

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

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ABSTRACT

Background

Timely antenatal sickle cell and thalassaemia (SC&T) screening for all women in primary care facilitates informed decision making, but little is known about its implementation.

Aim

To assess the feasibility of offering antenatal SC&T screening in primary care at the time of pregnancy confirmation.

Design of study

Cross-sectional investigation of GPs' beliefs and perceived practices.

Method

Informal face-to-face interviews with 34 GPs.

Setting

Seventeen inner-city general practices that offered antenatal SC&T screening as part of a trial.

Results

GPs identified both barriers and facilitators. Organisational barriers included inflexible appointment systems and lack of interpreters for women whose first language was not English. Professional barriers included concerns about raising possible adverse outcomes in the first antenatal visit. Perceived patient barriers included women's lack of awareness of SC&T. Hence, GPs presented the test to women as routine, rather than as a choice. Organisational facilitators included simple and flexible systems for offering screening in primary care, practice cohesion, and training. Professional facilitators included positive attitudes to screening for SC&T. Perceived patient facilitators included women's desire for healthy children.

Conclusion

GPs reported barriers, as well as facilitators, to successful implementation but the extent to which screening could be regarded as offering 'informed choice' remained fundamental when making sense of these barriers and facilitators.

Keywords

acceptability; general practitioners, genetic screening; primary care; sickle cell disease, thalassaemia.

INTRODUCTION

In England, an antenatal Sickle Cell and Thalassaemia (SC&T) programme is being implemented with the aim of offering timely antenatal SC&T screening to all women as a means of facilitating informed decision making.¹ Guidelines emphasise that antenatal SC&T screening, including prenatal diagnosis if indicated, should be completed by the end of the 12th week of pregnancy,² which, in effect, means that screening should take place by 10 weeks gestation.¹

Antenatal care in England is usually initiated when a woman reports her pregnancy to her GP, who then refers her to a community midwife to organise and initiate antenatal and maternity care. Screening is usually offered at this midwifery appointment, which commonly occurs several weeks after the initial GP visit, meaning that some women may not be seen until 15 weeks gestation.³ A recent study provides the first population-based estimate of gestational age at SC&T screening. The results reveal that most women present to their family doctors early in pregnancy but there are long delays before SC&T screening is implemented. On average, women attended their general practice to

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confirm their pregnancies at 7.6 weeks (75% by 10 weeks gestation). However, the median gestational age at testing was 15.3 weeks, a median delay of 6.9 weeks.⁴ The current screening process does not, therefore, always facilitate timely informed decisions. Tests are sometimes offered too late to allow women the full range of reproductive options, especially since women express reluctance to undergo invasive prenatal testing and termination late in pregnancy.⁵ A recent trial has demonstrated that offering antenatal SC&T screening as part of pregnancy confirmation consultations in primary care increases the proportion of women screened before 10 weeks gestation.⁶

Policy often assumes that implementing new ways of working, in this case more proactive involvement of primary care professionals to enable the offer of more timely screening, is unproblematic. Yet, dissemination and implementation strategies have costs, which may outweigh the benefits of the new technology. Traditional models of implementation, which assume healthcare providers and managers have the resources, skills and motivation to introduce new practices in their working environment, are often flawed because they neglect the barriers to introducing new practices.⁷ Barriers to implementation exist at many levels including the individual practitioner, the clinical team, the practice setting and the wider organisational context, in addition to patient preferences.^{8,9} Implementation research has tended to focus on the role of individual healthcare practitioners¹⁰ although even in a setting like general practice, where clinical autonomy is relatively strong, evidence suggests that practice can equally be a product of the social and organisational circumstances in which they occur.¹¹

There is limited evidence exploring how to implement a screening programme in primary care, although various practical difficulties have been raised,¹² such as the need to set up new practice systems; a lack of training and resources; a potential lack of commitment among GPs to play a proactive role and difficulties in facilitating informed choice.¹³ Further, patients from minority ethnic groups, who are most at risk of haemoglobin disorders, can be viewed as a 'burden' in primary care, creating another barrier to successful implementation.¹⁴ The study, from which this paper is drawn, addresses this question by providing evidence about the process of implementing SC&T screening in primary care.

METHOD

This qualitative study is nested within the SHIFT (Screening for Haemoglobinopathies In the First Trimester) Trial,¹⁵ designed to assess the feasibility, acceptability and effectiveness of offering antenatal screening for SC&T (haemoglobinopathies) in primary

How this fits in

Timely antenatal sickle cell and thalassaemia screening to all women in primary care may be beneficial as a means of facilitating informed decision making but little is known about its implementation. This study showed that successful implementation will depend on addressing a range of obstacles at the level of the organisation, professional and the patient. However, the extent to which screening could be regarded as offering 'informed choice' remained fundamental when understanding these barriers.

care when women first report their pregnancies. The aim of this paper is to describe the feasibility of GPs offering antenatal SC&T screening in primary care at the time of pregnancy confirmation.

A total of 123 general practices in two UK Primary Care Trusts (PCTs) were invited to take part in the trial. It is estimated that about 6% of pregnant women in the two PCTs carry a significant haemoglobin variant. The two PCTs are ranked among the most deprived in England (6th and 13th out of 354 boroughs) and have about 40% of their total populations from minority ethnic groups.¹⁶ A universal screening policy was operating during the data collection period; that is, antenatal SC&T screening was offered to all pregnant women regardless of their ethnicity or family origin.¹ Of 119 eligible practices, 29 expressed an interest in participation. Two practices withdrew from the trial; 27 practices participated; two hosted pilot studies and 25 completed the trial, 17 in the intervention arms and eight in the standard care group. The participating practices did not differ from non-participating practices in list size, number of GPs, social deprivation, or minority ethnic group composition of the practice population.¹⁶

A nominated person consented on behalf of the whole practice for two participants to complete recorded interviews. One lead GP from each of the intervention practices completed an interview directly after their practice had finished their involvement with the SHIFT trial ($n = 17$). Each lead GP was asked to identify a second informant for interview within the practice who was involved with the screening programme. This led to a further 17 GPs being interviewed. All interviews were carried out or supervised by an experienced qualitative researcher in each of the clinics and recorded with informants' consent. The interviewer used a topic guide to aid them which began with the general themes about the organisation of care of pregnant women within practices followed by specific themes about the experience of offering SC&T screening and finally, the obstacles and enabling factors to offering the test. This paper presents the analysis of themes about obstacles and facilitators which emerged both from the spontaneous (general) and prompted (specific) talk in the interviews.

The researcher began analysis of the interview data during the interview process. The data were analysed thematically across all groups, using the method of constant comparison. NVivo software package (version 7) was used to organise the coding and analysis of the transcripts. A provisional, inductive coding frame was derived from the early stage of the analysis and modified as new themes emerged. This was used to assign codes to the transcribed data. To increase reliability, a subsample of transcripts were double coded by other members of the research team.

RESULTS

The analysis revealed a range of perceived barriers and facilitators, concerning the feasibility of offering SC&T screening in primary care at the time of pregnancy confirmation (Table 1). These have been categorised at three levels: organisational, professional, and patient. These barriers and facilitators are linked and in some instances are cumulative. For example, the difficulty posed by a woman not speaking English is exacerbated by time constraints in consultations. Similarly, women’s positive attitudes towards care offered by GPs within a consultation would be less of a facilitator if they did not hold positive attitudes towards SC&T screening.

Organisational barriers

GPs perceived a lack of time during consultations as a major organisational barrier. Many acknowledged the need to offer screening and although not perceived as disruptive to the consultation, it was seen as an inconvenience. On average, GPs reported that an extra 5–10 minutes was required to offer SC&T screening:

‘I think the biggest thing was time — the general feeling of just how awful it was to take so much time.’ (HCP017)

‘It made us late for consultations and therefore stropky all afternoon and therefore not giving as good a service to other people as you could do.’ (HCP025)

When asked about the feasibility of offering SC&T screening in primary care, some GPs believed that perhaps it was best left to the midwives. They specifically felt that patients are more likely to be offered informed choice if offered screening by their midwife, who, the GP believed, had more time to spend in each consultation:

‘It [SC&T] should be offered by midwives when all the booking bloods are done because that is when they have a bit more time to counsel them, they do all the triple screening for the Down’s test, HIV, and this would be another addition to that. It might fit in a bit easier in that consultation.’ (HCP030)

GPs identified women’s inability to understand English as another major organisational barrier, when offering the test. If nothing else, it meant that consultation time was extended, which in turn caused further disruption to the GPs’ schedules. This is a common problem for those working in primary care, as many do not have the organisational resources available as in secondary care to offer interpretation services. GPs said that when patients did not have English as a first language it often took a long time to provide a background explanation about the test. One GP explained:

‘It’s not difficult to discuss but it’s time consuming and that’s always the constraint. We do have a significant number of patients who have difficulties with the English language and it’s quite a subtle concept to get across to someone who doesn’t speak English very clearly.’ (HCP023)

Another GP spoke of his frustration about attempting communication with particular communities who cannot speak English:

‘The new immigrants who are coming are a nightmare for all of us, particularly those who are coming from Eastern Europe and they speak Russian, Polish and some other languages. Those are very difficult patients, we usually communicate in sign language.’ (HCP023)

The strategy of delaying the offer of screening until

Table 1. GP perceptions of the barriers and facilitators to offering antenatal sickle cell and thalassaemia screening in primary care.

	Barriers	Facilitators
Organisational	<ul style="list-style-type: none"> • Inflexible appointment systems • Women not understanding English 	<ul style="list-style-type: none"> • Simple and flexible systems for offering SC&T screening in primary care • Practice cohesion • Training
Professional	<ul style="list-style-type: none"> • Raising possible adverse outcomes in first antenatal visit • Negative attitudes of GPs towards offering SC&T screening in primary care 	<ul style="list-style-type: none"> • Positive attitudes towards SC&T screening
GPs’ perceptions of women’s views	<ul style="list-style-type: none"> • Women’s negative attitudes towards undergoing SC&T screening • Women’s lack of awareness of SC&T 	<ul style="list-style-type: none"> • Women’s desire for healthy children • Women’s positive attitude towards care offered by GPs

SC&T = sickle cell and thalassaemia.

the patient had a means of understanding clearly was used as one GP explained:

'Sometimes it was difficult to get through to patients in the sense that there were language barriers and there were no translators and sometimes it just takes ages before you can get through to "language line" [a translation service available by telephone] so I usually did ask them to come back.' (HCP018)

Professional barriers. GPs expressed concern about raising interventions with possible negative outcomes, such as SC&T screening, in an initial consultation, when most women are feeling happy and excited about finding out they are pregnant. Especially sensitive was the relationship between screening and possible termination. One GP said:

'I don't mention termination because it's like I make them disappointed, they can be upset or make them more worried.' (HCP02).

For some informants, this reluctance to raise potentially negative outcomes an inopportune time, related to more general, negative views about offering SC&T screening in primary care. One GP, for example, thought the unreliability of doctors led to difficulties in implementing screening:

'I think that in the main GPs are a bit unreliable. It's probably partly that they're doctors and not nurses and nurses are better at following instructions than doctors I think.' (HCP032)

The GP was specifically concerned that GPs would 'do their own thing' rather than take advice from healthcare professionals with more experience of offering screening. Other GPs felt it was unacceptable and unnecessary to ask women to undergo multiple tests during pregnancy:

'Ideally you would see a woman within a few weeks of her getting pregnant, do the test then, and then she would see the midwife and get the rest of her blood tests done, in an ideal world. But often we were booking women late and then they were having a blood test for the sickle and then a week or two weeks later seeing the midwife, having more blood tests and it seemed a bit unfair.' (HCP010)

Perceived patient barriers. GPs perceived women's attitudes as a potential barrier to offering the test, offering several reasons why women might be reluctant to consider screening. Some women, particularly those from Northern Europe felt that the

test was irrelevant to them and therefore not a priority, as described by one GP:

'A lot of people thought it was completely irrelevant to them and had much more pressing questions that they were interested in asking.' (HCP 013).

'Informants also saw women's moral and religious views as reducing interest and uptake of the test. My impression is that based on religious grounds, they wouldn't consider a termination so there's no point discussing screening. They will accept what God has given them, is their attitude very often.' (HCP024)

GPs, however, were aware that context also generated potential patient barriers. GPs believed women knew little about SC&T before being offered this test, especially if they were from communities, where thalassaemia was prevalent and felt this lack of awareness meant they needed to spend time on providing background information about the conditions before offering the test. This added further time to the consultation:

'I was actually quite surprised to see how many patients of Mediterranean or African-Caribbean origin didn't really know [about SC&T] and then people did have a lot of questions about the why and what if, so that takes a long time to explain.' (HCP018)

Organisational facilitators. GPs were generally positive about the simple and flexible systems set in place by the trial for offering screening in primary care. Taking part in the SHIFT trial meant that every GP was invited 267 to a training session on antenatal screening for SC&T and provided with an introduction pack to give to each pregnant woman. These packs included information for women, a father's pack, an NHS leaflet about SC&T, a blood test request form, and a notification of pregnancy form. GPs felt that these materials made it easier for them to offer SC&T screening to women:

'I liked the presentation of the pack. I think it boosted your confidence when somebody said "here's your pack" and you just literally pull out that one little folder. That was nice because it made you feel 'yes it's going to be easy to do.' (HCP019)

Providing materials, which helped GPs implement screening, is obviously key to any future screening strategy, although doctors identified the salience of the more general organisational context. For example, GPs

in small, cohesive practices felt they had more control about offering screening, than GPs in larger practices where more organisational barriers may stand in the way of implementation:

'It's just in a small practice like ours it wasn't that difficult, there's a small team, so communication is easier, but I don't know how this would work in a practice where there are 10 GPs and 15 nurses and lots of people coming and going ... yeah.' (HCP027)

Access to training was also seen as a key organisational facilitator. GPs agreed that they needed specialist training to be able to offer the test to women. Indeed, many GPs believed that the training provided by the SHIFT trial had a positive effect on how they conducted their antenatal consultation:

'The training actually tried to crystallise the necessary information that I needed to pass on to the patient, and what I needed to obtain from the patient, so it made me more focused.' (HCP03)

Despite GPs believing that training was especially important in helping them facilitate informed choices, many believed that the test would still be offered as routine due to time constraints:

'I think the doctors need to be well trained to talk about the test and I think there would be a tendency as time went on to just say "this is what you have to do", rather than the full explanation because you can't afford that amount of time.' (HCP010)

Professional facilitators

Many GPs, as has been shown, emphasised the importance of educating their patients about SC&T. Having seen first hand the effects of SC&T on children and their families, GPs were acutely aware of the importance of this:

'The practice is mainly dominated by a south Asian population. Thalassaemia is common ... we have got patients with thalassaemia major and we see what they're going through.' (HCP01)

Earlier diagnosis was viewed especially positively by GPs as it meant women had more time to consider their options and if they choose termination, would experience less physical trauma, the earlier the procedure could take place. One GP explained:

'Picking things up earlier means you know what's going on. You are going to want to know this sort

of thing earlier rather than later and if you find this out early then it's still a horrible thing to be thinking about but at least you are getting people into service quickly. Going for a termination, is obviously more physically traumatic the later you leave it as well.' (HCP012)

Perceived patient facilitators

Women's desire to have a healthy child was perceived as a particularly important positive facilitator in the successful implementation of screening in primary care. When asked why they believed that women were so compliant, GPs sensed a key motivation for women's positive perceptions of screening was the mother's moral stance; that is, her obligation to undertake any test that would benefit her unborn baby:

'Women want an explanation about the health of their baby, to know a little bit more about the health of the baby. I think that's a priority when they come.' (HCP017)

However, this could be related to women's generally positive attitudes towards care offered by the GP. Despite doubts about the ability of primary care to implement screening, all GPs, except one, said they presented the test in a positive manner and encouraged women to have the test. When asked to explain this, GPs believed that women would want whatever tests were available and expected their GP to offer this. Some GPs specifically recommended that pregnant women underwent the test for safety reasons. GPs also believed that women would happily accept their advice if it meant that their child would benefit:

'We didn't talk much about choice, I mean maybe it only comes under the assumption that they have come for it and I'm offering what is available.' (HCP01)

'GPs felt women trusted them to offer good advice. I think fortunately your patients trust you and if we think screening is a good idea and not harmful so will they.' (HCP012)

Another GP, reflecting on the general high regard some patients had for their doctor, remarked:

'Generally patients go on what we say anyway because in a lot of cultures, the doctor still knows best.' (HCP020)

DISCUSSION

Summary of main findings

Overall, GPs saw the benefits of offering antenatal

SC&T screening in primary care, believing it improved the health care they provided. In particular, they perceived that screening early in pregnancy would provide additional options for pregnant women. This supports the perceived benefits of early testing expressed by women.¹⁷ GPs did perceive a number of barriers as well as facilitators to the successful implementation of screening, which mirror those identified more generally for the incorporation of genetic risk factor assessment in primary care.¹⁸

Strengths and limitations of the study

The methodology used in this study has certain limitations, and thus the findings and their transferability to other primary care settings, should be interpreted with caution. The study account is based on the experience of GPs who work in areas with a high prevalence of haemoglobin disorders and high levels of deprivation, and who were taking part in a trial. Such GPs may more be open to the idea of antenatal screening and thus be more positive about its benefits and committed to its implementation. Certainly, evidence from broader studies of GPs' attitude suggests substantial resistance to the provision of routine genetic services in primary care.^{19,20} In addition, barriers and facilitators identified are based on informants' reports which were not complemented by observational data: collection of such data was not feasible because of the risk of contaminating the trial intervention. However, these GPs' accounts are concordant with the stories of women who were offered screening.¹⁷

Comparison with existing literature

The current study supports the findings of other studies suggesting that implementing antenatal screening for SC&T in general practice may be problematic.^{5,12} A low priority, for example, may be placed on activities, such as antenatal screening, which are not part of primary care performance and quality targets. Moreover, prenatal screening in primary care involves more than the offer of a test, as it occurs within a historical and social context, in which roles and responsibilities are constantly being negotiated and renegotiated among key stakeholders such as patients, GPs, strategic health authorities, hospitals, and the Department of Health, as they support, implement, and challenge normative values and assumptions about healthcare provision, of which screening for genetic conditions is part.¹ In the context of this study, GPs' beliefs and attitudes and their working practices acted as both facilitators and barriers to implementation. However, research has suggested that the organisational factors, which are identified here as 'barriers', are emergent properties of the complex interactions that together create the

organisation and its structure and that it is the internal realities of the practice and organisation rather than individual preparedness that influence receptiveness to change.²¹

In a practical sense, inflexible appointment systems emerged as a particular organisational barrier, with many GPs believing there was insufficient time to offer screening in primary care, although time, or the lack of it, is a common theme in GPs' accounts of their working activities.²² On the other hand, GPs believed screening could be successfully implemented in primary care, and in this respect they identified the need for good communication within the practice, with their patients and with those who formulated policy, in addition to practice cohesion and accessible and appropriate training. GPs' positive attitudes towards antenatal SC&T screening could be largely explained by the perceived benefits of early diagnosis in facilitating timely choice for pregnant women. GPs also expressed the importance of educating patients about these conditions, particularly those at risk. Otherwise, the offering of screening occurs within a vacuum, with little meaning for mothers.

GP accounts do also raise specific tensions that go beyond the straightforward offering of the test. GP reports on the time constraints of a typical consultation, for example, reflect a more fundamental tension. GPs suggested that although they offered some choice to women, the lack of time made them question the extent to which this could be regarded as 'informed choice', particularly since they tended to present the test as routine and in a positive light. Women identified the need for more information in the consultation.¹⁷ GPs were also aware that women tended to accept the doctors' recommendations without a great deal of questioning, which the lack of time tended to further reinforce.²³ This was not seen as a necessarily bad thing by GPs, but one that reflected the realities of most primary care consultations. To this extent, women's 'blind or assumed trust' of their GP could help facilitate screening in primary care, but in a way that might not necessarily accord with demands of formal policy, which emphasises the importance of informed choice at all stages of the process. This might explain why women did not have particularly high expectations of being given a choice when making decisions about screening.¹⁷ GPs also linked this notion of trust to women's desire and, more broadly, sense of moral responsibility, to have a healthy child. This is why GPs believed women underwent screening, when offered it, because they felt obliged to adhere to medical advice, advice that most women trusted implicitly. Women who do not adhere to authoritative knowledge regarding the value of technology in childbearing are ultimately held responsible for the health of their baby.²⁴ GPs believed mothers keenly felt

this, when the issue of screening was raised, although they perhaps overestimated the impact of faith on mothers' decisions.²⁵

Women's trust in doctors and acceptance of their advice, in addition to expectations of their own role as new mothers, can question the more simplistic notions of autonomy embedded in informed choice. These problems are further compounded for women who do not speak English as a first language.²⁶ The difficulties of organising interpreting services in primary care are well known,²⁷ but continue to undermine the quality of care received by women. Again, women also raised concerns about language barriers in consultations.¹⁷

Implications for clinical practice and future research

GPs identified the benefits of offering antenatal SC&T screening in primary care but also reported different levels of barriers, as well as facilitators, to successful implementation of such screening within primary care. However, maintaining a commitment to the idea of informed choice raised a more fundamental tension, when offering antenatal screening in primary care, which was independent of the actual test itself. This is a finding that has been shown in other areas of prenatal screening where informed choice is facilitated less well for women from minority ethnic backgrounds.²⁸

It is important that practitioners recognise the way in which they may influence decision making and make this more a feature of their practice rather than assuming their role is to provide information.

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Ethical approval

Ethical approval was granted for the trial (05/Q0501/36).

Competing interests

One of the authors (Elizabeth Dormandy) is now employed by the NHS Sickle Cell and Thalassaemia Screening Programme.

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Discuss this article

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