**‘WHO’S THE GUY IN THE ROOM?’ INVOLVING FATHERS IN ANTENATAL CARE SCREENING FOR SICKLE CELL DISORDERS**

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**ABSTRACT**

Fathers are increasingly invited to take part in antenatal care of which screening for sickle cell trait is a part. Expectations about involvement reflect changing perceptions of fatherhood and negotiation of gendered identities. Current policy supports male involvement, but is less clear on what basis and with what consequences. In exploring this, our qualitative study, using semi-structured interviews, presents the experiences of fathers who have recently undergone antenatal screening for sickle cell. The sample was generated in discussion with eight non-governmental organisations. We recruited 24 fathers from nine UK cities. Our analysis outlines the importance of ‘presence’, in which fathers rely on nurturing definitions of fatherhood to display their sense of responsibility. Fathers, however, struggled to find a meaningful role as traditional masculinities became juxtaposed with new and complex forms of gender organisation, creating the potential for estrangement. To conclude, screening policy makes an appeal to emergent masculinities. It also generates risks and compromises choice, due to the normative values implicit in the screening process, reinforced by the more controlling aspects of health surveillance. This creates confusion among fathers, who are not sure why they have been invited into the antenatal space.

**KEY WORDS:** UK,Fatherhood, antenatal care, genetic screening, sickle cell, masculinity

**HIGHLIGHTS**

* Fathers’ expectations and experiences of antenatal screening for sickle cell
* Fathers’ expression of embodiment as part of screening process
* The extent fathers’ involvement might compromise the position of women
* How fathers negotiate masculinity through genetic screening for recessive disorders

Antenatal screening connects the development of new reproductive technologies with parents’ negotiation of gendered identities (Reed, 2009). In England, the aim is to provide timely antenatal screening for a variety of different conditions. This includes identifying families at risk of sickle cell disorders. If a mother is identified as a carrier (sickle cell trait), her partner should be offered screening, thereby enabling couples to make an informed reproductive choice. However, fathers are not always tested, even when their partner is a known carrier (Tsianakas et al, 2012). In exploring this, our qualitative study presents fathers’ experiences of sickle cell screening by locating their expectations within broader debates about the purpose of antenatal care.

Antenatal care is a feature of global health care and is aligned with a longstanding political commitment, in which women are morally positioned to assume responsibility for managing genetic and other health risks associated with the pregnancy (Hallowell, 1999). Increasingly, however, fathers find themselves targeted; offered various blood tests to determine their carrier status for a range of recessive conditions; screened for infectious diseases; or given advice on smoking cessation. Through such interventions, reproductive technologies impact on broader concepts of parenthood and family (Rapp, 2000). The materiality of the testing process for sickle cell reinforces this. Sickle cell disorders are life threatening hereditary blood conditions, causing severe pain, vulnerability to infection and long-term damage to organs. In the UK, those most at risk of sickle cell disorders (SCD) are of African-Caribbean or African origin (although ethnic origin has become a less reliable indicator of risk). Both the disorder and carrier status can be accurately diagnosed from a blood sample. If two carriers reproduce, there is a one in four chance - in every pregnancy- that their child will be born with the disorder. England introduced a sequential antenatal screening programme for SCD in 2002. If a mother is identified as a carrier, health professionals are tasked with inviting the father to take a blood test to determine his carrier status. If he tests positive, a joint-consultation is offered, usually with a general practitioner or midwife. A couple can discuss whether to continue the pregnancy or undergo prenatal diagnosis, such as amniocentesis or chorionic villus sampling to determine if the unborn child has SCD.

Targeting men represent changing perceptions of fatherhood; combining an instrumental concern to manage complex social problems by delineating ‘correct’ family roles, with a more reflexive commitment, in which fatherhood is a valued form of display (Finch, 2007). Debates about ‘modern fatherhood’ have been a policy theme for the past decade; with fathers’ active involvement seen as a key indicator in child development (Draper and Ives, 2013). Fatherhood is no longer understood solely in terms of being a provider but combines a physical and emotional presence, with economic and social responsibility (Connell, 1995). Emergent forms of masculinity assume meaning through this process, whereby caring, intimacy, nurturing and engagement come to define maleness as much as competition, control, detachment and autonomy (Inhorn and Wentzell, 2011). Consequently, child rearing becomes an emotionally intensive enterprise for women and men (Dermott, 2008), in which success is held to be a consequence of rational decision making and planning (see Beck, 1992). Expectations about equal involvement and parenting partnerships encourage such responsibilities, providing the opportunity for positive expressions of fatherhood (Sullivan, 2010).

Broader shifts in how family is understood connect with this, by assessing moral actors, ‘doing family, through social interaction (Morgan, 1996). Fatherhood is accorded significance by how people communicate to each other - and to relevant audiences - what they understand fatherhood to be (Budgeon, 2013). This process reflects normative values and assumptions - socially and historically situated - in which certain types of response are prescribed and expected (or believed to be expected), alongside creative agency, in which the father asserts and displays who he is and wants to be (Gabb, 2011). Expressing this requires compromise in which fatherhood is simultaneously defined and realised through the processes of social negotiation (Dheensa et al., 2013). These processes can facilitate and constrain (Jenkins, 2004), while supporting and challenging the normative expectations and creative practice of motherhood (Draper and Ives, 2013).

When their partner becomes pregnant, men negotiate fatherhood in relation to the ‘normalising gaze’ of antenatal care. This can empower men, while creating the potential to expose ‘risky’ behaviours (Shirani et al., 2012). Consequently, a positive emphasis on well-being intersects with the bio-politics of health surveillance; ensuring fathers’ presence is not enacted in a straightforward way. Fathers, for example, encounter uncertainty in negotiating the meaning of reproductive risk, as they assume responsibilities for the well-being of their unborn child (Reed, 2009). While the possibilities of choice disguise a potential shift in power relationships between mother and father (Deave and Johnson, 2008); re-connecting fatherhood back to more hegemonic forms of masculinity, seeking to reproduce patriarchal relationships (Budgeon, 2013).

For women, responsibility for the unborn child is embodied and nurturing; reinforcing their right to make autonomous decisions about reproductive health free from the constraints of patriarchy (Markens et al., 2003). However, changes in ideas about fatherhood – and father’s rights – alongside an increasing emphasis on genetic testing have reinforced ideas about shared parental responsibility, while highlighting men’s genetic link to unborn child (Ettore, 2002). This egalitarian notion of genetic contribution can subtly challenge the gendered notion of maternal responsibility (Rothman, 1995). Decisions about whether to accept testing or not (and dealing with the consequences of a positive test results) reflect this, creating an ambiguous emotional space for mother and father. This perhaps explains why women support greater male involvement in antenatal care, while expressing ambivalence (Dheensa et al., 2013).

Current policy although regarding it as legitimate to involve men in antenatal care, is more subdued when discussing on what basis and with what consequences (Marsiglio et al., 2013). Is equal decision making a realistic policy goal or does it create unrealistic expectations among fathers and undermine the rights of women? This question, we would argue, is at the heart of developing a more reflexive policy and an important starting point when thinking about how best to involve fathers in screening for recessive disorders.

**METHODOLOGY**

The research aimed to understand fathers’ experiences and expectations of sickle cell antenatal screening and received approval from the National (NHS) Research Ethics Service. Our sample was generated in discussion with eight (sickle cell) non-government organisations (NGOs), who recruited 24 fathers from nine cities in UK. Organisations were given a recruitment fee and in response to ethical debates about the need to acknowledge participation, fathers were paid expenses, of sufficient value to compensate them for taking part in the research, while ensuring it was not their main motivation.

There are no reliable databases of trait carriers among health agencies and pilot work suggested working with NHS partners to contact fathers would have been time consuming, requiring negotiation with numerous agencies, who could not guarantee a father’s carrier status had been recorded. However, discussion with NGOs suggested they had the necessary networks to meet the needs of a challenging sampling strategy, requiring cultural and social diversity. These organisations also have the advantage of being trusted by the local communities they serve. Participating organisations were presented with a recruiting pack, which included information sheets and background notes; and asked to recruit any father, aged over 18 years old, who had received a request to be tested after his partner was found to be a carrier of sickle cell test during antenatal screening. NGOs identified fathers from their existing records or at community events, in which they were taking part. Fathers were contacted either face-to-face or over the telephone. Fathers wishing to take part gave permission for their names to be forwarded to the research team.

The sampling strategy sought maximum diversity in terms of age, ethnicity and knowledge of carrier status (Table 1). To this extent it was purposive and theoretically informed. Our sample included fathers who knew their carrier status (n=21) and those who did not (although in all cases their partners were known carriers); a diverse range of ages between 20 and 50 years old; some of whom had experience of being offered more invasive prenatal diagnosis (n=9). Seventeen fathers were carriers; most identified during the antenatal process. Four fathers were also no longer with their partner, but still had contact with the child, thereby introducing different family contexts. This included one father who had separated from their partner before the birth of their child. In addition, given the distribution of sickle cell trait in England, our sample also needed to cover a degree of ethnic diversity. We were, however, wary of using ethnicity as an essentialising, sampling (and explanatory) variable and instead wanted our sample to reflect ethnic diversity rather than specific ethnicities.

Semi-structured, face-to-face, interviews, lasting between 30-90 minutes took place in the respondent’s own home or mutually agreed community setting. We spoke to most fathers (n=21) without their partners. Fathers’ expression of marginality during the antenatal process is a feature of the literature. We did not want to reinforce this by interviewing fathers with their partners present. When we did, it was at the father’s insistence. Fieldwork took place between 2013 and 2014. Before any interview, all participants provided written informed consent. We used a thematic guide that covered specific topics and literature, to facilitate ‘guided conversations’ (Fielding, 1993). We wanted to cover similar ground with our interviewees, to ensure we could compare responses, while at the same time creating an environment enabling them to reflect on their specific experiences. Interviews explored: biographical details as a way of building rapport and contextualising subsequent discussion; screening and involvement in antenatal care; understanding and perceived value of screening; expectations of fatherhood; and relationship with health professionals. The interviewer charted initial impressions to ensure subsequent interviews could connect to ideas introduced by other participants.

Interviews, with the respondent’s permission, were audio-recorded and transcribed. Analysis was aided by Atlas-ti and undertaken by the research team, who engaged in iterative debate at various key stages when negotiating different analytical themes. We began by identifying themes relevant to an interview. This combined opening coding with line-by-line analysis (Charmaz 2014: 51). These themes were first interrogated in relation to each individual account, as a means of understanding a particular case. They were then compared across cases by highlighting potential similarities and differences (see Silverman, 2013). We were interested in recurrent themes, in addition to more individual experiences, as we generated an explanation of how participants negotiate and ascribe meaning to screening, within their broader expectations and expressions of fatherhood.

As this research was being conducted by ‘white’ academics, including two men and a woman we tried to be aware of our own biases and limitations. At regular intervals, we would present provisional findings and ask for critical feedback from community and practice stakeholders. This provided oversight of the research process, built trust, and provided guidance. Our sample is also slightly skewed towards those who have had children with SCD and/or are carriers; perhaps reflecting our use of NGOs in generating the sample. This, however, did enable the research to reflect actual rather than hypothetical risk. We also had a large proportion of fathers participating in our study who were in their thirties (n=12) and described themselves ethnically as African-origin (n=14), most originating from West Africa. Our research, therefore, includes more mature fathers and a diverse ethnic sample, building on previous research in the UK that has largely associated sickle cell with Caribbean populations.

**FINDINGS**

In bringing together our theoretical interests and empirical material, we put forward three linked, interpretative themes, to explain fathers’ engagement with genetic screening. First, we explore the importance of ‘presence’, in which fathers rely on nurturing definitions of fatherhood (and masculinity), to display their sense of responsibility. Fathers, however, struggled to assume a clearly defined role. This informs the basis of our second theme in which more hegemonic expressions of masculinity find expression, alongside more nurturing responsibilities, when negotiating screening tests. Third, we examine how the struggle to find a meaningful role compromised fathers’ ability to exercise reproductive choices, raising the potential for disengagement, inconsistent with more empowering views of fatherhood advocated by current policy. Exploring these themes enable us to connect the social meaning of fatherhood with the policy (and theoretical) assumptions implicit in antenatal care, through which screening for sickle cell is enacted.

**The importance of presence**

If a mother tests positively for sickle cell trait, midwives or general practitioners are tasked to invite the father, independently of the mother, to provide a blood sample, to determine his carrier status. Fathers regarded the request as a necessary routine and part of their ongoing engagement with antenatal care. David said: ‘We wanted kids, so it was not a problem’. Kwame agreed: ‘To me it was normal’. Lewis remarked ‘It was no big deal’. Such views connect to father’s broad sense of commitment established earlier in the antenatal process and consistent with their idea of ‘doing’ family. Malik explained: ‘I am a father what takes care of my kids properly’. This is the initial basis of establishing ‘presence’.

Screening for sickle cell trait become accepted as part of this dutiful father role; giving men the opportunity to display visibly what they saw as the more positive and nurturing aspects of fatherhood, consistent with emerging masculinities and their sense of commitment. Lewis said: ‘I felt obliged to do it because it’s my child. I want to know what is happening’. Most men were pleased to have such an occasion, particularly given other uncertainties over their role (see below). Screening, therefore, assumed significance, beyond the straightforward offering of the test and facilitated a sense of (genetic) responsibility; although fathers could rarely provide a detailed account of what they were being tested for or the consequences of a positive test result. Matthew explained:

They [midwife] just said that if the test comes back and I’ve got the trait, then we would have to discuss options. That’s all they said really. They did not go into much detail.

Fathers’ commitment was more about ‘fatherhood’ rather than a proactive and informed acceptance of genetic testing. Fathers did not question the necessity of the tests. They are doing what they feel is necessary. Iyabo explained:

I want to get as much done, as much information done, as much tests done, as is reasonable.

Screening was not consciously rehearsed as an autonomous choice. It was accepted because this is what ‘good’ fathers do; connecting with the idea of the ‘good’ mother, well established in the literature (Tsianakas et al., 2012). Kwame remarked:

I just wanted the best for all of us. Because at the end of the day nobody will want to see a child suffer.

Consequently, screening provided the opportunity for a more bodily engagement, fulfilling the father’s concern to protect the unborn child and demonstrating their positive relationship with the mother.

It also shaped future responsibilities in which fathers can use their engagement with screening to prepare for active fathering once the child is born. The taking of their blood legitimated the process, with fathers believing it denoted a substantial, embodied commitment to the unborn child. This overcame the potentially fleeting nature of such an engagement. Isaac said:

A woman can feel everything that’s going on and as a dad you’re just watching her get bigger (…) going to the hospital and being in touch through those screening tests made it more real to me.

Fathers’ ability to embody the pregnancy, by consenting to tests involving their body, is not without consequences. A father estranged from his partner expressed specific annoyance; an invitation to be tested created the dilemma that non-engagement would (erroneously) be understood by health providers as indicative of a lack of intended support to the child once born. For others such as Ben, the acceptance of a test further reinforced previously established expectations about shared decision making and the exercise of choice. This is why fathers’ spoke of their frustration when the focus seemed to shift back on to mother (and her body) once their blood had been tested. This, however, reflected broader anxieties about involvement in antenatal care.

Fathers felt more confident when their involvement was initiated by their partner, although fathers were aware that the mother’s own uncertainties about their role could make this difficult. Ben explained how his sense of responsibility connected with the mother’s insecurities:

She will always say, ‘Oh, you have to come with me, you have to come with me. Make sure you come with me because you’ve been putting pressure on me, wanted a baby (…) so now I’m pregnant don’t let me alone, don’t leave me alone. Come with me’.

Fathers accepted the complex and daunting nature of antenatal care might be disempowering for women. This - they believed – partly explained why mothers struggled to articulate what they expected from fathers. In overcoming this, fathers would have liked more encouragement from health professionals. This, however, rarely happened. James said:

If I was about five minutes late I would have missed the first screening. But I made it, and it was interesting, but the first thing I sensed (…) I wouldn’t say anti-guy, I think that’s too much, it’s not anti-male. It was very, OK, mother, person doing the ultrasound, ‘Oh who’s that guy in the room?’

Consequently, modern fatherhood, informed by joint parental responsibilities and enforced by an invitation to be tested for sickle cell, is only partially reflected in current antenatal practices. This confused fathers, making it difficult for them to find a role. The relative lack of explicit inclusion of fathers by health professionals was at odds with the fathers’ broader expectations about fatherhood. Malik explained:

When we got there it was more involved with the mother, not the father. It was all the questions were directed at the mother and not the father, do you know what I mean? And like it was a together thing but it weren’t a together thing.

**Finding a role**

Fathers were aware that the offer of screening, although enabling them to demonstrate their commitment to the pregnancy, did not necessarily guarantee them a role. This connected with deep-seated insecurities, especially if they sensed ambivalence about their involvement in the antenatal process. Fathers were aware that the mother - and health professional - had to regard their involvement as legitimate. Thomas, for example, realised the importance of not letting his frustration with his partner’s midwife become too obvious. Like many fathers, he ‘decided’ to ‘co-operate’. Fathers were acutely aware of the need to negotiate a role within a space, which asserted and celebrated female autonomy. The taking of their blood did not negate this, suggesting fathers’ sense of embodiment did have limits. Jasinder said:

If I’m going to be honest (…) I was a bit in the background and I mean that is partly understandable because, you know, it’s her that’s having the baby and you know, it’s her that’s carrying the baby.

Consistent with their commitment to emergent masculinities, men generally accepted their secondary role, understanding it as part of the conditional settlement facilitating their invitation into the antenatal space. This, however, was not without its tensions. James, for example, attempted to reconcile the focus on the woman with the need to express his own viewpoint:

I got so frustrated but at the time I thought you know what, it’s not about me and how I feel. The most important thing is that she’s getting the right healthcare and the baby’s all right. But there are times where I’d almost want to be like ‘Guys, I’m here’.

The way in which sickle cell screening was presented, further encouraged fathers’ sense of marginalisation; particularly since it seemed to confirm the transient nature of their engagement. Many believed practitioners’ offer of testing emphasised a narrow and instrumental view of fatherhood, in which father’s claims to paternal responsibility were not acknowledged. Fathers felt little more than a source of genetic material and a potential repository of unhealthy behaviours; valued as an emotional resource for their partners, rather than someone who could contribute jointly to decision making. From this viewpoint, the surveillance aspects of antenatal services took precedence over the caring aspects.

However, fathers’ perceived sense of (partial) embodiment gave them confidence and encouraged assertiveness, creating the potential for more hegemonic forms of masculinity to find expression especially if the father felt challenged. The extent to which mothers were able to adopt a role as gatekeeper perturbed some men, potentially undoing more emergent masculinities. A few fathers said mothers controlled decision making and did not consult with them. John remarked: ‘I’m on the birth certificate, but she seems to think she’s in control’. Mothers were said to refuse male involvement; limit the information they give men; blame men for non-involvement; use men as a reason for not taking certain tests or let men take the responsibility for all decision making. Such comments, whatever their merit and validity, demonstrate the complexity of creating space during antenatal care, particularly since fathers often felt they had little opportunity to discuss mothers’ decisions with health professionals (see above).

Fathers knowingly negotiated an involvement, in which they accepted a woman’s opinions, had priority over their own. This, however, created an uneasy compromise. James, connecting to more emergent masculinities, said:

Mum and dad can have arguments (…) but now there is a new life involved (…) I know the woman’s doing the most, the majority of the work and there’s more focus on her. However, if the dads are going to play a more important part or a strong part, you have to involve us.

Kinsley reflected a more hegemonic view of masculinity:

The future of a child should take precedence over the happiness of both parents. That’s the way I see it. (…) Where you said it’s the woman’s prerogative to, because it’s in her body, I think that’s wrong.

Fathers had to know when to display emergent masculinities and when to revert to more hegemonic forms. Displaying ‘new’ intimate behaviours might be misrecognised, while performing ‘old’ masculinity behaviours (humour, anger, asserting presence) might be taken as delegitimising the opening up of hitherto female spaces to men. Fathers understood that they had to display themselves as passive, non-threatening males. They could not afford to be seen as overbearing or controlling. Jasinder recounted how in facilitating this, he allowed bodily and emotional displays of support to be initiated by professionals:

‘And then the midwife had to kind of say, you know, (laughs), ‘Do you want to hold your wife’s hand?’’

When reconciling these tensions, men found it easier to assume an emotionally supportive role; occasionally acting as an advocate; albeit in a subdued and discreet way. Such roles could accord legitimacy and help secure involvement. Discussions about sickle cell screening reflected this and included calming their partner (Ben); absorbing distressing news (Ibrahim); or as - Lewis remarked - ‘play Mr Nice Guy so as not to stress her out’. As long as they did not make too many demands or question the antenatal and screening process fathers believed their presence was accepted, although the extent this was readily adapted or imposed because men lacked confidence in what they regarded as a traditional female space is a moot point. Malik, for example, expressed relief that he ‘wasn’t condemned out of the room’, when raising questions about sickle cell early in the pregnancy. Nor did this completely fulfil a father’s expectations of responsibility and a more emotionally engaged role.

Displays of fatherhood can become especially intense when men are in gendered spaces (Doucet, 2011). Fathers knowingly searched for ways of positively responding to fatherhood, while countering social and cultural assumptions, suggesting they lacked family commitment. Involvement in screening helped establish fathers’ commitment, although when considered alongside concerns about their instrumental role, screening created a potential site for struggle in which ethnicity and masculinity became juxtaposed. In England screening policy for sickle cell is strongly connected to ethnicity. Fathers’ accounts reflected this and many felt targeted because of their ethnic origin. Antenatal care, therefore, offered a specific instance where fathers had to negotiate ‘race’. In doing so, they countered a subtle, implicit racism such that it found a muted reflection in their accounts. This, however, could underscore men’s uncertainty about how to display their masculinity when negotiating screening. Lewis reflected on why he felt neglected:

I’m not rich, I’m a minority (…) I’m not a priority, so why are they going to really care (…) Being a man, when you complain you don’t really get anywhere, to be quite honest (…)For one you’re not the one carrying the baby, a child, and for two, it’s like you’re a man, what do you know basically?

Most fathers were conscious of how they needed to distance themselves from perceived negative assumptions associated with Black fatherhood. These assumptions included uninterested and emotionally detached fathers, usually absent and who struggle to commit to family life. James explained:

They were (stereotyping me) but I’m not sure what stereotype. Is it the young black male who’s irresponsible, or is it the ‘Ah, he’s just the baby father’. I’m not sure what stereotype but all I know is it wasn’t very nice, because I’m the type of person, I’ve always been determined to do the right thing, you understand? And based on that, if I’m here and I’m making an effort, the least you can do is just, treat me normally.

He later added:

Okay, a lot of fathers, especially in certain areas and from ethnic minorities, they’re not really that supportive, so perhaps they had that perception. But I just thought it was unfair, ‘cos I wasn’t one of them.

Under such surveillance from health professionals, fathers avoided displays liable to be racialised and were reluctant to express cultural preferences or expectations. It also explains their embrace of rational decision making associated with antenatal screening, which they saw as a way of countering racist stereotypes.

**Exercising choice**

The potential for disempowerment and marginalisation has been noted as fathers struggle to display fatherhood. Some fathers explicitly commented on how their involvement in antenatal care (and beyond) was contingent. Chika explained:

But the thing is you’re dealing with professional people that are well educated (…)

They know the legal implications and they know how far they can push. It only takes a wrong phrase or a wrong sentence in a letter to ruin your chances, you know what I mean?

In presenting themselves fathers were careful to avoid being seen as a problem. Nonetheless, uncertainty about the right disposition to assume could limit father’s ability to articulate choices when discussing sickle cell screening. James remarked:

There’s two of us. All the information’s being thrown at her. She’ll pass the leaflets to me, I’ll hold it. They’ll [Health Professional] answer very briefly and then continue talking to her. And that just makes me think, ah (whispering), maybe I just need to shut up.

Fathers – as we have seen – are sensitive to how their involvement in decision-making around pregnancy could be conceived as a form of control over women. This is why greater involvement of fathers in decisions around screening cannot be reduced to a re-iteration of hegemonic masculinity, particularly since caring was seen by fathers as an embodied aspect of the antenatal space. Nor should male involvement be seen as necessarily leading to the expression of oppositional interests. The potential is there and sometimes realised, but most the fathers seemed genuinely concerned to take shared responsibility for the unborn child and support the mother.

This was consistent with fathers’ expectations that they should be involved in decisions or at least consulted if screening was offered. Fathers took the rhetoric about informed reproductive choice at face value, while also using it as opportunities to assert their role as a supportive father. In some ways, their difficulties in exercising choice are similar to those expressed by mothers (see Tsianakas et al., 2012). As we have seen, fathers, although enthusiastic about screening to the extent that it enables them to express their broader and symbolic expressions of fatherhood, felt ill-informed about the tests offered. Perhaps not surprisingly, fathers began to express doubts about how much choice they really had during sickle cell screening and few thought they had made informed decisions. This became especially evident if a decision about prenatal diagnosis was necessary.

Fathers’ responses reflected the normative values associated with the ‘good’ father and expectations about producing a healthy child (see above). This justified their involvement in screening. Fathers also believed health professions were unlikely to offer screening tests needlessly. Choices, therefore, connected to contextual factors, associated with the more controlling aspects of genetic screening, particularly since fathers believe they are morally judged when making decisions. To this extent, screening for sickle cell reflected fathers’ attempts to reconcile their emergent masculinity with the need to use reproductive technologies to make rational decisions that offer some control over the future. David explained:

I think if it’s something that I need to know as a person and also I need to plan my future then I need to have it done and so I got it done.

Thomas remarked:

Because, you know, when you are expecting a baby I think that the best thing for you to do is make sure that the baby’s coming under best condition, especially when you know that if you haven’t done something the baby may be affected. That was why I was ready to be tested for everything.

This, however, does not mean fathers are entirely at ease with screening. Iyabo said:

I think all this attention on screening is because it’s cheap. It’s taking the easy way out (…) and you see why I don’t like it in a way is, even though it’s a choice, and that’s something I’ve said to my wife, it is a way of being trying to, probably that’s reducing the, more people with sickle cell, so reduce the costs.

Decisions made during pregnancy necessarily affect the nature of parental responsibilities and relationships. At its most straightforward, one person can make decisions that affect another. Testing for sickle cell carries the possibility of blame and recrimination if ‘things go wrong’. Few fathers, however, anticipated the need to make further decisions about prenatal diagnosis. They assumed the blood test would confirm there was no problem. The need for more involved and invasive tests was rarely considered. When it became an option, fathers began to question their initial acceptance of the blood test as routine. Joshua, for example, spoke of how and he and his partner were unprepared, when needing to make a decision about prenatal diagnosis:

They took my blood and tested it. So it’s not really a big thing. Maybe I should have said more.

Jacob spoke about how his wife’s reaction on hearing that both were carriers made him realise that he should have taken testing ‘more seriously’: ‘She was really anxious. She started crying’. Nonetheless many fathers, such as Jacob felt the process confirmed their nurturing role and their right to be included in decision making. Matthew agreed and added that his partner also wanted his involvement:

I think more so for support, throughout all these tests. They can be quite nerve wracking really. So, yes, I think she wanted me more involved.

Fathers’ accounts suggest out-right conflict with the mother was rare. Ben discussed his experience:

‘We discussed it with each other. Because when I got married with her I loved her, I was always asking her, oh I want a baby, I want a baby (...) and then when they told her we should do the termination, we sat down in the house and said, ‘Oh this is our baby, this is our first baby. How can we terminate?’ We came to an agreement and said, ‘No, let us leave the baby’.

The consensus between partners could, however, be fragile as fathers negotiated the primacy of the women’s role, which found occasional expression in father’s concerns about mothers’ dominance (see above). Ben explained:

She said to me, if I refuse to go for the blood test, they can do the test from the baby. So they didn’t do it from the baby ‘cos I went there. I accepted and they did a blood test from me.

This – alongside negotiating broader expectations of fatherhood, individually asserted and socially accomplished - delimited their father’s role, potentially compromising choice. Exclusion is never quite resolved and an ever present possibility, underlying the fragility of the father’s role. Consequently, the potential for joint decision making is never quite realised, creating a sense of latent distrust, in which it was difficult for men to fully realise their expectations of fatherhood. However, their commitment to the more nurturing aspects of fatherhood made it difficult for them to wholly disregard the antenatal process, particularly since they wanted to be taken seriously as responsible fathers.

**DISCUSSION**

The qualitative study reported in this paper, considered fathers’ involvement with antenatal sickle cell screening. Through genetic screening women are morally positioned to take responsibility for their kin and to manage risks (Hallowell, 1999). However, when compared to screening for Down’s syndrome, antenatal screening for sickle cell is directed at mother and father (Reed, 2009). This raises questions about how best to engage men, in what has traditionally been regarded as a female space. Our findings suggest male involvement (or lack of it) is appropriately understood in relation to their attempts to display and negotiate a meaningful and legitimate sense of fatherhood. Screening gave fathers the opportunity to articulate a supportive role, although the more instrumental connotations - implicit in antenatal - made it difficult for these ideals to be realised. This contradicted the more expansive ideals of fatherhood, in which fathers expected to be present in ‘child-relevant spaces’ (Henwood and Proctor, 2003). Consequently, fathers although invited to be part of the antenatal process, are never quite sure what their role is. The contingency this generated – and its negotiation - came to define father’s experience of antenatal care and their more specific engagement with screening for sickle cell.

As fathers recounted their experiences, screening rarely seemed to be a focal point, from which to involve them in the broader aspects of antenatal care. This could be seen as appropriate, by ensuring antenatal care remained a female dominated space (see Draper and Ives, 2013). Nonetheless, policy attempts to facilitate greater male uptake of screening did create expectations among fathers of a more comprehensive involvement. Despite their commitment, fathers felt current provision rarely offered meaningful choices, consistent with ideas of nurturing responsibility. Involvement in decision making; assuming responsibility for the unborn child; and an assertion of their rights as a father (see Locock and Alexander, 2008), although articulated as part of a conscious commitment to fatherhood, were often difficult to realise in practice. Further, their search for ways of positively responding to fatherhood, while countering racist assumptions, suggesting they lacked family commitment made Black’ fatherhood even riskier to accomplish (Gabb, 2011). This explains why cultural displays were rare and why – more generally - fathers were reluctant to question directly the screening process.

Proactively assuming the correct disposition and having this recognised by others - including the mother and health professionals - became an important part of male display, albeit one that could be easily disrupted by current practices (see Dheensa et al, 2013). Genetic screening has a strong association with health surveillance, marginalising fathers at various points of the antenatal trajectory, only to re-focus urgently on them when further tests are required. This suggests a partial, biased and reductionist interest in them, as males at risk of a genetic condition rather than a holistic concern in them as supportive fathers (see Cornford et al, 2013). Fathers we spoke to, felt they had little choice but to assume a passive role as ‘bystanders’ or ‘outsiders’ (Locock and Alexander, 2006). They found this difficult to reconcile with their wish to be involved and incompatible with attempts to assert themselves as caring fathers.

The gendered nature of genetic responsibility reinforced this and as Rapp (2000) observes the discipline of biomedicine demands female compliance when pregnant, irrespective of their desire to be moral pioneers. Fathers’ claims had to be realised against normative assumptions, in which women are encouraged (or feel under pressure) to take responsibility for the health of their unborn child. Such distinction has routes in patriarchal thought (Rothman, 1995) and in particular the distinction between seed and soil (Rapp, 2000). Again, fathers felt this over-emphasised their role as genetic contributors. Their inability to experience the embodied nature of pregnancy was seen to further limit their role, although their genetic connection to the unborn child, implicit in the offering of a blood test can offer some reassurance and a perceived –albeit limited - opportunity to embody experience, while simultaneously encouraging. This, however, raises the intriguing possibility of women exercising control over men’s bodies, particularly given fathers’ anxieties about the partiality of their involvement.

Like women, fathers felt under pressure to take certain decisions consistent with ideas of the good father, yet complain their emotional needs are rarely acknowledged by health professional. This created a potential dissonance between non-exclusion and passive acceptance of a father’s involvement – which fathers would argue was the norm – and expectations about more active inclusion, in which they are recognised as having joint responsibility for the pregnancy (see Draper and Ives, 2013). Screening for sickle cell acts as a forum for making and re-making gender roles: and offers a space in which they are enacted; with fathers juggling diverse and fluid forms of masculinity, in which the caring and nurturing aspects of their role are articulated against more dominating expressions of masculinity (Collier, 2010). The possibility of exclusion was ever present, with fathers feeling ‘an autonomous subject [undermined] in the quest to control nature’ (Hyde and Roche-Reid, 2004; p2613).

If unacknowledged, an unresolved dynamic can come to characterise and define care. An instrumental and supportive role, secondary to that of the mother, constrains the expression of engaged fatherhood, creating the potential for estrangement and disempowerment (Hallowell, 1999). While a more active engagement, through which men express preferences over the pregnancy, could reinforce a more hegemonic masculine role, thereby maintaining gender power and privilege, while challenging the traditional moral ascendancy of the mother’s rights during pregnancy (Annandale and Clark, 1996). The right to be present is a moral issue, and has to be earned by adopting the ‘right’ disposition, which is a constant source of insecurity for fathers (also see Ives, 2014). To this extent, fathers struggled to overcome stereotypes of machismo found in clinical settings (see also Markens et al., 2003). They were also unsure of what it meant to be father of an unborn child and had few role models they could emulate (Dolan and Coe, 2011).

Professional bodies associated with midwifery reflect a broader policy commitment to ensuring fathers become engaged with the development of their child (Draper and Ives, 2013). Our fathers’ accounts suggest this commitment found expression in an instrumental or strategic rationality, which disregarded their more emotional investment in fatherhood. Screening, although often introduced as a positive means through which men can express involvement, rarely considers the anticipation it generates among fathers to be involved more meaningful in the antenatal process. Screening, therefore, embodies a fundamental ambiguity: is its purpose to engage men as genetic contributors or to embrace the emotional expectations of fatherhood? To work successfully, we would suggest screening strategies that engage men need to reflect the contingency of individual experience and the dilemmas such strategies create, particularly since the priorities of the individual might not be the same as those assumed by policy. The experience of screening is more than simply being at risk of a recessive disorder, it is an expression of a man’s negotiation of the social and cultural meaning of fatherhood. It is equally important not to portray men as powerless subjects, whose needs are denied by insensitive provision or the controlling aspects of motherhood. They display active agency in their struggle for legitimacy. Father’s subtle recourse to more hegemonic masculinity – with its potential to limit women’s ability to exercise choice over her body – provides evidence of this.

To conclude, screening is socially negotiated and ethically fraught. It makes an appeal to the reflexive self, able to use self-awareness and proactive engagement to make a decision about testing, while simultaneously generating risk and compromising choice, due to normative values and assumptions implicit in the screening process, reinforced by the more controlling aspects of health surveillance (Rapp, 2000). Not engaging with these broader reference points, means any isolated offer of testing for sickle cell - or advice on smoking cessation for that matter – becomes a potential source of unrealised expectations, which have the potential to confuse both mother and father. Fathers would prefer a clearer understanding of why they are involved in antenatal care, which policy needs to balance against meeting the needs of the mothers, particularly since they can also feel disempowered and undermined by antenatal care.

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**Table 1: Characteristics of the Sample of Fathers**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Name | Age | Employed | Ethnic origin (Self-identified and mapped to UK 2011 Census Categories) | Carrier Status |
| Jasinder | 40 | No | Asian (Indian) British | Not Known (probably non-carrier) |
| Malik | 37 | Yes | \*Caribbean | Not Known (probably non-carrier) |
| John | 36 | Yes | \*Caribbean | Not Known (probably non-carrier) |
| James | 27 | Yes | \*African (Sierra Leone) | Sickle Cell Disease (SCD): prenatal |
| Matthew | 20 | Yes | \*Caribbean | Non-Carrier: antenatal |
| Suleiman | 42 | Yes | \*African (Somalia) | Carrier: postnatal - found out after second child (child SCD) |
| Joshua | 32 | Yes | \*Caribbean | Carrier: prenatal (child CSD) |
| Isaac | 31 | Student | \*Caribbean | Carrier: antenatal (child SCD) |
| Lewis | 27 | Yes/Student | \*Caribbean | Carrier: antenatal: (child SCD) |
| Ben | 34 | Yes/Student | \*African (Uganda) | Carrier: antenatal (child SCD) |
| David | 32 | Yes | \*African (Ghana) | Non-carrier: prenatal (partner SCD) |
| Kwame | 46 | No | \*African (Ghana) | Carrier: postnatal (found out after the third child with second partner) |
| George | 35 | Yes | \*Caribbean | Carrier: postnatal |
| Jacob | 44 | Yes | \*African (Cameroon) | Carrier: postnatal |
| Umaru | 24 | Yes/Student | \*African (Nigeria) | Non-carrier: antenatal |
| Iyabo | 40 | Yes/Student | \*African (Nigeria) | Carrier: antenatal (tested in Nigeria, wrong status, children SCD) |
| Ike | 42 | Yes | \*African (Nigeria) | Carrier: postnatal (tested in Nigeria, wrong status/child SCD) |
| Mark | 50 | Yes | \*African (Nigeria) | Non-carrier: antenatal (second partner) |
| Samuel | 33 | Yes | \*African(Cameroon) | Carrier: antenatal (with second child) |
| Thomas | 38 | Student | \*African (Cameroon) | Carrier: antenatal (second partner) |
| Ibrahim | 37 | Yes | \*African (Ivory-Coast) | Carrier: postnatal (child SCD) |
| Mohammed | 31 | Student | Arab (Saudi Arabia) | Carrier: probably prenatal |
| Kingsley | 37 | No | \*African (Nigeria) | Carrier: antenatal (child SCD) |
| Chika | 42 | Yes | Mixed (White/African- Nigeria) | Carrier: prenatal (child SCD) |
|  | | | \*Black or Black British |  |