



Risk communication

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

Odette Wegwarth^{a,b,*}, Gerd Gigerenzer^{a,b}^a Max Planck Institute for Human Development, Germany^b Harding Center for Risk Literacy, Germany

ARTICLE INFO

Article history:

Received 14 January 2010

Received in revised form 15 July 2010

Accepted 17 July 2010

Keywords:

Informed decision-making

Mammography screening

Risk communication

Risk comprehension

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

* Corresponding author at: Max Planck Institute for Human Development, Lentzeallee 94, 14195 Berlin, Germany. Tel.: +49 30 82406 695; fax: +49 30 82406 394.

E-mail address: wegwarth@mpib-berlin.mpg.de (O. Wegwarth).

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

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