Perceived Vulnerability to Heart Disease in Patients with Familial Hypercholesterolemia: A Qualitative Interview Study

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ABSTRACT

PURPOSE Knowledge about the ways patients perceive their vulnerability to disease is important for communication with patients about risk and preventive health measures. This interview study aimed to explore how patients with a diagnosis of heterozygous familial hypercholesterolemia understand and perceive their vulnerability to coronary heart disease.

METHODS We did a qualitative study of 40 patients with familial hypercholesterolemia who were recruited through a lipid clinic in Norway. We elicited participants' perceptions about their vulnerability to heart disease in semistructured interviews. Data were analyzed by systematic text condensation inspired by Giorgi's phenomenological method.

RESULTS We found that participants negotiated a personal and dynamic sense of vulnerability to coronary heart disease that was grounded in notions of their genetic and inherited risk. Participants developed a sense of their vulnerability in a 2-step process. First, they consulted their family history to assess their genetic and inherited risk, and for many a certain age determined when they could expect to develop symptoms of coronary heart disease. Second, they negotiated a personal sense of vulnerability by comparing themselves with their family members. In these comparisons, they accounted for individual factors, such as sex, cholesterol levels, use of lipid-lowering medications, and lifestyle. Participants' personal sense of vulnerability to heart disease could shift dynamically as a result of changes in situational factors, such as cardiac events in the family, illness experiences, or becoming a parent.

CONCLUSIONS Patients with a diagnosis of familial hypercholesterolemia negotiate a personal and dynamic sense of vulnerability to coronary heart disease that is grounded in their understanding of their genetic and inherited risk. Doctors should elicit patients' understanding of their family history and their personal vulnerability to individualize clinical management.

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INTRODUCTION

Communicating with patients about their risk of future disease and preventive health measures is challenging for the doctor.[1] A strong predictor of patients' readiness for medical treatment and preventive behavior is their perceived vulnerability to disease.[2-6] The family history forms a basis upon which a person assesses his or her own vulnerability to common chronic diseases,[7,8] and the family history is becoming increasingly important as a medical devise to predict risk of future disease.[9] How do patients with a well-defined genetic disorder relate to their family history? How do patients with a diagnosed familial risk understand and perceive their vulnerability to future disease?

Heterozygous familial hypercholesterolemia is an autosomal dominant genetic condition, characterized by elevated low-density lipoprotein

(LDL) cholesterol and elevated total plasma cholesterol levels.[10] Familial hypercholesterolemia is caused by a defect in the gene for the LDL receptor, and the condition is strongly associated with coronary heart disease. A recent risk estimate is that 50% of untreated men aged 50 years and 30% of untreated women aged 60 years will develop coronary heart disease.[10] Research suggests that many patients do not achieve treatment goals.[11] Several factors are shown to be associated with an increased perceived vulnerability in patients with familial hypercholesterolemia: the pattern of heart disease in the family; high cholesterol levels; and experiencing symptoms of angina, anxiety, and depression.[12-15] A better understanding of how patients with familial hypercholesterolemia resolve their vulnerability to coronary heart disease may foster an individualized and improved clinical management.

The aim of this study was to explore how patients with a diagnosis of familial hypercholesterolemia understand and perceive their vulnerability to coronary heart disease. Our point of departure as medical doctors is a commitment to a patient-centered and biopsychosocial medicine, in which health professionals need to recognize patients' agendas and get insight into patients' own appraisal of their health-related risks and resources.[16-18]

The study was approved by the Regional Committee for Medical Research Ethics (Health Region East, Norway).

METHODS

Participants

Our sampling strategy aimed at a sample of mainly young and asymptomatic participants with familial hypercholesterolemia who had diverse social backgrounds, family histories of coronary heart disease, and times since diagnosis. Participants were recruited from a specialist clinic for metabolic lipid disorders in Norway. The clinic has a scheme for diagnosing familial hypercholesterolemia and treating these patients. The patients are mostly referred by their family doctor for diagnosis and evaluation based on their elevated lipid values, their family history of hypercholesterolemia, and coronary heart disease in their family. The Norwegian health service is predominantly publicly financed. Equal access according to need is a basic principle, and family doctors play a crucial role in the health service.[19] Norwegian attitudes and practices related to health, lifestyle, and drugs are not considered to differ substantially from common health-related values in modern Western societies.

Patients were approached through an invitation letter distributed by medical professionals at the clinic. The sample size of 40 participants was a result of data saturation as consecutive interviews yielded diminishing returns of new information. Participants' characteristics are displayed in Table 1; their mean age was 31 years. Seven participants had developed symptoms coronary heart disease, such as myocardial infarction or angina pectoris. Thirty-five participants used lipid-lowering medications.

Interviews

Semistructured, face-to-face, tape-recorded, qualitative interviews, lasting 45 to 90 minutes, were conducted by the first author. The 40 participants were interviewed in the interviewer's office (30), in interviewees' homes (8), and in the interviewees' work offices (2). The interviews were conducted from June 2000 until March 2002. All participants were informed about the purpose of the study and that they could stop the interview at any point without giving a reason. Written informed consent and an agreement that quotes from the interviews could be used anonymously were obtained from all participants.

An interview guide was developed on the basis of 8 weeks of fieldwork that involved informal conversations with patients and observation of consultations between health professionals and patients in the clinic. The interview questions were open-ended and covered issues about health and disease, addressing how participants perceived and managed their own risk of heart disease (Table 2). Emerging themes and hypotheses from the first interviews were explored in subsequent interviews.

Table 1. Characteristics of Participants (N = 40)

Characteristic	No. (%)
Age, years	
10-19	9 (22.5)
20-29	10 (25.0)
30-39	9 (22.5)
40-49	8 (20.0)
50 +	4 (10.0)
Sex	
Male	20 (50.0)
Female	20 (50.0)
Use of lipid-lowering medication	35 (88.0)
Symptoms of coronary heart disease	7 (18.0)
Children	
No	21 (52.5)
Yes	19 (47.5)
Occupation	
Professional or higher managerial	7 (17.5)
Other nonmanual	7 (17.5)
Skilled manual	4 (10.0)
Manual	7 (17.5)
Student, secondary education	14 (23.0)
Disablement benefit	1 (0.0)

Analysis

Audiotapes of the interviews were transcribed verbatim by the first author and analyzed qualitatively. The first author and the last author read 10 transcripts independently and developed a coding frame for the analysis. The first author coded all transcripts, and all authors independently read the material and contributed in negotiating the final categories and their contents. Material about participants' perceived vulnerability to coronary heart disease was identified and used for systematic text condensation, according to the principles of Giorgi's phenomenological analysis,[20] modified by Malterud.[21] The analysis followed 4 steps: (1) reading all the material to obtain an overall impression and bracketing previous preconceptions; (2) identifying units of meaning representing different aspects of participant's perceived vulnerability, and coding for these units; (3) condensing and summarizing the contents of each of the coded groups; and (4) generalizing descriptions and concepts concerning perceived vulnerability to coronary heart disease. Quotes from the interviews were translated from Norwegian to English by the first author in the process of writing this article.

Table 2. Interview Schedule

Understanding of health and disease
What does the word "health" mean to you?
How do people stay healthy?
Why do some people have better health than others?
Are people able to control their own health?
What is your image of the person who is at risk of heart disease?
What does fate mean to you?
Do you have a religious perspective on issues related to health and disease?
The condition
How did you get this condition and how was it diagnosed?
Do you have any symptoms, ailments, pains, of anything that limits your daily activities?
What influences how your condition will develop?
How will this condition influence your own future health?
To what extent are you able to influence how it develops?
Understanding of risk, own vulnerability to disease
What are the risks/uncertainties connected with your condition?
How do you estimate your own vulnerability of developing coronary heart disease?
Has the way you think about your own vulnerability to heart disease changed?
What does the risk mean for you personally?
What can you do to influence your risks?
Do you make any efforts at reducing your risk?
Experiences with the health service
How has your contact with the health service been?
How can health professionals help you manage your condition?
What do you think about the information you have been given?
Can health professional influence how you perceive your risk?
The psychosocial context
Has the condition influenced your quality of life?
Have you talked with people outside your family about your condition?
Can you give any examples of issues you would talk about?
How do your family and friends manage your condition?
How do you think other people perceive your condition (health professionals, friends, family, people in general)?
Sources of knowledge, media
What do you think about how your condition is portrayed in the media?
In what way does information in the media influence how you understand your condition?
Do you seek knowledge through other sources?

RESULTS

Most participants conveyed opinions about their vulnerability to coronary heart disease. Some were reluctant to discuss their own vulnerability, and a few said they had not reflected much on it. We found that participants negotiated a personal and dynamic sense of vulnerability to coronary heart disease that was grounded in notions of their genetic and inherited risk. Participants developed a sense of their vulnerability in a 2-step process. First, they consulted their family history to assess their genetic and inherited risk, and for many, a certain age determined when they could expect to develop symptoms of coronary heart disease. Second, they negotiated a personal sense of vulnerability through comparisons between themselves and their family members. In these comparisons, they accounted for such factors as sex, cholesterol levels, use of lipid-lowering medication, and lifestyle. Participants' personal sense of vulnerability to heart disease could shift dynamically as a result of changes in situational factors, such as cardiac events in the family, illness experiences, or becoming a parent. We elaborate further on these findings below.

Genetic and Inherited Risk

Participants consulted their family history when they assessed their genetic and inherited risk of coronary heart disease. Biographic data about family members, such as the age, lifestyle, cardiac events, and cardiac deaths, formed a basis on which participants recounted their genetic risk. Participants attributed most importance to first- and second-degree relatives they knew or assumed had familial hypercholesterolemia, particularly if the participant had witnessed the illness or death of a close relative. The pattern of coronary heart disease among family

members with familial hypercholesterolemia was used to develop a notion of how long one could expect to live without experiencing symptoms of heart disease. One participant explicitly described her impression of the genetic risk as the "family statistics" of heart disease. Her mother had been struck by a heart attack and died in her mid-30s. The participant was struck by a heart attack at the same age as her mother but received medical treatment and was subsequently followed up. She held this age pattern as a baseline and used it as a predictive device when commenting on her son's genetic risk of coronary heart disease.

"For [my son] it means that he could risk getting his first heart attack at the age of 35. This is our family's statistics. Someone else would perhaps suffer from it when they were 45 … in other families the heart attacks doesn't come before you are in the mid-50s" (participant 5, woman, 51 years).

This reasoning is limited to offspring who have familial hypercholesterolemia and is not considered valid for children without the condition. A less-severe family history influenced participants' understanding of their genetic and inherited risk. One woman thought that her genetic risk was moderately low because her grandfather lived until he was 60 years.

"I know it's not that bad, because my grandfather didn't die before he was 60 years old" (participant 22, woman, 30 years).

While many participants had a fairly accurate idea of their inherited risk or family statistics, others conveyed a vague notion of their genetic and inherited risk. Some questioned the trustworthiness of their family statistics as a predictive device after experiencing considerable variation in the onset of heart disease among family members assumed to have familial hypercholesterolemia.

"In my family … some have died early, in their 40s or their 50s. But many have become 80, so it's not given that I have to pass away early" (participant 33, woman, 21 years).

There were also participants who noted that they belonged to a different generation, and because their lifestyle and food habits were different, they questioned the predictive value of the pattern of heart disease in their family.

Negotiating a Personal Sense of Vulnerability

When negotiating a personal sense of vulnerability to heart disease, participants used their concept of genetic and inherited risk as a starting point and then compared themselves with relatives they knew or assumed had familial hypercholesterolemia. In such comparisons they accounted for individual factors, such as sex, cholesterol levels, use of lipid-lowering medication, and management of risk factors related to lifestyle (diet, exercise, smoking, and stress). A quote from the interview with a man aged 41 years who had no symptoms of heart disease offers a good illustration.

"My uncle is about 60 years old. He got his first heart attack when he was at my age, 40 years old. The difference between him and me is that I don't smoke, my lifestyle is healthy, and I take exercise. He has never taken any physical exercise, so I think I have an advantage there" (participant 1, man, 41 years).

When comparing himself with his uncle, he accounted for known risk factors and the advantages he had being a physically active nonsmoker. Typically, a certain age represented "what you could expect" given a genetic risk. A specific age was often referred to as the point at which a person could expect to develop symptoms of coronary heart disease. A woman who lost her 53-year-old father when she was 22 years old expressed how she felt about her vulnerability at that time.

"I was 22 years old and I was pregnant. It was hard … I was convinced that I would not be any older than [my father]. It was just like 53 years represented a limit" (participant 34, woman, 57 years).

Participants accounted for how they managed their condition by adding or subtracting years from a certain age that reflected their genetic and inherited risk. They were usually optimistic when they appraised their lifestyle and the effect of using medication. A statement by one participant, whose father died of a heart attack at 36 years, serves as an illustration:

"In a way I think I'll live longer … but let's say that I'll be 50 years old when I ought to start thinking about it, if we take into account that I have used medication since I was 8 or 9 years old" (participant 37, man, 28 years).

He conveyed that 36 years was when he could expect symptoms to occur given his genetic risk. When accounting for use of a lipid-lowering medication since he was a child, he added 14 years to this baseline.

There were also participants who emphasized the negative impact of their own lifestyle in comparisons with family members, as illustrated by the reasoning of a woman aged 34 years who weighed different risks against each other.

"My own risk compared with my mother's is quite similar … she has almost not smoked, and I have smoked, but she started using medication later than I did. I feel that these things that haven't been done right weigh up for each other" (participant 32, woman, 31 years).

The Dynamics of Perceived Vulnerability

Participants' perception of personal vulnerability to heart disease could change dynamically with time and was influenced by several factors, such as the psycho-

social context, cardiac events or deaths, illness experiences, approaching a perceived age limit, or becoming a parent.

The Psychosocial Context

Participants' accounts indicated they contacted the health service at a time in their life when they could manage the psychological, social, and practical consequences of recognizing their personal vulnerability to heart disease. A woman who had a diagnosis of familial hypercholesterolemia, and whose grandfather died of a heart attack at 50 years, waited for several years before she started lipid-lowering treatment:

"The reason was our 2 children, who were often ill. We went in and out of the hospital with their asthma and allergy, and pneumonias.… My husband … traveled all the time, so I almost had more than I could put up with at that moment" (participant 23, woman, 31 years).

A patient's life situation represented a broader psychosocial context in which a range of vulnerabilities were perceived and dealt with and could be a barrier to diagnosis and treatment. Patients might not have the energy needed to recognize their vulnerability to heart disease, or they might give the condition a lower priority than other competing obligations or risks.

Cardiac Events or Death

Cardiac events or deaths in the family could lead a person to reassess a family history, which in turn could change that person's understanding of genetic and inherited risk. One illustration of such a dynamic shift is a woman who had attributed family members' heart trouble to "bad luck" until 2 of her cousins had heart disease diagnosed in their 30s:

"Two of my cousins were diagnosed with heart trouble before they were 40. Then I thought: 'We have to do something' … then I knew it was inherited" (participant 4, woman, 47 years).

This quote illustrates how cardiac events in the family may heighten an awareness that heart disease is running in the family, which can be a trigger to seek health care.

Illness Experiences

Personal illness experiences can influence how patients perceive their vulnerability to heart disease. A person who experienced cardiac symptoms would feel more vulnerable, but other severe illnesses could also initiate a dynamic shift in perceived vulnerability. An example is a woman with a severe family history of coronary heart disease who had neglected her hypercholesterolemia for 10 years, until she experienced being severely ill with pancreatitis:

"When I was 22 years old, they told me that I would get my first heart attack before I was 40. I didn't really care at that time. I checked it from time to time, but I didn't really take it seriously before 1999. Then I started using medication,… without that pancreatitis, I don't think I would have thought much about it. That episode really scared me" (participant 35, woman, 36 years).

Severe illness probably increased an awareness of her health, which in turn influenced her perceived vulnerability to heart disease.

Approaching a Perceived Age Limit

Growing older can change a person's perceived vulnerability. As participants approached the age at which they would expect to develop symptoms of coronary heart disease, they might have felt an increased sense of vulnerability. A woman whose mother had died from a heart attack in her mid-30s was anxious about what would happen when she approached the same age. "I was very anxious of what would happen as I approached 35 years" (participant 5, woman, 51 years).

Becoming a Parent

Becoming a parent or planning to have children can initiate a shift in a person's perceived vulnerability. A woman, the mother of a 2-year-old girl, felt that becoming a parent had given her an increased sense of vulnerability.

"It's something about having children and all of a sudden growing up, having to take responsibility.… If I were to die, it would be a crisis for [my daughter]" (participant 32, woman, 31 years).

Her sense of social responsibility for her daughter was one reason why she started using a lipid-lowering medication 10 years after familial hypercholesterolemia initially was diagnosed. Becoming a parent may give a person an increased awareness of the future. Foreseeing the social consequences of an early cardiac death may be a trigger for a person to recognize a vulnerability to heart disease.

DISCUSSION

Validity and Transferability

This study explored how patients with a diagnosis of familial hypercholesterolemia understand and perceive their vulnerability to coronary heart disease. Participants were recruited through a clinic for metabolic lipid disorders. We have no indication that we selected for worriers or patients with multiple risk factors in our sample, but our sample probably included patients who felt positively about medical treatment. Those who were not motivated to seek medical treatment of their genetic lipid disorder would not have enrolled as patients. Con-

sequently, there were few participants in our sample who had a fatalistic attitude about their condition.

Referral and regular monitoring in a specialist clinic may have modified patients' understanding of their family histories. Even so, our results suggest that our participants developed and revised their notion of inherited risk before they made contact with the health service. The experience of cardiac events in the family may have fueled the notion of having a family history of heart disease.

Most participants in our sample were young and asymptomatic. Older participants provided valuable insights about how growing older and experiencing symptoms of heart disease might influence patients' perception of their vulnerability.

Our sampling strategy allows us to study perceived vulnerability to coronary heart disease in a group of patients with the same rare genetic disorder. We should, however, be cautious about arguing that our findings are transferable to and valid for patients in family practice.

What This Study Adds to Previous Knowledge

We know that individuals consult their family history when assessing their personal vulnerability to disease.[7,8,22] Earlier research has described a person's tendency to draw a distinction between their inherited risk and their personal vulnerability to disease.[23] Studies exploring how persons understand their inherited disposition to disease suggest that they count affected relatives and use similarities in looks, personality, or mannerism to assess whether they have inherited a certain constitution or disposition.[8,23,24] In our study, we found that participants seldom made reference to physical or mental similarities. One explanation might be that they were well aware that familial hypercholesterolemia is caused by a single-gene mutation, which is inherited independently of other traits, so they did not need to speculate on the basis of indirect evidence of inheritance; either they had the gene or they did not. The age pattern for onset of coronary heart disease in the family, referred to by some as the family statistics, was the predominant feature they used when developing their personal sense of vulnerability.

Our findings are consistent with research that points out associations between a perceived increased vulnerability and such factors as the pattern of heart disease in the family, high cholesterol levels, and experiencing symptoms of angina.[2-6] Our study adds to previous knowledge by showing how patients with a diagnosis of familial hypercholesterolemia develop a dynamic and personal sense of vulnerability to coronary heart disease that is grounded in notions of their inherited risk. We found several situational factors that can initiate a dynamic shift in perceived vulnerability: cardiac events in the family, experiencing symptoms of coronary heart disease or other serious illness, and changes in life situation. We observed that someone who could be fatalistic earlier in their life can develop an increased sense of vulnerability and increased motivation for medical treatment.

Implications for Clinical Practice

For those with familial hypercholesterolemia, a family history of premature coronary heart disease is among the most important determinants of early and severe cardiac events.[25] The clinical severity of familial hypercholesterolemia varies considerably among families, and information from the family history is usually more relevant than average risk estimates when assessing an individual patient's risk. Research indicates that patients are more motivated to seek medical treatment if they are given personally relevant information rather than information about average risks.[26] Doctors should therefore assess each patient's risk of coronary heart disease individually, on the basis of clinical data and information from the family history. Research indicates that doctors and patients may assess the patient's family history differently.[27,28] Doctors should therefore gain insight into the patient's perception of the family history and share their medical view of the information in the patients' family history with the patient. The goal of such a dialogue is to clarify misunderstandings and provide a common ground for a shared understanding and decision making.

In clinical practice it may be difficult to find time to obtain, organize, visualize, and analyze the patient's family medical history. Genograms can help doctors organize and continuously update family history information, and numerous tools are available to help patients record and organize their family histories.[9,29,30]

Our study shows that patients' personal sense of vulnerability to coronary heart disease emerges from unique biographical and social contexts and may shift dynamically with time. An understanding of the patient's psychosocial context and knowledge about how the patient understands a family history can offer important clues as to the patient's readiness for preventive behavior. Doctors need to be sensitive to their patients' individual preferences while recognizing that these preferences can change with time.

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