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Psycho-social challenges faced by caretakers of children and adolescents aged 0–19 years with sickle cell disease admitted in a tertiary hospital in Eastern Uganda

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ABSTRACT

Background: Families of children and adolescents living with sickle cell disease face several challenges ranging from psycho-social to social-economic challenges. This study aimed to explore psycho-social challenges experienced by caretakers of children and adolescents aged 0–19 years with SCD and the various coping mechanisms.
Methods: A mixed-methods cross-sectional study was carried out among caregivers of children with SCD who were admitted to the pediatric wards of the Mbale Regional Referral Hospital from September 2019 to November 2019. A total of 333 participants were interviewed using a pretested questionnaire and 11 in-depth interviews were conducted.
Results: Most participants 285(85.59%) reported that they experienced psychological challenges and almost all the participants in this study 297(89.19%) experienced social challenges during the care of their patients. Only 36(10.81%) reported not experiencing any social challenges. Almost all the participants reported coping with the situation in various ways of which, 296(88.89%) used acceptance, 9(2.7%) still lived in denial, while 9(2.7%) used talking with others and getting counseled to reduce the intensity of the feelings experienced.
Three themes were generated from the in-depth interviews; knowledge of the child's health condition; common symptoms and care, the experience of psycho-social challenges, and coping strategies.
Conclusion: Sickle cell disease has affected two sets of people; the people living with the disease and those who are caring for their loved ones. Being conscious of this will help health practitioners to be more empathetic to patients and caregivers when treating people living with sickle cell disease. The biggest proportion of caretakers of children and adolescents 0–19 years experienced psycho-social challenges. The main coping strategy used by the caretakers was acceptance.

List of abbreviations

SCD	Sickle Cell Disease
SCA	Sickle Cell Anemia
MRRH	Mbale Regional Referral Hospital
WHO	World Health Organization
CD	Compact Disk
SSA	Sub-Saharan Africa
IRB	Institutional Review Board
REC	Research and Ethics Committee
RBC	Red Blood Cell

Background

Worldwide, sickle cell disease (SCD) contributes a significant burden that is not amply addressed (Uyoga et al., 2019). Estimates suggest that about 312,000 children will be born worldwide with SCD annually and about 100 million people are living with the default gene for SCD (Piel et al., 2010). The greatest burden exists in Sub-Saharan Africa (SSA), where 75% of the world's sickle cell disease occurs (Makani et al., 2007). It has been established that Nigeria bears the greatest burden of sickle cell disease in the world with about forty million carriers of the gene in the country (Muoghalu, 2016). In Uganda, estimates suggest

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We recommend recognition of psychosocial problems among caretakers of children with SCD, by health workers through screening. When caregivers experiencing certain psychosocial problems are identified a support system from the family and groups of people with similar situations can be organized to enhance acceptance through sharing and encouraging each other. This could be part of the ongoing care provided at the specialized SCD clinic. Effective coping strategies such as positive thinking, counseling, and use of faith-based strategies (i.e. praying) can be encouraged and reinforced among caretakers to help them cope with psychological distress.

Limitations and alleviations to the limitations

This was a cross sectional study with participants recruited in one setting and the results may not be generalized to all settings. Self-reported information obtained from the participants could have some elements of bias. A well-secluded room was preserved for interviews such that patient privacy was fully ensured. Every caretaker was given a chance to participate at will. This was done to eliminate potential bias in the selection of participants.

Conclusion

This study found that caretakers of children with SCD experience psychosocial problems and invest in poor coping mechanisms. There was considerable variability in the ability of caretakers of people with SCD to cope with the condition. In this study, caretakers employed both internal and external coping methods to adjust to the new situation in life and fulfilling their caregiving roles. Caretakers largely depended on external coping mechanisms which they derived from close family members, health facilities, and community members.

Ethics approval and consent to participate

Ethical approval was sought from Mbale Regional Referral Hospital – Research and Ethics Committee (MRRH-REC) under reference number MRRH-REC OUT 039/2020. Informed written consent was obtained from all participants in the study before data collection; this was in line with the Uganda National Council for Science and Technology guidelines of human research. Participation in the study was voluntary; participants had a right to withdraw from the study at any time.

Consent for publication

Not required.

Authors' contributions

ACA, TC, and IJS conceptualized the idea.

TC and IJS supervised proposal writing and data collection.

ACA, TC, and IJS carried out the analysis, interpreted the result, participated in drafting the manuscript, revised the manuscript, and approved the final manuscript for submission.

All authors read and approved the final manuscript.

Declaration of Competing Interest

The authors declare no competing interests.

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