

Cancer Causes & Control

Factors related to longitudinal adherence in colorectal cancer screening: qualitative research findings --Manuscript Draft--

Manuscript Number:	CACO-D-17-00333R1	
Full Title:	Factors related to longitudinal adherence in colorectal cancer screening: qualitative research findings	
Article Type:	Original Article	
Keywords:	colorectal cancer; participation; Mass Screening; repeat adherence; barriers; qualitative study	
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Funding Information:	Department of Health of Catalonia (SLT002/16/00407)	Dr Llucia Benito
Abstract:	<p>Background: The effectiveness of screening in colorectal cancer prevention depends on sustained participation rates. The objective of this study was to explore factors related to the longitudinal adherence of screening behavior in the context of a biennial population-based cancer screening program.</p> <p>Methods: Eight focus groups were conducted with individuals who were invited two or three consecutive times to a population-based colorectal cancer screening program using a fecal occult blood test and who agreed to participate in the program at least once (n=45). The criteria used to select the study members included adherence to fecal occult blood test maintenance, factors regarding their initial participation in the colorectal cancer screening, sex and contextual educational level.</p> <p>Results: The participants expressed a high level of satisfaction with the program; however, they showed a low level of understanding with respect to cancer screening. Consulting a general practitioner was cited by all participants as an important factor that mediated their final decision or influenced their behavior as a whole with regard to the program. Fear played a different role in the screening behavior for regular and irregular adherent participants. In the adherent participants, fear facilitated their continued participation in the screening program, whereas for the irregular participants, fear led them to avoid or refuse further screening.</p> <p>Having a close person diagnosed with colorectal cancer was a facilitator for the regular adherent participants. The irregular adherent participants showed some relaxation with</p>	

	<p>respect to screening after a negative result and considered that further screening was no longer necessary.</p> <p>Conclusion: Considering the importance of primary healthcare professionals in the decision regarding sustained participation, it is important to better engage them with cancer screening programs, as well as improve the communication channels to provide accurate and balanced information for both health professionals and individuals.</p>
<p>Response to Reviewers:</p>	<p>Title: Factors related to longitudinal adherence in colorectal cancer screening: qualitative research findings (Ref: CACO-D-17-00333).</p> <p>We sincerely appreciate the time invested in your review. We have revised the manuscript based on your feedback, which helped us produce a manuscript with increased clarity and precision. We have presented all original concerns followed by our responses (in bold). We will gladly address any remaining concerns.</p> <p>REVIEWER #1:</p> <p>Thank you for sharing the finding of the study exploring factors related to longitudinal adherence to colorectal cancer screening based on a qualitative study approach. The focus of this paper is important, the approach is appropriate and as indicated by the authors, the results can help address barriers to participation and repeated participation. To improve the quality of the paper, some major and other minor revisions are recommended:</p> <p>Methods:</p> <p>1.The justification for using focus group was not appropriately explained Author response: Thank you for the suggestion. We have included a sentence that justifies the utilization of the focus group. “FGs were chosen as the primary method of data collection because of their emphasis on participant interactions and potential to encourage greater candor, which make them particularly well suited to investigate decision-making processes.”</p> <p>2.The data source for neighborhood with a poor educational level was not clear, was it based on census data? Is this data source validated? Author response: Thank you for the suggestion. We have clarified the data source in the manuscript. “The ‘educational level’ criterion was defined using aggregate data, obtained from the census data (L’Hospitalet de Llobregat City Council, 2010), given that we did not have information regarding individual educational levels. Thus, we selected individuals who lived in a neighborhood (Area 1) with a poor educational level (26.64% of individuals with a level lower than primary studies) and individuals from a neighborhood (Area 2) with a better educational level (18.73% of individuals with a level lower than primary studies).”</p> <p>3.The proposed composition of each focus group and the demographic characteristics of participants were not reported in the manuscript. Author response: We have included a new table (Table 1) that details this information.</p> <p>4.The authors mentioned that debriefing sessions after all FGs were completed for all facilitators. In principle, de-briefing sessions are recommended following each FG to identify strengths and weaknesses of the approach and for bracketing purposes. It was not clear why it was done after the completion of all FGs Author response: We thank the reviewer for noting this issue. We did not express this accurately in the manuscript as the debriefing sessions occurred after each session. We have amended the sentence to avoid confusion. “After each FG was completed, the facilitators participated in a structured, self-administered debriefing session and completed their field notes.”</p> <p>5.There was no mention of whether the discussion was audio-taped, which I believe it was since there was transcription of data Author response: We thank the reviewer. We have clarified this issue in the manuscript. “All FGs were audio or video recorded and transcribed verbatim. The transcripts were anonymized and reviewed by two members of the research team for accuracy.”</p> <p>6.There was no mention of the language of the discussion and whether the</p>

transcription used the original language or the translated Language
 Author response: We have included a paragraph that explains the language of the discussion and the transcription.
 "The FGs were conducted and transcribed in the native language of the participants (Catalan and Spanish). Selected data excerpts were then professionally translated into English for reporting."

7.The authors mentioned "debriefing discussions and field notes served as the basis for the initial coding". Methodologically, since there was no prior conceptual framework for conducting the analysis, the codes should emerge from the transcripts not from the debriefing notes. This should be either explained or corrected
 Author response: We have corrected this issue in the manuscript as debriefing notes were used to refine, rather than inform, the initial coding.
 "Debriefing discussions and field notes served as the basis to refine the initial coding."

8.it is not clear what was the role of the descriptive themes listed in Table 1. Were they the results of the axial coding? If they were, I find it interesting that some of those themes did not appear in the final analysis.
 Author response: The descriptive themes listed in former Table 1 (currently Table 3) resulted from our first cycle coding. We subsequently used focused coding (rather than axial coding) as our second cycle coding method, given that our overarching analytical approach was of a thematic nature. Therefore, the initial set of descriptive themes in Table 1 (currently Table 3) is reported as a matter of transparency of the analytic process to show how codes transformed from the first to second cycles. We have made several changes in the text to ensure the analytic process is reported as clearly as possible.

9.The categorization is appropriate but the reporting under each category needs more clarity. For example, why not to have sub-themes as sub-titles to make it clearer for the reader. For example, Common factors (heading 1), perceived benefit of prevention (heading 2 or sub-title).
 Author response: We thank the reviewer for the suggestion. We have included sub-headings throughout the results section to improve the clarity for readers.

10.I recommend putting most of the quotes in 3 tables and each table with three columns: table for common factors with one column for sub-theme, one for adherent quotes, one for non-adherent quotes.
 Author response: We have included a new table (Table 4) with all quotes organized by themes and sub-themes.

11.The results in the abstract are reported differently than the body of the manuscript
 Author response: As suggested by the reviewer, the abstract has been modified as follows:
 "Background: The effectiveness of screening in colorectal cancer prevention depends on sustained participation rates. The objective of this study was to explore factors related to the longitudinal adherence of screening behavior in the context of a biennial population-based cancer screening program.
 Methods: Eight focus groups were conducted with individuals who were invited two or three consecutive times to a population-based colorectal cancer screening program using a fecal occult blood test and who agreed to participate in the program at least once (n=45). The criteria used to select the study members included adherence to fecal occult blood test maintenance, factors regarding their initial participation in the colorectal cancer screening, sex and contextual educational level.
 Results: The participants expressed a high level of satisfaction with the program; however, they showed a low level of understanding with respect to cancer screening. Consulting a general practitioner was cited by all participants as an important factor that mediated their final decision or influenced their behavior as a whole with regard to the program. Fear played a different role in the screening behavior for regular and irregular adherent participants. In the adherent participants, fear facilitated their continued participation in the screening program, whereas for the irregular participants, fear led them to avoid or refuse further screening.
 Having a close person diagnosed with colorectal cancer was a facilitator for the regular adherent participants. The irregular adherent participants showed some relaxation with respect to screening after a negative result and considered that further screening was

no longer necessary.

Conclusion: Considering the importance of primary healthcare professionals in the decision regarding sustained participation, it is important to better engage them with cancer screening programs, as well as improve the communication channels to provide accurate and balanced information for both health professionals and individuals.”

Discussion

12.The purpose of this study is to help organized screening programs identify and address barriers for longitudinal barriers for participation. Unfortunately, the interpretation of results fell short of identifying measures to address those barriers. Authors need to provide evidence-based interventions that were successfully implemented to overcome some of those barriers.

Author response: We thank the reviewer for this suggestion. As the reviewer proposes, we have modified the discussion and have included a paragraph regarding the interventions implemented.

13.The limitations of the study were not properly articulated. The authors talked about addressing bias by using maximum variation, this is strength. Further, in the method section, authors indicated that the analysis was conducted after the completion of FGs and in the limitations, it was indicated that "the sample size was determined by "data saturation" using concurrent data analysis". Those are two opposing approaches, which one was used.

Author response: We have amended the text in the methods section to clarify that we used a concurrent data analysis approach and data saturation was the criterion implemented to determine the sample size.

14.The conclusion in the abstract is completely different than the conclusion in the manuscript.

Author response: As suggested by the reviewer, the abstract has been modified.

Other recommended revisions:

15.The authors use the following terms interchangeably: longitudinal adherence, maintenance of screening, adherence, repeated adherence. I recommend for consistency that the author use the term "longitudinal adherence" as shown in the title.

Author response: We appreciate the reviewer's comment. We have changed the terms to "longitudinal adherence".

16.English language use needs to be revisited.

Author response: We appreciate the reviewer's comment. The manuscript has been edited by a professional editing company.

REVIEWER #2:

The manuscript describes the results of a qualitative study about factors related to adherence in a colorectal cancer screening programme.

Some general and more specific issues should be taken into account.

GENERAL COMMENTS

1.The paper needs a major language revision. There are numerous grammatical and orthographic mistakes and several sentences are hard to read or even difficult to understand.

Author response: We appreciate the reviewer's comment. The manuscript has been edited by a professional editing company.

Methods are insufficiently explained. Readers need to know, among others:

2.The basic functioning of the Programme (how people are informed and invited to participate, how do they receive and deliver the test, how are the results provided etc.).

Author response: As the reviewer suggested, we have included information regarding the functioning of the colorectal cancer screening program:

“Our sample was derived from the population that had been invited to participant in CRC screening in 2010 in an industrial city of approximately 260,288 inhabitants, where the screening program was initially launched. From this population, we selected individuals who were invited at least twice, and the FGs were conducted after one year. The screening program comprised a free, public, biennial, population-based screening

program for colorectal cancer using the fecal occult blood test, which was provided free of charge to men and women aged 50 to 69 years. In the first four rounds, the guaiac test was used. An immunological test was subsequently applied. Eligible subjects were mailed a personal invitation letter, which was signed by the individual in charge of the screening program. Subjects with negative test results were informed by mail. All screened individuals with a positive FOBT were contacted by phone to provide information regarding the screening result and advise them that they would be referred for a colonoscopy examination. A more detailed description of the screening procedure is provided elsewhere (Peris et al., 2007)."

3. When the study was conducted (the only mention of a date or period is the one referring to the sample selection, 2010).

Author response:

"Our sample was derived from the population that had been invited to participate in CRC screening in 2010 in an industrial city of approximately 260,288 inhabitants, where the screening program was initially launched. From this population, we selected individuals who were invited at least twice, and the FGs were conducted after one year."

4. Was the study evaluated and approved by an ethics committee? If not, explain why it was deemed not necessary.

Author response: We have included a sentence to explain that the study was approved by the relevant Research Ethics Committee of the sponsoring institution.

"Written informed consent was obtained from all individuals who attended a focus group session. The study protocol was approved by the Clinical Research Ethics Committee of Bellvitge University Hospital (230/05)."

5. How was the sample size decided? I presume data saturation was the key determinant but there is no mention in Methods (only in Discussion). However, since debriefing and transcription was only done "after all FGs were completed" it is difficult to judge whether data saturation was indeed the factor that determined the sample size...

Author response: We have amended the methods section to clarify this issue. Data saturation was the criterion used to determine the sample size, and we used concurrent data analysis to enable this approach.

6. Composition of the groups is lacking (N, age, gender, etc.), either here or in Results

Author response: We have included a new table (Table 1) that details the composition of the focus groups and the characteristics of the sample.

Results: a general overview of the results of the study should be given before explaining the 3 types of factors.

7. Results: this section is difficult to follow and understand (see point 1); often there is a feeling of lack of analysis partially due to verbatim not illustrating the points made and eventually a sense of "over-interpretation" in some parts

Author response: We have included sub-headings to facilitate the flow of the text, revised the selection of quotes, included a new table (Table 4) with the selected quotes organized by themes and sub-themes, and revised the text to ensure clarity.

8. Verbatim quotations are difficult to read and understand, I believe that partially due to literal translation. Translation should be adapted to make it comprehensible to English readers.

Author response: We have revised the quotes and made corrections to ensure clarity.

9. Discussion is insufficiently structured and organized, lack of synthesis

Author response: The discussion has been revised to improve the structure and organization. Subheadings have also been included.

SPECIFIC COMMENTS

INTRODUCTION

10. Abbreviation gFOBT refers I assume to guaiac fecal occult blood test (not just "fecal occult blood test").

Author response: The reviewer is correct. We have revised the abbreviations.

11. Reference Steele 2013 seems to be incorrect, shouldn't it be "Steele RJ, Mc. Clements PL, Libby G, Carey FA, Fraser CG. Patterns of uptake in a biennial faecal occult blood test screening programme for colorectal cancer. *Colorectal Dis.* 2014 Jan; 16 (1):28-32" instead of "Steele CB,....Colorectal cancer incidence and screening..."? (perhaps worth checking the rest of references).
Author response: The reviewer is correct. We have revised and corrected all references.

12. Regarding to this last reference, it seems rather suspicious that precisely the one article whose adherence rates are higher are not specifically mentioned.
Author response: The review of the longitudinal adherence of other programs was not the scope or benchmark of this manuscript. The main focus of the article was factors related to the longitudinal adherence of screening behavior. However, following the reviewer's comment, we have performed a new search to update the references.

METHODS

Besides the more general comments,
13. Does "prior screening behavior" refer to 3 consecutive rounds or rather 2 or 3; it is not clear.

Author response: We have amended the methods section to clarify this issue. "The 'prior screening behavior' criterion was defined as colorectal cancer screening adherence in at least two consecutive screening rounds. We classified individuals as 'regular adherent participants' if they participated as many times as invited and as 'irregular adherent participants' if they participated fewer times than invited."

14. How is the "irregular adherent participants" group defined?
Author response: We have amended the methods section to clarify this issue. "We classified individuals as 'regular adherent participants' if they participated as many times as invited and as 'irregular adherent participants' if they participated fewer times than invited."

15. The sentence "if they did not continue to receive consecutive FOBT tests" is not clear, i.e. it could mean 1 out of 3, 2 out of 3, 1 out of 2...
Author response: We have amended the methods section to clarify this issue. The 'prior screening behavior' criterion was defined as colorectal cancer screening adherence in at least two consecutive screening rounds. We classified individuals as 'regular adherent participants' if they participated as many times as invited and as 'irregular adherent participants' if they participated fewer times than invited.

16. And in any case, why "receive" and not "participate" or "undertake"?
Author response: We have corrected and changed this term to "participate".

17. More details of the Interview guide would be desirable, such as main topics covered (or even included as complementary material).
Author response: We have included a new table (Table 2) that details this information.

18. What version of Atlas.ti, reference?
Author response: We have included the version of Atlas.ti utilized in the study. "...with the assistance of ATLAS.ti software for data management (Muhr, 2004)."
Reference: Muhr, T. ATLAS.ti 5.0 [Version 5:]. ATLAS.ti Scientific Software Development GmbH; Berlin, Germany: 2004. Available from <http://www.atlasti.com/>

RESULTS

19. Some of the verbatim quotations do not add much or illustrate the points made (for instance those referring to fear in regular adherent participants or those related to consulting a GP in adherents)
Author response: We have revised the selection of quotes included in the manuscript to ensure they illustrate the points made in the results section.

DISCUSSION

(See major comments)
Author response: The discussion has been revised to improve the structure and organization. Subheadings have also been included.

[Click here to view linked References](#)

Title: Factors related to longitudinal adherence in colorectal cancer screening: qualitative research findings

Running head: Factors related to longitudinal adherence

Keywords: colorectal cancer; participation; mass screening; longitudinal adherence; barriers; qualitative study

Abstract

Background: The effectiveness of screening in colorectal cancer prevention depends on sustained participation rates. The objective of this study was to explore factors related to the longitudinal adherence of screening behavior in the context of a biennial population-based cancer screening program.

Methods: Eight focus groups were conducted with individuals who were invited two or three consecutive times to a population-based colorectal cancer screening program using a fecal occult blood test and who agreed to participate in the program at least once (n=45). The criteria used to select the study members included adherence to fecal occult blood test maintenance, factors regarding their initial participation in the colorectal cancer screening, sex and contextual educational level.

Results: The participants expressed a high level of satisfaction with the program; however, they showed a low level of understanding with respect to cancer screening. Consulting a general practitioner was cited by all participants as an important factor that mediated their final decision or influenced their behavior as a whole with regard to the program. Fear played a different role in the screening behavior for regular and irregular adherent participants. In the adherent participants, fear facilitated their continued participation in the screening program, whereas for the irregular participants, fear led them to avoid or refuse further screening.

Having a close person diagnosed with colorectal cancer was a facilitator for the regular adherent participants. The irregular adherent participants showed some relaxation with respect to screening after a negative result and considered that further screening was no longer necessary.

Conclusion: Considering the importance of primary healthcare professionals in the decision regarding sustained participation, it is important to better engage them with cancer screening programs, as well

as improve the communication channels to provide accurate and balanced information for both health professionals and individuals.

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Factors related to longitudinal adherence in colorectal cancer screening: qualitative research findings

Introduction

Colorectal cancer (CRC) is one of the most common tumors in the population and the third leading cause of cancer death among both women and men in developed countries (Ferlay et al., 2013).

Screening for CRC provides a simple and effective public health intervention to prevent and minimize the impact of CRC on the community. Convincing evidence supports a guaiac fecal occult blood test (gFOBT), sigmoidoscopy and colonoscopy as screening tools (Atkin et al., 2010; Brenner et al., 2014a; Brenner et al., 2014b; Hardcastle et al., 1996; Hewitson et al., 2008; Krönborg et al., 1996; Mandel et al., 2000; Schoen et al., 2012; Segnan et al., 2011). However, a debate exists regarding which approach to implement. Benefits should be weighed against the costs, discomfort, complication rates, capacities needed, and potential differences in compliance. The Council of the European Union recommended the implementation of population-based screening programs for CRC using the gFOBT every 2 years in men and women between the ages of 50 and 74 years (CEC, 2003). Consequently, many countries, such as the United Kingdom, Spain, Finland, and France, have implemented population-based screening programs based on the gFOBT (Peris et al., 2007; von Wagner et al., 2011; Leuraud et al., 2013), whereas in regions of Italy, screening programs based on a fecal immunochemical test (FIT) have been adopted (Grazzini et al., 2004; Crotta et al., 2012). In several studies conducted in average-risk populations, a higher detection rate of advanced adenomas and CRC of the FIT, as well as a higher uptake rate have been identified compared with gFOBT screening (van Rossum et al., 2008; Hol et al., 2010; García et al., 2011; Tinmouth et al., 2015). Consequently, the FIT is becoming a widely favored option for replacing the gFOBT.

Decreases in mortality rates for cancer in the population as a whole predominately depend on the percentage of participation in the screening programs (Parkin et al., 2008). The European Commission considers 45% an acceptable participation rate, whereas it recommends a participation rate of 65-70% (von Karsa et al., 2008). Most European programs achieve this accepted minimum; however, according to the European Commission, only Finland and the Netherlands reach the

recommended rates (Ponti et al., 2017). Reductions in mortality may only be attained if uptake is adequate and sustained over time (Weller et al., 2009). Although high rates of adherence to repeat gFOBT screening have been reported in randomized trials (38-60%), longitudinal adherence to CRC screening in the population is expected to be substantially lower. A high level of ongoing and timely participation in screening is necessary to determine its effectiveness in reducing mortality from CRC (Calazel-Benque et al., 2011).

Screening invitations are typically repeated every 2 years, and the effectiveness of the gFOBT or FIT screening program is highly dependent on participation in multiple rounds, i.e., the longitudinal adherence. Ideally, eligible invitees accept the invitation to be screened at every screening round (Gellad et al, 2011; Steele et al., 2014; van der Vlugt et al., 2017).

A high rate of consistent participation increases the program sensitivity of CRC screening (Winawer et al., 1993; Nishihara et al., 2013; van der Vlugt et al., 2017). However, the success of a biennial screening program may be overestimated if there is a low willingness to participate in multiple rounds. To our knowledge, limited studies have examined longitudinal adherence to the FOBT over several years (Denis et al., 2015; Gellad et al, 2011; Kapidzic et al., 2014; Myers et al., 1993; O' Malley et al., 2002; Milà et al., 2012; Steele et al, 2014; van der Vlugt M, 2017). Most studies have focused on one-time screening rather than longitudinal adherence. Myers et al. evaluated compliance rates with the gFOBT over 2 years among adult members of a health maintenance organization. They determined that only 23% of subjects completed two rounds of screening, with predictors of adherence including initial adherence and an age >65 years (Myers et al., 1993). O'Malley et al. used a targeted household telephone survey to evaluate adherence to an annual gFOBT in women over a 2-year period. They determined that only 29% of women completed two gFOBTs during the study period (O'Malley et al., 2002). Gellad et al. concluded that the proportion of individuals who received an adequate gFOBT screening was 14.1% for men and 13.7% for women over a 5-year period (Gellad et al., 2011).

Therefore, these results show that longitudinal adherence is an important aspect of colorectal cancer screening, as participation is currently between 40-60%; thus, the loss of this percentage of participating individuals is an important aspect to consider. Moreover, there is limited knowledge

regarding the determinants of longitudinal adherence to fecal testing in population-based CRC screening programs.

The identification of potential determinants of inconsistent participation could aid in targeting the information to specific groups. Several studies and systematic reviews have been conducted to analyze reasons for participation in colorectal cancer screening (Honein-AbouHajar et al., 2016; Khalid-de Bakker et al., 2011; von Euler-Chelpin et al., 2010); however, limited studies have assessed the reasons for longitudinal adherence. These limited studies indicate the factors that determine initial participation are different from the factors that determine longitudinal adherence to cancer screening (Lo et al., 2014; Lo et al., 2015; Palmer et al., 2014).

To develop interventions to encourage routine screening for colorectal cancer, it may be important to understand the differences among individuals who do and do not undergo repeat screening. Thus, the objective of this study was to explore factors related to the longitudinal adherence of screening behavior in the context of a biennial population-based CRC screening program using the FOBT in Catalonia, Spain.

Methods

We conducted a qualitative study using focus groups (FGs) that consisted of men and women between the ages of 50 and 69 years who had been invited to participate in the CRC screening program. FGs were chosen as the primary method of data collection because of their emphasis on participant interactions and potential to encourage greater candor, which make them particularly well-suited to investigate decision-making processes.

Sample selection

Our sample was derived from the population that had been invited to participate in CRC screening in 2010 in an industrial city of approximately 260,288 inhabitants, where the screening program was initially launched. From this population, we selected individuals who were invited at least twice, and the FGs were conducted after one year.

The screening program comprised a free, public, biennial, population-based screening program for colorectal cancer using the fecal occult blood test, which was provided free of charge to men and women aged 50 to 69 years. In the first four rounds, the guaiac test was used. An immunological test

was subsequently applied. Eligible subjects were mailed a personal invitation letter, which was signed by the individual in charge of the screening program. Subjects with negative test results were informed by mail. All screened individuals with a positive FOBT were contacted by phone to provide information regarding the screening result and advise them that they would be referred for a colonoscopy examination. A more detailed description of the screening procedure is provided elsewhere (Peris et al., 2007).

Based on the available data from the CRC screening program, we devised a purposeful sampling strategy using a combination of intensity and maximum variation sampling (Patton, 2002) based on three criteria: 'prior screening behavior', 'sex' and 'educational level'.

The 'prior screening behavior' criterion was defined as colorectal cancer screening adherence in at least two consecutive screening rounds. We classified individuals as 'regular adherent participants' if they participated as many times as invited and as 'irregular adherent participants' if they participated fewer times than invited.

The 'educational level' criterion was defined using aggregate data, obtained from the census data (L'Hospitalet de Llobregat City Council, 2010), given that we did not have information regarding individual educational levels. Thus, we selected individuals who lived in a neighborhood (Area 1) with a poor educational level (26.64% of individuals with a level lower than primary studies) and individuals from a neighborhood (Area 2) with a better educational level (18.73% of individuals with a level lower than primary studies).

Data collection

The composition of the FGs was stratified by 'prior screening behavior', 'educational level' and 'sex' to ensure homogeneity in terms of the background and enable candid discussions regarding colorectal cancer screening procedures. In addition, we considered factors related to their initial participation in the colorectal cancer screening, such as the ease of recruitment (acceptance to participate immediately after receiving the screening invitation or six weeks after issue of the first invitation), the number of kits used and the FOBT result (negative or inconclusive FOBT) to ensure heterogeneity in terms of attitudes and experiences.

Eight FGs were conducted with 45 participants who had been invited two or three times to a population-based colorectal cancer screening program using the FOBT and who agreed to participate in the program at least once (Table 1). The sample size was determined by data saturation using concurrent data analysis. Prior to starting the FGs, the study team developed a topic guide that covered the key objectives of the study (Table 2). Written informed consent was obtained from all individuals who attended a focus group session. The study protocol was approved by the Clinical Research Ethics Committee of Bellvitge University Hospital (230/05).

After each FG was completed, the facilitators participated in a structured, self-administered debriefing session and completed their field notes. All FGs were audio or video recorded and transcribed verbatim. The transcripts were anonymized and reviewed by two members of the research team for accuracy. The FGs were conducted and transcribed in the native language of the participants (Catalan and Spanish). Selected data excerpts were then professionally translated into English for reporting.

Data analysis

Transcripts and field notes were subjected to thematic analysis (Braun & Clarke, 2006) with the assistance of ATLAS.ti software for data management (Muhr, 2004). Debriefing discussions and field notes served as the basis to refine the initial coding, which was subsequently discussed and refined by the research team, resulting in an initial set of 18 descriptive themes (Table 3). We subsequently generated analytical themes by further interrogating the data set drawing on the constant comparative method (Glaser, 1965). Codes and emerging themes were then discussed, revised, refined and agreed upon by the research team through critique and consensus. As a result, three overarching analytical themes were established: (1) common factors underpinning the screening experiences and decisions of regular and irregular adherent participants; (2) common factors interpreted in opposing ways by regular and irregular adherent participants; and (3) differential factors across regular and irregular adherent participants.

Results

Common factors underpinning the screening experiences and decisions of regular and irregular adherent participants

These factors were identified in both the regular and irregular adherent participants when explaining their views regarding the program and their screening experience.

Perceived benefit of prevention

One key overarching finding was that the system of beliefs concerning generic preventive health issues of both the regular and irregular adherent participants did not appear to significantly differ (Table 4, quotes 1-3).

With respect to the specific convergences between the regular and irregular adherent participants in relation to their screening experience and decisions, they were particularly significant because they were expected to play a decisive role in the participants' decision-making process during the screening period. However, this expectation was not supported because they were shared by the regular and irregular adherent participants. These factors were as follows: a *lack of comprehension*, a *lack of media information* and a *high level of satisfaction with the program*.

Lack of comprehension

The lack of comprehension referred to all manifestations of incomprehension that were more or less explicitly expressed by the participants, which mainly comprised difficulties in comprehension concerning the process to be followed to participate in the program, the periods established between rounds, the age limits established by the program and, in general, the rationale underlying a population-based screening program or the preventive health actions/policies that tend to collide with everyday life views (Table 4, quotes 4-6).

Initially, the possibility of incomprehension was valued as a handicap or a barrier to participation; however, these manifestations of incomprehension were identified in both the regular and irregular adherent participants. Therefore, it cannot be concluded that they influenced adherence to the program.

Lack of information regarding CRC in the media

The lack of information regarding CRC in the media was a recurrent complaint that both the regular and irregular adherent participants highlighted at various points during the FG sessions. They tended to refer mainly to the information provided on TV and the written press regarding CRC. They also identified differential treatment by the media, for example, in relation to other cancers, such as breast

or lung cancer, or in relation to other diseases that tend to be considered thematically relevant to the public in general (Table 4, quotes 7-9).

Satisfaction with the program

A high level of satisfaction with the program is another factor that was identified in the regular and irregular adherent participants. This satisfaction was expressed through three main considerations:

1. The elements of comfort provided by the program procedure, which enabled them to protect their health and act preventively without going to a hospital or consultation (Table 4, quote 10).
2. The clarity by which the instructions are given to the patient during every step of the screening process (Table 4, quote 11).
3. The health benefit that this type of service introduces to the population in general and to them in particular (Table 4, quote 12).

Therefore, the views and positions regarding preventive health activities in general and the screening program in particular were convergent and followed similar patterns. However, the narratives and arguments of the regular and irregular adherent participants also indicated key factors that helped explain the differences in their actual decisions regarding CRC screening.

These factors were divided into two types: (a) *common factors interpreted in opposing ways*, which were shared between the regular and irregular adherent participants but interpreted in opposing ways in each case's decision-making process; and (b) *differential factors*, which were identified exclusively in the adherent or non-adherent participants.

Common factors interpreted in opposing ways by regular and irregular adherent participants

These factors were identified in both the regular and irregular adherent participants as important factors that played a significant role in the decisions of the participants regarding the screening. The particularity of these factors is the fact that they were interpreted in opposing ways by the regular and irregular adherent participants: the same factors opposed implications. These two factors were *fear* and *consulting a general practitioner*.

The role of fear in participants' decision-making

Fear was recursively based on the regular and irregular adherent participants' views and explanations. These fears were related to the illness, colorectal cancer, and several questions that

typically surround it: fear of suffering, fear of the way of life of sick individuals, and other questions. Nevertheless, these fears were interpreted in two clearly opposed ways by the regular adherent and irregular adherent participants in terms of the decisions they made during the screening period.

In contrast, the regular adherent participants identified this factor to explain and argue why they decided to participate every time they were invited (Table 4, quotes 13-14). The irregular adherent participants also used this factor to explain and argue why they sometimes decided to stop participating (Table 4, quotes 15-16). Therefore, the possibility of being in fear acted as an encouragement to participate in every round for the regular adherent participants, whereas for the irregular adherent participants, fear was sufficiently paralyzing to modify their screening behavior over time.

Consulting a GP as part of the decision-making process

Consulting a general practitioner was a common practice between the regular and irregular adherent participants that was conducted after receiving the invitation to participate and before making the decision to participate and maintain this decision throughout the screening period. This factor was cited by all participants as an important factor that mediated their final decision or influenced their behavior as a whole with respect to the program. However, this influence was again exerted in two opposing ways for the regular and irregular adherent participants.

The regular adherent participants experienced an action of reinforcement (in the form of additional explanations, showing support, making the patient aware of the importance of the preventive action, and other factors) as feedback from the GPs when they told them about their invitation to the screening program (Table 4, quotes 17-18). The irregular adherent participants experienced a lack of reinforcement (not sufficient importance attached by the GP, a lack of needed explanations, and other factors) as feedback from the GP, which they tended to link to incorrect medical attention (Table 4, quotes 19-20).

Differential factors across regular and irregular adherent participants

These factors were identified solely in the regular or irregular adherent participants. Therefore, they appeared to be key factors in the decisions made during the screening period.

Regular adherent participants: having a close person diagnosed with CRC

Having a close person diagnosed with CRC was a distinct element of the regular adherent participants' experiences (Table 4, quotes 21-24). The effects of both the closeness of the experience and the level of affectation were of a relative nature, which indicates that the experience could refer to nuclear or extended relatives, as well as friends, work mates or neighbors. Furthermore, the participants' experiences could refer to fatal cases of CRC affectation or a wide range of cases that were perceived as difficult by the participants.

Although this factor was significant in all adherent groups, it was not used by the participants to attribute relevancy to their arguments when explaining their adherent behavior.

Irregular adherent participants: prioritization issues and being relaxed about screening after a negative result

A distinct factor that characterized the experiences of the irregular adherent participants was the prioritization of everyday tasks and activities over the actions needed to participate in the screening program.

As a result, all actions with regard to program participation (e.g., answer the letter, ask for the FOBT kit, collect the samples, and send them back) were not regarded as preferential in the context of the participants' everyday life. Therefore, these actions were postponed until or beyond the deadline established by the program to participate in each round (Table 4, quotes 25-26).

A key argument to explain these prioritization issues was the emergence of a relaxation effect after a negative screening result. The irregular adherent participants highlighted that after they obtained a negative result in a previous round, they tended to feel safe and reassured, thus assuming that 'everything is OK' with regard to their health as a two-year period was not viewed as sufficient time for anything to have changed in this respect (Table 4, quotes 27-28).

Discussion

Our study identified factors related to the longitudinal adherence of screening behavior for colorectal cancer in Catalonia, Spain. Facilitating factors and barrier factors were identified by irregular and regular participants in a CRC screening program through FGs. The factors identified by this study include a lack of comprehension, fear of the consequences of screening, inconsistent or inadequate support for screening from providers and the media, and a relaxation effect after a

negative result in the FOBT, which coincided with the results of other studies that analyzed facilitators and barriers for participation in colorectal cancer screening using qualitative methodology and the FOBT, colonoscopy or flexible sigmoidoscopy as screening methods (Honein-AbouHaidar et al., 2016; Jones et al., 2010; Wools et al., 2016).

Fear: The presence of fear as an important influence has been documented in other screening studies (Amonkar et al., 1999). Cancer fear may be a facilitator or a deterrent, depending on the specific aspect of the fear. The presence of cancer as the greatest health fear or substantially worrying about cancer facilitated intentions to attend, whereas uncomfortable thoughts of cancer did not affect the intention and were a deterrent to actual participation (Vrinten et al., 2015). Consistent with the results of other studies, cancer worry facilitated screening by enhancing the intention to attend, which may be motivated by a desire for reassurance, whereas a more visceral negative response to thinking about cancer acted as a deterrent in the action stage (Clemow et al., 2000; Jandorf et al., 2010; Wong et al., 2013). This deterrent effect is referred to as the “ostrich effect”, in which an individual prefers not to obtain information regarding her state of affairs because of the fear that she may receive bad news, despite the prospect of making better decisions based on this information (Panidi, 2014).

Lack of comprehension: It has been observed a lack of comprehension of cancer screening in both regular and irregular adherence participants, but it could be minimized by primary healthcare professionals.

Inconsistent or inadequate support from providers: Consistent with other screening tests, the population clearly expected to receive information regarding colorectal screening from their physicians. Our findings reinforce the importance of shared decision-making between providers and consumers. Decision aids to support doctors in their discussions with patients may be valuable, given the need to balance potential risks and benefits, as well as the different perspectives on test quality and acceptability that were expressed (Goel et al., 2004). Primary healthcare professionals can facilitate informed choices by patients who participate in CRC screening, and this role requires health care to have access to relevant, accurate and complete information.

Considering the lack of comprehension and the importance of primary healthcare professional in the decision on sustained participation, it is important to better engaged them with cancer screening programs, and also improve the communication channels. Possible methods for facilitating communication could include continuous briefings, regular message reminders or educational websites. Screening information is currently given to the individuals by a brochure sent by mail. This communication channel is certainly quick and economical but does not guarantee the individuals' good understanding of the benefits and risks of screening. It would be preferable that primary health care professional to have a private interview and to discuss such documents when their patients come in for a medical consultation. General practitioner could increase their involvement in CRC screening if they were more associated with patient information at different stages of screening. Their privileged mode of communication remains the face-to-face consultation with the patient (Papin-Lefebvre et al.2017).

Inconsistent or inadequate support from media: The participants also manifested the importance of information related to screening to encourage individuals to take the test regularly. They suggested that it is important to publicize the colorectal cancer screening program in the media. However, most studies highlight the lack of information and media interest in CRC screening, with more focus on the difficulty of discussing CRC screening with other individuals because it is considered a shameful subject (Beeker et al., 2000; Bridou et al., 2013).

Relaxation effect after a negative result in FOBT: Individuals who had once participated in the screening and had obtained a negative result in the FOBT indicated that they did not participate again because they believed that it was no longer necessary. However, this response is inconsistent with the available evidence because a high rate of consistent participation increased the program sensitivity of the FIT screening (Winawer et al, 1993; Nishihara et al, 2013). Therefore, the effectiveness of a FIT screening program is highly dependent on participation in multiple rounds. Consequently, once-in-a-lifetime participation is not sufficient to prevent colorectal cancer. This false relaxation does not occur in other types of cancer screening, such as breast or cervical cancer, in which women continue to participate after a negative screening test.

Another study has shown that non-adherence is not caused by a difficulty related to performing the test, as the participants generally considered the test to be relatively simple to perform with no particular problems, at least compared with other similar types of medical procedures. This finding confirms the results of several authors who reported that this type of test is convenient and relatively simple to use (Bridou et al., 2013). Although most countries in Europe currently use the immunological test, the reasons for longitudinal adherence to colorectal cancer screening are common for both immunological and guaiac tests.

An individual's experience during the initial screen has been shown to influence her longitudinal adherence to screening (Bulliard et al., 2003; Maxwell et al., 1996). Several studies have shown that individuals who expressed dissatisfaction or negative views regarding their initial screen were more likely to not re-attend (Marshall, 1994; Orton et al., 1991; Peipins et al., 2006). Thus, longitudinal adherence may be a good indicator of satisfaction because individuals who have been satisfied with the process are likely to re-attend during the subsequent round. Therefore, longitudinal adherence may be a proxy for measuring satisfaction in a feasible manner. Satisfaction with the cancer screening process should be an indicator that is evaluated on a regular basis. However, the determination of user satisfaction incurs significant costs. Consequently, ascertaining longitudinal adherence as an indicator of satisfaction could reduce costs and increase the feasibility of this indicator. In contrast and according to the current findings, non-adherence may result from not only non-satisfaction with the screening process but also a lack of knowledge, which was one factor identified in this study as a barrier to longitudinal adherence.

This study has several limitations. We attempted to minimize several forms of bias by recruiting participants from different areas of the city and including both men and women of different ages and with varying degrees of experience with CRC screening.

The qualitative nature of this study may limit the generalizability of our findings. However, qualitative research is concerned with generating insights that may be useful in different settings because the understanding that is generated is applicable to specific groups of individuals who share characteristics, engage in behaviors or live in circumstances relevant to the phenomenon investigated (Mays and Pope, 1995). This form of generalizability differs from that gained through statistical studies

and was ensured by our sample strategy, which focused on reflecting the diversity within the population under study relevant to the research (including differences in prior screening behavior, socio-economic background, age, sex, ease of recruitment and initial FOBT results) rather than aspiring to recruit a representative sample.

We will use the findings from our detailed analysis in this qualitative study to generate a framework to better understand facilitators and barriers that affect decision-making to participate in CRC screening. The results from these types of qualitative studies may be used to develop interventions to increase participation in colorectal cancer screening programs and specifically increase the longitudinal adherence.

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Table 1. Composition of the focus groups and demographic characteristics of participants.

Focus groups	Prior screening behavior	Educational level	Gender		Total
			Male	Female	
1	Regular adherent	Area 1		7	7
2			6		6
3		Area 2		7	7
4			7		7
<i>Total regular adherent participants</i>					27
5	Irregular adherent	Area 1		5	5
6			7		7
7		Area 2		3	3
8			3		3
<i>Total irregular adherent participants</i>					18
Total study participants			23	22	45

Table 2. Sample focus group topic guide

<i>Introductory question</i>
<ul style="list-style-type: none"> • What was the first thing that came to mind when you received the letter of invitation to participate in the screening program?
<i>Main topics</i>
<ul style="list-style-type: none"> • Perceptions on form of invitation, reminders and information given • Perceptions on colorectal cancer, risk and early detection • Experiences/expectations of enrolment and participation • Experiences/expectations of taking the FOBT and receiving results • Experiences/expectations of colonoscopy and receiving results • Perceptions on continued/discontinued participation • Perceived benefits/disadvantages of taking part

Table 3. Initial set of descriptive themes.

Attitudes regarding the health care system
GP's or relatives' involvement in CRC decision-making
Improvements
Attitudes regarding one's own health
Relatives or friends with CRC
Competing health risks
The value of screening (importance of early detection)
CRC imaginary
Regrets for having skipped at least one invitation to CRC screening
Communication issues about CRC
Implications of an initial negative result
Fear
Awareness of being adherent
Awareness of being non-adherent
Lack of information regarding the CRC screening process
Laziness
Completing the test
Reputation of the screening program

Table 4. Illustrative quotes from participants by themes and sub-themes.

Themes and sub-themes	Illustrative quotes
Theme 1: Common factors underpinning the screening experiences and decisions of regular and irregular adherent participants	
<i>Perceived benefit of prevention</i>	1 "early diagnosis is very important (...) the patient must have enough time to understand what he has and what will happen" (Regular adherent, Area 1, Male)
	2 "I would encourage all people who receive this, who have the opportunity, to do it. Because it is a... it is good. If you have problems, you will have it and it will be worse if they do not catch it in time. That's clear. No one is exempt from having anything." (Irregular adherent, Area 2, Male)
	3 "I find this to be very good, because it is designed to prevent. And if I do not have anything, then it's great. And if I have something, and they detect it in time, then it is much better (...) you'll be a little afraid, it's a hard pill to swallow, but sometimes it's better to know as soon as possible... Well, sometimes, not always, but knowing the unpleasant news as soon as possible may make it pass better." (Irregular adherent, Area 1, Female)
<i>Lack of comprehension</i>	4 "I think it is an initiative that is well taken, but it is something long-term because I have not received anything for two years, then it is clear in two years many things could happen ... I find that the main problem (...) if this test is performed every six months it would be better than every year, an example, an example ... I find that every two years is too long, it is my opinion..." (Regular adherent, Area 2, Male)
	5 "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's not like that" (Irregular adherent, Area 1, Male)
<i>Lack of information about CRC in the media</i>	6 "we have a greater chance of dying when we are older than when we are young, so surveillance should also be more stringent or more active when we become older than when we are young, so it is a request that I believe would be correct, that well, instead of cutting at 69, then after 69 years this disease, this damn cancer, does not rear its head, but what if? (...) well, I would like to be controlled at 69, 79 and 89 until ... until..." (Regular adherent, Area 1, Male)
	7 "[we need] more information: what can cause or prevent colon cancer, I have not heard. And, as well as for other [cancers] they can almost guarantee that if you don't smoke, don't drink... [you can prevent it]. And still I have not heard any comments about the colon [cancer], I have not heard comments" (Regular adherent, Area 2, Male)
	8 "Much more information about breast cancer than colon cancer is given on television, and Catalonia is, I think, a region that has more colon cancer [than breast cancer], and where is the information on television? (Irregular adherent, Area 1, Male)
	9 "well I read the newspaper daily, and I listen to the media, and the truth is that there is not much talk about it [colorectal cancer]" (Irregular adherent, Area 1, Female)

<i>Satisfaction with the program</i>	10	"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" (Irregular adherent, Area 1, Male)
	11	"The information is easy and can be understood very well. If I ever do not understand something, I ask my daughter, but it was not necessary because we understood it very well" (Irregular adherent, Area 2, Female)
	12	"everyone should be grateful that today we have this [the screening program]. Because before we did not have it [available to us] (...) If this is something scientifically studied and works well (...) I see it as correct, so that whenever that... if it is increasing, it is something that the administration does well." (Irregular adherent, Area 2, Male)

Theme 2: Common factors interpreted in opposed ways by regular and irregular adherent participants

<i>The role of fear in participants' decision-making</i>	13	"the word cancer is something that... when someone talks about cancer, you do not want to hear about it, because today it's him and tomorrow it could be me... and I do not want anything to do with this disease." (Regular adherent, Area 1, Male)
	14	"It [CRC] imposes respect, because lately you do not hear about anything else, and of course the least you think... [is that you might have it]" (Regular adherent, Area 1, Female)
	15	"I believe it [the reason why people does not participate] is what the lady says, that many people are afraid [of having cancer] and do not want [to know]" (Irregular adherent, Area 1, Female)
	16	"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" (Irregular adherent, Area 1, Female)
<i>Consulting a GP as part of the decision-making process</i>	17	"I went to my GP [before making a decision] and they talked me through it [the letter] a bit" (Regular adherent, Area 1, Male)
	18	"I think it is important to consult with your GP [before you make a decision]" (Regular adherent, Area 2, Female)
	19	"Well, I did ask my doctor, and he told me: that's fine, if you want to do it, well. He did not give me any more explanations" (Irregular adherent, Area 2, Female)
	20	"well, they do not tell you anything [about the program] in the health center. They have a lot of work and are... very serious. They do not tell you anything [about the program]" (Irregular adherent, Area 2, Female)

Theme 3: differential factors across regular and irregular adherent participants

<i>Regular adherent participants: having a close person</i>	21	"I have now a brother at the oncology department" (Regular adherent, Area 1, Female)
	22	"all my relatives from my father's side died of cancer, most of them (...) not from my mother's side, but from my father's side yes. I think I've got a fifty percent" (Regular adherent, Area 1, Female)

*diagnosed with
CRC*

- 23 "there are quite a lot of colorectal cancers, I... various friends of mine have died" (Regular adherent, Area 2, Male)
- 24 "my father died of colorectal cancer" (Regular adherent, Area 2, Male)
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*Irregular
adherent
participants:
prioritization
issues and
being relaxed
about
screening after
a negative
result*

- 25 "you are getting on with your life, you are doing your things and can do it tomorrow, I will do it tomorrow. And in this case, well it has happened to me, to misplace items, because there is nothing that pushes you. As there isn't something, unless a personal concern pushes you to do it, then you do not do it." (Irregular adherent, Area 1, Male)
- 26 "It [to participate in the programe] seems very well to me, but the last time I received the letter I was preparing, we were to go away a few months with my son, and I thought, I will go when I get back, I will. And in the end, I didn't do it" (Irregular adherent, Area 2, Female)
- 27 "not having blood detected in the [first] test, we then assumed that there would be no cancer. One is then so happy already [that] in the second test you no longer value it in the same way as if you really had doubts (...) And then it seems that you relax about it, as if you said, ok it does not have great importance. But the truth is that it does." (Irregular adherent, Area 1, Male)
- 28 "They sent us the results of the [first] test, [it was] satisfactory, it was good. Everything was very good, everything very well. We were very well informed, there was no problem. Then the second year [the letter] arrived, right? And then [what happened is] what we all have said, one day after another [all you see] is how well you feel, and you say, for example, well, what am I going to have..." (Irregular adherent, Area 1, Male)
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