

# Suffering in deference: a focus group study of older cardiac patients' preferences for treatment and perceptions of risk

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## Abstract

**Objectives**—To explore older people's experiences of health care in relation to their medical condition (ischaemic heart disease), their understanding of health risks, treatment preferences, and the impact of different treatments on their quality of life.

**Design**—Qualitative study based on five focus groups.

**Setting**—Five local heart support groups across London.

**Participants**—38 patients aged 56 and over who were members of local heart support groups, diagnosed with ischaemic heart disease.

**Main outcome measure**—Analysis of patients' narratives to identify key themes and issues using the framework method of qualitative data analysis.

**Results**—Cardiac patients would prefer to follow the cardiologist's recommendation for treatment, based on their medical expertise. If offered a choice, many said they would prefer to take medication, at least initially, as they would rather not undergo surgery. However, they accepted that, depending on their medical condition, they might not have a choice. Other factors that participants said affected their choice of treatments included their state of health, treatment outcomes, families' feelings, their age, and the previous number of operations they had undergone. They found it difficult to discuss risk in terms of numbers; most felt that a 3% risk of death from surgery was low. Instead, they discussed risk in terms of likelihood of treatment restoring quality of life. Patients expressed the fear that medication was not a cure and that surgical revascularisation is a traumatic experience that does not necessarily last forever. Participants felt that they needed further information on the impact of surgery and medication to make a more informed choice. Other barriers they felt they had faced in being treated were problems in accessing cardiologists and age discrimination.

**Conclusion**—It was apparent from these focus groups that few patients were involved in medical decision making about their treatment. Most preferred the doctor to make the decision and did want to be involved. Despite their experiences as cardiac patients, they required much

## Key messages

- There is little evidence of joint doctor-patient decision making despite the move towards greater user involvement.
- Greater use should be made of existing doctor-patient decision making models.
- Many patients are still unable to make fully informed choices and need more information.
- Older patients are more likely to accept medical professional advice without question.
- Older cardiac patients feel that they do not receive the same medical care and treatment as younger patients.
- Patients have difficulty in accessing specialist medical care for information.
- Patient preferences for treatment and perceptions of risk are based on outcomes and other factors such as state of health and family views rather than numbers.
- Information and communication systems require improvement through the greater use of named specialist nurses and self-help or patient groups.
- Further research is needed into the use of rapid access chest pain clinics to improve waiting times.

more information about treatment options for their condition before being able to make informed choices, where appropriate. Improved access to specialist care (cardiologists) and equal treatment by age are also required before patients' preferences can be elicited in practice.

(Quality in Health Care 2001;10(Suppl I):i23-i28)

**Keywords:** patient preference; treatment choice; decision making; patient-caregiver communication; ischaemic heart disease; geriatrics

While patients may expect their doctors to act in their best interests, there is evidence that clinical judgements in, for example, cardiology may be influenced by the sociodemographic characteristics of the patient, stereotyping, as well as health care resource constraints.<sup>1 2</sup> Patients, particularly older people, may not always be presented with the range of treatment alternatives appropriate for the treatment of their condition.

There is some evidence that older people consult their doctors later than younger people with symptoms of ill health, often present in an

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atypical manner, and they also experience a cumulative increase in diagnostic, referral, and treatment delays compared with younger people. These are among the most likely causes of the documented increases in emergency procedures in older people with cardiovascular disease, with their increased risks and costs.<sup>3,4</sup> Older people with acute myocardial infarction are also often denied access to specialist facilities such as admission to coronary care and cardiac rehabilitation services.<sup>4-11</sup> They are less likely to receive life saving thrombolysis where indicated, and are less likely to receive effective drugs such as  $\beta$  blockers on hospital discharge than patients aged under 60.<sup>9</sup> Documented age effects in the literature are independent of sex, and research also shows that women of all ages are less likely to receive effective cardiac treatments when needed than men. This is particularly disturbing given that heart disease is the main cause of death worldwide. It is also a major cause of death and disability among older people, particularly in the UK.

The evidence on treatment patterns by age and sex suggests that patients are not involved in the decision making process. It is ethically desirable to take account of patients' views before making policy or individual treatment decisions. Where quality of life and life expectancy issues are an important consideration, patients' informed preferences should be as important in health care decisions as the body of evidence on the clinical effectiveness and costs of a procedure. The active participation of patients in shared decision making about their health care is also an important dimension of contemporary models of patient centred care and of doctor-patient decision making, although these models are complex and many assume that patients are incapable of, or reluctant to, participate.<sup>12</sup> This is an area where empirical data are still required and our research aims to address this.

### Aims and recruitment

The study aimed to explore older patients' experiences of health care in relation to their heart condition, their understanding of health risks, treatment preferences, and the impact of different treatments on their quality of life.

The design was a qualitative study based on five focus groups held with local heart support groups across London and Essex, representing both affluent and socially deprived areas, during the spring and summer of 2000.

Recruitment of participants for the study was organised by the British Heart Foundation. Patients' permission to participate was sought verbally by the British Heart Foundation which personally approached five heart support groups to invite people aged over 60 with a cardiac condition to take part. Information was given to them about what the research was for and what participation would entail.

### PARTICIPANT CHARACTERISTICS

A total of 38 patients (26 men, 12 women) agreed to take part. All were aged 56 and over, 15 (40%) were aged over 70 years. All had been

diagnosed with ischaemic heart disease including myocardial infarction. Thirty five of the 38 participants had been referred to a cardiologist, two had not, and one did not respond. Nineteen of the participants (50%) said their condition had been treated with medication only, 11 (29%) had undergone surgical revascularisation (coronary artery bypass grafting), and six said that they had received both medication and surgical revascularisation.

### Methods

Five focus groups formed the main method of data collection. Focus groups are collective discussions that are designed to explore a specific set of issues. They are a qualitative technique appropriate for exploring patients' knowledge and experiences, examining not only what they think but why they hold a particular opinion. They can reveal dimensions of understanding that often remain untapped by quantitative data methods.<sup>13</sup> Focus groups explore people's understanding of issues by encouraging interaction between research participants. When group dynamics work well, the participants act as co-researchers taking the research into new and often unexpected directions and engaging in complementary and argumentative interaction in which common experiences and opinions can be shared or explored by questioning, challenging, and disagreeing with each other.<sup>14</sup>

A topic guide was developed from the literature on access to health care, and also from the findings of a prior qualitative study exploring the barriers to referral in patients with angina.<sup>15</sup> The topic guide was piloted successfully during the initial focus group and amended as required. It covered the patients' pathway through the health services from diagnosis, tests and treatment, aftercare, and outcome (impact on quality of life). All participants also completed a short structured questionnaire which collected demographic details. Patients were not offered information on the range of treatment options and their risks and benefits as it was intended to ground the data in their experiences and knowledge without our interference.

The discussions were audio recorded with participants' written permission and the tape transcribed for analysis. The transcripts were coded and analysed using the framework method<sup>16</sup> of qualitative data analysis. This method involves coding the transcripts from an index generated by views and experiences expressed in the focus group. The codes are then grouped together under themes that form the basis of the findings of this study. The themes presented here include: participants' preferences for involvement in decision making about treatment, need for information, age discrimination, perceptions of risk, and access to cardiologists.

### Results

#### THERE IS LITTLE EVIDENCE OF JOINT DOCTOR-PATIENT DECISION MAKING

The findings of the focus groups showed little evidence of joint doctor-patient decision

making—for example, many patients said that they were not involved in the decision making process about their treatment. Instead, participants said that medical professionals made decisions about their medical care and treatment.

*“He (the cardiologist) put me on medication, they didn’t want to do a bypass then . . .”* (Woman)

*“Well they decided, . . . after they done the angiogram they came back and said that the right coronary was blocked 90% and that they were deciding what to do, whether it would be medication, an angioplasty or open heart. So they decided it was an angioplasty.”* (Man)

One participant felt unhappy as the doctor refused his request for an angiogram. Instead, he was prescribed medication without having his arteries checked first.

*“No it wasn’t explained. Apart from telling me there’s an 18 month waiting list for an angiogram, that was the only explanation I got, so even though I wanted it and felt that I should have it, he wasn’t going to give it to me.”* (Man)

#### PATIENTS ARE UNABLE TO MAKE FULLY INFORMED CHOICES DUE TO LACK OF INFORMATION

Many participants also said that they were not fully informed about their medical condition, treatment options, and outcomes.

*“From the medical staff, i.e. the doctors etc you get very, very little information really, they don’t . . . you seem to be passed on one to the other down the line and everyone sees the big man first and from there on in you don’t really see him again until possibly something occurs to you or they need you for an operation or something like that.”* (Man)

Three participants were very confused about their ischaemic heart disease.

*“So what exactly is angina? I mean is it the tube . . . you know, your arteries furred up, just sort of the blood going to the heart or . . .?”* (Woman)

A few participants felt that information about treatment options was presented to them in a way that ensured compliance with medical advice. For example, one woman felt that the information she was given was designed to discourage her from wanting surgery by stressing its risks. Without sufficient information, patients are unable to make informed choices.

*“I don’t know really, I can’t say (about choice of treatment). I want to see someone to tell me exactly what is what. I know I’ve got angina, but Dr C I thought was pulling the wool over my eyes, saying it was mild just to calm me down, because she also told me there was a risk of flying, you know, sort of thing . . . So I know I’ve got more than mild angina, and I want to know what this syndrome thing is. I’m on the maximum dosage of this medication . . .”* (Woman)

#### PATIENTS ARE SOMETIMES TOO UNWELL TO TAKE PART IN THE DECISION MAKING PROCESS

A few patients stated that choice was not an issue when they were admitted as emergency patients or to intensive care.

*“I don’t think you’ve got a lot of choice when you’re in intensive care have you?”* (Man)

#### PATIENTS NEED INFORMATION

Participants wanted to be kept informed about their medical condition, treatment options, and outcomes as it provided them with feelings of control and reassurance in an unfamiliar and frightening situation.

A few participants gave examples of good information provision (see box 1). These included:

- Asking patients how informed they want to be.
- Use of specialist nurses.
- Referral to self-help groups such as the British Heart Foundation.
- Referral to local cardiac patient exercise and rehabilitation groups.

#### PATIENTS HAVE DIFFICULTY ACCESSING A CARDIOLOGIST

A number of participants said that they had difficulty accessing a cardiologist. Obstacles included difficulties obtaining a referral and long waiting times. As one participant pointed out, it is only the cardiologist who can give you all the relevant information about your medical condition, treatment options, and possible outcomes.

*“No they don’t tell you enough. One of the reasons I believe . . . especially these two local hospitals is that we’ve got an enormous turnover of people. We’ve only got one cardiologist, so the chances of you actually getting to see the heart specialist are 99 to 1.”* (Man)

*“But XX is about the only person I know of, or within the British Heart Foundation, who keeps you on the ball, who can tell you and give you . . . and get you the right information all the time . . .”* (Man)

*“I wrote to the Heart Foundation and got all the leaflets which is very, very good, ‘cos reading makes you feel safe . . . the Heart Foundation information, they’ve got all sorts of leaflets, and they have drawings and you more or less know what’s going to happen to you—it’s very, very reassuring.”* (Woman)

*“They did have a cardiac nurse . . . who took me aside before I came out and explained everything to me and gave me an exercise pack and also I could have gone to the . . . chest hospital . . . It was all explained to me before anything happened.”* (Man)

*“I was told all the way through what I was going to have and why. And I think it’s very important for people that one knows exactly what is going on.”* (Woman)

*“When I first had my angina they gave me a form asking the question did I want to know everything that was going on, did I want to know only part of it or nothing at all, and I ticked that I wanted to know everything that they were doing to me and they told me. Mind you some of the things frightened me but I did get told . . . So I didn’t have that worry of what was going on or what was going to happen, so I suppose I was lucky in that respect.”* (Woman)

Box 1 Good examples of patient information and informed consent.



*"But the registrar came round one day ... the operation was due for 11 o'clock, by 4 o'clock I still hadn't gone in. This went on for two days and on the third my children came down and they said look she's not a young woman...I was 73 at the time...you have got to do something about her now. So the registrar said well at her age we can perhaps give her another 3-4 years to live. Had she been 50 we could have guaranteed 10-15 years. So I said well I'd rather have, you know, 3-4 good years instead of having one bad year. Well I've managed for six and a half years now." (Woman)*

*"Because you're 65 you're classified as if you're half dead so just wait." (Man)*

*"After I had the angiogram and they told me I would have to have an operation, I went to see my doctor and he said to me . . . two things . . . you have a disadvantage because of your age . . . I'm 75; and you've got one advantage is that you're very healthy." (Woman)*

*"I think its diabolical to be honest, don't think they treat you...you're just a number. As I say I'm on the wrong side of 60 now, perhaps that has something to do with it." (Woman)*

Box 2 Perceptions of ageist treatment: patient views.

Several patients said that they had consulted with a cardiologist privately because of the difficulties they faced accessing one within the NHS.

*"I was getting nowhere with my GP at the time, so I made an appointment to go and see a private ... a specialist at the X hospital in Y. I went to see him at 5 o'clock in the afternoon and at 8 o'clock that night I was in X hospital and a fortnight later I was in the Z hospital having an angioplasty." (Man)*

Another participant said that the creation of a lunchtime chest pain clinic at her local hospital trust had significantly increased access and decreased waiting times.

*"The new (chest pain) unit that they've opened . . . you only have to go and see your doctor and get a letter and come up the next day. I was up last week between 12 and 2 and you were seen straight away . . . you don't have to go to A&E or anything like that . . ." (Woman)*

#### OLDER PATIENTS ARE MORE LIKELY TO ACCEPT MEDICAL PROFESSIONAL ADVICE

In addition, participants said that, due to their age, they were more likely to defer to the advice of medical professionals. As a number of cardiac patients pointed out, they are lay people while cardiologists are experts.

*"I think also this affects age. If you are of a certain age, and I think we're all of a certain age here, we tend to feel right we're in the doctor's hands and whatever they say should be right." (Man)*

#### AGE DISCRIMINATION

Several participants felt that they did not receive the same care and treatment by health professionals as other patients because of their age (box 2). Two participants said they were moved to the geriatric ward after treatment for acute myocardial infarction.

*"When you go in and you're over a certain age you are stuck in . . . or put in the geriatric ward regardless of whether you are geriatric or not." (Man)*

Participants' negative perceptions of geriatric wards are illustrated in box 3.

#### PATIENT PERCEPTIONS OF RISK

Participants found it difficult to discuss their perceptions of the risks of surgery beyond stating whether they thought that a 3% risk of death during an operation was either high or low. Most participants thought that a 3% risk of death was low, with two saying it was high.

*"Three per cent is very low. You know, you might just be the unlucky one... I'm not really worried... 3% I think is a very good figure actually if you take into account the number of operations that are done." (Man)*

#### FACTORS AFFECTING PATIENT DECISION MAKING

However, participants' perceptions of risk were not a reliable indicator of treatment preference. Many factors would influence their choice of treatment preferences such as their state of health, age, prognosis, medical advice, previous medical history, and the views of their family. Patients said that they would need information on all these factors before they could make a fully informed decision (box 4).

#### PATIENT PREFERENCES FOR TREATMENT AND PERCEPTIONS OF RISK BASED ON OUTCOMES

Participants found it helpful to discuss treatment preferences and perceptions of risk in terms of their impact on quality of life. For

*"I can tell you about the geriatric ward..." "Terrible." "My wife's been to visit people in there . . . she went in the toilet and there was no toilet rolls . . ." "The treatment in geriatric wards is . . . it's right next to the morgue usually isn't it, 'cos that's where they want to put you? Not joking, I mean it." "Not at XX hospital fortunately (chuckle), at the moment." "Geriatric ward is to get rid of you." "Yeah." "I was in the geriatric ward, they put me . . ." "Now this is a person under 60 that's been put in the geriatric ward . . ." "They put me in the geriatric ward with a heart monitor on, and I could not hear the heart monitor peeping because of the noise; and they brought the dinners round and it was like what the cat brought up . . . And they plonked it on this poor woman's bedside table there, and she was lying there, and she couldn't get up because she just could not get up, and when they come round to . . . take the dinners away it was exactly the same place where they left it. They (nurses) didn't come out, they didn't say to her 'Would you like me to feed you' . . . Nobody bothered." "They did clean up the ward when I was there (chuckle)." "See, the thing I'm trying to say is that if you're of a certain age . . ." "Yeah, they get rid of you." "Yeah, you're a burden." "You're a nuisance." "I mean, with all the best will in the world, it's wrong. You should be classified on what's wrong with you, not how old you are."*

Box 3 Perceptions of geriatric wards: transcript.

*"I don't think that any of us here are alone. You have family, you have people ... you don't make a decision on your own, you have a wife or children." (Woman)*

*"Not without knowing in detail what the conditions are which are different from person to person at any rate; but I rely on my consultant who knows the full details to decide and let me know. If he tells me it is imperative that I must have the operation I've got no option." (Man)*

*"After my last angiogram he (doctor) said to me, you know, would you like us to leave you on the same medication, it seems to be doing you good, or you know, we can do the surgery again. And my children said no ... no surgery. I spoke to my doctor and I heard him say, you know, this patient doesn't want it so I'll leave her on the same medication which will see me through." (Woman)*

*"I think one of the shortcomings is that when you say surgery or pills they don't tell you what the prognosis is on the pills ... either in terms of their effectiveness or in terms of their danger And that is what needs to be addressed." (Man)*

*"I've had so many operations through my life I'd had enough. If medicine would hold it and do the job then medication." (Woman)*

Box 4 Factors influencing patients' decision making.

example, participants who were unwilling to undergo surgery expressed fears about the physical impact of the procedure. Many said that they would prefer to take medication, at least initially.

*"I would try medication first . . . if I had the choice . . . definitely." (Woman)*

One participant felt that this preference for medication was based on their age.

*"If we were in our twenties or our thirties and were given the option of open heart surgery or pills, I'm sure a lot of us would have said open heart surgery because the extent of your life span is ahead of you, and you need to be 100% fit. Whereas with pills they may work but take an awfully long time to do so. So I think it's an age thing as well. If you're over a certain age you say to yourself, well it's very traumatic to have open heart surgery ... or any surgery for that matter, if pills are going to give me a chance I'd sooner go on the pills. I think it's a lot to do with age." (Man)*

Other participants expressed concerns about how long surgical revascularisation would last, potentially necessitating further operations in the future.

*"It's not just the case of having surgery and thinking to yourself, well that's it, that's cured 'cos it ain't . . . 'cos they wear out . . . they wear out . . . and you have to have it done again. So what you have to think about is, is it best to have it done and for 10 years think to yourself 'oh lovely', or is it best, as they say, to keep taking the tablets for the rest of your life." (Man)*

However, participants who were willing to undergo surgical treatment emphasised how it could improve and restore their quality of life in a way that medical treatment could not. They pointed out that medication was not a cure for blocked arteries, only stabilising their medical

condition without preventing continued deterioration.

*"Pills are not a cure, they contain a problem but they're not a cure." (Man)*

## Conclusions

Although this study was based on just five focus groups, they were spread between affluent and more socially deprived areas of London and Essex. The focus groups provided a qualitative means of obtaining insight into older patients' experiences, understandings, and preferences in relation to cardiovascular disease and treatment rather than being statistically representative of the total population. One limitation of the study was the lack of adequate representation of people from ethnic minorities—possibly due to the self-selecting nature of the sampling strategy. The perceptions of people from ethnic minority groups require addressing in any future research by using a sampling strategy that specifically targets these groups in the local population.

A preference is an attempt to weigh up, consider, and express a value for alternative choices of action. It is clear from this study that participants were unable fully to express their preferences for treatment (medication or revascularisation) as they were relatively uninformed about their condition. Most wanted more information before feeling able to discuss choices. Few participants were involved in medical decisions about their treatment, even when there might have been a choice. While most preferred the doctor to make the final decision about treatment options, they still wanted to be involved in the decision making process and expressed concern when they did not feel they were being treated with respect. Patients need to feel that medical professionals have taken into account all the factors that affect the decision making process including their state of health, medical history, personal, and family views. A more detailed discussion on patient preferences for participation in decision making appears in the paper in this supplement by Robinson and Thomson.<sup>17</sup>

Improved levels of communication with patients by medical staff and insight into the patients' fears and understanding of their condition and treatment is needed before patients' preferences for treatment can be exercised with any validity. Our findings show that communication can be better facilitated by the use of automatic systems of information provision by, for example, specialist cardiology nurses on admission to hospital and referral to self-help or patient groups—strategies that reduce patients' dependence on the cardiologist as the sole source of knowledge.

Improved and equitable access to specialist care is also required before patients' preferences can be elicited in practice by, for example, the use of rapid access chest pain clinics to reducing waiting times.

Patients inevitably have different understandings of their illness and treatment from doctors, based on their personal experiences, and it is important to elicit these for fully informed patient decision making. Listening to

patients as “experts” is also essential in order to address socially inequitable access to health services.<sup>15</sup> This is particularly important in the case of patients from socially deprived areas and in older age groups—those most at risk of cardiovascular disease and reduced access to treatment—who may be less confident in communicating with doctors. Because older patients suffer in deference does not mean that they are satisfied and would not like their care and treatment to be different.<sup>18</sup>

The authors would like to thank Stefanie Lillie of the British Heart Foundation for arranging access to the Heart Care Support Groups, the members themselves for their willingness to participate, and Jacqui Riesel and Fatema Hussain for assistance with the focus groups and Chris Williams for transcriptions.

Ann Bowling initiated and commissioned the study and, together with Catherine Kennelly, designed and set up the study; Catherine Kennelly carried out the five focus group interviews, analysed the data and reported the findings; Ann Bowling carried out the literature review; Catherine Kennelly and Ann Bowling interpreted the data for this paper. Funding: internal (AB).

Competing interests: none declared.

University College London is a member of the MRC Health Services Research Collaboration, of which Bristol is a lead centre.

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