

SYSTEMATIC REVIEW

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Experience and satisfaction of participants in colorectal cancer screening programs: a qualitative evidence synthesis

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Abstract

Background Experience and satisfaction of colorectal cancer screening program participants are among the key factors that determine adherence to these programs. Understanding them is crucial to ensure future participation.

Objectives To explore and gain understanding on the experience and satisfaction of the average-risk population participating in colorectal cancer screening programs.

Methods A Qualitative Evidence Synthesis. We conducted a literature search up to April 2023 in Medline, Embase, CINAHL, PsycINFO and ProQuest Dissertations and Thesis. We independently selected the studies for their inclusion, assessed their methodological quality (with CASP tool) and extracted data. Disagreements were solved by consensus. We thoroughly read the selected studies, and analyzed the data following a thematic synthesis approach. We evaluated the confidence in our findings with CERQUAL.

Results We included six studies: four had an appropriate quality, and two had some methodological limitations. We identified five main findings across studies: (1) Variability in the concerns about the results; (2) Challenges regarding procedure logistics; (3) Care received from the healthcare professionals; (4) Being adequately informed; (5) Expectations and experience with the program. All findings had a moderate level of confidence.

Conclusions Our qualitative review provides a picture of the experience and satisfaction of the average-risk population participating in colorectal cancer screening programs. Despite some logistical and expectation management issues, the overall satisfaction with the programs is high. More research is needed on the topic, as there are still important gaps in knowledge.

Keywords Colorectal neoplasms, Cancer screening, Qualitative research, Systematic review

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Background

Colorectal cancer and cancer screening

Colorectal cancer (CRC) is one of the most diagnosed cancers worldwide. Among men it is the third most diagnosed cancer (after lung and prostate cancer), and in women it is the second most incident, after breast cancer [1]. In many regions the risk of CRC is around 5%, and the 5-year survival rate is 57% for colon cancer and 56% for rectal cancer [2].

CRC is a disease that qualifies for screening as defined by the Wilson and Jugner criteria [3]. These required characteristics are a high incidence rate [1] with a long preclinical phase, a recognizable and tractable precursor (polyp) and a correlation between tumour stage at diagnosis and mortality rate [4, 5].

Organized screening programs have been proven to reduce incidence and mortality associated with CRC [6, 7]. These programs are targeted to the average risk population, normally defined as individuals aged 50 or older, with no other additional risk factors such as inflammatory bowel disease or a family history of CRC or polyposis syndrome. There are different tests for CRC screening, but the most recommended and used worldwide are [8, 9]: fecal blood test (guaiac faecal occult blood test [gFOBT] and faecal immunochemical test [FIT], both self-collection tests) [10], sigmoidoscopy [11] and colonoscopy, that is usually performed under light sedation [12]. Both fecal blood test and sigmoidoscopy, if positive, require a colonoscopy to explore the whole bowel.

Patient experience and satisfaction

Participation in CRC screening programs is vital as it determines the efficacy of the programs [13]. The European Council set the desirable participation rate for the average-risk population at 65%, but when looking at European Union citizens, in 2019 the participation ranged from 4.5–66.6% for gFOBT, to 22.8–71.3% for FIT [5]. Although FIT is more acceptable than gFOBT because it only requires one sample and does not require dietary restriction, participation rates are still low [14, 15]. This very low percentage might be improved by increasing awareness creation, repeated messages, sensitivity to tone and style, and ensuring the quality of the process so that participants have a positive experience of their participation [5, 16].

Experience and satisfaction of CRC screening program participants are among the key factors that determine adherence to them. In fact, studies showed that satisfaction with past stool test screening is a strong behavioural predictor of adherence to future screening rounds [17–19]. Furthermore, the fact that screening programs are aimed at asymptomatic populations that have not required or requested health care and that it is the health system itself that invites them to participate should be

borne in mind. For the foregoing reasons, it is important to know what the experience and satisfaction of participants in relation to CRC screening is.

Patient experience and satisfaction are often used interchangeably despite differing slightly in meaning [20, 21]. There is no standard definition for patient experience, but in general it refers to the interactions patients have with the healthcare system. It includes aspects such as getting timely appointments, easy access to information and good communication with healthcare providers [22]. Understanding patient experience is useful to determine whether something that should happen in a health care setting actually happened (e.g. clear communication with doctors or nurses). On the other hand, patient satisfaction measures the extent to which a patient is content with the care they received, it depends on the patient's expectations [22] and involves some sort of rating or evaluation [21]. Two people who receive the exact care can give different satisfaction ratings depending on what expectations they had about the care that was supposed to be delivered.

Why is it important to do this review?

Several studies have measured patient experience and satisfaction with CRC screening, most using self-reported questionnaires [23, 24] that are one of the most used methods to quantify and monitor patient satisfaction and experience. However, to delve into and understand the meaning people give to the phenomenon of interest, the qualitative approach is the most appropriate [25, 26]. This qualitative approach also enables the detection and identification of possible issues with the screening programs, which might help to improve its quality and acceptance.

Qualitative research on patient satisfaction already exists [27], but to our knowledge, there is no previous systematic review that summarizes and critically appraises this knowledge adopting a qualitative research perspective.

Objectives

Our main objective was to explore and gain understanding on the experience and satisfaction of the average-risk population participating in CRC screening programs. As secondary objectives, we aimed to explore any differences in experience and satisfaction of participants according to screening results (positive screening or negative screening) and according to the screening program nature (organized or opportunistic).

Methods

Study design

We conducted a Qualitative Evidence Synthesis (QES), which integrates findings from multiple qualitative

studies to gain understanding of a research topic, according to standardized methodology [28], and registered the protocol prospectively at PROSPERO (CRD42022339548). We reported results following the ENTREQ guidelines (Enhancing transparency in reporting the synthesis of qualitative research [29]).

Eligibility criteria

We structured our clinical question and established our eligibility criteria following the SPIDER framework [30], one of the available frameworks for qualitative questions recommended by the Cochrane Qualitative and Implementation Methods Group [31] (Table 1) : “What is the experience and satisfaction of people participating in CRC screening programs”.

We included:

Qualitative studies about participants of a CRC screening program, either organized or opportunistic, regardless of the screening test used, attending at least one screening test and which the primary focus is the experience or satisfaction of participants. Studies should use qualitative methods both for data collection and analysis.

- Mixed method studies where it is possible to extract disaggregated data that was collected and analysed using qualitative methods.
- Studies published in English, Spanish or French, the languages spoken by the research team.

We excluded:

- Studies on programs aimed at people with inflammatory bowel, or polyposis syndromes (Lynch Syndrome), or family history of CRC.
- Studies that collect data using qualitative methods but do not analyse these data using qualitative analysis methods.

Search methods

We conducted searches up to April 2023 in the following electronic databases without language or date restrictions: MEDLINE (via PubMed); Embase (via embase.com); CINAHL (via EBSCOHost); PsycINFO (via EBSCOHost).

Table 1 SPIDER framework

Parameters	
Sample	Participants with an average risk for CRC
Phenomenon of Interest	Colorectal Cancer screening programs
Study Design	Qualitative Evidence Synthesis
Evaluation	Experience and Satisfaction
Research Type	Qualitative

We developed a search strategy for each database. See **annex 1** for the detailed search strategies.

We tracked back from references and citations to relevant studies. We checked references lists from relevant studies and located their citations at the Web of Science and Google Scholar. We also searched for thesis and dissertations in ProQuest Dissertations and Theses Global and for gray literature in OpenGrey (www.opengrey.eu).

Selection of studies

We (CH and CS) independently assessed the titles and abstracts of the identified records to evaluate eligibility. We then retrieved the full text of all the papers identified as potentially relevant by one or both review authors. We (CH and CS) then assessed these papers independently. We resolved disagreements by consensus or, when required, by involving a third reviewer (AS). We used the software rayyan.ai (<http://www.rayyan.ai/>) to conduct the eligibility process, which facilitated the process by enabling efficient importation, collaborative screening, and resolution of conflicts among reviewers.

Data extraction and methodological quality assessment

We designed a data extraction template in an excel file and pilot tested it. One reviewer (CH) conducted the data extraction and a different reviewer (CS) verified that the data was correct. We extracted data on: context and participants (study setting, aims, population characteristics); study design and methods (methodological design and approach, methods for identifying the sample and for recruitment, data collection and analysis methods, any theoretical models used to interpret the findings); Study findings (themes, subthemes, findings and supporting quotations regarding patient satisfaction and experience).

We (CH and CS) independently assessed methodological limitations of included studies using the CASP tool for qualitative research [32]. We resolved disagreements by discussion or, when required, by involving a third review author [AS].

Data analysis and synthesis

We analysed the data according to a thematic synthesis approach [33], a method that consists of applying a thematic analysis to an evidence synthesis. It consists of iteratively refining themes based on initial data coding from individual studies included in the review and integrating findings to develop comprehensive and interpretative insights. The thematic synthesis approach consists in three stages which overlapped to some degree:

First, we read the results of all included studies and collected the verbatim findings. One reviewer generated codes based on the results according to its meaning and content (stage 1). We looked for similarities and differences between the codes to detect overlaps and group

the codes into a hierarchical tree structure and obtain descriptive themes that constitute our review findings (stage 2).

To answer our review question and try to develop an analytical theme (stage 3), we generated integrative concepts, understandings, and hypothesis from the descriptive themes or review findings.

One author wrote a draft summary of the review findings and then commented it with other review authors to agree on a final version.

Assessing our confidence in the review findings

We (CH and CS) used the CERQual (Confidence in the Evidence from Reviews of Qualitative research) approach to assess our confidence in each review finding [34]. The CERQual has four key components: Methodological limitations of included studies, coherence of the review finding, adequacy of the data contributing to the review finding and relevance of the included studies to the review question. The final assessment was based on consensus among the review authors. All findings started as high confidence and were then graded down if there were important concerns regarding any of the GRADE-CERQual components.

Review author reflexivity

We represent diverse professional backgrounds with a range of research experiences and expertise that could have biased our input in conducting this review (e.g., one of the reviewers coordinates a population screening programme and, therefore, might have interpreted the findings from the studies from her professional perspective rather than that of a candidate for screening participation). To avoid biases or skewing of the results, we considered how our beliefs would influence our choices while scoping the review and the methods we used, the interpretation of the data and our own interpretation of our findings. That is why we kept a reflexive attitude throughout the review process.

Ethical consideration

As this is a secondary research study, and it did not involve access to individual-level data, we did not seek ethical approval for conducting this systematic review.

Results

We retrieved 2348 references from the search, from which we excluded 806 duplicates and revised 1552 through their title and abstracts. We evaluated the full text of 62 studies. Finally, six studies fulfilled the inclusion criteria. A chart detailing the inclusion/exclusion process can be seen in Fig. 1. Main characteristics of the included studies are described in Table 2.

The included studies were published between 2003 and 2021 and were all in English. All studies reported on organised screenings programs. The studies were from Denmark [36, 38], Sweden [35], Spain [37], France [39] and UK [40]. Two studies explored the participant's experience undergoing CRC screening and their screening procedure [35, 36], two studies explored how participants experience a positive test result/ cancer diagnosis [38, 40] and the remaining studies explored the obstacles to mass colorectal screening [39], and the factors related to the longitudinal adherence of CRC screening related to experience and satisfaction of the participants [37].

The studies obtained data from 14 focus groups, 88 semi-structured and 24 open-ended interviews of adult individuals (aged 50–80), who had undergone CRC screening. Three of the studies included the experiences of both faecal testing and colonoscopy [35, 36, 39], two only included the participants' experience with faecal testing [37, 38], and one included the participants experience with either sigmoidoscopy or colonoscopy [40]. Aubin-Auger's study [39] included interviews to both General Practitioners and participants, clearly separated the findings of both, and only those related to patients were included in this review.

As for the analysis of the data, the studies used thematic analysis [37–39], an inductive qualitative content analysis [35], a funnel-structured research cycle analysis [36] and a constant comparative analysis [40].

Four of the studies had an appropriate methodological quality [35, 36, 38, 39], but the remaining had important limitations, due to the appropriateness of the analytic approaches used (authors reported opposite approaches to analyse data) [37] and the value of the research due to the time elapsed since the study was conducted [40].

The detailed methodological quality assessment can be seen in Table 3.

Review findings

We identified five descriptive themes: concerns about the results, challenges regarding procedure logistics, care received from the healthcare professionals, being adequately informed and expectations and experience with the program.

Variability in the concerns about the results

All studies reported the participants having varying degrees of concern regarding the possible outcome of the screening tests [35–40]. Some of them went through screening without any further reflections or concerns about the outcome, as they just assumed that the result would be fine. Having an abnormal FIT result did not shock some of the participants either, as the result was somewhat expected because of previous hemorrhoids

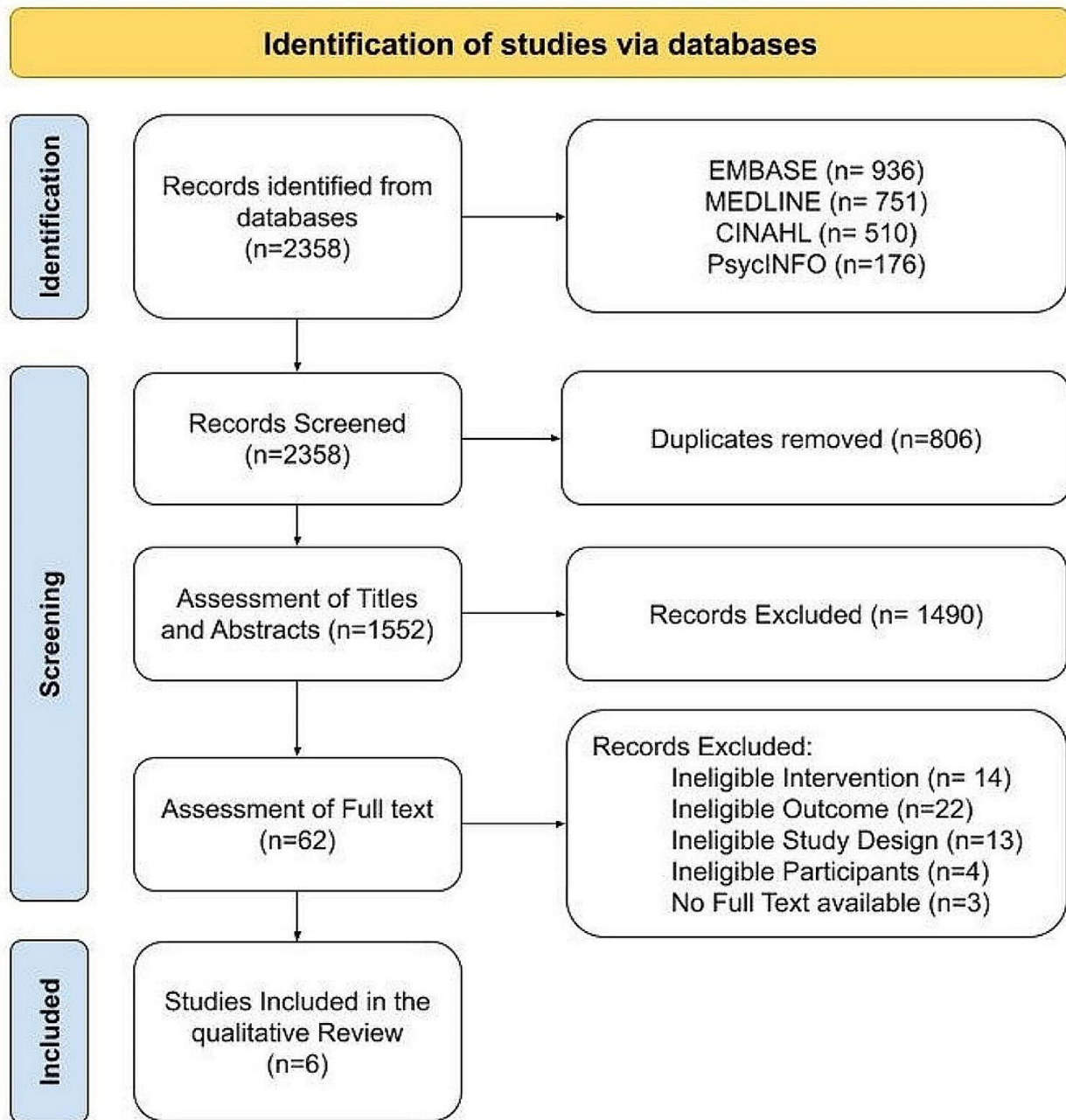


Fig. 1 PRISMA chart of the study selection process

or those who had polyps detected during their previous colonoscopies [35].

Really, I didn't think I was going to get any reply. When I had sent it away (.) it was in a way pretty much gone for me (.) then I'd done my part and didn't think about it until I received the result [35].

Others, however, did struggle with anxious thoughts about the screening outcomes, as they were worried about further medical procedures such as a colonoscopy

[35, 36]. For some participants, receiving an abnormal FIT result was often accompanied by a dooming mindset expressed as “now it is over” [35].

In sum, the interpretation of a positive FIT result and perceived risk of CRC was shaped by symptom appraisal and experiences with previous abdominal symptoms and investigation. [38]

Fear about results was reported to be a determinant factor to explain both why individuals decided to participate, as well as why they sometimes decided to stop participating [37]. Specifically women with established

Table 2 Main characteristics of included studies

Study	Aims	Settings	Population	Methodology	Recruitment Methods	Data collection	Analysis	Findings
Jonathan Wangmar et al. 2021 [32]	To explore how individuals in CRC screening experience the screening procedure.	Sweden	44 individuals aged 60–62 years (24 men, 20 women), who had undergone CRC screening: 15 faecal testing and/or 29 colonoscopies	Not Reported	Purposeful sampling strategy from the national randomized controlled screening of Swedish colons clinical trial (ID: NCT02078804)	6 focus group discussion and 20 individual semi structured interviews	Inductive qualitative content analysis	(1) From no worries to bothering emotions (2) Varying logistical concerns (3) Being well treated, but inconsistently informed and involved (4) Expectations not matching reality
Pia Kirkegaard et al. 2019 [33]	To explore perceptions of CRC screening among participants who have experienced a 'false alarm' for CRC, and to explore perceptions about the relevance of screening for themselves or others	Denmark	22 individuals aged 58–74 years (12 male, 10 female) who had undergone CRC screening program that had a positive FIT result but negative colonoscopy result	Phenomenology	Maximum variation sampling strategy through the call center of the regional screening provider	22 semi structured interviews	Funnel-structured research cycle analysis	1. "Nothing could escape" 2. "It is good to get through examination" 3. Moral obligation to participate
Lucia Benito et al. 2018 [34]	To explore factors related to the adherence of screening behaviour in the biennial FOBT population-based cancer screening program.	Spain	45 individuals aged 50–69 years (23 male, 22 female), invited at least twice to participate in the CRC screening program (and had participated at least once)	Not Reported	Purposeful sampling strategy (combination of intensity and maximum variation sampling) through the national CRC screening program	8 Focus groups	Thematic Analysis	(1) Perceived benefit of prevention (2) Lack of comprehension (3) Lack of information in the media (4) Satisfaction with the program (5) The role of fear (6) Consulting a GP
Pia Kirkegaard et al. 2018 [35]	to explore how screening participants experience a positive FIT result and cope with the pre-diagnostic waiting period between positive FIT result and colonoscopy	Denmark	22 individuals aged 50–74 years (11 male, 11 female) that had tested positive in the CRC screening program using FIT	Ethnographic research	Maximum variation sampling strategy	22 semi structured Interviews	Thematic analysis	1. Symptom appraisal and perceived CRC risk 2. Communication about the positive FIT test with healthcare professionals, family and friends
Isabelle Aubin-Auger et al. 2011 [36]	to explore the obstacles to mass colorectal screening in France.	France	GPs with different experience with CRC screening and 24 of their patients aged 50–74 years (13 male, 11 female)	Grounded theory	Purposive sampling of GPs in various districts of France and continuous process of data collecting analysis to fill missing categories of patients	24 semi structured interviews	Thematic Analysis	(1) The test (2) Information about the test (3) Organization of the screening (4) Colonoscopy

Table 2 (continued)

Study	Aims	Settings	Population	Methodology	Recruitment Methods	Data collection	Analysis	Findings
Anne Miles et al. 2003 [37]	to explore people's expectations surrounding the screening test, the process of finding out about their cancer diagnosis and their reactions to it	UK	24 individuals aged 59–68 years (12 male, 11 female) suitable for FS with no history of CRC, adenomas or inflammatory bowel disease	Grounded theory	Assessing patients diagnosed with cancer as a part of the UK Flexible Sigmoidoscopy Screening Trial	24 open-ended interviews	Constant comparative analysis	1. Expectations at screening 2. Finding out 3. Reaction to diagnosis 4. Most difficult time during cancer experience 5. Attitudes to screening

Table 3 Methodological quality assessment of included studies

Criteria	Johanna Wangmar et al. 2021 [35]	Pia Kirkegaard et al. 2019 [36]	Lucia Benito et al. 2018 [37]	Pia Kirkegaard et al. 2018 [38]	Isabelle Aubin-Auger et al. 2011 [39]	Anne Miles et al. 2003 [40]
Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes
Is a qualitative methodology appropriate?	Unclear, methodology not described	Yes	No, methodologic approach described is opposed*	Yes	Yes	Yes
Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes
Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes
Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Yes	Yes
Has the relationship between researcher and participants been adequately considered?	Unclear (not described)	Unclear (not described)	Unclear (not described)	Unclear (not described)	Unclear (not described)	Unclear (not described)
Have ethical issues been taken into consideration?	Yes (approved by regional ethical review board)	Yes (approved by the Danish Data Protection Agency)	Yes (approved by ethics committee)	Yes (approved by the Danish Data Protection Agency)	Unclear (No ethical approval)	Yes (local ethics approval was obtained)
Has the data analysis been sufficiently rigorous?	Yes, Inductive qualitative content analysis in concordance with the study framework	Yes, Funnel-structured research cycle analysis in concordance with the study framework	Unclear, study framework was unclear	Yes, thematic analysis in concordance with the study framework	Yes, thematic analysis in concordance with the study framework	Yes, constant comparative analysis in concordance with the study framework
Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes	Yes
How valuable is the research?	Yes	Yes	Unclear	Yes	Yes	Unclear (old article)

* Authors reported opposite approaches to analyze data: they used a thematic analysis framework, but also described a constant comparison analysis (usually used in the grounded theory framework) to analyze their findings. In consequence, this may have an impact on the study validity, although one might consider that a valid thematic analysis was properly conducted

screening habits (e.g., mammography, cervical smears) and individuals with familial exposure to gFOBT, were more likely to accept participation [39], as the previous experience reduced their fear, and therefore concern, of a possible positive result.

There are many people who prefer to ignore things, until there is no remedy and then you have to face the problem and say, ok because there is no choice.

but if I can avoid knowing. Then there will be a percentage of people who will also do it [to participate] out of fear. I think so [37] (Female).

Challenges regarding procedure logistics

When commenting on the FIT, participants agreed that the performance of the test was simple and easy, and appreciated being able to perform the procedure at home,

even though it sometimes was a bit time-consuming [35, 37]. Some patients forgot to perform the FIT, while others lacked time or were indifferent [39]. Furthermore, when a participant received a positive FIT result, the feeling of uncertainty regarding the upcoming colonoscopy was overwhelming and worries about the discomfort of it arose [35].

When it comes to doing the [FOBT] test (.) I consider it [the FOBT test] a very comfortable thing. You do it in your house, at the moment [37] (Male).

The colonoscopy itself proved to be more challenging than FIT, as both the investigation and the bowel preparation were perceived as physically unpleasant, exhausting, and disgusting [35, 36], regardless of the use or not of sedatives [35]. The bowel preparation was specially mentioned to be one of the worst and most troublesome aspects of the colonoscopy [35, 36].

The main concern regarding logistics was the interference with daily life. Individuals were required to plan or reschedule other activities to undergo colonoscopy [36], and that ultimately resulted in them prioritizing their everyday tasks and activities over the actions needed to participate in the screening program [37], postponing the procedure. Colonoscopy appointments required patients to plan for transportation after the examination, often involving a family member or friend accompanying them to and from the hospital. Having to repeat the FIT test twice was also considered burdensome and time-consuming [35].

Well yes, that (the bowel preparation) was probably the worst bit/Yes/(.)/Yes, that first litre goes very well but then the next gets tough [35].

Care received from the healthcare professionals

Four of the six included studies [35, 36, 38, 40] put an emphasis on the participants' report of the care received. In all studies, healthcare professionals were described as trust-promoting, empathetic, friendly, easy-going, and attentive. Feeling well treated and cared for was a shared experience among the participants.

She who performed it (the colonoscopy), was a really nice woman (.) and there was nothing wrong with anyone else either, but to me, it gets so much easier when you can take it lightly, make a joke and stuff [35].

Some patients discussed the positive FIT result with a healthcare professional to talk about the upcoming

colonoscopy [38], as doctors played a significant role in mitigating concern and providing reassurance.

Individuals also shared the importance of being involved during the procedure, especially when healthcare professionals explained real-time findings or removals during colonoscopies. This involvement helped increase trust in the skills of the professional performing the intervention [36]

It was such a positive experience. They told me during the whole procedure what they saw, and they blew up and removed some tiny little polyps. [36] (Female, 74).

Being adequately informed

A very commonly discussed theme was the information received by participants for the FIT and gFOBT tests, and whether it was adequate or sufficient [35, 37]. Most agreed that there was some confusion surrounding the bureaucratic aspects of the screening process, such as what process to follow to participate, time periods between rounds, age limits for the program, and where to confirm the colonoscopy appointment [35, 39].

We have all been relaxed about it because none of us knew that the maximum period between analysis and analysis of the colon are two years, we did not know. And then, well, they have done it and that's it. and it is not like that [37] (Male).

The lack of information regarding CRC screening in the media contributed to the general misinformation, which prompted many individuals to consult a general practitioner after receiving the invitation to make the decision to undergo the screening process [37]. Some patients were not convinced by the explanatory letter and asked their GPs for other reasons why screening was necessary, such as epidemiological factors. [39] Some other patients preferred managing their health in different ways, such as eating healthy food or exercising, and believed screening was only useful in the case of high-risk familial CRC. [39].

I went to my GP [before making a decision] and they talked me through it [the letter] a bit [37] (Male).

Some patients showed a complete lack of knowledge about the test (gFOBT), sometimes thinking that it was a colonoscopy. [39]

When talking about colonoscopy, participants referred to being well informed both before and during the procedure, which was highly valued as it gave them the feeling of being more involved [36, 37].

The way the results were communicated also brought up uncertainties, as participants were not sure whether they had gotten their result, as the letter they received was unclear [36]. General misinformation also affected how participants interpreted the results, with a positive result being automatically linked to cancer. [39]

In cases where the patients received a cancer diagnostic, initially they were only told that polyps had been found, interpreting this outcome as non-serious. Despite having a period in which they were essentially symptomatic, they failed to prepare themselves for the possibility that the polyps detected at screening might turn out to be malignant. [40]

Expectations and experience with the program

Individuals described their expectations not corresponding with the reality of the screening procedure both in a positive and negative way. Their experience with the FIT test was better than what they expected, and they were surprised by its cleanliness and simplicity.

Colonoscopy however, had contradicting experiences. While for some, despite being relatively painless and professional, was worse than what they expected [35], for others undergoing the colonoscopy was a better experience than anticipated, and the behaviour of healthcare professionals provided comfort, making patients feel less uncomfortable about undergoing a colonoscopy in the future. [37]

There was a sense of relief once the screening procedure was completed, as they felt pleased since it was considered “good to know” [35].

I think it is such a comfort to get screened and to be told that there is no cancer at all. I can only be content with this screening procedure. [36] (Female, 74).

There was a sense of gratitude towards screening offers, as participants appreciated and realized the health benefit that this type of service introduces, not only on an individual level but also on a populational level. Some even considered participating in these programs as a “moral obligation” [36, 37]. Even after a cancer diagnostic, no one expressed the view that they wished they had not gone for screening [40]. Many participants thought that screening can help detect disease at the stage when things can be done, offering a chance of cure, prolonged life, and a choice about whether to go ahead with treatment or not. [40].

Screening is just something you should do. It is no fun, but you should do it for your family's sake. This is a priority of society. Finally, when there is a screening offer for men, we should jump at the offer [36] (Male, 58).

Interpretive explanation of satisfaction with the screening programme

The actual experiences of individuals undergoing CRC screening, compared to initial expectations, significantly impact overall satisfaction, and so, how both factors are shaped will be decisive.

Regarding expectations, they might differ influenced by the participant's past experiences. On one hand, having undergone screening successfully in the past can encourage them to participate again, but on the other hand, concerns they might have about the procedures can affect how they face the tests, and even prevent them from participating at all. Fear of a positive result can also negatively impact expectations, as people with a more dooming mindset will meet the whole screening process with far worse prospects. Expectations are also easily defined by the information participants receive from both the letter they receive at their home as from the media or their GP. This information needs to be clear and straightforward, as being adequately informed will determine what the participants will assume the whole process will look like.

As for the experiences, the review highlights a wide range of concerns regarding the screening outcome, varying from no concern to anxious thoughts and a dooming mindset among participants. Logistic issues arising from the screening process, particularly challenges with FIT and colonoscopy procedures, were commonly reported. These challenges led to disruptions in daily life, often resulting in the postponement or rescheduling of tests to prioritize participants' everyday tasks. Notably, participants consistently praised the care provided by healthcare professionals throughout the screening program. The professionals were characterized as empathetic, attentive, and actively involved during procedures. This involvement significantly contributed to participants feeling well-informed both before and during the procedure, in contrast to the general lack of information received prior to the test. The confusion around bureaucratic aspects of the screening program led many individuals to consult GPs after receiving invitations to participate.

In essence, participant satisfaction is a complex interplay of emotional responses, logistical challenges, healthcare professional interactions, information adequacy, and the alignment of expectations with actual experiences during the screening process. Successfully managing these factors contributes to overall participant satisfaction. Therefore, to improve satisfaction with CRC screening programs, it is necessary that the experience of participants is good and that expectations are as aligned as possible with reality. An overview of the construction of the analytical theme can be found in Fig. 2.

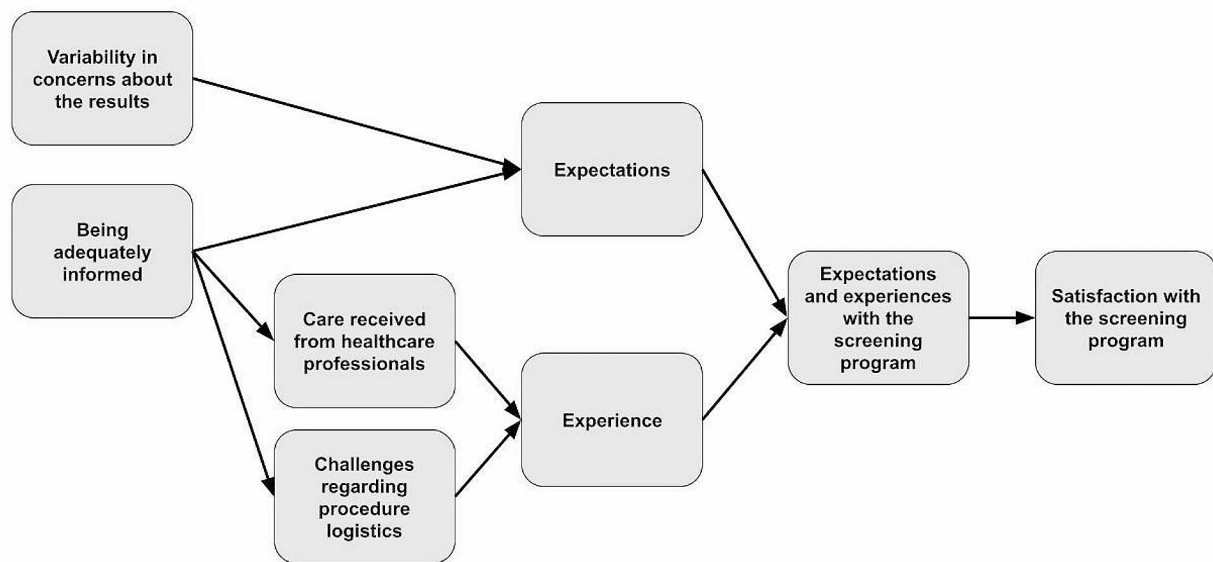


Fig. 2 Interpretive explanation of satisfaction with the screening programme

Despite disparities between expectations and the reality of the screening procedure, participants did not express dissatisfaction with the program. Upon finalisation, there was a shared sense of relief, and participants expressed gratitude towards the screening offers.

Confidence in our findings

We presented our confidence in review findings in a CERQual evidence profile table (Table 4). All findings had a moderate level of confidence due to the limited amount of data that supported the findings and due to concerns on relevance as the objectives of two included studies [37, 39] did not align completely with our research question.

Discussion

Summary of main findings

Overall, participants describe a generally satisfactory experience with the program.

The review highlights a wide range of concerns regarding the screening outcome, varying from no concern to anxious thoughts and a dooming mindset among participants. Logistic issues arising from the screening process, particularly challenges with colonoscopy procedures and forgetting to do the FIT, were commonly reported. These challenges led to disruptions in daily life, often resulting in the postponement or rescheduling of tests to prioritize participants' everyday tasks.

Notably, participants consistently praised the care provided by healthcare professionals throughout the screening program. The professionals were characterized as empathetic, attentive, and actively involved during procedures. This involvement significantly contributed to participants feeling well-informed both before and during

the procedure, in contrast to the general lack of information received prior to the test. The confusion around bureaucratic aspects of the screening program led many individuals to consult GPs after receiving invitations to participate.

Despite disparities between expectations and the reality of the screening procedure, participants did not express dissatisfaction with the program. Upon finalization, there was a shared sense of relief, and participants expressed gratitude towards the screening offers.

Strengths and limitations of the study

One of the strengths of this study is the extensive effort made to find and review all relevant primary studies by performing exhaustive bibliographic research in four different databases and searching for grey literature. Even though studies in English, Spanish and French were included, other studies relevant to this topic published in other languages might exist. Included studies were all conducted in Europe: three in Nordic countries, two in centre-European countries and one southern-European country which have health care and societal context differences. This proves to be a strength as identifying the most prevalent and convergent experiences of participants in CRC screening programs across countries further increases the confidence in our results. Finally, the originality of our work lies on the fact that, to our knowledge, there are no other qualitative evidence synthesis on this topic.

Our study has some limitations. The first one being the relatively small number of included primary studies in the review. We also could not find the complete text for three preliminarily included studies. All studies were

Table 4 CERQual evidence profile table

Summary of review finding	Studies contributing to the review finding	Methodological limitations	Coherence	Adequacy	Relevance	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment*
1. Variability in the concerns about the results Participants reported varying degrees of concern regarding the outcomes of the screening test	Wangmar et al., Kirkegaard et al., Benito et al., <i>Aubin-Auger et al.</i> , <i>Kirkegaard et al.</i> , <i>Miles et al.</i>	No or very minor concerns	No or very minor concerns	Moderate concerns	Minor concerns	Moderate confidence	Only six studies that offered moderately rich data. Two of the six studies aimed to explore factors related to adherence/obstacles to the screening programs. One of the studies was from 2003.
2. Challenges regarding procedure logistics Individuals experienced challenges regarding logistics of both FIT and Colonoscopy, as well as a general interference with their daily life	Wangmar et al., Kirkegaard et al., Benito et al., <i>Aubin-Auger et al.</i> , <i>Kirkegaard et al.</i>	No or very minor concerns	No or very minor concerns	Moderate concerns	Minor concerns	Moderate confidence	Only five studies that offered moderately rich data. Two of the five studies aimed to explore factors related to adherence/obstacles to the screening programs.
3. Care received from the healthcare professionals Participants received good care from healthcare professionals, and were well treated	Wangmar et al., Kirkegaard et al., <i>Kirkegaard et al.</i> , <i>Miles et al.</i>	No or very minor concerns	No or very minor concerns	Moderate concerns	No or very minor concerns	Moderate confidence	Only four studies out of the six reported data on the finding, which was moderately rich. One of the studies was from 2003.
4. Being adequately informed Individuals felt there was an overall lack of information about colorectal cancer screening that contributed to some confusion around the bureaucracy involved, but that during the procedure itself they were well informed	Wangmar et al., Kirkegaard et al., Benito et al., <i>Aubin-Auger et al.</i> , <i>Kirkegaard et al.</i>	No or very minor concerns	No or very minor concerns	Moderate concerns	Minor concerns	Moderate confidence	Only five studies that offered moderately rich data. Two of the five studies aimed to explore factors related to adherence/obstacles to the screening programs.
5. Expectations and experience with the program Patients were overall satisfied with their experience	Wangmar et al., Kirkegaard et al., Benito et al., <i>Aubin-Auger et al.</i> , <i>Kirkegaard et al.</i> , <i>Miles et al.</i>	No or very minor concerns	No or very minor concerns	Moderate concerns	Minor concerns	Moderate confidence	Only six studies that offered moderately rich data. Two of the six studies aimed to explore factors related to adherence/obstacles to the screening programs. One of the studies was from 2003.

European, which, despite them having different healthcare systems, limits the extrapolation of our results to other regions and contexts. Besides, the small amount of data and concerns about relevance limited the confidence in our findings and did not allow us to answer our secondary objectives.

Comparison to existing literature

One of the main findings of our study were the varying degrees of concern about the results of the screening test. However, after a negative FIT result, or after being cleared of a positive FIT result by a colonoscopy, people

felt a huge feeling of relief. This indicates that the confirmation of a good health outcome has a value ‘per se’ [41]. Just by accepting to participate in the program, individuals accept the risk of “false alarm”, which aggravates the concern of a positive result. At the same time, it has been suggested that participation elicits a feeling of being examined for good, and therefore causing a “relaxation effect” that delays future doctor visits and might deter them from participating again in future screening rounds [42]. From our findings, we can neither support nor contradict these suggestions.

We have found that many participants feel a moral obligation to participate in screening programs, from personal, interpersonal, and societal perspectives. This finding is reinforced when looking at breast and cervical cancer screening studies, which suggest screening might constitute a moral framework of obligation and responsibility, as these programs are both a social and medical intervention [43–45]. This might be even more relevant in countries with socialized healthcare systems, which often remind residents about the scarcity of resources, and therefore appeal to their sense of obligation to participate in the screening programs, explaining the high participation levels [46].

When discussing the tests themselves, previous research confirms that the FIT procedure is considered simple and easy [47], and participants preferred FITs that were single sample, used a probe and vial for sample collection, and had simple, large font instructions with colourful pictures [48]. Studies also validate the difficulties with colonoscopy bowel preparation [49] and suggest that offering different laxative alternatives might help relieve the stress and optimize the preparation [50].

Published quantitative studies based on surveys/questionnaires also reinforce our findings of a general positive experience with the screening, with room for improvement in the informative material and the colonoscopy preparation [51, 52].

Implications of our results and future research

Our study has identified some issues that might negatively affect participants' satisfaction with CRC screening programs. This knowledge can help in the design of interventions or changes to the current programs that might help alleviate these challenges, including: (1) Having a clearer presentation of the program and what timelines to follow in the letter sent home; (2) Implementing automated reminders via mobile apps or text messages, with prompts to complete the FIT test within recommended time frames (3) Provide a detailed and more realistic explanation about how the colonoscopy preparation is going to be like, so participants' expectations are better managed.

Our study also highlighted the relevance of HCP in the screening process. Especially General Practitioners, as their support and interactions with participants play a pivotal role in their decision to participate in the programs.

We tried to bring integrated knowledge on the understanding of the experience and satisfaction of participants of CRC screening programs. However, we could only include six studies, which sheds a light into the need of performing more qualitative research on this topic. There were no studies that considered the gender perspective, and whether the satisfaction with the program

varied if the participants was a man or a woman, or other demographic differences such as ethnicity or socioeconomic status. There is also a lack of studies answering any of our secondary objectives, such as: whether any differences existed in satisfaction with opportunistic or populational screening, or whether the final screening results impact the overall satisfaction with the programs.

Conclusion

Our qualitative evidence synthesis provided a picture of the experience and satisfaction of participants in CRC screening programs. There are varying degrees of concern about the results derived from their participation, and while the FIT test is easy and straightforward, bowel preparation for colonoscopy is a problem for participants. The screening process interrupts with daily life, which encourages individuals to postpone screening. During the procedure they feel well cared after and informed, but there is still some lack of information that contributes to the mismanagement of expectations. Despite this, the overall satisfaction with the screening programs is high.

Supplementary Information

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Supplementary Material 1

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Author contributions

C.H. wrote the main manuscript text. C.H. and C.S. performed the analysis. I.S. designed the search strategy. A.S. reviewed all analysis and provided feedback and guidance. All authors reviewed the manuscript and provided corrections.

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Data availability

All data generated or analysed during this study are included in this article. Further enquiries can be directed to the corresponding.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

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Competing interests

The authors declare no competing interests.

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