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How do patients at risk portray candidates for coronary heart disease? A qualitative interview study

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Abstract

Objective. To explore how patients at risk of coronary heart disease (CHD) portray candidates for CHD. *Design.* Qualitative interview study. *Setting.* Norway. *Subjects.* A total of 20 men and 20 women diagnosed with heterozygous familial hypercholesterolemia (FH) recruited through a lipid clinic. *Main outcome measures.* Participants' beliefs concerning persons who are considered candidates for CHD. *Results.* Some participants believed that CHD could happen to anyone, while the majority conveyed detailed notions of persons they considered to be likely victims of CHD. Participants often portrayed the coronary candidate as someone who was different from themselves. Among those who mentioned gender, all presented the candidate as a man. Some women said that they had to reconcile themselves to being at risk of CHD, since they at first had conceived CHD as a man's disease. While some participants considered their notions to be valid for assessing people's risk of CHD, others questioned how valid their notions were. *Conclusion.* Doctors should recognize that distancing is a way patients cope with risk and that such a strategy may have psychological and moral reasons. When communicating about risk, doctors should take into account that patients' notions of risk may differ from medical notions of risk.

Key Words: *Attitude to health, coronary disease, family practice, health promotion, hypercholesterolemia, risk factors*

Patients' perceived vulnerability to disease is a strong predictor of their readiness for medical treatment and preventive behavior [1,2]. Research suggests that public portrayal of likely victims of coronary heart disease (CHD) influences patients' sense of vulnerability to CHD [3–5]. Davison et al. investigated the "lay epidemiology" of heart disease in South Wales and found that people conveyed notions of "coronary candidates"; persons they considered likely to get "heart trouble" [6]. People used such notions to assess their own and other persons' risk, but also to explain why someone had been struck by CHD. Exceptions to the rule could be explained by good or bad luck or that some people were born with a healthy constitution.

Research indicates that the candidate for CHD is often portrayed as a man [7–9], and that women with symptoms of CHD appear to adopt risk assessment strategies that enable them conceptually to distance themselves from risk of CHD by attributing risky lifestyle behaviour to men [5]. A better understanding of how patients at risk of CHD

Public portrayal of likely victims of coronary heart disease (CHD) influences patients' sense of vulnerability to CHD, health-seeking behaviours, and motivation for medical treatment.

- Patients at risk of CHD portray "the coronary candidate" as a person, usually a man, who is different from themselves.
- Patients may cope with their risk by distancing themselves from persons they consider to be "coronary candidates".
- Doctors should take into account that patients' notions of risk may differ from medical notions of risk.

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conceive and reflect on their notion of "the coronary candidate" may foster improved clinical management.

Our point of departure as medical doctors is a commitment to patient-centered medicine, with an interest in how the public portrayal of CHD and also gender may have an impact on patients' understanding of disease [10,11]. We expected that patients at risk of CHD would convey notions of likely candidates, and that these notions might play a role in how they understood their own risk. We therefore conducted a study to explore how patients at risk of CHD portray candidates for CHD.

Material and methods

Participants

The first author (JCF) interviewed 20 men (aged 14–53 years, average 31 years) 20 women (aged 15–57 years, average 31 years) diagnosed with heterozygous familial hypercholesterolemia (FH) about their experiences of being diagnosed and living with increased risk of CHD. FH is characterized by elevated low-density lipoprotein (LDL) and elevated total plasma cholesterol levels [12]. The clinical severity of the condition varies considerably between families. A cumulative risk estimate suggests that, if the condition is untreated, 50% of men aged 50 years and 30% of women aged 60 years would have symptoms of CHD [12].

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 diversity regarding social background, family history of CHD, and time since diagnosis. Ethical approval for the study was obtained from the Regional Committee for Medical Research Ethics (Health Region East), Norway.

Data collection

We used semi-structured interviews, lasting 45 to 90 minutes, to collect data. The 40 participants were interviewed in the interviewer's office (30), in interviewees' homes (8), and in the interviewees' workplace (2). The interviews were conducted between June 2000 and March 2002. 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 of the health service. Participants were asked about their image of persons who are at risk of heart disease. The interviewer presented himself to participants as a researcher and aimed at not being perceived as a medical expert. All interviews were transcribed by JCF verbatim.

Analysis

We developed a coding frame through negotiations between the authors, based on a separate reading of transcripts. JCF coded all transcripts, with KM and PF joining when negotiating the final categories and their contents. Material concerning participants' notions of the candidate for CHD was identified and used for systematic text condensation [13,14]. 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 participants' notions of likely victims of heart disease, and coding for these; (iii) condensing and summarizing the contents of each of the coded groups; and (iv), generalizing descriptions and concepts reflecting participants' beliefs.

Results

Some participants believed that CHD could happen to anyone, while the majority conveyed detailed notions of persons they considered to be likely victims of CHD. Participants often portrayed the coronary candidate as someone who was different from themselves. Among those who mentioned gender, all presented the candidate as a man. Some women said that they had to reconcile themselves to being at risk of CHD, since they at first had conceived CHD as a man's disease. While some participants considered their notions to be valid for assessing people's risk of CHD, others questioned how valid their notions were. We elaborate further on these findings in more detail below.

Characteristics of candidates

Some participants had no specific notion of persons who they thought were likely victims of CHD, and they thought that CHD could happen to anyone. These participants were relatively young and had experienced few cardiac events in their family. Most participants gave detailed accounts of coronary candidates, as illustrated by this quote:

> *He's around 60 to 65 years old, on the plump side, wears a jogging suit, not very fit, and smokes a lot . . . a relatively lazy person.* (Participant 35, woman aged 36)

Participants listed characteristics they associated with being at risk of heart disease, such as over-

weight, little exercise, unhealthy food, raised cholesterol, smoking, stress, old age, and having a hereditary disposition. Participants distinguished between people who had increased risk due to heredity and due to lifestyle, as illustrated by this quote:

> *The inherited [risk] is something you are not to blame for, but you can do something to improve your situation . . . and then you have lifestyle, with the stressed businessman who travels and eats only business dinners and eats the food that is served, and much fat food, and smokes.* (Participant 28, woman aged 31)

Some participants mentioned characteristics such as being "pale and weak", "having a yellowish skin color", "being vulnerable because of previous illness", and "having deposits of cholesterol around the eyes".

The candidate is different from me

Participants often portrayed the candidate as a person who was different from themselves, and a typical example was businessmen or taxi-drivers. Some participants distanced themselves from the candidate by characterizing candidates in a morally degrading way, for example as "a fat, old pig". Among the participants who mentioned gender, all presented the likely candidate as a man, and gender appeared to be a characteristic many women emphasized when pointing to a difference between themselves and the candidate. Several women expressed the fact that they had been surprised to learn that they were at risk of heart disease, as illustrated by a woman's experience of being diagnosed when she was 35 years old:

> *It was a shock to me, because one has always heard it's a man's disease, that there are very few women, and if it happens then you're very old. . . so it was a shock . . . the thought that this had something to do with me. I was certain that my brother had it . . . since he's a man.* (Participant 38, woman aged 40)

Some women said that they had to reconcile themselves to being at risk of heart disease, and that at first they had considered it as man's disease. Few men conveyed similar experiences or reactions.

The notions are not always valid

Some participants considered their notion of the candidate to be valid for assessing a person's vulnerability to CHD and explaining coronary events, while others questioned how true their notions were. Some emphasized that you have no guarantees, and that "fate", "luck", and "chance" also could play an important role, as exemplified in this statement:

> *I have thought that if you eat a lot of unhealthy food and sit still all day, then you are more vulnerable to heart disease . . . But I really don't know . . . I don't know the statistics. My impression is that it hits quite accidentally.* (Participant 36, man aged 21)

Several participants mentioned heredity as a factor that could influence an individual's risk, and the belief that one could have an inherited risk or could inherit a favorable "constitution" was salient:

> *A man in our hunting party has smoked since he was 14 and he's now 72. He doesn't even have grey hair! Some have an iron constitution, and some do not.* (Participant 14, man aged 27)

Most participants used their notion of the candidate for CHD as a rough tool that could prove to be more or less valid in a given situation. When they assessed their own individual risk they emphasized that they had a hereditary condition and used a combination of their family history, personal health resources, and characteristic risk factors associated with their notion of the candidate.

Discussion

Validity and transferability

Participants were recruited from a specialist lipid clinic and were all diagnosed with FH. Patients with FH represent a special case because they have been diagnosed with a hereditary risk of CHD. Referral and regular monitoring in a specialist clinic may have modified our participants' notions of risk factors for CHD. Our findings are in accordance with previous research on the lay epidemiology of CHD [5,6,8] but our participants seem to be relatively more doubtful about how valid and useful their notions of the coronary candidate are [5,6,8]. An explanation for this may be that they have been diagnosed with a hereditary condition and therefore consider themselves as atypical in relation to the public imagery of likely victims of CHD. Our previous research suggests this, as we have found that patients with FH emphasize previous coronary events in the family when estimating their own risk of CHD [15]. Individuals without a hereditary risk also recount their family histories [16] but the public imagery of CHD is probably also important [3–9]. We thus assume that the findings in our study are transferable and relevant for patients at risk of CHD.

Reflexivity

We approached the material as medical doctors with an interest in exploring how patients at risk of CHD portray candidates for CHD. When analyzing the data we deliberately downplayed other types of knowledge participants used when they recounted their understanding of their risk of CHD, such as their family history and their evaluation of their personal health-related resources. The interviewer was a man, which may also have influenced how both women and men talked about their health and risk status. We approached the material with an interest in potential gender differences and did not investigate potential differences due to other factors such as participants' social or occupational background. Our data could have been interpreted by others as a sign of participants' lack of knowledge or denial of their risk. Our data suggest that patients' notion of the candidate for CHD may have psychological and moral functions, and that the public portrayal of candidates is important for patients when they make sense of the risk of CHD.

Patients' distancing and clinical management

The findings in this study are consistent with previous research on the portrayal of CHD by individuals, in the public, and in advertisements in medical journals [5–8,17,18]. Our study adds to previous knowledge by demonstrating that patients at risk of CHD convey notions of candidates for CHD, and that patients may question how valid these images are. We found that both men and women distanced themselves from their notion of the candidate. Our study also demonstrates that some women at risk report that they have to reconcile themselves to being at risk of CHD. Patients with FH are atypical due to their genetic condition and may be justified in distancing themselves from stereotypical notions of the coronary candidate. Nevertheless, we think there may be psychological and moral reasons for patients to underline the difference between themselves and persons they consider candidates of CHD. First, it may be a way of coping that relieves the sense of vulnerability and anxiety related to being diagnosed as at increased risk. Second, it may be a moral statement that signifies that one takes the risk seriously. If risk of CHD is on the patient's agenda the doctor's task is to assess the patient's risk and communicate about risk in ways that recognize the patient's pain limits and consider the patient's own notion of risk, health-related resources, and agency [19,20].

Public portrayal of CHD

Patients' portrayal of the candidate as a man echoes the portrayal of CHD among the general public [8,18]. Men have a higher age-related risk of CHD compared with women earlier in life, but CHD currently affect more women than men [21]. Research indicates that a lack of adequate signs and cultural imagery pose a challenge for individuals who search for ways to understand and frame their experiences and status as someone at risk [22]. Research suggests that women delay longer than men before they contact the health service with symptoms of CHD [23], though gender appears to be less important for delay compared with factors such as increasing age, and a history of angina or diabetes [24]. We think public health messages regarding CHD should focus on risk factors and challenge stereotypical notion of persons who are at risk of CHD.

So what?

Doctors should recognize that distancing is a way in which patients cope with risk and that such a strategy may have psychological and moral reasons. When communicating about risk, doctors should take into account that patients' notions of risk may differ from medical notions of risk.

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