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Socioprofessional Impact of Sickle Cell Disease among Workers with Sickle Cell Disease Monitored at Saint Camille Hospital in Ouagadougou in 2023

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Abstract

Background: Sickle cell disease (SCD) is a genetic condition highly prevalent among the Black population, with serious consequences for the daily lives of those affected. **Objective:** To study the impact of SCD on the professional and social experiences of workers with SCD monitored at Saint Camille Hospital in Ouagadougou in 2023. **Materials and Methods:** This was a descriptive cross-sectional study with data collection through questionnaires administered to adult workers with sickle cell disease who were regularly followed up on the active roster at Saint Camille Hospital in Ouagadougou. **Results:** We conducted interviews with 146 workers with SCD. Females were the most represented, accounting for 54.42%. The most commonly observed level of education was secondary education. The public sector was the most represented employment sector, with 33.82%. Vaso-occlusive crises were the most frequent recurrent clinical manifestation, at 27.97%, and chronic complications accounted for 21.97% of cases. Workers with sickle cell disease were absent from work an average of 3.75 days ± 3.63 days during crises. Eighty-four point thirty-five percent (84.35%) received emotional support from friends and extended family, while 38.69% did not participate in social association activities. **Conclusion:** Sickle cell disease influences the social and professional lives of workers. The establishment of a health policy within public and private companies, combined with proper management of the condition, would ensure the full well-being of these individuals.

Keywords

Sickle Cell Disease, Socioprofessional Impact, Ouagadougou, Workers

1. Introduction

Socioprofessional integration refers to the process by which an individual becomes part of a socioeconomic system (environment), gains access to employment, remains employed, and fully participates in social and economic life [1] [2]. Beyond professional access, socio-professional integration is essential because it is a factor in personal fulfillment, well-being, and individual, community, and social development. It contributes to social recognition, autonomy, and a sense of usefulness in society [1] [2]. Furthermore, individuals' state of health, including chronic illnesses, is a determining factor in socioprofessional integration and experience, which becomes highly precarious [3]. In the case of increasingly common congenital or acquired chronic illnesses, socio-professional integration and experience remain major challenges because of absenteeism and reduced capacities [3]-[7]. Indeed, studies have shown that the consequences of chronic illnesses on employment negatively impact good socioprofessional participation, causing departures, job losses and difficulties, disabilities, and early retirement [8] [9]. Sickle cell disease (SCD), or sickle cell anemia, is a monogenic genetic disorder transmitted in an autosomal recessive manner [4] [10]. It results from a mutation in the β chain of hemoglobin, which alters the morphology and function of red blood cells [4] [10]. With a worldwide prevalence of 310,000 annual births of major sickle cell cases, it is the most widespread genetic disease in the world [11]. This condition mainly affects the African population [4] [12]. Several studies have shown that SCD negatively impacts the socioprofessional life and productivity of those affected [4] [7] [8] [13]-[15]. In Burkina Faso, the situation is particularly concerning, with a prevalence of 4.63% in 2020 [16]. Despite the high prevalence of SCD, few studies have explored its socioprofessional impact on the experiences of affected workers. The challenges faced by these individuals, such as health-related discrimination, absenteeism, unsuitable working conditions, and employer prejudice, remain poorly documented [3] [4] [8]. Thus, this study aims to examine the socioprofessional impact of SCD on the experiences of workers living with it in the city of Ouagadougou to better understand the difficulties they face and make appropriate recommendations for better socioprofessional inclusion.

2. Materials and Methods

2.1. Study Setting

This study was conducted at the Saint Camille Hospital in Ouagadougou, Burkina Faso. Our choice was motivated by the fact that Saint Camille Hospital of Ouagadougou (HOSCO) has a medical care unit for SCD that brings together adult patients with SCD from the city of Ouagadougou. It is a Catholic hospital located in

District 5, Ouagadougou. It was founded and managed by the Servants of the Infirm. This unit was established through a partnership agreement between the Initiative Committee Against SCD in Burkina Faso and the Pierre Fabre Foundation.

2.2. Type and Study Period

This was a descriptive, cross-sectional study, with data collected from July 20, 2023, to June 20, 2024.

2.3. Study Population

The study involved all adult sickle cell workers who were regularly monitored on the active registry at the Saint Camille Hospital of Ouagadougou (HOSCO).

2.4. Sampling and Selection Criteria

This was a convenience sample of all sickle workers who met the study criteria.

The following were included in the present study:

- sickle cell workers registered in the active file of HOSCO;
- At least 18 years old and residing in the city of Ouagadougou;
- having attended at least three medical follow-up appointments in the past 12 months;
- freely consented to participate in our study.

Unemployed individuals with SCD were not included in our study.

2.5. Study Variables

The study variables were as follows:

- Socioprofessional characteristics: sex, age, marital status, level of education, sector of activity, job stability, and monthly income.
- Clinical characteristics: frequent clinical manifestations, frequency of crises, and chronic complications.
- Variables concerning the impact of SCD on socioprofessional life: absences from work, task rearrangement, work environment, care of patients within the services, leisure, participation in social life and associative activities, emotional support, and discomfort related to the disease.

2.6. Data Collection

Sickle cell workers meeting the inclusion criteria identified from the active registry follow-up records were contacted by telephone to schedule an individual interview and to complete an anonymous electronic data collection form.

2.7. Data Entry and Analysis

The data were drafted and analyzed using a microcomputer equipped with Word and Excel software, Epi Info 7.2.2.6, and Stata 16.1. A descriptive analysis of quantitative variables was performed in terms of the mean and standard deviation, while qualitative variables were expressed as frequencies and percentages. Mi-

crosoft Office 2016 Excel spreadsheet was used to create the charts.

2.8. Ethical Considerations

We obtained authorization number 2023-07-019 from the HOSCO Institutional Ethics Committee to carry out data collection after submission of the study protocol. Oral, free, and informed consent was obtained from all participants. Patient anonymity was maintained. The confidentiality of the information collected for this study was maintained.

3. Results

A total of 146 workers with sickle cell disease were included in our study.

3.1. Socioprofessional Characteristics of Workers with SCD

The average age was 35.37 ± 10.28 years, ranging from 18 to 57 years. The sex ratio was 0.82. The average monthly income of workers with SCD was 109,540.05 ± 75,082.51 FCFA, ranging from 30,000 to 300,000 FCFA. In the private sector, the average income was 89,992.00 ± 76,155.79 CFA, whereas in the public sector, it was 147,786.26 ± 56,410.05 FCFA. On average, workers with SCD worked 9.22 ± 3.57 hours per day. Those in the private sector worked an average of 9.28 ± 2.34 hours per day, while public sector employees worked an average of 7.56 ± 1.07 hours per day. The socioprofessional characteristics of workers with SCD are presented in Table 1.

Table 1. Socioprofessional characteristics of workers with SCD.

Socioprofessional characteristics	Number (n)	Percentages (%)
Sex		
Female	80	54.79
Male	66	45.21
Marital status		
Married	55	37.67
Single	86	58.90
Widowed	5	3.42
Level of education		
No schooling	20	13.70
Primary	14	9.59
Secondary	63	43.15
Higher	49	33.56
Sector of activity		
Public	51	34.93
Formal private	45	30.82
Informal private	50	34.25

Continued

Job stability		
Yes	134	92.06
No	12	7.94

3.2. Clinical Characteristics

Vaso-occlusive crises (VOC) account for the majority of the frequent clinical manifestations. The average number of crises over 6 months was 2.58 ± 7.84, with extremes ranging from 0 to 12. The major chronic complications observed were visual disorders, with a frequency of 50.98%, followed by femoral head necrosis, with a frequency of 49.02%. The results are presented in Table 2.

Table 2. Distribution of patients according to common clinical manifestations (N = 146).

Clinical characteristics	Number (n)	Percentage (%)
Common clinical manifestations		
Osteoarticular pain	134	91.78
Acute chest syndrome	97	66.44
Anaemia	72	49.32
Excessive fatigue	109	74.66
Chronic complications		
Visual disturbances	26	17.81
Femoral head necrosis	25	17.12

3.3. Impact of SCD on Socioprofessional Life of Workers

➢ **SCD and work**

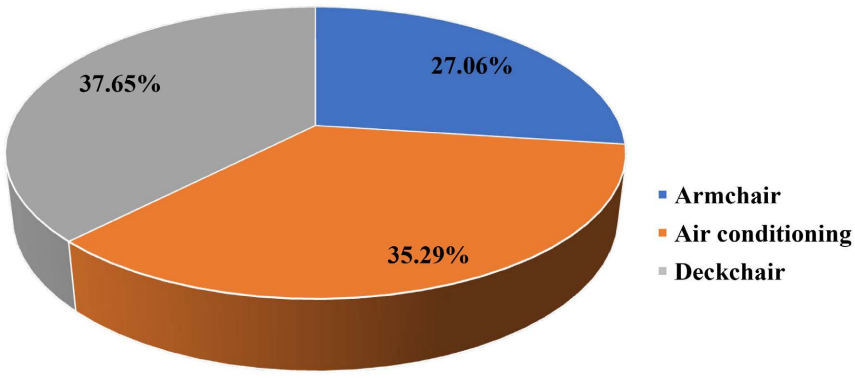

Figure 1. Distribution of sickle cell workers according to workplace adaptations.

On average, workers with SCD were absent from work for 3.75 days ± 3.63 over a 6-month period during crises, with extremes ranging from 0 to 14 days, and 7.5 days ± 7.26 over 12 months. According to 56.26% of the surveyed patients, there were no protocols in place to reorganize tasks in the event of unexpected crises.

The work environment was deemed unsatisfactory by 50.74% (69) of workers, satisfactory by 46.32% (63), and very satisfactory by 2.94% (4) of the 136 respondents. One hundred and twenty-two out of one hundred and thirty-six workers, or 89.71%, felt that their work environment was not adapted to their health condition. Thirty-five point twenty-nine percent (35.29%) of workers had air conditioning in their office. The distribution of workers with SCD according to workplace adaptations is shown in Figure 1.

➢ **Patient care within the departments**

Of the 107 workers with SCD, 79.44% reported receiving mandatory medical checkups, 9.35% reported receiving training, and 5.61% reported having health insurance and administrative leave or additional days.

➢ **Leisure**

Nearly half of the individuals with SCD (48.18%) did not experience any difficulties in engaging in leisure activities. The distribution of working individuals with SCD according to difficulties in participating in leisure activities is shown in Figure 2.

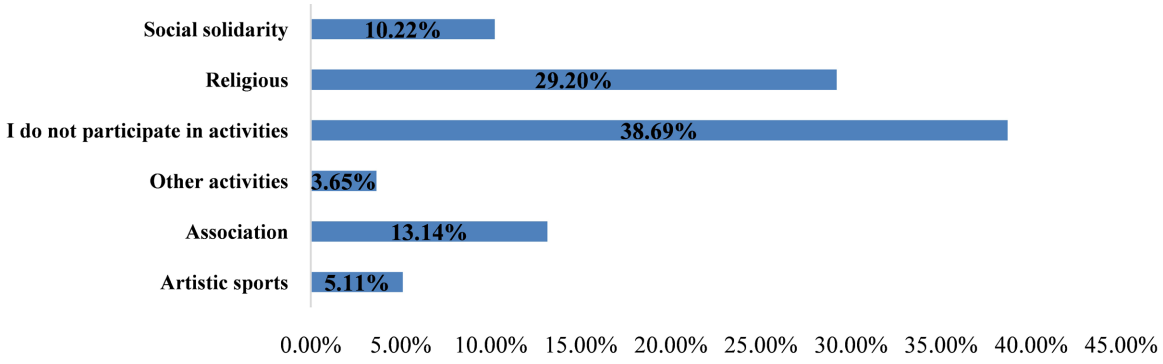

Figure 2. Distribution of sickle cell workers according to difficulties related to leisure activities (n = 137).

➢ **Participation in social life and community activities**

Of the 146 workers with SCD, 7 (4.79%) reported being excluded from social events. Of the 137 respondents, 38.69% did not participate in any group activities. The majority of workers with SCD, that is, 84.35%, stated that they had received emotional support from friends and family. More than half of the patients surveyed (56.16 %) said they were not bothered by how society viewed them, while 34.25% (50) and 9.59% (14) of the 146 workers with SCD thought that society saw them as people in need of help and pity.

4. Discussion

4.1. Socioprofessional Characteristics of Workers with SCD

In our study, the average age of workers with SCD was 35.37 ± 10.28 years, with a range of 18 - 57 years. This result is similar to those from Rizio (34.37 years ± 10.25 [15]), Tchicaya (32 ± 8.01 years [17]), Drahos (35.5 ± 10.4 years [18]), and Pires (33.78 ± 13.04 years [8]). Our results differ from those of other studies con-

ducted on similar populations. Igala *et al.* in Gabon found an average age of 30.4 ± 7.8 years, with a range of 18 - 53 years [19]. Osunkwo and Cunha found even lower average ages, specifically 24.7 and 30.1 years, respectively [20] [21]. This difference could be explained by variations in participant selection: Igala's study focused on a hospital population, which is often younger and affected by more severe cases, whereas our study included active workers, representing a population with better functional health. The relative youthfulness of this population reflects a more limited life expectancy in some African contexts where specialized care is less accessible. In contrast, the higher average age in our study could indicate better quality of care, progress in medical management, and the integration of people with SCD into the Burkinabe health system, enabling them to reach a more advanced adult age. Female workers with SCD comprised the majority (54.42%), with a sex ratio of 0.82. This is consistent with the findings of Pires (0.92 [8]), Holdford (0.72 [7]), Igala (0.5 [19]), and Cunha (0.36 [20]), who also observed a predominance of women. Conversely, Diop *et al.* in Dakar and Tchicaya in Abidjan found a male predominance, with sex ratios of 1.25 [22] and 2.42 [17], respectively. These different findings are likely related to the demographic data of each country, as the transmission of the disease is independent of sex or possibly due to higher healthcare utilization among women. Secondary education was the most represented, accounting for 42.86% of the sample. A similar finding was reported by Diop *et al.* in Senegal, with a rate of 47% [22]. However, Igala *et al.* and Tchicaya *et al.* found that higher education was the most represented level, with 42% [19] and 61% [17] respectively. Our results can be explained by the fact that the burden of illness and the expenses involved in its management make it difficult to continue school activities. Indeed, people with SCD must contend with acute crises of the illness that lead to absences, and consequently, to academic failure and school dropout. According to one study, more than 41% of people with SCD aged at least 18 years reported that SCD had a negative impact on their schooling and academic motivation [21]. In another study conducted in the USA, 42.2% of people with SCD stated that the illness had an adverse effect on their education, in terms of dropping out, delays, or needing to change their academic program [15]. This low level of education could affect their integration into the workforce. Generally, people with a low level of education hold lower-level jobs or jobs requiring significant physical effort, which is difficult or even incompatible for those with SCD. The public sector is the main sector employing workers with SCD in the city of Ouagadougou, accounting for 33.82%, followed by the formal and informal private sectors. The results of our study can be explained by several reasons, notably the costs associated with care, which mean that informal sector workers remain largely excluded from various healthcare services, and the lack of awareness about SCD among most workers in the informal sector, which results in their underrepresentation in consultations. In addition, the observed levels of education due to school dropouts caused by the disease could be one explanation for why workers with sickle cell disease are drawn to the private sector, especially

the informal sector.

4.2. Clinical Characteristics of Sickle Cell Workers

The most prevalent clinical manifestation was vaso-occlusive crisis (VOC), accounting for 27.97% of the cases. The same observation was made by Diop *et al.* in Senegal in 2003, who found that 96.3% of patients with SCD had experienced at least one vaso-occlusive crisis per year [22]. Similarly, Rizio *et al.* reported that 91.1% of patients had at least one VOC [15]. Drahos and Osunkwo corroborated our findings in their work, with a very high frequency of VOCs—at least 68.5% in the previous year [5] [14]. Painful crises dominate the symptomatology of SCD due to their frequency. They are most often referred to as vaso-occlusive crises. They may be spontaneous or triggered and are explained by the sickling of hemoglobin, which triggers a pain syndrome that is exacerbated by cold, acidosis, fever, dehydration, or any situation resulting in hypoxia. Ocular complications represented 50.98% of the complications, and osteoarticular complications, 49.02%. Tchicaya *et al.* (2016) found in Côte d'Ivoire that the majority of complications were osteoarticular, with a frequency of 71.4% [17]. Frequencies of 55.7% have been reported in Congo by Dokekias *et al.* [23] and over 44% by Osunkwo [14]. Most studies underestimate the actual frequency of these chronic complications because they are often asymptomatic and systematic screening is not always performed due to cost and accessibility. Thus, Manci *et al.* (2003) reported a frequency of 74.4% of chronic complications at autopsy in deceased homozygous sickle cell patients, compared to only 25.3% of complications detected through clinical and paraclinical arguments during their lifetime [24]. As these acute and chronic manifestations worsen over time, they determine the social and professional activities of individuals with SCD.

4.3. Impact of SCD on Socioprofessional Life of Workers

The average number of days absent from work was 3.75 ± 3.63 over six months, with extremes ranging from 0 to 14 days. Between crises and everyday discomfort, SCD forces patients to navigate the world of work and social life. In a study conducted in the USA by Rizio *et al.* in 2020, patients reported high absenteeism from work [15], as did Mohamed *et al.* [13]. Osunkwo *et al.* and Drahos *et al.* reported an average weekly absenteeism of 7 and 9.8 hours, respectively [5] [21]. Moreover, 53% of working individuals with SCD reduced their working hours [21]. Annual absenteeism of at least 10 days, and in some cases up to 36 days, was reported by some authors [7] [25], attributable to both acute manifestations and chronic complications of the disease. Studies have also revealed a low employment rate among people with SCD, ranging from 23% to 40.9% [7] [8] [15] [18]-[21] [26]. Painful crises, especially osteoarticular crises, and even chronic complications force patients to rest and seek frequent medical consultations, which in turn leads to repeated absences from work. These repeated absences may lead to exclusion if the patient's coworkers are unaware of their medical condition. Thus, studies have

shown job loss among employees with SCD at various, sometimes significant rates, up to 76.4% [17] [21] [25] [26]. According to 56.26% of the surveyed workers with SCD, there is a lack of job adjustments in both the private and public sectors. This result could be explained by employers and even colleagues being unfamiliar with SCD, as well as the absence of policies within the state or companies for the professional integration of people with SCD [13] [27]. This situation, combined with work absenteeism, may lead to decreased productivity and performance among these workers. In a study by Tchicaya, 9.8% of patients with SCD (Sickle Celle Disease) benefited from job accommodation [17]. This underscores the importance of collaboration between occupational physicians, hematologists, and employers to ensure constant health monitoring and necessary accommodations to preserve health and maintain employment [4] [27]. Eighty-nine point seventy-one percent (89.71%) of offices are not arranged to take into account the health status of workers with SCD. As SCD is recognized as a disabling illness, patients should benefit from adapted work environments, activities, and tasks, enabling them to receive regular medical follow-ups, necessary care, and adjustments to work schedules. The working environment and activities should be conducive to health promotion and help prevent crises [27]. Triggering factors such as heat, cold, prolonged standing, intense physical activity and effort, and stress should be avoided in the workplace [4] [17] [27]. In fact, an adapted job would be a protective factor against crises for 74.5% of workers [26]. Companies should also be mindful of all risks that could provoke painful episodes, infections, or other complications, including air conditioning, drafts, hygiene, and noise pollution. Our results may be explained by the lack of policies regarding the recruitment of patients with SCD. Socially, 4.79% reported being excluded from social events, and 38.69% did not participate in community or associative activities. This reality may have psychological effects and lead to stigmatization. According to Rizio, 50.5% of people with SCD reported that the illness negatively affected their human relationships [15] and, for some, their social, family, and friendship lives, as well as leisure and professional experiences [5]. In general, SCD can lead to psychosocial difficulties for the patient and their social environment, requiring psychosocial support and financial assistance in managing the disease [28]. In our case, many workers with SCD benefit from the support of their friends and families, which is of utmost importance in chronic and disabling diseases.

4.4. The Limitations of the Study

The limitations of our study were mainly selection bias, as only regularly monitored workers were included; memory and self-reporting bias may limit the generalizability of the results, as well as the lack of resources available for the study. Furthermore, the use of a non-probability sampling method and participants from an active registry at a single hospital means that our results may not be fully representative of all workers with sickle cell disease in Ouagadougou or throughout Burkina Faso. Patients regularly monitored at HOSCO may represent a specific

subgroup with potentially better access to care. Nevertheless, it provides insight into the socioprofessional experiences of workers with sickle cell disease and serves as a source of information paving the way for larger-scale and more in-depth analytical studies.

5. Conclusion

The socioprofessional experiences of workers with sickle-cell disease are faced with several challenges. Frequent clinical manifestations, notably vaso-occlusive crises and chronic complications, negatively impact workplace attendance, resulting in absences of varying lengths and reduced productivity. Insufficient adaptation to the work environment is a contributing factor to the onset of these crises. Social life is also often affected by this condition. Therefore, collective efforts must be made by political, social, and professional stakeholders to promote the integration, personal development, well-being, and quality of social and professional life of workers with SCD. However, we believe that, given the nature of our study, these results may underestimate the real situation, considering the high prevalence of the disease in our country. Thus, a prospective, larger-scale, or even nationwide study would provide a better understanding of the socioprofessional integration of workers with SCD in the country.

Conflicts of Interest

The authors declare that they have no conflicts of interest related to this article.

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