Anke Steckelberg, Jürgen Kasper, Michael Redegeld, Ingrid Mühlhauser

Unit of Health Sciences and Education, University of Hamburg

Risk information – barrier to informed choice? A focus group study

Summary

Objectives: To study consumers' information needs for informed choice on colorectal cancer screening, and to develop and evaluate information material that is evidence-based and communicates benefit as well as lack of benefit and risks as natural frequencies.

Methods: Design: Focus group study; during a first round consumers' needs and attitudes were surveyed, in a second round the information material was evaluated. The study was carried out in Hamburg, Germany. Participants: 50 women and men, 40 years or older without colorectal diseases.

Results: Consumers opted for traditional information that advises and guides them. If consumers were nevertheless given evidence-based information that considers the defined criteria it evoked cognitive dissonance which consumers tried to cope with by devaluating, minimising and not noticing the information. Cognitive dissonance inhibits processing of information. Researchers are confronted with a dilemma to either respect consumers' requests or to facilitate informed choice.

Conclusion: Cognitive dissonance may be a barrier to informed choice. This should be considered when aiming at communicating risk information.

Keywords: Decision making – Evidence-based medicine – Consumer participation – Cognitive dissonance – Mass screening – Colorectal neoplasm.

High quality information is regarded indispensable for informed choice. Various criteria have been defined for patient or consumer information on medical interventions. The information should be evidence-based (Sackett et al. 2000). It should communicate prognosis of the disorder or disease if left untreated. With respect to treatment options it should inform about probability of benefit, risk of failure and harm. About tests it should communicate likelihood of positive and negative findings and the possibility of false test results (General Medical Council 1999; Bundesausschuss der Ärzte und Krankenkassen 2003). Since framing of data has an important influence on risk perception results should be presented in natural frequencies (Edwards et al. 2002; Hoffrage et al. 2000). In addition, consumers should be involved in the development of the information material (Coulter et al. 1999). A basic production process has been suggested, comprising the identification of existing beliefs, concerns and information needs of the potential users of the information (Entwistle et al. 1998a; 1998b).

The aim of the present study was to firstly explore consumers' information needs and attitudes and secondly to develop and evaluate a booklet on colorectal cancer screening following these defined criteria. We now report on the conflicts that showed up during this process and on consumers' reactions to this kind of risk information. We think these observations have not yet been sufficiently acknowledged.

Methods

The decision to apply the focus group method was mainly influenced by the researchers' intention to warrant a maximal consumers' involvement in the process of the leaflets' development. Using a questionnaire would have been more economic but did not suite as survey method due to the premature character of the research questions. Due to the intensity and the specific communication focus groups potentiate a wide spectrum of aspects and opinions to surface. In contrast, the individual interview approach would have been not only much more time-intensive but also would have lacked the information generated in group discussions (Morgan 1998). We conducted two rounds of focus group sessions between October 2001 and June 2002. The first round intended to survey what information consumers think they need to make an informed choice on colorectal cancer screening and how they like it to be presented. Thereafter, we developed a booklet on colorectal cancer

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screening. The second round of focus groups was conducted to evaluate the booklet. We planned to involve 50 consumers and took into account about 10 drop outs (Morgan 1998). We recruited 83 subjects by announcements in local newspapers, 67 willing to participate fulfilled the inclusion criteria (40 years or older, no colorectal cancer or other colorectal diseases) and were invited. 50 participants attended the first round of focus group sessions and 46 of them the second round. Each round consisted of six focus groups with seven to 10 participants and lasted about three hours. The participants covered a wide range of sociodemographic characteristics: women (n = 35), mean age (yrs ± SD) 59 ± 10.6, secondary school nine years (n = 9), secondary school 10 years (n = 20), grammar school >12 years (n = 21). 34 of the 50 participants reported to have taken part in colorectal cancer screening before.

First focus group round

To point out, that we do not aim to persuade the consumers in any direction, we gave the participants a kind of equipoise statement (Elwyn et al. 2003). In the beginning of each focus group session we stated that concerning the identified particular question there is more than one way to deal with it. We used questionnaires containing semi-structured questions that contain several possible answers and also allow adding answers that are not mentioned, open questions and group discussions to survey information needs and experiences with screening for colorectal cancer. As a preparation for the following group discussion participants were instructed to reflect their individual information needs. These topics were discussed and clustered by the group. In a second step participants rated relevance of the resulting clusters using a scale from 1 (very important) to 6 (completely unimportant). Participants' intention to take part in colorectal cancer screening or not was surveyed using one specific item.

Production of the booklet

The first round of focus groups revealed that consumers ask for different information than we intended to communicate. Consumers' information needs were included as far as they fit into the topic. However, we stuck to our intention to develop evidence-based information according to our predefined criteria. In the following we present some examples of the information provided:

"Out of 1000 persons with faecal occult blood test screening every two years over a period of 10 years, about one person has a benefit insofar as he or she does not die from colorectal cancer during this period. We do not know who this one person is."

"About 999 out of 1000 persons do not have a benefit: 993 persons would not have died from colorectal cancer within the period of 10 years even without screening, and six die of colorectal cancer in spite of screening."

The benefit of faecal occult blood screening was also presented in absolute and relative risk reductions and illustrated in a chart:

> "Usually the benefit is presented as relative risk reduction: screening with faecal occult blood test reduces deaths due to colorectal cancer by 20%."
>
> "The presentation in absolute percentages results in the following benefit: screening with faecal occult blood test reduces deaths due to colorectal cancer by 0.1%. Both presentations are possible."
>
> "What does a positive test result tell? To the age group 40 to 59 years applies: Out of 1000 persons with a positive test result, about 100 have colorectal cancer and 900 do not have colorectal cancer."
>
> "What does a negative test result tell? To the age group 40 to 59 years applies: Out of 1000 persons with a negative test result, about 1 has colorectal cancer and 999 do not have colorectal cancer."
>
> "Out of 10000 persons, who have a colonoscopy, about 30 will suffer a major bleeding, about 10 a perforation of the colon and about 2 die. The frequency of complications depends on the experience of the doctor."

The booklet in German language is available on the internet (Steckelberg & Mühlhauser 2003).

Second focus group round

In the second round we evaluated the draft regarding content, comprehensibility, readability, and presentation. The quality of each chapter and finally the whole booklet were rated on a scale from 1 (excellent) to 6 (unsatisfying). At the end of the sessions we again surveyed intentions towards screening for colorectal cancer as described before. To document the participants' perception about the attitude of the researchers towards colorectal cancer screening participants were asked what they assume the researchers suggest regarding participation in screening.

Analysis

Questionnaires were analyzed quantitatively by calculating frequencies with SPSS. The resulting pool of interest clusters of the six focus groups contained 35 different clusters. Out of this pool two researchers independently extracted a set of categories. By comparing the remaining sets of categories discrepancies were identified and solved by consensual discussion (Krueger 1998). The individual ratings of relevance on the original clusters were attributed to one of the resulting 12 categories the cluster was subsumed in. The outcome data of this analysis procedure represent consumers' perception of relevance for all 12 fields of interests.

All focus groups were documented audio-visually and as abridged transcripts. The analysis of the group discussions based on the tape recordings as well as the transcripts were performed hermeneutically to identify central and characteristic statements.

Results

Table 1 shows the transferred ratings of the relevance of the expressed information needs in the first focus group round. Consumers did not perceive our intention and still expected information that encourages participation in colorectal cancer screening. (Box 1) Even after the second focus group round, still 39 of participants (74 %) assumed researchers to promote participation in colorectal cancer screening.

The quality of the individual chapters and the complete booklet were rated rather satisfiable: complete booklet mean ± SD score: 2.7 ± 0.9 (n = 41). However, consumers' comments revealed antagonism and rejection to parts of the booklet communicating risks. The comments in Boxes 2 and 3 indicate strategies of cognitive dissonance reduction. Participants devaluated the given material by e.g., suggesting putting a whole chapter which is essential for evidence-based information into a separate booklet. (Box 2, comment no. 5). Another strategy to reduce dissonance is possible by minimising the information as e.g., shown in Box 2, comment no. 4.

In the beginning of the first session 33 of 50 (66 %) participants stated that they intended to participate in colorectal cancer screening. After the second focus group 38 of 46 (83 %) would take part in colorectal cancer screening.

Table 1 Information needs

The six most relevant topics	
Screening methods in general	1.5 ± 1.1
Therapy of colorectal cancer	1.8 ± 1.4
Prevention of colorectal cancer	1.9 ± 1.5
Nutrition	1.9 ± 1.4
Symptoms of colorectal cancer	2.0 ± 1.1
Anatomy and physiology	2.0 ± 1.0
The six least relevant topics	
Quality of screening tests	2.3 ± 1.3
Benefit and harm of screening	2.2 ± 1.6
Adverse effects of screening tests	2.2 ± 1.2
Individual risk	3.1 ± 1.8
Sources of information	2.4 ± 1.5
Sponsoring	2.9 ± 1.6

The six most relevant and the six least relevant topics rated in focus group 1
Scale: 1 (high relevance) – 6 (low relevance)
Values are means ± SD

Box 1 Participants' misunderstanding of researchers' intention

1	"I would agree that it has to be recommended to take part in screening once a year."
2	"The aim is to lower the threshold of participation in screening."
3	"I think that people have to be told that it really isn't a big deal, it just takes a couple of hours until you can be certain that you are not ill."
4	"I am interested to see how people can be motivated to have a screening test."
5	"Why and what for do I have to know all this?"
6	"This kind of information could be summarized in a special leaflet for interested readers."

Box 2 Comments on the presentation of test quality of faecal occult blood test and benefit vs lack of benefit of faecal occult blood test screening programmes

1	"There is too much emphasis on the fact that a lot of people do the test and are not ill and therefore would not have had to do the test. The booklet is wonderful to read and comprehensible but the whole impression is negative. Is there any use in participating or can one just save time? There is too much emphasis that many people did the test without benefit, but there always is a benefit because you get the certainty."
2	"I do not understand the whole thing, why is there just one person who has a benefit?"
3	"If someone reads that there is just 1 person out of 1000 who has a benefit, he will turn over right away."
4	"You should write: it is the most harmless one can do, it does not hurt, does not cost any time and therefore it does not matter that the effect is rather small."
5	"We could put this information (the whole chapter) into a separate booklet addressing the interested reader."
6	"Well, I will not participate if I read up to page 18. I would say the benefit is too small. But that is not the aim of the booklet."
7	"Having doubts about the benefit this does not help me. I would like to read something positive but not that 999 have no benefit. Therefore I would not do the test. I just do it because I know that it surely is helpful."

Box 3 Comments on the presentation of colonoscopy

1 “If I read about complications of screening tests beforehand I would not have the test.”

2 “Reading about screening test complications makes me worry.”

3 “There is no positive perspective on this subject.”

4 “Why can someone die? That really shocked me. I did not know anything about side effects before so I was completely shocked when I read this. We do not get clarified about that.”

5 “I will cancel my appointment (colonoscopy) next week. I do not understand this. However we shall all take part in screening (…) it frightens me to have the test.”

Discussion

Involving consumers in the process of developing evidence-based information on colorectal cancer screening revealed that consumers opted for traditional information. This induces a dilemma for researchers: Should they stick to the defined criteria for consumer information or respect consumers’ requests? As consumers were nevertheless given information that accomplished the defined criteria it evoked cognitive dissonance as an expression of consumers’ cognitive conditionality which they tried to cope with by devaluating, minimising and not noticing the information. Irrational processing occurs basically and not exceptionally.

Cognitive dissonance has been studied by social psychologists. Information which contradicts one’s attitudes generates cognitive dissonance which is expressed by feelings of tension and uncertainty (Festinger 1997; Frey 1982). It threatens the self concept. A reduction of cognitive dissonance can be achieved by irrational behaviour like observed in the study: minimizing, devaluating or not noticing the information or changing one’s attitude.

A weakness of the study is due to the focus group method especially because we did not have a random sample. The generalisability of the results remains uncertain. The accumulation of screening friendly attitudes and the assessment of the material might have been an effect of motivational selection of the sample. This motivation to participate was not surveyed but regarding the announcement in the newspaper, a selection by interest in screening might be possible. The limited generalisability however, does not question the effect itself.

Many of the participants had already taken part in colorectal cancer screening and results may vary in groups who have not yet participated in colorectal cancer screening. In addition, consumers may be different across countries. German consumers might tend more towards the paternalistic model than others. On the other hand, the assumed motivational biased selection may be discussed controversially (Schwartz et al. 2004). The authors reported a prevalent enthusiasm for cancer screening in the USA. Most adults (87%) believed that routine cancer screening is almost always a good idea (Schwartz et al. 2004).

The focus group method allowed us to observe the conflicts arising in the process of developing the information material. The occurrence of cognitive dissonance in handling medical information has been observed before; however, this finding has not been sufficiently appreciated (Coulter et al. 1998). We suggest that the phenomenon of cognitive dissonance is inherent to risk communication. Its salience and dominance in our study could be due to the consequent application of our pre-defined criteria. It might come across astonishing, that even the Cochrane review (O’Connor et al. 1999), systematically analysing the field of decision aids does not mention theoretical approaches to explain effects of non-response. However, this may result from the focus of research questions and the paradigmatic mix of studies reported: „Equipoise“ is far from being a standard axiom (Elwyn et al. 2003) in creation of evidence-based information materials. In particular the presentation of benefit as well as lack of benefit and of risks as natural frequencies is not generally used in other evidence-based information material (Pignone et al. 2000; NHS Cancer Screening 1999). In addition, the extent of emotional involvement and cognitive dissonance may vary depending on the target disease.

In our study consumers’ existing attitudes towards screening were affirmed at the end of the survey despite the presentation of the information. Similar observations have been reported in a study on prostate cancer screening that provided extensive neutral counselling. Although 93% of the participating men interpreted the information as unfavourable towards screening, 75% still intended to be tested (Farrell et al. 2002).

Similar findings were reported by Chan et al. (2003). Their finding of an extreme overestimation of certainty in the scientific evidence seems to initially block seeking the necessary information for informed choice. In addition, the findings of an international survey of women’s perceptions of the benefits of breast cancer screening found that women clearly overestimated the benefits that can be expected from mammography screening and especially women who recently took part in screening were less well informed (Domenighetti et al. 2003).

These unexpected findings may also be interpreted as a coping strategy to reduce cognitive dissonance. People who have a strong attitude towards screening will seek information that is consonant with their position and they will avoid dissonant information (Frey 1982).

Our observations raise the question whether risk information may even be a barrier to informed choice. It may not be possible to communicate evidence-based information in a context where consumers expect advice and guidance or in case of strong preattitude.

It should be examined whether the theory of social psychology on cognitive dissonance is suitable for an approach to address biases of irrationality in the development process of consumer information. Further research should consider these findings if we really aim at facilitating patient participation and informed choice.

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Zusammenfassung

Risikoinformation – Hindernis für die informierte Entscheidung? Eine Fokusgruppenstudie

Fragestellung: Es werden die Informationsbedürfnisse von Verbrauchern zur informierten Entscheidung zur Darmkrebsfrüherkennung untersucht und Informationsmaterial entwickelt und evaluiert, welches evidenz-basiert ist und sowohl den Nutzen als auch den fehlenden Nutzen und Risiken in natürlichen Häufigkeiten darstellt.

Methoden: Studiendesign: Fokusgruppenstudie; in der ersten Diskussionsrunde wurden die Informationsbedürfnisse und Einstellungen der Verbraucher erhoben, in der zweiten Runde wurde das Informationsmaterial evaluiert. Die Studie wurde in Hamburg, Deutschland, durchgeführt. Teilnehmer: 50 Frauen und Männer, 40 Jahre und älter ohne Darmerkrankungen.

Ergebnisse: Die Verbraucher wählten traditionelle Informationen aus, die Ratschläge und Anleitung geben. Wenn Verbrauchern dennoch evidenz-basierte Informationen vorgelegt wurden, die die definierten Kriterien berücksichtigten, wurde kognitive Dissonanz evoziert, die die Verbraucher durch Abwertung, Minimierung und Nicht-Zur-Kenntnisnahme versuchten zu bewältigen. Kognitive Dissonanz hemmt die Informationsverarbeitung. Die Forscher sind mit dem Dilemma konfrontiert, entweder die Forderungen der Verbraucher zu respektieren oder aber die informierte Entscheidung zu fördern.

Schlussfolgerungen: Kognitive Dissonanz könnte ein Hindernis für die informierte Entscheidung sein. Dieses sollte berücksichtigt werden, wenn Risikoinformationen kommuniziert werden sollen.

Résumé

Information de risque: obstacle pour la décision ìnformée? Une étude de focus groups

Objectifs: Etudier quelles sont les informations nécessaires aux consommateurs pour que ces derniers soient en mesure de prendre une décision informée face au dépistage du cancer colorectal. Développer et évaluer un matériel évidence-basée sur les données probantes et qui mette en évidence aussi bien les avantages que les risques.

Méthodes: Etude par focus group: dans un premier temps, les besoins en matière d'information et les attitudes des consommateurs ont été identifiés; dans un second temps, le matériel informatif a été évalué. L´étude a été conduite à Hambourg (Allemagne), avec 50 femmes et hommes, âgés de 40 ans et plus sans maladie colorectale.

Résultats: Les participants ont préféré les informations traditionelles (conseils et information). Lorsqu'ils sont quand même données des information évidence-basée, dissonance cognitif était suscité, que ces personnes ont essayé de minimiser ces informations ou de les ignorer. Les enquêteurs sont donc confrontés au dilemme suivant: respecter les demandes des consommateurs, ou promouvoir la décision informée.

Conclusions: Le dissonance cognitif peut être un obstacle pour la décision informée. Ce point devrait être pris en compte lors de toute communication.

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References

Bundesausschuss der Ärzte und Krankenkassen (2003). Richtlinien des Bundesausschusses der Ärzte und Krankenkassen über die Früherkennung von Krebserkrankungen („Krebsfrüherkennungs-Richtlinien“). Dtsches Ärztebl *11*: 518–21. http://www.aerzteblatt.de/v4/archiv/artikel.asp?id=34420

Chan ECY, Vernon SW, O’Donnell FT, Ahn C, Greisinger A, Aga DW (2003). Informed consent for cancer screening with prostate-specific antigen: how well are men getting the message? Am J Public Health *93*: 779–85.

Coulter A, Entwistle VA, Gilbert D (1998). Informing patients: an assessment of the quality of patient information materials. London: King’s Fund.

Coulter A, Entwistle VA, Gilbert D (1999). Sharing decisions with patients: is the information good enough? BMJ *318*: 318–22.

Domenighetti G, Avanzo de B, Egger M, et al. (2003). Women’s perception of the benefits of mammography screening: population-based survey in four countries. Int J Epidemiol *32*: 816–21.

Edwards A, Elwyn G, Mulley A (2002). Explaining risks: turning numerical data into meaningful pictures. BMJ *324*: 827–30.

Elwyn G, Edwards A, Wensing M, Hood K Atwell C, Grol R (2003). Shared decision making: developing the OPTION scale for measuring patient involvement. Qual Saf Health Care *12*: 93–9.

Entwistle VA, Sheldon TA, Sowden A, Watt IS (1998a). Evidence-informed patient choice. Int J Technol Assess Health Care *14*: 212–25.

Entwistle VA, Watt IS, Davis H, et al. (1998b). Developing information materials to present the findings of technology assessments to consumers. Int J Technol Assess Health Care *14*: 47–70.

Farrell MH, Murphy MA, Schneider CE (2002). How underlying patient beliefs can affect physician-patient communication about prostate-specific antigen testing. Eff Clin Pract *5*: 120–9.

Festinger L (1997). A theory of cognitive dissonance. Stanford: Stanford Univ. Press.

Frey D (1982). Different levels of cognitive dissonance, information seeking, and information avoidance. J Pers Soc Psychol *43*: 1175–83.

General Medical Council (1999). Protecting patients, guiding doctors: seeking patients consent: the ethical consideration. www.gmcuk.org/global_sections/search_frameset.htm

Hoffrage U, Lindsey S, Hertwig R, Gigerenzer G (2000). Communicating statistical information. Science *290*: 2261–2.

Krueger RA (1998). Analyzing and reporting focus group results. Thousand Oaks: Sage.

Morgan DL (1998). The focus group guidebook. Thousand Oaks: Sage.

NHS Cancer Screening (1999). www.cancerscreening.nhs.uk/colorectal/ pilot.html.

O’Connor, Rostom A, Fiset V (1999). Decision aids for patients facing health treatment or screening decisions: systematic review. BMJ *319*: 731–3.

Pignone M, Harris R, Kinsinger L (2000). Videotape-based decision aid for colon cancer screening. Ann Intern Med *133*: 761–9.

Sackett DL, Straus SE, Richardson WS, Rosenberg W, Haynes RB (2000). Evidence-based medicine: how to practice and teach EBM. Edinburgh: Churchill Livingstone.

Schwartz LM, Woloshin S, Fowler FJ, Welch HG (2004). Enthusiasm for cancer screening in the United States. JAMA *291*: 71–8.

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Address for correspondence

Anke Steckelberg
Unit of Health Sciences and Education
University of Hamburg,
Martin-Luther-King Platz 6
D-20146 Hamburg
Tel.: +49 40 42838 3528
Fax: +49 40 42838 3732
e-mail: ASteckelberg@uni-hamburg.de