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Exploring research participants' perceptions of cardiovascular risk information—Room for improvement and empowerment

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ABSTRACT

Objective: The objective of this study was to explore research participants' (adults, age 50–65) perceptions of receiving cardiovascular risk information.

Methods: Five focus group interviews (N = 31) were performed with research participants aged 50–65 who participated in the Swedish CArdioPulmonary BioImage Study (SCAPIS). The interviews were analyzed using qualitative content analysis.

Results: The categories; the complexity of cardiovascular risk; insufficient presentation of test result; emotional responses; and health examinations provides confirmation, emerged. The test results were written in medical terms and lacked recommendations for further action which made it difficult for lay people to understand and use, and for some, also caused unnecessary worry.

Conclusion: There was inadequate guidance concerning the implications of the test results, especially for participants without clinical findings. In order to allow research participants to obtain better cognitive and behavioral control, improvements are needed with regard to how personal risk information is communicated in research projects connected to health services.

Practical implications: The participants largely relied on physical signs when assessing their own cardiovascular risk. Health examinations are crucial for helping to add nuance to individuals' risk perceptions. For personal health information to have any real value for individuals, it must be designed from a user perspective.

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1. Introduction

Cardiovascular diseases (CVDs) are the number one cause of death globally [1] and they contribute significantly to socioeconomic differences in health [2]. CVD risk factors are multifactorial and accumulate silently through the course of life; the first symptoms could entail a serious or deadly event. Many of these risk factors are modifiable and by eliminating unhealthy behaviors, over half of CVDs could be prevented [3].

Due to the silent development of CVDs, health examinations are necessary for detecting risk factors such as hypertension and high cholesterol. Awareness and understanding of personal risk can be the first step for individuals to take control of their own health, and are also required for successful prevention [4]. This can enable the start of an empowerment process, which Nutbeam & Kickbush describe as *"a process through which people gain greater control over decisions and actions affecting their health"* [5].

We live in the "information age" and technology is rapidly progressing [6]. Opportunities for the general public to "get tested" are increasing. However, it is not a given that all individuals have the ability to make sense of their test results, especially when they are only presented in written form. Therefore, the alleged relationship between risk information, prevention and empowerment may not be pertinent for everyone [7].

Individuals have difficulties understanding cardiovascular risk and tend to perceive it incorrectly [8]. Understanding cardiovascular risk might be obstructed by the fact that CVDs themselves can be perceived as an abstract concept that is difficult to grasp [9]. Many CVD risk factors, including hypertension and high cholesterol, are reported in numerical values. However, individuals generally have a hard time dealing with probabilities and numerical information [10,11]. Furthermore, for individuals with low health literacy, it can be especially challenging to comprehend written as well as verbal communication regarding their medical condition, and to understand their personal risk [12].

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Providing risk information, despite the level to which people understand that information, might also cause stress and anxiety and therefore reduce the individual's quality of life [13,14]. Emotional stress is itself a CVD risk factor [15] and should therefore be prevented.

It is important to ensure that the disclosure of test results from health examinations increases individuals' well-being and perceived control over their own health, and prohibits the negative consequences of risk information. The objective of this study was to explore research participants' (adults, age 50–65) perceptions of receiving cardiovascular risk information in order to collect data that can contribute to improving risk communication in the future.

2. Methods

2.1. Design

An explorative qualitative study using focus group interviews was used. Focus group interviews were chosen because they make use of the interaction between participants. Listening to other participants' statements can help participants verbalize their own emotions and opinions [16].

2.2. The participants

The only inclusion criterion for participating in the interviews was participation in the Swedish CArdioPulmonary BioImage Study (SCAPIS), see Box 1. Five focus group interviews were conducted with 31 participants in total. All groups consisted of four to eight participants. The duration of time since the participants had received their test results ranged from two weeks to six months. The groups included both women and men and all participants spoke Swedish. Participant characteristics are presented in Table 1.

Table 1
Characteristics of participants.

Characteristic	
Age	Mean: 61 Range: 52–65
Men	n: 15
Woman	n: 16
Educational level	
Primary school	n: 1
Secondary school	n: 9
University	n: 9
Country of birth*	
Sweden	n: 28
Other	n: 3
Referral**	
Not referred	n: 21
Primary health care center	n: 4
Hospital	n:6
Risk perception *** (missing:1)	Mean: 3.7 Range: 1-6
Lower than others	n: 11
Neither lower nor higher than others	n: 12
Higher than others	n: 7

* Two from a non-European county, one from a European country outside of Scandinavia.

** Were you referred or recommended to follow up on findings (related to the heart or vessels) at either a primary health care center (PHCC) or hospital?

*** Compared to similar individuals of the same sex and age, how do you perceive your risk of having a heart infarction? Answers ranged from 1 to 7, where 1 was much lower, 4 was neither lower nor higher and 7 was much higher.

2.3. Procedure

Invitations to participate in the focus group study were sent out to all SCAPIS participants who had visited one of six test centers during a time range of approximately six months and for whom e-mail addresses were available. Individuals who were willing to participate were consecutively scheduled for one of the interviews. When scheduling the participants to one of the groups, we strived to achieve gender balance, otherwise no other information about the participants was taken into account. No incentives were offered. The interviews were conducted in January and February 2018 and lasted between 52–72 min. They were moderated by the first author and assisted by an observer. The role of the observer was to take field notes and discuss the interview with the moderator afterward. The interviews were conducted in Swedish and took place in a conference room of Uppsala University. The participants filled out a survey consisting of seven items assessing age, gender, education level, time since receiving test results, referral and risk perception.

Participants were encouraged to speak freely and to address each other directly. A semi-structured interview guide was developed based on Krueger and Casey (2015) that included open-ended questions with themes revolving around the comprehensiveness of the test results and the impact of receiving the results on participants' lives. Probing questions e.g. "do the rest of you agree?" and "could you tell us more about that?" were asked to more deeply explore the participants' perceptions and facilitate a debate. See additional file A for the interview guide. At the end of each interview, the moderator summarized the discussion and asked for verification from the participants. Data were considered saturated after the fifth interview, since the themes that emerged were recurring and no new information was brought up [19]. The interviews were audiotaped and transcribed verbatim.

Box 1. Health examinations and test results provided in The Swedish CArdioPulmonary BioImage Study

SCAPIS is a prospective observational study in which data are collected from a cohort of 30,000 men and women between the ages of 50-64; they are randomly selected from the general Swedish population. The goal is to better understand, prevent, diagnose and treat cardiovascular and pulmonary diseases by creating an open-access, population-based cohort. Examinations are comprehensive and include e.g. computed tomography (CT), high-resolution ultrasound, spirometry, blood samples and traditional risk markers. Parts of the test results are given to participants in a written report, including Body Mass Index, waist circumstance, accelerometer results, hand power, oxygen levels in the blood, blood pressure, pulse and sleeping registration, all distributed via e-mail (see translated report in Additional file B). The results of the CT of atherosclerosis in the coronary arteries and blood samples may be accessed via their Patient Accessible Electronic Health Records (PAEHRs). The results was presented individually as numerical values. In some cases, reference levels were provided. No total risk score (e.g. Heart SCORE) or overall evaluation was provided. In the case of clinical findings (e.g. vulnerable strictures, hypertension, high cholesterol), the participants were referred to either primary health care or specialized care, where they received routine care [17]. In this article, "normal" and "abnormal test" results refers to whether or not the participants were referred for medical follow up or not.
For information about Patient Accessible Electronic Health Records in Sweden see Hägglund & Scandurra 2017 [18].

Table 2
Description of the steps taken in the content analysis.

Description of the steps taken in the content analysis process	
Reading the transcripts	The interviews were read through several times to obtain a sense of the whole and become familiar with the data.
Open coding	While reading, codes were written in the margin labelling different aspects of the content.
Sorting the codes into a coding sheet	The codes were sorted into a coding sheet in Excel and grouped together into different categories by comparing differences and similarities. Through interpretation, it was decided which codes belonged with each other, leading to abstraction of the text.
Reducing the number of categories	The material was condensed by reducing duplicates and collapsed by merging similar categories.
Labelling the categories	All categories were given a name describing the characteristics of the content.

2.4. Analysis

The transcripts were analyzed using qualitative content analysis [20]. A description of the steps in the content analysis is presented in Table 2. The initial analysis of the manuscripts was conducted by ÅG and ATH. To improve validity, the transcripts were read through and coded independently by the two researchers and then compared to each other. The classifications of the categories and sub-categories were discussed by all authors until consensus was reached. Examples of the analysis process are presented in Table 3.

3. Results

The analysis resulted in four main categories, each of which consisted of several subcategories, see Table 4. The categories are presented with quotations from the participants.

3.1. The complexity of cardiovascular risk

3.1.1. Relying on physical signs

Participants' personal risk was largely perceived based on how they felt in general. They relied on the body to indicate any problems and therefore expected normal test results in the absence of such an indication.

"I rely on the fact that if I am thirsty, I need to drink, and if I feel something, then I need to do something about it. But when you don't feel anything and feel perfectly healthy, why should you start some kind of thorough examination?" (Man, group 5).

3.1.2. Simplified and conflicting beliefs

Participants' perception of CV risk was occasionally simplified into an "either/or" approach that disregarded multifactorial associations. Family history of cardiovascular diseases was repeatedly raised as an important CV risk factor.

"Well, then you might have done something right or it's just your genes." (Woman, group 2).

While discussing explanatory factors, CVD was perceived as unpredictable and uncontrollable, especially by individuals who had personal experiences with a myocardial infarction.

"It just happens at once, without any indication [. . .] I had all sorts of normal - I exercised too, but it happened." (Man, group 2).

It was also common to bring up atypical cases of individuals who either practiced a healthy lifestyle but still had a heart infarction, or vice versa, making them doubt the significance of known risk factors.

"One of my colleagues, he was so healthy [. . .] he was lean and slim and always running around in the woods. He had two heart infarctions and a stroke within three months. Then I kind of felt like it's a lottery anyway, so it kind of doesn't matter." (Man, group 5).

3.2. Insufficient presentation of test results

3.2.1. Lack of understanding

The test results were perceived as difficult to understand, since they were written using technical language that contained many medical terms. Even when reference values were available, the participants found the results difficult to grasp because they did not understand what the test was intended to show in the first place. However, there were a couple of the participants working in the healthcare system and they did not express these difficulties.

"I had a hard time understanding that information; it's a bunch of numbers and . . . no, I don't even remember what it said, but it was numbers and letters and I don't know anything about such things." (Man, group 4).

The test results were reported separately, and the participants assumed they were all associated with each other but could not understand how. They therefore expressed a need for a qualified assessment of the overall picture and a personal comment on their specific situation.

"To have someone who weighs it all together, someone with experience, so that you don't feel so frightened if something is high, above normal, but it really might not be so bad." (Woman, group 1).

The participants expressed that they had many remaining questions and wanted to discuss their results with a physician. Participants who were referred were automatically given this opportunity. However, many of the participants who were not referred did in fact turn to someone medically trained for formal or informal help with interpreting the test results, such as a family member or their physician.

"My sister is a nurse, so I asked her, because you want to know, how normal is it? When you aren't medically trained, then it's

Table 3
Example of the analysis process.

Meaning unit	Code	Sub-category	Category
I had probably been really shocked if there was something that stuck, I feel healthy [. . .] so it shouldn't be anything.	Feel healthy, didn't expect findings.	Relying on physical signs	The complexity of cardiovascular risk
But you sort of don't know anything about whether it's different for different people, or if you're on the far edge . . . what happens if you are at the lowest or highest value?	Far or close to the edge	Only allowing dichotomous interpretations	Insufficient presentation of test result
I have had a heart attack [. . .]. I somehow feel grateful that there did not appear to be any risk factors today, and that I don't have to walk around with worry somewhere inside, because I do that sometimes.	Grateful letting go of worry	Worry, relief and gratitude	Emotional response
I dont think that it has changed so much because of the study . . . more confirmed that you are right . . . that you do the right things, when it was a good result, but it is nothing that I intend to change in my way of being or doing or so.	Confirmation of life style	Current life style: Confirmed or questioned	Health examinations provides confirmation

Table 4
Categories and subcategories.

Categories			
The complexity of cardiovascular risk	Insufficient presentation of test result	Emotional responses	Health examinations provides confirmation
Subcategories	Subcategories	Subcategories	Subcategories
Relying on physical signs	Lacking understanding	Worry, relief and gratitude	Relevance increases with age
Simplified and conflicting beliefs	Only allowing dichotomous interpretations	Passive waiting or action taken	Current life style: Confirmed or questioned
	Lack of recommendations		

difficult to understand. I felt a need to have her look at it and say it was okay." (Woman, group 2).

3.2.2. Only allowing dichotomous interpretations

When the participants did not understand the result, they relied on the fact that they would hear from the health services if something was wrong. This meant that only the outcome (referral or not) was interpreted in a dichotomous way, as either good or bad, and not the values themselves. Some participants were satisfied with these conditions. Others were interested in knowing their risk presented as a continuum, and wondered if they were close or far from the cut-off value. They were also interested in knowing their risk in relation to others and wondered about what was "normal" or "common" for their age.

"Regarding coronary vessels, it said that I had spread calcifications, and otherwise there were no coronary changes. [. . .] What does that mean then, some spread – well, how much is that, and does it matter or not? [. . .] Is it very common to have that at my age, I mean 63 years old? I suppose your vessels aren't completely clean by then." (Woman, group 5).

3.2.3. Lack of recommendations

Many participants wanted recommendations on how to behave in order to reduce their risk and improve their health. They also wanted guidance on how to navigate the healthcare system and where to seek further care. They perceived it as their own responsibility to take the necessary action, but required guidance from health services in order to do so.

"That way you can get some tips and advice, a bit about how to think and what to do. Something simple. Then you can keep searching on your own, but you get something. - Sure. Then it's up to each individual to face their own situation, of course. But at least you were given the opportunity." (Women, group 1).

3.3. Reactions to the test results

3.3.1. Worry, relief and gratitude

Participants who received normal test results felt reassured that everything was okay and expressed joy and a sense of relief. Some were able to let go of worry, especially participants who had previous experience with CVD.

"I have had a heart attack [. . .]. I somehow feel grateful that there did not appear to be any risk factors today, and that I don't have to walk around with worry somewhere inside, because I do that sometimes." (Man Group 3).

Reading something that they did not understand triggered worry in some participants, e.g. test results regarding arteriosclerosis. However, one woman asked a nurse who worked with the CT what she could expect the results to be. The nurse then prepared her for a possible answer while also trying to normalize the risk.

"Because I asked, what will it say? And she said, well, it will probably say that you have some calcifications . . . and that was good, because then I expected it to probably say something like that. That it is kind of normal for your age. A used car is not like a new one." (Woman, group 1).

Another woman had the experience of her cholesterol level being treated as "normal" in previous health examinations and as "abnormal" and in need of corrective measures in the SCAPIS health examination. This made her worried and uncertain about what to think with regard to her risk level.

"It made me think and [I] asked the doctor about these specific blood values, and he told me that they have a different template [. . .] than what, for example, a GP has [. . .] I guess that was really my thought, that you have different interpretations of these results – what is dangerous and what isn't dangerous? [. . .] . . . Yes, I was very worried, because I wondered whether I could really trust [this]." (Woman, group 2).

Being referred to the hospital due to coronary artery strictures, triggered worry for some of the participants, while others felt healthy and therefore did not worry. In their meeting with the physician, participants could receive emotional support and help with managing their worry. They felt safe being under the supervision of the healthcare system and expressed gratitude with regard to knowing about their condition.

"When you get this kind of answer, of course you can worry, but I didn't, because I thought, what is good is that I will find out some things I need to know. It's a gift to me, really." (Man, group 3).

3.3.2. Passive waiting or actions taken

The kind of measures taken to treat the participants' coronary artery strictures had different implications for their daily lives. One man was told to passively await impairment due to his condition while also slowing down his current active lifestyle. This left him frustrated and unable to act, and resulted in him thinking about his condition daily and paying frequent attention to his physical symptoms.

"They said, we'll wait, but I have coronary heart problems, they are there. [. . .] You tend to go around and try to sense how you feel. [. . .] It's always there, the thought is always there anyway. [...] But now I think they sort of have to do something."(Man, group 1).

Another man had a stent placed in his arteries due to findings in SCAPIS. This left him feeling happy and grateful for "getting something" that could potentially prolong his life. He felt that his problem was fixed and his risk was reduced.

"I can dismiss even more the notion that you might have to go around thinking about [. . .] whether there is any calcification or [. . .] But now I feel like I've actually gone through this and most things look pretty okay, and the things that weren't a hundred percent are fixed now." (Man, group 5).

3.4. Health examinations provides confirmation

3.4.1. The relevance increases with age

The participants expressed a positive attitude towards health examinations, no matter the outcome. A normal test result was seen as a confirmation of being healthy, while an abnormal test result was perceived as an opportunity for prevention and treatment. Health examinations were described as gaining relevance with increasing age, when symptoms and illnesses become visible and health is no longer taken for granted.

” You don’t get any healthier with age so it’s good to have an idea about your general health, only to see that there is nothing there.” (Man group 2).

3.4.2. Current life style: confirmed or questioned

The results were used for self-reflection on participants’ current lifestyle. Normal test results led to the perception that no lifestyle improvements were necessary. Participants with abnormal results questioned their current lifestyle and felt that they were not doing enough. Receiving abnormal results was described as the “fire” required to make necessary changes, something for which they expressed gratitude.

“When you need to lower your cholesterol, like in my case, well, it makes me think even more carefully about what I eat. I felt that I ate well before, but it probably wasn’t good enough, so I have to try to shape up a bit more. It’s a good motivator.” (Woman, Group 4).

4. Discussion and conclusion

4.1. Discussion

The aim of this study was to explore research participants’ perceptions of receiving cardiovascular risk information. The focus is on the healthy general population. Our results emphasize the importance of optimizing the presentation of written test result of findings related to CV risk.

The participants held complex perceptions of CV risk. They relied largely on physical signs when assessing their own CV risk, which may be one reason why worry was not present in any large extent. As in another study [21], participants considered CV risk in light of their own family history and disregarded known risk factors by referring to atypical cases. Participants’ perceptions of CV risk place an emphasis on the role of health examinations to give individuals additional feedback besides listening to physical signs in order to lend nuance to their risk perception. Test results within the normal range were perceived as a confirmation of health; they evoked feelings of relief and were highly valued by the participants. This might reflect that, after all, there is some intuitive uncertainty regarding relying on physical signs, which leads to a need to undergo health examinations to confirm that what they are feeling is real. Normal test results were also perceived as a validation of the participants’ current lifestyle and that they had no need to make improvements. These perceptions recur in studies of perceptions of CV risk [22,23], and can be an obstacle for the promotion of healthy lifestyle habits to the healthy general population, leaving individuals with a false sense of reassurance [24].

Overall, the participants perceived the test results from the health examinations as difficult to understand. They tended to interpret their risk levels in a dichotomous way, with the presence of an objective cut-off level. Tendencies to perceive risk as dichotomous have been studied repeatedly [25,26] and can be problematic, as risk is in fact continuous and different cut-offs are used by different healthcare units. Finally, the participants were interested in knowing their own risk compared to otherś to get a sense of what is “common” or “normal” at their age. They requested a qualified assessment of their total risk in which all of the different test results were taken into account in order to make sense of their personal risk.

The participants that were not referred expressed a need for guidance and support from medically trained personnel, to have their results explained and to get recommendations on what to do to reduce their risk as well as on how to navigate the health care system and find more information. A study of the NHS cardiovascular health check in the United Kingdom had similar findings: the participants expressed uncertainty about the implications of their test results and requested guidance from trained medical personnel [23]. These lacking factors were perceived essential in order to take charge over their own health, a responsibility that they expressed that they wanted to take if only they knew how. This indicates that the test results did not contribute to empowering the participants that were not referred, as they did not in fact increase their control over choices affecting their health [27].

There are many ways of defining and measuring empowerment. McAllister et al. focus on perceived personal control in their conceptualization of empowerment [28] and their framework can be used for designing and evaluating risk information [29,30]. Their definition include five constructs; cognitive control, decisional control, behavioral control, emotional regulation and hope. It is an appropriate tool for presenting CV risk information to non-patient groups since it is focusing on information provision and not on necessarily on achieving compliance to a certain treatment [28].

The Patient Activation Measurement (PAM) is another tool for achieving empowerment [28], suitable for the context of preventive cardiology [31] and is not restricted to chronic ill patients [32]. The concept of patient activation involves four stages: believing the patient role is important; having the confidence and knowledge necessary to take action; taking action to maintain and improve one’s health; and staying the course even under stress [33]. However, when improving risk information to the healthy public it is important to consider the dimensions of empowerment that dont́ involve any actions taken but instead can consist of a “feeling of control” where knowledge can be considered as power and influence an individuals’ cognitive control [29].

4.2. Strengths and limitations

One criticism of focus group interviews is that participants may feel inhibited with regard to sharing their emotions and dominant individuals might influence the group [19]. However, in this study, the participants asked questions directly to each other, laughed and openly disagreed with each other, indicating an open discussion climate.

The findings of a qualitative study cannot be generalized, but to achieve transferability it is important to provide a thorough description of the participants [34]. It is possible that the participants in our study are different from the general population. However, all participants in SCAPIS were randomly selected from the Swedish general population. SCAPIS can therefore be seen as a natural experiment suitable to examine how the general population perceive cardiovascular risk information.

No systematic assessments were carried out on participants’ backgrounds with regard to medical training. Two participants spontaneously mentioned that they had medical training and expressed no difficulties understanding the test results. This information could potentially inhibit the other participants to share their concerns or lack of knowledge. However, there were no differences in the themes that arose in these groups compared to the groups without medically trained individuals.

4.3. Conclusion

The participants’ perception of cardiovascular risk involved conflicting beliefs and reflected on its complexity. Their risk perception was influenced by their general health and multifactorial risk factors were disregarded. Health examinations were perceived as important at the participants’ age when health is no longer taken for granted. The test results were written in medical terms and lacked recommendations for further action which made it difficult for lay people to understand and use, and in some cases also caused unnecessary worry. Therefore, there is a need for improvements regarding how personal risk information is presented and communicated in research projects connected to health services. In order for the public to obtain better cognitive and behavioral control, improvements should include presentation and assessment of written test results.

4.4. Practical implications

The participants relied largely on physical signs when assessing their own CV risk. Health examinations are therefore crucial for helping to lend nuance to individuals' risk perceptions. At the same time, normal test results could lead to a false sense of reassurance and preclude preventive actions. For personal health information to have any real value for the individual, it needs to be designed from a user perspective. This could mean including aspects such as preparation before disclosure, improvements to written information and including guidance on how to act and where to find more information and support. Finally, according to the research participants in this study, disclosure of health information should include a qualified judgment based on a total assessment of the individual.

Ethical considerations

The study was approved by the Regional Ethical Review Board Reg. no. 2016/256. Before the interviews, the participants were given written and verbal information about the study and informed that participation was voluntary and could be withdrawn at any time. All participants signed a consent form.

We confirm that all personal identifiers have been removed or disguised so the individuals described are not identifiable and cannot be identified through the details of the story.

Conflict of interest

The authors declare that they have no conflict of interest.

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Appendix A. Supplementary data

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