



Enhancing support for patients with low anterior resection syndrome: insights and educational resources from the LARSCAT project

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Abstract

Purpose To address the educational gaps and support needs of patients with low anterior resection syndrome (LARS) following rectal cancer surgery. The LARSCAT project aimed to develop comprehensive resources to better inform patients and enhance their quality of life.

Methods A qualitative study was conducted between November 2022 and March 2023. Seven focus groups were formed, including six patients, two surgeons, and three nurses. Patients had undergone rectal cancer surgery with stoma reversal 2 to 12 years earlier, and all experienced major LARS. The focus groups, held in-person and online, explored the impact on daily life, social and sexual health, mood, rest, and relationships. Thematic analysis was performed to identify key issues and support strategies following the COREQ guidelines.

Results Participants reported insufficient information regarding potential dysfunctions after rectal cancer surgery, and difficulties finding reliable information online. The timing of receiving information varied according to individual coping mechanisms. LARS symptoms significantly impacted daily life, social activities, sexual health, and mood. Patients emphasised the need for more tailored information and supplementary written materials to read at their own pace. Consequently, three comprehensive documents were created and made available online.

Conclusion This study highlights a significant gap in patient education on the long-term effects of rectal cancer surgery. The resources developed by the LARSCAT project aim to provide essential support to patients and healthcare professionals. Future research should focus on integrating these resources into routine care and evaluating their impact on patient outcomes and quality of life.

Keywords Low anterior resection syndrome · Rectal cancer · Bowel dysfunction · Patient education · Quality of life · Support resources

Introduction

Colorectal cancer is the third most common cancer worldwide [1], with incidence rates among adults younger than 50 increasing in several high-income countries [2]. Advancements in early detection and treatment have significantly improved the overall survival rate of rectal cancer [3], leading to a growing population of cancer survivors. Additionally, improvements in surgical techniques and oncological treatments have also resulted in more sphincter-preserving surgeries for rectal cancer. However, patients' lives rarely return to normal due to potential bowel dysfunction, known as low anterior resection syndrome (LARS), which is characterised by variable and unpredictable bowel symptoms,

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including increased frequency, urgency, incontinence, and clustering [4]. LARS can significantly affect patients' lifestyles, quality of life, and mental health, and may also result in financial burdens depending on the healthcare system [5–7].

The development and publication of the LARS score [8], a simple screening questionnaire for LARS, underscored the importance of evaluating functional outcomes after rectal cancer surgery. It is estimated that between 50 and 90% of patients experience some degree of postoperative bowel dysfunction after rectal resection [9]. Recent meta-analyses including only studies using the LARS score report a prevalence of major LARS of 41% [10] and 44% [11]. Despite suboptimal functional outcomes, many patients choose to endure these outcomes to avoid living with a permanent colostomy. Therefore, it is essential to thoroughly inform patients about LARS before surgery, identify those affected, and provide them with optimal support to ensure the best possible quality of life [12].

To meet these needs, the LARSCAT project was initiated by an interdisciplinary group from the Catalan Society of Surgery to address various aspects of LARS including patient education, detection, evaluation, and treatment. The primary goal was to develop a comprehensive information resource for patients undergoing surgery for rectal cancer. To achieve this, a qualitative study was conducted to evaluate the informational needs and coping strategies of LARS patients.

Methodology

Study design and participants

Seven focus groups were formed, including six patients (three women and three men, aged 42 to 61 years with a mean age of 54), two surgeons (YR, AMD), and three nurses (CR, LR, MR). All patients had been operated by surgeons not involved in the focus groups, with stoma reversal performed between 2 and 12 years earlier. At the time of the discussions, all participants were experiencing major LARS [8]. Participants were chosen through healthcare contacts and had been treated at different hospitals. The snowball sampling method was used to ensure a representative sample profile.

The focus groups were led by a nurse with qualitative research expertise (CR) to gather information from patients, identify unmet needs, and understand coping strategies. The discussion guide for the focus groups is found in Appendix 1 (Supplementary material).

Seven focus groups were conducted between November 2022 and March 2023, consisting of two in-person meetings and five online sessions, all held outside the hospital.

The online meetings, conducted via Zoom, accommodated participants from different localities. Each online session lasted approximately 1 h and 15 min, was recorded, and then transcribed. The in-person meetings lasted 2 h.

Data collection and analysis

Data collection involved using notebooks and video recordings. The analysis process included reading and re-reading the transcriptions, categorising meanings, and validating both the transcriptions and their interpretations. The information from the focus groups was transcribed by a study team member following standard transcription practices. These transcriptions were reviewed by all members of the team and validated by the participants. The qualitative data were reported following the COREQ guidelines [13] (Appendix 2, Supplementary material).

Information was categorised into topics, achieving data saturation across all categories. The thematic areas addressed included the impact and adaptive strategies related to daily life, social life, sexual life, rest, mood, and family and personal relationships. The final version of the document was reviewed twice and approved by the entire group. Fig. 1 summarises the study methodology.

Research team and reflexivity

The interviews were conducted by YR (surgeon) and CR (nurse). The focus groups were led by CR, who has expertise in qualitative research and had no prior relationship with the participants. YR, AMD, FM, and MJT have extensive expertise in LARS. LR and MR are nurses specialising in the detection and conservative management of patients with LARS. AMD, LR, and MR also participated in the focus groups.

Ethical approval

This study did not require formal ethical approval, as it involved voluntary focus groups with verbal consent obtained from all participants, who were fully informed about the study's purpose and procedures.

Results

Patient-reported experiences and needs

Information gaps

The participating patients felt adequately informed about cancer treatment but noted insufficient information on

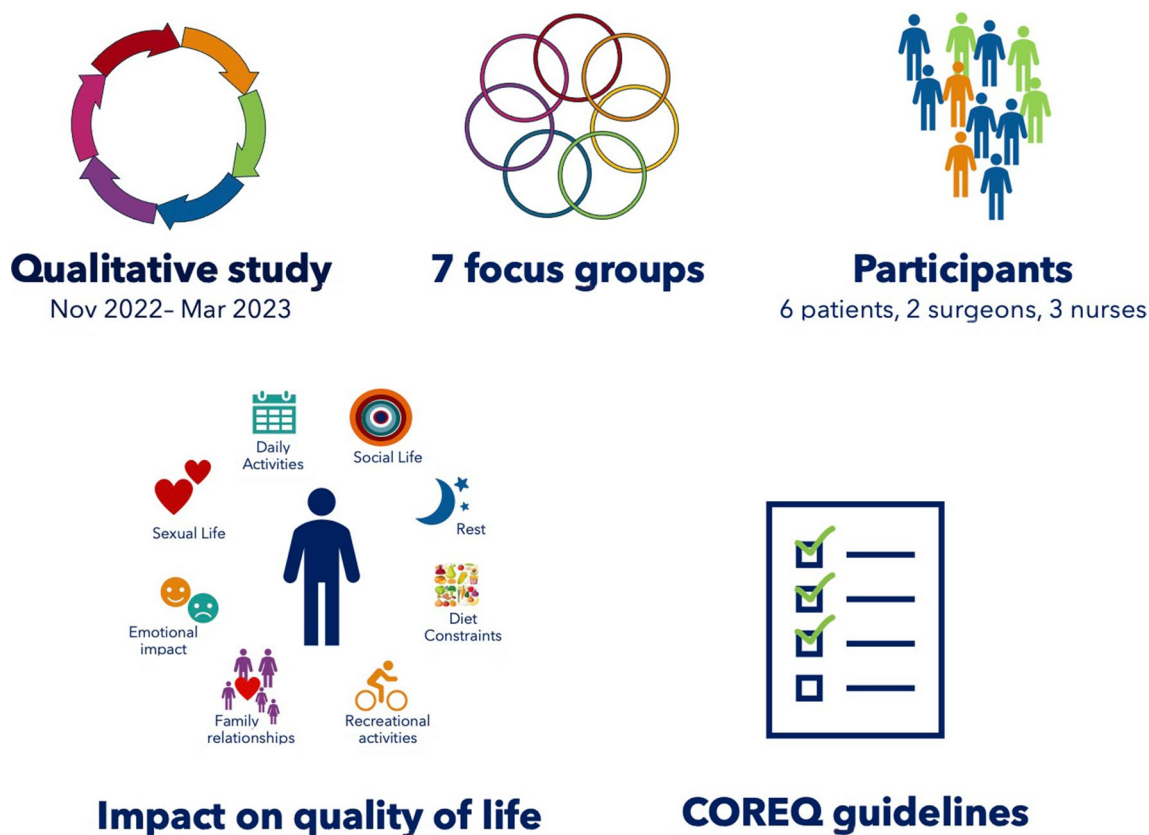


Fig. 1 Summary of study methodology

potential dysfunctions after surgery and how to manage them. They also emphasised the difficulty of finding reliable online resources.

Timing for receiving information

Preferences about the optimal timing for receiving information varied: two patients felt they should have been informed earlier to prevent unrealistic expectations, while four found receiving all the information at once would have been overwhelming.

Impact on daily and social life

Participants reported that a combination of symptoms—mainly fragmented defecation, defecatory urgency, and increased frequency of bowel movements—significantly impacted their daily lives and overall quality of life. They expressed difficulties in making appropriate dietary choices, and occasionally abstaining from eating before leaving home. To avoid uncomfortable and embarrassing situations, they planned outings around the availability of public toilets,

with some choosing to stay home rather than risk not finding a toilet when needed.

Patients also reported that LARS restricted social and recreational activities, such as dining out, engaging in sports, or attending events. Such situations can lead to social isolation, as exemplified by two participants who had scarcely left their home for 2 years. Quotes from patients are shown in Table 1.

Impact on sexual life

With respect to sexual health, men expressed uncertainty about whether erection difficulties were due to physical or psychological factors (due to fears and overplanning), or a combination of both. Women reported issues with lubrication. Both men and women shared concerns that resulted in avoidant behaviours and reduced libido.

Impact on sleep and emotional well-being

Sleep quality was often compromised, particularly for those needing to use the toilet multiple times at night. Emotional lability and mood swings were common, with activity

Table 1 Quotes from patients**Leisure and social life**

“Travelling is a hassle, just the idea of being stuck in traffic and needing a toilet—what do you do?”

“My friends make things easier when it comes to doing things, which really helps me relax. They say, ‘If we go by car, don’t worry; we’ll stop halfway, we’ll look for a room with a private bathroom,’ etc.”

Sex life

“I’m scared about having a leak, or if I’m clean enough, even if I really trust my partner”

“Everything ends up being very planned, nothing passionate or impulsive. This also affects the partner, who gets used to the situation, and the excitement gradually fades”

“Your libido drops, and you lose interest in everything. I had a partner, but everything got more complicated, and eventually, you start wondering whether you even want to have sex. You’re not sure if it’s because of the situation or if you’re losing interest in your partner. It’s more than just having sex or not”

“If you stop having sex and your partner is very understanding, they end up getting used to it. You might start wondering if your partner still desires you, if they still find you attractive, etc.”

“It’s impossible for someone who hasn’t been through this to understand our situation. If I thought about starting a new relationship, I think I’d struggle with this aspect, so now I hold back; I prefer to focus on myself.”

Mood

“My mood depends on how my stomach feels: if I need to go to the toilet at the start of the day, it affects everything. The days I don’t need to go are fantastic. I’ve learned to enjoy these moments.”

“Deep down, it’s like grieving the loss of the independence we had before cancer, and that affects your mood.”

“You have to constantly keep your mind and fears in check.”

Family and personal relationships

“You go through many ups and downs; I’m always worried about the future, about whether things will get worse as I get older. It’s a cycle, and I’m never at ease. I do things I don’t want to do so my partner doesn’t get tired of me. In the end, you feel guilty seeing that those around you struggle.”

“My partner makes travel plans that I don’t feel like going on, and although I wouldn’t go I also feel she’s pushing me to do things I wouldn’t do otherwise, so I wouldn’t go forward. I feel it’s complicated—it’s extra pressure that’s hard to handle and hard to explain to the other person because you can’t say no to everything, but really, there are things you don’t want to do out of fear.”

restrictions contributing to a negative mood and anxiety in social contexts. These mood disturbances and limitations in daily activities also strained family and personal relationships.

Coping strategies and support needs

Patients proposed several strategies to help fellow patients improve their quality of life, including more open communication with family and friends to foster understanding, facilitate group activities, and prevent isolation. Gradually resuming social activities with trusted people at one’s own pace was recommended. To improve sleep, suggestions included eating early, establishing relaxing routines, and reducing stimuli such as noise, light, and electronic device usage before bed. For mood management, they again emphasised the importance of communication and social support. Psychological help and specialised support when needed for both patients and family members were deemed crucial. Peer-to-peer support was also identified as valuable. However, no strategies were proposed for improving sexual relationships, as all participants continued to struggle with their fears.

All participants agreed on the importance of receiving information about LARS from their surgeons, followed by

support from specialised nurses, particularly before ileostomy closure. In addition to face-to-face support, patients expressed their need for supplementary written materials that could be reviewed at their own pace.

Development of comprehensive patient resources

Based on these findings, the group developed three comprehensive documents to support patients with LARS. The first two were also reviewed by two members of the Association for Faecal Incontinence (ASIA, www.asiasupport.org) to incorporate external perspectives and additional coping strategies and by a clinical psychologist to ensure the absence of bias. The documents are available on the website of the Catalan Society of Surgery (<https://racopacient.sccirurgia.org>) in Catalan and Spanish (the official languages of Catalonia) and are summarised below. Table 2 presents the key information for patients.

- “LARS information for patients”: This document offers patients a thorough understanding of LARS, including its definition, potential causes, and symptoms. It emphasises that each individual is unique and may exhibit only a subset of the symptoms, which can vary over time. It details how LARS may impact various aspects of life, such as daily activities, social inter-

Table 2 Key information for patients with low anterior resection syndrome (LARS)

Information for patients

- LARS (low anterior resection syndrome) refers to bowel dysfunction after rectal cancer surgery. Common symptoms include increased bowel frequency, fragmentation, urgency, incontinence, and incomplete evacuation. Symptoms usually improve over time, but adapting can be challenging
- LARS can have an impact on different aspects of life (work, leisure, and social activities). Concerns about finding toilets and fear of accidents may lead to avoiding social events. Gradual return to normal activities is encouraged, with open communication with friends and family to reduce isolation
- Sexual dysfunction is common, caused by physical and/or psychological factors. Men may experience erectile issues or retrograde ejaculation, while women might have lubrication issues. Open communication with partners is essential to maintain intimacy
- Frequent toilet visits can disrupt sleep, especially soon after ileostomy closure. Anxiety and emotional instability are common. Psychological support may be helpful in managing these challenges
- The emotional burden and daily limitations can strain relationships with family and friends. Honest communication with loved ones and seeking specialised support are crucial to maintain strong relationships

How can we help you?

- Treatment should be tailored to each patient, as everyone's experience with LARS is different. While bowel function may not fully return to normal, multiple strategies can improve symptoms and quality of life
- Options include dietary adjustments, medications to improve stool consistency and slow bowel movements, pelvic rehabilitation, and treatments such as transanal irrigation or neuromodulation. In severe cases, a colostomy may be considered to enhance quality of life
- Peer-to-peer support can offer valuable insights and emotional comfort

Alimentary recommendations

- Initial phase: Start with a restricted diet to manage symptoms. Avoid high-fibre foods (e.g. whole grains, raw vegetables), fatty meals, processed foods, and irritants such as caffeine and spicy dishes. Eat smaller, more frequent meals and maintain good hydration
- Progression: As symptoms improve, gradually reintroduce fibre-rich foods such as vegetables, fruits, and pulses, starting with small portions and assessing tolerance. Keeping a food diary can help monitor symptoms and guide dietary adjustments

actions, sexual life, sleep quality, mood, and personal relationships. By providing a clear overview of these effects, the document aims to help patients anticipate and manage the challenges associated with LARS.

- "How can we help you?": This resource provides practical recommendations on bowel management, coping strategies reported by other patients, and a summary of available treatments for LARS. Additionally, it includes contact information for a patient association, allowing patients to seek peer support.
- "Dietary recommendations": Developed by a team of nine dieticians, this document provides dietary advice for managing LARS. It includes general recommendations for the period immediately after surgery and guidance on dietary progression over time. A table categorises foods into recommended and not recommended groups, and a sample food diary helps patients track their intake and assess food tolerance, allowing them to adjust their diet accordingly.

The Catalan Society of Surgery has shared this information with surgeons treating rectal cancer patients in hospitals across Catalonia. To enhance patient access to these resources, healthcare professionals are

recommended to provide a QR code linking to these documents when informing patients (Fig. 2).

Discussion

The findings indicate that while patients received adequate information about their cancer treatment, there was a notable gap in information regarding potential dysfunctions after surgery and their impact on quality of life. This underscores the need for comprehensive patient education on LARS, a gap that has also been highlighted by other studies [5, 14–17].

Living with LARS demands significant lifestyle adjustments, such as modifying dietary habits, avoiding eating out, and consistently scouting for toilets when outside. These changes stem from the fear of bowel accidents, which restrict social activities, hobbies, and sexual life. The profound impact of LARS on quality of life, noted in other studies [5, 14, 16, 18–22], closely aligns with the experiences reported by participants in our study.

Insufficient information can lead to unrealistic expectations and inadequate preparation for challenges after the treatment. Patients frequently seek information online, struggling to find reliable resources. Garfinkle et al.

Fig. 2 QR code for patient access to LARS information



LARSCAT

**Informació
per pacients
sobre LARS**



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reviewed the information on LARS available online and found it suboptimal [23]. To address this issue, we made our materials available online through the website of the Catalan Society of Surgery (<https://racopacient.sccirurgia.org>) incorporating patients' perspectives with a few literal phrases in italics to align expectations with reality. A qualitative study [24] on patients with LARS 3–6 months after surgery found that, even when patients received information about LARS, they still struggled to fully understand its impact. This emphasises the importance of providing realistic information from healthcare professionals.

Balancing the provision of useful information without overwhelming patients and determining the optimal timing for discussing functional issues poses a significant challenge [5, 25]. As patients progress through their journey, their informational needs and coping mechanisms evolve, shifting from concerns about survival and avoiding a permanent stoma at diagnosis to regaining their lifestyle after treatment [18, 26, 27]. In our study, some participants expressed that they would have preferred to receive more information early in the process to better manage expectations, while others felt this would have been overwhelming. Nonetheless, all agreed that clear and realistic information should be provided before ileostomy reversal to prevent underestimating the long-term impact of LARS. This perspective is consistent with other studies indicating the need for tailored information delivery strategies to meet diverse patient needs [5, 14, 27, 28].

Our participants expressed a strong preference for receiving information from healthcare professionals, particularly surgeons, consistent with findings in other studies [17, 21].

However, they also valued supplementary materials they could review at their own pace. Participants in other studies have suggested pamphlets, high-quality internet-based resources [28], and educational videos [17]. The comprehensive documents developed by the LARSCAT project aim to meet these needs complementing the information provided by surgeons. These resources can be invaluable to patients who often struggle to fully understand the impact of LARS until they experience it firsthand. One of the primary concerns was dietary guidance, which prompted us to develop recommendations in collaboration with dietitians.

Patients frequently expressed that peer support would have been highly beneficial, a finding echoed in other studies [18, 18–20, 24, 27, 29]. In response, our documents include strategies to facilitate peer support among patients. Additionally, four out of six participants expressed interest in providing peer support themselves, and the Association for Faecal Incontinence (ASIA, www.asiasuport.org) will assist them in this effort. Moon et al. [30] identified that younger patients are particularly interested in online peer support for LARS and have launched a multicentre randomised study to assess the impact of an interactive online app featuring informational modules and a closed forum for interaction between peers and trained mentors. Our participants also emphasised the importance of family and social support, as reported by other authors [16].

Although the prevalence of LARS more than 12 months after surgery is estimated to be over 40% [10], several studies suggest that healthcare professionals underestimate its prevalence, duration, and impact on quality of life [25, 31, 32]. The focus often remains on survival rates rather than

long-term functional outcomes, and many surgeons might not fully understand how rectal cancer treatments affect patients' daily lives [5]. Providing QR codes that link to comprehensive informational documents highlights the need to integrate these resources into routine care, ensuring patients have easy access to reliable information at their own pace.

While this qualitative study provides valuable insights, it has limitations including a small and potentially biased sample size, as participants were selected through healthcare contacts and may not represent the broader LARS population. Additionally, known risk factors for LARS such as anastomosis height, TME, radiotherapy, or the timing of ileostomy closure were not considered. However, the experiences reported by participants align closely with observations from other patients in our clinics, suggesting our findings are relevant. Additionally, the study lacks an assessment of the feasibility and effectiveness of integrating the resources into clinical practice and the potential long-term impact on patient outcomes and quality of life. Finally, the findings may not be directly transferable to other regions or healthcare systems.

Conclusions

The present study highlights a significant gap in patient education regarding bowel dysfunction related to LARS, primarily due to insufficient information provided by healthcare professionals and the difficulty of finding reliable online resources.

Patients expressed a clear need for reliable accessible written information to complement the guidance provided by healthcare professionals. Such information should be available in formats that allow patients to review it at their own pace.

The LARSCAT working group, with active patient involvement, has developed comprehensive resources aimed at filling this educational gap and improving patients' quality of life. Integrating these resources into clinical practice through QR codes and targeted patient education holds significant potential for enhancing patient care.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s00384-024-04775-9>.

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Author contributions YR and CR conducted the interviews. AMD, LR, and MR took written notes during the interviews. All patients (MF, IG,

JP, OP, DR, JR) actively participated by providing invaluable insights into how LARS symptoms affected their lives.

YR, AMD, and CR made significant contributions to the design of the study. YR, AMD, LR, MR, and CR were responsible for the acquisition of data. YR, AMD, FM, MJT, and CR contributed substantially to the analysis and interpretation of data.

YR drafted the manuscript and prepared the figures and tables. AMD, FM, MJT, and CR critically revised the manuscript for intellectual content. All authors have approved the final version of the manuscript for submission.

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Data availability No datasets were generated or analysed during the current study.

Declarations

Competing interests The authors declare no competing interests.

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