

IMPLEMENTATION OF A FORMALIZED EVALUATION AND PLANNING TOOL TO IMPROVE PEDIATRIC ONCOLOGY OUTCOMES IN KENYA

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Abstract

Survival from pediatric cancers in low-middle-income countries is often very low compared to that of high-income countries due to multifactorial etiologies, including late presentation, delayed diagnosis, difficulty with accessing health care, drug unavailability and treatment abandonment. The St. Jude Pediatric Oncology Facility Integrated Local Evaluation Tool (PrOFILE) was developed to identify the strengths and weaknesses of individual institutions, as well as whole countries. Following the completion of data analysis from Kenyan institutions, the first PrOFILE hybrid in-person and virtual workshop was held. Multi-disciplinary stakeholders prioritized recommendations for improving care and developed smart objectives to accomplish identified goals over the following 2 years. Strengths and weaknesses of conducting a hybrid global workshop were identified.

Introduction

Survival from pediatric cancers in low-middle-income countries (LMICs) is much lower than higher income countries (HICs) due to late presentation, delayed diagnosis, difficulty with accessing health care, drug unavailability and treatment abandonment[1-13]. There is often an extreme shortage of trained health care providers and the referral pathway to a hospital equipped to care for children with cancer is burdened by long wait times, travel time and distance and financial barriers. Within Kenya, financial barriers, lack of standardized treatment protocols and inconsistent family education about the planned treatment, as well as concerns with treatment delays within the hospitals have been shown to lead to abandonment of curative therapy[14-19].

The Pediatric Oncology Facility Integrated Local Evaluation Tool (PrOFILE) assessment was developed to identify the strengths and weaknesses of individual institutions within a country, as well as the pediatric oncology services on a national level. Following an extensive needs assessment, workshops are conducted with key stakeholders to identify actionable goals to be achieved over the next few years to improve pediatric oncology care.

The ProFILE tool provides comprehensive, modular and self-guided institutional self-assessments. ProFILE had already been conducted in 61 pediatric oncology units in 16 countries. Each institution and country received score-based reports and then workshops were conducted either in-person or completely virtual. Outcome based goals were then set by each country to improve care within pre-determined time frames. Due to timing around an improving, but still ongoing pandemic, the Kenyan ProFILE workshop was the first one conducted in a hybrid format.

Methods

Foundational Pre-Workshop Activities

ProFILE Assessments

To assess the current situation of the participating hospitals, as well as identify strengths and opportunities at the national level, the abbreviated version of the St. Jude Pediatric Oncology Facility Integrated Local Evaluation (ProFILE) self-assessment tool was implemented in seven hospitals where pediatric oncology services are offered in Kenya. These hospitals were identified by Gertrude Children's Hospital and the National Cancer Institute (NCI) and as estimated by GLOBOCAN 2018, have an average of number of 6,000 new patients per year. ProFILE provides a snapshot of the pediatric hematology and oncology landscape and care continuum at both country and facility levels over the following 12 modules: national context, facility and local context, finances and resources, personnel, service capacity, service integration, diagnostics, chemotherapy, supportive care, surgery, radiation therapy and patients and outcomes. These modules are grouped into five specific components, including Context, Workforce, Diagnostics, Therapy, and Patients & Outcomes. One outcome of the tool is a comprehensive list of strengths and opportunities, as well as suggested collaborators and St. Jude support packages corresponding to each of them.

Foundational pre-work included an introductory online meeting with Kenyan NCI officials, Gertrude Children's Hospital in Nairobi, an American twinning partner to University of Nairobi, and the St. Jude ProFILE and Sub-Saharan Africa Regional Teams. During the meeting, St. Jude presented the ProFILE tool, its methodology, and previous experiences using the tool. Within Kenya, this initiative was coordinated by representatives from Gertrude Children's Hospital, NCI and WHO.

Data Analysis

Using the REDCap tool, data collection and entry took place from October 2021 to December 2021. The ProFILE team analyzed the data and prepared the reports in January 2022. The aggregate report was used in the Kenya National Stakeholder Workshop on Childhood Cancer activities (Supplemental File S1).

Workshop Planning

After the local results were disseminated, each participating institution was encouraged to present their results – strengths and weaknesses/reflections/impression at the weekly St. Jude Sub-Saharan Africa tumor board meeting. At this meeting, each site had the opportunity to present their impressions to a larger audience which led to thoughtful conversations, better insight of the situation of the institution and feedback from their colleagues.

To ensure the correct stakeholders were present at the national workshop, the core planning team (St. Jude, an American twinning partner at University of Illinois (UIC), NCI and Gertrude Children's Hospital) met to conduct a stakeholders analysis using the C5 (C-2) tool developed by St. Jude Global. During this meeting, the team met to identify, assess, and prioritize partners involved in the care of children with cancer in Kenya. The meeting outcome informed the invitation list which was sent by the NCI (Ministry of Health (MoH)). After this, the team reviewed the stakeholders list and using the objectives, drafted the meeting agenda. The agenda allowed time for both the care providers and the funding agencies/foundations to discuss ways they can collaborate to ensure improved outcomes for children with cancer in Kenya.

Workshop agenda

Essentially, the purpose of the workshop was to build consensus on opportunities and barriers to assist stakeholders with prioritizing projects that accelerate progress in health care for children with cancer in Kenya based on the Kenya Cohort Aggregate Results. The workshop aimed to connect national priorities to commitments and global targets. The aims included conducting a broad, multidisciplinary assessment of facility-based childhood and adolescent cancer care services in Kenya with the intent of identifying priorities for future work. To help address the priorities identified, we aimed to engage local, national, and external stakeholders through a series of data-driven prioritization exercises. We also aimed to identify challenges/barriers to pediatric hematology-oncology (PHO) care locally and define key strategies to bridge these in Kenya based on national, regional, and global priorities

Results

Workshop Attendees and Agenda

A total of 18 hybrid sessions were held over a 2-day period with approximately 57 on-site and virtual participants representing a diverse, multi-disciplinary group of national, regional, and international stakeholders. The participants included frontline healthcare workers (physicians providing medical oncology care, nurses, surgeons, radiation oncologists, pharmacists) from seven Kenyan hospitals, as well as representatives from civil society partners, international collaborators, and other multi-national implementation partners. There were 13 general sessions and one panel discussion with the participation of all the attendees. Participants were also separated into five working groups, each of which aligned with one of the five specific components of PrOFiLE, including Context, Workforce, Diagnostics, Therapy, and Patients & Outcomes. Each group conducted four PrOFiLE activities, including the categorization exercise (Table 1), collaboration exercise (Table 2), impact-effort matrix exercise (Figure 1), and action plan and timeline development (Table 3). Each activity was built on outputs from the previous exercise.

Session Output

Context working group

The projects designated as priorities for the context working group include improving drug procurement and increasing childhood cancer awareness. The first objective developed is to increase by 90% uninterrupted supply of essential pediatric oncology medicines in public health facilities in Kenya within 2 years, with a 9-month milestone of developing a tracking system to identify the proportion of patients getting treatment as per protocol. The second actionable objective is to increase awareness of childhood cancers in selected communities by 50% within 2 years, with a 9-month milestone of training champions for this effort.

Workforce working group

The projects designated as priorities for the Workforce working group include increasing treatment adherence by implementing appointment scheduling call backs and improving or upgrading hospital infrastructure. The first actionable objective is to establish systems and procedures to track missed appointments in the pediatric oncology unit and increase patient attendance to 100% by the end of 2 years, with an 8-month milestone of having established a process and completed training. The second objective is to establish a functional, dedicated, and comprehensive regional PHO center that will provide care to 100% of children presenting with cancer by the end of 2 years, with a 6-month milestone of construction of improved facilities and a 12-month milestone of establishment of human resource teams and treatment guidelines.

Diagnostics working group

The projects designated as priorities for the diagnostics working group include reducing time from first evaluation to diagnostic confirmation and increasing access and timelines for leukemia and solid tumor diagnostics. The first objective is to reduce the time from suspicion to confirmation to 4 weeks in 70% of children by implementing an effective referral system within a 24-month period, with a 2-month milestone of defining the referral pathway to be implemented, and a 9-month milestone of monitoring the number and percentage of patients in the pathway. The second objective is to reduce to 2 weeks the time for reporting

flow cytometry or immunohistochemistry results in 70% of samples submitted for analysis within a 24-month period, with a 10-month milestone of evaluating percentage of samples reported timely.

Therapy working group

The projects designated as priorities for the therapy working group include standardizing chemotherapy protocols and guidelines and prioritizing PHO surgery, including improving post-operative care. The first actionable objective is to develop PHO chemotherapy protocols for Kenya by April 2023 and to implement those protocols by April 2024, with a 1-year milestone of developing the protocols and obtaining approval from the MOH. The second objective is to create a PHO surgery group by 2023 and to establish a PHO surgery training program by 2024, with a 1-year milestone of establishing a PHO surgery working group.

Patients and outcomes working group

The projects designated as priorities for the patients and outcomes working group include tracking and reducing treatment abandonment and increasing the number of patients with a confirmed diagnosis. The first actionable objective is to reduce the treatment abandonment rate of patients with Acute lymphoblastic leukemia (ALL) and Wilms tumor (WT) by 50% within 2 years, with a 1-year milestone of establishing a registry to track patients in each PHO institution. The second objective is to establish a correct diagnosis in greater than 80% of children being treated for cancer, with a 1-year milestone of creating diagnostic algorithms for PHO diseases and establishing hospital-based pediatric cancer registries

Discussion

The ProFILE tool provided a baseline assessment of childhood cancer services in Kenya which was the first of its kind in the country. It allowed multidisciplinary teams from various locations in Kenya to work collaboratively. The workshop participants assumed an active role in identifying barriers and opportunities to achieve the common goal of improving the cure rate of children with cancer in Kenya. They were able to identify goals and develop actionable objectives that they can take ownership of accomplishing. Kenya was the first country to conduct this workshop in hybrid format, which was successfully completed, with demonstrated benefits and challenges.

The hybrid setting allowed participation of global collaborators and Kenyan teams from different regions with diverse access to resources, some of whom were not able to travel. To facilitate participation of on-line participants in this hybrid setting, an on-line presentation about concept definitions related to the respective activity and instructions was incorporated prior to each of the 4 ProFILE activities. However, one limitation of the hybrid setting includes virtual participants having limited interactions with in-person participants. The potential for less effective exchange of ideas and experiences when discussed virtually also exists. The focus of plans for the upcoming years was based on results from small group sessions, which were predominantly attended by in-person participants due to the availability and time differences of virtual attendees, especially the international collaborators.

The initiative and hybrid format were felt to be highly valuable by participants, with results able to encompass all the health systems that are needed to improve the survival of children with cancer in the country. The various members at the workshop were voluntarily assigned to each of the working groups after the conclusion of the workshop, with a team leader appointed for each; the National Context, Diagnostic, Workforce, Therapeutic and Patient Outcomes working groups. The working groups agreed to meet individually to accomplish their group objectives and monitor the milestones of their objectives at key time points to ensure that they are achieved before the 2-year period. The team leaders of each working group agreed to meet every 3 months to coordinate their activities.

Subsequent to this workshop, the Kenyan NCI developed a Multi-disciplinary Advisory Committee with 5 subcommittees, including 1) Awareness and Diagnosis, 2) Treatment, 3) Palliative Care, survivorship and rehabilitation, 4) Training, and 5) Commodities and oncology drugs. The plan is to incorporate the working group members who volunteered at the Profile workshop and then meet monthly initially to work toward

the identified goals. A follow-up PrOFiLE assessment 2 years after the action points will be conducted to evaluate childhood cancer services after the interventions made by the working groups.

Changing the outcomes of children with cancer in LMICs requires a stepwise approach that focuses on tackling specific problems over time. A formal way of evaluating the major challenges in each work environment is necessary to address the threats that effect each facility, but also on a national context, enabling them to foster collaborations that leverage on the strengths of each hospital. It is therefore our hope that in the 2-year period, the working groups will be collaborating and developing practical solutions to the major challenges impacting childhood cancer services.

Conflicts of Interest

None of the authors have conflicts of interest to declare.

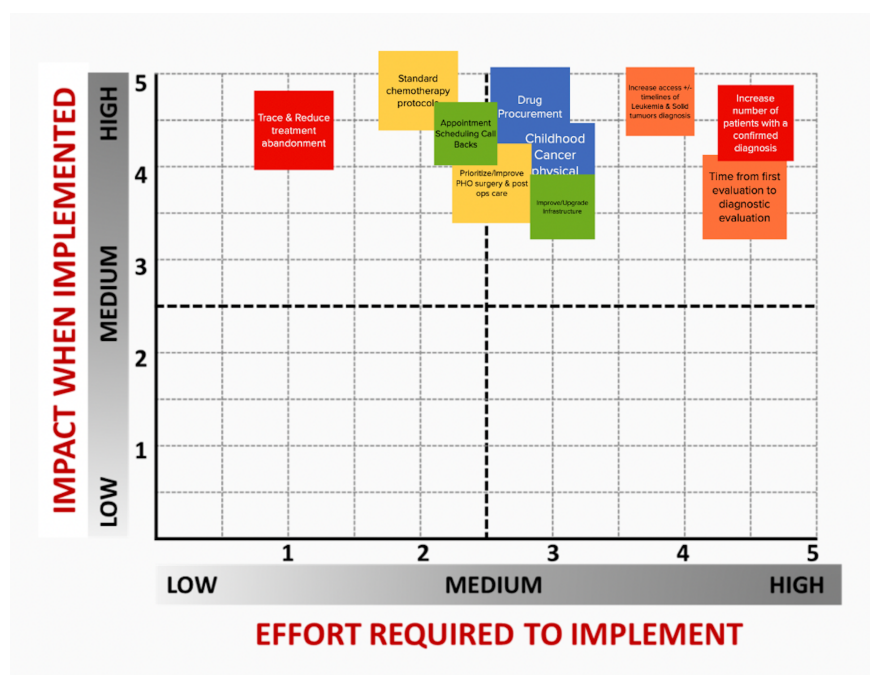
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