


ORIGINAL ARTICLE

Decision-making in screening positive participants who follow up with colonoscopy in the Dutch colorectal cancer screening programme: A mixed-method study

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Abstract

Objective: To explore worry and decision-making processes used by faecal immunochemical test (FIT)-positive participants in the Dutch national screening programme for colorectal cancer.

Methods: A mixed-methods study consisting of 22 semi-structured interviews in FIT-positive participants who underwent the recommended colonoscopy within 4–6 months after the FIT result, followed by a widespread questionnaire in a larger target population ($N = 1495$).

Results: In the interviews, we recognised two different decision-making processes. The first is an affective heuristic decision process where the decision to participate is made instantly and is paired with high-risk perception, worry and (severe) emotional turmoil. The second is a more time-consuming analytical decision process in which participants describe discussing options with others. In the questionnaire, high levels of cancer worry ($CWS > 9$) were reported by 34% of respondents. Decisional difficulties were reported by 15% of respondents, and 34% of respondents reported discussing the positive FIT result with their GP. Individuals with high levels of cancer worry contacted their GP less often than those with low levels.

Conclusions: The Dutch two-step screening programme may result in high levels of cancer worry in a non-cancer population. More research is needed to monitor worry and its role in decision-making in cancer screening, as well as ways to facilitate decision-making for participants.

KEYWORDS

anthropology, colorectal cancer, decision making, early detection of cancer, mass screening, medical, medical, oncology, Psycho-oncology, psychological distress, Public health, sociology

Lottie Bastiaans and Augustina Danquah shared third authorship.

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1 | BACKGROUND

Population-based screening programmes aim to identify cancer before it causes noticeable symptoms. In the Netherlands, a screening programme for colorectal cancer (CRC) was introduced in 2014 (Box S1).¹ For the success of a CRC screening programme, the subsequent follow-up of an unfavourable (positive) screening result with diagnostic colonoscopy is as crucial as initial participation. In 2019, the participation rate of the initial screening test (faecal immunochemical test or FIT) was 71.5%, and the follow-up rate was 85%.² Follow-up rates in past years have been comparable to those of other European nations.³ However, follow-up rates as low as 43% (United States) and 30% (Australia) have been reported.^{4,5} The design of the Dutch screening programme differs slightly from other population-based CRC screening programmes. In England, an appointment with a nurse is booked if participants have indicated they are willing to undergo colonoscopy.⁶ In Australia, screening positive participants are recommended to contact their GP to be referred for colonoscopy.⁷ In the Netherlands, however, participants receive a pre-planned appointment for colonoscopy intake in the letter that informs them of the positive FIT. There is no official involvement of a healthcare professional to discuss this FIT result.⁸ As such, the Dutch CRC screening programme has been designed on the premise that participants make an autonomous informed decision about initial participation and follow-up.⁹ The importance of (informed) decision-making in cancer screening has been recognised in recent decades,¹⁰ and has been emphasised by the Dutch screening organisation as well.¹¹ However, although some studies have documented factors that are associated with follow-up such as patient characteristics (e.g., knowledge and age), social support, provider characteristics, practice (e.g., having reminders systems), community and professional norms (e.g., quality measures), and policy (e.g., population based programmes),^{12,13} little is known about the decision-making process in participants who do follow-up after a positive FIT.

According to the rational decision model, two requirements must be met for making a well-informed decision.^{14,15} The decision outcome must reflect personal values, and individuals must have and understand relevant information to the decision.^{14,16} However, decision-making may be influenced by psychological, emotional and cognitive factors, such as risk-perception, worry, emotions, the way information is framed and social norms.^{17,18} In addition, previous research reports that decisions on participation in FIT screening may not take place in a way that reflects the rational decision-making model as relevant information may be overlooked.^{9,19} The way individuals make a decision regarding participation in follow-up of screening may thus influence the outcome of this decision as well as their psychological well-being. Therefore, this study aims to explore decision-making processes amongst FIT-positive participants who undergo follow-up colonoscopy. The use of a mixed-method design helps to first qualitatively identify decision-making processes and then quantitatively estimate the prevalence of these processes in a larger population by identifying variables, like worry that are associated with them. As such, this study may inform potential areas to

improve upon in the screening programme (e.g., the ways in which information is provided and discussed).

2 | METHODS

We examined reasons on colonoscopy participation after a positive FIT result with an exploratory sequential mixed-method design consisting of interviews and a questionnaire.

2.1 | Interview study—participants

First, between December 2016 and May 2019, semi-structured interviews were conducted amongst FIT-positive participants in the Dutch CRC screening programme who were willing to undergo a colonoscopy. This was part of an investigation on reasons for (non-) follow-up in CRC screening, as reported elsewhere.²⁰ Participants in the CRC screening programme were recruited in GP practices, by an online newsletter from a national elderly organisation (ANBO) and on social media (Facebook). Inclusion criteria were a positive FIT in the past 12 months followed by colonoscopy within 6 months hereafter. Exclusion criteria were a diagnosis of CRC or advanced adenoma during the colonoscopy. Participants were selected according to the principle of purposive sampling to ensure a somewhat even distribution of age, sex and education level. On social media and in the online newsletter participants were directed to a website where they could fill in a web form with their contact details.²¹ Participants were then contacted by telephone by one of the researchers (LBe, LBa, TiD) to screen them for eligibility, to receive information and to sign informed consent.

2.2 | Interview study—analysis

An interview guide was developed based on literature regarding (non)adherence to cancer screening and decision-making. Three pilot interviews were conducted, which were not included in this investigation. The interview guide contained questions on, participation, decision-making, risk perception and cancer worry (see Box S2). LBa and TiD (last year medical master students, female) were trained by LBe (MSc. Medical Anthropology and Sociology, PhD candidate, female) in conducting interviews. LBe received interview training during her previous education and had experience with conducting in-depth interviews. The interviews (23 in total) were conducted by either LBe alone (8 interviews) or by LBa and TiD together under close supervision of LBe (15 interviews). The interviews were conducted in Dutch at the participants' homes to ensure confidentiality, and were subsequently recorded, transcribed verbatim and coded in MAXQDA.²² Open coding was performed of all transcripts independently by LBa and TiD, and of eight transcripts by LBe. Classification of themes into a code tree was performed by LBe and discussed with BK and KvA until agreement was reached. Data saturation was reached, which we defined as the point where no new main themes

were found in three consecutive interviews.²³ Participants received a gift certificate worth €20.

2.3 | Questionnaire study—participants

Second, based on the outcome of the interviews, a questionnaire was designed and produced by the research team and external advisors (see Acknowledgements), previous studies on CRC screening follow-up and validated questionnaires. See Table S2 for an overview of questions included in this current study. Since the questionnaire was part of a larger research project and had to be as concise as possible (to maximise response rate), we had to make choices on the contents and did therefore not include more specific decision-making variables. Instead, based on our qualitative results, we included variables that served at proxies for the decision-making processes and that we could also use for other parts of the larger research project. Eligible participants ($N = 4009$) who were registered as having had a follow-up colonoscopy ($N = 1500$, random sample of 12,501 in total) and those who did not ($N = 2509$, all registered individuals within this group) were selected from the ScreenIT database (containing data on CRC screening invitees) in May 2019 by The National Institute for Public Health and the Environment (RIVM), which is responsible for the CRC screening programme in the Netherlands. Respondents who self-reported a colonoscopy were included in this study. The only exclusion criterion was a CRC diagnosis during the year before screening. The investigators were not directly involved in this selection process, ensuring anonymity of the individuals in the database.

2.4 | Questionnaire study—analysis

Only persons who reported having undergone a colonoscopy in their questionnaire were analysed in this study. For this group, frequency tables were made for questionnaire items measuring risk perception, cancer worry, decisional difficulties, having an alternative explanation for the positive FIT, and contact with the GP to discuss the positive FIT, as these items seemed to influence decision-making in the interview study. The six-item cancer worry scale is a validated scale to measure high levels of cancer worry.²⁴ Cut-off for high levels of cancer worry was established at >9 .²⁵ Risk perception was measured with questions on the personal risk of CRC after FIT and the risk compared to others on a 7-point Likert scale. The answers 'almost sure', 'very large risk' and 'large risk' were scored as high-risk perception. Associations between variables were examined with a Pearson's chi-squared test.

2.5 | Research ethics

This project was granted a waiver by the Medical Ethics Committee of the Amsterdam UMC, location AMC (METC AMC), reference

W19_120 # 19.153 and # 19.191. Participants in the interviews were informed that they could withdraw from the study at any time, and a written consent was obtained before interviews. Interview transcripts were anonymised. The interview study was reported in accordance with the 32-item checklist of Consolidated Criteria for Reporting Qualitative Research (COREQ) (Table S3). For the questionnaire, consent to participate followed from returning the filled out questionnaire. The result of the questionnaire was reported in accordance with the STROBE checklist (Table S4).

3 | RESULTS

3.1 | Interviews—inclusion

Twenty-three persons were interviewed, of which 1 was excluded due to detection of advanced adenoma during colonoscopy. Thus, 22 participants were included in this study (see Table 1). Interviews lasted 45 min on average.

3.2 | Results—interviews

In the interviews, most participants could be divided into two groups according to their described decision-making processes. The first group described undergoing a colonoscopy not to be a decision, but rather a natural consequence of participation. The second group described hesitation at some point in their decision-making process. In both groups, anticipated regret is an argument for a follow-up colonoscopy. Below, we will describe both groups.

3.2.1 | Participation as a natural consequence

Participants in the first group described that colonoscopy participation was something they did not have to think about, as it came naturally to them. They mentioned the decision was rapid, that they did not consider other options and thought that colonoscopy was something they had to have done.

I never considered not having it done (R02).

This was not a decision I had to think about (R03).

These participants often detailed a strong emotional response to the FIT result letter. Most mentioned they had not expected the result. We heard descriptions of shock and disbelief. Some participants mentioned crying.

I remember vividly, I was standing over here by the table. I opened the letter, I read the result and it was as if a hole opened up in the ground. It thought that this was it, that I was done (R10),

TABLE 1 Participant characteristics interviews

| Characteristics | Participants |
|--------------------------------|--------------|
| Number of participants | 22 |
| Age range participants, years | |
| 55–64 | 11 (50%) |
| 65–74 | 9 (41%) |
| >74 | 2 (9%) |
| Sex | |
| Female | 13 (59%) |
| Male | 9 (41%) |
| Recruitment method | |
| Elderly organisation | 1 (5%) |
| Social media | 15 (68%) |
| General practice | 6 (27%) |
| Educational level ^a | |
| Low | 11 (50%) |
| Middle | 5 (23%) |
| High | 6 (27%) |
| Relatives with CRC | |
| First grade | 7 (32%) |
| Other | 9 (41%) |
| None | 6 (27%) |
| Ethnicity | |
| Western-European | 21 (95%) |
| Other | 1 (5%) |

^aPrimary education or less = low education; Secondary education and vocational training = middle education; College and university = higher education.

You immediately assume the worst (R09),

I cried for a few hours. I was in absolute shock (R21),

This reaction was often paired with explanations of feeling at risk. Participants described this was due to the way the FIT result letter was formulated, to having any type of cancer in the family or having symptoms they associated with CRC.

I had been having stomach issues for a long time, so that made me think I may be more vulnerable for this type of thing (R02),

Out of seven participants with a first-grade relative with CRC, two described a strong emotional reaction and high levels of worry to the FIT result letter. One of them mentioned this was due to existing health problems, the other one described being worried due to a positive family history for CRC.

I felt worried because my mother had bowel cancer (R18).

Furthermore, some described having witnessed CRC in friends or partner, which prompted awareness and willingness to undergo colonoscopy.

My first wife died of a type of bowel cancer, and I remember very well that the doctor told her if they had caught it ten years earlier it could have been cured (R03).

Participants in this group detailed several reasons for finding colonoscopy participation important. They mentioned a need for reassurance, wanting to detect CRC in time, anticipating regret if they would not participate, and wanting polyps to be removed to reduce their risk of CRC.

It is very simply about catching things in time, at an early stage (R14)

I remember thinking 'If I do not do this I will never forgive myself if it turns out I have it later on' (R17).

It is a type of prevention that you have to do (R21).

If there is something there, they can remove it (R12).

I wanted to know if something was the matter or not, and if it was serious (R19).

3.2.2 | Participation as a deliberate decision

The second group of participants described a more elaborate decision-making process than the first group, where at some point they experienced hesitation regarding the decision to follow-up with colonoscopy. These participants did not detail a strong emotional response to the FIT result letter.

When I got the letter I thought: 'How can this be?' I did not notice anything different. So I read about it online and talked to other people. And I was like 'whatever' (R17).

I received a very proper letter; it said that blood was found, but that I should not worry. To be very honest, I was not worried because I did not have any particular complaints (R16).

Most of these participants mentioned that the reason they did not feel at risk was due to not having symptoms associated with

CRC, having an alternative explanation for the blood found in the stool or not having a family history of CRC.

I had a big nosebleed three days before I sent in the test, so I thought that would be why the test was unfavourable (R17).

It does not run in my family. I know people who had it, but only distantly (R05).

Most participants in this group described making the final decision by discussing their options with others. For some, this opportunity arose during the intake appointment for colonoscopy, where some asked about the possibility to do a second FIT. When this was not presented as an option, they agreed to undergo the colonoscopy.

During the intake I was trying to get out of it, I wanted to do another test. But that was not something they were willing to offer (R17).

Other participants found it helpful to talk about the FIT result with their GP, family or friends.

I discussed it with my children and they told me 'that is just something you have to do' (R04).

I phoned my GP, because I was angry that I had to go to a hospital so far away for the examination. I thought that was ridiculous. The GP arranged for me to go the hospital around the corner, and then I said: 'Well, fine' (R07).

I went to my GP to discuss my options and she told me it was sensible to get it checked out, certainly at my age. So I decided I would go ahead and do it (R16).

Other reasons mentioned in this group were wanting reassurance and anticipating regret when choosing against colonoscopy.

I did not want to think 'I wish I had done it' in three months' time (R16).

3.3 | Questionnaire—inclusion

From the original, total sample of FIT-positive individuals ($N = 4009$), 2257 questionnaires were returned (Figure S1). In approaching this sample, no distinction was made between those who had undergone a colonoscopy and those who had not. The response rate for this total sample was 56%. All respondents who self-reported colonoscopy ($N = 1495$) were included. Participants had a mean age of 66, were

more often male (60%), predominantly living with a partner (74%), were born in the Netherlands (94%) (Table 2).

3.4 | Questionnaire—results

For an overview of descriptive data, see Table 3. There was evidence of an association between a low cancer worry score and a low estimated probability of CRC after the positive FIT ($\chi^2(18) = 252,519$, $p < 0.001$). There was also an association between a low cancer worry score and having discussed the FIT outcome with the GP ($\chi^2(18) = 46,619$, $p < 0.001$). Lastly, there was an association between having an alternative explanation for blood in stool and lower perception of risk ($\chi^2(6) = 19,723$, $p = 0.003$).

4 | DISCUSSION

4.1 | Main findings

During the interviews, we found two different processes of decision-making in participants who followed up with colonoscopy after receiving a positive FIT in the Dutch CRC screening programme. In the first process, participation with follow-up colonoscopy is deemed important and urgent and there is little or no hesitation. Individuals in this group described shock, disbelief and emotional distress followed after reading the screening result, indicating high levels of worry and risk perception. In the second

TABLE 2 Participant characteristics questionnaire

| Items | Colonoscopy group ($N = 1495$) | |
|------------------------------------|-------------------------------------|-------|
| | N | % |
| Questionnaire filled out on paper? | 1231 | 82.3% |
| Mean age | 66.4 | - |
| Male | 861 | 59.7% |
| Living with partner | 1110 | 74.2% |
| Having at least one child | 1239 | 86.4% |
| Living in urban area | 570 | 40.5% |
| Educational level | | |
| Primary | 68 | 4.8% |
| Secondary | 397 | 28.2% |
| Vocational training | 509 | 36.2% |
| Higher education | 432 | 30.7% |
| No sufficient financial resources | 140 | 11.4% |
| Born in the Netherlands | | |
| Yes | 1348 | 93.7% |
| No | 91 | 6.3% |

TABLE 3 Descriptive data questionnaire

| Items | Colonoscopy group (N = 1495) | | Missing |
|--|------------------------------|------|---------|
| | N | % | |
| Cancer worry | | | |
| Cancer Worry Scale (CWS) score >9 | 421 | 33.7 | 16.4% |
| Decisional difficulties | | | |
| Difficulty with deciding upon colonoscopy | 98 | 6.8 | 3.8% |
| Wanting someone else to decide upon colonoscopy | 233 | 16.2 | 4% |
| Risk perception | | | |
| High estimated probability of CRC after FIT | 100 | 8 | 16.8% |
| High estimated probability of CRC compared with others | 92 | 6.3 | 17.7% |
| Contact with GP to discuss FIT | 484 | 33.5 | 3.3% |
| Alternative explanation for positive FIT | 609 | 40.7 | 2.7% |

Abbreviations: CRC, colorectal cancer; FIT, faecal immunochemical test.

process, individuals did not describe worry or feeling at risk, which for some was related to having an alternative explanation for the positive FIT. These individuals followed up with a colonoscopy after consideration. Here, input of others such as family, friends, the GP and medical professionals during the intake consultation for colonoscopy may play a role in deciding. In the questionnaire, we found that high levels of cancer worry were reported by almost one third of participants, decisional difficulties by 15% and high estimations of risk for CRC by 6%–8%. Low risk estimation was associated with having an alternative explanation for the positive FIT. In addition, one third of all participants reported a contact moment with their GP to discuss the positive FIT, and participants with lower levels of cancer worry more often did so than those with high levels of cancer worry.

4.2 | Interpretation of results and comparison with literature

The definition of an informed decision has been formulated as the making of a reasoned decision by a reasonable individual using relevant information, in accordance with one's beliefs.^{26,27} This is also the measure of informed-decision-making used in cancer screening programmes as formulated by the Dutch screening organisation.¹¹ The steps that are necessary to make such an informed decision have been described by Rimer et al. as understanding the test, understanding one's personal values and preferences, weighing the pros and cons of the test, clarifying decisional preferences, finding additional information and finally, deciding on an action plan.²⁸

Literature on decision-making has described a two-system view that makes a distinction between the use of reasoning and the use of intuition as the basis of decision-making processes.²⁹ Here, a decision-making process that is based primarily on reasoning is a

rational and analytical one that takes time. Oppositional from that is the heuristic decision-making process, which is based on intuition. This is a quicker and more affective process of deciding. The decision-making processes that we found in the interviews point towards a group that has an analytical decision-making process and a group that has a heuristic decision-making process. The first group does describe several steps of an informed decision-making process as described by Rimer et al.²⁸ They describe being aware of the decision problem to then structure it and evaluate different aspects before making a decision, and some described discussing their decision with others. In the latter group, the emotions described by the first group seem to overwhelm these participants to the extent that the several decision-making steps cannot be distinguished. They thus exhibit an affective response, which is a rapid and automatic reaction to a stimulus, judging it as either positive or negative. Heuristic decision-making based on affect has been termed affective heuristic decision-making, and this has been associated with higher levels of risk perception in cancer screening decisions.³⁰ Affective heuristics have been measured with items that measure cancer worry in previous research on risk bias regarding breast cancer.³¹ The results of the questionnaire may thus indicate that the heuristic decision-making process takes place in a small percentage of participants with a positive FIT test who follow-up with colonoscopy. Indications for this can be found in reporting high levels of worry and high estimations of risk for CRC between FIT result and colonoscopy. Evidence for the existence of a group with an analytical decision-making process may be found in participants who reported decisional difficulties, and participants who discussed the FIT with their GP—although the interpretation of causality of the latter is difficult due to the timing of the questionnaire. It is also possible that discussing the FIT with a GP lowered cancer worry levels. However, a recent study amongst individuals who received an invitation to participate in FIT in the Dutch CRC screening programme reported two similar decision-making styles in this population, corroborating our results.³² Although

affective heuristic decision-making is employed on a day-to-day basis, leading to decisions that are generally considered to be 'good', it is a decision-making process that derives its speed from the attribute that it does not take all available information into account.³³ As such, it may not be the most suitable for making decisions related to cancer screening. Although the higher perceptions of risk that are often underlying affective heuristic decision-making can offset protective behaviour such as screening participation and follow-up, it may also be accompanied with levels of anxiety that are high enough to have a negative impact on quality of life.³⁰ Recent research has shown that a higher perception of risk and the emotional distress that is associated with a positive FIT may persist for 6 months after receiving the screening result.³⁴ The persistence of negative psychological consequences of positive screening results have also been documented in breast cancer screening and cervical cancer screening.³⁵⁻³⁷

4.3 | Study limitations

The use of a mixed-methods design in this investigation strengthens the results.³⁸ However, certain limitations of this study may affect the generalisability. In the interview study, participants had to volunteer to participate, which may have created a self-selection bias, and participants were recruited mostly on social media, which could have created a selection bias of participants. The questionnaire consisted of self-reported data that may have been an inaccurate representation of follow-up attendance. In addition, reporting of cancer worry and risk perception may have been biased by knowledge of a favourable colonoscopy result, or it may have been biased by discussing the FIT outcome with others, such as the GP. Furthermore, the results might have been influenced by participants' understanding of risk (health literacy), which we did not measure. In addition, since no in-depth data can be obtained from a questionnaire, it is not possible to exactly identify and quantify the described processes from the questionnaire results. We therefore cannot determine how many questionnaire participants made a decision via these processes and whether other processes may have played a role. Furthermore, individuals who made the decision to participate in the questionnaire may not be representative for a larger population regarding decisional difficulties. Moreover, in this study, we did not include FIT-positive individuals who did not undergo colonoscopy; however, these were included in two other studies reporting on this research project.^{20,39} Lastly, the majority of participants in both the interviews and the questionnaire were born in the Netherlands, which limits conclusions to individuals with a similar background and does not account for potential cultural differences in decision-making.

4.4 | Clinical implications

Currently, the development of personalised screening approaches mainly focuses on the stratification of risk based on factors such as

family history and lifestyle.⁴⁰ Our results indicate that it may be worth considering broadening the concept of personalised screening to include personal abilities, for example, by assessing an individual's ability to process risk information. Furthermore, our study shows that although GPs are currently not officially involved in the Dutch CRC screening programme, they may still play an advisory role for one-third of patients. GP involvement may be advisable.

5 | CONCLUSION

A small proportion of Dutch CRC screening positive participants may have high levels of cancer worry, and may employ an affective heuristic decision-making strategy that may not take all available information into account. More research is needed to monitor worry and facilitate decision-making in participants with decisional difficulties and strong emotions.

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CONFLICT OF INTERESTS

The authors declare no conflicts of interest.

STATISTICAL METHODS STATEMENT

In the quantitative part of this study, frequency tables were made for questionnaire items. Associations between variables were examined with a Pearson's chi-squared test.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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