Factors involved in deciding to start preventive treatment: qualitative study of clinicians' and lay people's attitudes

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Abstract

Objectives To explore the views of clinicians and lay people about the minimum benefit needed to justify drug treatment to prevent heart attacks, and to explore the rationale behind treatment decisions.

Design Qualitative study using semi-structured interviews.

Participants 4 general practitioners, 4 practice nurses, and 18 lay people.

Setting 8 general practices and 6 community settings across Liverpool.

Results Participants varied widely in the minimum acceptable benefits chosen. Most people found the concepts difficult initially, and few appreciated that increased length of treatment should increase absolute benefits. Lay people usually wanted to make decisions for themselves, and clinicians supported this. Participants wanted to consider adverse effects and costs of treatment. Dislike of drug taking was common, and many people preferred lifestyle change to an imperfect treatment. Quality of life and personal views were more important than an individual's age.

Conclusions Evidence based guidelines make assumptions about people's preferences, and, by using 10 year estimates of risk, inflate the apparent benefits of treatment. It is unlikely that guidelines could incorporate the wide range of people's preferences, and true dialogue is necessary between clinicians and patients before starting long term preventive treatment.

Introduction

It is becoming accepted that patients' preferences and values should be explicitly incorporated into decisions about treatments, but the rationale behind decisions is poorly understood.[1 2] Most studies have examined groups of patients who are taking drugs, so excluding the views of those who have declined treatment,[3 4] and how general practitioners' beliefs might influence prescribing decisions has not been explored.[2]

The decision to treat an asymptomatic risk factor involves balancing expected benefits with expected harms.[5] Individual values and priorities, rather than facts, will determine the choice made,[6 7] and patients' values are at least as valid as professionals'.[2] Lipid lowering and blood pressure lowering drugs reduce the risk of ischaemic cardiovascular events.[8 9] The absolute benefit (proportion of people treated who benefit) is highest in people at greatest risk of having an event, but adverse effects and costs of treatment are similar whatever the baseline risk.

Little is known about the level of coronary risk at which either doctors or patients want treatment, yet current UK guidelines arbitrarily recommend treatment for those whose 10 year risk of coronary heart disease is at least 30%.[8 9] Assuming a relative risk reduction of about a third, this equates to an absolute benefit of about 10% over 10 years (or 5% over five years), though some argue for treating those at lower risk.[10 11]

We explored the views of primary care clinicians and lay people about the minimum benefit they thought would justify drug treatment to prevent heart attacks. Doctors, nurses, and lay people are likely to have different perceptions, values, and levels of knowledge when making treatment decisions, and doctors tend to have more power within the clinical relationship.[12] This can result in doctors unwittingly excluding patients' preferences from treatment decisions and pressing them to take treatments that they would decline if fully informed, or not offering treatments that they might choose. We used the same scenario to elicit responses from all groups and to learn about the factors influencing preferences for preventive treatment.

Participants and methods

Health professionals

We recruited four doctors from a randomised list of general practitioners in Liverpool, by contacting the first two male doctors and first two female doctors by telephone. As one male doctor declined, we approached the next man on the list. The practices of the next four general practitioners on the randomised list were contacted by telephone to invite their practice nurse to participate, and all four nurses agreed. No participants were known to the researcher (DKL), and all worked at different practices across Liverpool.

Lay people

We chose to interview people outside a healthcare environment. We recruited 18 lay people from the following settings across Liverpool (number of people in brackets): two meetings of the British Cardiac Support Group (5), two lunch clubs run by Age Concern (6), a

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Box 1: Scenario presented to participants and prompts used during interview

Scenario

"I would like you to think about a drug, a tablet, which can prevent heart attacks. It is not perfect in that it does not prevent them completely. What that means is that if, say, 100 or 1000 people take the tablets every day for five years, then some will be saved from a heart attack—they would have had a heart attack without the tablet, but the tablet has prevented it. Some will have a heart attack anyway, even though they take the tablet. And the rest will not have a heart attack, but would never have had one anyway even without the tablets. So the ones who are saved from a heart attack will have been helped by the drug. The rest would have been just the same if they had not taken the tablets at all. The problem is no one can say exactly who will be better and who will not, so they all had to take the tablets.

[clarify] "What I want to know is—of, say, 100 similar people, all taking the drug for five years, how many have to be saved from a heart attack for it to be worth while all of them taking the drug every day?"

Prompts used in all interviews

1. "Why did you choose that number and not, say, one a bit higher [or lower]?"
2. "How about if everybody has to take the tablet for 10 years instead of five? Would that make any difference?"
3. "Do you think it makes any difference how old the people taking the tablets are? How would that change your answer?"
4. "Is there anything else about the people taking the tablets which might alter your answer?"
5. "Let's say that the tablets are mostly safe, but that you have to have a blood test at least every year and that the long term side effects are not known"

At the end of interview

"Thank you. Would you still choose the same number now as you did at the beginning?"

[If someone said that one person benefiting out of 100 would be worth while] "OK. Let's say that 1000 people have to take it every day for just one to be better. Would that be worth it?" [increasing the number until they said that it would not be worth it]

course run by a Tenants' Association (6), and a university department (2). A key contact from each organisation asked for volunteers and passed their contact details to the researcher. Lay participants were told that the interviewer (DKL) was a researcher from public health, so that respondents would feel able to comment freely; they were told that he was a general practitioner only if they asked. Sample size was pragmatic, but we recruited lay people until no new themes emerged.

Interview

Participants were given the opportunity to read an information sheet and to ask questions, and then invited to take part in a confidential, face to face interview at a time and place convenient to themselves. They were presented with a hypothetical drug to prevent heart attacks, and asked for their views on the minimum benefit needed to justify people taking the drug, and the reasons for their choices (see box 1). It was stressed that there were no right or wrong answers. Interviews lasted 15-30 minutes and were audiotaped and later transcribed verbatim for thematic analysis of content. One of us (DKL) read the transcripts, identified themes, and re-read every transcript to search for each theme as it was identified. A second author (JR) read all transcripts and validated these themes.[13] Key findings were discussed by all authors.

Summary of participants' characteristics

Characteristic	General practitioners (n=4)	Practice nurses (n=4)	Lay people (n=18)
Men:women ratio	2:2	0:4	10:8
Age range (years)	31-52	28-52	45-89
Aged >65 years	0	0	13
Had coronary heart disease	0	0	7
Close person had heart attack*	1	3	7
Attended further education	4	4	8

*Participants were asked "Has anyone close to you ever had a heart attack?"

Results

The table describes the participants' background characteristics.

Understanding the scenario

Most participants, including the health professionals, found the concepts difficult to grasp at first (for example, stating they were confused) and gave different numerical answers through the interview, some of which were self contradictory. For example, one doctor changed the minimum absolute benefit from 20% to 5% without seeming to realise. All the doctors, half the nurses, and two of the 18 lay people seemed confident of their choice. Three clinicians initially said that a third should benefit from the drug because there were three categories of patients in the scenario. Some balanced an ideal against an acceptable benefit: one lay person (lay interview 10) wanted 99% of people to benefit but also thought that any benefit at all was worth while.

Minimum benefits chosen

Overall, doctors chose lower minimum absolute benefits (5%-10%) than nurses (10%-25%). Some lay people had high expectations of treatment, with minimum benefits varying from 10% to 99% (see box 2). One doctor, two nurses, and seven lay people felt that any benefit would justify a large number of people taking treatment, even up to a million treated for one to benefit, although many required the treatment to be guaranteed cost free and risk free.

Benefits over time

Even those who gave numerically consistent answers usually wanted the same benefit over 10 years as over five; just one doctor, one nurse, and one lay person stated that the benefit should be greater if the drug was taken for a longer time. Guidelines use 10 year estimates of risk and benefit, although they are based on treatment trials usually lasting five years.[8 9] Absolute benefit roughly doubles over double the time, but almost nobody we interviewed appreciated this. Rather, 10 and five years were viewed as "a long time."

Shared decision making (see box 2)

Most lay people wanted to make decisions for themselves, based on information provided by health professionals. One thought that most people aged over 60 years, like herself, would not want treatment but that "they should be given a chance" (lay interview 1). This view was supported by clinicians (three doctors and three nurses), who wanted to help patients make their own decisions, but one doctor acknowledged that professional values might influence patient choices: "It depends on the way you sell it" (general practitioner 1).

Only two lay people wanted health professionals to make the decision.

Box 2: Participants' views on shared decision making, side effects, effectiveness, and cost

Shared decision making

"You've just got to allow people to make an informed decision and leave it up to them"—General practitioner 4

"I think it should be their choice"—Nurse 3

"I've got a particularly good doctor, very very good doctor, and I would put my whole trust in her. . . . If she advised it, I'd take it but not otherwise"—Lay interview 7

"I would like to rely on . . . whatever it is that approves these drugs . . . I would want to be very influenced by the experts"—Lay interview 17

Side effects and guaranteed effectiveness

"Yes, if you were sure you reduce your risk of getting a heart attack by 1 in a million—you could be the one in a million. If there is no cost, financial or medical risk, then it's worth it"—Lay interview 17

"I'd take it. But if you'd say 'It could have these side effects,' then I'd say no. Only if it was guaranteed and didn't do any harm, then it'd be OK"—Lay interview 15

"You should have a tablet that is going to cure 99% of people before you start giving it out. With technology the way it is, the idea of who should and shouldn't be going to have heart attacks should be better forecasted"—Lay interview 12

Costs

"You can't put a figure on it unless you are aware of the costs and side effects"—General practitioner 2

"At the final analysis, it becomes a financial decision. You know, do we keep people alive indefinitely until they are 150, and can the country, the world, afford to do that?"—Lay interview 16

"Why go on giving me these pills for a dubious quality of life, when . . . the same money spent on, I don't know, on reducing teenage pregnancy could have an enormous impact on 60 years of somebody's life? The best you can do for me is to give me an extra three or four years at 85; well I don't rate that as highly as improving, say, child nutrition"—Lay interview 18

Side effects and guaranteed effectiveness (see box 2)

All of the doctors, half of the nurses, and five of the lay people wanted to know about side effects before making a decision about the benefit required, so that they could balance benefits against possible harms. One lay person would not take a new treatment if the risk of side effects was unknown; some said they would stop taking tablets if they noticed any side effects, whereas others were happy to tolerate mild inconvenience if this were balanced with greater effectiveness. Six lay people wanted a perfect drug—either that there should be no possible adverse effects, or that it should definitely prevent all heart attacks. Some felt that only those patients certain to suffer a heart attack should take preventive treatment.

Cost (see box 2)

Cost of the treatment was mentioned spontaneously by all of the doctors, three of the nurses, and a third of the lay people; they felt it was inappropriate to choose the minimum acceptable benefit without considering costs. One person balanced the opportunity costs of treatment.

Pill taking (see box 3)

Seven lay people did not like the idea of taking medication—for example, "Tablets are a terrible thing" (lay interview 9)—but one person was not bothered by pill taking. Others were reluctant to take a drug without understanding its purpose. Three of the nurses and one doctor commented that patients or they themselves disliked medication, and half of the clinicians pointed out that there was no point prescribing drugs that would not be consumed.

Lifestyle (see box 3)

Three of the practice nurses found it frustrating to give drugs to people who were not prepared to adopt a healthier lifestyle, although they would not withhold treatment. Some lay people made similar comments, and two suggested that people who refused to alter their lifestyle (such as by stopping smoking) should not receive preventive treatment from the NHS. Many people we interviewed said they would prefer lifestyle change to an imperfect treatment.

Labelling

One lay person described the detrimental effect on the family of labelling someone with an illness: "If it's your mother or father, we know they have got something that they are taking the tablet for, so it is making us wary and more watchful of them" (lay interview 12).

Age (see box 4)

Opinion was divided on the relevance of pill takers' age (prompt 3, box 1). One doctor, two nurses, and eight lay people said that age would not influence a person's choice to take preventive treatment, but their expected quality of life should always be taken into account. One lay person felt her own quality of life did not justify the treatment, but continued to take it on the advice of her

Box 3: Participants' views on pill taking and lifestyle

Pill taking

"The ethos of taking tablets I find difficult"—Nurse 2

"But then they don't enlighten you what they're for. When you start off with them."
Researcher: "Do you think they should?"
"Yes I do. Yes—last time I went in hospital they said, 'You've got to take these. There's four boxes there; take one every morning.' What they're for, God only knows. So . . . I stopped them"—Lay interview 9

Lifestyle

"I am very sceptical about wonder pills. I mean, I think . . . heart attacks probably fall in that group of things which . . . preventative things other than taking pills are likely to be effective and cheaper—you know, like walking the dog, like running up the stairs, and not eating fat and not smoking. . . . People who don't want to have heart attacks, I think, know what they have to do . . . and I certainly wouldn't give the pill to anybody who smoked, particularly if it was expensive—if they smoked, drank more than, say, a little, and took no exercise. I'd say, 'Well try those three first, and once you've got those going, you know, come back and we can give you the pill'"—Lay interview 18

"I just found it really strange . . . there's this man prepared to take a statin that could damage his liver, and he's still gaily having bacon butties, you know, fried in lard"—Nurse 2

Box 4: Age and quality of life

Two lay people, aged 78 and 88, thought that having to wait years before seeing benefit from treatment was not worth it, but would consider treatment if there was a chance of imminent benefit:

"Five years ahead that's, at our age, let's be honest, that's way out"—Lay interview 11

"Well, as you get older you are not able to look after yourself, and there is always one left. I'm left; I've been 25 years a widow now. No, if the doctor took my tablets off me tomorrow that would not worry me. No, it wouldn't worry me . . . Well, you know, I take them. I will admit I still take them."
Researcher: "Why do you take them?"
"Well I don't know; I suppose it's habit, being on them so long"—Lay interview 6

doctor. Nine others felt that the benefit should be greater to justify treatment with increasing age. Clinicians' reasons for this included that a heart attack when young was more significant and that older people were likely to die of other causes before benefiting from treatment. Lay reasons included that, over a certain age, people would not want to be bothered with this type of thing (two included themselves) or that older people could not cope with side effects, as well as that older people would die before benefiting.

Discussion

Many of the preferences expressed by the clinicians and lay people in this study are at odds with recommendations in guidelines. The doctors made decisions more confidently than others but were not necessarily more consistent or logical. All our respondents found it difficult to discuss benefits occurring in 10 years' time; by using 10 year estimates, guidelines may artificially inflate the benefit of treatment (halving the number need to treat), and skew the opinions of clinicians and patients. In addition, health professionals often accept smaller benefits (larger numbers needed to treat) from preventive treatment than those being treated expect, though a few patients opt for treatment even when there is no anticipated benefit.[14–17]

In the concordant model of prescribing, doctors present the scientific evidence and elicit patients' views; patients consider the information and voice their preferences.[2] Most people we interviewed seemed to follow this model, which includes asking a healthcare professional to decide, but one effect may be that people choose not to take treatment.[4 18 19] Many patients want to be involved in decision making, but not all.[1 20] Such negotiated decision making is believed to lead to more realistic and ultimately sustainable treatment decisions.[5] Unfortunately, in practice doctors may mistakenly think they know what patients' preferences are, communication may flow only from doctors to patients but not in reverse, and many prescribing decisions are not shared.[19 21]

Whether someone views taking a pill every day as affecting their quality of life greatly influences their choice whether to accept treatment.[22] Labelling asymptomatic people, by telling them that they need treatment, may cause a reduced sense of wellbeing, increased absenteeism from work, and a feeling of loss of personal control over health.[3 21 23 24] Our study confirms the finding that many people are averse to taking drugs unless absolutely necessary.[21] Even patients taking preventive treatment may feel that drugs are best avoided, but on balance choose to take them, and some patients we interviewed were ambivalent about their own treatment.[3] Despite, this a combination of drugs to prevent heart attacks, the polypill, has been advocated for everyone over age 55.[25]

These findings represent the views of a small number of general practitioners, nurses, and lay people using a hypothetical scenario rather than actual treatment decisions. It is possible that an alternative scenario, or the same one presented differently, would have elicited different responses. Whether people wish to take such a drug, or wish resources to be used in this way, requires public debate, but our study suggests that some would prefer risk to be reduced by improved lifestyle rather than polypharmacy. In the current enthusiasm for guidelines, there is little about the need to listen to patients' views and to ensure they understand that they may take tablets for years with no benefit to themselves.

What is already known on this topic

Most people want to be involved in decisions about their medical treatment, but many prescribing decisions are not shared. Patients' preferences are often different to those of clinicians, and may lead to choices contrary to guidelines

Little is known about the factors which clinicians or lay people use to decide whether to start preventive treatment

Guidelines are based on arbitrary judgments of what benefit is worthwhile

What this study adds

Understanding the numerical basis for decisions about preventive treatment is difficult for both clinicians and lay people. Participants in this study wished to consider costs before deciding when people should start treatment

Many people dislike the concept of taking pills every day, and might choose lifestyle change rather than medication, if possible. Some people want only a perfect treatment, with guaranteed effectiveness and no possible adverse effects

The diversity of beliefs makes consensus unlikely, and guidelines should reflect this. True dialogue is required if patients' preferences are to be used to make decisions

Conclusions

Both clinicians and lay people in this study found it difficult to make logical decisions about preventive treatment, but most wanted to be involved in determining their own treatment. Many people would prefer lifestyle change to medication. Despite the political reluctance to discuss rationing and prioritising, we found a general acceptance that resources are finite and should be targeted where they are most effective.

There is a danger that increased pressure on general practitioners to prescribe some drugs (either political, such as national service frameworks, or financial, such as the new GP contract) may distort practice and marginalise patients' preferences. People's values are not predictable,[1 17 21 22] so probably the best way to ascertain their preferences is to ask them. The wide range of preferences makes consensus unlikely, and we believe guidelines should reflect the importance of true dialogue between clinicians and patients before embarking on lifelong preventive treatment.

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Contributors: DKL had the idea for the study. DKL and EW designed the study. DKL recruited and interviewed participants and analysed the transcripts for themes. JR reviewed the data and validated the analysis. All authors discussed key themes and concepts. DKL wrote the paper, and all authors revised it. DKL is guarantor for the study.

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Commentary: A small study, but the results ring true

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My own lifetime experience of chronic illness and my role as president of Arthritis and Rheumatism International, a trustee of the Long Term Medical Conditions Alliance, and vice chair of Disabled Living Centres Council indicate that my experience, although unusual, is highly relevant to the issues raised by Lewis and colleagues. I know that many patients wish to avoid drugs and would prefer lifestyle changes, and they want to minimise side effects from treatment. Thus, any preventive treatment would have to have minimal intrusion on quality of life for patients to pursue such a strategy. A well researched treatment that met these criteria and which increased patients' capacity to enjoy life and to manage their own condition would be uniquely valuable.

For nearly 48 years, since the age of 3, I have been pursuing a variety of treatments for severe juvenile rheumatoid arthritis. My role in this process has evolved from initially subservient compliance with my NHS general practitioner and consultant to a dominant partnership in my own health care. Rough calculations indicate that, between 1956 and 1976, I took 40 000 aspirin and 20-30 000 other pills (prednisolone, phenylbutazone, mepacrine, etc).

The trigger for my taking responsibility for my own body was through learning transcendental meditation while at university in 1973. Direct benefits in pain reduction, increased mobility, and blossoming self confidence coupled with encouragement from a friendly retired surgeon allowed me to gradually eliminate all drugs. My rheumatologist was furious: "I gave you permission to vary the dose, not stop altogether." I changed consultant rather than try to work with a man who made no attempt to listen to my views and showed no understanding of my values.

Many years on, I have a warm relationship with two general practitioners who themselves meditate but only an impersonal annual visit to my consultant. My general practitioners, who are both qualified in maharishi vedic medicine, treat me as an equal, and we exchange views frankly and freely. I can take their advice on issues I raise, and they can suggest options without the slightest hint of offence if I decline. My use of maharishi ayurveda herbal preparations, lifestyle changes (diet, frequent swimming, etc), and regular meditation mean that I minimise the possibility of side effects and maximise my resistance to future problems.

My only real criticism of this paper by Lewis and colleagues is that such a small number of people were interviewed. Based on my own experience, I would like to amplify some points from their research.

- True dialogue between patient and doctor is essential, and patients' preference and values must be respected
- Patients want to make decisions to maximise their quality of life, and negotiated prescribing will yield better outcomes than imposed treatment
- Doctors will tend to have different values from patients, but the imbalance of power in the doctor-patient relationship causes them to have undue influence. To counter this, I would recommend that greater emphasis be placed on listening skills in doctor training and that more opportunities for "expert patient" training be provided on a routine basis
- People dislike unnecessary drug taking and would prefer lifestyle changes to "imperfect treatment." (Is there such a thing as perfect treatment?) Unnecessary drug taking, which could include preventive treatment, can lead to the feeling of loss of control over health and reduce wellbeing, with subsequent negative impact on physical and mental health
- There is an urgent need to research those who decline treatment, and to provide alternative options including complementary therapies as required
- Finally, the cost of treatment is a huge issue. Cost is the biggest problem facing me, as I am living on a low income from incapacity benefit and income support. NHS treatments would be free, but herbal options and lifestyle choices cost money. Perhaps the NHS should fund well researched and patient friendly solutions such as transcendental meditation and maharishi ayurveda for those with chronic conditions.