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Experiences of patients with haemorrhoidal disease – a qualitative study



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ABSTRACT

Purpose: To obtain a better understanding of the patients' experiences with haemorrhoidal disease' impact on their daily life and results of treatment by performing a qualitative study. **Method:** Individually interviews were conducted among patients with haemorrhoidal disease between 2016 and 2017. Each interview was recorded using an audio recorder and transcribed verbatim. A semi-structured interview guide was used with pre-specified topics, based on a previous conducted literature review. Transcripts were coded and the analysis consisted highlighting passages in the text and assigning each passage a code representing the predefined themes from the interview guide. This resulted in a three-level theme hierarchy: overarching theme, mid-level sub-theme and issues.

Results: Fifteen participants underwent individual interviews of whom thirteen were conducted by telephone. The mean age was 60.7 years (35–78); five of them were female (33.3%). Pain and blood loss were the most frequently reported symptoms. Participants indicated that these symptoms were directly associated with emotional burden, daily adjustments and social impact. Before diagnosis with haemorrhoidal disease blood loss resulted in feelings of fear and next in embarrassment during social activities. In daily life participants needed to get up early, used sanitary pads for blood loss and anal ice sticks to reduce pain. Participants were often not completely satisfied with the process and outcome of treatment. **Conclusion:** This first qualitative study provides detailed insight into the patients' experiences with haemorrhoidal disease, impact on daily life and results of treatment. This information may be used in daily practice to create awareness among clinicians.

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Experiências de pacientes com doença hemorroidária – estudo qualitativo

R E S U M O

Palavras-chave:

Hemorroidas
Anal
Pesquisa qualitativa
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Desfechos

Objetivo: Este estudo qualitativo teve como objetivo propiciar uma melhor compreensão das experiências dos pacientes com doença hemorroidária, o impacto em sua vida diária e os resultados do tratamento.

Métodos: Entre 2016 e 2017, pacientes com doença hemorroidária foram entrevistados individualmente. Cada entrevista foi gravada usando um gravador de áudio e transcrita na íntegra. Utilizou-se guia de entrevista semiestruturado, com tópicos pré-especificados baseados em uma revisão de literatura realizada anteriormente. As transcrições foram codificadas; a análise consistiu em destacar passagens no texto e atribuir a cada passagem um código representando os temas predefinidos no guia de entrevista. Isso resultou em uma hierarquia de temas de três níveis: tema abrangente, subtema de nível médio e problemas. **Resultados:** Quinze participantes foram submetidos a entrevistas individuais, das quais treze foram conduzidas por telefone. A média de idade foi de 60,7 anos (35-78); cinco deles eram do sexo feminino (33,3%). Dor e hemorragia foram os sintomas mais frequentemente relatados. Os participantes indicaram que esses sintomas estavam diretamente relacionados a sobrecarga emocional, ajustes nas atividades diárias e impacto social. Antes do diagnóstico de doença hemorroidária, a hemorragia levou a sentimentos de medo e de constrangimento durante as atividades sociais. No dia-a-dia, os participantes precisavam acordar cedo, usar absorventes higiênicos para perda de sangue e gelo na região anal para reduzir a dor. Geralmente, os participantes não estavam completamente satisfeitos com o processo e o resultado do tratamento.

Conclusão: Este primeiro estudo qualitativo apresenta uma visão detalhada das experiências dos pacientes com doença hemorroidária, o impacto na vida diária e resultados do tratamento. Essas informações podem ser usadas na prática diária para conscientizar os médicos.

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Introduction

Haemorrhoidal disease (HD) is one of the most common anorectal pathologies affecting a large number of people in the western world. The prevalence can vary from 4.4% in the general population to 36% in general practice.¹⁻⁵

HD concerns a swelling of the submucosal veins in the anal canal that results in prolapse. It is hypothesised that it is caused by an increased abdominal pressure and/or the degenerative effects in ageing.⁶⁻⁸ This prolapsed tissue is easily traumatised which may result in bleeding and the deposition of mucus on the perianal skin may cause itching.^{9,10}

Haemorrhoids are mostly classified according to the grading system of Goligher et al.¹¹⁻¹³ This grading system is important since the best therapeutic option is directed by the location and severity of the haemorrhoids. However, while many patients have reported benefits of specific treatments for different grades of HD, consensus on the ideal treatment option for each grade of HD has not been reached yet.¹⁴⁻¹⁶ This may be partly explained by the lack of consensus on what constitutes treatment success. In the majority of HD studies treatment success is based on quantitative measurement of parameters such as prolapse, recurrence, complications and duration of operation.¹⁷⁻¹⁹ However, these traditional clinical outcomes

– mostly selected by healthcare professionals – may not include all relevant benefits and harms as experienced by patients. There is some evidence that treatment preferences may differ substantially between healthcare professionals and patients.²⁰ However, differences in such preferences are difficult to predict and may vary for a given condition.²¹⁻²⁵

Conducting qualitative interviews can function as groundwork to gain a deeper understanding and obtain information directly from the patients about their experiences with a disease and treatment preferences.^{26,27} Qualitative research has established that patients' experiences and health beliefs are important factors in determining treatment success.²¹

To obtain a more in-depth understanding of patients' experiences with HD, impact on daily life and results of treatment a qualitative study was conducted.

Methods

Study design & participants

The study was a qualitative study involving individual interviews. Dutch-speaking, male and female participants (aged > 18 years) already diagnosed with HD (by their GP) who visited the outpatient clinic of an academic hospital (Maastricht University Medical Centre) for treatment was invited

by their treating colorectal consultant (SB or JM). The colorectal consultant (SB) informed eligible patients regarding the study and handed out a patient information sheet. If the patient agreed, one of two researchers (RT and SK) contacted the patient explaining the study purpose and procedures in depth. If the patient was willing to participate, written consent was obtained. Insufficient language proficiency was an exclusion criterion. Patients were included between June 2016 and March 2017. The sample size was based on the concept of 'saturation' defined as the point at which no new information or themes emerged from the data.²⁸

Semi-structured interviews

An interview guide supported the collection of data. Review of the literature resulted in a number of topics and open ended questions, exploring three target themes: (1) experience of HD; (2) impact on daily life and (3) treatment (Table 1).

The in-depth interviews were conducted by telephone or by face-to-face meeting in the outpatient clinic, dependent on the participant's preferences. One hour was scheduled for each interview. The interviews were conducted by two researchers (SK and RT). One Researcher (SK) was a medical student and the other a clinical investigator (RT). Both interviewers had no prior treatment relationship with the participants.

During the interview, participants were encouraged to describe their experiences and symptoms they encountered concerning HD. For example, the following question was used "How do you experience having haemorrhoids?" Symptoms were not pre-defined and the interviewer probed for details on the HD symptoms reported by participants. Subsequent questions could be, "What do you mean?" or/and "Could you tell me more about that?"

The same strategy was followed for the themes daily life impact and treatment.

Data analysis

All interviews were audio recorded and transcribed verbatim. To protect the anonymity of participants, all personal data were removed. The data were subjected to manual qualitative analysis by two data coders (RT and SK). Analysis consisted of two steps. First, coding was carried out by highlighting passages in the text and assigning each passage a code representing the predefined themes from the interview guide: (1) experience of HD; (2) impact on daily life; and (3) treatment. In the second step the data coders catalogued the passages into main issues expressed by patients. The analysis resulted in a three-level theme hierarchy: (1) overarching theme (the broadest category); (2) midlevel subtheme and (3) issues (the finest level of theme detail). RT and SK compared codes and identified issues for consistency and discussed discrepancies

Table 1 – Interview guide.

Characteristics of the interview

Individual interview

Informal and convenient location

Direct approach: participant informed about the purpose of the interview

Semi-structured interviews: main questions with potential sub-questions

Duration between 30 and 60 min

Audio recorded

Aims of the interview

To inform the development of the patient-reported outcome measure, with a focus on disease-specific items, by gaining knowledge and information about:

Patient experiences and perceptions of Haemorrhoidal disease (HD)

Diagnosis of HD

The impact of HD on daily life

Experience, expectations and satisfaction with treatment

Main questions and potential sub-questions

Would you please briefly introduce yourselves? Tell us your name, when you were diagnosed with Haemorrhoidal Disease (HD)?

What are your main symptoms or complaints of HD?

Are there symptoms we haven't discussed yet?

Do these symptoms bother you?

How do they impact on your daily life?

Do you feel hindered in daily activities by these symptoms?

Where you informed by your health care professional (specialist nurse or medical specialist) about the expected efficacy of the treatment?

What were your expectations?

Were your expectations met?

Do you have the feeling that treatment is effective? And if so, how do you notice?

It is possible that treatment reduces your blood loss, pain etc. Have you experienced this?

Do you feel that your general quality of life has improved? If so, how do you notice?

To what extent are you happy with your treatment?

What are you most satisfied about?

Does the treatment live up to your expectations?

Are there any issues that we haven't discussed that you would like to tell me about?

Do you have any final questions?

Table 2 – Participant characteristics (n = 15).

Characteristics	
Age (in years), mean (range)	61 (35–78)
Female, n (%)	5 (33)
Classification of haemorrhoids, n (%)	
Grade I	4 (27)
Grade II	8 (53)
Grade III	3 (20)
Prior treatment (100%)	
Basic treatment	6 (40%)
Rubber band ligation	7 (47%)
Haemorrhoidopexy	2 (13%)
Years since diagnosis, median (range)	8.5 (0.5–20)

with CD. Refinement of the issues continued with the other co-authors until the structure was perceived to adequately capture the observed data.

Results

Study participants

Fifteen patients with HD participated in the study. Twelve out of fifteen interviews were conducted by telephone and three were conducted face-to-face. The majority of patients (60%) had previously received rubber band ligation and presented with recurrent symptoms. Six participants received (GP-initiated) basic treatment (i.e. toilet training, high fibre diet and/or topical ointment) and visited the outpatient clinic to discuss rubber band ligation. At time of the interview, treatment (e.g. RBL or a haemorrhoidopexy) for all participants was scheduled. Participants' characteristics are presented in [Table 2](#).

Themes

An overview of the issues related to HD extracted from the interviews is provided in [Table 3](#).

Table 4 – Frequency of symptoms reported by participants.

Symptom	n (%)
Blood loss	10 (67)
Prolapse	5 (33)
Pain	4 (27)
Itching	3 (20)
Soiling	2 (13)

Experience of HD

Blood loss and prolapse were the most commonly reported complaints ([Table 4](#)).

Other complaints included pain, itching and soiling. “The itching is very annoying, I’d rather be in pain than have that itch” (ID 2, female). On average, participants reported one to two symptoms.

The presence of blood was sometimes associated with the thought of having a malignant condition by the patient. “Of course you are scared, [...] at first you always think that it might be cancer”, (ID 1, male). “At first, I did not know where [the blood] came from, it scared me” (ID 6, male). Going to the general practitioner or undergoing a clinical colonoscopy abated these feelings of fear. Other patients reported they never had any concerns regarding possible malignancy. “No, I was never worried that it might be cancer. [...] The difference is also quite clear, it is such fresh blood and I know where it comes from” (ID 13, female).

Most patients suffered from HD for a long period of time and were reluctant to seek help. Many patients felt ashamed or embarrassed resulted in a hesitation going to the general practitioner. “It started when I was sixteen, so I have been suffering [from haemorrhoidal disease] for the past twenty years. (...) It is a familiar phenomenon in the family, so at first I thought it was not necessary to seek help, but the pain worsened and I overcame my shame” (ID 3, male). “You do not talk about it, nowadays I do, but back then, I did not, because it is embarrassing. You also postpone the hospital visits. It is a painful area, so you postpone it” (ID 13, female).

Table 3 – Summary of responses extracted from the individual interviews (n = 15).

Themes	Sub-themes	Issues
Experience of HD	N/A	Blood loss, pain, prolapse, itching, soiling Fear/panic Delay Embarrassment Seeking help
Impact on daily life	Emotional burden Restrictions and adjustment Social support	Stigma/identity Impact on daily functioning (e.g. planning) Daily adjustments (e.g. sanitary pads) Sharing with partner Support in environment
Treatment	Procedure responses Treatment outcome	Communication Treatment outcomes Patient information Recurrence Satisfaction

After seeking treatment, most patients expressed they wished they had turned to the doctor sooner. "I know now: the result outweighs the pain" (ID 5, female).

Impact on daily life

Emotional burden

Many patients experienced a feeling of embarrassment regarding their haemorrhoidal disease. Haemorrhoids are considered as unhygienic and unclean. "(...). You feel ashamed because everyone else thinks it is embarrassing, that is society's opinion (ID 13, female). Another patient stated the same thing: "(...) the shame comes from talking about it. It is as if you're talking about your penis. Look, the meniscus or the heart or something like that, that does not matter, but this does" (ID 10, male). Other patients shared the following: "I do feel ashamed. Recently, I went to an athletics club and I took a shower with a white towel, after using it, the towel was covered in blood. I felt really ashamed then, because I am concerned about what others will think of me now" (ID 7, male). Despite the sentiments mentioned above, three other respondents stated that they did not experience feelings of shame.

Another feeling patients often experience is worry due to a relapse of the condition. "Yes, of course you think about that. In the past they have also relapsed." (ID 9, male).

Restrictions and daily adjustments

Asking patients if they felt restricted by their HD, all participants said "no". After probing this question, however, respondents reported several restrictions or adjustments in daily life. For example, one respondent reported: "Because of the massive blood loss, I could not function normally any more. I did not dare to go anywhere, not to a party, not to my son's soccer match" (ID 13, female). Another respondent claimed that his condition affected his sex life. "(...) my sex life, I do think it is difficult, because of the flap coming out of my anus" (ID 4, male). Examples of daily adjustments were getting up early in the morning to have sufficient time to pass stool at home and clean their bottom. "I did make changes [in my life], I have to get up one hour earlier to go to the bathroom. If I do this hastily, or not at all, I know I will have trouble with my stool" (ID 3, male). "Nowadays I eat early in the morning, go to the toilet and shower afterwards to clean my bottom, all before work" (ID 4, male).

To reduce the impact of frequent blood loss, patients often needed to use sanitary pads. "In the beginning you feel ashamed while admitting you have this problem and then your sister says 'I have some sanitary pads if you want'. Normally, these are used by women, which makes it even worse because I am a man." (ID 7, male).

To relieve the pain, a few patients used lidocaine cream. One patient was prescribed anal ice sticks by her general practitioner. This seemed to help the pain, although she stated that she was uncomfortable with the feeling of it (ID 13, female). Another patient created a tool against prolapse; "I have moments that I cannot sit down, so I have to sit on a frozen plastic bottle to push the haemorrhoids back inside" (ID 3, male). One patient also used an old household remedy by applying cold whipped egg whites to the affected areas.

"I tried egg whites, whipped and stored in the fridge. (...) It helped for a while, but at a certain point my haemorrhoids seemed to get used to it and the effect disappeared" (ID 2, female). Another patient said he benefited from meditation. "[Meditation] helped me a lot. (...) I have managed to create a sensation that makes the haemorrhoids bearable" (ID 3, male).

Social support

All respondents reported that they shared their complaints about having HD with their partner. "Of course I did not hide this [haemorrhoidal disease] from my wife and of course we talked about this from time to time" (ID 9, male). Another patient quoted "(...) I have been with my wife for the past 20 years. We share everything; we do not have secrets from each other" (ID 3, male). Another participant also explained that it was her own self-perception that was altered and not the way her partner reacted to it. "No, no, it is not a problem for my partner. (...) Of course it bothers me, because I don't think that it is aesthetically pleasing" (ID 13, female). In some cases, the partner of the patient took care of some aspects of the HD, and provided active support. "My partner salves my [haemorrhoidal] folds. I am really grateful for that, because not every partner does this. He also checks for changes in colour and thickness" (ID 2, female).

Some respondents discovered that more people in their environment were struggling with haemorrhoidal disease. "If you start talking about it, you will find out that many people experience [haemorrhoidal disease]. At a certain point, I thought 'I am not going to make it embarrassing for myself anymore, other people have something else and, coincidentally, I have this' (ID 13, female). Participants were receiving support from their personal environment.

Treatment

Procedure responses

The experiences of patients regarding haemorrhoidal procedures were diverse; they ranged from positive to negative and were mostly related to the information provided to the patient. "Quite pleasant, so relaxed, and also telling what they were doing. I worked in education all my life, it was an A+, and I felt in good hands" (ID 5, female). "It happens really quickly, just bend over, elastic around it, snap, snap, and go!" (ID 15, male).

However, several participants had expected more clarification concerning the interference and information regarding the post-treatment-care. "I had no idea [what to expect], nobody told me anything about it, I just sort of went with it" (ID 6, male). "I went to the surgeon for the haemorrhoids and prolapsed rectum, but all he treated was the rectum. I have not heard anything about the haemorrhoids; I think that is a disadvantage" (ID 2, female). "Think of pain, costs, etc. They could have been more transparent and open about these things in the time leading up to the procedure" (ID 4, male). "[Expectations] were formed by the information provided by other people I spoke with, who had already undergone the operation" (ID 3, male).

Treatment outcomes

A respondent defined treatment success as: "the moment when I do not have to make adjustments in life anymore"

(ID 3, male). "It is such a difference, now that I do not need to be aware of going to the toilet anymore when I am on my way to clients" (ID 6, male). Respondents reported that after treatment blood loss and/or prolapse should be resolved (ID 7, male and ID 13, female). A respondent even said "I can imagine that there is a discrepancy between the expectations of the patient, on the one hand and the opinion of the surgeon on the other". Therefore, treatment considerations should be discussed openly with a patient (ID 4, male).

Further, many patients conveyed that they worried about a relapse of the condition. "Yes, of course you think about that. In the past they have also relapsed, but if I touch that area now it feels different than the last time, so I have more faith this time" (ID 9, male).

Discussion

This is the first qualitative study that gives an insight into patients' experiences having HD. Blood loss and anal pains were the most commonly reported symptoms. Participants indicated that these symptoms were directly associated with emotional burden, daily adjustments and social impact. For example, in patients having blood loss before the diagnosis was known, this symptom resulted in feelings of fear. Besides blood loss resulted in embarrassment, and avoidance of social activities. Furthermore, participants used a variety of tricks and adjustments in their daily life to cope with HD (e.g. getting up early, sanitary pads, use of anal ice sticks to reduce pain). Participants were not always completely satisfied with the process and/or outcome of treatment. They appreciated greater openness and exchange of information regarding the different treatment options and the expected outcomes from their healthcare professionals.

We are not aware of other studies that have comprehensively investigated the symptoms and impacts of HD from the patient perspective. Nevertheless, the reported symptoms by our participants are in line with HD symptoms that are commonly evaluated in clinical trials.^{29,30} No studies were found regarding the impact on daily life and treatment experiences of HD.

This is the first study that showed that certain aspects relevant to the patient are overlooked when HD treatment effectiveness is assessed by only traditional endpoints such as prolapse, recurrence and complications. This study showed that, besides the traditional endpoints, patients are also concerned about the bothersomeness of the symptoms and the impact on their daily life. Furthermore, patients may have different preferences regarding the treatment options than the clinician has. This issue is an important reason why clinicians should ask patients what treatment they prefer and what they consider as treatment success.

This approach where clinicians and patients discuss the best treatment option is defined as Shared Decision Making (SDM).³¹ An important advantage of this approach by both taking in account the experiences of the patients as SDM, is that patients are more likely to be satisfied with the clinician-patient contact and the decision.^{32,33}

Nowadays next to traditional clinical outcomes, literature shows more and more the importance of using Patient

Reported Outcome Measures (PROMs) for assessing treatment outcome.³⁴ PROMs are questionnaires that measure the patient's experiences regarding health (outcomes) and sense of well-being. This study may contain clinical relevant information, which could be incorporated in the development of a future PROM for HD.

We acknowledge that a qualitative study has a number of limitations. First, the small number of participants may be considered as a limitation. Although, 15 participants are relatively common for this kind of study and further data collection and/or analysis was unnecessary since this provided us no new information. Secondly, only patients visiting the outpatient clinic with persistent HD were included in this study. This may resulted in an overrepresentation of respondent's with more severe HD and less treatment satisfaction. Thirdly, researchers' understanding and interpretation of the data may influence the results that could be different from that of others. Fourthly, socially desirable responses regarding treatment satisfaction or the lack of reporting of sensitive issues cannot be ruled out. However, two researchers conducted the interviews with no prior treatment relation with the participants. Finally, conducting the interview by telephone can create a distance between researcher and patient and corrode the trust. Nevertheless, the distance created by the telephone can also help the patient to narrate more easily regarding their complaint experience and personal life. We tried to make participants feel as comfortable and safe as possible and ensured their responses would be anonymised and not shared with anyone else. It appears that highly sensitive topics such as sexual barriers were openly addressed.

In conclusion, this is the first qualitative study that provided detailed insight into the patient's experiences with HD. This information may be used in clinical practice to create awareness among clinicians to take the patient's experiences and values into account when making HD treatment decisions. In addition, this study contains clinical relevant information, which could be incorporated in the development of a PROM for HD.

Compliance with ethical standards

Ethical clearance for this study was obtained from the hospital's ethical review board (file number METC 16-4-068.1/ab). All participants have provided written consent prior to commencing the interview.

Conflicts of interest

The authors declare no conflicts of interest.

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