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Empowering families: the role of family-centered programs in alleviating fatigue for chronically ill children and their parents

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Abstract

Background Chronic illness in children significantly affects their quality of life and that of their families. They often encounter numerous challenges, with fatigue being one of the most common. Creating opportunities for parents to care for their children, participate in caregiver support groups, and engage in discussions with healthcare professionals can empower them.

Objective To assess the impact of family-centered empowerment programs (FCEP) on reducing fatigue levels in children with chronic illnesses and their parents.

Methods A quasi-experimental study utilizing a single group pre/post-test design was carried out involving 328 mother-child pairs at Mansoura University Children's Hospital. Pre-test and post-test measurements were utilized, employing the Pediatric Quality of Life Multidimensional Fatigue Scale for children and the Checklist Individual Strength for parents. The FCEP comprised three educational sessions focused on managing fatigue and enhancing family support was introduced.

Results Post-intervention, children's fatigue scores significantly improved from 6.59 to 33.64 ($p \leq 0.001$). All fatigue subscales (general, sleep/rest, cognitive) demonstrated significant enhancements. Parental fatigue also showed a slight decrease, although it was less pronounced. Differences were observed in self-efficacy and coping strategies before and after the intervention, indicating a positive shift in these areas among families.

Conclusion The findings suggest that implementing family-centered empowerment programs is associated with reduced fatigue severity in children with chronic illnesses and their parents. This highlights the potential benefits of family involvement in care processes. However, it may be beneficial for future studies to utilize a larger randomized design to further validate these results and enhance the generalizability of the findings.

Keywords Chronic illness, Children's health, Empowerment, Family-centered care, Fatigue

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Introduction

Chronic illness is a type of non-communicable disease (NCD), characterized by a prolonged duration and gradual onset, potentially leading to mortality. The emergence of chronic illnesses is shaped by a combination of physiological, genetic, behavioral, and environmental factors [1]. Over the past 60 to 70 years, the prevalence of chronic illnesses and disabilities among children and adolescents has more than doubled. Common chronic conditions affecting children globally include bronchial asthma, cystic fibrosis, diabetes mellitus, epilepsy, developmental disabilities such as cerebral palsy, as well as congenital and hereditary disorders like hemolytic anemias and genitourinary issues [2]. The diagnosis of chronic illness in children is often a crisis for families, eliciting varied responses. While some families adapt well, others face challenges such as limited access to information, inadequate support, high treatment costs, and mental health issues [3]. Children with chronic illnesses may experience activity limitations, persistent pain, fatigue, abnormal growth, and increased medical interventions [4]. Psychosocially, they may struggle with fears about their environment and anxiety regarding peer reactions, leading to a heightened risk of depression, social withdrawal, and feelings of helplessness [5].

Families with a child suffering from chronic illness face considerable emotional and practical challenges. They may grieve the loss of the "ideal" child, neglect siblings, and incur significant financial and time burdens. Confusion from conflicting healthcare systems and missed work opportunities for caregivers add to their stress. Siblings might resent the attention given to the ill child, which, combined with existing family dynamics, can lead to significant strain and potential family breakdowns [6]. Children with chronic illnesses often encounter numerous challenges, with fatigue being one of the most common. This fatigue can significantly disrupt a child's development and social engagement. It may be triggered by inflammation or the initiation of treatment, but it can also persist and cause distress even when disease activity is low or absent [7]. Crucially, fatigue is not only associated with disease-specific biological factors; a range of modifiable biological, lifestyle, psychological, and social influences can also play a role in its development and persistence. Thus, comprehending the nature of fatigue in children with chronic illnesses, as well as the factors that may worsen it, is essential for effective management and enhancing their quality of life.

Recent advancements in chronic illness treatments have decreased mortality rates and extended life expectancy for affected children. Quality of life (QoL) is increasingly seen as a critical measure of healthcare effectiveness [4]. In the last two decades, there has been a rising focus on assessing and improving QoL for patients with chronic conditions, aiming to enhance their daily functioning and overall well-being. Chronic diseases impact various aspects of a child's life, emphasizing the necessity for support for both the child and their family. Therefore, a primary treatment goal is to enhance quality of life by alleviating the effects of the disease [8].

Parents are essential in caring for children with chronic illnesses, frequently facing challenges in balancing their child's needs with other responsibilities. This can result in increased stress, fatigue, family conflict, and a significant caregiving burden [9]. The way parents engage in caregiving greatly affects their children's well-being, whether at home or in healthcare settings. Providing opportunities for parents to care for their children, join caregiver support groups, and communicate with healthcare professionals can empower them, enhancing their skills and confidence in caregiving [10]. Efforts to improve children's self-care are increasingly focused on empowering their families. A popular approach among specialists is family-centered empowerment intervention, which combines family-centered services with educational planning to encourage active family involvement in both education and care implementation [11].

Family empowerment is a strategic intervention that includes three key concepts: Knowledge and Information by providing families with essential information about the child's condition and treatment options. Behavioral skills that equip families with the skills needed to manage care effectively. Responsibility means encouraging families to take an active role in the care process. This approach strengthens the family's involvement in caring for patients, ultimately improving outcomes [12]. The primary objective of family empowerment is to enable families to effectively support and care for members with chronic diseases, acknowledging their essential role in the overall care process [13]. Additionally, family empowerment can help reduce fatigue in both children and their parents during caregiving. By enhancing physical and mental functioning, it also boosts self-efficacy, allowing families to navigate the challenges of chronic illness more effectively [6]. Nursing interventions focused on empowerment should prioritize collaboration between nurses and families, aiming to reduce risk factors and promote health. Nurses should adopt a constructive approach that highlights the family's strengths rather than their challenges. An effective empowerment strategy fosters teamwork and shared responsibility, ensuring that family members recognize their difficulties and have the capacity to change their situations. This empowerment is facilitated through access to information, support, and the development of essential life skills [14].

Significance of the problem

Research shows that patients who take an active role in their care often experience better treatment outcomes compared to those who are passive participants. Families play a vital role in their children's health and can greatly impact their quality of life [15]. As a result, healthcare has shifted from a traditional child-centered model to a family-centered approach, emphasizing the involvement of parents in all decision-making processes and care measures for their children, both in and out of the hospital. Parents of children with chronic illnesses often invest considerable time in caregiving, which can lead to fatigue and a caregiver burden [16]. Moreover, although both children and parents wish to participate in self-care, they often lack the essential knowledge or skills, resulting in considerable difficulties in managing the care of their sick children [17].

Empowerment training enhances awareness of illnesses, increases motivation for self-care, and offers a valuable alternative to merely adhering to physician instructions. By promoting patient empowerment, individuals gain the information and skills necessary to manage their conditions and make informed decisions [10]. Empowerment-based interventions help identify patient challenges while enabling them to realize their potential in managing chronic illnesses. Parents often find it difficult to determine the best ways to support their children with chronic conditions, making empowerment-based interventions essential for them as well [18]. Both caregivers and patients share self-care responsibilities, and families play a crucial role in ensuring adequate healthcare. Given that most care occurs at home, families are vital in helping patients cope with the stresses of chronic illnesses [19]. Thus, this study aimed to investigate the effects of family-centered empowerment programs on reducing fatigue severity in both children with chronic illnesses and their parents.

Hypothesis

H1 The implementation of family-centered program significantly reduces the severity and prevalence of fatigue among children with chronic illnesses and their parents."

Methods

Study design & setting

A quasi-experimental research design was employed, utilizing a single group with pre-test and post-test measurements to align with the study's objectives.

Setting

This study was conducted in the outpatient and inpatient for the following departments Cardiac Care Unit, Endocrine & Diabetes Unit, Hemodialysis Unit and Hematology Unit affiliated to Mansoura University Children's Hospital and Pediatric Oncology department affiliated to Mansoura Oncology Center, Mansoura University, Egypt.

Sample

The study determined the sample size of 328 mothers and their children, using a significant level of 5% and a power of 80%, based on the following formula:

$n = Z2 \cdot P \cdot (1 - P)\ d2n = d2Z2 \cdot P \cdot (1 - P)$

Where: $Z = 1.96Z = 1.96$ for a 95% confidence level. $P = 31\%P = 31\%$ prevalence of fatigue among chronic patients (Goertz et al., 2021) [20]. $d = 0.05d = 0.05$ (margin of error)

The sample consisted of children aged 8–18 years with chronic illnesses or those who had undergone chemotherapy, along with their parents, who met these inclusion criteria: suffering from a chronic illness diagnosed for over a year and representing both genders. Children with cognitive and physical impairment were excluded from the study.

Tools of data collection

Two tools used for data collection

Tool 1: "pediatric quality of life multidimensional fatigue scale (PedsQL MFS)"

This tool assesses children's self-reported fatigue using the validated PedsQL Multidimensional Fatigue Scale, based on the research of Suzanne Gordijn et al. (2011) and Varni et al. (2002) [21, 22]. The scale comprises 18 items divided into three subscales: general fatigue (GF), sleep/rest fatigue (SRF), and cognitive fatigue (CF). It is tailored for various age groups: young children (ages 5–7), children (ages 8–12), and adolescents (ages 13–18), along with parent proxy-reports. Participants indicate how frequently they encountered specific issues in the past month on a 5-point Likert scale (0 = Never; 1 = Virtually Never; 2 = Sometimes; 3 = Frequently; 4 = Almost Always). Scores are calculated by reversing the item values (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), meaning that a higher score reflects a better quality of life and fewer fatigue symptoms, with 0 indicating significant fatigue and 100 representing minimal fatigue. Additionally, demographic and health information are gathered for the children, including their age, gender, educational level, birth order, diagnosis, duration of illness, and family history of the disease.

Tool 2: checklist individual strength (CIS) assessment questionnaire

Parental fatigue was evaluated using a checklist of individual strength, adopted from Van Riel and Knoop (2017) [23]. This questionnaire contains 20 items scored on a 7-point Likert scale, with total scores derived by summing the individual item scores. The tool features four

subscales: Fatigue Severity (8 items): Assesses the subjective experience of fatigue. Concentration (5 items): Measures issues related to concentration. Motivation (4 items): Evaluates reduced motivation. Activity (3 items): Assesses the reduction in activities. Some items are scored in reverse. The cut-off scores for identifying severe fatigue are ≥35 for the CIS-fatigue subscale and ≥18 for the shortened CIS. Both subscales are effective screening tools, exhibiting high sensitivity (0.98 and 0.99) and slightly lower specificity (0.83 for both). Parents were requested to reflect on their feelings over the past two weeks and rate their responses using a seven-point Likert scale, where 1 represents "fully agree" and 7 signifies "fully disagree." Higher total scores indicate greater severity of fatigue (range: 8–56) and higher levels of reduced concentration (range: 5–35), reduced motivation (range: 4–28), and decreased physical activity (range: 3–21).

Fatigue family centered empowerment program (FCEP) for parent and children with chronic illness

The researchers developed the fatigue management and prevention nursing intervention program by reviewing related literature [24, 25] and actively consulted with families to ensure that the program addressed their specific needs and perspectives. The procedure for the study follows four key phases: assessment, planning, implementation, and evaluation.

In the assessment phase, during routine visits at the outpatient and inpatient units of the selected hospital departments, children diagnosed with chronic illnesses and their parents were identified and screened for eligibility. Families meeting the inclusion criteria were invited to participate in the study. The researcher introduced the study, explained its purpose and nature, and obtained written informed consent from parents. Contact information was collected to facilitate follow-up. Data collection was conducted three days per week for six months, aligning with clinic schedules (Saturdays, Mondays, and Wednesdays) from 9 am to 2 pm. Individual interviews were held with parents to document demographic data, the child's health condition, and baseline levels of fatigue using validated fatigue assessment tools: the PedsQL-MFS for children and the CIS for parents. This phase typically requires 30 min per participant. Data was collected from the start of December 2023 to the end of May 2024.

In the planning phase, the FCEP was developed based on insights from the assessment phase and relevant literature and actively consulting with families. The educational materials were specifically designed to meet the identified needs and focused on several key areas: understanding chronic illnesses and fatigue, including their definitions, causes, signs, symptoms, and impacts; strategies for managing fatigue, such as energy conservation, activity scheduling, and emotional support techniques; and skills for family communication and collaboration. The educational tools consisted of a colorful, easy-to-read booklet that highlighted essential information, audio-visual materials like videos and PowerPoint presentations, practical examples and exercises to reinforce learning, and printed handouts to enhance engagement. The FCEP was organized into three sessions: **Session 1**: Introduction to chronic illnesses and fatigue, along with their effects on children and parents. **Session 2**: Practical strategies for coping with fatigue and enhancing family support. **Session 3**: Maintaining improvements through self-care and ongoing family collaboration to boost resilience. Each session was designed to last about 45 min and included clearly defined objectives, utilizing interactive teaching methods such as discussions, brainstorming, and role-playing exercises.

During the implementation phase, participants took part in FCEP sessions in small groups (3–5 parents and their children) according to their availability. These sessions were conducted in a private, comfortable setting within the healthcare facilities (MUCH & OCMU). Each session adhered to a structured format: Introduction: Overview of the session's objectives and topics for 5 min. Engagement: Brainstorming activity to discuss participants' existing knowledge and experiences (10 min). Instruction: A focused lecture on the session topic, supported by audio-visual aids and practical demonstrations (25 min). Feedback: Group discussion and summary to address questions and reinforce learning (5 min). The researcher facilitated these sessions, ensuring an interactive and supportive environment. Participants were encouraged to review and apply the strategies learned at home, use the materials provided for reference, and contact the researcher for additional support as needed. In the evaluation Phase, the effectiveness of the FCEP was evaluated at three intervals: baseline (pre-intervention), two months post-intervention, and six months post-intervention. The evaluation focused on Children: Changes in fatigue severity using the PedsQL-MFS. Parents Changes in fatigue levels and coping skills assessed through the CIS. Data was analyzed to compare pre- and post-intervention outcomes. The results were used to assess the FCEP's impact on reducing fatigue severity and enhancing participants' empowerment.

Validity and reliability

The reliability and validity of the tools used in this study were thoroughly assessed. A panel of five experts in pediatric nursing from Mansoura University reviewed these tools. The internal consistency for the Child Self Report showed a Cronbach's alpha of 0.87, with the specific items for General Fatigue, Sleep/rest Fatigue, and Cognitive Fatigue scoring 0.74, 0.65, and 0.83, respectively. The Checklist Individual Strength demonstrated excellent

reliability, with a high Cronbach's alpha of 0.95 for the overall scale and strong scores for each subscale: Fatigue Severity (0.94), Concentration (0.89), Motivation (0.84), and Activity (0.90). Additionally, the test-retest reliability was robust, with a Spearman rank correlation of 0.86 for the total score and respectable correlations for the subscales: Fatigue Severity (0.85), Concentration (0.79), Motivation (0.79), and Activity (0.73).

Pilot study

The researcher carried out a pilot study with 32 mothers and their children, which accounted for 10% of the total sample, to assess the clarity of the questionnaire items and their relevance. Based on the results of this pilot evaluation, no changes were deemed necessary.

Table 1 Demographic characteristics of studied mothers and children

Demographic data	No (n = 328)	%
Child Age (Years)		
Mean ± SD	9.85 ± 2.00	
Min-Max	6.00–14.00	
Sex		
Male	162	49.4
Female	166	50.6
Order of birth		35.4
1	116	39.9
2	131	21.3
3	70	3.4
4	11	
Child education		77.7
Primary	255	22.3
Preparatory	73	
Duration of the disease		
Mean ± SD	3.73 ± 1.71	
Min-Max	1.00–11.00	
Family History of chronic illness		
Yes	139	42.4
No	189	57.6
Co morbidities		
Yes	65	19.8
No	263	80.2
Other children suffer from chronic disease		
Yes	58	17.7
No	270	82.3
Mother's age		
Mean ± SD	36.37 ± 5.48	
Min-Max	25.00–72.00	
Mother's Education		
Read and write	45	13.7
Middle education	173	52.7
High education	110	33.5
Mother's Occupation		
Housewife	222	67.7
Worker	106	32.3

Ethics approval and consent to participate

The study was conducted in compliance with the Declaration of Helsinki and received ethical approval from the Research Ethics Committee at the Faculty of Nursing, Mansoura University, under reference number P 0561. The hospital chief authorized the study after the researchers provided a detailed explanation of its objectives and procedures. Informed consent was obtained from the mothers, who were given a thorough overview of the study's purpose and methods. The mothers were informed that contribution was deliberate, and they might withdraw at any time without needing to justify their decision. Furthermore, the mothers were secured that their personal data would remain private and would not be linked to the study's results.

Results

Table 1 outlined the demographic characteristics of the mothers and children participating in the study. The sample consisted of 328 mothers and children, with a nearly even gender distribution of 162 males (49.4%) and 166 females (50.6%). The average age of children was approximately 9.85 years, with ages ranging from 6 to 14 years. Most of the children were first or second-born, accounting for 75.3% of the sample. A significant majority, 255 children (77.7%), were enrolled in primary education. The average duration of their illnesses was about 3.73 years, indicating that many had been diagnosed relatively recently. Furthermore, 139 families (42.4%) reported a history of chronic illness, and 165 children (19.8%) had comorbid conditions. Regarding maternal education, a substantial majority of mothers (173, or 52.7%) had at least completed middle school.

Figure 1 illustrated the most common diagnoses among the children in the study. Notably, 90 children (27.4%) were diagnosed with type I diabetes, while another 80 children (24.4%) were diagnosed with cancer following chemotherapy.

Table 2 illustrates a substantial improvement in the pediatric quality of lifemultidimensional fatigue score, which increased from 6.59 before theintervention to 33.64 three months post-intervention. This notable risesuggests a significant reduction in fatigue levels following the intervention. Furthermore,the fatigue subscales (general, sleep/rest, and cognitive) demonstratedsignificant enhancements following the intervention, with statisticallysignificant differences observed. In contrast, maternal fatigue showed a slightdecrease in post-intervention, though the change was not as pronounced as thatseen in the children.

Relationship between child education, maternal education, and both the pediatric quality of life multidimensional fatigue score and maternal fatigue score were illustrated in Table 3. This table indicated that

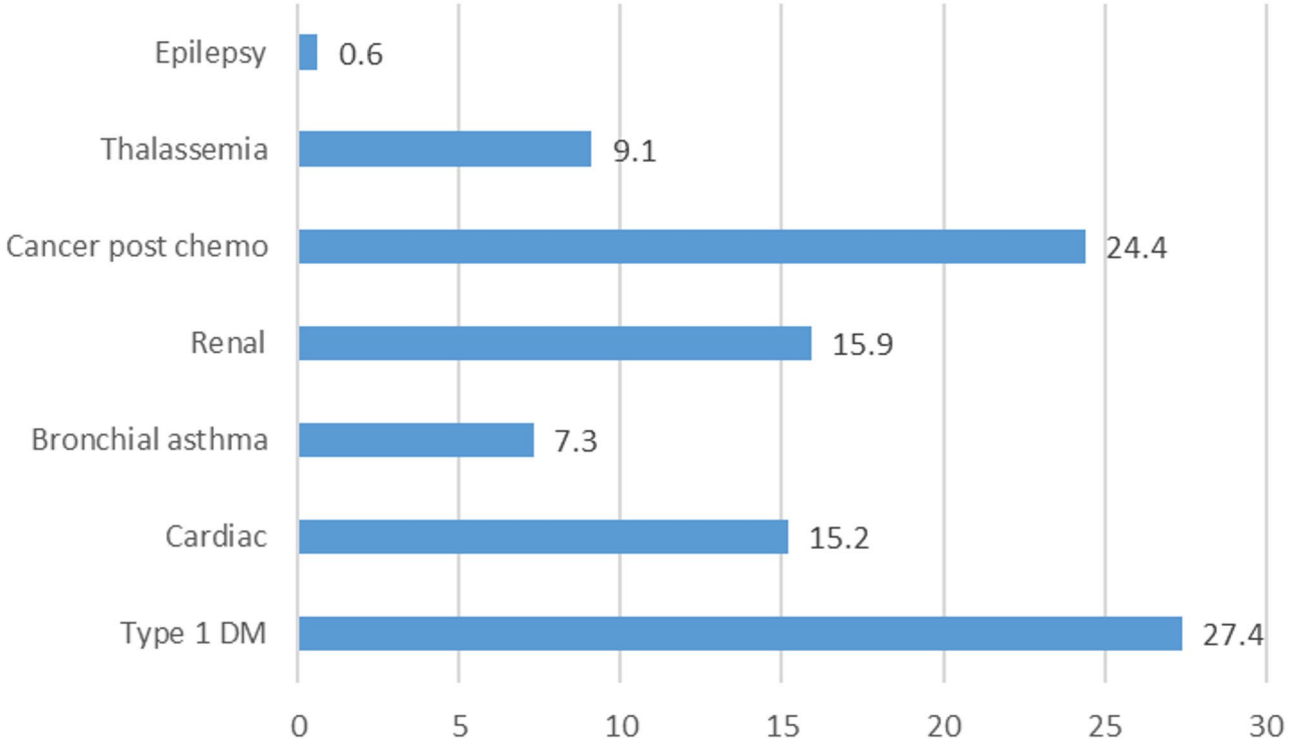

Fig. 1 Most common diagnosis of children

Table 2 Pediatric quality of life multidimensional fatigue score & parental fatigue score

Variables	Pre- intervention (n = 328)	3 months post-intervention(n = 328)	Paired t-test	*p* value
Total Children Fatigue	6.59 ± 3.38	33.64 ± 4.48	t = 87.96	≤ 0.001*
General Fatigue	3.36 ± 1.83	13.10 ± 1.97	t = 65.11	≤ 0.001*
Sleep/rest	3.02 ± 1.69	12.08 ± 1.68	t = 69.73	≤ 0.001*
Cognitive Fatigue	0.21 ± 0.46	8.46 ± 2.84	t = 51.69	≤ 0.001*
Total Parental fatigue	79.87 ± 2.32	74.90 ± 7.38	t = 11.78	≤ 0.001*
Fatigue severity components	36.82 ± 1.87	27.80 ± 2.95	t = 48.47	≤ 0.001*
Activity elements	14.97 ± 0.19	14.03 ± 1.94	t = 8.69	≤ 0.001*
Focus elements	17.20 ± 0.90	16.17 ± 2.33	t = 7.68	≤ 0.001*
Motivating elements	10.86 ± 0.97	16.89 ± 3.27	t = 56.35	≤ 0.001*

**$p < 0.001$

post-intervention scores showed a significant reduction in general fatigue for children across all education levels (t = 2.74, $p = 0.006$). For mothers, there was also a significant effect based on education (F = 28.77, $p \leq 0.001$), suggesting that higher maternal education correlated with lower fatigue levels. Both children and mothers exhibited significant reductions in total fatigue post-intervention (children: t=-2.91, $p = 0.004$; mothers: F = 10.93, $p \leq 0.001$).

Table 4 illustrated the relationship between child diagnoses, pediatric quality of life multidimensional fatigue scores, and maternal fatigue scores. Statistically significant differences were observed in general fatigue scores, rest and sleep, and total fatigue scores before and after the intervention ($p = 0.001$). However, no statistically significant difference was found in cognitive fatigue for children. Regarding parental fatigue in relation to child diagnosis, a significant difference was noted between diagnoses and both the focus & motivating element subscale and the overall parental fatigue scale ($p = 0.011$).

Table 5 illustrated the association between age, disease-related factors, and pediatric quality of life multidimensional fatigue score & maternal fatigue score. This table indicated that children with a disease duration of less than four years exhibited significantly higher scores in general fatigue, sleep/rest, and cognitive fatigue subscales after the intervention compared to those with longer disease durations ($p \leq 0.001$). A statistically significant relationship existed between the age of the child and the general fatigue subscale for children ($p = 0.006$), indicating that older children (over 12 years) experienced slightly higher fatigue scores than younger children. There were no significant differences found in fatigue scores between children with and without comorbidities.

Table 3 Relationship between education & pediatric quality of life multidimensional fatigue score & mothers fatigue score

Variables		Child Education		Test of significance	*p* value	Mothers' education			Test of significance	*p* value
		Primary	Preparatory			Read, write	Middle	High		
General Fatigue	Pre	3.36 ± 1.83	3.36 ± 1.82	t = 0.037	0.970	3.93 ± 1.82	3.23 ± 1.80	3.33 ± 1.84	F = 2.66	0.071
	Post	12.94 ± 1.88	13.65 ± 2.18	t = 2.74	0.006*	15.02 ± 3.01	12.78 ± 1.62 a	12.81 ± 1.44 a	F = 28.77	≤ 0.001*
Sleep/rest	Pre	3.00 ± 1.72	3.09 ± 1.58	t=-0.408	0.683	3.37 ± 1.55	2.96 ± 1.75	2.97 ± 1.65	F = 1.13	0.323
	Post	11.94 ± 1.70	12.56 ± 1.50	t = 2.77	0.006*	13.51 ± 1.51	11.82 ± 1.59 a	11.90 ± 1.60 a	F = 21.17	≤ 0.001*
Cognitive Fatigue	Pre	0.16 ± 0.40	0.35 ± 0.60	t = 3.08	0.002*	0.24 ± 0.43	0.20 ± 0.46	0.20 ± 0.48	F = 0.150	0.861
	Post	8.37 ± 2.99	8.76 ± 2.23	t = 1.04	0.297	7.88 ± 2.97	8.41 ± 2.87	8.76 ± 2.73	F = 1.55	0.213
Total Children Fatigue	Pre	6.53 ± 3.41	6.82 ± 3.26	t=-0.642	0.521	7.55 ± 3.21	6.40 ± 3.44	6.50 ± 3.30	F = 2.13	0.119
	Post	33.2 ± 4.46	34.98 ± 4.32	t=-2.91	0.004*	36.42 ± 6.00	33.02 ± 4.21 a	33.49 ± 3.74 a	F = 10.93	≤ 0.001*
Fatigue severity components	Pre	36.88 ± 1.82	36.63 ± 2.04	t = 1.02	0.305	36.48 ± 1.98	36.98 ± 1.78	36.71 ± 1.97	F = 1.557	0.212
	Post	27.85 ± 3.05	27.63 ± 2.59	t = 0.573	0.567	28.88 ± 3.77	27.73 ± 2.77 a	27.47 ± 2.76 a	F = 3.846	0.022*
Activity elements	Pre	14.97 ± 0.20	14.97 ± 0.16	t = 0.002	0.998	15.00 ± 0.00	14.97 ± 0.19	14.96 ± 0.23	F = 0.550	0.578
	Post	14.00 ± 2.02	14.12 ± 1.67	t = 0.446	0.656	13.13 ± 2.34	14.25 ± 1.72 a	14.05 ± 2.01 a	F = 6.109	0.002*
Focus elements	Pre	17.21 ± 0.91	17.19 ± 0.89	t = 0.165	0.869	17.24 ± 1.00	17.22 ± 0.88	17.16 ± 0.90	F = 0.198	0.820
	Post	16.05 ± 2.32	16.56 ± 2.36	t=-1.62	0.106	17.71 ± 2.72	15.83 ± 2.28 a	16.07 ± 2.01 a	F = 12.474	≤ 0.001*
Motivating elements	Pre	16.83 ± 3.37	17.10 ± 2.89	t = 0.630	0.529	10.86 ± 0.91	10.90 ± 0.95	10.80 ± 1.03	F = 0.341	0.711
	Post	10.86 ± 0.96	10.89 ± 1.00	t = 0.213	0.831	19.04 ± 3.14	16.65 ± 3.07 a	16.40 ± 3.32 a	F = 12.205	≤ 0.001*
Total mothers fatigue	Pre	79.93 ± 2.31	79.68 ± 2.35	t = 0.805	0.422	79.60 ± 2.51	80.09 ± 2.19	79.65 ± 2.42	F = 1.572	0.209
	Post	74.75 ± 7.65	75.42 ± 6.40	t = 0.68	0.497	78.77 ± 10.57	74.47 ± 6.33 a	74.00 ± 6.92 a	F = 7.599	0.001*

P-values were computed using ANNOVA (F- test). *$p < 0.05$. **$p < 0.001$

Table 4 Relationship between child diagnosis & pediatric quality of life multidimensional fatigue score & mothers fatigue score

		Diagnosis							*p* value
		DM	Cardiac	Bronchial asthma	Renal	Cancer	Thalassemia	Epilepsy	
General Fatigue	Pre	3.24 ± 1.75	3.70 ± 1.84	3.45 ± 1.81	3.11 ± 2.04	3.31 ± 1.68	3.46 ± 2.02	6.00 ± 0.00	0.288
	Post	12.36 ± 1.51	12.62 ± 1.27	12.16 ± 0.63	13.34 ± 2.17 abc	14.575 ± 2.32 abcd	12.53 ± 1.25de	13.00 ± 1.41	≤ 0.001**
Sleep/rest	Pre	2.97 ± 1.74	3.32 ± 1.64	3.20 ± 1.91	2.73 ± 1.91	3.07 ± 1.38	2.70 ± 1.70	6.00 ± 0.00	0.094
	Post	11.51 ± 1.77	11.86 ± 1.82	11.54 ± 0.93	12.51 ± 1.50 abc	12.88 ± 1.48 abc	11.60 ± 1.27de	14.00 ± 2.82cf	≤ 0.001**
Cognitive Fatigue	Pre	0.16 ± 0.45	0.24 ± 0.43	0.20 ± 0.50	0.21 ± 0.49	0.18 ± 0.42	0.33 ± 0.54	0.50 ± 0.70	0.699
	Post	7.82 ± 3.29	8.48 ± 2.99	8.04 ± 3.60	8.78 ± 2.41	8.80 ± 2.37	9.10 ± 2.04	10.00 ± 2.82	0.175
Total Children Fatigue	Pre	6.38 ± 3.39	7.26 ± 3.20	6.87 ± 3.57	6.05 ± 3.80	6.57 ± 2.91	6.50 ± 3.70	12.50 ± 0.70	0.129
	Post	31.70 ± 4.43	32.96 ± 4.17	31.75 ± 4.25	34.65 ± 3.69 abc	36.26 ± 4.47 abcd	33.23 ± 2.69 e	37.00 ± 1.41	≤ 0.001**
Fatigue severity components	Pre	36.83 ± 1.92	36.58 ± 2.00	36.54 ± 2.22	36.96 ± 1.98	36.86 ± 1.68	37.36 ± 1.18	33.50 ± 3.53	0.105
	Post	27.63 ± 3.22	27.26 ± 3.22	28.16 ± 2.42	27.44 ± 2.81	28.50 ± 2.88	27.83 ± 2.24	26.00 ± 0.00	0.214
Activity elements	Pre	14.98 ± 0.10	14.92 ± 0.39	15.00 ± 0.00	14.94 ± 0.23	15.00 ± 0.00	14.96 ± 0.18	15.00 ± 0.00	0.282
	Post	14.12 ± 2.16	13.84 ± 2.08	13.29 ± 2.52	13.71 ± 2.19	14.41 ± 1.07	14.23 ± 1.79	14.00 ± 0.00	0.177
Focus elements	Pre	17.20 ± 0.99	17.26 ± 1.06	17.20 ± 1.06	17.19 ± 0.68	17.16 ± 0.87	17.30 ± 0.65	17.00 ± 1.41	0.992
	Post	15.52 ± 3.26	16.00 ± 1.64	15.91 ± 1.63	16.38 ± 1.98 a	17.01 ± 1.83 abc	15.93 ± 1.61 e	17.00 ± 0.00	0.004*
Motivating elements	Pre	10.93 ± 1.05	10.90 ± 1.03	10.79 ± 0.88	10.69 ± 0.87	10.86 ± 0.92	10.93 ± 1.01	12.00 ± 0.00	0.532
	Post	16.51 ± 3.36	17.08 ± 3.50	16.04 ± 3.43	16.67 ± 2.92	17.81 ± 3.13 acd	16.13 ± 3.05e	20.50 ± 0.70	0.033*
Total Parental fatigue	Pre	79.95 ± 2.37	79.66 ± 2.69	79.54 ± 2.75	79.78 ± 2.08	79.88 ± 2.31	80.56 ± 1.07	77.50 ± 4.94	0.443
	post	73.78 ± 8.53	74.18 ± 6.45	73.41 ± 8.51	74.21 ± 7.27	77.73 ± 6.40 abcd	74.13 ± 5.32 e	77.50 ± 0.70	0.011*

a: significant with DM, b: significant with Cardiac, c: significant with BA, d: significant with Renal, e: significant with Cancer, f: significant with thalassemia by post hoc *$p < 0.05$. **$p < 0.001$

Additionally, a significant relationship existed between parental education levels and both total children's fatigue and total parental fatigue scores ($p = 0.001$).

Table 6 presents a multivariate logistic regression analysis exploring theindependent predictors of pediatric and maternal fatigue across variousdimensions. A significant association was observed between the children's agegroup and cognitive fatigue prior to any intervention or observation (OR =2.12, 95% CI [1.27-3.54], p = 0.004). Even after accounting for education,disease duration, and co-morbidities, older children were more than twice aslikely to experience cognitive fatigue compared to younger children atbaseline. Education level was significantly associated with sleep/rest fatiguepost-intervention

Table 5 Association between Age, Disease related factors and Pediatric Quality of Life Multidimensional Fatigue score & mothers fatigue score

		Age groups		Age groups	*p* value	Duration of the disease		Test of significance	*p* value	Co morbidities		Test of significance	*p* value
		6–12 y	6–12 y			< 4	> 4			Yes	No		
General Fatigue	Pre	3.36 ± 1.83	3.36 ± 1.82	t = 0.037	0.970	3.30 ± 1.84	3.42 ± 1.82	t = 0.61	0.542	3.35 ± 2.08	3.36 ± 1.76	t = 0.044	0.965
	Post	12.94 ± 1.88	13.65 ± 2.18	t = 2.74	0.006*	13.57 ± 2.14	12.6 ± 1.7	t = 4.37	≤ 0.001*	13.2 ± 1.97	13.07 ± 1.97	t=-0.579	0.563
Sleep/rest	Pre	3.00 ± 1.72	3.09 ± 1.58	t = 0.408	0.683	3.03 ± 1.68	3.01 ± 1.71	t = 0.132	0.895	3.13 ± 1.87	2.99 ± 1.64	t = 0.605	0.545
	Post	11.94 ± 1.70	12.56 ± 1.50	t = 2.77	0.006*	12.41 ± 1.46	11.76 ± 1.81	t = 3.55	≤ 0.001*	12.81 ± 1.83	11.90 ± 1.59	t = 4.00	≤ 0.001*
Cognitive Fatigue	Pre	0.16 ± 0.40	0.35 ± 0.60	t = 3.08	0.002*	0.20 ± 0.43	0.21 ± 0.49	t = 0.069	0.945	0.21 ± 0.45	0.20 ± 0.46	t = 0.097	0.923
	Post	8.37 ± 2.99	8.76 ± 2.23	t = 1.04	0.297	8.14 ± 2.70	8.77 ± 2.95	t = 2.02	0.043*	8.27 ± 3.21	8.50 ± 2.75	t = 0.579	0.563
Total Children Fatigue	Pre	6.53 ± 3.41	6.82 ± 3.26	t = 0.642	0.521	6.54 ± 3.39	6.64 ± 3.38	t = 0.274	0.784	6.70 ± 3.72	6.57 ± 3.29	t=-0.293	0.770
	Post	33.26 ± 4.46	34.98 ± 4.32	t = 2.91	0.004*	34.12 ± 4.47	33.18 ± 4.47	t = 1.905	0.058	34.32 ± 4.59	33.48 ± 4.45	t = 1.353	0.177
Fatigue severity components	Pre	36.88 ± 1.82	36.63 ± 2.04	t = 1.03	0.305	36.88 ± 1.86	36.76 ± 1.89	t = 0.577	0.564	36.66 ± 2.05	36.87 ± 1.83	t = 0.803	0.422
	Post	27.85 ± 3.05	27.63 ± 2.59	t = 0.573	0.567	27.95 ± 2.61	27.65 ± 3.25	t = 0.928	0.354	27.60 ± 2.76	27.85 ± 2.99	t = 0.624	0.533
Activity elements	Pre	14.97 ± 0.20	14.97 ± 0.16	t = 0.002	0.998	14.98 ± 0.13	14.96 ± 0.24	t = 0.823	0.411	14.92 ± 0.32	14.98 ± 0.15	t = 2.270	0.024*
	Post	14.00 ± 2.02	14.12 ± 1.67	t = 0.446	0.656	14.28 ± 1.19	13.78 ± 2.45	t = 2.313	0.021*	14.13 ± 1.51	14.00 ± 2.04	t = 0.484	0.628
Focus elements	Pre	17.21 ± 0.91	17.191 ± 0.89	t = 0.165	0.869	17.23 ± 0.83	17.17 ± 0.97	t = 0.632	0.528	17.20 ± 1.00	17.20 ± 0.88	t = 0.072	0.942
	Post	16.05 ± 2.32	16.56 ± 2.36	t = 1.623	0.106	16.69 ± 2.11	15.65 ± 2.44	t = 4.116	≤ 0.001*	16.69 ± 2.27	16.04 ± 2.34	t = 2.016	0.045*
Motivating elements	Pre	16.83 ± 3.37	17.10 ± 2.89	t = 0.630	0.529	10.85 ± 0.89	10.88 ± 1.05	t=-0.297	0.766	10.92 ± 0.98	10.85 ± 0.97	t = 0.499	0.618
	Post	10.86 ± 0.96	10.89 ± 1.00	t = 0.213	0.831	17.63 ± 2.89	16.16 ± 3.46	t = 4.178	≤ 0.001*	18.03 ± 2.98	16.61 ± 3.28	t = 3.162	0.002*
Total Parental fatigue	Pre	79.93 ± 2.31	79.68 ± 2.35	t = 0.805	0.422	79.96 ± 2.08	79.79 ± 2.54	t = 0.659	0.511	79.70 ± 2.54	79.92 ± 2.27	t = 0.659	0.510
	Post	74.75 ± 7.65	75.42 ± 6.40	t = 0.680	0.497	76.57 ± 5.92	73.26 ± 8.28	t = 4.157	≤ 0.001*	76.46 ± 6.78	74.52 ± 7.49	t = 1.904	0.058

Table 6 Multivariate logistic regression analysis for independent predictors of pediatric quality of life multidimensional fatigue & mothers' fatigue

	Children age groups		Education		Duration of the disease		Co morbidities	
	P value	OR (95%CI)	*P* value	OR (95%CI)	*P* value	OR (95%CI)	*P* value	OR (95%CI)
General Fatigue post	0.645	1.05 (0.86–1.26)	0.645	1.05 (0.86–1.26)	**0.007***	**0.80 (0.68–0.94)**	-	-
Sleep/rest post	0.302	1.12 (0.90–1.39)	0.302	1.12 (0.90–1.39)	0.309	0.92 (0.77–1.08)	**0.001***	**1.37 (1.14–1.65)**
Cognitive Fatigue pre	**0.004***	**2.12 (1.27–3.54)**	**0.004***	**2.12 (1.27–3.54)**	**0.017***	**1.12 (1.02–1.22)**	-	-
Total Children Fatigue post	0.390	1.04 (0.95–1.15)	0.390	1.04 (0.95–1.15)	-	-	-	-
Activity elements post	-	-	-	-	**0.016***	**0.78 (0.64–0.95)**	**0.019***	**0.24 (0.07–0.79)**
Focus elements post	-	-	-	-	**0.019***	**0.81 (0.68–0.97)**	0.995	1.00 (0.87–1.15)
Motivating elements post	-	-	-	-	**0.012***	**0.84 (0.74–0.96)**	**0.05***	**1.1 (1.01–1.22)**
Total mothers fatigue post	-	-	-	-	0.065	1.09 (0.99–1.21)	-	-

(OR = 1.37, 95% CI [1.14-1.65], p = 0.001), indicating thathigher education levels correlate with increased sleep/rest disturbances afterthe intervention, even when controlling for other variables. Additionally,longer disease duration was linked to reduced odds of general fatigue (OR =0.80, 95% CI [0.68-0.94], p = 0.007) and activity-related fatigue (OR = 0.78,95% CI [0.64-0.95], p = 0.016), suggesting a possible adaptation over time.

Discussion

The incidence of chronic diseases among children is rising globally, adversely affecting the quality of life for both children and their families. Fatigue is one of the most prevalent health issues faced by children with chronic conditions. Various factors, both somatic and psychosocial, have been linked to fatigue in children, and all parental physical and psychosocial factors are associated with pediatric fatigue [7]. Nurses play a crucial role in identifying, assessing, and intervening in the management of anxiety, stress, fatigue, and depression among family caregivers [26]. Therefore, implementing effective nurse-led empowerment programs is essential to enhance awareness, raise consciousness, and improve self-efficacy among family caregivers, enabling them to cope with their challenges more effectively. Greater family empowerment has been associated with reduced pediatric fatigue [27]. As medical care for childhood chronic illnesses advances, health-related quality of life has become an increasingly important outcome for children's treatment [28]. Thus, the present study aims to evaluate the impact of a family-centered empowerment program on reducing the severity of fatigue in parents and children with chronic illnesses.

In the studied cohort of children with chronic illnesses, there was an approximately equal distribution of genders, with a mean age of 9.85 years. Over a quarter of these children were either the first or second born in their families, aligning with previous studies. The mean duration since diagnosis was 3.73 years, suggesting many were diagnosed relatively recently compared to other research that reported longer durations [28–30]. Notably, a quarter of the children were diagnosed with type 1 diabetes and post-chemotherapy cancer, while other conditions including renal failure, cardiac disease, thalassemia, bronchial asthma, and epilepsy each accounted for less than a quarter of cases. These findings are consistent with some literature but highlight discrepancies in the prevalence of chronic conditions across different populations [31, 32]. In this study, the average age of mothers was 36.37 years, with more than half having completed middle education and over a quarter employed, differing from Sutthisompohn and Kusol (2020) [32], who reported younger caregivers.

Fatigue is highly prevalent among children with chronic diseases and is linked to various biological and psychosocial factors. It significantly affects their quality of life [7]. In the current study, the Pediatric Quality of Life Multidimensional Fatigue scores indicated a low mean quality of life (QOL) score of 6.5 (SD = 3.38) prior to the program intervention, reflecting increased symptoms of pediatric fatigue. However, after the intervention, the mean QOL score improved significantly to 33.64 (SD = 4.48), indicating fewer symptoms of fatigue among the children. This improvement was observed across the total fatigue scores and in the subscales of general fatigue, sleep/rest fatigue, and cognitive fatigue, with statistically significant differences noted.

Children with chronic diseases require ongoing care from their parents, which can lead to parental fatigue, depression, anxiety, sleep disturbances, and tiredness. These factors can impair daytime functioning, attention, memory, mood, and overall quality of life [33]. Additionally, caregiving responsibilities can significantly diminish parents' physical, psychological, social, and economic well-being [34]. In the present study, the mean parental fatigue score was high at 79.87 (SD = 2.32) pre intervention, this score decreased slightly to 74.90 (SD = 7.38) following the intervention. There was also a slight reduction in the scores of the subscales related to fatigue severity and focus after the intervention, with statistically significant differences observed. This suggests that parents of children with chronic diseases invest considerable time

in caregiving tasks, often necessitating modifications to their daily activities.

In the current study, a statistically significant relationship was found between the demographic characteristics of children and their quality-of-life multidimensional fatigue scores, as well as parental fatigue scores. Specifically, there were significant differences associated with children's age and education in relation to their total fatigue score ($p = 0.004$), as well as in the subscales of sleep/rest and general fatigue ($p = 0.006$) post intervention. The findings indicate that older children, particularly those over 12 years of age, experienced slightly higher fatigue scores compared to younger children. This aligns with the study by Emerson et al., (2016) [35], which reported that older children and adolescents with chronic illnesses often face physical problems and periods of hospitalization.

The current study found no significant differences between children's age or education and their parental fatigue scores. This suggests that while demographic characteristics of children may influence their own fatigue levels, they do not similarly impact the fatigue experienced by their parents. Furthermore, the study revealed that parental fatigue subscales such as fatigue severity, activity, focus, and motivation showed no significant changes and were not associated with the child's age or education after the program implementation. This finding aligns with research by Kramer et al., (2021) [36], which noted that while the age of the child significantly correlated with pediatric fatigue, parental distress was also linked to higher levels of pediatric fatigue. In children aged 8–18 years, increased parental distress corresponded with greater fatigue in the child. Older children tend to experience more fatigue, and parents in this age group face additional challenges, such as balancing the desire to care for and protect their child with the need to foster their autonomy. Additionally, the study found no significant differences between disease groups regarding any physical or psychological parental factors and pediatric fatigue, suggesting a commonality in fatigue experiences across various chronic diseases.

The current study observed a significant relationship between children's diagnoses and their Pediatric Quality of Life Multidimensional Fatigue scores. Specifically, there were statistically significant differences in general fatigue scores, sleep/rest fatigue, total fatigue scores, and across all types of diagnoses before and after the intervention ($p = 0.001$). However, no significant differences were found regarding cognitive fatigue in relation to children's diagnoses before and after the intervention ($p = 0.699$ and $p = 0.175$, respectively). In terms of parental fatigue, significant differences were noted between all diagnoses in children and both the focus and motivation subscales, as well as the overall parental fatigue scale following the program implementation. These findings are consistent with the study by Shin et al., (2019) [37], which identified a significant association between parental quality of life and factors such as the type of diagnosis, time since diagnosis, and length of hospitalization in children with chronic illnesses.

In a study conducted by Mendes et al. (2016) [38] titled "Family Cohesion and Adaptation in Pediatric Chronic Conditions: The Missing Link in Family Condition Management," the authors found that families of children with asthma faced fewer challenges in managing family life compared to families of children with diabetes mellitus and epilepsy. Similarly, Chusri et al., (2019) [39] found that caregivers of children with thalassemia reported lower mean family management scores than those caring for children with asthma. This may be attributed to the extended hospitalization needs of children with thalassemia, which can negatively impact their quality of life compared to those with asthma.

The current study found that children with a disease duration of less than four years exhibited significantly higher scores in general fatigue, sleep/rest fatigue, and cognitive fatigue subscales after the program intervention compared to those with longer disease durations ($p \leq 0.001$). This aligns with the findings of Sutthisompohn and Kusol (2021) [32], who noted that caregivers develop a deeper understanding of their children's chronic illnesses when the conditions have persisted for a longer period, particularly when the child has had the illness since infancy. Furthermore, higher levels of parental education, income, and age were identified as predictors that positively affect the quality of life of parental caregivers [40]. This finding is consistent with the current study, which showed no significant differences in fatigue scores between children with and without comorbidities. Additionally, a significant relationship was observed between parental education levels and both total children's fatigue and total parental fatigue scores ($p = 0.001$). However, these results contrast with those of Karava et al., (2022) [41], who reported no significant differences in the quality of life of children with chronic kidney disease concerning their parents' age and education. This discrepancy underscores the complexity of factors influencing fatigue and quality of life in pediatric patients with chronic conditions.

The burden of care for children with chronic illnesses typically falls on parents, who must balance their child's healthcare needs with those of other family members and their work obligations [42]. Looking after a child with cancer can considerably affect family members' work daily. Caregivers reported arriving late to work, spending time on the phone during work hours to attend to their relative's needs, and some even left their jobs due to caregiving responsibilities [43]. These findings align with our

study, which found a statistically significant difference between parents' occupations and pediatric quality of life multidimensional fatigue scores in the subscales of general pediatric fatigue and sleep/rest ($p = 0.023$) before the program intervention. However, there were no statistically significant differences between parents' occupations and other pediatric subscales, including cognitive fatigue, total children's fatigue, fatigue severity, and other parental subscales before and after the program intervention.

Limitation of the study & future work

This study has several limitations that need to be considered. First, the quasi-experimental design employed lacks randomization, which could lead to selection bias and restrict the generalizability of the findings to a wider population. The absence of random assignment raises the possibility that the effects observed from the family-centered empowerment programs on fatigue reduction may be affected by confounding variables or pre-existing differences among participants. Furthermore, the use of self-reported measures to evaluate fatigue in both children and parents may introduce subjective bias, as individuals might interpret and communicate their experiences in varying ways. Future research would benefit from utilizing a randomized controlled trial design to enhance the validity of the findings and provide stronger evidence for the effectiveness of family-centered interventions. Additionally, since this study was conducted in single settings, the applicability of the results to other healthcare settings may be limited. Future studies should aim to replicate this research in various contexts to improve the generalizability of the results. Lastly, longitudinal research could offer more comprehensive insights into the long-term impacts of empowerment programs on fatigue and overall quality of life for children with chronic illnesses and their caregivers.

Conclusion and recommendation

The findings suggest that family-centered empowerment programs may be associated with a reduction in the severity of fatigue among children with chronic illnesses and their parents. These programs appear to enhance quality of life by providing families with vital knowledge, skills, and support mechanisms. By actively engaging parents and caregivers in the management of chronic conditions, these initiatives may help cultivate resilience and improve overall emotional well-being. Additionally, the positive outcomes underscore the value of a collaborative approach in healthcare settings, highlighting the importance of family involvement as a crucial element in managing chronic illness. The research recommends the following: Ongoing training should be provided for healthcare professionals on the importance of family involvement in care and methods to effectively support families. Healthcare facilities should incorporate family-centered empowerment programs into standard care practices for children with chronic illnesses to enhance the overall caregiving experience.

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Data availability
All the data generated was included in this article.

Declarations

Ethics approval and consent to participate
The study was conducted in compliance with the Declaration of Helsinki and received ethical approval from the Research Ethics Committee at the Faculty of Nursing, Mansoura University, under reference number P 0561. The hospital chief authorized the study after the researchers provided a detailed explanation of its objectives and procedures. Informed consent was obtained from the mothers, who were given a thorough overview of the study's purpose and methods. The mothers were informed that contribution was deliberate, and they might withdraw at any time without needing to justify their decision. Furthermore, the mothers were secured that their personal data would remain private and would not be linked to the study's results.

Consent for publication
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