronic condition depended on the type of narrative chosen. The first type of narrative refers to the cases where complete recovery was possible and focused on medical interventions, while the second type of narrative referred to the cases where the child's full recovery was not possible and focused on the child and the family.</p>

			<ul style="list-style-type: none"> The absence of a possibility of recovery for the child caused disordered feelings in the family. 	
Celik et al., 2021, European Neurology [13]	<p>Population Sample: 116 mothers of children with epilepsy</p> <p>Tools: 1) Interview, 2) Beck's Anxiety Questionnaire</p>	<p>Aim: The assessment of the stress of mothers having children with epilepsy during the Covid-19 Pandemic</p> <p>Type of research study: Quantitative study</p>	<ul style="list-style-type: none"> Stress levels did not differ between mothers who visited their child's doctor and those who performed the review by telephone during the Pandemic. Mothers' stress levels depended on the frequency of seizures and the mothers' educational level. Mothers' likelihood of contracting the virus was influenced by frequency of visits and length of hospital stay. 	Throughout the pandemic, mothers' stress levels were positively affected by their children's seizure frequency. Treatment adherence, striving for a normal life and keeping parents fully informed contributed to the elimination of anxiety.
Commissariat et al., 2020, Pediatric Diabetes [30]	<p>Population Sample: 79 parents of children with T1DM</p> <p>Tools: Semi-structured interview</p>	<p>Aim: The analysis of the emotional burden of parents of children with T1DM</p> <p>Type of research study: Qualitative study</p>	<ul style="list-style-type: none"> Parents felt emotionally burdened by having to educate their child and the school environment about the special needs of 1DM. The inability to find an appropriately trained and trusted caregiver for the child also resulted in an additional 	The recognition of the causes of the emotional burden of parents of children with DM1 contributed to the improvement of the quality of life of such families. This was achieved through the provision of support and training, focused on the

			<p>emotional burden for the parents.</p> <ul style="list-style-type: none"> • Parents wanted continued education about T1DM to feel safe. 	<p>family's, child's and social environment's smooth adaption to the new life conditions due to DM1.</p>
<p>Continisio et al., 2020, Italian Journal of Pediatrics [21]</p>	<p>Population Sample: 47 parents of children with Cystic Fibrosis (CF)</p> <p>Tools: Abidin's Parental Stress Questionnaire</p>	<p>Aim: The assessment of the anxiety of parents of children with Cystic Fibrosis</p> <p>Type of research study: Quantitative research</p>	<ul style="list-style-type: none"> • Most parents reported normal levels of stress. • Parental stress levels were positively related to CF severity, number of children in the family, and parent-child interaction. 	<p>The diagnosis of a child with Cystic Fibrosis was related to the appearance of stress in parents, however, the creation of a plan that approached the family holistically and offered psychological support to family members could contribute to the elimination of parental stress.</p>
<p>Khorsandi et al., 2020, BMC Nephrology [1]</p>	<p>Population Sample: 17 parents of children with chronic kidney disease.</p> <p>Tools: Semi-structured interview with physical presence.</p>	<p>Aim: The identification of factors influencing parents regarding the care of children with kidney disease.</p> <p>Type of research study: Qualitative study</p>	<p>Two categories of factors emerged. Religious beliefs, family and social support belonged to the 1st category of factors, which made it easier for parents to take care of their children. Stress, duration of the disease and unfavourable treatment conditions belonged to the 2nd</p>	<p>The health workers' mapping of the factors contributed to the implementation of the necessary interventions to support the parents. Specifically, parents' access to information and financial and emotional support could</p>

			category, which included factors that made the children's care difficult.	improve the quality of care for them, in parallel with the elimination of factors that made it difficult to care for their children.
Van Gampelaere et al., 2020, Pediatric Diabetes [8]	<p>Population Sample: 105 families of children with TDM1 and 416 families of healthy children</p> <p>Tools: 1) Pediatric Patient Quality of Life (PedsQOL) Questionnaire, 2) Strengths and Weaknesses Questionnaire (SDQ), 3) Parental Stress Rating Scale (PSS), 4) Anxiety and Depression Rating System (PROMIS), 5) Protective Behavior Rating System, 6) Parental Autonomy Scale (POPS), 7) Parental Control Scale (PCS-YSR), 8) Report of Parenting</p>	<p>Aim: The comparison of families with a child with type 1 diabetes to families which are not confronted with chronic illness, with regard to children's well-being, parental distress, and parenting behavior. Additional aim was the exploration of differences between families whose child has optimal vs suboptimal glycemic control.</p> <p>Type of research study: Cross sectional study</p>	<ul style="list-style-type: none"> Families of children with T1DM reported a lower quality of life of their children compared to families of healthy children. Mothers of children with T1DM reported higher levels of anxiety, depression and worry compared to mothers of healthy children. Regarding Parental Behavior, fathers of children with DM1 reported lower levels of protective behavior than fathers of healthy children, while parents of children with DM1 reported lower levels of autonomy and responsibility than parents of healthy children. Regarding children with insufficient control of T1DM, a lower level of quality of life was obtained. Their mothers 	Children's quality of life, parental distress and parenting behavior were affected by T1DM and further by the degree of T1DM regulation. Under these circumstances, psychological support for the families of children with T1DM and the provision of quality care to children with T1DM are deemed necessary.

	Behavior Questionnaire (RPBI)		reported higher levels of anxiety and depression and lower levels of responsibility compared to mothers of healthy children.	
Kapiri et al., 2021, Archives of Greek Medicine [33]	<p>Population Sample: 123 parents of autistic children</p> <p>Tools: 1) FAS scale to assess perceived fatigue, 2) MSPSS scale to assess perceived social support, and 3) FACIT-SP-12 scale to assess spirituality</p>	<p>Aim: The evaluation of fatigue, in parents with children on the autistic spectrum, as well as the impact of spirituality and the support of the social environment on the fatigue.</p> <p>Type of research study: Quantitative study</p>	<ul style="list-style-type: none"> • Fathers showed a lower level of mental fatigue than mothers. • Family support from their environment reduced levels of mental fatigue. • Mental fatigue was highly dependent on physical fatigue. 	Parents of children with autism spectrum disorder were characterized by moderate levels of fatigue which was influenced by social support, spirituality and the gender of the caregiver.
Kosmidou, 2021, Thesis [9]	<p>Population Sample: 130 parents of children with Type 1 Diabetes Mellitus.</p> <p>Tools: 1) Demographic Data Record Form, 2) Parent Family Impact Acute Questionnaire, 3)</p>	<p>Aim: The identification of the causes that burden the parents of children with diabetes mellitus and the assessment of mental resilience and stress.</p>	<ul style="list-style-type: none"> • Parental stress was associated with children's self-care ability and parents' social status. • Chronic fatigue is related to chronic stress. • The age of the children with diabetes mellitus was associated 	The stress of parents of children with type 1 diabetes was associated with the parents' mental resilience, their time, their children's level of self-care, their age, as well as their financial situation. The burdened

	Resilience Scale Questionnaire, 4) Perceived Stress Questionnaire.	Type of research study: Cross sectional study	with the social relations of the parents. <ul style="list-style-type: none">• Parents' socialization improved their mental health.	mental state of the parents affected their quality of life. Support and guidance groups were essential.
Kostopoulou et al., 2021, Swiss Medical Weekly [19]	Population Sample: 1106 parents of children with and/or without chronic diseases Tools: Questionnaires 1) Demographics, 2) Pediatric Patient Medical History, 3) Anxiety Rating Scale (PSS), 4) Impact of Event Scale (IES-R)	Aim: The assessment of Parental Stress during the Covid-19 Pandemic, in Greece. Type of research study: Cross sectional study	<ul style="list-style-type: none">• Parents of children with chronic diseases reported higher levels of stress compared to parents of children without chronic diseases. Higher levels of stress were observed in parents of children with heart, respiratory and immunodeficiency diseases.• Mothers reported higher levels of stress compared to fathers.• 51.7% of parents of children with chronic illnesses reported high rates on the Impact of Event Scale, 51.7% of parents of children with chronic illnesses reported an increased level of impact since their child's diagnosis.	Parental Stress levels increased during the Covid-19 Pandemic and in particular higher levels of stress were observed in parents who cared for a child with a chronic illness.
Mpalaskas, 2021, Thesis [10]	Population Sample: 110 caregivers of children with Type 1 Diabetes Mellitus.	Aim: The assessment of the level of perception of parents of children with Type 1 Diabetes, regarding their	<ul style="list-style-type: none">• High levels of general discomfort and temporary anxiety were found in 2/3 of the parents.• The factors that influenced the occurrence of parental anxiety were	Parents of children with type 1 diabetes were characterized by high levels of stress and general discomfort, which were

	<p>Tools: 1) Parent-DDS Questionnaire, 2) Spielberger Questionnaire (STAI)</p>	<p>quality of life, as well as their psychological state.</p> <p>Type of research study: Cross sectional study</p>	<p>the financial situation, the age of the parents and the therapeutic regimens applied to their children.</p> <ul style="list-style-type: none"> • General parental distress was associated with complications of diabetes mellitus. 	<p>associated with their socio-demographic characteristics, as well as the progress of their children's disease.</p>
<p>Lagoudaki, 2021, Master's Thesis [6]</p>	<p>Population Sample: 192 parents-caregivers of children with Type 1 Diabetes Mellitus (T1D)</p> <p>Tools: 1) Demographic data recording form, 2) Questionnaire for the Evaluation of the Quality of Life of Pediatric Patients with T1DM, 3) Spielberger's State-Trait Anxiety Inventory, 4) Spielberger Anxiety Scale</p>	<p>Aim: The assessment of the difficulties faced by the parents of children with T1D</p> <p>Type of research study: Quantitative study</p>	<ul style="list-style-type: none"> • On the Temporal Anxiety Scale, most parents reported nervousness and worry. • On the Persistent Anxiety Scale, parents reported anxiety, low level of calmness and security, moderate level of overstress. • Parental stress was related to the child's age and the child's age of diagnosis. 	<p>The data supported that T1DM affected the daily life of the family, which had to respond to the needs of the affected member regarding prevention and treatment. The children's parents reported moderate levels of temporary and permanent stress that did not appear to be affected by the pandemic.</p>
<p>Terzi, 2021, Thesis [20]</p>	<p>Population Sample: 1487 parents of children without chronic or serious illness and 216 parents of children with serious or chronic illness.</p>	<p>Aim: The assessment of the psychological state of parents who cared for a child with a chronic disease, in relation to the Covid-19 pandemic, as well as the assessment of the</p>	<ul style="list-style-type: none"> • Increased stress was observed in parents caring for children with immunodeficiency. • Female and young participants were associated with increased stress. 	<p>Over time, parents' levels of anxiety about Covid-19 infection decreased as their knowledge about the virus increased. Parents' stress did not depend on the pandemic</p>

	<p>The participants were identified from the patient lists of 19 pediatricians in Greece.</p> <p>Tools: A Google Forms questionnaire with four sections (introduction page, general information section, children's medical history, psychometric scales).</p>	<p>stress of children with a chronic disease, as perceived by the parents.</p> <p>Type of research study: Cross sectional study</p>	<ul style="list-style-type: none"> • Complete vaccination against the Covid-19 infection reduced the stress on parents and children. • There was a positive correlation between children's age and anxiety 	<p>but on the type of chronic disease. Mainly, high levels of stress were observed in parents caring for children with immunodeficiency. On the other hand, the children's anxiety depended on their age and whether or not their parents had been vaccinated.</p>
<p>Belov et al., 2021, WLek [22]</p>	<p>Population Sample: 104 parents (40 fathers and 64 mothers) of children with chronic musculoskeletal problems.</p> <p>Tools: 1) Hamilton Depression and Anxiety Scale, 2) Buss Durkee Hostility Questionnaire</p>	<p>Aim: The analysis of the psychopathological condition of parents of children with chronic musculoskeletal problems.</p> <p>Type of research study: Quantitative study</p>	<ul style="list-style-type: none"> • Psychopathological effects between mothers and fathers differed and depended on the duration of chronic illness. • Mothers showed higher anxiety, depression and emotional instability and reported more frequent sleep disturbance than fathers. • Both mothers and fathers reported feeling tired. • Mothers experienced high mental stress while fathers experienced higher physical stress. 	<p>A chronic musculoskeletal condition in children seemed to affect parents differently. Mothers appeared to experience more unpleasant emotions than fathers, whose psychological state was expressed through aggression.</p>

			<ul style="list-style-type: none"> • Fathers showed higher levels of aggression than mothers. 	
Chan Sun et al., 2021, Journal of Pediatric Nursing [29]	<p>Population Sample: 11 mothers of children with T1DM</p> <p>Tools: Journal</p>	<p>Aim: The analysis of experiences of mothers of children with DM1</p> <p>Type of research study: Phenomenological study</p>	<ul style="list-style-type: none"> • Mothers reported that both themselves and the social environment were surprised at the announcement of T1DM • Mothers noticed changes in all areas of their daily lives. • Guilt, fear for their child's future and psychological fatigue were representative symptoms of the mothers. • Mothers reported difficulty adjusting to the demands of DM1 and physical fatigue due to the need for constant vigilance. • Mothers reported that any support was instrumental in improving adaptation to the demands of DM1. 	The diagnosis of a child with T1DM significantly affected the daily life of the mothers, who experienced a multitude of mixed emotions. The professionals' support and the social environment contributed to mothers' easier acceptance of their new everyday life.

<p>Mariyana et al., 2021, Journal of Pediatric Nursing [27]</p>	<p>Population Sample: 11 parents and caregiver of children with a chronic disease</p> <p>Tools: Interview</p>	<p>Aim: The description of the experience of parents and caregivers of children with chronic diseases.</p> <p>Type of research study: Descriptive qualitative study</p>	<ul style="list-style-type: none"> • Parents' first reaction to the announcement of their children's chronic illness included crying, denial and guilt. • Parents expressed fear regarding the possible death of their child due to the chronic disease. • Caregivers tried alternative and traditional ways of treating their children's chronic illnesses and followed health professionals' instructions precisely. • Parents felt pressure as they tried to meet their children's needs and cope with the role of parent. • Caregivers turned to religion for psychological support. 	<p>Parents experienced strong emotions when they were first informed about their child's illness, however, they adjusted to the new reality over time while experiencing the five stages of grief. In addition, the parents tried to take care of their children comprehensively, while spiritual support played a decisive role in the psychology and motivation of the caregivers when taking care of the children.</p>
<p>Wauters et al., 2021, Journal of Pediatric Psychology [18]</p>	<p>Population Sample: 599 parents of children with chronic diseases (sample for the first objective) 507 parents with chronic diseases (sample for the second objective) and</p>	<p>Aim: The assessment of the level of anxiety and depression of parents of children with chronic diseases.</p> <p>The analysis of the factors that hinder the quality of life</p>	<ul style="list-style-type: none"> • Parents of children with chronic illnesses reported more intense stress compared to parents of children without chronic diseases. Specifically, stress was more common among mothers and young parents. Parents who 	<p>The Covid19 pandemic has affected the parents of children with chronic diseases. These parents experienced burnout due to obligations, which burdened their psychological state.</p>

	<p>417 parents of healthy children</p> <p>Tools: 1) Demographic Record Form, 2) Parent Information and Outcome Reporting System (PROMIS), 3) Insomnia Index (ISI), 4) Impact Factor Questionnaire, 5) Parental Burnout Assessment Tool</p>	<p>and the psychological state of the parents.</p> <p>Type of research study: Cross sectional study</p>	<p>took care of their children alone showed depression.</p> <ul style="list-style-type: none"> • Parental stress was associated with the quality of care provided, the number of children in the family, the parent's responsibilities, burnout, and the family's financial situation. • Parents' depression was affected by their age, the quality of care provided, their responsibilities, burnout and the family's financial situation. • Parental sleep problems were associated with burnout, financial hardship, ethnicity, and quality of care provided. 	
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