



Published in final edited form as:

Patient Educ Couns. 2009 August ; 76(2): 233–239. doi:10.1016/j.pec.2009.01.010.

Individuals' responses to global CHD risk: A focus group study

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Abstract

Objective—To explore how individuals respond to global coronary heart disease (CHD) risk and use it in combination with treatment information to make decisions to initiate and maintain risk reducing strategies.

Methods—We conducted four focus groups of individuals at risk for CHD (n=29), purposively sampling individuals with each of several risk factors. Two reviewers coded verbatim transcripts and arbitrated differences, using ATLAS.ti 5.2 to facilitate analysis.

Results—Participants generally regarded the concept of global CHD risk as useful and motivating, although had questions about its precision and comprehensiveness. They identified several additional influential factors in decision-making (e.g. achievable risk, the quickness and self-evidence of results) and generally preferred lifestyle changes to medications (although most would accept medications under certain circumstances). They also noted the importance of participating in decision making.

Conclusion—Our results underscore the motivating potential of global CHD risk and the importance of patient participation in decision making.

Practice Implications—Global CHD risk is a useful adjunct to CHD prevention and can be presented in ways, and with information, that might improve CHD outcomes.

Keywords

focus groups; cardiovascular disease; decision making

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I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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1. Introduction

Coronary Heart Disease (CHD) is the most common cause of morbidity and mortality in the United States. This year an estimated 770,000 Americans will have their first myocardial infarction (MI) and 38% of those will die from it [1]. Several factors increase the risk for coronary events, including high blood pressure, abnormal cholesterol, and smoking. However, less than 50% of individuals with these elevated risk factors have them adequately treated based on major U.S. guidelines [2-5]. These low rates of risk factor treatment argue that better ways of addressing CHD prevention are needed.

One promising approach for improving CHD prevention is involving patients as active partners in prevention decisions. The value of patient involvement stems from patients' role as the final arbiters of CHD prevention: whether or not patients are formally involved in decision-making, they ultimately decide whether or not to adhere to CHD interventions. Formally involving patients in the decision-making process might allow them to choose interventions that circumvent known barriers to CHD risk reduction. It might additionally promote an environment in which choosing and adhering to one intervention would improve self-efficacy for future interventions. Preliminary data supports such assertions [6].

Capitalizing on potential benefits, several policy making bodies have made recommendations that embrace a patient-centered approach to CHD prevention. In 2002, the American Heart Association recommended that all patients 40 years of age or older should know their global CHD risk [7]. Additionally, the U.S. Preventive Services Task Force acknowledged shared decision making as an important approach for CHD prevention [8]. These recommendations have underscored the need for empirical work to understand how patients respond to global CHD risk information and how they might use it in combination with treatment benefit information in their decision-making.

To date, most empirical work on global CHD risk and decision making for CHD prevention has focused on the accuracy of patients' perception of CHD risk information [9-13], barriers to CHD decision making and prevention [14,15], or the efficacy of decision support in practice [6,16-21]. To our knowledge, no studies have addressed the very basic questions of how individuals respond to a global CHD risk approach, or how they might use it in combination with treatment benefit information to make decisions to initiate and maintain CHD risk reducing strategies.

Global CHD risk approaches are quite different than the traditional approaches to CHD prevention, which have focused on treatment of all elevated risk factors. Global risk approaches provide an opportunity for patients to consider their absolute CHD risk, decide how much risk reduction is desired and/or needed, and think about the tradeoffs in initiating and maintaining various risk reducing strategies to achieve risk reduction. In this paper, we report findings from a focus group study that explores how patients respond to global CHD risk information and use it in combination with treatment benefit information to make decisions to initiate and maintain risk reducing strategies. We additionally discuss how the results might be used to promote decision making and adherence for CHD prevention.

2. Methods

To determine how patients might respond to global CHD risk information and use it in their decision-making, we conducted a focus group study of patients and interested community individuals who were at risk for CHD. We used focus groups because they allowed us to obtain feedback on a presentation about global CHD risk and decision making, and provided opportunities for follow-up probing and group interaction that are not possible in more traditional telephone or mail surveys [22]. All study procedures were approved by University

of North Carolina at Chapel Hill's Biomedical Institutional Review Board (IRB), which serves to protect the rights and welfare of human subjects. In accordance with IRB standards, all participants provided signed written informed consent prior to participation.

2.1. Participant selection

For our focus groups, we recruited a convenience sample of participants who were at risk for, but with no prior history of, heart disease. Due to low response, we had to use two different recruitment strategies. First, we contacted 63 patients who we had previously determined to be at moderate (6-9%) to high risk ($\geq 10\%$) of heart disease over 10 years based on current guidelines for aspirin and cholesterol [23,24]; these patients were identified during a random chart review of new patients at our university general internal medicine practice. We sent each patient a letter notifying them we would be contacting them about a study on heart disease prevention and allowed them to opt out of further contact by returning a post-card indicating their desire for no further contact. Patients who didn't return their postcards (n=47) were telephoned about participation. Second, we recruited participants from a local decision support registry. From this registry, we identified 73 individuals who were interested in participating in decision making research, had no prior history of heart disease, and were likely to be at moderate or high risk of heart disease based on their age (e.g. men > 40 years and women > 50 years). In accordance with the routine practice of the registry, we sent these individuals an email inviting study participation and did not contact them further if they did not respond to the invitation. We continued to recruit members for groups until the team decided that we reached thematic saturation (n=29).

To ensure our sample included moderate to high risk individuals, we asked potential participants to provide their exact personal risk factor information so that we could calculate their CHD risk and verify their eligibility for our study. We did not require exact risk factor information, however, as long as potential participants met other criteria that would assure us they were at moderate to high risk (i.e. met age criteria and had two additional risk factors).

To ensure a well-rounded discussion, we additionally sampled individuals in such a manner as to ensure that at least one person with each CHD risk factor was in each group.

2.2. Conducting the focus groups

We conducted four focus groups between August and November 2005. Each session consisted of five parts: informed consent, a pre-focus group questionnaire, a warm-up discussion about participants' experience with heart disease, an expert presentation about global coronary heart disease risk with review of individual risk profiles, and a specific discussion about how participants viewed the concepts presented and approach decision making and adherence to CHD prevention. Groups lasted approximately 1 ½ hours each.

Groups were facilitated by a team of public health professionals with experience in focus group moderation. A single facilitator asked questions and guided all group discussions. The principal investigator, a physician, gave the presentation. One or more co-facilitator(s) obtained informed consent from all study participants, administered a brief pre-focus group questionnaire, operated the digital recorders, and compensated participants \$35 at the completion of each session.

2.3. Pre-focus group questionnaire

Prior to each group, we administered a pre-focus group questionnaire to all participants. In this questionnaire, we collected information that would allow us to define our participant characteristics and contextualize group responses. Specifically, we collected information on

participant demographics, CHD risk factors, numeracy skills, and preferred participation in decision making using questions from our previous work [25].

2.4. Presentation and risk profile content

To provide group participants with a starting point for discussion about being involved in CHD prevention decisions, the principal investigator delivered a 20-minute PowerPoint presentation on CHD prevention. This presentation began with an overview of CHD risk factors, effective therapies for CHD prevention, and an explanation of the concept of global CHD risk. It continued with a case presentation that illustrated how a man at high risk of CHD might use information about global CHD risk and the benefits and attributes of risk reducing therapy to make a personal decision about reducing his CHD risk.

After the presentation, each participant was provided with a personal profile that detailed his or her personal risk, and the absolute risk reduction and risk that could be achieved by intervening on each of their unique risk factors separately or in combination (see Figure 1). All global risks and risk reductions were calculated at www.med-decisions.com using the Heart to Heart tool [26]. This tool calculates the 10-year risk of angina, non-fatal MI, and CHD death based on data from the Framingham study [27]; shows this risk numerically and graphically; and then applies evidence based relative risk reductions from primary prevention trials to calculate and demonstrate post-treatment absolute risks. We based profile calculations on the risk factor information provided by participants during recruitment. For participants who were unable to provide exact information to allow risk calculation, a “mock” profile was provided based on stated risk factors and the average risk of persons their age and sex [28]. Participants were asked to review these profiles, think about how they would make decisions about CHD prevention using such a profile, and then rank six factors we anticipated might be important in their decision making (e.g. CHD risk, benefit of risk reducing therapy for CHD, other health benefits, side effects, cost, and effect on others).

2.5. Discussion content

We structured our focus group questions to encourage participants to discuss the major components of our conceptual model (see Figure 2). This model is based on three theories--the Protection Motivation Theory [17], the Integrative Theory [29], and the Self-Determination Theory [30]—and outlines the potential impact of global CHD risk information on CHD decision-making and adherence. The focus group guide consisted of five main questions (see Table 1) and accompanying probes.

2.6. Data capture, coding, and analysis of qualitative data

We used the following process to capture, code, and analyze our qualitative data. We digitally recorded all focus groups and transcribed the files verbatim. Members of the research team, then, verified the transcripts by listening to the original recordings. To analyze our data, we first created a coding scheme for analysis using both deductive and inductive methods. Our initial coding categories were based on our conceptual model, list of research questions, and hypotheses. Then we used inductive coding techniques as described by Strauss and Corbin [31]. Two coders reviewed each transcript to identify relevant themes and then designated each statement or dialogue with appropriate codes. Coders compared codes, arbitrated differences, and clarified themes.

We then used a qualitative data analyses software program, ATLAS.ti 5.2, to facilitate analysis. We retrieved text on specific codes or combination of codes to enable content analysis of particular topics. We assessed the saliency of themes and refined existing themes when necessary. We then summarized our findings and chose quotes representative of each theme for presentation. We additionally examined quotes by participants' level of CHD risk to

determine whether individuals at moderate (5-9% over 10 years), high (10-20% over 10 years), and very high (>20% over 10 years) risk expressed different ideas about or approaches to CHD prevention.

2.7. Data analysis of pre-focus group questionnaire

To help define our focus group population, contextualize focus group content, and allow inferences about the generalizability of our findings, we performed descriptive statistics on all data in our pre-focus group questionnaire using SAS Statistical Software (Cary, NC).

3. Results

We recruited 29 participants in four groups before achieving thematic saturation. Eighteen individuals were from the new patient pool at our university general internal medicine practice; the remainder were from a Decision Support Registry. Most participants were highly educated, in good health, and reasonably good with numbers using a well validated numeracy score [32] (see Table 2). Eighteen provided exact CHD risk factor data, and nine provided only a qualitative description of their risk factors. Using this data, we estimated that 31% were at moderate risk (6-9% over 10 years), 52% high risk (10-20% at 10 years), and 17% very high risk (>20% over 10 years) of CHD. A majority wanted to share in decision making.

Participants' ideas and approaches to CHD prevention did not differ by risk level, thus are presented for the whole group below. Table 3 contains illustrative quotes for key themes described below.

3.1. Reaction to concept of global CHD risk and risk reduction

Overall, participants in all focus groups found the concept of global CHD risk useful and most preferred it to looking at risk factors individually. They thought it increased their understanding of the value of CHD prevention and helped them to understand what remains to be done after addressing one risk factor. Further, global CHD risk helped participants understand that risk of heart disease can remain high even after addressing one risk factor. Participants additionally thought global CHD risk provided the motivation needed to reduce their CHD risk and some independence in accomplishing their goals.

Aside from the concept itself, participants across groups also expressed an appreciation for our presentation of the concept of global CHD risk and risk reduction. Visually, they liked the use of color and stated that the numbers “wake you up, puts it right there in front of you.” Many participants echoed the sentiment that the “graph gets my attention and will encourage me to pay a little more attention.”

Despite enthusiasm, however, participants in three of the four groups also raised several concerns about global CHD risk and/or our presentation of it. Several participants conveyed concern for the accuracy of the calculation, deeming it “too simple” or “imprecise.” Others felt global risk didn't include all relevant risk factors, and a few participants expressed confusion regarding the implications of the risk profile.

Furthermore, participants want to understand the numbers and values presented to them. Several explained they might take global risk more seriously if they knew exactly what the calculation is based on and how the numbers affect the final percentage. Many also stated the desire to know more information about the risk factors contributing to global CHD risk, such as what constitutes a “good” or “bad” cholesterol value, mostly because they needed this information to intervene.

3.2. How patients use global CHD risk in combination with treatment benefit information to make decisions about CHD prevention

In spontaneous discussion, participants in all groups discussed their CHD risk and appeared to use it in decision making. Additionally, when asked to rank the factors most important to their decision making, a majority ranked CHD risk the most important factor. Interestingly, however, participants focused less on their current global CHD risk level than on the absolute or relative risk reduction of the risk reducing strategy or the achievable absolute risk following intervention. They additionally valued not only interventions that would lower their risk as much as possible, but also interventions that would move them between levels of risk (“from any zone to a lower zone”), as defined by the medical community.

In addition to absolute and relative risk reductions and achievable CHD risk, participants used several other factors in decision making about CHD prevention. These factors overlapped to some extent with the factors we asked them to rank after the presentation about CHD risk. There, however, were notable exceptions and additions.

As we expected, participants highlighted the importance of side effects (four groups), cost (four groups), amount of effort (three groups), and effect on others (one group) in decision making. However, contrary to our expectations, they rarely talked about using the “benefits of medications for conditions other than heart disease” as a decision factor, despite the fact that a few participants ranked this as a high priority for decision making.

Participants also identified several decisional factors that we did not anticipate. First, three of the four groups wanted risk reducing options with quick and tangible results. Second, participants in three of the four groups voiced a preference for risk reducing options that have been around for a long time, are well-studied, and come from trusted sources. They expressed frustration about changing science and the potential risks it imposes. Third, participants in two groups expressed a preference for risk reducing options that would not interfere with their enjoyment of life. Fourth, nearly all participants voiced a preference for products that were natural and free of side effects. Almost universally, they largely preferred lifestyle changes to medication. Participants in all groups were willing to take medication under certain circumstances—for instance, when a medication was safe and inexpensive and the easier option; or a bridge to lifestyle changes—but, in general, medicines were seen as a “last resort.”

In the end, several participants intimated that their decisions came down to a gut feeling...and had a hard time expressing the exact tradeoffs they would be willing to make.

3.3. Adhering to CHD risk reduction plans

As noted earlier, participants thought that information about their global CHD risk and achievable risk reduction would help them adhere to CHD risk reduction plans. Participants in all groups also indicated that coming to one’s own decision and collaborating with a physician increases motivation for adherence. One individual noted, however, that the timing of collaboration is important: participation is not desirable when one is sick (regardless of the cause).

Participants also identified several other known important adherence supports. For instance, they mentioned the importance of regular follow-up and feedback (three groups), simple interventions (three groups), and support from family, friends, and external information sources (four groups) as factors that would help them adhere to CHD risk reducing strategies. All groups underscored the need for intrinsic willpower or drive to be successful in adherence, most often articulating the desire to do something for the sake of themselves or their families as the source of motivation.

4. Discussion and conclusions

4.1. Discussion

In four focus groups of highly educated and motivated individuals, we found participants generally regarded the concept of global CHD risk as useful and motivating, although they had many questions about its precision and comprehensiveness. Participants additionally identified many other factors that would influence their decisions about reducing their CHD risk, including several we anticipated (e.g. the benefit of treatments for CHD; and the other health benefits, side effects, cost, amount effort, and effect on others from treatments for CHD) and several we did not (e.g. the quickness and self-evidence of results, long standing medical use, and product naturalness of treatments for CHD). Participants generally preferred lifestyle changes to medications, although most were willing to accept medications when they met multiple decision criteria, provided a bridge to successful lifestyle change, or when lifestyle change was impossible. Participants identified many motivators and supports that might be used to promote adherence to CHD risk reducing strategies, including global CHD risk, participation in decision making, frequent follow-up and feedback, and friends, family, and external information.

These results are consistent with existing literature that suggest that global CHD risk may be motivating to patients [33] and that participation in decision making is important in promoting adherence [34]. They additionally confirm several barriers to CHD prevention [15,35]. Importantly, however, they provide new insights that will be helpful to clinicians and others (e.g. decision aid developers) trying to promote CHD prevention.

First, our results provide insights for global CHD risk presentation. Although participants ranked CHD risk calculation as the most important factor in decision making, they spontaneously discussed CHD risk (and valued CHD intervention) in terms of the absolute risk achievable. This underscores the importance of providing information about the combined benefit of risk reducing strategies along with global CHD risk information. Participants' favorable assessment of our visual representation of risk (a horizontal bar with colored grading of low, moderate, and high risk) argues that such features might also be considered for widespread use. Furthermore, participants' skepticism about the precision of global CHD risk and lack of inclusion of certain expected risk factors suggests clinicians and researchers should provide individuals with the rationale for the use of risk calculators and discuss how they might differ from traditional conceptualizations of CHD risk. Evidence suggests that individuals have traditionally negotiated their sense of risk by considering similarities and differences between themselves and family members or acquaintances [36,37]. Helping individuals understand the rationale for risk calculation and that fact that it improves the accuracy of risk estimates may reduce skepticism. Providing individuals with access to information about the creation and performance of risk calculators may also be helpful. Alternately, the research community might consider creating calculators that include such factors as family history, despite lack of additive predictive ability, simply for the added face validity for individual users.

Second, our results provide insights to facilitate CHD decision making. Participants' varied rankings of the factors important to their CHD decisions underscore the value of patient involvement in decision making. Additionally, participants' stated preferences provide guidance to those promoting CHD prevention and helping patients make decisions. Clinicians and decision aid developers should acknowledge patients' desire for safe, cheap, simple, and natural products that are well-studied and provide quick and tangible results. Because these are often not available or may be contraindicated, however, clinicians and decision aid developers should additionally be prepared to help patients understand the complex tradeoffs among these decision factors and come to a decision. They should also be prepared to help patients understand why a lifestyle approach (while appealing) may not help them achieve

appropriate risk reduction or their goals, and when medication might act as a necessary bridge to risk factor reduction through lifestyle change. Several researchers and recent decision aid quality standards provide guidance that might help clinicians in achieving these goals [38].

Such insights must be interpreted within the limitations of our research design. First, because global CHD risk is little known, we had to provide information about this to participants in a 20-minute presentation to facilitate discussion. The information we provided and/or the ranking and rating of decisional attributes that we asked participants to complete may have heightened their enthusiasm for CHD risk information and anchored their feelings regarding relevant decisional factors. Participants' honest criticism of the CHD risk approach and their identification of multiple decision factors we didn't anticipate suggest this is of minimal concern. Second, a physician was present at each of the focus groups, raising the possibility that participants offered socially desirable answers rather than their true thoughts. Participants' frequent comments about negative experiences with physicians and the pharmaceutical industry when talking about information sources argue against this as a significant bias. Third, different presentations of global risk and treatment benefits may have elicited different responses from participants. We chose to provide both numerical and graphical presentations of risk based on evidence that numbers are better understood than graphics for risk estimation [39] and the fact that we felt graphics were appealing and helped facilitate integration of information about global risk and suggested treatment thresholds. Because alternate risk formats can influence choices [40-45] and are variably preferred [12,40,46], exploration of individuals' reactions to alternate presentations of risk are warranted (including reactions to other numerical and graphical presentations; our same numerical and graphical presentation with the horizontal bar extending fully from 0% to 100% (rather than from 0% to a few % above an individuals' calculated risk); and presentations with and without comparative statements). Finally, as with all qualitative work, our conclusions are hypothesis generating only. Our participants form a non-representative sample and results may not translate across other patient groups (e.g. those with less motivation, lower CHD risk, or different preferences about medication).

4.2. Conclusion

Our results underscore the motivating potential of global CHD risk and the importance of patient involvement in promoting prevention and adherence. Despite potential limitations, we believe our work offers new insights to clinicians and researchers engaging patients in CHD prevention. Future work should explore these insights in different patient groups, quantitative research designs, and as part of interventions to promote initiation and maintenance of CHD prevention strategies.

4.3. Practice implications

Until additional research is available, clinicians should consider global CHD risk a useful adjunct to CHD prevention and address issues that may maximize the effectiveness of its implementation. For instance, clinicians might proactively raise issues about risk calculators' precision and comprehensiveness, and help patients understand how global risk fits with their traditional conceptions of risk and when safe, cheap, simple, quick-acting, well-studied, natural products are not available or sufficient for CHD prevention.

Acknowledgments

The authors would like to thank Alison Tytell Brenner of the Decision Support Lab at the Sheps Center for Health Services Research for her help facilitating focus groups. The authors would also like to thank Ziya Gizlice at the Center for Health Promotion and Disease Prevention for help with descriptive data analysis.

Funding: Dr. Sheridan was supported by a National Heart Lung and Blood Institute Career Development Award (1K23HL074375) and by an American Heart Association National Scientist Development Award (0530164N). Andrea Meier's time for this work was supported by the Communication for Health Applications and Interventions (CHAI) Core under grant number DK 56350.

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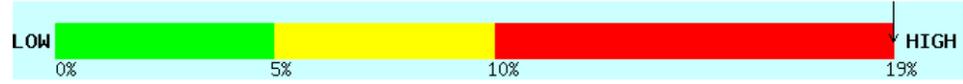
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Your Personal Heart Disease Profile

Risk factors for heart disease that you can change are:

Abnormal Cholesterol

Your chance of having heart disease in the next 10 years is 19%:



For comparison, a person your same age and sex who *has no risk factors* has a chance of heart disease in the next 10 years of 17%.

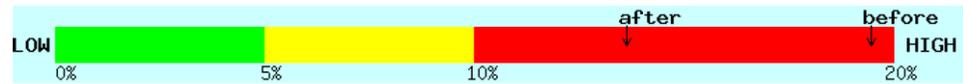
Your options to reduce your chances of heart disease are:

Take a cholesterol medication

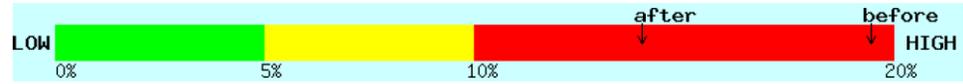
Take an aspirin

Here is how your options impact your chances separately:

Chance if you take a cholesterol medication:



Chance if you take an aspirin:



Here is how your options impact your chances when taken together:

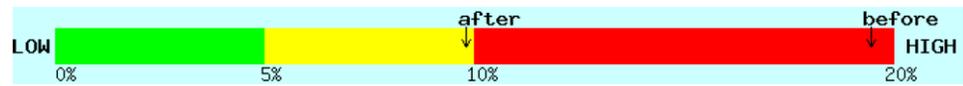


Figure 1. Example Profile Given to Focus Group Participants

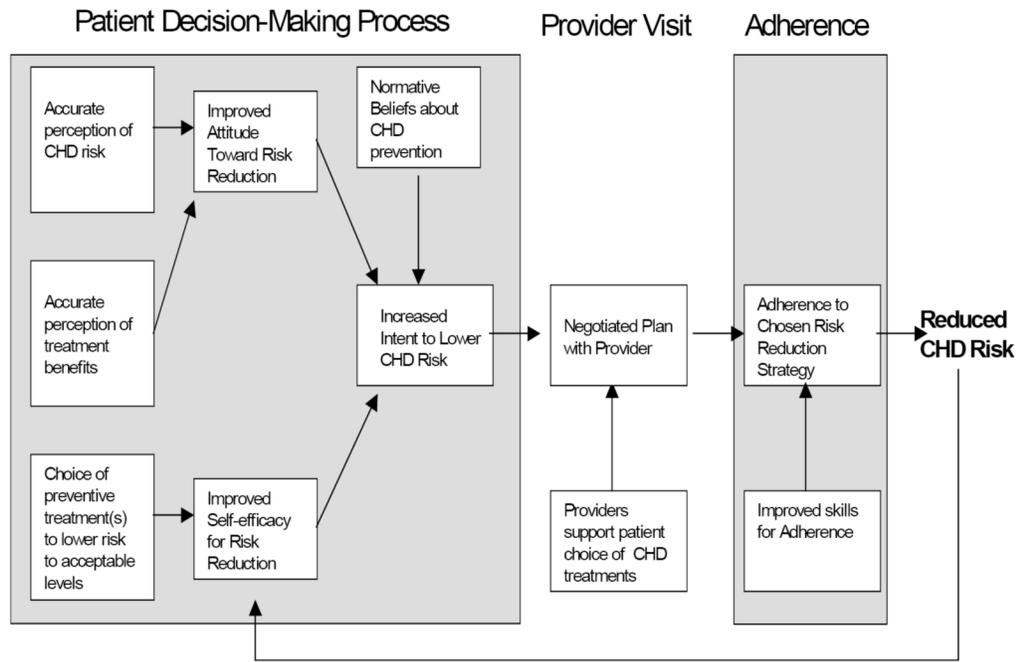


Figure 2.
Conceptual Model Underlying Questions and Coding Scheme

Table 1
Focus Group Discussion Guide Topics and Sample Questions

Topic	Sample Questions
Warm-up	-What has your doctor told you, if anything, about heart disease?
Reactions to Concept of Global CHD Risk and Risk Reduction	-If you were going to make a decision about lowering your chances of heart disease, would this concept be useful?
Process of CHD Decision Making	-If you were to participate in decision making, how would you go about deciding whether to lower your chances of heart disease? -What do you see as your role in lowering your chances of heart disease?
Process of Adherence	--How do you think participating in decision making (on your own or with a physician) would affect your ability to stick with your plans, if at all? --What kind of additional supports, if any, would you need to successfully lower your chances of heart disease?

Table 2
Participant Demographics

	Total N = 29 N (%)
Mean age (range)	62.7 (52-75)
Male gender	21 (72%)
At least some college education	25 (89%)
Good/excellent health status	25 (89%)
Exact Risk Factor Data Available (N)	18 (62%)
CHD Risk Factors:	
FH heart disease	7 (25%)
HTN	12 (43%)
Abnormal cholesterol	12 (43%)
Current smoking	5 (18%)
Diabetes	7 (25%)
Estimated CHD Risk	
Moderate (5-9%)	9 (31%)
High (10-20%)	15 (52%)
Very High (>20%)	5 (17%)
Consider themselves "good with numbers"	21 (78%)
Numeracy score (out of 3):	
0	1 (4%)
1	7 (26%)
2	7 (26%)
3	12 (44%)
Prefer a Shared Approach to CHD Decision Making	21(79%)

Table 3
 Illustrative Quotes for Key Themes

Theme	Illustrative Quote
<i>3.1 Reaction to concept of global CHD risk and risk reduction</i>	
Global CHD risk is useful	"I think the benefit of a [global] approach is if you are working on just one thing like cholesterol or something, you might still be high-risk."
Global CHD risk is motivating	"This [<i>knowing my global CHD risk</i>] definitely makes me think more about going with the cholesterol medication in the short term 'til I make the lifestyle changes as opposed to hoping and waiting 'til I make the lifestyle changes."
Global CHD risk raises some concerns	"It just seems too simple that you can take a couple, four or five factors...and come up with this percentage and then...I would say where did you get that information?"
	"To me [it] is a credibility issue. That is, how can you come up with a credible [risk] profile if factors like family history, exercise, stress are not part of the calculation?"
<i>3.2 How patients use global CHD risk in combination with treatment benefit information to make decisions about CHD prevention</i>	
Patients focus on absolute and relative risk reduction or achievable risk rather than baseline absolute risk	"If I was in the 40% range for example and I'm doing these things to get me in the 20% range – which is still high, right – it [<i>the overall risk reducing strategy</i>] cuts it in half, so I might consider doing it. It might be worthwhile to do that. It still may not make it [<i>the risk, low</i>], but at least you know... That's pretty strong information if you cut your risk in half. No matter where you start and where you end up, my thing here is will this help me a whole lot. I'm debating on this aspirin because my option is aspirin. It takes me down to 3% "
Patients make tradeoffs between risk and multiple other factors	"I suppose if uh someone said well you have this pill. It has no side effects and it's not expensive and it will reduce your risk by half or you can lose 15 pounds and accomplish the same thing, you know, there might be... a case where one would be an easy solution with almost no risk."
<i>3.3 Adhering to CHD risk reduction plans</i>	
Collaboration creates motivation	"I agree certainly that whatever comes out of the collaboration between me and a medical professional is probably going to be taken more seriously by me than if I dream it up on my own or that it's just handed to me."
Intrinsic motivation is essential	"I think the focus of the matter is it goes back to motivation...I think really, you know, I don't care what color the package is. I don't care how much you cost, if you don't want to do it for yourself..."
Adherence supports are useful	"So I think feedback is a very essential piece to get me to want to move along whatever it is. I just want to see progress."