Conceptualising the experience of health risk: the case of everyday management of elevated cholesterol

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Public health and individual health care are increasingly oriented towards managing risks. This ‘surveillance medicine’ does not target present illnesses but aims to prevent possible future conditions, greatly expanding the number of people implicated in medical interventions. In this paper, I interrogate the everyday experience of being at risk of illness. First, I suggest that we lack a comprehensive account of this experience, because current ways to characterise this phenomenon tend to equate risk with (chronic) illness and patient status. I then report a case study designed to avoid this starting point. I conducted interviews with laypersons with varying levels of elevated cholesterol, a common risk factor for cardiovascular diseases, who were recruited from a consumer panel in Finland in 2015. I found three elements that structure the health risk experience: the intangible nature of risk, the probabilistic character of risk estimates, and the ambivalent status of risk in terms of health and illness. While these findings overlap with previous literature in many ways, detaching health risk from illness foregrounds health management instead of patient behaviour. These findings call for caution in approaching health risk uncritically through illness categories or patient status, and I invite researchers to critically examine such elements in other cases and contexts.

Keywords: cardiovascular disease; elevated cholesterol; lay experiences; lifestyle; risk

Introduction

The emergence of risk in biomedicine has had profound consequences for medical practice, public health, and the pharmaceutical industry (Armstrong, 1995; Aronowitz, 2009; Dumit, 2012). One aspect of this is the effects on everyday experiences of health and illness. There is considerable agreement that risk-based approaches have significantly changed our relationship to health, making personal health risk management a key aspect of everyday life (Ayo, 2010; Lupton, 1993; Petersen, 1997). However, when searching for the characteristics of these everyday experiences of health risk, one is faced with a wide array of studies, which highlight different aspects of such experiences and do not cohere around an established concept of health risk experience. While this tendency testifies to the multiplicity of articulations of health risk, in this article I suggest...
a more fundamental reason for this situation. I argue that current ways of conceptualising
the health risk experience often draw on approaches and categories adopted from studies
on (chronic) illness, which tend to see at-risk individuals as patients. The experience of
health risk becomes defined as a subset of illness. I propose that we should instead
approach health risk as distinct from the experience of chronic illness. To test this idea,
I present the case of everyday management of elevated cholesterol, a common risk factor
for cardiovascular disease, in which steps were taken in the research design to avoid the
premise that at-risk individuals equal patients. I recruited interviewees from a consumer
panel, focusing on individuals who were worried about their cholesterol (typically but
not always backed with ‘objective’ medical findings) but who were not suffering from an
acute cardiovascular problem. The interviews focused on everyday risk management
practices instead of medical contact, although the latter was also addressed.

In the first section, I pose the question guiding the paper: if risk is the key
characteristic of a specific medical rationality, ‘surveillance medicine’ (Armstrong,
1995), what is the corresponding experience of being at risk? In the second section,
I survey existing research on cholesterol and cardiovascular risk, concluding that despite
many insights the field lacks a coherent concept of this experience. In the following
section, I suggest that a key reason for this omission is that the experience of risk has
typically been approached through chronic disease and patient status. In the fourth
section, I outline the research design, by which I aimed to avoid this dominant approach.
It is followed by the empirical analysis of the health risk experience of elevated
cholesterol. The analysis is organised around three key elements of health risk, the
intangible nature of risk, the probabilistic character of risk estimates, and the ambivalent
status of risk in terms of health and illness, which figured in various ways in participants’
accounts of their condition. While my findings overlap with the existing literature in
many ways, detaching health risk from illness foregrounds health management instead of
patient behaviour. My findings indicate a need for caution in framing health risk
uncritically in terms of illness or patient status. I conclude the article with a discussion
on the wider salience of the three elements for the study of health risk experience.

Risk (in) medicine

Risk is not a natural outlook on health and illness, but rather a historically rooted medical
rationality (Oppenheimer, 2006; Rothstein, 2003), which renders population health
governable in a specific way (see for example, Dean, 1998; O’Malley, 2008). In this
approach, risk is conceived as ‘a statistical and probabilistic technique, whereby large
numbers of events is sorted into a distribution, and the distribution in turn is used as
a means of making probabilistic predictions’ (O’Malley, 2008, p. 57). Risk rationality
does not describe individuals as detailed, unique cases but relies on a restricted number
of characteristics, whose values receive their meaning from their place in the larger
population distribution. In the process, cases are sorted into groups that ‘have a similar
probability to experience some uncertain condition in the future’ (ibid: 58), and conse-
quently will be dealt with similarly for risk mitigation.

In the medical domain, the effects of the risk technique have been captured by the
notion of surveillance medicine (Armstrong, 1995). Surveillance medicine dissolves ‘the
distinct clinical categories of healthy and ill’ and observes the whole spectrum of the
normal/pathological distribution, ‘attempting to bring everyone within its network of
visibility’ (Armstrong, 1995, p. 395). It subsumes symptoms and signs of illness into the
category of risk factor, ‘which encompasses any state or event from which a probability of illness can be calculated’ (Armstrong, 1995, p. 401; cf., Castel, 1991), irrespective of personally experienced dis-ease. Everyone is at risk, which calls for action, yet the adverse event is located in the future and is only probable. Surveillance medicine reaches beyond the therapeutic institutions into the community. It is preventive by nature, engaging in the continuous monitoring of the population and health promotion, which gives the responsibility for supervision to individuals themselves and works through lifestyle modification.

In this article, I interrogate how this pervasive but virtual state of being at-risk of a health problem is experienced in their everyday lives by individuals with a perceived cholesterol problem. More specifically, the paper focuses on the specific characteristics of health risk outlined above, which set it apart from other medical rationalities: its intangible and probabilistic nature, its tendency to diffuse the distinction between health and illness, and its consequent close connection to preventive practices. This task is not easy, since individuals cannot experience health risk directly, but only mediated through measurements and calculative practices. The task is further complicated by the tendency in the literature to treat individuals at-risk as (types of) patients and their status as a subset of chronic illness, as I will argue below. The aim of the paper is to see what becomes foregrounded, if the experience of health risk is detached from patient status, and to start to carve out a more analytical conceptualisation of the health risk experience, which acknowledges its singularity.

**Risk experience and heart conditions**

Research on everyday risk experiences and management is highly heterogeneous. As regards cholesterol and cardiovascular risk, the focus of this article, studies of a more applied nature have looked at ‘lay’ risk knowledge and perceptions from the perspective of health literacy (Goldmann et al., 2006; Whiteside & Robbins, 1989), treatment seeking (Yoon & Byles, 2002), medication adherence (Benson & Britten, 2002; Tolmie et al., 2003), or health promotion (Brorsson et al., 1995; Troein et al., 1997; Walter & Emery, 2005). These studies typically promote a more patient-centred approach to clinical practice, which is presented as key to a better patient/practitioner interaction and the dismantling of ‘barriers’ to behaviour change.

Closer to the intentions of this article are critical social science studies that have highlighted the originality and richness of everyday understandings of heart conditions and their assorted risk factors. In this line of research, the notions of lay epidemiology and coronary candidacy are especially salient. Introduced by Davison and colleagues (Davison et al., 1991; 1989; 1992; Frankel et al., 1991), these terms refer to the multiple cultural resources lay people utilise in assessing who is at risk of heart conditions and explaining why some get such a condition and some not. The majority of studies on lay experience of heart disease risk have worked in this vein, either explicitly adopting these concepts (Angus et al., 2005; Angus;; Emslie et al., 2001a; Jauho, 2017; Weiner, 2009) or using some related notion, such as (lay) knowledge, ideas, viewpoints, or narratives (Adelswärd & Sachs, 1996; Lauritzen & Sachs, 2001; Morgan & Watkins, 1988; Sachs, 1996; Snell & Helén, 2020), everyday medical reasoning (Felde, 2010), and vulnerability (JF Frich et al., 2006; Honkasalo, 2006; Ponder et al., 1996).

These studies have presented rich accounts of lay positions, highlighting key characteristics of health risk, such as invisibility (‘sneaky disease’, Angus et al., 2005),
virtuality (Durack-Bown et al., 2003), and technological enactment (Saukko et al., 2012; Will, 2005), the discrepancy between population and individual level risk (‘lucky survivors/unlucky victims’, Davison et al., 1992; Emslie et al., 2001a), or the levelling of the distinction between health and illness (‘liminality’, Farrimond et al., 2010; Felde, 2010). There is, however, great variation in the way and extent risk is discussed in the studies. Rather than being particular iterations of a ‘health risk experience’, in many studies the lay viewpoints are presented as resulting from the features of the health condition (coronary heart disease) or risk factor (cholesterol) under consideration. Especially the more practically oriented studies typically lack an analytical conception of health risk, subscribing to the medical definition of risk factors, although notable exceptions exist (see for example, Brett, 1991). Consequently, no focused, general conceptualisation of the health risk experience seems to be available.

**Risk as illness**

I want to suggest that a key reason for this omission is a tendency to define at-risk individuals as (some kind of) patients (see, Jauho, 2019). This is evident on many levels and not only related to cardiovascular conditions. First, as several authors have also pointed out, data to examine lay experiences of health risk are ‘generally drawn from patients’ (Almeling & Gadarian, 2014, p. 482; also Emslie et al., 2001b; Will & Weiner, 2013). Study participants are typically recruited from medical contexts, such as medical trials (e.g., Angus, 2008; Farrimond et al., 2010), screening projects (e.g., Adelswärd & Sachs, 1996; Troein et al., 1997) or general practices and clinics (e.g., Durack-Bown et al., 2003; Felde, 2010). Again, the applied studies lead the way, reflecting their interest in health promotion and clinical practice.

Second, some studies explicitly draw parallels between the experiences of health risk and chronic illness. For example, in his studies of individuals with elevated cholesterol or PSA levels, Gillespie adopted the ‘experience of illness framework’ (2012: 195) and looked for ‘parallels between being ill and being at risk’ (2015: 975). Consequently, the elements of his notion of risk experience – increased medical contact, a restructuring of everyday routines, and altered social relationships – correspond to the experience of illness (see, Bury, 1991; Pierret, 2002).

Third, the various designations for at-risk individuals and their condition in the literature typically allude to patienthood, even though individual at-risk status does not necessarily result in illness. Terms for at-risk individuals include ‘not-yet patients’ (De Swaan, 1990, p. 12), ‘potentially sick’ people (Kenen, 1996), ‘partial patients’ (Greaves, 2000), ‘perpetual patients’ (Finkler, 2001), ‘not-yet-ill’ persons’ (Lauritzen & Sachs, 2001), ‘pre-symptomatic persons’ (Konrad, 2003), and ‘patients-in-waiting’ (Timmermans & Buchbinder, 2010), while their condition is described as a ‘semi-pathological pre-illness at-risk state’ (Armstrong, 1995, p. 401), ‘proto-disease’ (Rosenberg, 2007), or ‘proto-illness’ (Gillespie, 2015).

A clean separation of health risk and illness is difficult. Attempts are complicated by the cultural ubiquity of risk knowledge related to e.g., cholesterol (Jauho, 2019) and the understanding of risk as a continuum (Jauho & Helén, 2018), where previous illnesses are inserted into new risk calculations; for example, a key risk factor for CHD is a previous coronary incident. However, detaching risk and illness is a valuable exercise, both practically and theoretically. First, uncritically foregrounding the parallels between (chronic) illness and risk might inadvertently facilitate the expansion of the scope of
biomedicine, as it effectively medicalises at-risk states and thus renders risk markers more amenable to treatment (see, Aronowitz, 2009; Dumit, 2012). Second, equating (chronic) disease and risk precludes us from doing justice to the novelty of risk-based surveillance medicine as a medical rationality and the potential uniqueness of the corresponding health risk experience.

In this article, I report a study that looked at everyday cholesterol management among laypersons with varying levels of elevated cholesterol, a common risk factor for cardiovascular diseases (see also, Jauho, 2019). Based on the case and in dialogue with previous studies on cardiovascular risk, I outline elements for a model of risk experience, which is not based on (chronic) illness but builds on characteristics that singularise risk in the field of health and illness. This aim is reflected in the strategy of inquiry, which we will turn to next.

Materials and Methods: Disengaging Risk Experience from Illness

Acknowledging the need to disentangle risk experience from illness, participants for this study were recruited from a Consumer Panel, maintained for research purposes by the [Name of the research institute]. The (now defunct) Panel was a register of around 1000 volunteers from different urban areas in Finland who could be characterised as active consumers. The recruitment letter invited Panel members who had elevated cholesterol or who were otherwise worried about their cholesterol to participate in a study of its everyday management. For practical reasons, only individuals from the capital area of Finland were invited.

The invitation letter detailed the standard issues related to informed consent, including background and topic of the study, use and management of the data, and principles of anonymity and confidentiality. The panellists could then volunteer to participate by responding to the invitation and filling in a small questionnaire on cholesterol. This was taken to signify consent. Panellists had received basic information on research ethics upon becoming members, and the responsibilities and rights of all involved were recapitulated at the start of the interview.

The questionnaire inquired about cholesterol anxiety, cholesterol levels, and use of cholesterol medication and experienced symptoms. Background (age, gender, stage in life) and socio-economic (education, employment) information was obtained from the Panel register. Respondents with an incomplete questionnaire, not worried about their cholesterol, or a history of severe heart conditions or symptoms (such as bypass surgery, atrial fibrillation, or pacemaker), or 68 years or older were excluded. The aim was to reach individuals who were sufficiently worried about their cholesterol to reflect on it, yet healthy enough to generate talk about risk experience instead of illness.

The remaining respondents were divided into four groups with increasing risk levels: 1) normal or somewhat elevated cholesterol (4.8–5.7 mmol/l), 2) high cholesterol (5.9–6.7 mmol/l), 3) cholesterol medication, and 4) minor cardiovascular symptoms (such as occasional arrhythmia or palpitations). The aim was to reach a good balance between homogeneity and variety among the participants, thus capturing the spectrum of risk experience. Four individuals from each group were selected for interviews. Due to the structure of the Consumer Panel, women, the middle-aged, the elderly, and the relatively well-educated were overrepresented among those responding to the call. This bias could be somewhat rectified in the participant selection. After two selected individuals (from Groups 2 and 3) dropped out on short notice, I ended up conducting 14...
interviews (in January 2015) with ten women and four men, aged between 42 and 65, half with a higher and half with a lower educational degree. Although a small group, the resulting data are well suited to articulating lay meanings attached to elevated cholesterol as a health risk.

The interviews combined a narrative approach with a semi-structured procedure. Interviews began with a personal ‘cholesterol story’, where the participants freely narrated their experiences with cholesterol in a loosely chronological order. Based on the story, I posed follow-up questions as well as complementary questions on themes not covered in the story. Major interview areas included: i) the sources of cholesterol awareness and anxiety; ii) the effects of cholesterol awareness or anxiety on everyday practices, habits and aspects of lifestyle; iii) ideas concerning the nature and effects of (elevated) cholesterol in the body; iv) ideas concerning risk, health and illness, and the relationship between these. Before the interviews, I tested the draft interview guide with a volunteer layperson for length, clarity and organisation.

The interviews lasted between 71 and 107 minutes. They were tape-recorded and transcribed verbatim by a professional company. All transcripts were imported into the Atlas/TI-program for qualitative analysis. Coding was a two-step process, with an initial content-oriented coding of a more grounded nature followed by more theoretical coding focusing on risk characteristics. I developed an initial code list based on the reading of one interview. A research assistant then coded the same interview, suggesting amendments to the code list. We compared our coding, discussed the differences and agreed on a common list of themes and codes. The research assistant then coded the remainder of the interviews. During the process, we discussed coding issues, and new codes were incorporated into the initial coding list and used throughout. After this initial coding, useful in familiarising oneself with the content of the interviews, I identified key themes salient to the characteristics of health risk. They served as higher order themes under which I assigned codes and quotations from the initial round. It is this analysis that will be presented below. The analysis proceeds thematically, leaving aside the narrative aspect of the data. Differences between the groups were observed in the analysis, but are reported only when crucial to the argument. The quotations use the four groups, alongside age and gender. All names are pseudonyms.

Findings: elements of the health risk experience

The reflections on cholesterol risk among the study participants clustered around three issues: that elevated risk does not produce manifest symptoms but is based on statistical calculations or requires technological enactment; the discrepancy between risk estimates and actual outcomes, which introduces an element of chance into the equation; and the ambivalent status of risk between health and illness.

Deciphering the intangible

The first issue typically was addressed indirectly, at the start of the interviews, when participants recounted the process of becoming aware of their condition. These accounts utilised a number of clues, which all point to the intangible nature of cholesterol risk beyond immediate experience. A few participants had a family history of elevated cholesterol or cardiovascular problems, which had made them
conscious of cholesterol as a health issue and to speculate on their own status. Physical characteristics, such as overweight, was another indicator that could signify elevated cholesterol. The participants were also generally aware that cholesterol levels tend to rise with age. For the majority, however, the key information was provided by a cholesterol test. Although a family history of cardiovascular disease, overweight, or old age could raise suspicion of a cholesterol problem, increase interest in taking a test, and be used alongside test results to assess overall risk, it was often testing that confirmed personal risk status.

The crucial test was often taken in a casual and unreflective manner, for example, at a health fair, or was obtained as part of a medical routine when changing jobs or in an age-related health check-up. For example, Elina’s (60, female, Group 2) first measurement was a quick test in a voluntary organisation’s public event. She recollects being surprised that her numbers were higher than her sister’s, despite her sister ‘being a bit rounder’ than her. Thus, the test result could come as a ‘surprise’ or even ‘shock’ (Pauliina, 62, female, Group 2), which attests to the intangible nature of cholesterol risk. The level of the surprise was a function of the perceived healthfulness of one’s lifestyle: the bigger the discrepancy between self-assessment of personal habits and factual cholesterol levels, the more likely test results were experienced as a surprise.

Despite the importance of cholesterol testing in providing evidence, many participants described feelings of ambivalence towards it. Regular testing was not automatically sought after, nor even necessarily considered welcome. The participants often referred to quite a modest testing history. Typical testing intervals were once or twice a year, even for individuals with medication or minor symptoms. Testing frequency was conditioned by age, health status, and more contingent factors such as frequency of changing jobs or access to health services. Participants without high cholesterol, medication, symptoms, or complementary illnesses often thought they did not need regular cholesterol monitoring, while participants with one or a combination of these were keener. They were also likely to be older.

A few participants described having come to prefer not to know. For example, Elina (60, female, Group 1), after years of regular monitoring and failed attempts to lower her cholesterol, no longer wanted to be measured: ‘Yes, [the cholesterol] has been monitored, but I thought I won’t say “take it [the cholesterol number]” anymore, since it just keeps rising’. For her tests were just a painful reminder of her failed attempts to change her levels through lifestyle modification.

Not even testing – and recent symptoms of mild arrhythmia – could convince Anna (61, female, Group 4) of the significance of her elevated cholesterol. Influenced by recent criticism in Finland of the cholesterol hypothesis in the causation of CHD (see, Jauho, 2016), she juxtaposed cholesterol and tobacco as risk factors, highlighting both cholesterol’s intangible nature compared to tobacco and her need to have visible proof – physical signs – of cholesterol’s presence:

‘I think the cause and effect relationship is so clear [with tobacco]. […] There are so many things tobacco causes. Someone I know had chronic obstructive pulmonary disease, clearly it couldn’t be from anything else than tobacco. And the other stuff, you lose your sense of smell and taste, teeth turn yellow, and the other awful things. Yuck. […] But you can’t see cholesterol, where would it show, not in me. Not on the skin, not anywhere. I would need to ask my heart to be opened or some vein and see, here is this plaque and it is the cholesterol, then I might believe.’
Faced with my probing during the interview, some respondents began to reflect on their indifference towards testing:

‘I wonder why I’m not really paying attention to [cholesterol testing], [although] I’m interested in fats and believe that I’m eating good fats. […] I eat oatmeal every morning these days, […] I’ve eaten it around ten years. Yet I have not really followed whether it has affected my cholesterol levels. But in principle I think [about my cholesterol] and in practice I consider what I eat. Why do I not follow my cholesterol levels then?’ (Nina, 49, female, Group 4.)

Nina both presents a further motivation to take tests, to follow the effects of lifestyle modification, and implicitly provides a possible explanation for their relative infrequency. On an everyday level, aspects of personal lifestyle, especially the perceived healthfulness of eating, act as a placeholder for individual risk status, diminishing the need for cholesterol testing. The connection of elevated cholesterol to heart conditions and the role of diet in controlling it has become a culturally entrenched notion, pointing to the role of lifestyle in managing risk factors. Problems with elevated cholesterol are ubiquitous, and individuals watch their diet pre-emptively, irrespective of their cholesterol status. Thus, it was possible to be aware and anxious about cholesterol even without elevated levels, like Liisa (50, female, Group 1), the one participant with medically normal levels in this study. Testing was thus secondary, since individual at-risk status could be read from individual habitus and personal habits.

Navigating probability

The second theme concerning cholesterol risk addressed the repercussions of the discrepancy between population-level regularities and individual-level idiosyncrasies: all individuals in the risk group are at risk, but we cannot predict who will actually be affected and get sick. Therefore, the relationship between risk and outcome is not certain but only probable: high cholesterol must not result in coronary heart disease, and low levels do not necessarily protect from it.

On an abstract or impersonal level, the participants were generally aware of this probabilistic nature of risk. Several participants pointed to the uncontrollable character of illness, discussed ‘chance’ or ‘luck’ in determining who becomes affected, and acknowledged that future health was difficult to predict. While various personal traits (overweight) and behaviours (smoking, eating fatty foods, sedentariness) were considered to increase the likelihood of future illness, these were not taken as causal determinants: ‘There are of course people who might weigh 150 kilos and smoke and drink and [still] live into their nineties’ (Niina, 49, female, Group 4). Similarly, it was thought that a commitment to a healthy lifestyle did not necessarily protect from illness: ‘Well you see all kinds of, there are people who run marathons and are healthy and still they get a coronary and that’s too bad’ (Outi, 47, female, Group 1). There was thus a shared understanding that meticulous adherence to a healthy lifestyle does not always preclude from illness and premature death, and a life filled with indulgence does not need to cut it short.

However, when the participants reflected on their personal characteristics and struggles with elevated cholesterol, a different picture emerged. The probabilistic nature of risk was only rarely mobilised, like in the following excerpt, in which Anna (61, female, Group 4) explicitly rejected risk avoidance due to the element of chance in risk calculations: ‘We will all die of something, and I can be run over by a car right here today, so
I can’t think of [taking medication for risk prevention]’. This stance tended to be adopted by those who regarded elevated cholesterol as a minor health issue and were less bothered about it as a risk. Most participants however suffered from cholesterol anxiety and were conscientious about their health care. After learning of their condition, they typically problematised some aspects of their lifestyle and made at least some attempts to change their diet or exercising habits. For these participants, elevated cholesterol, in other words risk, indicated (some kind of) a health problem that warranted immediate action.

A distinct feature among the participants was the close connection they made between their cholesterol levels and personal habits. During the interviews, almost all the participants immediately, without asking, problematised aspects of their lifestyle, especially eating and exercising, when accounting for their elevated cholesterol. Their interdependence was a self-evident point of departure when the participants assessed their own and others’ health, giving health care a deeply moral character. Healthy choices were considered essential, regardless of health status and cholesterol levels: normal values were attributed to them, while those at risk thought that healthy habits kept their levels in check and prevented even higher cholesterol.

The tight connection between personal habits and cholesterol levels also came up when the participants discussed the outcomes of their lifestyle changes. A good example of a success story is Liisa (50, female, Group 1). She described how her cholesterol levels rose to 5.6 mmol/l during her job alternation leave but that she had managed to normalise the levels again with a combination of cholesterol-lowering functional food products and dietary changes. This is how she explained the sudden rise in her cholesterol levels:

‘I was exercising then too, but I wasn’t working so I was lying around the rest of the time, that is, I was exercising a few hours a day and then only lounging. And I was eating all the time. I feasted and gained some weight’.

This, in turn, is how she accounted for the shift back to normal:

‘So, then I changed [my diet] a bit. […] I was already eating half healthily, half unhealthily. I increased a bit the amount of nuts I ate. For a while, I ate cholesterol-lowering bread. And at one point I ate a cholesterol-lowering yoghurt almost every day’.

While the reported sudden changes in cholesterol levels from 5 mmol/l to 5.6 mmol/l and back to 4.8 mmol/l are unusual and may indicate consistency problems in measuring, important in the example is the way in which Liisa unequivocally attributed the changes to personal efforts in lifestyle modification.

When the attempts to modify cholesterol levels remained unsuccessful, the participants describe a more complex picture, yet the connection to personal habits was no less stringent. A good example is the story of Elina (female, Group 2), a sixty-year-old nurse, who had a total cholesterol of 6.2 mmol/l. She had no other risk factors and thus no medication, yet was worried about her persistently elevated cholesterol. She had put great effort into lowering her levels, but without success. Neither restricting fatty foods (especially cheese) nor consuming cholesterol-lowering functional food products had created any effect, on the contrary, her levels had continued to rise. In order to identify unconsciously followed detrimental food habits, Elina had kept a food diary, noting all food items she consumed over a one-month period, yet could not find anything alarming.
‘I don’t know what [more] I can try, I think I’ve tried everything, the diet has no effect’. It attests to the power of the notion of personal responsibility in terms of health that only after submitting her personal habits to this very thorough assessment was she willing to consider other possible explanations for her constantly elevated cholesterol. These explanations included genetic factors, age, and a metabolic defect that produces excess cholesterol in her body.

Liisa’s and Elina’s narratives and positions were recurrent in the material. Success in lowering cholesterol was attributed to personal effort and signified self-mastery, while the opposite led to soul-searching, self-blame, and alternative explanations as exit strategies from the alleged moral failure to observe healthy habits. Alternative models typically evoked genetic factors, which placed the blame outside individual will and choices. Significantly, in this context, chance or bad luck were rarely mentioned. Hence, although the participants were in principle aware of the openness and indeterminacy of the probabilistic risk, when explaining their own (or another specific individual’s) condition, they disregarded these aspects and sought definitive, causal answers.

**Negotiating health and illness**

The third issue in the discussions on cholesterol risk was the status of people with elevated cholesterol: should they be considered healthy, ill, or something else? In contrast to the two other issues, this was asked directly during the interviews, both on a general level and regarding the personal situation of each participant.

The participants expressed nuanced ideas of the conditions under which elevated cholesterol signified illness. Four factors were addressed, in a hypothetical and explorative manner. The participants were prepared to regard a person with elevated cholesterol as ill, first, if it caused an illness with symptoms: ‘Well, I suppose [one might call a person with elevated cholesterol ill] when […] it begins to cause these other illnesses’ (Arto, 44, male, Group 1). Of course, in this case we are no longer in the realm of risk, since the ambivalence has been resolved in favour of sickness. The second factor was what were considered ‘outward signs of poor health’, especially excess weight, when combined with elevated cholesterol. According to Liisa (50, female, Group 1), ‘If somebody is very overweight they probably have other problems as well. Then I would say that [a person with high cholesterol is] ill’. Medication was the third factor that the participants considered. ‘Well, when you’re on medication, then you’re ill, right, because every disease has a medication’ (Elina, 60, female, Group 2). However, this factor could also be rejected, like when Ingrid (50, female, Group 1) referred to the power of pharmaceuticals to normalise cholesterol levels and reduce the risk. The fourth factor was impaired capacity to act. According to Elina’s (60, female, Group 2) definition, for example, ‘you might be [called] sick, if you can’t go to work because your cholesterol is high’. All the participants left room for subjective experiences of illness, which was regarded as decisive. ‘If there’s only the cholesterol level and it doesn’t affect him in any physical, mental or other way; if he feels well and healthy, then [a person with high cholesterol can be considered healthy]’ (Arto, 44, male, Group 1). This experience of illness was typically missing, since elevated cholesterol does not cause symptoms.

Interestingly, the participants used these factors to negotiate their own status along the risk continuum. Participants from all four groups said that they were keen to maintain the identity of a healthy person. For those with only somewhat elevated or high cholesterol this was easy, as they could refer to all factors
simultaneously. For those with medication or minor cardiovascular symptoms, the task was more difficult, since in principle their condition came under one of the factors. However, they also distanced themselves from illness. Those who were on medication could refer to the absence of symptoms or undiminished capacity to act as grounds for feeling healthy. They pointed out that a successful drug regime made one healthy again. Those with a minor cardiovascular condition were similarly reluctant to adopt patient status, justifying it with missing medication and their enduring vigorousness. For example, Hanna (63, female, Group 4), despite having 7.0 mmol/l total cholesterol and arrhythmia, refused to accept the status of an ill person on the basis of this point: ‘Well in these circumstances I can’t call myself ill, since I don’t take any medication regularly’. The symptoms among most participants were also minor, passing and unspecific. The only exception to this pattern was the participant with diabetes; not because of his CVD-related risk factors, but because of the confirmed diabetes diagnosis.

Thus, while the participants recognised the indeterminacy of at-risk states between health and illness, they were clear in their judgment that for them, personally, the risk did not (yet) signify proper illness. In this sense, the ambivalence between health and illness only existed on an abstract level. Instead of the disease/illness side of the risk ambiguity, the participants highlighted the health side. The accumulation of the various factors denoting illness signified increasing cause for alarm and the need to engage more intensively in personal health care. By gaining weight, exhibiting symptoms, or needing medication one moved along the risk continuum towards illness. This perceived shift could discredit personal habits and thus hinted at moral failure. The antidote in all locations along the continuum was participants’ monitoring of these habits and paying increasing attention to their health.

Discussion
In this article, I have outlined key elements of the lay experience of health risk, drawing on interviews with individuals at varying levels of cholesterol risk, both borderline and high, recruited outside a medical context. Starting from the premise that risk represents a specific medical rationality with singular characteristics, I have highlighted three elements of the health risk experience accompanying this powerful form of ‘surveillance medicine’ (Armstrong, 1995).

The first characteristic, the absence/presence of health risk, refers to the way in which health risk is located below the threshold of experience, as it does not produce symptoms. Health risk is enacted by statistical and technological means, but the resulting signs, markers of possible future conditions, are qualitatively different from traces of hidden illnesses. Risk is something that is simultaneously present and absent, since it denotes the merely possible. This raises the question as to how individuals become risk conscious, assess their risk status, and make sense of it: for example, start to consider themselves as having a cholesterol problem and being at risk of heart disease.

The second characteristic of health risk discussed in the interviews was the probabilistic nature of risk estimates. There is no linear relationship between the causes of risk, risk factor levels, and outcomes: all individuals with elevated cholesterol are at risk, but we cannot predict who will become ill; high cholesterol does not always produce coronary heart disease, and low levels do not necessarily protect from it. Although risk points to the future, it nonetheless calls for measures in the present. This situation opens
several possible lines of action to the individual, who might, for example, take a chance and do nothing, moderately adjust some habits, or engage in full-blown illness behaviour with regular medical contact.

The third characteristic is the ambivalent status of risk between health and illness. Elevated cholesterol is medicated like a disease, but the rationale of the treatment is preventive (Dumit, 2012). It is unclear what elevated cholesterol levels signify: latent disease or an increased likelihood of a future condition. Hence, elevated cholesterol has a dual status both as a risk marker for an illness and an illness itself. This raises the question of should a person with elevated cholesterol be considered ill, healthy, or something else?

All three characteristics have been discussed in previous studies on cardiovascular risk, but typically not together or simultaneously, as elements of a more comprehensive health risk experience. Moreover, the focus of this study on health (in contrast to illness), which resulted from the need to detach health risk from (chronic) illness and at-risk individuals from patients, introduces some crucial shifts when compared to the picture presented by previous research.

As regards the first characteristic, Davison et al. (1991) introduced the notion of ‘coronary candidacy’ to highlight the multiple interpretative resources for estimating personal risk status, including family history, physical complexion, and age (see, also Angus et al., 2005; Crinson et al., 2007; Weiner, 2009). The crucial role of tests and risk assessments in establishing the at-risk status has been stressed in relation to both medicine in general (e.g., Armstrong & Eborall, 2012) and elevated cholesterol in particular (Adelswärd & Sachs, 1996; Crinson et al., 2007; Cupit et al., 2020; Hann & Peckham, 2010; Sachs, 1995; Saukko et al., 2012; Will, 2005). Individuals have been found to have a multifaceted and often ambivalent relationship to tests, which can be embraced as checkpoints for progress but also avoided or delayed in fear of unwelcome results (JC Frich et al., 2007; Gillespie, 2012). Individuals interpret test results and risk scores within personal, familial, and social contexts through ‘narrative meaning-making’ (Snell & Helén, 2020) and other ‘tactics of everyday life’ (Sharon, 2015), making the impact of risk information on health beliefs and behaviour complex and uncertain (see e.g., Broholm-Jørgensen et al., 2019; Jenkins et al., 2013). Although the participants of this study did use cholesterol measurements as a means of ‘objective self-fashioning’ (Dumit, 2012, p. 21), it was primarily not to negotiate patiengthood but to assess personal success in the moral endeavour of health care. Participants approached test results not (only or always) as material indexes of cardiovascular disease status or as ‘placeholders for health’ (Gillespie, 2012, p. 205), but as indicators of the healthfulness of their lifestyle (for similar observations in relation to PSA testing, see, Bell & Kazanjian, 2011), with elevated levels calling for some adjustment of personal habits. However, since cholesterol testing played a rather minor part in the lives of most participants, it was creating neither ‘statistical panic’ (Woodward, 1999) and ‘measured vulnerability’ (Gillespie, 2012) nor ‘measured certainty’ (Bell, 2013, p. 133). Rather, the case highlights the relative insignificance of tests in a situation where risk knowledge is culturally ubiquitous and risk management an ethical imperative for all laypersons irrespective of risk status.

As regards the second characteristic, previous studies have illuminated individuals’ keen understanding of the discrepancy between personal habits and health status and of the role of chance in illness (Angus et al., 2005; Davison et al., 1992; Emslie et al., 2001a). Polak (2016) has observed how patients use this notion in their justification of either adopting or declining statin medication. The present study introduces the
distinction between the abstract and personal level to this theme. On an abstract level, also the participants in this study acknowledged that there is no linear relationship between level of risk and health outcome. However, when discussing their personal situation, their position was more complex. First, participants linked elevated cholesterol directly to their personal habits, which were thought to determine the levels. Epidemiological risk, a relative property of a group of people, thus was individualised to signify a definite property of the individual (see, Adelswärd & Sachs, 1996; Jovanovic, 2014). Second, participants typically assumed that their levels were immediately responsive to lifestyle changes. Only if this response was missing, for example, after a concerted attempt at dietary change, did participants start to look for explanations beyond their habits, such as heredity, personal metabolic idiosyncrasies, or stress generated by contextual issues. Other studies of coronary heart disease risk (Jovanovic, 2014; Saukko et al., 2012) and other health risks (e.g., Lawton et al., 2008) have identified a similar explanatory pattern. This distinction between the abstract and the personal has affinities with the need to translate population-level risk scores to personalised health advice in clinical settings (Cupit et al., 2020; Polak & Green, 2015), but transposes it into the context of everyday health care.

As regards the third characteristic, the ‘liminality’ of the risk experience between health and illness is an established theme in relevant research (Farrimond et al., 2010; Felde, 2010). This study gives more substance to the concept by showing how participants carefully negotiated their status according to several criteria, including symptoms, undergoing treatment, and capacity to act. As participants were clearly reluctant to regard themselves as ill, including those with a minor cardiovascular condition or on medication, they employed the criteria to distance themselves from patient status. Thus, cholesterol diagnosis did not erode trust in personal experiences, and test results were not regarded as the final arbiters of personal health (see, Sachs, 1995). This finding sets this study apart from many others on health risk experience, both related to cholesterol and to other chronic conditions and at-risk states, which have found that both clinicians and patients often equate at-risk states with illness and view the associated interventions not as prevention but as treatment (Gillespie, 2015; Jovanovic, 2014; Kreiner and Hunt 2013; Polak, 2016; Reventlow et al., 2008; Salter et al., 2011). For example, in the study on cancer genetics by Scott et al. (2005), low-risk ‘patient-clients’ actively sought both a deeper engagement with health services and a clearer definition as proper patients. While these participants were ‘dissatisfied of “not being a patient”’ (Scott et al., 2005, p. 1875), the findings I presented above show that my study participants were disappointed if granted patient status, since they considered it a sign of failure in the moral project of personal health care (for a similar construct related specifically to cardiovascular drug therapy, see, Eborall & Will, 2011; Polak, 2017).

Although elevated cholesterol was regarded as a problem and described as influencing everyday personal health care, the participants seemed to be rather detached from testing (or medical contact in general) and reluctant to see elevated cholesterol as granting or imposing patient status. They neither felt ill nor as patients, yet acted as if they had a health problem. I want to suggest that this apparent contradiction is resolved if the experience of health risk is disengaged from the medical context, the patient perspective, and the experience of (chronic) illness. Approached from the medical point of view, declining patient status, not seeking regular testing, and being reluctant to take medicines while worrying about cholesterol and engaging in personal health care seems incoherent or irrational. However, from the everyday point of view, avoiding
medical services and engaging in self-care to reduce cholesterol risk is consistent with maintaining the identity of a healthy person and merely extends and provides extra motivation for the mundane healthcare practices that such persons would engage in anyway. Hence, from this perspective, the experience of risk does not generate (proto) illness behaviour (cf., Gillespie, 2015) but rather is subordinated to a larger category of health behaviour (Jauho, 2019). Disengaging health risk from the ‘patient frame’ highlights this aspect of the health risk experience: the generalised moral imperative of constant vigilance in personal risk management and the role of the perceived healthfulness of individual habits when assessing personal risk, beyond probabilistic estimates.

Conclusion
In this study, I have argued for the specificity of the health risk experience. The analysis was organised around three key elements that structured the health risk experience in elevated cholesterol of the participants in my research. The generalisability and exhaustiveness of these elements should be the topic of subsequent research. While in the discussion I have offered some pointers to other types of conditions, the salience of the elements should be verified by further studies in other locations, among different types of participants, and with other risk factors. It is plausible that the health risk experience varies depending on the type of the risk factor and the nature of the illness under consideration. Moreover, risks discursively related to lifestyle choices, such as elevated cholesterol, are more likely to be approached from the everyday point of view than risks that are discursively constructed as more deterministic, such as genetic risk markers. Comparative research that looks at various illnesses and different types of risk factors in various contexts is thus needed in order to establish whether the elements identified in this article – the intangible nature of risk, the probabilistic character of risk estimates, and the ambivalent status of risk in terms of health and illness – also structure the health risk experience more generally.

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Note
1. One participant did not report that he was suffering from diabetes. Moreover, some had experienced cardiovascular symptoms they did not report in the questionnaire, while others with reported symptoms dismissed them during the interview. Nonetheless, the initial four categories are used to characterise participants.

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