Patients' Perceptions of Cholesterol, Cardiovascular Disease Risk, and Risk Communication Strategies

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ABSTRACT

PURPOSE Despite some recent improvement in knowledge about cholesterol in the United States, patient adherence to cholesterol treatment recommendations remains suboptimal. We undertook a qualitative study that explored patients' perceptions of cholesterol and cardiovascular disease (CVD) risk and their reactions to 3 strategies for communicating CVD risk.

METHODS We conducted 7 focus groups in New England using open-ended questions and visual risk communication prompts. The multidisciplinary study team performed qualitative content analysis through immersion/crystallization processes and analyzing coded reports using NVivo qualitative coding software.

RESULTS All participants were aware that "high cholesterol" levels adversely affect health. Many had, however, inadequate knowledge about hypercholesterolemia and CVD risk, and few knew their cholesterol numbers. Many assumed they had been tested and their cholesterol concentrations were healthy, even if their physicians had not mentioned it. Standard visual representations showing statistical probabilities of risk were assessed as confusing and uninspiring. A strategy that provides a cardiovascular risk-adjusted age was evaluated as clear, memorable, relevant, and potentially capable of motivating people to make healthful changes. A few participants in each focus group were concerned that a cardiovascular risk-adjusted age that was greater than chronological age would frighten patients.

CONCLUSIONS Complex explanations about cholesterol and CVD risk appear to be insufficient for motivating behavior change. A cardiovascular risk-adjusted age calculator is one strategy that may engage patients in recognizing their CVD risk and, when accompanied by information about risk reduction, may be helpful in communicating risk to patients.

INTRODUCTION

Despite recent advances in the diagnosis and treatment of cardiovascular disease (CVD), it remains the leading cause of death in the United States.[1] In 1985 the National Heart, Lung, and Blood Institute launched the National Cholesterol Education Program (NCEP), which issued the Adult Treatment Panel (ATP I, II, and III) clinical guidelines aimed at reducing the burden of CVD through improved cholesterol management.[2-4] The NCEP produced educational kits for clinicians and patient-oriented media programming including the "Know Your Cholesterol Numbers, Know Your Risk" campaign.[5,6]

Cholesterol knowledge is reported to have improved since the 1980s,[7,8] but important information gaps remain. One study reported that from 1983 to 1995, there was an increase in the percentage of Americans who had heard of high blood cholesterol levels, who had been informed of their levels, and who knew their total cholesterol number.[9] From 1983 to 1995,

the percentage of the public who had heard of high blood cholesterol levels rose from 77% to 93%, and the percentage who were told their cholesterol values rose from 21% to 65%. Furthermore, the percentage who reported that they knew their level increased from 3% to 49%.[9] Other studies, however, showed that only about one third of the population reporting an elevated total cholesterol concentration or using cholesterol-lowering medications were aware they had hyper-cholesterolemia,[10] and that whereas some individuals underestimate their risk of developing a disease,[11,12] others overestimate risk.[13] Even with some improvements in knowledge, patient acceptance of and adherence to cholesterol treatment recommendations remain subopti-mal,[9,14,15] as inaccurate perceptions of vulnerability to a disease can inhibit prevention behaviors.[16-18]

Information alone may not promote behavior change. Strategies are necessary to engage patients with how cholesterol levels relate to their CVD risk,[19,20] as well as mechanisms to address the impact of low functional health literacy on understanding.[21,22] Functional health literacy goes beyond written com-munication to include innumeracy and a person's abil-ity to comprehend oral communication.[23] Almost one half of all adults in the United States have literacy levels that impede their ability to understand health information and apply it to decision making.[22] Recent studies of patient-physician communication found innumeracy to be a major barrier to use of standard bounded probabilities (ie, 0 to 1, 0% to 100%) for comprehension of risk information.[24,25] One promis-ing method for overcoming some of these barriers is to use visual displays of numerical information[26-28] or to use analogies for expression of probability.[29] Recent thought on low health literacy also emphasizes strate-gic actions within health care systems[22] to ameliorate some of the consequences,[23,30,31] including use of new strategies for patient education.

As part of a project to enhance implementation of the ATP III guidelines in primary care practice, we conducted exploratory, qualitative research about patients' perceptions of cholesterol, CVD risk, and risk communication strategies. We report findings from that study in this article.

METHODS
Study Design, Participants, and Data Collection
The authors were part of a multidisciplinary group of primary care researchers with different theoreti-cal groundings and distinct methodological perspec-tives: an anthropologist (REG), an epidemiologist (DP), a family physician/anthropologist (JB), 2 family physicians (CE, RG), a research assistant (RC), and a

behavioral psychologist with a specialty in e-Health (DA). This group included both predominately qualita-tive (REG, JB) and predominantly quantitative (CE, DP, DA, RG) researchers, as well as a family physician who held a clear belief in the efficacy of interventions around cholesterol (CE) and one who was more skep-tical (JB). We discussed these biases and preferences openly during research development, implementation, and analysis phases, and considered the potential effect on our interpretation of data.

Between January and March 2003, we conducted 7 focus groups with 50 adults in the northeastern United States.[32-34] We used focus groups to benefit from the interactive discussion among participants these groups foster; participants respond not only to direct questions from the moderator but also to ques-tions and ideas posed by other participants.

Participants were recruited from primary care prac-tices and through a newspaper advertisement calling for adults to discuss physician-patient communication. We advertised this broader aim of our study to avoid limiting recruitment to those who were especially motivated to talk about cholesterol. To meet the study inclusion criteria, the participants had to be older than 18 years and able to speak English.

The tape-recorded focus groups were held in a hospital conference room or in community locations. Before beginning each 2-hour discussion, participants signed an informed consent that was approved by the hospital's human subjects protection review board. They received $25 in cash for their participation.

The groups were moderated by an anthropologist (REG) using a guide of open-ended questions supple-mented by spontaneous probes (available online-only in the Supplemental Appendix 1 at http://annfammed. org/cgi/content/full4/3/205/DC1). The subset of topics reported in this article are knowledge and perceptions of cholesterol, perceptions of risk associ-ated with cholesterol, and assessment of CVD risk com-munication methods. To compare patients' reactions to 2 standard visual risk communication strategies[26-28] and HeartAge (our developing strategy for communi-cating cardiovascular risk-adjusted age), we evaluated their responses to 3 visual representations of risk for a 10-year coronary heart disease event probability according to the Framingham Heart Study data.[35] The NCEP published in its 2001 evidence-based consensus ATP III guidelines a prediction equation for the 10-year coronary h eart disease risk (recognized myocardial infarction, silent myocardial infarction, coronary insuffi-ciency, and coronary heart disease death) by evaluating the multivariate risk associated with age, sex, current cigarette smoking, total cholesterol concentration, high-density lipoprotein cholesterol concentration, and

systolic blood pressure (treated or not treated).[4] This equation is based upon the 10-year follow-up of 2,489 men and 2,856 women from the original Framingham cohort and the first cycle of the Framingham Offspring study, aged 30 to 74 years at baseline in 1971 to 1974. This risk equation has been shown to be valid in multiple ethnic cohorts.[36]

For the visual displays, we presented data for a 42-year-old man with a high 10-year risk (0.25) of coronary heart disease based on the Framingham Heart Score. Participants were shown the following: (1) First they were shown a crowd chart[27] depicting 100 stick figures with 25 shaded to represent the proportion expected to experience a coronary heart disease event during the next 10 years and then an identical chart with the risk for a same-aged man who had no risk factors (0.01 probability, 1 figure shaded), which visually depicted both absolute and relative risk reductions. (2) Then they were shown a simple vertical bar graph comparing the current risk (0.25) as a full column with a column to represent the risk for a same-aged man who had no risk factors (0.01), which visually depicted relative risk reduction. (3) Finally, they were shown a simple horizontal bar chart displaying cardiovascular risk-adjusted age that we called HeartAge, which had 2 bars representing ages from 0 to 76 years. The first bar represented the individual's true chronological age (42 years) and the second bar showed how this individual compared with the average age of a same-sex person in the Framingham Heart Study having the same 10-year probability of experiencing a CHD event. For the demonstration case, the 42-year-old had the same risk as a 70-year-old.

Data Analysis

The coauthors conducted preliminary analyses on an ongoing basis as each focus group transcript was completed. We recognized we were reaching data saturation when we began to hear repetitive comments, with few new data generated in the final groups. After completion of the focus groups, from May through December 2003, we met regularly to conduct an in-depth analysis using the immersion/crystallization method.[37] This involved repeatedly listening to the audiotapes and reading and discussing the transcripts to identify emerging themes and salient topics. After we developed an initial codebook and clarified definitions, the transcript texts were subjected to line-by-line coding with the qualitative software NVivo.[38] The codebook was modified by team consensus as the need for new codes emerged. We used the coded reports to facilitate further analysis discussions, develop links between themes, finalize data interpretation, and identify supporting quotations. Searches for alternative interpretations were conducted and discussed before final decisions were made about how to report and discuss the findings.

RESULTS

Participant characteristics are displayed in Supplemental Table 1 (available online-only at http://annfammed.org/cgi/content/full4/3/205/DC1). Of the 7 focus groups, 2 were held in affluent communities; for 1 group we recruited from a primarily low-income clinic, though all groups included mixed income and education levels. Participants with college or higher degrees did not always have correspondingly higher income than those with less education, though for some a lower income might have been due to being currently retired. Overall, participants were aged 27 to 84 years; household yearly income ranged from less than $10,000 to more than $60,000; and education ranged from high school to postgraduate and professional degrees.

Knowledge and Perceptions About Cholesterol
Definitions of Cholesterol

All participants were aware that high cholesterol levels adversely affect health, though many were surprised that they only recently heard about this issue. Participants' explanations included that cholesterol is a newly discovered health problem, that the recent plethora of medication advertisements raised awareness, and that doctors only lately became concerned about cholesterol. Table 1 lists participants' perceptions about cholesterol.

There were similarities across socioeconomic

Table 1. Participants' Perceptions of Cholesterol

Characteristic	Perception
What it is	Goop
	Liquid
	Concentrated fats
	Saturated fats
Where it is	Fat in the blood
	Fat in your veins
	Fats in foods
What it is associated with	Steaks
	Pork
	Butter
	Lard
	Overweight
What puts you at risk	Fatty foods
	Impure foods
	Too little exercise
	Heredity
	Overweight
What it does	Clogs arteries
	Clogs veins
	Causes heart attacks and strokes

groups in the ways participants described cholesterol and their confusion about what cholesterol is, though some with higher education provided more accurate descriptions and focused on the more complex aspects of cholesterol risk. For example, a man who showed a good understanding of cholesterol still wondered:

"Since I've been on the medication a while, is it maintaining status quo? My concern is it may reduce the risk factor, but what's the relationship between the residual clogging you might have and the fact that you're taking medication?"

Some participants associated cholesterol with blood pressure, variously assuming that if one is low the other will be low, that high cholesterol levels cause the same physical symptoms as high blood pressure, and that high cholesterol levels and high blood pressure cause each other. Although many used appropriate words to talk about cholesterol, not all conceptualizations of biological processes were accurate. Some spoke of levels of cholesterol (high/low), while many across groups referred to cholesterol in absolute terms. As a participant admitted, "I don't even know what it's made up of. But I know some people have it and some people don't."

Desire for Information
Many participants wanted information about cholesterol that was clear and unchanging. They were frustrated by shifting health messages regarding diet and were reluctant to believe dietary recommendations. Some purposively avoided thinking about cholesterol, whereas others simply remained uninformed. For example, a man who was currently taking cholesterol-lowering medication had not received explanations from his physician, and he consistently forgot to ask questions. He disclosed, "I don't know what it is. I don't know where it comes from. I don't know where it goes."

Diet
Many participants told stories about a sibling or friend who eats "whatever he wants" and has normal cholesterol values, whereas others who eat a healthful diet have high cholesterol values. Nevertheless, despite prevailing doubts about the accuracy of dietary recommendations, most participants acknowledged some association of diet with high cholesterol levels. Fats were frequently mentioned, and some participants in every group cited health consequences of saturated fats or the benefits of certain oils. Participants also cited food- and preparation-related factors as contributing to high cholesterol levels: chemicals in animal feed; pesticides on plants; and foods that are not fresh and natural, that are pasteurized, have preservatives, and are processed, frozen, and canned. Participants often

conflated general issues about food quality and lifestyle with concerns about diet and cholesterol.

Participant 1: "This is my problem with the high cholesterol: They say fried foods, fatty foods, eggs. My grandfather lived to be 96 years old, North Carolina. He smoked, drank, and eat fried foods every day."

Participant 2: "Yeah, but the food was different in those days than it is nowadays."

Participant 1: "How is the food different? Pork, pig feet, chittlins, ham hocks, bacon."

Participant 2: "Yeah, but the foods aren't natural anymore."

Participant 3: "I would look at it another way. In our society we're sitting down. For me, I've sat down all day at my desk working, so, where your grandfather was, what did he do all day? He was outside working."

Overweight and Heredity
Many assumed that only overweight and older people are affected by cholesterol. Younger and thinner participants were surprised when others in the groups stated that anyone might have high cholesterol levels, and they found it difficult to overcome their limited view of the risk of high cholesterol levels.

"I associate high cholesterol with high weight gain, although I know very slender people can have very high cholesterol. But somehow in my mind's eye … I associate it with being overweight."

Stories emerged about overweight people with normal cholesterol levels who have thin siblings with high cholesterol levels. Participants talked about the impact of heredity on cholesterol and their ambivalence about heredity because familial patterns are inconsistent.

"There's a possibility [high cholesterol is] genetically inherited, … and then if they are predisposed to this, if they do not do certain controls, then their chances are they may follow their family that may have died at a young age because of cholesterol rather than cardiac infarction or even a heart attack. But maybe we can, I think we can control it."

HDL and LDL
Few participants were familiar with the terms "HDL" (high-density lipoprotein) and "LDL" (low-density lipoprotein), though many had heard of "good" and "bad" cholesterol. Although some understood that one type should be high and the other low, participants' greater familiarity with the generalized term "cholesterol" and their recognition that high (total) cholesterol levels are unhealthy resulted in confusion about cholesterol being both good and bad, with goals for high and low numbers.

"Cholesterol to me has like a negative connotation

to it, whether it's good or bad. Why didn't they just come up with another word?"

"Blood pressure should be low. Cholesterol should be low. Everything should be low."

Cholesterol Numbers

In the 2 focus groups with the most highly educated participants, almost all knew their total cholesterol number. There were a few in each of the other groups who knew their total number, and they were usually motivated by having serious cholesterol problems or a family history of high cholesterol. An additional few in each group knew that they had been tested; they could not recall the number, but they did know whether it was high or not. Only a few participants in the entire sample knew their HDL and LDL numbers, though a few in each group knew whether their levels of good and bad cholesterol were problematic.

"I don't even know my numbers. I just know it was high, and he put me on medication for it."

"I know the good is high and the bad is low. The exact numbers always escape me. "

Perceptions of Risk Associated With Cholesterol

Cholesterol Numbers and CVD Risk Perceptions

Throughout the focus groups, participants claimed that cholesterol numbers were not an effective means to understand their risk for CVD and indicated that they did not personally relate to the abstractions that the cholesterol numbers represented. None of the participants recognized the NCEP slogan, "Know your cholesterol numbers; know your risk," and none found it compelling.

The level of risk that participants ascribed to high cholesterol varied, with some viewing it as a serious disease in itself, and others considering it a contributor to disease. Some prioritized taking blood pressure medication over cholesterol-lowering medication. Most viewed high cholesterol levels as less serious than high blood pressure because of the views that cholesterol can be managed while blood pressure cannot, blood pressure leads more directly to a heart attack, they have known about high blood pressure for longer, and they continue to hear more from physicians about blood pressure. Participants reasoned:

"Cholesterol doesn't kill like blood pressure."

"They don't make it an issue like they do heart disease. Cholesterol, I would say, is down on the bottom of the totem pole as far as most people are concerned of it being a high-risk factor that could kill you."

Cholesterol Testing

Participants assumed that doctors regularly test cholesterol as part of a complete physical examination even if patients are not aware that it is being done. This

belief was especially strong among individuals whose physicians had ordered blood tests. Even though their physicians never spoke with them about cholesterol, nor informed them of their numbers, they assumed that their cholesterol level was normal:

"I never asked, so maybe they are testing my cholesterol. They just told me if there was anything wrong, they would let me know."

Response to 3 Risk Communication Visuals

The crowd chart was disliked by all participants. Many found the crowd chart confusing, and even those who understood the message assessed the presentation as unconvincing. Typical evaluations of the crowd chart were "busy," "your mind starts to lose the comprehension of the dots," "it doesn't have any oomph," and that it took a lot of thought to understand. The traditional bar graph showing the relative probability was viewed by most as lacking impact, "too dry," "too statistical," geared toward "scientific medical-types," and removed from personal experience. A few participants who were comfortable with statistics viewed the chart as a reasonable way to present risk information.

The third presentation, based on cardiovascular risk-adjusted age, was assessed by almost all participants as engaging and memorable. Reactions included "it's catchy," "it grabs you," "it's an eye-opener," "it's a wake-up call," and "it raises your consciousness." A few participants in each focus group, however, warned that patients might become alarmed if their calculated risk of a heart attack or dying of heart disease is similar to that of an older person. These statements generated considerable discussion among the participants. Some supported the idea that the message is simply frightening, and others countered that it is nevertheless important for people to have this information and that it may motivate them to change their behaviors. Some suggested that the cardiovascular risk-adjusted age strategy would be most useful and least alarming if it was accompanied by information about reducing one's risk for CVD. A few participants were skeptical about the validity of the age calculations and wanted more information about the variables used in the underlying formula.

Even among those who expressed concerns, participants found the concept of cardiovascular risk-adjusted age to be more engaging than the percentages provided by probability and relative risk reduction charts. They believed that remembering an age number would be easier than remembering cholesterol levels or percentages, and they were more likely to remember the calculated age changes from year to year. Some believed that the information about risk akin to an

older person would be motivating enough to consider life changes to improve their cholesterol numbers and heart health. Table 2 includes participants' reactions to the cardiovascular risk-adjusted age strategy that exemplified many responses.

DISCUSSION

Common themes throughout all the focus groups involved participants' inadequate knowledge and awareness about cholesterol and its association with CVD risk. Participants expressed surprise that they knew so little about cholesterol and that they may never have been tested. These results are consistent with recent findings that two thirds of patients younger than 40 years, as well as one half of the Hispanic and African American patients surveyed, reported never having received a cholesterol screen-

ing recommendation from their physicians.[39,40] A low rate of screening recommendations generally may be reinforcing the perception among our participants that their cholesterol levels had been measured as part of regular physical examinations, even if their physicians did not talk about it.

Participants used words commonly associated with cholesterol, though their descriptions of biological processes and CVD risk often contained inaccuracies. Participants with the highest education more completely described what cholesterol is and how it creates risk for heart attack and stroke, though some confusion remained. While one study found that from 1986 to 1995 the percentage of persons who knew that a desirable total cholesterol level is less than 200 mg/dL increased dramatically,[9] other studies support our findings that only a small portion of patients know their own cholesterol levels and risk for coronary heart disease[41,42] despite being generally knowledgeable about the health risks of high cholesterol.[41]

Giving patients more medical information may not mitigate the influence that prevailing beliefs have on patients' views of medical issues.[14,43-45] Furthermore, the trend in cholesterol education toward increasingly complex explanations (that include total, HDL, LDL, triglycerides, and non-HDL cholesterol) may not lead to optimal understanding of cholesterol and may, at the same time, be insufficiently motivating for patients to work with their physicians to reduce cholesterol-related CVD risk. Similarly, the "Know Your Cholesterol Numbers; Know Your Risk"[6,9] campaign may also be suboptimal, as most participants in our study did not know their cholesterol numbers and, possibly more importantly, did not think knowing their numbers would motivate them to personalize their risk profile and engage in behavior change.

Results of this study are limited by the small geographic area from which participants were recruited. In addition, it is not possible with focus groups to obtain the detailed accounts of participants' perspectives that

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Table 2. Participants' Representative Reactions to a Strategy for Communicating Cardiovascular Risk-Adjusted Age

Concerns

You've got to look at other things that most people won't look at. Is this clinical information, or is this statistical information? Have they actually ran these people through a series of physical tests to come up with these numbers? Or are they just drawing these numbers from medical records?

But you know, you've got to keep in mind that it may not be accurate. So you could be reading something on there. And when you walk in to see your physician, he can tell you something a little different. Something like that would make the person probably be concerned. So when he walks in there, now his blood pressure is up. I'm concerned about the numbers that this computer is going to show you which may not be accurate. It might give you a heart attack. You know.

I'm thinking that it's kind of overwhelming. It's intimidating for a man to come in who is 52 and find out he's got a heart age of 79. I think it's gonna be very upsetting. He's gonna be really shaken.

Participant 1: It's like he has one foot in the grave.

Participant 2: Because he's 50 years old. And you're saying his heart age is 72. You know? That's … he's almost done with life.

Participant 3: It is definitely scary. He needs to discuss the problem with his doctor immediately.

I think it's going to be startling to a lot of people. A lot of people will say, yeah, I'm 52; I feel like I'm 60. But when people see figures on a computer that's supposed to be accurate, they're going to say I'm 52, and I've got a heart of a 72 year old man, I think they're going to be in shock. Nobody wants to hear the truth.

Participant 1: So maybe you need a transition slide that says how can I improve this or what can I do.

Participant 2: So they don't walk away quaking.

Benefits

That [cardiovascular risk-adjusted age strategy] is easy, I can understand that. Yeah, that spells everything out. You can go to the doctor a year later, and boom [see how the calculated age has changed].

No, you ain't gonna forget that [the age]. Those numbers [actual age and cardiovascular risk-adjusted age] are a hell of a lot easier than the first 3 you plugged in there, the HDL, whatever the heck that is.

I think the idea of [cardiovascular risk-adjusted age] made it personal. Because this is your age. It brought you into it. The other [probability estimate bar chart], I mean, that's just another graph. It's too statistical.

I think the point is to wake up. I don't think anyone's gonna pass out from seeing that [cardiovascular risk-adjusted age]. If something is wrong you need to change the way you're living.

I think the average person looking at that [cardiovascular risk-adjusted age] is going to get depressed. And after they get depressed, they're probably going to reevaluate their life. I mean that's very revealing.

Your [cardiovascular risk-adjusted age] is telling you there's something medically going on. And you need to make some more changes.

result from individual interviews. We did, however, choose to use focus groups to benefit from the interactive discussion.

To engage patients' focus on cholesterol-related CVD risk and facilitate meaningful communication with physicians,[14] cholesterol education tools must be able to arouse the emotion necessary to enhance use of the teachable moment provided by cardiac risk factor assessment. Our focus group participants' reactions to 3 risk communication strategies indicate they preferred a method that engaged their attention in a manner to which they could personally relate. The personal element, therefore, may be critical for alerting patients to how they, as individuals, can be affected by CVD risk and may be important for motivating patients to talk with their physicians and change behaviors to improve their cholesterol levels. A cardiovascular risk-adjusted age strategy uses a calculation based on probability estimates and converts it into a concept using age that participants found meaningful, easy to understand, and memorable. Some, however, were concerned that the emotion aroused by the risk-adjusted age strategy may be frightening, indicating that such an approach must be accompanied by clear messages regarding how individuals can work with their physicians to reduce their CVD risk. The strategy avoids vaguely elastic terminology, such as "likely," "rare," and "chance of occurrence," and it may help overcome the barriers of interpretation of numbers for patient-physician communication.[24,27,46,47] Our participants' interest in the cardiovascular risk-adjusted age strategy is consistent with other observations that although patients often desire more information than they are getting from their clinicians, their wish is not for raw data, complicated medical explanations, or population estimates. Rather, they seek personally meaningful information that may prove helpful as they make their health care and lifestyle decisions.[27] If physicians can achieve this essential initial step of truly engaging patients with the notion of their own cholesterol-related CVD risk, then patients may be better prepared to understand and internalize the elements of traditional cholesterol education that our participants found to be confusing or irrelevant. The findings from this research, then, pose a question for debate concerning the type and amount of detailed information most appropriate for motivating behavior change. This study suggests a way forward and may help clarify our cholesterol education efforts.

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Key words: Methodological study; qualitative research; hypercholes-terolemia; cardiovascular disease; medical decision-making; informatics; communication; patient education; health promotion;

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