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Offering antenatal sickle cell and thalassaemia screening to pregnant women in primary care: a qualitative study of women's experiences and expectations of participation

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Abstract

Objective To describe the acceptability to women of being offered antenatal Sickle cell and Thalassaemia (SC&T) screening in primary and secondary care at the visit to confirm pregnancy; and to explore the implications of their views for participating in decisions about their health care.

Methods Qualitative semi-structured interviews were conducted with twenty-one ethnically diverse women registered at twenty-five general practices in two English inner-city Primary Care Trusts. The material was analysed thematically, using the method of constant comparison.

Results Women generally welcomed the opportunity of early diagnosis, although they expected screening to confirm they were carrying a healthy child. Women felt general practitioners did not present antenatal screening as a choice, but they did not necessarily see this as a problem. Doctors were believed to be acting out of concern for the women's well being.

Conclusions Women were generally positive about being offered screening in primary care at the first visit to confirm pregnancy. To this extent it was acceptable to them, although this was largely informed by assumptions associated with being a 'good mother' rather than a straightforward enactment of informed choice, assumed by health-care policy. This represents the context in which women participate in decisions about their health care.

Introduction

An antenatal sickle cell and thalassaemia (SC&T) program is currently being implemented in the UK, with the aim of offering timely antenatal screening to all women to facilitate participative informed decision making.[1] Timely informed decision making is an explicit objective. Accompanying guidelines propose that antenatal SC&T screening, including pre-natal

diagnosis, should be completed by the twelfth week of pregnancy.[2,3] To achieve this, screening should be offered by 10 weeks gestation.[1] When offered during the first trimester, pre-natal diagnosis seems highly acceptable, irrespective of ethnic origin.[4,5] Screening too late in pregnancy, however, may mean that women are reluctant to undergo invasive pre-natal testing.[6] This assumes particular resonance for UK policy, as most women are not screened until 15 weeks gestation,[7] many weeks after first reporting their pregnancies to their GPs. These problems, however, are not peculiar to the UK.

Access and acceptability of screening

The aim of this article is to explore women's acceptability of, and preferences expressed during, antenatal SC&T screening within a multicultural context. We were especially interested in the extent to which women think they participate in informed decision making about screening. We acknowledge that when women exercise preferences with regard to SC&T screening, they bring with them a set of values and assumptions as well as cultural resources which will influence their perceptions and experiences.[8] This is the context in which policy is enacted and one of the problems associated with antenatal screening is the failure to contextualise women's perceptions and experiences. In this article, acceptability of screening and women's expression of autonomy is explored in relation to this broader context rather than seen as rational choice made on the basis of information provided by health-care professionals.

There are generally high levels of acceptability of screening among women, who express feelings of maternal responsibility for the unborn child.[9] In the context of SC&T, mothers (and fathers) prefer screening as early as possible and in many cases, pre-conceptually.[5] Normative ideas of what makes a good mother have been used to explain women's enthusiasm for screening, especially when test results confirm there is no risk to the unborn child.[10] Other more specific factors also come to mediate women's responses. A woman's prior knowledge of SC or T, for example, is likely to influence her preferences related to the screening process.[11] This can be seen among African-Caribbean women who, because of their history, tend to have a stronger cultural repertoire in which to make sense of SC when compared with 'South Asian' women and thalassaemia.[12] Increased knowledge can help facilitate timely informed choices. Several studies, however, have highlighted how those from minority ethnic groups tend to be less aware of services or conditions affecting them, when compared with majority populations. Women who know nothing about thalassaemia are likely to experience difficulty in exercising choice, if the first time that they have heard about the condition is during the early stages of their pregnancies. When ethnic minority populations do access services, they may also be more likely to experience inappropriate provision, due to cultural insensitivity and institutional racism, which further undermine the acceptability of screening and the exercise of choice.[13–15] Preferences for pre-natal diagnosis (and termination) are incredibly sensitive to individual and cultural context; and many practitioners struggle to engage with this.[12]

Acceptability is mediated by health-care professionals and the broader institutional contexts in which they work. Health professionals are responsible for delivering information and increasing awareness about available procedures and can therefore influence screening and pre-natal diagnosis uptake and decisions about termination of affected pregnancies.[16,17] Evidence from the first part of this study suggests that GPs believe patients' trust in them would help facilitate offering screening to women in primary care.[18]

Methods

Qualitative in depth interviewing was chosen as the most applicable technique for a study that sought contextualised personal accounts of SC&T screening. This qualitative account was embedded in the Screening for Haemoglobinopathies in the First Trimester Trial, which aimed to assess the feasibility, acceptability and

effectiveness of offering antenatal screening for SC&T in primary care.[19] Ethical approval was granted for the whole study (05/Q0501/36). The trial took place in two UK inner city Primary Care Trusts (PCTs). The two PCTs ranked among the most deprived in England (sixth and 13th out of 354 boroughs) and 40% of their total populations are from minority ethnic groups.[17] Antenatal SC&T screening was offered to all pregnant women regardless of their ethnicity or family origin. Those eligible to take part in the trial were: pregnant women attending participating practices, who wanted to continue the pregnancies, were <20 weeks (19 weeks and 6 days) gestation at their first visit to primary care; and had no written record of their SC and T carrier status.[17]

Our qualitative sample was generated from this larger trial sample. A purposeful sample of women was gathered, with the aim of recruiting women who varied in ethnic origin, country of birth and carrier status (see Table 1). The specific aim was not to 'essentialize' ethnicity by exploring it in isolation from other aspects of a woman's experience. GPs asked all eligible women if their contact details could be passed to the research team so that information about the trial could be provided. Women were also asked if they would be willing to talk more about their experience. For those willing to take part, a researcher contacted women by telephone to seek formal consent for their participation in the qualitative study. Interviews were then set up. It is difficult to know a great deal about the types of people who do not take part in research. Diversity in the background and experience of our sample suggest we engaged with a broad range of women, although those from lower socio-economic groupings were probably less likely to have been interviewed.

Women were recruited from all three arms of the trial which were: Group 1: screening at pregnancy confirmation visit in primary care, with parallel father testing; Group 2: screening at pregnancy confirmation visit in primary care, with sequential father testing; and Group 3: midwife-led care, with sequential father testing. Of the women taking part in the qualitative part of the study, 16 were offered screening in

Table 1 Womens' demographic data

Participant	Trial arm	Age	Ethnicity*	Born in UK	Couple type	Carrier status
P1	2	27	Black African	No	Same – minority	Carrier
P2	1	32	Black Caribbean	Yes	Not known	Carrier
P3	2	26	White European	No	Same – white	Not carrier
P4	2	25	South Asian	No	Same – minority	Not carrier
P5	2	31	Black Carribean	Yes	Same – minority	Not carrier
P6	2	26	South Asian	Yes	Same – minority	Carrier
P7	2	28	South Asian	No	Same – minority	Not Carrier
P8	1	31	Black Caribbean	No	Same – minority	Carrier
P9	2	25	White	Yes	Not known	Not carrier
P10	2	29	Black African	No	Same – minority	Not carrier
P11	1	32	White	Yes	Same – white	Not tested
P12	2	31	South Asian	No	Same – minority	Carrier
P13	1	29	Black African	No	Same – minority	Carrier
P14	1	28	White	No	Same – white	Not carrier
P15	3	30	White	Yes	Same – white	Not carrier
P16	3	30	White	Yes	Same – white	Not carrier
P17	2	26	Chinese	No	Mixed minority	Not tested
P18	3	28	White	Yes	Same – white	Not carrier
P19	3	32	Black Caribbean	Yes	Not known	Not tested
P20	3	31	White	Yes	Same – white	Not carrier
P21	1	28	Black Caribbean	No	Same – minority	Carrier

*Patients self selected.

primary care and five were offered screening by a midwife in secondary care.

Seventeen interviews were conducted in English and four in Spanish, French or Somali. Although not perceived as good practice in qualitative research an interpreter was employed for these four interviews because no one in the research team spoke these languages. Women were given a choice of where they preferred the interview to take place. Nineteen women were interviewed in their homes and two at their GP practices.

All interviews were carried out or supervised by an experienced researcher. Each interview lasted approximately 45–60 min. Women received a £10 gift voucher for their time (and were informed of this prior to the interview). The interviewers used a topic guide, which was developed during the pilot phase of the study and modified as data collection took place. The topic guide began with the general themes about the offer of screening, including women's prior knowledge of SC&T; the timing of the test; and how the test was offered. It then focused on the woman's decisions about accepting or declining screening and where relevant, her experience with receiving results. Finally, women were asked to reflect on the screening process.

Our eventual sample included 21 women, with an average age of 29 years, eight of whom described themselves as 'white', three 'black African', five 'black Caribbean', four 'south Asian' and one 'chinese' origin (See Table 1). The sample was perceived to give sufficient diversity, reflecting the nature of a multi-cultural population and the different possible screening decisions and outcomes.

Informal interpretation began during the interview process because data collection and analysis were set up as an iterative process. This enabled the research team to clarify and further probe emerging issues. The team began formal analysis of the interview data after the transcription process was completed. Practically, transcripts were organized using NVivo software package.[20] The material was analysed thematically across all groups using the method of constant comparison in which common themes and ideas were identified as the basis of abstracting the meaning. Themes were interrogated within the context of each individual account, as means of understanding a particular case, compared across cases by highlighting potential similarities and differences and finally, related to those characteristics of the informant that could reasonably be justified as an explanation which mediated experience.

The research team conducted all interviews and discussed transcripts, to ensure quality and shared understanding of the significant issues. Five interviews were double coded by two of the authors. No substantial differences in interpretation occurred. There was, however, considerable discussion of how certain themes could be interpreted. This strengthened the analytical process and ensured that the research team could explore possible, alternative interpretations. Other specific issues, however, need to be considered when interpreting the material, particularly since design and methodology always limit the potential transferability of the findings. Although our sample is culturally diverse, the small size limits our conclusions about social class differences, which might be an important mediator of women's experience. The research was also carried out in urban localities with large ethnic minority population. Perhaps more importantly, our sample included women who by-and-large were told they were not 'at risk'. This might explain the generally positive response of our sample to screening and our discussion reflects on the implications of this. At the same time, however, we feel that our work provides a valuable thematic account reflecting the experience of women, faced with ante-natal screening for SC and T disorders.

Findings

In making sense of women's perceived participation in decisions about screening at the time of their pregnancy confirmation, three themes were identified: the perception of the benefits of early screening; satisfaction and expectations of

participation and involvement in decision making when offering screening; and the need for information.

The perceived benefits of early screening

Consistent with other studies, when asked about the most appropriate time to be offered SC&T screening, all women felt it should be offered as early as possible believing early diagnosis would provide them with more options when making decisions about their pregnancies. Women usually justified this by focusing on the 'danger' of late diagnosis. One woman said:

> It's important to have it done especially at an early stage…it could be very dangerous leaving it too late. It's best to know what's happening. If you are a carrier you can be treated….(P5).

The use of the phrase 'treated' is interesting in this context, illustrating a potential confusion between the boundaries of health and illness, ascribed to testing for genetic conditions. This as we shall see, is an underlying theme. Women specifically talked about the difficulty of termination in advanced stages of pregnancy, particularly when the mother has already started to 'bond' with her unborn baby. One woman argued that terminating a pregnancy would be far easier at 6 weeks, rather than later:

> At 19 weeks I'm already showing! If you know from earlier on that your child will suffer from sickle cell, you can make that choice to terminate but so late in the pregnancy? You have bonded with your child already…you just want to continue with it [the pregnancy] (P2).

Women, therefore, preferred to be offered screening early by their GPs rather than at a later stage by a midwife. They believed it important to know their status from the outset, giving them more time to work through their options. One woman specifically reflected on her own stressful experience of being diagnosed as a carrier of SC at an advanced stage of her pregnancy:

> I think we should have screening the first time we see the doctor. I was screened at the end of my third or fourth month of pregnancy and the results said I was a carrier. They called my husband and by then I was almost 4 months pregnant. I was worried that if my husband had the trait I might have to go for an abortion… at four, 5 months [gestation] it's very hard for anyone (P12).

Wanting a 'healthy' baby explained the women's advocacy for early screening and most emphasised the importance of obtaining their and their partners carrier status as early as possible. One woman stated:

> I want a healthy baby so in the early stages of pregnancy I would take any decision that will be safe for my child (P4).

Many women spoke of the importance of being prepared, either to continue with their pregnancies or for termination, and expressed the view that early diagnosis allowed for this. One woman remarked (while also reflecting a further blurring of the boundaries between health and illness):

> It's better to have it done earlier because you're just prepared for it. If you do have a disorder you are aware of it (P7).

Some women said SC&T screening should be done pre-conceptually in order for parents to be aware of their status before conceiving:

> I think if you do the blood test before [pre-conceptually] and find out that you're carrying a disease you won't get pregnant but if you're already pregnant and then you find out you have a condition, I think it's quite stressful (P3).

Women generally expressed such views in the context of responsible motherhood. A good mother would do all she could to facilitate a healthy pregnancy. Many of the women in our sample uncritically accepted this.

Nonetheless, in agreeing to be tested most women expected confirmation that they were carrying a healthy child. This is an important consideration when interpreting the above comments. Women's enthusiasm for screening was based on an assumption that all would be well and in doing so, were trying to make sense of a broader policy tension between prevention and early detection. Their commitment to screening was underpinned by a strong assumption that all would be well and that their

child would be healthy. This informs their more general expectations of participating in informed decision-making processes.

Satisfaction and expectations of being involved in decision making

Many women felt that GPs offered screening in a way that facilitated choice. They spoke about being given the time to think about whether they wanted to be screened, as this woman expressed:

> The doctor told me, 'you make up your mind about whether you want to do the test or not. If you don't want it, it's okay'. So he actually gave me time. After a week I went back in and made an appointment (P10).

At the same time, women also spoke about how their GPs encouraged them to undertake screening, presenting it in a positive light. One remarked:

> The doctor didn't go into detail…she said it's better to have the test done because Asian women were more prone to this disorder (P6).

Some women spoke about not being given a choice by their GPs, but did not necessarily see this as a problem:

> I don't think the doctor gave a choice. The doctor said 'go tomorrow for this test'. I'm happy because it's beneficial for us. That's why he's saying that (P12).

Several women specifically implied that 'doctor knew best'. Women spoke about trusting their GPs as they believed he or she would recommend whatever was in the women's best interests. Consequently, they did not really expect to participate in decision making about screening:

> You had a choice but why give a choice? If the doctor recommends it, you should do it. (P10).

Another woman agreed:

> I was given a choice whether I wanted to have it done or not. She told me it was better to have it done. I did it because she told me to do it and I trust her (P6).

Further, many women, irrespective of ethnicity, believed their GP had more authority than a midwife to offer screening. This confirmed their trust in doctors, which might not necessarily be conferred on other health-care professionals.

Women's expectations of the consultation process and the trust they had in doctors, meant their GP could exercise considerable influence, but another woman did not see this as a problem, simply a natural extension of the doctor's role, which was not questioned. When women were asked why they agreed to screening, they often responded that it was because it was prescribed by the GP: 'The doctor suggested it and I just followed their advice'.

Interestingly the few women who had been offered screening in secondary care by their midwives were less aware of being offered SC&T screening, largely because it became 'lost', part of a broader package of screening tests:

> I can't recall a very serious or specific conversation about sickle cell. Maybe it was contained in a wider range of tests and I've not picked up on it (P20).

So despite their low expectations of choice, women felt more involved in decision making when screened in primary care, than they did in secondary care.

The need for information

Despite their low expectations of choice, many women felt GPs did not spend enough time explaining the conditions for which screening was being offered. Consequently, they felt ill informed:

> It's just nice when you go to your doctor for the first time to have a little bit of information about what's going to be happening to you and the things that you have to go through (P7).

At the initial consultations with their GPs, women were given a leaflet about SC and T to take home and read. However, a number of women explained that in addition to that, GPs should have spent more time explaining the conditions face-to-face:

> When they explain the test to you and then you read about it you get a clearer understanding of it rather than just reading the leaflet on your own. Then you can make up your mind (P5).

Those women who had been diagnosed as carriers of SC were especially unclear about what this meant: 'I wouldn't mind knowing more. As a carrier I still don't know what it is'. Another said:

> I just found out that I was a carrier so I really want to know more about it, whether it's going to affect my baby or not, that's what I'm really concerned about. The doctor didn't give me that information (P8).

This seems to raise a potential contradiction in the women's accounts. They trust their GP, while criticising them for not providing enough information. For some women, anxiety explains their response; they want as much reassurance as possible in ensuring they are carrying a healthy child. On the other hand, for those confirmed as carriers of the condition the context has now changed. They are faced with making a decision they did not expect to have to make. This further suggests that their trust in GPs and broader acceptability and satisfaction with the screening process, depends on women assuming nothing is wrong.

This would change if a problem was identified and suggests their acceptability of screening is contingent. Women's passivity can transform in to more proactive engagement. Women identified at risk, for example, tended to re-evaluate their previous acceptance and retrospectively adapted a more critical approach to participation in the decision-making process, feeling their GP should have involved them more. This is consistent with the idea of being a good mother.

Finally, several women who did not have English as a first language felt especially disadvantaged by the screening process offered by their GPs: a recurring theme in the policy literature:

> I would like to know more about whether it is a serious matter because I don't understand very well English. I didn't really know what was going on. It was a surprise when they told me I had the condition because I never heard about it and I would have liked to know more about it. They can't explain to me everything, I asked them to send me an interpreter but they couldn't help me (P1).

Another woman despite being sent a letter saying that she was not a carrier, spoke of her alarm as she could not read English and as with the above quotation, confusion between trait and disorder also occurred:

> It affects me because I don't understand what it's all about. There was nothing in Spanish either. The doctor just said 'we are going to do this blood test'. I am confused till now because I don't know whether I have got sickle cell condition or not (P3).

Discussion

Women expressed generally positive views about being offered SC&T screening in primary care at a first visit to confirm pregnancy. To this extent screening was acceptable to them. They did, however, identify a strong need for more information and greater discussion about the conditions for which screening was being offered as well as the implications of testing. We now explore this in more detail and show how women's acceptability of screening and participation in informed decision making is best understood in terms of broader social processes.

Regardless of ethnic origin and whether women did or did not undergo screening, women's acceptability of SC&T screening was high; all recognised the benefits of early screening. Women expressed a desire for a healthy child and the need to know about the health status of their unborn babies. Similar findings were also expressed by GPs who offered the test to women.[18] Nonetheless, positive comments were largely related to women's expectation that screening would confirm a healthy pregnancy. This is a major part of women's acceptability of early screening: they did not think they would have to make a decision about whether or not to continue their pregnancies. This is reinforced by GPs offering the test, who were concerned about raising the possibility of adverse outcomes at the pregnancy confirmation visit.[18]

Many studies have portrayed the idealised view of the 'good mother' in Western society,[21–23] with women feeling responsible for bringing a healthy baby into the world. Indeed in all

cultures, women are encouraged to adhere to and abstain from certain practices in order to ensure the birth of a healthy child and fulfil their moral obligation to their child as a good mother.[24] This experience is linked to their internalised sense of responsibility for their children. Undergoing SC&T screening can be seen as meeting this moral responsibility and this is the basis of their participation. Woman in our study believed that it was their responsibility, as mothers, to follow the advice of health-care professionals in order to bring a healthy child into the world. The existence of screening implies that it might be a 'good' thing and that the birth of a child with a SC or T disorder might not be a good outcome. Rejecting screening when they were considered at risk may have been deemed irresponsible, particularly if there was a negative outcome. They did not wish to be judged as 'bad mothers'.[25]

The women in the study indicated that they trusted the doctors who were offering SC&T screening, felt safe and were grateful to be offered such an intervention. This further supported their sense of being a 'good mother'. Doctors were accepted as the source of 'authoritative knowledge' within the antenatal context.[26] It has been suggested that women may hand control to health providers as a consequence of their vulnerable state and the multiple risks involved in pregnancy.[27,28] This pattern of behaviour was found in a study of Muslim women[25] and in a study of British women's perceptions of midwifery care[29] suggesting such beliefs occur irrespective of ethnicity. This passivity reflects Porter and McIntyre's[30] thesis of 'what is must be best': women believe that available procedures provide the best options.

Interestingly, when mothers engaged in more pro-active behaviour, such as wanting more information about the test and its consequences, they were also acting in accordance with their expectations of what it is to be a 'good mother' by maximising the opportunities to have a healthy child. This begins to explain the potential tension in their accounts in which they are happy to trust and be directed by health-care professionals as long as this does not undermine the normative values associated with being a 'good mother'. Perceptions of previous decisions, for example, can be re-evaluated if these normative assumptions are later breached.

Women identified as carriers are known to retrospectively question the process of screening.[5] This complicates women's responses,[10] particularly when many women might not have known screening has taken place[5] or at least fail to understand the implications of screening.[31] Acceptance of testing, therefore, is contingent on but consistent with their ideas of being a good mother, although the idea she is now carrying a 'faulty' gene requires further social negotiation.[10]

The non use of English by many patients and the limited availability of interpreters are currently barriers to equitable, accessible and appropriate service provision.[32] In our study women who did not speak English fluently found it especially difficult to access and communicate their needs to GPs, often not being aware that they had actually undergone SC&T screening. This resulted in frustration and dissatisfaction, supporting Ahmed *et al.*'s[27] suggestion that there is a gap between the information women want and the information they receive from health professionals. GPs also expressed similar concerns about the lack of interpreters for women whose first language was not English.[18] This is one of the few ways in which 'ethnic' differences were expressed in the study. Few other differences were found among women of different ethnic groups, although it should be mentioned that 'white' women, did not consider themselves to be at risk of haemoglobin disorders because of their ethnic origin and used this to justify their refusal to have screening. Health professionals did not contradict these assumptions, raising the potential for inequitable treatment of 'white' women, which can also explain the anger sometimes expressed by white women, who are identified as a carrier.[31] This might create broad tensions when developing screening programmes, where there is a strong ethnic identification with specific genetic disorders, particular since evidence suggests that the relationship might be a little less clear cut.[11]

This raises the more general problem of health-care professionals' understanding of SC&T. General practitioners, for example, are known to struggle with basic ideas about transmission and risk,[32] a problem compounded by the cultural complexity evoked when women make decisions about screening (and the possibility of termination). Stereotypical views about faith and its implications for ante-natal screening, for example, can disadvantage women, with practitioners specifically under-estimating the diversity of people's responses, which show individual sensitivity to context, as people balance the need to take a life, while preventing suffering.[12,33]

While many women in the current study felt that they were given a choice by their GPs about SC&T screening, the same women also revealed how GPs presented the test in a positive light and encouraged them to undergo it. This is supported by GPs who report presenting the test as routine rather than a choice to avoid complex negotiations.[18] This raises the issue of informed choice and specifically women's definitions of choice in health care. It suggests that women's views of informed decision making may not necessarily be realised in policy or practice. Women did not have particularly high expectations of being given choice when making decisions about screening, but were satisfied with this. This is again consistent with their ideas of being a 'good mother'.

Pre-natal screening activities can lead some women to conceptualise their pregnancies as 'tentative'.[34] We had little evidence of this, although this was probably because women had little detailed prior knowledge of SC or T or the potential consequences of screening. Most of the women we spoke to also had a reassuring result, which confirmed their expectation that screening would confirm a healthy pregnancy. Moreover, women rarely considered that their child might have another genetic condition, or more general disability, after receiving confirmation that they were not a carrier of SC&T trait. This suggests choice can be further compromised as specific testing can give the illusion of more general reassurance. As we have seen, the screening process can also breach the liminal state between health and illness; adding further complexities to the process.

Realising informed choice is a longstanding problem.[9] Our findings suggest a need for those working in primary care to engage more with the context in which women make choices and in particular how women make sense of their pregnancy. This is a social and emotional response, which requires careful negotiation, particularly when practitioners attempt to facilitate informed choice.[34] Women and doctors are sometimes reluctant to acknowledge this, as both parties seek speedy and straightforward resolutions to what are complex decisions. Women seem happy to accept the relatively directive nature of informed choice during ante-natal care, as long as it provides news of a healthy baby, while confirming they are 'morally' worthy mothers. Testing often becomes reduced to a bio-technical act rather than an enactment of a socially negotiated practice.[35] Practitioners, while respecting autonomy also need to acknowledge that women will defer to medical authority. The task of the health-care professional, therefore, is to engage with what women understand is happening to them, within the context of current health-care practices. This is how meaningful choices emerge and autonomy should be seen as an 'ideal governing action rather than an empirical criterion'.[36] Health professionals have an ethical and 'conscientious' responsibility not to simply offer relevant information, under the pretext of informed choice, but also acknowledge the authoritative role they place in 'inculcating' patients into normative health-care practices.[37] This is the basis of a reflexive relationship, in which practitioners question how they 'imagine' informed choice in a way that enables them to respond to the needs of women without recourse to generalised notions of expectations, while working with women's own definitions of who they are.[37]

Conclusion

Overall, women had positive attitudes towards being offered SC&T screening in primary care at their first visits to confirm their pregnancies. To

this extent it was acceptable for them. They did, however, identify a strong need for more information and discussion about the conditions for which screening was being offered and the implications of the test. Discrepancies appeared between how women exercised choice and the ideals expressed in policy. Their sense of being a 'good mother' and 'trust' of health-care professionals is fundamental in understanding this and informs their participation in the screening process.

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Conflict of interest

The authors declare that they have no competing interests.

References

1 NHS. Sickle Cell and Thalassaemia Screening Programme. Standards for linked antenatal and newborn screening programme, 2007. Available at: http://www.sct.screening.nhs.uk/AimsObject.htm, accessed 6 June 2007.
2 Department of Health. National Service Framework on Maternity and Child Care. Available at: http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/ChildrenServices/ChildrenServicesInformation/fs/en, accessed 5 June 2007.
3 National Institute for Clinical Excellence. *Antenatal Care: Routine Care for the Healthy Pregnant Woman*. Clinical Guideline 6. London: RCOG press, 2006.
4 Modell B, Anionwu E. Guidelines for screening haemoglobin disorders: service specifications for low-and high-prevalence DHAs. In: *Ethnicity & Health: Reviews of Literature and Guidance for Purchasers in the Area of Cardiovascular Disease, Mental Health and Haemoglobinopathies. NHS Centre for Reviews & Dissemination, CRD Report No 5 Series*. University of York, 1996.
5 Locock L, Kai J. Parents' experiences of universal screening for haemoglobin disorders: implications for practice in a new genetics era. *British Journal of General Practice*, 2008; **58:** 161–168.
6 Thomas P, Oni L, Alli M *et al*. Antenatal screening for haemoglobinopathies in primary care: a whole system participatory action research project. *British Journal of General Practice*, 2005; **55:** 424–428.
7 Neuenschwander H, Modell B. Audit of process of antenatal screening for sickle cell disorders at a north London hospital. *British Medical Journal*, 1997; **27; 315:** 784–785.
8 Petrou M, Brugiatelli M, Ward RHT, Modell B. Factors affecting the uptake of prenatal-diagnosis for sickle-cell disease. *Journal of Medical Genetics*, 1992; **29:** 820–823.
9 Green JM, Hewison J, Bekker HL, Bryant LD, Cuckle HS. Psychosocial aspects of genetic screening of pregnant women and newborns: a systematic review. *Health Technology Assessment*, 2004; **8:** 1.
10 Reed K. 'It's them faulty genes again': women, men and the gendered nature of genetic responsibility in prenatal blood screening. *Sociology of Health & Illness*, 2009; **31:** 343–359.
11 Anionwu E. *The Politics of Sickle Cell and Thalassaemia*. Buckingham: Open University Press, 2001.
12 Atkin K, Ahmed S, Hewison J, Green JM. Decision-making and ante-natal screening for sickle cell and thalassaemia disorders – to what extent do faith and religious identity mediate choice? *Current Sociology*, 2008; **56:** 77–98.
13 Firdous R, Bhopal RS. Reproductive health of Asian women: a comparative study with hospital and community perspectives. *Public Health*, 1989; **103:** 307–315.
14 Ahmad WIU, Atkin K, Chamba R. "Causing havoc among their children: parental and professional perspectives on consanguinity and childhood disability". In: Ahmad WIU (ed.) *Ethnicity, Disability and Chronic Illness*. Buckingham: Open University Press, 2000: 28–43.
15 Ahmad WIU, Atkin K. Primary care and haemoglobin disorders: a study of families and professionals. *Critical Public Health*, 2000; **20:** 41–53.
16 Robinson A, Bender BG, Linden MG. Decisions following the intrauterine diagnosis of sex chromosome aneuploidy. *American Journal of Medical Genetics*, 1989; **34:** 552–554.
17 Dormandy E, Kavalier F, Logan J, Harris H, Ishmael N, Marteau TM. Maximising recruitment and retention of general practices in clinical trials: a case study. *British Journal of General Practice*, 2008; **58:** 759–766.

18 Tsianakas V, Calnan MW, Atkin K, Dormandy E, Marteau TM. Offering antenatal sickle cell and thalassaemia screening to pregnant women in primary care: a qualitative study of GPs experiences. *British Journal of General Practice*, 2010; **60:** p822–p826.
19 Dormandy E, Gulliford M, Bryan S *et al*. Delivering earlier antenatal screening for sickle cell and thalassaemia in primary care: the SHIFT cluster randomised trial. *British Medical Journal*, 2010; **341:** c5132.
20 NVIVO. QSR International Pty. NVIVO Version 7. ABN 47006357, 2006.
21 Oakley A. *Becoming a Mother*. Oxford: Martin Robertson, 1979.
22 McHanon M. *Engendering Motherhood: Identity and Self-transformation in Women*'s Lives. New York: The Guildford Press, 1995.
23 Lupton D. A love/hate relationship: the ideals and experiences of first-time mothers. *Journal of Sociology*, 2000; **36:** 50–63.
24 Tsianakas V, Liamputtong P. *Women, Gender and Health: Policies in East Asia, Australia and the Pacific, a Series in the Encyclopedia of Women and Islamic Cultures*. Leiden: Brill Academic Publishers, 2005.
25 Tsianakas V, Liamputtong P. Prenatal testing: the perceptions and experiences of Muslim women in Australia. *Journal of Reproductive and Infant Psychology*, 2002; **20:** 7–24.
26 Jordan B. *Birth in Four Cultures: A Cross-Cultural Investigation of Childbirth in Yucatan, Holland, Sweden, and the United States*, 4 edn. Prospect Heights: Waveland Press Inc, 1993.
27 Ahmed S, Green J, Hewison J. Antenatal thalassaemia carrier testing: women's perceptions of "information" and "consent". *Journal of Medical Screening*, 2005; **12:** 69–77.
28 Kabakian-Khasholian T, Campbell O, Shediac-Rizkallah M, Ghorayeb F. Women's experiences of maternity care: satisfaction or passivity? *Social Science and Medicine*, 2000; **51:** 103–113.
29 Bluff R, Holloway I. 'They know best': women's perceptions of midwifery care during labour and childbirth. *Midwifery*, 1994; **10:** 157–164.
30 Porter M, MacIntyre S. What is must be best: a research note on conservative or deferential responses to antenatal care provision. *Social Science & Medicine*, 1994; **19:** 1197–1200.
31 Dyson S. Genetic traits as pollution: 'White English' carriers of sickle cell or thalassaemia. In: Kirkham M (ed.) *Exploring the Dirty Side of Women*'s Health. London: Routledge, 2007: 270–283.
32 Dyson SM, Culley L, Gill C *et al*. Ethnicity questions and antenatal screening for sickle cell/thalassaemia [EQUANS] in England: a randomised controlled trial of two questionnaires. *Ethnicity & Health*, 2006; **11:** 169–189.
33 Rozario S. Genetics, religion and identity among British Bangladeshis: some initial findings. *Diversity in Health and Social Care*, 2005; **2:** 187–196.
34 Katz Rothmann B. *The Tentative Pregnancy*. London: Pandora, 1994.
35 Katz Rothmann B. *Rethinking Motherhood*. New Brunswick: Reutgers University Press, 2000.
36 Kukla R. Conscientious autonomy – displacing decisions in health care. *Hastings Center Report*, 2005; **35:** 34–44.
37 Dominelli L. *Social Work: Theory and Practice for a Changing Profession*. Cambridge: Polity Press, 2004.