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ARTICLE

Impact of Family-Centred Continuity of Care on Depression, Anxiety, Self-Esteem, and Quality of Life in Children With Leukemia

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Abstract

Aims/Background Leukemia is the most prevalent pediatric malignancy and has a significant impact on the psychological, emotional well-being, and quality of life of affected children. This study aimed to evaluate the effects of family-centred continuity of care (FCCC) on the psychological state, self-esteem, and quality of life in children with leukemia.

Methods A retrospective analysis was conducted on 243 pediatric leukemia patients admitted to the Fourth Hospital of Hebei Medical University between January 2019 and December 2022. Patients were divided into two groups: Routine care (n = 135), who received standard hospital care, and home care (n = 108), who received FCCC. Data were collected and analysed using the Self-Esteem Scale (SES), Screen for Child Anxiety Related Emotional Disorders (SCARED), Depression Self-Rating Scale for Children (DSRSC), and Pediatric Quality of Life Inventory Multidimensional Fatigue Scale (PedsQL MFS).

Results Post-intervention, the home care group demonstrated significant improvements in self-management, emotional and mental health functioning, and physical and social functioning ($p < 0.05$). The group also demonstrated decreased depression, enhanced self-esteem, improved quality of life, and reduced anxiety levels, indicating the efficacy of FCCC.

Conclusion FCCC significantly enhances psychological well-being and quality of life in pediatric leukemia patients by integrating family members into the care process and offering emotional support and empowerment.

Key words: leukemia; pediatric; family-centred care; quality of life; psychosocial support; continuity of care

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Introduction

Leukemia represents one of the most common and challenging malignancies within the pediatric population, accounting for approximately 30% of all childhood cancers (Jabbour et al, 2024; Lamba et al, 2024). Advances in treatment strategies over recent decades have significantly improved survival rates. However, the long-term psychosocial and emotional impact of the disease remains profound (Pratz et al, 2024). Children diagnosed with leukemia often endure prolonged and intensive treatment protocols, including chemotherapy regimens, which can substantially disrupt their psychological well-being, reduce self-esteem, and adversely affect their

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overall quality of life (Jen et al, 2024; Zhu et al, 2024). Research has shown that children with leukemia frequently exhibit symptoms of depression and anxiety (Myers et al, 2014). These psychological and psychosocial challenges highlight the necessity for integrative care approaches tailored to meet the multidimensional needs of young leukemia patients (Usuki et al, 2024).

Family-centred continuity of care (FCCC) offers a promising paradigm shift from conventional hospital-centric models to a more holistic framework that incorporates family members as integral components of the patient care team (Johanna Josepha Op't Hoog et al, 2022; Ronis et al, 2021). This model is based on the understanding that family systems play a critical role in managing chronic illnesses and can provide robust emotional support and stability for pediatric patients (Tan and Su, 2024). FCCC emphasises collaborative partnerships between healthcare providers and families, wherein caregivers are equipped with tailored health education, skill training, and ongoing care guidance to address both the medical and psychosocial needs of the child more effectively (Hao et al, 2023). Previous studies have reported positive outcomes of the FCCC approach in other clinical contexts. For example, in managing children with acute otitis media, FCCC significantly improved patients' mental health outcomes (Yang et al, 2025). This approach not only enhances medical care delivery but also fosters an environment that nurtures the psychological and emotional resilience of children facing life-threatening conditions such as leukemia (Yusuf et al, 2024).

The critical impact of FCCC on children's psychological well-being is supported by social support theory, which posits that a strong social network significantly buffers against stress and improves mental health outcomes (Kavand and Asgari, 2024). Through active participation in the care process, family members can offer essential emotional support, mitigating feelings of helplessness and isolation commonly experienced by pediatric oncology patients (Machut et al, 2021). Furthermore, family involvement enables the delivery of personalised health education and empowerment strategies, which promote a sense of autonomy and control over disease management, and potentially enhance self-esteem and self-management skills (Altman et al, 2023).

Despite its potential, empirical studies evaluating the efficacy of FCCC in pediatric leukemia populations remain limited. Historically, clinical research has focused primarily on pharmacological interventions and their physiological outcomes, often overlooking the psychosocial dimensions and family dynamics pivotal to comprehensive care (Lisanti et al, 2024). As healthcare models continue to evolve toward personalised and integrative care, there is a growing recognition of the need to systematically assess how family-centred approaches can reshape the treatment landscape and contribute to improved health outcomes (Ventres et al, 2024). This study aimed to fill this gap by systematically analysing the impact of FCCC on the psychological state, self-esteem, and quality of life in children diagnosed with leukemia.

Methods

Basic Design

This study was approved by the Ethics Committee of the Fourth Hospital of Hebei Medical University (Approval No: 2025KS036). As this retrospective study utilised de-identified patient data with no associated risk or impact on patient care, informed consent was waived by the Fourth Hospital of Hebei Medical University in accordance with applicable regulations and ethical guidelines, particularly in compliance with the Declaration of Helsinki.

A retrospective analysis was conducted on 243 pediatric patients diagnosed with acute leukemia who were admitted to the Fourth Hospital of Hebei Medical University between January 2019 and December 2022. Data collection for this study was carried out between January 2024 and June 2024, during which medical records were reviewed. Patients were assigned to two groups based on the type of care received. The routine care group consisted of 135 children who received standard hospital-based care, while the home care group included 108 children who received family-centred continuous care (FCCC).

Demographic information was collected from case records, including general data on the children and their families. Assessments included the evaluation of anxiety and depressive symptoms, quality of life using the Pediatric Quality of Life Inventory Multidimensional Fatigue Scale (PedsQL MFS), and self-esteem using the Self-Esteem Scale (SES). All assessment tools were jointly completed by the pediatric patients and their caregivers.

Study Design

This study employed a retrospective design, analysing past cases to compare outcomes among pediatric patients receiving different modes of care. Patients were categorised into two groups. The first group, comprising 135 children, received standard treatment and care from specialised haematology healthcare providers within the hospital setting. During follow-up visits, caregivers were actively involved in providing care, including explaining the outpatient process and introducing responsible medical personnel. This group was designated as the routine care group, with an observation period of five months.

The second group consisted of 108 children who received daily home care from family members residing with them. These caregivers provided the required support while gaining a thorough understanding of the specific conditions of both the child and the broader family. Health education tailored to the child’s cognitive development was delivered alongside regular communication to enhance the child’s self-care abilities. Additionally, caregivers received skill training in key areas such as medication adherence, nutritional support, and routine care. Continuous care guidance was also provided to correct any erroneous caregiving practices. This cohort was designated as the home care group, with an observation period also lasting five months.

Inclusion and Exclusion Criteria

Children With Acute Leukemia

Inclusion Criteria: Eligible participants were required to meet the following conditions: (1) A diagnosis of acute leukemia as outlined by the World Health Organisation's 2022 diagnostic and classification criteria (Park et al, 2022). (2) Age below 14 years. (3) Being in the maintenance or remission phase of treatment for acute leukemia, which includes completion of induction therapy and either ongoing or completed consolidation therapy. Patients were required to show no evidence of active disease, which was defined as normal blood counts and the absence of leukemic cells in the bone marrow post-treatment. (4) A clinically stable condition with no evidence of relapse or deterioration during the five-month observation period.

Exclusion Criteria: (1) Diagnosis of non-acute leukemia. (2) Age below 5 years. (3) Presence of comorbid organic diseases such as severe cardiac, hepatic, or renal diseases. (4) History of psychiatric disorders or severe psychological or cognitive impairments. (5) Inability to communicate physical or emotional states due to communication barriers or non-native language proficiency. (6) Presence of severe dysfunction in major organ systems, including cardiovascular, hepatic, or renal. (7) Prior history of bone marrow transplantation or exposure to radiation therapy.

Relatives

Inclusion Criteria: Eligible participants must be the primary caregivers of pediatric patients diagnosed with acute leukemia according to the 2022 World Health Organisation (WHO) standards (Park et al, 2022), reside in the same household, and with a sufficient understanding of the child's medical condition.

Exclusion Criteria: Relatives were excluded if they had a history of psychiatric disorders, suffered from chronic diseases such as hypertension, coronary heart disease, or malignant tumours, or were illiterate and unable to understand care-related instructions.

Both pediatric patients (children) and their primary caregivers (relatives) were required to meet all respective inclusion and exclusion criteria. Only families in which both fulfilled these criteria were included in the study, ensuring sample homogeneity and enhancing the validity of the data collected.

Assessment of Self-Esteem Scale (SES)

The children's version of the SES was used to evaluate the self-esteem responses of children during their care (Wood et al, 2021). This scale comprises 10 items rated on a four-point Likert scale, with total scores ranging from 10 to 40. Higher scores reflect higher self-esteem. The internal consistency reliability of the scale, as measured by Cronbach's alpha coefficient, was 0.842.

Assessment of Anxiety and Depression (SCARED and DSRSC)

To evaluate anxiety symptoms, the Screen for Child Anxiety Related Emotional Disorders (SCARED), an internationally validated tool, was employed for both children and their parents (Birmaher et al, 1997). The scale contains 20 items across five domains: Separation anxiety, social phobia, generalised anxiety, school phobia, and panic disorder, with four items in each domain. Responses were recorded using a five-point Likert scale ranging from 0 (almost never) to 4 (always), based on the frequency of symptoms over the past two weeks. Domain scores range from 0 to 16, with a total score range of 0 to 80. Higher scores indicate greater levels of anxiety. The Cronbach's alpha coefficient for this tool was 0.817.

The Depression Self-Rating Scale for Children (DSRSC) was used to assess depressive symptoms (Birleson et al, 1987). The scale includes 18 items, each scored from 0 to 2. Higher total scores indicate more severe depression. Clinical thresholds were set at $>$16 for boys and $>$15 for girls to indicate clinically significant depressive symptoms. The internal consistency of the DSRSC, measured by Cronbach's alpha coefficient, was 0.776.

Assessment of Quality of Life

The Pediatric Quality of Life Inventory Multidimensional Fatigue Scale (PedsQL MFS) is an 18-item questionnaire designed to assess the quality of life in pediatric patients. It comprises three subscales: General fatigue (6 items), cognitive fatigue (6 items), and sleep/rest fatigue (6 items). A total score is derived by averaging responses across all items, with possible scores ranging from 0 to 100. Higher scores indicate lower levels of fatigue (Varni et al, 2002).

Assessment of Leukemia Condition

The condition of the patient was evaluated by the attending physician during the fifth-month follow-up visit (Shah et al, 2024).

Critical Condition: Patients were classified as being in critical condition if the illness progressed rapidly, was complex and unstable, and posed an imminent risk of life-threatening complications. This was characterised by persistent high fever, a predisposition to severe bleeding, uncontrolled infections, and extreme fatigue due to anemia. These symptoms indicated a poor prognosis, low remission rates, and significantly abnormal hematologic indicators.

General Condition: Patients in this category exhibited a relatively slow disease progression with mild or infrequent complications and minimal organ dysfunction. Early symptoms included low-grade fever, fatigue, and occasional petechiae or other non-specific, non-life-threatening symptoms. These patients typically responded well to standard chemotherapy regimens, achieved early remission, and showed mild hematological abnormalities with stable biochemical indicators.

Significant Improvement: Patients demonstrated a marked reduction or resolution of symptoms such as fever, infection, and anemia. There was a notable improvement in physical strength and overall quality of life. Complications were well-managed and no longer life-threatening. Patients regained the ability to perform daily activities, with improved mental state, appetite, and sleep.

Mild Improvement: Patients showed partial symptom relief, including reduced fever frequency, decreased bleeding episodes, and alleviated fatigue. However, discomfort persisted, and bed rest was still necessary. Some complications were con-

Table 1. Baseline characteristics of children with acute leukemia.

Parameter		Routine care group (n = 135)	Home care group (n = 108)	t/χ^2	p-value
Age (years)		8.36 ± 2.33	8.21 ± 2.24	0.503	0.616
Disease duration (months)		9.52 ± 4.57	9.35 ± 4.69	0.284	0.777
Number of hospitalisations	≤10	84 (62.22%)	68 (62.96%)	0.054	0.973
	10–20	36 (26.67%)	29 (26.85%)		
	20–30	15 (11.11%)	11 (10.19%)		
Subtype of leukemia	ALL	93 (68.89%)	79 (73.15%)	0.526	0.468
	AML	42 (31.11%)	29 (26.85%)		
Gender	Male	71 (52.59%)	55 (50.93%)	0.067	0.796
	Female	64 (47.41%)	53 (49.07%)		
Ethnicity	Han	124 (91.85%)	98 (90.74%)	0.094	0.759
	Other	11 (8.15%)	10 (9.26%)		
Presence of complications	Yes	85 (62.96%)	67 (62.04%)	0.022	0.882
	No	50 (37.04%)	41 (37.96%)		
Other medical history	Yes	7 (5.19%)	3 (2.78%)	0.377	0.539
	No	128 (94.81%)	105 (97.22%)		
Primary caregiver identity	Parents	126 (93.33%)	104 (96.30%)	1.040	0.308
	Other	9 (6.67%)	4 (3.70%)		
Chemotherapy phase	Induction of remission	64 (47.41%)	52 (48.15%)	0.018	0.991
	Consolidation	58 (42.96%)	46 (42.59%)		
	Maintenance therapy	13 (9.63%)	10 (9.26%)		
Admission condition	Critical	47 (34.81%)	33 (30.56%)	0.493	0.483
	Stable	88 (65.19%)	75 (69.44%)		
WBC count ($\times 10^9$/L)		5.73 ± 1.08	5.81 ± 1.01	0.554	0.580
MRD level (ppm)		18.59 ± 5.47	17.94 ± 5.12	0.952	0.342

Note: ALL, acute lymphoblastic leukemia; AML, acute myeloid leukemia; WBC, white blood cell; MRD, minimal residual disease.

trolled, though residual risks remained, necessitating continuous monitoring and management. While quality of life improved somewhat, physical strength had not fully recovered, limiting daily living functioning and requiring additional time for recuperation.

No Improvement: Patients exhibited no significant symptom relief or experienced worsening of their condition, with persistent high fever, severe bleeding, and extreme fatigue. Complications remained uncontrolled, or new complications emerged, leading to a continuous decline in physical strength. Patients were unable to perform basic daily activities, showed poor mental state, and experienced ongoing appetite and sleep disturbances.

Table 2. Comparison of DSRSC scores between two groups of patients before and after care.

Assessment timepoint	Routine care group (n = 135)	Home care group (n = 108)	*t*-value	*p*-value
Pre-caring	14.75 ± 1.33	14.86 ± 1.38	0.611	0.542
Post-caring	13.07 ± 1.62	12.54 ± 1.62	2.541	0.012
Within-group *t*-value	9.313	11.308		
Within-group *p*-value	<0.001	<0.001		

Note: DSRSC, Depression Self-Rating Scale for Children.

Statistical Analysis

Statistical analyses were performed using SPSS version 29.0 (SPSS Inc., Chicago, IL, USA). Categorical variables were expressed as frequencies and percentages [n (%)]. Group comparisons for categorical data were conducted using the chi-square test. The Shapiro-Wilk test was employed to assess the normality of continuous variables. Data that followed normal distribution were presented as mean ± standard deviation ($\bar{x} \pm s$). Independent samples *t*-tests were used to compare means between groups for normally distributed data. Paired sample *t*-tests were used for within-group comparisons before and after care. A p-value < 0.05 was considered statistically significant.

Results

General Information

There were no statistically significant differences between the routine care group and home care group in terms of age, disease duration, hospitalisation frequency, leukemia subtype distribution, gender, ethnicity, presence of complications, other medical history, chemotherapy phases, primary caregiver identity, or admission condition (all $p > 0.05$). Similarly, no significant differences were found between the two groups in white blood cell counts or levels of minimal residual disease (all $p > 0.05$). Therefore, the baseline demographic and clinical characteristics were comparable between the two groups (Table 1).

DSRSC and SES Scores

At baseline, the DSRSC scores showed no significant difference between the routine care and home care groups ($p = 0.542$) (Table 2). Following the intervention, DSRSC scores significantly decreased in both groups (routine care group: $p < 0.001$; home care group: $p < 0.001$). Furthermore, the DSRSC scores in the home care group were significantly lower compared to those in the routine care group after care ($p = 0.012$), indicating a greater reduction in depressive symptoms.

Similarly, baseline SES scores were statistically comparable between the two groups ($p = 0.702$) (Table 3). After care, self-esteem levels significantly improved in both groups (routine care group: $p < 0.001$; home care group: $p < 0.001$). The home care group also exhibited significantly higher SES scores after care compared

Table 3. Comparison of SES scores between two groups of patients before and after care.

Assessment timepoint	Routine care group (n = 135)	Home care group (n = 108)	*t*-value	*p*-value
Pre-caring	12.19 ± 4.37	11.96 ± 4.88	0.383	0.702
Post-caring	25.12 ± 4.78	26.98 ± 5.41	2.843	0.005
Within-group *t*-value	23.197	21.424		
Within-group *p*-value	<0.001	<0.001		

Note: SES, Self-Esteem Scale.

to the routine care group ($p = 0.005$). These findings highlight the effectiveness of FCCC in enhancing psychological well-being and self-esteem in pediatric leukemia patients.

Anxiety

Before the intervention, there were no significant differences in separation anxiety scores between the routine care group and the home care group ($p = 0.331$) (Table 4). Similarly, no significant differences were observed in social phobia scores ($p = 0.486$), extensive anxiety scores ($p = 0.306$), school phobia scores ($p = 0.706$), or panic disorder scores ($p = 0.174$) between the routine care and home care groups. Additionally, there was no significant difference in the total score ($p = 0.883$) between the two groups. These findings suggest that baseline levels of anxiety were comparable between the two groups prior to nursing care.

Following the intervention, the home care group exhibited significantly lower separation anxiety scores compared to the routine care group ($p = 0.009$). Similarly, social phobia scores were significantly lower in the home care group than in the routine care group ($p = 0.005$). The home care group also showed significantly reduced extensive anxiety scores ($p = 0.028$). Furthermore, school phobia ($p = 0.005$) and panic disorder scores ($p = 0.003$) were significantly lower in the home care group compared to the routine care group.

Both groups showed a significant reduction in total SCARED scores after the intervention ($p < 0.001$). Notably, the home care group had significantly lower total SCARED scores compared to the routine care group ($p < 0.001$), indicating an overall reduction in anxiety symptoms. These findings indicate that FCCC was effective in alleviating anxiety symptoms in children with leukemia.

Quality of Life

Before receiving care, there was no significant difference in general fatigue scores between the routine care and home care groups ($p = 0.647$) (Table 5). Similarly, sleep-related fatigue ($p = 0.973$) and cognitive fatigue scores ($p = 0.749$) showed no significant differences between the groups. Additionally, the total fatigue scores between the routine care and home care groups were comparable ($p = 0.657$), suggesting similar levels of fatigue between the groups before the intervention.

Following care, the home care group exhibited significantly lower general fatigue scores compared to the routine care group ($p = 0.011$). Sleep-related fatigue

Table 4. Comparison of anxiety scores in children with leukemia before and after nursing care.

Parameter	Routine care group (n = 135)	Home care group (n = 108)	t-value	p-value
Pre-separation anxiety	5.69 ± 1.13	5.88 ± 1.78	0.974	0.331
Post-separation anxiety	5.33 ± 1.54	4.82 ± 1.37	2.652	0.009
Pre-social phobia	5.71 ± 1.56	5.57 ± 1.62	0.697	0.486
Post-social phobia	5.41 ± 1.78	4.82 ± 1.45	2.828	0.005
Pre-extensive anxiety	5.98 ± 1.59	5.77 ± 1.69	1.026	0.306
Post-extensive anxiety	5.64 ± 1.21	5.23 ± 1.56	2.219	0.028
Pre-school phobia	3.12 ± 1.66	3.06 ± 1.11	0.378	0.706
Post-school phobia	2.98 ± 0.86	2.68 ± 0.78	2.864	0.005
Pre-panic disorder	5.76 ± 1.78	6.05 ± 1.56	1.365	0.174
Post-panic disorder	4.66 ± 1.25	4.12 ± 1.49	3.009	0.003
Pre-total score	26.26 ± 3.32	26.33 ± 3.76	0.147	0.883
Post-total score	24.01 ± 2.86	21.67 ± 3.25	5.964	<0.001
Within-group t-value	5.966	9.744		
Within-group p-value	<0.001	<0.001		

scores were also significantly reduced in the home care group than in the routine care group ($p = 0.033$), as were cognitive fatigue scores ($p = 0.014$). Total fatigue scores were significantly lower in the home care group compared to the routine care group after care ($p = 0.017$). While the routine care group did not show a statistically significant change in total fatigue scores after care ($p = 0.081$), the home care group exhibited a highly significant reduction in total fatigue scores ($p < 0.001$). These findings highlight the effectiveness of FCCC in improving various dimensions of fatigue and overall quality of life in children undergoing leukemia treatment.

Post-Caring Condition

In terms of significant improvement, 52 children in the routine care group and 45 in the home care group experienced this outcome, with no statistically significant difference between groups ($p = 0.619$) (Table 6). Mild improvement was observed in 55 children from the routine care group and 48 from the home care group ($p = 0.562$). The number of children showing no improvement was 28 in the routine care group compared to 15 in the home care group, a difference that did not reach statistical significance ($p = 0.164$). Overall, post-caring clinical outcomes were comparable between the two groups, suggesting similar levels of physical recovery in the observed period.

Discussion

The present study explores the significant impact of FCCC on the psychological well-being, self-esteem, and quality of life of children diagnosed with leukemia. The observed improvements in self-management and emotional functioning in the home care group may primarily be attributed to the active involvement of family

Table 5. Pediatric quality of life Inventory Multidimensional Fatigue Scale (PedsQL MFS) scores before and after nursing care.

Parameter	Routine care group (n = 135)	Home care group (n = 108)	*t*-value	*p*-value
Pre-general fatigue	70.28 ± 9.72	69.74 ± 8.35	0.458	0.647
Post-general fatigue	72.28 ± 8.39	75.03 ± 8.15	2.575	0.011
Pre-sleep-related fatigue	61.13 ± 8.34	61.09 ± 7.96	0.034	0.973
Post-sleep-related fatigue	63.86 ± 7.74	65.97 ± 7.49	2.143	0.033
Pre-cognitive fatigue	64.17 ± 8.91	63.81 ± 8.72	0.320	0.749
Post-cognitive fatigue	65.46 ± 7.96	67.98 ± 7.84	2.472	0.014
Pre-total score	65.38 ± 9.01	64.88 ± 8.35	0.444	0.657
Post-total score	67.20 ± 8.03	69.66 ± 7.83	2.397	0.017
Within-group *t*-value	1.752	4.340		
Within-group *p*-value	0.081	<0.001		

Table 6. Clinical condition following nursing care.

Parameter	Routine care group (n = 135)	Home care group (n = 108)	χ^2	*p*-value
Significant improvement	52 (38.52%)	45 (41.67%)	0.248	0.619
Mild improvement	55 (40.74%)	48 (44.44%)	0.337	0.562
No improvement	28 (20.74%)	15 (13.89%)	1.934	0.164

members in the care process (Nelson et al, 2024). By tailoring health education to match the cognitive level of each child and equipping families with appropriate skill training, these young patients likely developed a sense of empowerment and control over their health circumstances, contributing to improved self-management outcomes (BeLue et al, 2024; Ramachandran et al, 2023). This level of active engagement may have reduced feelings of helplessness, thereby substantially enhancing emotional functioning (Franck et al, 2023). Moreover, the consistent support and presence of family members likely created a stable and comforting environment, offering the child emotional security and resilience throughout the treatment process (Abukari et al, 2022).

On a psychological level, the improvement in mental health and reduction in depressive symptoms observed in the home care group can be viewed through the lens of social support theory (Vakil et al, 2023). This theory posits that the presence of a supportive social network serves as a crucial buffer against stress and contributes positively to overall mental health outcomes (Kim et al, 2023). The active participation of family members in daily care and medical decision-making likely provided a robust emotional support system, helping to alleviate the feelings of fear and isolation often experienced by children with chronic illnesses (Gómez-Cantarino et al, 2020). Furthermore, family involvement may encourage open communication, allowing children to express their thoughts and emotions more freely, thus reducing anxiety and depressive symptoms (Resnick et al, 2023).

The observed improvements in physical and social functioning may be closely linked to the continuous care and tailored health education provided by family members, which likely contributed to a more stable and nurturing home environment. As family members become proficient in managing medications, addressing nutritional needs, and providing daily care, children may experience fewer disruptions to their physical health, potentially resulting in improved physical functioning (Franck et al, 2020). Additionally, by facilitating effective social interactions and preventing isolation, families may promote healthier social functioning (Yi et al, 2022). These findings align with existing evidence suggesting that patients recovering in familiar environments, supported by loved ones, exhibit faster recovery rates and demonstrate improved functional outcomes.

Self-esteem scores significantly improved in children receiving family-centred care, which may be attributed to the empowerment and autonomy encouraged by such care models. When family members actively participate in care and tailor their approaches to the child's developmental level, they help foster a sense of competence and self-worth (Yi et al, 2022). This type of familial involvement may also reassure the child of their importance and value within the family unit, thereby enhancing overall self-esteem (Lewis et al, 2022). Furthermore, as children participate more in self-care and healthcare-related decision-making, they may gain confidence in their abilities, thereby improving their self-perception and esteem.

While significant improvements in quality of life and psychological well-being were evident, the reduced levels of fatigue among children in the home care group could be a result of personalised and attentive care strategies that ensure sufficient rest and recuperation (Lewis et al, 2022). Family members, attuned to the individual needs and behavioural cues of the child, can structure daily routines to optimise rest periods and reduce physical exertion, accounting for the noted differences in fatigue levels (Zatzick et al, 2021). This personalised approach to care, balancing activity with rest, likely contributes to improved energy levels and cognitive alertness among children. Our findings also highlight that, despite the benefits of family-centred care, not all outcome dimensions showed significant differences between the care models. This suggests that underlying clinical factors, such as leukemia severity or the presence of coexisting medical complications, may exert a significant influence, potentially overshadowing the observable benefits of specific care models (Yu et al, 2024). It is plausible that certain clinical conditions require more intensive medical interventions beyond the scope of family-centred care, thereby limiting its impact on some post-care outcomes.

Moreover, the absence of significant differences in post-caring conditions between the groups suggests that, although psychological and quality of life indicators improved, clinical outcomes were largely determined by the underlying nature of leukemia. This underscores the importance of integrating high-quality clinical care with family-centred approaches to achieve optimal health outcomes for pediatric leukemia patients. It should be acknowledged that the involvement of skilled clinical practitioners may inherently standardise certain aspects of care delivery across both groups, thereby influencing clinical outcomes.

Our findings highlight the sustained value of involving family members in pediatric care settings, particularly for chronic and life-threatening conditions like leukemia. This participatory approach not only augments the psychological resilience and self-management skills of pediatric patients but also enriches the care experience with empathy, understanding, and personalised support, elements that medical professionals alone may not fully deliver (Zatzick et al, 2021). The observed disparities in anxiety and depression outcomes further support the argument for family involvement, indicating that emotional and psychological improvements are driven by consistent engagement and reinforcement from family caregivers.

These results also underscore a critical call to action for healthcare systems to formally acknowledge and integrate families into the continuum of care, equipping them with the appropriate training, resources, and support to perform this role effectively. Awareness campaigns, structured family involvement programs, and collaborative decision-making initiatives may serve as powerful tools for reshaping pediatric care practices (Lewis et al, 2022). However, future research is essential to determine the most effective strategies to balance medical and family-centred care, ensuring that holistic and comprehensive care pathways are crafted for children diagnosed with leukemia.

While this study offers valuable insights into the benefits of FCCC for pediatric leukemia patients, several limitations must be acknowledged. First, the sample size may not represent the broader pediatric leukemia population, potentially limiting the generalizability of the findings. Additionally, the study utilised self-reported measures for psychological well-being and quality of life assessments, which may introduce bias or inaccuracy due to the subjective nature of these assessments. The lack of long-term follow-up data further limits our understanding of the sustained impact of family-centred care practices. Furthermore, variations in family dynamics and support systems were not extensively controlled, which could have influenced the outcomes. Future research should address these limitations by incorporating larger and more diverse populations, employing objective assessment tools, and examining long-term impacts to validate and extend these findings.

Conclusion

In conclusion, the integration of FCCC represents a promising approach to significantly improve the psychological and emotional well-being and overall quality of life of children with leukemia. This aligns with contemporary shifts towards more personalised and empathetic care practices. Empowering family members to serve as active participants in the care process may foster improved health outcomes, instilling resilience and confidence in pediatric patients as they navigate the complexities of their treatment journey. Future advancements in care strategies should account for diverse family dynamics and clinical realities to tailor interventions that optimally support the psychological and physical recovery of each child.

Key Points

- Family-centred care improves self-management and emotional functioning by instilling a sense of empowerment and control over the child's medical experience.
- Family involvement reduces stress and depressive symptoms through consistent emotional support and open communication, serving as a protective buffer against psychological distress.
- Tailored health education and continuous care by family members improve physical and social functioning, reducing disruptions in daily activities and promoting healthier interactions.
- Active family participation boosts self-esteem in children by fostering a sense of competence and self-worth, appropriately adapted to developmental stages.
- Personalised caregiving by family members reduces fatigue levels by optimising rest and minimising physical strain, contributing to improved energy and cognitive performance.
- While family-centred care offers substantial benefits, clinical outcomes remain influenced by the severity of leukemia, highlighting the need to integrate specialised clinical care with family-centred support approaches.

Availability of Data and Materials

All data included in this study are available from the corresponding authors upon reasonable request.

Author Contributions

YHZ, YS, QZ, FW, YWW, CFZ, YQD and DX designed the research study. YHZ, YS, QZ, FW, YWW, CFZ, YQD and DX performed the research. YHZ and DX analysed the data. YHZ drafted the manuscript. All authors contributed to the important editorial changes in the manuscript. All authors read and approved the final manuscript. All authors have participated sufficiently in the work and agreed to be accountable for all aspects of the work.

Ethics Approval and Consent to Participate

This study was approved by the Ethics Committee of the Fourth Hospital of Hebei Medical University (NO. 2025KS036). Given that this retrospective study utilised de-identified patient data without any risk or impact on patient care, informed consent was waived by the Fourth Hospital of Hebei Medical University in accordance with the relevant regulations and ethical guidelines, particularly in compliance with the Declaration of Helsinki.

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Conflict of Interest

The authors declare no conflict of interest.

References

Abukari AS, Acheampong AK, Aziato L. Experiences and contextual practices of family-centered care in Ghanaian nicus: a qualitative study of families and clinicians. BMC Health Services Research. 2022; 22: 1051. https://doi.org/10.1186/s12913-022-08425-0

Altman MR, Afulani PA, Melbourne D, Kuppermann M. Factors associated with person-centered care during pregnancy and birth for Black women and birthing people in California. Birth. 2023; 50: 329–338. https://doi.org/10.1111/birt.12675

BeLue R, Kuzmik A, Dix M, Luckett C, Paudel A, Resnick B, et al. An exploration of the cultural appropriateness of the family-centered function-focused care intervention. Dementia (London). 2024; 23: 7–22. https://doi.org/10.1177/14713012231206288

Birleson P, Hudson I, Buchanan DG, Wolff S. Clinical evaluation of a self-rating scale for depressive disorder in childhood (Depression Self-Rating Scale). Journal of Child Psychology and Psychiatry, and Allied Disciplines. 1987; 28: 43–60. https://doi.org/10.1111/j.1469-7610.1987.tb00651.x

Birmaher B, Khetarpal S, Brent D, Cully M, Balach L, Kaufman J, et al. The Screen for Child Anxiety Related Emotional Disorders (SCARED): scale construction and psychometric characteristics. Journal of the American Academy of Child and Adolescent Psychiatry. 1997; 36: 545–553. https://doi.org/10.1097/00004583-199704000-00018

Franck LS, Gay CL, Hoffmann TJ, Kriz RM, Bisgaard R, Cormier DM, et al. Maternal mental health after infant discharge: a quasi-experimental clinical trial of family integrated care versus family-centered care for preterm infants in U.S. NICUs. BMC Pediatrics. 2023; 23: 396. https://doi.org/10.1186/s12887-023-04211-x

Franck LS, Waddington C, O’Brien K. Family Integrated Care for Preterm Infants. Critical Care Nursing Clinics of North America. 2020; 32: 149–165. https://doi.org/10.1016/j.cnc.2020.01.001

Gómez-Cantarino S, García-Valdivieso I, Moncunill-Martínez E, Yáñez-Araque B, Ugarte Gurrutxaga MI. Developing a Family-Centered Care Model in the Neonatal Intensive Care Unit (NICU): A New Vision to Manage Healthcare. International Journal of Environmental Research and Public Health. 2020; 17: 7197. https://doi.org/10.3390/ijerph17197197

Hao X, Wang D, Xiao X. Influence of Family-centered Health Intervention on Perioperative Mental Health of Patients Receiving Coronary Interventional Therapy. Alternative Therapies in Health and Medicine. 2023; 29: 401–405

Jabbour E, Kantarjian HM, Aldoss I, Montesinos P, Leonard JT, Gómez-Almaguer D, et al. Ponatinib vs Imatinib in Frontline Philadelphia Chromosome-Positive Acute Lymphoblastic Leukemia: A Randomized Clinical Trial. JAMA. 2024; 331: 1814–1823. https://doi.org/10.1001/jama.2024.4783

Jen WY, Jabbour E, Short NJ, Issa GC, Haddad FG, Jain N, et al. A phase 2 trial of mini-hyper-CVD, blinatumomab, and ponatinib in Philadelphia positive acute lymphoblastic leukemia. American Journal of Hematology. 2024; 99: 2229–2232. https://doi.org/10.1002/ajh.27463

Johanna Josepha Op't Hoog SA, Eskes AM, Johanna van Mersbergen-de Bruin MP, Pelgrim T, van der Hoeven H, Vermeulen H, et al. The effects of intensive care unit-initiated transitional care interventions on elements of post-intensive care syndrome: A systematic review and meta-analysis. Australian Critical Care. 2022; 35: 309–320. https://doi.org/10.1016/j.aucc.2021.04.010

Kavand B, Asgari P. An investigation of the effect of the universal model of family-centered care on patient and family outcomes in patients under home invasive mechanical ventilation. Family Practice. 2024; 41: 807–816. https://doi.org/10.1093/fampra/cmae027

Kim YJ, Lee G, Choi S. Validation of the Korean Version of Patient-Centered Care Tool: For Outpatients. Patient Preference and Adherence. 2023; 17: 1525–1540. https://doi.org/10.2147/PPA.S411109

Lamba JK, Marrero R, Wu H, Cao X, Parcha PK, Karol SE, et al. Pharmacogenomics, Race, and Treatment Outcome in Pediatric Acute Myeloid Leukemia. JAMA Network Open. 2024; 7: e2411726. https://doi.org/10.1001/jamanetworkopen.2024.11726

Lewis H, Trowbridge A, Jonas D, Rosenberg AR, Bogetz JF. A Qualitative Study of Clinicians and Parents of Children with Severe Neurological Impairment on Tools to Support Family-Centered Care. Journal of Palliative Medicine. 2022; 25: 1338–1344. https://doi.org/10.1089/jpm.2021.0579

Lisanti AJ, Min J, Golfenshtein N, Marino BS, Curley MAQ, Medoff-Cooper B. Perceived family-centered care and post-traumatic stress in parents of infants cared for in the paediatric cardiac intensive care unit. Nursing in Critical Care. 2024; 29: 1059–1066. https://doi.org/10.1111/nicc.13094

Machut KZ, Gilbart C, Murthy K, Michelson KN. Parental Perspectives on Neonatologist Continuity of Care. Advances in Neonatal Care. 2021; 21: E162–E170. https://doi.org/10.1097/ANC.0000000000000895

Myers RM, Balsamo L, Lu X, Devidas M, Hunger SP, Carroll WL, et al. A prospective study of anxiety, depression, and behavioral changes in the first year after a diagnosis of childhood acute lymphoblastic leukemia: a report from the Children's Oncology Group. Cancer. 2014; 120: 1417–1425. https://doi.org/10.1002/cncr.28578

Nelson MLA, MacEachern E, Prvu Bettger J, Camicia M, García JJ, Kapral MK, et al. Exploring the Inclusion of Person-Centered Care Domains in Stroke Transitions of Care Interventions: A Scientific Statement From the American Heart Association. Stroke. 2024; 55: e169–e181. https://doi.org/10.1161/STR.0000000000000462

Park HS, Kim HK, Kim HS, Yang Y, Han HS, Lee KH, et al. The new diagnostic criteria for myelodysplasia-related acute myeloid leukemia is useful for predicting clinical outcome: comparison of the 4th and 5th World Health Organization classifications. Annals of Hematology. 2022; 101: 2645–2654. https://doi.org/10.1007/s00277-022-05002-7

Pratz KW, Jonas BA, Pullarkat V, Thirman MJ, Garcia JS, Döhner H, et al. Long-term follow-up of VIALE-A: Venetoclax and azacitidine in chemotherapy-ineligible untreated acute myeloid leukemia. American Journal of Hematology. 2024; 99: 615–624. https://doi.org/10.1002/ajh.27246

Ramachandran M, Bangera K, Anita Dsouza S, Belchior P. A scoping review of family-centered interventions in dementia care. Dementia (London). 2023; 22: 405–438. https://doi.org/10.1177/14713012221144485

Resnick B, Kuzmik A, Best I, Jones JR, Hermann RM, Boltz M. Treatment Fidelity of the Family-Centered Function-Focused Care Intervention. Research in Gerontological Nursing. 2023; 16: 165–171. https://doi.org/10.3928/19404921-20230606-01

Ronis SD, Westphaln KK, Kleinman LC, Zyzanski SJ, Stange KC. Performance of the Person Centered Primary Care Measure in Pediatric Continuity Clinic. Academic Pediatrics. 2021; 21: 1077–1083. https://doi.org/10.1016/j.acap.2020.12.006

Shah B, Mattison RJ, Abboud R, Abdelmessieh P, Aldoss I, Burke PW, et al. Acute Lymphoblastic Leukemia, Version 2.2024, NCCN Clinical Practice Guidelines in Oncology. Journal of the National Comprehensive Cancer Network. 2024; 22: 563–576. https://doi.org/10.6004/jnccn.2024.0051

Tan X, Su X. Continuity of Nursing Service Platform under "Smart Elderly Care" and Its Application Value in Family Nursing of Elderly Patients after Discharge. Alternative Therapies in Health and Medicine. 2024; AT10193. (online ahead of print)

Usuki K, Miyamoto T, Yamauchi T, Ando K, Ogawa Y, Onozawa M, et al. A phase 1/2 study of NS-87/CPX-351 (cytarabine and daunorubicin liposome) in Japanese patients with high-risk acute myeloid leukemia.

International Journal of Hematology. 2024; 119: 647–659. https://doi.org/10.1007/s12185-024-03733-z

Vakil K, Desse TA, Manias E, Alzubaidi H, Rasmussen B, Holton S, et al. Patient-Centered Care Experiences of First-Generation, South Asian Migrants with Chronic Diseases Living in High-Income, Western Countries: Systematic Review. Patient Preference and Adherence. 2023; 17: 281–298. https://doi.org/10.2147/PPA.S391340

Varni JW, Burwinkle TM, Katz ER, Meeske K, Dickinson P. The PedsQL in pediatric cancer: reliability and validity of the Pediatric Quality of Life Inventory Generic Core Scales, Multidimensional Fatigue Scale, and Cancer Module. Cancer. 2002; 94: 2090–2106. https://doi.org/10.1002/cncr.10428

Ventres WB, Stone LA, Joslin TA, Saultz JW, Aldulaimi S, Gordon PR, et al. Storylines of family medicine III: core principles-primary care, systems and family. Family Medicine and Community Health. 2024; 12: e002790. https://doi.org/10.1136/fmch-2024-002790

Wood C, Griffin M, Barton J, Sandercock G. Modification of the Rosenberg Scale to Assess Self-Esteem in Children. Frontiers in Public Health. 2021; 9: 655892. https://doi.org/10.3389/fpubh.2021.655892

Yang L, Wang Y, Fang Y, Lin C, Hu X. Clinical Efficacy of a Family-Centered Nursing Model on Emotional Behavior and Quality of Life in Children With Acute Otitis Media. Quality Management in Health Care. 2025. https://doi.org/10.1097/QMH.0000000000000511 (online ahead of print)

Yi YZ, Su T, Jia YZ, Xue Y, Chen YZ, Zhang QS, et al. Family-centered care management strategies for term and near-term neonates with brief hospitalization in a level III NICU in Shenzhen, China during the time of COVID-19 pandemic. The Journal of Maternal-Fetal & Neonatal Medicine. 2022; 35: 5923–5926. https://doi.org/10.1080/14767058.2021.1902499

Yu S, Zhang Y, Yu G, Wang Y, Shao R, Du X, et al. Sorafenib plus triplet therapy with venetoclax, azacitidine and homoharringtonine for refractory/relapsed acute myeloid leukemia with FLT3-ITD: A multicenter phase 2 study. Journal of Internal Medicine. 2024; 295: 216–228. https://doi.org/10.1111/joim.13738

Yusuf A, Purba JM, Putri DE, Aditya RS, Alruwaili AS, AlRazeeni DM. Family-Centered Care Experiences in Elderly with Chronic Diseases in Communities: Qualitative Study of Patients, Families, Nurses, and Volunteers. Health Equity. 2024; 8: 338–350. https://doi.org/10.1089/heq.2024.0009

Zatzick D, Moloney K, Palinkas L, Thomas P, Anderson K, Whiteside L, et al. Catalyzing the Translation of Patient-Centered Research Into United States Trauma Care Systems: A Case Example. Medical Care. 2021; 59: S379–S386. https://doi.org/10.1097/MLR.0000000000001564

Zhu Y, Huang J, Wang Y, Han Y, Xue S, Yang Y, et al. Olverembatinib treatment in adult patients with newly diagnosed Philadelphia chromosome-positive acute lymphoblastic leukemia. Annals of Hematology. 2024; 103: 4643–4648. https://doi.org/10.1007/s00277-024-06027-w