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'Who's the guy in the room?' Involving fathers in antenatal care screening for sickle cell disorders

Karl Atkin [a, *], Maria Berghs [a], Simon Dyson [b]

[a] Department of Health Sciences, University of York, Seebohm Rowntree Building, York YO10 5DD, UK
[b] De Montfort University, Room 1.27, Hawthorn Building, Leicester LE1 9BH, UK

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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.

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;

* Corresponding author.
E-mail addresses: karl.atkin@york.ac.uk (K. Atkin), maria.berghs@york.ac.uk (M. Berghs), sdyson@dmu.ac.uk (S. Dyson).

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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); reconnecting 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, 2013). 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.

1. 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-

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[a]	Not Known (probably non-carrier)
John	36	Yes	Caribbean[a]	Not Known (probably non-carrier)
James	27	Yes	African (Sierra Leone)[a]	Sickle Cell Disease (SCD): prenatal
Matthew	20	Yes	Caribbean[a]	Non-Carrier: antenatal
Suleiman	42	Yes	African (Somalia)[a]	Carrier: postnatal – found out after second child (child SCD)
Joshua	32	Yes	Caribbean[a]	Carrier: prenatal (child CSD)
Isaac	31	Student	Caribbean[a]	Carrier: antenatal (child SCD)
Lewis	27	Yes/ Student	Caribbean[a]	Carrier: antenatal: (child SCD)
Ben	34	Yes/ Student	African (Uganda)[a]	Carrier: antenatal (child SCD)
David	32	Yes	African (Ghana)[a]	Non-carrier: prenatal (partner SCD)
Kwame	46	No	African (Ghana)[a]	Carrier: postnatal (found out after the third child with second partner)
George	35	Yes	Caribbean[a]	Carrier: postnatal
Jacob	44	Yes	African (Cameroon)[a]	Carrier: postnatal
Umaru	24	Yes/ Student	African (Nigeria)[a]	Non-carrier: antenatal
Iyabo	40	Yes/ Student	African (Nigeria)[a]	Carrier: antenatal (tested in Nigeria, wrong status, children SCD)
Ike	42	Yes	African (Nigeria)[a]	Carrier: postnatal (tested in Nigeria, wrong status/child SCD)
Mark	50	Yes	African (Nigeria)[a]	Non-carrier: antenatal (second partner)
Samuel	33	Yes	African (Cameroon)[a]	Carrier: antenatal (with second child)
Thomas	38	Student	African (Cameroon)[a]	Carrier: antenatal (second partner)
Ibrahim	37	Yes	African (Ivory-Coast)[a]	Carrier: postnatal (child SCD)
Mohammed	31	Student	Arab (Saudi Arabia)	Carrier: probably prenatal
Kingsley	37	No	African (Nigeria)[a]	Carrier: antenatal (child SCD)
Chika	42	Yes	Mixed (White/African-Nigeria)	Carrier: prenatal (child SCD)

[a] Black or Black British.