

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

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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 under-reporting 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.¹ 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.^{1,2}

Evidence of inequalities in health and in access to health services, including services for people with coronary heart disease, is well documented.^{3,4} Notably, an inverse correlation exists between deprivation and rates of cardiac revascularisation.^{5,6} This is reflected across the South Yorkshire coalfields, where communities with the greatest need have lower referral rates and uptake of services than more affluent communities. We studied barriers and facilitators to referral.

Participants and methods

We used qualitative methods to allow us to explore the complexity of, and inter-relationship between, the issues and processes identified.⁷ 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.⁸⁻¹⁰

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 interviewed 14 patients individually who had had angina diagnosed for 10 years or less. The sample 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 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.

We also interviewed seven general practitioners, one health visitor, and a community pharmacist individually. We held group interviews with eight general practitioners and five community groups (table). The groups were based in village communities previously reliant on the coal industry.

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. Individual interviews were audiotaped.

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

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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

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 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 single handed 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.

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.

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

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.

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, independ-

ence, 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.¹¹ 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.

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.¹² 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.

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A memorable patient An unmerciful end

I was doing my visits when the surgery telephoned me. Ambulance Control had called—a crew were attending an 82 year old woman who had collapsed—would I go? Three weeks before, Phyllis had had a coronary event; she was treated at home by one of my partners and was doing quite well. Her daughter Diane had called to make some lunch. For the first time since she was ill, Phyllis said she would have some pudding. As she ate, she suddenly clutched her chest, gasped, gazed at her daughter, and died, falling from her chair. Diane, in her anxiety, did what most people would probably do—telephoned the emergency services.

As I drove into the quiet little cul de sac of terraced council houses, I saw, there at the end and occupying the whole width of the road, two stunningly painted emergency vehicles with blue lights flashing—a paramedic car and an ambulance. Phyllis's front door was open, and just inside was Diane, sitting at the foot of the stairs with her head in her hands weeping. "She wouldn't have wanted all this, doctor. She hated hospitals."

As I stepped into the living room, I was greeted by a scene that would have done justice to Frankenstein's laboratory. There were monitors, large bags of kit, oxygen cylinder, tubes, wires, bits of debris, and three uniformed stalwarts, one thumping, one blowing, and one twiddling knobs. In the middle of the chaos on the floor lay the buxom form of Phyllis—dress ripped apart, ample breasts, pendulous with age, bouncing in rhythm with the cardiac massage. A disembodied, Stephen Hawking-like voice was issuing instructions: "Check patient. Analysis: no shock advised." Even an untrained eye could see from her blue-grey blotchiness that Phyllis was now a corpse.

As I picked my way through the jumble on the floor, Phyllis's other daughter arrived with her own 12 year old girl. They had been told to hurry over, and they came straight into the room. I glimpsed the look of horror on their faces as they recoiled into the hall. The

child had probably never seen her grandmother's breasts before.

"We have given her two shots of adrenaline, doc. There is still some activity on the scope if we enhance it." I knelt down by Phyllis, took out my stethoscope to establish my medical credentials, and listened knowingly to her chest. I shone a light in her widely dilated, fixed pupils—it was now at least 20 minutes since she collapsed—and said, "I think you have done all you can, gentlemen."

Without a word the resuscitation team disconnected their kit, packed up in no more than a minute, and were about to leave when I asked, "Can you give me a hand to tidy her up and put her on the bed before you go?"

"We are not supposed to lift, doc." And they were gone.

I tidied her up and went out to the hall, where the three female relatives were gently weeping. Putting my arm round Diane's shoulder, I said, "I'm afraid she has died."

"I knew she was dead, doctor, and I told them that she wouldn't have wanted them to try and revive her, but they asked if I had that in writing. I just wanted to cuddle her."

I have learnt since that ambulance crews and paramedics are particularly worried about being sued if they fail to attempt resuscitation. How the murky spectre of the legal profession lurks round every corner, affecting all our lives, and our deaths, in more ways than we could imagine.

Paramedics are well trained and skilled, and I respect their professionalism. They surely save some lives, but has not the advent of the technology deprived us of some humanity? Phyllis's demise was undignified; the image of her lying on the floor looking like the victim of a rapist will stay with her daughters and granddaughter for a long time.

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