

# RECENT EVIDENCE REGARDING FAMILY-CENTRED EMPOWERMENT IN IMPROVING QUALITY OF LIFE AND TREATMENT OUTCOMES AMONG ASIAN AND AFRICAN CHILDREN WITH CHRONIC DISEASES: A SCOPING REVIEW

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## **Abstract**

Chronic diseases directly impact children's physical, psychological, and social health, determining their quality of life (QoL). Family support is essential for children with chronic diseases, and family-centred empowerment (FCE) programs may improve treatment outcomes and QoL. Using a scoping review, this study aimed to investigate the effectiveness of implementing FCE to improve QoL and other treatment outcomes among children with chronic diseases. The study followed the Arksey and O'Malley's framework (2005) and the Preferred Reporting Items for Systematic Review and Meta-analysis (PRISMA) for Scoping Reviews checklist. Studies were systematically searched on PubMed, CINAHL, ScienceDirect, and DOAJ. The quality of the included studies was assessed using the Joanna Briggs Institute appraisal checklist for randomized controlled trials and quasi-experimental studies. The scoping review included 20 studies from the 4,380 retrieved in the initial search. The studies reported that FCE effectively improved QoL, and the physical, emotional, social, educational, and clinical outcomes among children aged 2–20 years suffering from chronic haematological, respiratory, renal, neurological, hepatological, and neurobehavioral disorders. Overall, FCE is a potentially effective, sustainable model for improving QoL among children with chronic diseases.

**Keywords:** Children, Chronic Disease, Family, Family-Centred Empowerment, Quality of Life

## **Introduction**

Over the past 50 years, the prevalence of chronic diseases and disabilities among children and adolescents has steadily increased worldwide (1). Chronic diseases in children are an increasing global health problem, especially in Asia and Africa. Over 30 million children in Asia suffer from chronic diseases such as asthma, diabetes, and heart disease. Meanwhile, children account for approximately 27% of the total chronic disease burden in Sub-Saharan African countries. The prevalence of chronic diseases among children in these two regions is influenced by various factors, such as lifestyle changes, increased urbanization, and limited access to healthcare services. This highlights the urgent need for concerted action to improve child health in Asia and Africa (2, 3) countries in this region are undergoing a demographic transition leading to increasing

prevalence of non-communicable diseases (NCDs). Of interest, the prevalence of chronic diseases such as asthma, cancer, diabetes mellitus, cardiovascular disorders, and stunting in toddlers is high in Indonesia (4, 5).

Managing chronic diseases in children is a prolonged and complex process (6). The prolonged treatments and care of children with chronic diseases affect their physical, psychological, psychosocial, spiritual, cognitive, emotional, nutritional, and day-to-day well-being (6, 7). Children living with chronic diseases may have various other health issues, such as poor growth and development, decreased appetite, malnutrition, susceptibility to infection, bleeding, weakness, lethargy, hair loss, constipation, mucositis, gastrointestinal problems, gastritis, nausea, dysphagia, malabsorption, vomiting, neuropathy, retention of urine, diarrhoea, sleep disturbances, and a round moon face (8,

9). In addition, children with chronic diseases may also experience psychological and psychosocial problems, such as anger, anxiety, depression, maladaptive behaviour, low self-confidence, and hopelessness (7, 8). These issues can potentially decrease a child's quality of life (QoL).

Previous studies have reported that there is a correlation between health status and QoL in children with chronic diseases (10, 11) with a large number of people living with chronic diseases that can adversely affect their quality of life. The aim of the present paper is to study quality of life and especially Health-related quality of life (HRQoL). Children with chronic diseases also often experience developmental delays, require intensive medical care, and are limited in their ability to function and be productive (11) with a large number of people living with chronic diseases that can adversely affect their quality of life. The aim of the present paper is to study quality of life and especially Health-related quality of life (HRQoL). Therefore, children with chronic diseases need more support from their caregivers, particularly their parents, and family.

Investigative researchers have shown that a family-centred approach is essential for preventing and treating disease. According to studies, most families are willing to participate in all areas of care for their hospitalized children, and most parents describe this participation as beneficial for both themselves and their children (12). Ensuring family support through advocacy, instruction, information, assessment, and emotional and social support is essential to caring for children with chronic diseases (13). Involving the family in caring for children with chronic diseases will increase their participation and involvement in the decision-making process and improving the QoL of children, both in the hospital and at home (14). However, for families to engage in childcare, they must possess the appropriate knowledge and skills related to the disease, its treatment, and the attendant care needs. Empowering the family means helping them to make the necessary changes, such as promoting healthier lifestyle choices and managing their children and the care they receive.

There exist several systematic studies and reviews on the effectiveness of family-centred empowerment (FCE) in improving the QoL and treatment outcomes among children with chronic diseases (15–17). However, reviews focusing on paediatric populations in Asia and Africa are comparatively limited. Hence, scoping reviews can contribute significantly to evaluating the impact and effectiveness of FCE programs across different geographical locations and cultural contexts. A comprehensive scoping review can also provide new insights and uncover opportunities for further research. Therefore, this scoping review is valuable in expanding our understanding of FCE in relations to children with chronic diseases in Asia and Africa.

Nurses play a significant role in FCE programs in terms of optimizing care, promoting independence, and helping heal children with chronic diseases (6). The FCE model is one of the fundamental family-centred care (FCC) concepts.

It is a paediatric nursing approach that aims to strengthen families' capacities to sustainably improve their health (18). In addition, the FCE model can improve individual and family roles in increasing motivation, self-esteem, self-control, and self-efficacy. It can build knowledge, the right attitudes, and the ability to cope with perceived threats (14).

Assessing various models and study reports regarding the impact of the FCE model on treatment outcomes and QoL among children with chronic diseases are required to comprehensively review the model and its efficacy. This review suggests that increasing nurses' understanding and practice of FCE to improve QoL among children with chronic illnesses will also improve other treatment outcomes. This study aims to conduct a systematic scoping review to identify the effectiveness of FCE in improving the treatment outcomes and QoL in children with chronic diseases.

## **Materials and methods**

### **Study design**

This study employed a systematic scoping review that followed the Arksey and O'Malley framework (2005) and the Preferred Reporting Items for Systematic Review and Meta-analysis Expanded for Scoping Review (PRISMA-ScR) checklist (19, 20). A scoping review was suitable for this study as it enabled thorough analysis of FCE domains on the QoL of Asian and African children with chronic diseases.

### **Search strategy**

A systematic search was conducted using four databases: PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), ScienceDirect, and Directory of Open Access Journals (DOAJ). Keywords in the medical subject heading (MeSH) included child or children; chronic disease or chronic illness; family empowerment, family empowering, or family-centred empowerment; quality of life, QoL, health-related quality of life, or HRQoL.

### **Eligibility criteria**

The criteria in this review were based on the PCC (population, concept, context) framework. The populations used in this review are Asian and African children with chronic diseases, the concept is FCE, and the context is QoL. Articles published between 2010 and 2023, those that were not open access, those compiled in languages other than English, and those that were not based on randomized controlled trials (RCTs) or non-randomized controlled trials were excluded from the review. Three authors, W.R., A.M.M., and F.A., independently screened the articles.

### **Data extraction and analysis**

The three authors isolated the included studies using Microsoft Excel and analysed the data using a qualitative method. The studies were categorized by title, author, year of publication, research objectives, setting, country, sample, age, study design, intervention method, and

results. Then, the extracted data were analysed using a qualitative method. The quality and risk-of-bias were assessed using the Joanna Briggs Institute’s (JBI) appraisal checklist for RCTs and quasi-experimental studies.

**Results**

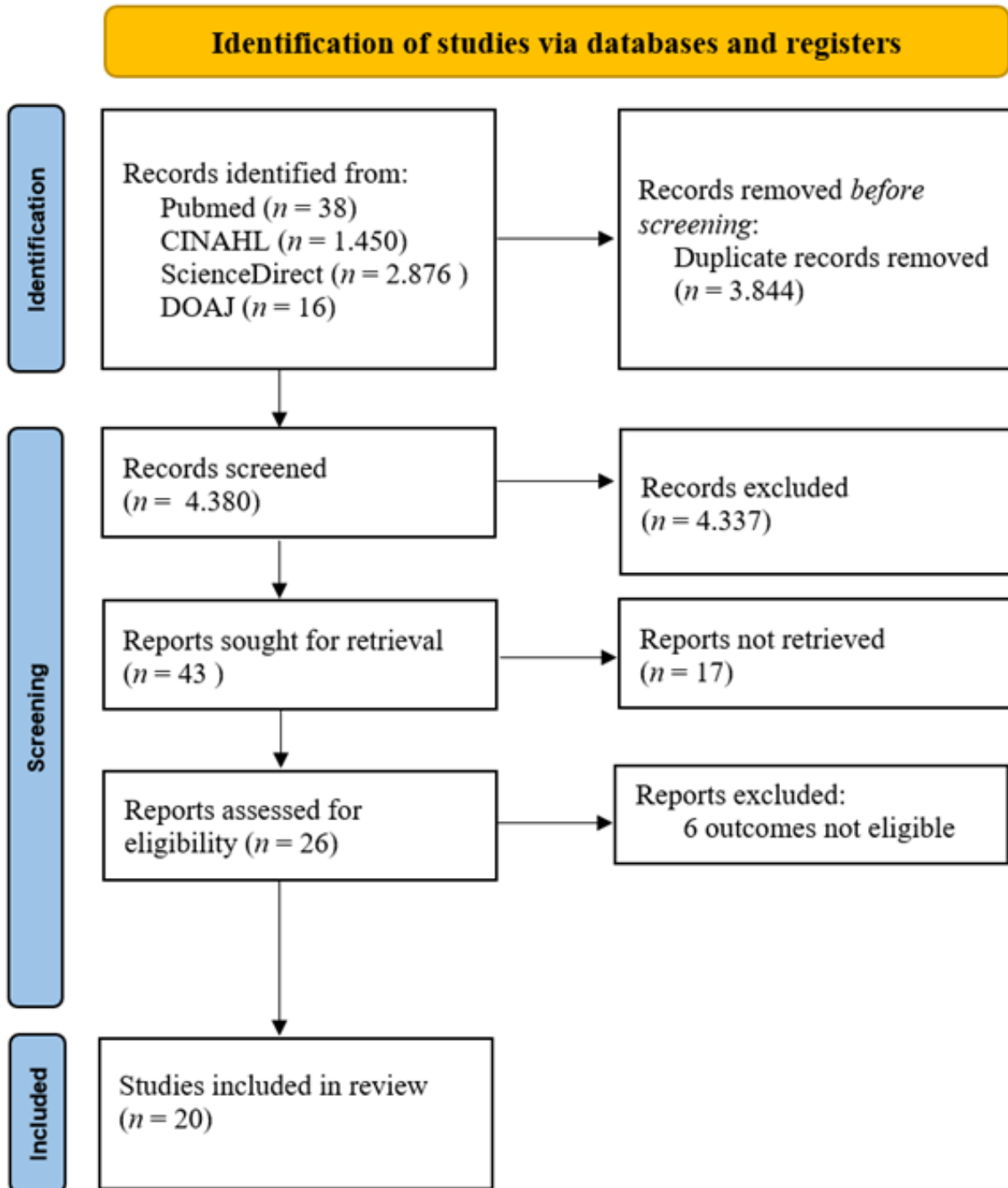
**Selection of included studies**

An initial search identified 4,380 articles. Screening based on title and abstract criteria narrowed the selection to

43 studies. Further screening based on the full text of the article led to the retrieval of 20 studies that met the inclusion criteria for extraction and analysis. The study selection process is shown in Figure 1.

**Characteristics of the study**

The included studies used a quasi-experimental design/ non-randomized trial approach (13 studies) or were RCTs (seven studies). The pooled sample consisted of 1,256 children with chronic diseases, with 468 children in RCTs



**Figure 1: PRISMA Flow diagram.** The flow diagram illustrates the number of records identified (4,380 articles), screened (43 articles), assessed for eligibility (26 studies), and included in the final review (20 studies)

having chronic illnesses—including, thalassemia, asthma, leukaemia, epilepsy, and rheumatoid arthritis—and 788 children in the quasi-experimental studies having chronic illnesses involving chronic kidney disease, asthma, thalassemia, autism, hepatitis C, and leukaemia. The age

range of the children in this review was 2–20 years. The included studies were conducted in Iran ( $n = 11$ ), Egypt ( $n = 4$ ), Indonesia ( $n = 2$ ), Taiwan ( $n = 1$ ), and Tunisia ( $n = 2$ ), while the study settings included hospitals, clinics, special service centres, communities, and schools (Table 1).

**Table 1:** Characteristics of studies

Study	Study design	Country	Settings	Sample (N)	Age (year)	Chronic Disease	Intervention model	Step	Gender (Female)	
									IG	CG
Arief et al. (2019) (22)	Quasi-experimental	Indonesia	Hospital	30	NA	Leukaemia	FCE	Three stages	NA	NA
Farahani et al. (2018) (23)	RCT	Iran	Hospitals	60	18-12	Leukaemia	FCE	Five stages	7(46.7)	9(60)
Borhani et al. (2011) (14)	Quasi-experimental	Iran	Thalassemia Centre	86	6-12	Thalassemia major	FCE	Three stages	NA	NA
Shahdadi et al. (2018) (21)	RCT	Iran	Special Disease Centre	90	12-17	Thalassemia major	FCE	Four stages	NA	NA
Borimnejad et al. (2018) (49)	Quasi-experimental	Iran	Special disease centre	35	12-18	Thalassemia major	FCE	Four stages	26 (74.3)	30 (85.7)
Dardouri et al. (2020) (26)	RCT	Tunisia	Hospital	34	7-17	Asthma	FCE	Four stages	18	14
Kashaninia et al. (2018) (27)	Quasi-experimental	Iran	Paediatric asthma clinic at the hospital	45	6–12	Asthma	FCE	Nine stages	7(30.4)	10(45.5)
Yeh et al. (2016) (28)	RCT	Taiwan	Health Centre	76	6–12	Asthma	FCE	NA	14 (41.2)	12 (38.7)
Fouda et al. (2015) (29)	Quasi-experimental	Egypt	Paediatric asthma clinic at the hospital	47	6-12	Asthma	FCE	Nine stages	10 (43.5)	10 (41.7)
Teymouri et al. (2017) (30)	Quasi-experimental	Iran	Primary school	60	2-8	Asthma	FCE	Four stages	NA	NA
Payrooee et al. (2014) (31)	Quasi-experimental	Iran	Paediatric asthma clinic at the hospital	45	7-11	Asthma	FCE	Nine stages	7 (30.4)	10 (45.5)
Abdalla et al. (2019) (7)	Quasi-experimental	Egypt	Children's Hospital	55	8–20	CKD	FCE	Three stages	28 (50.9)	NA
Ghazavi et al. (2014) (33)	Quasi-experimental	Iran	Hospital	64	8-12	CKD	FCE	Four stages	18 (56.2)	21 (65.2)
Minooei et al. (2016) (34)	Quasi-experimental	Iran	Paediatric nephrologist services	68	8-12	CKD	FCE	Four stages	(58.8)	(58.8)
Ahamed (2018) (35)	Quasi-experimental	Egypt	Hospital	60	8-12	CKD	FCE	Four stages	14 (46.6)	10 (33.3)
Pilevar et al. (2019) (24)	RCT	Iran	Hospital	60	8-12	RA	FCE	Four stages	18 (60)	19 (63.3)
Dardouri et al. (2021) (32)	RCT	Tunisia	Hospital	68	7-17	Asthma	FCE	Four stages	18 (52.5)	14 (41.2)

**Table 1:** Characteristics of studies (continued)

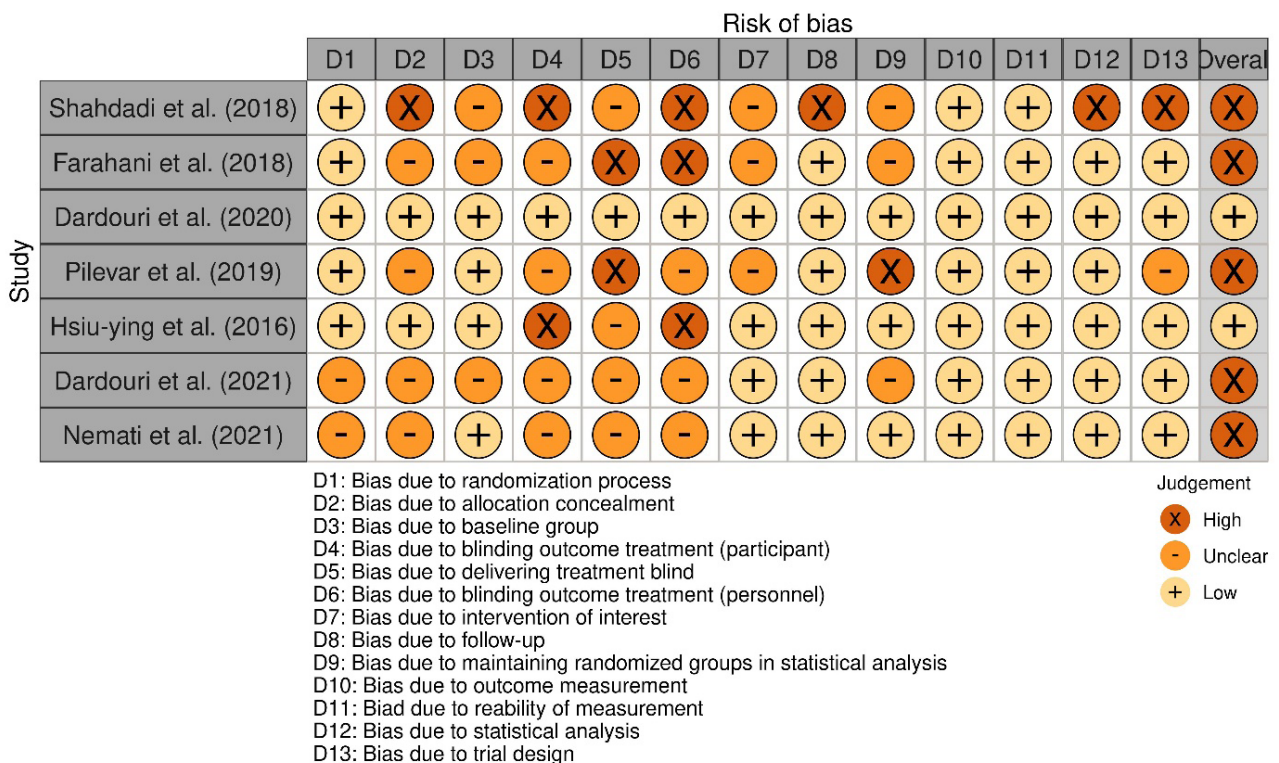
Study	Study design	Country	Settings	Sample (N)	Age (year)	Chronic Disease	Intervention model	Step	Gender (Female)	
									IG	CG
Suprajitno (2017)(37)	Quasi-experimental	Indonesia	Autism Service Centre	33	5-18	Autism	FCE	Three stages	NA	NA
Nemati et al. (2021) (25)	RCT	Iran	Clinic	80	4-8	Epilepsy	FCE	Two stages	21 (52.5)	15 (37.5)
Mostafa et al. (2021) (36)	Quasi-experimental	Egypt	Clinic	160	3-12	Hepatitis C	FCE	Four stages	70 (43.75)	NA

Family-centred empowerment (FCE); quality of life (QoL); chronic kidney disease (CKD); rheumatoid arthritis (RA); randomized controlled trials (RCT)

**The risk-of-bias**

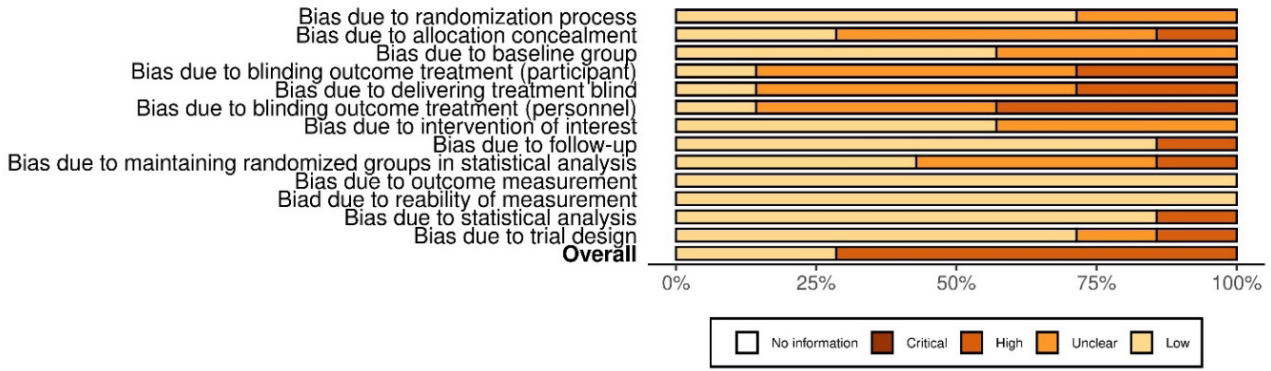
According to the JBI’s appraisal checklist, the included RCT studies were generally high-risk biased, particularly regarding allocation concealment, double-blind treatment, follow-up, intention to treat, and trial design (Figures 2 and 3). In contrast, the included non-randomized trials or quasi-experimental studies showed low bias. The bias

was due to participant selection, intervention deviation from intention, outcome measurement, and measurement reliability (Figures 4 and 5). Figures 2 and 4 present the traffic-light plot of the individual performance-bias risk, while Figures 3 and 5 present the summary risk-of-bias for the non-randomized trials and RCTs.

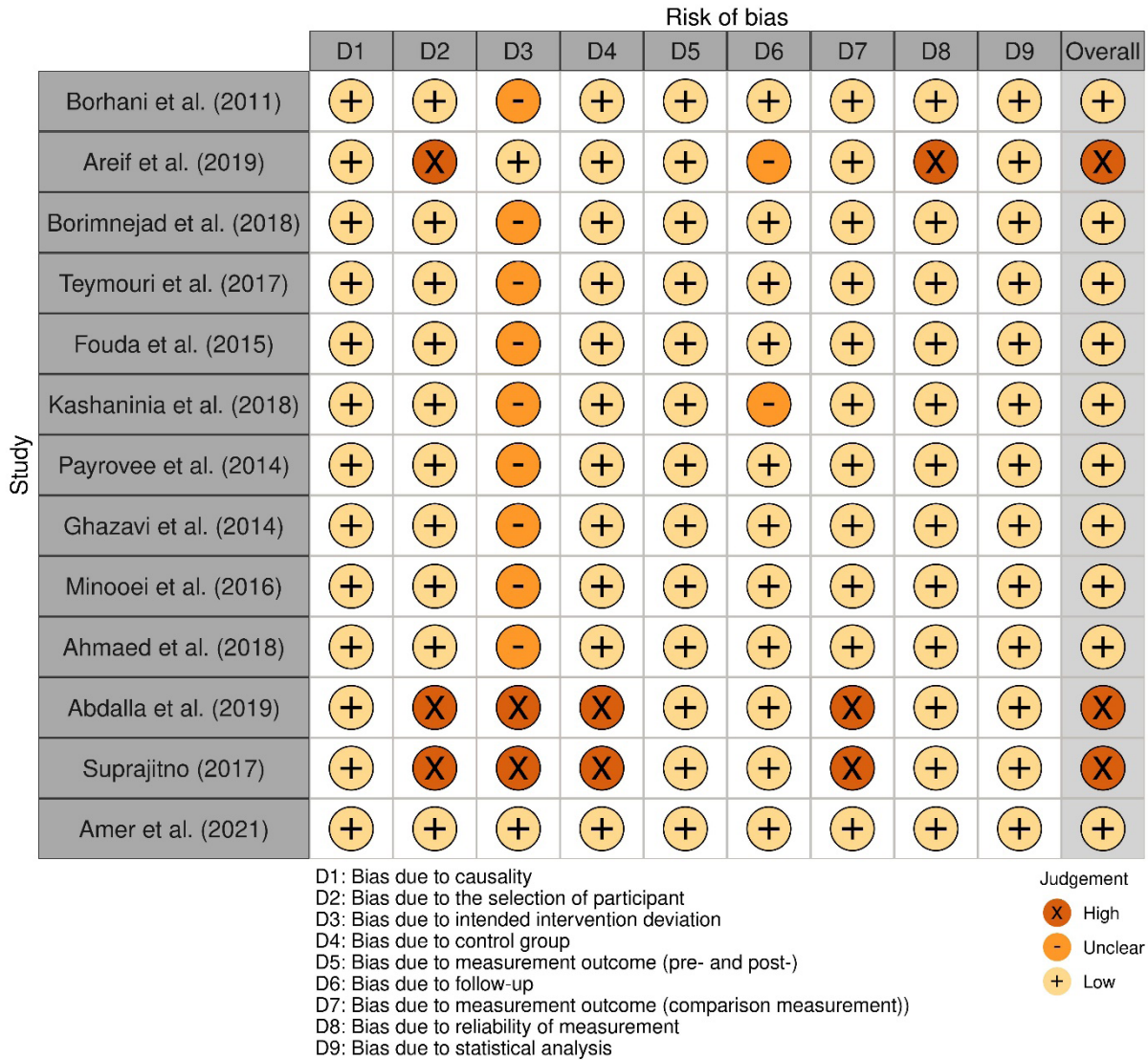


**Figure 2: Risk of bias for RCTs via traffic light plot.** The plot uses three colors similar to a traffic light. Each color corresponds to a specific level of performance or status. The coding of D indicates the individual components of each item to observe any patterns or trends across the items or categories. The dark zone (4 studies) indicates overall good performance, they spread across the brightness zones (2 studies), indicating areas of concern

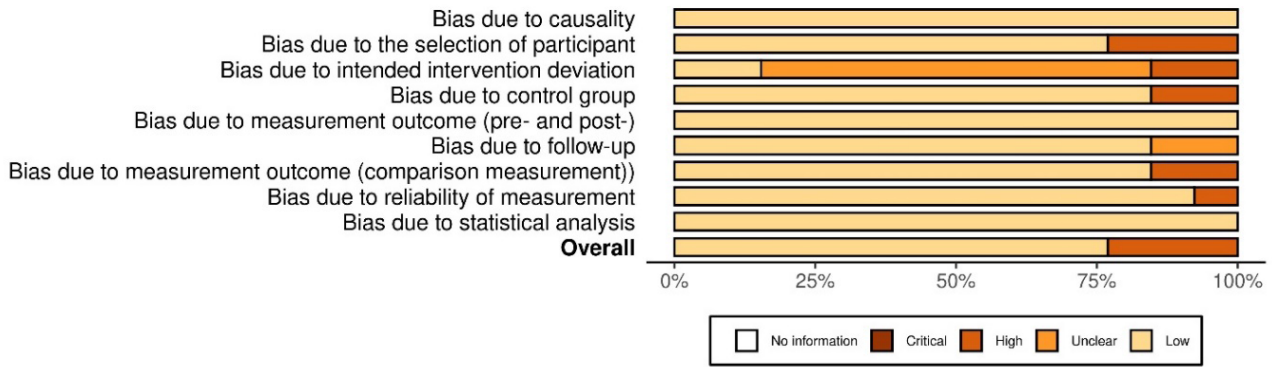




**Figure 3: Summary risk of bias for RCTs.** The figure summarizes different domains or criteria in included RCTs. The different colors represent each judgment. The dark color indicates “Low risk,” brighter colors indicate “Unclear risk,” and “High risk”, respectively. The horizontal line shows the percentage of each color or bias



**Figure 4: Risk of bias for quasi-experimental studies via traffic light plot.** The plot uses three colors similar to a traffic light. Each color corresponds to a specific level of performance or status. The coding of D indicates the individual components of each item to observe any patterns or trends across the items or categories. The dark zone (three studies), indicate overall good performance; they spread across the brightness zones (10 studies), indicating areas of concern



**Figure 5: Summary risk of bias for quasi-experimental studies.** The figure summarizes different domains or criteria in included Quasi-experimental studies. The different colors to represent each judgment. The dark color indicates “Low risk”, brighter color for “Unclear risk” and “High risk”, respectively. The horizontal line shows the percentage of each color or bias

**Study outcome**

Table 2 presents a summary of the findings. The results were analysed based on disease groups, with five disease groups in total.

**The FCE model for children living with chronic diseases**

The FCE model has several variations consisting of three to nine steps. Generally, the intervention steps are as

**Table 2: Study outcomes**

System	Chronic Disease	Study	Measurement / Instrument	Indicator	Intervention		Control group	
					M (SD)	p-value	M (SD)	p-value
Haematology (n = 5)	Leukaemia	Arief et al. (2019) (22)	Physical and haematological assessment	Weight (kg)	13.69 (2.461)	0.000*	17.39 (6.086)	0.150
				Leukocyte (uL)	6266,0 (2623.79)	0.002*	6672.67 (1799,668)	0.001*
				Incidence of bleeding (OR)	3.87 (1.06)	0.041*	4.27 (1.335)	0.064
	Leukaemia	Farahani et al. (2018) (23)	Questionnaires on demographic information, lifestyle, and the four dimensions of empowerment	Lifestyle	6.4 (79.8)	<0.001*	9.6 (55.4)	0.208
Thalassemia major	Thalassemia major	Borhani et al. (2011) (14)	PedsQL 4th ed	Physical	10.37 (1.77)	<0.001*	7.88 (2.15)	<0.001
				Emotional	8.58 (1.33)	<0.001*	5.77 (1.85)	1.00
				Social	6.98 (1.56)	<0.001*	6.05 (1.83)	0.32
				School	9.35 (1.93)	<0.001*	8.33 (2.10)	0.57
				Total	35.28 (3.97)	<0.001*	28.02 (4.71)	0.01
Thalassemia major	Thalassemia major	Borimnejad et al. (2018) (49)	GSE-10 and SCSES	General self-efficacy	31.45 (5.49)	<0.01*	28.02 (4.17)	0.02
				Disease-related self-efficacy	33.94 (6.73)	0.02*	30.6 (5.53)	0.02
thalassemia major	thalassemia major	Shahdadi et al. (2018) (21)	PedsQL 4th ed	QoL	84.2 (80.2- 86.9)	<0.001*	48.4 (43.2- 53.5)	<0.001
Respiratory (n = 7)	Asthma	Dardouri et al. (2020) (26)	PAQLQ	Emotional	6.39 (0.7)	<0.001*	5.26 (1.26)	0.26
				Symptoms	6.41 (0.71)	<0.001*	5.66 (1.07)	0.005
				Activity limitation	5.89 (1.28)	<0.001*	5.01 (1.41)	0.05
				Total score	6.29 (0.78)	<0.001*	5.39 (1.10)	0.02

**Table 2:** Study outcomes (continued)

System	Chronic Disease	Study	Measurement / Instrument	Indicator	Intervention		Control group		
					M (SD)	p-value	M (SD)	p-value	
Asthma	Asthma	Teymouri et al. (2016) (30)	Self-Efficacy Questionnaire and Standardized Self-Esteem Scale	Self- efficacy	3 (0.49)	<0.0001*	2 (0.40)	<0.0001*	
				Self- esteem	0 (0.08)	0.001*	0 (0.13)	0.001*	
Asthma	Asthma	Fouda et al. (2015) (29)	PAQLQ	Activity limitation	4.43 (1.68)	0.010*	1.96 (.89)	0.038	
				Symptoms	4.58 (1.61)	0.006*	2.3 (.68)	0.384	
				Emotional	5.03 (1.54)	0.028*	2.9 (1.2)	0.915	
				Total score	4.73 (1.50)	0.003*	2.4 (79)	0.133	
Asthma	Asthma	Kashaninia et al. (2018) (27)	C-ACT	Asthma control score	3.61 (0.26)	<0.001*	3 (0.42)	<0.001*	
Asthma	Asthma	Payroovee et al. (2014) (31)	PAQLQ	Activity limitation	6.52 (0.37)	<0.001*	5.98 (0.57)	0.052*	
				Symptoms	6.56 (0.28)	<0.001*	6.10 (0.35)	<0.001*	
				Emotional	6.23 (0.31)	<0.001*	5.23 (0.56)	0.091	
				Total score	6.43 (0.28)	<0.001*	5.77 (0.37)	<0.001*	
Asthma	Asthma	Yeh et al. (2016) (28)	FES and PSI	Pulmonary function					
				PEF	211.18 (55.96)	<0.0001*	169.68 (40.29)	<0.0001*	
				FEV1	1.49 (0.43)	<0.0001*	1.19 (0.28)	<0.0001*	
				FEV1/FVC	97.17 (3.70)	0.208	96.52 (2.66)	0.208	
				Asthma symptoms					
				Sleep problem	0.12 (0.33)	<0.0001*	0.58 (0.50)	<0.0001*	
				Cough	0.35 (0.49)	<0.0001*	1.29 (0.64)	<0.0001*	
				Wheeze	0.09 (0.29)	<0.0001*	0.23 (0.50)	<0.0001*	
				Activity	0.35 (0.49)	<0.0001*	0.77 (0.76)	<0.0001*	
				Asthma	Asthma	Dardouri et al. (2021) (32)	GINA and validated inhaler technique checklists	Asthma symptom control	NA
AHCU	NA	0.007*	NA					0.6	
Adherence to controller	NA	0.79	NA					0.5	
Inhalation technique	NA	0.001*	NA					0.6	
Renal (n = 4)	CKD	Ghazavi et al. (2014) (33)	PedsQL 4th ed	Physical	87.3 (9.4)	0.02*	79.4 (15.3)	0.02*	
				Psychosocial	86.5 (7.6)	0.01*	78.3 (16.2)	0.01*	
				Total QOL score	86.8 (7.4)	0.007*	78.7 (14.7)	0.007*	
	CKD	CKD	Minooei et al. (2016) (34)	PedsQL 4th ed	Physical	79.8 (6.1)	0.000*	70.8 (11.9)	0.000*
					Psychosocial	84.3 (7.8)	0.01*	76.8 (15.1)	0.01*
					Total QOL score	83.2 (6.0)	0.003*	75.3 (13.5)	0.003*
	CKD	CKD	Ahamed (2018) (35)	PedsQL 4th ed	Physical	85.8 (8.3)	< 0.01*	78.4 (14.1)	< 0.01*
					Psychosocial	86.0 (6.5)	< 0.005*	77.8 (15.0)	< 0.005*
					Total QOL score	86.8 (7.1)	< 0.05*	78.1 (13.8)	< 0.05*
	CKD	CKD	Abdalla et al. (2019) (7)	PedsQL 4th ed	Physical	1.61 (1.12)	0.001*	NA	NA
					Emotional	0.93 (0.78)	0.002*	NA	NA
					Social	1.15 (0.98)	0.014*	NA	NA
Educational					2.23 (1.44)	0.948	NA	NA	
Total QOL score					1.49 (0.91)	0.030*	NA	NA	



**Table 2:** Study outcomes (continued)

System	Chronic Disease	Study	Measurement / Instrument	Indicator	Intervention		Control group	
					M (SD)	p-value	M (SD)	p-value
Neurology (n = 2)	RA	Pilevar et al. (2019) (24)	PedsQL 4th ed	Physical	69.5 (14.1)	< 0.001*	40.8 (21)	0.42
				Emotional	74.7 (14.5)	< 0.001*	47.3 (23.1)	0.11
				Social	78.7 (13.9)	< 0.001*	47.8 (26.6)	0.12
				Educational	74.7 (14)	< 0.001*	45.5 (23.9)	0.72
				Total QOL score	73.7 (10.8)	< 0.001*	46.5 (19.6)	0.47
	Epilepsy	Nemati et al. (2021) (25)	QOLCE and HRQoL	Cognitive	66/2 (01/3)	<0.001*	07/18 (19/6)	0.036*
				Emotional	08/4 (38/3)	<0.001*	84/8 (33/1)	0.350
				Social	49/7 (26/4)	<0.001*	12/18 (05/2)	0.476
				Physical	91/5 (13/5)	<0.001*	17/19 (44/4)	0.151
				Total	01/3 (20/4)	<0.001*	55/13 (40/0)	0.850
Neurobehavioral (n = 1)	Autism	Suprajitno (2017) (37)	Sensory integration checklist scale	Vision	10.42 (2.42)	0.000*	NA	NA
				Hearing	6.27 (1.82)	0.000*	NA	NA
				Motoric	4.24 (1.95)	0.000*	NA	NA
				Invite to play	9.06 (2.29)	0.000*	NA	NA
				Total score	30.00 (6.42)	NA	NA	NA
Hepatology (n = 1)	Hepatitis C	Mostafa et al. (2021) (36)	MCSI and PedsQL 4th ed	Parent report for toddler (2-4 years)				
				Physical function	85.61 (13.4)	<0.001*	NA	NA
				Psychosocial function	86.62 (12.9)	<0.001*	NA	NA
				Quality of life total score	85.77 (9.6)	<0.001*	NA	NA
				Young child report (5-7 years)				
				Physical function	80.37 (13.6)	<0.001*	NA	NA
				Psychosocial function	84.23 (12.1)	<0.001*	NA	NA
				Quality of life total score	82.29 (8.7)	<0.001*	NA	NA
				Child report (8-12 year)				
				Physical function	89.63 (11.1)	<0.001*	NA	NA
				Psychosocial function	84.68 (11.9)	<0.001*	NA	NA
				Quality of life total score	88.53 (10.5)	<0.005*	NA	NA

\*p-value < 0.05 indicates significance. Almost all components in all intervention group studies showed significant results, except for FEV1/FVC by Yeh et al. (2016) and Adherence to controller by Dardouri et al. (2021). On the other hand, almost all components in each control group study showed non-significant results, except for Leukocyte (uL) by Arief et al. (2019), Self-Efficacy Questionnaire and Standardized Self-Esteem Scale by Teymouri et al. (2016), C-ACT by Kashaninia et al. (2018), FES and PSI by Yeh et al. (2016), PedsQL 4th ed by Ghazavi et al. (2014), Minooei et al. (2016), Ahamed (2018), and PAQLQ by Payroovee et al. (2014).

Family-centred empowerment (FCE); Collaborative Care model (CCM); quality of life (QoL); chronic kidney disease (CKD); rheumatoid arthritis (RA); children's maximum speed of expiration, as measured with a peak flow meter (PEF); forced expiratory volume in the first second (FEV1); the ratio represents the proportion of a person's vital capacity that they can expire in the first second of forced expiration (FEV1/FVC); questionnaire of the core pediatric quality of life Inventory 4th ed (PedsQL 4th ed); general self-efficacy scale (GSE-10) and sickle cell self-efficacy scale (SCSES); paediatric asthma quality of life questionnaire (PAQLQ); Childhood Asthma Control test (C-ACT); Family Environment Scale (FES); parental stress index (PSI); Global Initiative for Asthma (GINA); Quality of Life in Childhood Epilepsy Questionnaire (QOLCE); the health-related quality of life (HRQoL); Modified Caregiver Strain Index (MCSI)

follows. First, increasing the knowledge of families and children using media, materials, and methods for delivering information on the types of diseases children suffer from and the associated problems. Second, increasing self-efficacy by demonstrating disease management practices, problem-solving approaches, and treatment resources. Third, increasing self-esteem by encouraging children and their families to transfer the knowledge they have obtained, and finally, evaluating the intervention at the end of the session.

### ***Impact of FCE on treatment outcomes and QoL among children living with haematological disorders***

Five studies discussed the effect of FCE on children with chronic haematological disorders, including leukaemia ( $n = 2$ ) and thalassemia major ( $n = 3$ ). The FCE group showed a significant increase in QoL compared to the control group, as measured using the paediatric quality of life inventory (PedsQL) (14, 21). The QoL improvement was observed in physical, emotional, social, and educational domains. Physically, the children receiving FCE showed decreased bleeding and improved weight compared to the control group. Moreover, there was an increase in the number of leukocytes after FCE, while this was not significantly different from the control group (22). Behaviourally, the children receiving FCE showed increased self-efficacy (mainly related to the disease) and improved lifestyle outcomes. However, the differences in lifestyle outcomes between the FCE and the control groups were insignificant (23).

### ***Impact of FCE on QoL among children living with neurological disorders***

Only two studies discussed the effects of FCE on neurological diseases, specifically rheumatoid arthritis (RA) and epilepsy. The mean QoL parameters significantly increased among the children living with RA across all domains, as measured by PedsQL (24) discomfort, treatment complications, and frequent absences from school leading to academic failure. No research similar to the present investigation was performed in this area. Aim: We aimed to evaluate the problems of children with rheumatoid arthritis. Moreover, we assessed the effect of family-centered empowerment on the QoL of these children. Method: This randomized clinical trial was performed on 60 children aged 8-12 years diagnosed with rheumatoid arthritis in Akbar Pediatrics Hospital, Mashhad, Iran in 2018. The subjects were divided into test and control groups. The four stages of family-centered empowerment model, namely improvement of knowledge, self-efficacy, self-esteem, and assessment were executed for the test group. After a month, the inventory of pediatric quality of life was completed again. Data analysis was performed by Mann-Whitney U test, independent t-test, and paired t-test using SPSS version 16. Results: No significant difference was observed between the groups regarding age ( $P=0.351$ ). In addition, FCE intervention improved the total scores and all

domains of QoL and HR-QoL among children with epilepsy (25) which remarkably affects children's performance and behaviors. Epileptic children are at greater risk of cognitive and behavioral disorders compared to healthy children. In this regard, a variety of factors associated with this disease may affect the patients' families. Materials & Methods The present study was a randomized controlled clinical trial, which aimed to evaluate the effect of family empowerment on the quality of life in epileptic children referred to the concerned centers (the Bessat Clinic affiliated to the Kerman University of Medical Sciences and Shiraz's Imam Reza Clinic).

### ***Impact of FCE on treatment outcomes and QoL among children living with respiratory disorders***

Six studies discussed the effects of FCE on children with chronic respiratory disorders, specifically asthma. The FCE group showed a significant increase in QoL compared to the control group, as measured by the paediatric asthma quality of life questionnaire (PAQLQ) (26–28) how to empower whole families to manage their children's asthma is a challenge that requires innovative nursing intervention based on family-centred care. Aims: To evaluate the effectiveness of a family empowerment program on family function and pulmonary function of children with asthma compared to those receiving traditional self-management only. Design: A randomized control trial. Methods: Sixty-five families were recruited from one asthma clinic in a medical centre in Taiwan. After random assignment, 34 families in the experimental group received the family empowerment program consisting of four counselling dialogues with the child and its family. We empowered the family caregiver's ability to manage their child's asthma problems through finding the problems in the family, discovery and discussion about the way to solve problems, and enabling the family's cooperation and asthma management. The other 31 families received the traditional care in asthma clinics. The Parental Stress Index and Family Environment Scale of family caregivers, and pulmonary function, and asthma signs of children with asthma were collected at pre-test, 3-month post-test, and one-year follow-up. We utilized the linear mixed model in SPSS (18.0). The QoL improved across all domains, including emotional well-being, illness symptoms, and activity levels (26, 28) how to empower whole families to manage their children's asthma is a challenge that requires innovative nursing intervention based on family-centred care. Aims: To evaluate the effectiveness of a family empowerment program on family function and pulmonary function of children with asthma compared to those receiving traditional self-management only. Design: A randomized control trial. Methods: Sixty-five families were recruited from one asthma clinic in a medical centre in Taiwan. After random assignment, 34 families in the experimental group received the family empowerment program consisting of four counselling dialogues with the child and its family. We empowered the family caregiver's ability to manage their child's asthma problems through finding the problems in the family, discovery and discussion about the way to

solve problems, and enabling the family's cooperation and asthma management. The other 31 families received the traditional care in asthma clinics. The Parental Stress Index and Family Environment Scale of family caregivers, and pulmonary function, and asthma signs of children with asthma were collected at pre-test, 3-month post-test, and one-year follow-up. We utilized the linear mixed model in SPSS (18.0). However, a previous study reported that QoL only improved significantly in the Symptoms domain. Physically, children receiving FCE showed a significant improvement in pulmonary function (PEF, FEV1, FVC), activity levels, sleeping problems, coughing, and wheezing (29). However, compared to the control group, the differences were insignificant. Behaviourally, FCE increased asthma control, self-efficacy, and self-esteem (30-32).

### ***Impact of FCE on QoL among children living with renal disease***

Four studies discussed the effects of FCE on children with chronic renal disease, specifically chronic kidney disease. The FCE group showed a significant increase in QoL compared to the control group. The QoL improved in the physical, psychosocial, educational, and emotional domains as measured by the PedsQL questionnaire. While FCE led to an increase across all aspects of QoL, with no significant differences observed in educational attainment compared to other outcomes in the intervention group (7, 33-35).

### ***Impact of FCE on QoL among children living with hepatology problems***

One study reported on the effects of FCE on hepatology problems, specifically hepatitis C, which is a common infection in children caused by the hepatitis C virus (HCV). The implementation of FCE significantly improved QoL among children with hepatitis C across both physical and psychosocial functioning, as measured by the Modified Caregiver Strain Index (MCSI) for toddlers and the PedsQL (4th edition) for children over four years old (36).

### ***Impact of FCE on treatment outcomes among children living with neurobehavioral disorders***

One study discussed the effects of FCE on children with neurobehavioural disorders, particularly autism (37). Autism is a persistent neurological disorder with visible symptoms of developmental impairments in social interactions and behaviour. Implementing FCE significantly improved their sensory integration skills, such as vision, hearing, motor skills, and play engagement (38). The Suprajitno study demonstrated that FCE had a stimulating effect on autistic children, including two-way communication, responding, sometimes eating alone, wearing their clothes, asking to go to the toilet, memorizing letters from A to F, recognizing numbers from 1 to 20, writing their name, colouring, going home unaccompanied, imitating a few words, and following simple commands to take out the trash and dry clothes (37).

## **Discussion**

### ***Principal findings***

Children living with a chronic disease often require prolonged and comprehensive care that significantly impacts their QoL (14, 39, 40). The QoL of these children spans multiple physical, psychosocial, emotional, social, and educational domains (40), and is influenced by physical pain, discomfort, complications, treatment processes, learning disorders, poor communication, and low self-efficacy, as well as insufficient support and independence (33, 37).

The present study demonstrated that FCE improves the clinical outcomes and QoL among children with chronic diseases. The FCE model fosters a collaborative and supportive approach to care that prioritises the physical, emotional, and social well-being of children with chronic diseases and their families (41-43). The approach prioritises the needs and experiences of the child and their family, recognising that they are the primary caregivers and decision-makers in the child's care (44). The model empowers families to actively participate in their child's care, helping them acquire the knowledge, skills, and confidence to manage their child's condition and navigate the healthcare system (43, 45). By involving families in the decision-making process, the model ensures that care plans are tailored to the unique needs and circumstances of each child and their family (38, 46, 47). Furthermore, the FCE model also focuses on building resilience and coping skills, helping families to better manage the emotional and psychological impact of chronic illnesses and improve their overall QoL (16, 36, 48).

The study found that FCE enhanced the physical, emotional, social, academic, and psychosocial functions in children with chronic diseases. In children with a chronic haematological disorder, there is an increase in optimal weight, increased leukocytes, decreased bleeding events, and improved lifestyle across all domains of QoL and self-efficacy. In children with a chronic respiratory disorder, there is an increase in pulmonary function, clinical outcomes (coughing, wheezing, and shortness of breath), QoL, self-efficacy, self-esteem, and asthma control. In children with a chronic neurological disorder, there is an increase in the entire domain of QoL. In children with neurobehavioural disorders, there is an increase in sensory integration skills.

The results of this study are aligned with previous reviews. The review conducted by Alhani et al. demonstrated that the FCE model improved both physical and mental QoL in adults with chronic diseases (15). In addition, the review conducted by Mardhiyah et al. concluded that FCE effectively reduces psychological problems among children with chronic diseases (16).

### ***Implications for practice***

The FCE approach is an intervention nurses use to assist families in caring for and supporting family members

with chronic diseases and is the most critical aspect of effective treatment. In their role as healthcare providers, nurses must consider not only the characteristics of the respondents in terms of their knowledge, attitudes, and healthcare abilities but also the family and cultural aspects that can influence health evaluations (17). The FCE program can build self-efficacy, motivation, threat recognition, responsibility, and attention such that families can work together with nurses to reduce problems among children, carry out their roles and independent care, and reduce costs for improving a child's QoL (22, 49).

Awareness regarding the role of nurses and caregivers can lead to positive outcomes when nursing services are provided to these families. Nurses can deploy FCE to help patients take effective steps in the care process, consultation, and participatory problem-solving, to lessen parents' dependence on the medical team, and to enable them to meet as many of their requirements as possible. In addition, by empowering patients' families and increasing their adherence to therapeutic regimens, FCE programs play a crucial role in managing children's physical and mental health.

The results of this study encourage the adoption of intervention programs by nurses that enable families to perform self-care, particularly when the patient returns home. This intervention approach can be implemented in hospitals, whether the patient is an inpatient or an outpatient. When followed outside of the hospital, the FCE program can be monitored remotely through telenursing or internet-based parenting-mediated intervention (PMI). Internet-based PMI effectively improves parenting outcomes for parents of children with chronic illnesses (50) it is costly and requires extensive resources to be effective. This inaccessibility is also further worsened by the ongoing COVID-19 pandemic, making the shift to a digital approach a sensible option. Among the available ASD therapies, parent-mediated interventions (PMIs).

The clinical implication of this study is that the FCE approach can effectively improve both QoL and treatment outcomes in children with chronic diseases in Asia and Africa. Healthcare professionals may consider adopting the FCE approach in their clinical practice to improve patient experience and treatment outcomes.

An additional research implication is the significance of further research focusing on paediatric populations in Asia and Africa to examine the effectiveness of FCE in improving health outcomes and patient experience. Future research may also consider exploring the factors influencing FCE implementation in different societies and cultures.

### **Strengths and limitations**

This study is the first scoping review to comprehensively identify the effectiveness of FCE in improving the treatment outcomes and QoL of Asian and African children with chronic diseases. Despite this significant contribution, several limitations need to be acknowledged.

First, the search strategy employed to identify relevant studies may have overlooked some essential articles or data sources. The search may have been restricted to particular databases or certain categories of publications, omitting potentially relevant studies from other sources. Second, as mentioned in the discussion section, several studies included in this scoping review had methodological limitations, particularly regarding study design and quality. Specifically, allocation concealment, blinding, intention to treat, and statistical analysis were seriously flawed in the included RCT studies. These biases may have affected the quality of available evidence, necessitating additional RCT studies and higher-quality research to strengthen the evidence-based outcomes in this field. This may have affected the reliability of the review's conclusions. Third, the included studies were conducted primarily in Asia and Africa, which may limit the generalisability of the findings to other regions or populations. Moreover, cultural and contextual factors that influence the implementation and efficacy of FCE interventions may vary between settings. The included studies may also be susceptible to publication bias, in which studies with positive or statistically significant results are more likely to be published than those with negative or null results. Consequently, the efficacy of FCE interventions may be overestimated. This study provides valuable insights into the potential of FCE to improve the lives of children with chronic diseases; however, additional research is required to validate these findings and ensure that they can be applied to a broader spectrum of settings.

### **Conclusion**

Most studies with low-quality evidence show that FCE is an effective and sustainable intervention to improve QoL and treatment outcomes of children with varied chronic diseases. This model may also help reduce the caregiver burden for parents of children with chronic diseases. Using the FCE model would benefit nurses in developing intervention programs by encouraging families to perform self-care and childcare plans when the patient returns home. Our study recommends emphasizing collaboration and shared decision-making between healthcare providers, patients, and their families in developing and implementing care plans.

Further research investigating the effectiveness of FCE on parent outcomes is needed to understand the impact of this model fully. It is important to continue exploring ways to reduce caregiver burden and improve QoL and treatment outcomes of children with chronic diseases.

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### **Competing interests**

The authors declare that they have no competing interests.



### Ethical clearance

We declare that ethical approval was not required for our study and there are no ethical issues.

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