Title: Psychosocial challenges and coping mechanisms of adolescents with Rheumatic Heart Disease attending Cardiac Clinic in Mbarara Regional Referral Hospital.

Abstract

Background:

The burden of RHD is increasing and it's disproportionately high in developing countries. Advances in treatments have resulted in life long time survival of adolescents, hence increased risk of acquiring mood and anxiety problems because their emotional health is frequently neglected or undertreated. The psychosocial challenges and coping mechanisms of individuals with chronic illnesses have been extensively studied but not in adolescents and specifically RHD. Therefore, the purpose of this study was to evaluate the psychosocial challenges and coping mechanisms of adolescents with RHD in care at Mbarara regional referral hospital.

Methods:

This was a cross-sectional study with a qualitative approach. Triangulation was done, adolescents were consecutively selected, consented and assented depending on the age, had in depth interviews and FGDs with them, had FGDs with caretakers and key informant interviews with health workers. Seventeen in-depth interviews and two FGDs were carried out with adolescents, two FGDs with caretakers and six key informant interviews with health workers. Questions that probed medical history, physical, social and psychological challenges and how they coped were asked. Sample size was iteratively appraised till saturation was reached. Interviews were audio-recorded and transcribed. Thematic content analysis was used to analyse the data and the MAX QDA 2020 guided data analysis

Results: Majority of adolescents were female consisting of 52.9%, average age was 15.7 years, majority had attained primary education 58.8% and average duration in care was 2.8 years. The participants' experiences were explored in relation to perceived social and psychological

challenges of living with RHD and how they were able to cope. The social challenges identified were failure to thrive, limitation in age-related physical activities, decline in school performance and economic challenges. Psychological challenges included challenges to adherence, feelings of sadness and uncertainty about the future. Adolescents responded with a variety of coping mechanisms, including acceptance, divine intervention, social and emotional support and denial.

Conclusion: Adolescents experienced numerous social and psychological challenges, which negatively affected their quality of life, therefore, there is an urgent need to integrate psychosocial support services and screen for psychosocial challenges in our routine chronic care management to help adolescent navigate better and adhere to treatment.