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Towards more effective online information support for mammography screening decisions

Jessica Martucci^{a,*}, Harald Schmidt^b

^a University of Pennsylvania, Department of Medical Ethics and Health Policy, Perelman School of Medicine, Blockley Hall, 14th Floor, 423 Guardian Drive, Philadelphia, PA 19104-4884, United States

^b University of Pennsylvania, Medical Ethics and Health Policy, Perelman School of Medicine, Blockley Hall, 14th Floor, 423 Guardian Drive, Philadelphia, PA 19104-4884, United States

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ABSTRACT

We sought to determine the extent to which web-based patient-directed resources of U.S. public health agencies and professional groups offer consistent and relevant information on the benefits and harms of mammography screening. Between August 2016–February 2017, we identified, collected and analyzed information about mammography screening from the websites of 14 well-known governmental public health agencies and professional groups. We recorded and compared the qualitative and quantitative information the sites offered on (1) breast cancer mortality; (2) false-positive results; (3) unnecessary biopsy; and (4) overdiagnosis. Our results show considerable variation on which benefits and harms are mentioned, whether they are discussed in qualitative and/or quantitative terms, and how this information is delivered and framed. We argue that it is ethically problematic that benefit and harm information is presented in inconsistent and incomplete ways, and we suggest that organizations work towards the adoption of uniform categories to genuinely support preference-sensitive decision making.

1. Introduction

Mammography screening is widely taken to be effective in reducing the breast cancer death rate, despite conflicting data on the subject, and disagreement about the exact magnitude of breast cancer mortality reduction (Shapiro, 1977; Tabár et al., 1985; Van den Ende et al., 2017). However, as with other screenings, these benefits are accompanied by trade-offs (Kalager et al., 2012; Miller et al., 2014a; Bleyer and Welch, 2012). The primary downsides of mammography are the physical, psychological and financial harms that can stem from false positive results, overdiagnosis and overtreatment (Johns et al., 2010; Barratt et al., 2005; Baines et al., 2016). Organizations which promote mammography screening frequently overstate benefits and underplay risks (Woloshin and Schwartz, 2012). Analyses of breast cancer screening pamphlets in Europe demonstrated that these information sources can be highly directive and in tension with enabling health agency (Gigerenzer et al., 2009; Gigerenzer, 2014). Researchers have also reported recently that women are far more likely to be aware of the benefits of mammography than they are of its harms (Yu et al., n.d.).

Because of differing personal values and life circumstances, appropriately informed women in otherwise similar circumstances make

different choices about screening. For these reasons, ethicists and economists generally characterize the decision to participate in screening as one that is “preference-sensitive” (O’Connor et al., 2003). Adopting a preference-sensitive approach in the case of mammography screening requires that women have access to accurate and intelligible information about both the benefits and the risks of the procedure. Research that assesses the quality, content, and impact of information offered to women about mammography screening is sparse, but collecting these data is necessary to help ensure that women are being empowered to make informed decisions about their health (Carles et al., 2017; Esserman, 2017).

In the U.S., which lacks a centralized health agency to oversee cancer screenings, little has been done to map the information available to women on mammography harms and benefits. In an effort to begin addressing this gap, we collected and analyzed online information provided to women on the benefits and harms of mammography screening from 14 major governmental health agencies and professional groups. We located, documented, and archived the information these groups provided for the public on their websites and evaluated the information using the analytic categories provided by the U.S. Preventive Services Task Force (USPSTF) in its current breast screening

* Corresponding author.

E-mail addresses: jmartucc@penmedicine.upenn.edu (J. Martucci), schmidth@upenn.edu (H. Schmidt).

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guidelines (Siu and U.S. Preventive Services Task Force, 2016). Our findings highlight the need for groups to provide meaningful and consistent information for women contemplating mammography screening.

2. Background

Public discussion around mammography screening typically emphasizes its benefit in reducing deaths from breast cancer in order to encourage women to participate. Messaging commonly features the slogan “screening saves lives” and suggests that the test has high sensitivity and specificity (*Living Proof that Screening Saves*, 2015). The concept of “survivors” features prominently in this literature and implies that screening mammography rescues seemingly healthy women from death’s door, with every woman diagnosed with cancer otherwise condemned to certain breast cancer death. But such characterizations are both inaccurate and unhelpful oversimplifications that furthermore ignore the fact that mammography screening has been shown to have no impact on all-cause mortality (Grady and Redberg, 2017; Nelson et al., 2016; Miller et al., 2014b; Moss et al., 2006; Nyström et al., 2002; Aron and Prorok, 1986).

Internet-based health information continues to be an increasingly important tool in public outreach and health education (Hartzband, 2010). Studies on the processes of patient education highlight the important role that online information plays in disseminating basic health information to the public (Sun, 2012). 132 million Americans are online, with almost 64% seeking health information from the Internet. The Health Information National Trends Survey has found that of the nearly 40% of the U.S. population that has specifically sought out information on cancer at some point, 55.3% accessed the internet as their first and most frequent source, compared to just 24.9% who relied on their health care providers. The most common characteristics of those who sought information on cancer online were white, non-hispanic women between the ages of 35 and 64 (*Hints Briefs*, 2005; *Hints Briefs*, 2010). Despite the ubiquity of internet health information, however, critical evaluation of the information provided by professional medical organizations on common radiological practices suggests that these sites do not always provide adequately accessible, clear or consistent health information across a wide range of medical and screening procedures (National Institutes of Health, 2016; Hansberry et al., 2014; Bowden et al., 2017). Given these background data on the general accessibility and readability of online medical and radiological information, we sought to evaluate internet-based information on mammography screening for content and tone using the categories offered by the USPSTF.

3. Methods

3.1. Sampling

We evaluated publicly-available internet-based health information on mammography screening provided by major professional organizations and public health agencies with an established record of participation in mammography screening guidelines and policy discussions. For our data-set, we selected organizations and agencies involved in the USPSTF’s 2015–2016 revision of its mammography screening guidelines and identified five organizations who provided direct comment.¹ We also included a public-focused website co-hosted by one of these organizations.²

¹ AAFP/American Academy of Family Physicians, ACS/American Cancer Society, ACR/American College of Radiology, ACP/American College of Physicians, ACOG/American Congress of Obstetricians and Gynecologists.

² This yielded the website of the Mammography Saves Lives Coalition, which is jointly operated by the American College of Radiology, the American Society of Breast Disease, and the Society of Breast Imaging.

To ensure we examined other relevant sources, we conducted cited-reference searches of published guideline updates by the American Cancer Society and the USPSTF (Oeffinger et al., 2015).³ Of the 122 articles turned up by this search, we identified an additional four organizations/agencies who contributed to the ongoing discussions surrounding the guideline updates.⁴ Finally, since federal public health agencies have an established obligation to provide health information on significant health issues, we also included the Centers for Disease Control (CDC), the Department of Health and Human Affairs’ Office of Women’s Health (DHHS), and the Veterans’ Health Administration’s National Center for Health Promotion and Disease Prevention (NCHPPD). The USPSTF data were used as analytic reference points. This selection process provided us with 14 websites from government and professional organizations which we examined in detail.

3.2. Data collection and analysis

The authors and two additional research assistants separately searched for all public-oriented textual, audio and video materials regarding breast cancer screening and mammography on each organization’s website, navigating sites using tabs, headings and search masks using keywords ‘breast cancer screening’ and ‘mammography.’

We compared the available online data through the set of categories on risks and benefits derived from the 2016 USPSTF recommendation on mammography screening, included in Tables 1 and 2 (Göttsche and Jørgensen, 2013; Elwyn et al., 2006). The authors separately analyzed all materials on inclusion of information on: 1) mortality reduction, 2) false-positives, 3) unnecessary breast biopsies, and 4) overdiagnosis. We also noted whether sites provided 5) information on benefits and harms qualitatively, quantitatively, or both, and 6) identified screening start age and 7) interval recommendations. All data were collected and analyzed between August 2016 and February 2017 (archived copies are available upon request). Minor discrepancies and errors in the analysis were resolved in discussion among the authors. These compiled data are available, along with detailed information on our search paths and source links, in Supplements 1, 2 and 3.

4. Results

The Internet-based information on mammography screening varied considerably and not all the organizations we evaluated provided information the USPSTF deemed relevant. Neither the NCCS nor the ONS provided information on mammography screening. This is likely due to the organizations’ orientation to the treatment of cancer, rather than screening. Aside from the USPSTF, the remaining eleven organizations studied provided an array of risk/benefit information that varied greatly from site to site. The NCHPPD stood apart for its discussion of cancer screening in general, and while its materials were some of the most detailed in this regard, it provided little specific information about breast cancer screening. It has been evaluated and included in Tables 1–3, but the bulk of our analysis omits discussion of its materials. Information from these 10 sites differed primarily in terms of what risks and benefits were included as relevant, how the information was conveyed (i.e. in qualitative vs. quantitative terms), the depth of explanations of risks and benefits offered, and in the overall tone in which the information was provided.

4.1. Mortality reduction

Despite variation in public information across these organizations’

³ This search was completed in January 2017 to capture articles published through December 2016.

⁴ AMA/American Medical Association, NCI/National Cancer Institute, NCCN/National Cancer Care Network, Oncology Nursing Society/Oncology Nursing Society.

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