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PRIMARY SUBJECT AREA: Complex Care

BACKGROUND: Children with medical complexity (CMC) are a highly medicalized population of children who require specialized care across various settings including the hospital, home and community, making care coordination challenging. Care-maps, a visual representation of the people and places involved in a patient's care, are one such tool to facilitate care coordination (Figure 1). To date, care-maps have not yet been used in a clinical environment, examined in real time or used via a standardized approach.

OBJECTIVES: The aims of our study were to develop a shareable standardized online tool that supports the parental creation of a care-map, and to assess the utility of care-maps in clinical care from a parent, health care provider (HCP), and community perspective.

DESIGN/METHODS: Parents of CMC were invited to use a standardized online care platform called Connecting2gether for 6-months and create online care-maps that could be shared with their HCPs and other community members (i.e., teachers, secondary caregivers). Demographics and internet usage surveys were completed at baseline and an acceptability survey was completed at 6-months. Surveys were analyzed using descriptive methods and care-maps were analyzed via descriptive visual analysis.

RESULTS: Thirty-seven parents enrolled on the platform and 25 (70%) created a care-map and used it for the duration of the study. Of the 25, 14 (66%) went back and made revisions and 17 (80%) reported using it in clinic, home or school. Visual analysis demonstrated 11 categories (bubbles) that were commonly included. All care-maps included a Medical Team, School/Daycare and Family and Friends category, which automatically populated. The majority of care-maps included a central child bubble with the child's photo (92%), and Community Medical Services (i.e. rehab centers) (60%). Less frequent categories included Home Care (28%), Goals (16%), and 12% included What I Like, Funding, and Community/Foundation individual bubbles. Some parents reported initial uncertainty, but at end-of-study, some reported care-maps as the most useful feature of the platform. Fifty seven percent (12/23) of HCPs viewed the created care-map and only 20% used it in the child's care. The majority (83%) of HCPs specifically valued seeing the big picture of the child's care, found it easy to navigate and the detail it provided.

CONCLUSION: The ability of care-maps to illustrate the intricate web of medical and non-medical care supporting CMCs in their daily life provides insight and value for parents, HCPs and non-HCPs. Care-maps were found to be valuable from the perspective of HCPs. Parents reported initial uncertainty, highlighting the importance of the HCP promoting the use of care-maps with their patients and families.

83

UNDERSTANDING COMPLEX COMMUNITY STRUCTURES TO IMPROVE SEXUAL REPRODUCTIVE HEALTH FOR ADOLESCENTS IN UGANDA

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PRIMARY SUBJECT AREA: Global Child and Youth Health

BACKGROUND: Based on the 2014 census, 35% of Uganda's population is between 10-24 years old. Health indicators show concerning sexual and reproductive health (SRH) trends such as high teen pregnancy, unsafe abortions, limited contraceptive use, and access to antenatal and postnatal care. However, the barriers to adolescents seeking and receiving care are complicated due to pre-existing social structures in smaller, closely linked communities.

OBJECTIVES: To understand the social structures and motivation of communities in western Ugandan districts that impact SRH in adolescents to better implement Healthy Adolescent and Young people (HAY!).

DESIGN/METHODS: In September 2020, a qualitative study was conducted in 2 districts, in southwestern Uganda. Fourteen focus group discussions and 3 key informant interviews consisted of 94 participants were carried out with a purposive sample of adolescents, parents, community health workers (CHWs), community leaders, health facility staff, and district health officers. Ethics approval was obtained and COVID-19 prevention guidelines were strictly followed. Data was audio-recorded, transcribed, and thematically analyzed.

RESULTS: Based on our qualitative inquiry, participants recognized that adolescents face numerous SRH challenges and expressed their tension for change and motivation to support interventions that may positively impact SRH behavior and outcomes in adolescents. However, participants who were mothers highlighted that their motivation was due to better marriage prospects for their daughters, which is determined by respect and social standing in the community. In situations of unwanted pregnancies, participants shared that because of the fear of shame, and desire to keep adolescents in school, mothers often supported unsafe abortion to maintain community standing. This is an unusual and interesting finding. Similarly, aunties and uncles were traditionally regarded as champions for protecting and guiding adolescents, but participants highlighted a negative shift in this dynamic; aunties and uncles put female adolescents at risk by connecting them with interested men in exchange for gifts and money. Consequently, they are no longer trusted. Despite these gaps, volunteer CHWs who work closely within their communities by conducting home visits, educating, and providing referrals, emerged as a trusted resource by adolescent participants in accessing SRH related information. CHW participants also shared that adolescents often confided in them when unable to speak openly with their parents.

CONCLUSION: Although participant groups were motivated towards supporting adolescents, interventions must first understand and navigate complex community structures to deliver a comprehensive and targeted intervention to improve SRH outcomes in adolescents.

84

LOOKING BACK TO MOVE FORWARD; CAN FETAL PLACENTAL INFLAMMATORY RESPONSE PLAY A ROLE IN RISK OF SEPSIS AND CLINICAL DECISION MAKING IN PRETERM INFANT

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