Adjunct Psychotherapy as an intervention for Burkitt Lymphoma related stigma and depression among children and adolescents undergoing Burkitt Lymphoma Cancer treatment in Northern Uganda: A pilot study

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Executive summary

Objectives: In this pilot phase, we proposed to document the attitudes toward cancer-related stigma and depression among children, adolescents and young adults under treatment and survivors in long-term remission in order to design an adjunct psychotherapy intervention to be deployed in a well-designed Randomized Clinical Trial. We enlisted the support of patients and patient advocates from Soleterre, a non-government organization for those affected by cancer and Soleterre involvement was at every stage of the project.

Activities: From July 2024 to October 2024, we performed 2 focus group discussions and 61 interviews with patients, survivors and patient partners to discuss various aspects of the project.

Outcomes: Patient advocates were part of the study protocol team and provided crucial feedback on the objectives and design of the project. Though subtle, we noted that stigma from healthcare workers in their communication with patients was a common theme. Also, guardians and parents directly discriminated against their children; Some children who had recovered from Burkitts Lymphoma dropped out of school because their parents said they do not waste money on "dying people" or, according to them, people who will die anytime. To address this issue, we have created awareness among patients diagnosed with Burkitts Lymphoma, their parents and healthcare workers in our community about depression and stigma.

Challenge

Shortage of African contextualized data on the role of psychotherapy in Burkitts Lymphoma cancer treatment.
There was insufficient data on stigma and depression and its effect on quality of life among Burkitts Lymphoma cancer patients and survivors from northern Uganda. We formed a collaborative framework for the implementation of psychotherapy in Burkitts Lymphoma cancer patients undergoing treatment in northern Uganda. For the first time, we rallied a team of experts that included physicians, epidemiologists, psychologists, pathologists and social workers to collaborate with patients and patient advocate groups in designing a protocol to study adjunct psychotherapy in northern Uganda.

The Task

Direct involvement of patient experts

The patient advocates for this project were led by Soleterre and they were part of the entire project continuum from grant application, project design and protocol drafting, implementation and reporting. They led the research team's engagements with patients and survivors through:

i. Focus group discussions and interviews with patients
ii. Participation in collaborative framework activities
iii. Psychotherapy protocol development and feedback
iv. Led the research team in adapting standard published assessment tools to fit the context of the study area.
v. Participation in survivor Focus Group Discussion to refine study approach and tools

Incorporating feedback

Throughout the project, we discussed key content relevant to the eventual clinical trial focus. We solicited specific input from Soleterre on designing Cognitive-Behavioral Therapy (CBT) as an intervention for testing in a clinical trial project. The main focus of the clinical trial proposal is depression; a direct outcome of the discussion with patients and patient advocates during the Focus Group Discussions throughout all the phases of the pilot project.

Impact on study design

It was apparent through our interaction with patients at the Focus group discussions that depression profoundly affects a patient's mental health, psychosocial behavior, and treatment outcomes. By recognizing the psychological impact of cancer related stigma, our proposed research approaches were adjusted to allow for qualitative interview as we examined levels of depression. The patients advocate group provided insights that informed the design of a follow-on clinical trial to focus on the efficacy of Cognitive-Behavioral Therapy (CBT) in delaying the onset of depression.

Conclusions

This pilot phase successfully resulted in formation of a psychotherapy focused network of clinical researchers in partnership with patients and patient advocates. The patients assembled in this study supported follow-on the clinical trial protocol for the follow-on study. It is apparent from this pilot that the need to study the role of non-pharmacological treatments in the management of Burkitt's Lymphoma cancer remains a significant gap.

1 **Applying for the pre-application grant**

2 **Activities proposed**

3 **Outcomes & incorporating them back into endpoint and trial design**

4 **Conclusion**

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