

Scarce information about breast cancer screening

An Italian websites analysis

Francesco Attena, MD^{a,*}, Mariagrazia Cancellieri, MD^b, Concetta Paola Pelullo, MD^b

Abstract

Although the public should have complete and correct information about risk/benefit ratio of breast cancer screening, public knowledge appears generally scarce and oriented to overestimate benefits, with little awareness of possible disadvantages of the screening.

We evaluated any document specifically addressed to the general female public and posted on internet by Italian public health services. The presence of false positive, false positive after biopsy, false negative, interval cancer, overdiagnosis, lead-time bias, exposure to irradiation, and mortality reduction was analyzed.

Of the 255 websites consulted, 136 (53.3%) had sites addressed to the female public. The most commonly reported information points were the false-positive (30.8% of sites) and radiation exposure (29.4%) rates. Only 11 documents mentioned overdiagnosis, 2 mentioned risk of false positive with biopsy, and only 1 mentioned lead-time bias. Moreover, only 15 sites (11.0%) reported quantitative data for any risk variables.

Most documents about breast cancer screening published on the web for the female public contained little or no information about risk/benefit ratio and were biased in favor of screening.

Abbreviations: AO = Aziende Ospedaliere - major hospitals not affiliated with the ASL, ASL = Azienda Sanitaria Locale - local health authority, PO = Presidi Ospedalieri - local hospitals affiliated with the ASL, SSN = Servizio Sanitario Nazionale - national health service.

Keywords: breast cancer screening, informed choice, mammography, overdiagnosis, prevention

1. Introduction

Although breast cancer screening has been widely studied, the efficacy and appropriateness of this intervention is still controversial within the scientific community.^[1–5] However, among the public, knowledge appears generally scarce and oriented to overestimate benefits and with little awareness of the possible disadvantages of the screening.^[6–9] The main cause of

this lack of knowledge is the scarce information conveyed to the public by health care providers or by written documents (leaflets, brochures, pamphlets).^[10–15]

This situation is caused by well-meaning but opposing concerns: the public's right to complete and correct health information versus the fear that more complete information about the risks and benefits of screening may reduce compliance. Therefore, according to the European guidelines for quality assurance in mammography screening, women should be told about both risks and benefits of the screening, to make decisions based on informed choices.^[16] For example, since September 2013, women in England invited for breast cancer screenings have received more detailed information than previously.^[17] However, although the modern view of patients encourages their greater understanding of screening, paternalistic approaches still exist.

Information about breast cancer screening derived from various sources (websites, journals, television, oncological centers, or other health organizations) is provided in varying formats (leaflets, booklets, brochures, pamphlets, technical reports), and can be directed to different audiences (public, administrators, health care providers). An analysis of invitation letters and leaflets, conducted by Giordano et al^[18] from 60 Italian breast cancer screening programs reported limited information on these documents. Now, as internet searches for health information have become increasingly common, and the share of the public who do not use the internet decreases, we have focused our study on any document specifically addressed to the general female public and posted online by the National Health Service, Italian regional health services, local health authorities, and major hospitals.

Editor: Yong Liu.

Authorship: FA, the principal investigator, designed the study, contributed to data interpretation, and wrote the article. CPP and MC contributed to data collection, performed data entry, and contributed to data interpretation. All authors have read and approved the final version of the manuscript.

The authors have no conflicts of interest to declare.

Supplemental Digital Content is available for this article.

^a Department of Experimental Medicine of the Second University of Naples,

^b School of Hygiene and Preventive Medicine of the Second University of Naples, Naples, Italy.

* Correspondence: Francesco Attena, Department of Experimental Medicine, Second University of Naples, Via Luciano Armanni, 5, 80138 Naples, Italy (e-mail: francesco.attena@unina2.it).

Copyright © 2016 the Author(s). Published by Wolters Kluwer Health, Inc. All rights reserved.

This is an open access article distributed under the Creative Commons Attribution-NoDerivatives License 4.0, which allows for redistribution, commercial and non-commercial, as long as it is passed along unchanged and in whole, with credit to the author.

Medicine (2016) 95:50(e5615)

Received: 13 May 2016 / Received in final form: 30 September 2016 /

Accepted: 17 November 2016

<http://dx.doi.org/10.1097/MD.0000000000005615>

2. Methods

2.1. Types of webpage

We analyzed any webpage specifically addressed to the general female public and posted online by the National Health Service, Italian regional health services, local health authorities, or major hospitals. We excluded technical documents specifically directed to health care personnel, but included the few documents whose audience was unclear.

2.2. Search strategy

Although Italy has a national health service (Servizio Sanitario Nazionale; SSN), each Italian region has its own regional health service (Servizio Sanitario Regionale). Therefore, organization of, and communication about, mammography services vary throughout Italy. Furthermore, each region has various local health authorities (Aziende Sanitarie Locali; ASL) and major hospitals (Aziende Ospedaliere; AO). Local hospitals (PO) were excluded as affiliated with ASL. Therefore, our search strategy included national, regional, and local levels hierarchically.

On the national level, we searched official websites of the 4 main national health institutions: Ministero della Salute, Istituto Superiore di Sanita, Agenas (Agenzia Nazionale per i Servizi Sanitari), and the Osservatorio Nazionale Screening. For regional and local information, we examined the health services section of each region's official website, and all ASL and AO official websites within each region. The search for all these websites was performed starting from engines Google. We thought this is the main strategy of Italian women. We excluded private health organizations, as an official list was not available.

2.3. Keywords

In each official website, we performed a site search using the following terms: mammografia (mammography), prevenzione dei tumori (cancer prevention), tumore della mammella (breast cancer), screening tumore della mammella (breast cancer screening), prevenzione (prevention). When there were no documents using these terms, we also conducted additional searches inside the websites.

2.4. Assessment of the health information

We evaluated the presence of information on potential harms, including false positive, false positive after biopsy, false negative, interval cancer, overdiagnosis, early diagnosis without improved prognosis as lead time bias, and radiation exposure, and potential benefits, including reduced mortality and increased survival.

Two independent reviewers assessed each of these variables as being Clear (information contained in the document is complete, clear, and understandable even to a nonexpert); Unclear (information contained in the document is vague, just mentioned or poorly explained); or Absent (information is completely missing). In addition, the presence of quantitative data (e.g., relative risk reduction, number needed to screen) was searched.

Other collected data included free of charge for examination (yes/no), justification for absence at work (yes/no), letter of invitation for each woman (yes/no), range of age, and frequency. The sites were accessed between September 15, 2014, and January 15, 2015.

The ethics committee approval was not required because the study did not involve patients.

Table 1

Information about risk/benefit ratio of breast cancer screening in websites of the Italian public health organizations.

Risk/benefit ratio	n	%	
Documents/websites	136/255	53.3	
Documents with at least 1 risk	59	43.4	
Risks	n	q	%
False positive	42	4	30.8
False positive with biopsy	2	0	1.4
False negative	27	5	19.9
Interval cancers	30	3	22.1
Overdiagnosis	11	3	8.0
Lead-time bias	1	0	0.7
Radiation exposure	40	0	29.4
Total	153	15	
Benefits			
Reduction of mortality	47	17	34.5

q=Number of websites that offered quantitative information about the indicated risk or benefit.

3. Results

Of the 255 websites we examined, 136 (53.3%) had sites addressed to female public. An overview of these sites showed very little information about the risk/benefit ratio. The most reported information was mortality reduction (34.5%); the most commonly reported risks were false positive (30.8%) and radiation exposure (29.4%). Only 11 documents reported the risk of overdiagnosis, only 2 the risk of false positive with biopsy, and only 1 lead-time bias. Seventeen websites with quantitative data about mortality reduction were detected, but only 15 had data for all risk variables. Overall, the mean of the reported risks for each document was slightly more than 1 (153/136), whereas 77 (56.6%) sites reported on no risks (Table 1).

Data were then disaggregated by type of health organization (local health authorities, hospitals, Regions) and for clarity of information (clear/unclear). Data about the national website were not reported because of the lack of documents addressed to women. Although most local health authorities (111) published documents, only 11 of the 91 hospitals published documents. Despite these very low numbers, hospitals and regional websites had more information than local health authorities websites. Although classifying this information as clear or unclear could be difficult, much of the information was considered unclear where the reported risk was not complete, difficult to understand, or presented in an inappropriately reassuring manner (Table 2).

Most health organizations (77.2%) send letters of invitation to all women and provide screenings free of charge (77.2%). Some women also received justified absences from work (5.9%). Although recommended scheduling and age classes significantly differed, the most common by far was biennial screening for women aged 50 to 69 years. We have defined those websites as "enthusiastic" (39.8%) that specially emphasized benefits of screening without mentioning risks, in an inappropriately non-neutral manner (Table 3).

4. Discussion

Our study provides a general overview of all online information from public health organizations about breast cancer screening, and addressed to the female public. Most of these webpages contained little or no information and were biased in favor of screening. False positive and exposure to radiation were the most

Table 2
Information about risk/benefit ratio disaggregated by health organization type.

Risk/benefit ratio	Local health authorities		Hospitals		Regions	
	Documents/websites	111/144	77.0%	11/91	12.0%	14/20
Risks	n (U)	%	n (U)	%	n (U)	%
False positive	32 (17)	28.8	4 (2)	36.4	6 (1)	42.8
False positive with biopsy	1 (1)	0.9	1 (1)	9.1	0	0.0
False negative	16 (4)	14.4	4 (0)	36.4	7 (1)	50.0
Interval cancer	22 (6)	19.8	3 (1)	27.3	5 (1)	35.7
Overdiagnosis	5 (1)	4.5	4 (1)	36.4	2 (1)	14.2
Lead time bias	0	0.0	1 (0)	9.1	0	0.0
Radiation exposure	35 (2)	33.3	1 (0)	9.1	4 (0)	7.1
Benefits						
Reduction of mortality	35 (0)	31.5	5 (0)	45.5	7 (0)	50.0

U (Unclear)=information contained in the document is vague, just mentioned or poorly explained.

reported risks; interval cancer, overdiagnosis, and lead-time bias were scarcely reported.

This lack of information for women who must make decisions about mammography is a much-debated issue. This deficiency is quite widespread in several countries, as shown in recent and less recent papers, both in websites analysis^[10,19] and in written documents (e.g., leaflets, brochures) available for women.^[12,13,18,20,21] Three possible reasons for this scarce information can be identified: fear that correct and complete information may reduce compliance to screening, self-interest, and sometimes, poor knowledge of the topic by health care providers. The possibility that fully informed patients may be less willing to undergo screening cannot justify providing them with inadequate information; moreover, no reliable data support this hypothesis, <http://links.lww.com/MD/B467>.^[22–24] We intended self-interest when the same occupational categories (rather than patients, scientists, etc.) both provide certain services and determine how useful the services are and who should receive them.^[25] For example, the Society of Breast Imaging and American College of Radiology recommends annual mammograms for women aged 40 years and older with medium risk.^[26] Finally, lack of

knowledge of the topic is attributable both to the well-known delay between research and practice, and to the consideration that most important studies on validity of screening are epidemiological, whereas clinicians who promote and perform screening usually have other expertise. Furthermore, criticism of screening for breast cancer, at least in Italy, is “politically incorrect.” However, in more recent years, several initiatives has been undertaken to provide more information to the women.^[11,16,17,24]

Although overdiagnosis has been a focus of more recent studies of mammography,^[27–30] only 11 of our subject webpages mention this risk. Overdiagnosis, besides being more recently recognized and therefore less known among healthcare providers, is probably the most harmful risk, and could thus further dissuade women. Waller et al^[23] evaluated changes in women’s intention to undergo screening in response to information on overdiagnosis, and concluded that, although intention to be screened remained high after overdiagnosis information, 5% of age-eligible women, and 8% of younger women, were less inclined to participate in screening.

Much information was categorized as unclear; possibly, information on risks could have been deliberately presented in an ambiguous or overly euphemistic manner to avoid alarming patients. Finally, the absence of quantitative information could be explained by the great difficulty of summarizing the widely variable data in the literature in a simple but accurate way that would be accessible to nonexperts.

The main limitation of our study is that we did not analyze informed consent forms given to women before undergoing mammography, which could contain more information than their corresponding websites. Also, as we excluded private treatment centers, we do not know whether they offer more or less complete information than public centers.

In conclusion, our results show that the documents posted on Italian websites do not provide correct and complete information to women who want to undergo breast cancer screening, and prevent women from making fully informed choices about their health.

References

- [1] Printz C. Mammogram debate flares up: latest breast cancer screening study fuels controversy. *Cancer* 2014;120:1755–6.
- [2] Mukhtar TK, Yeates DR, Goldacre MJ. Breast cancer mortality trends in England and the assessment of the effectiveness of mammography screening: population-based study. *J R Soc Med* 2013;106:234–42.
- [3] Fitzgerald SP. Breast-cancer screening. *N Engl J Med* 2012;366:191–2.

Table 3
General information about breast cancer screening in websites of Italian public health organizations.

General characteristics	n	%
Documents/websites	136/255	53.3
Justified absence at work	8	5.9
Free of charge test	105	77.2
Letter of invitation	105	77.2
Screening programs by age groups	N	%
50–69 y.o. biennial	71	52.2
45–74 y.o. biennial	11	8.0
45–49 y.o. annual/50–69 y.o. biennial	11	8.0
50–69 y.o.	9	6.6
45–49 y.o. annual/50–74 y.o. biennial	6	4.4
Over 50 y.o. biennial	4	3.0
50–70 y.o. biennial	4	3.0
45–69 y.o. biennial	3	2.2
No information	2	1.5
Others	15	11.1
Communication tone	n	%
“Enthusiastic”*	54	39.8

y.o.=years old.

*“Enthusiastic” websites were those that overemphasized the benefits of screening without mentioning the risks, rather than taking a neutral tone.

- [4] Duffy SW, Smith RA. More on screening mammography. *N Engl J Med* 2011;364:283author reply 285–286.
- [5] Esserman L, Shieh Y, Thompson I. Rethinking screening for breast cancer and prostate cancer. *JAMA* 2009;302:1685–92.
- [6] Waller J, Osborne K, Wardle J. Enthusiasm for cancer screening in Great Britain: a general population survey. *Br J Cancer* 2015;112:562–6.
- [7] Baena-Cañada JM, Rosado-Varela P, Expósito-Álvarez I, et al. Women's perceptions of breast cancer screening. Spanish screening programme survey. *Breast* 2014;23:883–8.
- [8] Gigerenzer G, Mata J, Frank R. Public knowledge of benefits of breast and prostate cancer screening in Europe. *J Natl Cancer Inst* 2009;101:1216–20.
- [9] Silverman E, Woloshin S, Schwartz LM, et al. Women's views on breast cancer risk and screening mammography: a qualitative interview study. *Med Decis Making* 2001;21:231–40.
- [10] Jørgensen KJ, Gøtzsche PC. Presentation on websites of possible benefits and harms from screening for breast cancer: cross sectional study. *BMJ* 2004;328:148.
- [11] Webster P, Austoker J. Does the English Breast Screening Programme's information leaflet improve women's knowledge about mammography screening? A before and after questionnaire survey. *J Public Health* 2007;29:173–7.
- [12] Gummertsbach E, Piccoliori G, Zerbe CO, et al. Are women getting relevant information about mammography screening for an informed consent: a critical appraisal of information brochures used for screening invitation in Germany, Italy, Spain and France. *Eur J Public Health* 2010;20:409–14.
- [13] Gøtzsche PC, Jørgensen KJ. The breast screening programme and misinforming the public. *J R Soc Med* 2011;104:361–9.
- [14] Gigerenzer G. Breast cancer screening pamphlets mislead women. *BMJ* 2014;348:g2636.
- [15] Moutel G, Duchange N, Darquy S, et al. GRED French National Cancer Institute Women's participation in breast cancer screening in France: an ethical approach. *BMC Med Ethics* 2014;15:64.
- [16] Perry N, Broeders M, de Wolf C, et al. European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis. 4th ed. Luxembourg: Office for Official Publications of the European Communities; 2006. Available at: http://ec.europa.eu/health/ph_projects/2002/cancer/fp_cancer_2002_ext_guid_01.pdf. Accessed January 8, 2015.
- [17] Forbes LJ, Ramirez AJ. Expert group on information about breast screening offering informed choice about breast screening. *J Med Screen* 2014;21:194–200.
- [18] Giordano L, Rowinski M, Gaudenzi G, et al. What information do breast cancer screening programmes provide to Italian women? *Eur J Public Health* 2005;15:66–9.
- [19] Ferreira D, Carreira H, Silva S, et al. Assessment of the contents related to screening on Portuguese language websites providing information on breast and prostate cancer. *Cad Saude Publica* 2013;29:2163–76.
- [20] Slaytor EK, Ward JE. How risks of breast cancer and benefits of screening are communicated to women: analysis of 58 pamphlets. *BMJ* 1998;317:263–4.
- [21] Kurzenhäuser S. What kind of information do German health information pamphlets provide on mammography screening? *Z Arztl Fortbild Qualitatssich* 2003;97:53–7.
- [22] Giordano L, Stefanini V, Senore C, et al. The impact of different communication and organizational strategies on mammography screening uptake in women aged 40–45 years. *Eur J Public Health* 2012;22:413–8.
- [23] Waller J, Whitaker KL, Winstanley K, et al. A survey study of women's responses to information about overdiagnosis in breast cancer screening in Britain. *Br J Cancer* 2014;111:1831–5.
- [24] Gummertsbach E, in der Schmitt J, Mortsiefer A, et al. Willingness to participate in mammography screening: a randomized controlled questionnaire study of responses to two patient information leaflets with different factual content. *Dtsch Arztebl Int* 2015;112:61–8.
- [25] Quanstrum KH, Hayward RAN. Lessons from the mammography wars. *N Engl J Med* 2010;363:1076–9.
- [26] Lee CH, Dershaw DD, Kopans D, et al. Breast cancer screening with imaging: recommendations from the Society of Breast Imaging and the ACR on the use of mammography, breast MRI, breast ultrasound, and other technologies for the detection of clinically occult breast cancer. *J Am Coll Radiol* 2010;7:18–27.
- [27] Jørgensen KJ. Mammography screening. Benefits, harms, and informed choice. *Dan Med J* 2013;60:B4614.
- [28] Hersch J, Barratt A, Jansen J, et al. The effect of information about overdiagnosis of breast cancer on women's decision-making about mammography screening: study protocol for a randomised controlled trial. *BMJ Open* 2014;4:e004990.
- [29] Pace LE, Keating NL. A systematic assessment of benefits and risks to guide breast cancer screening decisions. *JAMA* 2014;311:1327–35.
- [30] Paci E, Broeders M, Hofvind S, et al. EUROSCREEN Working Group European breast cancer service screening outcomes: a first balance sheet of the benefits and harms. *Cancer Epidemiol Biomarkers Prev* 2014;23:1159–63.