Field Epidemiology Training Program

Cancer Curriculum: Principles of Cancer Registries

Case Study:

Establishment and maintenance of a cancer registry in Uganda

PARTICIPANT GUIDE

Overview

Participants will apply what they learned in Module 3: *Principles of Cancer Registries* to the establishment and maintenance of the cancer registry in Uganda. Participants will work in small groups as instructed by the Facilitator.

Objectives

- Review the history of the population-based cancer registry in Uganda.

- Participants will work through necessary information, and key decision points that contributed to the success of the registry.

- Make the case for the establishment of a cancer registry.

Scenario

You work in the Ministry of Health in your country, where until recently the primary focus of all programs has been the prevention and control of infectious diseases such as malaria, tuberculosis, and HIV. However, the Minister of Health knows that the burden of non-communicable diseases (NCDs), including cancer, is rising disproportionately among lower income countries and populations. The Minister of Health in your country (and your boss) is forward thinking and knows that something must been done to curb the impending NCD epidemic. Specifically, the Minister is interested in understanding and addressing the cancer burden in your country. As a result, you have been asked to investigate how other lower income countries have been able to establish successful population-based cancer registries. Through research, you learn that Uganda had the first population-based cancer registry in tropical Africa. The registry was established in 1951 at the Makerere Medical School under Prof. J.N.P.Davies. Your role is to understand the history of the registry, how it was conceptualized and established, and what factors have contributed to the continued success of the registry. You will use this information to provide suggestions to your Minister of Health on the approach that could be taken on establishing a population-based cancer registry in your country. If you believe that a population-based cancer registry is not possible, given the current situation, then make the case for the establishment of a hospital-based cancer registry.

Instructions

We have 90 minutes to work through this case. Read the background material on the Uganda Cancer Registry (provided in your guide). Work in groups to answer the questions in this document. Read the required background material on the Uganda Cancer Registry.

Required readings for the related to the Uganda Cancer Registry include:

- Davies JN, Wilson BA, Knowleden J: Cancer in Kampala. A survey in an underdeveloped country. Brit Med J 2:439-445, 1958. Read pages 439-441 (http://pubmedcentralcanada.ca/pmcc/articles/PMC2026071/pdf/brmedj03064-0043.pdf).

- Wabinga HR, Nambooze S, Amulen PM, Okello C, Mbus L, Parkin DM. Trends in the incidence of cancer in Kampala, Uganda 1991-2010. Int J Cancer. 2014 Jul 15;135(2):432-9. Read pages 432-433 (http://onlinelibrary.wiley.com/doi/10.1002/ijc.28661/full).

Optional readings:

- Davies JN, Knowelden J, Wilson BA. Incidence rates of cancer in Kyandando County, Uganda, 1954-1960. J National Cancer Inst 35(5): 789-821, 1965. Read pages 789-94.

- Templeton AC, Hutt MS. Distribution of tumours in Uganda. Recent Results Cancer Res. 1973;41:1-22. Read pages 1-13.

Part I: Understanding the History

Your first step is to understand the history of the cancer registry in Uganda. *[Add sufficient detail on the history to answer the question.]*

1. What were the essential items and resources needed to establish the Ugandan Cancer Registry in 1951? (Read: Davies JN, Wilson BA, Knowleden J: Cancer in Kampala. A survey in an underdeveloped country. Brit Med J 2:439-445, 1958. Read pages 439-441)

2. How did the Ugandan Cancer Registry evolve over time and what were key items/resources needed at different time points? (Read: Davies JN, Wilson BA, Knowleden J: Cancer in Kampala. A survey in an underdeveloped country. Brit Med J 2:439-445, 1958. Read pages 439-441)

3. What actions were taken for data quality control? (Read "Materials and Methods": Wabinga HR, Nambooze S, Amulen PM, Okello C, Mbus L, Parkin DM. Trends in the incidence of cancer in Kampala, Uganda 1991-2010. Int J Cancer. 2014 Jul 15;135(2):432-439)

4. What important conclusions do you draw from the incidence data from the Ugandan Cancer Registry? (See Table 1 and Figures 2-4: Wabinga HR, Nambooze S, Amulen PM, Okello C, Mbus L, Parkin DM. Trends in the incidence of cancer in Kampala, Uganda 1991-2010. Int J Cancer. 2014 Jul 15;135(2):432-439)

5. In what ways would you expect those data to have been used in Uganda to guide health policy? (based on answers from the previous question #3)

Learning points:

- *Identify essential items/resources needed to establish the registry*

- *Recognize the challenges to maintaining and sustaining a cancer registry*

- *Interpret information on cancer incidence and mortality*

Part II: Developing an Approach

Your second step is to think through the steps of establishing and then maintaining a cancer registry.

[NOTE: This section will focus on the key elements of establishing a cancer registry that were learned over the course as well as the experiences of the Kampala cancer registry.]

1. Although the requirements for a cancer registry depend on the local circumstances with respect to the level of development of medical services (diagnostic, therapeutic, and palliative) for cancer patients, the size and geographical dispersion of the population, and the resources, there are several key aspects that must be met. When planning a registry, it is desirable to (list as many key factors as you can):

2. Use GLOBOCAN estimates (http://globocan.iarc.fr) to obtain information about the burden of cancer in your country, including:

   a. Overall cancer incidence and mortality rates

   b. Figure illustrating the top 10 types cancer diagnosis and cancer deaths in men and women

   c. Projected increase of cancer incidence and mortality by the year 2035

   d. From the "Data Sources and Methods" tab, obtain the information about data availability for the estimation of incidence and mortality rates in your country

Learning points:

- *Name the necessary elements for establishing and maintaining a cancer registry*
- *Obtain cancer statistics using international databases (GLOBOCAN)*

Part III: Making the Case

Your third and final step is to make a strong case for the establishment of a cancer registry to the Minister of Health. You need to convince the Minister of Health that your approach will lead to the establishment of a sustainable cancer registry in your country.

1. Using the GLOBOCAN information obtained in Part II question 2:

    a. Briefly describe the burden of cancer in your country (2a , 2b)

    b. Comment on the expected increase/decrease of cancer (2c)

    c. Comment on the quality of the GLOBOCAN data to justify the need of a cancer registry given that what is known about the burden of cancer is based on estimations from available data (2d). Note: some countries do not have incidence and/or mortality data available.

2. Describe the current cancer control plan of your country.

3. Briefly justify the importance of a cancer registry in cancer control (e.g. focus efforts and limited resources for cancer control activities, need to know who is affected, where, type of cancer, stage at diagnosis).

4. Explain how you plan to involve key players in cancer control in backing the progress and ensuring the sustainability of the registry (think back on the answers to Part I, and Part II question 1).

5. Describe the involvement of non-governmental organizations (NGOs) in the for cancer control (if any).

6. Given the cost of cancer registration, explain that adequate budget is needed as expenses tend to increase as time goes by.

7. Justify the need of governmental support for the establishment and maintenance of the cancer registry.

Learning points:

- *Apply the principles of cancer registration*
- *Communicate the necessary elements of a cancer registry*
- *Interpret cancer statistics using GLOBOCAN estimates*