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Women's awareness of and responses to messages about breast cancer overdiagnosis and overtreatment: Results from a 2016 national survey

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Abstract

Background—Scientists, clinicians, and other experts aim to maximize the benefits of cancer screening while minimizing its harms. Chief among these harms are overdiagnosis and overtreatment. Although available data suggest that patient awareness of these harms is low, we know little about how patients respond to information about these phenomena.

Objectives—Using the case of breast cancer screening, this study assesses women's awareness of and reactions to statements about overdiagnosis and overtreatment.

Methods—We draw on data from a 2016 population-based survey of U.S. women aged 35–55 years that oversampled women of lower socioeconomic position (those living at or below 100% of federal poverty level) (N=429).

Results—Results showed that women's awareness of overdiagnosis (16.5%) and overtreatment (18.0%) was low, and women under age 40 were least likely to have heard about overdiagnosis. Most women did not evaluate statements about these harms positively: Fewer than 1 in 4 agreed with and found statements about overdiagnosis and overtreatment to be believable, and even fewer evaluated them as strong arguments to consider in their own mammography decision making. Women with a recent mammogram history were particularly unconvinced by overdiagnosis and overtreatment arguments.

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Conflicts of interest

The authors have no conflicts of interest to disclose.

Conclusions—A majority of women were unaware of two important harms of breast cancer screening: overdiagnosis and overtreatment. Most did not find statements about these harms to be believable and persuasive. Communication interventions, supported by evidence from health communication research, are necessary to improve patient understanding of screening's harms, promote informed decision making, and, in turn, ensure high value care.

Keywords

Mammography screening; Breast cancer; Overdiagnosis; Overtreatment; Health communication

Introduction

In recent years, questions about the appropriate use of cancer screening have risen to the fore, as scientists, clinicians, and other experts weigh the extent to which harms of screening may outweigh the benefits.¹ One such harm is overdiagnosis, which refers to a diagnosis of cancer that would otherwise never have caused symptoms or death in a person's lifetime.² Overdiagnosis typically gives rise to overtreatment, defined as the unnecessary use of tests and treatments. Although it is difficult to pinpoint just how common cancer overdiagnosis is—its prevalence must be estimated indirectly, based on the results of large-scale screening programs and population studies³—there is growing expert consensus that the phenomenon is real and may require a reevaluation of aggressive screening strategies. For example, a recent Danish study estimated that one-third of breast cancers detected by mammography represent overdiagnosis.⁴ Ensuring that patients understand harms such as overdiagnosis and overtreatment is central to informed decision making about cancer screening and, in turn, the promotion of patient-centered care.⁵

Yet despite increasing dissemination of information about cancer overdiagnosis and overtreatment via both news media coverage^{6,7} and health-related websites,⁸ patient awareness remains low. Recent survey studies in Australia⁹ and the UK^{10,11} found that roughly one-third to one-half of respondents had previously heard the term “overdiagnosis” or “overdetection,” though qualitative and text analyses suggest that actual understanding of these terms may be even more limited.^{10,12–14} A recent U.S. population-based survey study,¹⁵ which provided definitions of overdiagnosis and overtreatment and asked respondents whether they had heard these before, identified similarly low levels of awareness (less than 40% aware) to those reported in the recent Australian and UK studies and an older U.S. study.¹⁶

Although there have been some efforts to improve patient awareness and understanding of overdiagnosis through patient decision aids¹⁷ and mass media campaigns (e.g., Choosing Wisely¹⁸), researchers have identified a need for better communication about these issues.^{19,20} Specifically, in a recent analysis, McCaffery and colleagues (2016) called for “studies about what the public, patients, and clinicians currently know, understand, and want to know about overdiagnosis and their attitudes, reactions, and choices when provided with such information.”¹⁹, p. 3

Using the case of breast cancer screening, the current study responds to this call by asking: 1) To what extent are women aware of breast cancer overdiagnosis and overtreatment, and 2)

How do women respond to statements about overdiagnosis and overtreatment? In other words, do they find the arguments to be believable and persuasive? We draw on data from a 2016 population-based survey of U.S. women aged 35–55 years to answer these questions. Additionally, to better understand observed descriptive findings, we examine potential predictors of awareness of and reactions to statements about overdiagnosis and overtreatment, including sociodemographic (age, education, poverty status, race/ethnicity), clinical (mammogram history, breast cancer history), and health care (health insurance, usual source of medical care) characteristics. Documenting such correlates will enable us to identify subpopulations that may be important targets of interventions to promote informed decision making about screening.

Methods

Data and Sample

We use data from a 2016 population-based survey of U.S. women aged 35–55 years (N=429) administered by GfK, a survey research firm that maintains a probability-based panel of approximately 55,000 U.S. adults aged 18 and over (KnowledgePanel®). Given *a priori* interests in assessing variations along socioeconomic lines, GfK oversampled women living at or below 100% of the federal poverty level (n=222). The overall survey completion rate among eligible panelists randomly selected to participate was 51.3%. The Institutional Review Board approved this study.

Measures

Awareness of breast cancer overdiagnosis and overtreatment—Amid evidence that patient understanding of overdiagnosis and overtreatment is limited,^{10,12–14} there is reason to believe that simply asking respondents whether they have heard the terms “overdiagnosis” and “overtreatment” may lead to overreporting of awareness. We therefore presented two statements that provided definitions of overdiagnosis and overtreatment, both adapted from prior research:^{9,13,15,16} “Some breast cancers found by mammograms are so slow-growing that they would not have caused any health problems for women in their lifetime” (overdiagnosis), and “Some breast cancers that are treated (such as with surgery or medications) would not have needed such treatment after all” (overtreatment). Following each statement, we asked respondents: “Have you ever heard a statement like this before?” Response options for each statement included “yes,” “no,” and “I don’t know.” For multivariable analyses, awareness was dichotomized: yes (1) versus no/don’t know (0).

Responses to statements about breast cancer overdiagnosis and overtreatment—Using established methods to evaluate the overall perceived strength of arguments for use in subsequent health messages,²¹ we asked women to evaluate each statement about overdiagnosis and overtreatment using three adapted survey items: “This statement is believable,” “Overall, I agree with this statement,” and “This statement gives me a strong reason to think carefully about whether I will get a mammogram.” For each item, responses options ranged from “strongly disagree” (1) to “strongly agree” (5). Such items have been used in other work establishing the persuasive potential of health messages.^{22–25}

For multivariable analyses, an overall perceived argument strength scale was created for each statement. Following the methods laid out by Zhao and colleagues,²¹ we averaged the three message evaluation items to create an overdiagnosis scale ($M=2.57$, $SD=.89$, range=1–5, Cronbach's $\alpha=.80$) and overtreatment scale ($M=2.65$, $SD=.90$, range=1–5, Cronbach's $\alpha=.84$). Increasing values represent greater perceived argument strength.

Sociodemographic characteristics—Respondents were categorized into one of four age ranges: 35–39, 40–44, 45–49, and 50–55. This enabled us to assess whether women in their 30s (for whom a breast cancer diagnosis may be less salient) might differ from women in their 40s or 50s in their awareness of and reactions to statements about overdiagnosis and overtreatment. Other sociodemographic data were provided by GfK, including education (less than high school, high school, some college, Bachelor's degree or higher), poverty status (living at or below versus above 100% of the federal poverty level), and race/ethnicity (White, non-Hispanic; Black, non-Hispanic; Other, non-Hispanic; Hispanic).

Clinical characteristics—Prior experience with mammography screening and/or breast cancer history could influence women's awareness of or shape their reactions to statements about breast cancer overdiagnosis or overtreatment. To assess mammography history, we adapted a measure from the National Cancer Institute's Health Information National Trends Survey (HINTS): "When did you have your most recent mammogram to check for breast cancer?" Response options included "1 year ago or less," "more than 1 year ago, but within the past 2 years," "more than 2 years ago, but within the past 3 years," "more than 3 years ago, but within the past 5 years," "more than 5 years ago," "I have never had a mammogram," and "I don't know." For multivariable analysis, categories were collapsed into "never had a mammogram" (included don't know), "had a mammogram more than one year ago," and "had a mammogram in the past year." Breast cancer history was assessed by asking, "Have you ever had breast cancer?" Responses options included "yes," "no," and "I don't know" (collapsed into yes versus no/don't know).

Health care characteristics—Respondents without health insurance or a regular health care provider may have had fewer discussions about screening's benefits and harms, which could, in turn, shape awareness of or responses to messages about overdiagnosis and overtreatment. Both health insurance and usual source of medical care were assessed using items adapted from NCI's HINTS survey: "Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare?", and "Do you have a particular doctor, nurse, or other health professional that you see most often?" Responses options included "yes," "no," and "I don't know" (collapsed into yes versus no/don't know).

Analytic Approach

Frequency analyses were used to calculate levels of awareness and statement evaluations. Multivariable logistic regression models were estimated to predict awareness of overdiagnosis and overtreatment, and multivariable linear regression models were estimated to predict overall perceived argument strength for statements about overdiagnosis and overtreatment. All analyses were conducted in Stata 13.1 and included GfK survey weights

to adjust for potential biases in sampling and nonresponse to produce nationally representative estimates.

Results

Nearly one-quarter of women were 35–39 (22.8%), 40–44 (23.1%), and 45–49 (23.5%); 30.6% were 50–55. Just over one-third (36.3%) had a Bachelor's degree or higher, and 10.9% had less than a high school degree. Nearly half (45.6%) reported having had a mammogram in the past year; 25.2% reported never having a mammogram. A majority of women were insured (83.7%) and reported having a usual source of care (83.4%). Additional sample characteristics are provided in Table 1.

Women's awareness of overdiagnosis (16.5%) and overtreatment (18.0%) was low, and most did not evaluate the statements positively (Table 2). Fewer than 1 in 4 women agreed with and found statements about overdiagnosis and overtreatment to be believable, and even fewer evaluated them as strong arguments to consider in their own mammography decision making. Many women (29.8%–42.2%) expressed uncertainty about whether such arguments were credible and convincing (by indicating "neither agree nor disagree").

Several predictors of awareness of overdiagnosis and overtreatment were identified. Awareness of overdiagnosis was higher among women aged 40–44 (OR=3.20, 95% CI=1.13–9.01), and there was at least some evidence that it was higher among women aged 45–49 as well (OR=3.50, 95% CI=0.99–12.44, $p=.053$), compared with women under 40. Overdiagnosis awareness was also higher among better educated women, particularly among those with a Bachelor's degree or higher, compared with those with less than a high school degree (OR=5.50, 95% CI=1.60–18.89). In contrast, awareness of overtreatment was lower among better educated women, particularly when comparing women with high school (OR=0.15, 95% CI=0.03–0.74) or some college education (OR=0.17, 95% CI=0.04–0.73) to those without a high school degree.

Whereas the above select sociodemographic factors predicted awareness of overdiagnosis and overtreatment, select clinical and health care factors were stronger predictors of overall perceived argument strength for statements about overdiagnosis and overtreatment. Specifically, prior mammography screening was associated with lower overall perceived argument strength for both overdiagnosis and overtreatment statements. This was particularly true for women who had a mammogram in the past year, compared with those who never had a mammogram (overdiagnosis OR= -0.57, 95% CI= -0.87– -0.28; overtreatment OR= -0.50, 95% CI= -0.80– -0.20). In addition, women with a usual source of medical care reported lower perceived argument strength for the overdiagnosis statement, compared with women who did not have a usual source of care (OR= -0.29, 95% CI= -0.57– -0.02).

Discussion

Consistent with prior research, we found that U.S. women's awareness of breast cancer overdiagnosis and overtreatment is limited, with less than 20% of women reporting being aware of these concepts. This is lower than awareness rates reported in recent survey studies

in Australia⁹, the UK,^{10,11} and the U.S.,¹⁵ although these differences could be explained in part by question wording (e.g., asking whether respondents have heard the terms “overdiagnosis” and “overtreatment” versus statements reflecting their definitions) or sampling differences (e.g., general population versus oversampling for respondents of lower socioeconomic position). Perhaps more importantly, when survey respondents were presented with statements describing these phenomena, most indicated that they did not find them to be persuasive.

We also identified important correlates of awareness of breast cancer overdiagnosis and overtreatment. Women in the age 40–49 window, and particularly those 40–44, reported greater awareness of overdiagnosis than those under 40. Expert disagreement on whether the benefits of mammography screening outweigh the harms has focused on women in the 40–49 age range,⁶ which could have increased issue salience for these women. Moreover, women with higher education were more likely to be aware of overdiagnosis, but surprisingly the opposite finding was observed for overtreatment, where greater education was associated with less awareness. It is important to assess whether such opposite findings persist in future studies and, if so, to explore reasons underpinning these patterns.

The key predictor of overall perceived argument strength, both for statements of overdiagnosis and overtreatment, was prior mammogram history: Women who have had mammograms, especially within the past year, were less likely to find such statements to be believable and persuasive. Women with a strong screening history might be important targets for informed decision making interventions, if future research finds that such women are in fact less familiar with the harms of screening than the benefits.

Low awareness of overdiagnosis and overtreatment—and the fact that women with a usual source of medical care were less convinced by an overdiagnosis argument—might be explained, at least in part, by patient–provider communication patterns about the benefits and harms of cancer screening. Studies suggest that provider discussion of cancer overdiagnosis and overtreatment is infrequent, at least as reported by patients.^{12,26} Such patterns are consistent with data from providers, who often underestimate screening’s harms and overestimate its benefits.²⁷ Recent efforts to improve provider understanding of high- and low-value screening practices—for example, by the American College of Physicians¹—may help to strengthen patient–provider communication about cancer screening, generally, and about overdiagnosis and overtreatment, specifically.

There also have been deliberate efforts to bolster patient understanding of these issues. Visual aids such as pictograms have been shown to improve patient comprehension of screening’s benefits and harms,²⁸ and decision aids can increase patient knowledge of overdiagnosis and informed decision making about breast cancer screening.¹⁷ Yet there is also evidence that psychological factors, including prior beliefs about screening’s effectiveness, could undermine comprehension and informed decision making.^{28,29} Like providers, patients continue to overestimate the benefits of medical interventions such as screening and underestimate its harms.³⁰ Recent population-based data from the UK suggest that enthusiasm for screening is “overwhelmingly positive,” with almost 90% of respondents agreeing that screening “is almost always a good idea.”^{31, p. 562} Thus, while some believe

that patients should be told about both the harms and benefits of screening,⁹ and while others, at least in the abstract, believe that information about overdiagnosis is important,^{14,15,32} such beliefs may not necessarily influence attitudes or intentions toward screening. For example, in one study Waller and colleagues¹³ found that although women thought information about overdiagnosis was important, it had little impact on their overall intentions to be screened. Ultimately, then, these findings may help explain why, in our study, women did not find statements about overdiagnosis and overtreatment to be persuasive and important to mammography decision making—and why those with a recent history of mammography screening were even less convinced by such arguments.

The current study has several strengths, including the use of nationally representative data with an oversample of lower socioeconomic position respondents, but it is not without limitations. First, although our sample size was sufficiently large for a survey of this kind, some model estimates may be noisy, given that we were predicting two relatively rare outcome variables (awareness of overdiagnosis and overtreatment). Future studies with larger sample sizes, ideally also using population-based data, would be helpful in determining if trends identified here are stable. Second, although we collected data on women's mammography history and personal breast cancer history, we did not collect data on whether family members or close others have had breast cancer. It is conceivable that knowing a family member or close friend whose breast cancer was detected with screening mammography could influence responses to overdiagnosis and overtreatment, and this possibility should be considered in future work. Third, we adapted our statements reflecting the definitions of overdiagnosis and overtreatment from prior research,^{9,13,15,16} and chose a statement-based (rather than term-based) approach given concerns about overreporting awareness. However, it is possible that women interpreted the statements differently than intended. Last, we asked women to evaluate the perceived argument strength of each statement using only three items adapted from Zhao et al.'s²¹ approach; including different items might have yielded distinct results.

Given the public's entrenched public favorability toward screening,^{16,31} it is plausible that exposure to dissonant messages about overdiagnosis and overtreatment could have negative consequences, such as prompting patients' counter-arguing and limiting their engagement in shared decision making.²⁸ Rigorous health communication research is necessary to inform communication interventions that could improve patient understanding of overdiagnosis and overtreatment, promote appropriate use of screening and, in turn, ensure high value care. Such efforts may be particularly important among those with strong screening priors, who may or may not have had the opportunity to discuss screening's benefits and harms with providers, and with medically underserved communities, given existing disparities in informed decision making about cancer screening.³³

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TABLE 1

Sample Characteristics (N=429)

Characteristic	Weighted % ^a
Age	
35–39	22.8
40–44	23.1
45–49	23.5
50–55	30.6
Education	
Less than high school	10.9
High school	24.6
Some college	28.2
Bachelor's degree or higher	36.3
Poverty status	
At or below 100% federal poverty level	12.8
Above 100% federal poverty level	87.2
Race/ethnicity	
White, non-Hispanic	61.6
Black, non-Hispanic	13.0
Other, non-Hispanic	8.7
Hispanic	16.6
Health insurance	
No	16.3
Yes	83.7
Usual source of medical care ^b	
No	16.6
Yes	83.4
Breast cancer history	
No	96.4
Yes	3.6
Mammogram history	
Never had mammogram	25.2
Had mammogram more than one year ago	29.2
Had mammogram in the past year	45.6

^aPercentages may not sum to 100 due to rounding.

^bUsual source of medical care was assessed with the following question: "Do you have a particular doctor, nurse, or other health professional that you see most often?"

TABLE 2

Levels of Awareness and Evaluations of Breast Cancer Overdiagnosis and Overtreatment Statements (N=429)

	Awareness of statements, % ^{a,b}		Evaluations of statements, % ^d							
			Believable ^c		In agreement with ^c				Gives reason to think carefully ^c	
	Yes	No	Strongly agree/agree	Neither agree nor disagree	Strongly disagree/disagree	Strongly agree/agree	Neither agree nor disagree	Strongly disagree/disagree	Strongly agree/agree	Neither agree nor disagree
Overdiagnosis ^e										
Some breast cancers found by mammograms are so slow-growing that they would not have caused any health problems for women in their lifetime.	16.5	71.2	12.4	20.7	33.1	46.2	15.1	37.1	47.8	16.0
Overtreatment ^e										
Some breast cancers that are treated (such as with surgery or medications) would not have needed such treatment after all.	18.0	69.3	12.7	21.3	42.2	36.5	15.4	40.2	44.4	15.0

^aPercentages may not sum to 100 due to rounding.

^bAfter viewing each statement, participants were asked, “Have you ever heard a statement like this before?”

^cParticipants evaluated each statement by responding to three items: “This statement is believable”, “Overall, I agree with this statement,” and “This statement gives me a strong reason to think carefully about whether I will get a mammogram.”

TABLE 3

Multivariable Logistic Regression Models Predicting Awareness of Breast Cancer Overdiagnosis and Overtreatment^a (N=429)

	Aware of overdiagnosis		Aware of overtreatment	
	OR (95% CI) ^b	P Value	OR (95% CI) ^b	P Value
Age				
35–39 (ref)	1.00		1.00	
40–44	3.20 (1.13–9.01)	.028	1.11 (0.39–3.18)	.842
45–49	3.50 (0.99–12.44)	.053	0.53 (0.10–2.83)	.456
50–55	2.39 (0.70–8.12)	.162	2.65 (0.81–8.67)	.106
Education				
Less than high school (ref)	1.00		1.00	
High school	2.61 (0.64–10.59)	.179	0.15 (0.03–0.74)	.019
Some college	3.65 (0.94–14.22)	.062	0.17 (0.04–0.73)	.017
Bachelor's degree or higher	5.50 (1.60–18.89)	.007	0.57 (0.14–2.24)	.419
Poverty status				
At or below 100% federal poverty level (ref)	1.00		1.00	
Above 100% federal poverty level	0.82 (0.42–1.62)	.572	1.04 (0.48–2.26)	.913
Race/ethnicity				
Non-white (ref) ^c	1.00		1.00	
White, non-Hispanic	0.78 (0.37–1.64)	.508	0.89 (0.43–1.85)	.762
Health insurance				
No (ref)	1.00		1.00	
Yes	1.71 (0.67–4.33)	.261	2.07 (0.68–6.23)	.198
Usual source of medical care				
No (ref)	1.00		1.00	
Yes	1.06 (0.40–2.81)	.899	1.40 (0.44–4.48)	.572
Mammogram history				
Never had mammogram (ref)	1.00		1.00	
Had mammogram more than one year ago	0.51 (0.19–1.36)	.176	0.70 (0.22–2.19)	.535
Had mammogram in the past year	0.43 (0.16–1.14)	.089	0.43 (0.14–1.35)	.148
Constant	0.03 (0.004–0.27)	.002	0.31 (0.07–1.33)	.115

OR indicates odds ratio; CI indicates confidence interval.

^aBreast cancer history was not included in models given low overall prevalence.

^bDerived using binary logistic regression where the outcome variable was coded as 0=not aware/don't know and 1=aware.

^cNon-Hispanic Black, non-Hispanic Other, and Hispanic combined is the reference category (see Table 1 distribution).

TABLE 4

Multivariable Linear Regression Models Predicting Overall Perceived Argument Strength for Statements about Breast Cancer Overdiagnosis and Overtreatment^a (N=429)

	Argument strength: overdiagnosis		Argument strength: overtreatment	
	<i>b</i> (95% CI) ^b	<i>P</i> Value	<i>b</i> (95% CI) ^b	<i>P</i> Value
Age				
35–39 (ref)	--		--	
40–44	–0.14 (–0.41–0.14)	.329	0.003 (–0.30–0.31)	.984
45–49	–0.18 (–0.51–0.14)	.267	–0.12 (–0.50–0.26)	.531
50–55	–0.06 (–0.39–0.28)	.747	0.003 (–0.34–0.35)	.986
Education				
Less than high school (ref)	--		--	
High school	0.21 (–0.23–0.65)	.343	–0.09 (–0.56–0.37)	.689
Some college	0.19 (–0.28–0.65)	.432	–0.27 (–0.75–0.21)	.267
Bachelor's degree or higher	0.30 (–0.16–0.75)	.201	–0.10 (–0.57–0.38)	.686
Poverty status				
At or below 100% federal poverty level (ref)	--		--	
Above 100% federal poverty level	–0.05 (–0.27–0.16)	.637	–0.01 (–0.21–0.20)	.948
Race/ethnicity ^b				
Non-white (ref)	--		--	
White, non-Hispanic	–0.04 (–0.29–0.21)	.744	0.04 (–0.21–0.30)	.742
Health insurance				
No (ref)	--		--	
Yes	0.01 (–0.27–0.28)	.954	–0.16 (–0.44–0.13)	.281
Usual source of medical care				
No (ref)	--		--	
Yes	–0.29 (–0.57– –0.02)	.038	–0.08 (–0.36–0.21)	.596
Mammogram history				
Never had mammogram (ref)	--		--	
Had mammogram more than one year ago	–0.41 (–0.68– –0.13)	.003	–0.24 (–0.53–0.04)	.094
Had mammogram in the past year	–0.57 (–0.87– –0.28)	.000	–0.50 (–0.80– –0.20)	.001
Constant	3.06 (2.62–3.50)	.000	3.23 (2.80–3.65)	.000

CI indicates confidence interval.

^aBreast cancer history was not included in models given low prevalence.

^bDerived using multiple linear regression where the outcome variable was a continuous scale (range=1–5, with increasing values representing greater perceived argument strength). For each statement, three message evaluation items were combined to create an overall perceived argument strength scale (see Table 2 footnote).

^cNon-Hispanic Black, non-Hispanic Other, and Hispanic combined is the reference category (see Table 1 distribution).