

A COMPREHENSIVE EXAMINATION OF QUALITATIVE RESEARCH ON THE PERSPECTIVES OF PARENTS NURTURING CHILDREN AFFLICTED WITH CHRONIC KIDNEY DISEASE

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ABSTRACT:

Aim: The main purpose of our current investigation was to elucidate encounters come across by parents who have offspring affected by chronic kidney disease.

Methods: Our research entailed a comprehensive examination and meta-synthesis of investigations employing in-depth interviews or focus groups, aiming to delve into the encounters encountered by parents having children suffering from chronic kidney disease in various stages. Researchers thoroughly explored five electronic databases, namely Medline, Embase, PsycINFO, Cumulative Index to Nursing and Allied Health Literature, and Sociological Abstract, up until May 2021, alongside reviewing the reference lists of pertinent articles.

Results: Our analysis encompassed a total of eighteen articles that documented the encounters recounted by parents caring for 405 children afflicted by chronic kidney disease. Through this examination, we identified eleven distinct themes, which we subsequently classified into four interconnected clusters. These clusters encompassed intrapersonal factors, such as coping with persistent uncertainty, stress, and the need for unwavering vigilance despite enduring fatigue. The interpersonal cluster involved aspects such as the medicalization of parental roles, reliance on and conflicts with healthcare professionals, and disruptions in peer relationships. Additionally, we explored external

issues, which encompassed the management of medical regimens, the pursuit of information, logistical considerations such as transportation and accommodation, financial challenges, adhering to liquid and dietary restrictions, and striking a balance between medical care and domestic responsibilities.

Conclusion: Apart from the typical responsibilities of parenting, the role of a parent with a child suffering from chronic kidney disease necessitates the acquisition of exceptional skills in healthcare provision, problem-solving, information retrieval, and financial management. These obligations emerge exactly when one's ability to deal is weakened by physical tiredness, uncertainty, and the dissolution of support networks both inside and beyond the family unit. It is crucial for parents of children having chronic kidney disease to receive comprehensive care from a multidisciplinary team, as this approach has the potential to enhance results for their offspring.

Keywords: Chronic Kidney Disease, Offspring, Renal replacement therapy.

INTRODUCTION:

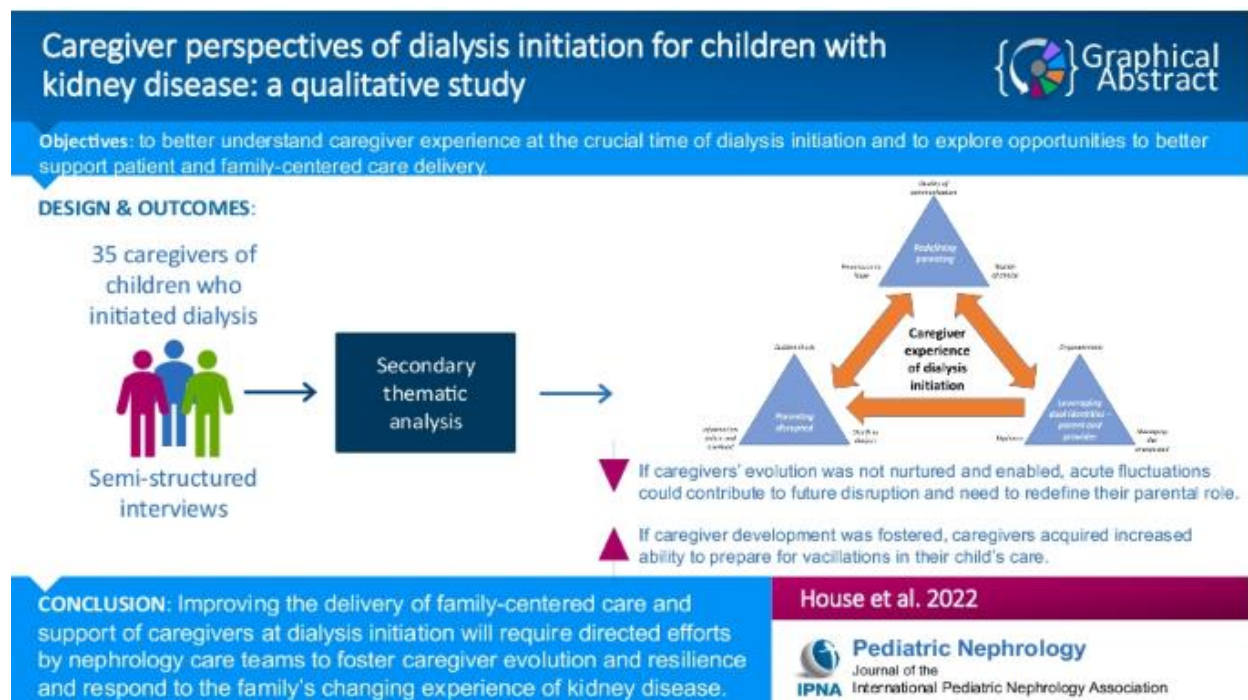
Chronic kidney disease is the debilitating disorder that has an impact on millions of people global, including a significant number of children [1]. The impact of CKD on the lives of these young patients is profound, and it extends beyond their physical health to encompass their emotional well-being and overall quality of life.

In this context, the perspectives of parents who are tasked with nurturing children afflicted with CKD become paramount [2]. These parents play a crucial role in supporting their children through the challenges posed by the disease, advocating for their healthcare needs, and ensuring their overall well-being [3].

The journey of parents nurturing children with CKD is one filled with unique experiences, emotional upheavals, and the need for constant adaptation. From the moment of diagnosis, parents are thrust into a world of medical

terminology, treatment options, and lifestyle adjustments that can be overwhelming [4]. The impact of CKD on their child's growth, development, and day-to-day activities requires parents to develop a deep understanding of the disease and its management [5]. This knowledge equips them to make informed decisions, communicate effectively with healthcare professionals, and advocate for the best possible care for their children.

Image 1:



One significant aspect of parental perspectives in the context of nurturing children with CKD is the emotional toll it takes on the entire family [6]. Parents often find themselves grappling with feelings of guilt, fear, and frustration as they witness their child facing the challenges of the disease. The need for frequent medical appointments, hospitalizations, and complex treatment regimens can disrupt the family's routine and strain their financial resources. Balancing the needs of other family members and

providing a supportive environment for siblings can also be demanding [7].

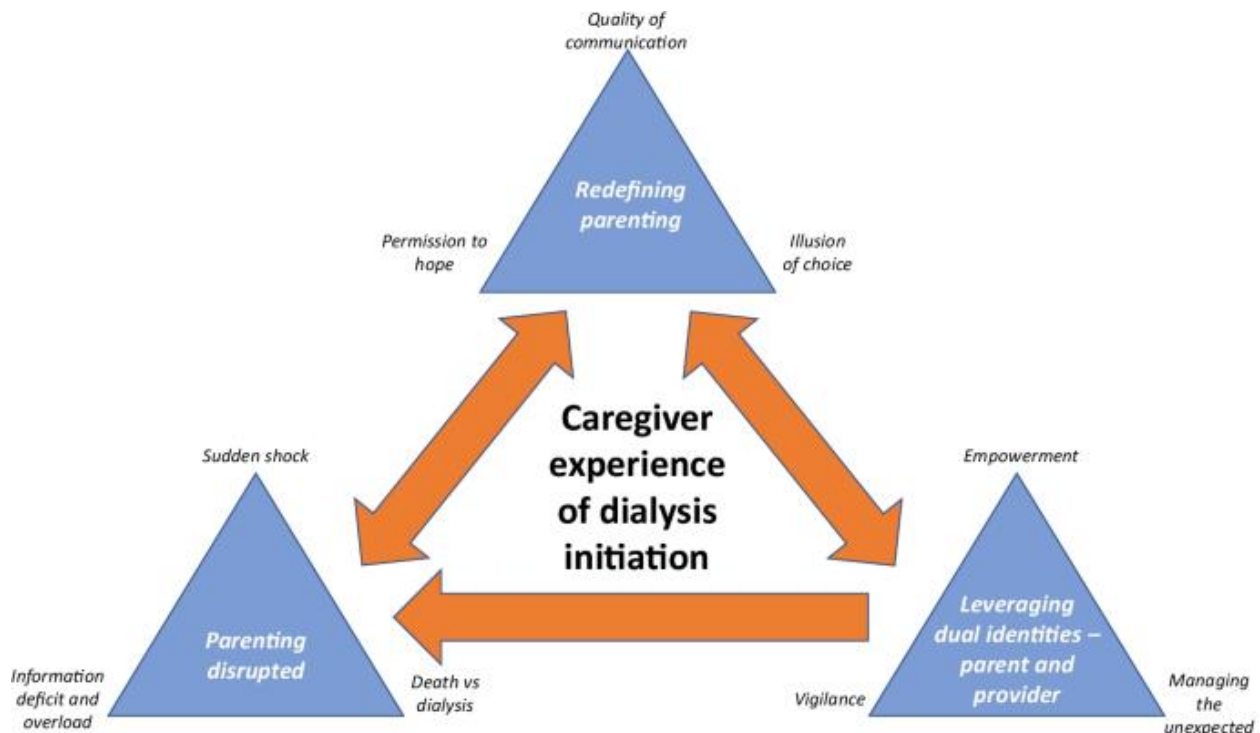
Furthermore, parents face the challenging task of explaining the disease to their child, who may be too young to fully comprehend the implications of CKD [8]. This necessitates open and honest communication that considers the child's age, developmental stage, and emotional well-being. Parents must strike a delicate balance between providing information and reassurance, while

also encouraging their child to take an active role in managing their own health [9].

Parental perspectives also extend to the social aspects of raising a child with CKD. Parents often find themselves navigating the complexities of school life, where their child may face challenges related to attendance, medication administration, and dietary restrictions. Educating teachers, classmates, and school administrators about the specific needs of their child becomes crucial to ensure a supportive and inclusive educational environment [10].

Amidst the difficulties and uncertainties, parents nurturing children with CKD also demonstrate immense resilience, strength, and determination. They develop a network of support through connecting with other parents facing similar challenges, participating in support groups, and engaging through patient advocacy organizations [11]. These interactions provide a platform for sharing experiences, exchanging information, and finding solace in the knowledge that they are not alone in their journey.

Image 2:



Understanding the perspectives of parents nurturing children afflicted with CKD is essential for healthcare professionals, researchers, policymakers, and society as a whole [12]. By recognizing and addressing the unique needs and challenges faced by these parents, we can enhance the care provided to children with CKD and improve their overall well-being. It is through collaborative efforts, empathy, and a holistic

approach that we can empower parents and ensure the best possible outcomes for children navigating the complex landscape of chronic kidney disease [13].

METHODOLOGY:

The purpose of our current research is to explore perspectives of parents who are nurturing offspring afflicted through CKD. Understanding the challenges, coping strategies, and support

systems used by parents in this context can provide valuable insights for healthcare professionals, researchers, and policymakers to improve the quality of care and support available to these families. This section outlines the methodology adopted for this research, involving the research design, participant selection, data collection, and analysis procedures.

Research Design:

To get an in-depth knowledge of parents' viewpoints, the present investigation used a qualitative research approach. Qualitative research is particularly suitable for exploring subjective experiences and complex phenomena. Through interviews, this study aims to capture the rich narratives and nuanced perspectives of parents caring for children with CKD.

Participant Selection:

Participants for this study will be selected through purposive sampling. Eligibility criteria include being a parent or guardian of the baby diagnosed with CKD, actively involved in their child's care, and willing to share their experiences. Efforts will be made to ensure diversity in terms of socioeconomic status, ethnicity, and geographical location to capture a wide range of perspectives.

Data Collection:

Data will be collected through semi-structured interviews conducted either face-to-face or via video conferencing, depending on participants' preferences and logistical constraints. The interview guide will be created after a comprehensive examination of the available literature and input from experts. The guide will explore various aspects related to nurturing children with CKD, such as challenges faced, coping mechanisms employed, support systems utilized, and experiences with healthcare providers.

Upon the consent of the respondents, every conversation will be audio-recorded, and extensive note-taking will be made to capture nonverbal cues and contextual information. The interviews are expected to last approximately 60

minutes, allowing sufficient time for participants to express their perspectives comprehensively. Data saturation will guide the determination of the sample size, i.e., The data gathering process will be repeated till no fresh thoughts or themes arise from the interviews.

Data Analysis:

The data analysis will follow a thematic approach to identify recurring patterns, themes, and categories within the dataset. The interviews will be transcribed verbatim, and the transcripts will be coded independently by two researchers using qualitative analysis software. Initial codes will be generated through an inductive process, allowing emergent themes to surface from the data itself. Subsequently, a thematic framework will be developed, and codes will be organized into meaningful categories.

The researchers will engage in a process of constant comparison, discussing and refining the emerging themes until a consensus is reached. Any disagreements or discrepancies will be resolved through discussion or consultation with a third researcher if necessary. The identified themes and categories will then be analyzed in relation to the research objectives and relevant theoretical frameworks.

Ethical Considerations:

Before beginning gathering information, the appropriate institutional review board will be consulted. Every participant will provide informed consent, and their anonymity and identity will be rigorously safeguarded throughout the course of the research. Subjects will have the opportunity to opt-out of the research at any time without penalty. To protect the confidentiality and anonymity of the individuals, the results of the investigation will be combined and anonymous.

By employing a qualitative research design and engaging parents as active participants, this study aims to get the inclusive understanding of perspectives of parents nurturing children afflicted through chronic kidney disease. The data

collected through interviews will be subjected to rigorous analysis to identify key themes and provide valuable insights. The results of our current research can contribute to improving support and care provided to these families, ultimately enhancing the well-being and quality of life of children through CKD.

RESULTS:

Chronic Kidney Disease is very challenging condition that impacts millions of children globally. Nurturing a child with CKD requires immense dedication, resilience, and adaptability on the part of parents. In this article, we delve into the various perspectives of parents who are nurturing children afflicted with CKD and explore the results of their experiences.

The 18 studies involved 375 children with CKD, and their parents participated in research. Out of the 13 studies that provided information on the child's CKD stage during data collection, 38 children were in predialysis stage, 40 offspring remained undergoing peritoneal dialysis, 116 remained receiving hemodialysis, and 109 offspring had already undergone the kidney

transplant. Frequently, parents shared their skills not only from the current stage but also from previous stages of the disease. Nine studies focused on parent experiences throughout predialysis stage, 15 during dialysis, and 10 throughout transplant stage. Among 12 researches that reported sum of respondent's fathers and mothers distinctly, mothers accounted for 84% (176) of the individuals interviewed.

Emotional Rollercoaster:

Parents of offspring having CKD often go through the whirlwind of emotions. The initial diagnosis can be devastating, leading to feelings of shock, fear, and uncertainty about the future. Over time, parents learn to cope with these emotions, developing resilience and a deepened appreciation for life. Many parents find solace in support sets or online communities where they can connect through others going via alike experiences.

Table 1: Evaluation of Research Methodology Disclosure:

Item	No. of Studies
Interviewer/facilitator characteristics	7
Credentials	
Sex	15
Occupation	8
Sampling	17
Contact	6
Sample size	17
Nonparticipation	9
Setting of data collection	13
Presence of nonparticipants	8
Interview guide	18
Audio/visual recording	9

Vigilant Caregiving:

Parents of children with CKD become expert caregivers, vigilantly monitoring their child's health and adhering to complex medical regimens. They diligently follow treatment plans,

administer medications, and keep track of appointments with various healthcare providers. This level of caregiving requires parents to be proactive, organized, and well-informed about their child's condition.

Lifestyle Adjustments:

CKD often necessitates significant lifestyle adjustments for both the child and the entire family. Parents must manage dietary restrictions, ensure adherence to fluid restrictions, and maintain a hygienic environment to prevent infections. Balancing the child's health needs with their social life and education can be a delicate juggling act for parents. They may need to educate teachers, classmates, and friends about the condition to create a supportive environment for the child.

Financial Burdens:

Caring for a child with CKD can place a substantial financial burden on parents. Frequent hospital visits, diagnostic tests, medications, and specialized equipment can lead to increased medical expenses. Additionally, parents may face challenges in maintaining employment due to the demands of caregiving. Financial planning and seeking available resources become crucial to ensure adequate support for the child's medical needs.

Parental Stress and Self-Care:

Nurturing a child with CKD can take a toll on parents' mental and physical well-being. Constant worries about their child's health, managing treatments, and the uncertainty surrounding the long-term prognosis contribute to high levels of stress. It is essential for parents to prioritize self-care, seek respite when needed, and maintain a strong support network. Engaging in activities that promote relaxation and seeking professional counseling can help parents cope with the stress associated with caregiving.

Advocacy and Empowerment:

Parents of children with CKD often become fierce advocates for their child's health. They actively participate in medical decision-making, engage with healthcare professionals, and strive to stay informed about the latest research and treatment options. Many parents contribute to raising awareness about CKD, participating in fundraising activities, and supporting organizations dedicated to kidney health.

Table 2: Impact of stress on parent child relationship:

	Mean (SD)
Parental Stress	8.48 (3.26)
Harsh parenting	70.87 (12.13)
Parent child relationship	40.51 (11.80)

Nurturing a child afflicted with CKD is an arduous journey that demands extraordinary strength and resilience from parents. The emotional rollercoaster, vigilant caregiving, lifestyle adjustments, financial burdens, parental stress, and advocacy efforts are significant aspects of their experiences. Despite the challenges, parents of children with CKD demonstrate immense love, dedication, and adaptability, creating a nurturing environment that promotes their child's health and well-being. Their perspectives shed light on the realities faced by families coping with CKD and inspire us to

appreciate the strength and determination of these remarkable parents.

DISCUSSION:

Nurturing a child with CKD poses unique challenges for parents, as they must navigate the complex medical landscape while providing emotional support and ensuring their child's overall well-being [16]. This discussion explores the various perspectives of parents who are nurturing children afflicted with CKD, shedding light on their experiences, coping strategies, and the importance of a comprehensive support system.

Parents of children with CKD often find themselves on an emotional rollercoaster ride. The diagnosis itself brings shock, fear, and worry about their child's health and future [17]. They may experience guilt, wondering if they could have done something differently to prevent the disease. Additionally, parents constantly worry about their child's well-being, face sleepless nights, and cope with anxiety and stress. Emotional support, counseling, and connecting with other parents facing similar challenges become crucial in helping parents navigate these overwhelming emotions [18].

Caring for a child with CKD entails numerous medical challenges. Parents need to navigate a complex treatment regimen, including medication management, dialysis, or kidney transplantation [19]. This necessitates frequent hospital visits, medical procedures, and dietary restrictions. Parents must become adept at understanding medical terminology, coordinating with healthcare professionals, and advocating for their child's needs [20]. The burden of constantly monitoring their child's health and ensuring adherence to medical protocols can be exhausting and overwhelming.

Children with CKD require significant lifestyle adjustments, which impact the entire family. Strict dietary restrictions, fluid intake limitations, and adherence to medication schedules can disrupt family routines and social activities [21]. Parents need to be vigilant about their child's nutritional needs, ensuring they receive appropriate nutrients while avoiding foods that may exacerbate the condition. This can be challenging, as it requires constant planning, meal preparation, and monitoring of the child's nutritional status [22].

The financial burden of caring for the child through CKD can be substantial. Medical expenses, including hospital stays, medications, dialysis, and transplantation, can place substantial strain on a family's resources. Parents may need to navigate insurance coverage, apply for

financial assistance programs, and seek community support to manage these costs effectively. The stress of financial strain can further compound the emotional and psychological challenges faced by parents [23]. Parents nurturing children with CKD greatly benefit from a strong support network. Connecting with other parents who share similar experiences allows for the exchange of information, emotional support, and practical advice. Support groups, both online and offline, offer a platform for parents to share their concerns, ask questions, and find solace in knowing they are not alone in their journey. Additionally, involving extended family, friends, and the child's school community in understanding and supporting the child's needs fosters a more inclusive environment [24].

Despite the challenges posed by CKD, parents strive to help their child lead as normal a life as possible. Encouraging independence, fostering age-appropriate activities, and addressing the child's psychological well-being are paramount [25]. Parents work with healthcare providers to ensure their child's educational needs are met, making necessary accommodations when required. Empowering the child to take an active role in their self-care and disease management helps them develop resilience and a positive outlook on life [26].

Nurturing a child afflicted with CKD is a demanding journey for parents, both emotionally and practically. Understanding the perspectives of these parents highlights the significant challenges they face, from emotional turmoil and managing medical complexities to financial strain and lifestyle adjustments [27]. It emphasizes the need for comprehensive support systems that provide emotional, medical, and financial assistance. By fostering a nurturing environment and encouraging independence, parents can help their children with CKD navigate their condition while leading fulfilling lives [28].

CONCLUSION:

In conclusion, the perspectives of parents nurturing children afflicted with chronic kidney disease highlight the immense challenges they face while providing care and support. These parents exhibit unwavering dedication, emotional resilience, and determination to ensure their children's well-being. Their perspectives shed light on the need for comprehensive medical and psychological support systems that cater to the unique needs of both children and their parents. It is crucial to acknowledge the critical role these parents play in managing their child's chronic illness and promote initiatives that provide them with the necessary resources, education, and emotional support. By recognizing and addressing the perspectives of these parents, we can enhance the overall quality of life for offspring through chronic kidney disease also their families.

REFERENCES:

1. Marshall, D. (2023). *Positive Psychology Practices With African Americans: Managing Chronic Kidney Disease and Stress* (Doctoral dissertation, Capella University).
2. Myhre, A., Råbu, M., & Feragen, K. B. (2023). Are We Together in This? Relationship Experiences of Parents of Children with Craniofacial Anomalies. *The Cleft Palate Craniofacial Journal*, 10556656231180512.
3. Stern, A., Duran, B., Streisand, R., Wang, C. H., Tully, C., Clary, L., ... & Hilliard, M. E. (2023). Parent Perspectives of School/Daycare Experiences in Young Children Newly Diagnosed With Diabetes. *Journal of pediatric psychology*, 48(5), 490-501.
4. Choi, E. K., Park, J., Kim, K., Bae, E., Ji, Y., Yang, S. H., ... & Yun, H. (2023). Factors affecting the transition to adulthood of Korean young adults with spina bifida: a qualitative study. *BMC nursing*, 22(1), 46.
5. Yang, L., Ji, J., Lu, Q., Tang, P., Jiang, Y., Yang, H., & Tang, W. (2023). Caregivers' experiences in the management of children with epilepsy: A Systematic synthesis of qualitative studies. *Seizure*.
6. Nogueira, A. J., & Ribeiro, M. T. (2023). "The Key Is to Value Every Little Achievement": A Qualitative Study of the Psychological Experience of Parent Caregivers in Paediatric Palliative Care. *Clinics and Practice*, 13(3), 670-683.
7. Clarke, E. L. (2023). *Diagnostic disclosure in Turner Syndrome: a qualitative exploration of the experiences and needs of individuals living with Turner Syndrome and family members* (Doctoral dissertation, Manchester Metropolitan University).
8. Gilcrease, G. W., Sciascia, S., Padovan, D., Sciullo, A., Cioffi, M., Ricceri, F., ... & Nikiphorou, E. (2023). Health inequalities and social determinants of health: The role of syndemics in rheumatic disease. *Autoimmunity Reviews*, 103351.
9. Gilcrease, G. W., Sciascia, S., Padovan, D., Sciullo, A., Cioffi, M., Ricceri, F., ... & Nikiphorou, E. (2023). Health inequalities and social determinants of health: The role of syndemics in rheumatic disease. *Autoimmunity Reviews*, 103351.
10. Elorza, C. L. C., Santos Junior, A. D., & Celeri, E. H. R. V. (2023). Quality of life, depression and anxiety in children and adolescents with CKD and their primary caregivers. *Brazilian Journal of Nephrology*.
11. Xie, C., Li, L., & Li, Y. (2023). "Alive Day is the Day": A Qualitative Study of

- Experiences of Learned Helplessness in Maintenance Haemodialysis Patients. *Risk Management and Healthcare Policy*, 231-245.
12. Duryan, V. (2023). *Parental Role on the Emotional Development of Child and the Relation to Beliefs About Feeding Styles Leading to Childhood Obesity Among Armenian-Americans* (Doctoral dissertation, Northcentral University).
 13. Sharp, R., Muncaster, M., Baring, C. L., Manos, J., Kleidon, T. M., & Ullman, A. J. (2023). The parent, child and young person experience of difficult venous access and recommendations for clinical practice: A qualitative descriptive study. *Journal of Clinical Nursing*.
 14. Guha, C., Khalid, R., Van Zwieten, A., Francis, A., Hawley, C. M., Jauré, A., ... & Wong, G. (2023). Baseline characteristics of participants in the NAVKIDS2 trial: a patient navigator program in children with chronic kidney disease. *Pediatric Nephrology*, 38(5), 1577-1590.
 15. Suryatna, Y. (2023). Education Sustainability Development in the Effectiveness of Parents' Role to Build Students' Competence. *Journal of Social Studies Education Research*, 14(2), 118-141.
 16. Doğan Keskin, A., Kaytez, N., Damar, M., Elibol, F., & Aral, N. (2023, May). Sharenting syndrome: an appropriate use of social media?. In *Healthcare* (Vol. 11, No. 10, p. 1359). MDPI.
 17. Mosca, C., Colucci, A., Savoia, F., Cali, C., Del Bene, M., Ranucci, G., ... & Mandato, C. (2023). Vitamin D Levels in the Pre-and Post-COVID-19 Pandemic Periods and Related Confinement at Pediatric Age. *Nutrients*, 15(9), 2089.
 18. Delrue, C., De Bruyne, S., Speeckaert, R., & Speeckaert, M. M. (2023). Urinary Extracellular Vesicles in Chronic Kidney Disease: From Bench to Bedside?. *Diagnostics*, 13(3), 443.
 19. Mak, C. (2023). *Mental Health and Relational Needs Assessment of Cambodian Refugee Families in the United States: A Transgenerational Ecological Perspective* (Doctoral dissertation, University of Georgia).
 20. Onjoro, Z., Li, J., LAN, X., & Liji Ao, W. (2023). The impact of genetics on reproductive decisions, such as preimplantation genetic diagnosis.: Pre-implantation genomic diagnosis. *ScienceOpen Preprints*.
 21. Jamal, M. N. (2023). Original article RESTLESS LEGS SYNDROME: DIFFERENCE IN QUALITY OF LIFE PARAMETERS BETWEEN HEMODIALYSIS PATIENTS WITH AND WITHOUT RESTLESS LEGS SYNDROME: Maira Pervez, Ehtisham ul Haq, Muhammad Nauman Jamal, Sameen Saeed, Sana Arif. *Journal of Akhtar Saeed Medical & Dental College*, 5(02), 84-89.
 22. Rousou, E., Apostolara, P., Papadopoulos, I., Kalokairinou, A., Sakellaraki, O., Velonaki, V. S., ... & Kouta, C. Lived Experiences of Migrant and Refugee Parents: Challenges Encountered During Their Journey and Settlement in Europe. *Available at SSRN 4480888*.
 23. Mwaka, A. D., Achan, J., & Orach, C. G. (2023). Traditional health practices: A qualitative inquiry among traditional health practitioners in northern Uganda on becoming a healer, perceived causes of illnesses, and diagnostic approaches. *Plos one*, 18(4), e0282491.
 24. Dockins, C., Dussaux, D., Griffiths, C., Hoffmann, S., & Simon, N. (2023). Valuing a reduction in the risk of chronic

- kidney disease: A large scale multi-country stated preference approach.
25. Beehler, C. (2023). *Paternal Gender Stereotypes and Child Gender-Typed Behaviors: A Correlational, Quantitative Study* (Doctoral dissertation, Capella University).
 26. Ouattara, A., Resseguier, N., Cano, A., De Lonlay, P., Arnoux, J. B., Brassier, A., ... & Chabrol, B. (2023). Individual and Family Determinants for Quality of Life in Parents of Children with Inborn Errors of Metabolism Requiring a Restricted Diet: A Multilevel Analysis Approach. *The Journal of Pediatrics*, 254, 39-47.
 27. Demers, C. (2023). The adoption of healthy behaviours or how to "better survive" pediatric cancer: A program evaluation.
 28. Perlman, P., Vorstman, J., Hoang, N., Summers, J., Baribeau, D., Cunningham, J., & Mulsant, B. H. (2023). Support to caregivers who have received genetic information about neurodevelopmental and psychiatric vulnerability in their young children: A narrative review. *Clinical Genetics*.