Developing Pediatric Patient centered navigation program for children receiving cancer care at Mulago National Referral Hospital, Kampala, Uganda

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Executive summary

Objectives. Treatment abandonment contributes to poor outcomes for children with cancer in low-middle countries like Uganda. Our project aimed to develop a patient-centered navigation program that can address high treatment abandonment rates.

Activities. From February –November 2024, we did a retrospective chart review, and conducted in-depth interviews and focus group discussions with children and their parents on the challenges they faced in initiating and remaining in cancer care

Outcomes. Treatment abandonment rate was 12%. Reasons for treatment abandonment were at family level e.g. financial constraints, community e.g. myths on cancer outcomes and cancer center level e.g. complex workflows. With extensive input from patients' families and multi-disciplinary professionals, we have developed a culturally appropriate, patient centered *3-domain pediatric cancer navigation program* that includes:*1.Family Navigation* – a team of pediatric cancer nurse navigators, a clinical psychologist, and a social worker to support families, 2. *Community Navigation* – a team of childhood cancer survivors, caregivers of patients on long-term follow-up to provide support in the communities where patients live and 3. Cancer center navigation- a team of pediatric cancer nurses to support patients and families through the complex clinic work flows at the tertiary cancer care center.

Challenge

Inaccurate data on treatment abandonment rates and lack of a pediatric patient cancer navigation program to support children to start and remain in care for cancer

With support from the Rising Tide Foundation, we held interviews and focus group discussions with children with cancer and their parents. We conducted home visits to select patients who had abandoned treatment. Together, these activities provided much-needed insights into the causes of treatment abandonment and patients provided recommendations on the kind of navigation program that would best address the challenges they face in remaining in cancer care

Direct involvement of patient experts

Patients as investigators: A cancer survivor on long-term follow-up was actively involved in the research process. They contributed to study design, conducted training, and facilitated interviews.

Patient Group Organization Involvement: A member of a patient advocacy group participated as an investigator.

Patients and patient group representatives participated in interviews and focus group discussions

Patients as study participants. Children with cancer and their caregivers participated in the interviews and focus group discussions.

Incorporating feedback

Data analysis was done using a thematic approach –including thematic categories such as patient experiences, role of a navigation program, and type of navigation programs for children with cancer

This feedback directly informed the type of navigation program. From the feedback, we developed a patient focused 3 domain pediatric navigation program that addresses patient needs for initiating and remaining in cancer care at multilevel of family, community and health care center.

Impact on study design

Patients advised on a qualitative study design to allow patients to express their thoughts.

We have designed a prospective type II hybrid effectiveness implementation science trial that incorporates both qualitative and quantitative methods, to assess the effectiveness of the patient-centered navigation program while also assessing implementation outcomes that directly affect patients. The effectiveness outcomes also focuses on patient outcomes such as patient experiences and satisfaction and not only clinical outcomes. During the trial, we shall assess what patients like or don't like about the program and use the feedback to continually improve the navigation program.

Conclusions

One in ten children abandon cancer care at the Mulago National Referral Hospital. The reasons for abandoning care are multi-faceted and are at family, community, and health facility levels. A 3 domain patient-centered pediatric navigation program that supports patients at family, community and health center levels can reduce treatment abandonment rates and improve both clinical and patient outcomes for children receiving cancer care in Uganda. Patient engagement in research highlights important outcomes for the patients and fosters trust and confidence in the pediatric cancer navigation program.

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Applying for the pre-application grant

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Activities proposed

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Outcomes & incorporating them back into endpoint and trial design

Providing pre-application funding for patient involvement

A new grant mechanism called "pre-application grants" has been launched. These small grants are to close the funding gap for patient experts to provide input to the development of a grant application/protocol.

We are aiming at supporting patient organizations during this early phase with a budget. The budget should be planned to cover travel costs to preparatory meetings and the work time invested by staff or patient experts. This work should be carried out as a preparation step prior to the submission of a clinical research grant application to RTFCCR

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Conclusion

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