

## Barriers to referral in patients with angina: qualitative study

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*BMJ* 1999;319:418-21

### Abstract

**Objectives** To explore barriers to patients being referred for possible revascularisation.

**Design** Qualitative study using semi-structured interviews.

**Participants** 16 patients aged under 75 years with stable angina and their doctors.

**Setting** General practice in Toxteth, Liverpool.

**Results** Fear of both hospitals and medical tests was common and largely hidden from the doctors.

Patients felt they were old, had low expectations of treatment, viewed angina as a chronic illness, and knew little about new developments in angina treatment. Patients and doctors had difficulty in recognising angina symptoms that were not textbook definitions amid multiple comorbidity. Patients saw doctors as busy and did not want to bother them with their condition. Cultural gaps and communication difficulties existed despite all but one patient having English as their first language.

**Conclusions** Listening to patients is vital to address inequitable access to health services: how patients are treated by doctors today affects acceptability of referral tomorrow. Primary care groups in deprived areas should work with communities to address local fears. This will involve collaboration between primary, secondary, and tertiary care. Cultural gaps exist between patients and doctors in deprived areas, and diagnostic confusion can occur particularly in the presence of other psychological and physical morbidity. Adequate time and resources—for example, education for doctors and patients and provision of interpreters—need to be provided if inequitable access to revascularisation procedures is to be addressed.

### Introduction

For six years one of the authors (KG) had struggled to refer a patient with severe angina for possible revascularisation. Although surgery visits were preceded by concerned phone calls from the patient's family, the patient played down the symptoms. The author's practice in Toxteth, Liverpool is situated 3 miles from the nearest cardiology provider units and serves three very deprived inner city wards. An inverse correlation exists between deprivation and rates of revascularisation in Liverpool, reflecting inequalities throughout the

United Kingdom.<sup>1</sup> Contributing factors cited include socioeconomic status,<sup>2-5</sup> ethnicity and race,<sup>6,7</sup> and sex.<sup>8,9</sup>

In 1994, when the issue of inequitable access was highlighted by public health professionals, the author's practice decided to refer patients with new or recently diagnosed stable angina without severe comorbidity to a cardiologist for assessment. A review of patient records indicated that reasons for non-referral might include multiple physical and mental health problems and a combination of beliefs and attitudes in patients and their doctors. Payne and Saul<sup>5</sup> documented inequitable access in Sheffield and recommended "an audit of referral of angina patients particularly seeking to redress apparent inequality." Green and Britten<sup>10</sup> highlighted the value of qualitative work in understanding and enriching quantitative studies. Our study attempted to discover barriers to referral in patients aged under 75 with stable angina, and we explored barriers in the patients and within the patient-doctor interaction.

### Participants and methods

Our study was approved by the local research ethics committee as it was part of practice audit.

We identified patients aged under 75 years with stable angina diagnosed within the past 10 years from computer search and drug use. If the diagnosis was unclear we confirmed it from medical records. Overall, we identified 68 patients. Our study group comprised 15 patients who had not been referred to a cardiologist for assessment and without prohibitive comorbidity—for example, severe asthma or cerebrovascular accident. We interviewed these patients and their four doctors. KG's patient was included. The study patients were typical of those living in the practice area.

### Interviews

We invited patients by letter to participate. Their doctor explained to them that the practice wanted to improve services for patients with angina, and that interviews would be conducted by a doctor from the practice (KG) who was on a year's sabbatical. Most of the patients knew KG, at least by sight. No patient refused to be interviewed. The problems of doctors interviewing their own patients are discussed elsewhere.<sup>11</sup> Patients were interviewed, usually in their own

homes, using a semi-structured interview guide. The doctors were also interviewed. Interview guides (KG, personal communication) were developed after studying the literature on access to health care, focusing on ischaemic heart disease, health beliefs, and referrals from doctors. The interviews were audiotaped and fully transcribed by KG.

### Analysis

Emerging themes (or categories) were developed by studying the transcripts repeatedly and considering possible meanings and how these fitted with developing themes. Diagrams were used to focus on what was emerging and to link patient and doctor themes into major barriers to referral. Transcripts were also read "horizontally", which involved grouping segments of text by theme.<sup>12</sup> Towards the end of the study no new themes emerged, which suggested that major themes had been identified.

A debate exists about how best to ensure reliability. The authors agree with Morse<sup>13</sup> that only the interviewer really knows the material in depth. However, two transcripts were read independently by the coauthor (AC) to check on major themes emerging. Although this was a small study in one practice, themes emerged that coincide with findings from studies currently in progress (H Richards, personal communication).

## Results

Barriers to referral were centred in patients within their cultural and social environment and in the doctor-patient interaction.

### Fear of hospitals, operations, and medical tests

The major barrier was fear of hospitals, operations, and medical tests. This was mentioned by 12 patients but remained largely hidden from their doctors. Feelings ranged from intense dislike to terror. Fears were based mainly on the patients' experiences or those of their relatives but also on community myths. Patients talked about relatives and friends who had died in hospital:

"Me mum went in there, she never came out. Me brother went in and he never came out. He came out in a pine box." (Patient 6)

Several patients mentioned cowardice in relation to medical tests:

"Every time I go there [for a blood test] my bottle goes ... I'm just a coward." (Patient 6)

Although doctors felt that the approachability of cardiologists should be one of their most important qualities, they underestimated the extent of patients' fears. The doctor of patient 6 mentioned a "culture of illness" within the local community, misinterpreting fear as a desire to remain ill for financial benefits. He did, however, know of myths about hospitals among black elderly patients in the practice area:

"They give you anecdotal stories saying my friend went in and died. It might be that people are not taking things seriously until it creates a terminal problem. They probably end up in hospital and die. Then it reinforces the myth." (Doctor M)

### Angina as a chronic illness to be managed or denied

Patients knew little about angina treatments, especially revascularisation procedures. They coped with angina by limiting their lifestyle and sometimes by denying their illness:

"I manage the angina. ... If I get pains in my arm I lie down, take an extra aspirin and hope for the best." (Patient 1)

"I sleep a lot in the day. There's nothing else to do. If I get up and start dashing around it makes me bad, so I take it easy and have a sleep. That's the best cure you know." (Patient 12)

One patient, with a controlled psychotic illness, illustrated the use of denial:

"Going to hospital every day with something wrong with you, it's just admitting to yourself, if you dwell on those things, that you're not valuable, you're not part of normal life." (Patient 7)

### Patients' perception of age and its effect on expectations of treatment

Patients generally had a fatalistic view of their health and life expectancy. One patient said about referral:

"If I was taking someone else's place younger I'd say no I've had my life, I'll take my chance." (Patient 1, aged 68)

Patients perceived themselves as old and unworthy of attention:

"As far as the heart, it's probably old age, and you know the whole change of life." (Patient 7, aged 54)

The partner of one patient (patient 8, aged 53) with a moderately well controlled psychotic illness said:

"He says he's in his twilight years doc."

### Diagnostic confusion

Diagnostic confusion was a barrier for both doctors and patients, especially in the presence of other morbidity. The two most commonly confused problems were anxiety and heartburn or indigestion. Two patients had confused myocardial infarction with indigestion:

"I get these feelings in my neck, probably when I get upset about something or when I've eaten a heavy meal. I get a lot of indigestion. Whether that's indigestion or truly a symptom of—you know." (Patient 11)

Several patients had both angina and anxiety:

"It's not a pain or anything, it's er, a horrible feeling, as though my last day had come... I tend to panic as well like." (Patient 5)

Patients with little knowledge of angina are likely to describe vague symptoms, constituting a barrier to both diagnosis of angina and assessment of severity. As one doctor stated:

"It's just not neat and tidy." (Doctor B)

### Cultural gaps in the doctor-patient interaction

English was the first language of all the patients except one. A cultural gap, however, existed between the doctors and the patients despite the practice having a reputation for openness and informality. Patients perceived doctors as busy and did not want to bother them with angina. They often had many problems to discuss, and only mentioned angina at the end of the consultation. Patients' choice of words frequently made their accounts difficult to follow:

"There's different things besides like as I say me angina and me arthritis and plus other things, like I go dizzy if I'm up for an amount of time. I've started walking into walls sort of type." (Patient 3)

Thus doctors did not always pick up the extent of patients' suffering, which was in any case submerged in a host of other problems:

"Patient 3 is another example where the consultation tends to get crowded with a variety of things and the point of exit is: can I have my GTN spray? ... the longer you know a patient the more you get into their social and psychological problems and they become higher up in most of their consultations." (Doctor M)

One patient from the Yemen, interviewed through an interpreter, described pain as:

"In the chest, the ribs, under the chest and all her body." (Patient 10)

This patient was unable to read English, was not taking the drugs prescribed, and had a history of missing outpatient appointments. The patient's doctor felt that angina was present, but that the patient was unlikely to comply with referral to clarify the diagnosis or instigate investigations.

## Discussion

Listening to patients as "experts"<sup>14</sup> is essential in addressing inequitable access to health services. Qualitative research is generalisable in certain circumstances.<sup>15</sup> Although this was a small study in one inner city practice, it may help to sensitise doctors and other health professionals to issues involved in referring patients with angina.

Patients from deprived areas may be less confident in dealing with doctors than their more affluent neighbours. They may be ashamed of their fears and unwilling to admit them. Efforts have been made recently to improve communication between doctors and patients in primary care.<sup>16</sup> Similar efforts should be made in secondary and tertiary care if self-perpetuating myths and fears in patients and local communities are to be dispelled. A bad experience today has negative consequences for tomorrow.

Life expectancy of people in deprived areas is less than that of people in more affluent areas, and they tend to perceive themselves as old and therefore unworthy of attention. This, coupled with patients' perception of angina as a chronic illness and their deference to doctors (not wishing to waste their time), negatively influences their expectations of treatment. Patients in our study accepted their fate and the limitations angina imposed.

Angina as experienced in primary care, particularly in a deprived multicultural inner city area, may not be the same as a textbook definition. Patients with comorbidity had difficulty highlighting symptoms for themselves. In a study of patients who had had heart attacks Ruston et al<sup>17</sup> noted: "The most crucial factor influencing time between onset of symptoms and calling for professional medical help is that patients and others recognise their symptoms as cardiac in origin." Defining whether patients had angina for the purposes of our study was sometimes difficult. Possibly neither patients nor doctors correctly attribute symptoms to angina. Cultural gaps between doctor and patient regarding angina have been documented in minority

## Key messages

- In different communities and patient groups different myths and fears operate and need to be addressed, as experiences of hospital can profoundly affect patients' confidence
- Patients in deprived areas with high mortality rates perceive themselves as "old" at a young age, and expectations of treatment are limited
- Angina symptoms in inner city primary care may not be the same as those in a textbook, and this has implications for care of patients
- Cultural gaps exist even between committed doctors and their patients in deprived areas—time and resources are needed to address these gaps
- Qualitative studies are necessary to understand quantitative evidence of inequitable access to specialist health services

ethnic groups, particularly south Asian patients.<sup>18</sup> The study practice has a high (35%) black and minority ethnic population with substantial numbers from Somalia and Yemen. Patient 10 was illustrative of many patients who need extra time and help to access the healthcare system effectively. Our study also, however, highlighted cultural gaps within the white British population, connected with class, language, and probably literacy levels. Pendleton et al<sup>16</sup> examined the doctor-patient consultation and found that "the main category of communication difficulties appears to be interference of some sort in the transmission of information. These interferences may be cognitive, emotional and social." To compensate for these, consultation time and resources (for example, education for patients and doctors) are essential.<sup>19</sup>

We thank the patients, Robin Cope, Lisa Williams (Liverpool Primary Care Information Initiative), Helen Doyle and Hermione Lovel (Department of General Practice, University of Manchester), and colleagues from Liverpool Health Authority and Liverpool Cardiothoracic Centre.

Contributors: KG had the original idea for the research which was refined by AC. KG carried out the study. AC was involved throughout in supervising the research and in discussing data analysis. AC enabled KG to understand the potentials and pitfalls of qualitative research. AC commented on the finished paper. Martin Roland (National Primary Care Research and Development Centre, University of Manchester) advised on the research proposal, contributed to the ongoing discussions, and commented on the paper. Trevor Gibbs (Department of Primary Care, University of Liverpool) enabled KG to structure the paper. KG will act as guarantor for the paper.

Funding: This study was carried out as part of a one year full time MSc in primary care at the University of Manchester and was funded by an extended study leave grant from the Department of Health.

Competing interests: None declared.

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(Accepted 4 May 1999)

## Commentary: Generalisability and validity in qualitative research

Judith Green

Gardner and Chapple's study illustrates both the valuable insights that can be derived from qualitative work and the difficulties of demonstrating the credibility of such findings in medical journals. This study "sensitises" practitioners to possible barriers to referral, such as fear of hospitals and fatalism about the inevitability of morbidity with ageing. It also reminds us that in the real world symptoms are experienced and accounted for in consultations not as diseases with textbook clarity but as facets of a more diffuse illness experience. Rather than identifying the exact proportion of a population with particular health beliefs, qualitative research can unearth beliefs that may be hidden in less respondent centred study designs or within a busy consultation with a doctor.

Such insights, however, can also be derived from novels, patient anecdotes, or journalism, which clinicians have always used to inform their communication with patients, alongside evidence from research studies. It is the purported credibility of findings that sets qualitative research apart from these other non-research sources: it makes claims, however implicitly, to being valid and to having some generalisability beyond the particular situation or setting described.

Set against the conventions of good research design, a study carried out by a single general practitioner on patients from his or her own practice in one site surely raises legitimate questions about objectivity and generalisability. To what extent are the barriers reported here an artefact of the interviewer-interviewee relationship—for instance, what patients thought the general practitioner wanted to hear? To what extent is fear of hospitals rooted in local myths, which have no relevance in other parts of the country? How far can we really conclude from this evidence that cultural gaps between deprived populations and their healthcare providers really contribute to the "health divide" without a comparative group of more affluent patients?

In qualitative research, issues of validity and generalisability are essentially the same as those in quantitative studies—establishing the truth of accounts (in that they represent some reality outside the research itself)

and adding to theory (in that the findings are applicable to a population or setting wider than that of the study). Attention to questions of reliability is essential.<sup>1</sup> In interview studies, this involves careful transcription, thorough and systematic coding, and a justification for data extracts chosen for illustration—for instance on grounds of representativeness. In addition, credibility in the findings and conclusions drawn depends on information about context. This includes information about the prompts used to generate data and the research setting, both of which can have a significant impact on the content of accounts given by participants,<sup>2</sup> and the theoretical framework used to make sense of the data. Data extracts taken out of context tell us little about the situated nature of beliefs and behaviour, and inferences that are not rooted in a theoretical understanding are unlikely to be generalisable to other settings. Most important is evidence that the researchers have explicitly sought to falsify emergent hypotheses, for instance by theoretical sampling and accounting for deviant cases within their dataset.<sup>3</sup>

The use of a single site or a small sample size does not in itself threaten the validity or potential generalisability of a qualitative study. Although there is not enough space in a short paper to ground the findings in a broader literature or to discuss how deviant cases were handled, the authors have used comparative material to strengthen the credibility of their findings, and the second author was involved in the analysis providing some analytical distance on the data. The generalisability of this study does not derive from the representativeness of the sample, but from the concepts (such as fear of hospitals or fatalism about ageing) that may well be relevant to other settings and patient groups.

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