Interprofessional perspectives on care for patients with low anterior resection syndrome: a qualitative study.

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The study was approved by the ethics committees of both hospitals (B670201629451). Written informed consent was obtained from every participant.

Abstract

Aim

Many patients are confronted with low anterior resection syndrome after rectal surgery. The perspectives of both healthcare professionals and patients on the impact of bowel problems may differ. This study aimed to explore experiences of healthcare professionals on how to provide, organise and optimise care for patients with low anterior resection syndrome from an interprofessional perspective.

Method

An explorative qualitative design was used. Healthcare professionals were recruited in October 2018 in one general teaching hospital and one university hospital. 21 healthcare professionals from different professions caring for patients with low anterior resection syndrome were included in three focus group interviews.

Results

Healthcare professionals confirmed a lack of focus on patients who are confronted with low anterior resection syndrome and stated a need for a standardised approach of care. Additionally, three levels for care optimization emerged from the data: information before surgery with strong emphasis on the timing of informing, counselling of patients when confronted with low anterior resection syndrome and organisation of care.

Conclusions

Healthcare professionals find it important to adopt the moment and amount of information to the coping mechanism and timing of the trajectory. Counselling and follow-up of patients with LARS should be organised proactively and should not remain restricted to

pharmacological and nutritional advice. A possible strategy is to develop and implement late effects nurse-led clinics coordinated by the clinical nurse specialist.

What does this paper add to the literature?

This manuscript is to our knowledge the first study with a qualitative design that gives insights into how the care of LARS patients can be organised and optimised from an interprofessional perspective. It describes experiences of several healthcare professionals regarding LARS and formulates suggestions to improve care for these patients.

Introduction

The avoidance of a permanent stoma is one of the priorities of patients after a rectal cancer diagnosis, and in most cases, sphincter-saving procedures are feasible [1-4]. After treatment, patients expect to resume their normal life [5]. Unfortunately, many patients suffer from low anterior resection syndrome (LARS) [6], with a negative impact on their quality of life [7].

Only a few studies have explored the perspectives of healthcare professionals (HCPs) related to awareness, perception and knowledge about LARS, suggesting that HCPs underestimate the prevalence of major LARS (the most severe form of LARS) [8, 9]. Major LARS occurs in 58% of patients at 3 months [7] and in 41% one year after surgery [10]. Additionally, HCPs underestimate the duration of LARS believing that LARS will resolve within six months [11]. In contrast, the literature suggests that patients frequently suffer from LARS up to one or two years after surgery [12, 13]. Some patients even experience lifelong problems [7]. There appear to exist knowledge gaps about LARS amongst physicians and colorectal nurses [8, 11]. HCPs have been reported to underestimate the impact of urgency and clustering on patients' lives [14].

Our previous studies explored the experiences and needs of patients with major LARS [15, 16] as part of a larger research project. This study showed that patients are confronted with fluctuating hope during their trajectory and loneliness, presenting in different forms and layers [15]. They expressed several needs to the HCP [16]. Firstly, a varying need for information according to their coping mechanism of preference. Secondly, when confronted with major LARS, a need for an explanation of the expected evolution of their symptoms and recognition of the impact of LARS on patients' lives by the HCP were deemed necessary. Additionally, patients preferred proactive counselling [16].

It is important that LARS is approached interprofessionally, but it remains unclear how this should be organised. This study aimed to gain insight into the experiences of HCPs providing care for LARS patients and to explore their perspectives on how care processes can be organised and optimised.

Materials & Methods

This study is part of larger research project (NCT04896879) where the experiences and needs of several stakeholders regarding LARS were explored. Simultaneously, a grounded theory study was set up to explore the experiences and needs of patients [15, 16]. This current study executed an explorative qualitative design using focus groups with HCPs. This research methodology is appropriate for identifying opportunities and difficulties in optimising care for LARS patients, based on the expertise and perceptions of HCPs [17].

Setting and participants

HCPs caring for patients with rectal cancer of one general teaching hospital and one university hospital were recruited. Subsequently, 21 HCPs from different professions (Table 1) participated in three focus groups. Each focus group consisted of seven participants, which is considered optimal for effectiveness [18]. An equal distribution of different health professions in each group was sought to obtain rich data and detailed insights from different and diverse perspectives. The study was approved by the ethics committees of both hospitals (B670201629451). Written informed consent was obtained from every participant.

Data collection

HCPs were purposefully recruited by the researchers in October 2018. Both researchers (DVH, EP) were present at the time of the focus groups to reduce subjectivity of the interviewer because of a pre-existing relationship. One researcher, working as a psychologist in one of the participating hospitals, led the focus groups (DVH). The other researcher, working as a clinical nurse specialist (CNS) in the other hospital, was also present and observed the non-verbal communication (EP). To increase reflexivity, the researchers wrote out their frame of reference [19]. The interview guide was based on themes from literature and observations in daily practice (table 2). This was purely used as a guide, new themes and more in-depth topics could also be discussed. Although, the moderators encouraged open discussion, asked for clarification if uncertainties arose and ensured that all participants had a chance to speak. Some participants were more silent than others, these were mostly participants who were less familiar with the care of LARS patients as their professional activity focused on the treatment phase. Each session lasted an average of one hour, was recorded and afterwards transcribed verbatim.

Data-analysis

Thematic analysis was used during data analysis [17]. Initially, the content of each interview was arranged into meaningful groups of data by two researchers (EP and DVH). The data were converted inductively into identifiable themes and later grouped into subthemes. These subthemes were eventually labelled into themes. New concepts were checked in previous interviews. Data saturation was obtained for the main themes. Investigators' triangulation was used. All four researchers read two or more transcripts of the coded focus groups. During analysis, codes and themes were discussed and re-arranged. This increased the depth and credibility of the concepts' significance and dynamics [20]. Two researchers had experience in qualitative research (AVH and EP) and three researchers had experience with care for LARS patients (EP, DVH and AL).

Results

During the focus groups, HCPs reflected on how care could be optimised. Three levels of care emerged: information before surgery, counselling after surgery/restoration of bowel continuity and organisation of care. The needs and experiences of the HCPs are integrated into these levels. A figure illustrating current and optimal care was created based on information provided by the participants (figure).

Moment and amount of information before surgery.

Several HCPs described that the quality of informing patients about possible bowel problems was suboptimal.

> *Digestive oncologist: Preoperatively they are prepared for the possibility of a temporary stoma, but perhaps they are not sufficiently prepared for what will come after [restoration of bowel continuity].*

> *Psychologist: The confrontation with LARS is difficult. Patients count down the days for such a long period to something, for which they were utterly unprepared.*

They reflected that finding a balance between giving useful information and not over-informing was crucial. Hereby, they also stated that it was difficult to estimate how much information patients were willing to take in, and what the best timing was to offer this information. HCPs indicated that this moment should be chosen carefully. Three possible strategies were suggested: firstly, brief mentioning of LARS before surgery, and focussed counselling after surgery as too much information could lead to anxiety and confusion for some patients.

> *Physiotherapist: In the long run, overwhelming patients with information is pointless, so you have to keep the conversation informative without overly preparing patients.*

A second approach was briefly informing patients before surgery and providing more extensive information before stoma reversal. HCPs doubted if patients were able to fully understand the information as patients could be in survival mode or feel euphoria about the avoidance of a permanent stoma.

> *Surgeon: The information about bowel problems is only correctly perceived from the moment they have their stoma reversal. When it is indicated that a permanent stoma is unnecessary, the rest of the explanation is not properly understood.*

HCPs mentioned that patients were not always able to focus on bowel problems after restoration of bowel continuity, as this was set to happen in the future.

> *Surgeon: When we explain that patients can expect bowel problems after treatment, that information is only correctly understood after stoma reversal. All other information is not retained correctly, as it is planned for the future.*

> *Psychologist: The question is what will be retained if you give information in advance?*

Lastly, some HCPs suggested incorporating shared decision making (SDM) if this is possible from an oncological point of view. This implicates informing the patients about different surgical options. However, HCPs felt that a permanent stoma was often unacceptable to patients.

> *Physiotherapist: I think it is important to discuss this with patients. Yet I think there will be few patients who are going to respond by saying "give me a stoma".*

> *Radiotherapist: There is often a tremendous psychological resistance towards a permanent stoma, and patients have a high preference for sphincter-sparing surgery.*

Counselling when confronted with bowel problems

HCPs stated that there was a lack of standard of care. This was difficult because of the complex and individual experience of the symptoms. HCPs relied on trial and error mostly based on previous experience or empirical advice.

> *Digestive oncologist: It is trial and error. We do not have or follow specific guidelines. We say all kinds of things, "try this, try that". We evaluate and see if those things helped, and if not - we try something else.*
>
> *Dietitian: I try to give nutritional tips to prevent LARS, but not everything can be solved through nutrition and that makes one feel helpless.*

Some HCPs advised patience because they were confident that bowel symptoms would improve over time. They also mentioned that it was difficult to tell patients that there was no solution fit for everyone.

> *Digestive oncologist: Not everything can be solved and sometimes it is difficult to explain to patients: 'It is up to here that we can help you, but you are going to have some kind of residual injury'.*

Some physicians did not label the bowel problems as LARS. Other HCPs stated that labelling the complaints as LARS can help patients feel acknowledged and can facilitate communication.

> *Specialised nurse: Coming to the doctor and still not getting recognition. For the patient, it makes a huge difference. The fact that LARS was a diagnosis and not self-imagined or exceptional.*
>
> *Psychologist: Patients often feel that they are the only ones experiencing LARS.*

Organisation of the interprofessional care processes

HCPs stated that care for patients with bowel problems after rectal cancer treatment was something that the entire interprofessional team should undertake.

Resources

HCPs described a need for a care pathway to define an adequate timeline for the responsibilities, roles and tasks of each HCP. Currently, there is no clear agreement among the interprofessional team about who should inform, counsel, or provide follow-up.

> *Digestive oncologist: I think that it is good that you define who is responsible for what or appoint a team expert.*

A treatment algorithm could help to standardise treatment.

> *Surgeon: it would be good to develop hospital-wide guidelines to ensure that everyone is doing the same thing at the same time. That there is a logical order of what we do first and when we move on to other options.*

The routine use of the LARS-Score could assess complexity and extensiveness of the complaints. Additionally, the development and use of educational material would also be an added value according to HCPs.

> *Digestive oncologist: It would be good to make a brochure or video about LARS. One brochure for all hospitals. The risk of a brochure is that you then actually overload the patient with brochures during the consultation so that you do not have to give any more explanation yourself.*

> *Surgeon: You cannot just leave it with that video, you have to give information too.*

Nurse-LED clinic

HCPs indicated that the CNS would be the most suited person to coordinate care.

> *Surgeon: Ideally, we should have a nurse-LED clinic, where all the patients could turn to.*

> *Digestive oncologist: It would not be bad if we had a separate nurse-led consultation. That can become a recognisable consultation where patients can go to be assessed by an expert.*

Because of lack of time and focus on the oncological aspects of follow-up, the digestive oncologist found it difficult to address bowel issues.

> *Digestive oncologist: These patients are followed up by us to detect any relapse of disease, so they are nervous about the results. When you first ask them if they have any symptoms, they are nervously sitting on the chair because they want to know if the scan results are good. And if you tell them that the follow-up scan results are good, then they want to go home. This is the time point you have to be able to talk about LARS too.*

Physicians felt more comfortable referring patients to a CNS.

> *Radiotherapist: I think, if there is an entity to which you can refer, then the assessment would also be easier because there is organised follow-up. So that you are not left with this problem, and you can pass it on to the CNS, which is easy. It will facilitate management.*

The CNS can then refer to other team members if a specific approach is required.

> *Specialised nurse: I referred the patient to the dietician and also to a physiotherapist. I also referred her to a psychologist, because it was very difficult for her psychologically as well.*

> *Psychologist: Because it is such a limitation of patients' quality of life, I think they will be happy to be referred at that point*

Proactive approach

A proactive approach with an accurate history taking of the complaints and follow-up could help to reduce patients' feelings of shame to discuss LARS with the HCP.

> *Digestive oncologist: You have to actively ask: "Do you need to go to the toilet more often?" So, you have to make time for that, not only for LARS but also for other things. You'll gather a lot more information than if you keep waiting for patients to start talking.*

> *Dietitian: I think nowadays lots of patients just live with the symptoms and lock themselves up. and do not seek help.*

Besides support in the search for solutions, HCPs described that there is a need for emotional support.

> *Head nurse: Usually HCPs focus on how to resolve symptoms, but not really on the [patients'] experience.*

Discussion and conclusion

This study aimed to explore the needs and experiences of HCPs providing care for LARS patients from an interprofessional perspective and to explore their perspectives on how care can be organised and optimised. Firstly, the HCPs in our study indicated that the timing and amount of information about bowel symptoms were important. Not properly informing patients beforehand as suggested by a few HCPs in our study does not seem appropriate. This can lead to unrealistic expectations and being unprepared for LARS, which in turn may result in anxiety [5, 21, 22]. However, there is ambiguity about the best timing for providing this information. A qualitative study reported that one-third of patients (32,9%) prefer information about bowel function before surgery, whereas 37,3% of patients prefer being informed after surgery during hospitalisation [23]. Another qualitative study suggests giving information before surgery and repeating information afterwards [24] which is in line with perception of the HCPs in our study, who suggested briefly giving information before rectal surgery but repeating it before stoma reversal. This seems possible because most patients will receive a temporary stoma after surgery [25, 26].

Some physicians in our study suggested that SDM could be incorporated. Yet, this implicates giving information about LARS before surgery. Patients feel not capable of regarding deciding on surgery and leave it to the judgement and expertise of the HCP [27, 28]. However, SDM is a collaborative process and does not mean that patients have to decide on their own. Hence, it is key to explore patients' informed preferences [29].

The HCP must assess patients' understanding of the information [30]. In our study HCPs pointed out that patients may not have retained the initial information given that this was not a priority for them at that stage. A qualitative study in patients before rectal surgery illustrates that patients' focus lies with being cancer-free, getting through surgery and dealing with the temporary stoma [27]. Additionally, the study of Park et al. [21] states that the patient's attitude plays an important role in their expectations about LARS.

As part of a larger research project, the experiences and needs of patients with major LARS were explored as well [15, 16, 31]. Patients described a contrast between information during their cancer trajectory and information about possible LARS. Therefore LARS came unexpected for most patients [15]. Yet the need for information before surgery varied according to their coping mechanisms, which was also confirmed by the HCPs during the focus groups. Additionally, patients were forced into a pathway of trial and error based on the advice of the HCP, family and friends [15]. To address this, HCPs in this study indicated a need for more standardised care.

Several treatment algorithms have been suggested in the literature to improve standard of care [32, 33]. Yet, because of the complex and individual profile of the symptoms and needs, a flexible patient-centred approach is crucial. The advice of HCPs currently often is limited to pharmacological and dietary advice, which is frequently insufficient [34, 35].

Our previous study also showed that patients needed clarification of the expected evolution and recognition of their symptoms by the HCPs when confronted with LARS. Otherwise, they feel insecure and uncertain [16]. Thus, advice to be patient, as suggested during the focus groups, did not seem to be the optimal approach. HCPs in our study additionally stated that it is important to identify and label the bowel problems as LARS and to indicate that the patient's experience is not exceptional. A qualitative study indicated that the threshold to contact the hospital is high [27]. Some patients feel too ashamed to talk about it [34, 36]. Others thought that the bowel problems would eventually return to normal or were convinced that this was the price to pay after treatment [8, 34, 36]. A proactive counselling approach could address these issues as suggested by the patients in our previous studies [16].

The development of a LARS care pathway can be an added value. This pathway can start before surgery and go further into the follow-up phase. Although the setting can be different, so some barriers in terms of resources (time, funding, personnel etc) can arise, common steps can be the same. A nurse-led LARS clinic can be a care model to coordinate this pathway together with the interprofessional team. A pilot study confirms that LARS can be successfully managed during a nurse-led clinic with a significant decrease of LARS symptoms [37]. The CNS is a crucial member of the interprofessional team and is well-placed to counsel the patient through its trajectory [38]. The CNS is also in connection with other members of the interprofessional team [38].

Strengths and limitations

The strength of this study is the inclusion of multiple professions incorporating different perspectives. Using investigators' triangulation increased credibility. A study at two sites was performed. The hospitals varied in a context that increased transferability. Both hospitals had long experience in rectal cancer treatment and personnel resources were approximately similar. The university hospital has a larger unit so more professionals of the same discipline are available. Data saturation was obtained for the main themes and most themes were repeated in the three focus groups. Some themes, such as the knowledge of the HCP and the role of the HCP extramurally could be explored in more detail in further focus groups. A limitation is a fact that no member checking has been done. Another possible limitation is the fact that the organisation of care is bound to local context and region. For example, the role of the CNS and the access and use of other HCPs may differ. Our results can be a starting point for explorative research in other contexts. Further research about the needs of informal caregivers of patients with LARS is necessary to develop a care pathway. In this way, the needs of all stakeholders will be disclosed, and care can be optimised.

Conclusion

HCPs find it important to inform patients about LARS and adapt the timing and amount of the information to the coping strategy of patients. According to HCPs counselling and follow-up of patients when confronted with LARS should be organised proactively, possibly through a nurse-led clinic.

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Focus group 1 University Hospital	**Focus group 2 University Hospital**	**Focus group 3 General hospital**
Psychologist	Digestive oncologist	Digestive oncologist
Psychologist	Digestive oncologist	Digestive oncologist
Specialized nurse	Radiotherapist	Specialized nurse
Social worker	Radiotherapist	Head nurse
Ward nurse	Colorectal surgeon	Ward nurse
Dietician	Colorectal surgeon	Dietician
Physiotherapist	Colorectal surgeon	Physiotherapist

Table 1: composition of the focus groups

Themes	**Subthemes**
LARS	Experience with LARS
	Experience about the evolution of LARS
	Management of LARS
Needs	Needs of patients with LARS
Support of the HCP	Timing of information and counselling
	What can be improved in the management and counselling of LARS
	Which HCP are involved

Table 2: themes and subthemes interview guide

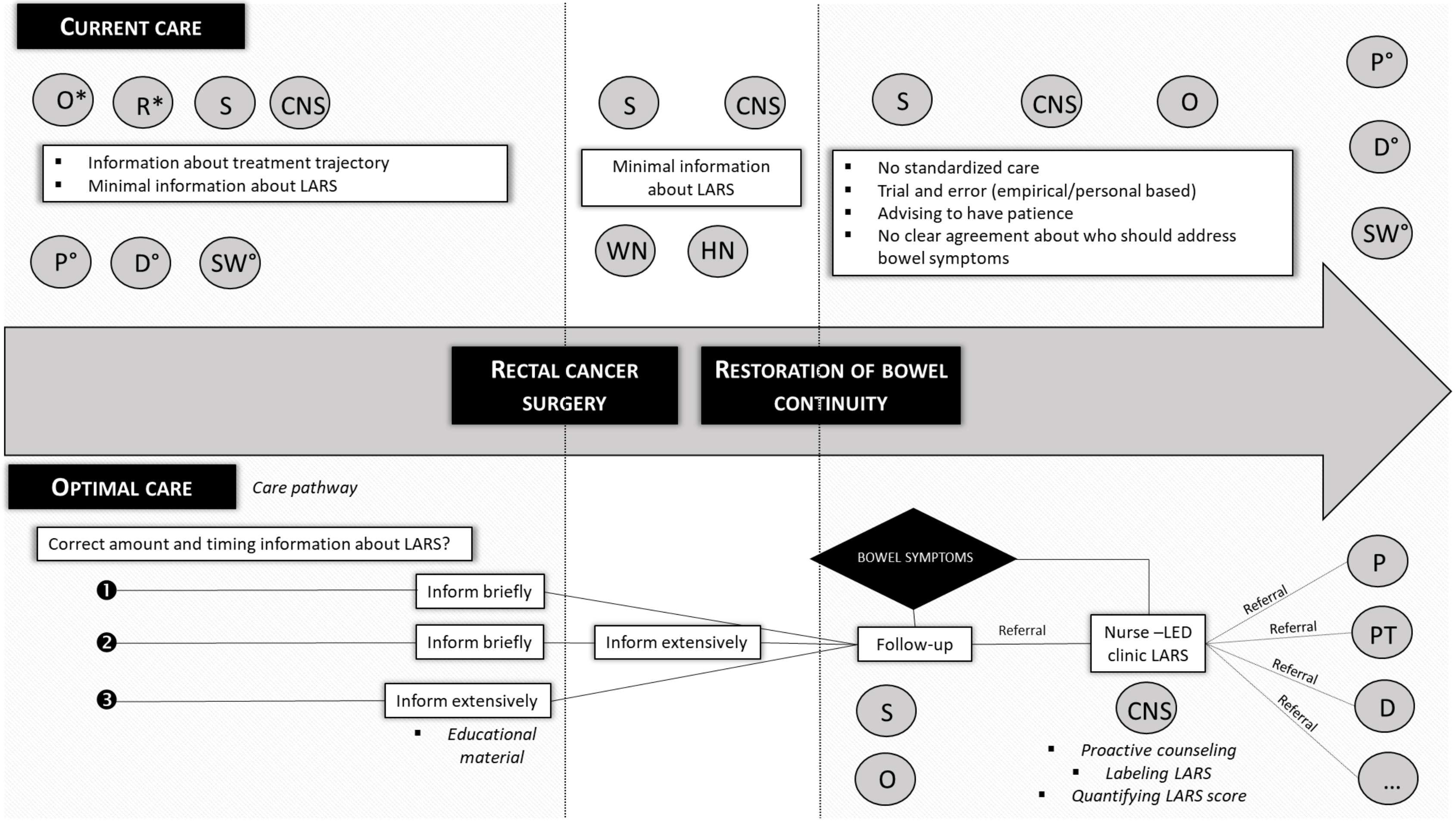

Figure: Figure current and optimal care based on the opinions of the participants

O: Oncologist; R: Radiotherapist, S: Surgeon, CNS: Clinical Nurse specialist/Specialist Nurse; P: Psychologist; PT: Physiotherapist; D: Dietician; SW: Social Worker; HN: Head Nurse; WN: Ward Nurse; °: on demand; *: If neoadjuvant therapy