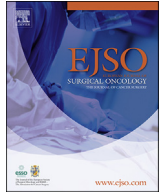




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## What you should know about the low anterior resection syndrome – Clinical recommendations from a patient perspective

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### ABSTRACT

*Introduction:* Functional bowel complaints, referred to as Low Anterior Resection Syndrome (LARS), are common after sphincter-saving surgical procedures and have a severe impact on quality of life (QoL). Care for LARS patients is complex and surgeons underestimate or misinterpret its associated symptoms. This study aimed to explore the impact of LARS from a patient perspective facilitating the construction of a set of recommendations improving current care stratagems.

*Methods:* In a non-academic Dutch teaching hospital, three focus group sessions were conducted with 16 patients (males = 50%) who had undergone colorectal surgery between 2012 and 2017. A trained moderator orchestrated patient-discussion regarding illness perception and health-care needs. Transcripts were analysed using inductive content analysis.

*Results:* Three themes were identified: illness perception, preoperative care and postoperative supportive care. Specific attention and screening for LARS is deemed necessary for breaking the taboo surrounding it. Extension of preoperative counselling on the normal postoperative course, including ways to optimize social support, were identified as crucial. After discharge, patients experienced a lack of supportive care regarding functional complaints and did not know who to counsel. In addition, they felt intrinsically motivated to actively prepare for surgery, i.e. by participating in prehabilitation programs.

*Conclusion:* Exploring perspectives in LARS patients resulted in the identification of potential improvements in current care pathways. Recommendations on ways to improve information provision, screening of LARS and methods to intervene in the gap of supportive care after discharge are presented. We recommend to implement these measures as QoL of patients undergoing colorectal cancer surgery may be improved.

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### Introduction

Advances in surgical techniques as well as optimal locoregional and systemic treatment options have improved survival after rectal or distal sigmoid cancer surgery [1]. These surviving patients have to live with the aftermath of their disease and treatment [1,2]. Long-term outcome and quality of life (QoL) after cancer treatment are therefore becoming an increasingly important focus of care. Low anterior resection (LAR) with total mesorectal excision (TME) is now

the gold standard for the treatment of non-disseminated rectal or distal sigmoid cancer. However, symptoms such as faecal incontinence, urgency and frequent bowel movement are frequently seen after this procedure [3]. These listed symptoms, collectively referred to as Low Anterior Resection Syndrome (LARS), occur in 70–90% of patients and have a severe adverse effect on the QoL [4–6].

The LARS score is often used as rapid screening instrument to objectify this syndrome and is considered to cover complaints that disturb patients the most (appendix A: LARS score) [7]. While no standard treatment is currently available, multiple treatment options are being used which include probiotics, medication, pelvic floor therapy, sacral nerve stimulation and trans-anal irrigation [8]. Although the severity of the LARS syndrome may lessen during recovery from treatment, nearly half of patients become “toilet-dependent” and report severe constraints on social life, work and physical functioning [3,9,10]. Therefore, adequate preoperative

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counselling is essential for patient education to be effective [11]. Satisfaction with information and active patient engagement leads to better QoL and better psychosocial outcomes [12]. Earlier studies showed that many patients are willing to engage in a discussion on the balance between the benefits of treatment (in terms in local recurrence and survival) and the possible complications (a higher risk of bowel dysfunction) [13–15].

In patients at risk for LARS, a large part of the recovery process occurs at home where guidance from health-care professionals is minimal. To adapt physically and psychologically, patients have to rely on the information they are given during preoperative counselling, hospital stay and follow-up appointments. Adequate post-operative guidance is therefore also of vital importance for patients in coping with the consequences of cancer treatment and surgery [16].

Adopting a patient perspective is of utmost importance for proper identification of key intervention points in the current colorectal care pathway. A valid method to achieve such goals is the conduction of focus groups [17]. This type of qualitative research has become increasingly popular in the realm of needs assessment. It allows investigators to look beyond quantitative data that might be obtained via questionnaires/surveys studies and broadens the scope of research [18–20]. These focus groups are preferred above semi-structured interviews because patients are encouraged to discuss with peers. By doing so, the information obtained is less influenced by preconceived thoughts of medical experts and makes it possible to capture the full range of aspects of this complex health-care problem.

This study aims to elucidate the ways and extent to which LARS affects the QoL in patients after rectal surgery. Using this information, we aim to identify key intervention points in the current pathway to improve patient QoL.

## Methods

### Study population

Three 2-h focus group meetings were organized in April 2017 with patients treated between 2012 and 2017 at the Máxima Medical Centre in Veldhoven (the Netherlands). Patients treated with a low anterior resection for rectal or distal sigmoid malignancy were included, regardless any additional treatment or presence of major LARS. All eligible patients were approached for participation during regular follow-up appointments in the surgical outpatient clinic. For each focus group session, eight former patients were approached to achieve the optimal number of 5–8 participants for sessions to be effective [17]. In the end, 16 patients participated. Patients were excluded when they had a stoma at time of inclusion, recurring disease or difficulty understanding or participating in the focus groups due to linguistic barriers or severe dementia.

The focus groups were organized at the treating medical centre, without presence of treating staff. The aims of the study and procedures were explained at the start of a session. Patients were given the opportunity to report on various aspects of their experience with LARS. Subsequent discussions were led by a certified trained moderator. The categories for the issues reported by participants were established after the first two focus groups and subsequent discussions were used to add further detail to the information in these categories. Nevertheless, the specific content of the discussion was mainly based on patient input. Patients were encouraged to discuss topics amongst themselves, facilitating a form of “structured eavesdropping” for the investigators [17]. When two consecutive focus groups failed to generate new issues, no further sessions were scheduled [18]. Sessions were recorded and at the end of each session, the patients were asked to complete a form

with several additional questions covering marital status, the LARS score, and the evaluation of the focus groups.

## Statistical analysis

Data were analysed using inductive content analysis. This qualitative approach is useful for the analysis of written, verbal or visual communications [21,22]. After every session, an initial analysis was made. Tapes of the discussions were transcribed by one of the investigators using the transcription software F4-Transcript. The moderator of the focus groups (GT) and a second investigator (JvdH) analysed the tapes and transcribed documents independently. All assessments were clustered in categories and participant input was processed using these categories. Where there were disagreements, the opinion of a third person (SM) was sought to arrive at a decision. Final recommendations were member-checked with participants. Patient characteristics were presented with medians and interquartile ranges or means and standard deviations depending for their distribution.

## Results

### Participants

Three focus-group discussions, which existed of 5–6 patients, were conducted. Participants were between 60 and 87 years old, with a median age of 69 years. Gender was equally distributed. Median time between operation and focus group date was 12 months (IQR 30.5). Approximately half of the patients received additional treatment and sixty-two percent of the patients had a protective stoma, with a median time to reversal of 92 days (7–196 days, IQR 162). A substantial proportion (40%) of the participants had major LARS at the time of the discussions, see Table 1 for all patient characteristics.

Analysis of the transcripts resulted in the identification of three broad themes illness perception, preoperative and postoperative supportive care. The results are described below for these themes, accompanied by quotations from the participants. Different speakers in dialogues between the participants are shown as A or B. As a result, all feedback and suggested changes in the colorectal care pathway are summarized in Fig. 1.

### Theme 1: illness perception

Patients reported a severe impact on psychosocial functioning as a result of LARS. In particular, the combination of clustering, urgency and high frequency had a major effect on daily functioning.

*- I had to go to the toilet 15 to 23 times, and at once! So I wasn't able to go out of the front door.*

Several patients referred to depressive symptoms as a result of these limitations:

*- 20 times a day was the minimum [...] I could not go out for a walk, nothing was possible. Shopping? I did not dare to think of it. So then you stay at home. That gets you a bit depressed.*

Even within the boundaries of their own home, patients described impaired functioning:

*- It happened to me that I was sitting on the couch and that I felt the urge and could not make it to the toilet.*

*- I had to get an extra toilet installed for when I had to go (defecate) during the night.*

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