Deliverable D2.1

"Report on the identified needs"

Lead Beneficiary
FGB

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Revision date
27/11/2020

Dissemination Level	
PU = Public	☑
CO = Confidential, only for members of the consortium (including the Commission Services)	❑
CI = Classified Information (Commission Decision 2005/444/EC)	❑

Start date
01/01/2019
Duration
48 months
Project Coordinator
Fedele Bonifazi
FONDAZIONE PER LA RICERCA FARMACOLOGICA GIANNI BENZI onlus (FGB)

Reference WP: WP2 - Implementing eHealth technologies to support a Newborn screening programme in African countries and Lebanon
Reference Task: Task 2.3 - Analysis of the needs

"This project has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No 824021"

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2. Glossary and abbreviations

SCD - Sickle Cell Disease

NBS - Newborn screening

ARISE - African Research and Innovative Initiative for Sickle cell Education: Improving Research Capacity for Service Improvement

ED - Emergency Department

SDoH - Social Determinants of Health

DPIA - Data Protection Impact Assessment

GDPR - General Data Protection Regulation, Regulation (EU) 2016/679

NHREC - National Health Research Ethics Committee of Nigeria

HPLC - High-Performance Liquid Chromatography

3. Summary

This document aims to describe the needs of patients suffering from Sickle Cell Disease (SCD) and healthcare professionals involved in SCD management in four clinical centres in Nigeria. It provides relevant information on country-specific issues to be used for the management of SCD in Nigeria.

Evaluating patients and healthcare workers needs is crucial to tailor educational programs, enhance clinical services, including a Newborn screening (NBS) programme and to reduce the burden of illness so that improved quality of life for the patient is ensured.

Paper surveys were adopted to assess these needs; simple and clear language was used for the questionnaire addressed to the patients in order to overcome any linguistic barrier.

Moreover, focus group discussions with healthcare professionals were organised.

This study has been designed as a pilot to be extended, during the course of the project, to the whole Nigerian country, Kenya and Lebanon. It was conducted within the African Research and Innovative Initiative for Sickle cell Education: Improving Research Capacity for Service Improvement – ARISE project, in collaboration with the Nigerian researchers carrying out their secondments at Fondazione per la Ricerca Farmacologica Gianni Benzi Onlus (FGB) that leads this task.

This Deliverable will be amended as the same experience will be conducted in Lebanon and Kenya.

4. Background

SCD is worldwide the most common serious inherited disease affecting mainly people born in sub-Saharan Africa. It is estimated that over 80% of over 300,000 annual births occur in sub-Saharan Africa, the largest burden from Nigeria and Democratic Republic of Congo[1]. SCD is a multi-organ, multi-system disorder with several life-threatening complications. Most of patients experience both acute and chronic pain, primary cause of hospitalization[2], that significantly impact the patients' health related quality of life[3]. SCD is also associated with tissue ischemia and necrosis with organs injury as consequence[4]. SCD increases susceptibility to infections, notably bacterial sepsis and malaria in children under five years. Respiratory infections can trigger the sickle-cell acute chest syndrome, with a high risk of death[3]. A prompt diagnosis is the first step in improving outcomes of patients with SCD. Preventive diagnosis allows for parental education on pathophysiology of disease and recognition of specific signs to seek immediate medical care[5]. Highly effective evidence-based interventions can reduce mortality from infection (prophylactic penicillin, pneumococcal vaccines) and to prevent stroke (transcranial Doppler ultrasound screening). Currently the only available treatments to reduce the severity of SCD are hydroxycarbamide and L-glutamine. Additional therapy is blood transfusion to raise the haemoglobin for improved oxygenation in severe anaemia. The only curative therapy is stem cell transplantation, but it requires a histocompatible donor and it is associated with severe side-effects and reactions. Recent advancements on the molecular genetics and gene therapy offer new hope to SCD patients[3]. SCD is a complex disorder, with a range of barriers to multifaceted care needs at the individual, family/friend, clinical organization, and community levels. Care delivery is complicated by disparities in health care: access, delivery, services, and cultural mismatches between providers and families[6].

[1] Piel, F.B.; Patil, A.P.; Howes, R.E.; Nyangiri, O.A.; Gething, P.W.; Dewi, M.; Temperley, W.H.; Williams, T.N.; Weatherall, D.J.; Hay, S.I. Global epidemiology of sickle haemoglobin in neonates: A contemporary geostatistical model-based map and population estimates. Lancet 2013, 381, 142–151

[2] J. James, B. Andemariam, B. Inusa, F. El-Rassi , B. Francis-Gibson , A. C. Nero, C. P. Minniti, C. Trimnell, M. R. Abboud, J. Arlet , R. Colombatti , M. de Montalembert, S. Jain , W. Jastaniah, E. Nur, L. DeBonnett, I. Osunkwo. Management Strategies and Satisfaction Levels in Patients with Sickle Cell Disease: Interim Results from the International Sickle Cell World Assessment Survey (SWAY). Blood (2019) 134 (Supplement_1): 1017.

[3] Baba P. D. Inusa , Lewis L. Hsu , Neeraj Kohli , Anissa Patel , Kilali Ominu-Evbota , Kofi A. Anie and Wale Atoyebi. Sickle Cell Disease—Genetics, Pathophysiology, Clinical Presentation and Treatment. Int. J. Neonatal Screen. 2019, 5, 20; doi:10.3390/ijns5020020

[4] G. Buchanan, E. Vichinsky, L. Krishnamurti, S. Shenoy. Severe Sickle Cell Disease – pathophysiology and therapy. Biol Blood Marrow Transplant. 2010 January ; 16(1 Suppl): S64–S67. doi:10.1016/j.bbmt.2009.10.001.

[5] M.E. Houwing, P.J. de Pagter, E.J. van Beers, et al., Sickle cell disease: Clinical presentation and management of a global health challenge, Blood Rev. 2019 Sep;37:100580. doi: 10.1016/j.blre.2019.05.004. Epub 2019 May 20

[6] Lewis L. Hsu, Nancy S. Green, E. Donnell Ivy, et al. Community Health Workers as Support for Sickle Cell Care. Am J Prev Med. 2016 Jul;51(1 Suppl 1):S87-98. doi: 10.1016/j.amepre.2016.01.016.

4.1. Assessment of needs

Health needs' assessment is the systematic approach to ensure that the healthcare system uses its resources to improve the health of the population in the most effective and efficient way. It involves epidemiological, qualitative, and comparative methods to describe health problems of a population. Needs' assessment aims to identify inequalities in health and access to services and determine priorities for the use of resources. Health needs are those that can benefit from either healthcare or wider social and environmental changes[7]. 'Need' may have a direct effect on satisfaction with care but the direction of the relationship is not clear. For example, patients may have a need for more or better information on some aspect of health. If this need is unmet, it may result in dissatisfaction with services. Alternatively, better-informed patient tends to have higher expectations and so be dissatisfied with care. Both scenarios directly influence quality of life.

Patients' satisfaction is related to the extent to which general health care needs and condition-specific needs are met[8].

4.1.1. *Current experiences*

Currently several studies assessing SCD patients' needs have been performed. However, few studies are reported in literature to evaluate the needs of patients and healthcare workers in the countries involved in the ARISE initiative.

A study conducted in South Carolina (United States - US) in 2012 used a state-wide administrative dataset to perform a needs assessment for people with SCD by assessing demographic variation in acute care utilization. The study aimed to collect information to inform state and regional policy and clinical educational efforts to improve care and that can be modelled in other states with a similar intent[9].

The needs of SCD patients in Emergency Department (ED) were evaluated by Tanabe P. et al. in 2010. This is a qualitative study that used either individual interviews or participation in a focus group. Adult patients with SCD and physicians and nurses with experience providing care to patients with SCD in the ED were interviewed in the US. The study aimed to identify data and process elements important in making decisions regarding evaluation and management of adult patients in the ED with painful episodes of SCD[10].

[7] John Wright, Rhys Williams, John R Wilkinson. Development and importance of health needs assessment. BMJ. 1998 Apr 25; 316(7140): 1310–1313. doi: 10.1136/bmj.316.7140.1310

[8] Mohsen Asadi-Lari, Marcello Tamburini and David Gray. Patients' needs, satisfaction, and health related quality of life: Towards a comprehensive model. Health and Quality of Life Outcomes 2004, 2:32 doi:10.1186/1477-7525-2-32

[9] Schlenz AM, Boan AD, Lackland DT, Adams RJ, Kanter J. Needs Assessment for Patients with Sickle Cell Disease in South Carolina, 2012. Public Health Rep. 2016;131(1):108-116. doi:10.1177/003335491613100117

[10] Paula Tanabe, Christopher Reddin, Victoria L. Thornton, Knox H. Todd, Ted Wun and John S. Lyons. Emergency Department Sickle Cell Assessment of Needs and Strengths (ED-SCANS), a Focus Group and Decision Support Tool Development Project. Acad Emerg Med. 2010 August ; 17(8): 848–858. doi:10.1111/j.1553-2712.2010.00779.x.

Socioeconomic differences also influence health and well-being. The World Health Organization has identified Social Determinants of Health (SDoH) as "mostly responsible for health inequities - the unfair and avoidable differences in health status - seen within and between countries"[11]. While the health of all children is influenced by SDoH, patients with chronic illnesses, such as those with SCD, may be more affected. A quality-improvement initiative was conducted by Power-Hays A. et al in 2019 aimed to introduce universal screening for SDoH into the routine flow of the paediatric haematology clinic and to identify the socioeconomic needs of SCD patients facilitating referrals to community organizations via this low-touch intervention[12].

In 2017-2018, the Sickle Cell Care Coordination Initiative (SCCCI) surveyed and interviewed 58 people with SCD ages 15 – 48 years and 56 of their healthcare providers and community leaders in Northern California with the aim to gather perspectives from SCD stakeholders about challenges faced by adolescents and adults with SCD in order to develop interventions to improve their healthcare[13].

Moreover, a needs assessment survey with ED providers was conducted throughout North Carolina (NC) in 2019. The study includes also focus groups and an interview with ED providers from three healthcare facilities in central NC. The study aimed to describe the challenges and facilitators to caring for SCD in the EC setting[14].

5. The ARISE survey to assess needs of patients and healthcare professionals

A specific initiative has been designed within the ARISE project, in the framework of task 2.3 "Analysis of the needs" to understand:

1. The needs of patients in terms of SCD management in their reference centre
2. The needs of healthcare professionals having in care SCD patients.

A pilot study (NCT04505969) involving four clinical centres established in Nigeria was designed in order to set this experience to be extended to other clinical centres in Nigeria, Lebanon and Kenya.

The study was planned, developed and run in collaboration with two of the secondees involved in the ARISE staff exchange programme: Abubakar Abdulkareem, researcher from Barau Dikko Teaching Hospital (BDTH), as principal investigator, and Aliyu Mande, health information officer at Ahmadu Bello University Teaching

[11] WHO - Social determinants of health. Available at https://www.who.int/gender-equity-rights/understanding/sdh-definition/en/#:~:text=The%20social%20determinants%20of%20health%20are%20mostly%20responsible%20for%20health,seen%20within%20and%20between%20countries (last access 24/11/2020)

[12] Alexandra Power-Hays, Stephanie Li, Akosua Mensah, Amy Sobota. Universal screening for social determinants of health in pediatric sickle cell disease: A quality-improvement initiative. Pediatr Blood Cancer. 2020 Jan;67(1):e28006. doi: 10.1002/pbc.28006. Epub 2019 Oct 1.

[13] Sickle Cell Care Coordination Initiative. Sickle Cell Care Coordination Initiative: Community Based Needs Assessment to Inform Strategies to Reduce Healthcare Disparities in Northern California. Executive Summary. Available at https://casicklecell.org/wp-content/uploads/2019/04/SCCCIExecutiveSummary.pdf (last access 24/11/2020)

[14] Masese RV, Bulgin D, Douglas C, Shah N, Tanabe P (2019) Barriers and facilitators to care for individuals with sickle cell disease in central North Carolina: The emergency department providers' perspective. PLoS ONE 14(5): e0216414. https://doi.org/10.1371/journal.pone.0216414

Hospital (ABUTH), who contributed to the analysis on Nigerian ethical and legal requirements, including the submission to the ethics committees.

Approvals from the National Health Research Ethics Committee of Nigeria (NHREC/01/01/2007-29/05/2020) and local ethics committees were sought.

Two different approaches were implemented to assess the needs of patients and healthcare professionals involved in the management of SCD.

In order to gather relevant information, two questionnaires were developed to be administered to SCD patients/parents and healthcare workers respectively.

Moreover, focus groups were organised in the selected clinical centres to explore the opinions and the needs of healthcare workers involved in SCD management such as physicians, nurses and laboratory technicians.

Data collection started in August 2020 and ended in November 2020.

5.1. Methods

5.1.1. *Questionnaires design*

Following an exploratory literature review[15,16], the principal investigator drafted two study questionnaires: one tailored on SCD patients/parents of children with SCD and another one for healthcare workers. They were initially drafted in English and were discussed within the ARISE Steering Committee and Scientific Coordinator to get their feedback.

The following personal data were collected for patients/parents: age, sex, diagnosis, education and profession. They were asked to indicate the main source of information on SCD, rate the quality of services and level of satisfaction regarding the provided services and provide suggestions to improve the management of SCD in the reference centre. Questionnaire for patients/healthcare professionals is available in Annex I (English version).

Once finalised it was translated in local language (Hausa).

The following data were collected for healthcare professionals: reference centre, area of specialization and weekly working hours. Detailed information related to the training courses received, number of patients attending the clinic, level of satisfaction regarding the provided services were asked as well.

[15] Bolarinde Joseph Lawal, Schadrac C Agbla, Queen Nkeiruka Bola-Lawal, Muhammed O Afolabi, and Elvis Ihaji. Patients' Satisfaction With Care From Nigerian Federal Capital Territory's Public Secondary Hospitals: A Cross-Sectional Study. Journal of Patient Experience 2018, Vol. 5(4) 250-257. DOI: 10.1177/2374373517752696

[16] I. Osunkwo, M. Abboud, B. Andemariam, J.-B. Arlet, R. Colombatti, M. de Montalembert, F. El Rassi, B. Francis-Gibson, B. Inusa, S. Jain, W. J. Jastaniah, C. Minniti, A. Nero, E. Nur, L. DeBonnett, J. Waller, J. James. Impact of sickle cell disease from patients' and physicians' perspectives: results from the International sickle cell world assessment survey (SWAY). HemaSphere. 2019;3:S1

Questionnaires were self-completed and coded to ensure confidentiality. Moreover, a Data Protection Impact Assessment (DPIA), including an evaluation of the ethics risks related to the data processing, according to the Article 35 of the European General Data Protection Regulation (GDPR)[17], as well as the assessment of risks related to the misuse of personal data, were performed as required by the ARISE Grant Agreement. More details are included in the deliverables D8.9 and D8.6 respectively.

5.1.2. *Identification and recruitment of study participants*

The needs assessment involved adult SCD patients/parents of children suffering from SCD and healthcare professionals from four clinical centres in Kaduna and Katsina state, Nigeria: Barau Dikko Teaching Hospital Kaduna State University (BDTH), Ahmadu Bello University Teaching Hospital Zaria (ABUTH), National Hospital Abuja (NHA), and Federal Medical Centre Katsina (FMC). Centres were selected to be easily accessible to the principal investigator and his collaborators. Their multiethnic demographics cause some to regard these states as a microcosm of the country.

Adult SCD patients and parents of children suffering from SCD have been recruited according with the following inclusion criteria:

- Aged ≥ 18
- Have SCD diagnosis or having a child with a SCD diagnosis
- Attending the centre from at least 6 months
- Nigerian nationality
- Informed Consent signed

Healthcare professionals were recruited if they met the following inclusion criteria:

- Working in a SCD clinic
- At least 5 years of experience with SCD patients
- Informed Consent signed

Patients/parents and health workers who withdraw the informed consent or were illiterate or suffer from any psychiatric conditions impairing their participation in this study were excluded. A random and purposive sampling technique was adopted.

5.1.3. *Outcomes*

We evaluated the perceived satisfaction with the quality of care and services.

[17] European Parliament and Council of European Union (2016) Regulation (EU) 2016/679. Available at: https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:32016R0679&from=EN (last access on 25/11/2020)

The satisfaction of patients/parents and healthcare professionals in terms of SCD management was measured as following: they were asked to indicate their satisfaction level on several items, indicating their opinion/experience on 5-point Likert Scale for Satisfaction. A point value was assigned to each response from 1 to 5 (very poor/very dissatisfied/very inadequate at 1 point and very good/very satisfied/very adequate at point 5). Frequency, mean and standard deviation were calculated for each item.

5.1.4. *Focus group discussion*

In addition to the questionnaire, focus groups were organised to explore the opinions and the point of view of healthcare professionals involving in the management of SCD patients in the 4 selected centres.

The discussion lasted from 45 minutes to one hour and it was focused on the perception of the facilities both in the clinic and the laboratory such as adequacy and functioning of services.

The major needs concerning the management of SCD disease in the clinic were discussed as well as the possible ways to improve the provided services.

The discussion was recorded and transcribed by the principal investigator.

5.1.5. *Data analysis*

Data collected in the questionnaires were transcribed by the principal investigator in an Microsoft Excel spreadsheet that was used for the data analysis. Descriptive statistics were performed using IBM® SPSS® Statistics 19[18] to describe all variables. Frequency, mean, standard deviation and mode were calculated for each item.

Outcomes of focus group discussions were transcribed by the principal investigator and qualitatively analysed. Interview data were converted from audiotapes to transcribed text. A thematic analysis coding process as described by Miles M. B. and Huberman M. A. (1994)[19] was used to code the underlined words and recorded narratives. Using these coding steps, the narratives were read and re-read thoroughly to identify variance, similarities and relationships in themes by underlined using pen (open code). Recoded in plain sheets of paper. The aim is to condense the data into a smaller and more manageable size. The strategy for the data analysis is summarized in Table below (Table 1).

[18] IBM® SPSS® Statistics 19. Available at https://www.ibm.com/products/spss-statistics (last access 25/11/2020)

[19] Miles, M. B, Huberman M. A, Saldaña J. Qualitative data analysis: a methods sourcebook. Arizona State University. Third edition. 2013 ISBN 978-1-4522-5787-7

Data Reduction	*Data Display*	*Conclusion Drawing & Verification*
Initial read and re-read interview transcripts while searching for similarities and differences in themes by underlined using pen (open code). Recoded in plain paper. The aim is to reduce the data into a smaller and more manageable size	Data display began by listing all the codes and creating meaning out of relevant text segment (open codes). Narratives coded into **210** open codes	**210** number of open codes labels and narrowing down to final overarching themes or categories into **7** emergent categories (wider categories)

Table 1. Strategy adopted for qualitative data analysis

5.1.6. *Ethics approval*

The study protocol, the informed consent forms and the questionnaire were drafted by the secondee in collaboration with FGB team. They were revised and approved by the ARISE Steering Committee and the Ethics Advisor.

The study sought the approval from the National Health Research Ethics Committee of Nigeria (NHREC/01/01/2007-29/05/2020) on 29 May 2020. Approval from local ethics committees were obtained as well between July and October 2020.

Personal data, including health data, were collected through the questionnaires. They were processed according to the European GDPR and local rules in terms of data protection (Nigeria Data Protection Regulation[20]). Data were kept strictly confidential and were made available to third parties as pseudonymised data.

Written informed consents were obtained from participants, both healthcare workers and patients/parents, in particular a Hausa version was developed for patients/parents.

The study (NCT04505969) was also registered in the ClinicalTrial.org database on 10 August 2020.

6. Results

6.1. Patients/parents

112 SCD patients/parents were recruited in the 4 centres to complete the questionnaire. Following verification of inclusion criteria, 4 subjects were excluded. 108 questionnaires were included in the analysis. Most patients come from the North-West region of the country, particularly 43.5% from Kaduna State and 23.1% from Katsina State. North-Central, North-East and South regions are less represented (Fig. 2).

[20]National Information Technology Development Agency. Nigerian Data Protection Regulation. 2019. Available at: https://nitda.gov.ng/wp-content/uploads/2020/11/NigeriaDataProtectionRegulation11.pdf (last access on 25/11/2020)

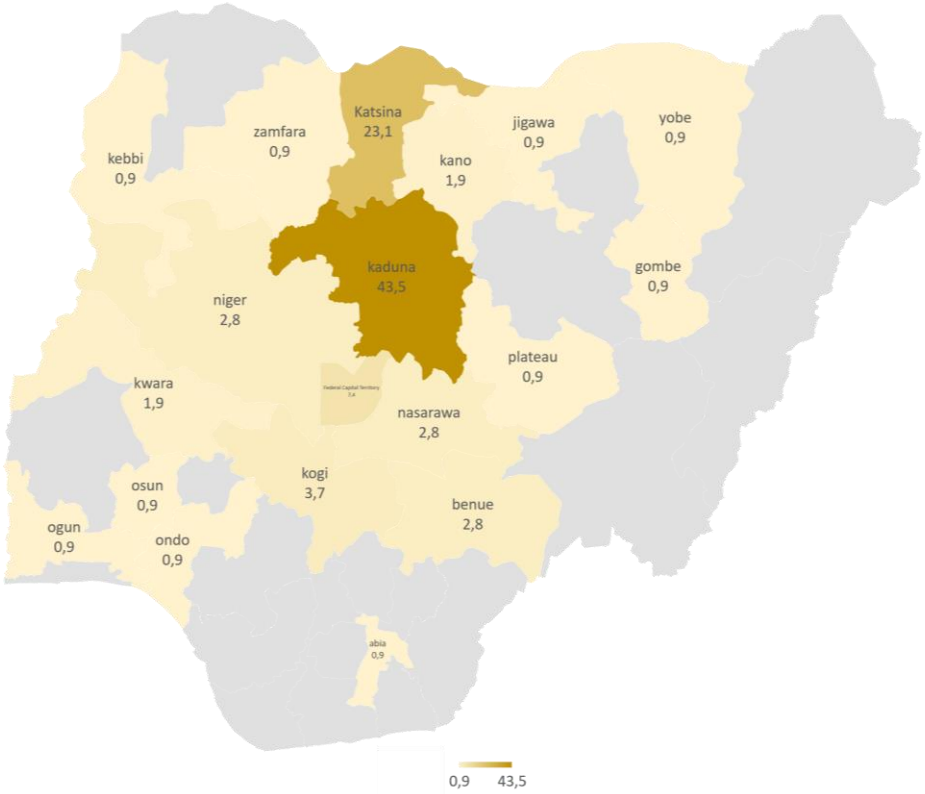

Fig. 2. Patients' distribution by State

a. General information

Participants main features are detailed in table 2. All participants have a confirmed SCD diagnosis or have a child with a confirmed SCD diagnosis.

Variable	Nr. of responding participants	Category	Participants count and percentage
Sex	100	Female	51 (51%)
		Male	49 (49%)
Clinical centre	108	ABUTH	29 (26.9%)
		BDTH	28 (25.9%)
		FMC	22 (20.4%)
		NHA	29 (26.9%)
Education	101	Primary	16 (15,8%)
		Secondary	33 (32,7%)
		University	43 (42,6%)
		Nursery	7 (6,9%)
		Other	2 (2,0%)
Transfusion regimen	106	Not transfused	56 (52.8%)
		Transfused once	6 (5.7%)
		Occasionally transfused	28 (26.4%)

Variable	Nr. of responding participants	Category	Participants count and percentage
		Regularly transfused	16 (15.1%)

Table 2. Participants (SCD patients/parents) main features

b. Source of information on Sickle Cell Disease

Participants were asked to indicate their usual information source on SCD. Most of respondents (56, 51.9%) refer to their doctor or nurse in the centre, but TV and social networks are also largely used as source of information (NN, 17.6% and NN 13.9%, respectively). Personal contacts and religious leaders are less represented. Full details in Figure 3.

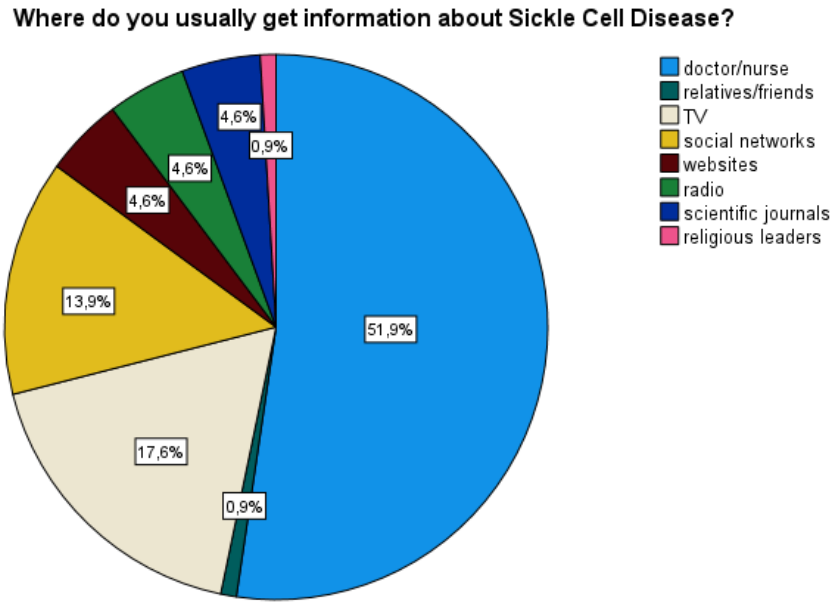

Fig. 3 Source of information on SCD

c. Reported satisfaction on their experience in the centre

Respondents were asked to judge their reference facilities giving a score from 1 (very inadequate/poor) to 5 (very adequate/good) to several items.

Globally considered, participants are satisfied of the experience they have as patients in the concerned clinical centres with reference to communication with healthcare professionals about SCD and its treatment, also considering the information they received at the time of the diagnosis. They feel involved in the decisions that affect their health. Also, communication with nurses and laboratory technician have been positively judged by most of participants (table 3.A).

On average, waiting times to get an appointment in the clinic, to see the doctor or to get feedback from laboratory are considered good (table 3.B).

Participants seem to be satisfied by services provided in the laboratory. In terms of support facilities, 61 participants (56.5%) declared the existence of facilities for psychological support, that are considered quite good in terms of services. Remarkably, it seems that psychological support is not available or used by participants (Table 3C). Participants are overall satisfied with the global SCD management in the centre. However, a lower satisfaction score was highligthed with reference to the access to treatment. More details in the Table 3D.

RATE YOUR SATISFACTION FOR EACH OF THE FOLLOWING ITEMS:	*1 (very poor)*	*2*	*3*	*4*	*5 (very good)*	*mean*	*SD*
Communication about SCD and its treatment (N=107)	0	6 (5.6%)	7 (6.5%)	48 (44.9%)	46 (43.0%)	4.25	0.81
Information received at the time of the diagnosis (N=107)	2 (1.9%)	1 (0.9%)	5 (4.7%)	51 (47.7%)	48 (44.9%)	4.33	0.77
Involvement in decisions affecting disease (N=108)	0	3 (2.8%)	5 (4.6%)	51 (47.2%)	49 (45.4%)	4.35	0.70
Communication with laboratory technicians (N=107)	0	1 (0.9%)	13 (12.1%)	70 (64.4%)	23 (21.5%)	4.07	0.61
Communication with nurses (N=108)	0	4 (3.7%)	9 (8.3%)	58 (53.7%)	37 (34.3%)	4.19	0.74

Table 3A. Satisfaction on communication and information received

RATE WAITING TIMES FOR THE FOLLOWING:	*1 (very long)*	*2*	*3*	*4*	*5 (very short)*	*mean*	*SD*
See the doctor (N=108)	1 (0.9%)	6 (5.6%)	16 (14.8%)	47 (43.5%)	38 (35.2%)	4.06	0.90
Having next clinic appointment (N=107)	1 (0.9%)	18 (16.8%)	61 (57.0%)	18 (16.8%)	9 (8.4%)	3,15	0.83
Having feedback from laboratory (N=108)	3 (2.8%)	6 (5.6%)	14 (13.0%)	61 (56.5%)	24 (22.2%)	3.90	0.91

Table 3B. Waiting times

RATE YOUR SATISFACTION FOR EACH OF THE FOLLOWING ITEMS:	1 (very poor)	2	3	4	5 (very good)	mean	SD
Services provided in the laboratory (N=108)	0	2 (1.9%)	12 (11.1%)	65 (60.2%)	29 (26.9%)	4.12	0.66
Psychological support (N=70)	2 (2.9%)	4 (5.7%)	11 (15.7%)	40 (57.1%)	13 (18.6%)	3.83	0.90

Table 3C. Perceived quality of facilities

RATE YOUR SATISFACTION FOR EACH OF THE FOLLOWING ITEMS:	1 (very poor)	2	3	4	5 (very good)	mean	SD
Nursing care in the clinic (N=108)	1 (0.9%)	0	14 (13.1%)	51 (47.7%)	41 (38.3%)	4.22	0.74
Instructions on pain control (N=108)	0	3 (2.8%)	10 (9.3%)	43 (39.8%)	52 (48.1%)	4.33	0.76
SCD treatment and management (N=106)	0	5 (4.7%)	10 (9.4%)	58 (54.7%)	33 (31.1%)	4.12	0.76
Overall service quality (N=103)	0	0	8 (7.8%)	49 (47.6%)	46 (44.7%)	4.37	0.62
Access to treatment (N=108)	1 (0.9%)	16 (14.8%)	31 (28.7%)	46 (42.6%)	14 (13.0%)	3.52	0.93

Table 3D. Reported satisfaction on global SCD management in the centre

d. Costs

Cost of treatments is considered a particularly sensitive item for most participants, that judge this too expensive (table 4). This is relevant considering that treatments are mainly paid by patients and families directly (N=98, 91.6%) or by private health insurance (N=7, 6.5%). In one case health insurance is provided by employers.

RATE YOUR SATISFACTION ON:	1 (very expensive)	2	3	4	5 (very cheap)	mean	SD
Cost of treatment (N=108)	28 (25.9%)	47 (43.5%)	22 (20.4%)	9 (8.3%)	2 (1.9%)	2.17	0.97

Table 4. Rating about cost of treatment

e. Need for moving to other centres

82 out of 108 participants need to move from the reference centre to other centres mainly to perform periodical visits (51, 62.2%), special examinations (13, 15.8%) or visits (13, 15.8%) and laboratory analyses (5, 6.1%).

For those in needs of moving to other centres, distances are quite high (Fig. 3).

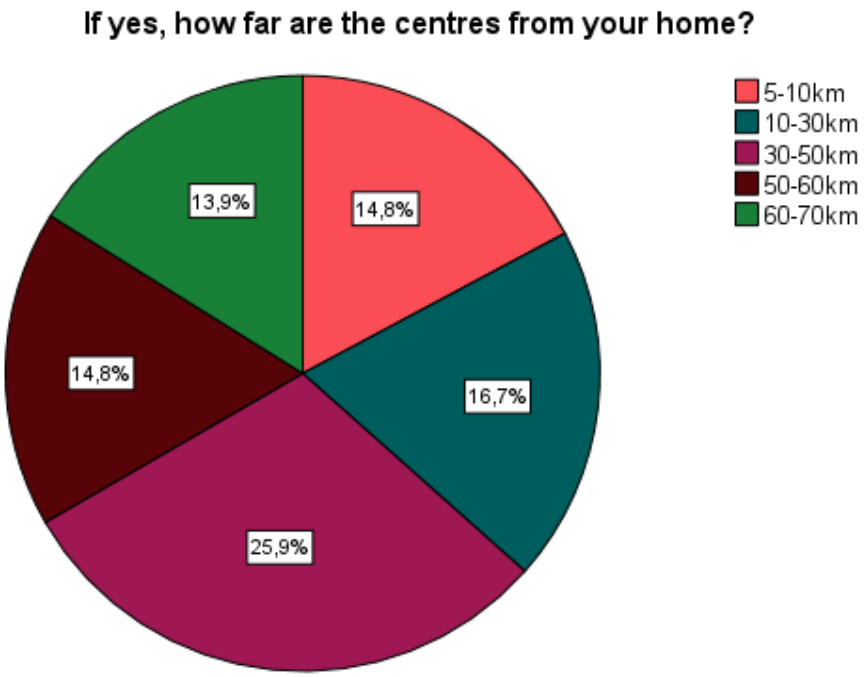

Fig.3 Distance from home to centres

f. Global satisfaction about the management in the centre and perception of health status

Most of participants (72/108, 66.7%) would recommend their reference centre to relatives and friends, even if there is a relevant percentage having doubt in this. 5/108 participants (4.6%) would discourage relatives and friends from attending the centre (fig.4).

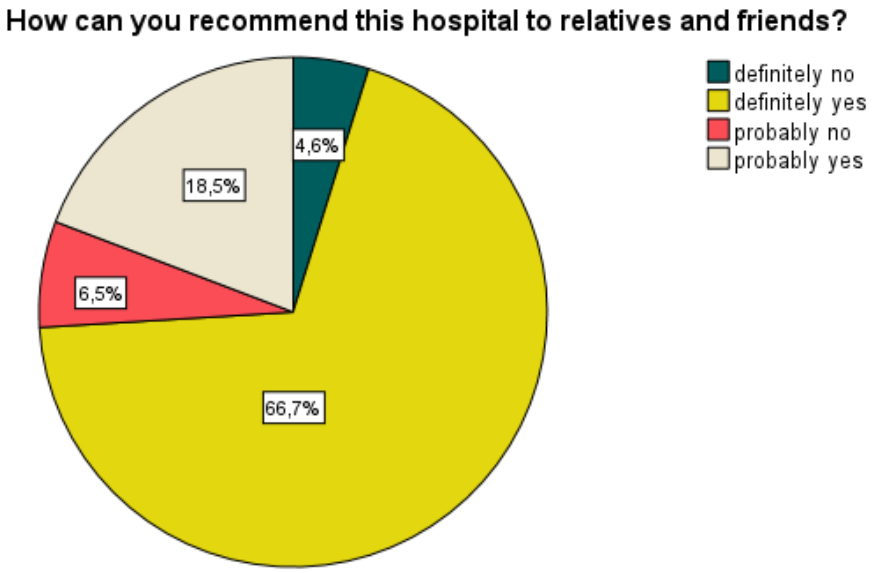

Fig. 4 Global satisfaction with the centre

Current health status is generally self-perceived as good, even if a small percentage of participants declared it very poor (N=4, 3.7%).

	1 (very poor)	*2*	*3*	*4*	*5 (very good)*	*mean*	*SD*
Evaluate your current health status	4 (3.8%)	0	9 (8.6%)	74 (70.5%)	18 (17.1)	3.97	0.78

Table 5 Health status self-perception

Participants were asked to propose any additional aspect to improve the management of SCD. 22 provided answers on this, mentioning one or more of the following items:

- Free access to medicines (6)
- Cope with medicines shortage (1)
- Global improvement in patients management (4)
- Free access to health facilities (2)
- Adequate coordination in management (1)
- Regular orientation by nurses to patients and parents (1)
- Need to have more awareness on SCD (2)
- Health insurance (2)
- Need for counselling session (1)

6.2. Healthcare professionals

84 healthcare professionals answered to the questionnaire in the 4 clinical centres.

a. General information

Respondents are mainly form the North-West region of Nigeria, 46.3% from Kaduna State and 18.3% from Katsina State followed by Benue (8.5%), Federal Capital Territory – FTC Abuja (7.3%) and Nasarawa (6.1%) in the North-Central region of the country. Full data on the geographical distribution of the professionals in the figure 5.

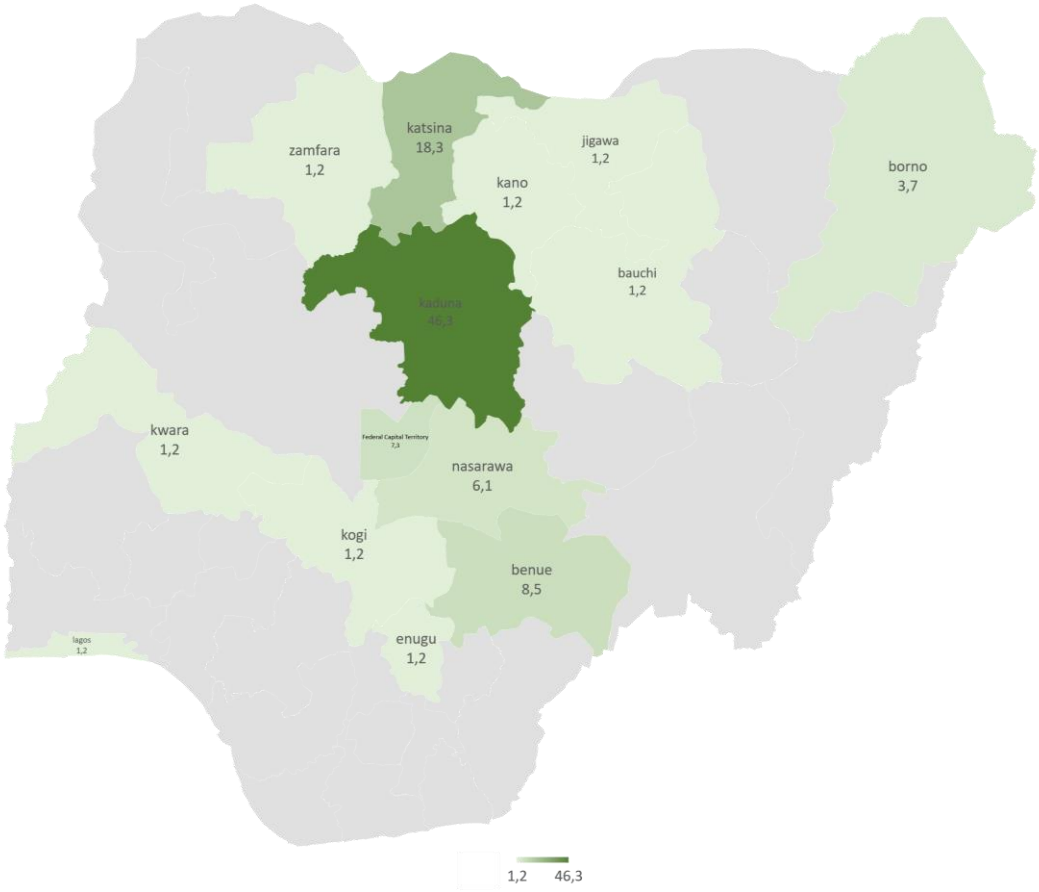

Fig. 5. Healthcare professionals' distribution by State

Medical doctors account for more than one half of participants (N=47, 56%), while lab technologists and nurses are less represented (table 1).

Variable	Nr. of responding participants	Category	Participants count and percentage
Gender	80	Female	40 (50.0%)
		Male	40 (50.0%)
Clinical centre	82	ABUTH	21 (25.0%)
		BDTH	20 (23.8%)

Variable	Nr. of responding participants	Category	Participants count and percentage
		FMC	15 (17.9%)
		NHA	28 (33.3%)
Age, Categorical	82 participants Mean age: 39.87, SD 7.765	19 – 26 yrs	5 (6.1%)
		27 – 34 yrs	11 (13.4%)
		35 – 42 yrs	47 (57.3%)
		43 – 50 yrs	12 (14.6%)
		51+ yrs	7 (8.5%)
Professional role	84	Healthcare attendant	2 (2.4%)
		health records officer	3 (3.6%)
		lab technology	17 (20.2%)
		medical doctor	47 (56.0%)
		nurse	13 (15.5%)
		pharmacist	2 (2.4%)

Table 6. Participants (healthcare professionals) main features

b. Workload

Reported weekly working hours with SCD patients is extremely variable, ranging from 6 to 72 (mean 30 hours, SD 16,3). Most of healthcare professionals (N=52, 61.9%) manage from 10 to 20 SCD patients, with 8.3% being involved in the management of more than 40 SCD patients.

Indeed, most of respondents (N=57, 67.9%) consider adequate to manage from 5 to 10 SCD patients.

In terms of difference between current number of patients and desirable number, 62 (73.8%) healthcare professionals reported higher workload.

Full details about the number of patients that respondents have in care and the adequate number of SCD patients they would like to have for an optimal management is detailed in table 7.

Number of patients you currently have in care (N=84)		Adequate number of SCD patients for a proper care (N=84)	
Range of patients number	Frequency and %	Range of patients number	Frequency and %
<5	0	<5	1 (1.2%)
5 to 10	20 (23.8%)	5 to 10	57 (67.9%)
10 to 15	19 (22.6%)	10 to 15	10 (11.9%)
15 to 20	33 (39.3%)	15 to 20	8 (9.5%)
20 to 40	4 (4.8%)	20 to 40	5 (6.0%)
>40	7 (8.3%)	>40	1 (1.2%)
n.a.	1 (1.2%)	n.a.	2 (2.4%)

Table 7. Current and suggested number of SCD patients managed by study participants

c. Training on SCD management

63 (75%) out of 84 respondents received training on SCD management in the three months before the study, attending seminar/workshop (38,1%), conferences (19%) or receiving individual training (14.3%). Less than 4% of participants had the chance to attend different type of training, while 25% of participants did not attend any training (Fig. 6).

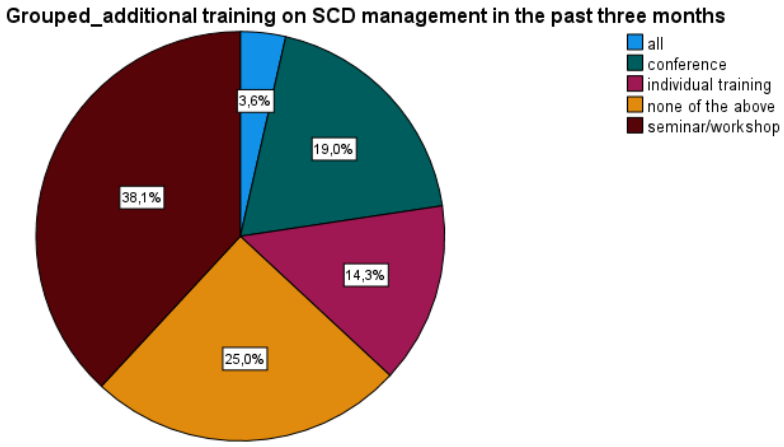

Fig. 6 SCD training received in the three months before the study

In terms of training being delivered to patients for the self-management of the disease, most of healthcare professionals train patients how to avoid complications (N=30, 35.7%) and pain management (N=24, 28.6%). Other themes include symptoms (N=5, 6%), suggestions on nutrition (N=1, 1.2%) and advices on how to take care (2, 2.4%). Full details in figure 7.

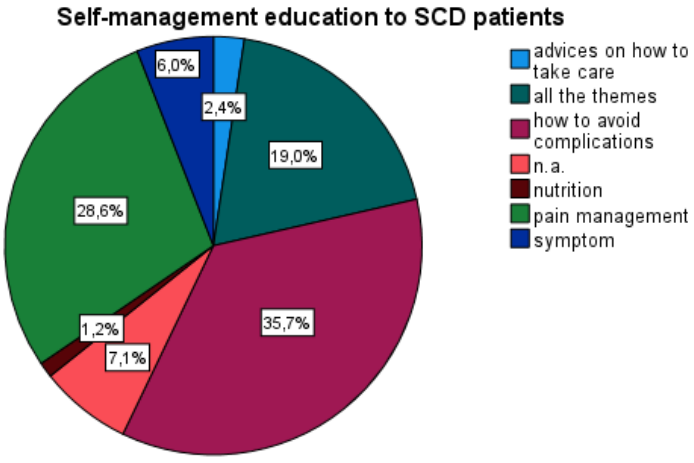

Fig. 7 Topics of training healthcare professionals deliver to SCD patients

d. Facilities quality and global management, individual professional satisfaction and work with patients

Respondents were asked to judge the adequacy of facilities for SCD in terms of quantity and quality. Score distribution ranges from 1 (very inadequate/poor) to 5 (very adequate/good).

In terms of items referring to individual professional development, most of respondents judged adequate how they are protected from injuries and professional risks, as well as their involvement in decision-making process of the centre. They also considered good the chance they have for career advancement, the level of responsibility they have, the decision-making autonomy and how their work is acknowledged/appreciated. Tables 8A, 8B and 8C show full data.

Globally, 76 healthcare professionals (90.5%) are satisfied of their work with SCD patients, that is one of the items having the highest satisfaction score.

RATE YOUR SATISFACTION FOR EACH OF THE FOLLOWING ITEMS:	*1 (very poor)*	*2*	*3*	*4*	*5 (very good)*	*mean*	*SD*
Adequacy of facilities for SCD (quantity) N=82	0	25 (30.5%)	6 (7.3%)	25 (30.5%)	26 (31.7%)	3.63	1.22
Adequacy of facilities for SCD (quality) N=83	0	3 (3.6%)	16 (19.3%)	32 (38.6%)	32 (38.6%)	4.12	0.85
Global management of the clinic N=83	0	1 (1.2%)	11 (13.3%)	44 (53.0%)	27 (32.5%)	4.17	0.69

Table 8A. Facilities adequacy

RATE YOUR SATISFACTION FOR EACH OF THE FOLLOWING ITEMS:	*1 (very poor)*	*2*	*3*	*4*	*5 (very good)*	*mean*	*SD*
Protection from injuries and professional risks N=83	0	5 (6.0%)	15 (18.1%)	38 (45.8%)	25 (30.1%)	4.00	0.85
Involvement in decision-making N=83	1 (1.2%)	4 (4.8%)	12 (14.5%)	38 (45.8%)	28 (33.7%)	4.06	0.88
Possibility of career advancement N=82	0	2 (2.4%)	14 (17.1%)	38 (46.3%)	28 (34.1%)	4.12	0.78
Level of responsibility adequacy N=83	0	1 (1.2%)	11 (13.3%)	40 (48.2%)	31 (37.3%)	4.22	0.72

Decision-making autonomy N=82	2 (2.4%)	5 (6.1%)	5 (6.1%)	40 (48.8%)	30 (36.6%)	4.11	0.94
Level of appreciation of the work N=84	0	0	14 (16.7%)	35 (41.7%)	35 (41.7%)	4.25	0.73

Table 8B. Professional satisfaction

RATE YOUR SATISFACTION FOR:	***1 (very poor)***	***2***	***3***	***4***	***5 (very good)***	***mean***	***SD***
relationship with the patients N=84	0	0	2 (2.4%)	39 (46.4%)	43 (51.2%)	4.49	0.55

Table 8C. Work with SCD patients by healthcare professionals

12 respondents provided more details about the poor adequacy of facilities, giving the following reasons:

- limited space and furniture (4)
- poor staff training (2)
- manpower shortage (3)
- need for specific equipment/suppliers. The following ones were mentioned: advanced HPLC machines (1), child blood bags, vein finders (1), Exchange Blood Transfusion sets (1)
- need for specific facilities: functional facilities for early diagnosis (1), laboratory support (1), consulting rooms and terminals
- delaying in supplying drugs (1)

In addition, one of the partecipants highligthed the inadequate welfare for SCD patients.

Healthcare professionals who were not satisfied of their work with the patients (8/84) provided explanations to this. Poor equipment and training have been reported as main impairing factors for a satisfactory patients' management. Full answers are reported in table 9.

	Frequency and % (N=8)
Poor equipments	4 (50.0%)
Poor training	4 (50.0%)
Poor collaboration from patients	2 (25.0%)
Work overload	3 (37.5%)
No social/psychological support	1 (12.5%)
Poor collaboration from colleagues	1 (12.5%)
No health insurance	1 (12.5%)
Inadequate economic remuneration	1 (12.5%)

Table 9. Main reasons impairing work with patients

e. Suggestions to improve the work

33 out of 84 respondents gave suggestions to improve their work with SCD patients. Answers have been following summarised and grouped under each item:

Service organisation/ Infrastructure

- expansion of haematology day care (3)
- extension of the day care department
- increase staff units (5)
- global facilities improvement (5)
- collaboration among units and specialists (2)
- provision of point of care diagnostics for older children
- increase infrastructural equipment in the diagnosis and management

Equipment/suppliers

- Personal Protective Equipment
- proper waste disposal (2)
- proper hazard management
- provision of HPLC and blood exchange machine
- technological and automated equipment

Training

- Global staff training
- Specific training on equipment

Funding

- funds for patient care (5)
- funds for research (1)

Support for patients

- Improve doctor patient relationship
- patient centred management
- social orientation for SCD patient on how to avoid complications and early presentation to the hospital in case of any emergency

Other

- supply drugs at the right time

- to improve access to drugs, investigations and blood transfusion

6.3. Focus groups

Focus group discussions were initially foreseen with patients and parents, but this was unfeasible due to the COVID-19 pandemic. The following issues were reported in involving patients in discussions: lack of patients in the hospitals, patients not feeling comfortable to remain in the hospital for the focus group discussion, movement restrictions, missing authorisation from the hospital authorities to hold discussions with patients. Thus, the principal investigator rearranged the study to involve healthcare professionals in focus groups discussions held from September to November 2020. The protocol was amended accordingly and a notification letter was submitted to the NHREC in November 2020.

Focus Group discussions were conducted in the four selected centres (ABUTH, BDTH, FMC and NHA) involving 4 healthcare professionals (mainly physicians, nurses and laboratory technicians) per each centre. A total of 12 healthcare professionals were interviewed.

a. Description of Emergent Categories

This section describes the 7 categories and 210 open codes that emerged from the transcribe interview. The categories and quotations were arranged properly, to allow the reader an opportunity to draw on the reflection of thoughts given to the participants' responses.

1. Facilities and Equipment's

This category provides some explanations quotes from the participants' responses on perceptions about the facilities and equipment's particularly in the SCD clinic and laboratory in terms of adequacy and functionalities as detailed by these respondents:

"*we need machine like point of care machine that can give us some results on time in the clinic, these are the basic things in the clinic I can talk about*"

Another respondent stated that*:*

"In the lab we need hand gloves, syringe and nitrogen analyzer, if we can also get bypath is a very sensitive machine dedicated for SCD patients"

Similarly, this respondent mentioned:

"HP *electrophoresis machine and G.C.E machines, HPLC machine and the IEF machine unfortunately we don't have state of the art facilities here if we have them it will assist greatly worked faster"*

2. Training and Re-training

This category was generated from participants and explains that nurses and laboratory technicians need for more training in order to improve or gain more knowledge on SCD as expressed by the following respondents:

"*we need to attend training specifically on sickle cell disease in order to gain more experience and knowledge to improve our services*"

In the same vein this respondent also explained that:

"*we need to attend conference, workshops and seminar outside, this will help us in improving our services and gain more knowledge on SCD*"

Similarly, these laboratory staff described conferences and workshop as very important to them:

"*most of the doctors here attend conferences and workshops only we laboratory staff that we are not attending so we need to attend conferences and workshop to improve our knowledge on sickle cell disease*"

3. More Space in the Clinic and Lab

Participants expressed the need of more space in both clinic and laboratory. Actually, they are too small to properly run the clinic and laboratory tests as explained by these respondents:

"*actually we need more space in the clinic to improve our services*"

Another respondent revealed that:

"*The clinic generally is not really specific for sickle cell clinic, it is just generally an Hematology clinic, it would have been better if we can structure it in such a way that the clinics have specific directions"*

Other respondents stated that:

"*Our lab is too small we need expansion and good structure that will help us to improve*"

4. Policies Standard

This category provides narratives from participants about the need of standardisation policies that will guide them restructuring their clinical and diagnostic services as explained by these respondents:

"*we need a guiding document and policy that will tell us or explain what to you need to do, especially when or during taking sample and process it, so sometimes it prolongs the delay time at which a doctor may*

have requested for an investigation and maybe they need the result to decide on what to do, but the result may not come out till maybe 24 hours later for things that are simple"

Other respondents stated that:

"*we need a policy that will guide us to link pediatric, adult clinic, emergency and lab, so that our sample will immediately be process at a giving time, there will be no delay in getting the result"*

The respondent added that:

"the policy will help us in getting blood donation. The policy will also guide us in blood transfusion service"

5. Electronic Patients Registry

This category comprised explanations from respondents about the need for electronic patient's registry specifically for patients with SCD to improve their services. Respondents expressed the importance of having electronic patient's registry to their facilities, as follows:

"*we need electronic patient's registry to keep our data for the patients for easy access*"

Similarly, other respondents specified that:

"*Yes, electronic patient's registry is very important to retrieve our patients data, this is because is good to keep record and make a backup*"

In the same vein this respondent pinpoint out that:

"*when somebody say this is my number it becomes that number within this facility, nobody will have that number again, that is the idea of an E-Registry now so that, somebody will have a particular number. That number and your information can be reached from anywhere in the world. But for now, it's on paper and the numbering is just based on the hospital numbering system it's not like there is a specific system for sickle cell"*

The respondents also explained that:

"*We need electronic patient's registry too specifically for sickle cell disease to improve the patients' follow-up visit*", "*an electronic patient management system that is easy to relocate patient. If we have software that is electronic medical recording register in the clinic will greatly assist us in clinics"*

6. Raising Awareness

This category provides responses on the need to increase awareness on SCD patients. Healthcare workers stated that the majority of SCD patients do not attend clinic. They prefer traditional medicine than attending the clinic, thus creating awareness is crucial as expressed by the following respondents:

"*we need community mobilizers' people that will go around the community and create awareness to go to clinic, community mobilizer that will encourage them to go to clinic. Creating awareness to be coming to clinic is very important*"

Similarly, this respondent explained that:

"*lack of awareness made many sickle cell disease patients not to come to the clinic, they preferred traditional medicine than coming to the clinic*"

7. Controlled Drugs Prescription

This category provides some narratives related to the prevention of drug abuse. The respondents revealed that the need for controlling drug abuse is very important. It also revealed that some patients were denied buying appropriate drugs, especially analgesics, prescribed by the doctors as explained by these respondents:

"*What am saying for both pediatrics and adults, there are times when, somebody will prescribe a medication, a doctor prescribe a narcotic because of pain and then a patient go out to buy and then the person selling refuses to give them medication*"

The respondents stated that*:*

"There is need to provide those drugs in SCD clinic"

Other respondents detailed that:

"there is need for a policy guiding the administration of those medication, so if a patient needs those control drugs, the prescriber knows those drugs are controlled and the prescriber has to follow all the rules and regulations to prescribe those drugs"

"So if the prescriber follows the rules and regulations of prescription, we write the name of the patient, age, number, sometimes the weight of the patient and then you prescribe the medication the way you are supposed to prescribe them, prescribe the drug for one day or two day as against open prescription so this are the kind of rules and regulations"

b. Discussion of Findings

All the interviewees emphasised the need for adequate and more sensitive diagnostic equipment for genotyping, such as the high-performance liquid chromatography (HPLC) machine or point of care tests that allow getting the results in a short time in the clinic.

Some challenges related to the management of the SCD patients were presented during the discussion.

It was underlined the need for standardisation of the procedures through specific policies guiding the diagnosis and the management of patients to ensure them timely and appropriate care. A more robust governance structure is needed to better organise the SCD patients' management.

All the interviewed healthcare professionals revealed the need for more space for the laboratory services as well as the transfusion service.

Training of personnel, including either physicians, technicians, or nurses, is one of the main needs experienced in all the selected centres. Regular training activities are needed to increase the knowledge on the latest advancements on SCD in terms of prevention, diagnosis, genetic counselling and treatments as well as to improve the current procedures adopted in the clinical centre.

In terms of recording of patients' data, the majority of interviewees highlighted the need for an electronic SCD patients' registry to improve the patients' follow-up.

In order to improve the disease outcomes all the interviewees agreed on the need for raising awareness of SCD among patients, relatives and the community as well. Several awareness initiatives have been implemented but it is still a challenge. Increasing the patients' engagement in the management of their health together with doctors and nurses was also identified as a way to improve the services in the centres.

In two of the selected centres, it was discussed the issue related to the controlled drug prescription that aims to avoid abusing of controlled drugs such as analgesics prescribed to SCD patients to manage the pain. The prescribers should fulfil the rules of prescription related to these drugs, such us writing the patient name, age or route of administration in order to prevent abuses on one hand and on the other hand to guarantee the needed medicines to patients.

In this framework, another issue to be considered is the health insurance. In particular the need for a health insurance was revealed by the interviewees in order to facilitate the access to the adequate treatments for patients with SCD.

7. Conclusions and next steps

Results show an adequate satisfactory rate among patients and healthcare professionals about their experience with SCD management in the centre. The principle limitation of the data is the sample size, but

these pilot study numbers are similar to published needs assessments in SCD. The self-completion nature and the blinding of questionnaires helped to reduce the interviewer effect; thus, results can be considered quite realistic.

Despite the study was run during the COVID-19 pandemic, it was feasible to administer paper questionnaires to patients and healthcare professionals in their reference clinical centres. However, to speed up the data collection process and simplify the experience for patients and healthcare professionals, the possibility to have online questionnaires will be adopted as more as possible in next steps. Moreover, specific measures to complement the perspectives from patients and parents will be in place using online instruments to run interviews and discussions, considering the possible issues (costs and efforts) in running face to face focus groups in the whole country.

Results of this pilot experience will be considered according to different perspectives:

1. What can be improved through the ARISE project: for example, the delivery of reliable information on SCD for patients through the project website and social networks; the identification of thematic areas for healthcare professionals training
2. What can be improved in each of the centres being investigated: further analyses related to each of the involved centres could be discussed with site leaders to identify specific areas for improvement and what is needed
3. Support to systemic policy actions: some of the items that have been reported by participants (treatment costs, workload, need for equipment) require a long-term and global change in SCD management approach and specific resources to do this.
4. This experience can provide data supporting policy actions and interactions with stakeholders. For this reason, as next step, further Nigerian centres will be identified in order to expand the analysis and cover a wider area.

Evaluating patients and healthcare workers needs is crucial to tailor implementation measures to improve clinical and diagnostic services paving the way for a successful management of SCD in Nigeria, where the burden of the disease is significant.

This pilot phase allowed to set this experience, that will be extended to other clinical centres in Nigeria and also in Lebanon and Kenya. Currently, specific study protocols are under discussion with principal investigators from Strathmore University (Kenya) and American University of Beirut (Lebanon).

This deliverable represents a preliminary report that will be reviewed and finalized once experiences in Nigeria, Kenya and Lebanon are concluded.

8. Document History

Date	Author	Changes
13/11/2020	L. Ruggieri A. Didio	1st draft
19/11/2020	A. Abdulkareem	Additional comments
20/11/2020	L. Dogara	Additional comments
23/11/2020	A. Mande	Additional comments
25/11/2020	A. Landi	Additional comments
26/11/2020	F. Bonifazi	Final revision
27/11/2020	ARISE Steering Committee	Approval

9. ANNEXES

9.1. Annex I. QUESTIONNAIRE FOR NEED ASSESSMENT OF PATIENTS/PARENTS INVOLVED IN SICKLE CELL DISEASE MANAGEMENT

Questionnaire code: _____

SECTION A

Bio Data

1. State _____
2. Local Government _____
3. Name of SCD Clinic/Hospital _____
4. Age _____
5. Gender Male [ ] Female [ ]
6. Education: University [ ], Secondary [ ], Primary [ ], Nursery [ ] other (please specify) _____
7. Occupation: Business [ ], Civil Servant, [ ], Farmer [ ], other (please specify) _____

SECTION B

1. **If you are a patient, what is your diagnosis? If you are a parent, what is the diagnosis of your child?**
   A. Sickle cell disease [ ]
   B. Sickle cell/b-thal [ ]
   C. **Sickle Beta-Plus Thalassemia [ ]**
   D. Other (please specify) _____

2. **How is your/your child current transfusion regime?**
   A. I am not transfused [ ]
   B. I am regularly transfused [ ]
   C. I am occasionally transfused [ ]
   D. Other (please specify) _____

3. **Where do you usually get information about Sickle Cell Disease?**
   A. Websites
   B. Social Networks
   C. Scientific journals
   D. TV
   E. Radio
   F. Leaflets/booklets
   G. Doctor/nurse
   H. Other patients
   I. Relatives/friends

J. Religious leaders
K. Other (please specify) _____

4. Please, indicate your main information source: _____

5. How satisfied are you with the communication about Sickle Cell Disease and its treatment?

A. Very satisfied [ ]
B. Satisfied [ ]
C. Neither satisfied Nor dissatisfied [ ]
D. Dissatisfied [ ]
E. Very Dissatisfied [ ]

6. Following your/your child Sickle Cell Disease diagnosis, who did you/your child get support from to deal with the disease?

_____

7. How satisfied are you with the support you/your child received at the time of the diagnosis?

A. Very satisfied [ ]
B. Satisfied [ ]
C. Neither satisfied Nor dissatisfied [ ]
D. Dissatisfied [ ]
E. Very Dissatisfied [ ]

8. How satisfied are you with your involvement by doctor in the decisions that affect your/your child disease?

A. Very satisfied [ ]
B. Satisfied [ ]
C. Neither satisfied Nor dissatisfied [ ]
D. Dissatisfied [ ]
E. Very Dissatisfied [ ]

9. How satisfied are you with the instruction given by doctor about pain control?

A. Very satisfied [ ]
B. Satisfied [ ]
C. Neither satisfied Nor dissatisfied [ ]
D. Dissatisfied [ ]
E. Very Dissatisfied [ ]

10. How satisfied are you about the waiting times to see doctors in the clinic?

A. Very satisfied [ ]
B. Satisfied [ ]
C. Neither satisfied Nor dissatisfied [ ]

D. Dissatisfied [ ]
E. Very Dissatisfied [ ]

11. How short or long on the next clinic appointment giving by the doctors?

A. Very short [ ]
B. Short [ ]
C. Neither short Nor long [ ]
D. Long [ ]
E. Very long [ ]

12. How satisfied are you about the services provided in the lab?

A. Very satisfied [ ]
B. Satisfied [ ]
C. Neither satisfied Nor dissatisfied [ ]
D. Dissatisfied [ ]
E. Very Dissatisfied [ ]

13. How satisfied are you during or when communicating with lab technicians?

A. Very satisfied [ ]
B. Satisfied [ ]
C. Neither satisfied Nor dissatisfied [ ]
D. Dissatisfied [ ]
E. Very Dissatisfied [ ]

14. How satisfied are you about the waiting times in the lab?

A. Very satisfied [ ]
B. Satisfied [ ]
C. Neither satisfied Nor dissatisfied [ ]
D. Dissatisfied [ ]
E. Very Dissatisfied [ ]

15. How satisfied are you with the nursing care in clinic?

A. Very satisfied [ ]
B. Satisfied [ ]
C. Neither satisfied Nor dissatisfied [ ]
D. Dissatisfied [ ]
E. Very Dissatisfied [ ]

16. How satisfied are you during or when communicating with nurses?

A. Very satisfied [ ]
B. Satisfied [ ]
C. Neither satisfied Nor dissatisfied [ ]

D. Dissatisfied [ ]
E. Very Dissatisfied [ ]

17. How satisfied are you with your/your child SCD current treatment and management for SCD (e.g. Hydroxyurea, blood transfusion, pain medications, vaccination, surgeries etc.)?

A. Very satisfied [ ]
B. Satisfied [ ]
C. Neither satisfied Nor dissatisfied [ ]
D. Dissatisfied [ ]
E. Very Dissatisfied [ ]

18. How expensive about the cost of treatment in the hospital?

A. Very expensive [ ]
B. Expensive [ ]
C. Neither expensive Nor inexpensive [ ]
D. Cheap [ ]
E. Very cheap [ ]

19. How good about the about the overall service quality?

A. Very good [ ]
B. Good [ ]
C. Neither good Nor poor [ ]
D. Poor [ ]
E. Very poor [ ]

20. How would you rate access to the treatment centre (in terms of distance, cost etc.)?

A. Very easy [ ]
B. Easy [ ]
C. Neither easy nor difficult [ ]
D. Difficult [ ]
E. Very difficult [ ]

21. Who pays for your treatment? (tick all that apply)

A. My self/my family [ ]
B. Health insurance (private) mine [ ]
C. Health insurance (private) my employer's [ ]
D. State goverment provide free healthcare [ ]
E. Other (please specify) _____

22. Do you need to move to other centres to perform one of the following?

A. Periodical visit [ ]
B. Specialist visit [ ]
C. Special examination [ ]
D. Laboratory analysis [ ]
E. Other (please specify) _____

23. If yes, how far are the centres from your home?

A. 5-10km [ ]
B. 10-30km [ ]
C. 30-50km [ ]
D. 50-60km [ ]
E. 60-70km [ ]

24. Are there facilities for psychological support in this hospital?

A. Yes [ ]
B. No [ ]

25. How satisfied are you with the support received from the psychological support facilities?

A. Very satisfied [ ]
B. Satisfied [ ]
C. Neither satisfied Nor dissatisfied [ ]
D. Dissatisfied [ ]
E. Very Dissatisfied [ ]

26. How can you recommend this hospital to relatives and friends?

A. Definitely no [ ]
B. Probably no [ ]
C. Definitely yes [ ]
D. Probably yes [ ]

27. How would you describe your/your child current health?

E. Very poor
F. Neither poor nor good
G. Good
H. Excellent

Is there any additional aspect you would like to propose to improve the management of SCD?

_____

_____

9.2. Annex II. QUESTIONNAIRE FOR NEED ASSESSMENT OF HEALTH WORKERS INVOLVED IN SICKLE CELL DISEASE MANAGEMENT

Questionnaire code: _____

SECTION A - Bio Data

1. State _____

2. Local Government _____

3. Name of SCD Clinic/Hospital _____

4. Age _____

5. Gender Male [ ] Female [ ]

6. Please indicate your area of specialization

A. Medical Doctor [ ]
B. Nurse [ ]
C. Laboratory technology [ ]
D. Pharmacist [ ]
E. Others (please specify) _____

7. Average weekly effective working hours_____

SECTION B

1. **Which of the following additional training did you receive on Sickle Cell Disease management in the past three months?**

A. Seminar [ ]
B. Conference [ ]
C. Workshop [ ]
D. Training [ ]
E. None of the above [ ]
F. Other (please specify) _____

2. **How often do you see or attended to Sickle Cell Disease patients?**

A. Once in a week [ ]
B. Twice in a week [ ]
C. Once in a month [ ]
D. Twice in a month [ ]
E. Other (please specify) _____

3. **How many Sickle Cell Disease patients do you see or attend in the clinic?**

A. 5-10 [ ]
B. 10-15 [ ]

C. 15-20 [ ]
D. Other(please specify) _____

4. How many SCD patients do you think is adequate for you to see or attend?

A. 5-10 [ ]
B. 10-15 [ ]
C. 15-20 [ ]
D. Other (please specify) _____

5. How satisfied are you with the relationship you have with the patients?

A. Very satisfied [ ]
B. Satisfied [ ]
C. Neither satisfied Nor dissatisfied [ ]
D. Dissatisfied [ ]
E. Very Dissatisfied [ ]

6. At the clinic, do you educate patients with SCD on self-management aspect of their disease? If yes, what type of information do you give them?

A. Information about how to avoid complication [ ]
B. Information about pain management [ ]
C. Information about symptom [ ]
D. Other (please specify) _____

7. How adequate are the number of facilities in the clinic/lab?

A. Very adequate [ ]
B. Adequate [ ]
C. Neither adequate nor inadequate [ ]
D. Inadequate [ ]
E. Very inadequate [ ]

8. How good are the facilities provided to manage SCD patients?

A. Very good [ ]
B. Good [ ]
C. Neither good nor poor [ ]
D. Poor [ ]
E. Very poor [ ]

9. If the facilities have any problems, please state them below

_____

10. How satisfied are you with the management of your clinic?

A. Very satisfied [ ]
B. Satisfied [ ]
C. Neither satisfied nor dissatisfied [ ]
D. Dissatisfied [ ]
E. Very Dissatisfied [ ]

11. Do you feel protected from injuries and professional risks?

A. Very good [ ]
B. Good [ ]
C. Neither good nor poor [ ]
D. Poor [ ]
E. Very poor [ ]

12. How do you judge your involvement in the decision-making process of your centre?

A. Very good [ ]
B. Good [ ]
C. Neither good nor poor [ ]
D. Poor [ ]
E. Very poor [ ]

13. How satisfied are you with your career advancement (if you are willing to)?

A. Very satisfied [ ]
B. Satisfied [ ]
C. Neither satisfied nor dissatisfied [ ]
D. Dissatisfied [ ]
E. Very Dissatisfied [ ]

14. How satisfied are you with the level of responsibility you have?

A. Very satisfied [ ]
B. Satisfied [ ]
C. Neither satisfied nor dissatisfied [ ]
D. Dissatisfied [ ]
E. Very Dissatisfied [ ]

15. How satisfied are you with on the decision-making autonomy you have?

A. Very satisfied [ ]

B. Satisfied [ ]
C. Very Dissatisfied [ ]
D. Dissatisfied [ ]
E. Neither satisfied nor dissatisfied [ ]

16. How do you judge the level of appreciation of your work?

A. Very good [ ]
B. Good [ ]
C. Neither good nor poor [ ]
D. Poor [ ]
E. Very poor [ ]

17. In general, are you satisfied with your work with SCD patients?

A. Yes
B. No

If not, please indicate the reason:

A. Poor collaboration from colleagues and other staff [ ]
B. Poor collaboration from patients [ ]
C. Work overload [ ]
D. Poor training [ ]
E. Poor equipments [ ]
F. Poor organisation [ ]
G. Poor career possibility [ ]
H. No social/psychological support [ ]
I. Inadequate economic renumeration [ ]
J. Other (please specify) _____

18. In general, what do you think is more important to improve your work?

_____
_____