

Barriers to Healthcare for Sickle Cell Disease Patients in Democratic Republic of Congo



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Abstract

Introduction: The World Health Organization estimates that up to 70% of sickle cell deaths in sub-Saharan Africa are preventable by implementing measures that include early diagnosis, information, education and prophylaxis of infections. In the city of Kisangani, in the Tshopo province of the Democratic Republic of the Congo, identifying difficulties in access to care will help guide interventions to fight sickle cell anemia. The aim of this study was to identify the barriers preventing sickle cell patients from accessing care in the Democratic Republic of Congo.

Methods: This cross-sectional study involved 158 sickle cell patients who consulted at least once in one of the general hospitals in Kisangani in 2010. The interview guide included questions about social representations and knowledge about the disease, perceptions and knowledge of the provision of health services and financial accessibility to health facilities.

Results: For 44.9% of the study participants attribute sickle cell disease to demonic origin or divine curse. The cost of care associated with sickle cell anemia is unaffordable for 93.6% of participants. The 77.8% and 44.9% indicated that it is in the church and in traditional healer's places respectively that the care is more prompt than in formal health system. However, only 22.8% patients in health facilities felt that they waited a long time before commencing treatment.

Conclusion: Sickle cell control in Kisangani should focus on raising awareness, information and education of population, sickle cell disease patients and their families. In addition, centers for the comprehensive management of sickle cell disease supported by the state should be developed. Similarly, research on medicinal plants used by traditional healers is necessary.

Key words: barriers, care, sickle cell disease, Democratic Republic of the Congo.

Résumé

Introduction : L'Organisation Mondiale de la Santé estime que près de 70% de décès liés la drépanocytose en Afrique subsaharienne sont évitables par la mise en place des mesures englobant le diagnostic précoce, l'information, l'éducation et la prophylaxie des infections. À Kisangani, identifier les difficultés d'accès aux soins contribuera à orienter les interventions de lutte contre la drépanocytose. **Matériel et Méthodes :** Cette étude transversale a concerné 158 patients drépanocytaires ayant consulté au moins une fois dans l'un des hôpitaux généraux de la ville de Kisangani en 2010. Le guide d'entretien comprenait des questions relatives aux représentations sociales et connaissances sur la maladie, aux perceptions et connaissances de l'offre des services de santé et à l'accessibilité financière aux formations sanitaires. **Résultats :** Pour 44,9%, la drépanocytose est une maladie d'origine démoniaque, une malédiction divine. Le coût des soins liés à la drépanocytose est inabordable pour 93,6% ; 77,8% indiquent que c'est à l'église que la prise en charge est prompte tandis que 44,9% ont parlé de la prise en charge chez le guérisseur. Pour 22,8%, dans les formations sanitaires, le temps d'attente est long avant le début de la prise en charge.

Conclusion : La lutte anti-drépanocytaire à Kisangani devrait s'atteler sur la sensibilisation, l'information et l'éducation de la population, des drépanocytaires ainsi que leurs familles. En outre, des centres de prise en charge globale de la drépanocytose appuyée par l'Etat devraient être développés. De même, des recherches sur des plantes médicinales utilisées par les guérisseurs s'avère nécessaire.

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Introduction

Sickle cell disease is the most common hemoglobin disease in the world. Each year nearly 300,000 babies are born with this disorder, 75% of which are in sub-Saharan Africa (SSA) [1]. The homozygous form, SS anemia, occurs frequently in the Democratic Republic of Congo (DRC) [2,3,4] and is associated with very high infant mortality. The World Health Organization (WHO) estimates that 70% of these deaths are preventable by implementing measures including early diagnosis, information, education and prophylaxis of infections. However, the effectiveness of these measures remains linked to the access sickle cell patients have to health services [5]. However, few studies in SSA have examined the various barriers that may prevent them from accessing care. Generally, in sub-Saharan Africa, the virtual non-existence of the health insurance system means that the expenses generated by the management of the disease are borne by the patient himself or his family. In Congo-Brazzaville for example, in 54.6% of the cases, inaccessibility to care was linked to poverty, leading to patients commencing treatment at an advanced stage of the disease [5]. In Kisangani, nearly 1% of newborns have the homozygous form of the disease; therefore, knowledge about difficulties families meet in accessing care is one of the excellent prerequisites in designing successful sickle cell disease interventions in SSA [3].

The objective of this study is to identify the access barriers for sickle cell patients in the Democratic Republic of Congo.

Material and methods

This is a cross-sectional study including sickle cell patients who had consulted at least once in one of the general hospitals of the city of Kisangani in the year 2010. Of the 181 patients registered this year, we found only 166 subjects at the addresses indicated in the files. An interview was solicited from them, but only 158 agreed to participate in the study. The place and maintenance records were of the respondents' convenience. These were semi-directed interviews. Interviews were recorded at the same time as the notes taken. The respondents were either sickle cell adults or parents or guardians of sickle cell children. The interview guide, which was tested beforehand, included questions relating to (1) social representations and knowledge about the disease, (2) perceptions and assessments of health service provision, and (3) accessibility to health facilities.

The data were collected from October 26 to December 31, 2011. The responses were scored, the notes taken against the recordings, and then grouped according to the categories of the above mentioned questions.

Results

Concerning barriers related to social representations and knowledge about sickle cell anemia (Table 1), 77.8% of subjects felt that there was no significant improvement or cure by modern medicine.

For 44.9% of the subjects questioned, sickle cell disease was a disease of demonic origin and/or a divine curse. Finally, 22.8% of the cases had misconceptions about the mode of transmission of the disease.

Table 1. Barriers due to social representation and knowledge of the disease

| Responses | n | % |
|---|-----|------|
| No major improvement nor healing with modern medicine | 123 | 77.8 |
| Demonic origin, God curse | 71 | 44.9 |
| Wrong belief about the route of transmission of the disease | 36 | 22.8 |

Concerning the barriers related to the perceptions and the evaluation of the supply of the health services and its affordability (Table 2), 93.6% of the respondents declared that the cost of care related to sickle cell anemia was unaffordable.

On the subject of prompt take-up in crisis management, 77.8% indicated that it was in the church that the care was more prompt while and 44.9% pointed to the taking in charge in the traditional healer. For 22.8% of the subjects, the waiting time in the health facilities was long before commencing treatment.

Table 2. Barriers due to perception, assessment of services offered and financial accessibility

| Responses | n | % |
|---|-----|------|
| Non affordable cost | 148 | 93.6 |
| Prompt management at church | 123 | 77.8 |
| Prompt management at traditional healers | 71 | 44.9 |
| Long waiting time before management at hospital | 36 | 22.8 |

Discussion

Social representations and knowledge about the disease

Sickle cell anemia is considered an orphan disease in some countries [7], including the DRC. Studies by Batina *et al.* [3] and Tshilolo *et al.* [4] on neonatal screening for sickle cell disease in the DRC reported prevalences of 0.96% and 1.4% for the homozygous form and 23.3% and 16.9% respectively for the heterozygous form. Moreover, the

WHO estimates that in the DRC the rate of heterozygous (AS) carriers is 25% and the annual incidence of the SS homozygous form is around 15‰ of births [2]. However, to date there is not yet an effective implementation of activities to fight this disease. WHO recommends that in countries where the incidence of sickle cell anemia is greater than 0.5 per 1,000 births, a full-fledged disease control program should be established [7]. This program has existed in the DRC since 2006 but without concrete activities of sickle cell control in the field, especially in Kisangani, as a result of a lack of funds. Early detection, as recommended by the WHO, has so far been carried out only in the city of Kinshasa.

One consequence of this shortcoming has been a lack of information and education about sickle cell anemia in Kisangani and DRC in general; some of our subjects spoke of the spiritual or demonic origin of the sickle cell disease (44.9%). Many of them (77.8%) even adopted a defeatist and resigned attitude, arguing that this disease could not be improved or cured. A similar result was reported by Sangho *et al.* in Mali, who found that 58% of the subjects were unaware of the causes of sickle cell anemia [9]. However, our findings diverge from those reported by Guédéhoussou *et al.* in Lomé (Togo) who reported that 74.8% of respondents had good knowledge of the cause of sickle cell anemia and 64.3% of the prognosis [9]. Togo has reported the existence of anti-sickle cell strategies implemented by the country's health authorities, as well as efforts to prevent and manage sickle cell anemia initiated by the Togolese Association for the Control of Sickle Cell Disease. Such initiatives are still in their early stages in the DRC and could reflect the results of this study. Health education, awareness-raising and education campaigns of the population in general, and sickle cell anemia in particular, are therefore necessary and could contribute effectively to the fight against sickle cell disease in Kisangani by improving knowledge of the population on this disease.

Perceptions and appreciation of the supply of health services and affordability

In sub-Saharan Africa, the financial accessibility of sickle cell patients to quality care remains a challenge. Two major factors account for this situation. First, a very large number of families in this region of the world live in extreme poverty [10]. Second is the very nature of sickle cell anemia, which is an impoverishing disease due to its recurrent complications [11].

The present study showed that for 93.6% of the subjects, the cost of medical care related to sickle cell anemia was unaffordable. This corroborates the result of Diagne *et al.* [12] in Dakar, Senegal, who reported that only 21% of sickle cell patients had been vaccinated against pneumococcus. In Lubumbashi, Shongo *et al.* [2] observed that nearly 70% of sickle cell patients were from poor

families. As reported by Luboya *et al.* [13], poverty, along with ignorance of the disease, and a sense of the powerlessness of modern medicine, may cause some affected families to resort to alternative medicines. In Kisangani, the management of sickle cell disease is not holistic. It remains focused solely on medical aspects. The psychological management of patients is still lacking. This, in our opinion, could encourage frequent use of traditional medicine and churches.

This study also identified the delay in the management of sickle cell anemia, which usually reaches the hospital in crisis. This is an additional factor in sickle cell anemia and/or their families to favor traditional medicine and churches. Our observation differs, however, from that of Sangho *et al.* [8] in Bamako, where 58.3% of sickle cell mothers said they wanted to use a first-line health facility, compared with 13.9% for traditional healers.

Conclusion

This study indicates that anti-sickle cell control in Kisangani should address, among other things, awareness, information and education of the population, sickle cell anemia and their families. In addition, centers for the comprehensive and continuing management of sickle cell disease supported by the Congolese government should be developed. Similarly, research on medicinal plants used by healers is necessary.

Competing interests

The authors do not declare any competing interests.

Author contributions

SAB and PKK participated in the design of the study, data acquisition, analysis and interpretation of results. SAB, PKK, MPS, CTK, BG participated in the review of the literature and editing of the manuscript.

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