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Narrative Accounts of Hereditary Risk: Knowledge About Family History, Lay Theories of Disease, and "Internal" and "External" Causation

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In this study, the authors sought to examine how risk information is articulated in relation to health problems that people identify as personally important and relevant. The respondents were receptive to health education messages, using different types of information in relation to its personal relevance and as a resource for managing and exercising control over perceived risk. People were not fatalistic about disease risk, as reported in previous research. Instead, they were responsive to complex public health messages and actively engaged in rationalizing their health risks, although this did not necessarily result in behavioral change. Consequently, a theoretical distinction exists between taking responsibility for evaluating complex public health messages and taking responsibility for behavioral change. The authors conclude that people's rationalizations about health risks often mirror the medical model of disease, suggesting that they are responsive to, and not fatalistic toward, such public health information.

Keywords: *genetics, family history, narrative, risk perceptions, heuristics*

Although the main impetus of recent sociological research has been the perceptions of hereditary risk among people with a range of diseases, such as Huntingdon's disease, it is less clear how people use information in relation to health conditions that they consider to be of greatest importance (Green, Richards, & Murton, 1997; Hallowell, 1998; Kenen, Ardern-Jones, & Eeles, 2003b, 2004; Marteau, 1999; McAllister, 1998; Weinstein, Atwood, & Puleo, 2004). The emphasis on studying the role of hereditary risk information in relation to conditions such as cancer has possibly detracted attention from a broader range of health problems (Lim, Macluran, Price, Bennett, & Butow, 2004; Lynch, Lemon, & Durham, 1997; Metcalfe & Narod, 2002; Miesfeldt, Jones, & Cohn, 2000; Ponder & Green, 1996). In this article, we report findings from an exploratory qualitative interview study with a sample of individuals from the general population to show how they conceptualized disease risk in relation to health conditions that had most personal meaning. We illustrate the importance of heuristics, or "cognitive shortcuts," in explaining risk perceptions. The analysis focuses to a large extent on the role of the availability and the representativeness heuristics, as these were the most striking themes to emerge from the data.

Tversky and Kahneman (1981) referred to the availability heuristic in relation to the process by which people make decisions based on the availability of specific health-related information. People might refer to information that is readily available to them, which might entail identifying family myths about disease or hereditary patterns and tendencies in a family. In a similar vein, Kenen, Ardern-Jones, and Eeles (2003a) suggested that lay understanding of heredity can also be shaped by fragmented accounts of family

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history, which can lead to misconceptions about hereditary risk. Information about certain familial illnesses might be withheld from certain relatives and communicated to others. For example, McAllister (2003) reported a relationship between gender and engagement status, whereby women talked about, and engaged with, their cancer risk more than men, who were often excluded from such discussions (McAllister 1998; Kenen et al., 2004).

The ease with which people are able to recall information about certain life events often plays a pivotal role in shaping their understanding of risk (Marteau, 1999). For instance, dramatic or painful instances in a person's family history might often be recalled more readily than less dramatic ones. Tversky and Kahneman (1989) have shown that people are often biased in their evaluations because, unsurprisingly, they tend to assess information in relation to the recall of one key event, such as the death of a relative from cancer, rather than the complete information relating to the instance that they recall. It should also be acknowledged that people might sometimes forget about important events in their lives. Van de Mheen, Stronks, and Looman (1998) found that people are frequently prone to recall bias, which is associated not necessarily with memory loss or older age but with the interference of other types of information possessed by individuals. People also make decisions on the basis of emotional and idiosyncratic factors, which might appear objectively to be irrational from a scientific view point but which usually have a logic that often makes rational sense within the social context of a person's life (Cox & Mckellin, 1999; Metcalfe & Narod, 2002; Richards, 1997; Watson, Lloyd, & Davidson, 1999; Wroe, Salkovskis, & Rimes, 1998).

Kenen et al. (2003a) illustrated the active employment of heuristics among women when making sense of their hereditary risk of breast and ovarian cancer. They referred to the concept of representativeness, whereby respondents used information relating to an illness episode that was thought to be representative of similar episodes in the same category. Therefore, for instance, some women perceived a greater genetic risk of inheriting breast cancer because a close relative had died from the disease in the past. This pattern has been reported in relation to women's preferences for treatment in breast cancer (Charles, Redko, Whelan, Gafni, & Reyno, 1998). Kenen et al. (2003a) also reported "illusions of control" (p. 855) by some respondents, which involved their constructing personal theories about disease risk prevention that were unrealistic or false. In this case, some individuals thought that a genetic mutation might be reversible through the employment of health-enhancing behavior.

In this article, we report our analysis of qualitative interviews with members of the general public, to examine how people rationalize risk in relation to health problems that have greatest personal meaning and relevance. We will explore this issue to illustrate how personal "control" over risk information and mixed public health messages shape people's conceptions of disease risk.

Method

Sample

We conducted this exploratory study to examine how a small cross-section of the community perceived the concept of inheritance and hereditary risk in relation to health problems that they identified as particularly important. The rationale for undertaking the study was to focus on the condition or conditions that had the most meaning for the respondents and to explore the impact that hereditary risk had on their lives. A sample of 40 respondents was identified from four general practices, 10 people from each practice. To obtain a representative set of perspectives, respondents were selected from a mixture of economically deprived and more affluent areas. In total, 16 people agreed to participate in an interview.

Out of the 40 people contacted from general practitioners' (GP) lists, 22 refused to take part without giving a reason, 1 person lived too far away to be interviewed, and 1 had a parent with cancer and did not want to pursue the subject further. We anticipated that the reason for the 45% response rate was related to the sensitive nature of the subject matter, which many people would potentially find difficult to discuss, especially if they had close relatives with chronic or life-threatening health problems. The distribution of demographic characteristics of the nonresponders, in relation to attributes such as age, sex, and socioeconomic status, was similar to that of the responders. As mentioned above, this was a small exploratory investigation from which it was not possible to generalize to the wider population, and therefore we urge caution as to the generalizability of the themes beyond our immediate study population. However, as with most qualitative studies, our intention was to make some preliminary inferences from the data and to develop a number of key theoretical insights that might contribute to the existing literature.

Ethical approval was granted from a local research ethics committee (LREC) prior to commencement of the study.

Data Collection and Analysis

Semistructured qualitative interviews provided an opportunity to probe deeply and open up areas of interest to the informants (Glaser & Strauss, 1967), who were encouraged to discuss any aspect of their family medical history. We also considered the possibility that the interviews could give rise to issues that respondents might find worrying or that might suggest an increased risk of certain health problems. To minimize the potential for this, participants were encouraged to raise topics that they considered most important, and the discussions were conducted in a way as to limit the implication of hereditary risk. Consequently, respondents were probed only about the possibility of inheriting certain illnesses in cases where they had already raised the issue and agreed to discuss the topic further. The GPs of each participant were informed of the research, so that they could discuss any concerns raised in the interview, and we offered all participants the opportunity to discuss any matters that concerned them with a consultant clinical geneticist who was attached to our study. None of our respondents opted to contact the geneticist. Most interviews lasted approximately an hour.

The interviews were transcribed in full, coded using a coding frame, classified according to the emerging themes, and analyzed systematically using the constant comparison method (Becker & Geer, 1984; Glaser & Strauss, 1967; Ritchie & Spencer, 1994). The findings and descriptive accounts were discussed during regular meetings with members of the research team, where themes were cross-validated and checked for consistency and credibility. Pseudonyms have been used to hide the identity of the informants, and interview quotes were chosen because they were representative of the themes as a whole. Also, several quotes from the same respondents are presented in the article to illustrate the evolving nature of views and to provide an ongoing story line.

Findings

Weighing up Hereditary Risk: The Role of Family Illness History

It has been reported that people tend to remember dramatic and painful events most vividly, such as bereavement in the family or a diagnosis of a serious illness. Kenen et al. (2003a) reported that women with a family history of breast/ovarian cancer were likely to rely on feelings of gain and loss rather than statistical probability when making lifestyle choices. Similarly, our analysis has revealed that the extent of knowledge about a family history of disease played a pivotal role in shaping people's views about inheritance and the particular health problems that they could develop. The following 48-year-old woman thought that she had an increased chance of inheriting breast cancer due to a significant past history of the disease on the paternal side of her family.

> *Brenda:* Well, I think things like breast cancer perhaps would be more likely to run in families possibly.
> *Interviewer:* Right, why do you think that?
> *Brenda:* It's a twofold approach. One is having read about it. But the other, because on my father's side, his mother was one of many girls and all of them in turn died of breast cancer. Now, we're going back a few years before surgery was what it is today and I know that my grandmother was petrified that she was going to be the same and also obviously my aunt, her daughter, because not only did her sisters die but quite a number of their female children also developed breast cancer. I was growing up at the time and obviously that nervousness passed onto me because I started to think "well, I am part of this family, hang on a minute you know, is it going to come down to me?"

She thought that her risk was nevertheless limited, because neither of her parents developed the disease, which, from a medical perspective, is an accurate reflection of her hereditary risk. The presence of two or more first-degree relatives increases the risk of inheriting the breast cancer mutation, but the risk is not as great if only second- or third-degree relatives are affected.

> *Brenda:* Being as neither of my parents ever developed cancer, you know, it sort of to me, there's a nice break there so if anything happened to any one of us, it's perhaps going to start it again (the "chain reaction") if you like.

However, she revealed a much stronger conviction in the genetic basis of migraines, which had affected several first-degree relatives in her family, indicating a raised genetic risk.

> *Interviewer:* What makes you say they [migraines] run in the family?
> *Brenda:* Well because my father had them, his sister had them, I had them, my brother had them, and my daughter actually has got them now.

Interviewer: Right, do you think that's related to lifestyle, sharing the same environment . . . ?
Brenda: No. I think that's genetic because my father and I initially were out in Brazil, so lifestyle was very different there to what it is here.

Brenda's reference to the genetic basis of migraines in her family provides an interesting contrast with her views about the hereditary tendency to breast cancer, which she believed was weaker, as there was a "break" in the genetic chain of events as characterized by the fact that her parents had not developed the disease. However, living in Brazil with her father from a young age suggested that environmental factors could not explain the high prevalence of migraines among most members of her family. Moreover, the heuristic adopted in relation to migraines was informed by representativeness, or the large number of cases known to Brenda in the family. In this case, perceived hereditary risk was weighed up with reference to the prevalence of both conditions in the family.

The following 44-year-old female respondent claimed that there was a family predisposition toward "mental" illness. However, there was also a family history of lung cancer, which she attributed to environmental causes, signifying a limited risk.

Interviewer: Are there reasons why you don't think genetics is involved in lung cancer?
Vivian: Well, only because of what I've read basically, that mostly you know, lung cancer is mostly caused by smoking, and that's basically it I think, I've just read about it and all that you hear in the press and everything it's all about smoking isn't it.

There was a "natural" tendency in the family toward "mental" illness, of which all relatives were aware, and this seemed to pose a greater hereditary risk.

Vivian: Well, I've got a feeling that there are some types of mental illness that might have passed down in my family. *Hopefully I am not going to be affected* but types of depression and things like that, which both my mother and my mother's sister have had and I know that my grandfather had it as well.
Interviewer: A depressive illness?
Vivian: Yeah a depressive sort of illness yeah.
Interviewer: Is it something that you noticed yourself or is it something that's actually been diagnosed?
Vivian: No, it's just something that we've just sort of realised that there seems to be something there.

She continues:

Vivian: Well I suppose because of the mental problems that I was mentioning earlier on, I suppose I've got an awareness about that and a dread of it, and so I am looking for little signs that I'm about to go a bit do-lally-tap every now and again you know.

The presence of depression in the family exhibited an elusive status, because no one seemed to know for sure if it was "real." This was reinforced by the fact that the disorder had not been formally diagnosed. In this scenario, family stories can be passed down from previous generations, providing people with a fragmented or uncertain impression of their family illness history. Knowledge about the mental illness "in the family" was perceived as a potential cause for concern and, on the other hand, as only a "possible" risk rather than a "definite" risk because of its "elusive" nature. This is evident in Vivian's expression of hope that the mental illness would not affect her. Her interpretation of her genetic susceptibility to lung cancer and mental illness mirrors medical knowledge, in that the presence of several first-degree relatives with a particular condition is suggestive of an increased genetic risk. In addition, Vivian's interpretation of her lowered genetic risk of lung cancer was an accurate reflection of medical thinking, given the proven link between smoking and lung cancer.

The respondent in the following interview passage had a genetic condition, acquired from his paternal side, known as hyperlipidemia. Approximately half of all relatives on the paternal side of his family had acquired the disorder. Consequently, Mark accurately believed that he was also at a high risk of a heart attack.

Interviewer: Do you feel at risk of cancer at all, of inheriting it or developing it in some way?
Mark: It's not something I want to think about really, I am hoping . . . I've got enough worries about whether I am going to drop dead with a heart attack. No, you can't spend your life worrying about these things. But it's [cancer] not a specific problem in our family, possibly because we don't live long enough anyway. I mean, a lot of cancers appear late in life don't they?

He suggested that his genetic condition strongly influenced the way in which he now perceived the importance of genetics in explaining the pattern of disease.

Interviewer: Do you think that your views are shaped by your experience of hyperlipidaemia?

> *Mark:* Yes, yes. I think if it wasn't for the fact that I've been found to have this defect, which is being treated and all the rest of it, I would have looked back on father's heart attack as just, you know, he was unlucky or he ate too much saturated fat or whatever. . . . In my case with this particular problem when I was first diagnosed as having high cholesterol, your first reaction is right I am going to sort this out with my diet. So I tried every diet in the book, eating oat bran muffins for months on end, cardboard and cutting out all red meat and all the rest of it. And they found at the end of several months that my cholesterol had actually risen slightly. So it was doing no good at all. So that was one piece of evidence that I have that environmental things you would try to influence it are of less significance than what your [genetic] predisposition is.

Mark attempted unsuccessfully to control his high cholesterol through lifestyle changes, and his example illustrates how knowledge is sometimes used instrumentally (through testing various theories) rather than acquired passively in the construction of risk. His diagnosis shaped his view that genetics can play a dominant part in explaining the onset of disease. Consequently, Mark's knowledge of his condition, a consequence of his clinical diagnosis, enabled him to conclude accurately that he was at an increased risk of a heart attack, which also led him to reject the possibility that lifestyle changes could reduce its risk.

Others made similar rationalizations in relation to genetic risk, even though environmental factors might have provided equally plausible explanations. A strong family history of "back problems" signaled a hereditary tendency in one respondent's family.

> *Andy:* As far as, you know, all the family that I've known especially from say, my father's side I would say 75, 80% of them have always had trouble with their backs. On my mother's side, I couldn't really tell you that much about it because again the family was a lot smaller and as I say, my mother died early and I think most of her family died early but there was no known problem of backs or any other illness that we knew of at the time.

Two respondents in the study were adopted at a young age and, consequently, had no knowledge of their biological family history. Their constructions of disease risk were influenced primarily by lifestyle and environmental factors, which seemed to offer more control over their lives than genetics, as the following 58-year-old woman claims.

> *Maggie:* I am a believer that most behaviour for example is learned rather than inherited. That's probably because I am adopted and that's the way. . . . I also don't think it's fair to dump on somebody "oh well that's the way your father behaved so that's why you're behaving like this." It's more learned than inherited.

Barbara, who was 42 years old, also claimed that having no knowledge of her biological family history diminished her perceived risk of inheriting breast cancer.

> Not knowing that anyone in the family has it, you don't feel at quite that same risk of getting breast cancer. If I knew that various people had it in the family, I think that my anxiety would be heightened.

Personal Theories of Inheritance

Informants often used information about genetic risk with reference to highly personalized theories, which extended beyond the immediate context of their family medical histories to encompass issues relating to their knowledge about friends with chronic disease or aspects to do with their personal understanding of lifestyle and environmental factors (in contrast to genetics). For instance, the significance that people attached to certain types of information was frequently related to the context in which they obtained it.

> *Jill:* I think of heart disease as being much more of a risk, external risk factor than I do of a genetic problem.
> *Interviewer:* Why do you say that?
> *Jill:* Because of the people I have known with heart disease of one sort or another, there's nearly always been a way of linking cause and effect.

People often associated various health conditions with the specific lifestyle that was adopted by the individual concerned, so a heart attack was often thought to be a consequence of an unhealthy diet or a lack of exercise.

Derek and Duncan viewed cancer and heart disease as having a potentially hereditary basis because of the way in which they have been represented in the mass media and through public health messages.

> *Derek:* Well I don't know, I mean like, it seems that certainly in females, you know, the breast cancer bit seems to be a little bit hereditary . . . I think the medical profession seem to worry more about people that have had close relations, relatives with the same complaints yes.

Duncan, however, believed that heart disease was genetic due to the strong emphasis that insurance companies often place on cardiovascular problems when recording personal medical information. A strong family history of heart disease would quite correctly indicate a raised genetic risk.

> *Duncan:* I think it's because it's the one question that you always get asked on questionnaires "has your family had, have your parents, has anyone in your family died of heart disease?" You tend to get that question more often, you know, filling in insurance forms or life insurance policies rather than "has anyone had cancer in your family?"
> *Interviewer:* Right. Why do you think they ask you those kinds of questions about heart disease more than any other?
> *Duncan:* Presumably they think it's, you know, genetics has a fairly strong bearing on the issue.

Other informants referred to the influence of aging in explaining the causes of certain diseases.

> *Neil:* Something they say that, you know, I am reaching an age now where say for example prostate trouble may be a problem, you know, and this sort of thing. Well that's very common amongst males. As far as I am aware there's nobody in my family ever suffered with it so there's no real reason why I should be any worse than Joe public out there. It's not morbid but I must admit you do occasionally think, and I've reached a stage where you get the odd twinge or you feel rough for a couple of days and you start to think "my God" is it something serious or isn't it? It certainly focuses the mind a little bit the older you get.

Neil's belief that "older" men were more at risk of prostate cancer mirrored current medical thinking, especially if there had been a family history. Brenda, however, believed that the general public is more aware of breast cancer, which has made women more vigilant about the early signs of the disease, but it has also enabled them to seek medical advice when needed. This suggests that lay knowledge about risk is formed through exposure to certain conditions, sometimes at the expense of others, which receive less public attention.

> *Brenda:* I suppose being a woman, one tends to think that one's more likely to get breast cancer or maybe cancer of the cervix and you tend not to think so much about the other cancers but in reality we're as prone to any of the others . . . and I think it actually makes it easier perhaps for people who get breast lumps to go and do something about it rather than perhaps when people left it for a long time before they went because they really weren't quite sure what it was. So they're more aware to go and seek some advice earlier.

Many respondents in this study did not report having an immediate family history of cancer or heart disease, and their inclination to ascribe a genetic cause could be viewed as a means of distancing from the possibility of developing the condition(s). They might have found it more comfortable to assign a hereditary cause to cancer or heart disease, as there was no need to feel threatened in their particular case.

The selective use of information can be defined as a process by which people use certain types of knowledge or information in favor of different types of knowledge to help rationalize complex health issues. The process of "counting" relatives who have been affected by a life-threatening condition was another heuristic that was used and that influenced perceptions of risk. This process of evaluating risk reflected the medical model, which is based on the scientifically proven idea that the presence of several close relatives with a particular health problem often indicates an increased risk.

> *Neil:* If it's one [with cancer] I mean it's like my brothers and sisters, seven of us in all, counting my parents in the family. If one of us died of a certain cancer I wouldn't be that concerned for myself, but if it was three or four of my family out of seven who died of the same illness I would be worried then . . . If one of us died through [heart disease] I wouldn't be quite so concerned to be honest.
> *Jane:* It depends what happens within your family isn't it? We've only had really one incident of cancer within a large family, so you think your chances are, well, you hope your chances are less really because there's more of us that haven't had it than have had it.

The task of assessing disease risk was highly subjective in terms of the factors that any individual chose to consider in the first place. Several respondents, for instance, claimed that perceptions of genetic risk were often mediated by factors such as family size, in which respondents attributed a low risk of inheriting cancer when only a small number of members were affected within the context of a "large" family. The above quotations illustrate how family size could have a buffering effect on perceived risk.

In the following excerpts, Jane (age 38) specified lifestyle and age as possible reasons for the high

prevalence of cancer in her mother's family, whereas she seemed to be playing down her hereditary risk in favor of a nonhereditary explanation.

> *Jane:* My grandmother died of cancer of the gut and so did all of her brothers and sisters. There seems to be a *weakness* in the gut in my mother's family. *But they were all heavy smokers as well.*

She continues:

> *Jane:* All of her [grandmother's] siblings died of cancer. *But they were all in their seventies* I think. I think if it was sort of early, if it was fifties I'd be more worried.

Jane's assessment of her genetic predisposition to "cancer of the gut" indicates that her perceived risk was negligible, given the importance that she attributed to lifestyle, aging, and the absence of first-degree relatives with the disease. Furthermore, her belief that the genetic risk would increase if one of her relatives had died of the illness in his or her 50s was a scientifically accurate description reflecting her awareness of current medical thinking.

Respondents also claimed that strong physical similarities or differences between relatives influenced their perception of genetic susceptibility to various conditions. Timothy (age 55), in the following narrative, for instance, claimed that both his father and his sister died of the same type of cancer. Consequently, he thought that his sister had inherited the disease from her father, a view that was influenced by their apparent physical similarities. The example illustrates how certain physical characteristics were used quite selectively to demonstrate a certain narrative and seemed to make rational sense to our respondents, even though such comparisons do not always have a clear scientific basis.

> *Timothy:* Well they both looked very similar and also, like I say, they both died of cancer, presumably in the stomach, and both diabetic. You know, so there is sort of two links there straight away. Plus the looks and the features, eye colouring, fair skin, you know.

Similarly, several respondents associated raised risk perceptions with the physical "suffering" or "pain" experienced by a close relative. The following respondent's father was diagnosed with Parkinson's disease (PD), although he died when she was young and her memories of his illness were vague. Her mother, however, had rheumatoid arthritis (RA), which caused her severe pain, and Catherine (64) can still remember her mother's suffering, which subsequently had a significant emotional impact on her perception and understanding of the condition. She consequently typified it as more relevant to her experience. During the interview, when asked to discuss both conditions, she attached more importance to her mother's RA and believed that she might inherit the same illness.

> I suppose of the two, the one that concerns me the most is the Rheumatoid Arthritis. I mean I don't go around sort of thinking; oh I am going to get Parkinson's disease and live in fear of it and everything . . . I have warned both my children of the factor. But as I say I'd have to say with Rheumatoid Arthritis it does concern me more because of the pain and suffering that my mother was in.

Internal and External Causes

In search of greater certainty about their risk status, respondents frequently drew on a combination of factors relating to lifestyle (external) and family medical history (internal). Many respondents articulated theories about their genetic status with regard to cancer and heart disease but often placed a stronger emphasis on the role of lifestyle as a means of asserting greater control over the uncertainty surrounding their perceived risk. The following respondent with a family history of colon cancer and illnesses of the "gut," as described above, attributed significance to both genetic and lifestyle factors.

> *Jane:* I am at mid risk I would say, probably because I smoke, every year for a certain amount of months. I seem to be better than I used to be, but because of that like I've got [a higher chance]. There's a cause because my grandmother's family all died of cancer or they seemed to and I think I've probably caught a chance, 25% chance of dying of cancer myself. I do think that.

She also employed the genetic and lifestyle explanation to rationalize her husband's risk of heart disease.

> *Jane:* Like *my husband's father died of a heart attack*, so I recently started to say to him—I mean he's only 37—but I did say to him that as soon as he's 40 he should start having routine tests for heart disease, which I think is important.
> *Interviewer:* Why 40?
> *Jane:* Don't know. He has a very *stressful job* as well and I think that was when those problems started with his father. He had a complete by-pass at 55 I think, which is quite young.

The following respondent also illustrates how knowledge of family medical history led him to develop a belief that he was at an increased risk of heart disease.

> *Neil:* I've lost my father [to heart disease] so that tends to focus the mind a little bit and makes you stop and think about where you're going yourself, and what you know and what you can do to influence it. Yes, I need to lose weight and yes, I am going to do something about it. But I am basically fairly fit, I am very rarely ill, as my mother will tell you, I get the odd cough or cold.

Although there was a strong history of heart problems in the family, indicating a genetic tendency, Neil believed that a healthy lifestyle could nevertheless have a positive effect on reducing the risk of heart disease, as the following interview excerpt illustrates.

> My friend is two years younger than me and had major heart surgery in his 40s, nearly 10 years ago, and we led fairly similar lifestyles over a number of years. . . . I was always a lot fitter than him. He smoked right up until he had his heart attack, although I gave up 20 odd years ago and I am convinced that if I'd continued I'd perhaps be in the same state as he is. . . . If you accept that lifestyle can be an influencing factor, then perhaps there's an opportunity to change your lifestyle and perhaps decrease your odds of developing a particular disease.

Neil's risk perceptions were influenced by knowledge (availability heuristic) about his family history of heart disease, as well as by a competing belief system (lifestyle), which provided some personal control over his risk of heart disease. Neil's reference to lifestyle factors indicated that people have a personal responsibility to avoid ill health, which he illustrated by contrasting his own risk with that of his colleague who had suffered a heart attack.

Discussion

Our respondents were aware of the various risks to health, but they did not indicate that they also wanted to change their behavior accordingly. Some authors have referred to this observation as the prevention paradox, possibly resulting from fatalistic attitudes (Davison, Davey-Smith, & Frankel, 1991). Indeed, the perceived dominance of the genetic explanation might be expected to result in increased public ambivalence toward health risks. Our findings, however, show that this was not the case. Instead, our respondents actively evaluated the main risks to health in relation to a wide range of factors, not only genetics, demonstrating a good understanding of the dominant public health messages about advances in genetics and the role of lifestyle. Despite their awareness, nonetheless, people seemed reluctant to change their behavior in response to the competing public health messages, because these often failed to offer conclusive answers to questions about health risks. The tendency to evaluate risk information in a more balanced way that does not prioritize genetics over lifestyle, and vice versa, might help to explain the previously reported reluctance of the public (Blaxter, 1983, 1990) to change their illness behavior, even when perfectly aware of the risks for certain health problems. Even though genetics might have become a dominant discourse in the scientific community in explaining the pattern of disease, it has not necessarily become so for our respondents: As one of our respondents claimed, "Genetics does not answer everything."

A common strategy adopted was to play down the perceived risk for certain potentially hereditary health problems, especially if they were life-threatening conditions, such as cancer and heart disease. Such a strategy might be dubbed diffusion. Although respondents recognized the genetic basis of disease, they frequently balanced it against the possible environmental influences. This enabled them to exercise some control over the inevitability of disease and the uncertainty frequently generated by public health campaigns. Contrary to Macintyre's (1995) contention that the geneticization of health and illness will lead to fatalistic attitudes about disease causation, our respondents demonstrated a strong desire to assert some personal control over the often ambiguous public health messages through active evaluations of the information. Jane's (above) contention, for instance, that bowel disease was prevalent on the maternal side of her family, indicating a genetic risk, was diffused with the suggestion that nongenetic factors, such as smoking and aging, could also account for the causes of disease. To this extent, respondents used information selectively as means of neutralizing personal health risks. Recent research findings on issues such as coronary candidacy concur with our results. These studies, for instance, highlight a similar tendency for people to weigh up the lifestyle risks

to health against the potential genetic risk factors in an attempt to establish an understanding of their predisposition toward heart disease (Backett & Davison, 1995; Davison et al., 1991).

The question of responsibility for personal health has been identified in past research (Blaxter, 1990; Hallowell 1998), often invoked by the large volume of public health education messages encouraging individual accountability for maintaining a healthy lifestyle. Our interviews, however, suggest that respondents were less concerned about exercising responsibility over their own health than over the public health messages, which often gave rise to confusion and uncertainty about the "right" recipe for a healthy lifestyle. The views expressed had a strong resonance with current biomedical knowledge, particularly in how people correctly identified the illnesses that are believed to have a strong genetic basis, as well as those that are not. This suggests that the public is receptive to public health information about disease prevention and is prepared to examine the pros and cons of alternative theories of disease causation.

Our respondents attempted to engage with these public health messages using different strategies, which involved weighing up risks in relation to their family illness history, using personal theories of inheritance, and through their knowledge of internal and external disease processes. All of these strategies entailed a proactive and instrumental approach to the evaluation of information, which was frequently tested for its personal relevance. The task of testing whether they might be at risk of developing lung cancer, for instance, was assessed in relation to both the relative risk of a positive family history and the environmental impact. In a similar vein to our findings, Lambert and Rose (1996) have shown that clinical knowledge becomes relevant to people only once they have been able to test out the various theories of disease in relation to personal experiences of health and illness, as in the example of Mark, above. In other words, scientific knowledge that does not have personal relevance might be viewed as disembodied or abstract knowledge without personal meaning, and therefore might be less likely to affect subsequent behavioral change. This observation is supported by other studies that have emphasized the importance of the social and cultural origin of people's risk perceptions (Davison et al., 1991; Kenen et al., 2003a).

A number of past research studies have paid attention to lay misrepresentations of disease risk, focusing on how such rationalizations differed from the biomedical model. Most illustrate the important impact of social and cultural influences on people's risk perceptions and health behaviors, which often stand in contrast to the biomedical model. Van De Mheen et al. (1998) showed how people are prone to recall bias, giving them an inaccurate view of disease risk. Others, such as Kenen et al. (2003a), have shown that people's understanding of hereditary risk is misconceived because of illusions of control over their perceived risk or because they possess fragmented accounts of their family medical history. In contrast, we found that although our respondents used heuristics, their risk evaluations seemed to illustrate a good grasp of the mixed health messages to which they have been exposed, in many respects reflecting quite accurately the medical model of disease. This could be due to the fact that they identified the health problems that affected them or their relatives directly, rather than high-profile diseases such as cancer and heart disease, and, consequently, about which they possibly had better knowledge and understanding. Mark's diagnosis of hyperlipidemia offered him the opportunity to access information about the disease from his interactions with the health care system and affected relatives, providing him with a more clinically accurate view of his condition. Others were able to obtain more scientifically accurate perspectives on certain health problems by reading books and magazine articles on the subject, through personal experiences of the health care system, or through direct contact with health professionals. Consequently, the selective means of rationalizing complex information about health risks was used alongside a scientifically more objective stance.

Conclusion

In conclusion, the public often have to contend with complex, and often contradictory, information regarding the onset of disease. The current social expectation to be informed about health issues, and the need to prevent illness, might explain why they deployed a range of strategies to rationalize complex health-related information. However, what such rationalizations also revealed was the confusion and uncertainty people expressed when attempting to reconcile the competing influences, particularly of genetics and the environment. Respondents grappled with such dilemmas by attaching different weights to genetics and to environmental causes, in the

context of their specific family histories, illness beliefs, and social circumstances. The picture that this paints is one of increasing uncertainty about disease causality but that also suggests a belief that health risk can sometimes be controlled. The competing discourses of genetics and the environment to which the public is frequently exposed require that individuals exercise a degree of discretion (or selectivity) in making sense of such complexity. As our study has indicated, the public are not passive consumers of health education messages but active participants in their interpretation and social construction.

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