



Lay interpretations of genetic risk factors and their impact

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Questions

- Do lay people perceive genetic risk factors as “special” and do they make them anxious?
- Does knowledge about genetic risk factors motivate behaviour change?



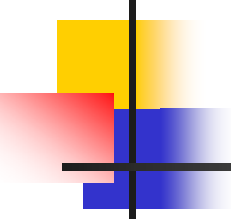
Projects

- Qualitative interviews (n=42) with patients, who had undergone testing for genetic susceptibility for deep vein thrombosis in mainstream medicine
- Videorecording of consultations between clinician and patient (n=23) on family history in the context of coronary heart disease (CHD) risk assessment, interview 2wks after
- Qualitative interviews with patients (n=38) at high risk of CHD 2wks and 6 mths after consultation on risk and lifestyle/medications with or without family history (nested within a randomised study of 800 participants) – on-going



Thrombophilia study

- Most patients did not perceive the genetic test as “special” even if it was genetic
 - *No, [being genetic did not make the test different]. I mean, obviously, **if it was a serious genetic disease** then of course I suppose it would have done. But no, to me it's **like**, you know, **testing for cholesterol** or testing for umm ... I don't know, **red blood cells** or whatever [P13thrombo].*
- Participants perceived DVTs as preventable and triggered by e.g. the Pill, HRT, pregnancy, travel
 - *I'm **fine unless** I'm **pregnant** [P28thrombo]*

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- Patients had typically stopped taking the Pill, HRT and taken precautions during flights and pregnancy but had not changed their lifestyle (diet, smoking)

- *PS Did [your doctor] tell you ... any other things that you should take into account?*

*I: Mmm, I think she mentioned something about flying in aeroplanes, but I don't fly in aeroplanes so. ... No, it was **mostly about the pill**. [P20thrombo]*

- Some (n=7) participants unaware of having had the genetic test, these individuals were older, sicker and less educated

- *I don't remember ever having had the test. ... But I **have had lots of blood tests**. But I've never known ... really what they were doing with it. [P15thrombo]*



Family history of heart disease

- Patients had a multifactorial understanding of family history of CHD, referring to shared, or not shared, genes, habits, social position and historical era
 - *I suddenly thought, gosh, there's an awful lot of heart disease. My **family were probably overweight** and there was still an **awful lot of sugar and fat involved in the cooking at that time** ... It's interesting to see if I can stop that turn of events, it's so easy to go down the generations and not be aware of what's behind you... I really want to try and stop the disease progressing ... **that's possibly your genes going to come down, and I was hoping they would get weaker and weaker as the generations go on [P01FHx01].***

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- High risk patients sometimes reported small changes to lifestyle, medications most significant change

- *Well, I've been doing **a few more walks** in evenings and weekends [P].*

- *R: So what would you say has been the main difference for you that [the assessment] made, if anything?*

- *I: I suppose **the introduction of Simvastatin** into my life. And that's obviously done a good job, anyhow, hasn't it? You know, it's **reduced my cholesterol down to 4** [P01FHx02].*

- Barriers to lifestyle change

- Self-understanding that one is living relatively healthily

- *I'm 51, and I don't feel 51, and **I feel I'm fairly fit**, and when I look around at my counterparts, **my peers, I'm a lot fitter than them**. I get more exercise, job-wise. I do smoke, like, obviously that wouldn't help. But I certainly **don't drink that much**. I only go out once a week and at the very most twice a week. **I'm a bit puzzled, where they come to the fact that I'm slightly higher risk** [P021FHx02].*

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- Lack of follow-up

R: Did you expect them to get in touch with you about the cholesterol and the blood pressure and follow you up?

*I: Well, yeah, **I thought if there was a problem, I thought they would get back**, so I'm assuming everything must be normal [P013FHx02].*

- Social constrains

*I should work a nice 9 to 5 job, five days a week, have weekends off, take up a bit of **golf** or fishing or something and do a bit of exercise, but **then we'd be looking at [living] in a tent** [P011FHx02].*

- Disappointment with modest results of lifestyle change

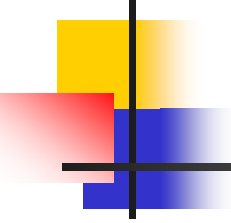
R: So, you sort of tried to lower the cholesterol, before you went on the tablets?

*I: **Before I went on the cholesterol tablets, yes, I tried to lower the intake of fat and sugar and that. The doctor said he thinks it's, because cholesterol, high blood pressure is hereditary. 'Cause I said I'm watching me diet and all this and he said, 'well, it might not be that,' he said, 'it might be just hereditary'** [P02FHx02].*



Conclusion

- Lay people do not necessarily perceive genetic risk information as “special”
- They do not view genes as determining their health but have a multifactorial understanding of what causes cardiovascular disease (DVT & CHD)
- Participants had made small changes in their habits, particularly in relation to medications (not taking the Pill or HRT or taking statins) but genetic risk information had not motivated significant lifestyle change

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- Preventive genetics often predicated on the idea of health-information seeking/choosing “expert patient,” older and less privileged individuals do not conform to this ideal but expect direct advice from their doctors and end up at a loss without it
 - Information on genetic risk factors do not, on their own, motivate lifestyle change, which needs to form a part of sustained, long-term follow-up of patients and societal approaches addressing broad contextual issues e.g. inequality
 - Messages of healthy lifestyle promise “results,” individuals are disappointed with modest change, particularly as fast, significant reductions can be achieved with drugs--sometimes the tenacity of high cholesterol or blood pressure then interpreted as “down to genes”
 - Both negative (anxiety, determinism) and positive (behaviour change) hype about genetic risk factors seem exaggerated in the case of genetic thrombophilia and family history of heart disease



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