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"Well, I knew this already" - Explaining personal genetic risk information through narrative meaning-making

Abstract

This article presents results from a Finnish focus group's study conducted among participants of a project called GeneRISK, in which the participants received a personal risk score for having a cardiovascular event based on genetic analysis, lifestyle and laboratory results. In the discussions, interpretations of the genetic risk score and its meaning were incorporated into personal narratives of health and illness. We argue that instead of serving as an explanation for health and illness, which can help guide people's lives and choices, the genetic risk information became an object of explanation. Therefore, the risk information didn't create new conceptions of personal risk, nor did it generate enough power to push people to change their lifestyles. Instead, the risk information was used to strengthen the existing impression of personal risk and the narrative of personal health and illness.

Keywords: genetic risk, cardiovascular disease, focus groups, narratives, lifestyle, biographical disruption

Introduction

Finland is aiming to be a model country in utilisation of genomic information (Ministry of Social Affairs and Health 2015). It is expected that with the help of genome knowledge and by utilising the linked health databases, healthcare costs can be cut, new innovations and business opportunities will be created and people can and will make preventive life style changes. A large-scale pilot project called GeneRISK was launched in 2014 to achieve these goals. GeneRISK continued a long tradition of developing tools to estimate personal cardiovascular disease (CVD) risk both in Finland and internationally (Will 2005; Puska 2009; Jauho 2017) and introduced an analysis of new genetic markers to the CVD risk score. The objectives of GeneRISK were to develop methods to gather, analyse and interpret genome data related to CVD; utilize genome knowledge in public and private health care; and provide some information directly to research participants. GeneRISK and other projects in personalised genome medicine (e.g. 100,000 Genomes Project in the UK, Genomic Medicine Sweden, the Precision Medicine Initiative in the USA, the international ICPerMed and ePerMed in Estonia) and health strategies all over the world aim to offer genetic knowledge to healthcare

providers and users. The intention is to enable people to make informed choices and lifestyle changes to improve their health with the help of genetic knowledge.

A number of studies demonstrate, however, that genetic risk information related to common multifactorial diseases, such as CVD, has little impact on peoples' habits and lifestyle choices (Collins et al. 2011; Gordon et al. 2012; Li et al 2016; Marteau et al. 2012). Few studies have sociologically explored the empirical and theoretical aspects of this identified inefficacy. This article presents new empirical and theoretical insights into discussions on why genetic risk information on common multifactorial diseases has little impact on people's choices (e.g. Weiner 2009, Sharon 2015). In addition, we contribute to the literature on illness narratives (e.g., Bury 1982, 2001; Hillman et al. 2018; Hydén 1997), how people make sense of risk information (e.g. Atkinson et al. 2013; Chilibeck et al. 2011) and the discussion on the liminal state experienced by people receiving genetic test results (e.g., Gillespie 2015; Konrad 2003; Timmermans and Buchbinder 2010).

We analysed, via focus groups, how people participating in the GeneRISK project translated cardiovascular genetic risk information into understandable, manageable and in some cases actionable knowledge. The GeneRISK participants received through an Internet portal a personal risk score that provided an estimate of their risk of experiencing a cardiovascular event during the next ten years. The risk score consisted of a genetic component where 40 000 single nucleotide polymorphisms (SNPs) were analysed and a 'traditional' part based on a lifestyle questionnaire, physical measurements and laboratory tests. The results also included an estimated lifetime expectancy and selected laboratory results, such as cholesterol level. The focus groups were recruited and arranged in Kotka, where over 4000 inhabitants 45-65 years old were enrolled in GeneRISK. Kotka is an industrial and harbour town in Southeast Finland with a somewhat dubious health reputation, as it has been named 'the sickest town in Finland'.

The focus groups provided a venue for the research participants to discuss and reflect on the risk information they had received. We studied how participants translated the risk information into understandable and manageable knowledge and claim that it was achieved through *narrative meaning-making*, which means that understanding of the genetic risk score and its meaning was incorporated to the personal narrative of health and illness. Sharon (2015) points out that translating genetic risk information into more concrete and familiar terms is a common tactic that people who have had a genetic test are using. The process of meaning-making transforms abstract and complex issues into categories that make sense in people's lives. It can involve complex interpretation and questioning of the risk information through previous personal experiences of health and illness and sharing of the results with family members, friends and healthcare providers (see Atkinson et al. 2013; Jenkins et al. 2013; Skinner et al. 2016). Narrative meaning-making is a way to create order and sense from new and potentially disruptive information (Becker 1997; Richardson et al. 2006), and it tells not only about the past but also the present and the future (Alaszewski and Burgess 2007; Lorenzen 2012). Harris et al. (2014) use the term 'autobiologies' to describe the narratives told on YouTube, in which people receive and deliberate over results of consumer genetic testing. Through autobiologies, people interweave personal and family history, biology and self-making in narratives. Focus groups offer an insight into how these autobiologies are expressed and used in discussion.

To change their lifestyles, people not only have to change their habits but also the stories they tell about themselves and their choices, i.e. their narratives of self-identity (Giddens 1991). Personal health and illness

are also associated with social and contextual factors in these narratives. Thus risk information becomes interpreted through multiple contexts, such as age and life cycle, family history and local socioeconomic situation (Atkinson et al. 2013; Richardson et al. 2006). Weiner (2009) has demonstrated how genetic susceptibility for CVD is only one component for people suffering from familial hypercholesterolemia to explain the reasons behind their personal health risk or condition. Personal accounts of CVD are a combination of genetics, lifestyle and social conditions. Chilibeck et al. (2011) have demonstrated the complexity of disease causation in the narratives of people.

Weiner (2009) has shown that people have an ideal profile of the person who is likely to suffer from CVD, and she emphasises that this 'coronary candidacy' is a core element in the narratives of her interviewees. Furthermore, decades of public health promotion and interventions as well as availability of various CVD risk calculators have brought the risk discussions to everyday lives of people (Holmberg et al. 2012; Jauho 2017; Will 2005; Pajari et al. 2006).

In addition to the notion of coronary candidacy, we take the idea of biographically anticipated illness (Williams 2000; Pound et al. 1998) as another premise of our analysis to demonstrate that genetic risk information is not always unexpected, nor does it always create biographical disruptions (Bury 1982). Instead, with common multifactorial diseases, expectations of health and illness can be grounded on local, social and personal contexts that anticipate illness (Larsson and Grassman 2012). Pound et al. (1998) claim that older people, especially from the working class, have lower health expectations and consider illness unavoidable in old age (see also Brown et al. 2013). Therefore, the time and life situation of those receiving risk information plays an important role in adapting the information.

Honkasalo (2001) studied elderly people in Finland and showed that chronic illness can become a large part of their identity, but it is only one biographical disruption among many other events like, for example, war, unemployment or death of a family member people have encountered in their lives (see also Larsson and Grassman 2012). Monaghan and Gabe (2015) wrote about 'biographical contingency'. With this concept, they refer to how a chronic illness may be perceived only sometimes as a problem, and in other moments, the illness might have a dormant nature. Their research revealed tendencies to normalise potential illness, symptoms or health risks as a part of everyday life. Will and Weiner (2014) discuss the temporality – of not only symptoms and illness – but also lifestyle choices such as healthy eating habits. Lifestyle choices are influenced by events such as receiving bad laboratory result, but they are also linked to more mundane aspects, such as pleasure eating over weekends. The coming and going of illness or symptoms is also linked to actionability. Whether the illness requires action depends on the symptoms, meanings and consequences at the moment and the accumulation of incentives to take action. Genetic risk information rarely provides people or the practices of daily care in the clinics new tools (Stivers and Timmermans 2017).

We also discuss the applicability of concepts such as 'patients-in waiting' (Timmermans and Buchbinder 2010) and 'pre-symptomatic patients' (Konrad 2003), developed to describe the liminal state between health and illness in relation to monogenic diseases, in receiving and managing risk information on common multifactorial diseases (see also Jauho 2019). Timmermans and Buchbinder (2010) argue that patients-in-waiting can be used as an overarching concept to illuminate common experiences among people confined between a state of sickness and health characterised by uncertainty about disease, a liminal state they describe as prolonged diagnostic uncertainty. Tavory and Timmermans (2014) theorise, for example, that

receiving a genetic diagnosis can put people in a frameless state in which they cannot act on their previous frame of health, and they have no common shared frame of sickness to which they can adjust their reasoning.

The studies discussed above and concepts they introduce attempt to grasp how people make sense of their illness or the probability to fall ill. In other words, these studies focus on the ways by which genetic or other medical information acquire meanings as regards to people's lives and biographies. They discuss the effects such information may have on individuals' self-understanding and everyday life, and they emphasize that personal narratives are central in making sense of health-related information. In this article, we contribute to these discussions with an empirical analysis of reception of genetic CVD risk information. We point out that with cardiovascular diseases family history and social context in particular offer existing frames, or possibilities for narrative meaning-making of genetic risk information, as we call them.

Material and Methods

The research material comprises of nine focus groups (a total of 40 participants) conducted in autumn 2016 in the town of Kotka in Kymenlaakso in Southeast Finland. The public healthcare system in Kymenlaakso was one of the three routes for recruitment of research participants into the GeneRISK project. The target for the Hospital District of Kymenlaakso was 5000 research subjects, and by the end of 2017, all 5000 people had been recruited. Most of them (approximately 80%) came from Kotka, the biggest town in the region with 54 000 inhabitants, and the rest came from nearby communities. The almost 4000 45-65-year old research subjects from Kotka represent a quarter of the respective age cohort in the city (15 900 inhabitants between 45 and 65 years old in 2015). So the project had strong local relevance and presence. Kotka is a traditional harbour and industrial town that has suffered from an ageing population and high unemployment rates during the last decades. It has also been dubbed 'the sickest town in Finland'. Research by the National Institute of Health and Wellbeing (2015) shows that Kotka has the highest morbidity index from the Finnish towns with over 50 000 inhabitants. Specifically, the high incidence rate of cardiovascular disease contributes to Kotka's morbidity figures. All Finnish residents are entitled to public health care organised by local authorities and hospital districts, and the employers have to arrange preventive healthcare for their employees. This means that people in working life get their health check-ups and basic services through this parallel system where the employer usually buys the services from private healthcare companies while unemployed and retired people use mainly the public health care services.

The ethics committee approval for the whole GeneRISK project included the possibility of recontacting the participants for focus group research. Focus group members were recruited in the hospital district, where research nurses sent invitation letters to people from the list of participants that were in the beginning of the GeneRISK recruitment list, who hopefully had already received a personal risk score. We sent 20-30 letters of invitation per focus group to people identified in the list. People who wanted to participate in a focus group were asked to contact one of the authors. The author received over hundred contacts by e-mail or phone. Most people were positive and wanted to participate in a focus group discussion, which was not always possible due to schedule restrictions. Some declined, as they had not received their results yet, and a handful of people were not willing to discuss their results. Altogether, nine groups were arranged with 3-6 participants in each group. The age and gender distribution were similar to those of the GeneRISK cohort, with 65% being female and 35% being male and ages varying from 46 to 65. The participants were mainly working-class or lower-middle-class people, and almost a quarter of them were pensioners.

The focus groups were moderated by the first author. The authors were not part of the GeneRISK project but belonged to a larger consortium together with GeneRISK. One task in the consortium was to do sociological research on research participants' as well as medical professionals' (Snell and Helén 2017) experiences and opinions on receiving and using the risk score. During the recruitment and in the beginning of discussions it was emphasised that the moderator is a social scientist and cannot answer medical questions or those related to the functioning of the internet portal. Many participants were however interested in these aspects and were thus guided to contact GeneRISK personnel or health care providers. The focus group participants signed an informed consent form, and the groups' purpose and uses were also explained orally. The discussions lasted from a little over an hour to two hours and were held at the Kymenlaakso Central Hospital, where the participants had also participated in the GeneRISK health check and sample taking. The discussions were digitally recorded and transcribed to text files in which all the participants' names were changed to codes. The codes used in this article are based on the focus group's number (1-9), the participant's gender (F/M) and a number to differentiate between participants of the same gender (1-5). The quotations have been translated to English by the author/moderator. The discussions were free but followed a similar pattern that touched on first experiences and the decision to participate in GeneRISK and then moved on to receiving the personal risk score and its implications. The interview guide included questions such as how it felt to receive the score, whether the information was easy or difficult to understand, with whom they had discussed the risk score, whether the information had caused something such as lifestyle changes or doctor visits and their expectations of and feeling about further research on genetics.

The focus group participants represented two-way-positive people, those who had participated in GeneRISK and were willing to participate in a focus group. Recruiting them was rather easy, as people were interested in talking about their experiences. In general, the focus group participants were interested in receiving personal results and helping advance medical research in general. This research did not make it possible to recruit people who had declined the invitation to participate in GeneRISK and would presumably have been more negative towards genetic risk scores or medical research. However, many participants expressed freely critical opinions towards the project and how it was managed.

The material has been analysed by systematically coding the focus group text in dialogue with the existing literature on sociology and science and technology studies focusing on health and genomics, health promotion and patient experience. Thus, the analysis was a mixture of data-led observations and theory based analysis that gave us the possibility to raise new findings from the material, and then reflecting the findings on what has already been discussed in literature. After dialogical coding, we identified key themes in relation to how people made the results meaningful for themselves in the discussions: family and personal history, social context, sharing of the results, actionability or unactionability as well as anticipated or unanticipated results. Then we analysed how these themes were combined and employed in the discussions. This analysis resulted in our understanding of the narrative meaning-making. Focus groups as a method invite people to share their thoughts and experiences, and thus the formation of narratives is characteristic for the focus groups. Previous research shows that making sense of abstract and complicated issues happens often through translating them into meaningful narratives (Sharon 2015, Chilibeck et al. 2011). Therefore, focus groups provide a good method of analysing these processes.

Findings

Our analysis of the focus group discussions concentrated on the elements of meaning-making – how the focus group participants discussed the results they had received and how they created order and sense from the information. We present first how family history and local context offered an existing framing for the discussants that formed the basis for narrative meaning-making, which in turn placed the risk information as an object of explanation. Furthermore, we discuss how the risk information became mainly unactionable because of the meaning-making process. Finally, we analyse the cases in which the information was not easily explained by existing frames and narrative meaning-making was not possible.

Narratives of personal life, family history and local context

All of the focus groups started with a question: Why did you take part in the GeneRISK project? A large majority of the participants referred to family members and relatives who had had cardiovascular diseases or had died from them. Many also mentioned personal health issues such as elevated blood pressure or high cholesterol level as an incentive to participate in the project.

> I have the same grounds.... I have also, my both parents have died of cardiovascular diseases and I have high cholesterol, to which I have medication. So out of interest. (7M2)

Cardiovascular diseases were familiar to the participants and were already part of their narratives of personal and family history. Many continued explaining their motivation by stating that they had expected the results to tell about their inheritance and new possibilities to influence their health. When the discussion moved to the received results, most participants expressed, however, that the results were as expected. Many stated the results included nothing new and they already knew their risk. As there was hardly any new information, participation in the research was seen to produce very few new means or tools for achieving better health. They nevertheless stressed that it was interesting to know the results and hoped that others would benefit from the project. This type of reasoning applied to almost all irrespective of whether they had received high or low risk scores.

> Well the answers were not that special.... It is always like, well I knew this already … but interesting. I liked to read them and saved them. (1F3)
> I had an expected result. We don't have inherited propensity. So it was in the negative so that I don't have anything. (9F1)

Prevention of cardiovascular diseases has been part of the public health agenda in Finland for decades. An internationally renowned health intervention program related to cardiovascular disease was started in North Karelia in the 1970s (Puska et al. 2009). The project was instrumental in popularising the risk factors for cardiovascular disease among the Finnish population (Jauho 2017). The North Karelia project and its success in reducing mortality and morbidity with the help of dietary and lifestyle changes is well-known among Finns, and some referred to it in the focus groups. Also, the poor morbidity rates in the Kotka area were discussed, and the town was seen to suffer from low income, an aging population and increasing unemployment. Besides family history, these collectively shared ideas of the Finns and local people as 'coronary candidates' (Weiner 2009), prone to encounter cardiovascular diseases, frame the expectations and narratives of the discussants.

- This is beginning to be there, but we are not quite North Karelia. (8F3)
- No, South. (8M1)
- But anyway, we have a rather poor situation here with these diseases. (8F3)

Most focus group participants had been subjected to regular health checks and health instruction provided by public or occupational health services for most of their lives. Due to this and intensive public health promotion in Finland for over 40 years, with a particular focus on prevention of CVD (Jauho 2017), our discussants were well aware of a variety of health risk factors and had adopted knowledge of what comprises a healthy lifestyle (Pajari et al., 2006). The (un)healthy lifestyle was also a significant part of discussants' narratives, and the diet and exercise recommendations by professional health promoters were well-absorbed into their reasoning. Many pointed out that they already had a healthy lifestyle and gave examples:

> There should not be anything in my lifestyle, at least, nothing too risky. I don't drink, I don't smoke. Haven't done it for decades. I don't eat fats, all products are usually fat free. I don't eat many sausages in a year, some barbeque in the summer. Because I have known all my life that my values are high. But there is no reason for it. (1M2)

The results portal through which the GeneRISK participants received their risk scores included links to electronic "coaching" where the participants could read about exercise and healthy eating. The information offered in these services was regarded as familiar but a "nice reminder". In some of the focus groups, the discussion around the received results centred more on laboratory results than the genetic risk score. The discussion about genetic risk was then passed over very quickly. In most of these cases, the discussants had received a low genetic risk score or they had not understood which number or sign in fact pointed out the genetic risk. Some even stated that they had not seen any personal genetic information. Instead of a risk score, some participants had expected information about whether they had specific mutations. In addition, the lab results were more concrete to many discussants and already formed a big part of their personal narratives. The lab results were compared to those presented in public or occupational healthcare. The discussions tended to turn to more familiar aspects and factors in the participants' lives and to issues the participants thought they could influence. Cholesterol level, blood pressure or level of sugars were, for many, more concrete issues that could be acted on, compared to the genetic risk score.

Whether it was the genetic risk score, cholesterol levels or life expectancy estimate, the results were easily incorporated into the personal narrative. Through this incorporation and interpretation, the discussants made the results meaningful and congruent with their ideas of themselves. One participant stated happily that the life expectancy rate she had received and printed out was just as she had anticipated and even had aimed at.

> It was in the papers that if you change [lifestyle] you would gain this much lifetime. The life expectancy was at least with me that, it was just like I had considered to live, up until that age. (5F2)

Personal family history as well as local social knowledge about CVD enabled easy incorporation of the results into the personal narrative. But what we want to emphasise becomes apparent in the previous quote. This statement clearly demonstrates that the risk information did not serve as an explanation for health and illness that can help in guiding peoples' lives and choices. Instead, the participants explained the results through their experiences and reasoning, and thus *the risk information became an object of explanation*. In other words, the risk scores were biographically anticipated, and thus they were easily adjusted to fit in the existing narratives of health and illness. The participants recounted that the results were as predicted and

the risk information did not cause diagnostic uncertainty, which is, according to Timmarmans and Buchbinder (2010), characteristic of patients-in-waiting. Although many participants stated they had medication for high blood pressure or cholesterol and therefore can be considered in a liminal state between illness and health, the personal risk results did not affect this status. Therefore, they did not have to choose between health and illness frames (Tavory and Timmermans 2014) because of new information. Instead, they could stick to their existing frame upheld by a personal narrative.

Becoming actionable through accumulation of incentives

As the results of CVD risk analysis were interpreted through the existing narrative of personal health and illness and the information was perceived to offer mainly previously known information, the results had little capacity to create new action. Few people indicated that the results had made them change their lifestyle or had caused them to contact a healthcare provider. Most participants had already, however, made lifestyle changes many times in their lives or had taken interest in their health during the last decade or so as they had aged. Among those who received advice to change their lifestyle, most had already made some kind of effort in the recent past. The GeneRISK information was perceived to be only one wake-up call among others or even "business as usual". The personal narratives of health and illness included many accounts of previous concerns and efforts to increase exercise and make diet changes.

> I have been a little worried already earlier. When I retired and was not eligible to occupational health service any more. And when the values started to rise.… Was it too little exercise? It changed as I didn't bike to work 7 km any more. Of course your lifestyle changes then. I have gotten the values down every time I have tried to get a grip on myself. But that is of course difficult. (2F2)
> Compared to the situation that was then when these tests were taken. I knew already then that I can only go up. That everything that comes from the results, it is only positive. So I already started before the results came. I knew that I had to act. (4F3)

A tendency to talk about several attempts to adopt a healthier lifestyle and the GeneRISK perhaps providing one opportunity for change resembles biographical contingency, introduced by Monaghan and Gabe (2015). Symptoms might become more acute, and new lab results or a loved one's illness can all be wake-up calls and initiate action. In other moments, thinking about lifestyle changes or doctor visits are not on the top of the agenda. As actions had already been taken, the GeneRISK scores were for some yet another potentially passing incentive to concentrate on improving lifestyle.

Many focus group participants said they needed social or expert help to interpret the information and, in particular, make it actionable. Being alone with the results did not easily lead to action. Some had sought interpretation or confirmation from a doctor. Many compared the accompanying lab results to previous values from lab tests, and others stated that they had discussed the results with a family member who had given them a push. Action was also said to be taken when the research coincided with a suitable phase in life such as retirement. After retirement, people are not eligible to occupational health services anymore. Many described how it was easier to get lab test through occupational health services than through public health care and wanted to get "all done" before retirement. Many also referred to their age and talked about the last opportunity to influence one's health. Despite the opportunities for action, often, none was taken. In the next passage, the focus group moderator returns to an earlier discussion in which a participant had mentioned a doctor's appointment.

- And 4N3 had the risk information with her [at the doctor's appointment] but did not talk about them? (Moderator)
- Well, I thought that it would be kind of imposing myself. (4N3)

Although cholesterol level and blood pressure were considered something to act on, genetic risk information was more alien, and some considered taking genetic information to the doctor too pushy: perhaps even the doctors would not know what to do with it. The genetic risk score was also less concrete and convincing than the laboratory results, and many discussants considered it 'only an estimate'. The virtual coaching and links to dietary and exercise advice were considered by most – just like the risk scores – already familiar information. The advice was also on a general and not a personal level, which made many discussants wonder what more one could do to improve his or her lifestyle. Health promotion ideas were said to be known – everyone knew basically what to do. Some admitted that they did not do enough, and others asked in frustration what more they could do.

I remember as my daughter also looked at the values and she said, as there was that with changing lifestyle I would have couple of extra years. So my daughter asked, what more can you change because you exercise and eat well? What can you do and what does it mean to change lifestyle? (9F4)

The lack of concrete personal measures that could be used to help in dietary or exercise choices also made the results unactionable.

Disturbing information

Although the large majority of focus group participants claimed that they had anticipated or already known about the results they had received, some had received unexpected results, such as higher than expected risk scores or results that contradicted their personal health narratives. This kind of information can be described as disturbing rather than disruptive, as it caused unrest and confusion among the participants. For example, a couple of participants expressed that they had always believed they had a high hereditary risk. When their results demonstrated that there was no particular association to genetic risk but their lifestyle risk was elevated, they became confused or were not willing to accept the information (see Shostak et al. 2011).

With me it was good [genetic risk score], so I had contradictory feelings. Because there have been incidents [in the family] but it seems that this thing is ok with me. So, I felt a bit strange. I had been afraid that there would be something else. (6F3)
Both my father and mother have had heart disease. And I have been conscious that my own genetic background is rather rough…. I have tried to take care of my health and was thinking that would it show in this research. How well have I succeeded in it? But I thought it was rather peculiar as the significance of my genetic thing was negative and still I have a high risk of getting ill. I don't get it. (2F3)

Disturbing, unexpected and conflicting information was difficult to incorporate into the existing narrative or it created a frameless situation, as Tavory and Timmermans (2014) described it. Some simply refused to believe the information, but others contested the research's scientific credibility and premises. One discussant described and questioned the results he had received. According to him, the laboratory results shown in the portal have been wrongly interpreted in his risk score, as he had studied the recent research on cholesterol levels.

> Well guess when you get this kind of a paper, when you have first put all your blood values right. And then comes the great research result: your risk is high! I can say straight forward that the only risk there is, is that I will lose my temper so that my blood pressure will rise and I'll bite the dust. But I won't die of that disease. That is for sure! (2M1)

Another participant commented on the estimated life expectancy score he had received:

> I don't believe it. In our family all live over 90. So I don't believe that I die a lot younger. (1M2)

Unexpected information, however, was not considered a wake-up call. Because the information was not easily accepted without criticism or made compatible with personal narrative, it didn't become actionable. In these cases, even when the received results were not 'bad news' but 'not-matching news', deliberation and counselling were needed. It is important to note that even with results that did not point to high genetic risk, people needed support, i.e. someone to explain to them why the risk results did not meet their expectations.

> Well I looked at it. If you eat a bit smarter it would be even more on the minus side…. I understood that I have rather big hereditary risks, I'm not sure I read it right. I should ask a doctor sometime. I knew more or less, I have cholesterol, we had a yearly checkup.… So it was not a big surprise, but it was a surprise that I thought that we were heart diseased people, but we were not. Or at least I'm not. (9F3)

When the information could not be explained by the personal narrative or incorporated into it, it remained unintelligible to the participants. Therefore, this kind of information also caused more confusion than action.

Discussion

In this article, we presented how people participating in the GeneRISK project translated cardiovascular genetic risk information into understandable, manageable and in some cases actionable knowledge. The focus group participants were 45-65 years old and from Kotka, 'the sickest town in Finland', and they had received a genetic and a traditional risk score and some laboratory results related to CVD. We argued that because the results people received were perceived to contain very little or no new knowledge, the results were in fact biographically anticipated. In addition, we claimed that instead of explaining their conditions and personal health with the results, the participants explained the risk scores through their experiences and reasoning – i.e. by narrative meaning-making. Thus, the risk score became an object of deliberation, and the participants made them meaningful by referring to personal narratives of health and illness. The fact that genetic risk information was interpreted through the personal narrative instead of personal events being interpreted in the light of risk information offers a new insight into why genetic risk information about common multifactorial disease has little impact on peoples' lifestyle choices. Narrative meaning-making is a way to create sense and order from new, abstract and complicated information (Sharon 2015; Becker 1997; Richardson et al. 2006). But while translation renders the information to an understandable format, it also diminishes the explanatory and incentive power of the risk scores.

With common chronic multifactorial diseases such as CVD, the concepts like biographical disruption or patients-in-waiting that emphasize uncertainty and disruption do not seem to offer a model for understanding how people make sense of health risk and potential illness. Instead, research that points to many different frames, contexts and relations through which people interpret their risk and evaluate different types of information describe better the reasoning and meaning-making processes.

In light of our analysis, information about the personal genetic CVD risk seemed rather insignificant. In general, people did not discard personal genetic risk information as uninteresting, intruding or wrong. Most of them simply did not find additional information about personal CVD risk providing new knowledge or being actionable, and tended to talk more about blood cholesterol level or other laboratory test results that they were more familiar with. Chilibeck et al. (2011) have shown how people in an Alzheimer susceptibility study found the visible evidence of risk provided by family history more compelling than that based on a genetic test. Similarly in our research, genetic risk was only one component and it was often subordinate to the more traditional evidence of coronary candidacy.

In addition, our results point to what Monaghan and Gabe (2015) termed 'biographical contingency'. The term refers to the sometimes dormant nature of disease that requires action or consideration only as symptoms emerge or worsen. In our focus groups, biographical contingency was related to the annual laboratory test results, dropping away from occupational healthcare, cardiovascular illness of a family member or other wake-up calls. The GeneRISK research was for some just another wake-up call among others. Repeated or cumulative incentives were part of all participants' narratives. For the information to become an actionable concern, it usually required more than one incentive. Therefore, genetic risk information such like GeneRISK feedback is not necessarily enough.

For our focus group participant, acquiring information about personal cardiovascular risk was barely disruptive, and its reception did not seem to lead to biographical anticipation of a chronic disease. They can hardly be described as patients-in-waiting (Timmermans and Buchbinder 2010), as the discussions and narratives in the focus groups did not indicate a 'liminal' state of uncertainty and disorientation between being healthy and illness to come. Instead of uncertainty, participants' narratives painted a picture of anticipated outcome. Many expected that they will encounter cardiovascular problems, or were already taking statins. Having health problems was also regarded as natural process of aging (see Pound et al. 1998). In a way, the focus group participants described *living with being-at-risk* of CVD, and they were quite accustomed to such living. With life style choices and healthy living, most of them tried to avoid or postpone the onset of illness. They can also be called 'chronically healthy' individuals (Varul 2010) who are actively trying to avoid becoming patients (see also Jauho 2019). Most had made improvements in diet or started to exercise more several times in their adult life, and they knew, in principle, how to avoid coronary candidacy. At the same time, many named getting new information about one's health and how to influence it, as the main motive for participating in GeneRISK study. This looks slightly paradoxical, but it seems that people were motivated to participate in GeneRISK not only to receive new information about their CVD risk but also to confirm their existing understandings. When the participants situated the GeneRISK information in the context and stories of their own lives, they noticed that the project hardly managed to produce any new knowledge or tools for personal health promotion. This also confirmed their existing knowledge and actions as morally sound and responsible (Weiner 2009; Will & Weiner 2014).

Despite the emphasis of our analysis on anticipated results, some participants had, however, received unexpected information. Sometimes this was a higher than expected risk score, but in other cases it was an unmet belief of the risk being in the genes while the results pointed to an increased lifestyle risk. The information was considered confusing and disturbing, and it did not prompt action. Our analysis stresses that contested information or information that does not fit in a personal narrative (see Chilibeck et al. 2011), and

therefore challenges the accustomed way of living with being-at-risk, does not easily transform into actionable knowledge.

The GeneRISK project exemplifies a worldwide tendency to experiment with and promote predictive personalized medicine embedded in high-tech biomedicine and appropriation of large depositories of medical data (Hogle 2016; Hoeyer 2016; Tarkkala et al. 2019). Social scientific studies on genomic and other forms of predictive medicine have emphasized the key role of risk reasoning and tried to define and characterize the subject at risk in the context of such medicine. Our study contributes to this discussion with analysis of contextualised narrative meaning-making that makes risk scores either intelligible or disturbing information to people. Our analysis also sheds light on the pressing question of why individuals do not change their lifestyles after receiving genetic risk information about common multifactorial diseases. It seems that when people translate the CVD risk scores into information that makes sense to them and their lives – by the means of narrative meaning-making – genetic risk information tends to become unactionable as regards to personal health promotion. Information on genetic health risks does not have enough incentive power unless it is domesticated in people's experiences and existing knowledge of their personal health by practical means of, for example, lifestyle coaching or personal follow-ups.

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The authors of this article declare no competing interests.

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