Scarce information about breast cancer screening
An Italian websites analysis

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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 Ospedalieri - 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.\textsuperscript{[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.\textsuperscript{[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).\textsuperscript{[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.\textsuperscript{[16]} For example, since September 2013, women in England invited for breast cancer screenings have received more detailed information than previously.\textsuperscript{[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\textsuperscript{[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.
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 Sanità, 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

| Risk/benefit ratio                  | n   | %   |
|-----------------------------------|-----|-----|
| Reduction of mortality            | 47  | 17  |
| Reduction of mortality            | 59  | 43.4|
| Reduction of mortality            | 153 | 58  |
| 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
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 and in written documents (e.g., leaflets, brochures) available for women. 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. When the same occupational categories (rather than patients, scientists, etc.) both provide certain services and determine how much information is available to women, the possibility that self-interest and the need for self-protection are important factors to be considered.

We intended self-interest and the need for self-protection are important factors to be considered. 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. 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. Although overdiagnosis has been a focus of more recent studies of mammography, 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 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.

Table 2

| Risk/benefit ratio | Local health authorities | Hospitals | Regions |
|--------------------|--------------------------|-----------|---------|
| Documents/websites | 111/144 (77.0%)          | 11/91 (12.0%) | 14/20 (70.0%) |
| Risks              | n (6)                   | n (6)     | n (6)  |
| False positive     | 32 (17)                 | 4 (2)     | 6 (1)  |
| False positive with biopsy | 1 (1) | 1 (1) | 0 (0) |
| False negative     | 16 (4)                  | 4 (0)     | 7 (1)  |
| Interval cancer    | 22 (6)                  | 3 (1)     | 5 (1)  |
| Overdiagnosis      | 5 (1)                   | 4 (1)     | 2 (1)  |
| Lead time bias     | 0                       | 1 (0)     | 0 (0)  |
| Radiation exposure | 35 (2)                  | 1 (0)     | 4 (0)  |
| Benefits           |                         |           |        |
| Reduction of mortality | 35 (0)      | 5 (0)    | 7 (0)  |

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

Table 3

| 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 |
| 45–69 y.o. annual/50–69 y.o. biennial | 11 | 8.0 |
| 50–69 y.o.              | 9  | 6.6 |
| 45–69 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.

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