International Journal of Research in Medical Sciences
Samena HSC et al. Int J Res Med Sci. 2022 Nov;10(11):2376-2380
www.msjonline.org
pISSN 2320-6071 | eISSN 2320-6012
DOI: https://dx.doi.org/10.18203/2320-6012.ijrms20222832

Original Research Article

Psychosocial experience of mothers of children with sickle cell disease in Antananarivo and Toamasina, Madagascar

Hanitriniaina S. C. Samena[1]*, Rina J. Rasamoelison[2], Safidisoa N. Razanamanana[3], Annick L. Robinson[1,4]

[1]Department of Pediatrics, Tsaralalana Mother-Child University Hospital, Antananarivo, Madagascar
[2]Department of Neonatalogy, Befelatanana Maternity, Antananarivo, Madagascar
[3]Department of Pediatrics, Itaosy District Reference Hospital Center, Antananarivo, Madagascar
[4]Faculty of Medicine, Antananarivo, Madagascar

Received: 11 September 2022
Revised: 04 October 2022
Accepted: 06 October 2022

***Correspondence:**
Dr. Hanitriniaina S. C. Samena,
E-mail: samena.christelle@gmail.com

ABSTRACT

Background: Sickle cell disease in children can disrupt life of their mothers who are at the forefront of care. The objectives of this study were to describe the psychosocial experience of these mothers, to identify factors associated to maternal anxiety and depressive disorders.
Methods: A cross-sectional study was conducted from December 2017 to February 2018 with mothers of children with sickle cell disease under the age of 15 in Antananarivo and Toamasina. The abbreviated Beck and Hamilton scales were used to assess respectively depression and anxiety.
Results: Of 134 mothers surveyed, 61.2% had depression and 35.8% had anxiety. Depression significantly affected mothers with more than one child with sickle cell disease (aOR=4.31, CI- 1.12-16.58) and mothers of children hospitalized at least three times per year for vaso-occlusive crisis (aOR=13.55, CI- 1.56-117.5). Anxiety was associated with blood transfusion more than three times (aOR=9.06, CI- 2.05-40.00). Pity (74.6%) and fear of death (55.2%) were the main feelings reported. Negative occupational repercussions were reported by 48.5% of mothers, marital conflict by 15.6%, financial difficulties by 43.3%.
Conclusions: A global approach focused on the child and his family would be optimal for success in the management of pediatric sickle cell disease.

Keywords: Anxiety, Children, Depression, Mothers, Sickle cell disease

INTRODUCTION

Sickle cell disease (SCD) is a hereditary haemoglobinopathy characterized by the presence of abnormal hemoglobin, hemoglobin S. Each year, nearly 300,000 children are born with a major hemoglobin anomaly, 70% of them with SCD.[1] On the African continent, this disease is extremely widespread in sub-Saharan Africa with a high prevalence zone defining the sicklemic belt.[2] In Madagascar, its overall prevalence is 9% with a higher prevalence (18.5%) in the South-east region.[3] However, the ethnic mix suggests that the disease is present throughout the country.

Due to its hereditary, chronic and sometimes disabling nature, SCD can have an unfavourable psychosocial impact on children, their families and more particularly on mothers who are at the forefront of child care. According to the literature, maternal psychological adaptation and that of the child are closely linked.[4] Any maternal psychosocial disturbances could thus influence the management of the child's illness. The objectives of

this study were mainly to describe the psychosocial repercussions of childhood SCD on mothers, and secondarily to identify the factors associated with maternal anxiety and depression.

METHODS

A cross-sectional study was conducted among mothers of children with SCD. The study was carried out from December 2017 to February 2018 within the association for the fight against sickle cell disease (LCDM). The subjects were recruited during monthly member meetings at the Joseph Ravoahangy Andrianavalona University Hospital in Antananarivo and at Analakininina University Hospital in Toamasina. Only mothers of children under 15 with confirmed SCD were included in the study. The data were obtained after an interview with the mothers. Mothers who refused to be interviewed were excluded.

The sampling was exhaustive. All mothers of children with SCD encountered during the study period were candidates for the study. The sample size was 134 mothers.

The variables studied were the maternal sociodemographic data, the family history of SCD, the financial, professional, psychological and marital repercussions of SCD. Beck's abbreviated scale and Hamilton scale translated into local language (by a linguistic expert) were used to assess depression and anxiety, respectively.[5,6] The interpretation of the Beck score was as follows: absence of depression for a score of 0 to 3; mild depression from 4 to 7; moderate depression 8 to 15; severe depression for a score of 16 or more.[5] For the Hamilton score, the interpretation was as follows: absence of anxiety for a score of 0 to 5; minor anxiety from 6 to 14; major anxiety for a score of 15 or more.[6] The Data were analyzed using Epi info 7® software. The Chi square test and Fischer exact test were used for the comparison of proportions. A two-sided $p<0.05$ was considered statistically significant. Variables with a p value <0.05 in the univariate model were included in the multivariate model. Univariate and multivariate analyses of the variables allowed the calculation of the odds ratio (OR) and the adjusted odds ratio (aOR) respectively expressed with a 95% confidence interval (95% CI).

The informed verbal consent of the mothers was requested before each interview. All responses provided were considered without any value judgment. The confidentiality of the data as well as the anonymity of the mothers were respected.

RESULTS

During the study, 134 mothers were interviewed including 71 mothers in Antananarivo and 63 mothers in Toamasina. The average age of the mothers was 35.2±7.9 years. Majority of mothers (73.9%) had a high school education (secondary school and above). More than half of mothers (56%) were married at the time of the study. Twenty mothers (14.9%) had more than one child with SCD. The family history of SCD was reported in 30.6% of cases (Table 1).

Table 1: Demographic data of mothers of children with sickle cell disease.

Variables	Frequency	Percent
Mother's age in years		
20-29	34	25.4
30-39	59	44
40-49	35	26.1
50-59	6	4.5
Mother's education		
No schooling	2	1.5
Primary school	33	24.6
Secondary school and above	99	73.9
Marital status		
Single	15	11.2
Currently married	75	56
Formerly married[a]	44	32.8
Number of children of mothers		
≤2	83	61.9
>2	51	38.1
Number of children with SCD[b] of mothers		
1	114	85.1
≥2	20	14.9
Family history of SCD[b]		
Yes	41	30.6
No	93	69.4

[a]Included divorced, widowed; [b]Sickle cell disease.

More than 3 annual hospitalizations for vaso-occlusive crisis (VOC) were reported in 2.2% of cases. A history of blood transfusion was mentioned in 65.6% of cases. The chronic complications of SCD encountered in the study were osteo-articular complications (8 cases), cholelithiasis (2 cases), growth retardation (3 cases), and stroke (4 cases).

The negative professional repercussions reported were absenteeism (48.2%), voluntary work stoppage (28.9%) and dismissal (1.2%). On the marital level, SCD was the cause of parental separation in 6.4% of cases and deterioration of the couple's relationship in 12.7% of cases. From a financial point of view, 43.9% of mothers reported financial difficulties. Psychologically, 82 mothers (61.2%) had depression, of which 45 were mild, 26 were moderate and 11 were severe. The frequency of anxiety was 35.8% including 32.1% minor anxiety and 3.7% major anxiety. On the other hand, 32 mothers (28.4%) were neither anxious nor depressed. After the announcement of the diagnosis of SCD, the mothers showed irritability (20.2%), felt pity (74.6%), despair (17.2%), guilt (11.9%) and feared the death of their child (55.2%).

Table 2: Univariate analysis of factors associated to maternal depression.

	Depression		OR (95% CI)	P value
	Yes (n=82)	No (n=52)		
Sickle cell children ≥2	17	3	4.27 (1.18-15.39)	0.02
Total number of hospitalisations ≥5	33	8	3.70 (1.55-8.87)	0.003
Hospitalisation for VOC ≥3 per year	23	1	19.88 (2.59-152.43)	0.004
Blood transfusion >3 times	19	1	15.38 (1.99-118.83)	0.009
Chronic complications of SCD	16	1	12.36 (1.59-96.34)	0.02

95% CI: 95% confidence interval; OR: odds ratio; SCD: sickle cell disease; VOC: vaso-occlusive crisis.

Table 3: Multivariate analysis of factors associated to maternal depression.

Factors associated to maternal depression	aOR	95% CI	P value
Sickle cell children ≥2	4.31	1.12-16.58	0.03
Total number of hospitalisations ≥5	1.95	0.61-5.20	0.24
Hospitalisation for VOC ≥3 per year	13.5	1.56-117.5	0.02
Blood transfusion >3 times	9.96	0.99-99.85	0.05
Chronic complications of SCD	1.06	0.06-1.30	0.96

aOR: adjusted Odds ratio; 95% CI: 95% confidence interval; SCD: sickle cell disease; VOC: vaso-occlusive crisis.

Maternal depression was associated in univariate analysis with the number of children with SCD, the total number of hospitalizations, the number of annual hospitalizations for VOC, the number of blood transfusions, and the existence chronic complications (Table 2).

In multivariate analysis, only a number of children with SCD greater than or equal to two and a number of annual hospitalizations for VOC greater than or equal to 3 were associated with maternal depression (Table 3).

On the other hand, the factors associated to maternal anxiety in univariate analysis, were the number of annual hospitalizations for VOC, the number of blood transfusions and the existence of chronic complications (Table 4).

Table 4: Univariate analysis of factors associated to maternal anxiety.

	Anxiety		OR (95% CI)	P value
	Yes (n=48)	No (n=96)		
Sickle cell children ≥ 2	5	15	0.55 (0.19-1.62)	0.28
Hospitalisation for VOC ≥3 per year	14	10	3.13 (1.26-7.75)	0.01
Blood transfusion >3 times	16	4	10.25 (3.18-33.00)	0.0001
Chronic complications of SCD	12	5	5.40 (1.77-16.46)	0.003

95% CI: 95% confidence interval; OR: odds ratio; SCD: sickle cell disease; VOC: vaso-occlusive crisis.

Table 5: Multivariate analysis of factors associated to maternal anxiety.

Factors associated to maternal anxiety	aOR	95% CI	P value
Hospitalisation for VOC ≥3 per year	2.09	0.71-6.15	0.18
Blood transfusion >3 times	9.06	2.05-40.00	0.004
Chronic complications of SCD	0.90	0.17-4.71	0.90

aOR: adjusted Odds ratio; 95% CI: 95% confidence interval; SCD: sickle cell disease; VOC: vaso-occlusive crisis.

In multivariate analysis, only blood transfusion more than 3 times was significantly associated with maternal anxiety (Table 5).

DISCUSSION

The announcement of the diagnosis of SCD generates various feelings among mothers including pity and fear of death as found in a togolese study.[7] According to the literature, chronic diseases are the main sources of depression.[8] Compared to fathers, mothers of children with chronic illness have higher levels of anxiety and depression.[9] Being a chronic disease, childhood SCD thus psychologically affect their mother. The results of the present study attest to the existence of anxiety-depressive disorders in mothers of children with SCD. A similar study carried out in Congo-Brazzaville found a prevalence of 70.2% for maternal depression and 81.7% for maternal anxiety.[10] The psychological state of mothers, main people involved daily in the care of the child, could condition the quality and observance of the

child's care. Psychological support and care for mothers could then optimize the management of the child's SCD.

In this study, a deterioration in the couple's relationship was reported by 12.7% of mothers and a parental separation by 6.4%. The negative impact of chronic diseases, including SCD, on conjugal life is also known in the literature.[7,11,12] Because of the hereditary nature of SCD, transmitting the disease could generate guilt in the mother and challenge the appropriateness of the choice of their partner.

On the other hand, a restriction of the professional activities of mothers was observed in this study. It would be linked to the complications inherent in the disease.[13,14] Intensive socio-medical intervention allows sustained clinical improvement in seriously ill children with SCD according to a Beninese study.[15]

In this study, the cost of care was borne by the family. The financial difficulties reported in our study are also found in the literature.[16,17] Poverty and the lack of universal social security in developing countries could explain this finding.

Maternal depression was associated with more than three annual hospitalizations for VOC, which is consistent with the findings of Nika et al.[10] Indeed, the violence of pain during VOC awakens in parents a feeling of despair, frustration, impotence in front of the impossibility of sharing the pain but also the fear of the child's death.[18,19] Moreover, a number of children with SCD greater than one was a determinant of maternal depression. Indeed, it is suggested that both the psychological and financial burden would be greater heavy when a mother raises more than one child with SCD. According to Daher Habeeb et al., the presence of at least two children with SCD in the family significantly affected family financial status.[16] A feeling of guilt, component of depression, would come to be added to it in front of the hereditary character of the disease in which the mother passed on the sickle cell gene to sick children.

In contrast, the anxiety of mothers of sickle cell children was associated with a blood transfusion of more than three times. The transfusion procedure has an anxiety-inducing character as Nika et al. testifies.[10] In the literature, blood was considered the product that made the difference between life and death.[20] In addition, transfusion accidents are not uncommon, especially in polytransfused patients. Thus, a proper use of blood transfusion and an optimization of transfusion safety are essential.

The main limitation of this study is its cross-sectional nature, which does not allow any causal link to be inferred, hence the interest of conducting other longitudinal studies. Nevertheless, the results of the study call for better attention to identify and manage the psychosocial impact of children SCD on mothers because they can affect the quality of the child's daily care.

CONCLUSION

The negative psychosocial impact of children SCD on mothers is real fact. Theses repercussions were mainly psychosocial. The success of the management of SCD lies in a global approach focused on the child and his family, involving a multidisciplinary collaboration including a psychologist, social workers, patient associations, in addition to health professionals of different specialties.

ACKNOWLEDGEMENTS

The authors would like to thank all the mothers and children with SCD participating in this study, the staff of the LCDM association for their cooperation and assistance in carrying out this study.

Funding: No funding sources
Conflict of interest: None declared
Ethical approval: The study was approved by the Institutional Ethics Committee

REFERENCES

1. World Health Organization. Thalassaemia and other haemoglobinopathies: Report by the Secretariat. Geneva, Switzerland: WHO; 2006. Available from: https://apps.who.int/gb/archive/pdf_files/EB118/B118_5-en.pdf. Accessed on 16 October 2017.
2. Mulumba LL, Wilson L. Sickle cell disease among children in Africa: An integrative literature review and global recommendations. Int J Afr Nurs Sci 2015;3:56-64.
3. Ministry of Public Health. National sickle cell disease control program in Madagascar. Madagascar: MSANP; 2011.
4. Brown RT, Kaslow NJ, Doepke K, Buchanan I, Eckman J, Baldwin K, et al. Psychosocial and family functioning in children with sickle cell syndrome and their mothers. J Am Acad Child Adolesc Psychiatr. 1993;32(3):545-53.
5. Alsaleh M, Lebreuilly R. Validation of the French translation of a short questionnaire Beck Depression (BDI-FS-Fr). Ann Med Psychol. 2017;175(7):608-16.
6. Maier W, Buller R, Philipp M, Heuser I. The Hamilton anxiety scale: reliability, validity and sensitivity to change in anxiety and depressive disorders. J Affect Disord. 1988;14(1):61-8.
7. Assimadi JK, Gbadoé AD, Nyadanu M. The effects of sickle cell disease on families in Togo. Arch Pediatr. 2000;7(6):615-20.
8. Clarke DM, Currie KC. Depression, anxiety and their relationship with chronic diseases: a review of the epidemiology, risk and treatment evidence. Med J Aust. 2009;190(7):54-60.

9. Van Oers HA, Haverman L, Limperg PF, van Dijk-Lokkart EM, Maurice-Stam H, Grootenhuis MA. Anxiety and depression in mothers and fathers of a chronically ill child. Matern Child Health J. 2014;18(8):1993-2002.
10. Nika ER, Mabiala Babela JR, Moyen E, Kambourou J, Lombet L, Mouanga Mpolo P, et al. Psychosocial issues of mothers whose children have sickle cell disease. Arch Pediatr. 2016;23(11):1135-40.
11. Brown BJ, Okereke JO, Lagunju IA, Orimadegun AE, Ohaeri JU, Akinyinka OO. Burden of health-care of carers of children with sickle cell disease in Nigeria. Health Soc Care Community. 2010;18(3):289-95.
12. Macedo EC, da Silva LR, Paiva MS, Ramos MNP. Burden and quality of life of mothers of children and adolescents with chronic illnesses: an integrative review. Rev Lat Am Enfermagem. 2015;23(4):769-77.
13. Luboya E, Tshilonda JCB, Ekila MB, Aloni MN. Psychosocial repercussions of sickle cell disease on parents of children living in Kinshasa, Democratic Republic of Congo: a qualitative study. Pan Afr Med J. 2014;19:5.
14. Olatunya OS, Ogundare EO, Fadare JO, Oluwayemi IO, Agaja OT, Adeyefa BS, et al. The financial burden of sickle cell disease on households in Ekiti, Southwest Nigeria. Clin Outcomes Res. 2015;7:545-53.
15. Rahimy MC, Gangbo A, Ahouignan G, Adjou R, Deguenon C, Goussanou S, et al. Effect of a comprehensive clinical care program on disease course in severely ill children with sickle cell anemia in a sub-Saharan African setting. Blood. 2003;102(3):834-8.
16. Daher Habeeb A, Alhussain B, Hassan M, Ahmed B. Psychosocial impact of sickle cell disease on families in Basra, Southern Iraq; an experience of caregivers. Int J Med Pharm Sci. 2015;5:41-52.
17. Adegoke SA, Kuteyi EA. Psychosocial burden of sickle cell disease on the family, Nigeria. Afr J Prim Health Care Fam Med. 2012;4(1):380.
18. Palermo TM, Riley CA, Mitchell BA. Daily functioning and quality of life in children with sickle cell disease pain: Relationship with family and neighborhood socioeconomic distress. J Pain Off J Am Pain Soc. 2008;9(9):833-40.
19. Graumlich SE, Powers SW, Byars KC, Schwarber LA, Mitchell MJ, Kalinyak KA. Multidimensional assessment of pain in pediatric sickle cell disease. J Pediatr Psychol. 2001;26(4):203-14.
20. Petermann R, Pêchard M, Gesbert C, Assez N. Blood representations associated to chronic transfused patients: Symbolic interpretations and ethical perspectives. Transfus Clin Biol. 2016;3(23):157-67.

Cite this article as: Samena HSC, Rasamoelison RJ, Razanamanana SN, Robinson AL. Psychosocial experience of mothers of children with sickle cell disease in Antananarivo and Toamasina, Madagascar. Int J Res Med Sci 2022;10:2376-80.