

# Primary care

## Barriers to uptake of services for coronary heart disease: qualitative study

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Angela M Tod, Cathy Read, Anne Lacey, Jo Abbott

Public Health,  
Rotherham Health  
Authority, Bevan  
House, Rotherham  
S60 3AQ

Angela M Tod  
*researcher*

Jo Abbott  
*coronary heart disease  
national service  
framework facilitator*

Public Health,  
Sheffield School of  
Health and Related  
Research, Sheffield,  
S1 4DA

Cathy Read  
*senior registrar in  
public health medicine*

Anne Lacey  
*research fellow*

Correspondence to:  
A M Tod  
cm4at@sheffield.  
ac.uk

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### Abstract

**Objectives** To identify factors within the South Yorkshire coalfields that influence use of health services by people with angina.

**Design** Qualitative study using semistructured individual and group interviews.

**Setting** General practice and community settings in Barnsley and Rotherham health authorities.

**Participants** 14 patients with stable angina and nine primary care staff had individual interviews plus five community groups and one group of general practitioners.

**Main outcome measures** Barriers to accessing health services.

**Results** A complex web of factors was identified that prevented, delayed, or facilitated referral to secondary care. Delay, denial, and self management by patients meant that the full extent of symptoms often remained hidden from general practitioners, resulting in a delayed or missed referral. Barriers identified fell into six categories: structural, personal, social and cultural, past experience and expectations, diagnostic confusion, and knowledge and awareness.

**Conclusions** Many of the factors influencing referral operate before general practitioners become involved. Community development could be one way of tackling inequalities and promoting sustainable change. Structural changes are needed to improve access and increase the acceptability of general practice services. Primary care staff should be educated to detect underreporting of symptoms and promote appropriate referral.

### Introduction

Coronary heart disease is the main cause of premature death in the United Kingdom, but there are regional and socioeconomic differences in its incidence and prevalence.<sup>1</sup> Death rates in Barnsley, Rotherham, and Doncaster, the area which makes up the South Yorkshire Coalfields Health Action Zone, are among the highest in England and Wales.<sup>1,2</sup>

Evidence of inequalities in health and in access to health services, including services for people with coronary heart disease, is well documented.<sup>3,4</sup> Notably, an inverse correlation exists between deprivation and rates of cardiac revascularisation.<sup>5,6</sup> This is reflected across the South Yorkshire coalfields, where communi-

ties with the greatest need have lower referral rates and uptake of services than more affluent communities. In inner city Liverpool, Gardner and Chapple found that fear of hospitals, denial of ill health, and low expectations were preventing people with angina from accessing secondary care.<sup>7</sup> We used similar qualitative research methods to identify barriers and facilitators to referral across the former coalfields area.

### Participants and methods

We used qualitative methods to allow us to explore the complexity of, and inter-relationship between, the issues and processes identified.<sup>8</sup> As the aim was to explain experiences from the perspective of the participants, we took a naturalistic approach. By building an overall picture from the participants, we were able to unravel how people understand their situation from a cultural and social perspective.<sup>9-11</sup> The study was approved by Barnsley and Rotherham local research ethics committees.

### Setting

The study was conducted in Barnsley and Rotherham health authorities, two of the three areas in the South Yorkshire Coalfields Health Action Zone. People in these areas experience great socioeconomic disadvantage and health inequalities, and these have worsened since the demise of the coal mining industry. Most of the population is white, British, and working class and lives in communities based in former mining villages.

### Sampling

We used purposive and theoretical sampling for the individual and group interviews to ensure that participants represented a range of ages, sex, locations, employment, and ethnicity.

The patients who were interviewed individually were all under 75 and had had angina diagnosed for 10 years or less. We used the Rose chest pain questionnaire as an objective measure to confirm a diagnosis of angina.<sup>12</sup> Patients were identified and recruited with the help of practice managers and general practitioners on the basis of the criteria and characteristics provided by the researcher.

The sample of 14 patients comprised six from an urban practice in Rotherham and eight from a former mining village in the Barnsley area. There were seven men and seven women. Their ages ranged from 52 to

**Table 1** Characteristics of primary care staff who had individual interviews

	No of GPs in practice	Location
General practitioners:		
1	2	Former mining village
2	9	Urban
3	2	Urban
4	4	Former mining village
5	1	Former mining village
6	1	Former mining village, 2 sites
7	3	Former mining village
Community staff:		
Community pharmacist	—	Former mining village
Health visitor	—	Former mining village

73. All participants had other medical problems such as asthma, arthritis, depression, or diabetes. They had all been manual workers in heavy industry or had semiskilled jobs. It emerged that all patient participants had also experienced various social problems that had had a detrimental effect on health—for example, bereavement, social isolation, and long periods of caring for elderly and dependent relatives.

We also interviewed seven general practitioners, one health visitor, and a community pharmacist individually (table 1). We held group interviews with eight general practitioners and five community groups (table 2). We recruited participants for the community groups with the help of local authority community development workers. The groups were based in village communities previously reliant on the coal industry. Three were established groups that met weekly. They invited the researcher to conduct the interview as part of a regular meeting. Two groups were set up especially for the research. These groups consisted of people who had attended a local smoking cessation project.

The group interviews allowed the early results to be tested and challenged. They created a forum to incorporate the views of a broader range of participants. Sampling continued until no new themes were being identified.<sup>13–15</sup>

### Collection of data

Both individual and group interviews were semistructured and based on a schedule of key questions and themes. Additional issues were incorporated in later interviews in response to emerging data. Examples included issues relating to delays in reporting symptoms to general practitioners, knowledge and awareness, and perception of risk of coronary heart disease.

We collected data between January and June 2000. Patients were interviewed in their own homes. The interview with the south Asian participant was conducted through an interpreter. Primary care staff were interviewed at their workplace. Group interviews took place in local community centres.

Individual interviews were audiotaped with the participants' permission. The communication and content of the group interviews were recorded by a scribe (JA), in the form of notes and diagrams. Field notes were taken of all interviews. Where necessary, a point was fed back to the participant during the interview to check the researcher's understanding and

interpretation. The researcher (AMT) conducted all interviews, which lasted between 30 and 60 minutes. Informed consent was obtained before the interview started.

### Analysis

The transcripts, diagrams, and field note data were anonymised and entered into QSR NVIVO, a computer software package for the management of qualitative data. In the database, general practitioners were identified by number and patients were referred to by a pseudonym. The data were coded, and we identified general themes and categories using thematic analysis and constant comparison of the data, both between and within interviews. The dynamic relations between the categories were explored. Relevant knowledge from previous and new research and from health policy was integrated into the constant comparison of data.<sup>16</sup>

The main researcher (AMT) coded all data. A random selection of data was coded and checked by another researcher (AL). The criteria of "trustworthiness" laid down by Lincon and Guba were used throughout the analysis as a verification of validity.<sup>17</sup> These criteria are credibility, transferability, dependability, and confirmability.

### Results

A picture emerged of delay, denial, and self management, reducing access to both primary and secondary health care. In some instances our respondents would delay reporting symptoms for years, not months. A related scenario was for people to have angina diagnosed and then deny or manage the illness themselves. This often meant that the full extent of the symptoms remained hidden from the general practitioner resulting in a delayed or missed referral.

Factors identified as influencing access to health care fell into six categories: structural, personal, social and cultural, past experience and expectations, diagnostic confusion, and knowledge and awareness.

#### Structural factors

Where access to transport was poor, participants reported a tendency to delay reporting the onset or deterioration of symptoms. Several participants were reliant on buses that did not have convenient routes for their general practitioner's surgery. Although general practitioners understood the problems people had with transport, some did not appreciate the extent of the inconvenience.

At one time there used to be a bus service here, but now there isn't. It used to drop me off roughly outside ... but it

**Table 2** Characteristics of groups that were interviewed

Participants	No in group	Details
Rotherham general practitioners	8 men	Conducted as part of education session on evidence based management of angina
Community group 1	3 women	Attended by people who had used a nicotine replacement stop smoking scheme
Community group 2	3 men, 3 women	Attended by people who had used a nicotine replacement stop smoking scheme
Women's group	7 women	Established group of young mums; meets weekly, creche worker cares for children
Senior citizens group	8 women, 1 man	Established group, meets weekly
Luncheon club	>20 men and women	Established group, meets weekly

don't now, and I mean that would have been ideal. But now—it's that hill that does me. There's a very good bloke at the bottom of that hill and he keeps—every time he sees me, he winds that hill steeper! And one of these days I'm going to catch him and I'll bloody kill him.

When the general practitioner did not have a strong presence in the community, people reported a delay in accessing services. Examples cited included singlehanded general practitioners with surgeries in several villages. In these cases, people often registered with a group practice in a neighbouring village. The distance, combined with lack of transport, exacerbated delay in accessing health care. Respondents were not critical of general practitioners but rather acknowledged the difficult workload most had to deal with.

Now there's more doctors there's more time.

[There are only] two evening surgeries in ... so by the time you get to see GP the pain is better, so they don't bother.

Inconvenient surgery times, difficulty in getting through to the surgery by phone, the absence of a nurse led clinic, and the perception of the general practitioner as always busy were also cited as contributing to a delay. Almost all patient and community group participants would have preferred a non-appointment system at surgeries. People reported being more inclined to report symptoms of chest pain early if you could go straight down to the surgery. The combination of the episodic nature of angina pain and having to make and wait for an appointment added to a tendency to ignore it.

I prefer just to go and take my chances.

It usually takes you four days to get in to see your doctor anyway, so by the time you've got in to see him you're better.

Living on a health authority and local authority boundary impeded access to health care. Participants from these communities reported a lack of continuity of care and confusion about where they could and should access health care. There was a strong belief that their location allowed all agencies to avoid investing in local community and health services.

Most general practitioners said that the development of cardiology services at the local hospitals had increased the number and appropriateness of referrals and the level of intervention. They reported that referral was facilitated when the consultant was approachable and communicated well with patients as well as the general practitioner. There was concern about the limitations of the service, with cardiologists emerging as victims of their own success. The length of the wait to see a cardiologist was becoming a disincentive to refer.

I think investigations were less aggressive in the past. Onward referral was also very little when we look behind to what has happened in the past. Yes—with the availability of a proper cardiologist, certainly the referral rate has gone up.

We do not refer to specialties where the waiting list is very long, because it's almost not worth it.

#### Personal factors

We identified a dynamic relation between fear and the tendency to deny and self manage illness. In the presence of fear, respondents coped by either denying symptoms or managing the illness themselves. All participants perceived fear as a factor in obstructing use of

health services. The most prevalent fears related to the illness itself and the impact and implications of having heart disease.

They won't go to the doctor because they're frightened of what the doctor's going to say. Part of the fear is losing the ability to cope. They are fiercely independent. (community pharmacist)

Fear I suppose ... to be honest with you I thought, "If I've got something else it's something I don't want to know I've got."

Denial was a common strategy adopted by people with all stages of heart disease. Participants explained that if you avoid going to the doctor you can pretend there isn't a problem. Denial was motivated by fear, but also anger at having developed heart disease and grief resulting from the loss of health.

You think it'll go off. I think a lot of people, they think, well what I don't know won't hurt me.

I hate it, don't I? I hate it if he has to tell anybody or I have to tell any everybody I've got it, because I hate having it.

The respondents' ability to delay reporting symptoms was maintained by limiting lifestyle and avoiding activity, sometimes for years. When denial and management of the illness were combined with poor knowledge and use of drugs, this meant an unnecessary deterioration in their condition and quality of life. Some patients used their glyceryl trinitrate spray to manage their symptoms and maximise activity. Others, however, never needed to use their spray because they avoided anything that might bring on the pain.

#### Social and cultural factors

Participants referred to social mores and expectations that emerged from what they referred to as the "pit" or "South Yorkshire" culture. These included a disposition to cope with whatever life offered. Strength and ability to cope and maintain independence were all highly valued. In some circumstances, these characteristics may provide a health benefit or a mechanism to cope with adversity. In other ways, however, the resulting delay in accessing health care put people at a disadvantage.

People from round here cope. They don't like making a fuss. They have a depth of character.

Patients will be getting angina on a daily basis and ... they brush it off. It's almost par for the course. I'm astonished at their laid backness about this.

Associated with the tendency to cope was a fierce protection of independence. People valued self reliance and did not willingly seek any form of dependence, whether on doctors or on family members. Strength and stoicism regarding health seemed to be valued. This manifested itself in a tendency not to "talk or tell" people about illness and also an ability to tolerate, at times, extreme discomfort.

#### Past experiences and expectations

Previous experiences of health, health services, and health professionals influenced subsequent use. Being blamed, negative attitudes of health professionals, and previous problems accessing health care were all cited as barriers. Sometimes these were not experienced personally but were reported by family or community members.

Previous bad experiences of the health service resulted in low expectations. Low expectations were also attributed to participants' experiences as members of mining communities. They reported a lack of investment in services and felt that they had been let down in various ways.

There was an expectation of chronic ill health at a comparatively young age. This, alongside coping and stoicism, generated a tendency not to complain or report symptoms until they were seriously affecting quality of life.

### Diagnostic confusion

An inclination to delay seeking medical help was exacerbated when a clear diagnosis was not possible. Diagnosis was confounded by problems in describing symptoms. Diagnostic confusion was reported when people did not attribute the symptoms to the heart or if they had more prevailing and disabling health and social problems. Chronic ill health was often linked to mining and other heavy industry. This created a delay in reporting symptoms. Chest discomfort and breathlessness were attributed to lung problems rather than the heart.

It is easy to attribute pain to the chest rather than recognise it as angina, so I think patients in this area are at a disadvantage, because they probably blame their symptoms rather on their lungs and their chest than their heart ... I'm sure people delay a lot because they think it is their chest and if it doesn't resolve they might come to the doctor, or if they think it's another exacerbation of their chest problem. I'm sure there's delay from general practice.

And I get these pains and they tell me, like, with having this arthritis and that and dust, you see, you can get pains through your chest with arthritis and I can get pains in my chest with the dust—so I don't know whether I'm coming or going.

### Knowledge and awareness

The patient and community groups all had a lack of knowledge and awareness about the causes, treatments, and risks of heart disease. Some patients had become better informed since diagnosis, but overall awareness was low.

There was a low perception of risk of heart disease, which did not match the high incidence of the condition. The older participants of community groups saw themselves as more at risk of lung disease. The younger participants, especially the women, saw themselves at risk of cancer.

Low visibility of the disease in the community seemed to lie behind the low perception of risk. For example, people did not know what the symptoms were to recognise them in others or themselves. Attributing symptoms to lung disease and stoicism meant that people didn't talk or complain about heart disease.

My mother and father died of a heart attack so they didn't have heart disease.

I never ... well you could have knocked us over with a feather, couldn't you, that day Dr ... said it's angina. I didn't believe it, did I? Never even dreamt.

## Discussion

The study identified a complex web of factors that either prevented or delayed referral and some that facilitated referral. The barriers were reported to act

independently and to interrelate with one another. Participants stories revealed tremendous strength, stoicism, and self reliance. Over time, however, the tendency to delay or try to manage the illness or symptoms themselves put people at a disadvantage. There was a risk of death, disability, and deterioration that might have been avoided with earlier referral and intervention.

Many of the barriers we identified were similar to those found in the Merseyside population by Gardner and Chapple.<sup>7</sup> The two study populations differed demographically, and this raises the question of whether other deprived communities may be experiencing similar barriers in accessing services.

Most of our sample did not identify with the experience of refusing referral to a cardiologist. This was strongly corroborated by the community groups, who reported a tendency to delay reporting symptoms to their general practitioner.

### Reasons for delayed reporting

The area's industrial past, and its associated culture, contributed to delays in ways that could be specific to the study population—for example, coping, independence, and attributing symptoms to industrially related lung disease. However, some of the reasons for delay were similar to those identified as contributing to delay in seeking medical help by people having a myocardial infarction.<sup>18</sup> Our study indicates that improved public awareness of the nature, causes, and risks of coronary heart disease is necessary to prompt people with acute and chronic cardiac problems to seek help.

Our results agree with other research that has highlighted the influence of lay knowledge, beliefs, and expectations on accessing health services.<sup>19–21</sup> Solutions to existing inequalities can start to be identified by listening to the public's perceptions and experiences.<sup>19,20,22</sup> The role of sociological inquiry in informing the provision of accessible and acceptable services needs to be acknowledged. This requires the relevant sociological literature to be incorporated into the evidence base for health care.

### Overcoming barriers

Many of the barriers that we identified operate before general practitioners become involved. Multiagency initiatives that involve sectors other than health care may therefore be required to solve the problems. One long term and sensitive solution would be to explore a community development approach. Community development recognises the social, economic, and environmental causes of ill health and links user involvement and commissioning to improve health and reduce inequalities.<sup>23</sup> It can therefore empower populations, provide a way of tackling the geographical and cultural inequalities, and promote sustainable change that is embedded in community participation.

Implementation of the national service framework targets and standards for coronary heart disease will overcome some of the barriers we identified, particularly through more rapid access to primary care and specialist cardiology services. Other mechanisms and solutions are required to address the under-reporting of symptoms and to promote appropriate referral. These may include specialised education of primary care staff and the use of standardised tools to assess severity of disease.

### What is already known on this topic

An inverse correlation has been shown between deprivation and cardiac revascularisation

Fear of hospitals, denial of ill health, and low expectations may prevent people with angina accessing health services

### What this study adds

Fear, denial, and low expectations were important barriers to accessing health services, reinforcing earlier findings

Other factors may be specific to the study population—for example, coping, independence, and attributing symptoms to industrially related lung disease

Many of the barriers operate before general practitioners are involved, making it difficult to identify solutions

Difficulties in recruiting general practitioners and the large list sizes in the area may have contributed to some of the barriers to access. These time and resource constraints could inhibit the change necessary to avoid existing inequalities in access becoming worse. Structural issues, such as access to services and persistent deprivation, need to be considered. Primary care groups and trusts, as well as health action zones, will have an important role in delivering this complex agenda for change.

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