



Scandinavian Journal of Primary Health Care

ISSN: 0281-3432 (Print) 1502-7724 (Online) Journal homepage: informahealthcare.com/journals/ipri20

Women at risk of coronary heart disease experience barriers to diagnosis and treatment: A qualitative interview study

Jan C. Frich, Kirsti Malterud & Per Fugelli

To cite this article: Jan C. Frich, Kirsti Malterud & Per Fugelli (2006) Women at risk of coronary heart disease experience barriers to diagnosis and treatment: A qualitative interview study, Scandinavian Journal of Primary Health Care, 24:1, 38-43, DOI: 10.1080/02813430500504305

To link to this article: https://doi.org/10.1080/02813430500504305



Published online: 12 Jul 2009.



Submit your article to this journal 🕑



View related articles 🗹



Citing articles: 1 View citing articles 🗹



ORIGINAL ARTICLE

Women at risk of coronary heart disease experience barriers to diagnosis and treatment: A qualitative interview study

JAN C. FRICH^{1,2}, KIRSTI MALTERUD^{3,4} & PER FUGELLI¹

¹Department of General Practice and Community Medicine, University of Oslo, Oslo, ²Department of Neurology, Ullevål University Hospital, Oslo, ³Section for General Practice, Department of Public Health and Primary Health Care, University of Bergen, Bergen, Norway, and ⁴Research Unit and Department of General Practice, University of Copenhagen, Denmark

Abstract

Objective. To explore barriers in the health service to diagnosis and treatment experienced by women at increased risk of coronary heart disease (CHD). *Design.* Qualitative study using semi-structured interviews. *Setting.* Norway. *Subjects.* Twenty women diagnosed with heterozygous familial hypercholesterolemia (FH) recruited through a lipid clinic. *Results.* Women reported three specific barriers related to diagnosis and treatment of CHD. They had to struggle to take a cholesterol test; they experienced that their risk was being downplayed by doctors; and that their symptoms of CHD were misinterpreted when they consulted doctors for evaluation and treatment. *Conclusion.* Stereotyping CHD as a man's disease may result in barriers to diagnosis and treatment for women. Doctors should ask the patient about the family history of CHD if a concern about heart disease is on the patient's agenda.

Key Words: Coronary disease, family practice, health services, hypercholesterolemia, hyperlipidemia, physician-patient relations, risk factors, women

Coronary heart disease (CHD) is a leading cause of death and a significant cause of morbidity in women. The risk of CHD increases with age, and on average CHD is manifested one decade later in women than in men [1]. At all ages men have higher rates of CHD compared with women, though the same proportions of men and women eventually die of coronary heart disease as the disease occurs later in women [1]. There are marked gender differences in symptoms, diagnosis, treatment, and referral of CHD [2–5]. Women are less likely to receive lipid-lowering medication and to have a coronary revascularization procedure when diagnosed with CHD [2–5].

As doctors, we have an interest in gender inequalities in health, and we are interested in facilitating patient-centred healthcare. From previous research, we have seen that knowledge about women's experience of barriers to diagnosis and treatment can give insights important for improving healthcare [6,7]. Our motivation for this study was to understand There are gender differences in how people at risk of coronary heart disease (CHD) are managed in the health service. Women are less likely to receive lipid-lowering medication and are also less likely to have a coronary revascularization procedure when diagnosed with CHD.

- Women at risk of CHD experience barriers to diagnosis and treatment.
- Stereotyping of CHD as a man's disease may result in barriers for women.
- Doctors should ask the patient about the family history of CHD if a concern about heart disease is on the patient's agenda.

more about the gender inequalities in relation to CHD: Does gender play a role in doctors' management of women who think they are at risk

(Received 23 August 2005; accepted 1 December 2005) ISSN 0281-3432 print/ISSN 1502-7724 online © 2006 Taylor & Francis DOI: 10.1080/02813430500504305

Correspondence: Jan C. Frich, Department of General Practice and Community Medicine, PO Box 1130 Blindern, University of Oslo, NO-0318 Oslo, Norway. E-mail: jancf@medisin.uio.no

of CHD? The aim of this study is to explore barriers in the health service to diagnosis and treatment experienced by women at risk of CHD.

Material and methods

Participants

Women diagnosed with heterozygous familial hypercholesterolemia (FH) represent an extreme case of women at risk of CHD. FH is a common (1:500) inherited condition with elevated levels of total blood cholesterol and low-density lipoprotein (LDL) [7]. Women with FH have increased risk of CHD; at least 30% of women with this condition will develop heart disease by the age of 60 if they are not given medical treatment [8]. A family history of early CHD is an important determinant of early cardiac events [9]. If barriers to diagnosis and treatment exist for women at risk of CHD, these women have probably been confronted with them. In this respect our sample represents a strategic case.

The first author (JCF) interviewed 20 women aged 15–57 (average 31 years) about their experiences of being diagnosed and living with FH, and their experiences with the health service formed one of the themes investigated. Participants were recruited from the Lipid Clinic at Rikshospitalet University Hospital in Oslo. We purposefully sampled a majority of asymptomatic and relatively young participants, aiming for a diversity regarding social and professional background. We obtained ethical approval for our study from the Regional Committee for Medical Research Ethics (Health Region East), Norway.

Data collection

We used semi-structured interviews (45 to 90 minutes) to collect data. Thirteen interviews were conducted at the interviewer's office; six interviews were done in participants' homes, and in one case at the interviewee's workplace. The interviews were conducted in the period June 2000 to March 2002. An interview guide had been developed on the basis of eight weeks of fieldwork, which involved informal conversations with patients and observation of consultations between doctors and patients in the Lipid Clinic. The interview questions covered general beliefs about heart disease and health, how participants perceived and managed their own risk of heart disease, and their experiences with the health service. We did not question them specifically about barriers to diagnosis and treatment. Participants were asked open questions such as: "Tell me about your experiences with the health service", and "How have health professionals communicated with you

about your condition?". All interviews were transcribed verbatim by JCF.

Analysis

We developed a coding frame for the data. The coding frame was developed through negotiations between the authors, based on a separate reading of transcripts. JCF coded all transcripts, with KM joining in when negotiating the final categories and their contents. The categories emerged from the data during the analysis. Material concerning experienced barriers in the health service to diagnosis and treatment was identified and used for systematic text condensation, according to the principles of Giorgi's phenomenological analysis [10], modified by Malterud [11]. The analysis followed these steps: (i) reading all the material to obtain an overall impression and bracketing previous preconceptions; (ii) identifying units of meaning, representing different aspects of the barriers experienced by women and coding for these; (iii) condensing and summarizing the contents of each of the coded groups; and (iv), generalizing descriptions and concepts reflecting apparently significant barriers.

Results

Of 20 participants, seven women spontaneously reported that they had experienced barriers to diagnosis and treatment when they were asked about their experiences with the health service. Two of these were students at university level, two did manual work, two did non-manual work, and one was in receipt of disablement benefit. Two women were diagnosed with angina pectoris, and one of them had suffered from a myocardial infarction. The other five women had no history of CHD. Thirteen participants in our study conveyed no barriers to diagnosis and treatment. Among them were women who had been diagnosed as children or adolescents due to an established contact between their families and the Lipid Clinic. Women who reported barriers had typically been diagnosed as adults, and they shared experiences of resistance in the health service:

"You know things about you own health ... and they challenge you with everything they know: Authority, knowledge, history. It becomes a barrier so great that you need a strong will to get through." (Participant 5, aged 51).

Women reported three specific barriers related to diagnosis and treatment of CHD: They had to struggle to take a cholesterol test; and they experienced that their risk was being downplayed by doctors; and that their symptoms of CHD were misinterpreted when they consulted doctors for evaluation and treatment. We elaborate on these findings in more detail below.

"... you can't have raised cholesterol."

Some participants reported that they had to struggle to have their cholesterol tested. One woman refers to how, during her twenties, she experienced resistance from several GPs when she asked for a test:

"This is what even doctors have told me: 'Yes, but a young and healthy woman like you can't have raised cholesterol.' And then, you know, when even doctors pass on this view it becomes something you don't want to mention." (Participant 32, aged 31)

Some women felt that GPs did not recognize the clinical importance of their family history of heart disease:

"Well ... I don't know how doctors are educated, but there is probably not much emphasis on the genetic My feeling is that there is ignorance among GPs. We have not been taken seriously." (Participant 32, aged 31)

The story of a 27-year-old participant is illustrative. Her grandfather died of a heart attack when he was 50 years old. Some years later her father was diagnosed with raised cholesterol. His GP suggested to him that the condition might be hereditary, and her father advised her to take a cholesterol test. She was 20 years old when her struggle for a diagnosis started:

"My father advised me to take a test after a doctor had told him that it could be hereditary. When I visited my own GP for some other reason I asked him for a cholesterol test. He replied: 'No, what's the point of that, you're so young." (Participant 25, aged 27)

She visited several different doctors and found that her family history of CHD was not taken into consideration:

"Then I told [my GP] that my grandfather had died and that my father had it, but still: 'No, there was no point.' After a while I went to see another doctor. Her opinion was that there was no use in that. One day I just walked down to the health centre and told them I wanted to have that test. Finally, I was allowed to take it, and it revealed a figure of ten-point something [mmol/l]... they actually phoned me up in the evening to inform me." (Participant 25, aged 27) These examples indicate that doctors do not associate being "a young and healthy woman" with being at risk of CHD.

"... it's probably not a problem"

Women experienced that their risk of heart disease was being played down by their doctors after they had been diagnosed with hypercholesterolemia. Some reported a considerable delay before they were offered lipid-lowering medication or were referred to a specialist. One participant, aged 31, was diagnosed with cholesterol levels of 10–11 mmol/l. Her mother was diagnosed with angina in her thirties. She consulted several GPs over a period of five years before she was offered lipid-lowering medication and referred for a specialist evaluation at the age of 30:

"During the last five years I have tried to have it checked on a regular basis, but I was met with very little understanding I got the feeling that 'well, well, but you are not a man, and you are not fifty, you don't smoke and are not overweight, so it's probably not a problem'." (Participant 32, aged 31)

Other women shared this experience of not being recognized as someone at risk. These experiences may indicate that these women lacked characteristics doctors usually would associate with the typical person at risk of developing CHD.

"I knew I was suffering from a heart attack"

The two women with CHD had both experienced that their cardiac symptoms were not recognized when they consulted doctors for evaluation and treatment. A woman who suffered from a myocardial infarction when she was 34 years old recalls that her symptoms were questioned by both the local GP and physicians at the hospital because her symptoms were "untypical":

"I knew what it was, but like many of us I didn't have the typical symptoms. You visit the general practitioner and you don't have this radiating pain in your left arm. I was sent to the hospital and felt the nausea coming. Worst of all I could not lift my arms, they were like two heavy sacks I can clearly remember the distress I felt when they phoned the ambulance from the hospital and asked them to turn round, because they were so busy: 'She is too young and she is a woman', they argued. At that moment I was horrified because I knew I was suffering from a heart attack." (Participant 5, aged 51) Another woman was left with the impression that her angina was not taken seriously when she was assessed by a cardiologist. She recounts the conversation she had with her GP after the consultation at the hospital; she emphasized that even her doctor was surprised that no further investigations were planned:

"[My GP] doesn't understand why I wasn't even discussed [for coronary angiography]. She suggested that it's because I'm a woman." (Participant 34, aged 57)

These accounts suggest that there may be several reasons why women's symptoms are not being recognized. Besides having the wrong gender and being the wrong age, women's bodily symptoms of CHD may also be considered "untypical".

Discussion

Validity and transferability

We approached the material with the aim of exploring barriers in the health service experienced by women at risk of CHD. We have thus not highlighted participants' experiences of being taken seriously by doctors. We have not studied aspects related to women's own self-image and possible reluctance to perceive themselves as at risk of CHD. This is a factor that may influence women's interactions with the health service. We have no data on what actually took place in the medical encounters that our participants refer to. Their accounts reflect the patient's experience. Patients' felt disagreements with doctors may, however, represent a valuable source of knowledge for the health service [12].

The participants in this study were recruited from a specialist lipid clinic and were all diagnosed with FH. One may question whether there has been a selection to the clinic of patients with negative experiences with GPs. The contrary may also be the case: that these women have been recognized by GPs who have referred them for a specialist evaluation. However, we should be cautious in arguing that our findings are transferable to and valid for general practice.

Gender and clinical management

The findings in this study are consistent with welldocumented gender inequalities concerning diagnosis, referral, and treatment of CHD [2–5]. Recent experimental research among GPs in the UK and USA suggests that being a woman is a characteristic associated with lower quality of care [13]. There are many barriers to successful primary prevention of CHD in general practice [14], and there is room for improving clinical management of patients at risk of CHD [15]. The participants in our study are relatively young. For some participants barriers seem to be constructed by a combination of young age and being a woman. Age is obviously a contributing factor when doctors perceive someone to be at low risk of CHD [16]. Our results indicate that gender is also a factor that influences doctors' perception of a patient's risk. Our study adds to previous knowledge by suggesting how gender may play a role in doctors' management of risk factors and symptoms of CHD in women. One possible explanation for our findings is that a proportion of doctors see CHD primarily as a man's disease.

Stereotypes and gendered interpretations of patients

Lippmann claimed that a stereotype is a "picture in our heads" [17]. Such images influence how we perceive and evaluate reality: "For the most part we do not first see, and then define, we define first and then see" [17]. According to Goffman, individuals are "sign vehicles" that set off interpretive processes in others [18]. People will interpret signs and seek to acquire information in order to define the other, the situation, or the encounter. People often use stereotypes when interpreting and organizing reality.

Lay people convey specific images of the "candidate" when being asked about persons they consider at risk of developing CHD [19]. In a study from Scotland, people's accounts of coronary candidates all centred on men [20]. In the public, CHD has for a long time been represented as a man's disease [20-22]. Our study suggests also that doctors may stick to stereotype images of persons they consider at risk of CHD. Barriers we identify appear to be a result of a mismatch between women who are concerned about their risk and doctors' stereotypes of the candidate. In our study women report that doctors confront them with the fact that they are not men. We have no data on doctors' imagery of the coronary candidate, but our results suggest that the typical coronary candidate is a man with certain characteristics.

The issue of medicalization

Barriers to diagnosis and treatment for women at risk of CHD operate in clinical encounters between individual patients and doctors. Medical knowledge, culture, and the priorities of the health service are factors that influence GPs' clinical performance. In addition, GPs are often faced with

42 J. C. Frich et al.

people with fairly low risks of CHD and they need to consider issues related to medicalization and allocation of limited resources in the health service [23]. Such issues may explain why doctors may have a resistance to what they consider unnecessary tests and referrals. However, gender inequalities in care represent a challenge for the health service. Quality assurance programmes in the health service, focusing on gender-equal care, may be a helpful intervention. An observational study of a national quality assurance programme for secondary prevention of CHD in Sweden concludes with no major gender differences in the quality of care after a follow-up period of one year [24].

The family history of CHD

Our results suggest that doctors do not sufficiently recognize the medical importance of women's family history of CHD. There is an increasing awareness of patients' family history and its importance in the prevention and management of common diseases [25]. The family history of CHD provides important medical information that should be considered when assessing a patient's risk of CHD.

So what?

Our study suggests that the health service should be concerned with gender inequalities in management of patients at risk of CHD. Diagnostic stereotypes are necessary tools in clinical practice, and may help doctors to distinguish between patients at high and low risk of CHD. The cost of stereotyping of CHD as a man's disease may be barriers to diagnosis and treatment for women. Our study emphasizes that doctors always need to be sensitive to exceptions to a rule. Family history may give useful clues to why a certain, and perhaps "untypical", patient seeks healthcare for an evaluation of his or her risk of CHD.

Acknowledgements

The research was funded by the Norwegian Research Council (grant number 130435/330), with the aid of the EXTRA funds from the Norwegian Foundation for Health and Rehabilitation (grant number 2003/2/0239).

References

- Mosca L, Manson JE, Sutherland SE, Langer RD, Barrett-Connor E. Cardiovascular disease in women. Circulation 1997;96:2468–82.
- [2] Raine R. Does gender bias exist in the use of specialist health care? J Health Serv Res Policy 2000;5:237–49.

- [3] Carroll K, Majeed A, Firth C, Gray J. Prevalence and management of coronary heart disease in primary care: population-based cross-sectional study using a disease register. J Public Health Med 2003;25:29–35.
- [4] Tonstad S, Rosvold EO, Furu K, Skurtveit S. Undertreatment and overtreatment with statins: The Oslo Health Study 2000–2001. J Intern Med 2004;255:494–502.
- [5] Bowling A, Bond M, McKee D, McClay M, Banning A, Dudley N, et al. Equity in access to exercise tolerance testing, coronary angiography, and coronary artery bypass grafting by age, sex and clinical indications. Heart 2001;85: 680–6.
- [6] Werner A, Malterud K. It is hard work behaving as a credible patient: Encounters between women with chronic pain and their doctors. Soc Sci Med 2003;57:1409–19.
- [7] Soderlund A, Malterud K. Why did I get chronic fatigue syndrome? A qualitative interview study of causal attributions in women patients. Scand J Prim Health Care 2005;23: 242–7.
- [8] Marks D, Thorogood M, Neil H, Humpheries SE. A review on the diagnosis, natural history, and treatment of familial hypercholesterolaemia. Atherosclerosis 2003;168:1–14.
- [9] Jansen ACM, van Wissen S, Defesche JC, Kastelein JJP. Phenotypic variability in familial hypercholesterolaemia: An update. Curr Opin Lipidol 2002;13:165–71.
- [10] Giorgi A. Sketch of a psychological phenomenological method. In: Giorgi A, editor. Phenomenology and psychological research. Pittsburgh, PA: Duquesne University Press; 1985. p. 8–22.
- [11] Malterud K. Shared understanding of the qualitative research process: Guidelines for the medical researcher. Fam Pract 1993;10:201-6.
- [12] Annandale E, Hunt K. Accounts of disagreements with doctors. Soc Sci Med 1998;46:119–29.
- [13] Arber S, McKinlay J, Adams A, Marceau L, Link C, O'Donnell A. Influence of patient characteristics on doctors' questioning and lifestyle advice for coronary heart disease: A UK/US video experiment. Br J Gen Pract 2004;54: 673-8.
- [14] Van Steenkiste B, van der Weijden T, Stoffers HEJH, Grol R. Barriers to implementing cardiovascular risk tables in routine general practice. Scand J Prim Health Care 2004; 22:22–37.
- [15] Sigurdsson EL, Jónsson JS, Thorgeirsson G. Medical treatment and secondary prevention of coronary heart disease in general practice in Iceland. Scand J Prim Heath Care 2002; 20:10–5.
- [16] LaCharity LA. The experiences of younger women with coronary artery disease. J Women's Health Gend Based Med 1999;8:773–85.
- [17] Lippmann W. Public opinion. New York: Simon & Schuster; 1997.
- [18] Goffman E. The presentation of self in everyday practice. Garden City, NY: Doubleday; 1959.
- [19] Davison C, Smith GD, Frankel S. Lay epidemiology and the prevention paradox: The implications of coronary candidacy for health education. Social Health Ill 1991;13:1–19.
- [20] Emslie C, Hunt K, Watt G. Invisible women? The importance of gender in lay beliefs about heart problems. Sociol Health Ill 2001;23:203–33.
- [21] Helman CG. Heart disease and the cultural construction of time: The Type A behaviour pattern as a Western culture bound syndrome. Soc Sci Med 1987;25:969–79.
- [22] Riska E. The rise and fall of Type A man. Soc Sci Med 2000; 51:1665–74.
- [23] Getz L, Kirkengen AL, Hetlevik I, Romundstad S, Sigurdsson JA. Ethical dilemmas arising from implementation of the

European guidelines on cardiovascular disease prevention in clinical practice Scand J Prim Health Care 2004;22: 202-8.

[24] Nilsson P, Brandström H, Lingfors H, Erhardt L, Hedbäck B, Israelsson B, et al. Gender differences in secondary prevention of coronary heart disease: reasons to worry or nor? Scand J Prim Health Care 2003;21:37-42.

[25] Walter FM, Emery J. "Coming down the line"—patients' understanding of their family history of common chronic disease. Ann Fam Med 2005;3:405–14.