Pre-implementation assessment of a national Ethiopian pediatric cancer registry

Atalay Mulu Fentie,1 Kaitlyn Buhlinger,2 Adam Borlagdan,2 Adam Bernstein,2 Sheila Weitzman,3 Wondwessen Bekele,3 David Korones,3 Thomas B. Alexander,2,3 Julie Broas,3 Aziza Shad,3 Ali Mamude Dinkiye,1 Daniel Hailu,1 and Benyam Muluneh2
1Tikur Anbessa Specialized Hospital, Addis Ababa University, Addis Ababa, Ethiopia; 2University of North Carolina Medical Center, Chapel Hill, NC; and 3The Aslan Project, Washington, DC

Background

In Ethiopia, cancer accounts for about 5.8% of total national mortality. It is estimated that the annual incidence of cancer is ~60,960 cases and the annual mortality is more than 44,000, which is likely an underestimation.1 Tikur Anbessa Specialized Hospital (TASH) in Addis Ababa is home to the nation’s first and largest pediatric hematology-oncology service, opened in 2013 in partnership with The Aslan Project (hereafter called Aslan). Although the survival rate for acute lymphoblastic leukemia is 80% or better in the United States, it is estimated that the survival rate is below 20% in Ethiopia. Part of the problem is that there is minimal well-documented demographic information regarding patients, their diseases, and disease outcomes. The World Health Organization (WHO) provides recommendations for creating cancer registries.2 Aslan provided funding to support data clerks in 2 hospitals in Ethiopia: TASH and Jimma University Specialized Hospital (Jimma, Ethiopia). Aslan also supported initial training on data collection for staff at those institutions, as well as staff at St. Paul’s Hospital Millennium Medical College (Addis Ababa, Ethiopia), and Ayder Comprehensive Specialized Hospital (Mekelle, Ethiopia).3 As part of the collaboration with the TASH/Aslan/University of North Carolina (UNC) pediatric hematology-oncology team, a team of UNC pharmacists traveled to TASH in March 2019 with the objective of performing a pre-implementation assessment for introducing a national pediatric cancer registry.

Methods

There were 3 specific aims around which the methods were designed: (1) assessment of the perceptions of the registry by hospital staff (eg, physicians, nurses, pharmacists, and data clerks who would be impacted by it), (2) evaluation of workflow gaps in how patient data are collected and entered into the medical chart and the registry, and (3) characterization of the current registry across participating sites, including which variables were being collected and how these variables compared with standards set by the WHO, and description of how the data were entered, including completeness.

We assessed the first aim by using a validated Organizational Readiness for Change (ORC) survey, which we administered to a multidisciplinary group of health care workers before and after a workshop presented by our team on the importance and benefits of a registry (Table 1). We assessed the second aim by using a structured problem-solving approach (A3 strategy) to map out the workflow and propose interventions (Figure 1). We achieved the third aim by comparing Excel spreadsheets from 2 different hospitals for differences between them as well as completion, consistency, and inclusion of variables recommended by WHO (Table 2).
Results

Table 1. WHO ORC survey results before and after the session

| Question                                                                 | Average response |
|--------------------------------------------------------------------------|------------------|
| How committed is your facility to implementing this change?             | 2.6              |
| How motivated is your facility to implementing this change?             | 2.8              |
| How willing is your facility to work hard to implement this change?     | 2.8              |
| How much does your facility want to implement this change?              | 2.6              |
| How confident are you in effectively using the resources that are currently available to implement the program? | 2               |
| How confident are you in effectively supporting clinicians as they adjust their clinical practice in response to this program? | 2.6              |
| How confident are you in effectively solving problems that might arise in implementing this program? | 2               |
| How confident are you in effectively coordinating the efforts of those involved in implementing this program? | 1.8              |

Perception graded on a Likert scale from 1 (not motivated, committed, or willing) to 3 (very motivated, committed, or willing).

ORC, Organizational Readiness for Change.

Figure 1. Workflow assessment (from A3 Strategy). Our team illustrated the workflow surrounding patient care and medical records upkeep in the medical file throughout a patient’s hematology/oncology care to facilitate visualization and discussion of changes in workflow needed to support the introduction of a pediatric cancer registry. Chemo, chemotherapy; MAR, medication administration record; MD, doctor of medicine [physician]; RN, registered nurse; Rx, prescription.
The hospital staff and leadership have generally positive perceptions of the pediatric cancer registry, which were enhanced by the workshop. The workflow assessment revealed several gaps that were systematically addressed by using a 3-phase implementation approach. The existing spreadsheet-based registry was missing WHO-recommended variables and had inconsistent completion because of the workflow gaps. During one of the upcoming visits by the implementation team, a pediatric oncology summary sheet will be incorporated into the patients’ medical records to better summarize their journey starting from diagnosis. This will be used by the data clerks in an enhanced spreadsheet to create a more complete data set (Table 3).

Table 2. Completeness compared with WHO recommendations

| WHO/IARC Variable                  | Present in TASH Registry | Present in Jimma Registry |
|------------------------------------|--------------------------|---------------------------|
| **The person**                     |                          |                           |
| Personal identification            | Yes                      | Yes                       |
| Date of birth                      | No                       | No                        |
| Sex                                | Yes                      | Yes                       |
| Ethnic group                       | Yes                      | Yes                       |
| Address (postal/ZIP code and phone number) | Yes                      | Yes                       |
| **The tumor**                      |                          |                           |
| Incidence date                     | Yes                      | Yes                       |
| Primary tumor site                 | Yes                      | Yes                       |
| Laterality                         | No                       | No                        |
| Primary tumor histology            | No                       | Yes                       |
| Behavior                           | No                       | No                        |
| Basis of diagnosis                 | No                       | No                        |
| Stage (condensed TNM)              | Yes                      | Yes                       |
| Initial therapy                    | Yes                      | Yes                       |
| Surgery                            | Yes                      | Yes                       |
| Radiotherapy                       | Yes                      | Yes                       |
| Chemotherapy                       | Yes                      | Yes                       |
| Endocrine (hormones)               | No                       | No                        |
| Sources of information             | Yes (diagnostics means)  | No                        |
| **Follow-up**                      |                          |                           |
| Last follow-up date                | No                       | Yes                       |
| Vital status (at last follow-up date) | No                       | No                        |
| Date of death                      | Yes                      | Yes                       |

We noted many differences between the data sheets for the 2 hospitals and with WHO/International Agency for Research on Cancer (IARC) recommended variables. We estimated the overall rate of completion to be <50%.

Summary

The hospital staff and leadership have generally positive perceptions of the pediatric cancer registry, which were enhanced by the workshop. The workflow assessment revealed several gaps that were systematically addressed by using a 3-phase implementation approach. The existing spreadsheet-based registry was missing WHO-recommended variables and had inconsistent completion because of the workflow gaps. During one of the upcoming visits by the implementation team, a pediatric oncology summary sheet will be incorporated into the patients’ medical records to better summarize their journey starting from diagnosis. This will be used by the data clerks in an enhanced spreadsheet to create a more complete data set (Table 3).
Authorship
Conflict-of-interest disclosure: The authors declare no competing financial interests.

References

1. International Agency for Research on Cancer: Globocan 2018. http://gco.iarc.fr/today/data/factsheets/populations/231-ethiopia-fact-sheets.pdf. Accessed 21 September 2018.

2. Jedy-Agba EE, Curado MP, Oga E, et al. The role of hospital-based cancer registries in low and middle income countries-The Nigerian Case Study. Cancer Epidemiol. 2012;36(5):430-435.

3. The Aslan Project: The Aslan Project Holistic Model. https://www.aslanproject.org. Accessed 19 September 2018.

DOI 10.1182/bloodadvances.2019GS121614

© 2019 by The American Society of Hematology