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Original Research Article

The financial burden of sickle cell disease among parents of children with sickle cell disease in Lagos, Nigeria

Adeyinka Adeniran[1], Esther O. Oluwole[2], Omobola Y. Ojo[3]*

[1]Department of Community Health and Primary Health care, Lagos State University College of Medicine/Teaching Hospital, Ikeja, Lagos, Nigeria
[2]Department of Community Health and Primary Care, College of Medicine, University of Lagos, Surulere, Lagos, Nigeria
[3]Department of Community Medicine and Primary care, Federal Medical Centre, Abeokuta, Ogun, Nigeria

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***Correspondence:**
Omobola Y. Ojo,
E-mail: vinegbogs2007@gmail.com

ABSTRACT

Background: Sickle cell disease is a genetic condition that affects millions of people globally. In view of this, the study aims at determining the financial burden of sickle cell disease among caregivers of children with sickle cell disease in Nigeria.
Methods: It was a descriptive cross sectional study and systematic sampling method was used in selecting 162 caregivers amongst the patients in the Lagos State University Teaching Hospital. Semi-structured questionnaires were used to collect data and analysed using SPSS version 22 software and Microsoft Excel 2007. Results were presented in frequency tables, chi-square to test association between categorical variables and the statistical significance level was set at $p<0.05$.
Results: The mean age of the caregivers was 34.3 years with an increase in frequency of hospitalization 39% amongst respondents and a cost of hospital bill was over thirty thousand naira (US$76.82).
The reason given mostly by 77% of the respondents for non-usage of health insurance was that the enrolment's premium was high and 53% of the caregivers took loan to treat their wards. Catastrophic healthcare expenditure was found among a quarter 21% of the respondents due to non-usage of health insurance. There was a statistical significance association between level of education and Catastrophic healthcare expenditure at p value <0.05.
Conclusions: Due to high level of financial burden on caregivers and family members, it will be an important step for the government to strengthen the health insurance scheme, intensify campaigns and subsidize costs of healthcare for these patients.

Keywords: Sickle cell disease, Caregivers, Financial burden, Insurance scheme, Nigeria

INTRODUCTION

Sickle cell disease is an autosomal recessive genetically transmitted haemoglobinopathy responsible for considerable morbidity and mortality. It is the most prevalent genetic disorder in sub-Saharan Africa.[1,2] Worldwide, Sickle cell disease afflicts as many as 100 million people, largely amongst Black people in Africa, Europe and the America, Arabian people, and those of Asian ancestry and it is responsible for 50 percent mortality in those with the severe form of the disease.[3,4]

Sickle cell disease remains a significant public health challenge especially in Nigeria with an estimated 150,000 children born with sickle cell anemia annually and prevalence of 20-30 per 1000 live births. About forty million people carry the Sickle cell disease gene in

Nigeria and the disease affects about 2% of the population.[5,6]

Sickle cell disease is the most common genetic disorder amongst black people and one of the major chronic non-communicable diseases affecting children, poses a significant psychosocial burden, not only on the sufferers but also on the caregivers and their families.[7]

Presently, there is no cure for sickle cell disease but cost-effective treatment is available for the relief of symptoms and signs of the disease. Nigeria has been documented to bear the greatest burden of sickle cell disease in the world with a result of 100,000 infant death equivalents of 8 percent of infant mortality in the country.[5]

Manifestation of Sickle cell disease differs widely with some children exhibiting severe manifestations requiring frequent hospital visits and admissions. The condition poses huge amount of stress and financial burden on the parents of children with Sickle cell disease who are usually the primary caregivers in most instances. Since, health care in most developing countries is mostly funded through out-of-pocket spending. Therefore, Sickle cell disease has the tendency to greatly drain the finances of households in developing countries where there is high level of poverty and inequitable distribution of wealth and resources.[8-11]

The life of people affected with Sickle cell disease is negatively influenced by the chronic, degenerative and self-incapacitating nature of the disease which affects the patient and their family in an intense and permanent way. Also, the clinical complications and the recurrent hospitalizations and blood transfusions, along with other prevailing factors such as unemployment, low income, and lack of access to health services.[12]

The level of support given to the children may reflect the dynamics of intra-family relationships and the emotional state of family members, especially the mothers.[13]

It has been shown from clinical and epidemiological data in the developed nations that the rates and costs of hospitalization, emergency department and outpatient visits by Sickle cell disease children are substantial.[14-16] However, the situation differs in most developing countries like Nigeria where there is paucity of data on Sickle cell disease cost of care and economic burden of this disease on the family of the affected children and the National health services. Hence, determining the financial burden of sickle cell disease among households in Lagos, Nigeria will help in designing evidence-based health interventions such as health care financing and social insurance schemes which in turn will reduce the financial burden of the disease on families. The objective of the study is to determine the financial burden of sickle cell disease among parents of children with sickle cell disease in Lagos, Nigeria.

METHODS

Description of the study area

The study was carried out in Lagos state. Lagos state is the smallest in area among the 36 states and Federal capital territory in Nigeria with population density of 5,900/km and population of 21,000,534 people. Bounded in the north and east by Ogun state Nigeria, in the west by Republic of Benin and the south by the Atlantic Ocean.

The Lagos State University teaching hospital emerged from a modest cottage hospital which was established on June 25th 1955 by the old Western Regional Government to provide health care service for the people of Ikeja and its environs. It is a tertiary health facility which provides 24 hour pharmacy services, diagnostics services, accident and emergency care, and also with specialties in cardiology, dermatology, endocrinology, gastroenterology, neurology, respiratory, rheumatology, burns and plastic, cardiothoracic surgery, ears, nose and throat surgery, neurosurgery, orthopaedics, ophthalmology, paediatrics, obstetrics and gynaecology, community medicine and anaesthesiology. Sickle cell clinic is one of the clinics in the teaching hospital and it's open on Thursdays to provide care and services for patients. The clinic is attended by an average of fifteen patients weekly.

Eligibility criteria

Inclusion criteria's were: care givers of sickle cell disease patients attending the hospital sickle cell clinic and care givers of sickle cell disease patients that are admitted in the paediatric ward of the hospital. Exclusion criteria included, care givers of patients with other disease conditions(co-morbidity) attending the hospital's sickle cell clinic.

Study population

The study participants are care givers of children attending sickle cell clinic at the paediatrics department, and also those on the wards from July 2016 to March 2017.

Study design

The study was a descriptive cross-sectional survey to determine the financial burden of sickle cell disease on care givers.

Sample size determination

The minimum sample size for the study was determined using the formula:

$$n= (z^2pq)/d^2$$

Where n=the minimum sample size; z standard normal deviation usually set at 1.96 which corresponds to 95% confidence level; the prevalence rate of households in financial instability from catastrophic health expenditure p=20% or 0.2; precision (1-p or 0.8); d=margin error (0.05).

$$n=(1.96^2\times0.2\times0.8)\div0.05^2=245$$

Since population is <10,000

$$nf=n/1+(n)\div(N)$$

Where; nf is the desired sample size when study population is <10,000, n is the desired sample size when the study population is >10,000 = 245. N is the estimate of the population size=400.

$$nf = 245/1+(245)\div(400)=151$$

Thus, nf was estimated as 155 with 10% non-response rate. A total of 162 respondents participated in the study.

Sampling technique

A total of 162 respondents were selected using a systematic sampling technique. Minimum of 60 clients were being attended to in the sickle cell clinic of this facility in a month. Therefore, a sample interval of 3 was used to select the respondents.

Data collection tools and techniques

A semi structured questionnaire which was interviewer administered by trained health personnel was used for data collection in this study. Based on the objective of the study, the questionnaire had a total of 32 questions covering questions on socio-demographic data of the patient and their caregivers such as age, gender, religion, ethnicity, social burden of caring for sickle cell patients on the caregivers, such as adverse effect on physical health, stigmatization, lack of attention for other family members, and strain amongst family members due to the patients' care. And finally, questions that attempted to show the economic burden of sickle cell disease on the caregiver such as aggregate family's annual income, number of hospitalizations, and length of stay during each hospitalization and cost of hospitalization were also asked. The socioeconomic class was determined based on the occupation and the highest level of educational attainment of the caregiver.

Data analysis

Data were analysed with Statistical package for the social sciences (SPSS) version 22 software and Microsoft Excel 2007. Simple descriptive and inferential statistics were performed and results presented in frequency tables. Chi square was used to test association between categorical variables and statistical significance was set at $p<0.05$.

Determination of health expenditure and family income

The total health expenditure during the period (HET) was computed by adding up all the expenditures made by households to maintain the health of each participating child. The total household (family) income during the period (TFI) was computed by summing up all the monthly income of the household members (addition of parent's income).

Catastrophic healthcare expenditure

Catastrophic healthcare expenditure CHE estimation requires measuring the extent to which health expenditure exceeds different thresholds of household income or consumption expenditure. Studies have put the threshold for catastrophic healthcare expenditure at values exceeding 10% of the total household income or 40% of the household non-food income. In this study, we used the former (health expenditure >10% of total household income) to adjudge whether or not a household was involved in catastrophic healthcare expenditure while caring for their wards with sickle cell disease.

Thus, percentage of the total household income spent as health expenditure on each child (THE/FI) was calculated using the following equation; Percentage income spent as health expenditure (THE/F1)=HET/TFIx100. Where HET is the total health expenditure during the study period and TF1 is the total household (family) income during the study period. Any household with health expenditure proportion (THE/FI)>10% was designated as being involved in Catastrophic Healthcare expenditure for the period of the study.

RESULTS

Demographic characteristics of patients

All the children and their parents (households) completed the study. The mean age of the children was 6.5 years with a range of 1-20 years. There were 89 (54.9%) males and 73 (45.1%) females. The mean number of siblings in each of the patients' household was 2.6. Majority 93 (57.4%) were of Yoruba ethnicity, 97 (60%) practice Christianity as their religion and about 69 (43%) of the respondents were first born of the family (Table 1).

Socio-demographic characteristics and household's income of care givers

More than half of the care givers 83(51.2%) were aged 31-40 years with a mean age(SD) of 34.3(7.2) years. Majority 128(79%) were females and married 128 (79%). About half 84(52%) were semi-skilled while about 16 (10%) were unemployed. Most of the caregivers 66

(41%) had tertiary level of education and 146 (90%) were parents of the children (Table 2).

Table 1: Demographic characteristics of children (n=162).

Variables	Frequency(%)
Age group of children (years)	
<8	115 (71.0)
9-12	40 (24.7)
>12	7 (4.3)
Child gender	
Male	89 (54.9)
Female	73 (45.1)
Religion	
Christianity	97 (59.8)
Islam	61 (37.7)
Others	4 (2.5)
Ethnicity	
Yoruba	93 (57.4)
Igbo	51 (31.5)
Hausa	11 (6.8)
Others	7 (4.3)
No. of Siblings	
1	40 (24.7)
2-3	80 (49.4)
>3	42 (25.9)
No. of siblings with SCD	
1	145(89.5)
≥ 2	17 (10.5)
Position of patient in the family	
First	69 (42.6)
Second	49 (30.2)
Third	27 (16.7)
Forth	15 (9.3)
Fifth	2 (1.2)

Majority 146 (90%) of the children live with their parents. More than half (56%) said "yes" to the fact that the care of the children has adverse effects on them; in form of neglect of other siblings which occur sometimes 35 (22%), stigmatization 22 (14%) and strain on family members 26 (17%). The median (IQR) monthly household income was ₦60.000 (US$153.65) with an inter-quartile range of ₦70.000. Only eight (5%) households had their monthly income below the Nigerians' average national minimum wage of ₦18,000 (US$46.10). Most 69 (43%) had been hospitalized one to two times in the last one year while about 9 (6%) had been hospitalized about four times or more with most 39 (39%) spent less than a week and 18 (18%) spent over a month in the hospital with an average hospital bill of over thirty thousand Naira (US$76.82) paid by 63 (39%) of respondents. Majority 138 (85%) of the care givers had been absent from work because of child care in the last one year. About 36% of them were absent for 4 or more times. Some of the respondents 24 (15%) had lost their job/business due to child care (Table 3).

Only 18 (11%) were enrolled with health insurance scheme, while about 89% were not enrolled. Reasons for not enrolled includes "not aware" 88 (61%); too high premium (77%) and scheme not cover sickle cell disease 5 (9%). However, about a quarter of the care giver (25%) had took a loan for patient's care in the past while 86 (53%) said patient's care was affecting other family expenditure especially in the area of feeding 50 (31%); housing 45 (28%); clothing 35 (22%) and education of siblings 40 (25%). The degree to which patients' care affected family expenditure was described as moderate by 36 (42%) of the respondents. Catastrophic health expenditure was found among almost a quarter 34 (21%) of the respondents (Table 4). There is no statistically significant association between age of children, number of siblings, number of siblings with sickle cell disease and catastrophic health expenditure $p>0.05$ (Table 5). However, a statistically significant association was found between level of education and catastrophic health expenditure $p<0.05$. Respondents with no formal education or primary education (46.2%) were more likely to suffer catastrophic health expenditure compared to those with higher education (13.5%), $p<0.05$ (Table 6).

Table 2: Socio demographic characteristics of care givers (n=162).

Variables	Frequency (%)
Age of care giver(years)	
<30	51 (31.5)
31-40	83 (51.2)
>40	28 (17.3)
Gender of care giver	
Male	32 (19.8)
Female	130 (80.2)
Marital Status of care giver	
Single	7 (4.3)
Married	128 (79.0)
Divorced	18 (11.1)
Others	9 (5.6)
Occupation of care giver	
Professional	18 (11.3)
Skilled	34 (21.0)
Semi-skilled	84 (51.8)
Unskilled	10 (6.2)
Unemployed	16 (9.9)
Educational level of care giver	
None	17 (10.5)
Primary	16 (9.9)
Secondary	63 (38.9)
Tertiary	66 (40.7)
Relationship with child	
Parent	146 (90.1)
Grand parent	15 (9.3)
Others	1 (0.6)

Table 3: Social and economic burden of sickle cell disease (n=162).

Variables	Frequency(%)
Person patient is living with	
Parents	146 (90.1)
Grand Parents	15 (9.3)
Others	1 (0.6)
Adverse effect of children care on care giver	
Yes	15 (9.3)
No	90 (55.5)
Sometimes	57 (35.2)
Cause neglect of other siblings	
Yes	6 (3.7)
No	121 (74.7)
Sometimes	35 (21.6)
Caregiver feel stigmatized	
Yes	22 (13.7)
No	140 (86.3)
Patient's care cause strain on family members	
Yes	26 (16.6)
No	136 (83.4)
Estimated household monthly income (N)	
<18,000	8 (4.9)
18,000 - 100,000	102 (63.0)
>100,000	24 (14.8)
Non-Response	28 (17.3)
No of hospitalization in the last one year, n=100	
0	62 (38.3)
1-2 times	69 (42.6)
3-4 times	22 (13.6)
>4 times	9 (5.6)
Average duration of the last hospitalization	
<24 hours	20 (20.0)
<1 week	39 (39.0)
<1 month	23 (23.0)
>1 month	18 (18.0)
Average hospital bill	
<10,000	26 (16.0)
10,000 - 30,000	52 (32.1)
>30,000	63 (38.9)
Non-Response	21 (13.0)
Absent from work due to patient care	
Yes	138 (85.2)
No	24 (14.8)
No of times absent from work care in last one year	
0	24 (14.8)
1x	15 (9.3)
2x	23 (14.2)
3x	42 (25.9)
≥4x	58 (35.8)
Loss of job/business due to patient care	
Yes	24 (14.8)
No	138 (85.2)

Table 4: Utilization of Health Insurance among respondents.

Variables	Frequency(%)
Enrolled with health insurance	**n=162**
Yes	18 (11.1)
No	144 (88.9)
Reasons for not enrolling with health insurance (n=144)	
Not Aware	00
Yes	88 (61.1)
No	56 (38.9)
Premium too high, (n=56)	
Yes	43 (76.8)
No	13 (23.2)
Does not cover SCD (n=56)	
Yes	5 (8.9)
No	51 (91.1)
Ever took a loan for patient's, care (n=162)	
Yes	41 (25.3)
No	121 (74.7)
Patient's care affects other family expenditure	
Yes	86 (53.1)
No	76 (46.9)
Areas of affects (yes only)	
Feeding	50 (30.9)
Housing	45 (27.8)
Clothing	35 (21.6)
Education of siblings	40 (24.7)
Degree of effects on other family exp.	
Mild	34 (39.5)
Moderate	36 (41.9)
Major	16 (18.6)
CHE (n=162)	
No	93 (57.4)
Yes	34 (21.0)
Non-disclosure	35 (21.6)

Table 5: Association between demographic characteristics of patients and catastrophic healthcare expenditure (CHE).

Variables (Mean±SD)	CHE		t test	P value
	Yes	No		
Age of patient	6.26±2.85	6.65 ±3.61	-0.563	0.574
No. Of siblings	2.62±1.2	2.63±1.5	0.1	0.952
No. of siblings with SCD	1.03±0.4	1.10±0.5	0.7	0.487

Table 6: Association between demographic characteristics of parents and catastrophic healthcare expenditure.

Variables	CHE		Total	Chi Square	P value
	Yes	No			
	N (%)	N (%)	N (%)		
Child age					
<8	27 (30.7)	61 (69.3)	88 (100)	2.2	0.399*
8-12	6 (18.2)	27 (81.8)	33 (100)		
≥13	1 (16.7)	5 (83.3)	6 (100)		
Total	34 (26.8)	93(73.2)	127(100)		
Child gender					
Male	17 (23.9)	54 (76.1)	71 (100.0)	0.7	0.418
Female	17 (30.4)	39 (69.6)	56 (100.0)		
Total	34 (26.8)	93 (73.2)	127 (100.0)		
Number of sibling with SCD					
0	2 (25.0)	6 (75.0)	8 (100)	0.6	0.858*
1	29 (28.2)	74 (71.8)	103 (100)		
2 or more	3 (18.8)	13 (81.2)	16 (100)		
Total	34 (26.8)	93 (73.2)	27 (100)		
Age group of caregivers					
<30	6 (15.4)	33 (84.6)	39 (100)	4.3	0.118
30-40	20 (29.9)	47 (70.1)	67 (100)		
>40	8 (38.1)	13 (61.9)	21 (100)		
Total	34 (26.8)	93 (73.2)	127 (100)		
Marital status					
Single	27 (25.2)	80 (74.8)	107 (100)	3.5	0.180*
Married	3 (23.1)	10 (76.9)	13 (100)		
Divorced	4 (57.1)	3 (42.9)	7 (100)		
Total	34 (26.8)	93 (73.2)	127 (100)		
Occupation					
Professional /skilled	7(16.7)	35(83.3)	42 (100)	3.7	0.155
Semi-skilled	23 (33.3)	46 (66.7)	69 (100)		
Unemployed/unskilled	4(25.0)	12 (75.5)	16 (100)		
Total	34 (26.8)	93 (73.2)	127 (100)		
Education level					
None	6 (46.2)	7 (53.8)	13 (100)		
Primary	6 (46.2)	7 (53.8)	13 (100)	10.1	0.018
Secondary	15 (30.6)	34 (69.4)	49 (100)		
Tertiary	7 (13.5%)	45 (86.5)	52 (100)		
Total	34 (26.8)	93 (73.2)	127 (100)		
Health insurance					
Yes	1 (6.2)	15 (93.8)	16 (100)	3.9	0.069
No	33 (29.7)	78 (70.3)	111 (100)		
Total	34 (26.8)	93 (73.2)	127 (100)		

*fishers-exact p-value

DISCUSSION

Sickle cell disease is a chronic disease condition with a long duration, slow progression and limitation of person's daily activities, usually requires ongoing medical care and high medical costs. With the increase in technology and advancements in medical researchers, persons with chronic conditions are now living longer and spending more money to do so. Although there is no cure for sickle cell disease, researchers have found ways to improve the quality of life of these patients.[17] The cost of treatment of any sickness is high when you factor in cost of treatment, cost of treatment related activities, cost of opportunity forgone, social costs and cost of misery.[18] The aim of this study was to determine the financial burden of sickle cell disease among parents of children with sickle cell disease in Lagos, Nigeria. The physical stress, financial stress

and trauma all constitute the burden of caring for people living with sickle cell disease.[4]

In this study, about 35% of the respondents felt the care of sickle cell disease children sometimes has adverse effects on them, while 22% felt the care sometimes causes the neglect of other siblings. This finding is lower compared to a study on psychosocial burden of sickle cell disease on the family conducted in Nigeria reported that caring for children with sickle cell disease reportedly made 42.2% of the caregivers neglect other family members.[13] The reason for this may be because of the difference in study settings. Unlike similar researches carried out in Nigeria which reported that families of individuals with sickle cell disease deny evidence of stigmatization,[19,20] about 14% felt stigmatized about the condition of their children in this study. However, this finding is lower compared to another study in Nigeria which reported that about half of the caregivers reported the existence of stigmatization.[13] Study in developed countries have also reported stigmatization as a conspicuous social problem in mothers of Afro-Caribbean children with sickle cell disease who are living outside Africa.[21]

It has been documented that the cost of treatment for sickle cell disease is a great burden to parents of people living with the disease.[13] A study in Nigeria has documented a high financial burden on the families of people with sickle cell disease.[19] This study found that almost half of the children with sickle cell disease have been hospitalized in the last one year and most for about one week, with an average hospital bill of about ₦30, 000. Similarly, majority of the respondents have been absent from work due to patient's care for about four times or more while about 15% have lost their job due to child care. About one-tenth of the respondents in this study were enrolled with health insurance scheme, about a quarter of the care giver had taken a loan for patient's care in the past while more than half said patient's care was affecting other family expenditure especially in the area of feeding housing, clothing and education of siblings. The degree of effects was described as moderate by most of the respondents. A similar study has documented that more than half of the caregivers reported that the expenses of the child's illness adversely affected the family's basic needs such as food and house rent.[19]

About 89% of the respondents in this study were not on National health insurance scheme, this finding is similar to that of a study conducted in South West Nigeria where more than 90% of the children were not on National health insurance scheme.[22] This is not surprising as only about 10% of Nigerians are enrolled on National health insurance scheme,[23] which contributes to the hardship and pain the parents of children with chronic diseases experience in hospital getting care for the children. As seen in this study, the job loss is also a great contributor to financial hardship for the parents and care givers of children with sickle cell disease.[24] In Nigeria, the predominant form of health- care financing is out-of-pocket payment. It has been documented that between 70% and 100% of household health expenditures in Nigeria are financed through out-of-pocket payment.[22]

In this study, 21% households were involved in catastrophic health expenditure. This finding is similar to that of the study in Nigeria which reported 20.7%.[22] This is not surprising as the Nigerian Health Insurance Scheme which is a form of risk protection covers only about 10% of the Nigerian population, and this fact buttresses the high incidence of Catastrophic Health Expenditure among uninsured households in Nigeria.[23] This is consistent with the findings in Nigeria.[25] Studies have documented the need for the government to strengthen the health scheme as well as subsidizing the cost of care to alleviate the Catastrophic Health Expenditure on the family. National health insurance scheme will increase access of this group of children to health care and also protect them against the risk of incurring huge and unaffordable medical expenses.[26] However, studies in other African countries have reported low catastrophic health expenditure for healthcare, Uganda (2.9%), Burkina Faso (15%), and Kenya (15.5%).[27-29] In this study, a high proportion of respondents (more than 60%) were not on any insurance plan because they were not aware of health insurance schemes. This finding was similar to what was found in some developing countries with unawareness of this health scheme but in contrast to the reports obtainable in developed counties with high patronage due to their prepayment methods through health insurance policies.[22,27,30] This suggests the need to create more awareness amongst the populace for the uptake of health insurance scheme in Nigeria. Also, a majority of respondents who were aware of health insurance but still not enrolled on any health insurance scheme stated 'high premium' as the reason. Systems-wide factors stated as part of the reasons in a study done in Ghana included inadequate distribution of social infrastructure such as health care facilities, weak administrative processes within the National health insurance scheme and poor quality of care.[31] The lack of funds with the trust of the health insurance scheme system were other major reasons for low insurance uptake coverage, then attention must be paid to these issues that militate against the success.[32]

This study found no statistically significant association between age of children, number of siblings, number of siblings with sickle cell disease and catastrophic health expenditure $p>0.05$. However, a statistically significant association was found between level of education and catastrophic health expenditures $p<0.05$.

CONCLUSION

This study documents both social and financial burdens borne by parents of people living with sickle cell disease in Lagos, Nigeria. High level of catastrophic health expenditure was found among the respondents which

indicate the huge financial burden that parents and family experience in course of taking care of their children with sickle cell disease. There is a need for the government to strengthen the health insurance scheme at the national level and State health insurance scheme at the state level, as well as subsidize the cost of care of patients to alleviate the catastrophic health expenditure on the family and caregivers. There is also a need to intensify campaigns to promote and create awareness on health insurance especially among patients with chronic conditions like SCD.

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