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Prevalence and Factors Associated with Severe Depression Among Caregivers of Children with Sickle Cell Disease in Northern Uganda

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Abstract

Depression is a mental disorder characterized by low mood and affects more than 300 million people globally. Caregivers of children with Sickle cell disease (SCD) experience psychosocial distress which predisposes them to depression. This study aimed to determine the prevalence of and factors associated with severe depression among caregivers of children with SCD attending a large hospital in post conflict northern Uganda. A cross sectional study was conducted at the SCD clinic of St. Mary's Hospital Lacor (SMHL). Caregivers of children aged between 0 to 17 years with SCD were interviewed using Patient Health Questionnaire-9 and socio-demographics questionnaire developed by the researchers. Bivariable analysis using chi square test and multivariable logistic regression were conducted to assess associated factors. 310 participants were recruited consecutively of whom 90% were female and 10% male with mean age of 32.7 years. The prevalence of severe depression among caregivers of children with SCD at SMHL was 18.4% and was associated with increasing age of caregiver (adjusted odds ratio (aO.R) = 1.06, C.I = 1.02-1.10). Having more than one child (aO.R = 0.321, C.I = 0.107-0.967), and extended family type (aOR = 0.284, CI = 0.114-0.537) were protective against depression. The study findings indicate that a substantial proportion of caregivers of children with SCD suffer from severe depression which is mostly undiagnosed and hence untreated. Therefore, policymakers need to focus on designing strategies aimed at controlling and managing depression among caregivers of children with SCD such as routine screening.

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Introduction

Depression is a mood disorder associated with unexplained deep level of sadness and loss of interest in previously pleasurable activities of life for at least two weeks, additionally; depressed mood, poor sleep (insomnia or hypersomnia) feelings of worthless, self-blame, low self-esteem, extreme thoughts about death and self-harm, and gives rise to individual and societal burden including lost wages, low productivity, and impaired interpersonal relationships (WHO, 2017).

In Africa, close to 30 million people suffer from depression while in Uganda the available literature shows prevalence among the general population to be around 4.6-10.5% (WHO, 2017). In Northern Uganda, some studies have shown a higher prevalence of 44.5% compared to other regions like Masaka with 24.5% (Vinck et al., 2007). Depression is highly prevalent among patients with chronic illnesses such as Sickle cell disease (SCD) and their caregivers. Sickle cell disease is characterized by chronic anemia, chronic pain and intermittent painful episodes, musculoskeletal problems, septicemia, organ infarctions and chronic organ damage; repeated hospitalizations which predispose to depression and significantly reduce life expectancy (Ayun & Odame, 2012; Subarna Chakravorty & Williams, 2015). Caregivers experience psychosocial distress which predisposes them to depression as care giving involves rendering of physical, social, economic, emotional and spiritual support among others (Madani et al., 2018). Thus caregivers are subjected to continuous pressure since the affected children totally depend on them for general care and treatment (van den Tweel et al., 2008). They also continually have emotional challenges due to thinking about the chronicity and severity of the disease with fear of sickle cell crises at any given moment and missing work (Adegoke, 2012). In a study conducted at Mulago National Referral Hospital, it was found that 9 out of 12 caregivers of children with SCD suffered chronic sorrow which was due to chronicity of the disease, recurrent hospitalization, uncertainty of the future and inadequate or limited family support (Olwit et al., 2018). However, factors associated with feelings of sorrow, sadness, or depression vary geographically (Ambe et al., 2021; Johnson et al., 2022; van den Tweel et al., 2008). While considerable attention has focused on improving the detection of depression, assessment of severity is also important in guiding treatment decisions (Kroenke et al., 2001).

Unfortunately, depression and its associated factors have not been well studied among caregivers of children with SCD (Moskowitz et al., 2007) despite the high prevalence of the disease in Uganda. Therefore, this study aimed to determine the prevalence and factors associated with severe depression among caregivers of children with SCD at St. Mary's Hospital Lacor (SMHL), Gulu city in Northern Uganda.

Methods

A cross sectional study was conducted among caregivers of children with sickle cell disease aged between 0 to 17 years at the SCD clinic of SMHL. SMHL is a private not for profit hospital in Northern Uganda with a main site in Gulu district and three peripheral health centers. Gulu district comprises the Acholi and Lango both of whom speak Luo. However, over the years other tribes have come to settle within the district making the languages spoken diverse but commonly Luganda and Kiswahili are spoken as well. The major economic activity is agriculture and associated business enterprises of agro-processing and marketing. The hospital acts as a teaching hospital for medical students from Gulu University. On top of this it runs a nursing school hence a teaching hospital for those students as well. The hospital is located 340 km North of Kampala City and 6 km West of Gulu town. It offers both in-patient and outpatient services with the four major disciplines of Obstetrics and Gynecology; Internal Medicine, Surgery, and Pediatrics. It has a functional Intensive Care Unit, specialists and other lower cadres in each discipline. The SCD clinic is an outpatient clinic a part of the Young Child Clinic which is under the department of pediatrics, usually operates every Wednesday and is run by staff of the pediatrics department. The hospital has a bed capacity of 550 and employs about 600 employees. Its serves mostly the districts of Gulu and Amuru though serves patients in Uganda and South Sudan. The patient number is about 330,000 people per.

The study included all caregivers of children with SCD who attended the SCD clinic on days of data collection. We included adult caregivers of children with SCD attending SMHL who had stayed with the child for a minimum of 6 months, to allow certainty that the caregiver knows the child and has borne the perils that come with care giving. Caregiver of a child in any Sickle cell crisis which disabled them to promptly respond to study questions and caregivers who could not answer study questions due to any reason were excluded. Participants were recruited by the investigators consecutively until the sample size goal was achieved. Introduction and explanation of the purpose of the study was done in the waiting area and written informed consent was obtained from caregivers who were interested in participating and met the study inclusion criteria. The participants were then interviewed by researchers for about 20 minutes each.

A questionnaire that included sociodemographic variables of the caregiver like age, sex, number of children, education level, religion, marital status, occupation, sociodemographic variables of children like age, sex, medical variables of children like duration since diagnosis, number of hospitalizations, average duration of hospitalization and family type like nuclear or extended family was used. It also included the patient health questionnaire 9 (PHQ-9), a nine-item questionnaire which has been widely used in many countries and validated with Ugandan adults (Akena et al., 2013). The responses range from "0=not at all" to "3=nearly every day" for each symptom of Depression. These responses were scored and summed up. A total score of 0-4 signifies no depression, 5-9 mild depression, 10-14 moderate depression, 15-19 severe depression and 20-27 very severe depression (Kroenke et al., 2001). This study adopted the tool and a score of >15 was used to indicate severe depression.

All data collected were coded and analyzed using STATA version 14. Continuous variables were summarized in a table as means and standard deviation. Categorical variables were summarized in a table as frequency and percentage. Bivariable analysis and logistic regression done to assess association between independent variables and severe depression. The measure of association was odds ratio considering the corresponding 95% confidence interval. A p value of less than 0.05

was considered statistically significant.

The data collection tool was pretested and piloted for standardization before commencing the actual collection of data. The interviews were conducted by the research group member who speaks Acholi which is the local dialect. All data collection tools and consent form were translated into Acholi language.

Results

A total of 310 caregivers of children with SCD were recruited and majority 279 (90%) were female because the caregiving role is more to women and 31(10%) caregivers were male, majority of the caregivers 200 (64.5%) had primary level education, and 216 (69.7%) had an average monthly family income of < 200,000 Uganda shillings (see table 1).

The prevalence of severe depression (PHQ-9 score >15) among caregivers of children with SCD at SMHL Gulu city was 18.4%.

Table 1. Participant Descriptive Characteristics

Variable	Frequency n; (%)	Mean(μ), S.D
Age of caregiver		32.7, 10.4
Sex of caregiver		
Male	31; (10)	
Female	279; (90)	
Number of children		3.05, 1.03
Education level		
None	25; (8.06)	
Primary	200; (64.5)	
Secondary	63; (20.3)	
Tertiary	22; (7.1)	
Religion	298; (96.1)	
Christian		
Moslem	12; (2.87)	
Marital status		
Single parent	35; (11.3)	
Married	180; (58.1)	
Separated	46; (14.8)	
Others ^a	49; (15.8)	
Occupation		
Homemaker	42; (13.6)	
Trader	94; (30.3)	
Unemployed	138; (44.5)	
Others ^b	36; (11.6)	
Average family monthly income		
< 200,000	216; (69.7)	
> 200,000	94; (30.2)	
Age of child		5.76, 3.07
Sex of child		
Male	146; (47.1)	
Female	154; (52.9)	
Average age at diagnosis		1.33, 7.02
Duration since diagnosis		4.43, 2.80
Average number of hospitalizations		13, 7.11
Average duration of hospitalizations		7.17, 2.61
Family type		
Nuclear	124; (40.0)	
Extended	186; (60.0)	
Total PHQ-9 score		10.9, 5.89

%- percentage, S.D- standard deviation, μ - mean, n- frequency; Others: a-widowed 12(3.87), divorced 9(2.90%), cohabiting 28(9.03%); b- office employee 20(6.45%), student 16(5.16%)

Factors associated with severe depression among caregivers of children with SCD

At bivariable analysis number of children (more than one child), marital status (married), average monthly family income (>200,000), duration since diagnosis, number of hospitalization and family type (extended) were statistically significantly associated with severe depression among caregivers. (see Table 2)

Table 2: Bivariable Analysis of Factors Associated with Severe Depression Among Caregivers of Children with SCD.

Variable	Crude odds ratio	Confidence interval	P value
Age of caregiver	0.987	0.959-1.02	0.391
Sex of caregiver			
Male	Reference		
Female	0.749	0.306-1.83	0.526
Number of children			
One	Reference		
Two	0.230	0.089-0.595	0.002
Three	0.093	0.362-0.240	0.000
More than three	0.131	0.579-0.295	0.000
Education level			
None	Reference		
Primary	0.734	0.256-2.10	0.564
Secondary	1.48	0.479-4.56	0.479
Tertiary	0.889	0.206-3.83	0.874
Religion			
Christian	0.433	0.126-1.490	0.184
Moslem	Reference		
Marital status			
Single parent	Reference		
Married	0.348	0.148- 0.821	0.016
Separated	0.608	0.216- 1.710	0.346
Others ^a	1.21	0.471- 3.12	0.690
Occupation			
Homemaker	Reference		
Trader	0.802	0.295- 2.18	0.666
Unemployed	1	0.396- 2.53	1.00
Others ^b	3.18	1.11- 9.11	0.031
Average family monthly income			

< 200,000	Reference		
> 200,000	0.627	0.320- 1.23	0.174
Average age of child	0.772	0.682- 0.874	0.000
Sex of child			
Male	Reference		
Female	0.491	0.273- 0.885	0.018
Age at diagnosis	0.583	0.362- 0.938	0.026
Duration since diagnosis	0.760	0.663- 0.870	0.000
Number of hospitalizations	0.914	0.872- 0.959	0.000
Average duration of hospitalizations	1.047	0.943-1.16	0.387
Family type			
Nuclear	Reference		
Extended	0.257	0.140- 0.473	0.000

At multivariable logistic regression analysis, factors with p values less than 0.2 and those that were found to be associated with depression from literature (age and sex of caregiver) were included in the model. Increasing age of caregiver was associated with having severe depression while number of children (more than one child) and extended family type were protective against severe depression (see Table 3).

Table 3. Multivariable Analysis of Factors Associated with Severe Depression Among Caregivers of Children with SCD.

Variable	Adjusted odds ratio	Confidence interval	P value
Age of caregiver	1.06	1.02- 1.10	0.003
Sex of caregiver			
Male	Reference		
Female	1.41	0.403- 4.93	0.590
Number of children			
One	Reference		
Two	0.321	0.107- 0.967	0.043
Three	0.154	0.456- 0.518	0.002
More than three	0.169	0.453- 0.629	0.008
Religion			
Christian	1.047	0.206- 5.32	0.955
Moslem	Reference		
Marital status			
Single parent	Reference		
Married	0.583	0.209- 1.62	0.302
Separated	0.687	0.200- 2.36	0.551
Others ^a	0.877	0.274- 2.80	0.825
Occupation			
Homemaker	Reference		
Trader	0.869	0.217- 3.48	0.842
Unemployed	0.900	0.314- 2.58	0.845
Others ^b	2.00	0.45- 8.80	0.359
Average family monthly income			
< 200,000	Reference		
>/= 200,000	0.478	0.152- 1.51	0.209
Age of child	0.776	0.594- 1.01	0.061
Sex of child			
Male	Reference		
Female	0.579	0.290- 1.16	0.122
Age at diagnosis	0.905	0.501- 1.63	0.739
Number of hospitalizations	1.05	0.946- 1.17	0.355
Family type			
Nuclear	Reference		
Extended	0.248	0.114- 0.537	0.000

Discussion

The study aimed to determine the prevalence of and factors associated with severe depression among caregivers of children with SCD at SMHL, Gulu city in Northern Uganda. The prevalence of severe depression among caregivers of

children with SCD at SMHL was 18.4% which is consistent with a study in Nigeria where the prevalence of depressive symptoms ranged from 11-45% (Ambe et al., 2021). This finding is also in line with the findings of Adegoke who stated that caregivers of children with SCD experience psychosocial distress which predisposes them to depression and who established that caregivers continually have emotional challenges due to thinking about the chronicity and severity of the disease with fear of sickle cell crises at any given moment, missing work (Adegoke, 2012). In this light therefore, (Olwit et al., 2018) found out that caregivers report feelings of anxiety, mood changes, being overwhelmed and hence depression. Unlike other forms of depression, severe depression is of significant clinical relevance in that it needs urgent psychiatric treatment in a specialized setting as it is commonly associated with suicidality (WHO, 2021). Unfortunately, all the participants with severe depression were regularly attending to their sick children without getting any mental health care for themselves which puts their lives at risk. This high prevalence of severe depression can be explained by the fact that 90% of the participants were female and depression is commonly higher among females compared to males (NIMH, 2022). This is due to the belief in most African setting that care for sickly children falls predominantly on mothers (Ambe et al., 2021).

These findings also relate to a study which found that more than 50% of caregivers of children with sickle cell at Mulago National Referral Hospital had depressive symptoms (Grace, 2022). The difference in findings could be due to the focus on severe depression which is of most clinical importance in this study while her study focused on having any depressive symptoms.

Increasing age of the caregiver was also found to be associated with higher odds of suffering from severe depression. The mean age of caregivers was 32.7 years which falls in the typical age of late 20s to early 30s that is associated with high prevalence of major depressive disorder (Lazarus, 2018; NIMH, 2022). This means that our participants were at risk of developing depression which was worsened by the excessive demands and burnout that come with taking care of a chronically sick child with SCD. Whereas depression can start at any age, chronic diseases like SCD are associated with poverty since most time and money are spent in caring for the child which consequently causes psychosocial burden over time resulting into depression among the affected people in the long run (Kuerten et al., 2020; Lazarus, 2018). Hence the risk of developing depression and its worsening may become higher with increasing age of caregiver due to persistent financial burden.

Having more than one child was protective against severe depression among caregivers of children with SCD because in some East African settings including Uganda having many children is desirable compared to few children and comes with social and cultural privileges from the community (Muhoza et al., 2014). To a caregiver having more children on the other hand brings comfort and hope in the other children as compared to having only one child suffering from SCD (Wonkam et al., 2014).

In the same line, living in an extended type of family was also protective against severe depression among caregivers since this forms very strong source of social support to the caregiver and child (Castiglia, 1999). In such extended families, most of the family members work towards the wellbeing of the family including caring for children with SCD, as compared to nuclear families where the parents are the only source of social support. Members of the extended family can also work

together to provide financial support for the family hence aiding in meeting some of the basic financial needs of the child with SCD. In most rural African settings, this is the predominant family structure and has been documented to be a very important source of support to children suffering from chronic conditions and their caregivers (Mafumbate, 2019). These findings are in line with those from other studies by existing evidence which shows that extended families are associated with good psychological well-being hence protecting against depression (Cherry, 2022; Vila, 2021). However, in some settings an extended family type was more associated with depression and this could be due to sociocultural differences among communities. Hence, there is need to further expound on this association with larger community studies.

Conclusions and Recommendations

The findings indicate that severe depression is a big public health challenge among caregivers of children with sickle cell disease and this is mainly influenced by family and social support related factors. Therefore, policymakers need to focus on the designing of strategies aimed at preventing or managing depression among caregivers of children with sickle cell disease through approaches such as integrating mental health services into routine care for children with sickle cell disease. These may include routine screening of depression using simple and brief tools such as PHQ-9 and creating a referral system whenever necessary. There is also potential for designing interventions based on family structure and social support since this seems to have a protective effect against depression.

Suggestion for Further Research

There is need for further comprehensive studies to explore how depression among caregivers affects their quality of life and productivity as well as effect on the health and quality of life of the children with SCD.

Limitations

Despite the high prevalence of sickle cell disease in northern Uganda, a single health institution was used, therefore the results may not be generalised to all caregivers of children with sickle cell disease in the region. Hence extensive research in multiple health facilities on the prevalence and factors associated with depression among caregivers of children with sickle cell disease would be beneficial.

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