

## RESEARCH ARTICLE

# Cancer Registration in Basrah-Southern Iraq: Validation by Household Survey

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### Abstract

On an international scale, the burden of cancer in absolute numbers continues to increase, mainly due to aging of population in many countries, the overall growth of the world population, changing lifestyle with increasing cancer-causing behavior, like cigarette smoking, changing dietary habits and sedentary life. Cancer is the second-leading cause of death and disability in the world, after only heart disease. Recently, increasing incidence and mortality of cancer have also become evident in the developing world. In Iraq and particularly in Basrah in the southern part of the country, the burden has definitely increased and deserves extensive research. The present paper is part of an extensive household survey carried out in Basrah in 2013. Among the objectives was to validate official cancer registration in the governorate. The cross-sectional survey had a retrospective component to inquire about the incidence of cancer and cancer-related deaths during the three years preceding the date of inquiry (2010-2012). A convenient sample of 6,999 households with 40,688 inhabitants using multistage cluster sampling was surveyed involving all urban and rural areas of Basrah. The official cancer registration activities in Basrah seemed to have attained a high level of registration coverage (70-80%) but the gap, represented by missed cases, is still high enough to criticize the system. Most of the missing cases were either not notified by treating facilities or they were diagnosed and treated outside Basrah. Using a set of parameters, the pattern of cancer was consistent based on data of the household survey and data of the cancer registry but a gap still existed in the coverage of incident cancer and mortality by cancer registration. Integrated serious steps are required to contain the risk of cancer and its burden on the patient through improving the registration process, improving early detection, diagnostic and management capabilities and encouraging scientific research to explore the hidden risk factors and possible causes of low registration coverage. Periodic household surveys seemed feasible and essential to support routine registration.

**Keywords:** Cancer registration - Basrah - validation - household survey

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### Introduction

Cancer registration is a process of continuing and systematic collection of data on the occurrence and characteristics of new cases of cancer for the purpose of quantification of its burden and assessment of the control measures (Jensen and Whelan., 1991). The cancer registry is an organization for the purpose of cancer registration. The data compiled are stored, analyzed, interpreted, and reported. At least three types of cancer registries are available: hospital-based, histopathological and population-based, and from a functional point of view, they can be epidemiological, clinical and histopathological (WHO., 1999). The three types of registries are only useful from epidemiological point of view when they are linked to each other and attain a high coverage of incident cases expected in the catchment population (WHO., 1999). Population based registry is the ultimate goal of all countries because the data obtained can be

used to describe the extent of cancer, to provide material for aetiological studies, and to assist in monitoring progress in control measures (Jensen and Whelan., 1991, IARC., 2014). A successful population-based registration is conditioned upon clear definition of the catchment population and filtration of cases by residence, availability of reliable population denominators, availability of medical care and ready access to medical facilities and easy access to case-finding sources (Jensen and Whelan., 1991).

Population-based cancer registries in developing countries usually face enormous logistic problems concerning the above mentioned conditioning factors and are constrained by shortage of trained personnel, proper denominators, shortage of health care services and deficient record linkage (WHO., 1999, Valsecchi., 2008).

In Basrah, Iraq, cancer registration is one of the principle components of the national cancer control strategy and it is run under the guidance of the Iraqi

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Cancer Board. The Iraqi Cancer Board was established in 1985 and is still working as the main body for the planning of all cancer control services including a national network of population-based cancer registries. In Basrah, cancer registration was initiated since the early 1990s and the governorate now has a good coverage of new cases and deaths related to cancer. The registry is under the administration of Basrah Directorate General of Health Services and is linked to the Iraqi Cancer Board Office in Baghdad. It is based on cancer registration units in major hospitals, oncology centers and a reporting system using Can-reg -4 as data collection form. The data are all directed to the Cancer Control Centre which is the governmental image of the national cancer registry. The work of the cancer registry in Basrah has been very much enhanced since 2005. When a group of researchers of medical, environmental, and physics background was established as an informal Basrah Cancer Research Group (BCRG) started a project to explore cancer and environmental determinants and made some useful documentation on cancer (Habib., 2005, Habib et al.,2007, Habib et al., 2008, Habib et al., 2010, Al-Haroun et al., 2013). This article reports some of the results of a household survey which was designed to explore, among other objectives, the extent to which cancer registration activities succeeded in covering incident cancer in Basrah.

## Material and Methods

The details of the methods and sources of data for the household survey can be found in other documents (Hussain and Habib., 2015, Hussain and Habib., 2015). To validate the extent to which population-based cancer registration in Basrah has covered incident cancer over the last decades, we used two sources of data:

First: the pool of data on incident cancer cases available at Basrah cancer registry for the years 2005-2012. This is the official cancer registry which is linked to the national cancer registry run by the Iraqi Cancer Board.

Second: data of a large scale household survey carried out during 2013 to identify incident cancer cases during three recall period (2010-2012). The household survey involved 6999 households randomly selected from all administrative parts of Basrah governorate using multistage cluster sampling.

For the purpose of validation, four comparative approaches were used:

Approach 1: Comparing the age-specific and sex-specific incidence rates based on data obtained from the household survey and the cancer registry.

Approach 2: Comparing the site/cancer-specific incidence rates also based on data obtained from the household survey and the cancer registry.

Approach 3: Tracing each and every patient identified during the household survey in the records of the cancer registry to match names, ages, diagnosis and address.

Approach 4: Searching for the reasons behind non-registration of patients (if any).

From ethical point of view, the original protocol was approved by the Ethical Committee of the College of Medicine, University of Basrah. Data were analyzed

Table 1. Incidence Rates per 100,000 Population of New Cancer Cases in Basrah Governorate Using Household Data 2005-2012, by Age and Sex.

Variable	IR per 100,000 per year	
	Household data	Cancer registry data
Age (years)		
<5	11.8	15.5
September-05	16.3	14.3
October-14	32.9	12.0
15-19	32.7	18.6
20-24	27.3	28.4
25-29	42.8	32.9
30-34	80.2	46.3
35-39	94.1	75.6
40-44	136.7	120.9
45-49	251.6	200.0
50-54	299.0	242.9
55-59	375.0	240.9
60-64	740.7	453.6
65-69	297.6	464.9
70-74	914.6	658.4
75 and above	687.3	391.0
Total	91.8	71.4
Gender		
Male	74.3	63.8
Female	109.7	77.6
Total	91.8	71.4

for the years 2010-2012 and cancer registry data for the years 2005-2012, by age and sex.

using SPSS (Statistical Package for Social Science-Version 15). Crude incidence rates were computed and compared accordingly.

## Results

### *Comparative incidence rates by age and sex*

Table 1 shows a comparison of the age specific incidence rates of cancer of all sites using the household data and the population-based cancer registration in Basrah. An illustrative diagram is also made (Figure 1). It is clear that the two age patterns are very similar with consistent excess (with few exceptions) of incidence rates from household data over incidence rates from population-based cancer registration. The excess is also seen for gender specific rates particularly for females. Assuming that the household data are more accurate, the coverage rate of incident cancer by population-based cancer registration is approximately 77.9% of the expected incidence at population level.

### *Comparative incidence rates by cancer site*

The cancer site specific incidence rates shown in Table 2 and Figure 2 display consistent higher incidence rates with the household data as compared to incidence rates based on cancer registration. Exceptions do exist but these

Table 2. Comparison of Site Specific Incidence Rate of Cancer by Site between Household Survey Data and Cancer Registration Data

CA31:C41	Household survey data 2010-2012	Cancer registration data 2005-2011
Breast	22.9	12.6
Lymphomas	4.1	5.5
Bladder	4.9	5.3
Lung	6.6	4.3
Leukaemias	5.7	4.3
Skin	1.6	3.6
Brain	4.1	3.0
Colon-rectum	6.6	3.0
Stomach	3.3	2.4
Bones	4.1	2.2
Uterus-cervix	2.5	2.0
Larynx-pharynx	5.7	1.7
Ovary	0.8	1.7
Kidney	2.5	1.6
Thyroid	2.5	1.5
Pancreas	4.1	1.3
Prostate	1.6	1.0

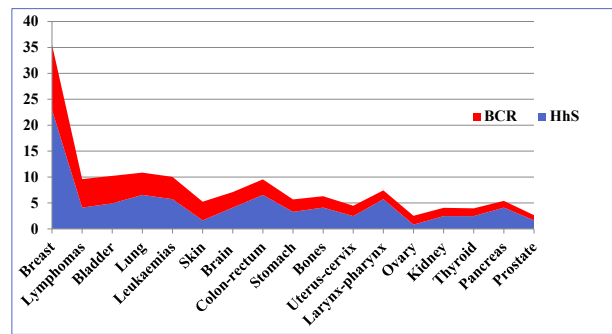


Figure 2. Cancer - Specific Incident Rate in Basrah: Comparison of Household Survey Data and Registration data.

a coverage rate of 68.7%. Thus 31 cases need further tracing to identify the reasons why they did not appear in the cancer registry records.

### Discussion

One of the principle components of a successful cancer control programme and of the effective surveillance of cancer at population level is the availability of population –based cancer registry (Alwan., 2010, Wild., 2014, UN., 2014). To be effective, a cancer registry needs to cover the highest number of incident cases at population level to facilitate the calculation of reliable indicators of incidence, mortality and survival. These epidemiological parameters are themselves indicators of impact of interaction among exposures to risk factors, social determinants of disease and responsiveness of the health care system. The results of the present study revealed two important apparently contradicting aspects of cancer registration in Basrah. The first aspect is that cancer registration in Basrah has been going in the right direction over the last few years. This is at least recognized through two indicators presented in this study. The first indicator is based on comparing the overall incidence rates of cancer using data obtained from the present household survey and the cancer registration sources. Here we found that cancer registry covered about 77.8% of the expected incident cancer. The second indicator is the very consistent pattern of age-specific and site-specific incidence rates between the two sources. Such consistency suggests that the registered cases are fairly representative of the whole universe of cancer cases at population level. The second aspect is that a substantial portion of incident cancer in Basrah (22.2%) is still unrecognized by the registration

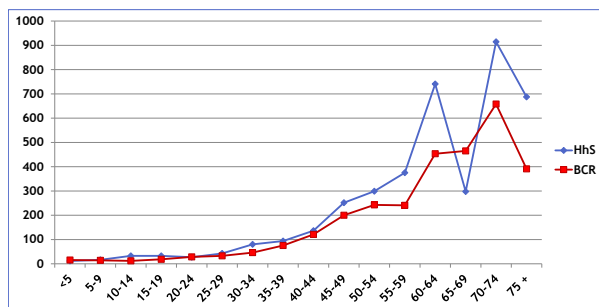


Figure 1. Age - Specific Incident Rate of Cancer in Basrah: Comparison of Household Survey Data and Registration Data.

are very few. The comparison is restricted to sites common to both sources of data

#### Validation by verification of individual cases detected in the household survey

Out of the total 112 incident cases identified during the household survey, 13 were totally diagnosed and treated outside Basrah. Of the remaining 99 cases, 68 were found correctly registered in cancer registry records giving

Table 3. Validation of Cancer Registry by Individual Cancer Cases Matching

YearA54:F60	Cases of the household survey				Effectiveness of registration(%) D/C
	Total cases identified during the household survey (A)	Cases which are not expected to register in Basrah* (B)	Cases which are expected to register in Basrah (C)	Cases registered in Basrah (D)	
2010	37.0	3.0	34.0	22.0	64.7
2011	29.0	3.0	27.0	21.0	77.8
2012	46.0	7.0	42.0	28.0	66.7
Total	112.0	13.0	99.0	71.0	71.7

\*Cases which were totally diagnosed and treated outside Basrah

activities and therefore a defect does exist in assessing the burden of cancer and in the preparatory efforts by the Ministry of Health to provide effective coverage (universal coverage) to the true (the diagnosed cases) and the potential cases (ought to be earlier diagnosed cases).

Definitely, some of the missed cases were seen at one or another medical encounter but they were not properly notified to the institutions of cancer registration. The unregistered cases were of two kinds. Some were totally medically managed outside Basrah and therefore they are not expected to be registered. The others (the majority) were not registered due to defect in the process of care and flow of the information. This defect was further confirmed in this study when we traced each case identified in the household survey in the records of the two major sources of the cancer registration: the Official Cancer Registry and the Histopathological Registry. Further work (beyond the resources of this study) is needed to trace the missing names in the original medical care documents to identify the missing links in the process of registration.

How good is cancer registration in Basrah compared to regional examples?

This is very difficult to judge because no validation study could be traced on cancer registries in neighbouring countries. However, some of the registries must be good enough to be considered at favourable status as compared to cancer registration in Iraq and in Basrah. The criteria to judge the quality of these cancer registries is their inclusion in some of the IARC documents such cancer in five contents (Coleman et al., 2008) and the Globocan Statistics Reports. We highly recommend a periodic well organized household survey made by academic and health care institutions to support routine cancer registration.

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