PAPER

Would you terminate a pregnancy affected by sickle cell disease? Analysis of views of patients in Cameroon

Ambroise Wonkam,1,2 Jantina de Vries,2 Charmaine D Royal,3 Raj Ramesar,1 Fru F Angwafo III4

ABSTRACT
Sickle cell disease (SCD) is a debilitating illness that affects quality of life and life expectancy for patients. In Cameroon, it is now possible to opt for termination of an affected pregnancy (TAP) where the fetus is found to be affected by SCD. Our earlier studies found that, contrary to the views of Cameroonian physicians, a majority of parents with their children suffering from SCD would choose to abort if the fetuses were found to be affected. What have not yet been investigated are the views of people suffering from surviving with SCD. We used a quantitative sociological method, with administered structured questionnaires, to study the attitudes of adult patients suffering from SCD on prenatal genetic diagnosis (PND) and possible TAP. The majority of the 89 participants were urban dwellers (84.3%), women (57.3%), Christian (95.5%) and single (90.9%), with a secondary/tertiary education (79.5%). The majority (89.2%) would consider PND for SCD; almost half (48.5%) would reject TAP while 40.9% would consider it. Respondents who rejected TAP claimed mostly ethical reasons (78.1%) while those who found TAP acceptable cited fear of having an affected child (88.9%) and the poor quality of the affected child’s health (81.5%). Cameroonian patients with SCD are generally supportive of PND and a remarkably high number of patients living with SCD reported that they would consider terminating a pregnancy based on their assessment of the future well-being of the child. Research is required to investigate the burden of SCD on families and their quality of life.

INTRODUCTION
Sickle cell disease (SCD) is a monogenic condition, where a dual copy of the variant (ie, homozygote) results in severely malformed red blood cells. People carrying only one copy of the HbS variant and one ‘normal’ haemoglobin gene (the heterozygote) do not have SCD and may in fact be better protected against other diseases such as malaria.1 People with SCD (eg, homozygote HbSS) can suffer from anaemia, painful episodes, susceptibility to infection, stroke and chronic organ damage (kidneys, lungs, heart and brain).2 There is currently no cure available for SCD, but the condition can be managed using a variety of therapies. This can extend life expectancy to about 45 years.3 When the condition is not managed, patients tend to die in early childhood as is the case in many countries in Africa.4 In developing countries, it has been estimated that haemoglobinopathies alone represent a health burden comparable with that of all communicable diseases combined.5

Cameroon has a population carrier (HbAS) frequency of 8–34% with 1.6% incidence at birth.6 The country has about 20 million inhabitants and has no universal medical insurance coverage. Although Cameroon has developed a national control programme for SCD, this remains largely unimplemented and care for SCD patients is still woefully inadequate. Specifically, there are not yet specialised centres for SCD in the public sector and the routine treatment regimen is often limited to analgesics, anti-bacterials, anti-malarials, blood transfusions and intravenous fluids, when needed. The recommended penicillin prophylaxis for children, targeted vaccine programme and provision of hydroxyurea that greatly improves morbidity and mortality in some cases are seldom provided to SCD patients.

It is possible to test for sickle cell homozygosity (HbSS) before birth, and in fact prenatal genetic diagnosis (PND) represents one type of preventive strategy, as it offers reproductive options to at-risk parents.7 In this article, we use the abbreviation ‘PND’ to indicate prenatal genetic diagnosis. We avoid use of the abbreviation ‘PGD’ as this acronym is frequently used to refer to preimplantation genetic diagnosis used when embryos are fertilised outside of the body and desired ones implanted. This is not the topic of our article. PND provides parents with a reproductive option to test at-risk pregnancies and make decisions regarding medical abortion, which we will call termination of an affected pregnancy or TAP in the remainder of this article.

Abortion in Cameroon
Legal bans on abortion exist in virtually all African countries8 and medical abortion when allowed is often restricted to direct threats to maternal health. For instance, under Cameroonian law, although voluntary abortion is a criminal offence, medical abortion is permitted “…if it is done by an authorised professional and justified by the need to save the mother from grave health jeopardy” (Act 339; exception 1; the Cameroonian Penal Code). Fetus pathology like SCD is not considered and abortion of affected fetuses would therefore be illegal. Nonetheless, in lower income countries like
Reproductive ethics

Cameroon neither the healthcare services nor families can afford to pay for the long-term treatment of SCD. This raises important ethical questions regarding the desirability of TAPs.9

PND and abortion for SCD in Cameroon

In previous work, we demonstrated that despite a low acceptance (36.1%) of TAP for SCD by Cameroonian physicians10 up to 95% of Cameroonian parents of children with SCD would request PND and 65% would opt for TAP.11 The high demand from parents opened an ethical debate on the introduction of PND for SCD in Cameroon. Various discussions involving medical professionals, SCD patient associations and the national ethics committee of the Ministry of Public Health discussed the conflicting challenges between the parents’ needs, medical doctors’ views and the legal restriction. In one of the public debates on PND for SCD, some opponents to PND of SCD argued that SCD-affected fetuses were viable human beings and that a SCD-affected pregnancy does not challenge the health of the pregnant mother. However, drawing on the background of traditional African moral sensibility and sensitivity, a Cameroonian bioethicist had previously argued that embryos do have human status and that a morally significant line cannot be drawn between human embryos and other human beings.12 Moreover, based on the WHO definition of health that does not just include diseases or disabilities, those who favoured introduction of PND argued that the social and psychological health of a mother with a pregnancy at risk for SCD could be considered to be in jeopardy, since up to 21.4% of Cameroonian at-risk mothers disclosed an illegal voluntary abortion for fear of producing another SCD-affected child.11

Although the ethical debate is ongoing, it was decided that PND for SCD, with the necessary non-directive careful genetic counselling to women and couples, was compatible with African moral values and Cameroonian law requirements. PND for SCD was initiated in Cameroon in August 2007.13 14 In actual practice, to date 90% of parents with SCD-affected pregnancies elected for medical abortion.15

Views of SCD patients on prenatal diagnosis and abortion

It is clear in Cameroon that many parents currently caring for a child with SCD opt to abort a fetus that is also suffering from SCD. What has not yet been investigated is whether people suffering from or living with SCD would also elect to terminate an affected pregnancy. To date, little work has been done in Africa to investigate patients’ attitudes towards preventive genetics of SCD, including attitudes to possible TAP. To the best of our knowledge, the only data available are those reported almost two decades ago in Nigeria, where more than 85% of female patients would like PND for SCD to be offered in Nigeria; but only 35% of the patients would like the same.16 To date, no study has been conducted in Cameroon about patient views. With ongoing improvements in medical care, it could be anticipated that a lower proportion of parents will request PND and TAP11 and SCD patients in Africa will live longer and reach reproductive age and will constitute an influential group in society. Their views are critical to the development of appropriate policies involving PND and TAP for SCD.

Purpose of the present study

We examined the attitudes of a sample of Cameroonian SCD patients towards PND and TAP. There were two major research questions: (1) whether they agreed with PND and pregnancy termination in general and (2) whether they agreed with PND and TAP for SCD and the reasons for their attitudes.

METHODS

Design

This research was a quantitative social science study with structured administered questionnaires. A detailed description of the study methods was reported elsewhere.11 The quantitative method was chosen to allow inclusion of a large number of adult patients within a limited time period. This method also allowed a reasonable comparison with previous studies among Cameroonian parents and doctors, where the same approach was applied.10 11 For the purposes of this article, we only provide a summary of the study methods.

Sample population and eligibility criteria

The sampling methods used included both purposeful sampling and convenience sampling. In an attempt to ensure inclusion of adult SCD-affected patients reflecting the entire spectrum of severity in this illness, we issued a call for participation using national Cameroonian media. We also approached two SCD patients’ associations in Cameroon. Participants needed to be at least 18 years old with a diagnosis of SCD that was confirmed by a laboratory documentation of haemoglobin electrophoresis in the medial record of each participant. Patients’ medical records were also reviewed to delineate their clinical and biological features.

Questionnaire format

The data were collected by means of a structured questionnaire consisting of three sections of closed-ended questions. These were (1) sociodemographic characteristics; (2) attitudes towards adult SCD-affected prenatal diagnosis and TAP if the participant’s unborn child was proven to be affected. Response options were ‘Yes’, ‘No’ or ‘Undecided’. A pilot study with four selected participants was conducted to establish whether the items on the questionnaire were easily understood.

Research setting and data collection

The study was conducted at the Yaoundé Central Hospital. An introductory explanation informed patients of the purpose of the study. Informed consent was also obtained at this stage. In addition to the introductory explanation, each patient was given full non-directive genetic counselling with neutral information concerning PND and its reproductive options. Images were used to explain the obstetric procedure of PND and risks (specifically 1% induced miscarriages). Information on the available therapeutic options and follow-up for patients with SCD was reviewed and the participants were given an opportunity to ask questions. The information provided during this counselling session was equivalent to the information that prospective parents would have received had they been seeking PND for SCD.

Face-to-face questionnaires were administered immediately after the counselling session in a private consultation room by two investigating physicians: a medical geneticist and a general practitioner. Due to the sensitive nature of some questions, a follow-up visit was proposed if the participants felt it was needed. None of the patients requested this option.

Data analysis

Data were analysed using SPSS, V17.0 (Statistical Package for Social Sciences, Chicago, IL, USA). Descriptive statistics were used to measure proportion, mean or median of participants’ variables. Because of the non-random sampling, relationship
between two or more variables was evaluated by non-parametric tests (H test of Kruskal–Wallis or Z test of Kolmogorov–Smirnov, when applicable). The p values were considered significant if they reached 95%.

RESULTS

Sociodemographic characteristics

A total of 89 patients agreed to participate in the study. The majority lived in urban areas (84.3%), were women (57.3%), 20–30 years old (73.1%), Christian (95.5%), single (90.9%) and unemployed (84.3%), with a secondary or tertiary education (79.5%) (table 1).

Pedigree analysis

Up to 16.8% (n=15) of the participants had at least one sibling also living with SCD. About one-third of the participants (29.6%, n=23) indicated that one or more of their siblings had died due to causes believed to be related to SCD, and 31.8% of the patients (21/66) reported that there were also one or more children affected with SCD in their extended family.

Clinical and biological features of our patient participants

The clinical profile of participants indicated that they suffered from (relatively) severe forms of SCD. Indeed, only 17.9% (n=5) of patients were diagnosed before 24 months of age; the median age at diagnosis was 100 months (8.3 years; range: 6–360 months). Late diagnosis is associated with more severe forms of the disease; indeed, about half (50.7%, n=36) of the patients reported more than three painful crises per year over the past 5 years (median value of 4 a year, range 0–30). The majority of patients had attended the hospital at least once a year over the past 5 years (60.9%), the median hospital attendance was 4.5 visits a year (range 0–54) and 71.8% of participants had been admitted at least once over the past 5 years. The median for hospital admission per year was 2.5 (range 0–30).

The majority of research participants received poor treatment for their SCD. Only 4.4% of participants received the only treatment currently available to manage SCD, hydroxyurea treatment. Nearly 90% (89.7%) had received traditional medicine for their conditions on at least one occasion in the past, which could indicate a failure on the part of the healthcare system to offer appropriate care for these patients. All of our research participants had received an analgesic in the past, 97.1% an anti-bacterial treatment, 70.6% a blood transfusion and 89.7% an intravenous fluid, indicating some clues regarding economic burden on family finances in the absence of universal medical insurance coverage.

As indicated by their blood scores, all of our research participants were anaemic (7.9±1.5 Hb g/dL) with a high white cell count (15.3±5.5×109), both of which indicate a poor prognosis.

Cost of medicines

For the 15 participants who could report their income, the mean direct income was about US$165.3±151 per month. Patients (n=59) reported a mean cost of medicines of US$67±120 per month, representing 40% of mean direct income.

Attitudes and practice regarding SCD screening in families

Patients with SCD were very supportive of preventive genetic practice as evidenced by the fact that 84.4% of our participants indicated that they supported genetic counselling. Moreover, all of them (100%) supported premarital screening, retrospective cascade screening (90.3%, n=65), antenatal care systematic screening in pregnant women (91.4%, n=64) and neonatal screening (97.1%, n=68); all of which could lead to prevention of SCD.

Attitudes about SCD PND and TAP

The majority of patients supported the general principle of prenatal diagnosis (96.5%, n=85) and termination of pregnancies in general (53.0%, n=47) (figure 1). However, when we questioned participants about PND and TAP for SCD specifically, a significantly lower proportion (p<0.01) of interviewed patients accepted the principle of PND for SCD (88.2%, n=79) and medical termination of an SCD-affected pregnancy (40.9%, n=36) (figure 1). However, 40.9% acceptance of the principle of TAP for SCD is remarkably high, as these patients living with SCD reported that they would consider terminating a pregnancy of a fetus that has the same condition as themselves. The acceptance of the principle of medical termination for SCD was not influenced by age, gender, religion, marital or unemployment status, number of affected siblings and affected family members in the extended family.

Reasons for attitudes about SCD PND and TAP

We examined responses specific to patients willing to accept PND for SCD (88.7%, n=63) and responses specific to those willing to accept TAP for SCD (40.9%, n=36). For both groups, negative personal life experience of SCD, fear of having an affected child, fear of the poor quality of the child’s health, ‘ethical’ issues (without any further specification) and economics were the main reasons given to explain their attitudes

<table>
<thead>
<tr>
<th>Table 1 Patients’ sociodemographic characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Characteristics</td>
</tr>
<tr>
<td>-------------------------------------------</td>
</tr>
<tr>
<td>Patients (N=89)</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Urban dwellers</td>
</tr>
<tr>
<td>Age categories (years) (N=89)</td>
</tr>
<tr>
<td>Median: 23 years (range: 18–47)</td>
</tr>
<tr>
<td>18–20</td>
</tr>
<tr>
<td>21–30</td>
</tr>
<tr>
<td>31–40</td>
</tr>
<tr>
<td>41–50</td>
</tr>
<tr>
<td>Marital status (n=73)</td>
</tr>
<tr>
<td>Married</td>
</tr>
<tr>
<td>Single/informal</td>
</tr>
<tr>
<td>Marriage type (n=13)</td>
</tr>
<tr>
<td>Monogamous</td>
</tr>
<tr>
<td>Polygamous</td>
</tr>
<tr>
<td>Religion (n=66)</td>
</tr>
<tr>
<td>Christian</td>
</tr>
<tr>
<td>Muslim</td>
</tr>
<tr>
<td>Traditional*</td>
</tr>
<tr>
<td>Level of education (n=70)</td>
</tr>
<tr>
<td>No formal</td>
</tr>
<tr>
<td>Primary</td>
</tr>
<tr>
<td>Secondary</td>
</tr>
<tr>
<td>University</td>
</tr>
<tr>
<td>Employment status (n=81)</td>
</tr>
<tr>
<td>Employed</td>
</tr>
<tr>
<td>Unemployed</td>
</tr>
</tbody>
</table>

*Traditional refers to practice of indigenous African ancestral cult.
(figure 2A). The most frequently cited reason to support PND and TAP was negative personal life experience of SCD, followed by fear of having more affected children, fear of the poor quality of the child’s health, respectively, and to a significantly lower extent, economic reasons (p<0.01).

Patients rejecting TAP (48.5%, n=43) claimed mostly ethical (78.1%) and religious considerations (45.5%). Interestingly, ethical reasons were cited by the majority to justify TAP (61.5%) as well as to reject it (78.1%) (figure 2B). We did not unpack the category ‘ethical’ with our research participants; this would be an important component of future work.

DISCUSSION

As far as we are aware, the present study is one of the first attempts in sub-Saharan Africa to explore patients’ attitudes towards prenatal diagnosis of SCD and TAP.

The patient participants in this study indicated a surprisingly high (40.9%) rate of acceptability of TAP. This is surprising as one could argue that a decision to terminate a pregnancy where the future child would suffer from the same condition that is affecting the parent seems to imply a value judgement about the individuals’ quality of life. Patients who participated in this study presented with severe forms of SCD. We wonder whether our results mean that approximately four out of 10 of the patients included in this study had such poor quality of life that they did not find their lives worth living and did not want their child to have the same experience. This is a disturbing finding that requires further attention of policy makers and medical professionals in Cameroon.

Our finding may well reflect the failure of professional stakeholders to provide adequate care services to patients with SCD in Cameroon. For instance, the late average diagnosis of the condition in our participants leads to greater clinical severity. In addition, the very low number of people who receive adequate medical care (including pharmacotherapy) to manage their condition, as well as the large number of people who received traditional medicine, may also indicate the failure of medical professionals in Cameroon to adequately manage SCD. Many patients with SCD require the expertise of specialised centres. Lifelong medical care and surveillance are not yet available in Cameroon, where provision of healthcare services is hampered by major economic and organisational and infrastructural difficulties.

In developed countries, newborn screening with appropriate follow-up and care of affected children in specialised centres has resulted in a reduction in the SCD mortality rate from 16% to <1%. Similarly, in the Republic of Benin, following neonatal screening, counselling and follow-up, the under-five mortality rate was 15.5 per 10,000, a figure 10 times lower than the general rate recorded. Unfortunately, the national control programme for SCD in Cameroon has remained a policy document without implementation. This could also explain the strong positive attitude by most patients towards SCD screening policies. A similar finding was reported in Jamaica more than 20 years ago, where 83% of female patients considered SCD a very serious disease to have, 94% would want PND available and 30% would elect for TAP. It could be interesting to perform a similar study in Europe or in the USA or in African countries with better SCD care, such as Benin, to explore whether a similar number of well-treated SCD patients would also consider TAP. It is possible that with better care, people would be less inclined to embrace TAP, while the failure or inability of medical professionals to offer appropriate care for SCD patients in Cameroon could contribute significantly to our finding that SCD patients may not consider their lives worth living.

On the contrary, the finding that six out of 10 patients would not opt for TAP despite their acceptance of PND could be seen as patients expressing a positive value judgement about their own lives—that is, that they are worth living. Alternatively, some patients might not consider SCD severe enough, with appropriate medical care, to warrant pregnancy termination. Unfortunately very few patients had benefitted from appropriate care to allow meaningful evaluation of their viewpoints as compared with patients whose conditions were not managed. Further investigation of participant/patient experience of the healthcare system with regard to their SCD would be worthy of further follow-up. Interestingly, the rate of acceptance of TAP among patients is considerably lower than that of parents of a child affected by SCD and slightly higher than that of physicians. We found in a previous study that close to two-thirds of parents with affected children reported that they would accept TAP for SCD.
explained by the perceived severity and experiences of affected patients and the psychosocial and/or economic impact of SCD on families. Yet fewer people living with SCD themselves would also terminate a pregnancy. Although this finding needs more substantive investigation, it could indicate that caregivers of people with SCD experience the condition as more debilitating than patients themselves experience it. Literature on PND and selective abortion of disabled people has warned that decisions to terminate pregnancies of people who are ‘abnormal’ constitute not only a value judgement about what is considered a life worth living, but also a step down the slippery slope towards eugenics.21 22

These differential views of patients, physicians and parents also indicate potential ethical conflicts between various segments of the Cameroonian society regarding TAP for SCD. Additional studies among various groups may provide detailed insight into the range of moral, legal and social perspectives held by the lay public and the healthcare community regarding genetic technology and prenatal diagnosis in Cameroon.

Limitations
Patients with access to televisions and those who read the newspaper would have been more likely to be recruited in this study, which could have excluded some poorer families. Patient

---

**Figure 2** Patients’ reasons for their attitudes towards prenatal diagnosis for sickle cell disease (SCD) and pregnancy termination. When we selected only the patients willing to accept prenatal diagnosis for SCD (88.7%, n=63) and those willing to accept termination of an affected pregnancy (TAP) for SCD (40.9%, n=36) in both groups, negative family life experience of SCD, fear of having more affected children and fear of the poor quality of the child’s health were reported as their main reasons for acceptance (Panel A). Patients rejecting TAP (48.5%, n=43) claimed mostly ethical (78.1%) and religious considerations (45.5%) (Panel B). PND, prenatal genetic diagnosis.
support groups, which were also involved in participant recruitment, are more likely to be used by city dwellers and those with resources to travel than by those in rural communities. The population of Yaoundé and its surroundings is predominantly of Christian faith. Geographical access from the North of Cameroon to Yaoundé, where the study occurred, would have been limited for Muslims. In addition, adult illiteracy ranges from less than 20% in the Central provinces, where Yaoundé is located, to as much as 70% in the Northern provinces. Thus, the results of this study could only be considered applicable to the relatively well-resourced, urbanised population.

Another possible limitation of our study is our choice of quantitative methods where qualitative methods should also be used. Since we did not engage with research participants in interviews or focus group discussions, we are not in a position to offer deep insight into why participants felt the way they did and what motivated their choices. We see the contribution of this study as demonstrating trends and topics for further investigation through qualitative social science research, which is currently being planned.

Policy and practice implications

As we indicated, the major finding of this study is the surprisingly high level of acceptability of TAP by patients. We hope that this finding will contribute to the discussion about the urgency of the implementation of the national Cameroonian policy for management of SCD, including possible legal adjustment for SCD-related prenatal diagnosis and TAP. Whether appropriate national screening and treatment strategies for SCD could affect the attitudes of patients towards PND and pregnancy termination is an unresolved question. However, a clue to the ethical dilemma of patients is indicated in this study by the significant lower proportion of the acceptance of SCD-related prenatal diagnosis and termination of pregnancy when compared with the acceptance of prenatal diagnosis and TAP as a general principle (figure 1).

Research recommendations

The burden of SCD on Cameroonian families, including parents and patients, will need further investigation, as does the difference in attitudes towards TAP between caregivers of individuals with SCD and SCD patients. Our finding that four out of 10 SCD patients would terminate a pregnancy where the fetus is affected with SCD also needs to be unpacked. Lastly, research needs to focus on understanding the ‘ethical reasons’ that people cite when justifying their attitudes towards TAP.

CONCLUSIONS

In conclusion, this group of Cameroonian SCD patients appears to accept the principles of preventive genetic medicine, including SCD prenatal diagnosis, and in a surprisingly high proportion, TAP. The study reveals and emphasises the need to improve screening practices and services for care of patients with SCD in Cameroon.

Author note This article will be part of the PhD thesis of AW.

Acknowledgements For their input, we thank the patients’ association, ‘Globule Rouge’, and the parents who participated in the survey.

Contributors AW and FFA designed the study, collected the data and drafted the manuscript. JdV, CDR and RR contributed to data analysis, manuscript conception and writing.

Funding This study was supported by the Commission for Humanitarian Affairs of the Geneva University Hospitals, Geneva, Switzerland.

Competing interests None.

Patient consent Obtained.

Ethics approval National ethical committee of the Ministry of Public Health, Republic of Cameroon No 033/CNE/DNM/007.

Provenance and peer review Not commissioned; externally peer reviewed.

REFERENCES

1 Kwiatkowski D. How malaria has affected the human genome and what human genetics can teach us about Malaria. Am J Hum Genet 2005;77:171–90.
Would you terminate a pregnancy affected by sickle cell disease? Analysis of views of patients in Cameroon

Ambroise Wonkam, Jantina de Vries, Charmaine D Royal, Raj Ramesar and Fru F Angwafo III

*J Med Ethics* published online August 5, 2013

Updated information and services can be found at: [http://jme.bmj.com/content/early/2013/08/05/medethics-2013-101392](http://jme.bmj.com/content/early/2013/08/05/medethics-2013-101392)

**References**

This article cites 22 articles, 4 of which you can access for free at: [http://jme.bmj.com/content/early/2013/08/05/medethics-2013-101392#BIBL](http://jme.bmj.com/content/early/2013/08/05/medethics-2013-101392#BIBL)

**Email alerting service**

Receive free email alerts when new articles cite this article. Sign up in the box at the top right corner of the online article.

**Topic Collections**

Articles on similar topics can be found in the following collections

- Research and publication ethics (490)
- Genetic screening / counselling (15)

**Notes**

To request permissions go to: [http://group.bmj.com/group/rights-licensing/permissions](http://group.bmj.com/group/rights-licensing/permissions)

To order reprints go to: [http://journals.bmj.com/cgi/reprintform](http://journals.bmj.com/cgi/reprintform)

To subscribe to BMJ go to: [http://group.bmj.com/subscribe/](http://group.bmj.com/subscribe/)