findings

From The Health Variations Programme

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

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'It's a family affair'. Lay understandings of a 'family history' of heart disease

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- Coronary heart disease (CHD) is a major cause of ill health and premature death, and accounts for much of the inequalities in mortality by class and gender. Recent evidence suggests that targets set in the early 1990s for improvements in coronary-relevant behaviours, particularly smoking, are unlikely to be met, and that class differences in CHD and smoking are increasing.

- Current government policy is directed towards improving the health of the nation, and of those in poorest health in particular. Reduction of CHD is a major target for public health.

- People's decisions about behaviours like smoking, which affect the risk of CHD, are complex and take account of many aspects of their lives, including knowledge about the lives and health experiences of family members.

- In this study, people's ideas about their 'family histories' of heart disease and health-related behaviours were investigated using in-depth interviews with 61 men and women from a range of social circumstances.

- The study confirms that some people see themselves as definitely 'having' or 'not having' a family history of heart problems. However, it also highlights that others, and in particular men from less affluent backgrounds, are ambivalent.

- Many people drew a distinction between notions of 'family risk' for their family as a whole and for themselves personally. Some people who thought that heart disease 'ran' in their family did not feel at increased personal risk themselves because they thought that they differed in crucial ways from affected family members.

- This study shows that lay people (as well as the medical profession) tend to think of heart disease as a 'male' disease. As a result, CHD signs, symptoms and risk factors may be underplayed among women.

- The study identified two common cultural notions which undermine coronary prevention advice: the image of heart disease as a 'good way to go'; and the perception that past health-damaging exposures (including family history, childhood circumstances, past working experiences, history of exposure to smoking and past diet) left a legacy which could not be undone by making positive lifestyle changes. It confirmed that lay notions of 'coronary candidacy' (the sorts of people who are most and least likely to get CHD) are widespread, but the lack of certainty in predicting coronary events at an individual level is another barrier to behavioural change.

- This study shows that lay and medical views about which factors determine whether someone is at heightened risk of heart disease because of a family history overlap but do not fully coincide.

- Our findings suggest that it is important for doctors to establish the extent to which they and their patients share a common understanding of the patient's familial risk if they wish to offer effective health promotion. Health promotion messages should acknowledge common 'barriers' to change. Our research on lay beliefs about inheritance will be increasingly relevant for health policy makers and practitioners, with developments in genetic testing for multifactorial diseases.

Background

Coronary heart disease (CHD) accounts for around a quarter of deaths in the UK. While coronary death rates are declining in general, the gap between those in manual and non-manual occupational groups is widening. Socio-economic disadvantage is associated with a higher risk of having a heart attack and a lower chance of reaching hospital alive. Men have higher rates of CHD than women at all ages, but CHD is the major cause of death amongst women as well as men. The government has recently stated that reducing the impact of CHD on people is a priority and have also pledged to reduce inequalities in risks of developing heart disease.

Health-related behaviours are known to affect the risk of CHD, but the exclusive emphasis on personal responsibility for changing to a more healthy 'lifestyle' has been criticised for being too simplistic. Decisions about behaviours like smoking are complex and take account of many factors, including knowledge about the lives and health experiences of family members. The aim of this project was to examine people's ideas about their 'family histories' of heart disease and explore whether these influenced their decisions about health-related behaviours.

Data and methods

We conducted in-depth interviews with 61 people in their forties, living in the West of Scotland. It was important to interview both men and women, as well as talking to people in manual and non-manual occupational groups. Interviews covered a wide range of areas, including beliefs about heart disease, discussions of whether illnesses or weaknesses 'ran' in the family, and discussion about inheritance.

Findings

The importance of heredity in people's perception of heart problems

This study confirms the importance that heredity has in lay notions of the causes of heart problems. Genes, or heredity, were mentioned spontaneously as a cause of heart problems by more than two thirds of the people in this study, and almost all agreed that heredity was an important factor when asked specifically about it later in the interview. Nearly everyone was also well aware of the health promotion advice about the dangers of smoking, a fatty diet and lack of exercise.

Table 1: Factors which influenced whether people thought that heart problems "ran" in their family

Factor	Example
Extent of knowledge about the health of family members	Some people had lost touch with one 'side' of their family, and because of this lack of information, found it difficult to judge whether heart problems 'ran' in the family
The number of relatives who had heart problems	One distant relative with heart problems could be put down to chance, but a larger number, particularly on one side of the family, often provided evidence for a 'family' history' of heart problems
Which relatives had heart problems	Illness, or death, of a parent from heart problems was treated as much more salient than heart problems in other family members
The age of relatives with heart problems	The premature death of a parent in their fifties from heart disease was given much more weight than death in older age
Gender and class background	Men, particularly men in manual jobs, often required more affected relatives than women before considering that heart problems 'ran' in their family

Deciding whether heart problems 'run' in the family

Table 1 shows the main things people considered when assessing whether or not heart problems 'ran' in their family. While some people saw themselves as definitely 'having' or 'not having' a family history of heart problems, others (in particular men in manual socio-economic groups) were much more ambivalent. These people tended to revise their opinions as they reviewed the evidence for and against heart problems 'running' in their family. Thus, perceptions are not necessarily static, and can change with ongoing family and personal health events.

Separating personal and family risk

People often made a distinction between inherited risk within their family as a whole and for themselves personally. Some people believed that, while heart problems ran in their family, they themselves were not at any greater risk, as they did not 'take after' affected family members in crucial ways (for example, in appearance, build, or health-related behaviours). Thus, believing that heart disease 'ran' in the family was *not* automatically translated into a belief that they themselves were at higher risk.

The image of CHD as a 'male' disease

People's accounts of those who were both likely and unlikely 'candidates' for heart problems all centred on men. Only when specifically asked about particular relatives, did people talk about women with heart problems. While accounts about male 'victims' focused on sudden, fatal heart attacks, accounts about female 'victims' usually concentrated on long-term illness caused by heart problems. This suggests that CHD is implicitly perceived as a male disease by lay people.

Barriers to behavioural change

People who believe that heart problems 'run' in their family do not necessarily think they should be particularly careful about health-related behaviours (such as smoking) which are known to increase the risk of heart disease. Some think there is little point in taking care if they are at increased risk anyway. This study confirms that the lack of certainty in predicting coronary events at an individual level acts as a barrier to behaviour change. New barriers identified by our study include:-

- "A good way to go?" One powerful image that recurred when people were weighing up their decisions about health-related behaviours was of CHD as a 'good way to go'. This was often seen as preferable to a painful and lingering death, typically from cancer. Most descriptions of heart disease described fatal heart attacks, with graphic accounts that emphasised the suddenness and quickness of death. Very few accounts referred to the pain, disability or restrictions of living with heart disease.

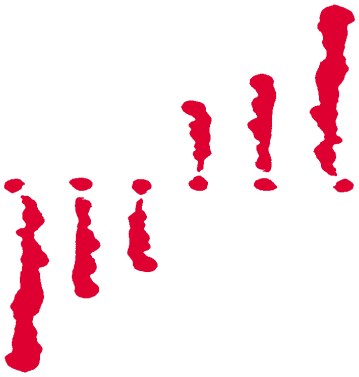
- "Past legacies" Some people identified a number of 'legacies' from their past which they felt could not be undone. Their family history, past exposure to tobacco smoke and particularly past diet were commonly mentioned. Some people from poorer backgrounds made explicit links between diet and wealth, or social class. Thus, some people felt that positive changes now - improving their diet for example, or giving up smoking - were not sufficient to counteract past experience and exposures.

Policy implications

In general, our need for information about lay understandings of inheritance is more pressing as the possibility of genetic testing for susceptibility to common chronic diseases becomes more likely. This research has specific implications for doctors and health promotion professionals.

If doctors wish to offer effective health advice, it is vital that they establish whether they and their patients share a similar understanding of familial risk. In addition, they need to be aware that patients do not necessarily translate an increased family risk into an increased personal risk; for people in this study, the perception of heightened personal risk depended not only on recognition that heart problems 'ran' in the family, but also on the degree of personal resemblance to particular family members or 'sides' of families.

In addition, our research has implications for health promotion experts as it highlights some specific ways in which coronary advice can be discounted or undermined. Interventions need to address the perception that heart disease is a "male" disease and that a heart attack is often seen as a "good way to go". Finally, the idea that past "legacies" cannot be overcome with behavioural change needs to be tackled.



Disseminating our findings: "Real people talking about heart health"

We have worked with colleagues at the Health Promotion Department at Greater Glasgow Health Board to integrate these research findings into new health promotion material. A draft leaflet has been produced called "Real people talking about heart disease and heart health; making sense of the messages and moving forward". This uses quotations from our interviewees to draw attention to what 'real people' have to say about heart problems. The leaflet tries to take a new approach in acknowledging that lay people are knowledgeable about health and illness and in trying to address some of the cynicism that members of the public express about existing coronary health promotion. It acknowledges that health is not just dictated by 'lifestyle' and that we cannot predict exactly who will suffer from heart problems and who will not. It follows the trend of some more recent health promotion about the health benefits of exercise by emphasising the incremental benefits of small changes which can be more easily incorporated into people's lives.

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Selected papers drawn on for these Findings

Emslie, C., Hunt, K. and Watt, G. 'What constitutes a 'family history' of heart disease? A qualitative study of lay reasoning', *submitted to journal.*

Emslie, C., Hunt, K. and Watt, G. 'Invisible women? The importance of gender in lay beliefs about heart disease, *submitted to journal.*

Emslie, C., Hunt, K. and Watt, G. '"I'd rather go with a heart attack than drag on!" Lay images of heart disease', *to be submitted.*

Hunt, K., Emslie, C. and Watt, G. (in press), 'Barriers rooted in biography: how interpretations of family patterns of heart disease and early life experiences undermine behavioural change in mid-life' in H. Graham (ed), *Understanding Health Inequalities,* (in press) Buckingham : Open University Press.

Hunt, K., Davison, C., Emslie, C. and Ford, G. (2000), 'Are perceptions of family history of heart disease related to health-related attitudes and behaviour?' *Health Education Research: Theory and Practice,* 15 (2), 131-143.

Watt, G., McConnachie, A., Upton, M., Emslie, C. and Hunt, K. (in press), 'How accurately do adult sons and daughters report and perceive parental deaths from coronary disease?' *Journal of Epidemiology and Community Health.*

Information about Programme

The Health Variations Programme was established by the Economic and Social Research Council in 1996 to focus on the causes of health inequalities in Britain. Over the last two decades, Britain has got healthier and richer, but inequalities in health and income have increased. Death rates have fallen but mortality differences between social class I and V have widened; real incomes have risen but so has the proportion of the population living in poverty. The Programme aims to:

- advance understanding of the social processes which underlie and mediate socio-economic inequalities in health;
- advance the methodology of health inequalities research;
- contribute to the development of policy and practice to reduce the health gap between socio-economic groups.

There are 26 projects in the Programme, based in university departments and research units across the UK. The projects have been established in two phases: in 1996/7 and in 1998/9. They address questions at the cutting-edge of health inequalities research, including the influence of material and psycho-social factors across the lifecourse, the influence of gender and ethnicity and whether and how areas have an effect on the socio-economic gradient over and above the influence of individual socio-economic status. The potential contribution of policy, at national and local level, is also addressed.

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