Genetic Traits as ‘Pollution’ The Case of White English Carriers of Haemoglobinopathies

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Ethnic/Family Origins and Screening
Lecture 4 of 4
Background

- “A linked programme of neonatal and antenatal screening for the haemoglobinopathies by 2004” [NHS Plan, 2000].
- EQUANS Study [Ethnic QUestion and Ante Natal Screening for Sickle Cell/Thalassaemia]
Methods

- 16 in-depth taped recorded interviews with 27 specialist haemoglobinopathy counsellors who counsel carriers of sickle cell and beta-thalassaemia.
Sickle Cell/Thalassaemia

- Four haplotypes (three African, one Arabian-Indian) so does not not index African ancestry.
- Widespread in Africa, South Asia, South-East Asia, Mediterranean, Arab, North Africa, Iran.
- Here ‘White English’ referred to **not** Mediterranean, Arab, North Africa, Iran, or mixed heritage who might self-identify or be visually ascribed white status.
Key Findings

- The reported reliance of midwives, on 'commonsense' judgements based on 'race-thinking' (judging someone by the colour of their skin; by physical facial features)
- The reported lack of confidence of the midwife in asking an ethnicity question
- A reported association of both midwives and the general public of sickle cell with 'black'.
- A reluctance on the part of the midwife to challenge an answer which suggests the client has not understood the reason for the question
- The complexities of the relationship between mixed heritage and carrier risk.
- The fear of asylum seekers in answering ethnicity questions to officials
- The association of ethnicity with clients and risk produces task-orientation not patient orientation on the part of the health professional, thereby reduces the quality of service the individual receives
- Sickle cell and thalassaemia are perceived as marginalised by health service managers in terms of resources.
Two Findings

- The negative reaction of white English clients to being identified as a haemoglobinopathy carrier
- The skill of the haemoglobinopathy carriers in ‘cooling out’ white carriers
Negative Reaction of White Carriers

[...] because I think that’s where sometimes they are a little bit worried, somewhere, somebody in my background that was black that I didn’t know about, you know, and it’s about the tainting of them [...] Because if you always ‘knew’ that you were White British or Caucasian and, and you imagine you have feelings of er, what it, what it means to be black. And then to find out that you might have, you have something in you that could suggest that you, you’ve got black in your ancestry, that can be you know, that’s what they’re worried about. And that can cause problems and that, that’s why I say, it can and does occasionally occur in the white population without their having been any, anything in the ancestry.
Reactions

- ‘Tainted’; question parentage; question parents!; annoyed; ‘freaking out’; ‘not white after all’; ‘I’m not black’; I’m not Asian’; disbelief; demand further tests; not accept results; been an error; amazed; resentful; created in waiting room; contaminated; gave husband a hard time; reveals non-paternity; ‘flew off the chair’; go red; very puzzled; shock; ‘put it in a box for a hundred years’; how dare you ask me where my parents are from; don’t want to say half African; felt she was pure Aryan race; screwed it up and threw in bin; anger, denial; are you taking the mickey; fear; unclean.
Exception (that approves the rule)

- “In fact the woman had this as her party piece, you know. Ooh I’ve got Sickle, you know it was like a party piece to tell her friends. It’s like being cool, you know, I’ve probably got a bit of black somewhere”.
Counsellors as Black Professional Women

D1: And some of them negative you know sort of, it’s a condition that affects black people, by their GP, who was Asian as well, you wouldn’t believe it. And erm, they come here with sort of thinking you know sort of well you know, where did this come from and the blaming started. And sometimes I’m sitting here with the last, the last lot I had actually was quite horrendous because I had to sit there and sort of explain to them what was the Spanish Armada, you know sort of erm, history. So you’re really in this, you have a sort of global view of what happen historically so that you’re able to explain or educate people. Because erm, many people don’t know actually what happened, They don’t know about their history, so that, that can cause quite a bit of problem.

Inter: Right. Why do you think it bothers them so much, that that they carry Beta Thalassaemia?

D1: Oh it’s race isn’t it. It’s, and, and you know and it’s the way that we’re told, you know sort of. And remember you know, they’ve looked at people that are still sort of full (inaudible) you know have, and to be told you know sort of. And when they come and see you what, what I find, the d/dynamics within that is very interesting actually as a professional black woman sitting there, they don’t see me as a black woman.

Inter: Right.

D1: They see me as a, well that’s the impression I get, because the things that were said there. But is actually when everything is finished, sitting there professionally explaining things to them they said, when they’re going said, oh I hope you didn’t mind, you know sort of erm, I said mind in what sense, you know sort of you’re you know black and we did say some stuff didn’t it, we said, so nobody knows.
Cooling Out White Carriers

- F: First thing she said, my baby hasn’t got any Sickle Cells. And you know, you know and it really got very, very difficult. So I said, well look come down and we talk about it and you know, it’s just sort of routine and you know we could have made an error and we’d like to just check again. And interesting she brought her husband, her mother, her father, his mother, his father. It’s like saying, look at all of us, can you see black in any of us, you know, it was that sort of thing. And it’s interesting because as a counsellor (chuckling) you kind of, you know, you’re meant to be professional but you’re kind of, you can be quite intimidated by that. And I can remember saying to her things like well you know, you might have had, you know a great grandfather from India. He might have been a Raj in the British, British army, and that sort of went down well. (still chuckling) The thought that she had a great grandfather who might have been a Raj or a Colonel in the British army in India. And she responded to that, you know, but I felt I couldn’t touch on anything to do with black or ethnicity. I had to treat it in terms of, maybe her forbearers lived in an area, and you know, and this to him, of course was a form of defence against malaria. You know, and this is how I was more counselling the woman about her not having any black in her than were around the baby's haemoglobin.
Conclusion

- Skill of counsellors who have to absorb racism; counsel ‘racial views’; distance from back African (refer to Spanish Armada; Indian Raj; Romans rather than Black Africa) and then start their haemoglobinopathy counselling work
- Universal neonatal screening from 2004.