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Wendy Jo Svetanoff
Children's Mercy Hospital

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Psychosocial Factors Affecting Quality of Life in Patients with Anorectal Malformations and Hirschsprung's Disease – A Qualitative Systematic Review

Wendy Jo Svetanoff MD MPH; Christina Low Kapalu PhD; Joseph J Lopez MD; James A Fraser MD, Kayla B Briggs MD, Rebecca M Rentea MD MS

Children's Mercy Kansas City; University of Missouri Kansas City School of Medicine

Introduction

- Great strides have been made for
 - 1) anorectal malformations (ARM)
 - 2) Hirschsprung disease (HSCR)
- Little is known about psychosocial and behavioral factors that impact quality of life (QoL).

Aim

- Highlight themes that affect QoL of patients with ARM or HSCR:
 - Psychosocial
 - Emotional
 - Behavioral Wellbeing

Methods

- Literature Review
- 1980 – 2019
- PubMed and CINAHL databases
- Inclusion Criteria:
 - Patients 0-21 years old
 - Article in English
 - Focused on Quality of Life



Results

Infancy

Concerns

- Fears about the future
- Frustration from lack of provider information
- Mother-infant separation
- Lack of social and home-health support

Recommendations



- Clear, complete and frequent communication 
- Encourage bonding, holding, and performance of cares 
- Social work and resource assistance

Childhood

Concerns

- Anxiety
- Problems with peer relationships
- School absenteeism
- Behavior problems

Recommendations



- Psychosocial GI support
- Discussion on barrier to play and socialization 
- Evaluation of resources, school plans 
- Medical therapy needs

Adolescence

Concerns

- Depression
- Low self-esteem
- Poor body image
- Development of autonomy over disease
- Difficulties in school
- Psychiatric disorders

Recommendations


- Supervised peer support networks
- Discuss how to talk to peers about diagnosis 
- Behavior Testing
- IEP or 504 school plans 
- Psychosocial treatment and support

Young Adulthood

Concerns

- Anxiety about personal relationships
- Limitations in sexual function
- Reproductive capabilities
- Transitioning to adult care

Recommendations

- Patient-private discussions about reproductive health 
- Early step-wise initiation and planning for transitional care
- Frequently revisit transition plan

Conclusion

- Multiple psychosocial issues and stressors are present.
- Medical, psychological, and community-based supports are required at all ages.
 - Addressing stressors provide resilience and an improved quality of life.