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Abstract

In February 2014, the non-governmental Swiss Medical Board recommended that mammography programmes in Switzerland may eventually be closed down because they might not deliver more benefits than harms. In the resulting uproar the board was accused of being "unethical." Controversy about mammography has persisted in the UK, US, Canada, and elsewhere, and disputes about overdiagnosis exist in prostate cancer, chronic kidney disease, attention-deficit/hyperactivity disorder (ADHD), and many other conditions. People concerned about overdiagnosis are compelled by evidence of harms outweighing benefits. But not everyone is equally compelled. This may be because of disagreements over the evidence, conflicts of interest, or cognitive biases. Another possible cause of disagreement is that some people may not think that benefits and harms are the most important consideration. This contrast, between people who think outcomes are what matters most and people who disagree, is central to the discipline of ethics. It is a crucial difference between utilitarian ethicists and non-consequentialist ethicists. Broadly, utilitarians think that, given several options, we should choose the one that produces the best overall outcome (the most utility among the whole group of affected people), ensuring that each person counts equally in the calculation. Non-consequentialists don't consider outcomes to be so important: other ethical concerns, such as rights, duties, or respect for people's dignity or autonomy, matter more.

Keywords

than, why, problems:, outcomes, trolley, matter-an, essay, ethics, overdiagnosis, factors, other

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ANALYSIS



ESSAY

Overdiagnosis, ethics, and trolley problems: why factors other than outcomes matter—an essay by Stacy Carter

If the only ethically important consideration was the balance of benefit to harm, overdiagnosis might be less contested, writes **Stacy Carter**. But evidence and intuitions from famous thought experiments could explain some peoples' willingness to accept the harms of overdiagnosis—other factors may feel more important to them

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In February 2014, the non-governmental Swiss Medical Board recommended that mammography programmes in Switzerland may eventually be closed down because they might not deliver more benefits than harms. In the resulting uproar the board was accused of being “unethical.”¹

Controversy about mammography has persisted in the UK,² US,³ Canada, and elsewhere,⁴ and disputes about overdiagnosis exist in prostate cancer,⁵ chronic kidney disease,⁶ attention-deficit/hyperactivity disorder (ADHD),⁷ and many other conditions. People concerned about overdiagnosis are compelled by evidence of harms outweighing benefits. But not everyone is equally compelled. This may be because of disagreements over the evidence,⁸ conflicts of interest,^{9 10} or cognitive biases.¹¹ Another possible cause of disagreement is that some people may not think that benefits and harms are the most important consideration.

This contrast, between people who think outcomes are what matters most and people who disagree, is central to the discipline of ethics. It is a crucial difference between utilitarian ethicists and non-consequentialist ethicists. Broadly, utilitarians think that, given several options, we should choose the one that produces the best overall outcome (the most utility among the whole group of affected people), ensuring that each person counts equally in the calculation.¹² Non-consequentialists don't consider outcomes to be so important: other ethical concerns, such as rights, duties, or respect for people's dignity or autonomy, matter more.¹³

The few or the many?

For decades, non-consequentialists have used thought experiments known as trolley problems, ostensibly to show that

utilitarians are wrong. Two classic trolley problems are “switch” and “bridge.”

In the switch problem, a trolley (tram) is hurtling down a track. Five workers are on the main track. One worker is on a branch track. If the trolley continues, it will kill the five workers. A switch will divert the trolley onto the side track, and it will kill one worker.^{14 15} Should you throw the switch?

In the bridge problem, five workers are on the track. A large, heavy person stands on a bridge. If you push the person off the bridge and onto the track it will stop the trolley. The large person will die; the five will live.^{14 15} Should you push the person?

Many utilitarian philosophers would not recognise an ethical difference between throwing the switch and pushing the person: in both scenarios one person dies so that five people live. So you should throw and push, respectively—you should harm one person to benefit five.

In empirical studies of ordinary people, however, responses to the two scenarios differ. About 90% of people say it is acceptable to throw the switch,^{16 17} whereas only 10% of people are comfortable with pushing the person.¹⁶ Non-consequentialists say that this shows that utilitarians are wrong: something more than outcomes must matter.¹⁴⁻¹⁹

Reactions are generally even stronger to a medical example known as “transplant.” A skilled transplant surgeon has five patients who will die without immediate transplantation, each of a different organ. A passerby happens to be a perfect donor for all five patients. Should the surgeon anaesthetise the passerby and transplant their organs, saving the five but killing the donor? Almost everyone says no emphatically,²⁰ even though it results in one dead person and five survivors, just as in “switch.”

Biography

Stacy Carter is associate professor at Sydney Health Ethics, a centre for theoretical and empirical ethics research at the University of Sydney. She specialises in the ethics of public health and conducts empirical studies to understand peoples' values and reasoning about public health interventions. She tweets sporadically @stacycarter.

Clearly then, say the non-consequentialists, you can't just use outcomes to determine the right thing to do.

Intuitions about what matters

Why do people respond differently to the trolley scenarios even though they result in the same number of lives saved and lost? Theoretical and experimental research indicates that framing is important, including the order in which options are presented and the terminology used (for example, "saving" versus "killing").¹⁷⁻²¹ People may be less willing to trade lives for lives and more willing to trade injuries or property loss for lives.¹⁷ Avoiding harm may seem more important than providing benefit.¹⁴⁻²² Serious outcomes may not be exchangeable for (even many) more trivial outcomes.¹³

Rights may be seen as trumping utility.¹⁴⁻²² Harms may seem morally worse if intended.¹⁶ Trade-offs between already affected groups may be more acceptable than putting new people at risk.¹⁶ Certain harms may be considered more salient than uncertain harms.¹³⁻²³ And proximal and identifiable victims may be considered more salient, especially if they are kin.¹³⁻²³

These intuitions can't necessarily be morally justified, and ethicists argue about their moral significance. They do, however, indicate likely reactions when people are asked to trade off outcomes among people or to agree to harm a few people to benefit or save more.

Overdiagnosis as a trolley problem

Overdiagnosis is often presented like a trolley problem, for two good reasons: to make the concept comprehensible and because it is a fundamentally utilitarian concept.

When we use the label "overdiagnosis," we indicate that an accepted practice in a health system that had been thought to be doing good is, counterintuitively, doing harm.²⁴ A screening test, a diagnostic standard, or a routine check-up that had been considered beneficial is in fact harmful. Of course, most diagnoses do good and harm: they avert harms for some and cause harms to others. So thinking about overdiagnosis requires trading-off bad outcomes against other bad outcomes, often in different people who are not always identifiable.

Consider, for example, 10 000 men who are invited to undergo screening for abdominal aortic aneurysm. Over 13-15 years, about 46 will avoid death due to abdominal aortic aneurysm, while 176 will start unnecessary lifelong surveillance. Of these 176 men, 37 will have unnecessary surgery, from which 1-2 will die.²⁵

In a cohort of children diagnosed as having ADHD, some are helped, on balance, by treatment, whereas others experience no benefits, only weight loss, growth suppression, stigmatisation, and reduced family finances because of medication costs.⁷

When such evidence is summarised to help with communication, it looks even more like a trolley problem. A decision aid might show, for example, that for every four women who avoid preventable death from breast cancer through screening, 19 will be overdiagnosed as having breast cancer.²⁶

If overdiagnosis is presented like a trolley problem, then it seems likely to elicit similar moral intuitions to trolley problems (table

1). The responses to trolley problems might help to explain why people are willing to accept high levels of overdiagnosis harm, as shown in some empirical studies.²⁷

Ethicists disagree strongly about whether items in the left hand column are good reasons or provide justification.¹³⁻²¹ These are moral intuitions that people are likely to hold rather than moral truths.

Weaknesses in utilitarian reasoning

Two other recognised problems with utilitarianism are relevant to overdiagnosis.

Firstly, utilitarians appear cold hearted towards the minority who suffer for the benefit of others. In utilitarianism, what matters is the overall outcome, not the effect on specific individuals, so they may accept a small number of people suffering a great deal if many benefit as a result. Utilitarians are thus accused of indifference to the suffering minority.

This seems relevant to policy on overdiagnosis. Decision makers may stop a screening programme or move a diagnostic boundary to improve outcomes overall. But a few people are likely to be worse off as a result, and the new policy may seem to disregard their suffering.

A related problem is that many people falsely believe that they are alive only because they had disease detected early through screening and endured sometimes onerous treatment. Preventing future harm from overdiagnosis requires being publicly honest about the overdiagnosis that has happened in the past. But this will alert such people to the possibility that they may have been needlessly harmed through overdiagnosis. This harm needs to be taken seriously, and these people may require support.

The second problem with utilitarianism is that it requires calculation and comparison of all the benefits and harms that will result from different courses of action. Identifying and measuring all relevant benefits and harms is extremely difficult, especially because people evaluate the benefits and harms that they experience very differently, in ways that can't always be reflected well in a hard outcome measure.²⁸ Nonetheless, without their perspective, we can't really understand the relevant outcomes.

Mental health diagnoses and treatments, for example, are sometimes dismissed as predominantly overdiagnosis and overtreatment. In some cases this is justified. In others it may give insufficient weight to the suffering and stigma that accompany such problems and the complexity of finding a combination of treatments that can provide relief. Before researchers declare, for example, that most diagnoses of depression are unjustified, they may need to interrogate whether they have taken sufficient account of the full range and weighting of benefits and harms that matter to the people who are diagnosed as having depression and their loved ones.

Implications for action

These observations have implications for researchers, policymakers, and clinicians. A commonly proposed response to overdiagnosis is clearer, simpler communication to aid decisions about policy and care, such as the excellent decision aid for mammographic screening I mentioned above, which

contrasts four deaths against 19 overdiagnoses in 1000 women over 20 years.²⁶ This simplification is done for good reasons; but it also creates a trolley-like problem, with inherent limitations. It elides probability and uncertainty, which affect people's judgments.²⁰ It neglects human willingness to accept many injuries and inconveniences to prevent one death, and it ignores other things that—justifiably or not—people might consider important (for example, a “right” to screening).

If overdiagnosis is a utilitarian concept, it may need a utilitarian solution. Overdiagnosis occurs because the standards in healthcare systems are set at the wrong point—excessive screening targets, a condition too broadly defined, a diagnostic threshold set too low. If the problem is with the system, perhaps we should not expect individual clinicians or patients to fix it, even if armed with better information. Responsibility should arguably lie upstream, with those who measure outcomes (researchers) and those who design the system (policymakers and planners).

Epidemiologists, policymakers, and planners think in utilities, so are susceptible to the weaknesses of utilitarianism (neglecting disadvantaged minorities and problems with measurement). Countering this is challenging but not impossible. When measuring mammography outcomes, for example, qualitative and health economic studies with both the general public and affected women could help determine relevant benefits and harms and refine their relative weights.

If evidence of overdiagnosis is sufficient to justify policy change, decision makers should not just focus on overall utility, but also publicly acknowledge that a minority might be worse off and communicate how they will be cared for. If mammography programmes were stopped, for example, a small number of women may develop life-threatening cancer that would have been detected earlier with screening. This could be acknowledged and public efforts made to ensure these women have access to the best treatment.

Researchers testing public attitudes to overdiagnosis should be aware that the same problem framed in different ways may elicit different moral intuitions. It may be informative to systematically compare people's perceptions of overdiagnoses that demand different trade-offs (for example, for fatal and non-fatal conditions; for interventions that aim to benefit and those that aim to prevent harm) and to compare people who have and have not experienced conditions directly (for example, people who have had kin with breast cancer and those who have not).

Clinicians talking with their patients about overdiagnosis may encounter the moral intuitions described here: discussing them directly might be useful. Some clinicians may be sceptical about overdiagnosis and have these same moral intuitions; they might consider exploring these further, remembering that they are common but not always justified.

Good decisions and communication about overdiagnosis in policy and clinical care are demanding. Every example of overdiagnosis requires different trade-offs. In any intervention to prevent overdiagnosis, some will gain and others will lose. The utilitarian problem of overdiagnosis demands a utilitarian solution: changing healthcare systems so that, on balance, they increase rather than undermine wellbeing. The challenge is not just to show that the gains outweigh the losses, but also to show

proper care and respect for those who lose and to recognise the outcomes that matter to people on both sides.

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Key messages

The concept of overdiagnosis relies on utilitarian reasoning, where the right action is the one that produces the best outcome overall, ensuring everyone counts equally in that calculation

Overdiagnosis is often presented in the form of a trolley problem—that is, as a trade-off between imminent harms to identifiable victims (eg, four women saved from cancer death against 19 women harmed by overdiagnosis)

Three decades of research on trolley problems suggests that this may elicit a range of moral intuitions that go beyond maximising benefit and minimising harm

Clinicians and researchers working on overdiagnosis can't avoid utilitarian reasoning but should acknowledge and allow for its recognised weaknesses

Table

Table 1 | Theoretical analysis and experimental findings about trolley problems and their relevance to overdiagnosis

Responses to trolley problems	Possible relevance to overdiagnosis
The acceptability of a trade off may depend on what is traded or how it is presented—eg, saving v killing, injuries or property loss v lives, lives v lives	Some interventions likely to produce overdiagnosis (eg, some cancer screening, screening for abdominal aortic aneurysm, troponin screening) promise to save lives. Those who dismiss overdiagnosis as a concern often emphasise the importance of saving lives, which may increase willingness to trade off against injury of even large numbers of people. People may be more compelled by examples of overdiagnosis that cause death (“kill”)
Avoiding harm may seem more important than providing benefit	A few overdiagnosing interventions offer benefits—eg, diagnosing low testosterone promises improved wellbeing through treatment—but generally overdiagnosing interventions offer avoidance of harm (eg, of cancer, diabetes, or kidney disease). If people are primed to avoid harm, they may be more reluctant to give up these interventions
Serious outcomes may not be exchangeable for (even a large number of) trivial outcomes	People may be less receptive to information about overdiagnosis of potentially fatal conditions (eg, cardiovascular disease, cancer) than of non-fatal conditions (eg, ADHD). In cancer, especially, the trade-off tends to be small numbers of preventable deaths against many unnecessary injurious treatments (but not deaths). People may be primed to accept such trade-offs to prevent cancer death
Rights may trump utilities	Justifiably or not, people may feel that removing overdiagnosing services undermines important rights (eg, to life, to health or control of their health, to screening services) and that these rights are more compelling than increasing utility
Harms may seem morally worse if intended	People may perceive the harms arising from overdiagnosis as unintended, and thus less problematic. Ethicists disagree over whether intentions are morally important: utilitarians hold that they are not
Trade-offs between already affected groups may be more acceptable than putting new people at risk	This may help explain why overdiagnosis from screening well people feels morally different to overdiagnosis of symptomatic people. Symptomatic people are arguably already affected; in clinical care there is always a number needed to treat, some are harmed and some benefit, but all were previously ill and presented for care. By contrast, well people are previously unaffected: when they are recruited to screening and overdiagnosed they experience new harms that they would have otherwise avoided
Certain harms may be more salient than uncertain harms	The harms averted and harms caused by overdiagnosing services are always uncertain: the evidence is both probabilistic and contested, and it is rarely possible to know who will be harmed or benefit. This uncertainty may decrease the perceived salience of the harms
Victims may be more salient if they are proximal and identifiable, especially if they are kin	Direct experiences of loved ones’ illness may increase the emotional salience of those diseases; eg, personal experiences of breast cancer may make harms from breast cancer highly salient