



Perceptions and misperceptions of overdetected of breast cancer

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An overview of overdetected

In the rapidly progressive world of cancer research and discovery, concerns about overdetected, or overdiagnosis, whether relating to breast cancer or other types of cancer, seem remote and counterintuitive. Yet overdetected is a well-documented phenomenon that is both biologically plausible and epidemiologically demonstrable (1-5). In population cancer screening, overdetected generally refers to the detection of cancer that, in the absence of screening, would not have been diagnosed nor caused harm in the affected person's lifetime, and would not have become symptomatic or clinically apparent (4,6). Routine screening of asymptomatic individuals has the potential to identify such 'overdetected' disease, leading to the harms of unnecessary treatment (referred to as overtreatment) (3,4). Mechanistically, population mammography screening confers the benefit of breast cancer mortality reduction by finding and hence treating disease at an early stage of growth and development. Therefore, it is not surprising that some of the early-detected disease revealed through screening may not have become biologically manifest, for example if the disease is inherently an indolent subtype, or if the individual's remaining lifespan is shorter than the time required for the disease to biologically progress to clinical presentation (3,4). The latter explanation for cancer overdetected is particularly relevant in older individuals, who are the focus of a recent study that explored older women's perceptions of overdetected of breast cancer (7). Before elaborating on how older women perceive overdetected from breast cancer screening, we first consider the complex issues relating to overdetected in a broader context.

Although the possibility of overdiagnosis from screening

programs has been raised as far back as the 1960's (8), overdetected of breast cancer attributed to population mammography screening has been an ongoing debate amongst stakeholders in health practice, and more generally in society, for nearly two decades (4,9). It is noteworthy that overdetected of cancer from population screening is not limited to breast screening—it exists for several other cancers such as prostate and lung cancer (2,9). In a further example, in a scenario where screening of asymptomatic individuals is not routinely recommended, overuse of imaging has witnessed a substantial increase in the incidence of thyroid cancer (specifically low-risk thyroid cancer) in many countries (10), highlighting the widespread manifestation of cancer overdetected in contemporary health systems.

Whilst population screening is a major contributor of cancer overdetected, there are other perhaps less appreciated causes adding to the burden of overdetected and overtreatment, across cancer and numerous other conditions. Shifting thresholds and definitions for ruling in/out conditions and abnormalities that widen the boundaries for disease labelling increase overdiagnosis (11). Examples are altering the threshold for treatment of conditions (such as hypertension) or diversifying criteria for diagnosis of disease (for example, attention deficit disorder) (11).

Quantifying overdetected

One of the most challenging aspects of overdetected relates to quantifying its magnitude, and the lack of consensus on the most appropriate methods to estimate its frequency (1,2,4,5,12). Focusing on breast cancer as the exemplar, variable study designs yield an extremely broad

range of estimates of breast cancer overdiagnosis from 0.3% to 76.0% (2). Some of the variability may be due to differences in study-specific definitions of overdiagnosis, however, substantial variability in the methods used to estimate the 'excess number of cancers' from screening drive the divergent estimates of breast cancer overdiagnosis, with many studies suffering from biases or incorporating assumptions that could over- or under-estimate the true extent of overdiagnosis (2,12,13). At present, polarised views on the magnitude of breast cancer overdiagnosis from mammography screening have reached a 'stalemate', and it may be more valuable to focus future research on defining strategies that help mitigate the consequences of overdiagnosis, specifically identifying and agreeing on ways to reduce over-treatment. Uncertainty around the frequency of overdiagnosis attributable to screening is not unique to breast cancer, there are parallels in overdiagnosis estimates from screening for other cancers, reflecting similar methodological issues as outlined for breast cancer, for example the range of estimates of overdiagnosis of prostate cancer is similarly very broad (1.8% to 88.1%) (2).

An alternate approach to framing the amount of overdiagnosis is to estimate the absolute number of overdiagnosed cases alongside the number of individuals who receive the main benefit, for example the number of BC deaths averted in the context of breast screening. Mandelblatt and colleagues (14) used simulation models to estimate the cumulative outcomes of breast screening, and reported the median value across models for each outcome per 1,000 women screened versus no screening. This work estimated that for biennial mammography screening from age 50 to 74 years, 7 (range, 4–9) BC deaths are averted and 19 (range, 11–34) cases are overdiagnosed (14). Across various scenarios for screening frequency and start ages, modelling consistently showed that for each BC death averted by screening around 2.5 cases are overdiagnosed (14). Expressing the amount of overdiagnosis relative to the amount of benefit using absolute numbers may help women understand the 'trade-off' between these key outcomes of breast cancer screening and could assist research into how women understand or perceive both the benefits and harms of cancer screening.

Women's perceptions of overdiagnosis of breast cancer

Recent research from Pappadis and colleagues (7), conducted in the USA, has explored the perspectives of women aged 70 years and older (without a history of breast cancer) regarding overdiagnosis of breast cancer. The researchers conducted semi-structured interviews of

59 older women who were recruited using purposive sampling based on race/ethnicity, age and educational level. In the interview, women were presented with two hypothetical scenarios illustrating the benefits and harms of screening including the harm of overdiagnosis (based on Hersch *et al.*, 2015) (15). This study found that few women had heard of overdiagnosis, and even after receiving information explaining overdiagnosis still half did not understand the concept. Many women were sceptical of overdiagnosis and feared it was being used as a way to ration breast screening (7). An overwhelming majority of women (86%) said that the information about overdiagnosis did not change their mind about screening (7). Women who understood the concept of overdiagnosis were more likely to report that they were considering stopping screening than women who lacked understanding of the concept. Women's views did not differ by race/ethnicity, education, age or screening preferences (7). These findings on the perspectives of older women regarding overdiagnosis are very similar to those from studies conducted in younger women, summarized in *Table 1*.

Knowledge and understanding

Surveys in Australia (20), the United Kingdom (21,22) and the USA (23,24) found that awareness of overdiagnosis is generally low—between 9 and 50% of respondents in these studies reported that they had heard about overdiagnosis or overdiagnosis. Qualitative studies in the context of breast cancer screening report even lower levels of awareness and understanding of overdiagnosis (*Table 1*). Overdiagnosis clearly is an unfamiliar concept for many women, however providing information about overdiagnosis has been shown to increase women's understanding, especially in younger women (18) and when more detailed information about overdiagnosis is provided (15). This suggests that providing brief information about overdiagnosis (such as presented in the study by Pappadis) might not be sufficient to effectively increase understanding about overdiagnosis and support informed choice (15–17). Importantly, most women across the different studies report they value receiving information about overdiagnosis and believe other women should be informed (7,15–19).

Attitudes and intention to screen

For decades, women have been surrounded by public health messages that emphasize the benefits and somewhat ignore the harms of breast cancer screening. This makes the concept of overdiagnosis unfamiliar, counterintuitive, and difficult to understand (25). Pappadis (7) and several other studies

Table 1 Women’s perceptions and understanding of overdetetection (OD) of breast cancer (BC)[†]

Study author; country	Study design, methods and population	Women’s awareness, knowledge	Women’s perceptions, emotions and attitudes	Screening intentions and behaviour	Individual differences
Pappadis <i>et al.</i> 2018 (7); USA	Design: mixed-methods study of older women’s perceptions of OD and its influence on BC screening intentions	Few women familiar with OD	Resistant and suspicious about OD, equated to rationing	For majority (86%) OD information did not influence screening decision	Results the same across race/ethnicity, education, age and screening preferences at baseline
	Methods: semi-structured interviews with women aged 70 and older (n=59) with purposive sampling based on ethnicity, age and educational level	Limited/moderate understanding of OD after information presented	Uncertainty/distrust of information, “how can they know”	Women who did not understand OD more likely to intend to screen	No all women wanted to know about potential presence of cancer in absence of symptoms, women who preferred not to know understood OD better
	Information about overdetetection: hypothetical scenarios illustrating OD (10–30% of screen-detected BCs), numerically and conceptually	OD confused with other potential harms such as false positives or misdiagnosis	Distrust source of information, preference to receive information from physician	Several agreed it is a personal choice	
Hersch <i>et al.</i> 2013 (16); Australia	Design: qualitative study of women’s responses to OD information and its influence on attitudes and screening intentions	Prior awareness of OD was minimal	Concept of OD challenges existing beliefs	50% OD estimate made some think more carefully about screening	Information preferences varied: many considered OD important to take into account in making an informed choice, others wanted to be encouraged to screen
	Methods: focus groups with women aged 40–79 years (n=50) with varying levels of education and screening history	Most women came to understand the concept of OD	Disbelief and surprise; “how can they know”	1–10% and 30% estimates had limited impact on attitudes and intentions	Women with less screening experience more concerned about OD than regular screeners
	Information about overdetetection: presentation explaining OD, including different estimates (1–10%, 30%, 50% of screen-detected BCs)		Suspicion OD is used as justification to reduce spending on screening	For some, OD was more relevant for treatment than screening decisions	Many preferred full, balanced information

Table 1 (continued)

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Study author; country	Study design, methods and population	Women's awareness, knowledge	Women's perceptions, emotions and attitudes	Screening intentions and behaviour	Individual differences
Waller <i>et al.</i> 2013 (17); UK	Design: qualitative study of the influence of OD information on women's decisions about BC screening	Few knew about OD. Some found statistical information difficult to understand	Surprise, shock and for some anger; "how can they know"	OD information considered more relevant for treatment than screening decisions	Preferences for amount of information varied
	Methods: focus groups with women aged 50–71 years (n=40) of varying screening history	Others demonstrated good understanding of OD	Some suspicious OD is used to justify a cost-cutting exercise		
	Information about overdetection: brief information referring to OD as 'slow-growing cancer' (12.5–37.5% of screen-detected BCs), in addition to NHS leaflet		Did not affect core screening beliefs		
Hersch <i>et al.</i> , 2015 (15); Australia	Design: quantitative study to test effect of OD information on informed choice	Compared with controls more women in the intervention group:	Attitudes towards screening remained positive overall, but fewer women in the intervention group expressed positive attitudes	Positive screening – intentions overall, but fewer women in intervention group intended to be screened	
	Methods: community-based, parallel-group, RCT in a cohort of women aged 48–50 years (n=879) who had not had mammography in the past 2 years	Made an informed choice (defined as adequate knowledge and consistent attitudes and intentions)	Belief that women should be given balanced information, inclusive of OD		
	Information about overdetection: explanatory and quantitative information in a decision aid. Estimate based on UK Independent Review (1 BC death averted to 3 OD cases)	Had better knowledge			

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Study author; country	Study design, methods and population	Women's awareness, knowledge	Women's perceptions, emotions and attitudes	Screening intentions and behaviour	Individual differences
Waller <i>et al.</i> 2014 (18); UK	<p>Design: quantitative study assessing effect of OD information on understanding/screening intentions</p> <p>Methods: population-based survey amongst women who were either age-eligible (n=954) or not yet eligible for screening (n=1,318)</p> <p>Information about over-detection: brief information presented in one of three formats. Estimate based on UK Independent Review (1 BC death averted to 3 OD cases)</p>	57% of women had correct understanding of OD	Not measured in this study	Screening intentions remained high after OD information	<p>Younger women's understanding was better than older women's</p> <p>Younger women more likely than older women to show decreased intentions to screen after OD information</p>
Nagler <i>et al.</i> 2017 (19); USA	<p>Design: quantitative study to assess awareness of and reactions to OD information and potential predictors (sociodemographic, clinical, and health care characteristics)</p> <p>Methods: population-based survey of women aged 35–55 years (n=429) oversampling women of lower socioeconomic position</p> <p>Information about over-detection: brief statement: "<i>some breast cancers found by mammograms are so slow growing that they would not have caused any health problems for women in their lifetime</i>"</p>	16.5% of women were aware of OD	Most women did not believe and did not agree with statements about OD	Not measured in this study	<p>Particularly unconvinced by OD were women with: recent screening history vs those who never screened</p> <p>Had a usual source of medical care vs women who did not have a usual source of care</p> <p>Awareness of OD was higher in: women aged 40–49 vs. aged <40</p> <p>Better educated women</p>

†, studies summarised in the above table did not include women with a personal history of breast cancer.

have found that women are often sceptical of the concept of overdetection and distrust the information provided, suspecting that overdiagnosis is being used as a justification to reduce spending on screening, and questioning how scientists and doctors know that overdetection exists (7,16-19). This can result in emotionally charged and sometimes hostile responses to the concept of overdetection and the idea that breast cancer screening can potentially cause harm (17). It is therefore not surprising that negative responses to information about overdetection seem particularly common in older women and those with a strong screening history (16,18,19) which might also partly explain the findings of Pappadis and colleagues (7).

These results are consistent with an overwhelming enthusiasm for breast cancer screening found across studies, and the limited effect that providing overdetection information has on screening intentions (7,15-19). However, women who are provided with information about overdetection are less likely to say they will start or continue screening compared to women not receiving this information (*Table 1*). The Pappadis study suggests that this is particularly the case for women who have better understanding of the concept of overdetection (7). Importantly, younger women and those who have never been screened before are more open to the idea of overdetection (16,18,19), perhaps because they are not yet as invested in breast screening as older women. Regardless, across studies, including the study from Pappadis, a majority of women recognise that screening decisions are personal decisions and that women should receive balanced information about potential harms as well as benefits, with a minority preferring to be encouraged to screen (16,17). Studies suggest that for some women information about overdetection might not influence their decision to screen, rather it might change their treatment decision-making once diagnosed, potentially opting for alternative approaches such as watchful waiting (16,17).

Women's concerns about overdetection information.

Women have reported concerns about the potential for overdetection information to upset women who had previously accepted invitations to screening or those already diagnosed with breast cancer, and that it might dissuade others from screening (although it would not dissuade them personally) (16,17). Fears have also been raised that changing the conventional pro-screening message to include more balanced information on screening outcomes could unleash widespread public confusion and distrust in the health system (16). On the other hand, women in several studies expressed concerns about the harms of potentially unnecessary treatment for

screen-detected breast cancer and the importance of making information about overdetection widely available (16,17). Others have commented that awareness of overdetection might help newly diagnosed women to feel less afraid and more hopeful about their prognosis (16,17).

Conclusions

Understanding and quantifying overdetection from breast screening is a complex issue (with parallels in screening for other cancers), highlighted in the ongoing non-consensus about breast cancer overdetection amongst screening experts and stakeholders. It is not surprising then that communicating information to women about overdetection from breast screening is challenging. The findings from Pappadis and colleagues (7) emphasise the need for providing good-quality information on screening outcomes and to communicate this information effectively, so that women can understand the concept and are better positioned to make well-informed decisions. Future research is needed to determine how information about overdetection in breast cancer screening can be communicated in a way that is believable and not so counterintuitive, and how we can tailor such information to meet the needs of women from different ages and screening histories, varying levels of health literacy and in line with their information preferences.

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