

Concept of unbearable suffering in context of ungranted requests for euthanasia: qualitative interviews with patients and physicians

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ABSTRACT

Objective To obtain in-depth information about the views of patients and physicians on suffering in patients who requested euthanasia in whom the request was not granted or granted but not performed.

Design In-depth interviews with a topic list.

Setting Patients' homes and physicians' offices.

Participants 10 patients who explicitly requested euthanasia but whose request was not granted or performed and eight physicians of these patients; and eight physicians of patients who had requested euthanasia but had died before the request had been granted or performed or had died after the request was refused by the physician or after the patient had withdrawn his or her request.

Results Not all patients who requested euthanasia thought their suffering was unbearable, although they had a lasting wish to die. Patients and physicians seemed to agree about this. In cases in which patients said they suffered unbearably there was less agreement about what constitutes unbearable suffering; patients put more emphasis on psychosocial suffering, such as dependence and deterioration, whereas physicians referred more often to physical suffering. In some cases the physician thought that the suffering was not unbearable because the patient's behaviour seemed incompatible with unbearable suffering—for instance, because the patient was still reading books.

Conclusions Patients do not always think that their suffering is unbearable, even if they have a lasting wish to die. Physicians seem to have a narrower perspective on unbearable suffering than patients and than case law suggests. In an attempt to solve the problem of different perspectives, physicians should take into account the different aspects of suffering as described in the literature and a framework for assessing the suffering of patients who ask for euthanasia.

INTRODUCTION

In 2005, about 8400 people in the Netherlands made an explicit request for euthanasia. Of these, about 6000 requests were not granted or performed. Dutch Euthanasia Act (2002) describes six requirements for due care in the performance of euthanasia.¹ One of the requirements is that the physician must be convinced that the patient's suffering is unbearable, with no prospect of improvement. Unbearable suffering is not further specified in the act, but the views of the Royal Dutch Medical Association,² the regional euthanasia review committees,¹ and case law³ provide some indications: unbearable suffering is not limited to physical suffering, the suffering must at least be recognisably unbearable for the physician, and unbearable suffering is subjective.

According to Cassell,⁴ suffering is experienced when an impending damage of the person is perceived by that individual. This damage, or loss, can occur in different aspects of personhood, such as the person's history, his or her cultural and societal attachments, a person's perceived or desired future, and the spiritual life of the person. According to Cassell, the only way to know whether suffering is present is to ask the person.

Physicians say that the suffering of the patient is the most difficult requirement to form a judgment on.⁵ Doubts about the presence of unbearable suffering are the most frequently mentioned reason given by physicians for refusing a request.^{6,7} We examined how patients whose request for euthanasia was not granted or performed described their suffering and how their physicians assessed suffering in those specific cases, and how they describe unbearable suffering in general.

METHODS

Recruitment and sampling

We recruited patients from a large cohort study focusing on people with advance directives (that is, advance euthanasia directive, refusal of treatment document, durable power of attorney for health care, will to live statement). Eligible participants included 51 respondents who had requested euthanasia in the past three years but the physician had refused, one respondent who had withdrawn his request, and 135 respondents who had known a relative who had requested euthanasia but euthanasia was not performed.

WHAT IS ALREADY KNOWN ON THIS TOPIC

Unbearable suffering is the most debated requirement for euthanasia and is experienced by physicians as the most difficult to determine

More than half of the explicit requests for euthanasia in the Netherlands are not granted or are granted but not performed

WHAT THIS STUDY ADDS

Not all patients who want to die consider their suffering as unbearable

Patients and physicians have different perspectives on what constitutes unbearable suffering
To assess the severity of a patient's suffering, physicians could use a framework specifying different aspects of suffering

We selected respondents for the present interview study on the basis of health status (terminal illness, chronic illness, no physical illness). We included cases with varying reasons why the request was not granted or performed.

Interviews

We interviewed 10 patients, eight of whom gave us consent to approach their physician. We also interviewed eight physicians about seven different patients who had asked for euthanasia but had died before the request had been granted or performed or had died after the

request was refused by the physician or after the patient had withdrawn his request.

The interviews took place from December 2005 to September 2007. Interview topic lists for both the patients and the physicians included the current situation of the patient, including suffering, the situation of the patient at the time of the request, reasons for asking for euthanasia, and reasons why euthanasia was not granted or performed. Patients and physicians were asked how they would describe unbearable suffering in general and in their specific case.

Data analysis

We analysed data from the interviews with the 10 patients and the 16 physicians, covering 17 different cases. As our study was explorative we used open coding.⁸ We categorised the transcripts into similar subject areas using inductive coding. Two researchers generated the list of codes that was discussed with the other researchers.

RESULTS

Characteristics of patients and physicians

The patients had various diseases and illnesses, most of them were aged over 80, and half of them were women (see bmj.com). Of the 16 physicians interviewed, 10 were general practitioners, four were nursing home physicians, one was a geriatrician, and one was an internist. Most of them had performed euthanasia in the past.

Considering suffering to be unbearable

Some patients explicitly stated that their suffering was unbearable, while others said that they did suffer unbearably but not all the time or said that their suffering was severe but questioned whether it was unbearable. All patients had a lasting death wish. The physicians also did not call all suffering unbearable, and the perspectives of the patient and the physician were similar in most of the cases in which both perspectives had been described.

In some cases the physician thought that the suffering was not unbearable because the patient behaved in a way that the physician did not think was compatible with unbearable suffering. For instance, one physician said that the patient was still reading books and therefore seemed not to be suffering unbearably.

Is unbearable suffering physical suffering?

Most of the patients mentioned pain as an element of their suffering, but this was not the only cause, and the pain did not make their suffering unbearable. For the patients themselves, the suffering seemed to mainly consist of non-physical suffering, such as (fear of) dependence, no longer being able to participate in normal daily life, or mental suffering because of deterioration (box 1).

For the physicians, physical suffering and pain seemed to be a more important element of suffering. In cases in which the physician thought that the patient's suffering was unbearable, the physicians described the suffering as severe pain and chronic fatigue. Moreover, in their description of unbearable suffering in general, about

Box 1 | Unbearable suffering; patients' perspective of patients and physicians

Patient 5 (woman aged >80, paralysed after stroke)

- Interviewer (I): And now they say that patients must meet a few requirements, and one important requirement is unbearable suffering—you already mentioned that yourself. What do you think unbearable suffering is?
- Respondent (R): That you are alive, but not living. They call it living, because you're breathing, but I'm not living. You can't call this living, can you?
- I: And what does living mean to you then?
- R: Being part of everyday life. For instance, if I can read, see a play.

General practitioner (woman aged <40)

- I: Have you, yourself, any idea about what unbearable suffering is?
- R: Lots of pain, difficult to treat, so much trouble with the medicine, side effects, that people really do suffer, yes suffer, have pain, are tired, can't function any more, and also, can't do certain things any more, that they lie there crying, they lie in bed moaning.

General practitioner (man aged >50)

- I: Do I understand well that for you, unbearable suffering is not necessarily associated with physical suffering?
- R: Somatic no, certainly not. But it must be—the problem is that it also has something to do with my own powerlessness. Of course you prefer the somatic symptoms just because they're more apparent, and of course there can be much more discussion about the psychological aspect.

Box 2 | Empathising with the patient's suffering is not enough

General practitioner (man aged 40-50)

- Respondent: I mean, if I knew that I could no longer see and I came into a different setting where I had no idea where anything was, I mean, I realise very well, I really can understand that this is what she wants. But you see, in my work I experience so many situations in which the agony and the suffering are evident. But that doesn't mean that my role in these cases is that I end their life... Empathy is not always enough—however difficult it is, because it's certainly not easy.

Box 3 | Is unbearable suffering subjective?

Patient 4 (man aged <50, Crohn's disease)

- Respondent (R): I don't want a stoma. No way! I'd rather you got rid of me. A bag of shit on my stomach, I've lived for so many years in a degrading situation. These are degrading situations you lie in. You just lie there, because there was a hole in it, wallowing in your own shit in the bed. Isn't that lovely! And then you also have to walk around with a bag of shit on your stomach! Don't be silly, I'm not that type. I've been through such hell already. I still have a certain feeling of self esteem, that I can't accept it, I just don't want it. Even if thousands of people say "I'm feeling better with it, I don't mind at all, it doesn't bother me, I can swim with it, I can do this and that with it." OK, good for them!

General practitioner (woman aged 40-50)

- Interviewers: What do you understand by unbearable suffering?
- R: Well, that's a whole range of what people... It often has to do with how people have lived and what their condition is now. So that can range from you don't have any pain but you're lying in bed and you have to poo and wee in a nappy and you can't do anything else. I could certainly consider that to be unbearable suffering without any pain involved. So it very much depends on how your life has been and what you find unbearable.

half of the interviewed physicians mentioned physical suffering or said that it is easier to define the suffering as unbearable if it is physical (box 1).

Empathising with the patient's suffering is not enough

Most of the physicians could understand that their patient wanted to die. Some physicians said that they would, perhaps, also have wanted to die if they were in a similar situation. For most of the physicians, however, empathy with or understanding of the death wish was not enough to persuade them to grant the request for euthanasia (box 2).

Is unbearable suffering subjective?

Several patients thought that certain situations (such as having a stoma or becoming dependent) would be unacceptable and therefore unbearable for them, whereas similar situations might well be acceptable for other patients. Some of the physicians also thought that unbearable suffering is subjective. Some physicians, however, thought otherwise (box 3).

DISCUSSION

Patients who request euthanasia do not always consider their suffering as unbearable, and patients and physicians seem to agree about this. If the patients say they suffer unbearably, however, there is less agreement between patients and physicians. The patients evoke several aspects of personhood when they speak about their suffering. They put more emphasis on psychosocial suffering, whereas the physicians refer more often to physical suffering.

Strengths and weaknesses of the study

We looked at unbearable suffering from different perspectives. One limitation of our study is that we looked only at cases in which a request for euthanasia had not been granted or granted but not performed, and perspectives might be different in cases where euthanasia was performed.

Nature of suffering

Physicians in our study defined unbearable suffering more often than patients as physical suffering. This confirms Cassell's notion that, in medicine, suffering is generally related to the body and not to the mind.⁴ In the context of euthanasia, the difference can also be influenced by the different interests of patients and physicians: patients want euthanasia and physicians want certainty about the legal aspects. It is possible that physicians therefore use a rather strict definition of unbearable suffering as being physical suffering. Furthermore, physical suffering is probably the most apparent and recognisable suffering, and physicians might be most familiar with this physical domain.

Suffering is subjective

In legal euthanasia proceedings, unbearable suffering is considered to be subjective. Some of the physicians stated that the personhood of the patient was part of their assessment, but others did not take personhood

into account; they compared the situation of the patient with that of other patients. Physicians also do not seem to comply with this notion when they expect congruence between behaviour and suffering as expressed by the patient.

Is unbearable suffering an applicable term in the assessment of euthanasia requests?

Some patients themselves had doubts about whether or not their suffering was unbearable. And yet, these patients considered their suffering to be severe and clearly indicated that they had a lasting wish to die. This gives rise to the following question: how can patients consider their suffering to be so severe that they no longer wish to live, but not consider it to be unbearable? It is possible that patients reserve the term "unbearable" for the most extreme situations and find it unreasonable to consider their own suffering in this way.

Conclusions and implications for practice

Patients and physicians have different perspectives on the nature and extent of suffering. Physicians commonly focus on bodily suffering and seem to have a narrower perspective on unbearable suffering than patients and than Dutch case law suggests.³ Physicians should take into account the various aspects of suffering, looking beyond the body-mind dichotomy.

One consequence of using a broad perspective of suffering could be that physicians more often assess the suffering of a patient as unbearable, though the opposite is also possible. In any case, a structured way of assessing suffering the assessment will at least be more in line with the nature of suffering.

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Competing interests: None declared.

Ethical approval: The study protocol was approved by the Medical Ethics Committee of the VU University medical center (METC VUmc registration No 2005/82).

Data sharing: No additional data available.

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Aspirin for primary prevention of cardiovascular events in people with diabetes: meta-analysis of randomised controlled trials

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EDITORIAL by Haynes and colleagues

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STUDY QUESTION What is the efficacy and safety of low dose aspirin in people with diabetes and no cardiovascular disease?

SUMMARY ANSWER A clear benefit of aspirin for the primary prevention of major cardiovascular events or mortality in people with diabetes could not be identified in our meta-analysis. The risk of major cardiac events was not significantly reduced with aspirin compared with placebo or no treatment. Taken together, these data indicate either low efficacy of aspirin in people with diabetes or insufficient evidence on this matter.

WHAT IS KNOWN AND WHAT THIS PAPER ADDS

The role of aspirin in the primary prevention of major cardiovascular events in diabetes remains controversial. This meta-analysis suggests that the benefit of aspirin for the primary prevention of major cardiovascular events or mortality in people with diabetes may be lower than in other high risk populations.

Selection criteria for studies

We searched Medline, the Cochrane central register of controlled trials, and reference lists of articles for any randomised controlled trials comparing aspirin with placebo or no intervention in people with diabetes and no cardiovascular disease. We also included data on subsets of people with diabetes enrolled in larger studies of the general population. Searches were limited to English language articles.

Primary outcome(s)

The primary outcome was the occurrence of major cardiovascular events (death from cardiovascular causes, non-fatal myocardial infarction and stroke, and all cause mortality).

Main results and role of chance

Six of 157 potentially eligible studies were included (10 117 patients). When aspirin was compared with placebo there was no significant reduction in the risk of major cardiovascular events (five studies, 9584 participants; relative risk 0.90, 95% confidence interval 0.81 to 1.00), cardiovascular mortality (four studies, n=8557; 0.94, 0.72 to 1.23), or all cause mortality (four studies, n=8557; 0.93, 0.82 to 1.05). There was no significant decrease in the risk of myocardial infarction with aspirin (six studies, n=10 117, 834 events; relative risk 0.86, 95% confidence interval 0.61 to 1.21). Heterogeneity was moderate ($I^2=62.2\%$; $P=0.02$). There was also no significant reduction in the risk of stroke with aspirin compared with placebo or no treatment (five studies, n=9584, 382 events; 0.83, 0.60 to 1.14), and a moderate heterogeneity among the trials ($I^2=52.5\%$; $P=0.08$). Aspirin significantly reduced the risk of myocardial infarction in men (relative risk 0.57, 95% confidence interval 0.34 to 0.94) but not in women (1.08, 0.71 to 1.65; P for interaction=0.056). Evidence relating to harms was inconsistent.

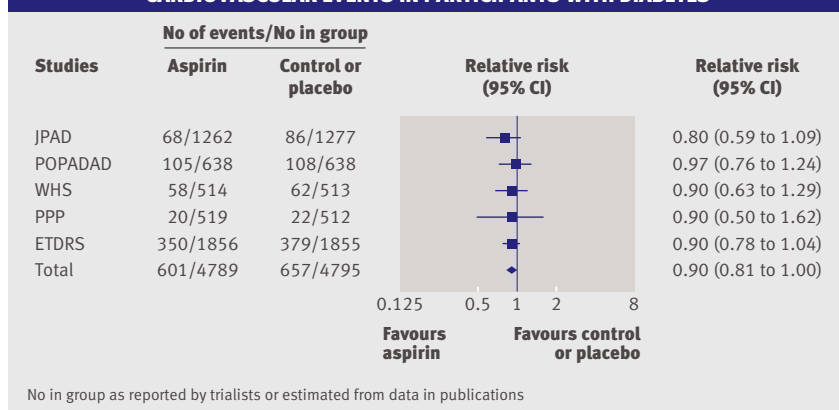
Bias, confounding, and other reasons for caution

The main weakness of this study was the paucity of high quality randomised trials. A possible explanation for some of our findings may be the lack of adequate power in existing trials to detect the effects of aspirin, either because the efficacy of aspirin is in itself moderate to low or because diabetic status is an effect modifier. In addition, there were methodological concerns with existing data. Half the studies evaluated failed to specify whether randomisation allocation was concealed and some were relatively outdated and hardly applicable in current practice. Some analyses showed heterogeneity between the trials, which most likely reflects a sex interaction. Other causes of heterogeneity could not be explored owing to limited data.

Study funding/Potential competing interests

We have no competing interests.

EFFECT OF ASPIRIN ON PRIMARY PREVENTION OF MAJOR CARDIOVASCULAR EVENTS IN PARTICIPANTS WITH DIABETES



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Applicability and generalisability of published results of randomised and non-randomised controlled studies evaluating four orthopaedic procedures: methodological systematic review

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STUDY QUESTION Is the reporting of applicability data consistent between randomised controlled trials and non-randomised studies of four orthopaedic procedures (minimally invasive and computer assisted navigation techniques for arthroplasty of the hip or knee)?

SUMMARY ANSWER The reporting of applicability data between randomised and non-randomised studies did not differ. Both trial types were mainly single centre studies, with one or two participating surgeons.

WHAT IS KNOWN AND WHAT THIS PAPER ADDS In the specialty of surgery, randomised controlled trials are often criticised for results that are poorly applicable to clinical practice compared with non-randomised studies. Our results show that results of surgical non-randomised studies do not have better applicability than those of randomised controlled trials: reporting of applicability items was poor with both trial designs, and both were mainly conducted in single centre studies.

Selection criteria for studies

We searched Medline and the Cochrane central register of controlled trials for English language randomised controlled trials and non-randomised comparative studies evaluating minimally invasive or computer assisted arthroplasty of the hip or knee.

Primary outcome(s)

Items essential for interpreting the applicability of the procedures were identified by a survey of a

sample of orthopaedic surgeons. The proportion of essential items reported was then calculated for three components of applicability: description of patients, description of the experimental intervention, and context of care (number of centres and surgeons). The applicability of context of care was evaluated by comparing the number of surgeons and centres involved in each trial type. When such data were not reported, the corresponding author of the selected trials was contacted.

Main results and role of chance

Eighty four articles were identified (38 randomised controlled trials, 46 non-randomised studies). Essential applicability items for minimally invasive and computer assisted total hip arthroplasty and total knee arthroplasty were selected by a sample of 77 orthopaedic surgeons. The median (interquartile range) percentages of essential items reported for non-randomised studies compared with randomised controlled trials for items about patients was 38% (25-63%) versus 44% (38-45%), for items considered essential for all interventions was 71% (43-86%) versus 71% (57-86%), and for items about the context of care was 38% (25-50%) versus 50% (25-50%). More than 80% of both study types were single centre studies with one or two participating surgeons.

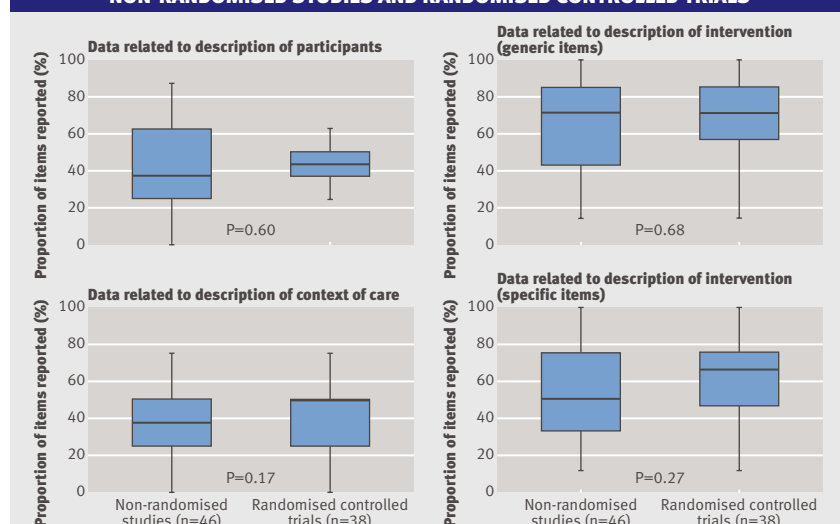
Bias, confounding, and other reasons for caution

The study has some limitations. Firstly, these findings should be confirmed in other surgical areas. Secondly, we focused on the reporting of essential applicability information, and for practical reasons we evaluated the actual applicability of the study results only from data related to the context of care. Because of lack of information, we were unable to compare reports of the two trial types for representativeness of patients. Finally, we assumed that the involvement of more centres and surgeons implied better applicability of results, but this assumption is not true for multicentre trials when all participating centres and surgeons have high expertise. However, our results highlighted that most trials involved only one centre and one or two surgeons, and the applicability of results from such trials is probably questionable.

Study funding/Potential competing interests

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PROPORTION OF ESSENTIAL ITEMS REPORTED BY NON-RANDOMISED STUDIES AND RANDOMISED CONTROLLED TRIALS



Solid line is median of distribution; upper and lower ends of boxes are upper and lower quartiles of data
Whiskers extend to most extreme values within 1.5 times interquartile range

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Evaluating the causal relevance of diverse risk markers: horizontal systematic review

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STUDY QUESTION What is the most robust method for systematically reviewing evidence on a full range of risk markers and producing a clinically relevant field synopsis of aetiology, in this case for coronary heart disease?

SUMMARY ANSWER This horizontal systematic review pinpoints deficiencies and strengths in the evidence for depression, exercise, C reactive protein, and diabetes as unconfounded and unbiased causes of coronary heart disease.

WHAT IS KNOWN AND WHAT THIS PAPER ADDS Traditional vertical systematic reviews focus on one risk marker and one research design at a time. Horizontal comparisons across different types of risk markers, incorporating different research designs each with differing limitations, could be used to develop a field synopsis and prioritise future development of guidelines and research.

Selection criteria for studies

Studies were identified through Medline and a hand search of guidelines. Two reviewers independently determined eligibility of studies across three sources of evidence (observational studies, genetic studies, and randomised controlled trials) related to four risk markers: depression, exercise, C reactive protein, and type 2 diabetes. For each risk marker, the largest meta-analyses of observational

studies and genetic studies and meta-analyses or individual randomised controlled trials were analysed.

Primary outcome(s)

The primary outcomes were fatal coronary heart disease and non-fatal myocardial infarction (aetiological and prognostic studies) and all cause mortality (prognostic).

Main results and role of chance

Meta-analyses of observational studies reported adjusted relative risks of coronary heart disease for depression of 1.9 (95% confidence interval 1.5 to 2.4), for top compared with bottom fourths of exercise 0.7 (0.5 to 1.0), for top compared with bottom thirds of C reactive protein 1.6 (1.5 to 1.7), and for diabetes in women 3.7 (2.6 to 5.2) and men 2.2 (1.8 to 2.6). Prespecified study limitations were more common for depression and exercise. Meta-analyses of studies with formal mendelian randomisation were identified for C reactive protein (and did not support a causal effect), and were lacking for exercise, diabetes, and depression. Randomised controlled trials were not available for depression, exercise, or C reactive protein in relation to incidence of coronary heart disease, but trials in patients with diabetes showed some preventive effect of glucose control on risk of coronary heart disease. None of the four randomised controlled trials of treating depression in patients with coronary heart disease reduced the risk of further coronary events. Comparisons of this horizontal evidence review with two guidelines published in 2007 showed inconsistencies, with depression prioritised more in the guidelines than in our review.

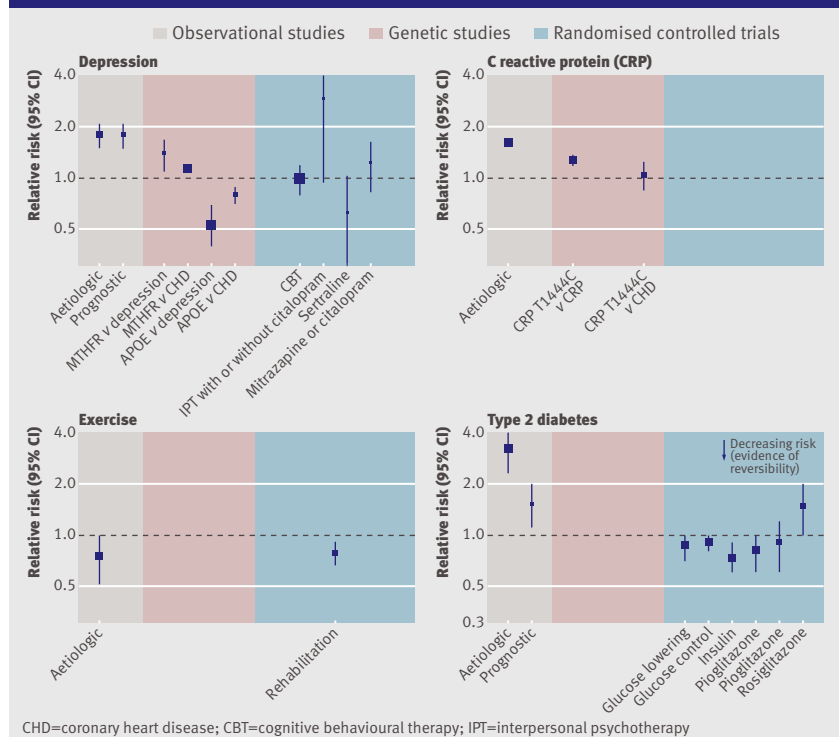
Bias, confounding, and other reasons for caution

The horizontal systematic review is narrative, without novel methods for data analysis, offering no explicit ranking of causal relevance nor attempting to posit a decision threshold above which a marker might be considered causal. The method depends on the availability and quality of large scale syntheses of evidence.

Study funding/Potential competing interests

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META-ANALYSES OF DIFFERENT FORMS OF EVIDENCE FOR RISK MARKERS



Reliability of self reported smoking status by pregnant women for estimating smoking prevalence: a retrospective, cross sectional study

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STUDY QUESTION What is the accuracy of self reported smoking status during pregnancy and what is the impact of reliance on these figures for targeting access to smoking cessation services for pregnant women in Scotland?

SUMMARY ANSWER Self reporting underestimates the prevalence of smoking in pregnant women in Scotland by 17%, resulting in over 2400 pregnant smokers not being offered specialist smoking cessation services.

WHAT IS KNOWN AND WHAT THIS PAPER ADDS Self reporting underestimates the true prevalence of smoking during pregnancy. In Scotland this results in thousands not being offered specialist cessation services. More accurate methods to identify pregnant smokers are needed.

Participants and setting

A random sample (n=3475) of pregnant women who opted for second trimester screening in the West of Scotland was used.

Design

A retrospective, cross sectional study of cotinine measurements in stored blood samples (from second trimester screening) linked to self reported smoking data routinely collected at maternity booking. Maternal area deprivation was based on postcode of residence (Scottish Index of Multiple Deprivation).

Primary outcome(s)

Smoking status validated with cotinine measurement by area deprivation category.

Main results and the role of chance

Seventy per cent (n=21 029) of pregnant women in the West of Scotland opted for second trimester screening, and 3475 were randomly selected and analysed for serum cotinine concentration. According to their self reported smoking status, 24.1% of them were current smokers, significantly lower than the cotinine validated estimate of 30.1%. The difference between cotinine validated and

self reported smoking prevalence was greater in the most deprived areas compared with the least deprived areas (see table). Projected figures for Scotland, adjusted for differences between the West of Scotland and the Scottish population, estimated that reliance on self reported smoking results in 2400 pregnant smokers going undetected each year (representing 17% of pregnant smokers), with nearly twice as many undetected smokers in the most deprived areas (n=1196 in deprivation categories 4+5) compared with the least deprived areas (n=642, categories 1+2).

Bias, confounding, and other reasons for caution

A characteristic that relates to a woman's decision to opt for screening and also relates to the accuracy of her reported smoking status could potentially introduce bias. Neither self reported smoking nor maternal age was related to the decision to opt for screening. There was a small, but statistically significant, difference in area deprivation between women who opted for screening and those who did not, but this related to the large sample size rather than an important difference (see full article).

Serum cotinine concentration can be raised by exposure to environmental tobacco smoke and nicotine replacement therapy. However, cotinine levels resulting from environmental tobacco smoke are generally below the cut-off level we used to denote a smoker, and nicotine replacement therapy was seldom used in the study population during the time period examined.

Generalisability to other populations

These findings are relevant to other regions and other countries, several of which have reported substantial proportions of pregnant smokers misclassifying themselves as non-smokers when asked at maternity booking.

Study funding/potential competing interests

Funding was provided by a Glasgow Centre for Population Health Grant. No competing interests were declared.

PREVALENCE OF SELF REPORTED SMOKING AT BOOKING APPOINTMENT (8-12 WEEKS GESTATION) AND COTININE VALIDATED SMOKING AT ABOUT 15 WEEKS GESTATION

	Self reported smoking		Cotinine validated smoking*		Difference		
	No of women	Percentage (95% CI)	No of women	Percentage (95% CI)	Percentage points	z score	P value
Total sample (n=3475)	839	24.1 (22.7 to 25.6)	1046	30.1 (28.6 to 31.6)	6.0	8.27	<0.001
Deprivation category†:							
1+2 (n=985)	101	10.3 (8.5 to 12.3)	142	14.4 (12.3 to 16.7)	4.1	4.23	<0.001
4+5 (n=1753)	587	33.5 (31.3 to 35.7)	706	40.3 (38.0 to 42.6)	6.8	6.03	<0.001

*Concentrations ≥ 13.7 ng/ml indicate current smoking

†Scottish Index of Multiple Deprivation, categories 1+2 are least deprived, 4+5 are most deprived

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