

The Perception of Parents with a Child with Sickle Cell Disease in Ghana towards Prenatal Diagnosis

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Abstract

Sickle cell disease is a global health concern. In Europe and USA, where the condition is common, prenatal testing is a routine aspect of antenatal care and offered on the basis, of informed reproductive choice. Notwithstanding considerable advances in testing technologies, prenatal diagnosis for sickle cell disease is not common in Africa. There is a particular lack of research examining parental perceptions about the acceptability of antenatal screening. This qualitative paper explores the perceptions of parents, who had lived experiences of caring for a child with SCD, towards prenatal testing for sickle cell in Ghana. A purposive sample of 27 parents (four fathers and 23 mothers), were recruited via a sickle cell clinic in Accra, Ghana. Material was collected using semi-structured interview, using a topic guide that explored parental views on prenatal testing, along with factors influencing decision making about antenatal care. The findings suggest parents lack knowledge about prenatal testing. However, the majority would accept testing should the process be available and affordable. Parents believed the decision to accept screening should be negotiated between both parents rather than the extended family. The decision to accept testing did not mean that parents would use the information to terminate a child with SCD. They were more likely to use the test result to prepare themselves for the birth of their child. Parents accepted, however, that choice was important and that some parents may wish to terminate, given the impact of SCD on a person's quality of life. The paper concludes that policy needs to establish and promote sickle cell prenatal testing awareness among at-risk populations, bearing in mind the cost implication of the technology and the importance of informed decision making, which connects to the parents' experience of screening.

Introduction

Sickle cell disorders (SCD), a recessive, life-threatening blood disorder has been identified as the most common global hereditary disorder (Tshilolo et al. 2019; Piel et al. 2017). Sickle cell disorders represent a global health challenge, which is particularly significant in a country like Ghana, where there is high incidence, but limited resources, and many competing priorities. It is estimated that almost one in four (25%) of the Ghanaian population have sickle cell trait. Two per cent of all babies born (20 for every 1000 live births) have a form of SCD (Asare et al. 2018; Dennis-Antwi et al. 2018). Comprehensive management of the disease has yet to be fully realised in Ghana. Many children with the condition are either not diagnosed or experience delays in diagnosis and therefore, may not receive timely medical care. Consequently, children with SCD living in Ghana continue to die at an early age (Ohene et al. 2011).

Prenatal diagnosis and antenatal genetic counselling services is commonly offered as part of State-sponsored healthcare in the Global North (Hill et al. 2017; Vass et al. 2019; Gaboon et al. 2017; Ishaq et al. 2012; Wonkam et al. 2011). The diagnosis of SCD (and sickle cell trait) can be made at different stages of the life course but antenatal screening of expectant mothers (followed by partner testing and if appropriate, prenatal diagnosis of the unborn child) is the ideal. The aim of antenatal testing is to facilitate reproductive choice (Hodgson and McClaren 2018; Raz et al. 2019; Gaboon et al. 2017), by identifying potential sickle cell trait carriers and determining whether an unborn child is at a risk of

inheriting SCD. Antenatal testing (and prenatal diagnosis) can arrest the rate of infant death by offering an early diagnosis and timely intervention or by offering the option of prevention and termination. Antenatal screening assumes particular significance in how countries attempt to manage genetic conditions such as SCD. The acceptability of screening is especially important when facilitating informed decision making. Consequently, policy and practice must appropriately engage with the perspectives of those on whom screening is focused (WHO 2020).

Ghana is currently introducing antenatal screening, and while there is an emerging evidence base, few studies locate this within the specific experience of Ghanaian society. When exploring antenatal screening and prenatal diagnosis, there needs to be consideration of relevant psychosocial factors. For example, the technical developments of prenatal diagnosis must be set against the ethical context, which questions the right to control the biological makeup of future generations of families at risk of disease (Gates 1993; Katz Rothman 1994), in addition to the social context, in which decision making is negotiated (Chen et al. 2015; Moyer et al. 1999). Beginning to understand these contextual factors and in particular, the relationship between mother and father, offers the basis of understanding informed reproductive decision making. In Ghana, for example, much importance is attached to the institutions of marriage and childbearing (Nukunya 2003; Luginaah et al. 2006; Dyer 2007), which like most societies are also underpinned by pronatalist and patriarchal assumptions (Adomako-Ampofo 2000). Inequalities also remain when accessing appropriate antenatal care (Gyimah et al. 2006; Bosu 2012; United Nations 2018), thereby potentially undermining choice. Consequently, given their potential significance in the success of any screening programme, there is a need to understand parents' views.

Methods

This qualitative study used face-to-face, in-depth, semi-structured interviews, to explore the perceptions of parents of children with SCD towards prenatal diagnoses in Ghana, as the basis for generating evidence-based screening policy and practice. Parents with children with SCD were interviewed, because of their experiences with the condition. The views on screening, therefore, would not be hypothetical but informed by lived experience. A constructivist approach was adopted, with the focus on attaining comprehensive accounts from participants, with a strong emphasis on investigating how they negotiated meaning and experience, when making sense of prenatal diagnosis (see Atkinson and Hammersley 1994). Purposive selection method was used as there is no available data of those who carry the trait or have children with SCD in Ghana. By working with two health care professionals, participants (twenty-three mothers and four fathers) were recruited from the sickle cell clinic at a hospital in Accra-Ghana. Participants were interviewed once, with interviews lasting between 35–45 minutes. The interviews were informed by a topic guide, developed by the researchers to assist with 'guided conversations' (Fielding 1993). Topics included 'knowledge and meaning of prenatal diagnosis' and 'decision making'. The topic guide was piloted before the main interviews. The selection of the study site, and parent participants were based on three conditions:

1. a well-established and coordinated sickle cell clinic;

2. willingness of the clinic to take part in the study; and
3. accessible patient records and parents.

Participants had to be a mother or father, who had at least one child with SCD, who was under five years old. Two health care professionals initially contacted parents when they attended a clinic appointment and gave them the study information sheet. Where parents could not read English, the study information was relayed verbally by the health care professional. The purpose of the research and expectations of participant involvement were explained. The contact details of parents who gave permission were given to the researcher, who then contacted the selected participants by telephone. The details of involvement were reiterated, and participants were contacted again after three days, and if they wished to take part, an interview was arranged, and initial informed consent was taken. For anonymity, pseudonyms have been used for all participants included in the study.

The researchers began the interview by ensuring that respondents understood the study, why they were being asked to take part, and what would be involved if they agree to involve themselves and reminded them that they could withdraw from the study at any time, without it impacting on their care. Participants were also made aware of how their data would be handled, and that the researcher would always respect their anonymity and confidentiality. All interviews were conducted by (MOA).

In total 35 mothers and fathers (including four couples) living in Accra were contacted for inclusion in the study. Eight individuals, however, did not attend arranged interview appointments. The eventual sample included 23 mothers and four fathers (two couples), with an age range of 26–45 years of age for mothers and 42–56 years for fathers. Twenty-five participants were interviewed at the clinic and two in their home. For a more detailed socio-demographic description of the participants see Table 1.

Table 1
The Study Sample: Socio-demographic description of parent participants

Participants (Pseudonyms)	Ages (in yrs)	Marital Status	Religion	Level of Education
Ama	37	married	Christian	JHS
Mary	26	married	Christian	HND
Maame	24	single	Christian	SHS
Kate	37	married	Christian	JHS
Victoria	39	married	Christian	Middle school
Ahisa	36	married	Muslim	Tertiary
Akos	26	single	Christian	SHS
Martha	46	married	Christian	Middle school
Esther	33	separated	Christian	SHS
Emefa	32	married	Christian	Tertiary
Omotola	43	married	Christian	JHS
Gina	35	married	Christian	Tertiary
Pat/Philip*	36	married	Christian	SHS
Vera	45	widow	Christian	None
Adowa/Yaw#	41	married	Christian	Tertiary
Pokuaa	43	married	Christian	Middle school
Obiriwa	38	married	Christian	SHS
Janet	42	married	Christian	Tertiary
Gladys	44	widow	Christian	Tertiary
Boatemaa	44	married	Christian	Middle school
Jennifer	42	married	Christian	Diploma
Serwaa	26	remarried	Christian	None
Sally Moi	37	married	Christian	SHS
Sam	56	married	Christian	GCE O' level
Philip/Pat*	42	married	Christian	Technical school
*# partners				
JHS (Junior High School); SHS (Senior High School); HND (Higher National Diploma)				

Participants (Pseudonyms)	Ages (in yrs)	Marital Status	Religion	Level of Education
Yaw/Adwoa#	45	married	Christian	GCE O' level
Abu	42	married	Muslim	A' levels
*# partners				
JHS (Junior High School); SHS (Senior High School); HND (Higher National Diploma)				

GCE O' (General Certificate of Education, Ordinary) A' (Advance).

The initial plan was to recruit a sample of diverse faith and religious beliefs (i.e., Christianity, Islam, and African Traditional). However, due to time constraints this was not possible. A diverse selection of people was initially approached (including five Muslim couples). Nonetheless, for various reasons, these interviews did not happen. Fathers were also difficult to engage with and seemed reluctant to be interviewed; this is a known problem (see Atkin et al. 2015). This left the team with a predominantly female Christian sample. Whilst this does not invalidate the study findings, it needs acknowledging, when interpreting the findings (see Schofield 2002). As mentioned, the study intentionally focused on parents, who had a child with SCD. This grounded the study in the lived experience, but having such an understanding of SCD, could impact on parents' choices. We explore this below. It should also be remembered that prenatal diagnosis for SCD was not widely available in Ghana. Participants, therefore, were not familiar with the process; and had to be given information on it during the interviews (see below). Where possible our analysis has attempted to contextualise their findings within the broader literature, as the basis of exploring the representativeness of what they present and in particular, as a way of avoiding essentialisation of participants' experience.

The study received ethics approval from the Institutional Review Board of a Teaching Hospital where the study took place, in Accra, Ghana (Ref: 37MH – IRB IPN 007/2014) and a Departmental Ethics and Governance Committee at the University of York.

Interviews were audio-recorded. Those conducted in Twi (Ghanaian Language) (n = 9) were translated into English. All interviews were transcribed. The transcribed interviews and field-notes, written by the researcher shortly after ending the interview, formed the basis of analysis. Some a-priori codes were established from the interview schedule and observation template, but detailed coding was developed through iterative retrospective analysis. Initial empirical analysis focused on generating themes and establishing the number of times a characteristic pattern emerged from the accounts given (Braun and Clarke 2006). Unique categories and subcategories were developed and given labels which were then related to a theme. The researchers continued organizing and improving the categories and subcategories for each theme, which were further contextualised relative to each other. This process generated theoretical constructs, which informed the basis of our findings, which make sense of the context in which decision making and prenatal diagnosis occurs. Findings present participants' accounts on negotiating reproductive decision-making in the context of Ghana, and specifically explore the

influence this understanding may have on future reproductive choices, including the acceptability of antenatal screening.

Findings

Reproductive decision making

Mothers and fathers agreed on the normative importance of having children. Parents felt there was strong societal expectations to reproduce and that their extended family and the wider social network would think it odd, if they did not have children. The priority giving to having children is not unique to Ghana (see Atkin et al. 2014). Nonetheless antenatal screening policy is required to engage with these strong pronatalist assumptions, particularly in how parents negotiate reproductive choices. Fathers expected to be included in the reproductive decision-making process. They believed that men should initiate the discussion on reproductive choice, in their role as the head of the family, which included decision making on childbearing and more specifically prenatal testing for SCD. It fulfilled their normative sense of responsibility (and authority) for their family. It was also seen as supportive. Sam, who had lost two children with SCD and has one surviving 4-year-old with SCD, offered a common explanation:

The man has to make the decisions and then tell the wife that these are our problems. You the man must make the decision, and secondly, call your wife and tell her (...) you the man will have to say, let us go and test to know the status before we can carry on.

Men are, therefore, important gatekeepers, but there is (a potentially contradictory) nuance to this, in which responsibility and support become juxtaposed. All fathers shared the view that as a responsible husband, your decision should not be final and any decision on screening must be negotiated with their partner (see Kaufman, 2004 who identified a similar tension). Fathers, therefore, expected their authority to be respected, while acknowledging the importance of joint decision making. Yaw who has lost one child with SCD, and has a 4-year-old with SCD, remarked:

When it comes to such decisions, we both make that decision. We at least put our heads together and decide, knowing the pros and cons, and the likelihood of what is ahead so we draw a line, and we go ahead.

Philip, when further reflecting on his role as head of the family, believed mothers should have the final say on any testing:

Because she will be carrying the child, so if I say she should go and do the test and she say 'no', I can't say anything. Because I cannot drag her to the hospital to go and do the test, so she needs to give her consent.

The majority (21) of mothers agreed that joint-decision making was important and expected full involvement in any decision about screening during pregnancy. Gina, who had three children, two of

whom have SCD, remarked:

Well, every decision concerning us; as the children, my husband and I, are between me and my husband. We usually talk over things that concern us a lot, and there is always a common understanding (...) so, we always decide together, and to help one another. That is how we can get the family going and supporting the children as much as we can. We are very much together as husband and wife.

Emefa whose eldest child had SCD, agreed:

The two of us; I and my husband make such decisions (...). Again, it is going to be the two of us. We must come into agreement on it. I believe if it's available, my husband will gladly accept it to be done.

However, two of the mothers said that their understanding (and experiences) of their child's condition, meant that they would take informed reproductive decision making 'into their own hands' irrespective of any decisions they may reach with their spouse. One of the mothers, Agnes, who has two children with SCD, for example, confirmed during the interview that she has been using family planning measures without her husband's knowledge. She was determined to prevent any further pregnancy, even if the husband insists on having more children.

When negotiating decisions about screening, most fathers and mothers felt there was no need to involve their extended family, as suggested by some African studies. Only one parent (Yaw) felt it wise to consult with the wider family, particularly as they may be involved in offering care, if a child had SCD:

You take one decision as a family, everybody is considered in decision making, because if something happens it's not only me, yes as a family, and even as friends, and even the church, we put all those into consideration.

This was the exception, and these three responses were more typical:

No, I don't think so. It should be between my husband and I, no one else matters. Yes, it has to be between me and my husband to take that decision (laughs)" (Obiriwaa)

Nobody, it's about us, yes, it's our life and future. (Emefa).

No! (...) It is all about us and the children. It is our problem, and we must handle it the way we want, and we are happy about it. We are close as a family, but we try not to involve them as much as possible". (Gina).

The negotiation of reproductive decision-making means successful screening needs to be sensitive to diverse responses. Men are important gatekeepers, who expect their authority to be expected, but women are equal partners and, in some cases, expected to make decisions, without consulting their partner. The influence of the extended family was not great, although this may be explained by the urban setting of the study. Nonetheless, mothers and fathers regarded decision making about testing as a private matter

that was between them and their spouse. There was, however, another important influence on the exercise of choice. This included parents' understanding of the condition and the procedures to identify it.

Understanding of Prenatal Diagnosis

Most parents were not aware or had any prior knowledge of prenatal diagnosis, except for one father, who had worked outside Ghana. This is perhaps understandable as prenatal testing for SCD was not routine at the time of this study and few parents knew about the options available. Mothers, such as Jennifer, felt they did not have any option other than to have their baby: *'I got to know after birth, that my baby had SCD. I felt this was too late'*. Another mother, Ama on realising how common SCD was in Ghana, expressed surprise about the lack of options: *'Do we have it in Ghana? (SCD) Then we are dead'*. Following this initial questioning, prenatal diagnosis was explained to all the participant as part of the interview process. This was to ensure some level of understanding, to facilitate a meaningful discussion. Once explained to them, parents expressed enthusiasm for antenatal screening and prenatal diagnosis. All felt it was an aide to reproductive decision making. Parents did articulate concerns about the implications of passing on the condition to their unborn child, although two distinct responses emerged. These reflected quite different reasons for the acceptability of screening.

By far, most parents, said they wanted to have testing to enable them to prepare for having a child with SCD. They did not, however, associate this decision making with possible termination. Sally-Moi, like many mothers, believed that prenatal testing would be reassuring, as you would know the outcome of the pregnancy:

So, if I can get to know from the beginning, before the baby is born then I would not be that worried, because I will know of it in advance.

This was a common view among fathers too. Few would use a prenatal diagnosis of SCD to terminate their unborn child. Pat, who had one child with SCD and was planning for another child, said:

So that if I know it; I will prepare myself. If you see it is negative, you prepare yourself and if it is positive, you also prepare yourself. During counselling, the nurse told us that it is better to know it from the beginning to start treatment, than it being late and having an attack before you know. If I do the test and know what it is, then I can start preparing.

Parents also pointed to the benefits of early diagnosis, for treatment, which they felt was not available for their other children with SCD. A few parents, however, overestimated advances in current treatment or its availability on Ghana. Emefa, for example, claimed that a vaccine can be given, should the test be positive, and that when born, the child would have SCD, but not have a painful crisis. Parents' experience underlines the importance of discussions about the potential consequences of the condition, along with available treatments, when offering screening. It is important part of their decision making.

A minority of parents advocated screening and prenatal diagnosis on the basis it offered the possibility of termination. Victoria was one of the few parents, who would consider a termination following a

prenatal diagnosis of SCD. She talked about the importance of avoiding the 'pains and suffering':

Meaning if it was available, you will know it early that it is this, and that you will decide early to have the baby or not, instead of the baby being born and suffering after. So that all of that will not happen, so it is good. If it were available earlier, we would not have suffered like we are doing now.

Several other parents also felt the availability of prenatal testing could be used to prevent the 'suffering' associated with having a child with SCD. Abu, who was not sure if he would terminate an unborn child with SCD, nonetheless, he felt it important to have the option.

Yes, to make sure this child I am giving birth to, this is the blood group (sickle cell status); if I accept it, then I must prepare for the consequences. Because I have had one already and I know the sort of pain the first one went through. It will be left for both of us to decide if we should plan something else, rather than keeping the pregnancy for the benefit, and to avoid the pain that the child will go through if given birth to.

In considering termination, parents made judgements about the potential clinical severity of the condition, along with the life opportunities available to someone with SCD. This again suggests the importance of parents having access to informed discussions about the clinical and social consequences of having a child with SCD.

The use of antenatal genetic testing to either prepare for the birth of a child with SCD or to use the information to consider the possibility of termination, represent generic parental responses, irrespective of culture context (see Hodgson and McClaren 2018; Boardman 2017). They are not peculiar to Ghana. Cost, however, was identified as a more 'local' problem. Most of the parents, although willing to have prenatal test, expressed concerns about affordability. The cost, therefore, deterred many parents from having the test and was seen as a particularly important barrier in facilitating choice. Sam said:

I think the doctors must do something about it. If you are not financially sound, it would not be easy to have it. But it will be good to go for it.

Some parents may not have the test, should it be available. Mary, who has one child with SCD, indicated, that she initially thought testing was a good idea. She, however, changed her mind during the interview and believed prenatal diagnosis was dangerous, as one could lose the baby during the process. Again, this provides further argument for information and counselling, as there is indeed a risk to the unborn baby. Gina who was pregnant when interviewed and had two children with SCD expressed reservations about the possible anxiety of knowing your unborn child had SCD. It was, therefore, best not to know. Several other parents expressed similar concerns. Parents like Gina preferred to having testing when they child was born (neonatal testing):

But not when the child is in my womb (...) it's good, it's good in a way, but it can make one very anxious, (...) depress, and it can make one sad, especially when it turns out that the baby you are expecting is SS. (...), because for now, I don't know. So, I am going about my things normally (laughs). You see, I don't know, and I feel okay. I think the prenatal testing can depress a woman in her state of pregnancy.

Yaw would not want to know the sickle cell status of an unborn child, but perhaps for more complex reasons. He expressed concerns that his decision to keep the child, may conflict with his wife's view:

I will not go for it in one area, until may be my wife and I have agreed on one thing. That whether negative or positive, we will hold up to what decision we must hold. If she agrees well, it will help you to prepare your mind and get you ready for the task ahead.

Although when questioned further, he expressed concerns that doctors may advocate for termination if they knew the child had SCD:

So, it means, why won't I wait when it comes? There is a saying that when you get to the bridge, we shall surely cross. When it happens that the child comes, and the after-birth test is done, whatever it is then we put necessary measures in place and go on.

These concerns have been expressed in other parts of the world, such as the UK (See Ahmed et al. 2006) and articulate a tension when negotiating informed choice, relative to biomedical assumptions about a 'healthy' birth. Jennifer who was initially enthusiastic about prenatal testing, begun to change her mind during the interview. She would prefer more emphasis on the education about SCD, so people with sickle cell trait do not get married and have children with the condition. This found favour with some other parents too, suggesting this is a preferable strategy to antenatal screening. Other parents identified a value of having a multi-faceted approach involving testing and broader community education.

Parents are aware of the challenges of caring for a child with SCD. They are also aware of the difficulties a child may face when growing up with SCD. This partly explains their support for prenatal diagnosis. While few parents said they would terminate an unborn child with SCD, they felt the option should be available because of the impact of SCD has on quality of life. To some extent this may reflect their personal experience of SCD and attachment to a child with the condition. Their experience, however, did not suggest they considered SCD a condition that required termination. Having the option, however, was supported. Parents' accounts suggest available care could also be an important consideration when making reproductive choices. This raises the possibility that better prospects for someone living with SCD may have an impact on parents' willingness to accept prenatal diagnosis. This highlights how societal context can mediate individual decision making, which must be balanced against the value of having children in Ghanaian society. Parents sometimes struggled with this tension.

Discussion

This is the first qualitative investigation to explore the perception of Ghanaian parents, who have a child with SCD, towards prenatal diagnosis. It is accepted that individuals, choosing to undertake antenatal screening (PND) for any genetic condition, should have access to information, along with a supportive social context (Brown et al. 2011). People find it challenging to appreciate risks and in applying such information when making reproductive decisions (Timmermans 2005). Our parental accounts confirmed this.

Antenatal testing is generally acceptable to parents, although lack of knowledge is evident. Most parents perceived prenatal diagnosis as a possible option for knowing the sickle cell status of their unborn baby. The study also found that most parents would accept a prenatal test, should it be available and affordable, as they felt it would enable them to make informed reproductive decisions. Parents wanted prenatal testing to be instituted in Ghana, although they acknowledged that current costs represented an unacceptable barrier to accessibility. Parents carrying the sickle cell gene, predisposing children to SCD, were concerned about transmitting the gene mutation to their children. This is consistent with other research (see Quinn et al. 2009; Fortuny et al. 2009), although the parents did not necessarily associate this concern with prevention. The experience of SCD meant they emphasised the value of prenatal diagnosis for facilitating early treatment, when the child is born. They also spoke about the importance of using prenatal diagnosis to help prepare for having a child with SCD. Few would use the information to terminate a child (also see Ahmed et al. 2006; Lakeman et al. 2008). Understanding the consequences of SCD along with the opportunities available to a child with SCD do influence the decision-making process. Parents, for example, may consider termination, because of their perceived impact on a child's quality of life and of the perceived societal valued placed on having 'healthy' children. This highlights the complex ethical and emotional framework in which choice is realised (see Hodgson and McClaren 2018).

Parents, who objected to prenatal diagnosis, felt that knowing they were carrying a baby with SCD, would cause too much anxiety (see Bombard et al. 2010). Some also feared losing the baby during the procedure and would prefer the baby to be tested at birth. Parents appreciated provision of straightforward information telling them about the options available; the consequences of SCD; and the risks involved in screening. This they felt, would enable them to make an informed decision, while encouraging a positive view of screening. Currently, parents expressed various misconceptions, particularly about possible treatment, which policy and practice would need to challenge. There is, however, no widespread opposition to screening, nor any particularly cultural barriers to successful take up. However, this does not necessarily resolve the more ethical challenges presented by screening within a Ghanaian context, in which parents recognise the challenges of caring for a child with SCD and the difficulties of establishing future opportunities for them. This is a further reminder that informed choice is not simply about the provision of information (see Atkin et al. 2015).

The findings highlight the complexity and diversity of reproductive decision-making among parents (see also Brown et al. 2011). Screening services would need to take this into account. Factors such as: good information; parental experiences of caring for a child with SCD; current healthcare management of SCD in the context of Ghana; the normative value of children; and issues of normative male gatekeeping, were seen to influence reproductive decision making. Our findings suggest possible interventions likely to facilitate informed decision making. Developing awareness of prenatal diagnosis is an important starting point and ensuring discussion about prenatal diagnosis becomes part of public discourse, with the aim of generating a familiarity with screening. More general awareness, for example, would help parents be aware of the possibilities of screening before becoming pregnant, rather than having to decide, with little prior knowledge or understanding, at a later stage in the pregnancy. It is recommended, therefore, for policy makers in Ghana to consider a public education approach on screening, emphasising its value in

facilitating informed choice, before conception and during pregnancy, in addition to more public awareness about SCD. This might be a more appropriate political strategy in which the individual is empowered to make choice rather than one seemingly prescribed by the government.

Any education strategy may have to tackle misunderstandings, while also engaging with how inequalities may mediate the process of generating greater awareness. Inclusion is key and will include focusing on rural as well as urban settings, in addition to ensuring social-economic disadvantage does not become the basis of social exclusion (see Dyson 2019). Educational strategies may also need to engage with the different roles of men and women in reproductive decision making, along with the broader social and cultural values associated with pregnancy. This is challenging and is likely to require the Ghanaian Government working with civil society, including religious and faith organisations, which may have some legitimacy, when discussing reproduction. Consequently, to be successful, any programme would need to work with how people give meaning to their lives.

In conclusion, parents have no objections to prenatal diagnosis, and many believe it is of value. This acceptance, however, is contingent and negotiated. Cost of testing is an issue, along with the emotional impact the offer of testing may bring. Parents may also lack information and understanding to make an informed choice. Policy must acknowledge broader social influences, in which the individual makes reproductive decisions. These findings suggest future policy should focus on improving the knowledge and understanding of parents. This would empower them and reduce their anxieties. The cost of testing should also be reasonable, if not free, in order not to prevent people from undertaking the test.

Declarations

Conflict of interests:

Menford Owusu Ampomah, Karl Atkin, and Kate Flemming declares that they have no conflict of interest.

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

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Authors contributions

Menford Owusu Ampomah (MOA) conducted the study from conception to completion. Karl Atkin (KA) and Kate Flemming (KF) supervised the study from conception to completion. Karl Atkin and Kate Flemming also contributed with the appropriate methods and discussion of the results, and critically reviewed it for important intellectual content. Menford Owusu Ampomah, Karl Atkin and Kate Flemming approved of the final version for publication.

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Compliance with Ethics Guidelines

Ethical approval:

The study received ethics approval from the Institutional Review Board of a Teaching Hospital in Accra, Ghana (Ref: 37MH – IRB IPN 007/2014) and a Departmental Ethics and Governance Committee at the University of York.

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

Consent to participate

Informed consent, both written and verbal, was obtained from all individual participants included in the study, prior to the interview.

Consent to publish

Not applicable

Data availability statement

The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request with participants permission.

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