Conceptual Framework for Hypospadias-Specific Health-Related Quality of Life

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BACKGROUND

- Hypospadias is the presence of a urethral opening proximal to the glans penis
- Occurs in 1/300 live male births worldwide [1]
- Urologists and psychologists have begun to study the implications of hypospadias and hypospadias repair for psychosocial, behavioral, and sexual development.[2, 3]
- Research has been piecemeal
  - no conceptual framework of health-related quality of life (HRQOL) specific to youth with hypospadias exists to guide work

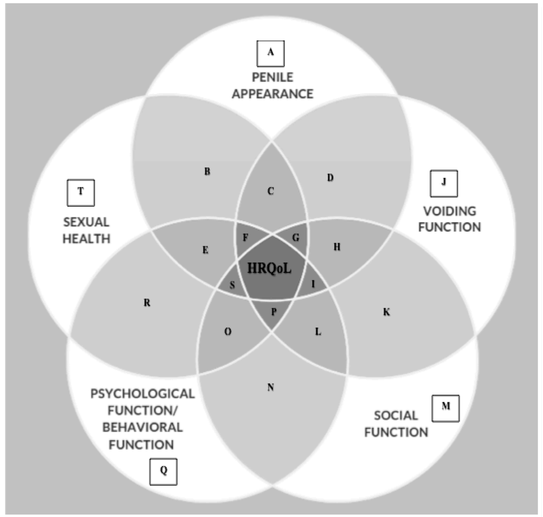
PURPOSE

To introduce a new conceptual framework for hypospadias-specific HRQoL to guide future research and counseling approaches for patients with hypospadias.

METHODS

- Conducted a comprehensive literature review
  - search in Embase and Pubmed
  - key words:
    - "hypospadias"
    - "quality of life"
    - "patient-reported outcomes"
- Further investigations of commonly identified domains by subject
- We designed conceptual framework representing hypospadias-specific HRQoL
  - Literature review results
  - review of HRQoL literature in other pediatric populations (spina bifida)

Fig 1 Conceptual Framework:



Description: The figure displays the domains that comprise hypospadias-specific HRQoL and their areas of overlap. In this model, we suggest that the intersections of all domains, in addition to the domains themselves, comprise HRQoL, labeled in the center of our diagram.

Fig 3: Intersecting Concepts/Concerns

Intersecting Concerns
• Fear of Pursuing Relationships Related to Penile Appearance (Area B)
• Sitting to Void due to Penile Appearance (Area D)
• Self-Esteem Related to Penile Appearance (Area E)
• Fear of Participating in Sports or Group Activities due to Penile Appearance (Area H)
• Fear of Using Public Restrooms or Change Rooms (Area I)
• Avoidance of Public Restrooms due to Altered Urinary Stream (Area K)
• Fear of Ridicule/Teasing Related to Voided Stream (Area L)
• Missed Days of School Due to Stress of Hypospadias/Mental Health (Area N)
• Marriage/Partnering Practices, Paternity Rates (Area O)
• Inhibition in Sexual Contact (Area R)
• Fear/Worry/Stress related to Penile Appearance (Area S)

Fig 2: Concepts Central to the Hypospadias-Specific Domains

Domains of HRQoL[t]	Domain-Specific Concerns
Penile Appearance (Area A)	Glans Shape/Location* Meatal Shape/Location* Flaccid Penile Size/Length* Penile Thickness* Erection* Curvature Fistula* Skin arrangement* Scars* Scrotum/Testes* General Appearance*
Voiding Function (Area J)	Satisfaction with Urinary Function Stream Quality* Spraying* Post-Void Dribbling Position During Voiding Maximum Flow Straining Incomplete Emptying Frequency Urgency Nocturia
Social Function (Area M)	Participation in Clubs/Sports Embarrassment Performing in Public Close Friendship Job employment Social Adjustment
Sexual Health/ Function (Area Q)	Masturbation Frequency Erectile Function Masculinity or Sexuality Ejaculatory Function Satisfaction Intercourse Frequency
Psychological/Behavioral Function (Area T)	Anxiety Depression Coping mechanisms/Stress Management Self-Esteem Externalizing/Internalizing Behaviors

Description:
- Currently included in a validated, hypospadias-specific measure

[t] Corresponding Areas in Figure 1 are labeled

RESULTS

- 56 studies identified and reviewed in detail
- 5 routinely studied domains for youth with hypospadias:
  - Penile appearance (20 studies)
  - Voiding function (6 studies)
  - Social function(19 studies)
  - Psychological or behavioral function (9 studies)
  - Sexual health (17)
- Penile appearance (Area A) was the most-studied hypospadias-specific patient-reported outcome
  - Fewer studies focused on voiding and psychological function
- Non-validated hypospadias-specific surveys suggested many concerns exist within the intersections of these domains

CONCLUSION

- Conceptual Framework: A novel first step towards understanding hypospadias-specific HRQoL
- Provides a biopsychosocial map to better visualize the effects of hypospadias on day-to-day life
- A guide for surgical, clinical, and behavioral interventions that aim to improve quality of life outcomes for hypospadias patients.

REFERENCES

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