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Thesis available via Biblio or on request via e-mail

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RECTAL CANCER SURVIVORS CONFRONTED WITH LOW ANTERIOR RESECTION SYNDROME (LARS)

Quality of life, experiences and needs of patients,
informal caregivers and healthcare professionals



Eva Pape

More sphincter-saving procedures are feasible in the treatment of rectal cancer due to neoadjuvant chemoradiotherapy and improved surgical techniques. Afterwards, patients are often confronted with **low anterior resection syndrome (LARS)**. LARS is characterized by various bowel problems and a variable and unpredictable bowel function. The etiology of LARS is multifactorial and different risk factors may aggravate the symptoms. Moreover, there is no gold standard in treatment. LARS has a major impact on the lives of patients and informal caregivers. In addition, there is a lack of knowledge and understanding among healthcare professionals (HCPs). More in-depth knowledge from the perspective of various stakeholders on how to organize care for patients with major LARS and their informal caregiver is needed.

Study 1: Systematic review to identify and synthesize the experiences and needs of patients with rectal cancer confronted with bowel problems after stoma reversal.

Study 2: cross-sectional study to assess the relationship between LARS and quality of life (QoL). In patients with major LARS, therapeutic management options were explored.

Studies 3 & 4: Grounded theory to explore the experiences and needs of rectal cancer survivors confronted with major LARS and their informal caregivers.

Study 5: Focus group study to explore the experiences of healthcare professionals on how to provide, organize and optimize care for patients with LARS from an interprofessional perspective.

Results



Patients

- Major LARS is closely associated with QoL
- Uncertain what to expect after surgery
- Need for information before surgery varies according to their coping mechanism
- LARS has a physical and emotional impact
- Trajectory of hope for improvement
- Loneliness in different layers
- Trial and error to manage it (mostly conservative measures)
- Need for recognition of its impact and clarification of the evolution by HCPs.
- Need for proactive counseling
- Need for an easy accessible and approachable HCP



Informal caregivers (partners)

- Partners failed to live a normal life
- Felt that they were standing at the side line
- Loneliness in different layers



Healthcare professionals

- Little attention for LARS
- No standardized approach
- Suggestion of 3 levels of care optimization
 - Information before surgery. Attention for the correct timing.
 - Counseling when confronted with LARS
 - Organization of care



Curriculum Vitae

Education

- 2006-2009: Bachelor of science in Nursing
- 2010-2013: Master of science in Nursing & Midwifery
- 2012-2013: Postgraduate oncology (BBT)
- 2017-Present: PhD student

Work experience

- 2009-2012: General surgery/neurosurgery HC
- 2012-2014: General surgery/neurosurgery HC –Oncology Nurse Navigator (ONN) Digestive Oncology
- 2014-2016: ONN Digestive Oncology – Study Nurse gastrointestinal surgery
- 2017-2018: ONN Digestive Oncology – PhD student
- 2019-Present: CNS Digestive Oncology – PhD student

Publication of this thesis

- **Pape, E.,** Pattyn, P., Van Hecke, A., Somers, N., Van de Putte, D., Ceelen, W., Van Daele E., Willaert W., Geboes K. & Van Nieuwenhove, Y. (2021). *Impact of low anterior resection syndrome (LARS) on the quality of life and treatment options of LARS—A cross sectional study.* Eur J Oncol Nurs. 50, 101878.
- **Pape, E.,** Vlerick, I., Van Nieuwenhove, Y., Pattyn, P., Van de Putte, D., van Ramshorst, G. H., Geboes K. & Van Hecke, A. (2021). *Experiences and needs of patients with rectal cancer confronted with bowel problems after stoma reversal: A systematic review and thematic-synthesis.* Eur J Oncol Nurs 54, 102018.
- **Pape, E.,** Decoene, E., Debrauwere, M., Van Nieuwenhove, Y., Pattyn, P., Feryn, T., Pattyn P.R.L., Verhaeghe S. & Van Hecke, A. (2022). *The trajectory of hope and loneliness in rectal cancer survivors with major low anterior resection syndrome: A qualitative study.* Eur J Oncol Nurs. 56, 102088.
- **Pape, E.,** Decoene, E., Debrauwere, M., Van Nieuwenhove, Y., Pattyn, P., Feryn, T., Pattyn P.R.L., Verhaeghe S. & Van Hecke, A. (2022). *Information and counselling needs of patients with major low anterior resection syndrome: A qualitative study.* J Clin Nurs.
- **Pape, E.,** Van Haver, D., Lievrouw, A., Van Nieuwenhove, Y., Van De Putte, D., Van Ongeval, J. Rogge S. & Van Hecke A. (2022). *Interprofessional perspectives on care for patients with low anterior resection syndrome: a qualitative study.* Colorectal Dis.
- **Pape, E.,** Decoene, E., Debrauwere, M., Van Nieuwenhove, Y., Pattyn, P., Feryn, T., Pattyn P.R.L., Verhaeghe S. & Van Hecke, A. (2022). *Experiences and needs of partners as informal caregivers of patients with major low anterior resection syndrome: A qualitative study.* Eur J Oncol Nurs, 102143.