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Review Article

Participants' satisfaction with colorectal cancer screening programs: A systematic review

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ABSTRACT

Introduction: Since satisfaction with cancer screening experience can increase adherence to programs and contribute to reduce morbidity and mortality, its assessment is crucial for programs' effectiveness. Our aim was to conduct a systematic review about satisfaction of participants with organized colorectal cancer screening.
Methods: We searched relevant scientific databases (MEDLINE, EMBASE, PsycINFO, and CINAHL) from inception to May 2022. We selected cross-sectional studies and clinical trials reporting a quantitative survey-based measure of satisfaction towards CRC screening.
Results: A total of 15 studies were included, being published from 1992 to 2019 for an overall number of 21 surveys. Of those, 16 (76%) investigated satisfaction with screening tests (fecal occult blood test, fecal immunochemical test, sigmoidoscopy, colonoscopy, computed tomographic colonography), 4 (19%) with colonoscopy as assessment test after suspicious findings, and 2 (10%) with both the screening and assessment phase. None of the included surveys used a validated questionnaire. Most surveys reported a high level of satisfaction for both screening and further assessment phases. Temporary pain, discomfort, embarrassment, and anxiety while waiting for results were the commonest negative aspects perceived, with some variability across studies and considered procedures.
Conclusions: Satisfaction with the information and communication about screening was generally good, but some authors reported participants' sub-optimal understanding of informative material. Satisfaction with CRC screening is generally high, but its evaluation is performed using non-validated instruments, which limits the interpretation of results and prevents comparability of the current body of evidence.

1. Introduction

Colorectal cancer (CRC) is the third most common cancer by prevalence and the second by incidence worldwide, accounting for 10% of the new diagnosed malignancies in 2020 (Wild et al., 2020). With almost 900,000 deaths annually, it is the second major cause of cancer mortality (Keum and Giovannucci, 2019).

CRC screening is aimed at lowering the risk of mortality from the disease by its early detection, as well as the rate of complications associated with cancer diagnosis at a later stage (Lauby-Secretan et al., 2018). By identifying and removing premalignant lesions, CRC screening is also aiming to reduce the incidence of CRC (Lauby-Secretan et al., 2018). Furthermore, early diagnosis can also spare many patients from adjuvant treatment and can hence have a great impact on health

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care costs and the patients´ quality of life. According to the literature, different screening procedures show different impacts on the CRC incidence and especially mortality rates. Declines in mortality rates among screening program participants range between 18% and 32% for Fecal Occult Blood Test (FOBT) (Zauber, 2015), while reduced mortality rates of about 41% for Fecal Immunochemical Test (FIT) (Gini et al., 2020), or even higher (50–70%) for more invasive tests like Flexible Sigmoidoscopy (FS) or optical colonoscopy (OC) have been reported (Brenner et al., 2014). Evidence on the effect of CT colonography (CTC) screening on CRC mortality rates is limited (Lauby-Secretan et al., 2018); according to estimates by the U.S. Preventive Services Task Force, this test could prevent 26 deaths per 1000 people screened if performed at 5-year intervals starting at age 45–50 (Lin et al., 2021). In general, approximately 50 % of the reduction in CRC incidence and mortality between 1975 and 2010 on the population level is considered attributable to the increases in CRC screening rates and the use of more effective tests (Zauber, 2015).

Despite their confirmed effectiveness, CRC screening procedures also bring along some undesirable effects that vary by test and should be considered carefully. The most common undesirable effects related to FOBT and FIT are embarrassment, difficulties with the stool collection process, anxiety, false-negative results leading to interval cancers, and false-positive results, leading to fear of cancer and unnecessary further examination (Lin et al., 2021). In a minority of cases, people undergoing endoscopic examinations may experience discomfort, nausea, vomiting, moderate to severe pain during or after the procedure, bleeding, and problems related to sedation (Jodal et al., 2019). Severe adverse events are rare: perforation risk is 3.1/10,000 for colonoscopy and 0.2/10,000 for FS, while major bleeding risk is 14.6/10,000 for colonoscopy and 0.5/10,000 for FS (Lin et al., 2021). The risk of major adverse events following a screening CT-colonography is low to nonexistent, according to the available data; however, exposure to ionizing radiation and frequent detection of extra-colonic findings represent significant drawbacks of this technique (Lin et al., 2021). Finally, in older subjects or those with concomitant diseases, bowel preparation for endoscopic exams can potentially result in electrolyte imbalances or dehydration (Lin et al., 2021).

To achieve the desired population level impact of organized screening programs, it is critical to reach high participation rates but also high adherence rates among participants (von Karsa et al., 2013). Adherence to screening programs is influenced by different factors, including the participants' experience and satisfaction (Selva et al., 2021). The level of satisfaction with a previous stool test screening, for example, has been found to be a powerful behavioral predictor of adherence to future screening rounds (Duncan et al., 2012; Duncan et al., 2014; Osborne et al., 2017). Furthermore, patient satisfaction can affect health outcomes (Crow et al., 2002; Fitzpatrick, 1991), and its evaluation can provide useful elements to improve clinical strategies (Travaglia and Debono, 2009a). The measurement of participants' satisfaction with screening programs can be invaluable in evaluating and monitoring the quality of healthcare services and identifying areas for improvement (Beattie et al., 2015; Doyle et al., 2013), so it has been proposed as a quality indicator (Jover et al., 2012; Lee et al., 2012; von Karsa et al., 2010). As a result, assessing participants´ satisfaction is an important aspect of evaluating the screening services quality and it is also a way to improve adherence to screening programs.

However, there is no widely accepted definition for satisfaction in the literature. Satisfaction is a Patient-Reported Outcome Measure (PROM) (Kingsley et al., 2023) and reflects a personal assessment of the quality of care in relation to a subjective standard (Pascoe, 1983); a working definition may be the extent to which health care practitioners and/or services meet the participants´ intended expectations, objectives, and/or preferences (Travaglia and Debono, 2009b). When attempting to measure participants' satisfaction, different issues can occur, and it is not possible to rely on a single assessment method. According to literature, surveys, critical incident techniques, questionnaires, and interviews are the most commonly used instruments (Travaglia and Debono, 2009b). Although there are different methods to assess patient satisfaction, the most used by far are self-reported questionnaires (Travaglia and Debono, 2009b).

This systematic review summarizes satisfaction of screening participants with their experience with different kinds of organized CRC screening programs in order to understand the key determinants of good screening experience and satisfaction. A better experience with screening programs could lead to greater participation and hence improved effectiveness of the screening programs.

2. Methods

We conducted a systematic review to address the question of how satisfied people are with organized colorectal cancer screening programs. We registered the review protocol in PROSPERO (http://www.crd.york.ac.uk/PROSPERO) [registration number CRD42021225343]. This systematic review followed the standard Cochrane Collaboration methodology (Higgins et al., 2019) and adhered to the PRISMA statement for reporting of systematic reviews (Moher et al., 2015).

We adapted a search strategy from a systematic review on patient reported experience measures (Selva et al., 2021). It combined controlled vocabulary from each database and text words related to the review topics (e.g., satisfaction and colorectal cancer screening). We conducted the search in MEDLINE (PubMed), EMBASE (Ovid), PsycINFO (EBSCOHost) and CINAHL (EBSCOHost) without language or date restrictions from inception to May 2022. The detailed search strategies are available in Supplementary File I.

We included quantitative cross-sectional studies (i.e., surveys) and controlled clinical trials that measure the participants´ satisfaction or experience with organized colorectal cancer screening programs that used FOBT, FIT, FS, colonoscopy, or computed assisted colonography (CT-colonography) as screening test. Systematic reviews were considered to locate the primary studies included. We limited the inclusion to studies published in English, Spanish or Italian. We excluded qualitative studies, studies on non-organized screening programs, studies on screening programs based on bowel capsule, magnetic resonance imaging, or peripheral blood biomarkers, studies not assessing participants' satisfaction or experience as the main outcome, and studies only assessing discomfort with the test without any other aspect of the provision of services considered. Two authors independently assessed the titles and abstracts of retrieved references, and then made a final decision based on the full text of the references deemed eligible. Disagreements were resolved with the help of a third reviewer.

We developed and pilot-tested a case report form (CRF) using Google Forms. The CRF is available from the authors on request. Two authors independently extracted data from the surveys contained in the included studies and disagreements were resolved with the help of a third reviewer. Surveys were considered to be distinct when they: i) contained different questions depending on the respondent's subgroup ii) investigated different aspects of participants' experience AND were administered at separate times. We extracted the following data: 1. General characteristics of the study (country, year of publication, study design); 2. Characteristics of the colorectal cancer screening protocol (screening test, stage of the program assessed, screening round); 3. Population characteristics (age, sex, sample size); 4. Data collection procedure (measurement tool and evidence of instrument validation); 5. Response rate; 6. Outcomes assessed; 7. Satisfaction domains assessed, based on definitions provided in previous research (Deandrea et al., 2018; Pagliarin et al., 2021) (Accessibility; Staff's interpersonal skills; Staff's technical skills; Information transfer/communication; Physical surroundings; Discomfort, physical/physical experience; Discomfort, psychological/psychological experience; General satisfaction); 8. Satisfaction according screening result (positive vs negative). Our main outcome was general satisfaction with the screening program at any stage. When studies collected satisfaction concerning both the screening

phase and the assessment phase, we extracted those independent surveys as individual records.

We assessed the methodological quality of cross-sectional studies using the NICE Critical Appraisal Checklist for surveys performed by means of questionnaires (Excellence, N.I.f.H.a.C, 2012). This checklist consists of 17 items exploring eight domains (1. Validity and reliability; 2. Format; 3. Piloting; 4. Sampling; 5. Distribution, administration, and response; 6. Coding and analysis; 7. Results; 8. Conclusions and discussion). This checklist does not provide guidance on assessment criteria, so we defined some criteria for each item in order to be objective and transparent when assessing the studies. The assessment criteria defined can be found in Supplementary File II. Final scores were obtained by summing the scores of individual items and reported as final score out of the maximum score. We planned to apply the Cochrane risk of bias tool to assess the methodological quality of controlled trials (Boutron et al., 2019). Two reviewers independently assessed the risk of bias for each study. Differences were solved by consensus or by consulting a third reviewer.

We used descriptive statistics to synthesize findings, calculating absolute frequencies and proportions for categorical variables and means (or medians) and standard deviations or percentiles for continuous variables. We planned to quantitatively pool the results reported by different studies, but we were not able to do so as studies were too heterogeneous in the outcomes assessed and scales used. Therefore, we reported review findings as a narrative synthesis distinguishing screening and assessment phases and in tabulated summaries.

2.1. Ethical approval and consent to participate

No ethical approval was required as this study is a systematic review.

3. Results

3.1. Study selection

A total of 4420 individual citations were retrieved, 3970 references were reviewed by title and abstract, 164 articles were read in full text. Among full texts assessed for eligibility, 149 were excluded mainly

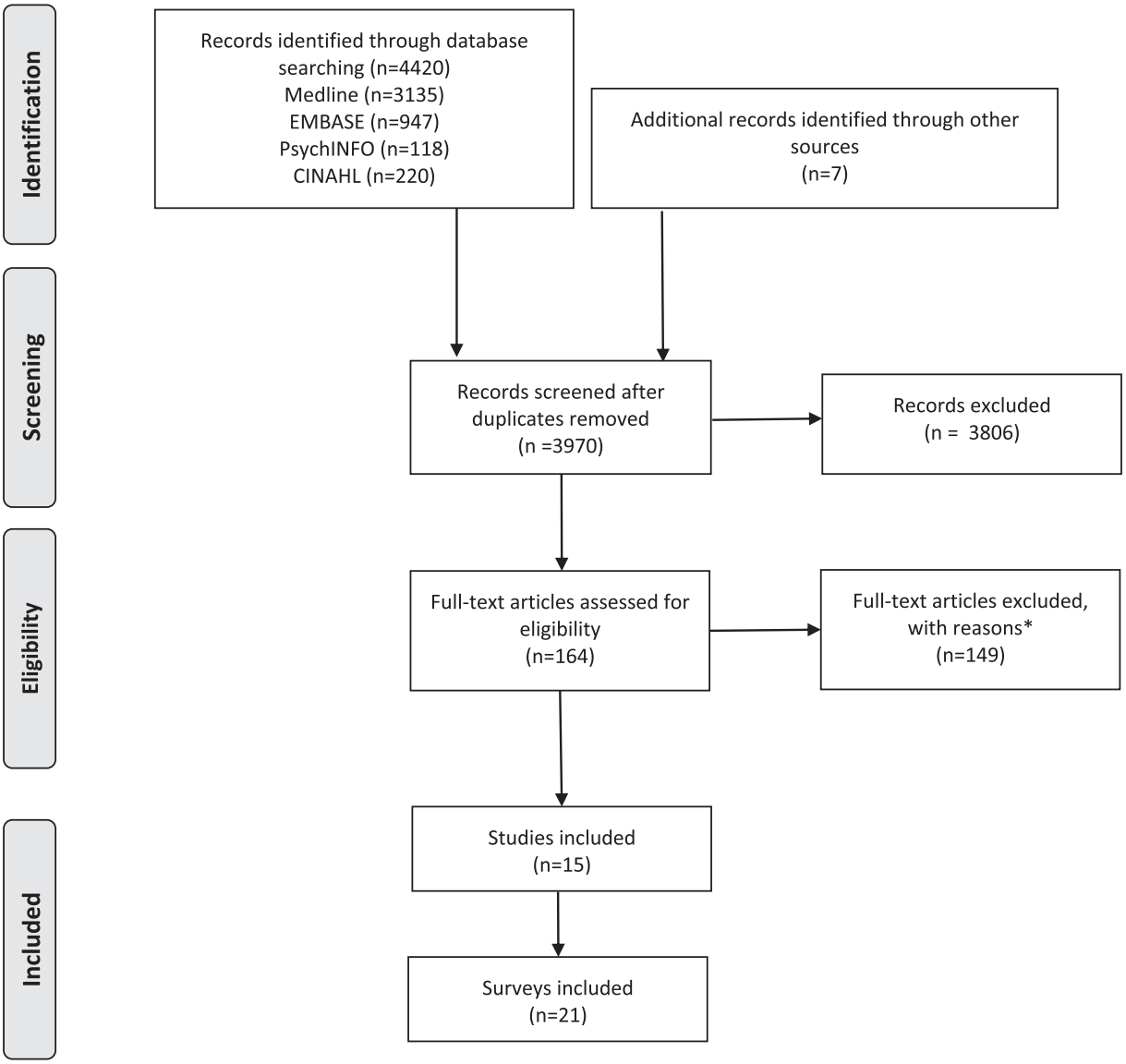

Fig. 1. Flow-chart of study selection process according to PRISMA statement.
*Reasons for exclusion: Not measures satisfaction with colorectal cancer screening as main outcome (n = 53); Not uses a questionnaire (*n* = 13); Narrative review (*n* = 6); Measures satisfaction with the decision to participate in a study (*n* = 3); Not about organized colorectal cancer screening (n = 41); Study protocol (n = 1); Language (n = 3), Duplicate (n = 4), Measures satisfaction in relation to a small part of the process or an specific technique n = 25).

because not measured satisfaction with CRC screening as a main outcome ($n = 53$), were not about CRC organized screening programs ($n = 41$) or measured satisfaction in relation to a small part of the screening process or a specific technique ($n = 25$). We finally included 15 studies. A PRISMA flow diagram describing the records identification, the selection process and all reasons for exclusion is reported in Fig. 1.

3.2. Characteristics of included studies

Table 1 shows the characteristics of the included studies. The included studies were mainly conducted in European countries, and were predominantly published after 2000. Almost all included studies followed a cross-sectional design (7/15, 47%) (Arveux et al., 1992; Bevan et al., 2015; Burón et al., 2017; Ghanouni et al., 2016; Hambleton and Jones, 2017; Plumb et al., 2017; Shin et al., 2018) or were cross-sectional substudies nested in either a clinical trial (6/15, 40%) (Blom et al., 2004; Bretthauer et al., 2002; Denters et al., 2013; Hol et al., 2010; Kinner et al., 2007; Sali et al., 2019) or in a case-controlled study (Sarkar et al., 2012), except for one study, which had a longitudinal design (Robb et al., 2012). The selected studies contained 24 satisfaction surveys, of which 21 were suitable for inclusion in the systematic review (Table 2) and investigated satisfaction with screening tests (16/21, 76%), further assessment tests (4/21, 19%) or both screening and assessment tests (1/21, 10%). Overall, 144,223 subjects were invited in participating the included surveys, 114,155 responses were collected (average response rate 79%), and the final analyzed samples involved a total of 113,258 participants (although both the Sali et al. and Robb et al. studies contained two surveys whose participants were partially overlapping). All the surveys used non-validated questionnaires (mostly written and self-administered) developed for the purpose of the study. Despite Kinner et al. (2007) stated that they used a written, self-administered validated questionnaire, they did not provide further information about the development nor validation of the questionnaire. We tried to contact authors to obtain information about the questionnaire development and/or validation studies without success.

The screening protocols differed in organization and type of tests used. Seven studies (Arveux et al., 1992; Burón et al., 2017; Denters et al., 2013; Ghanouni et al., 2016; Plumb et al., 2017; Sarkar et al., 2012; Shin et al., 2018) referred to programs in which FIT or FOBT were performed at the beginning and, if positive, were followed by a colonoscopy or a CT-colonography, seven referred to protocols in which colonoscopy or flexible sigmoidoscopy or CT-colonography (Bevan et al., 2015; Blom et al., 2004; Bretthauer et al., 2002; Hambleton and Jones, 2017; Kinner et al., 2007; Robb et al., 2012; Sali et al., 2019) was the first screening test, while three surveys from the same study (Hol et al., 2010) assessed satisfaction with FOBT, FIT, and FS as primary tests respectively.

3.3. Methodological quality of included studies

With regard to the methodological quality of included studies, final scores ranged from 7.5 to 14 out of a maximum of 17. All included studies scored badly for the validity and reliability domain because there was no evidence that questionnaires measured what they set out to measure or that their responses were stable over time. Many studies also lack information on questionnaire piloting (only three reported some sort of pilot testing) and include small and non-representative samples (only five studies include a sufficiently large and representative sample). Supplementary material (Supplementary File III) contains further information.

3.4. Satisfaction dimensions investigated

The most frequently assessed dimensions in the included surveys were: 1) the physical experience, including physical discomfort and ease of execution (20/21, 95%); 2) general satisfaction (17/21, 81%), and 3) psychological experience, including psychological discomfort and state of mind while waiting for results (11/21, 52%) (Fig. 2). Table 3 describes the eight dimensions of satisfaction assessed by all surveys and the questions used to explore them.

3.5. General satisfaction

General satisfaction was conceptualized, measured and expressed in different ways across surveys. This heterogeneity precluded pooling of the results. Supplementary File IV summarizes how general satisfaction was measured across surveys and their results.

Regarding the screening phase (16 surveys), the overall satisfaction was high regardless of the type of test used (Arveux et al., 1992; Bevan et al., 2015; Blom et al., 2004; Bretthauer et al., 2002; Burón et al., 2017; Hambleton and Jones, 2017; Hol et al., 2010; Kinner et al., 2007; Robb et al., 2012; Sali et al., 2019; Shin et al., 2018). Respondents were mostly willing to repeat the test (Arveux et al., 1992; Bevan et al., 2015; Blom et al., 2004; Hol et al., 2010; Sali et al., 2019; Sarkar et al., 2012; Shin et al., 2018) or recommend it to friends or relatives (Arveux et al., 1992; Bevan et al., 2015; Blom et al., 2004; Bretthauer et al., 2002; Hol et al., 2010; Robb et al., 2012; Sali et al., 2019). Hol et al. (Hol et al., 2010) compared satisfaction with FOBT, FIT, and FS, and found that, although the percentage of participants willing to repeat the test and to recommend it to others was generally high, it was lower in those who underwent FS. The “pharmacy strategy”, which involves pharmacies in the distribution and collection of FITs and FOBTs, received good feedback in terms of general satisfaction (Burón et al., 2017). Among the factors affecting satisfaction with FIT there were sex, age and income, since satisfaction was higher among women, those under 65 years old, and individuals with greater income (Shin et al., 2018); on the other hand, general satisfaction was not affected by the result of the FS (Hambleton and Jones, 2017). Robb et al. pointed out that the attitude and behavior of staff may be key factors for general satisfaction (Robb et al., 2012).

Overall satisfaction with the assessment tests was high in both included surveys that evaluated this domain (Denters et al., 2013; Sarkar et al., 2012). Denters et al. (2013) did not find differences in the level of overall satisfaction (mean: 7.9/10) according to sex, age or test results. Results from the study conducted by Sarkar et al. (2012) showed that the satisfaction of subjects undergoing colonoscopy within the British national Bowel Cancer Screening Programme was similar to that of the ones receiving colonoscopy outside a screening program.

Also in the case of the surveys that assessed participants’ experience with both the screening and assessment phases, overall satisfaction with the programs as a whole was high (Burón et al., 2017).

3.6. Physical discomfort and physical experience

Results show high variability, even in accordance with the screening protocol phase and procedures considered in the different surveys.

The execution of FOBT was considered simple by >95% of responders (Arveux et al., 1992; Burón et al., 2017), and both FOBT and FIT were found to be only slightly troublesome (Hol et al., 2010). The surveys evaluating the FS as a screening test found it was usually well tolerated (Bevan et al., 2015; Blom et al., 2004; Bretthauer et al., 2002; Hambleton and Jones, 2017) or less painful than expected (Robb et al., 2012). However, the percentage of participants reporting severe discomfort during the test execution varied widely, ranging from 0% (Bretthauer et al., 2002) to 17.4% (Hol et al., 2010). Two surveys investigated symptoms after FS examination (Hol et al., 2010; Robb et al., 2012), with abdominal pain, and flatulence as the most reported side effects. Furthermore, Hol et al. (2010) reported women were more likely to experience discomfort during FS, which was also rated as more burdensome than both FOBT and FIT.

Both in the study by Ghanouni et al. (2016) and Plumb et al. (2017),

Table 1
Characteristics of included studies ($N = 17$).

Study	Urveys	Country	Study design	Population	Phase of screening process	Test	Sample size[#]	Dimensions of satisfaction	Risk of bias score[*]
Arveux et al. (1992)	1	France	Cross-sectional	General population (45–74 y)	Screening	FOBT	705	Accessibility/ waiting time Information transfer/ communication Discomfort, physical/ physical experience Discomfort, psychological/ psychological experience General satisfaction	8/17
Bevan et al. (2015)	1	United Kingdom	Cross-sectional	General population (>55 y)	Screening	FS	528	General satisfaction	8/17
Blom et al. (2004)	1	Sweden	Cross-sectional nested in a clinical trial	General population (59–61 y)	Screening	FS	468	Information transfer/ communication Physical surroundings Discomfort, physical/ physical experience Discomfort, psychological/ psychological experience General satisfaction	10.5/18
Bretthauer et al. (2002)	1	Norway	Cross-sectional nested in a clinical trial	General population (50–64 y)	Screening	FS	185	Discomfort, physical/ physical experience General satisfaction	9.5/17
Burón et al. (2017)	2	Spain	Cross-sectional	General population (50–69 y)	Screening and assessment	FOBT + OC	473	Accessibility/ waiting time Information transfer/ communication Discomfort, physical/ physical experience Discomfort, psychological / psychological experience General satisfaction Others	14/17
Denters et al. (2013)	1	Netherlands	Cross-sectional nested in a clinical trial	General population (50–75 y)	Assessment	OC	273	Discomfort, physical/ physical experience Discomfort, psychological/ psychological experience General satisfaction Others	13.5/17
Ghanouni et al. (2016)	1	United Kingdom	Cross-sectional	General population with abnormal FOBT (≥60 y)	Assessment	FOBT	50,858	Staffs' interpersonal skills Staff's technical skills Information transfer/ communication Physical surroundings Discomfort, physical/ physical experience	10.5/18
Hambleton (2017)	1	United Kingdom	Cross-sectional	Adults aged 55 years from the general population	Screening	FS	110	General satisfaction Others	9/17
Hol et al. (2010)	3	Netherlands	Cross-sectional nested in a clinical trial	General population (50–74 y)	Screening	FOBT, FIT, FS	1784	Discomfort, physical/ physical experience Discomfort, psychological / psychological experience General satisfaction	10/17
Kinner et al. (2007)	1	Germany	Cross-sectional nested in a clinical trial	Insurants of a national health company (≥50 y)	Screening	OC	284	Discomfort, physical/ physical experience General satisfaction Others	11/17

(*continued on next page*)

Table 1 (*continued*)

Study	Urveys	Country	Study design	Population	Phase of screening process	Test	Sample size[#]	Dimensions of satisfaction	Risk of bias score[*]
Plumb et al. (2017)	1	United Kingdom	Cross-sectional	General population (60–74 y)	Assessment	OC + CTC	52,945	Accessibility/ waiting time Staffs' interpersonal skills Information transfer/ communication Physical surroundings Discomfort, physical/ physical experience Others	10.5/17
Robb et al. (2012)	2	United Kingdom	Longitudinal	General population (58–59 y)	Screening	FS	1587	Staffs' interpersonal skills Information transfer/ communication Physical surroundings Discomfort, physical/ physical experience General satisfaction	11.5/18
Sali et al. (2019)	2	Italy	Cross-sectional nested in a clinical trial	General population never screened (54-65y)	Screening	CTC	1866	Discomfort, physical/ physical experience Discomfort, psychological/ psychological experience General satisfaction	12/18
Sarkar et al. (2012)	1	United Kingdom	Cross-sectional nested in a case-control study	Subjects in the general population (≥18 years old) undergoing day-case colonoscopy	Screening	OC	131	Discomfort, physical/ physical experience General satisfaction	11.5/17
Shin et al. (2018)	2	Korea	Cross-sectional	General population (50–74)	Screening	FIT	1657	Discomfort, physical/ physical experience General satisfaction	13.5/17

OC: optical colonoscopy; CTC: computed tomographic colonography; FIT: fecal immunochemical test, FOBT: fecal occult blood test; FS: Flexible sigmoidoscopy.
[#] Some of the surveys in the included studies did not contain relevant information for the purpose of this systematic review and were therefore excluded. For this reason, the sum of the sample sizes of the included studies does not coincide with the sum of the sample sizes of the included surveys.
[*] Denominator varies because sometimes the judgment criteria are not applicable.

about 21% of the participants declared having experienced more pain than expected during colonoscopy. Subjects in the Sarkar et al. (2012) study rated pain during colonoscopy as low (median: 1 on a 0–5 likert scale) but Denters et al. (2013) reported 85% of participants referred some degree of pain.

The bowel cleansing procedure was reported as more unpleasant than the insertion of the endoscope (Burón et al., 2017; Kinner et al., 2007), particularly among younger subjects (Kinner et al., 2007). Sali et al. (2019) found reduced cathartic bowel preparation was significantly more tolerable than full cathartic preparation without affecting significantly physical discomfort during CTC (participants rating the procedure as painful: 16% in the reduced preparation group vs 13% in the full preparation group, $p = 0.14$).

3.7. Psychological discomfort and psychological experience

Regarding the screening phase, although most respondents did not report that the procedure made them feel embarrassed, mixed results emerged in regard to anxiety while waiting for the test result. Arveux et al. (1992) found people with positive FOBT results were more often upset by the result than those with negative FOBT. Robb et al. (2012) found no significant change in the anxiety symptoms of participants between the pre-FS period and the following three months, while Blom et al. (2004) observed that anxiety before FS was associated with pain, showing that reassurance might be an efficient way to reduce discomfort. CTC was reported to be more embarrassing than optical colonoscopy (Sali et al., 2019).

In assessment phase, the mean level of satisfaction was good, although more than a third of respondents (38%) reported some degree of embarrassment with the colonoscopy (Denters et al., 2013).

3.8. Physical surroundings and privacy

Respondents expressed high levels of satisfaction with the environment of the screening facilities, including respect for privacy (Blom et al., 2004; Robb et al., 2012), and almost all participants felt that their privacy was maintained during the visit in the assessment phase (Ghanouni et al., 2016; Plumb et al., 2017).

3.9. Information transfer and communication

The satisfaction level for information transfer and communication was generally high in the included surveys. However, Buron et al. (Burón et al., 2017) found that about a third of participants reported incomplete understanding of information material regarding the FOBT and 16% of participants did so regarding the colonoscopy. Authors found that both the understanding of the instructions and the sample collection process was more difficult for participants with positive FOBT results (7.0%) than for participants with negative FOBT results (1.5%) and stated that this difference could be explained by a memory bias. Ghanouni et al. (2016) found the level of satisfaction was not affected by deprivation, sex, or age.

3.10. Accessibility and waiting time

One study found high satisfaction related to return time, which was considered rapid or quick enough by 98.8% of responders (Arveux et al., 1992). Another study (Burón et al., 2017) found that pharmacy care, its accessibility and its role as a test collection and drop-off centre were particularly noteworthy (score above 9.3/10.0 on average), as was the waiting time to be seen at the pharmacy and the waiting time to receive

Table 2
General characteristics of included surveys ($N = 21$).

Characteristics	Screening ($n = 16$, 76%)	Assessment (n = 4, 19%)	Screening + assessment (n = 1, 10%)	Total number n (%)
Geographical area				
Europe	14	4	1	19 (90.5%)
Asia	2	0	0	2 (9.52%)
Survey year				
1980–1989	1	0	0	1 (4.76%)
1990–1999	1	0	1	2 (9.52%)
2000–2009	7	2	1	9 (42.86%)
2010–2019	7	2	1	9 (42.86%)
Sample size				
≤500	7	2	1	10 (47.62%)
501–1000	8	0	0	8 (38.10%)
>1000	1	2	0	3 (14.29%)
Response rate				
<50%	0	0	0	0 (0.00%)
50–74%	4	2	0	6 (28.57%)
≥75%	12	2	1	15 (71.43%)
Assessed test				
Fecal occult blood test (FOBT)	3	0	0	3 (14.29%)
Fecal immunochemical test (FIT)	3	0	0	3 (14.29%)
Flexible sigmoidoscopy	7	0	0	7 (33.33%)
Colonoscopy	1	3	0	4 (19.05%)
CT-colonography	2	1	0	3 (14.29%)
FOBT followed by colonoscopy	0	0	1	1 (4.76%)
Screening round				
First	11	0	0	11 (52.38%)
Second	0	1	0	1 (4.76%)
Mixed	5	2	1	8 (38.10%)
Unclear	0	1	0	1 (4.76%)
Data collection				
Self-administered questionnaire	15	3	0	18 (85.71%)
Telephone interview	1	1	1	3 (14.29%)
Validated questionnaire				
Yes	1	0	0	1 (4.76%)**
No	15	4	1	20 (95.24%)
Time of administration of the questionnaire				
Same day of the exam or the day after	9	0	0	9 (42.86%)
After two days – Within the first week	3	0	0	3 (14.29%)
After a week – Within a month past the exam	1	2	0	3 (14.29%)
After one month	3	1	1	5 (23.81%)
Not reported	0	1	0	1 (4.76%)

* Authors were contacted without exit to ask for the questionnaire development and/or validation studies.

the FOBT result. On the other hand, participants reported issues with telephone assistance concerning difficulties in contacting the program staff (27.1%) and incomplete call resolutions (18.8%).

3.11. Staff's interpersonal skills

Regarding screening phase, results from one survey on FS (Robb et al., 2012) showed that 99.4% of participants were 'satisfied' or 'very satisfied'. Authors suggested that this dimension may be a fundamental factor in determining overall satisfaction with the screening procedure. Regarding assessment phase (two surveys), almost all participants felt treated with respect by hospital staff in the conduction of colonoscopy (Ghanouni et al., 2016; Plumb et al., 2017).

3.12. The staff's technical skills

None of the surveys investigated this domain.

Satisfaction according to screening results.

Four surveys reported satisfaction according to screening results: there were no differences in general satisfaction according to screening results in FS and OC protocols (Denters et al., 2013; Hambleton and Jones, 2017). Regarding FOBT protocols, participants with positive results reported higher psychological discomfort (Arveux et al., 1992) and more difficulty in the sample collection process (Burón et al., 2017), although authors state that this last result could be explained by a memory bias.

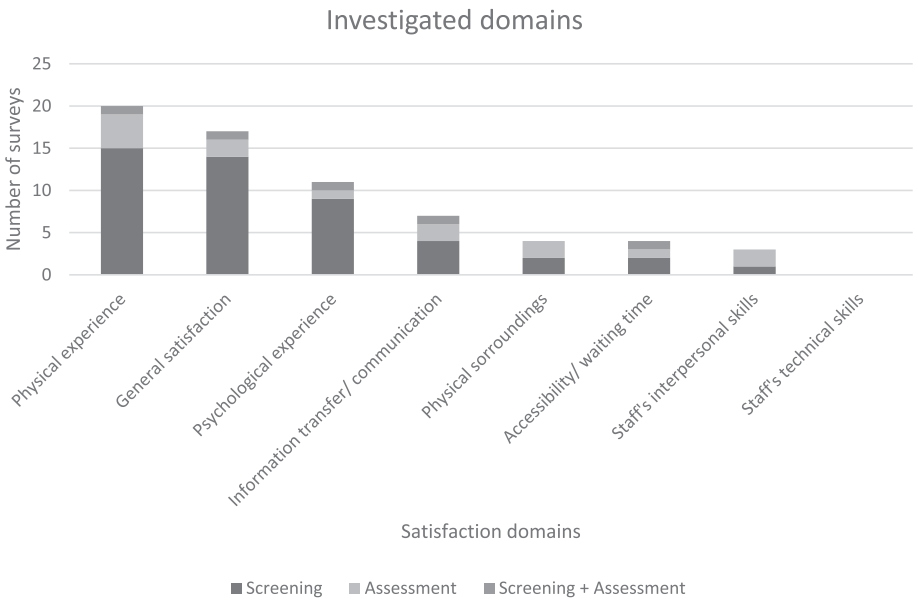

Fig. 2. Satisfaction domains assessed in included surveys.

Table 3
Description of dimensions of satisfaction.

Dimension	Questions explored	Screening test surveys (N = 16)	Assessment tests surveys (N = 4)	Screening + assessment surveys (N = 1)
General Satisfaction	Willingness to participate again in the future; willingness to recommend test to relatives/friends; overall rating of procedure; satisfaction with the experience; how participants found the procedure; acceptability of the procedure; other generic questions about general satisfaction	14 (87.5%)	2 (50.0%)	1 (100.0%)
Discomfort, physical/ Physical experience	Easiness of test execution; pain experienced during procedure and its different parts; burden experienced during procedure; necessity to use of sedation or to stop the procedure; pain and symptoms after the procedure; unpleasantness of the bowel preparation; procedure more or less painful than expected; difficulty collecting the FOBT sample; level of discomfort; sensation of distension;	15 (93.8%)	4 (100.0%)	1 (100.0%)
Discomfort, psychological/ Psychological experience	Embarrassment related to touching fecal material; embarrassment with effects of bowel prep, with introduction of colonoscope or colonoscopy itself; state of mind while waiting for results; anxiety prior to examination; fear of finding a tumor; apprehension of long examination time	9 (56.3%)	1 (25.0%)	1 (100.0%)
Physical surroundings (privacy included)	Privacy was maintained as much as possible; satisfaction with facilities at the center; participants felt exposed	2 (12.5%)	2 (50.0%)	0 (0.0%)
Information transfer/ Communication	Staff gave clear and reassuring or repulsive and complicated explanations; participants were informed of risks and benefits of the procedure and about how to take the bowel prep medicine; users were satisfied with information they were given before the test or would like to have known more about the procedure before they arrived at the Centre; users were satisfied about the way the results were explained; the staff explained the procedure in terms users could understand; users understood invitation letter and information brochure; information at the pharmacy was clear and useful	4 (25.0%)	2 (50.0%)	1 (100.0%)
Accessibility (waiting time included)	Satisfaction with return time of the test; satisfaction with easiness of telephone contact with the program and resolution of the reason for calling, waiting time to be seen at the pharmacy, assessment of accessibility at the pharmacy	2 (12.5%)	1 (25.0%)	1 (100.0%)
Staff's interpersonal skills	Staff was courteous; staff treated participant with respect; staff made to feel at ease during appointments; staff had a good attitude	1 (6.25%)	2 (50.0%)	0 (0.0%)
Staff's technical skills		0 (0.0%)	0 (0.0%)	0 (0.0%)

4. Discussion

This systematic review has identified 15 studies that assessed participants' satisfaction with organized CRC screening through 21 different surveys. All studies used questionnaires designed for the conduction of each study and none had been evaluated regarding their measurement properties (validation). Methodological quality of included studies was limited mainly due to the lack of evidence on validity and reliability of questionnaires used, but also to the absence of a pilot test phase and to the inclusion of small and non-representative samples.

General satisfaction with organized CRC was high both for screening and assessment phases and for different tests used. Only one study compared satisfaction using different tests and found higher satisfaction for FIT and FOBT than for FS (Hol et al., 2010). The satisfaction domain most frequently assessed was physical discomfort and physical experience, showing high heterogeneity according to the test used: in general, physical discomfort was similar for OC, CTC, and FS, and was specially

related to bowel preparation, and it was much lower for fecal tests. Psychological discomfort was frequently assessed, showing low levels of embarrassment while conducting the screening process but some extent of anxiety while waiting for the screening test result. Other satisfaction domains were less assessed, for example, participants were not asked for perceived staff's technical skills in any study.

To our knowledge, this is the first systematic review to assess satisfaction with organized CRC screening programs. As far as we know, the only systematic review summarizing the results of studies investigating the experience of participants in organized cancer screening programs was focused on breast cancer screening (Pagliarin et al., 2021). Even though the studies included in that review mainly relied on non-validated questionnaires, as happens in the present work, satisfaction with breast cancer screening programs resulted in being generally high. This finding, although referring to different populations and settings, contributes - in line with our study - to suggest that participation in organized cancer screening programs is experienced positively by participants. Effective communication, good staff interpersonal skills and prompt delivery of test results emerged as key elements in determining participants´satisfaction with breast cancer screening. The results of the current systematic review indicate a good level of satisfaction with these dimensions also for CRC screening, although only a minority of the included studies focused on their evaluation. In fact, the specific characteristics of CRC screening protocols (laboratory test for FIT, invasive procedure for FS and colonoscopy) caused a shift of research focus towards participants' embarrassment and pain/discomfort, at the expense of operator communication and staff's technical skills. High satisfaction scores are common in surveys of satisfaction with health and preventive services (Pagliarin et al., 2021; Perneger et al., 2020). This can reflect a true association between patient satisfaction with health services and adherence to preventive care. However, it's essential to acknowledge the potential for an upward bias in satisfaction scores, which can arise from an overrepresentation of satisfied individuals among survey respondents. This notion is supported by a study on 717 hospital surveys which shows a positive correlation between higher satisfaction scores and survey response rate, suggesting that the most satisfied patients are those more likely to participate and return satisfaction questionnaires (Jerant et al., 2014; Perneger et al., 2005; Perneger et al., 2020).

None of the included studies used a validated questionnaire and none of the self-developed questionnaires has been tested for their validity and reliability. A recent systematic review on validated patient reported outcome measures (PROMs) (Selva et al., 2021) found some validated questionnaires for measuring patient satisfaction with screening colonoscopy(Brotons et al., 2019) and sigmoidoscopy (Schoen et al., 2000). The Colonoscopy Satisfaction and Safety Questionnaire-CSSQP (Brotons et al., 2019) was developed and validated in the Spanish population and has sufficient content validity and internal consistency but indeterminate structural and construct validity (Selva et al., 2021). However, this questionnaire has been available only since 2019, and this could explain why none of the studies included in this systematic review (that were all conducted before 2019) used it. On the other hand, the Screening Flexible Sigmoidoscopy Assessment Questionnaire, developed in USA and available from 2000 (Schoen et al., 2000), has sufficient internal consistency, responsiveness and reliability, but inconsistent content validity, that is the most important measurement property, and indeterminate structural validity and measurement error (Selva et al., 2021). All studies assessing FS included in our systematic review were published from year 2002 onwards but none used or mentioned this already available and validated questionnaire. It has been a lost opportunity to have not further validated this existing questionnaire, translating it to different languages and assessing its measurement properties in different populations. The use of non-validated questionnaires limits trustworthiness of results and precludes the comparison across different studies. Furthermore, the development of new questionnaires when there are validated ones available supposes an unnecessary waste of time and resources. On the other hand, the systematic review of PROMs did not identify any validated questionnaire for assessing participants' satisfaction with CRC screening programs using stool tests (Selva et al., 2021). Our systematic review has identified four studies that have already developed questionnaires to assess this aspect, and that should be validated in the future.

4.1. Strengths

This study has several strengths. To our knowledge, it is the first systematic review assessing satisfaction with organized CRC screening programs. Moreover, we conducted systematic searches in four different databases and both the selection and data extraction processes were conducted in duplicate to minimize selection bias and possible errors. The average response rate of included surveys is quite high (79%), similar to that found in a similar systematic review on satisfaction with breast cancer screening (76%), mitigating the risk of potential non-response bias(Compton et al., 2019; Pagliarin et al., 2021). In addition, a significant portion of the surveys were administered close to the phenomenon being measured, minimizing the risk of potential recall bias.

4.2. Study limitations

As we only included studies published in English, Spanish or Italian and we did not search for grey literature, we cannot exclude a possible selection bias. As we did not limit searches for language and excluded only three studies due to language in the eligibility phase, we can assume that the language restriction has had a limited impact. The major limitation is that our literature search did not find any original studies using validated questionnaires, which highlights the need for further research in this field. Additionally, due to heterogeneity in questionnaires used and the way results were reported across surveys, we could not pool the data and hence we could only provide a narrative summary of results.

Even though we only could provide a narrative summary of this topic, we are confident that we were able to identify the most commonly used domains and items in this context. These data could be used as a starting point for the development of structured tools to measure satisfaction and experience of CRC screening participants in relation to aspects for which a validated questionnaire does not exist, for example, for assessing satisfaction with stool test-based screening programs. Also the themes and results from another systematic review in breast cancer screening (Pagliarin et al., 2021) could be considered in this context.

To be able to develop a generally acceptable methodology, wide collaborative efforts among health care organizations responsible for screening, researchers in the fields, health care professional societies, and patient organizations, are required. This is needed to ensure that all aspects concerning this multifaceted topic would be heard and taken into account to guarantee applicability and acceptability of the developed methods. In the meantime, screening programs should anyway take into consideration the collection of their users' feedback, considering the inclusion in their tools the themes highlighted in this study, and in particular those mostly impacting on satisfaction.

5. Conclusions

This systematic review showed that satisfaction with CRC screening was generally high, but its evaluation is performed using non-validated instruments, which limits the interpretation of the results and prevents comparability of the current body of evidence. The few surveys available comparing tests showed higher satisfaction scores for FIT and FOBT than for FS.

Author contributions

Conceptualization, S.D., A.S., I.S., L.P.; methodology, A.S., I.S., N.T.;

data curation, G.M., S.C., S.R.; writing—original draft preparation, G. M., S.C., L.P., A.S., N.T.; writing—review and editing, G.M., S.C., L.P., A. S., N.T., S.D.; supervision, E.C., A.O., S.D. All authors have read and agreed to the published version of the manuscript.

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Informed consent statement

Not applicable.

Declaration of Competing Interest

The authors declare no conflict of interest.

Data availability

Data will be made available on request.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ypmed.2023.107706.

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