

ANALYSIS



Walking the tightrope: communicating overdiagnosis in modern healthcare

Communication that empowers the public, patients, clinicians, and policy makers to think differently about overdiagnosis will help support a more sustainable healthcare future for all, argue **Kirsten McCaffery and colleagues**

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Overdiagnosis and overtreatment have serious implications for individuals, healthcare systems, and society,^{1,2} and effective strategies are urgently needed to help the public, clinicians, and policy makers address this problem. Communication about overdiagnosis has been highlighted as essential for moving forward but presents several challenges, such as the potential to confuse the public, undermine trust, and adversely affect people who already have a diagnosis. Various communication based strategies offer real promise; we describe what is known and what we need to know to communicate effectively and safely about overdiagnosis and overtreatment.

What are the key messages to be communicated?

Understanding of overdiagnosis among the general public and health professionals is limited, so it is essential to communicate what it means for individuals, the health system, and society (box 1). By definition, overdiagnosis will not improve prognosis and will probably harm individuals (for example, by unnecessary intervention) or society (opportunity costs). For individuals, it is important to communicate the nature (physical or psychological), likelihood, and duration of the harms. For societies with free public healthcare, the financial strain and opportunity cost are usually at system level—resources wasted on unnecessary tests and treatments are unavailable for people in greater need. But in private healthcare systems, overdiagnosis

can be a huge personal financial burden, even for those with insurance.

Communication is further complicated because it is usually impossible to know whether an individual has been overdiagnosed or benefited from the diagnosis—overdiagnosis can only be observed at the aggregate level. Recent efforts to communicate the concept and likelihood of overdiagnosis in breast screening have had some success, albeit with much room for improvement. When given a patient decision aid including an infographic and icon array (figure 1), 29% of women understood both the concept and quantitative outcomes of breast screening (including deaths avoided, false positive results, and overdiagnosis); 59% of women understood the conceptual information alone.³

Communication based strategies to mitigate overdiagnosis

Several communication based strategies have been applied in the areas of overtreatment and directed at individual, community, or policy levels (box 2).

Strategies for individuals

Shared decision making is a consultation process where a clinician and patient jointly make a health decision. It changes

Box 1: Overdiagnosis and its consequences^{1 2}

Overdiagnosis occurs when a diagnosis is “correct” according to current professional standards but when the diagnosis or associated treatment has a low probability of benefiting the person diagnosed.² It is caused by a range of factors such as:

- Use of increasingly sensitive tests that identify abnormalities that are indolent, non-progressive, or regressive (overdetection)
- Expanded definitions of disease—for example, attention-deficit/hyperactivity disorder and dementia—and lowering of disease thresholds, such as osteoporosis (overdefinition)
- Creation of pseudodiseases (also called disease mongering), such as low testosterone and restless leg syndrome
- Clinicians’ fear of missing a diagnosis or litigation
- Public enthusiasm for screening or testing and desire for reassurance
- Financial incentives

Potential consequences of overdiagnosis

- Psychological and behavioural effects of disease labelling
- Physical harms and side effects of unnecessary tests or treatment
- Quality of life affected by unnecessary treatment
- Hassles of unnecessary tests and treatments
- Increased financial costs to individuals
- Wasted resources and opportunity costs to the health system
- Overmedicalisation of society

the way decisions are framed by identifying that there is a decision to be made (not an obligatory test or default treatment), and explaining the range of options available and their benefits and harms. It also involves deciding with patients “what is most important to them” in terms of their values, preferences, and circumstances.⁴ Importantly, the option of doing nothing or active surveillance can be discussed as a deliberate or positive action⁵ to counter people’s bias for tests and treatment, especially in cancer.⁶ Consumer led interventions that teach patients to ask about benefits and harms of different options have shown some success.⁷ Shared decision making is increasingly part of clinical training, often combined with evidence based healthcare,⁸ and this should be enhanced to include understanding and communicating about overdiagnosis.

Patient decision aids support shared decision making. High quality evidence from 115 trials shows that they improve patients’ knowledge and understanding of options and their risks and benefits, and increase consistency between patients’ values and choices.⁹ Decision aids have successfully informed women about overdiagnosis in breast screening,³ reduced men’s desire for prostate specific antigen (PSA) testing¹⁰ or surgical management for prostate cancer, and reduced preferences for potentially unnecessary elective surgery.⁹ A trial of a decision aid communicating overdiagnosis in breast screening (879 women approaching age 50) increased informed choice compared with controls and did not increase anxiety; worry about breast cancer decreased (box 2).³ A pilot study of a breast screening decision aid for women over 75 years (n=45) including information on overdiagnosis had similar findings.^{11 12} However, information on the harms of overdiagnosis and overtreatment is rarely presented.^{13 14} Consumers consistently overestimate the benefits of screening, tests, and treatments and underestimate the harms,¹⁵ and although shared decision making is widely espoused, it is not often implemented.¹⁵

Strategies for communities

Mass media and direct to consumer campaigns can influence large numbers of people simultaneously and promote sustained beneficial changes in behaviour.¹⁶ For example, a mass media campaign about back pain, driven partly by concerns about unnecessary back imaging, changed both community and general practitioner beliefs about management, resulting in reduced imaging, work insurance claims, and healthcare usage.¹⁷ Scaled down versions of the programme have been replicated in several

countries.¹⁶ Other important initiatives include the Choosing Wisely campaign, now operating in nine countries (www.choosingwisely.org), and the UK’s “do not do” list.

Policy directed strategies

Deliberative democratic methods (such as community juries) support policy decisions by gathering informed public responses about disputed issues, such as what services are available or reimbursed by health funds. Because overdiagnosis is scientifically and politically contested, this topic is ideal for deliberative democratic methods. Deliberative methods must meet exacting standards and are time consuming.¹⁸ Community juries have considered PSA testing in Australia^{19 20} and mammographic screening in New Zealand, where participants changed their recommendation at least partly because of potential harms from overdiagnosis.²¹ Disseminating findings from juries could enhance community health literacy, leading to better informed citizens and more transparent decision making.

Changing terminology: Behaviours can be influenced by medical terminology, and changing the names for medical conditions may help reduce the effect of overdiagnosis. In one study, describing ductal carcinoma in situ as “non-invasive cancer” resulted in 13-16% more women choosing surgical treatment (rather than medication or active surveillance) compared with calling it a “breast lesion” or “abnormal cells.”²² Similar findings were reported in Australia.^{23 24} Independent experts convened by the US National Cancer Institute²⁵ and National Institute of Health have proposed dropping the word “cancer” entirely in this case, arguing for it to be reserved for lesions likely to progress if untreated.^{25 26} Similar arguments exist for thyroid and prostate cancer,²⁷ but effects of disease labels extend beyond cancer. Parents were more likely to accept medication when “gastro-oesophageal reflux disease” (compared with no label) was used to describe excessive irritability in infants, even when told the drugs would not control the symptoms.²⁸

Potential challenges to effective communication

Low levels of awareness: Awareness of overdiagnosis is low, particularly for cancer screening with few people understanding overdiagnosis of cancer is even possible.^{29 30} In one study, 18% of Australian men and only 10% of women said they had been

Box 2: Examples of effective communication strategies for overdiagnosis or overtreatment*Community back pain campaign (three year campaign 1997-99)¹⁷*

- Significant improvements in community (n=4730) beliefs about back pain over three years in Victoria (where campaign was run) versus New South Wales (no campaign)
- General practitioners' (n=2556) knowledge improved—for example, time when patients can return to work, not prescribing complete bed rest. In a patient scenario, GPs in Victoria were 2.51 times less likely to order tests for acute low back pain and 0.40 times as likely to order lumbosacral radiographs. Over the duration of the campaign insurance claims for back pain reduced by 15%

Patient decision aids⁹

- Cochrane review of 115 randomised controlled trials reported that decision aids reduced number of people choosing major elective surgery in favour of more conservative options (relative risk 0.79) and reduced number of men choosing PSA testing (RR 0.87) in nine studies
- A randomised trial of a decision aid for women approaching 50 years (n=879), which explicitly explained the concept of overdiagnosis and presented quantitative information on its likelihood, found that it increased informed choice by 9% (intervention 24% v control 15%), reduced intentions to screen by 13% (74% v 87%)³

Changing disease terminology

- Study of 394 women compared the commonly used cancer term for ductal carcinoma in situ (non-invasive cancer) with non-cancer terms (breast lesion, abnormal cells). Results showed 47% preferred surgery when cancer term was used compared with 34% and 31% respectively²²

Citizen juries

- 27 men randomly allocated to PSA screening community jury (12 men) or control (15 men). The jury concluded that the Australian government should not invest in PSA testing and recommended an education programme for GPs with better quality and consistent information about PSA for doctors and patients. After the jury, men had significantly lower intentions to screen compared with controls⁸⁴

told about overdiagnosis in screening for prostate and breast cancer respectively.³¹ Similarly, a US survey reported only 9.5% of men and women (aged 50-69 years) said they had been informed about overdiagnosis when discussing cancer screening.³² Further US and UK studies reported that only about half of respondents had heard of “cancers that grow so slowly that they are unlikely to cause [you] problems in [your] lifetime.”^{33, 34} There are few publications reporting clinician awareness, but one recent survey among 126 university affiliated clinicians in the US found 28% listed overdiagnosis as a potential harm of PSA testing, and 56% listed unnecessary treatment.³⁵

Cognitive biases and counterintuitive messages: Longstanding, prominent public health messages have emphasised the benefits and ignored the harms of early diagnosis for many diseases.^{36, 37} This makes the concept of overdiagnosis unfamiliar, counterintuitive, and difficult to understand. There is widespread faith in the importance of early detection,^{38, 39} and people may choose cancer screening because it is the apparent default decision, even if their informed preferences would be different.⁴⁰⁻⁴² Furthermore, when people are predisposed towards an intervention, they may perceive benefits to be high and risks low, even when explicitly told otherwise.⁴³ Suggesting a reduction in tests that are popular with the public can provoke emotionally charged, even hostile responses,⁴⁴ reflecting cognitive dissonance.⁴⁵

Uncertainty and trust: Intolerance of uncertainty and anxiety about missing rare cases underpin much medical excess.⁴⁶ Communicating about overdiagnosis requires us to acknowledge the inherent uncertainty in the size and extent of the problem and its consequences. These issues are often hotly contested.⁴⁷ Communicating uncertainty adds complexity and may lead to confusion and avoidance of decision making⁴⁸ and can undermine trust in the healthcare provider.⁴⁹ However, distrust can also arise when patients discover that information about harms has been withheld. Clinicians often avoid discussing uncertainty with patients,⁴⁸ but studies of breast and prostate screening show that people want to be told about overdiagnosis.^{19, 29}

Vested interests and persuasive communication: Vested interests may influence how information is presented in the media and the scientific arena. Pharmaceutical and device manufacturers

have direct interests in maximising product sales. Industry funded disease awareness campaigns often increase the numbers of people portrayed as patients.⁵⁰ Narrowing the boundaries that define disease or raising diagnostic thresholds is a threat to turnover, profit, and professional interests.⁵¹ Similarly patient advocacy groups, often also industry funded, can have interests in portraying their condition as widespread, severe, and treatable to optimise media, professional, and policy attention and to attract resources.⁵² Politicians too have seen mileage in supporting screening programmes without offering more nuanced assessments of their benefits and harms, including risks of overdiagnosis.⁵³

Further research directions

We need 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. Then we can research effective communication—how to increase understanding among all parties and the effectiveness and acceptability of such strategies. Once effective interventions are identified, we need to understand how to implement them within healthcare systems that currently reward overdiagnosis. However, research must also consider potential harms of communicating overdiagnosis, and herein lies the tightrope. Possible harms include cognitively overburdening and confusing the public, adversely affecting patients already diagnosed and treated, and creating distrust in conventional medicine.²⁹ A careful evidence based approach is essential.

Achieving widespread understanding about overdiagnosis will take time, but we have some tools to move forward. Given that high health anxiety is largely a consequence of the health system itself, the health community must be patient with and sympathetic towards those who do not share this concern about overdiagnosis. Successful communication that empowers the public, patients, clinicians, and policy makers to think differently about overdiagnosis will help support more sustainable healthcare for all.

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Key messages

- Overdiagnosis provides no benefits to patients and is a challenge to the sustainability of modern healthcare systems
- Communication based strategies could help reduce overdiagnosis and its negative impact on individuals and health systems
- Mass media education, shared decision making, terminology changes for disease states, and deliberative methods (juries) all have potential as effective communication strategies

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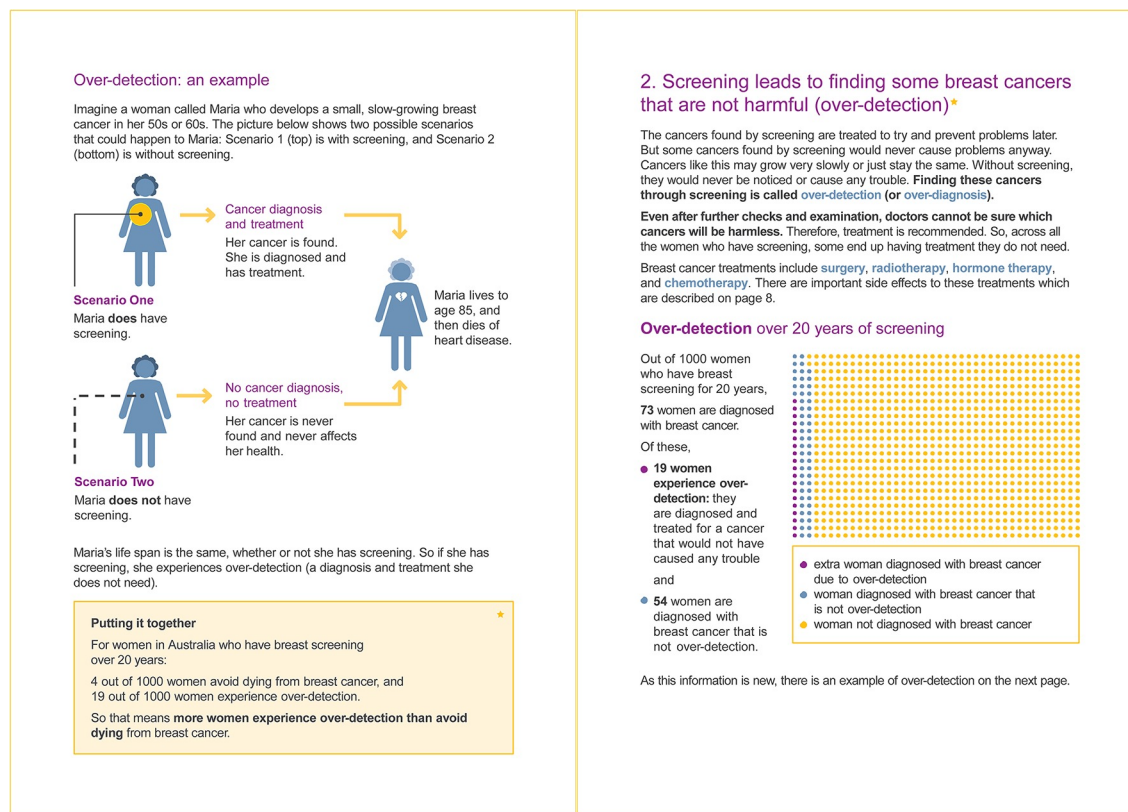
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Figure



Infographic and icon array explaining overdiagnosis in breast screening in a patient decision aid developed by Hersch et al³