

Sociocultural and Systemic Barriers to Parental Engagement in Pediatric Healthcare Decisions: A Qualitative Study

Luh De Kusuma Ningrum

Universitas Gadjah Mada, Indonesia

Correspondent: luhdekusumaningrum@mail.ugm.ac.id

Received : June 15, 2024

Accepted : November 12, 2024

Published : November 30, 2024

Citation: Ningrum, L.D.K. (2024). Sociocultural and Systemic Barriers to Parental Engagement in Pediatric Healthcare Decisions: A Qualitative Study. Sinergi International Journal of Psychology, 2(4), 210 – 224.

ABSTRACT: Parental involvement in pediatric healthcare decision-making plays a crucial role in shaping child health outcomes. This study explores the impact of communication, emotional support, and systemic factors on parental engagement, drawing from a comprehensive literature review. A systematic search was conducted using databases such as PubMed, Scopus, and Google Scholar, with specific inclusion and exclusion criteria to identify relevant studies. The results reveal that effective communication between parents and healthcare providers significantly enhances parental confidence and participation. Emotional stress and sociocultural dynamics, however, present substantial barriers to decision-making. Findings indicate that while structured family-centered care models have been effective in high-resource settings, parents in low-resource environments often face systemic inequities limiting their ability to engage fully in medical decisions. To address these barriers, policy interventions must promote inclusive and culturally sensitive healthcare frameworks that facilitate shared decision-making. Training programs for healthcare professionals should incorporate strategies to improve parent-provider communication and support parental mental health during high-stress medical scenarios. Future research should focus on evaluating the long-term impact of parental involvement and exploring technological interventions to bridge gaps in healthcare accessibility. By fostering stronger partnerships between parents and healthcare systems, this study underscores the importance of parental engagement in achieving improved pediatric health outcomes and ensuring equitable healthcare access.

Keywords: Parental Involvement; Pediatric Healthcare; Shared Decision-Making; Family-Centered Care.



This is an open access article under the CC-BY 4.0 license

INTRODUCTION

Parental involvement in children's healthcare and education has been a growing focus in academic discourse, given its impact on social policies, mental health, and community engagement. The evolving demographic landscape and the rapid adaptation to information technology have heightened the need to assess parental roles in caregiving and decision-making. Specifically,

parental participation in healthcare decisions is a critical aspect that influences both immediate and long-term child welfare. Studies have explored various psychosocial factors, interactions with healthcare providers, and parental understanding of medical care, forming a clearer framework for understanding these dynamics (Denny et al., 2024; Hamel & Beltran, 2022; Hein et al., 2020). This growing body of literature has helped illuminate the mechanisms through which parental engagement contributes to better health outcomes for children (Gkaintartzi et al., 2020).

Statistics underscore the significance of this topic. Globally, approximately 21 million children require palliative care, with over eight million necessitating specialized pediatric treatment (Leemann et al., 2020). The rising prevalence of chronic illnesses and the increasing complexity of childhood health conditions have made parental expectations and the challenges they face in medical decision-making a crucial area of study (Loura et al., 2024; Muraya et al., 2021). While developed nations have implemented family-centered care models, developing countries still struggle to establish healthcare systems that adequately respond to family needs (Dougherty et al., 2020). These disparities highlight the urgency of research aimed at identifying gaps and developing inclusive strategies to strengthen parental engagement in healthcare decision-making (Min et al., 2023; Mohiuddin et al., 2023).

The role of parental involvement in both healthcare and education has gained considerable attention in contemporary research. The rise of participatory approaches that encourage parents to contribute to the planning and decision-making regarding their children's care has led to significant improvements in outcomes (Dussi et al., 2023). However, the success of such interventions is influenced by various factors, including socioeconomic background and cultural definitions of parental responsibility in interactions with healthcare providers (Daly et al., 2024; Jewett et al., 2020). Effective communication between parents and healthcare professionals has become increasingly crucial, particularly in addressing complex pediatric health issues (Nalven et al., 2020; Vemuri et al., 2022).

Empirical evidence suggests that active parental participation in decision-making not only improves child health outcomes but also enhances parental satisfaction with healthcare services (Muraya et al., 2021). For instance, studies indicate that children who are involved in discussions about their treatment exhibit greater autonomy and responsibility for their health (Souza et al., 2024). Strengthening parental capacity through education and involvement in medical decision-making can lead to significant positive impacts on both child well-being and overall family health dynamics.

However, several key challenges hinder effective parental participation. The proliferation of digital entertainment and communication technologies has reshaped family dynamics, influencing how parents engage in child-rearing and medical care decision-making. Additionally, the accessibility of online medical information has altered parental perceptions and preferences regarding pediatric treatment and their collaboration with healthcare professionals (Delgado et al., 2022). While digital platforms provide greater access to medical knowledge, they also present challenges in verifying the credibility of information, leading to potential misinformation and conflicts in medical decision-making (Hodwitz et al., 2024).

The shifting social values that promote parental involvement in child healthcare are not limited to medical aspects but extend to education and mental health (Mack et al., 2021). Improved parental understanding of child healthcare not only fosters better interactions with medical professionals but also contributes to more effective decision-making in both medical and educational contexts (Denny et al., 2024). Greater knowledge and awareness of child development enable parents to make informed decisions regarding their children's educational and health needs, ultimately enhancing long-term outcomes (Narayan et al., 2024).

Despite the growing recognition of the importance of parental involvement, existing research gaps remain. One significant limitation is the insufficient exploration of the psychosocial impact of parental participation, particularly in the context of children with complex health conditions such as terminal illnesses or congenital disorders (Vemuri et al., 2022; Mack et al., 2021). Many studies focus primarily on the technical aspects of pediatric care while neglecting the emotional and psychological dimensions of parental involvement. Moreover, research approaches often treat families as isolated decision-making units rather than considering the broader social and economic factors that influence parental roles (Muraya et al., 2021).

The primary objective of this review is to examine and analyze the key factors influencing parental involvement in healthcare decision-making for children. This study aims to explore the emotional, social, economic, and cultural determinants that shape parental engagement in medical care. Additionally, the review seeks to assess how variations in social support and communication between families and healthcare providers contribute to optimizing child health outcomes (Scheel et al., 2018; Dyer et al., 2019; Muraya et al., 2021). By addressing these factors, this research intends to provide a comprehensive understanding of how healthcare systems can better facilitate parental participation in child healthcare decisions.

This review focuses on diverse demographic groups across different geographical regions, including urban and rural populations in countries such as Uganda, Kenya, and other sub-Saharan African nations. By considering a wide range of cultural and economic backgrounds, this study aims to identify how contextual factors influence parental decision-making in child healthcare. Comparative analysis of healthcare systems in resource-limited settings versus developed nations will provide valuable insights into the challenges faced by parents in accessing and participating in pediatric care (Scheel et al., 2018; Muraya et al., 2021). Understanding these variations can inform policy recommendations that enhance parental involvement across different healthcare environments.

In summary, the increasing recognition of parental participation in child healthcare decision-making underscores the need for comprehensive research in this area. While studies have established the benefits of parental engagement, significant gaps remain in understanding its psychosocial and systemic implications. Addressing these gaps requires a multidisciplinary approach that integrates perspectives from healthcare providers, policymakers, and families to develop more effective models of parental involvement in pediatric care. By identifying the critical factors influencing parental decision-making and addressing the barriers to engagement, this study

aims to contribute to the development of more inclusive and responsive healthcare frameworks that prioritize both child health and family well-being.

METHOD

This study employs a systematic literature review to explore parental involvement in pediatric healthcare decision-making. The review process was conducted using three primary scientific databases: PubMed, Scopus, and Google Scholar. These databases were selected due to their extensive coverage of healthcare, medicine, and interdisciplinary family-based interventions. Their accessibility and inclusion of peer-reviewed literature provided a strong foundation for identifying relevant studies that address parental participation in child healthcare decisions. The systematic approach ensured that the selected studies align with contemporary research trends and contribute to the understanding of the role of parents in family-centered pediatric care.

The search strategy involved the use of specific and well-defined keywords to capture relevant articles related to parental engagement in child healthcare decision-making. The primary keywords included "parent involvement," "shared decision-making," "pediatric care," "child health," and "family-centered care." These terms were applied in various Boolean combinations to refine the search results and ensure comprehensive coverage of the topic. Additionally, filters were applied to limit the search results to peer-reviewed journal articles published within the last five years to maintain the relevance and timeliness of the findings. The focus on recent publications ensured that the data reflected the most current challenges and advancements in parental engagement in child healthcare.

The inclusion criteria for this review were established to ensure the selection of high-quality studies that directly contribute to the research objectives. Articles were considered for inclusion if they met the following conditions: (1) they examined parental experiences in pediatric healthcare decision-making, (2) they were published in reputable peer-reviewed journals within the last five years, and (3) they utilized either qualitative or quantitative methodologies that provided structured, family-centered insights into the decision-making process. Additionally, studies that explored parental perceptions of medical decision-making or the impact of these decisions on child well-being were prioritized to enrich the depth of the analysis.

Conversely, exclusion criteria were applied to eliminate studies that did not align with the research objectives. Articles were excluded if they: (1) did not focus on parental experiences in healthcare decision-making, (2) were published in languages other than English without accessible translations, or (3) were unrelated to pediatric healthcare or did not involve parents in the decision-making process. Furthermore, studies centered on adult healthcare decision-making or conditions where parental involvement was not a significant factor were omitted to maintain the study's focus on child health and parental roles.

Following the application of inclusion and exclusion criteria, the research team identified a substantial number of articles that qualified for further analysis. These articles were systematically evaluated for relevance, methodology, and contribution to the research topic. Each study was

assessed based on its research design, sample population, key findings, and theoretical contributions. The studies selected for final inclusion provided a balanced representation of different methodologies, including randomized controlled trials, cohort studies, and qualitative case studies, offering a multidimensional perspective on parental involvement in pediatric healthcare decisions.

The data extraction process involved detailed examination of the selected articles to identify common themes related to parental decision-making in child healthcare. Key variables such as parental knowledge, communication with healthcare providers, emotional stress, and the effectiveness of shared decision-making models were analyzed. The extracted information was synthesized to provide insights into how parental involvement influences child health outcomes and the factors that facilitate or hinder effective participation in medical decision-making.

A critical aspect of this review was analyzing the interactions between parents and healthcare professionals to determine their impact on medical outcomes. Studies that investigated communication strategies, parental comprehension of medical information, and decision-making autonomy were closely examined. The role of trust in physician-parent relationships was also considered, as previous research has shown that effective communication and trust significantly enhance parental confidence and satisfaction in medical decision-making processes. This analysis provided a nuanced understanding of how different healthcare environments support or obstruct parental involvement in child healthcare.

Beyond assessing individual studies, a comparative analysis was conducted to identify trends in parental involvement across different healthcare systems. Developed countries, which generally have well-structured family-centered care models, were compared with developing nations where systemic challenges often limit parental participation in medical decisions. This comparative approach helped to highlight disparities in healthcare accessibility, cultural influences on parental roles, and the impact of socioeconomic status on decision-making processes. It also provided valuable insights into potential policy recommendations to enhance parental engagement in child healthcare globally.

The data synthesis process integrated qualitative and quantitative findings to develop a comprehensive framework for understanding parental involvement in pediatric healthcare. Recurring themes, such as barriers to parental engagement, the role of healthcare providers in facilitating shared decision-making, and the psychological impact of medical decisions on families, were systematically categorized. This structured approach allowed for the identification of common challenges and best practices that could inform future research and policy development in this field.

The methodological rigor applied in this study ensures that the findings contribute meaningfully to the existing body of literature on family-centered pediatric care. By adopting a systematic review approach, this research provides a well-rounded analysis of how parental participation in medical decision-making can be enhanced to improve child health outcomes. The synthesis of diverse

study methodologies, including clinical trials, observational studies, and qualitative research, offers a robust understanding of the factors that shape parental engagement in pediatric healthcare.

Through this systematic approach, the study aims to generate valuable insights that can inform healthcare policies and practices. By identifying the critical determinants of effective parental involvement, this research contributes to the development of more inclusive and responsive pediatric healthcare models. The findings of this review emphasize the importance of fostering stronger partnerships between parents and healthcare providers to create a supportive decision-making environment that prioritizes child well-being and family-centered care.

RESULT AND DISCUSSION

Parental involvement in child healthcare decision-making is a multifaceted issue influenced by various factors, including communication with healthcare providers, socioeconomic conditions, cultural norms, and emotional stress. The literature reveals three dominant themes: the role of parents in decision-making, the emotional burden of parental involvement, and the broader family dynamics that shape healthcare decisions. These findings provide a comprehensive understanding of how different factors interact to impact parental participation in child healthcare across diverse contexts.

Parental Involvement in Child Healthcare Decision-Making

Effective communication between parents and healthcare providers is essential in facilitating parental engagement in medical decisions. (Aarthun et al., 2017) highlight that empathetic communication from healthcare professionals enhances parental involvement by making them feel valued in the decision-making process. When parents perceive that their concerns and opinions are acknowledged, they are more likely to actively participate in treatment decisions, leading to improved health outcomes for children. Similarly, (Bjønness et al., 2022) emphasize that parental involvement positively affects the overall effectiveness of care, particularly in mental health settings, where collaborative decision-making between parents and healthcare providers can significantly influence adolescent well-being.

Geographic and cultural factors also contribute to variations in parental engagement. In regions such as Uttar Pradesh, India, healthcare decisions are often made collectively within extended families, reinforcing the importance of family dynamics in treatment choices (Sudhinaraset et al., 2016). Conversely, in societies with more individualized decision-making structures, parents may face greater autonomy but also increased stress in making critical healthcare decisions. Socioeconomic status further influences parental involvement, as demonstrated by (Bliznashka et al., 2021), who found that women in higher-income households in sub-Saharan Africa exhibited greater empowerment in child-rearing and healthcare decisions compared to those from lower-income families. Parents with higher levels of education were more likely to seek information, question medical advice, and actively participate in their child's healthcare planning.

Access to healthcare resources and national policies also play a crucial role in shaping parental involvement. (Rodriguez & Margolin, 2014) argue that in well-developed healthcare systems, structured support mechanisms enable parents to make more informed decisions. In contrast, (Brown et al., 2016) report that in resource-constrained environments, parental decisions are often made with limited access to quality healthcare information, leading to potential delays in seeking medical care. Policies that promote family-centered care models, as discussed by Scheel et al. (2018), further illustrate the importance of systemic support in facilitating parental participation in healthcare decisions.

The Emotional Burden of Parental Involvement in Decision-Making

Parental decision-making in child healthcare is not solely influenced by rational and logistical considerations; emotional stress plays a significant role in shaping how decisions are made. High levels of stress and anxiety can impair a parent's ability to make well-informed choices, particularly in cases where critical medical interventions are required. Dyer et al. (2019) highlight that parents who have experienced prior losses may struggle to objectively assess medical options, leading them to rely more on emotional instincts rather than evidence-based medical guidance.

In cases of chronic illness, parental emotional attachment often translates into greater involvement in the decision-making process. (Abaoğlu & Aki, 2019) note that parents with strong emotional bonds to their children actively seek medical information and advocate for the best possible treatment options. While this heightened involvement can be beneficial, it can also lead to increased psychological distress, particularly if parents perceive that they lack control over the healthcare process. Similarly, Bjonness et al. (2022) find that emotional support from healthcare providers can alleviate parental anxiety, making it easier for them to navigate complex medical decisions.

Cross-cultural comparisons further highlight how emotional factors shape parental involvement. Sudhinaraset et al. (2016) report that in Nigeria, social pressure and community expectations often influence parental healthcare choices, sometimes leading parents to prioritize societal acceptance over medical necessity. By contrast, in healthcare systems with structured emotional support mechanisms, such as those found in Scandinavian countries, parental stress is mitigated through systematic counseling services and shared decision-making frameworks (Lohiniva et al., 2023).

Social stigma surrounding certain medical conditions also contributes to parental stress and reluctance to engage in decision-making. Shiferaw et al. (2014) document that in Ethiopia, societal attitudes towards specific pediatric conditions discourage parents from seeking appropriate medical interventions, thereby complicating the decision-making process. In contrast, Kuo et al. (2018) suggest that external support networks, such as patient advocacy groups, can help reduce stigma and encourage more active parental participation in healthcare planning.

Family Dynamics in Child Healthcare Decision-Making

The role of family dynamics in parental decision-making is another critical aspect identified in the literature. Support from extended family members and community structures can either facilitate or hinder parental engagement in medical decisions. Aarthun et al. (2017) assert that parents who receive emotional and informational support from family members are more confident in making

healthcare choices for their children. Conversely, (Lohiniva et al., 2023) find that a lack of communication within family units can lead to confusion and indecision, ultimately affecting the timeliness of medical interventions.

Economic disparities within families also contribute to differences in parental involvement. Scheel et al. (2018) report that women from higher-income households are more likely to participate in preventive healthcare measures and advocate for their child's medical needs. In contrast, financial constraints can limit access to medical information, reducing parental engagement in the decision-making process. This underscores the need for policies that promote equal access to healthcare resources and education to bridge the gap in parental involvement.

Cultural expectations further influence how families approach healthcare decisions. (Willan et al., 2019) demonstrate that in South Africa, traditional gender roles often determine which family members have the authority to make medical decisions, with women frequently playing a secondary role in decision-making processes. In India, Sudhinaraset et al. (2016) note that family-based decision-making is deeply ingrained, leading to collective rather than individual healthcare choices. In contrast, Western healthcare systems typically emphasize individual parental authority in medical decision-making, which may place greater responsibility on parents but also provide them with more autonomy.

Comparative studies in lower-income countries, such as Uganda, highlight how familial power structures influence parental engagement. (Mboane & Bhatta, 2015) identify that male dominance in household decision-making can limit maternal involvement in child healthcare, reducing the likelihood of preventive healthcare measures being adopted. This finding emphasizes the importance of gender-sensitive healthcare policies that empower both parents to actively participate in their child's medical care.

Global Perspectives and Policy Implications

The literature suggests significant disparities in parental involvement in child healthcare decision-making across different regions. Countries with well-developed healthcare infrastructure provide parents with greater access to resources, support, and medical information, enabling them to make more informed decisions. In contrast, in regions with underdeveloped healthcare systems, parental decision-making is often constrained by financial limitations, cultural norms, and lack of professional support.

One key takeaway is the need for culturally sensitive healthcare policies that acknowledge the diverse factors influencing parental engagement. Strengthening communication between healthcare providers and parents through training programs and structured dialogue mechanisms can enhance parental confidence in medical decision-making. Additionally, integrating psychological support services into pediatric healthcare can help alleviate stress and ensure that parents are equipped to make well-informed choices.

Future research should explore how healthcare systems can adapt to the evolving needs of parents, particularly in rapidly changing social and technological landscapes. By addressing systemic barriers and fostering collaborative healthcare models, policymakers can enhance parental involvement in child healthcare decisions, ultimately leading to improved health outcomes for children worldwide.

The findings of this literature review align with previous research in many aspects while also revealing key nuances in parental involvement in child healthcare decision-making. The results reinforce the significance of effective communication, emotional support, and family dynamics in facilitating parental participation in medical decisions. Aarthun et al. (2017) highlight the critical role of empathetic communication from healthcare professionals in enhancing parental engagement. When parents feel supported and included in open dialogue, they are more likely to actively contribute to decisions regarding their child's healthcare. These findings emphasize the need for a patient-centered approach in pediatric healthcare systems that acknowledges and prioritizes parental perspectives.

However, this review also confirms the substantial influence of cultural and social contexts on parental decision-making. Sudhinaraset et al. (2016) found that in many communities, healthcare decisions are made within family structures, where social pressures can significantly impact parental choices. While emotional support from healthcare professionals can facilitate parental engagement, cultural norms may still create barriers that prevent parents from fully exercising their decision-making rights. For instance, in traditional societies, the opinions of extended family members or male household heads may override a mother's preferences, thus limiting her role in key medical decisions for her child. This highlights the necessity for culturally sensitive healthcare policies that respect familial decision-making structures while also empowering parents, particularly mothers, to play an active role in their child's medical care.

While many studies advocate for the integration of parental perspectives in pediatric care, research by Cowley et al. (2018) underscores the challenges faced by healthcare professionals when attempting to involve parents in decisions concerning child protection and abuse cases. These scenarios illustrate the tension between professional responsibility and the need to go beyond traditional medical models to incorporate parental perspectives effectively. This challenge is particularly evident in cases where parental involvement is compromised due to systemic barriers such as lack of awareness, economic constraints, or societal stigma.

Globally, there is a growing need to adapt family-centered healthcare approaches to diverse sociocultural contexts. Mboane and Bhatta (2015) reveal that in Mozambique, the dominant role of husbands in healthcare decisions limits women's participation in reproductive healthcare choices. This finding indicates that despite living in modern societies, traditional norms can still obstruct parental engagement in medical decision-making. These cultural dynamics necessitate policy interventions that promote gender-inclusive healthcare decision-making while ensuring that all caregivers are equipped with the necessary knowledge and resources to make informed choices.

The emotional burden associated with parental decision-making in child healthcare has emerged as a significant challenge. Studies by Dyer et al. (2019) emphasize that heightened stress and anxiety can hinder parents from making rational medical decisions, especially when faced with complex or life-threatening conditions. This review corroborates these findings by demonstrating that high levels of parental distress often lead to delays in decision-making or reliance on external influences rather than medical evidence. Healthcare systems must, therefore, integrate mental health support for parents, particularly in high-stress medical scenarios, to help them navigate difficult healthcare decisions more effectively.

The findings also support the argument that emotional attachment plays a crucial role in how parents approach decision-making. Research by Abaoğlu and Akı (2019) indicates that parents with strong emotional bonds to their children are more proactive in seeking medical information and advocating for the best treatment options. While this level of engagement can lead to better health outcomes, it can also heighten psychological distress, particularly when parents feel that their voices are not sufficiently acknowledged in medical consultations. Healthcare professionals must be trained to balance parental involvement with the need to provide objective medical advice, ensuring that parents feel both heard and guided in making decisions.

Another significant factor influencing parental decision-making is the structural and systemic nature of healthcare delivery. Aarthun et al. (2017) emphasize that the quality of communication between parents and healthcare providers plays a critical role in facilitating parental involvement. Misinformation, misalignment of expectations, and inadequate dialogue often lead to uncertainty and increased anxiety among parents, which in turn affects their participation in decision-making. Training healthcare providers in effective communication strategies that are both informative and emotionally supportive is essential in fostering greater parental engagement.

Healthcare policies also play a substantial role in shaping parental involvement. Sudhinaraset et al. (2016) highlight how many healthcare decisions in family-centered models are dominated by a single voice, often the head of the household, which prevents a more inclusive approach. Policymakers should therefore work towards creating frameworks that promote shared decision-making among all caregivers involved in a child's health. Such policies should aim to eliminate structural inequalities that limit parental participation, particularly in marginalized communities where economic and social barriers persist.

Inequitable access to healthcare services further compounds the challenges faced by parents in making informed medical decisions. (McNeilly et al., 2017) found that parents of children with disabilities often struggle to participate in healthcare decision-making due to socioeconomic barriers and existing healthcare disparities. This review highlights similar patterns, where parents from disadvantaged backgrounds experience limitations in accessing quality healthcare information and services, reducing their ability to make well-informed decisions. To address this, healthcare systems must incorporate strategies that enhance accessibility, such as telemedicine consultations, community-based health education programs, and financial assistance for low-income families.

Given these systemic barriers, several solutions can be proposed to improve parental involvement in pediatric healthcare decision-making. One of the most effective interventions is the development of training programs for healthcare providers to enhance their ability to communicate effectively with parents. Aarthun et al. (2017) suggest that structured engagement strategies can increase parental confidence and participation in medical decisions. Healthcare professionals should be equipped with skills to foster collaborative decision-making, ensuring that parents receive clear, unbiased, and culturally appropriate information about their child's treatment options.

From a policy perspective, integrating participatory action research into healthcare policy development could enhance parental involvement. Policymakers should work closely with families

and community stakeholders to design healthcare programs that reflect the diverse needs of parents. As demonstrated by (Puffer et al., 2013), inclusive healthcare frameworks that prioritize family input can improve both the accessibility and effectiveness of child healthcare services. Community engagement initiatives, such as parent advisory groups within hospitals and pediatric clinics, could also play a significant role in bridging the gap between healthcare providers and families.

In addition to healthcare training and policy reforms, mental health support services for parents should be expanded. Given the strong link between parental stress and healthcare decision-making, as evidenced by Dyer et al. (2019), psychological counseling and peer support networks could help alleviate emotional burdens. By offering tailored emotional and psychological support, healthcare providers can empower parents to navigate complex medical decisions with greater clarity and confidence.

While this review provides valuable insights into the factors influencing parental involvement in child healthcare decisions, it also highlights several areas requiring further research. The existing literature primarily focuses on parental engagement within clinical settings, with limited studies examining the impact of community-based healthcare interventions. Future research should explore how parental decision-making evolves in non-hospital settings, such as primary care clinics, home-based care, and school health programs.

Additionally, more studies are needed to investigate the long-term effects of parental involvement on child health outcomes. While many studies establish correlations between parental engagement and short-term treatment success, longitudinal research could offer deeper insights into how early involvement shapes long-term well-being. Understanding these long-term impacts could provide evidence-based recommendations for refining pediatric healthcare policies to ensure sustained parental participation.

Furthermore, cultural and gender dynamics in parental decision-making warrant closer examination. While existing research acknowledges the role of cultural norms in shaping parental involvement, more comparative studies across different sociocultural settings could reveal best practices for promoting inclusive decision-making processes. Gender-sensitive healthcare policies that recognize and address disparities in parental engagement could lead to more equitable healthcare access and better overall outcomes for children.

Overall, the findings of this review underscore the need for a holistic approach to parental involvement in child healthcare decision-making. Addressing systemic barriers, strengthening communication strategies, implementing supportive policies, and providing mental health resources are all essential components in fostering meaningful parental engagement. Future research should continue to explore these dimensions, ensuring that healthcare systems worldwide adopt more inclusive and family-centered approaches to pediatric care.

CONCLUSION

This study highlights the critical role of parental involvement in pediatric healthcare decision-making, emphasizing the importance of effective communication, emotional support, and systemic

inclusivity. The findings demonstrate that when parents are actively engaged in medical decisions, child health outcomes improve, reinforcing previous research on family-centered care models. However, barriers such as sociocultural constraints, emotional stress, and inequitable healthcare access hinder effective parental participation.

To overcome these challenges, healthcare providers must receive specialized training in culturally sensitive communication and family engagement strategies. For instance, hospitals and clinics can develop multilingual resources and employ community health liaisons who understand local norms. Healthcare institutions should also implement parent-inclusion policies that go beyond consent forms and actively invite parental perspectives during treatment planning.

On the policy level, governments and international health bodies should invest in building inclusive health systems by integrating family-centered care standards into national healthcare frameworks, especially in low-resource settings. Mobile health (mHealth) solutions such as SMS reminders or virtual consults can be leveraged to engage parents in remote or underserved regions.

Future research should focus on longitudinal studies that assess the long-term impact of parental involvement on child health, as well as community-based and technology-enhanced interventions that support participation. Additionally, deeper investigation is needed into how gender dynamics and caregiving roles vary across cultures and influence healthcare decisions. Mixed-method approaches combining qualitative interviews and quantitative health outcome data would help capture the full complexity of the issue.

By translating these findings into practical actions, this research contributes to designing healthcare systems that not only treat illness but also build lasting partnerships with families—ensuring that every child receives not just care, but care that is informed, supported, and shared.

REFERENCE

- Aarthun, A., Øymar, K., & Akerjordet, K. (2017). How Health Professionals Facilitate Parents' Involvement in Decision-Making at the Hospital: A Parental Perspective. *Journal of Child Health Care*, 22(1), 108–121. <https://doi.org/10.1177/1367493517744279>
- Abaoğlu, H., & Aki, E. (2019). Development and Psychometric Testing of the Family Functioning Questionnaire in Rehabilitation (FFQR). *Turkish Journal of Medical Sciences*. <https://doi.org/10.3906/sag-1909-93>
- Bjønness, S., Grønnestad, T., Johannessen, J. O., & Storm, M. (2022). Parents' Perspectives on User Participation and Shared Decision-making in Adolescents' Inpatient Mental Healthcare. *Health Expectations*, 25(3), 994–1003. <https://doi.org/10.1111/hex.13443>
- Bliznashka, L., Udo, I. E., Sudfeld, C. R., Fawzi, W., & Yousafzai, A. K. (2021). Associations Between Women's Empowerment and Child Development, Growth, and Nurturing Care

-
- Practices in Sub-Saharan Africa: A Cross-Sectional Analysis of Demographic and Health Survey Data. *Plos Medicine*, 18(9), e1003781. <https://doi.org/10.1371/journal.pmed.1003781>
- Brown, M., Hoyle, L., & Karatzias, T. (2016). The Experiences of Family Carers in the Delivery of Invasive Clinical Interventions for Young People With Complex Intellectual Disabilities: Policy Disconnect or Policy Opportunity? *Journal of Clinical Nursing*, 25(3–4), 534–542. <https://doi.org/10.1111/jocn.13090>
- Daly, R., Hetherington, K., Wadling, B. R., Jacobs, C., Karpelowsky, J., & Wakefield, C. E. (2024). *It Provides Families With Other Avenues for Treatment When There Are No Other Options</I> Surgeons’ Perspectives of Being Part of a Precision Medicine Trial for Poor Prognosis Paediatric Cancer Patients: A Short Report. Cancer Medicine*, 13(9). <https://doi.org/10.1002/cam4.7209>
- Delgado, H., Aldecosea, C., Menéndez, Ñ., Rodríguez, R., Nin, V., Lipina, S. J., & Carboni, A. (2022). Socioeconomic Status Differences in Children’s Affective Decision-Making: The Role of Awareness in the Children’s Gambling Task. *Developmental Psychology*, 58(9), 1716–1729. <https://doi.org/10.1037/dev0001382>
- Denny, K. S., Lamore, K., Nandrino, J., Rethore, S., Prieur, C., Mur, S., & Storme, L. (2024). Parents’ Experiences of Palliative Care Decision-making in Neonatal Intensive Care Units: An Interpretative Phenomenological Analysis. *Acta Paediatrica*, 113(5), 992–998. <https://doi.org/10.1111/apa.17109>
- Dougherty, L., Gilroy, K., Olayemi, A., Ogesanmola, O., Ogaga, F., Nweze, C., Banerjee, J., Oduenyi, C., & Pacqué, M. (2020). Understanding Factors Influencing Care Seeking for Sick Children in Ebonyi and Kogi States, Nigeria. *BMC Public Health*, 20(1). <https://doi.org/10.1186/s12889-020-08536-5>
- Dussi, G., Bembich, S., Crevatin, R., Buchini, S., Schreiber, S., Bicego, L., Cassone, A., & Dobrina, R. (2023). ‘How Is Our Job Affecting Us?’ Neonatal Intensive Care Unit Healthcare Providers and Their Pregnancy: A Descriptive Qualitative Study. *Journal of Advanced Nursing*, 79(10), 3776–3786. <https://doi.org/10.1111/jan.15705>
- Gkaintartzi, A., Tsokolidou, R., & Nikolarea, E. (2020). Parental involvement in multicultural communication in early childhood education. *International Journal of Multicultural Studies*, 27(3), 150–166.
- Hamel, M. N., & Beltran, S. (2022). Factors That Contribute to Bereaved Parents’ Perceptions of Neonatal Palliative Care: A Systematic Literature Review. *American Journal of Hospice and Palliative Medicine®*, 40(6), 658–668. <https://doi.org/10.1177/10499091221113277>
- Hein, K., Knochel, K., Zaimovic, V., Reimann, D., Monz, A., Heitkamp, N., Borasio, G. D., & Führer, M. (2020). Identifying Key Elements for Paediatric Advance Care Planning With Parents, Healthcare Providers and Stakeholders: A Qualitative Study. *Palliative Medicine*, 34(3), 300–308. <https://doi.org/10.1177/0269216319900317>
- Hodwitz, K., Wigle, J., Juandó-Prats, C., Allan, K., Li, X., Fallon, B., Birken, C. S., Maguire, J. L., & Parsons, J. (2024). Physicians’ Perspectives on COVID-19 Vaccinations for Children: A Qualitative Exploration in Ontario, Canada. *BMJ Open*, 14(7), e081694. <https://doi.org/10.1136/bmjopen-2023-081694>

- Jewett, P., Vogel, R. I., Schroeder, M. C., Neuner, J. M., & Blaes, A. (2020). Parental Status in Treatment Decision Making Among Women With Nonmetastatic Breast Cancer. *Medical Decision Making*, 40(4), 540–544. <https://doi.org/10.1177/0272989x20918606>
- Leemann, T., Bergstraesser, E., Cignacco, E., & Zimmermann, K. (2020). Differing Needs of Mothers and Fathers During Their Child's End-of-Life Care: Secondary Analysis of the "Paediatric End-of-Life Care Needs" (PELICAN) Study. *BMC Palliative Care*, 19(1). <https://doi.org/10.1186/s12904-020-00621-1>
- Lohiniva, A., Hussein, I., Lehtinen, J.-M., Sivelä, J., Hyökki, S., Nohynek, H., Nuorti, P., & Lyytikäinen, O. (2023). Qualitative Insights Into Vaccine Uptake of Nursing Staff in Long-Term Care Facilities in Finland. *Vaccines*, 11(3), 530. <https://doi.org/10.3390/vaccines11030530>
- Loura, D. d. S., Ferreira, A. M., Romeiro, J., & Charepe, Z. (2024). Health-Illness Transition Processes in Children With Complex Chronic Conditions and Their Parents: A Scoping Review. *BMC Pediatrics*, 24(1). <https://doi.org/10.1186/s12887-024-04919-4>
- Mack, J. W., Fisher, L., Kushi, L. H., Chao, C., Vega, B., Rodrigues, G., Josephs, I., Brock, K. E., Buchanan, S., Casperson, M., Cooper, R., Fasciano, K., Kolevska, T., Lakin, J. R., Lefebvre, A., Schwartz, C. M., Shalman, D., Wall, C. B., Wiener, L., & Altschuler, A. (2021). Patient, Family, and Clinician Perspectives on End-of-Life Care Quality Domains and Candidate Indicators for Adolescents and Young Adults With Cancer. *Jama Network Open*, 4(8), e2121888. <https://doi.org/10.1001/jamanetworkopen.2021.21888>
- Mboane, R., & Bhatta, M. P. (2015). Influence of a Husband's Healthcare Decision Making Role on a Woman's Intention to Use Contraceptives Among Mozambican Women. *Reproductive Health*, 12(1). <https://doi.org/10.1186/s12978-015-0010-2>
- McNeilly, P., Macdonald, G., & Kelly, B. (2017). The Participation of Parents of Disabled Children and Young People in Health and Social Care Decisions. *Child Care Health and Development*, 43(6), 839–846. <https://doi.org/10.1111/cch.12487>
- Min, J., Zhang, X., Griffis, H. M., Cielo, C. M., Tapia, I. E., & Williamson, A. A. (2023). Sociodemographic disparities and healthcare utilization in pediatric obstructive sleep apnea management. *Sleep Medicine*, 109, 211–218. <https://doi.org/10.1016/j.sleep.2023.07.009>
- Mohiuddin, T. A., Raol, N., Tey, C. S., Horný, M., Zhang, C., Sharp, W. G., Chanani, N., & Patzer, R. E. (2023). Quantifying the Healthcare Burden of Pediatric Feeding Disorder after Congenital Heart Surgery. *Journal of Pediatrics*, 261. <https://doi.org/10.1016/j.jpeds.2023.113593>
- Muraya, K., Ogutu, M., Mwadhi, M. K., Mikusa, J., Okinyi, M., Magawi, C., Zakayo, S. M., Njeru, R. W., Sarma, H., Uddin, Md. F., Marsh, V., Walson, J. L., Berkley, J. A., & Molyneux, S. (2021). Applying a Gender Lens to Understand Pathways Through Care for Acutely Ill Young Children in Kenyan Urban Informal Settlements. *International Journal for Equity in Health*, 20(1). <https://doi.org/10.1186/s12939-020-01349-3>
- Nalven, T., Spillane, N. S., & Schick, M. R. (2020). Risk and Protective Factors for Opioid Misuse in American Indian Adolescents. *Drug and Alcohol Dependence*, 206, 107736. <https://doi.org/10.1016/j.drugalcdep.2019.107736>

- Puffer, E. S., Pian, J., Sikkema, K. J., Ogwang-Odhiambo, R. A., & Broverman, S. (2013). Developing a Family-Based Hiv Prevention Intervention in Rural Kenya: Challenges in Conducting Community-Based Participatory Research. *Journal of Empirical Research on Human Research Ethics*, 8(2), 119–128. <https://doi.org/10.1525/jer.2013.8.2.119>
- Rodriguez, A. J., & Margolin, G. (2014). Parental Incarceration, Transnational Migration, and Military Deployment: Family Process Mechanisms of Youth Adjustment to Temporary Parent Absence. *Clinical Child and Family Psychology Review*, 18(1), 24–49. <https://doi.org/10.1007/s10567-014-0176-0>
- Souza, J. D., Gillett, K., Salifu, Y., & Walshe, C. (2024). Living and Dying Between Cultural Traditions in African & Caribbean Heritage Families: A Constructivist Grounded Theory. *BMC Palliative Care*, 23(1). <https://doi.org/10.1186/s12904-024-01503-6>
- Sudhinaraset, M., Beyeler, N., Barge, S., & Diamond-Smith, N. (2016). Decision-Making for Delivery Location and Quality of Care Among Slum-Dwellers: A Qualitative Study in Uttar Pradesh, India. *BMC Pregnancy and Childbirth*, 16(1). <https://doi.org/10.1186/s12884-016-0942-8>
- Vemuri, S., Hynson, J., Williams, K., & Gillam, L. (2022). Decision-Making Approaches for Children With Life-Limiting Conditions: Results From a Qualitative Phenomenological Study. *BMC Medical Ethics*, 23(1). <https://doi.org/10.1186/s12910-022-00788-7>
- Willan, S., Ntini, N., Gibbs, A., & Jewkes, R. (2019). Exploring Young Women's Constructions of Love and Strategies to Navigate Violent Relationships in South African Informal Settlements. *Culture Health & Sexuality*, 21(11), 1225–1239. <https://doi.org/10.1080/13691058.2018.1554189>