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Silence as a Coping Strategy: Non-Disclosure of Sickle Cell Disease and its Psychosocial Consequences for Families in Urban Cameroon: An Analytical Cross-Sectional Study

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ABSTRACT

Purpose: This analytical cross-sectional study evaluated the occurrence of non-disclosure and its psychosocial effects among 184 families in two pediatric units in Yaoundé-Cameroon.

Methodology: Predefined questionnaires evaluated disclosure behaviors, stigma perception, emotional distress, family bonding, and social support. Data analysis was done using descriptive statistics, Pearson correlations, and linear regressions.

Findings: Findings indicated that participants (63.6%) do not disclose information partially or completely and non-disclosure had a positive relationship with stigma perception ($r = 0.50$) and emotional distress ($r = 0.40$), a negative relationship with family bonding ($r = -0.38$) and social support ($r = -0.30$), acting as an independent predictor of psychological distress ($\beta = 0.34$). Silence protects against stigma but creates negative social and psychological impacts, demonstrating the need for stigma prevention measures and disclosure assistance.

Unique Contribution to Theory, policy, and Practice: The results of this research indicate that stigma, communication, and psychological outcomes in families with sickle cell disease are related to one another. And, further to that, the data provides information on what to do in terms of policy and the need for reducing stigma through the provision of psychosocial support and the development of guidance for healthcare providers about disclosing sickle cell disease. Lastly, the practice as nurses emphasizes the need for recognizing silence as a sign of vulnerability and delivering culturally competent, family-centered nursing to families impacted by sickle cell disease.

Keywords: *Sickle Cell Disease; Non-Disclosure; Stigma; Psychological Distress; Family Functioning*

1. INTRODUCTION

Sickle cell disease (SCD) is a chronic, autosomal recessive blood condition that results in repeated crises, infections and chronic problems (Ballas, 2018). Families of children with the disease in Cameroon are greatly burdened by caregiving responsibilities (Bekui et al., 2023). Factors that shape how and when families are open about their child's condition include social and cultural factors.

Even though Sickle SCD has better clinical outcomes due to more clinical advances, it is still seen as a chronic and stigmatizing illness in Sub-Saharan Africa by some who believe there are misperceptions held by people through social misconceptions and/or negative cultural narratives. Stigma against SCD is often expressed through the use of judgmental and derogatory labels and/or the use of social discrimination (Munung et al., 2024). This can result in people with SCD being socially isolated and having to live with reduced quality of life, both for themselves and their families, due to how stigma negatively impacts their own self-image. Cultural beliefs about underdevelopment and supernatural causes related to SCD can result in fear of being judged by both their extended family and/or other people in their community, and therefore, many families choose not to disclose that their family members have SCD (Anie, 2024a). Receiving support from others as a result of disclosing a chronic condition can help families get support that lessens the burden of care on caregivers; however, because of the fear of being judged based on their family member's SCD, many families whose family members have SCD choose to use silence or non-disclosure to cope with the anticipated stigma related to disclosure of their family member having SCD. The psychosocial impacts of using silence or non-disclosure as a coping strategy have not been fully quantified and understood among urban African populations; however, there is limited information available that has primarily focused on either clinical outcomes or generalized psychosocial risk factors related to SCD among the families of children with SCD, while there is less than adequate information available about how using silence or non-disclosure as a coping strategy and/or how using silence or non-disclosure as opposed to disclosing the SCD impacts mental health and/or use of family/household supports, and does not provide sufficient evidence regarding the impact of nondisclosure practices on the overall family well-being of the family with a child with SCD(Frey et al., 2025a).

The purpose of this study was to measure non-disclosure practices in the caregiving community of children with sickle cell disease in urban Cameroon and assess the relationships between non-disclosure, perceived stigma, psychological distress, family cohesion, and social support.

2. STATEMENT OF THE PROBLEM

The burden of sickle cell disease (SCD), especially in Sub-Saharan Africa, continues to weigh heavily upon families and caregivers, and the stigma, cultural misconceptions and negative

societal attitudes that society has against the disease are still prevalent in many communities and poorly understood. Caregivers often times experience society's judgement and ostracism based on the societal misunderstanding of SCD. As a result, caregivers often use coping strategies such as withholding or minimizing sharing their child's diagnosis with extended family members and their social networks (Munung et al., 2023). Caregiver fear surrounding not sharing the SCD diagnosis deprives them and their family members of emotional, informational and tangible support; however, the psychosocial impact on caregivers and families is still poorly understood, especially in a quantifiable research context.

Much of the recent literature points to the intrinsic link between the psychosocial difficulties that caregivers and families encounter as a result of SCD and the societal attitudes towards SCD, caregiver demands and the accompanying stress and anxiety and decreased quality of life created by the caregiving role (Lelo et al., 2023). In addition, newer health services research has begun to identify family-level stressors experienced by caregivers and identify risk factors and mental health challenges of caregivers providing care to children with SCD (Frey et al., 2025b). Despite these advancements, a large gap still exists in the available quantitative evidence to understand how caregiver non-disclosure of their child's SCD diagnosis impacts how caregivers experience perceived stigma, psychological distress, family cohesion, and access to social support in the sociocultural context of urban Africa.

To fill this gap, research on the culturally appropriate interventions (e.g., communication, stigma reduction) related to managing SCD based on social determinants of health is essential in informing design of culturally appropriate public health and nursing-based interventions related to the social determinants of health that are involved with managing SCD. Research that examines stigma reduction, communication practices, and psychosocial support within the caregiving context will be important for improving the overall well-being of families affected by SCD, providing positive coping strategies, and providing a basis for policy makers to develop their response to the medically and socially burdensome nature of SCD in regions of the world that are afflicted (Anie, 2024b); (Adeleke et al., 2024). Research on the dynamics associated with disclosure and the psychosocial effects of such disclosures will help health providers develop effective, evidence-based interventions that incorporate both the clinical and social components of care for families with a child with SCD.

3. MATERIALS AND METHODS

3.1.Study Design and Setting

An analytical cross-sectional investigation was conducted within the hematology units of the Central Hospital and Chantal Biya's Foundation in Yaoundé, Cameroon.

3.2.Study Population and Sampling

A total sample size of 184 primary caregivers was selected through a systematic sampling method by utilizing the two pediatric hematology units located in Yaoundé; therefore, all caregivers were recruited from both hospitals within one-year prior to the participation date. Caregivers must have cared for their sickle cell disease child for at least 12 continuous months prior to the recruitment date. Caregivers of children with other chronic comorbidities were excluded from eligibility. Cluster samples were obtained to recruit the minimum sample size of 150 (with an effect size of moderate, an alpha level of 0.05, and a power of 0.20) in order to have sufficient statistical power to detect statistically significant differences between the two groups being analyzed.

3.3.Data Collection Instruments

Structured questionnaires were utilized to collect quantitative data: full, partial, or no disclosure of disclosure practices. Perceived stigma was measured with an eight-item scale (α=0.82) and caregiver psychological distress was measured with a 10-item scale (α=0.85). Family functioning was evaluated with a 12-item cohesion & routine scale (α=0.79), while social support was assessed using six-items perceived social support scale (α=0.77).

3.4.Data Analysis

Data analyses were done using the SPSS 31.0 software program. Descriptive statistics were used to summarize and describe the demographic information collected and the practices described by the participants. Pearson correlation coefficients were calculated to examine the relationship between disclosure of the cause of a caregiver's child's death and the psychosocial outcomes. In addition, one-way ANOVA followed by Tukey's test was used to compare the psychosocial outcomes of each category of disclosure. Finally, multiple linear regressions were conducted to find the independent predictors of caregiver psychological distress while controlling for care provider age, education level, and level of family income. For example, significance was established at $p <= 0.05$.

3.5.Ethical Considerations

The Regional Ethical Committee and the Institutional Ethics Committees of both hospitals provided ethical approval for this project. All individuals taking part in the study received written informed consent, confidentiality, and voluntary participation.

4. RESULTS

4.1.Sociodemographic Characteristics of Caregivers

Table 1. Sociodemographic Characteristics of Caregivers (n = 184)

Variables	Frequency (n)	Percentage (%)
Sex		
Male	54	29.3
Female	130	70.7
Age {years}		
<30	42	22.8
30–40	79	42.9
40 +	63	34.3
Level of Education		
Primary	42	22.8
Secondary	89	48.4
University	53	28.8
Living standards		
Low - class	101	54.9
Middle - class	59	32.1
Upper - class	24	13.0

Based on the information in Table 1, the majority of the participants were females (70.7%), while males accounted for 29.3% of the population. According to the age distribution of caregivers, the most representative group is composed of those in the 30-40 range (42.9%), although we also include a significant proportion of individuals over 40 years old. The fewest caregivers were those less than 30 years old (22.8%). As for the level of instruction of caregivers, 48.4% have a secondary education, 28.8% are university graduates, and 22.8% have an elementary education. As to the participants' socioeconomic background according to standard of living, 54.9% have a low socioeconomic background, 32.1% have a high standard of living, and 13.0% have a moderate representative one.

4.2.Disclosure Practices

Table 2. Disclosure Patterns Among Caregivers (N = 184)

Categories of Disclosure	Frequency (n)	Percentage (%)
Total disclosure	67	36.4
Limited disclosure	76	41.3
Non-disclosure	41	22.3

From Table 2 above, incomplete disclosure is the most frequent option, accounting for 41.3% of the cases. Complete disclosure is second with 36.4%, while non-disclosure accounts for 22.3%. Overall, more than two-thirds of caregivers did not disclose all the information. It is therefore evident that partial or non-disclosure is a reality to which many caregivers are accustomed. It seems there are social, emotional, or situational impediments to the disclosure of all the information involved.

4.3.Psychosocial Outcomes by Disclosure Category

*Table 3. Mean Psychosocial Scores by Disclosure Category (***Mean (SD)**

Attitudes/Score	Total disclosure	Limited disclosure	No disclosure
Stigma perception	13.2 ± {2.1}	16.8 ± {2.5}	19.8 ± {3}
Mental burden	16.5± {3.2}	20.2 ± {4.1}	22.7± {4.5}
Family unity	55.4 ± {7.7}	49.7± {6.9}	45.1± {7.3)}
Social assistance	22.8± {3.5}	20.2 ± {3.0}	18.4 ± {2.7}

From the table, comparing the three groups, those in the full disclosure group showed a higher average rating in their psychosocial scores with a lower stigma score (M=13.2 (SD=±2.1)), compared to limited disclosure (M=16.8 (SD=±2.5)) and those who practice no disclosures (M=19.8 (SD=±3.0)). There was also a significant difference in the amount of mental burden that was experienced between the various groups, and again the full disclosure group had a much lower score than the limited or no disclosure groups (M=16.5 (SD=±3.2)); the limited disclosure group

(M=20.2 (SD=±4.1)); and the no disclosure group (M=22.7 (SD=±4.5)). Scores from the family unit demonstrated similar results, as did evidence of social support from the participant's community. Family units were correlated to decreases in the amount of stigma associated with the mental health condition and the social support available to the participant from their family. In general, as the number of disclosures decreased for the participant, the greater the degree of negative impact was seen in these variables within the participant's life.

4.4.Correlation Between Non-Disclosure and Psychosocial Variables

Table 4. Pearson Correlations between non-disclosure and psychosocial distress

Variable	Disclosure	Stigma	Distress	Cohesion	Support
Disclosure	1	- .50*	- .40*	.38*	.30*
Stigma	- .50*	1	__	__	__
Distress	-.40*	__	1	__	__
Cohesion	.38*	__	__	1	__
Support	.30*	__	__	__	1
Note: Higher score = more disclosure				***p < 0.01***	

The research findings demonstrated that disclosure established significant relationships with essential psychosocial elements because the analysis resulted in statistical evidence at $p < 0.01$ threshold. The study revealed that disclosure had a moderate negative relation with stigma ($r = -0.50$) and distress ($r = -0.40$) which showed that people who disclosed more information experienced less perceived stigma and had lower psychological distress. The study showed that people who shared more about their lives experienced better family relationships and received stronger social support because they showed positive relationships with family cohesion ($r = 0.38$) and social support ($r = 0.30$).

The strongest link between the two variables occurred between disclosure and stigma followed by the second strongest link to distress which established the third strongest link to cohesion and support. The research results showed that people who increased their disclosure practice experienced better psychosocial results because they had less negative experiences from stigma and distress while gaining better protective results from their social support and cohesion relationships. The research findings demonstrate that disclosure functions as a protective mechanism which assists individuals in maintaining their psychological well-being.

4.5.Predictors of Psychological Distress

Table 5: Multiple Linear Regression for Predictors of Psychological Distress

Predictor	β	SE	p-value
Disclosure score	- 0.34	0.07	< 0.001
Age of participants	0.08	0.06	0.21
Educational attainment	- 0.12	0.05	0.03
Standard of living	- 0.09	0.04	0.08

Model $R^2 = 0.37$, $p < 0.001$

A multiple linear regression was carried out to understand the predictors of psychological distress. The disclosure score was a meaningful negative predictor of psychological distress (β = -0.34, SE = 0.07, p = < 0.001). This means that as disclosure increased, the level of psychological distress decreased. In this study, level of education was another meaningful predictor of level of psychological distress (β = -0.12, SE = 0.05, p = 0.03). This means that as education level increases, psychological distress decreases. However, age (β = 0.08, SE = 0.06, p = 0.21) and standard of living (β = -0.09, SE = 0.04, p = 0.08) were not meaningful predictors of psychological distress, meaning that these two variables did not have any effect on psychological distress.

5. DISCUSSION

5.1.Prevalence of Non-Disclosure of Sickle Cell Disease

The findings of this study confirm that the practice of concealing one's child's sickle cell disease is a frequently used coping mechanism utilized by families in urban Cameroon who have a child with sickle cell disease and that it has been consistently associated with unfavorable psychosocial consequences for those families. The 63.6% of caregivers surveyed who disclosed either partially or totally about their child's condition underscores the continuing influence of stigma around having sickle cell disease in sub-Saharan Africa, and the majority of caregivers exhibiting this behavior is consistent with previous African studies that have documented how fear of being identified socially, discrimination, and negative community perceptions all serve to shape caregivers' decisions to disclose their child's condition (Okoibhole & Ebenso, 2023).

5.2.Non-Disclosure and Perceived Stigma

The findings of this study confirm the hypothesis that caregivers who concealed their child's sickle cell disease reported higher levels of perceived stigma and psychological distress

compared to caregivers who disclosed their child's sickle cell disease. These findings are in line with findings from contemporary research on stigma that show that concealing a stigmatized health condition decreases overt discrimination toward the concealer but increases internalized stress, hypervigilance, and emotional exhaustion (Munung et al., 2023). There is emerging quantitative evidence that supports the hypothesis that caregivers of children with sickle cell disease experience heightened psychological distress due to stigma management, which is an ongoing issue for caregivers of children with sickle cell disease (Alinda et al., 2025).

5.3.Non-Disclosure, Family Cohesion, and Social Support

The decline in family cohesion seen in families caring for children with chronic illness who do not disclose the child's illness suggests the relational cost of silence. The concealment of the child's illness from the rest of the family and community appears to lead to disrupted communication, confusion surrounding roles, and emotional distancing between family members. The family systems literature shows that open communication regarding chronic illness in children facilitates the restructuring of the family system to enable adaptive family coping; whereas secrecy reinforces the relational strains of families and hampers their ability to cope as a collective unit (Larson et al., 2025). The results of this study suggest that non-disclosure impacts the caregiver's external social relationships and the family's internal functioning.

Non-disclosure was found to be significantly negatively correlated with the caregiver's perceived social support. These results align with earlier public health studies, which suggest that perceived social support is a significant protective factor for the mental health of caregivers for children with chronic conditions, including those in need of assistance (Onu et al., 2025). By offering insufficient or no information about their child's condition, caregivers might unintentionally restrict access to emotional and practical support, thereby isolating themselves further socially

5.4.Non-Disclosure and Caregiver Psychological Distress

Most importantly, the regression analysis demonstrated that years of not disclosing one's sickle cell status independently predicted a caregiver's psychological distress after controlling for other variables, which include the caregiver's age, level of education, and annual income level. This finding indicates that the psychosocial burden of a caregiver's nondisclosure is not only a by-product of socioeconomic disadvantage but may also reflect a separate pathway of stress related to managing stigma and limiting social interaction. Other recent psychosocial studies have reached similar conclusions, indicating that concealing stigmatized identities (stigma) is also a strong predictor of poor mental health outcomes across a variety of cultural settings (Camacho et al., 2020).

In the regression analysis, educational attainment was found to be a modest protective factor against psychological distress, possibly as a result of a caregiver's increased health literacy,

improved coping mechanisms, or higher level of confidence with selective disclosure. In contrast, the variable of household income was not found to significantly predict psychological distress in caregivers, providing support for previously published research indicating that stigma-related behaviors and decisions about disclosure are more influenced by social norms and perceptions of judgment than by factors related to income or economics (Foster, 2021).

Overall, the process of using non-disclosure as a coping mechanism is a complex interaction. Whereas silence helps the caregiver gain temporary protection from stigma, it also adds to the caregiver's level of psychological distress, decreases the caregiver's level of support from family members, and limits the caregiver's potential access to social supports. Recent studies published in both the clinical and public health literature have increasingly recommended that psychosocial and stigma-informed care be incorporated into the management of individuals with sickle cell disease (Blakey, 2025). Nurses and public health practitioners are particularly well positioned to support families through culturally sensitive disclosure counseling, stigma reduction initiatives, and family-centered psychosocial interventions.

6. CONCLUSION

This study shows that many families living in large cities in Cameroon use the strategy of not telling others that their child has sickle cell disease (SCD). As a result of not informing others of the child's illness, caregivers often perceive a greater level of stigma and significantly greater levels of psychological distress, as well as lower family cohesion and less access to support from others. The researchers assert that the act of withholding this information is intended to shield the family from being judged but carries with it a tremendous cost in terms of the family's emotional and relational well-being. Non-disclosure was also found to be an independent predictor of psychological distress for caregivers.

7. RECOMMENDATIONS

In light of these findings, healthcare organizations, health policymakers, and nursing practitioners should focus on developing strong stigma reduction and psychosocial support for sickle cell disease families (which should particularly address safe, culturally appropriate disclosure). Provision of specialized training on family-centered communication, psychological counseling, and disclosure counseling for healthcare providers would further enable family caregivers to deal with discrimination and enhance family coping. In addition, the inclusion of frequent psychosocial assessments, peer support groups, and community awareness on sickle cell disease children should be an integral component of pediatric sickle cell care services to address stigma feelings, enhance social coping, and reduce psychopathology of caregivers and sickle cell disease family caregivers. Enhanced sickle cell disease national policy by integrating interventions on mental health and psychosocial support in clinical standards of care would foster compassionate family management. Little is known about how to best achieve adaptive disclosure and promote

resilience in families with SCD, and therefore focus should also be placed on the development of longitudinal clinical research studies to identify and test causal mechanisms and promote adaptive disclosure.

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