

## CONCEPTUAL FRAMEWORK FOR HYPOSPADIAS-SPECIFIC HEALTH-RELATED QUALITY OF LIFE

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**Background:** Hypospadias, or the presence of a urethral opening proximal to the glans penis, is surgically corrected with the goal of creating an orthotopic meatus and preserving voiding and ejaculatory function. Urologists and psychologists have begun to study health-related quality of life (HRQoL) to understand the implications of hypospadias for psychosocial, behavioral, and sexual development. However, this research has been piecemeal, as there is no hypospadias-specific model for HRQoL. To fill this gap, we synthesized the existing literature relevant to HRQoL in hypospadias to create and introduce a new conceptual framework for hypospadias-specific HRQoL.

**Materials/Methods:** We conducted a comprehensive literature review to identify the concepts relevant to HRQoL in hypospadias. Our literature search in Embase and Pubmed used the key word "hypospadias" in combination with "quality of life" and "patient-reported outcomes." We then retrieved and investigated the commonly identified domains by subject. To design a conceptual framework for hypospadias-specific HRQoL, we summarized the research in each domain and highlighted areas of overlap that supported a unitary HRQoL conceptualization.

**Results:** We identified five domains related to HRQoL for youth with hypospadias: penile appearance, voiding, social interaction, sexual health, and psychological or behavioral function. Most survey studies focused on specific aspects of HRQoL, with less study of the psychosocial or sexual aspects of HRQoL. We now propose a unifying conceptual model of hypospadias-specific HRQoL based on these 5 domains and their areas of overlap. In our review, we also noted that the quality of previous research is limited by the lack of available measurement tools designed to assess experiences relevant to living with hypospadias.

**Conclusions:** Evaluation of hypospadias-specific HRQoL has been challenging due to the absence of a guiding conceptual model and a lack of validated measures designed for the concerns of this patient population. Our new Hypospadias HRQoL Model can be the theoretical foundation for the development of a hypospadias-specific HRQoL metric, and thereby drive research and clinical care practices that optimize the aspects of living with hypospadias from childhood through adulthood.