Salud, Ciencia y Tecnología. 2025; 5:1807
doi: 10.56294/saludcyt20251807

ORIGINAL

Psychological Aspect and Parental Experiences in Managing Fluid Adherence among Children Undergoing Haemodialysis

Aspecto Psicológico y Experiencias de los Padres en la Gestión de la Adherencia a los Líquidos entre los Niños Sometidos a Hemodiálisis

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Cite as: Arnis A, Rustina Y, Allenidekania A, Darari F. Psychological Aspect and Parental Experiences in Managing Fluid Adherence among Children Undergoing Haemodialysis. Salud, Ciencia y Tecnología. 2025; 5:1807. https://doi.org/10.56294/saludcyt20251807

Submitted: 05-01-2025 **Revised:** 27-03-2025 **Accepted:** 24-06-2025 **Published:** 25-06-2025

Editor: Prof. Dr. William Castillo-González

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ABSTRACT

Introduction: children undergoing haemodialysis often face psychological fatigue due to strict fluid and dietary restrictions. These limitations can significantly affect their emotional well-being and quality of life, while also placing a heavy burden on parents who must ensure adherence at home. However, limited attention has been given to the lived experiences behind these challenges, particularly from both the child's and caregiver's perspectives.
Objective: this study explores the psychological experiences of children with chronic kidney disease (CKD) undergoing haemodialysis, alongside parental emotional challenges faced by parents in maintaining fluid adherence at home.
Method: a qualitative descriptive design with a phenomenological approach was applied. Twelve parents of children aged 8-18 years receiving regular haemodialysis were selected using purposive sampling for in-depth interviews. Data were thematically analysed using Clarke and Braun's six-phase framework.
Results: three major themes emerged: (1) children's emotional exhaustion due to fluid restrictions, (2) parental emotional strain in maintaining adherence, and (3) the necessity for sustained psychosocial support and structured education.
Conclusion: these findings underscore the importance of a holistic care model that integrates medical, psychological, and educational components. Digital interventions, such as Remote Patient Monitoring (RPM) systems equipped with chatbot features, may bridge existing care gaps. Future research should prioritise the development and evaluation of such technology-driven supports to enhance family-centred care in paediatric nephrology.

Keywords: Caregivers; Child; Patient Compliance; Psychological; Remote Consultation; Renal Dialysis.

RESUMEN

Introducción: los niños sometidos a hemodiálisis suelen sufrir fatiga psicológica debido a las estrictas restricciones de líquidos y dieta. Estas limitaciones pueden afectar significativamente a su bienestar emocional y a su calidad de vida, al tiempo que suponen una pesada carga para los padres, que deben garantizar el cumplimiento en casa. Sin embargo, se ha prestado poca atención a las experiencias vividas que subyacen a estos retos, en particular desde la perspectiva tanto del niño como del cuidador.
Objetivo: este estudio explora las experiencias psicológicas de los niños con enfermedad renal crónica (ERC) sometidos a hemodiálisis, junto con los retos emocionales a los que se enfrentan los padres para mantener

la adherencia a los líquidos en casa.
Método: se aplicó un diseño cualitativo descriptivo con un enfoque fenomenológico. Se seleccionaron doce padres de niños de entre 8 y 18 años que recibían hemodiálisis periódica mediante un muestreo intencional para realizar entrevistas en profundidad. Los datos se analizaron temáticamente utilizando el marco de seis fases de Clarke y Braun.
Resultados: surgieron tres temas principales: (1) el agotamiento emocional de los niños debido a las restricciones de fluidos, (2) la tensión emocional de los padres para mantener la adherencia, y (3) la necesidad de apoyo psicosocial sostenido y educación estructurada.
Conclusiones: estos hallazgos subrayan la importancia de un modelo de atención holística que integre componentes médicos, psicológicos y educativos. Las intervenciones digitales, como los sistemas de monitorización remota de pacientes (RPM) equipados con funciones de chatbot, pueden colmar las lagunas existentes en la atención. La investigación futura debe priorizar el desarrollo y la evaluación de tales apoyos impulsados por la tecnología para mejorar la atención centrada en la familia en nefrología pediátrica.

Palabras clave: Cuidadores; Niño; Cumplimiento del Paciente; Psicológico; Consulta a Distancia; Diálisis Renal.

INTRODUCTION

Children undergoing haemodialysis often face profound emotional fatigue stemming from rigid medical regimens, particularly fluid restrictions that conflict with basic need like thirst. Many respond with frustration, while others withdraw emotionally as a coping mechanism. Parallel to this, parents navigate a dual burden: enforcing medical adherence while witnessing their child's psychological struggle—an emotionally dissonant experience that characterizes daily life in paediatric haemodialysis care.(1, 2)

Psychological distress in children with chronic kidney disease (CKD) on dialysis is well-documented, including symptoms of anxiety, depression, and social isolation.(3-5) The emotional toll of these restrictions is shared by parents, particularly mothers, who describe their caregiving role as psychologically overwhelming, compounded by a lack of formal support systems.(6, 7) In Indonesia, these challenges are intensified by limited access to paediatric nephrology services and delayed diagnosis,(8, 9) while current healthcare models continue to prioritise physical outcomes over psychosocial needs.(10, 11)

Emerging evidence support a shift towards biopsychosocial care models that integrate digital health technologies, such as Remote Patient Monitoring (RPM) and chatbot-based support, to extend psychosocial interventions into the home environment.(12, 13) These tools, when designed with empathy and family-centred principles, may offer practical support for emotional and behavioural challenges beyond the hospital setting.(13)

This study aims to explore the psychological experiences of children undergoing haemodialysis—particularly around fluid restriction—and the emotional tensions faced by their parents. By amplifying these lived experiences, the research seeks to inform future psychosocial interventions that are both culturally relevant and technologically supported.

METHOD

This qualitative descriptive study employed a phenomenological approach to explore the emotional experiences of children undergoing haemodialysis and the challenges faced by their parents in maintaining fluid restriction adherence.

Participants and Recruitment

Twelve mothers of children with CKD receiving haemodialysis were purposively selected with support from the Indonesia Paediatric Kidney Foundation (YAGIN). Children ranged in age from 10 to 16 years and had been on haemodialysis for 3 months to 4,5 years. Inclusion criteria included being the primary caregiver of a child aged 8-18 receiving haemodialysis for at least three months. Informed consent was obtained prior to participation.

Data Collection

In-depth, semi structured interviews were conducted in two sessions per participant, in locations preferred by the family (e.g., home, hospital waiting rooms). Interviews lasted 30-45 minutes and explored emotional responses to fluid restriction, parental coping strategies, and daily caregiving tensions. Data collection continued until thematic saturation was reached.

Sample guiding questions included: "How does your child respond to thirst when restricted from drinking?" and "How do you help your child comply with fluid limits?". Seven children were also interviewed, depending on their ability and willingness, to triangulate parental accounts. Reasons for exclusion included hearing impairment, communication difficulty, or discomfort with recording.

Data Analysis

All interviews were transcribed verbatim and analysed thematically following Braun and Clarke's six-step framework.(14) Manual coding supported in-depth engagement with the data. Coding and thematic development were discussed within the research team to ensure credibility and reduce bias. Child interviews served to complement rather than validate parental narratives.

RESULTS

This study involved twelve mothers who served as primary caregivers to children aged 10 to 16 years undergoing chronic haemodialysis (HD) for periods ranging from three months to four years and five months. Through in-depth interviews and thematic analysis, three principal themes emerged: (1) psychological fatigue in children related to fluid and dietary restrictions, (2) emotional tension experienced by parents in enforcing adherence, and (3) the need for sustained psychosocial support and education.

Theme 1: Children's Psychological Fatigue from Fluid and Dietary Restrictions

Children undergoing HD often experience emotional and psychological strain due to persistent limitations in fluid and food intake. These restrictions—necessary to prevent fluid overload and manage electrolyte balance—lead to frustration, sadness, and a sense of deprivation, particularly when they are unable to satisfy basic needs like thirst.

Several mothers described their children's emotional responses to these constraints. A common coping mechanism, such as sucking ice cubes, was often inadequate in alleviating thirst, leading to behavioural changes such as irritability or emotional withdrawal:

"When she's very thirsty, we just buy ice cubes. The doctor said if she's thirsty, just suck on ice cubes, but not too much." (P5)

Beyond thirst, restricted intake also caused physical discomfort, such as constipation, which further intensified the children's emotional burden:

"She has difficulty having bowel movements…it's common among children on haemodialysis because their fluid intake is restricted" (P2)

Food monotony also led to psychological resistance. Children disliked the lack of salt or flavor in their meals, and some expressed anger or refused to eat. Other covertly consumed restricted items, indicating both emotional fatigue and defiance:

"Just the other day, he drank one of those bottled coffee drinks…then he started coughing…eventually, he confessed." (P12)

This theme illustrates how the burden of constant dietary and fluid regulation compromises children's emotional well-being. Their resistance is not merely behavioural noncompliance but reflects deeper psychological exhaustion. These findings underscore the need for psychological interventions that support emotional resilience, coping strategies, and adherence to complex regimens.

Theme 2: Parents' Emotional Tension in Maintaining Adherence

Parents articulated considerable emotional distress as they navigated the responsibility of enforcing medical restrictions while witnessing their child's suffering. Denying water or snacks—actions that contradict their instincts as caregivers—led to inner conflict:

"It feels like whatever we do is wrong—giving in is wrong, but saying no is also wrong." (P4)

Many parents reported actively trying to uplift their children during HD sessions, using encouraging language to reduce anxiety and physical discomfort:

"We just try to cheer her up—like, it's almost done, just ten more minutes…" (P2)

Outside the hospital, managing adherence was more challenging. Parents could not always monitor their child's behaviour, especially at school or with peers. Several participants expressed concerns over secretive drinking or a lack of self-control:

“At school, he manages his thirst by sucking on ice cubes.” (P10)
“Kids sneak drinks whenever they can. That’s what they do at home.” (P4)

Participants acknowledged that their children’s cognitive and emotional development influenced adherence. Many children lacked the maturity to fully grasp the long-term consequences of dietary or fluid excess:

“It’s human nature, right? And kids aren’t like adults who can fully understand things.” (P4)

This theme highlights how parental roles oscillate between being disciplinarians and emotional anchors. The emotional load associated with this duality calls for caregiver-specific interventions, including emotional support, peer group discussions, and skill-building to help manage adherence in home and community settings.

Theme 3: Psychosocial and Educational Support Needs

Beyond the clinical and emotional daily struggles, caregivers emphasized a strong need for comprehensive psychosocial support and continuous education to empower both themselves and their children.

Mothers often relied on emotional presence to help their children manage nighttime anxiety, panic, or feelings of despair:

“Early this morning, around 2 a.m., she couldn’t sleep…I told her, ‘Be patient, dear. Today is your dialysis day.’” (P2)

Parents also utilized spiritual narratives to instill hope and meaning in the treatment experience:

“Stay strong and keep your spirit to get better…This is all part of God’s plan.” (P2)

In addition to emotional reassurance, caregivers valued technical knowledge regarding medical procedures, particularly in managing vascular access (e.g., Cimino fistulas) and symptoms at home:

“Now that her Cimino fistula is being used...the nurse said, ‘Mama, if it swells, apply a warm compress.’” (P2)

Participants relied on digital tools like WhatsApp to communicate with healthcare professionals during urgent situations:

“If the child has symptoms like a fever…I call the doctor, and the doctor immediately told me to go to the emergency room.” (P10)

Dietary guidance provided by nutritionists was also crucial. Participants expressed gratitude for tailored meal plans that supported high-protein, low salt diets:

“We’ve been taught how to prepare a healthy meal to support a high-protein diet.” (P10)

Children’s gradual acceptance of their condition was seen as a key milestone. While initial resistance to treatment was common, emotional support and education facilitated compliance over time:

“At first, she refused to go through with dialysis…but now, she has accepted that she needs dialysis.” (P3)

This theme underlines the importance of holistic and family-centred approaches in paediatric haemodialysis care. Interventions should integrate emotional counselling, education, and digital communication strategies to enhance both child and caregiver coping capacities.

DISCUSSIONS

This qualitative study explored the emotional and psychological burden experienced by children undergoing haemodialysis and the caregiving challenges faced by their parents. Unlike studies focused primarily on clinical outcomes, our research foregrounds the lived experiences of families navigating home-based care. It adds to the growing understanding of the psychosocial dimensions of paediatric haemodialysis and underscores the need for a more holistic, family-centred care model.

Three central themes emerged: (1) children's emotional fatigue related to fluid restrictions, (2) emotional tension among parents in enforcing adherence, and (3) the lack of sustained psychosocial and educational support. Together, these findings suggest that current healthcare approaches—rooted largely in biomedical routines—are insufficient to address the multifaceted needs of families affected by paediatric chronic kidney disease.

The first theme, psychological fatigue in children, reflects their emotional struggle with constant fluid and dietary restrictions. Children expressed distress when unable to satisfy basic physiological needs like thirst, compounded by discomforts such as constipation and appetite loss. Social context—such as shared meals or school environments—intensified this burden, reinforcing their sense of isolation. Moreover, fluid restrictions interfered with medical intake, further complicating treatment adherence.(15) These findings are consistent with previous studies highlighting heightened psychological distress in paediatric haemodialysis patients compared to other chronic conditions, including thalassemia,(2) often resulting in treatment fatigue and diminished motivation.

The second theme concerns the emotional strain experienced by parents who must act as both caregivers and enforcers of medical guidelines. Participants described internal conflicts, especially when denying their children's natural urges for water or food. This emotional tension—between compassion and compliance—led to persistent stress and feeling of helplessness. Our findings echo earlier studies in which caregivers, particularly mothers, reported disrupted sleep, emotional exhaustion, and a lack of support systems.(16, 17) Prolonged caregiving without respite has been linked to poorer quality of life and increased psychological distress among parents of children with chronic illnesses.(18, 19) These observations suggest the need for psychosocial interventions that support caregivers as much as patients.

The third theme highlights a significant gap in continuous psychosocial and educational support. Parents described feeling isolated in managing their child's condition, especially when healthcare provider interactions were brief and medically focused. They expressed a desire for more accessible, empathetic communication and structured guidance to build both their children's emotional resilience and their own caregiving competence. These findings are consistent with literature identifying unmet psychosocial needs in families coping with CKD.(11,20) Additionally, barriers such as fragmented service delivery, unclear diagnoses, and limited peer support hindered adaptation, particularly in the early stages of the disease.(21, 22)

These findings call for a comprehensive care approach that integrates emotional, social, and educational dimensions alongside clinical management. Digital health innovations offer a promising pathway to bridge these gaps. Several participants described relying on informal channels, such as WhatsApp, to seek clarification or emotional reassurance—revealing a broader unmet need for structured, home-accessible support tools.

To address this need, the study proposes a conceptual model for a chatbot-based Remote Patient Monitoring (RPM) system tailored to paediatric haemodialysis. This idea emerged directly from participants' insights and caregiving experiences. The envisioned tool could deliver timely reminders, provide dietary and fluid intake guidance, and offer psychological support during daily caregiving routines. It is important to note, however, that this proposal remains conceptual and has not undergone usability testing or clinical implementation. Further research will be essential to co-design, pilot, and evaluate such interventions in collaboration with children, parents, and clinicians.

The potential of RPM tools and AI-powered chatbot are supported by existing evidence, showing improvements in patient engagement, data sharing, and care coordination.(23, 24) In paediatric chronic care, such technologies have been shown to enhance emotional support and behavioural self-regulation. While earlier challenges such as digital access and literacy posed barriers. However, many middle-income countries like Indonesia are now better equipped to implement such solutions, Nevertheless, issues related to rural equity, age-appropriate content, and clinical integration remain important areas for development.(25)

To ensure meaningful adoption and long-term impact, these digital solutions must be developed through participatory design that involves the very users they aim to serve. Co-design with families ensures cultural relevance, emotional responsiveness, and alignment with real-world caregiving needs. Moreover, integration into clinical workflows and personalised education can strengthen both child and caregiver engagement.

Limitations

This study has several limitations. First, all participants were mothers, which may limit the diversity of caregiver perspectives and exclude paternal or extended family experiences. Second, only seven of the twelve children were interviewed due to age, communication barriers, or reluctance to participate, which may have restricted the richness of child-centred narratives. Additionally, the use of self-reported data may be influenced by social desirability bias, particularly when discussing emotionally sensitive caregiving challenges. These limitations should be considered when interpreting the findings and underscore the need for broader, more inclusive future research.

CONCLUSIONS

This study sheds light on the significant psychological and caregiving burdens experienced by children on haemodialysis and their parents, particularly regarding fluid restrictions and emotional exhaustion. The findings reveal critical gaps in psychosocial and educational support within current clinical practices, indicating a need for more holistic, family-centred care.

Digital innovations such as chatbot-based RPM systems represent promising solutions to extend emotional and educational support into the home. These tools can empower families, enhance treatment adherence, and reduce caregiver strain. Future research should focus on co-developing and rigorously evaluating such interventions to ensure they are accessible, culturally appropriate, and capable of meeting the dynamic needs of families managing paediatric haemodialysis.

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ETHICAL CONSIDERATION

This study received ethical approval from the Health Research Ethics Committee of University Indonesia, with the approval letter number KET-075/UN2.F12.D1.2.1/PPM.00.02/2024. All participants were provided with verbal and written explanations regarding the study's objectives, procedures, potential benefits and risks, and data confidentiality assurances prior to signing the informed consent form.

FUNDING

This research received no external funding.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

AUTHORSHIP CONTRIBUTION

Conceptualization: Amelia Arnis.
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