Building cancer registries in a lower resource setting: The 10-year experience of Golestan, Northern Iran

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ABSTRACT

Introduction: The Golestan population-based cancer registry (GPCR) was established in Golestan province, Northern Iran, within the Asian belt with predominance of upper-gastrointestinal cancers. We aimed to present the experiences of the registry in a resource–limited setting over the 10 years since its inception (2004–2013).
Methods: The GPCR was established as a research project to enable sustainable funding. A clear plan was developed for use of the GPCR data. New primary cancers were registered based on international standards, indices of data quality were routinely assessed and age-standardized incidence rates (ASR) per 100,000 person-years calculated using IARC's CanReg-5 software.
Results: Overall, 19807 new cancer cases were registered during the study period, an average of 1981 cases per annum, with overall ASR of 175.0 and 142.4 in males and females, respectively. The GPCR data suggested gastrointestinal and breast cancers as the most common malignancies in Golestan province. We observed increasing incidence rates of breast and colorectal cancers but declining trends of esophageal cancer. Overall, indices of data quality were within acceptable ranges.
Conclusions: The GPCR data have been included in IARC's *Cancer Incidence in Five Continents* series, were used in 21 research projects, and published as 30 research papers. The key ingredients for the successful establishment and maintenance of the GPCR included sustainable sources of funding, a clear action plan for the use of data as well as stakeholder cooperation across all areas of the registration. The GPCR may be considered as a model for planning population-based cancer registries in lesser-resourced settings.

1. Background

According to worldwide data available in the GLOBOCAN series of the International Agency for Research on Cancer (IARC), 14.1 million new cases of cancers and 8.2 million cancer-related deaths occurred in 2012 [1]. During the last decades, the number of cancer cases have

certainly increased, in part due to population ageing and growth, increasing the priority for operational national cancer control programs. Access to epidemiological data from population based cancer registries on the scale and profile of new cancer cases and deaths is a cornerstone in cancer control planning.

The first population-based cancer registries were initiated in the 1920s in Europe and the U.S. some years later [2]. The formal relations developed between the International Agency for Research on Cancer (IARC) and the International Association of Cancer Registries (IACR) in the early-1970s, meant cancer registration activities were advocated according to internationally accepted protocols and standards. According to the *Cancer in Five Continents* (CI5) Volume X, there were more than 290 population-based cancer registries considered of high quality in 68 countries worldwide, but most of these registries are from developed countries [3].

The Golestan province of Northern Iran has been known as a high risk area for upper gastrointestinal cancers since the 1970s [4,5]. Determining the underlying risk factors of these cancers has historically been a major challenge for health authorities in this high risk region during recent decades. To address this, the "Gastric and Esophageal Malignancies in Northern Iran" (GEMINI) project was conducted by the Digestive Diseases Research Institute (DDRI) in collaboration with the IARC, the National Cancer Institute (NCI) and Golestan University of Medical Sciences (GOUMS) [6]. The GEMINI project consisted of a series of studies including case-control studies, ecological studies, screening studies and the Golestan Cohort Study (GCS). Establishment of cancer registry was considered as a prerequisite condition to conduct these studies, especially the GCS. To meet this requirement and as a first step to cancer control in this high-risk population, the Golestan Population-Based Cancer Registry (GPCR) was established to provide reliable cancer statistics to GEMINI research group as well as to local and national health policy makers. The GPCR data were published in the CI5 and the registry was accepted as a voting member by the IACR in 2007 [3]. Early results of the GPCR have published previously [7,8]; in this paper we describe the process of establishing and maintaining the GPCR. By sharing the 10-year experience of the GPCR, we hope to provide a practical example on how a population-based cancer registry can flourish in a low resource setting.

2. Methods

2.1. Registration area

The GPCR covers the population of Golestan province, located in the northeast of Iran. The total land area of the province is $20438 \, km^2$, about 1.3% of total land area of Iran and about half of the population lives in urban areas. Almost all cancer-related diagnostic and therapeutic services including cancer surgery (open and laparoscopic surgeries), radiotherapy, chemotherapy, CT-scan, MRI, upper endoscopy, colonoscopy, sonography, mammography and pathological examinations are provided within the province. There are seven referral hospitals in covering the Western and Eastern parts of the province.

2.2. Population data

National population censuses are officially undertaken every five years by the Iranian Statistical Center, with the last census done in 2016. In addition, provincial population census is officially done every year by the Deputy of Health of GOUMS. There are only minor differences between the national population census data and those for the provincial population; we therefore used the latter in our registry, given the data were consistently available for all individual years.

2.3. Source of funding

Access to permanent and stable financial support was an important

challenge in the establishment and maintenance of the GPCR. We assessed different scenarios and were able to attain research grants as a means of sustainably funding the GPCR; we conducted the GPCR as a research project that was later approved by the GOUMS review board.

Another key aspect of the registry's development was to ensure comprehensive cooperation of the stakeholders involved the registration process. We invited motivated healthcare professionals, in both the public and private sectors, as well as staff from the health, research, treatment, information technology and food/drug domains within the GOUMS to join as GPCR collaborators; as a stakeholders' group, the GPCR collaborators were given priority access to the GPCR data.

2.4. Organization of the GPCR

The GPCR was established by the Golestan Research Center of Gastroenterology and Hepatology (GRCGH), affiliated to GOUMS, under the supervision of DDRI affiliated to Tehran University of Medical Sciences (TUMS). The GPCR included a steering committee comprising the principal investigators (PIs) of the GPCR research project and the Chancellor of GOUMS. A Secretariat consisted of representatives from GRCGH, the stakeholders listed above, as well as a consultant pathologist and an epidemiologist.

2.5. Study design

The GPCR included two phases with different designs for data collection. During the first phase (in 2001), data on cancer patients diagnosed between 1996 and 2000 were retrospectively collected and the results published [8]. After a few years where the registry ceased to function, a second (prospective) phase of GPCR data collection began in 2004, as a population-based cancer registry. In the present paper, we focus on a 10-year prospective phase of the GPCR: from 2004 to 2013.

2.6. Definitions, rules and standards

The GPCR registered only primary cancers, with all definitions and protocols of data collection were defined according to standards and rules developed by the IARC and IACR, including multiple primary rules [9–11]. We aimed to register tumors with malignant or in situ behaviors. In other words, the GPCR did not register tumors with benign or uncertain behaviors. Based on IARC and IACR guidelines, certain patient and tumor characteristics were considered as necessary items for data collection. These included patient's registration number, first name, last name, sex, age and address as well as topography of tumor, morphology and behavior of tumor, method of diagnosis, date of diagnosis and source of data. The GPCR also collected available data on optional items including patients' national identification number, father's name, ethnicity, marital status and phone number as well as grade of tumor, modalities of treatment, vital status and date of death. The GPCR data collection form was developed to ensure the collection of the above-mentioned variables.

2.7. Sources of data

We determined all potential sources of data including health care centers throughout the province. This information was obtained from the deputy of treatment affairs of the GOUMS and the list was updated annually. All public and private diagnostic and therapeutic centers (hospitals, pathology/laboratory centers, imaging centers and selected specialist physician's offices) as well as primary health centers throughout the Golestan province were considered as potential sources of data.

The Death registry unit was another source of the data; the GPCR regularly received information on cancer-related deaths from this unit housed within the health department of GOUMS. We matched this data against the incident cancer case file using linkage methods to identify