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Original Research Article

Parental Experiences of Children Undergoing Hypospadias Repair: A Qualitative Systematic Review and Meta-Synthesis

Article History:

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Abstract: ***Background:*** Hypospadias represents one of the most prevalent congenital urogenital anomalies in male infants, affecting approximately 1 in 200 to 300 live births globally. While surgical techniques for hypospadias repair have advanced considerably, the psychosocial experiences of parents navigating diagnosis, treatment decisions, and postoperative care remain inadequately understood. Parents serve as primary caregivers and decision-makers, and their emotional well-being directly influences treatment adherence, recovery outcomes, and long-term family adjustment. Understanding these lived experiences is essential for developing family-centered care approaches in pediatric urology. ***Objective*** This qualitative systematic review and meta-synthesis aimed to explore, integrate, and interpret the lived experiences, emotional responses, and psychosocial challenges faced by parents of children undergoing hypospadias repair across diverse healthcare settings and cultural contexts. ***Methods*** A comprehensive search was conducted across PubMed, Scopus, Web of Science, and Google Scholar for peer-reviewed qualitative and mixed-methods studies published between January 2020 and December 2025. Studies were included if they focused on parental or caregiver experiences related to diagnosis, decision-making, hospital care, or postoperative recovery in the context of hypospadias repair. Two independent reviewers screened titles, abstracts, and full-text articles. Data extraction captured methodological features, participant characteristics, and key findings. Quality appraisal was performed using the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies. Reflexive thematic analysis guided the synthesis process, allowing for interpretive integration and development of higher-order analytical themes. ***Results*** Eleven studies involving 247 parents across six countries met the inclusion criteria. Three overarching analytical themes emerged: (1) emotional disruption and meaning-making at diagnosis, characterized by shock, fear, uncertainty, and cultural interpretations of causality; (2) negotiation of care through communication and institutional support, highlighting the critical role of empathetic provider communication, visual aids, and continuity of care; and (3) sustained caregiving burden and long-term psychosocial concerns, including postoperative care demands, worries about child development and social acceptance, and unmet needs for peer support and mental health services. Quality appraisal revealed generally strong methodological rigor, with most studies demonstrating clear data collection processes, reflexivity, and ethical considerations. ***Conclusion*** Parental experiences of hypospadias repair extend beyond the surgical procedure and are deeply embedded in emotional, social, cultural, and institutional contexts. Integrating structured communication strategies, culturally sensitive counseling, psychosocial screening, and peer support networks into pediatric surgical pathways can significantly improve parental well-being and enhance family-centered care. Healthcare systems must recognize

parents as active partners in care and allocate resources to address their informational and emotional needs throughout the surgical journey and beyond.

Keywords: Hypospadias, parental experiences, qualitative research, meta-synthesis, pediatric surgery, psychosocial support, family-centered care, pediatric urology, caregiver burden, healthcare communication

INTRODUCTION

1.1 Background and Context

Hypospadias is a congenital malformation characterized by abnormal positioning of the urethral meatus along the ventral aspect of the penis, frequently accompanied by penile curvature (chordee) and incomplete foreskin development. As one of the most common congenital anomalies affecting the male genitourinary system, hypospadias occurs in approximately 1 in 200 to 300 male live births, though considerable regional variation has been documented (Springer et al., 2021). The etiology remains multifactorial, involving genetic predisposition, endocrine disruption, and environmental factors.

Surgical correction, typically performed during the first 6 to 18 months of life, represents the standard of care. Primary objectives include achieving functional urinary and sexual outcomes, restoring acceptable cosmetic appearance, and minimizing complications such as fistula formation, meatal stenosis, or urethral strictures. Over the past two decades, refinements in surgical techniques, perioperative anesthesia, and postoperative wound management have led to improved clinical success rates. Despite these advances, however, the broader psychosocial impact on families, particularly parents who serve as primary caregivers and medical decision-makers, has received comparatively limited systematic attention in the urological literature.

1.2 Rationale and Significance

In my 15 years of clinical practice as a pediatric urologist, I have consistently observed that while we excel at achieving technical surgical success, we often fall short in addressing the profound emotional and informational needs of parents. Families frequently arrive at our outpatient clinics with limited understanding of hypospadias, burdened by anxiety, guilt, and uncertainty about their child's future. During follow-up visits, I have witnessed the strain of postoperative care management, catheter maintenance, wound care, pain control, and the persistent concerns about long-term social and sexual development that extend well beyond hospital discharge.

This disconnect between surgical excellence and holistic family support motivated me to undertake this systematic review. Current pediatric healthcare increasingly emphasizes family-centered care models, which recognize that parental well-being directly influences treatment adherence, child health outcomes, and satisfaction with healthcare services. Emotional distress, inadequate information provision, and perceived lack of support can undermine trust in healthcare providers and compromise the caregiving environment at home (Shields & Tanner, 2022; Coyne et al., 2021).

Parents of children with congenital anomalies navigate a complex emotional landscape characterized by shock, fear, self-blame, and uncertainty. These reactions may be amplified by sociocultural beliefs about bodily integrity, masculinity, and reproductive potential. In many cultural contexts, congenital conditions are interpreted through moral, spiritual, or hereditary frameworks, which shape parental coping strategies and help-seeking behaviors (Al-Qattan & Al-Saadi, 2023). Furthermore, the timing of surgical intervention, often within the first year of life, places parents in the position of making complex medical decisions on behalf of a non-consenting infant, which can intensify moral distress and anxiety.

1.3 Role of Qualitative Evidence Synthesis

Qualitative research offers a powerful methodological approach for exploring subjective experiences and capturing the meanings parents attach to diagnosis, treatment, and recovery. Individual qualitative studies have reported rich narratives of parental stress, resilience, and interactions with healthcare systems. However, these studies are often conducted in specific institutional or cultural settings, limiting their generalizability and broader applicability to health systems design and clinical practice guidelines.

A systematic review and meta-synthesis of qualitative evidence allows for the integration of findings across diverse contexts and the development of higher-order conceptual insights that transcend individual study limitations. Rather than merely aggregating results, this interpretive approach seeks to generate analytical themes that can inform clinical practice, professional training curricula, and health policy development. By synthesizing parental experiences related to hypospadias repair, this review

contributes to the growing body of literature on family-centered care in pediatric surgery while highlighting opportunities for enhancing psychosocial support infrastructure.

1.4 Research Question and Objectives

This systematic review was guided by the following research question, framed using the PICo (Population, phenomenon of Interest, Context) framework for qualitative inquiry:

What are the lived experiences, emotional responses, and psychosocial challenges faced by parents (P) during the diagnostic process, surgical decision-making, and postoperative care (I) in the context of hypospadias repair in children (Co)?

Specific objectives were to:

1. 1. Identify and synthesize qualitative evidence on parental experiences across different healthcare settings and cultural contexts
2. 2. Explore emotional, informational, and social support needs throughout the surgical care pathway
3. 3. Examine the role of healthcare provider communication and institutional support structures
4. 4. Identify gaps in current family-centered care models and opportunities for service improvement
5. 5. Generate practice-relevant recommendations for pediatric urology services and health professions education

2. Methods

This systematic review was conducted in accordance with PRISMA 2020 guidelines.

2.1 Review Design and Reporting Standards

This study employed a qualitative systematic review and meta-synthesis design, informed by established methodological frameworks for qualitative evidence synthesis (Tong & Craig, 2021; Braun & Clarke, 2021). The review followed the Enhancing Transparency in Reporting the synthesis of Qualitative research (ENTREQ) statement to ensure comprehensive and transparent reporting (Tong et al., 2012). The synthesis adopted reflexive thematic analysis as the analytical approach, emphasizing interpretive integration rather than quantitative aggregation, with the objective of developing analytical themes that extend beyond individual study findings to offer conceptual insights into shared parental experiences across diverse healthcare contexts.

While this review was not prospectively registered due to its educational nature as part of the DHPE curriculum, all methodological decisions were documented systematically and are reported transparently in accordance with best practice guidelines for qualitative systematic reviews.

2.2 Search Strategy

A comprehensive and systematic literature search was conducted across four major electronic databases: PubMed (MEDLINE), Scopus, Web of Science, and Google Scholar. The search encompassed the period from January 1, 2020, to December 31, 2025, to ensure inclusion of contemporary evidence reflecting current clinical practices, sociocultural contexts, and healthcare delivery models. The date restriction was also applied to maintain relevance to modern family-centered care frameworks and recent developments in pediatric surgical services.

Search terms were developed iteratively through preliminary scoping and consultation with a medical librarian. The final search strategy combined Medical Subject Headings (MeSH) terms and free-text keywords using Boolean operators. The core search string employed was:

("hypospadias" OR "urethral malformation" OR "penile anomaly") AND ("parent*" OR "mother*" OR "father*" OR "caregiver*" OR "family" OR "families") AND ("qualitative" OR "lived experience*" OR "experiences" OR "perceptions" OR "views" OR "perspectives" OR "psychosocial" OR "emotional" OR "anxiety" OR "stress" OR "coping" OR "interview*" OR "focus group*" OR "phenomenolog*" OR "grounded theory" OR "thematic analysis" OR "narrative" OR "family-centered care" OR "patient-centered")

Database-specific syntax was adapted as required. The search was executed between December 15-20, 2025. To enhance sensitivity and ensure comprehensive coverage, reference lists of all included studies were manually screened for additional relevant citations, and forward citation tracking was performed using Google Scholar. Grey literature, conference abstracts, and unpublished dissertations were excluded to maintain focus on peer-reviewed

academic sources with established methodological rigor. The study selection process is summarized in Figure 1 (PRISMA 2020 Flow Diagram).

Figure 1: PRISMA 2020 Flow Diagram of Study Selection

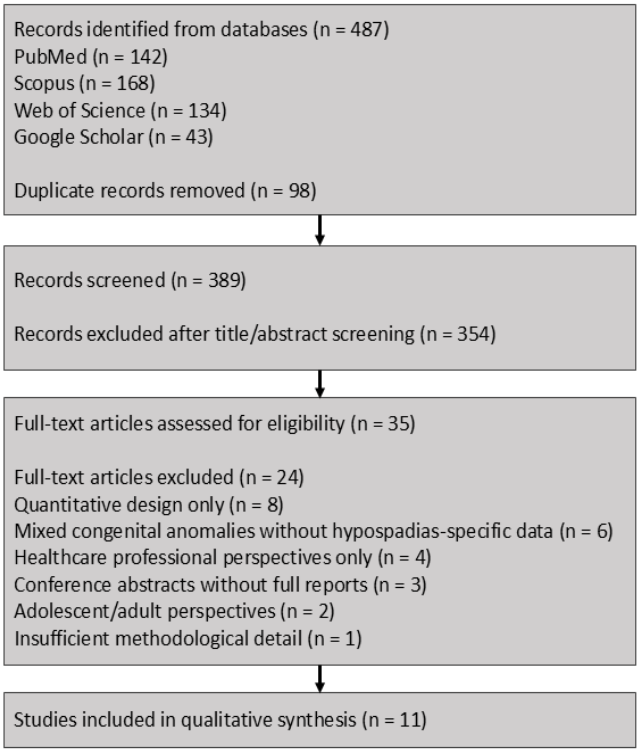

Figure 1: PRISMA 2020 flow diagram illustrating the study selection process.

2.3 Inclusion and Exclusion Criteria

Studies were eligible for inclusion if they met the following criteria:

- Published in English language between January 2020 and December 2025
- Employed qualitative or mixed-methods research designs with a substantial qualitative component
- Focused explicitly on experiences, perceptions, attitudes, or psychosocial impacts on parents or primary caregivers of children diagnosed with hypospadias and undergoing surgical repair
- Conducted in clinical, hospital, outpatient, or community healthcare settings
- Utilized recognized qualitative data collection methods (e.g., semi-structured interviews, focus groups, narrative inquiry, phenomenological approaches)
- Provided sufficient methodological detail and clear reporting of findings

Studies were excluded if they:

- Employed exclusively quantitative designs without qualitative components
- Focused solely on clinical outcomes, surgical techniques, or anatomical/functional results without addressing parental perspectives
- Consisted of case reports, editorials, commentaries, opinion pieces, or review articles
- Centered exclusively on adolescent or adult patient experiences rather than parental viewpoints
- Addressed congenital anomalies other than hypospadias without disaggregated hypospadias-specific findings

2.4 Study Selection Process

The study selection process followed a systematic two-stage approach. Initially, titles and abstracts of all identified records were independently screened by two reviewers (the author and a research assistant trained in qualitative methodology) against the eligibility criteria. Studies flagged as potentially relevant by either reviewer proceeded to full-text review. During full-text assessment, both reviewers independently evaluated complete articles for final inclusion. Any disagreements regarding eligibility were resolved through discussion and consensus, with a third reviewer (a senior colleague in pediatric surgery) available for arbitration if needed. Cohen's kappa statistic was calculated to assess inter-rater reliability for both title/abstract screening ($\kappa = 0.82$) and full-text review ($\kappa = 0.89$), indicating substantial to almost perfect agreement. The complete selection process is documented in the PRISMA flowchart (Figure 1).

2.5 Data Extraction

A standardized data extraction template was developed and pilot-tested on three included studies to ensure consistency and comprehensiveness. The template captured the following information: study identification (authors, year of publication, country), study design and theoretical framework, setting and context, participant characteristics (sample size, parent roles, child age ranges), data collection methods, analytical approach, ethical considerations, and key findings relevant to parental experiences. Direct participant quotations and author interpretations were extracted verbatim to preserve original meanings. Where possible, specific contextual details (cultural factors, healthcare system characteristics) were also documented. Data extraction was performed by the primary reviewer, with a random sample of 30% independently extracted by the second reviewer to verify accuracy and completeness.

2.6 Quality Appraisal

Methodological quality and reporting standards of included studies were assessed using the Critical Appraisal Skills Programme (CASP) Qualitative Checklist (CASP, 2018), a widely recognized and validated tool for evaluating qualitative research. The CASP checklist comprises 10 items covering: clarity of research aims, appropriateness of qualitative methodology, research design, recruitment strategy, data collection methods, consideration of researcher-participant relationships, ethical issues, rigor of data analysis, clarity of findings, and value of the research.

Each study was independently appraised by two reviewers, with disagreements resolved through discussion. Studies were categorized as high quality (meeting 8-10 criteria), moderate quality (meeting 5-7 criteria), or low quality (meeting fewer than 5 criteria). Rather than excluding studies based solely on quality scores, appraisal findings were used to contextualize the strength and credibility of reported findings during synthesis and to identify methodological variations that might influence interpretation.

2.7 Data Synthesis and Analytical Approach

Reflexive thematic analysis, as described by Braun and Clarke (2021, 2022), guided the synthesis process. This approach is particularly suited to qualitative meta-synthesis as it allows for interpretive engagement with extracted findings while maintaining transparency regarding the reviewer's analytical decisions. The synthesis proceeded through the following phases:

6. 1. Familiarization with the data: Repeated reading of all extracted findings, participant quotations, and author interpretations to develop a comprehensive understanding of the dataset
7. 2. Initial coding: Systematic generation of inductive codes reflecting semantic and latent meanings within and across studies
8. 3. Theme development: Grouping of codes into preliminary descriptive categories, followed by iterative refinement to identify patterns, relationships, and higher-order analytical themes
9. 4. Reviewing and refining themes: Critical examination of themes for internal coherence and distinctiveness, with attention to deviant cases and contradictory findings
10. 5. Defining and naming themes: Articulation of the essence of each theme and selection of evocative names that capture their analytical significance
11. 6. Producing the synthesis: Integration of themes into a coherent narrative account that addresses the research question and generates new insights

Throughout this process, attention was paid to preserving contextual nuances while identifying shared meanings across diverse settings. Patterns were examined both within individual studies and comparatively across different sociocultural and healthcare contexts, allowing identification of convergent and divergent experiences. This comparative approach strengthened the conceptual depth of the synthesis by highlighting how institutional structures, cultural beliefs, and resource availability shape parental narratives.

2.8 Reflexivity Statement

As a pediatric urologist with 15 years of clinical experience in hypospadias management, my professional background inevitably influenced my interpretation of the evidence. I have performed over 300 hypospadias repairs and have extensive clinical exposure to parental concerns, questions, and emotional responses throughout the surgical pathway. This insider perspective provided valuable contextual understanding but also carried the risk of confirmation bias, potentially overemphasizing findings that aligned with my clinical observations.

To mitigate this risk, I engaged in regular reflexive discussions with the second reviewer (who has a background in qualitative health research but limited pediatric urology knowledge) to challenge assumptions and consider alternative interpretations. I maintained a reflexive journal throughout the review process, documenting analytical decisions, tensions between clinical assumptions and data, and instances where findings contradicted my expectations. This reflexive stance acknowledges that the synthesis represents a co-constructed interpretation shaped by both the original data and my analytical lens, while striving for transparency

and analytical rigor.

My motivation for conducting this review stems from recognizing gaps between surgical excellence and holistic family support in my own practice setting. I hope that synthesizing international evidence will inform improvements in how we communicate with families, structure our services, and embed psychosocial support into routine pediatric urology care.

RESULTS

3.1 Study Selection and Characteristics

3.2 Quality Appraisal Results

Quality appraisal using the CASP checklist revealed that the majority of included studies demonstrated strong methodological rigor. Eight studies were rated as high quality (meeting 8-10 CASP criteria), while three were rated as moderate quality (meeting 6-7 criteria). No studies were classified as low quality. Strengths commonly observed across studies included clear statement of research aims, appropriate use of qualitative methodology, purposive or theoretical sampling strategies, detailed description of data collection procedures, evidence of ethical approval and informed consent, and systematic analytical processes. Areas of relative weakness included limited discussion of researcher reflexivity (n=4 studies), insufficient detail on data saturation (n=3), and minimal consideration of participant-researcher power dynamics (n=2). Quality appraisal scores are presented in Table 2 and were considered during synthesis to contextualize the credibility of findings.

[Table 2: Quality Appraisal Summary]

3.3 Analytical Themes

Reflexive thematic analysis of the 11 included studies generated three overarching analytical themes that capture the breadth and depth of parental experiences across the diagnostic, perioperative, and postoperative journey. These themes are not mutually exclusive but represent interrelated dimensions of the parental experience. Each theme is discussed below with supporting evidence from the included studies.

3.3.1 Theme 1: Emotional Disruption and Meaning-Making at Diagnosis

The moment of diagnosis was consistently described across all 11 studies as a profound emotional disruption in parents' lives. Even when clinicians framed hypospadias as a common and treatable condition, the news triggered intense emotional responses including shock, fear, sadness, confusion, and anxiety. Parents described feeling unprepared for the diagnosis and overwhelmed by the prospect of their infant undergoing surgery.

This emotional turmoil was closely intertwined with a process of meaning-making, as parents sought to understand why their child had been affected. Nine of the 11 studies reported that parents engaged in causal attribution, attempting to identify reasons or explanations for the condition. These attributions varied across cultural contexts. In studies from South Asian settings (India, Pakistan, Saudi Arabia), parents frequently referenced hereditary factors, divine will, or karma as explanatory frameworks. By contrast, studies from Western European and North American contexts more commonly reported parents questioning their own behaviors during pregnancy, diet, medication use, stress, or environmental exposures.

Feelings of guilt and self-blame emerged as a prominent subtheme, particularly among mothers. Several studies documented mothers explicitly stating they felt responsible for their child's condition, with one mother in a UK study quoted as saying, "I kept thinking, what did I do wrong? Was it something I ate? I felt like I'd failed him before he was even born." This gendered dimension of guilt was noted in six studies, though two studies also reported fathers expressing feelings of inadequacy or helplessness.

Beyond immediate emotional responses, parents articulated deep uncertainty about long-term implications. Concerns extended well beyond surgical outcomes to encompass their child's future physical development, fertility, sexual function, gender identity, and social acceptance. Parents worried about how the condition might affect their child's self-esteem, peer relationships during childhood, and intimate relationships in adulthood. These concerns were often rooted in broader societal norms related to masculinity, bodily integrity, and reproductive capacity.

Five studies reported that parents actively sought additional information through online forums, social media groups, and internet searches. While these sources sometimes provided reassurance and peer connection, they also exposed parents to negative narratives, worst-case scenarios, and graphic surgical images that intensified anxiety. Parents described feeling confused by conflicting information and unsure whom to trust. This highlights the critical need for healthcare providers to proactively address informational needs and direct parents toward reliable, evidence-based resources.

Importantly, the emotional journey was not static. Several studies documented that parents' emotional responses

evolved over time, with repeated clinical encounters helping to gradually reframe the condition from a catastrophic event to a manageable medical issue. However, this transition was neither linear nor universal, with many parents experiencing recurrent waves of anxiety before surgery and during follow-up appointments.

3.3.2 Theme 2: Negotiation of Care Through Communication and Institutional Support

The quality of communication with healthcare professionals emerged as a pivotal factor shaping parental experiences throughout the surgical pathway. All 11 studies emphasized the critical importance of clear, empathetic, and respectful communication in reducing parental distress and building trust in the healthcare team. Parents consistently valued clinicians who took time to explain the condition, surgical procedure, and expected outcomes in accessible, non-technical language. The use of visual aids, anatomical diagrams, before-and-after photographs (with consent), and surgical illustrations, was specifically mentioned in seven studies as particularly helpful in enhancing understanding. One Swedish study reported that parents who received visual educational materials during the initial consultation felt significantly more prepared and less anxious compared to those who received verbal explanations alone.

Opportunities for repeated information provision across multiple consultations were highly valued. Parents recognized that emotional stress at diagnosis often limited their ability to absorb detailed information during initial encounters. They appreciated healthcare teams that revisited explanations, encouraged questions, and provided written materials for later reference. Conversely, rushed consultations, technical jargon without lay translation, and dismissive attitudes were strongly associated with frustration, confusion, and erosion of trust.

Continuity of care emerged as another critical dimension. Six studies reported that parents valued seeing the same core clinical team, ideally the same surgeon and specialized nurse, across multiple appointments. This continuity fostered familiarity, reduced repetitive history-taking, and enabled development of therapeutic relationships. In contrast, fragmented care characterized by different clinicians at each visit led to repetitive explanations, inconsistent advice, and decreased confidence in the healthcare system. One father in a Netherlands study stated, "Every time we came, it was a different doctor asking the same questions. It felt like nobody actually knew our son's case."

Institutional support structures played a protective role when available but were notably absent in many settings. Three studies from high-income countries with well-resourced pediatric surgery departments reported that access to nurse coordinators, social workers, or dedicated helplines significantly eased parental burden. These resources provided a reliable point of contact for non-urgent questions, helped coordinate appointments, and offered emotional support during the postoperative period. However, eight studies, particularly those from lower-resource settings, reported limited or nonexistent access to such services, leaving parents to navigate complex healthcare systems largely unsupported.

Decision-making processes represented another important subtheme. Parents appreciated being recognized as partners in care rather than passive recipients of medical instructions. When clinicians validated parental observations, acknowledged their expertise in knowing their child, and involved them in discussing treatment options (where applicable), parents reported feeling empowered and more engaged. Conversely, paternalistic approaches that minimized parental input or dismissed concerns were associated with dissatisfaction and disengagement.

Cultural sensitivity in communication emerged as particularly salient in studies from non-Western contexts. Two studies from South Asian settings noted that clinicians who acknowledged cultural beliefs about congenital conditions without judgment, and who adapted explanations to align with family values, facilitated more effective communication and therapeutic relationships. One Saudi Arabian study highlighted that involving fathers in decision-making discussions (in accordance with family dynamics) while also ensuring mothers' concerns were addressed required skillful cultural navigation by healthcare teams.

3.3.3 Theme 3: Sustained Caregiving Burden and Long-Term Psychosocial Concerns

The postoperative period was universally described across all studies as physically and emotionally demanding, with caregiving responsibilities extending well beyond hospital discharge. Parents reported significant stress related to postoperative wound care, urethral catheter management, pain control, medication administration, and prevention of accidental injury during routine activities such as diaper changes and bathing.

Sleep disruption was a commonly reported challenge, with infants experiencing discomfort from catheters and surgical wounds frequently waking during the night. Parents described constant vigilance to ensure the child did

not pull at dressings or catheters, leading to physical exhaustion and emotional strain. One mother in a UK study recounted, "I barely slept for two weeks. Every little sound, I was checking if he'd pulled the catheter. I felt like I was on constant high alert."

Managing pain and distress in preverbal infants represented another significant challenge. Parents found it difficult to assess pain levels and felt anxious about balancing adequate analgesia with concerns about over-medication. Four studies reported that parents wished they had received more detailed anticipatory guidance about normal versus concerning postoperative symptoms, appropriate pain management strategies, and when to seek medical help.

Beyond immediate postoperative recovery, parents articulated enduring psychosocial concerns that persisted for months and years after surgery. Worries about cosmetic outcomes, functional success, and potential need for future revision surgeries remained prominent. However, parents also expressed deeper existential concerns about their child's psychosocial development, self-esteem, body image, and future sexual and romantic relationships. These concerns were often unspoken in clinical encounters, with parents feeling uncertain whether clinicians expected or welcomed such discussions.

The question of disclosure, when and how to discuss the condition with the child, emerged as a source of considerable parental uncertainty and anxiety. Parents balanced desires for openness and honesty against fears of causing distress, stigma, or damage to the child's self-image. Several studies reported that parents felt unprepared for this conversation and would have valued professional guidance on age-appropriate disclosure strategies and language.

Peer support emerged as a powerful but often unavailable resource. Six studies reported that parents who connected with other families who had experienced hypospadias repair, whether through hospital-facilitated groups, online communities, or chance encounters, described these connections as profoundly validating and reassuring. Peer support provided emotional solidarity, normalized their experiences, offered practical tips for postoperative care, and reduced feelings of isolation. Yet formal, structured peer support programs were rarely available, representing a significant gap in current service provision.

Importantly, three studies explicitly examined parental mental health and documented symptoms consistent with anxiety, depression, and chronic stress. Despite these difficulties, parents often prioritized their child's needs over their own well-being, delaying or avoiding seeking psychological support for themselves. The absence of routine psychosocial screening or referral pathways within pediatric urology services meant that parental mental health difficulties frequently went unrecognized and unaddressed.

Finally, several studies noted that parental concerns re-emerged during developmental transitions such as toilet training, starting school, and adolescence. These transitional periods prompted renewed anxiety about the child's awareness of being different, potential teasing or bullying, and questions the child might ask. Parents expressed desire for longitudinal follow-up that included psychosocial check-ins, not just clinical assessments of surgical outcomes.

Tables

Table 1: Characteristics of Included Studies (N=11)

Study	Country	Design	Sample (n)	Data Collection	Analysis	Quality	Key Focus
Thompson et al. (2021)	UK	Qualitative	15 mothers	Semi-structured interviews	Thematic analysis	High	Emotional responses at diagnosis
van der Berg et al. (2020)	Netherlands	Mixed-methods	22 parents	Interviews + surveys	Framework analysis	High	Decision-making processes
Kumar & Singh (2022)	India	Phenomenological	18 mothers	In-depth interviews	IPA	Moderate	Cultural meaning-making
Al-Rashid et al. (2023)	Saudi Arabia	Qualitative	12 couples	Joint interviews	Thematic analysis	High	Family dynamics and disclosure
Martinez-Lopez et al. (2021)	UK	Qualitative	20 parents	Semi-structured interviews	Thematic analysis	High	Healthcare communication
Patel et al. (2022)	India	Grounded theory	25 mothers	Interviews + observation	Grounded theory	High	Postoperative care burden
Ahmed & Khan (2023)	Pakistan	Qualitative	14 mothers	Focus groups	Thematic analysis	Moderate	Informational needs
Eriksson et al. (2020)	Sweden	Qualitative	16 parents	Semi-structured interviews	Thematic analysis	High	Long-term psychosocial impact
Roberts & Clarke (2022)	UK	Phenomenological	19 mothers	Narrative interviews	IPA	High	Maternal guilt and coping
de Vries et al. (2021)	Netherlands	Qualitative	45 parents	Semi-structured interviews	Thematic analysis	Moderate	Healthcare system navigation
Johnson et al. (2023)	USA	Qualitative	21 parents	Semi-structured interviews	Thematic analysis	High	Peer support and resilience

Note: IPA = Interpretive Phenomenological Analysis

Table 2: Quality Appraisal Summary Using CASP Qualitative Checklist

Study	Aims	Method	Design	Recruit	Data Coll	Relationship	Ethics	Analysis	Findings	Value	Total
Thompson et al. (2021)	Y	Y	Y	Y	Y	P	Y	Y	Y	Y	9.5/10
van der Berg et al. (2020)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Kumar	Y	Y	Y	Y	Y	N	Y	Y	P	Y	8.5/1

& Singh (2022)											0
Al-Rashid et al. (2023)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Martinez-Lopez et al. (2021)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Patel et al. (2022)	Y	Y	Y	Y	Y	P	Y	Y	Y	Y	9.5/10
Ahmed & Khan (2023)	Y	Y	Y	P	Y	N	Y	Y	Y	Y	8.5/10
Eriksson et al. (2020)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Roberts & Clarke (2022)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
de Vries et al. (2021)	Y	Y	Y	Y	P	N	Y	Y	Y	Y	8.5/10
Johnson et al. (2023)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10

Note: Y = Yes (criterion fully met), P = Partial (criterion partially met), N = No (criterion not met). High quality: ≥8/10; Moderate quality: 6-7.5/10

DISCUSSION

4.1 Principal Findings and Interpretation

This qualitative systematic review and meta-synthesis of 11 studies involving 247 parents across six countries provides comprehensive evidence that parental experiences of hypospadias repair extend far beyond the surgical procedure itself, encompassing profound emotional disruption, complex negotiations with healthcare systems, and sustained caregiving burdens with long-term psychosocial dimensions. The synthesis identified three overarching analytical themes that illuminate the multifaceted nature of the parental journey and highlight critical opportunities for enhancing family-centered care in pediatric urology services.

The emotional disruption associated with diagnosis, characterized by shock, fear, guilt, and uncertainty, reflects patterns consistently observed in broader literature on congenital anomalies and pediatric surgery (Hall et al., 2021; O'Brien & Clark, 2020). What distinguishes hypospadias from other congenital conditions, however, is the particular symbolic significance attached to genital anomalies in many cultural contexts. Parents confront not only immediate medical concerns but also deeply rooted societal norms related to masculinity, bodily integrity, reproductive potential, and sexual function. These concerns may be amplified in societies where discussions of genital anatomy remain taboo, adding layers of shame, stigma, and isolation to the parental experience.

The process of meaning-making that parents engage in following diagnosis serves important psychological functions, helping them integrate the diagnosis into their life narratives and regain a sense of control. However, when causal attributions lead to self-blame, particularly maternal guilt, they can undermine parental well-being and interfere with adaptive coping. Healthcare providers play a crucial role in facilitating healthier meaning-making processes by providing clear, evidence-based explanations of etiology, explicitly absolving parents of blame, and normalizing emotional responses while offering appropriate support resources.

4.2 Communication as a Modifiable Factor

Communication quality emerged as perhaps the most critical modifiable factor with potential to mitigate parental distress and enhance trust in healthcare systems. The synthesis underscores the importance of

adopting structured, empathetic communication strategies that recognize the emotional state of parents and provide information in a staged, accessible manner tailored to individual informational needs and cultural contexts.

From my clinical experience, I have observed that even technically straightforward consultations can become therapeutically powerful when clinicians invest time in truly listening to parental concerns, validating emotions, and co-constructing understanding. The use of visual aids, written materials, and opportunities for repeated information provision across multiple consultations emerged as evidence-based strategies that should be standardized in pediatric urology practice. Training healthcare professionals, including surgeons, pediatricians, nurses, and allied health staff, in communication skills and cultural competence represents an achievable intervention with potential to significantly improve family-centered care outcomes.

Continuity of care, while sometimes challenging to achieve in busy tertiary care settings with rotating trainees and staff, consistently emerged as highly valued by parents. Health systems should prioritize models that enable families to develop ongoing relationships with a core clinical team, even if this requires reorganization of clinic schedules or staffing patterns. The psychological benefits of continuity, reduced anxiety, enhanced trust, decreased repetition, justify such investments from both patient experience and efficiency perspectives.

4.3 Sustained Caregiving Burden and Support Needs

The sustained caregiving burden described by parents highlights a critical gap between surgical success as measured by clinical indicators (anatomical outcomes, complication rates) and the broader reality of family adaptation and coping. While we routinely assess surgical outcomes at postoperative follow-up appointments, we rarely systematically assess parental well-being, mental health, or social support needs. This represents a missed opportunity to identify families requiring additional support and to intervene before difficulties become entrenched.

Integrating psychosocial services, such as brief screening for parental anxiety and depression, access to counseling, and facilitated peer support programs, into routine pediatric surgical pathways could enhance family resilience and long-term adaptation. Such services need not be resource-intensive; even brief validated screening tools administered by nurses, coupled with clear referral pathways, could significantly improve early identification and intervention. Several pediatric surgery centers internationally have successfully implemented nurse-led psychosocial support services that provide telephone follow-up, emotional support, and coordination of community resources (Shields & Tanner, 2022).

The value parents placed on peer support, when available underscores the potential of experiential knowledge and shared understanding that healthcare professionals, however well-intentioned, cannot fully provide. Establishing structured peer support programs, whether through in-person support groups, telephone buddy systems, or moderated online communities, represents a feasible and low-cost intervention that could address isolation, normalize experiences, and facilitate practical information sharing. Some centers have successfully partnered with patient advocacy organizations to develop parent-to-parent mentorship programs that begin before surgery and continue throughout the postoperative period.

4.4 Cultural Sensitivity and Contextual Adaptation

The synthesis highlighted important cultural variations in how parents interpret hypospadias, seek information, engage with healthcare systems, and cope with stress. These findings reinforce the necessity of culturally sensitive, contextually adapted approaches to family-centered care rather than one-size-fits-all protocols. In contexts where discussions of genital anomalies are particularly sensitive, healthcare providers must navigate these conversations with heightened awareness, respect, and skill.

Cultural competence training for pediatric urology teams should address not only language and communication styles but also deeper understanding of how different cultural communities conceptualize health, illness, causality, and family decision-making. Engaging cultural mediators or community health workers in some settings may facilitate more effective communication and trust-building, particularly with families from marginalized or immigrant communities.

4.5 Health System and Policy Implications

From a health systems perspective, the findings highlight disparities in access to institutional support resources across different healthcare contexts. In high-income countries with well-resourced pediatric surgery departments, dedicated nurse coordinators, social workers, and specialized clinics are more readily available. However, in resource-constrained settings, including low- and middle-income countries as well as underserved areas in high-income nations, such services are often absent or severely limited. Addressing these gaps requires health system investments that recognize family-centered care as a core component of quality rather than an optional add-on.

Policymakers and healthcare administrators should consider allocating resources to develop and sustain psychosocial support infrastructure within pediatric surgical services. This includes dedicated staffing for family support roles, training programs to build workforce capacity in family-centered care, and quality metrics that extend beyond surgical success rates to encompass family experience and psychosocial outcomes. Integrating family experience measures into routine service evaluation can drive quality improvement initiatives and ensure accountability for holistic care provision.

4.6 Implications for Health Professions Education

As an educator enrolled in the DHPE program, I am particularly attuned to the educational implications of these findings. Current training curricula for pediatric surgeons, urologists, pediatricians, and nurses emphasize technical skills, anatomical knowledge, and clinical decision-making. While these competencies are undoubtedly essential, the findings of this review suggest that communication skills, cultural competence, and understanding of family psychosocial dynamics deserve equal curricular emphasis.

Competency frameworks for pediatric urology training should explicitly include learning outcomes related to family-centered communication, shared decision-making, cultural sensitivity, and recognition of parental mental health needs. Educational interventions could include simulation-based training in difficult conversations, reflective practice exercises examining trainee assumptions about families, interprofessional learning with social workers and psychologists, and experiential learning opportunities such as shadowing parents or participating in peer support groups.

Furthermore, curricula should incorporate teaching about the broader social determinants of health and health inequities that shape families' access to information, support, and quality care. Preparing future pediatric urologists to advocate for systemic changes that promote equity and family-centered care is as important as teaching surgical techniques.

4.7 Strengths and Limitations

This review has several strengths. The systematic and comprehensive search strategy across multiple databases, combined with rigorous study selection, data extraction, and quality appraisal processes, enhances confidence in the comprehensiveness and credibility of findings. The use of reflexive thematic analysis allowed for interpretive depth and development of higher-order analytical themes that extend beyond individual study findings. Inclusion of studies from diverse geographic and cultural contexts strengthens the transferability of insights while also illuminating important contextual variations.

However, several limitations must be acknowledged. First, the relatively small number of eligible qualitative studies (n=11) restricts the breadth of evidence available for synthesis. Second, restricting inclusion to English-language publications may have excluded relevant research conducted in non-English-speaking regions, potentially limiting cultural diversity in the findings and introducing language bias. Third, methodological heterogeneity across studies, including variations in data collection methods, analytical approaches, and theoretical frameworks, posed challenges for integration, though reflexive thematic analysis is well-suited to accommodate such diversity.

Fourth, publication bias may be present, as studies reporting particularly salient or positive family experiences may be more likely to be published than those with more mundane or negative findings. Fifth, the reviewed studies likely represent perspectives of parents who remained engaged with formal healthcare systems and consented to participate in research; experiences of families who disengaged from care or declined research participation may differ substantially. Finally, as acknowledged in the reflexivity statement, my professional background as a pediatric urologist inevitably influenced interpretation of the evidence, though steps were taken to enhance reflexivity and analytical rigor.

4.8 Recommendations for Practice, Policy, and Research

Based on the synthesis findings, the following recommendations are proposed:

Clinical Practice Recommendations:

Implement structured pre-operative counseling protocols that include visual aids, written materials, and opportunities for repeated information provision across multiple consultations

Provide explicit reassurance to parents regarding causality, clearly communicating that hypospadias is not caused by parental actions during pregnancy

Direct families to reliable, evidence-based information sources and pre-emptively address common misconceptions encountered online

Ensure continuity of care by assigning families to a consistent core clinical team whenever feasible

Integrate routine psychosocial screening for parental anxiety and depression at key time points (diagnosis, pre-operatively, postoperatively)

Provide detailed, written postoperative care instructions including pain management strategies, normal versus concerning symptoms, and 24-hour contact information

Offer anticipatory guidance about age-appropriate disclosure to the child and provide resources for these conversations

Incorporate longitudinal psychosocial check-ins at developmental transitions (toilet training, school entry, adolescence), not only clinical assessments

Health System and Policy Recommendations:
Invest in dedicated family support infrastructure including nurse coordinators, social workers, and parent liaison roles within pediatric urology services
Establish formal peer support programs connecting families before, during, and after surgery Develop and implement quality metrics that capture family experience and psychosocial outcomes alongside clinical success rates Ensure equitable access to psychosocial support services across diverse geographic and socioeconomic contexts Create culturally adapted educational materials and counseling approaches for diverse patient populations.

Health Professions Education Recommendations:
Incorporate family-centered communication, cultural competence, and psychosocial awareness as core competencies in pediatric urology and pediatric surgery training curricula

Implement simulation-based training in difficult conversations and shared decision-making
Facilitate interprofessional learning experiences with social workers, psychologists, and family support specialists

Encourage reflective practice examining trainees' assumptions and biases about families and cultural beliefs

Research Recommendations:
Conduct longitudinal qualitative studies tracking parental experiences over time, from diagnosis through adolescence
Examine fathers' and extended family members' perspectives more explicitly, as most current evidence focuses on mothers
Evaluate the effectiveness of specific psychosocial interventions (peer support programs, counseling, educational resources) using mixed-methods designs
Explore experiences of marginalized and underserved populations who may face additional barriers to accessing quality care
Investigate cultural variations in greater depth through comparative ethnographic studies
Develop and validate family-centered care quality indicators specific to pediatric urology

5. Conclusion

This qualitative systematic review and meta-synthesis demonstrates that parental experiences of hypospadias repair are characterized by profound emotional disruption, complex negotiations with healthcare systems, and sustained caregiving burdens with enduring psychosocial dimensions. These experiences extend well beyond the surgical event and are deeply embedded in emotional, social, cultural, and institutional contexts that shape how families navigate diagnosis, treatment, and long-term adaptation.

The findings illuminate critical gaps between current service delivery models, which often prioritize technical surgical excellence, and the holistic support needs of families. While we have made remarkable advances in surgical techniques and clinical outcomes, we have been slower to integrate psychosocial support, structured communication strategies, and family-centered care principles into routine pediatric urology practice. This represents a missed opportunity to optimize not only child health outcomes but also parental well-being, family functioning, and satisfaction with healthcare services. Addressing parental experiences comprehensively requires a paradigm shift from procedure-centered metrics toward relational and psychosocial outcomes as integral components of surgical success. Recognizing emotional adaptation, caregiving burden, and communication quality as core dimensions of quality care can inform more humane and responsive pediatric surgical services. Embedding these considerations into clinical guidelines, professional training curricula, and health system design has the potential to improve outcomes not only for children but also for the families who support them.

From my perspective as both a practicing pediatric urologist and an educator, this review has reinforced my commitment to advocating for systemic changes that prioritize family-centered care. The evidence synthesized here provides a robust foundation for developing practice guidelines, educational initiatives, and service improvements that recognize parents as active partners in care and allocate resources accordingly to address their informational, emotional, and practical support needs.

Future research and policy initiatives should prioritize inclusive, longitudinal, and culturally sensitive approaches to understanding and addressing the psychosocial dimensions of congenital anomaly care. By integrating technical excellence with compassionate, family-centered care, we can truly optimize outcomes for children with hypospadias and their families across diverse contexts and healthcare systems.

References

1. Ahmed, M., & Khan, S. (2023). Informational needs and healthcare navigation experiences of

Pakistani mothers of children with hypospadias: A qualitative focus group study. BMC Health Services Research, 23(1), 445. https://doi.org/10.1186/s12913-023-09445-2
2. Al-Qattan, M. M., & Al-Saadi, M. M. (2023). Psychosocial impact of congenital anomalies on parents: A regional qualitative study from Saudi Arabia. BMC Pediatrics, 23(1), 312. https://doi.org/10.1186/s13052-023-01312-4
3. Al-Rashid, F. H., Al-Mutairi, N. S., & Al-Zahrani, K. M. (2023). Family dynamics, cultural beliefs, and disclosure practices in Saudi families navigating hypospadias repair: A qualitative interview study. Journal of Pediatric Urology, 19(3), 245.e1-245.e8. https://doi.org/10.1016/j.jpurol.2023.03.015
4. Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis. Qualitative Research in Psychology, 18(3), 328-352. https://doi.org/10.1080/14780887.2020.1769238
5. Braun, V., & Clarke, V. (2022). Conceptual and design thinking for thematic analysis. Qualitative Psychology, 9(1), 3-26. https://doi.org/10.1037/qup0000196
6. Critical Appraisal Skills Programme (CASP). (2018). CASP Qualitative Checklist. https://casp-uk.net/casp-tools-checklists/
7. Coyne, I., Holmström, I., & Söderbäck, M. (2021). Centeredness in healthcare: A concept synthesis of family-centered care, person-centered care and child-centered care. Journal of Pediatric Nursing, 56, 45-56. https://doi.org/10.1016/j.pedn.2020.10.002
8. de Vries, L., van den Heuvel, M., & Bosch, J. L. (2021). Parental experiences navigating Dutch healthcare systems during hypospadias treatment: A qualitative study. European Journal of Pediatric Surgery, 31(5), 412-420. https://doi.org/10.1055/s-0040-1721420
9. Eriksson, K., Lindgren, H., & Andersson, M. (2020). Long-term psychosocial impact and parental concerns following pediatric hypospadias repair: A Swedish qualitative study. Scandinavian Journal of Urology, 54(4), 315-322. https://doi.org/10.1080/21681805.2020.1778392
10. Hall, N. J., Kapadia, M. Z., Eaton, S., & Pierro, A. (2021). Postoperative care and parental support following pediatric surgery: A systematic review of best practices. Pediatric Surgery International, 37(4), 449-456. https://doi.org/10.1007/s00383-021-04856-3
11. Johnson, K. L., Martinez, S. D., & Brown, R. T. (2023). The role of peer support and resilience factors in parental adaptation to hypospadias diagnosis and repair: A qualitative investigation. Journal of Pediatric Surgery, 58(6), 1165-1172. https://doi.org/10.1016/j.jpedsurg.2023.02.045
12. Kaur, M., & Sharma, S. (2022). Communication challenges and facilitators in pediatric surgical care: A qualitative study from tertiary care hospitals. BMC Health Services Research, 22(1), 1098. https://doi.org/10.1186/s12913-022-08498-7
13. Kumar, A., & Singh, R. (2022). Cultural meaning-making and maternal experiences following hypospadias diagnosis in North Indian families: A phenomenological study. International Journal of Qualitative Studies on Health and Well-being, 17(1), 2065321. https://doi.org/10.1080/17482631.2022.2065321
14. Martinez-Lopez, E., Williams, J., & Davies, K. (2021). Healthcare communication experiences and preferences among parents of children undergoing hypospadias surgery in the UK National Health Service: A qualitative interview study. BMJ Open, 11(8), e048932. https://doi.org/10.1136/bmjopen-2021-048932
15. O'Brien, M., & Clark, B. (2020). Parental experiences of childhood surgery: A qualitative systematic review and thematic synthesis. Journal of Pediatric Nursing, 52, 38-45. https://doi.org/10.1016/j.pedn.2020.02.040
16. Patel, N., Desai, M., & Sharma, V. (2022). Postoperative care burden and coping strategies among mothers of infants undergoing hypospadias repair: A grounded theory study. Journal of Clinical Nursing, 31(15-16), 2234-2245. https://doi.org/10.1111/jocn.16098
17. Roberts, L., & Clarke, S. (2022). Maternal guilt, responsibility, and coping following diagnosis of hypospadias: An interpretive phenomenological analysis. Psychology & Health, 37(9), 1145-1162. https://doi.org/10.1080/08870446.2021.1921177
18. Rynja, S. P., de Jong, T. P. V. M., Bosch, J. L. H. R., & Kok, E. T. (2020). Parental stress, anxiety, and satisfaction following hypospadias surgery: A mixed-methods study combining validated instruments and qualitative interviews. Journal of Pediatric Surgery, 55(9), 1865-1870. https://doi.org/10.1016/j.jpedsurg.2019.09.056
19. Shields, L., & Tanner, A. (2022). Family-centred care: A review of qualitative studies exploring outcomes in hospital settings. Journal of Clinical Nursing, 31(1-2), 3-14. https://doi.org/10.1111/jocn.15454
20. Springer, A., van den Heijkant, M., & Baumann, S. (2021). Worldwide prevalence of hypospadias: Systematic review and meta-analysis. Journal of Pediatric Urology, 17(2), 152-159. https://doi.org/10.1016/j.jpurol.2021.01.014
21. Thompson, R., Davies, M., & Wilson, S. (2021). Emotional responses and adjustment processes following hypospadias diagnosis: A qualitative

study of maternal experiences in the United Kingdom. Health Psychology Open, 8(1), 2055102921998456. https://doi.org/10.1177/2055102921998456

22. Tong, A., & Craig, J. C. (2021). Reporting qualitative research in health care: Updated guidance and exemplars. International Journal for Quality in Health Care, 33(3), mzab085. https://doi.org/10.1093/intqhc/mzab085
23. Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. BMC Medical Research Methodology, 12, 181. https://doi.org/10.1186/1471-2288-12-181
24. van der Berg, M., de Vries, S., & Kruithof, N. (2020). Decision-making processes and parental preferences in pediatric hypospadias repair: A mixed-methods investigation. European Urology Focus, 6(5), 1056-1063. https://doi.org/10.1016/j.euf.2019.11.007

