



## Risk communication

## “There is nothing to worry about”: Gynecologists’ counseling on mammography

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## ABSTRACT

**Objective:** In Germany, approximately 10 million women between the ages of 50 and 69 are eligible for biennial mammography screening. Mammography is at the center of much controversy, however, which means gynecologists must provide women considering mammography with sufficient and transparent information. The present study analyzed the information gynecologists share with a person seeking advice about the benefit and harms of mammography screening.

**Method:** To receive realistic data, we called 20 gynecologists practicing in different large cities across Germany and took telephone counseling sessions on the benefit and harms of mammography.

**Results:** The majority of gynecologists described mammography as safe and scientifically well grounded. Harms were rarely mentioned or described as negligible. A minority of gynecologists provided numerical information; when they did, they often quantified the benefit using relative risk reduction and harms using absolute risk increase.

**Conclusion:** A sample of German gynecologists was not able to correctly and transparently communicate the benefit and harms of mammography screening to a patient.

**Practice implication:** Gynecologists should be taught how to understand and transparently explain medical risk information in simple terms.

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## 1. Introduction

## 1.1. Screening for breast cancer

Breast cancer is a leading cause of death in women, which mammography screening is hoped to attenuate by enabling early detection. Several Western countries recommend mammography for women 40–50 years of age and older, although much controversy surrounds the effectiveness of this screening due to a delicate balance between the benefit and harms [1,2]. In November 2009, the United States Preventive Services Task Force (USPTF)—a panel of independent experts—reversed a long-standing guideline for mammography in the United States, which recommended starting annual screening at the age of 40. Because mammography causes considerable overdiagnosis and overtreatment, the panel now recommends starting the screening at age 50 and screening less frequently—biennially rather than annually.

If the benefits of a medical intervention do not clearly outweigh its harms, every patient considering such an intervention should receive sufficient information on it. In the classical view of shared

decision-making [3], this knowledge is held by clinicians, who are urged—even mandated—to share it with their patients and help them make an informed decision.

Our article deals with the information that gynecologists share with a medically unsophisticated person seeking information about the benefit and harms of mammography screening. We conducted our study 2 years after an exhaustive Cochrane review on mammography screening was published [2]. Four questions were addressed: Do gynecologists provide correct information on a woman’s risk of actually having cancer? What do gynecologists tell a patient about the benefit of mammography screening? Do gynecologists provide information on harms? Are the benefit and harms quantified in a transparent way that patients can understand?

## 1.2. The risk of having cancer

An investigation of 58 pamphlets informing women about mammography in Australia [4] found that the majority (35, or 60%) included information about the lifetime incidence (assuming a person lives to reach the age of 85), but none included information on the risk for different age groups of actually having breast cancer (prevalence). Naturally, lifetime incidence looms large and thus contributes to increased anxiety among patients. This measure has also been criticized for being abstract and hard to comprehend [5,6]. If a campaign truly aims at providing patients with a transparent idea of how big the cancer threat is, the information of

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choice should be the actual risk of having a specific cancer at a specific age—the prevalence. For instance, in Germany, the risk of a 50- to 69-year-old woman actually having cancer is about 1.5% (<http://www.berlin.de/gkr/>). Prevalence is a less abstract figure than lifetime incidence and sets the threat of the disease in context. In addition, it is this number that is needed for calculating the chance of actually having cancer after a positive test result.

### 1.3. What is the benefit of mammography screening?

The goal of screening is to reduce mortality, both disease-specific and overall mortality. In 1996, results of four randomized trials on mammography screening including approximately 280,000 women [7] showed that of 1000 women between the ages of 50 and 69 three died of breast cancer in the group attending screening for 10 years, and four died of breast cancer in the group not attending screening. Further analysis showed similar effects: the breast cancer mortality decreased from 5 to 4 women out of 1000 in favor of the screening group [8]. In 2006, a subsequent Cochrane review of these and further randomized controlled trials carried out in North America and Europe showed the absolute risk reduction to be smaller. It was now estimated that mammography screening would save only one woman in 2000 (11 vs. 10 in 2000) [2]. In all reviews, analyses did not show a reduction of the overall mortality; that is, compared to the nonscreening group, in the screening group approximately one less woman out of 1000 died from breast cancer, but one more woman out of 1000 died from another cause.

### 1.4. What are the harms of mammography screening?

Screening can be harmful—a fact that is rarely recognized by patients. Asking a stratified sample of 479 American women, Schwartz et al. [9] found that very few had ever heard of potential harms except from false positives. Ninety-two percent believed that mammography could not harm a woman without breast cancer. Only 7% agreed that some breast cancers grow so slowly that they would never affect a woman's health, and only 6% had ever heard of ductal carcinoma in situ—a breast cancer abnormality that can be picked up by mammogram but that does not always become invasive.

#### 1.4.1. Misses and false alarms

Women who attend screening risk receiving false results. On the one hand they may receive negative mammogram results although they actually have breast cancer—a so-called miss. Of 100 women with breast cancer, mammography will miss detecting about 10 women, depending on the women's age. Although misses do not lead to direct and invasive harm to a woman, they provide a

woman with the illusion of certainty of being free of breast cancer. Such an illusion may at worst make women less attentive to physical symptoms of breast cancer. On the other hand, women may receive positive mammogram results without having breast cancer—a so-called false alarm. For 1000 women attending mammography screening regularly for 10 years, between 50 and 200 women will receive at least once a false alarm that results in an invasive biopsy [10].

#### 1.4.2. Overdiagnosis and overtreatment

Probably the worst harm of mammography is that it leads to overdiagnosis and overtreatment of cancers never destined to cause symptoms or death. The extent of overdiagnosis and overtreatment due to mammography screening has been estimated: For every women saved (1 in 2000), 10 healthy women will be overdiagnosed with breast cancer [2] and overtreated by lumpectomy, mastectomy, or other treatments. Overdiagnosed women experience no benefit from screening—they experience only the anxiety of unnecessary diagnosis and the harm of unnecessary treatment.

#### 1.4.3. Danger from radiation

Mammography works by X-rays. It has been estimated that within a group of 10,000 screened women there will be between one and five additional breast cancer cases caused by X-rays [11].

### 1.5. How to communicate benefit and harms transparently

The benefit and harms of mammography screening can be explained in different “currencies.” One way would be to talk about the reduction or increase of risk in terms of verbal qualifiers. For example, one could say, the risk of mammography is negligible. Because verbal qualifiers are often vague, however, they produce considerable individual variation in the understanding and interpretation of the information [12,13]. If people are meant to understand the true effect of screening, they need numbers [14]. But a specific numerical format can also have shortcomings. For example, the benefit of mammography can be presented as an absolute risk reduction, which would read: Mammography reduces the risk of dying from breast cancer from approximately 5 to 4 women in 1000; that is, 1 woman will be saved from dying from breast cancer. The same information can also be communicated as a relative risk reduction, which would be 20% for the reduction from five to four women, or 25% for the reduction from four to three women. In contrast to absolute risk, relative risk often produces big numbers, which makes the benefit appear larger and more persuasive [15–17]. A review of experimental studies clearly showed that many patients do not understand the difference

**Table 1**

Basic information about breast cancer and mammography screening: while lifetime incidence, relative risk information, and verbal qualifiers confuse people's perception of medical risks, prevalence of a disease for respective age groups and absolute risk help people make sense of medical facts.

Key information	Nontransparent and misleading information (relative risk; verbal qualifiers)	Transparent information (absolute risk)
Risk of breast cancer at a certain age	Lifetime incidence, e.g., 10%, or verbal qualifier, e.g., the risk is high	Prevalence for a specific age group, e.g., 15 in 1000 (1.5%) women aged 55
Effect of mammography screening over 10 years for women aged 50–69		
Benefits		
Reduction of breast cancer mortality	20–25%, or verbal qualifier, e.g., to claim that mammography prevents many deaths from breast cancer	1 less in 1000 screened women (from 5 to 4)
Reduction of overall mortality	Verbal qualifier, e.g., to claim that mammography achieves it	0 in 1000 women
Risks		
Misses	Verbal qualifier, e.g., misses do not occur	10 in 100 screened women <i>with</i> breast cancer
False alarms (resulting in biopsy)	Verbal qualifier, e.g., false alarms do not occur	50–200 in 1000 screened women
Overdiagnosis and overtreatment	Verbal qualifier, e.g., the risk is small or does not exist	5 in 1000 screened women
Breast cancer from X-rays	Verbal qualifier, e.g., the risk is small or does not exist	1–5 in 10,000 screened women

between relative and absolute risk reduction and highly overestimate the benefit if expressed in terms of relative risk reduction [18].

Without an accurate sense of how well mammography screening works, women cannot begin to make informed decisions. Verbal qualifiers and relative risk do not help to achieve this goal; absolute numbers, in contrast, do [5,19,20]. Fortunately, there is growing evidence that people can understand numbers if they are presented clearly [14,21] (Table 1).

### 1.6. Counseling on mammography screening in Germany

In 2002, the German Ministry of Health introduced biennial mammography screening to the approximately 10 million women in Germany between the ages of 50 and 69. Until then, mammography was only covered by health insurance if there was a suspicion that a woman might have breast cancer. Now women between the ages of 50 and 69 receive a written invitation every 2 years to attend mammography screening. The introduction of the program received high praise from German breast cancer survivor groups and is considered a flagship program by the German Medical Association. Considering the large number of women now invited to attend mammography screening it seems evident that gynecologists should be prepared to adequately counsel these women about the uncertainties involved.

## 2. Methods

We deliberated at length on the appropriate method for revealing the counseling behavior as realistically as possible. Questionnaires and other paper-and-pencil methods were ruled out as they tell little about actual counseling sessions. For instance, these methods do not allow physicians to pose their own questions in order to get further information or to use their own estimates of the relevant statistical information rather than those provided by the experimenter. These methods also remove the element of actual concern for the patient, because either the patient is fictional or the case was resolved years ago [22,23]. In addition, many physicians are not comfortable with the idea of having their knowledge tested. We thus decided to take a more direct approach and contact gynecologists personally. Because neither of the authors was a 50-year-old or older woman, we decided to take telephone counseling sessions. For this, we contacted gynecologists' practices and made an appointment for telephone counseling. When the actual telephone counseling took place, one of us told the gynecologist the following story: The client's mother had received an invitation to attend mammography screening but doubted its effectiveness. The client, in contrast, believed that attendance might be advisable and wanted to learn in more detail about both its benefit and its harms. The mother was described as a 55-year-old woman with no history of breast cancer in her family and without any symptoms.

Because it was important to us that we elicit counseling behavior that a medically unsophisticated patient would experience, we refrained from overly elaborate questions and asked only three questions in the telephone sessions (unless the gynecologists provided the information unprompted):

- (1) What is the actual risk of my mother having breast cancer?
- (2) What is the benefit of mammography screening?
- (3) Are there any harms?

A pilot study with three gynecologists indicated that if the caller asked a question more than once, the gynecologists were likely to become irritated. There are various potential reasons for this reaction, one of which might be that clinicians do not often experience patients insisting on clarification. Thus, patients who do so may violate the norm of patient–doctor communication.

Based on these pilot sessions, the scheme of the interview was as follows: If the answer was qualitative (e.g., “mammography reduces deaths from breast cancer”) or if a gynecologist misunderstood or avoided answering the question, then the caller asked once more for further clarification. If this attempt was also unsuccessful, the caller did not push any further but went on to the next question. If the answer was a quantitative estimate (e.g., number for benefit) or if the gynecologist said that he or she did not know a precise answer, the caller moved straight on to the next question. Gynecologists' answers on each of the questions were coded during the telephone counseling session using the coding scheme found in the Appendix. We considered the gynecologists to have given complete information if they provided all the information shown in Table 1. Information was considered transparent if it was given as prevalence and absolute risk.

## 3. Results

Altogether, 20 gynecologists practicing in hospitals or teaching hospitals in different large German cities (>500,000 inhabitants) were involved in the study. In deference to the German privacy law, we did not record any personal data about our participants (see Section 4.3 for more details on ethical consideration).

### 3.1. Risk of having cancer

To the question of the mother's risk of actually having cancer at her age, 9 of the 20 gynecologists provided information. Three of the nine gynecologists only stated qualitatively that breast cancer is the most common cancer in women. The other six quantified the risk with numbers: Whereas one gynecologist explicitly said that the actual risk of the 55-year-old mother having cancer is about 25.4%, the other five said that her risk of having cancer is about 10%—an estimate that is likely inspired by the 10% lifetime incidence of breast cancer in Germany. Thus, instead of providing us with information about the actual risk of a 55-year-old woman having cancer (1.5% in Germany), most of the gynecologists who answered the question used the problematic lifetime incidence, leaving the impression that the actual risk is high.

### 3.2. Benefit of mammography screening

When asked about the benefit of mammography screening, 17 gynecologists strongly recommended it, emphasizing that it is a safe and scientifically well-grounded intervention. Of these, seven referred to the disease-specific mortality and quantified it in terms of a relative risk reduction. Numbers ranged from 20% to 50%, with a majority estimate of 25%, which corresponds to the results of the early review by Nyström et al. [7] that found a reduction of breast cancer death from 4 to 3 women in 1000 in favor of the screened group.

Another gynecologist claimed that mammography screening can reduce incidence, referring to studies from the Netherlands; a further gynecologist said that it is not clear whether mammography saves lives at all. Only one gynecologist spoke against mammography saying that its detection rate (sensitivity) is not high enough, recommending instead the more sensitive sonography, which is not reimbursed by German health insurance plans. Apart from the one gynecologist who said that it is unclear whether mammography saves lives at all, none of the gynecologists commented on mammography's effect on overall mortality.

### 3.3. Harms of mammography screening

When asked about harms, eight gynecologists described mammography screening merely as harmless without any

specification. Five others brought up the potential danger of radiation. Three of these five gynecologists described this danger only qualitatively, as “negligible.” Two provided numbers for the risk of getting radiation-induced breast cancer, which was specified as one woman in 26,000 and one in 10,000, respectively. Eight gynecologists brought up the possibility of false results. Of these eight, five mentioned false alarms (false positives)—an event that they described qualitatively as “negligible” and “harmless.” The other three brought up misses (false negatives), and one of them quantified the miss rate of mammography screening as being between 10% and 60%. All three of these gynecologists recommended further tests such as magnetic resonance imaging (MRT) and sonography. None of the gynecologists mentioned the risk of being overdiagnosed and overtreated due to mammography screening.

### 3.4. How is risk information communicated?

A minority of gynecologists provided numbers to communicate the actual risk of having cancer or the benefit and harms of mammography, most of which were incorrect. For the benefit, only 7 out of 20 gynecologists provided numerical estimates, and only 3 provided numerical estimates of specific harms. In these cases, however, numbers on the benefit and on the harms were often communicated in different currencies. Whereas relative risk reductions (big numbers) were used to inform about the benefit, absolute risk increases (small numbers) were used to inform about the harms. We call this phenomenon *mismatched framing* [20]. One gynecologist's responses illustrate this phenomenon: First, he told us that the caller's mother's present risk of having cancer is 10% (which, however, is the lifetime incidence). He then informed us that by attending screening, her mother could reduce her risk of dying from breast cancer by 25% (relative risk reduction). For the harms, he only mentioned the potential harm of radiation exposure, which he quantified as one in 10,000 (absolute risk increase).

If gynecologists were sufficiently trained in how to present and communicate medical risks, neither the reporting of lifetime incidence nor mismatched framing should have taken place. In an ideal world, a gynecologist would communicate the requested facts in the following way:

*Risk of actually having cancer:* A 55-year-old woman's risk of actually having breast cancer is 1.5%. That is, if you imagine 1000 women at that age, approximately 15 will have breast cancer and 985 will not have breast cancer.

*Benefit of mammography screening:* Mammography can reduce breast cancer mortality. Right now it is estimated that mammography reduces women's chances of dying from breast cancer from approximately 5 to 4 women out of 1000 if regularly administered for 10 years. That is, around 1 woman out of 1000 will be saved from dying from breast cancer. However, the overall mortality does not differ between the group of women who attend mammography screening and the group who do not. That is, in the screening group one more woman will die from another cause compared to the nonscreening group.

*Harms of mammography screening:* Like every form of cancer screening, mammography screening entails harms such as the risk of false results and potential overdiagnosis and overtreatment. Imagine again 1000 women who attend mammography screening regularly over the course of 10 years. Of these women, between 50 and 200 will receive a false alarm at least once, resulting in unnecessary biopsy. Approximately five healthy women will be overtreated for breast cancer. Also, of the approximately 15 women having breast cancer within a group of 1000, the mammography will miss detecting between

one and two cases. Because mammography works on X-rays, mammography may also cause additional breast cancer, with less than one expected case per 1000 women.

### 3.5. Where does nontransparent medical information come from?

Kurzenhäuser's investigation of 27 German pamphlets on mammography [24]—available to gynecologists and patients alike—may reveal some parts of the problem: The information reported most often in these brochures was lifetime incidence (10 pamphlets) and harms from X-rays (12 pamphlets). Information on other harms and on the benefit were scarce. Only 5 of the 27 pamphlets reported information on the reduction of breast cancer mortality, and only 3 of these 5 did so in a transparent format. None of the pamphlets said anything about a reduction of overall mortality. The risk of overdiagnosis and overtreatment was only mentioned in three pamphlets. Although a few transparent pamphlets have emerged since then in Germany, not too much has changed since that investigation in 2003 [25].

Leading medical journals also seem to be a source of nontransparent medical information. Of 359 articles published in *Annals of Internal Medicine*, *British Medical Journal (BMJ)*, *Journal of the American Medical Association (JAMA)*, *The Lancet*, and *The New England Journal of Medicine*, only 25 reported absolute risk reduction [26]. Another analysis of *BMJ*, *JAMA*, and *The Lancet* from 2004 to 2006 found that one in three studies used mismatched framing and did not report the benefit in the same metric as the harms [27]. Brochures and articles such as these will make neither gynecologists nor patients any wiser but instead will impede informed decision-making.

## 4. Discussion and conclusion

### 4.1. Discussion

The findings of our study show that a sample of German gynecologists are not prepared to inform patients correctly and transparently about their actual risk of having breast cancer and the benefit and harms of mammography. Although all gynecologists appeared motivated and concerned with sufficiently answering our questions, they lacked information as well as knowledge of how to communicate information on medical risk. The following key problems were identified in this study:

- (1) On the question of a woman's risk of actually having cancer (prevalence), gynecologists provided either qualitative information (most common cancer) or information on a woman's lifetime incidence.
- (2) Most gynecologists expressed medical risk information in verbal (qualitative) qualifiers rather than in quantitative terms.
- (3) For the benefit of mammography, only one gynecologist mentioned its effect on overall mortality.
- (4) If the disease-specific benefit was quantified, it was done so in the nontransparent format of a relative risk reduction.
- (5) None of the gynecologists informed the caller about all potential harms of mammography. In fact, the majority left the impression that harms are “negligible.”
- (6) On the few occasions that gynecologists provided quantitative information on benefit and harms, most used mismatched framing.

### 4.2. Conclusion

The present study used a convenient sample of 20 German gynecologists, thus we do not know how representative these

results are for the counseling on mammography of other gynecologists in Germany or in other countries. Our study appears to be the first of its kind, which is surprising given the high use of mammography in Western countries. Yet, our results are consistent with findings of a representative study in nine European countries that investigated women's and men's understanding of the benefit of mammography and PSA screening [28]. Across these countries, frequent consulting of physicians was associated with a higher overestimation of the benefit of these screenings, and the overestimation was highest in Germany. The findings of our study may shed some light on what prompted these overestimations, while the findings of the European study suggest that nontransparent counseling is not confined to our sample.

#### 4.3. Ethical considerations

Investigating gynecologists' performance without their knowledge raises ethical concerns, which is why we requested the ethical approval for the study from the Ethics Board of the Max Planck Institute (MPI) for Human Development. For a comparable study, one of the authors (GG) additionally contacted the Ethics Committee of the German Association of Psychology to obtain their opinion on undercover studies in the context of medical counseling. The Ethics Committee informed the author that the expected utility of such a study could justify deceiving counselors as public medical counseling is public behavior. Potential and unwanted shortcomings of doctors' counseling can pose a risk to patients' physical and emotional well-being. An unbiased evaluation of the counseling quality of gynecologists should, thus, be of high public interest. Nevertheless, in deference to the German privacy laws, we decided not to record the telephone sessions on tape and not to record any private or personal information about the gynecologists in order to protect their anonymity. We apologize to all of the gynecologists for using this covert method, but believe that the results of our study justify this approach because it reveals which improvements need to be made in future mammography counseling.

#### 4.4. Practice implications

The lesson of our study is that teaching gynecologists and physicians in general how to understand and transparently explain medical risk in simple terms is important. Neither in Germany nor in the United States is risk communication an obligatory part of curricula in medical schools [29]. The consequences of this negligence are reflected in several studies that found many doctors of different specialties suffer from statistical illiteracy (e.g. [30–34]), which in turn makes them unlikely to provide transparent numerical risk information to their patients. From our own experience in teaching doctors, we know that it takes little time and expense to teach them the difference between absolute and relative risk, and to make them aware of the phenomenon of mismatched framing. We hope that studies such as ours will raise awareness in medical associations of the existing problem. The subject of risk communication, eventually, needs to make its way into medical curricula so that doctors can be taught how to truly inform their patients.

#### Conflict of interests statement

The authors declare no conflict of interest.

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*Contributions:* Both authors have participated in the study design, analysis, and interpretation of data and in the writing of the report and have seen and approved the final version.

#### Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at [doi:10.1016/j.pec.2010.07.025](https://doi.org/10.1016/j.pec.2010.07.025).

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