Ethnicity Question and Antenatal Screening for Sickle Cell and Thalassaemia [EQUANS]: Interview and Observation Study

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Ethnic/Family Origins and Screening Lecture 2 of 4
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Objectives

- To describe the understandings that clients and midwives have of ethnicity and ethnicity screening questions
- To explore barriers to the successful implementation of an ethnicity screening question for sickle cell.
Design

- Observation of 121 antenatal bookings.
- Interviews with 111 mothers
- 115 interviews with 61 midwives.
- Fieldwork data of 76 further meetings
Setting

- First ante-natal booking-in interview between midwife and mother in four contrasting areas of expected foetal prevalence of sickle cell disease in England.
Participants

- 61 midwives and 121 pregnant women at first ante-natal clinic with midwife.
Main Outcome Measures

(1) Descriptions of the observations of antenatal bookings between mothers and midwives

(2) Mothers' and midwives' understandings of ethnicity and views of being asked an ethnicity screening question elicited by interview

(3) Number of times midwives were observed to permit clients to self-assign ethnic/family origins.
Selectivity

- Errors in screening may will arise from women not being asked the relevant ethnic question at all.
- 14,335 of 19,546 (73%) eligible women were not invited in to the study.
- This low attempted recruitment rate was reported by the midwives to be based on their busy schedules, and their own judgements about whom to invite to be screened.
- Examining reasons behind this selectivity is vital.
Types of Selectivity

1) 4.58% (12/262) of midwives stated unprompted to researchers that they, the midwives, decided whom to offer a screen or whom to ask an ethnicity screening question.

2) 6.87% (18/262) of midwives stated to researchers that they were not administering the ethnicity screening questions under review at all.

3) 5.2% (6/115) cases the midwife rather than the mother was observed to assign ethnicity. In a further 7/115 (6.1%) of instances relatives were observed to assign the client's ethnicity for her.

4) Midwives reported using intuitive cues such as skin colour to assess ethnicity, and also suggested that the need to establish rapport at the first booking meant that they would not probe ethnic/family origins if they felt this would inhibit a friendly relationship.
Time Pressures

- Midwives reported a lack of time to undertake bookings, and the researchers observed that in such circumstances explanations about sickle cell/thalassaemia were not provided.

- Both the quality of informed consent, and the comprehensiveness of required follow-up action to screening by an ethnicity question, may be compromised by these time pressures.
Flexible Meanings of ‘Ethnicity’ and ‘Family’

- There was no consistency in whether or not 'ethnicity' was interpreted as meaning place of birth, place of upbringing, family, ancestors, or ethnic identity.
- 'Family' was interpreted in a social, rather than a genetic, sense so that a relative who had abused or a father in prison could be discounted as 'family'.
- The meaning of 'ethnic/family origins' for clients is not therefore the same as the strict meaning of family for clinical genetics purposes.
- The wish of clients to assert their ethnic identity, or define their family links in social rather than only biological terms, means that an ethnicity question draws on the wrong domain of experience for assessing haemoglobinopathy risk.
Lack of Cultural Competency

- Midwives and mothers used terms, ‘I’ve got white blood’, that would suggest that they were operating with beliefs in distinct biological ‘races’, beliefs widely shown to be incorrect.
- Several midwives used the inappropriate term ‘Caucasian’, or pre-empted ethnic assignment by leading the respondent ‘You’re Devon born-and-bred aren’t you?’
- Mothers took their 'White' ethnicity for granted, struggled to see their ethnicity as anything more than usual or normal, whereas the ethnicity of others was considered to represent difference, or even to be exotic.
- Minority ethnic respondents were much more acutely aware of their own ethnicity, being more likely to conceptualise it in complex terms.
‘Race’-thinking

- For both midwives and clients, "White" frequently becomes code for normal, one of us, people who naturally belong. By implication both ethnic minority and sickle cell status become indices for being unusual, different and not one of us. Scientifically accurate non-racial thinking disrupts this commonsense stereotyping and is resisted by some clients. Many respondents lack understanding of their own ethnicity, and "White" as an index of 'normality' becomes their refuge from this lack of understanding. The 'racial' thinking of the mother may be reinforced by the use of discredited 'race' categories by the midwife. In some instances this 'racial' thinking is so strongly expressed that any attempt to probe or challenge the assumptions behind this thinking would involve considerable emotional work on the part of the midwife.
Knowledge of Sickle Cell

- In the low prevalence area, researchers observed in 23/25 cases that the midwife either provided no information or else glossed quickly over information about sickle cell and thalassaemia. Midwives reported a lack of knowledge and confidence about sickle cell and thalassaemia. Some midwives continued to see sickle cell as restricted to African/Caribbean populations and thalassaemia to those of Mediterranean descent. This led to situations where explanations to the client were omitted. The midwives felt the encounter went more smoothly with clients who had heard of, or were knowledgeable about, sickle cell/thalassaemia, confirming that appropriate community education could reduce time required for antenatal explanations.
Conclusions

- Creating sustained educational opportunities for health professionals (primarily midwives) who carry out the screening, on the complex relationship between ethnicity categories and carrier status for sickle cell and thalassaemia.
- Allocation of sufficient time within routine service provision to administer a screening question based on full consultation with the mother about her needs.
Conclusions

- Expansion of numbers, and use of the skills of, specialist haemoglobinopathy counsellors.
Article

- Dyson, SM; Cochran, F; Culley, LA; Dyson, SE, Kennefick, A; Kirkham, M; Morris, P; Sutton, F; and Squire, P (2007) Observation and Interview Findings from the Ethnicity Questions and Antenatal Screening for Sickle Cell/Thalassaemia [EQUANS] Study. *Critical Public Health* 17 (1): 31-43. [ISSN 0958-1596] http://dx.doi.org/10.1080/09581590601045188

End of Presentation