Childhood Cancer Survivorship Intervention Program in Western Kenya

PROTOCOL VERSION: 01-05-2024

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BACKGROUND/ LITERATURE REVIEW

Survival of childhood cancer in Kenya has increased in the last decade.[1,2] As a result, an emerging number of childhood cancer survivors will be in need of care. Survivors may experience either physical or psychosocial late effects due to treatment toxicity.[3,4] In addition, survivors are vulnerable to challenges regarding education, career, relationships and financial security.[5,6]

International survivorship guidelines incorporate follow-up strategies to prevent, detect and manage late effects.[7,8] Also, survivorship care plans have been implemented to increase cancer knowledge among survivors, increase their follow-up adherence, and enhance their perception and risk of late effects.[9,10]

Despite the attempt to harmonize guidelines suitable for a diverse international clinical practice, current recommendations do not seem to reflect the every-day reality of pediatric oncology care in low and middle-income countries (LMICs). A survey among South-African pediatric oncology healthcare providers, showed that most clinicians need to adapt existing guidelines according to their local practice.[11] Insufficient staffing, a lack of time and possibly knowledge, may hamper healthcare providers to provide optimal survivorship care.[12] Furthermore, healthcare facilities may not offer necessary investigations, or patients may not be able to afford them.[11] Without available support to sustain follow-up care, follow-up adherence of survivors has traditionally been low in LMICs.[13,14]

Survivorship infrastructure should be strengthened in LMICs, and healthcare providers and survivors should be facilitated with practical tools to deliver necessary and holistic care taking the local capacity into consideration. Education about therapy-related complications or late effects could effectively improve risk awareness, especially when delivered at different time points.[15] Video-based educational interventions on cancer awareness can be beneficial in targeting low-literacy audiences. Dissemination through multiple social media platforms can raise attention among different age groups.[16]

Available studies about follow-up care in Sub-Saharan Africa have mainly focused on a single diagnosis or single late effect.[17] In reality, many survivors experience a multitude of late effects, that may sequentially occur during their lifetime.[3] Survivorship care plans, comprising of education, a treatment summary, and recommendations based on individual, diagnosis or treatment specific risks, have been developed to approach late effects from a survivor-centered perspective.[10]

In Sub-Saharan Africa, particularly the psychosocial long-term burden of childhood cancer has received little attention.[17] Childhood cancer stigma, experienced in healthcare facilities, in school or in families, may contribute to enduring social isolation of survivors.[18,19] Demystifying childhood cancer and survivorship, may normalize disclosure, and eventually reduce psychological distress.[20] A compassionate first endorsement of a survivors' cancer history, has showed to be a predictor of future disclosure in other social environments.[21] Peer support has proven an effective method to address the social needs of young cancer survivors and their parents.[22,23] Interacting with peer survivors could raise self-worthiness and confidence.[24] In several low and middle-income countries, peer support groups have also gained responsibility for integral parts of survivorship services, such as providing rehabilitation aids, covering health insurance fees and tracking of patients who are lost to follow-up.[25,26]

OBJECTIVES

- Increase adherence to follow up clinic among childhood cancer survivors at MTRH
- Enhance the detection of late effects among childhood cancer at MTRH
- Increase social reintegration of childhood cancer survivors treated at MTRH

STUDY DESIGNS

The survivorship education program will be a prospective comparative study**.** The follow-up program and the support program will be prospective cohort studies but without a comparison group.

SAMPLE SIZE

Education Program

The investigators aim to improve follow-up adherence from 30% to 60% at two years following treatment completion. To reach 80% statistical power, investigators aim to include at least 80 participants. Anticipating that 20% may stop participating in the study and may not be reachable afterwards for a knowledge assessment, investigators aim to include 50 participants in the control group and 50 in the intervention group.

Follow-Up Program

Training about childhood cancer survivorship will be provided to an estimated 30 healthcare providers within the first two months from approval of study. Data from the

medical records of childhood cancer survivors attending the follow-up clinic will be extracted from the start of the study.

Support Program

A maximum of three WhatsApp support groups will be formed for caregivers of childhood cancer survivors. Caretakers of 10-15 childhood cancer survivors will participate in each WhatsApp support group.

SETTING

The study will be performed at Moi Teaching and Referral Hospital (MTRH), which is situated in Eldoret, Western Kenya. It is a large tertiary care referral hospital whose service area covers a population of approximately 24 million. The total bed capacity of MTRH is approximately 1,000 of which 35 are for the pediatric oncology department. Treatment modalities offered in the department include surgery, chemotherapy, and radiotherapy. Yearly an estimated 300 children are diagnosed with cancer, with an event-free survival rate of 32%.[2] After discharge from the wards, patients are seen in the outpatient clinic where follow-up reviews upon treatment completion are also done. Roughly 30% of survivors remain in follow-up two years after completion of treatment.

1) SURVIVORSHIP EDUCATION PROGRAM

The purpose of this part of the study is to investigate whether implementation of a Survivorship Education Program results in improved follow-up adherence at the outpatient clinic by enhancing knowledge of caretakers. This quasi-experimental / comparative prospective study will include 100 participants. The study will take place from approval in 2024, up to the moment of reaching the inclusion goal. The intervention group of 50 will receive the Survivorship Education Program: a video presentation, information booklet and Survivorship Card. The intervention group will be compared with a historical control group of 50 caregivers who did not receive a video presentation, information booklet and Survivorship Card: the current standard of care.

Inclusion criteria:

Control group:

1) Caregivers of children diagnosed with childhood cancer at age 0-14 years with:
2) No treatment failure (abandonment of treatment, progressive or relapsed disease)
3) Finalizing childhood cancer treatment (in the last 2 months of treatment).

Intervention group:

1) Caregivers of children diagnosed with childhood cancer at age 0-14 years with:

2) No treatment failure (abandonment of treatment, progressive or relapsed disease)
3) Finalizing childhood cancer treatment (in the last 2 months of treatment).

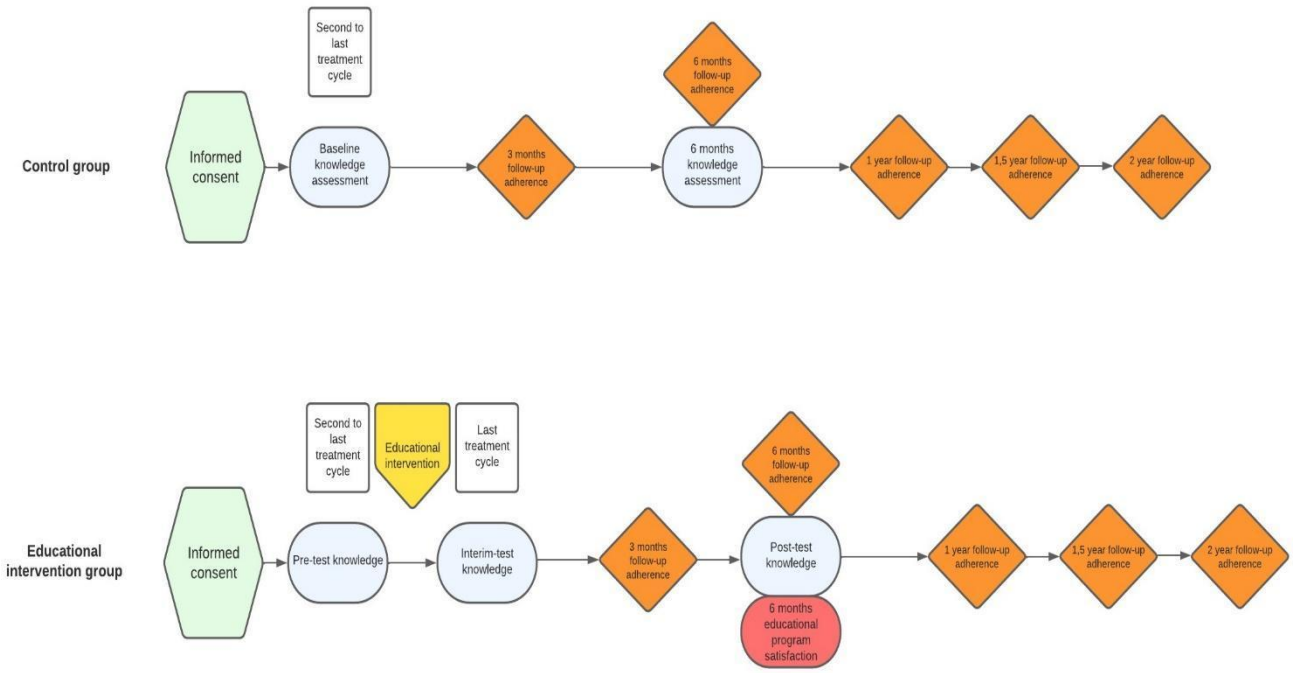
Study design:

Two Survivorship Education Sessions (one for participants in the outpatient clinic and one for participants in the wards) will be provided at MTRH weekly, depending on the number of admitted patients who are almost finishing treatment.

This will be a prospective, comparative study. Investigators aim to improve follow-up adherence from 30% to 60% at two years following treatment completion. To reach 80% statistical power, the aim is to include at least 80 participants (40 in the control group, 40 in the intervention group). Anticipating that 20% may stop participating in the study and may not be reachable afterwards for a knowledge assessment, the aim is to include 50 participants in the control group and 50 in the intervention group. The percentage of relapsed disease in the control group after reaching the goal of enrolling 50 participants should be considered to define the final number of both cohorts. The study participants will be identified in the wards and outpatient clinic. Consecutive sampling will be used to recruit them from the moment of study approval, planned for early 2024, up to the moment of reaching the inclusion goal.

After completing enrolment of the control group in the study (anticipated 3-6 months), investigators will begin enrolment of the intervention group and start the Education Program.

Figure 1: Time course of Survivorship Education Program



Components of Survivorship Education Program:

a) Video presentation: Caregivers will be invited to attend a video presentation in one of the rooms at the Chandaria building during their last two months of treatment. In case the person who takes care of the patient in the wards or brings the patient to the outpatient clinic is not a primary caregiver, they will be requested to ask the primary caregiver to plan and attend the next video presentation. Those attending the outpatient clinic (e.g. ALL patients) will be attending the video sessions after their blood samples have been taken as they await the results. The video will be shown during a group session by a healthcare provider to caregivers of children and teenagers, who are soon finalizing their cancer treatment. The video addresses the importance of follow-up after completion of treatment, physical late effects, psychosocial late effects, stigmatization, social reintegration, and the Survivorship Card usage. In the video, healthcare providers explain the medical aspects, and caregivers of survivors and a young adult survivor share their experiences. During this group session a healthcare provider will be present to answer questions of the attending caregivers. Each session will take 60-90 minutes, and will be organized weekly to monthly, depending on the availability of study participants.

b) Information booklet: After watching the video presentation, the accompanying healthcare provider will give an illustrated educational information booklet to the caregivers. The booklet contains the same topics, covering survivorship information as presented in the video: importance of follow-up after completion of treatment, physical late effects, psychosocial late effects, stigmatization, social reintegration, the Survivorship Card usage and information about coping strategies.

c) Survivorship Card: After watching the video presentation, the accompanying healthcare provider shares the Survivorship Card with the caregivers. An explanation about the content and purpose of the Survivorship Card will be given to the caregiver individually. This is a record of the patient's cancer and treatment history and required check-ups after treatment completion. It also lists possible late effects of received treatment that the caregiver should be aware of. Most information will be pre-filled, according to the standard treatment administered per protocol. Personalized information will be filled by the treating doctor on the survivorship card at the first follow-up visit. The survivor and family take one survivorship card home, and a duplicate copy of the survivorship card remains in the medical file.

Participant recruitment:

Control group:

Caregivers will be identified weekly at the Pediatric Oncology Unit, during their last 2 months of treatment. Study information will be provided, and informed consent will be requested. Upon approval, a knowledge assessment will take place during their last 2 months of treatment, and at six months after treatment completion. In case the survivor and caregivers do not appear at the six months follow-up appointment, they will be called to reschedule their appointment. If they then will still be unable to attend the follow-up clinic, caregivers will be requested for a phone interview to assess knowledge and satisfaction.

Follow-up adherence will be prospectively evaluated by checking in the medical records at the end of every weekly clinic day, whether families were present at their scheduled hospital appointment at 3, 6, 12, 18 and 24 months after treatment completion or not. In case of follow up non-adherence, investigators will make a call to the specific study participants to find out reasons for non-adherence and to assess outcome.

Intervention group:

This group will be recruited after the sample size for the control cohort has been reached. Caregivers will be identified weekly at the Pediatric Oncology Unit, during the last two months of treatment. Study information will be provided, and informed consent will be requested. Upon approval, caregivers will be subjected to a pre-test (see attachment) to measure their knowledge of the various survivorship topics that will be addressed in the educational material. After treatment completion, all caregivers will fill in an interim-test (see attachment). The assessment will be performed by a researcher, who will fill the assessment form according to the participant's answers. Six months after treatment completion, caregivers will fill in a combined post-test and satisfaction questionnaire (see attachment) during a scheduled follow-up appointment at the outpatient clinic. In case the survivor and caregivers do not appear at the six months follow-up appointment, they will be called to reschedule their appointment. If they then will still be unable to attend the follow-up clinic, caregivers will be requested for a phone interview to assess knowledge and satisfaction.

Implementation measures (percentage of new survivors having received education, percentage of survivors attending follow-up clinic, and percentage of these survivors who bring their Survivorship Card) will be evaluated weekly.

Follow-up adherence will be prospectively evaluated by checking in the medical records at the end of every weekly clinic day, whether families were present at their scheduled hospital appointment at 3, 6, 12, 18 and 24 months after treatment completion or not.

Data collection:

Available data about patient and treatment characteristics will be collected:
-From the medical records:

- Patient characteristics: Hospital IP number, sex, date of birth, enrollment in NHIF during/after treatment, comorbidities (HIV, sickle cell disease, other chronic diseases)
- Disease characteristics: Age at diagnosis, year of diagnosis, diagnosis
- Treatment characteristics: Date of planned completion of treatment, type of treatment, (surgery/chemo/radiotherapy), type and location of surgery, type and dosage of chemotherapy, type and dosage of radiotherapy

-Using a questionnaire during a Phone interview in case of non-adherence:

- Reasons for non-adherence: Medical reasons (death, cause of death, relapse, date of death/relapse) or other reasons (time, finances, no added value, no reason).
- Intention to revisit follow-up clinic.

Additional data will be obtained through the data collection tools

a) Participant background information:

- Caregiver characteristics: Interviewed caregiver, date of interview, primary caregiver, age of interviewed caregiver, education of caregivers, occupation of caregivers, marital status biological parents, number of siblings, number of household members, residence (county), regular income, distance to MTRH, travel time to MTRH

b) Follow-up adherence

Follow-up adherence will be evaluated by checking in the medical records whether families attended to their scheduled hospital appointments at 6, 12, 18 and 24 months after treatment completion or not. Missed appointments will be counted.

Survivors will be considered non-adherent when they did not appear for their scheduled visit (within 4 weeks before or after the scheduled visit)

Survivors will be considered lost to follow-up when an appointment has been missed, and they have not revisited the follow-up clinic since the missed appointment for more than six months.

c) Knowledge

Caregivers:

- Diagnosis and treatment (type of cancer, name of cancer, specific name of cancer, location of cancer, treatment of cancer, surgery and type of surgery, chemotherapy and type of chemotherapy, radiotherapy and location of radiotherapy)
- Late effects and follow-up care (why to come for follow-up, how frequent to come for follow-up, where to go for follow-up, late effects general, late effects specific, late effects risk)

d) Satisfaction

- Acceptability (e.g. helpful information, would recommend tool to others)
- Feasibility (e.g. easy to understand, interesting for all ages, usage of the tool when having health problems)
- Potential effectiveness (e.g. new information, know when to seek help from healthcare provider)

e) Implementation

- Reach (percentage new survivors having received the booklet, video and survivorship card)
- Adoption (percentage of survivorship card taken to clinic appointment)
- Implementation (At 6 months: Symptoms reported as a result of video / booklet / survivorship card information)
- Maintenance (At 6 months: Recommendations for future implementation, any missed topics)

Study intervention materials (video, information booklet, survivorship card) and data collection tools will be available in English and Kiswahili. The tools will be developed in English, forward-translated into Kiswahili by a translator, and backward-translated to English by a native Kiswahili speaker to check for inaccurate or inappropriate translations.

2) SURVIVORSHIP FOLLOW-UP PROGRAM

The purpose of this program is to assess whether implementation of a Survivorship Follow-Up Program results in enhanced knowledge about survivorship of healthcare providers taking care of children with cancer at MTRH, and increased detection and management of physical and psychosocial late effects among childhood cancer survivors. Training about childhood cancer survivorship will be provided to an estimated 30 healthcare providers within the first two months from approval of study. Data from the medical records of childhood cancer survivors attending the follow-up clinic will be extracted from the start of the study.

Inclusion Criteria:

- Healthcare providers:
Thirty healthcare providers (the total pediatric oncology workforce comprises of an estimated 30 staff members) working in the Pediatric Oncology Unit at MTRH: Pediatric Oncologists, Fellows, Registrar, Medical Officers, Clinical officers, Nurses, Patient Navigators, Child life specialists.

- Childhood cancer survivors

The medical records of children visiting the follow-up clinic with: 1) Diagnosis of childhood cancer 2) Successfully having completed childhood cancer treatment 3) No treatment failure (abandonment of treatment, progressive or relapsed disease)

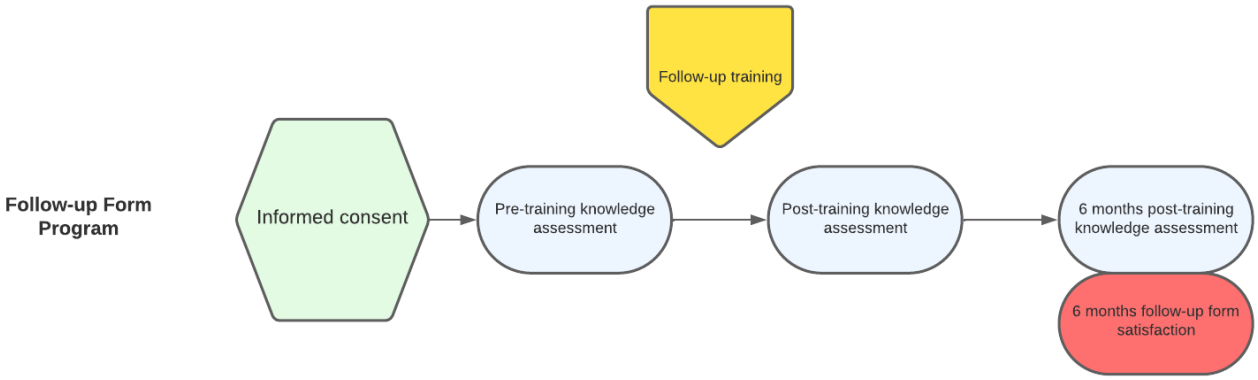


Figure 2: Healthcare providers follow-up program timeline

Components of Survivorship Follow-Up Program:

a) Training of healthcare providers about childhood cancer survivorship:

All 30 healthcare providers involved in the care of children with cancer at MTRH are invited to attend a presentation about survivorship care (physical late effects, psychosocial late effects, stigmatization, social reintegration). The Survivorship Card and the Follow-up Form will be introduced. In addition, practical instructions will be provided about using the new survivorship tools. The presentation will take 2 hours. Investigators aim that 10 participants will be present at every training session, with a minimum of 5 participants per session.

b) Follow-up Form usage at follow-up outpatient clinic:

The Follow-up Form will include questions referring to symptoms specific for certain late effects. The first part of the follow-up form will focus on detecting relapses. Specific questions will be included per subcategory: hematological malignancies, solid tumors or central nervous system (CNS) tumors (such as a question referring to cardiomyopathy after anthracycline treatment for survivors of hematological diagnoses).[27] In addition, the form addresses general health issues such as fatigue, pain, dental hygiene, neurocognitive (concentration/memory), and psychosocial issues (in school or in the community). In case a symptom will be identified, subsequent investigations or referrals are recommended according to international guidelines. Considering the high financial burden of screening (for example close to 500 cardiac echo's to avert one case of heart failure), investigators have chosen for a well-structured symptom-based approach, focusing on a thorough history and physical examination.[28] Every follow-up visit, a new follow-up form will be included in the medical record, enabling the healthcare provider to easily address new symptoms, and keep track of previously identified health problems.

c) Effects identified

Participant recruitment:

- Healthcare providers:

Training about childhood cancer survivorship will be provided to an estimated 30 healthcare providers within the first two months from start of study. Investigators will reach out to all pediatric oncology staff members, according to information from the department leadership. Informed consent will be requested before the presentation. After approval has been given, a knowledge pre-test will be provided at the beginning of the training session. The test should be self-completed before start of the training session. After the session investigators will share a knowledge post-test to evaluate knowledge. The test should be self-completed before they leave the training venue.

At six months after completing the training, a late knowledge test and satisfaction questionnaire will be shared with healthcare providers who handle the follow-up form in follow-up clinic.

Data (reported symptoms and clinician usage) in the Follow-up Forms, included in the medical records of childhood cancer survivors attending the follow-up clinic, will be weekly extracted from the start of the study.

- Medical records of childhood cancer survivors:

Medical records of all childhood cancer survivors attending follow-up clinic will be evaluated. Evaluation of these medical records will start from the moment all the healthcare workers have been educated for a period of 1 year.

Data collection:

Available data about patient and treatment characteristics will be collected from the medical records (follow-up forms):

a) Survivor background information

- Patient characteristics: Hospital IP number, sex, date of birth, residence (county), distance to MTRH, travel time to MTRH, enrollment in NHIF during/after treatment, comorbidities (HIV, sickle cell disease, other chronic diseases)
- Disease characteristics: Age at diagnosis, year of diagnosis, diagnosis
- Treatment characteristics: Date of planned completion of treatment, type of treatment (surgery/chemo/radiotherapy), type and location of surgery, type and dosage of chemotherapy, type and dosage of radiotherapy

Additional data will be obtained through the data collection tools.

a) Healthcare providers knowledge assessment:

- Demographics: sex, age, cadre (function)
- Knowledge level: years practicing in pediatric oncology, survivors seen per week, survivorship care training, confidence managing late effects
- Late effects and follow-up care (why to come for follow-up, how frequent to come for follow-up, where to go for follow-up, late effects risk, late effects general, late effects specific, chemotherapy associated late effects, surgery associated late effects, radiotherapy associated late effects)
- Diagnosis and treatment (surgery history, type of surgery, chemotherapy history, type of chemotherapy, radiotherapy history, location of radiotherapy)

b) Reported late effects Follow-up Form:

- Physical outcomes: relapsed disease, subsequent neoplasm, subfertility, heart failure, hypothalamic-pituitary dysfunction (hormonal dysfunction), motor problems, hearing problems, disfigurements, visual problems, reduced joint mobility, renal insufficiency, osteonecrosis, myocardial infarction, pulmonary dysfunction, seizures, posterior fossa syndrome (speech loss, unsteady gait, reduced spontaneous movements, emotional lability), stroke (hemorrhagic or ischemic), temperature dysregulation, male sexual dysfunction, under / overweight
- Psychosocial and neurocognitive outcomes
    - Physical aspects of quality of life: fatigue, sleep, challenges exercise / chores / physical labor, challenges personal care

- Psychosocial aspects of quality of life: anxiety / worrying, sadness, anger/ trouble getting along with others, avoidance / exclusion / bullying
- Neurocognitive aspects of quality of life: memory / concentration problems, educational problems (miss school because of condition, trouble keeping up with homework)

d) Satisfaction

A questionnaire containing the following parts will be used to assess satisfaction of healthcare workers

- Acceptability (relevant potential late effect symptoms, addresses late effects comprehensively, like using the follow-up form, recommend using the follow-up form)
- Feasibility (easy to use, fast to use in practice, makes documentation easier, has become part of my routine, would like to continue using the follow-up form)
- Potential effectiveness (has helped to identify late effects, has helped to address late effects, has helped to refer survivors, reminds healthcare providers of things that otherwise would have forgotten, has improved follow-up care)

e) Implementation

- Reach (percentage of new survivors, having received the follow-up form in clinic)
- Adoption (percentage follow-up forms used by clinician; percentage follow-up forms completely filled by clinician)
- Implementation (investigations done as a result of reported symptoms, referrals done as a result of reported symptoms, additional investigations done, not as recommended by the form, referrals done, not as recommended by the form)
- Maintenance (how did implementation go in practice, and any ideas on how to maintain the program and improve for future implementation?)

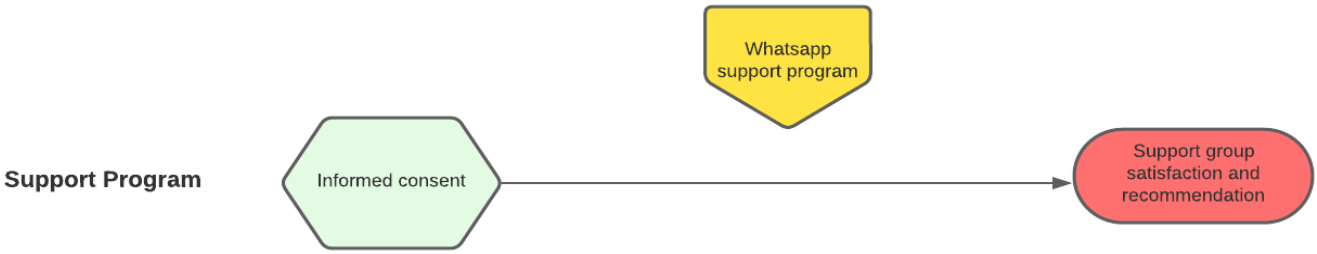
3) SURVIVORSHIP SUPPORT PROGRAM

The purpose of this part of the study is to explore whether implementation of a WhatsApp support group increases social support among caretakers of childhood cancer survivors. Acceptability and feasibility of the WhatsApp support group will be explored. The study also explores willingness to continue participating and moderating future support groups.

Inclusion criteria

Caregivers of children with: 1) Diagnosis of childhood cancer 2) No treatment failure (abandonment of treatment, progressive or relapsed disease) 3) Completed childhood cancer treatment 4) WhatsApp access through personal phone, or someone's phone in the social network

Figure 3: Support Program timeline



Components of Survivorship Support Program:

A maximum of three WhatsApp support groups will be formed for caregivers of childhood cancer survivors. Caretakers of 10-15 childhood cancer survivors will participate in each WhatsApp support group. The involved researchers will be the moderators of these groups initially. This platform will be used for: a) educational purposes and b) sharing experiences among parents and survivors themselves. The educational content will cover six themes ('hospital, family, selfcare, community, wrap-up, recap') during six consequent months. Participants will introduce themselves within the first week of the group forming. In the following weeks, the topics 'hospital, family, selfcare, community' will be discussed, finishing with a wrap up during the last month. Every theme will be split among four weekly sessions (for example the topic 'family' will be split into one session on siblings, one session on partner, one session on extended family and one session on challenges within the family). Participants will be encouraged to respond to the raised topics, share their experiences and also ask questions. There should also be the possibility to raise questions or concerns unrelated to the weekly topic. A recap will follow three months after the last session. After finalizing the recap session of the educational course, caretakers will be asked to evaluate the WhatsApp the support group through a questionnaire.

Participant recruitment:

- Caregivers will be recruited, and the informed consent procedure will be performed, similarly to the caregivers in the Educational Program in the last two months of receiving cancer treatment. Caretakers should be able to prove they can access a mobile phone device with WhatsApp; preferably their own device, or a device of someone in their personal network that they can frequently access. After start of the study, recruitment will take place for a duration of three months. Each group will have caretakers of 10-15 childhood cancer survivors. All participants of the same WhatsApp group will start at the same time, and no new members will be added to the group after start of the first session. Implementation measures (percentage of eligible participants with WhatsApp access, percentage participants active at every weekly session, percentage of participants actively contributing to the discussion, percentage of participants prompting questions irrespective of the weekly topic, topics discussed by moderators, topics discussed by caregivers, time to respond to questions raised by moderators) will be evaluated weekly. After finalizing the recap session of the educational course, the WhatsApp support groups will be evaluated by the caretakers through a questionnaire. Participants of the support group will be subjected to the questionnaire at their next visit to the follow-up clinic after the recap session. In case caregivers do not attend the follow-up clinic, they will be phone called to encourage them to come for their next follow-up visit. In case they are unable to visit, their satisfaction will be evaluated through a phone call.

Data collection:

<u>Available data about patient and treatment characteristics will be collected from the medical records.</u>

a) Survivor background information

- Patient characteristics: Hospital IP number, sex, date of birth, residence (county), distance to MTRH, travel time to MTRH, enrollment in NHIF during/after treatment, comorbidities (HIV, sickle cell disease, other chronic diseases)
- Disease characteristics: Age at diagnosis, year of diagnosis, diagnosis
- Treatment characteristics: Date of planned completion of treatment, type of treatment (surgery/chemo/radiotherapy), type and location of surgery, type and dosage of chemotherapy, type and dosage of radiotherapy

<u>Additional data will be obtained through the data collection tools.</u>

a) Participant background information:

- Caregiver characteristics: Interviewed caregiver, date of interview, primary caregiver, age of interviewed caregiver, education of caregivers, occupation of caregivers, marital status biological parents, number of siblings, number of household members, residence (county), regular income, distance to MTRH, travel time to MTRH

b) Satisfaction

- Acceptability (quality information, friendly / safe environment, like participating in the support group, would recommend the support group)
- Feasibility (easy to use, can be used by caregivers of all ages, has become part of my routine, can use the support group when I want to, can use the support group how I want to)
- Potential effectiveness (has taught participant new information, has connected participant to like-minded people, has allowed participant to share experiences, has given participant social support)

c) Implementation

- Reach (percentage of eligible participants with WhatsApp access, percentage participants active at every weekly session)
- Adoption (percentage of participants actively contributing to the discussion, percentage of participants prompting questions irrespective of the weekly topic)
- Implementation (topics discussed by moderators, topics discussed by caregivers, time to respond to questions raised by moderators, implementation costs)
- Maintenance (how did implementation go in practice, and any ideas on how to maintain the program and improve for future implementation?)

d) Content

- Rate the monthly topics on a scale 1 to 10 (introduction, hospital, family, selfcare, community, wrap up, recap)
- Relevant topics missed
- Rate importance of aspects of WhatsApp group (meeting other caregivers, having a place to express feelings, hearing other caregivers' experiences, getting advice on how to cope with condition / treatment / stress and anxiety, family and relationship issues, self-care, community issues, school issues, work issues, support from other caregivers
- Evaluation (recommend the support program, stay in touch with other participants, would participant like to continue joining, would participant be willing to moderate, recommendations)

Data management and analysis

Data will be entered on paper data collection forms, subsequently transferred to an online data storage, or will be entered directly online in Castor EDC, a secured cloud data storage system designed for research purposes. Paper data collection forms will be stored in a cabinet in a research office. A limited number of pediatric oncology department staff members have access to this office. Analyses will be performed in IBM SPSS or in R Studio.

Univariate analysis will be used for descriptive data (percentages, frequencies), dichotomous data will be analyzed with Chi-Square testing or logistic regression, and continuous data will be analyzed with t-testing or linear regression. Progression in levels of knowledge of caregivers and healthcare providers between the first, second and third assessment will be calculated. Levels of knowledge will be compared between the educated group and non-educated group at six months after treatment completion. Investigators will also compare the treatment adherence between the educated group and non-educated group at 6,12,18 and 24 months after treatment

completion. Multiple regression analyses will be performed to identify associated factors with follow-up non-adherence and knowledge uptake.

ETHICAL CONSIDERATIONS

Participants who meet the inclusion criteria will be given a written informed consent (see attachments) to sign. The informed consent will be written in both English and Kiswahili. The participants will be asked to choose which language they are most proficient in and then they will be given to read and sign if they consent, or the form will be read out loud by the researcher. There will always be a researcher present, for clarification of the study content and to address questions.

STUDY IMPLICATIONS

This study aims to improve survivorship care in Kenya through a holistic approach. Investigators aim to improve follow-up adherence of survivors. Investigators also aim to set an example for other paediatric oncology centres in low and middle-income settings, by showing that well-informed survivors may be at a lower risk of follow-up non-adherence. In addition, investigators aim to build a case for implementation of context-sensitive tools, based on international guidelines, to enable healthcare providers to provide care in a comprehensive but feasible way. At last, investigators acknowledge the importance of peer support, and aim to address the psychosocial needs of caregivers of childhood cancer survivors. Facilitating network building between survivor families, may help to empower them to advocate for their own specific needs in future.

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Appendix: Budget

Survivorship Intervention Program Budget	
Item	Cost (€)
Research Nurse	14,750
Support group meetings/Association registration	16,701
Educational materials	314
Stationery	464
Communication	1276
IREC fee	400
NACOSTI license	80
Total	33,985