



## Long-term Outcome of Hirschsprung Disease: Impact on Quality of Life and Social Condition at Adult Age

Submitted by Stéphanie Pinot on Thu, 06/06/2019 - 10:04

Titre	Long-term Outcome of Hirschsprung Disease: Impact on Quality of Life and Social Condition at Adult Age
Type de publication	Article de revue
Auteur	Drissi, Farouk [1], Meurette, Guillaume [2], Baayen, Corine [3], Wyart, Vincent [4], Crétolle, Célia [5], Guinot, Audrey [6], Podevin, Guillaume [7], Lehur, Paul-Antoine [8]
Editeur	Lippincott Williams & Wilkins
Type	Article scientifique dans une revue à comité de lecture
Année	2019
Langue	Anglais
Date	Juin 2019
Numéro	6
Pagination	727-732
Volume	62
Titre de la revue	Diseases of the colon and rectum
ISSN	1530-0358

**BACKGROUND:** Hirschsprung disease is a rare congenital disease typically requiring surgical treatment during childhood. Quality of life and social condition at adult age can be impaired by disease-specific sequelae.

**OBJECTIVE:** This study aimed to assess the quality of life and social outcome of adult patients operated on for Hirschsprung disease during childhood.

**DESIGN:** Patients operated on for Hirschsprung disease during childhood were identified and specific questionnaires were sent to them.

**SETTINGS:** Data from 2 referral centers were used.

**PATIENTS:** Patients who completed the questionnaires regarding quality of life and social condition were included.

**MAIN OUTCOME MEASURES:** The Hirschsprung's Disease and Anorectal Malformations Quality of Life disease-specific questionnaire (8 dimensions explored; each scored from 0 to 100 maximum score) and a sociodemographic questionnaire were sent to identified patients. Sociodemographic data were compared with those of the French general population.

**RESULTS:** Thirty-four patients had Hirschsprung disease (men, 76%; mean age, 32 years) were included in the study. Mean total Hirschsprung's Disease and Anorectal Malformations Quality of Life score was 611 of 800 (maximum score 800). The 2 most impaired dimensions were "physical symptoms" and "diarrhea" (62.9/100 and 73.6/100). Fecal continence was only marginally affected (mean score, 89/100). Patients with Hirschsprung disease achieved better educational levels than the French general population. Parental and marital status did not differ between the 2 groups.

**LIMITATIONS:** This study had the limitations inherent to a retrospective study.

**CONCLUSION:** The quality of life of adult patients with Hirschsprung disease sequelae is marginally impaired in this study. Despite the consequences of this congenital abnormality, the condition eventually achieved can be considered as satisfactory. See Video Abstract at <http://links.lww.com/DCR/A917> [9].

Résumé en anglais

URL de la notice

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DOI

10.1097/DCR.0000000000001363 [11]

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Titre abrégé

Dis. Colon Rectum

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## Liens

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[13] <http://www.ncbi.nlm.nih.gov/pubmed/30807458?dopt=Abstract>

