

Health-Related Quality of Life and Psychosocial Well-Being among Children with an Enterostomy – A Scoping Review

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Background:

Although most enterostomies formed in childhood are reversed, the time frame with an enterostomy may range from months to years. Adult studies have found that having an enterostomy can negatively impact body image and cause psychological distress, even when patients perceive the ostomy as life-enhancing.

Aims:

- To map the available evidence about the impact of enterostomies on the Health-Related Quality of Life (HRQOL) and psychosocial health of children
- To identify potential research gaps.

Methods:

PRISMA-Scoping Review guidelines were adhered to. A broad literature search was conducted in Pubmed, Embase, Cochrane Library and PsychInfo, including all studies from inception until May 30, 2024. Studies were reviewed individually by two members of the team for inclusion/exclusion based on predefined criteria. Quality assessment of the included studies was conducted using the Quality Appraisal for Diverse Studies (QuADS) tool. Baseline data and a summary of results relating to HRQOL/psychosocial health was gathered for each study.

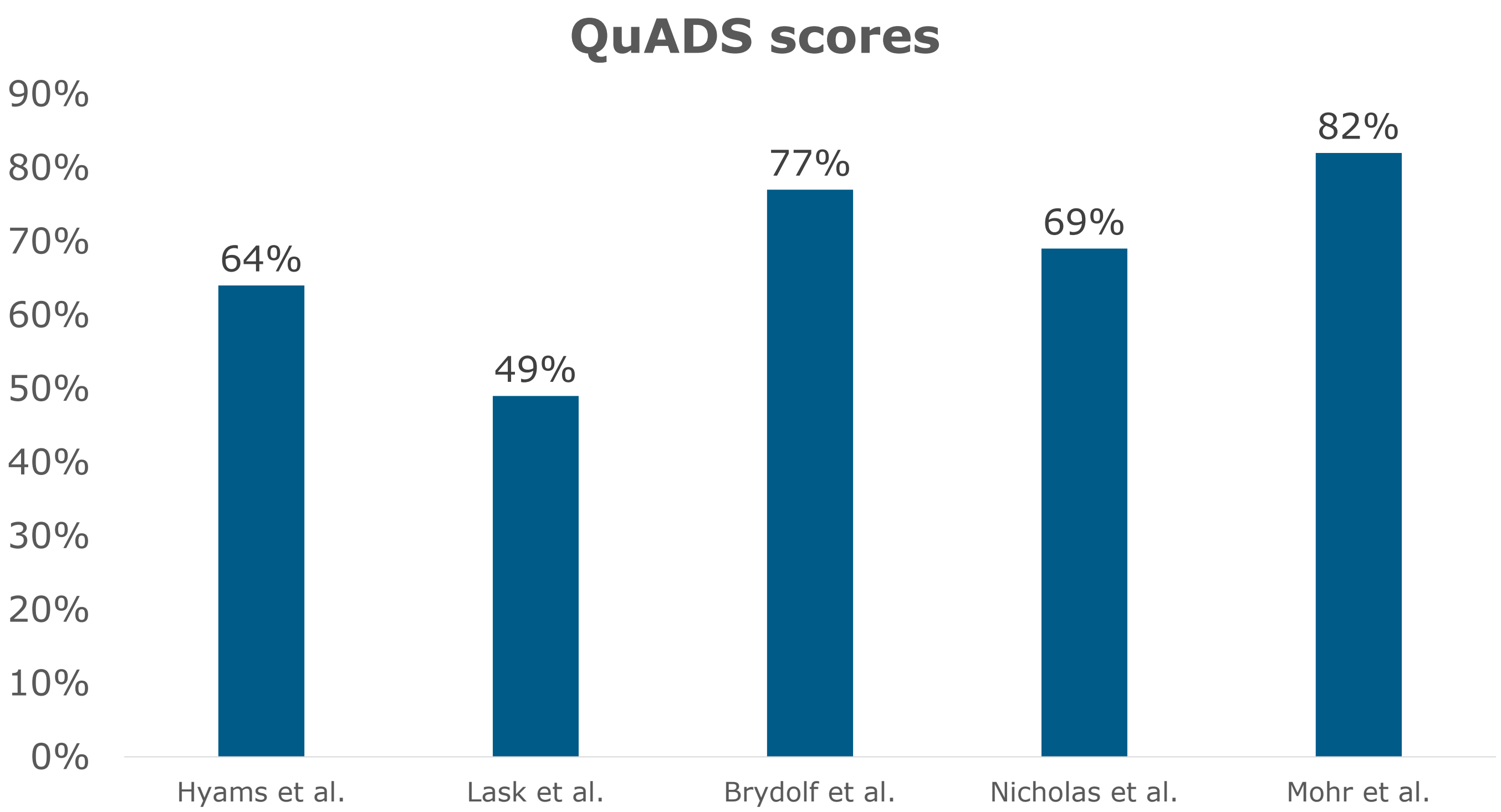
Author	Year	Design	Location	Patients	Methods/ Measures
Hyams et al.	1982	Quantitative	USA	32	Mail questionnaire
Lask et al.	1987	Mixed methods	UK	38	Validated questionnaires, Semi-structured interviews
Brydolf et al.	1996	Qualitative	Sweden	28	Semi-structured interviews
Nicholas et al.	2008	Qualitative	Canada	20	Semi-structured interviews
Mohr et al.	2016	Qualitative	USA	10	Semi-structured interviews

Results:

Of 1813 studies screened, five were included, all conducted in the Western part of the world and published between 1987-2016. The studies were heterogenous in methodology and varied in quality, with QuADS scores ranging between 49%-82% of the maximum possible score. The number of patients in each study ranged from 10-38. Although the evidence is limited, several of the studies described a process of initial isolation after enterostomy surgery, low self-esteem, and dependence, followed by increasing confidence and acceptance alongside increasing independence with the ostomy care.

Conclusion:

Although scarce and of varying quality, the evidence available suggests that children and adolescents may go through a challenging time after ostomy surgery. More importantly, this scoping review has highlighted a critical gap in the literature, underscoring the need for further research to inform better care and support for paediatric ostomy patients.



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