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Impact of telenursing-based family empowerment program on self-efficacy and treatment adherence in children with cystic fibrosis "telenursing and CF"

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ABSTRACT

Purpose: This study aimed to investigate the impact of a telenursing-based family empowerment program on self-efficacy and treatment adherence in children with cystic fibrosis (CF).
Design and methods: This is a clinical trial study conducted on CF patients between 9 and 17 who were randomly assigned to two groups: an intervention group (received twelve-week telenursing training via the SendBig website and Skype messenger) or a control group (routine care). The child and caregiver demographic information questionnaire, Pediatric Rating of Chronic Illness Self-Efficacy, and Adherence to Treatment Questionnaire were evaluated before, immediately, and one month after the intervention. The results were analyzed using SPSS V26, considering a significant level.
Results: A total of 50 patients were recruited for this study (25 in each group). The results showed a significant difference in the mean total scores of self-efficacy and treatment adherence between the two groups, immediately and one month after the intervention (P-value < 0.001). In addition, intra-group comparisons showed that the impact of time was significant in the intervention group (P-value < 0.001).
Conclusion: Considering the improvement of self-efficacy and treatment adherence in the intervention group, it is recommended to use a telenursing-based family empowerment program for children with CF.
Implications to practice: The findings support the integration of telenursing-based family empowerment programs into routine nursing practice to promote long-term disease management and family-centered care.

Background

Cystic fibrosis (CF) is one of the most common progressive genetic disorders of childhood, typically diagnosed during infancy and inherited as an autosomal recessive disease (Hockenberry & Wilson, 2018). The prevalence of CF varies significantly among different populations, with an incidence rate of approximately 1 in every 3500 newborns. CF affects multiple organ systems, including the respiratory, endocrine, digestive, pancreatic, biliary, and reproductive organs (Polgreen & Comellas, 2022). Pulmonary symptoms are the major source of complications and mortality in CF. These complications result from impaired mucociliary clearance, which leads to airway obstruction, chronic inflammation, and recurrent infections. Over time, these processes contribute to progressive decline in lung function (Faint et al., 2017).

To maintain their health, patients with CF must follow a complex daily regimen that includes airway clearance techniques, adherence to prescribed medications, and a high-calorie diet (Szabo, 2014). Current therapies are primarily symptomatic and demand substantial time and consistent adherence from the patients (Brucefors et al., 2015). Studies show that despite the best health recommendations, treatment adherence among children with CF remains low, with rates reported at less than 50 % (Goodfellow et al., 2015; Modi & Quittner, 2006). Poor adherence increases disease burden and leads to worse health outcomes, including reduced baseline lung function, more frequent pulmonary exacerbations, and a higher risk of hospitalization. It also contributes to increased healthcare costs (Eakin & Riekert, 2013). In

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contrast, optimal adherence maximizes treatment benefits, improves quality of life, and extends life expectancy in children with CF (Balfour et al., 2014). However, treatment adherence levels vary widely among patients and are influenced by individual and contextual factors (Sawicki et al., 2015). School-aged children and adolescents are particularly at risk for poor adherence due to developmental challenges, engagement in risk-taking behaviors, and the strong desire for peer acceptance (Faint et al., 2017). As a result, chronic illness can isolate these children from their peers, disrupt normal developmental processes, and make disease management more difficult (Segal, 2008).

One important factor that can influence treatment adherence in children with CF is self-efficacy. Self-efficacy, a concept derived from Bandura's social cognitive theory, refers to an individual's belief and confidence in their ability to organize and carry out the necessary actions to achieve desired therapeutic outcomes (Bandura, 2010). Higher self-efficacy is linked to better treatment adherence, healthier behaviors, effective pain management, and improved emotional well-being in children with chronic illnesses (Cramm et al., 2013). Children with stronger self-efficacy are more resilient, set higher goals, and demonstrate better self-management skills when facing disease-related challenges. In contrast, those with low self-efficacy may feel discouraged when symptoms worsen and are more likely to abandon their treatment efforts (Azhdari Mamaghani et al., 2021).

Given the high treatment burden and limited opportunities for peer support among children and young people with CF, healthcare providers, including nurses, continue to seek effective strategies such as family empowerment to improve treatment adherence (Fairweather & Jones, 2022). Family empowerment aims to strengthen the skills and knowledge of both the child and family members so they can better recognize, manage, and adapt to the challenges of the disease (Payrovee et al., 2014). During the empowerment process, nurses can use strategies such as telenursing at every stage of the nursing process to provide education, counseling, emotional support, follow-up, and ongoing evaluation throughout the child's care (Administration, H. R. A. S, 2022). Telenursing can reduce hospitalization, promote greater independence and self-management in children and their families, and lower healthcare costs (Hassibian & Hassibian, 2016). Telenursing, using a remote platform, facilitates peer connections and the sharing of experiences among patients (Gur et al., 2017). This study aimed to evaluate the impact of telenursing-based family empowerment programs on self-efficacy and treatment adherence in children with CF.

Methods and materials

Study design

This study was designed as a single-blind randomized controlled trial. Participants were recruited through convenience sampling based on the inclusion criteria. After enrollment, they were randomly assigned to either the intervention or control group using a simple randomization procedure. A lottery was conducted prior to data collection to determine the allocation method, with even numbers assigned to the intervention group and odd numbers to the control group. Only the researcher was aware of the type and purpose of the intervention. The telenursing program was provided at a single medical center, and all participants in the intervention group received the same intervention.

Participants and sampling

The inclusion criteria for the study were: the child's fluency in Farsi (speaking, writing, and reading), a confirmed diagnosis of cystic fibrosis (CF) for at least one year by a specialist, absence of cognitive or mental disorders or other chronic diseases, and no speech, hearing, or vision impairments. Participants were also required to live with both parents and have access to a smartphone with internet connectivity to send voice and text messages via Skype. Exclusion criteria included unwillingness to continue participation, recent pulmonary exacerbation or hospitalization during the intervention, or inability to follow and participate in at least two Q&A sessions. The sample size was calculated using a formula with a type I error of 0.05 ($Z = 1.96$), a type II error of 0.20 ($Z = 0.84$), a power of 0.80, and an effect size of 0.80 based on Gur et al. (Gur et al., 2017). This resulted in 25 participants in each group. Participants were recruited during routine outpatient clinic visits at Mofid Children's Hospital from April to October 2023. The principal investigator provided the participant information and consent form during the initial face-to-face meeting with the children and their caregivers.

Intervention

A total of 50 children and adolescents with CF aged between 9 and 17 years participated in this study. An overview of the study process is shown in Fig. 1, following the CONSORT guidelines. The researcher installed the selected communication platform (Skype) on the caregivers' and, when possible, the children's mobile devices. Participants assigned to the intervention group were added to a Skype group named “Cystic Fibrosis Companions”. Patients in the control group did not receive any educational or supportive content through Skype. They continued with routine care, including monthly clinic visits and prescribed medications.

The intervention group received a telenursing-based program and follow-up twice weekly for twelve weeks. The intervention content was developed by the research team using resources from www.cff.org and www.cfsource.com websites. Topics included disease education, symptom management, physical activity adjustment, medication adherence, nutritional recommendations, and mental health support. The intervention consisted of two components. First, a one-day educational workshop was conducted via Skype for children and their caregivers. During this session, group members were introduced to each other, and instructions on accessing the content were provided. Second, the educational content was created according to a predefined schedule. Materials were prepared as 5–10-min audio recordings, videos, or educational texts. These files were uploaded to the SendBig website, and upon completion, a link was provided to the user. The corresponding link was shared with participants through the group.

After confirming that the participants received and viewed the content (acknowledged in the “Cystic Fibrosis Companions” group), remote follow-up sessions were held twice weekly (Sundays and Tuesdays between 6:00–8:00 PM). During these sessions, the researcher reviewed the weekly content, answered questions from children and caregivers, facilitated peer interaction and experience sharing of experiences within the group, and allowed feedback to be received. To prevent exposure of the control group to the intervention content, a separate Skype group with a different name was created for them. At the end of week 12, after the intervention was completed, the PRCISE and MATQ questionnaires were sent to the children's or caregivers' accounts in both groups for completion. Additionally, the same questionnaires were administered again 4 weeks after the intervention by both groups, and outcomes were compared between the two groups. At the end of the study, to observe ethical considerations, all contents were provided to the control group in the form of a compressed file containing videos, images, audio, and booklets.

Data collection

Four different scales were used in this study. The child's demographic and clinical information questionnaire was developed by the research team based on the child's clinical records. It included six

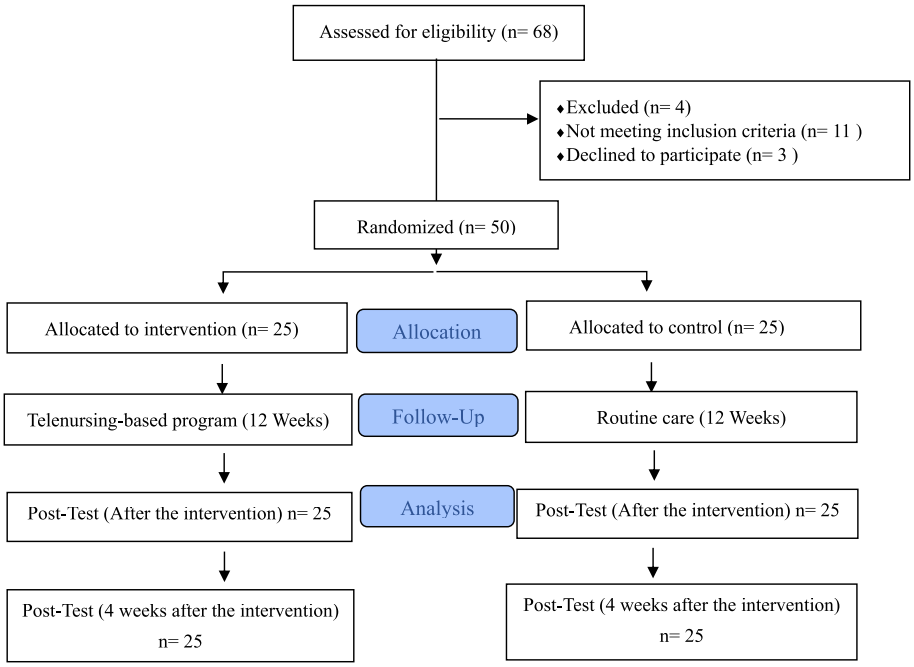

Fig. 1. CONSORT flow diagram.

components: basic demographic information (age, sex, weight, birth order, place of residence, number of school absences), sleep status, disease history over the past three months, mental-emotional status, nutritional assessment, motor status, and the recent spirometry results.

The caregiver demographic questionnaire collected information on age, education level, employment status, number of children in the family, history of physical and mental health conditions, smoking and alcohol use, and insurance coverage. This questionnaire was completed by the child's caregiver.

The Pediatric Rating of Chronic Illness Self-Efficacy scale (PRCISE) was developed by Emerson et al. (2018) to investigate the level of self-efficacy in children with chronic illnesses (Emerson et al., 2018). The final version includes 15 items scored on an 11-point Likert scale, with total scores ranging from 0 to 150. In the first step, permission to use the scale was obtained through correspondence with the developers. The questionnaire was then translated into Farsi according to the guidelines made by Wilde et al. in 2005 (Sarhadi et al., 2023; Valadkhani et al., 2023; Wild et al., 2005).

The Modanloo Adherence to Treatment Questionnaire (MATQ) was developed in 2018 to examine the level of adherence to treatment in patients with chronic disease (Seyed Fatemi et al., 2018). It contains 40 items with 7 dimensions and is scored on a 6-point Likert scale ranging from 0 “Not at all” to 5 “Completely”, with some reverse-scored items. Total scores range from 0 to 200, with higher scores indicating better treatment adherence. Face validity of both the PRCISE and MATQ questionnaires was evaluated by 10 children who met the inclusion criteria. A survey was conducted about vague items. Information was also collected on how to phrase the scales. Content validity was assessed qualitatively by 10 experts in nursing, management, and scale development, who evaluated Farsi grammar, appropriate wording, item placement, and scoring. Reliability was examined through internal consistency and test-retest methods. Cronbach's alpha coefficients were calculated after 10 children completed the questionnaires. The Cronbach's alpha was 0.78 for the PRCISE and 0.90 for the MATQ. To examine stability reliability, a test-retest was done, and the results were compared. The same 10 children completed the questionnaires again two weeks later. Intraclass correlation coefficients (ICCs) were 0.86 for the PRCISE and 0.82 for the MATQ, indicating acceptable reliability.

Data analyses

In this research, the Kolmogorov–Smirnov test was used to examine the normality of the data. Independent *t*-tests were applied to compare mean scores between the intervention and control groups. To investigate the effect of the intervention over time and compare the two groups at different measurement points, analysis of covariance (ANCOVA) was used. Repeated-measures ANOVA was also applied to compare the mean scores at three different time points within each group, in both control and intervention groups. The results were analyzed using SPSS V26, with the significance level set at 0.05.

Ethical considerations

Ethical approval for this study was granted by the Ethics Committee of the School of Nursing and Midwifery, Shahid Beheshti University of Medical Science, with the identification code IR.SBMU.PHARMACY.REC.1401.280. As this research is a clinical trial, it was registered in the Iranian Registry of Clinical Trials under the registration code IRCT20230717058822N1. The study protocol was also registered on ClinicalTrials.gov under the identifier NCT06660745.

Findings

The mean age of children in the intervention and control groups was 12.24 and 12.36 years, respectively. In both groups, 56 % of participants were boys, and 50 % were in elementary school. The distribution of demographic variables was similar in both groups (P-value > 0.05) (Table 1). Regarding caregivers' demographic information, the mean age was 38.00 years in the intervention group and 39.12 years in the control group. Overall, 90 % of caregivers were married, and 74 % were homemakers. No significant differences were observed between the groups in caregiver demographics (P-value > 0.05) (Table 2).

Comparison of self-efficacy and treatment adherence scores showed significant differences between the intervention and control groups before and after the intervention. ANCOVA results confirmed significant group differences in mean self-efficacy and treatment adherence scores immediately and one month after the intervention ($P < 0.001$).

Table 1
The demographic information of children with cystic fibrosis (CF) participating in the study.

Variable	Variable values	Intervention group ($N = 25$)		Control group ($N = 25$)		Total Percentage	P-value
		Frequency	Percentage	Frequency	Percentage		
Sex [a]	Female	8	32	14	56	44.0 %	0.87
	Male	17	68	11	44	56.0 %	
Education Level [a]	Elementary	12	48	13	52	50.0 %	0.81
	Middle School	9	36	7	28	32.0 %	
	High School	4	16	5	20	18.0 %	
Place of residence [b]	City	23	92	23	92	92.0 %	1.00
	Village	2	8	2	8	8.0 %	
Nationality [b]	Iranian	23	92	22	88	90.0 %	0.63
	Non-Iranian	2	8	3	12	10.0 %	

[a] According to the Chi-square test.
[b] According to Fisher's exact test.

Repeated measures ANOVA for intraclass comparison demonstrated significant changes over time in all dimensions of self-efficacy and treatment adherence within the intervention group (P-value < 0.001) (Tables 3 and 4). Pairwise comparisons using the Bonferroni correction indicated that mean self-efficacy scores significantly increased from baseline to both immediately after the intervention and one month later. However, no significant difference was found between the immediate and one month after the intervention (P-value > 0.05) (Table 5).

For treatment adherence, pairwise comparisons showed significant improvements from baseline to both immediately after the intervention and one month later. In addition, the mean difference between immediately after the intervention and one month later was positive and statistically significant, indicating a slight decrease in treatment adherence at the one-month follow-up. Despite this decline, adherence at one month remained significantly higher than at baseline.

Discussion

In the present study, self-efficacy in children with cystic fibrosis (CF) improved immediately after the telenursing intervention and remained higher one month later. These findings align with previous studies demonstrating the positive impact of remote or digital interventions on self-efficacy. A study conducted in, 2022 demonstrated that visual digital content, such as peer-modeling videos, increased self-efficacy and improved disease management and treatment adherence in adults with CF (Hutchings et al., 2022). Similarly, a randomized single-blind clinical trial by Cummings et al. found that a web- and mobile-based self-monitoring application can be a beneficial approach for improving self-efficacy. It enhanced both self-efficacy and quality of life in individuals with CF (Cummings et al., 2011). However, some studies have reported different outcomes. Agarwal et al. examined a telenursing intervention delivered through a mobile app for patients with type 2 diabetes and found no significant improvement in HbA1c levels or secondary outcomes, such as self-efficacy, quality of life, and health care behaviors (Agarwal et al., 2019). Low engagement with the mobile app — reported in nearly half of the participants — may explain the discrepancy between their findings and the result of the present study. This highlights the importance of active participation and sustained interaction in achieving the desired effects of remote interventions.

The present study also demonstrated that the telenursing-based family empowerment program significantly improved treatment adherence in the intervention group compared with the control group. This finding aligns with previous studies. Chrysochoou et al. showed that regular telephone communication with a healthcare team, which included asking questions about disease exacerbation, infections or respiratory symptoms, weight gain, medications, and similar issues, improved treatment adherence among children with CF, particularly those living far from medical centers (Chrysochoou et al., 2017). A study by Wood et al. reported that the use of smartphone-based symptom-monitoring applications increased treatment adherence by up to 77 % in people with CF (Wood et al., 2020). Another study examining treatment adherence among adolescents and young adults with CF found that tele-coaching interventions increased participant

Table 2
The demographic information of caregivers of children with CF participating in the study.

Variable	Variable values	Intervention group ($N = 25$)		Control group ($N = 25$)		Total Percentage	P-value
		Frequency	Percentage	Frequency	Percentage		
Age (years) [a]	mean ± SD	38.00 ± 6.50		39.12 ± 7.20		38.56 ± 6.57	0.12
Education Level [b]	Elementary	3	12	3	12	12.0 %	0.50
	Middle School	5	20	7	28	24.0 %	
	Diploma	13	52	8	32	42.0 %	
	University	4	16	7	28	22.0 %	
Occupation [b]	Student	1	4	1	4	4.0 %	0.45
	Homemaker	21	84	16	64	74.0 %	
	Employee	1	4	5	20	12.0 %	
	Self-employed	2	8	3	12	10.0 %	
Marital status	Single	1	4	1	4	4.0 %	0.60
	Married	22	88	23	92	90.0 %	
	Divorced	1	4	1	4	4.0 %	
	Widowed	1	4	0	0	2.0 %	
Economic status [b]	Sufficient	10	40	11	44	42.0 %	0.77
	Insufficient	15	60	14	56	58.0 %	
Relationship of [b] Caregiver with Child	Mother	22	88	21	84	86.0 %	0.83
	Father	1	4	3	12	8.0 %	
	Sister	2	8	1	4	6.0 %	

[a] According to an independent t-test.
[b] According to the Chi-square test.

Table 3
Self-Efficacy: A Comparison of Mean Overall Scores Between Groups Before, Immediately After, and One Month after the Intervention.[a]

Group/ self-efficacy score	Intervention Mean (SD)	Control Mean (SD)	P-value
Pre-intervention	88.60 (23.47)	88.92 (32.38)	0.968[a]
Immediately after the intervention	106.04 (22.36)	89.60 (32.24)	<0.001[b]
One month after the intervention	106.44 (22.01)	89.92 (31.88)	<0.001[b]
p-value [c]	P < 0.001	*P* = 0.262	

[a] According to independent *t*-test.
[b] According to ANCOVA.
[c] According to One-way repeated measures ANOVA (intraclass comparison).

Table 4
Treatment Adherence: A Comparison of Mean Overall Scores Between Groups Before, Immediately After, and One Month After the Intervention.[a, b]

Group/Treatment adherence score	Intervention Mean (SD)	Control Mean (SD)	P-value
Pre-intervention	140.24 (23.49)	125.44 (32.89)	0.073[a]
Immediately after the intervention	173.28 (12.28)	130.84 (31.42)	<0.001[b]
One month after the intervention	154.04 (12.73)	128.04 (31.61)	<0.001[b]
p-value [c]	*P* < 0.001	P < 0.001	

[a] According to an independent t-test.
[b] According to ANCOVA.
[c] According to One-way repeated measures ANOVA (intraclass comparison).

satisfaction and led to positive changes in treatment adherence, particularly in airway therapy and clearance (Polineni et al., 2020). According to Faint et al., knowledge and awareness of the disease are closely associated with treatment adherence in adolescents with CF. Telenursing can help address knowledge gaps by providing accessible education to patients and their families (Faint et al., 2017). However, the findings of Gur et al., who investigated the effects of telehealth interventions (including text messaging and video communication) on patients with CF, did not show improvements in disease knowledge, treatment adherence, or satisfaction among participants. It should be noted that their intervention was implemented in a small sample, which limits the generalizability of the results and indicates the need for studies with larger populations to more accurately determine the effectiveness of such interventions (Gur et al., 2017). This methodological limitation may explain the differences between their results and the findings of the present study. From the researcher's perspective, factors such as the beneficial and effective impacts of education, simplicity, cost-effectiveness, greater accessibility of the intervention method, multidisciplinary approach, and the use of various tools may explain similar major results.

Strengths and limitations

A major strength of this study was the active engagement of participants in group discussions and question-and-answer sessions. These sessions encouraged children to express their views, discuss issues with peers and members of the healthcare team (including the nurse researcher, psychotherapist, or physiotherapist), and collaboratively identify effective solutions. This interactive approach likely contributed to improvements in self-efficacy and treatment adherence.

This study also has limitations that should be acknowledged. Since participants were recruited from a single center, the generalizability of the findings is limited. Future studies with larger and more diverse samples are recommended to improve external validity. Additionally, participants and their caregivers may have been exposed to other educational programs such as city seminars or interventions from other research projects, which were beyond the researcher's control.

Implications for practice

Telenursing played a major role in building and strengthening trust between the children and the healthcare provider. The supportive and engaging interaction during remote sessions helped children feel comfortable sharing their challenges, which contributed to the development of mutual trust.

Conclusion

The findings of this study demonstrate that a telenursing-based family empowerment program can effectively improve self-efficacy and treatment adherence among children with cystic fibrosis (CF). Both outcomes increased significantly during the intervention, indicating the positive impact of structured remote education and support. Empowering family members, especially primary caregivers, appears to play a critical role in strengthening children's confidence, motivation, and engagement in disease management by creating a safe place for them to share information and concerns. Furthermore, most active participants were mothers, and their involvement appeared to enhance family knowledge and motivate continued adherence to treatment. Overall, these results suggest that telenursing is a feasible, cost-effective, and modern approach that facilitates timely access to care and can improve the quality of services for pediatric patients with chronic conditions such as CF.

CRediT authorship contribution statement

Fatemeh Rameh: Methodology. **Azam Shirinabadi Farahani:** Writing – review & editing, Supervision, Project administration, Conceptualization. **Manijeh Nourian:** Validation, Data curation. **Seyyed Ahmad Tabatabayi:** Project administration, Investigation. **Malihe Nasiri:** Supervision, Software.

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Declaration of competing interest

The authors declare that they have no conflicts of interest related to this study.

Table 5
The results of Bonferroni's pairwise comparison of the mean scores of SE and TA in children with cystic fibrosis in the interventional group over time.

Intervention group	Time	Pre-intervention	Immediately after intervention	One month after the intervention
Self-efficacy	Pre-intervention	–	−17.44 *	−17.84 *
	Immediately after intervention	–	–	−0.40
Treatment adherence	Pre-intervention	–	−33.04 *	−13.80 **
	Immediately after intervention	–	–	19.24 *

* P-value<0.05 ** *P*-value <0.001.

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