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“He’s a surgeon, like I’m not going to waste his time”: interviews to determine healthcare needs of people with low anterior resection syndrome (LARS) after rectal cancer surgery.

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Abstract

Aim: The purpose of the study was to determine views of people on their healthcare needs when managing their bowel symptoms following an anterior resection.

Method: One-to-one, semi-structured interviews were undertaken, after consent and completion of three questionnaires. Results were analysed using a modified framework analysis and presented narratively.

Results: Twenty-three participants were interviewed; aged 38-75 years, 10 were men. Most had Low Anterior Resection Syndrome (LARS) scores indicating ‘major LARS’, Bowel Function Index scores ranged from 28-65. The two most bothersome symptoms were faecal incontinence and unpredictable bowel function. Data were grouped into three broad themes: ‘treatment consequences’, ‘strategies and compromises’ and ‘healthcare needs.’ Each theme had four sub-themes, such as ‘bowel dysfunction’ in the theme ‘treatment consequences.’ Bowel symptoms were common and persistent. Symptom management often required multiple interventions. Expressed healthcare needs included managing expectations through clinician-led information. Participants needed knowledgeable clinicians to enquire about and assess symptoms, providing and reiterating information as well as making an onward referral to enable symptom management. Peers improved the adaptation process through support and advice. The findings indicate that participants’ needs are not being fully met.

Conclusion: People with LARS have unmet healthcare needs to meet their individual goals. We propose these are addressed by using the acronym ‘LARS’; being a **L**earned clinician who **A**sks and assesses bowel symptoms, **R**evisiting the topic to address new or persisting symptoms as well as **S**ignposting, advising or referring onwards as needed.

What does this paper add to the literature?

The study describes healthcare needs of people following an anterior resection for rectal cancer. People with LARS need knowledgeable clinicians to ask about bowel symptoms, assessing,

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signposting or referring on. Clinicians should provide realistic expectations, enabling people to improve and cope with their altered bowel function using long-term management strategies.

Introduction

Rectal cancer is commonly treated with an anterior resection. Rectal cancer treatment is known to cause bowel symptoms in up to 80% of people [1] with severe bowel symptoms in 40% [2]. Bowel symptoms such as unpredictable bowel function [3] can persist for years, potentially life-long [4]. Bowel function is worse in patients who undergo a low rectal cancer, a temporary stoma (as opposed to having no stoma) and/or chemoradiation [5]. Bowel symptoms can collectively be termed low anterior resection syndrome (LARS) [6]. LARS has recently been defined in a consensus [3] to include eight bowel symptoms that result in one or more consequence or impact. LARS can negatively impact quality of life [7] affecting work, and social activities [8]. LARS is poorly understood by some clinicians [9] so preoperative discussion with patients, to set expectations about bowel function, may be inadequate. Management of LARS requires timely assessment and appropriate clinical intervention [10]. Management options include pads for incontinence, through a range of conservative and/or invasive options to permanent stoma formation for uncontrollable symptoms [11]. However, little is known about healthcare needs of people with bowel dysfunction after rectal cancer surgery. To determine what these patients' needs are, to enable improvement of their bowel symptoms, requires qualitative inquiry.

Aims and objectives

The aim of this study was to answer the question 'After rectal cancer surgery, what elements of a symptom management service are important to people with LARS?' The objectives were to describe:

- What bowel symptoms participants require help with
- Treatments tried
- If questionnaires are acceptable to establish their bowel symptoms and goals
- Information needs

Method

Three questionnaires (see below) were completed prior to one-to-one, online or telephone, semi-structured interviews with participants who had undergone surgical treatment for rectal cancer and had subsequently experienced LARS. Interviews were conducted by JB, using an interview guide

developed from a previous systematic review [12]. Participants were invited to tell their story with the opening question 'how have things been since your surgery?'

Participant recruitment and selection

An advert was posted on a charity website (Bowel Research UK) and Twitter. Following an expression of interest, the consent form and questionnaires were emailed or posted to potential participants. After completion and return of these an interview was undertaken with participants meeting the inclusion criteria (adults who had undergone an anterior resection for rectal cancer, who defecated anally and had encountered bowel dysfunction, could communicate in English and give informed consent).

Questionnaires

Questionnaires consisted of nine demographic questions, plus three validated questionnaires :

1. The LARS (low anterior resection syndrome) score; no LARS (0-20), minor LARS (21-29) or major LARS ≥ 30 [6]
2. The BFI (bowel function index) resulting in a total score of 18 to 90 [13]; a higher score indicates better bowel function [14]
3. Mymop2 contains questions about symptoms, their bother and individual goal setting [15]

The LARS and BFI questionnaires describe the participant sample. Questionnaire completion also enabled participants to report the appropriateness of the questionnaires to assess their symptoms.

Ethical approval

Prior to applying for ethical approval, the research paperwork including the interview guide was reviewed by five people who had undergone treatment for bowel cancer. Ethical approval was granted by King's College London (HR/DP-21/22-26011).

Analysis

Interviews were recorded and transcribed verbatim. Data were analysed using a modified framework method [16,17] and mapped into a framework table. Interview data were analysed iteratively, sequentially and thematically by JB; with themes developing over time. Discussion occurred with CN and CT during the analysis process, to ensure the process was consistent and important themes detected.

The five stages to framework analysis were: 1) data familiarisation; 2) framework theme identification; 3) data indexing; 4) data charting and sub-theme adjustment and 5) data mapping and interpretation into the framework table [17]. Data collection stopped when no new important themes emerged, presuming data saturation was reached.

Data are presented narratively with anonymous quotations, with participant numbers in brackets e.g. (P1).

Results

Twenty-three interviews occurred between 20 December 2021 and 16 May 2022. Participants were aged 38 to 75 (median 53 years) and included 10 men. Interviews lasted 18-83 minutes, 20 used an online video platform and three were telephone interviews. Twelve additional people showed interest in the study but either did not meet the inclusion criteria or chose not to participate. A summary of participants is given in Table 1, with a full description of each participant in online supplementary Table 1.

Table 1 –participant details

Time since stoma reversal or primary surgery (if no stoma)	Median 3 years; (range 0-11 years)
Radiotherapy	Yes=13; No=10
Chemotherapy	Yes=16; No=7
Temporary stoma	Yes=19; No=4
LARS score	Median 37; (range 13-42)
BFI score	Median 54; (range 28-65)
Most bothersome symptom	Anal incontinence (reported by 4 participants) Unpredictable bowel function; clustering (each reported by 3 participants) Bloating (reported by 2 participants) Urgency; incomplete evacuation; nocturnal incontinence; tenesmus;

	flatus and pain; pain; locating toilets when out of the house; flatus and frequency when out of the house; psychological effect of frequency; unpredictable and poor control; no symptom reported (each reported by one participant)
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Themes

Three broad themes, influenced by the interview guide, were derived from the interviews. Within each theme were four sub-themes (Figure 1).

Figure 1 – Framework themes and sub-themes



Theme 1: Treatment consequences

Consequences encompassed four sub-themes about bowel and other symptoms and their causes. Symptoms often settled to a 'new normal', but participants were uncertain about the longevity of symptoms before getting: *"Back to some semblance of normality"* (P11).

Bowel dysfunction

Bowel dysfunction varied and often persisted for years, including altered stool consistency, urgency and for 11 participants frequency. Emptying difficulties were common including incomplete evacuation, clustering: *"I got what I call poo cystitis, I went nine times in an hour"* (P4) and 14 participants reported fragmentation. Lack of faecal control described occurred at home, overnight and when out. Also, a lack of flatus control or an inability to differentiate between flatus and faeces was reported. Twelve participants described unpredictable bowels: *"Some days I don't go at all and some days I go like double figures"* (P22). Unpredictability improved over time but might affect

sleep, work and socialising. Two participants expressed uncertainty if bowel symptoms might indicate cancer recurrence.

Other symptoms

Pain was reported by 14 participants often the result of perianal skin damage. Ten participants described issues with emotional wellbeing: *"There are a lot of emotional issues"* (P5) that persisted for years such as anxiety when leaving the house. Five participants reported changes in sexual relations: *"Intimacy is actually a real challenge"* (P16). Four participants had received assistance with their emotions, but sexual relations were rarely discussed with clinicians.

New normal

Eleven participants reported settling into a new bowel function, others hoped for further improvement. Symptoms evoked anxiety when socialising and six participants reported they were easier to cope with at home. Participants learnt to adjust to their new normal, within new constraints such as eating a bland diet: *"I think that's what I'm gonna be on forever"* (P21).

Cause of consequences

Participants expressed a need to understand the cause of bowel dysfunction. Information was often self-taught rather than from a clinician, which participants would have preferred: *"I can only hear it from my surgeon"* (P2).

Theme 2: Strategies and compromises

The theme strategies and compromises included ways participants prevented or managed their bowel dysfunction, what triggered symptoms as well as who they discussed symptoms with and choices they made about LARS. Despite strategies, participants had to make compromises, and: *"Still on occasions have to cancel things because it's just not been a good day"* (P17). New ways of toileting were needed such as defecating at the roadside, in the woods or onto a pad as well as different ways to clean after defecation such as four participants choosing to use wet wipes and six a bidet/shower.

Triggers

Participants tried to learn their symptom triggers, either carefully avoiding these, or accepting consequences but identifying triggers was not always possible: *"I haven't noticed any major triggers"*

(P9). Trigger foods, when they existed, included rich foods, fruit, vegetables and for seven participants alcohol. Other triggers included physical activity and for six participants stress was a trigger.

Management and prevention strategies

Participants adopted one or more coping strategy with varying success, requiring determination, planning: *“I’m trying to like plan my entire world around this now”* (P13) and 13 participants reported the need for experimentation. Strategies were not always successful or simple to undertake, as it was: *“very difficult to plan any social activity”* (P7). Strategies for 15 participants included limiting the volume or types of food taken and restricting dietary choices: *“I’m having to watch what I’m eating now”* (P19). Participants also tried transanal irrigation, eight reported wearing a pad, 13 participants took anti-diarrhoeals, eight participants used bulking agents. Other strategies included not leaving the house too early, knowing toilet locations and planning journeys.

Divulging to others

Participants divulged some symptoms to selected peers: *“I’m probably quite sanitised when I tell my work... I just don’t want to overwhelm them”* (P14). Some participants were open, others answered questions only if asked, while some did not discuss their symptoms at all with anyone because of embarrassment.

Choices

Some participants initially doubted their choice to have cancer surgery or stoma reversal when symptoms were at their worst but doubts usually reduced over time. Participants made choices to avoid medication, eat a healthy diet, manage their weight or eat foods they liked: *“Symptoms I’ve experienced are due to overindulging”* (P23). Diet to manage bowel dysfunction might disrupt other medical conditions such as diabetes or lead to weight gain: *“Most of us are fat”* (P8). Seven participants discontinued management options because they caused more problems than they resolved. Sometimes it was stressful making choices, such as balancing healthy foods with bowel dysfunction as well as balancing medication and its side-effects.

Theme three: Healthcare needs

Participants needed information from someone knowledgeable to enable understanding, set appropriate expectations and manage symptoms: *“I found that really weird that there was nothing,*

no booklet on stoma reversal" (P6). Initial information needed to be high-level; a treatment and symptom overview with additional information to be subsequently accessed if needed. Participants searched for information but often wanted 'permission' from clinicians before commencing interventions. Self-assessment enabled recognition of symptom triggers. Family, friends and patient forums were supportive; the latter also provided advice. Table 2 shows an excerpt of the framework for theme three, illustrating sub-themes and the interpretation process, including quotations to show the breadth of the interviews.

Expectations

Twelve participants described inaccurate expectations of bowel symptoms, leaving them unprepared: *"Nobody mentioned anything that your life would never really be the same ... this was all quite shocking"* (P20). Participants had expected more clinical support for their symptoms. Information would have enabled appropriate setting of expectations but would not have altered their cancer treatment decisions.

Clinicians

Participants reported a preference for clinician-initiated discussions, as seven participants reported clinicians would simply answer their questions: *"Somehow the door needs to be opened because ... it's an embarrassing topic"* (P5). Ten participants were uncertain who to approach or were cautious approaching clinicians because they were perceived to be 'too busy'. Additionally, nine participants reported that discussing bowel dysfunction seemed to criticise clinicians and participants felt grateful: *"I owe him my life ... I don't want to bother him"* (P10). Alternatively, participants reported some clinicians were dismissive of symptoms now their cancer was removed.

Information

Participants wanted bite-size information to avoid information overload, with subsequent revisiting, as too much information prior to symptom development seemed irrelevant. They sought information via face-to-face conversation, email, telephone or video calls to provide reputable information that was easy to understand with diagrams, potentially written, online or videos. Information needed to include recovery timelines, potential LARS symptoms: *"Even if it's not good news, I'd rather know"* (P10), management options as well as who to contact and when. Some participants found it useful to record their food intake and bowel function looking for triggers and improvements using diaries or apps: *"I know what I ate the night before ... and I could feel how that's impacting on me"* (P8), but trigger foods were not always evident.

Peers and supportive others

Twelve participants described themselves as being part of the ‘LARS community’ which enabled them not to feel alone. Support and information sharing was possible via charities, social media, hospital support groups and 11 participants reported using patient forums including the LARS Facebook group. Information was not always useful and could be scary. A supportive boss and partner were beneficial, but participants did not want to ask too much of others: *“I don’t feel like I wanna heap too much onto her”* (P3). Seven participants also wanted to help others by providing information.

Table 2 – Part of analytical framework of participant needs

Theme 3: Needs – what participants need to help manage their symptoms		
Sub-theme	Quotations	Interpretation
Expectations	<i>“You never get back to normal and I really think that should be said. Your bowel movements are going to be different”</i> (P16)	Poorly set expectations about the longevity of bowel symptoms
	<i>“I understand I’m not going to be able to do everything I want to do every day, so I do what I can and let go of the expectations of the other stuff”</i> (P15)	Expectations of life have altered and been adjusted to enable coping
	<i>“I don’t think anyone walked me through surgery really; how you’re going to feel afterwards and actually how long it’s gonna take to recover”</i> (P4)	Unmet expectations lead to difficulty knowing when life can ‘begin’ again

Clinicians	<p><i>"I'm gonna have to be the one to bring up this stuff and ... it shouldn't be me having to bring this up ... it should be them that's asking the questions"</i> (P13)</p> <p><i>"There's every chance with the lower resection that ... you are going to have bowel issues for the rest of your life. You need to develop strategies when you go anywhere"</i> (P1)</p> <p><i>"I've never had a health professional really kind of try to engage me in a conversation about what life's like post-surgery"</i> (P9)</p>	<p>Participants want clinicians to initiate discussions about LARS</p> <p>Strategies are needed, clinicians should assist and enable this to happen</p> <p>Participants want to discuss bowel issues following surgery with clinicians</p>
Information	<p><i>"I think they could have warned me more on the potential of the problems I was gonna have after my stoma was reversed"</i> (P19)</p> <p><i>"Nice to have it all there at the beginning and then you can go back to it, you know, pamphlet or brochure or a small novel or something ... pictures and diagrams are always helpful"</i> (P12)</p> <p><i>"I was given leaflets by Macmillan nurses which were very useful, generally speaking"</i> (P23)</p>	<p>People want to know what might happen, even if it is uncertain what this might be</p> <p>Start early with information so that it can be revisited, with appropriate content to be useful to people with LARS</p> <p>Information when received was beneficial</p>
Peers and supportive others	<p><i>"I went back to work ... luckily my head of department was rather understanding so he gave me a rather light load"</i> (P7)</p> <p><i>"A huge percentage of them say I thought I was the only one, now how can that be? There must be 20,000,000 in the world that are in this state right now"</i> (P18)</p> <p><i>"I don't know anybody else with it"</i> (P21)</p>	<p>A supportive boss is helpful when returning to work</p> <p>Participants feel alone but there are so many potential people that need help</p> <p>Need not to feel alone</p>

Discussion

The interviews explored participants' personal experiences and healthcare needs. 'Bowel dysfunction' and 'strategies and compromises' characterised participant's symptoms and the management options used. Interviews revealed the range of symptoms participants experienced; all bowel symptoms were as described in the LARS definition consensus [3]. Participants used many bowel management options described in the LARS management consensus [11]. A recent NICE document [18] reported limited evidence to support management options for people with LARS, meaning not all potentially useful interventions may be offered by clinicians. Within the final theme participants discussed often unmet healthcare needs. They also reported a similarity of need, correlating with those reported in other studies [19] for example a perceived lack of guidance, as identified by Pape et al. [20].

Intensity of feelings was strong, participants explained how the surgeon had saved their life or the nurse was very supportive. A strong desire not to be critical was evident, but despite praising care, limitations in service provision were highlighted. Additionally, although participants reported a deterioration in their quality of life since their cancer treatment, they recognised that without treatment, they would be dead. Notwithstanding a respect for their clinicians, participants were able to express their unmet healthcare needs. They also described a desire to improve future care for others.

Conversations about bowels can be difficult and embarrassing. Participants needed clinicians to ask about bowel symptoms as they generally felt uncomfortable broaching the topic and do not want to bother busy clinicians, as previously reported [3]. It is also important to remember that the participants were a self-selected group who were able to articulate their concerns and have their opinions 'heard' whereas other people may not know how to begin sensitive conversations with their clinicians. Discussions may be assisted using relevant questionnaires such as those used in this study. However, it is not currently clear which is the best questionnaire to use. The LARS score [6], for example does not enquire about all symptoms now used to define LARS [3]. Also, anal incontinence was described in this study as the most bothersome symptom by participants but is not associated with a high LARS score. Additionally, patients may not want to be critical of their 'life-saving' clinician, so may complete questionnaires favourably rather than factually [21]; potentially clarified during subsequent clinical discussions. Furthermore, participants need clinicians to acknowledge symptoms exist and offer a LARS diagnosis, which has been previously reported [20]. Additionally, participants need clinicians to understand LARS symptoms, also reported by Chen et al. [9]. Self-management involves trial and error and participants valued clinical support and

‘permission’ in decision-making processes. Clinician-led information enabled participants to make sense of their environment and bowel changes.

Participants valued support from others including friends, family and the LARS community. Peers offered self-management suggestions which participants might initiate such as wearing incontinence pads [22]. Being part of the LARS community enabled participants not to be alone with their bowel symptoms; they could share their cancer journey within the LARS community and gain support from those who had this lived experience.

Information was needed, from trusted sources, in various formats and on several topics, also previously described [23]. Information additional to clinician-led conversation enabled participants to review it when ready, preventing overload. Pape et al. [20] report clinicians recognise the risk of information overload, which may account for withholding information, however, participants want information. Participants desire information on management options including diet but despite NICE guidelines [18] recommending dietetic input, only a quarter of hospitals have colorectal dietetic outpatient follow-up [24]. Changing dietary intake to reduce symptoms was common amongst participants as previously described [25] but may require clinician support to enable a healthy diet [26]. There are other potentially useful interventions described in some expert guidelines [11] that include transanal irrigation [27]. Participants wanted information but did not always follow it, instead accepting the consequent symptoms and using management strategies to mitigate effects.

Participants with LARS report that the burden of symptoms can lead to an almost daily reminder of their cancer journey. Even years after cancer treatment, bowel dysfunction and its management remain a large concern.

Study limitations

Limitations include a potential lack of objectivity associated with qualitative research, but appropriate when opinions are needed. It is recognised that interviews gain the view of a few, but narratives from participants in this study concur with other similar studies. Bias may have occurred in recruitment, attracting participants who were motivated, computer literate and younger than the norm as well as potentially having worse symptoms as they had often sought help on social media and this was a requirement for inclusion in the interviews. However, data concur with findings of other studies. It was not possible to recruit more purposively from clinical sites as COVID-19 restrictions were in place, leading to under-representation of older participants. Interview bias is possible but mitigated by using an interview guide and team discussion. Using the framework table and a reflexive diary enabled transparency and self-awareness of decision-making processes. Having

a team member with LARS involved in the analysis and examining data from other sources has improved the validity of results.

Future work includes a focus group of people with LARS to further examine their information needs, prior to co-designing a symptom management pathway to meet these needs; although it is understood that people adapt to their bowel changes, it is less certain how to best facilitate this process. People with LARS need to discuss their bowel problems, initiated by knowledgeable clinicians who can assess, diagnose, advise, signpost or refer to colleagues. Participants valued clinical expertise but recognise surgeons are not necessarily appropriate clinicians to treat symptoms. People with LARS do require reiteration of information as their bowel symptoms can change over time. To meet the unmet healthcare needs of people with low anterior resection syndrome, it is our summary that clinicians need '*LARS*'; to be a **L**earned clinician who **A**sks and assesses bowel symptoms, **R**evisits the topic to address new or persisting symptoms and **S**ignposts, advises or refers as needed.

Conclusions

Participants explain that clinicians need to be knowledgeable about LARS, discussing potential bowel symptoms before and after surgery to appropriately set expectations. Ongoing assessment after surgery as well as knowing which clinician is the most appropriate to be contacted for additional assistance is important. The need for clinician-led information is evident throughout the interviews, including about management strategies, permission to commence management options or signposting as necessary. Bowel symptoms change and people with LARS value continued clinician support when managing altered bowel function.

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