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Understanding adolescent transitions for youth with Spina Bifida in a LMIC: Using Focused Group Discussions to evaluate successes and challenge areas identified by young adults living with Spina Bifida.

AIC Kijabe Hospital
Health Care to God's Glory

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Background for the proposed study

Transitioning from adolescence to adulthood is often considered to be one of the most difficult transitions in life. It consists of a multitude of changes in one's body and life circumstances. Typically adolescents require knowledge, skills, and guidance. This guidance is influenced from both formal and informal settings and is necessary to having a 'successful' transition into adulthood. These influences come from parents, teachers, medical professionals, mentors, pastors, general society, culture and a variety of other sources.

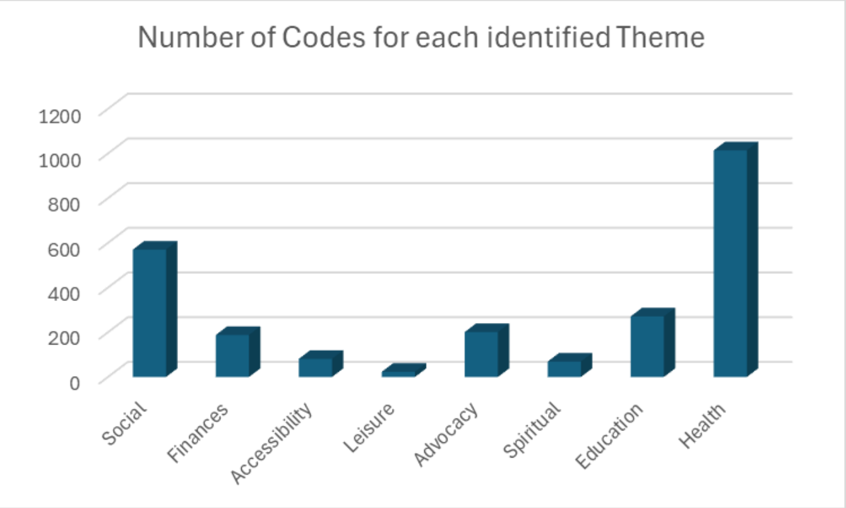
Individuals with Spina Bifida have some additional challenges during this transition into adulthood which complicates this period of their lives even more. Individuals living with Spina Bifida in LMICs face even greater challenges due to significantly limited resources. As a result there is a significant need for entities to learn how to better support these individuals so that they can successfully transition into adulthood. (Jenkins, et al, 2021 & Rague, et al, 2021)

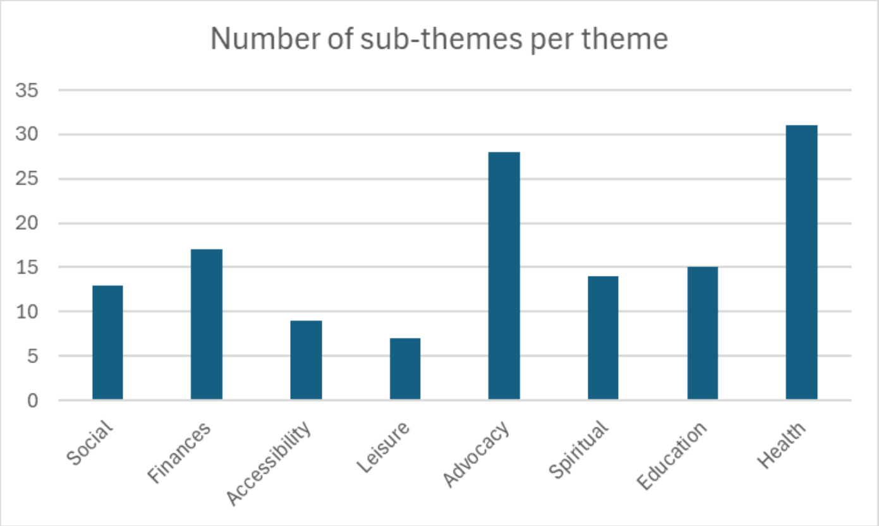
Methods

Our study methodology is an in-depth qualitative study using semi-structured interviews with focus group discussions which was approved by the Kijabe ISERC (KH/ISERC/02718/0044/2023) and NACOSTI license (NACOSTI/P/23/26006) obtained. Moderators (unknown to the participants for their privacy) guided participants through a series of open ended questions. Participants were gathered in groups of four to eight after having the study explained to them and being provided with a written consent to sign. The groups were put together as same gender groups with a moderator of the same gender and consisted of the following; married women, married men, single women, single men single women with at least one child, and professionals associated with Bethany*Kids* and/or AIC Kijabe hospital.

Participants in this study were a convenience sample selected and recruited from a client database managed by Bethany*Kids*. The participants were individuals with Spina Bifida living within Kenya as legal adults. (Note: BethanyKids funded the research study and as such bias was mitigated via the use of external moderators, transcriptionists and collaborative thematic analysis including a wide number of professionals)

The approach to the analysis was thematic. The research team employed a highly collaborative process after the de-identified transcription of the FGDs was complete. Eighteen healthcare professionals were involved in the initial coding exercise. The first stage of coding resulted in a plethora of codes which were then narrowed into major themes. The themes were then placed into subthemes in order to ascertain the areas of importance. The graph shows the various themes that were identified.

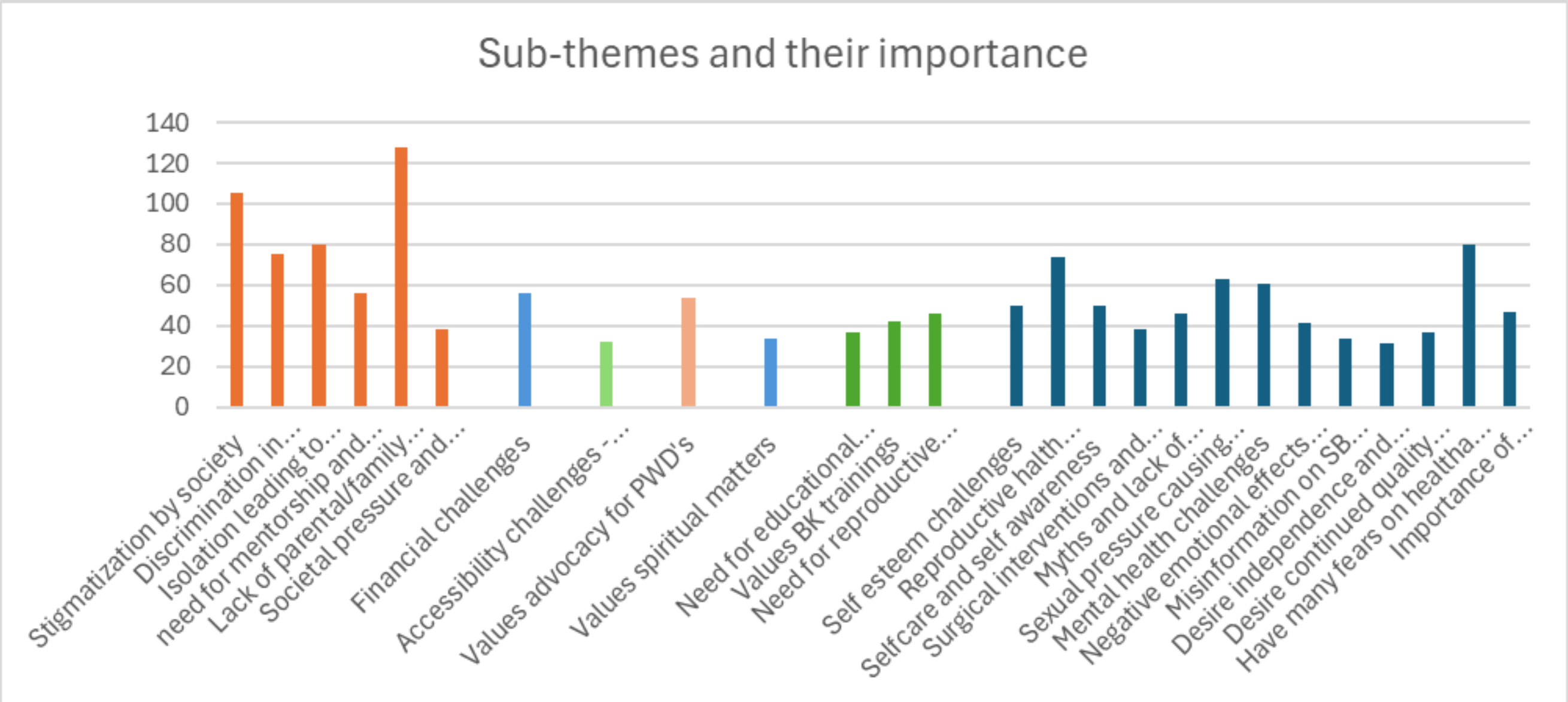




FINDINGS

Our study demonstrated both positive and negative transition experiences. The positive experiences primarily revolved around support received by family, friends and supporting organizations such as Bethany*Kids* and Kijabe Hospital. The negative experiences often focused on common areas of difficulty for transition, however the youth participating in the FGDs were able to explain in more depth how their unique experiences may have compounded the difficulty of the experiences and also offered suggestions. For example; One of the participants mentioned that because of the social pressures of having a child and not knowing if they were able to reproduce they (and their friends) were more likely to 'try things out.'

The major themes that came out as areas of difficulty for these youth (as shown in the graph on the left) were also divided into sub-themes (as shown on graph to the left). These sub-themes demonstrated several stand out areas that were areas of difficulty (only areas with 30 or more codes are displayed below). The top sub-themes were identified as the following; **Stigmatization by society (105 codes in the Social theme), lack of parental/family support (128 codes in the Social theme), Isolation leading to psychological distress (80 codes in the social theme), Discrimination in relationships (75 codes in social theme), Reproductive health challenges (74 codes in Health), Sexual pressure causing experimentation (63 codes in health), Myths and lack of information on CIC (68 codes in health), Have many fears on health and well being (80 codes in health),**



Interpretation

The themes and sub-themes of this qualitative study demonstrate several areas in which extreme care needs to be taken in order to assist these youth in transitioning well into adulthood. The main areas appear to be related to social, health and education concerns with specific focus on stigmatization, isolation, discrimination in relationships, reproductive health challenges, sexual pressures, myths and lack of SB information, and fears associated with future health and wellbeing.

The 2,417 codes produced through this thematic analysis of the FGDs demonstrate a need for change in both management and trainings for this population. This study will inform the development and modification of trainings for the population as well as inform areas of gaps when it comes to lifelong management of those with SB.

Poster Citations

Health Concerns of Adolescents and Adults With Spina Bifida. Starowicz J, Cassidy C, Brunton L.Front Neurol. 2021 Nov 12;12:745814. doi: 10.3389/fneur.2021.745814. eCollection 2021. PMID: 34867728 Free PMC article.

Adolescents and Young Adults With Spina Bifida Transitioning to Adulthood: A Comprehensive Community-Based Needs Assessment. Jenkins AM, Burns D, Horick R, Spicer B, Vaughn LM, Woodward J. Acad Pediatr. 2021 Jul;21(5):858-867. doi: 10.1016/j.acap.2021.02.002. Epub 2021 Feb 10. PMID: 33577992

Assessment of Health Literacy and Self-reported Readiness for Transition to Adult Care Among Adolescents and Young Adults With Spina Bifida. Rague JT, Kim S, Hirsch JA, Meyer T, Rosoklija I, Larson JE, Swaroop VT, Bowman RM, Bowen DK, Cheng EY, Gordon EJ, Chu DI, Isakova T, Yerkes EB, Chu DI.JAMA Netw Open. 2021 Sep 1;4(9):e2127034. doi:10.1001/jamanetworkopen.2021.27034.PMID: 34581795 Free PMC article.