

Making decisions about colorectal cancer screening. A qualitative study among citizens with lower educational attainment

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Background: Few decision aids (DAs) have been developed to support an informed choice to citizens with lower educational attainment about colorectal cancer screening. The aim of this study was to identify information needs and preferences for formats and content in a DA for this group of citizens. **Methods:** Four focus groups were conducted among Danish men and women aged 50–74 years with lower educational attainment. A semi-structured interview guide was developed to explore participants' perceptions about colorectal cancer screening and wishes for a DA. The interviews were transcribed and analysed using an ethnographic approach. **Results:** The participants appreciated information about the causes, symptoms, incidence and mortality of colorectal cancer compared with other common cancers. The majority preferred the information to be presented in a clear and simple way with numbers and figures kept to a minimum. Values clarification exercises were not found useful. Receiving a screening kit to collect a sample of faeces along with the invitation letter was seen by the participants as a clear request from the health authorities to get screened. However, the overall message in the DA was perceived as ambiguous by the participants as it both recommended screening and seemed to disclaim responsibility for it. **Conclusion:** The results are relevant to a discussion of the delicate balance between participants' call for a clear recommendation, and the purpose of a DA to present options in a neutral and balanced way. This discussion is relevant beyond the group of citizens with lower educational attainment.

Introduction

Colorectal cancer is the second most common cancer in Europe with 447 000 new cases and 215 000 deaths each year. Denmark has the highest age-standardised incidence rate of colorectal cancer in men (69.2 per 100 000) and the second-highest age-standardised incidence rate of colorectal cancer in women (53.4 per 100 000) among the Northern European countries.¹ Mortality is related to time of diagnosis,² and since symptoms are diffuse with low positive predictive values, screening may be a feasible method to ensure early detection and reduce mortality.³ Screening with biennial faecal occult blood test (FOBT) has shown a 15% relative risk reduction in colorectal cancer mortality in general and a 25% relative risk reduction for those attending at least one round of screening.⁴

Colorectal cancer screening programmes using FOBT have shown uptake rates between 53 and 67% with the highest rates in programmes using immunochemical faecal occult blood test (iFOBT) compared with guaiac faecal occult blood test.⁵ In 2005–2006, colorectal cancer screening based on direct mailing of iFOBT test kits to citizens was pilot tested in two Danish counties among 177 148 citizens aged 50–74 years with an uptake of <50%.

In March 2014, the colorectal cancer screening programme was implemented in all of Denmark. Data from the first 3 months showed an uptake rate of 58%.⁶

Citizens with lower educational attainment report greater uncertainty in decision-making about colorectal cancer screening compared with citizens with higher educational attainment.⁷ Lower educational attainment is associated with lower screening uptake,⁸ lower chances of receiving curative treatment and increased mortality from colorectal cancer.⁹ In colorectal cancer screening with FOBT, the decision to participate and taking the

test is performed in the citizens' own home. This is mainly supported by written information included in the invitation letter and a minimum of contact with healthcare professionals.^{10–12}

Previous studies have shown that decision aids (DAs) can assist citizens in making informed decisions about healthcare options, e.g. participation in screening programmes.¹³ DAs should describe options, the course if no action is taken and describe the benefits and harms associated with the options.¹⁴ It should target the information needs and preferences of a specific population with respect to a specific decision. However, little is known about the needs and preferences of citizens with lower educational attainment regarding a DA about colorectal cancer screening, and only few DAs have been developed.¹⁰ The aim of this study was to identify information needs about colorectal cancer screening and preferences for format and content in a DA among citizens with lower educational attainment.

Methods

Participants and recruitment

A qualitative design with focus group interviews was used.¹⁵ The target was to include 10 participants for each of four focus groups. The participants were sampled on a purposive basis and included men and women aged 50–74 years who had completed no more than short first tertiary education (typically occupationally specific and practically based education).¹⁶ Recruitment was carried out by a commercial recruitment company. As instructed by the authors, the company made randomised telephone calls using the White Pages to citizens in the second largest city in Denmark (Aarhus) with more than 300 000 inhabitants, and to citizens in the town Herning counting <50 000 inhabitants. The calls were ended when respondents did not meet the inclusion criteria.

Your answers

Enter your answers in this table to get an overview

Please enter between one and five pluses depending on how important each question is to you. Insert one plus if it is not important to you and five pluses if it is really important to you.

	In favour of screening	Not sure	Against screening	Important to me
The risk of getting colorectal cancer before you turn 75 years				
The risk of colorectal cancer disseminating				
The risk of dying from colorectal cancer				
Collecting a stool sample				
The risk of being called in for a colonoscopy				
The risk associated with having a colonoscopy				
The risk of getting a cancer diagnosis if there is blood in the stool				
The risk of getting a false result				
Waiting eight years for the next colonoscopy if the first one is negative.				
Total				

Figure 1 Value clarification exercise

Participants were invited on a first come, first serve basis until 10 participants for each of four focus groups were attained which was 10 men and 10 women from Aarhus area and 10 men and 10 women from Herning area. It was emphasised in the recruitment process that participants with positive, neutral or negative attitudes towards screening were equally welcome.

Design of a DA draft

Before conducting the focus group interviews, a DA draft of 15 pages was designed by the researchers based on a literature review. Plain language with a low readability index was used, i.e. LIX 25-34 consistent with weekly magazines.¹⁷ The DA draft was sex-specific as incidence, prevalence and mortality differ between sexes. It contained a brief description of colorectal cancer, iFOBT screening and colonoscopy in case of a positive iFOBT test. Benefits and disadvantages were described for each option (screening or no screening). A value clarification exercise (figure 1) and a deliberation exercise were inserted. When presenting probabilities, the same denominator was used throughout the DA draft (x out of 1000) and risk information was given in both absolute and relative numbers. Comparative data with everyday risks were inserted and numbers were supported by crowd figures and pie charts. A flow chart of the screening process (figure 2) and a one-page decision aid were

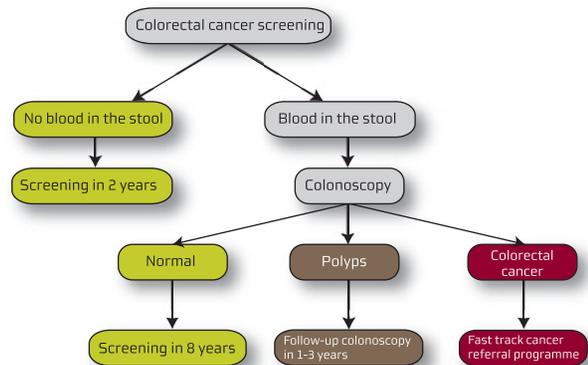


Figure 2 Flow chart of the screening process

included¹⁸ (figure 3). Finally, three comic-like illustrations were presented to test an alternative visual layout. The DA draft did not contain scientific references, and the layout was kept simple.

Focus group interviews

The focus groups were moderated by two researchers; a female researcher guided the female focus groups and a male researcher

Colorectal cancer screening – it's your choice

What affects the risk of colorectal cancer within ten years?	What are the benefits of screening?	What are the drawbacks of screening?	Think about it...	What are my choices?
The risk of colorectal cancer increases with age	Precancerous lesions can be removed	It may be repulsive to take a stool sample	What are my expectations?	To read the decision aid 'Colorectal cancer screening – it's your choice' to get more information and decision support
The risk of colorectal cancer is higher for men than for women	Colorectal cancer which is diagnosed before you get symptoms is easier to cure and the treatment is more gentle	Five out of 100 men who return a stool sample will be offered a colonoscopy afterwards due to occult blood in the stool. The colonoscopy may be uncomfortable	How do I feel about taking a stool sample?	To participate in colorectal cancer screening by returning a stool sample
The risk of colorectal cancer increases with the number of close relatives (parents, siblings, parents' siblings, grandparents) who have colorectal cancer. The risk is higher if most of your relatives with colorectal cancer are on the same side of the family (e.g. your mother's family), or if they had colorectal cancer before the age of 60.	Colorectal cancer screening reduces the risk of dying from colorectal cancer	There is a slight risk associated with getting a colonoscopy	How do I feel about getting a colonoscopy in case of occult blood in the stool sample?	To cancel this time and await the next round of screening
			How do I feel about the risk of getting colorectal cancer – with or without screening?	To cancel all future colorectal cancer screening invitations
Healthy living can reduce the risk of colorectal cancer <ul style="list-style-type: none"> • Exercise • Normal body weight • Limited alcohol consumption • No smoking 				

Afdeling for Folkeundersøgelser

Figure 3 One-page decision aid

guided the male focus groups. Each focus group lasted about 2 hours and consisted of two parts. The first part was a group interview based on a semi-structured interview guide, in which the participants were asked about their perception of screening in general, individual attitude to get screened, knowledge about colorectal cancer and individually perceived risk of getting colorectal cancer. At the end of the interview, the participants were asked about their immediate needs and preferences regarding information and decision support about colorectal cancer screening.

The second part of each focus group was a guided discussion in which the DA draft was introduced by the moderator, read by the participants, and discussed among them. At the end of the discussion, they were asked whether the DA had changed their perception of screening for colorectal cancer.

They were also presented with the option of additional information that could extend the DA and asked to discuss if this additional information would be useful in their decision-making process.

To minimise a potential courtesy bias, participants were explained that the moderators were independent researchers not involved in drafting the DA.

The interviews and discussions were recorded and transcribed verbatim by the two researchers who moderated the discussions.

Data analysis

The themes explored in our study came from data which were explicit in all four focus groups.

An ethnographic approach was used in a funnel-structured research cycle of ongoing questions, data production and analysis.^{19,20} This implied an iterative process in which preliminary analytic insights obtained from the first focus group were used to refine the interview guide for the next focus group. NVivo QSR International software was used to make the initial coding of the

data into categories and themes. They were compared with existing empirically based literature about DAs and cancer screening. Theory triangulation was used to strengthen the analysis by drawing on literature about public health discourses.^{21,22} The themes were discussed among the authors on a regular basis, and this process guided the final analysis of the data.

Ethics

According to Danish Legislation and the Central Denmark Region Committees on Biomedical Research Ethics, the study did not need formal ethical approval, due to the qualitative nature of the study. Similarly, the study did not require approval from the Danish Data Protection Agency as no personal information on the informants was collected. However, the study obtained informed consent from the participants and followed the ethical guidelines of the American Anthropological Association.²³

Results

Eighteen men and 20 women showed up for the focus groups. In the female groups, ages ranged from 50 to 74-years-old, with a mean of 61, and in the male groups, ages ranged from 53 to 73-years-old, with a mean of 63.

Perceptions of colorectal cancer and needs for information about screening

The majority of the participants perceived colorectal cancer as a severe disease with few or no symptoms prior to diagnosis. Colorectal cancer was described as 'tricky', as something that 'sneaks up on you' and 'strikes like lightning from a clear sky' with 'no warning signs'; and when it is discovered, 'it may very

well be too late'. Most participants expressed that their knowledge about colorectal cancer was minimal and they appreciated the opportunity to get screened:

I think it's a good thing. There are more screening programmes now, so the health authorities have to be really careful not to use scare tactics. But it's a general experience in our age group that it's becoming increasingly relevant. And I believe that statistical information confirms this. So it's a good thing that the choice is here. You can always take it or leave it. (Female focus group, Herning).

A few participants dismissed screening for colorectal cancer, arguing that they did not feel personally susceptible to colorectal cancer. They pointed out the risk of getting a false test result and felt that screening programmes triggered unnecessary worries:

As long as you feel healthy, there's no use in filling your head with worries about sickness. You should enjoy life while you're here. . . I suppose they offer these screening programmes to different people, based on which type of cancer they are most likely to get. But I could just as easily live without. (Male focus group, Herning).

Preferences for information detail

Most participants' first response to the 15-page long DA draft was that the sheer volume was overwhelming, and the information overload hindered their decision-making:

Who would want to read all that? This is too much. My mind starts wandering and then it doesn't make sense anymore. To many people, this is going to be too many words, too many numbers and too much information. You just put it away before you even have time to really consider your options. (Female focus group, Aarhus).

They recommended that the DA draft should be shortened into 3–4 pages. Simple, concise information in bullet points or flow charts were preferred. They wished information about colorectal cancer and symptoms, and a list of benefits of screening. An explanation of the iFOBT screening procedure should also be included. They appreciated the one-page decision aid (figure 3) but requested a more comprehensible layout. They felt that statistical information should be kept to a minimum as it only played a minor role in their decision-making process. One in four of participants appreciated the level of detail as presented in the DA draft and said that they would read it carefully in order to make an informed decision:

Before I make up my mind, I would consider the risks of getting colorectal cancer. I would read the DA and let the information sink in properly. I wouldn't make up my mind about screening just now, but if the facts are convincing, I just might participate. If the facts are not convincing, I probably won't do the test. (Male focus group, Herning).

All participants agreed that an extended version of a DA, including detailed information about colorectal cancer and screening, should be available on the Internet and provided in leaflets by e.g. general practitioners and pharmacies.

Most participants dismissed the detailed information about colonoscopy and colorectal cancer that, they argued, should only be provided later to those with a positive screening test result. The detailed information about colonoscopy in the DA draft led some to believe that people would react with fear and might reject screening altogether:

They present you with all the risks of a colonoscopy. You don't want to receive all that. You should get that information only in

case it is relevant for you. It's simply not relevant at this point and I believe that it will only scare people away from screening. Then they'd rather not deal with it at all. (Female focus group, Herning).

The participants who wished for detailed information found the information about colonoscopy relevant to their decision to be screened:

I would want to know about that from the start. It's all part of the same package, because once you say 'yes' to screening, you have to go all the way. And then you want to know what comes next. Actually, I think it would only create uncertainty if you left out that information. (Male focus group, Aarhus).

Information in numbers and figures

Most participants struggled to make sense of the statistical probabilities in the DA draft and apply it to their own life-situation:

These comparisons are made with 1000 people. I find it difficult to keep those kinds of numbers in my head. Why don't they turn them down to 100? Then it's much easier to calculate it into something you know. I mean, we were 25 in my class at school. That means that one in 25 will get so and so. You know, that's more recognizable sizes. (Female focus group, Herning).

The participants found the crowd figures unworkable. Some misinterpreted them as depictions of cemeteries or simply patterns without any meaning. Many were also confused about the step format using the same denominator of 1000 to describe different populations and patient groups. While most participants were also dismissive about the pie charts, all agreed that the flow chart (figure 2) was an informative format.

The absolute numbers were regarded unanimously as clear and informative. In the male DA draft it read:

Each year almost 2200 Danish men are diagnosed with colorectal cancer. In other words: every day, six Danish men are told that they have colorectal cancer. Colorectal cancer is the third most common cancer in Denmark. Only prostate cancer and lung cancer are more common.

This information was described as 'finally something concrete'.

The participants agreed that the comparisons with everyday risks (such as the chance of winning the lottery or dying in a car crash) and the comic-like illustrations were confusing or even inappropriate.

Ambiguity in the DA

According to the values clarification exercise (figure 1), 33 in 38 participants were in favour of participating in the colorectal cancer screening programme. The description of the risk of false negatives and the overall risk reduction of screening led approximately one in four to temporarily express 'uncertainty', but many still asserted that it had not changed or affected their decision:

In the end, you add up all your choices and see if you want to participate or not. This exercise doesn't work for the simple reason that this is not how your decision is made (male focus group, Aarhus).

The values clarification exercise was discarded as irrelevant or superfluous by the participants.

Most participants preferred a clear recommendation from the health authorities about colorectal cancer screening, including a list of benefits and harms. However, the participants felt that the message of this DA was too ambiguous because it left them in a dilemma about participation. The DA draft carried the headline:

'Screening for colorectal cancer – it's your choice.' Many found this accentuation of individual choice intimidating:

Of course it's my own choice but I don't think they should put it like that. I feel as if it's my own fault, if I should get cancer. There's this thing with doctors; they do not take responsibility. Previously, you just did what the doctors told you to do. Nowadays, the patient is supposed to be the expert and decide what is appropriate. This [DA] is like that. The doctors say 'It's your choice', but what they're really saying is: 'We're just sitting over here, if you want anything from us, then come and get it. Otherwise stay away' (Female focus group, Herning).

The majority did not readily accept this responsibility and the pressure it put on them. They argued that the screening programme must be offered for a good reason and getting the directly mailed invitation and iFOBT kit implied a request for participation:

It's important that you have that kit sent to you. It makes all the difference, really. I was uncertain about my decision, and when I saw all the numbers [in the DA] it was just too much. In the end, I didn't feel it was necessary to participate. But I doubted this decision when I realised just how easy it is to participate. All I had to do was to take a sample and drop it in the mail. It made me think that if I got this kit, I probably would go along anyway. But if they did not send it to me, I would think that it was unimportant to participate when the risks of colorectal cancer is so low. (Male focus group, Herning).

In this way, some imagined that the iFOBT kit in itself would influence decision making and increase screening uptake.

Discussion

Three in four participants in this study preferred a DA containing brief information about prevalence, incidence and mortality of colorectal cancer as well as its causes and symptoms, presented in a simple way using e.g. bullet points. They found the DA draft's numerical risks and crowd figures confusing. The majority also felt that the information about further diagnostic procedures should not be included in the DA but only be provided to participants who should subsequently undergo a colonoscopy in case of a positive screening test. The remaining participants preferred a higher level of detail (in line with the tested draft). Most participants appreciated a flow chart depicting the course of the screening programme and a one-page decision aid (figures 2 and 3). Conversely, most participants found the comparative everyday risks and comic-like illustrations inappropriate, and a value clarification exercise was perceived as irrelevant to their decision about participation. Finally, our data showed that many participants preferred a clear recommendation from the health care authorities rather than a seemingly neutral DA.

The same-sex focus group design was chosen to create confidential settings for participants to express themselves, since experiences with health matters may be gendered and emotionally sensitive.²⁴ Still, the social interaction between participants may be affected by consensus-seeking group dynamics with high social desirability.²⁵

Lower educational attainment is typically closely linked to low sociodemographic status (SDS) and low health literacy (HL); people with lower SDS and HL have lower levels of knowledge about health care options, they experience more uncertainty when presented with information about benefits and risks, and are less likely to make informed decisions about screening.¹¹ In this study, the vast majority of participants was in favour of colorectal cancer screening and wished brief information about it, also about symptoms. It would, however, have been strengthened by a

detailed exploration of the participants' SDS (marital status, economical status and ethnicity) and exact HL levels. Such an exploration might reveal if most were married (more married men than unmarried men are in favour of screening), or if many had in fact higher levels of HL, which might explain the recurring positive attitude to health authority screening promotion.²⁶ Finally, a positive selection bias may have created more positive attitudes to screening as individuals with positive attitudes to screening may be more inclined to participate in studies such as this. However, other studies have shown that even citizens who do not participate in screening programmes also tend to hold very positive attitudes towards them.²⁷

A randomised controlled trial about colorectal cancer screening for people with lower educational attainment in Australia showed that introducing a DA had a negative effect on both attitude and uptake.¹⁰ Participants who received a DA were significantly less positive about colorectal cancer screening and had a significantly lower screening uptake than participants in the control group. Thus, the introduction of the DA ran counter to the aim of the screening programme that requires a certain level of participation to generate a positive effect on public health. This paradoxical finding pinpoints the ethical conflict inherent in DAs which was also expressed by participants in our study: the imperative to protect individual autonomy, and the imperative to ensure public health.^{28,29}

It has previously been reported that citizens with lower HL tend to refrain from making 'active' decisions, and they expect public screening programmes to take on an authoritative role and promote screening in a more direct way.³⁰ This is also in accordance with results from our study where participants expected to participate if the iFOBT kit was sent directly to them because it skipped several steps in a decision-making process.

It was proposed in a BMJ editorial to adopt a policy of informed uptake rather than informed decision-making in colorectal cancer screening. Following this argument, screening for colorectal cancer screening should be described 'within a framework that encourages adherence to recommendations'. Sending the iFOBT kit with the invitation letter strongly encourages adherence and may thus contribute to informed uptake. This adds to the above-mentioned ethical discussions about public good and autonomy.^{31–33} It is not clear how to deal with these dilemmas but it might be considered to differentiate the level of information detail, e.g. into a very brief 'quick guide' and an easily accessible extended version on the Internet. However, it still remains a challenge to tailor information to citizens with lower educational attainment.

Conclusion

Most participants in this study preferred a colorectal cancer screening DA with a low information detail and a simple framing. However, a wish for more detailed information was expressed by some participants, underpinning the need for an easily accessible extended version of a DA.

The results from this study suggest that citizens with lower attainment may have certain needs regarding information level and information load, and these needs may *not* include all the items that usually define a DA.

The results are relevant to a discussion about the purpose of a DA in colorectal cancer screening and the balance between autonomy and public good in the framing of information. Such a discussion is relevant beyond the subgroup of citizens with lower educational attainment, e.g. citizens with higher educational attainment, disabilities, etc.

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Key points

- The study identifies preferences among citizens with lower educational attainment for brief information about benefits and disadvantages, and only a minimum of risk numbers, figures or decision clarification exercises, as otherwise promoted as feasible formats to address citizens with lower educational attainment.
- The findings suggest that some citizens with lower educational attainment may expect public health authorities to promote cancer screening in a more direct way, rather than to encourage and support individual choice.
- The study raises a discussion about public health authorities' dual role in supporting public health by promoting screening, and protecting citizens' autonomy to make personal decisions about his or her own health.
- Public health policy should continuously explore new ways to accommodate information about colorectal cancer screening to different groups of citizens, and reflect upon non-discriminating ways to identify the groups.

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