

Incidence of cancer in Almdinah Almunawarah, Saudi Arabia from 1st Jan. to 31st Dec., 2008

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Abstract

Background The data of cancer incidence is the backbone of the registry. These data in Saudi cancer registry was collecting passively. Despite the importance of local cancer data in developing and evaluating control measures, many existing ones lacked financial or technical resources to collect complete, accurate, and timely data of requisite quality.

Objective Assessing the completeness and reliability of cancer registry in Almadinah Almunawarah.

Subjects and methods This is a descriptive retrospective cohort record reviewing study. It included all cancer cases confirmed and registered in all hospitals in Almadinah Almunawarah throughout the period 1st January to 31st December, 2008. The percentage of all cancer sites was calculated and compared with those of Saudi Cancer Registry.

Results the present survey collected data from 401 cancer cases compared to 563 cases reported in Saudi Cancer registry. The commonest site was colo-rectal representing 16.4% of

cases compared to 9.1% reported in SCR, $p=0.001$. NHL represented 8.9% of SCR data compared to only 1.7% of the current survey, $p<0.001$. There was no statistically significant difference between the current survey results and SCR results in other sites. The results of both surveys were not identical in any site.

Conclusion There is an apparent discrepancy between active cancer surveillance and passive surveillance results (SCR) mainly in non-Hodgkin's lymphoma and colo-rectal cancer. Definite and accurate evaluation of SCR couldn't achieved due to obstacles with the quality of medical records.

Keywords: Incidence; Cancer; Surveillance; Record reviewing; Saudi Arabia

Running title: Incidence of cancer in Saudi Arabia

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INTRODUCTION

The cancer is a fatal disease and the cost of health services to the cancer patient is high and constitutes a big health economic burden on ministry of health and other health sectors.⁽¹⁾ Measuring the morbidity of the cancer is very important to estimate the burden of the disease.⁽²⁾

In 2007, the total number of cancer incident cases reported to the SCR was 12,309. Overall cancer was slightly more among women than men. Cancers affected 5,982 (48.6%) males and 6,321 (51.4%) females with a male to female ratio of 95:100. 9,347 cases were reported among Saudis, 2,590 among Non-Saudis. The total number of cases excluded from analysis includes 361 cases of unknown nationalities. ⁽³⁾

Diagnosis of malignancy was confirmed histologically in 86.2% of the cases, and haematological and cytologically in 8% of cases. Clinically confirmed cases were 0.3%; radiologically confirmed cases were 2%; cases confirmed by Death Certificate Only were 2.7% and the method of diagnosis was unknown for 0.8% of the cases. 11,651 cases were analyzed, of which 9,124 (78.3%) were Saudis and 2,527 (21.7%) were Non-Saudis. The crude incidence rate (CIR) of all cancers among Saudi Population was 52.3/100,000 (49.4/100,000 among males and 55.1/100,000 among females). The overall age-standardized incidence rate (ASR) for all Saudis with a world standard population reference was 82.1/100,000 (80/100,000 in males and 84.2/100,000 in females). For all sites, the age-specific incidence rate (AIR) increased with age for both males and females. After the age of 64 years, the increase was nearly one and one half fold for males compared to females. The median age at diagnosis was 59 years for men and 50 years for women. ⁽³⁾

The five geographic regions with the highest ASR were Riyadh Region at 108.5/100,000, Tabuk Region at 105.0/100,000, Eastern Region at 104.4/100,000, Makkah Region at 89.3/100,000 and Madinah Region at 73.8/100,000. ⁽³⁾

Worldwide, it is estimated that 12,662,554 people developed cancer in 2008. Of these, 56.1% were in developing countries and 43.9% were in developed countries. According to 2008 estimates, the most common cancer site worldwide among men was lung cancer, followed by prostate then colo-rectal then stomach. However; in developed countries prostate was the leading cancer in men followed by lung, colo-rectal, and bladder, while in developing countries, lung cancer was first followed by stomach, liver, colo-rectal and oesophagus cancers. In women, the most common cancer site was breast followed by colo-rectal then cervix uteri then lung cancers. Among women, breast cancer was the most common followed by colo-rectal, lung and corpus uteri cancers in developed countries. While in the developing countries breast cancer was the leading cancer followed by cancers of the cervix, lung then stomach. ⁽⁴⁾

The Saudi Cancer Registry (SCR) of Saudi Arabia is a population-based registry established in 1992 under the jurisdiction of the Ministry of Health (MOH) by the order of His Excellency the Minister of Health. The SCR commenced reporting cancer cases from 01 January 1994. The primary goal of the SCR is to define the population-based incidence of cancer in Saudi Arabia. Additional objectives include programs for early detection and cancer screening, as well as cancer research projects. ⁽³⁾

A Board of Directors was appointed to include representatives from the MOH, King Faisal Specialist Hospital and Research Center (KFSH&RC), and the Medical Services Departments of the Ministry of Defense and Aviation, Ministry of Interior, the National Guard, King Saud University, King Faisal University, King Abdul-Aziz University and King Khalid University. The Board is charged with the responsibility of overseeing the SCR's establishment,

defining demographic and cancer-related data to be collected, approving research requests, and reporting findings, as well as disseminating information collected while ensuring the confidentiality of all data reported the SCR. The SCR Main Office, including administrative and technical staff, is located in the premises of the KFSH&RC in Riyadh. Additionally, five regional branches and four hospital-based offices were set up to ensure comprehensive data collection from all over the Kingdom.⁽³⁾

As the data of cancer incidence is the backbone of the registry, and because these data in Saudi cancer registry was collecting passively, collecting data regarding cancer incidence in Almadinah in 2008 actively and comparison of these data with cancer registry in the same period will help to evaluate the reporting system of cancer registry, hence further steps will be taken for improving the system.

Saudi cancer registry is the method of collecting the data of cancer incidence in the kingdom, so the completeness of these data is necessary to ensure the completeness of the registry to give the real picture of the burden of the disease on the community.

Almadinah Almunawarah region is considered one of the important sites for cancer registration, where cancer registry was not assessed. By assessment of cancer registry in that region and compare it with other region it will open the door to other analytical study to estimate the risk factors in that region and in making health policies built on these studies to control and prevent the cancer. While the Saudi cancer registry is the solely method of collecting data of cancer incidence, assessing the completeness of these data is very important

to ensure the completeness of the registry and we chose Almadinah almunawarah registry as a sample of Saudi cancer registry.

This study aimed to estimate the incidence of cancer in Almadinah Almunawarah from Jan 1 to 31 dec 2008 (crude and specific) and to compare the data of incidence of cancer in Almadinah Almunawarah with the corresponding data collected and registered in Saudi cancer registry in the same period hence assessing the completeness and reliability of cancer registry in Almadinah Almunawarah

METHODS

This is a descriptive retrospective cohort record reviewing study conducted at Almadinah Almunawarah, Saudi Arabia over a period of four months. Almadinah Almunawarah hospitals including governmental hospitals (king fahd - Maternity and child – Ohud – Alansar - Almeqat), private hospitals (Saudi Germane Almuasah – Almagrebi – Alzahraa – Alrahmah - Almadinah national – Aldar) and Private laboratories (Alborg, zain - Anes alkair)

Date was collected through active surveillance using questionnaire including file number, name of the patient, age, sex and site of cancer. We included the positive cases histologically and/or hematological from all participated hospitals in Almadinah almunawarah city. Permission from MOH has been obtained before study conduction.

SPSS (statistical package for social science) was used for data analysis. Frequency and percentage was applied for data description. Chi-square test was utilized to test for the difference between active and passive surveillance of cancer (SCR).

RESULTS

The present survey collected data from 227 male cancer cases compared to 289 cases reported in Saudi Cancer registry. Table (1) shows that the commonest site was colorectal cancer representing 18.7% of cases compared to 9% reported in SCR, $p < 0.001$. The commonest site reported in SCR was leukaemia (11.1%) compared to 8.4% in the present survey. However, this difference was not statistically significant. NHL represented 9.3% of SCR data compared to only 1.8% of the current survey, $p < 0.001$. There was no statistically significant difference between the current survey results and SCR results in other sites. The results of both surveys were identical only for Hodgkin's lymphoma (3.5%).

Table 1: Comparison between Maddinah cancer survey and Saudi Cancer Registry results among males according to sites

Site	Survey %	SCR	p-value
Leukaemia	8.4	11.1	0.307
NHL	1.8	9.3	<0.001
Colorectal	18.7	9.0	<0.001
Lung	4.8	8.0	0.157
Liver	4.8	6.6	0.251
Prostate	4.5	5.2	0.680
Thyroid	3.5	4.2	0.715
Brain & CNS	3.1	3.8	0.882
Stomach	7.8	3.5	0.026
Skin	2.2	3.5	0.426
HL	3.5	3.5	-----
Other sites	36.9	32.5	0.228
Total	227*	289	

*4 missing cases

Table (2) demonstrates that the present survey collected data from 165 female cancer cases compared to 274 cases reported in Saudi Cancer registry. The commonest site was breast representing 20% of cases compared to 20.4% reported in SCR, $p > 0.05$. NHL represented 8.4% of SCR data compared to only 1.8% of the current survey, $p = 0.005$. There was no statistically significant difference between the current survey results and SCR results in other sites. The results of both surveys were not identical in any site.

Table 2: Comparison between Maddingah cancer survey and Saudi Cancer Registry results among females according to sites

Site	Survey %	SCR %	p-value
Breast	20	20.4	0.913
Colorectal	13.9	9.1	0.117
Thyroid	5.5	8.4	0.251
NHL	1.8	8.4	0.005
Leukaemia	5.4	6.9	0.235
Oesophagus	3.6	4.0	0.536
Corpus uteri	4.8	4.0	0.745
Ovary	1.2	3.6	0.129
Liver	2.4	2.9	0.628
Bone	3.6	2.6	0.549
Hodgkin's disease	2.4	2.6	0.856
Other sites	35.4	27.0	0.071
Total	165*	274	

*8 missing cases

As seen in table (3), the present survey collected data from 401 cancer cases compared to 563 cases reported in Saudi Cancer registry. The commonest site was colo-rectal representing 16.4% of cases compared to 9.1% reported in SCR, $p = 0.001$. NHL represented 8.9% of SCR data compared to only 1.7% of the current survey, $p < 0.001$. There was no statistically significant

difference between the current survey results and SCR results in other sites. The results of both surveys were not identical in any site.

Table 3: Comparison between Maddinah cancer survey and Saudi Cancer Registry results according to sites

Site	Survey %	SCR %	p-value
Breast	8.0	10.6	0.163
Colo-rectal	16.4	9.1	0.001
Leukaemia	6.6	9.1	0.146
NHL	1.7	8.9	<0.001
Thyroid	4.1	6.2	0.128
Liver	3.6	4.8	0.215
Lung	3.4	4.8	0.302
Osoepagus	1.9	3.0	0.324
Hodgkin`s disease	2.9	3.0	0.854
Skin	2.2	2.8	0.657
Brain/CNS	2.7	2.8	0.911
Other sites	46.5	35.2	<0.001
Total	401*	563	

*12 missing cases

DISCUSSION

Despite the importance of local cancer data in developing and evaluating control measures, many existing ones lacked financial or technical resources to collect complete, accurate, and timely data of requisite quality.^(5, 6) The main objective of the present research is to evaluate the accuracy of existing Saudi Cancer registry through comparing results of the present survey in Al-Maddinah, 2008 with those of SCR.

In the present survey, we did not collect information from the military hospital individually since in 2008 it sent all samples to the histopathology department of king Fahd hospitals.

The apparent discrepancy between the results of the current survey and those of the Saudi Cancer Registry could be due to our failure to collect information from some hospitals (private hospitals and laboratories) because of absence of an accurate system for keeping records of 2008 at these hospitals, namely; Saudi Germane, Alrahmah, Almadinah national, Aldar hospitals and Anes alkair laboratory.

Cancer registry data are primarily used to estimate cancer incidence rates.^(7, 8) These estimates are vulnerable to pitfalls regarding numerators, denominators, and methods of estimation. Changes in numbers of cases, misclassification, and missing data can substantially distort numerators and, consequently, rates.⁽⁹⁾ In our survey, a considerable volume of data was either missing or not available.

The computerization of pathology, hospital, and other medical records poses new challenges to cancer registries. Although these changes provide opportunities for enhancing the efficiency—and possibly reducing the costs—of cancer registration, the development of software and acquisition of hardware needed for automating some procedures is expensive, as is the maintenance of computerized systems.⁽¹⁰⁾ In addition, increased concerns over confidentiality may require more complex and costly procedures to protect privacy.⁽¹¹⁾ Furthermore, the current revolution in molecular biology will undoubtedly lead to new ways of classifying tumors, based not on their site of origin and morphology but on their underlying

genetic profiles or etiology, and cancer registries will have to change to accommodate these new classification procedures.⁽¹²⁾ Cancer registrars will have to be trained in new classification schemes, and software that supports registry operations will have to be modified. These changes will require a national effort to standardize the new procedures, train local registry personnel, and defray the costs. Focusing such efforts on selected registries meeting the above-mentioned criteria would be much more efficient, and less costly, than a more diffuse effort in all governorates.

If registries were to collect additional primary data and systematically review outpatient medical records (as was done in this study), the additional cost would be added annually. However, the costs associated with data collection are borne by the reporting facilities.^(13, 14) Unless central registry organizations (e.g., Saudi Cancer Registry) assume a more active role in data collection, the costs of additional data collection would likely be borne by the reporting hospital registries and passed on to the purchasers of health care. Although this amount is a substantial investment, this amount is only about 0.2% of the estimated overall annual costs for cancer of.^(15, 16) This value is well within the range of investment in quality assessment and improvement made by other sectors of the economy, reported to be between 2% and 10% of total sales.^(17, 18) Accurate data on the quality of cancer care are urgently needed. Health care purchasers and policy makers should consider investing in our cancer registry system to obtain these data.

To ensure complete and timely reporting in each governorate in KSA, MOH requires governorate-specific laws authorizing the cancer registry along with 8 categories of regulations

intended to (1) require mandatory reporting of newly diagnosed cancer cases by hospitals and other health care facilities, (2) require reporting of cancer cases by physicians and other practitioners, (3) guarantee access by the regional cancer registry to all medical records of persons with cancer, (4) require use of standardized reporting formats, (5) ensure confidentiality of cancer case data, (6) allow use of confidential data by researchers, (7) authorize studies using cancer registry data, and (8) protect persons complying with the law from liability. The same has been adopted in USA. ⁽¹⁹⁾

Conclusively, we could not assess definitely the accuracy of SCR due to obstacles regarding the availability of accurate data in medical records. The same has been reported previously by Al-Zahrani, 2003 who concluded that cancer registration will require substantial improvements in both completeness of reporting and data quality at the hospital level. Use of multiple data sources and estimation of missed cases will help ensure completeness of case registration. ⁽²⁰⁾

In conclusion, there is an apparent discrepancy between active cancer surveillance and passive surveillance results (SCR) mainly in non-Hodgkin's lymphoma and colo-rectal cancer. Definite and accurate evaluation of SCR couldn't achieved due to obstacles with the quality of medical records. In the light of the current survey, we recommended improving hospital record quality through training of physicians, nurses and medical record technicians in cancer registration, encouraging active cancer surveillance and training of data collectors, collaborative work between different hospitals and the regional cancer registry should be emphasized and

finally more organized research should be done to evaluate Saudi Cancer registry overcome obstacles reported in the current research.

REFERENCES

- 1- Adami HO, Day NE, Trichopoulos NE, Willett WC. Primary and secondary prevention in the reduction of cancer morbidity and mortality. *European Journal of Cancer*. 2001; 37: S118-S127.
- 2- Colditz G, DeJong W, Hunter D, Trichopoulos D, Willett W. Harvard report on cancer prevention. Volume 1: Causes of Human Cancer. *Cancer Causes and Control*. 1996; 7: S3-S58.
- 3-) Saudi Cancer Registry [internet]. Riyadh: Saudi Cancer Registry;2007[cited 2012 march 17] . Available from: <http://www.scr.org.sa/>
- 4- International Agency for Research on Cancer [internet]. France: International Agency for Research on Cancer, 2008 [cited 2012 march 18]. Available from :<http://www.iarc.fr/>
- 5- Pillitterre D. SEER to collect data on underrepresented populations. *J Natl Cancer Inst*. 2000; 92:871.
- 6- Izquierdo JN, Schoenbach VJ. The potential and limitations of data from population-based state cancer registries. *Am J Public Health*. 2000 May; 90(5):695-8.
- 7- David B. Thomas. Alternatives to a National System of Population-Based State Cancer Registries. *Am J Public Health*. 2002 July; 92(7): 1064–1066.
- 8- Ries LAG, Eisner MP, Kosary CL, et al., eds. *SEER Cancer Statistics Review, 1973–1997*. Bethesda, Md: National Cancer Institute; 2000.
- 9- Kwong S, Perkins C, Snipes K, Wright W. Improving American Indian cancer data in the California Cancer Registry by linkage with the Indian Health Service. *J Registry Manage*. 1998; 23:17–20.

- 10- Kahn KL, Malin JL, Adams J, Ganz PA. Developing a reliable, valid, and feasible plan for quality-of-care measurement for cancer: how should we measure? *Med Care*. In press 2002.
- 11- NAACCR (North American Association of Central Cancer Registries). Standards for completeness, quality, analysis, and management of data. Vol 3. North American Association of Central Cancer Registries. Standards for Cancer Registries; September 2000. Available from:
<http://www.naacr.org/Standards/files/Volumellwithprefaceandrefs.pdf>
- 12- Bertram JS. The molecular biology of cancer. *Mol Aspects Med*. 2000 Dec;21(6):167-223.
- 13- Hewitt M, Simone JV, editors. Enhancing data systems to improve the quality of cancer care. National Cancer Policy Board, Institute of Medicine and National Research Council. Washington (DC): National Academy Press; 2000.
- 14- Malin JL, Kahn KL, Adams J, Kwan L, Laourian M, Gan PA. Validity of Cancer Registry Data for Measuring the Quality of Breast Cancer Care. *J Natl Cancer Inst* 2002; 94(11):835-844
- 15- American Cancer Society. Cancer facts and figures 2000. [Accessed 04/23/2002]. Available from: <http://www.cancer.org/downloads/STT/F&F00.pdf>.
- 16- Brown ML. *The national economic burden of cancer: an update*. *J Natl Cancer Inst* 1990;82:1811-4.
- 17- Halevy A, Naveh E. *Measuring and reducing the national cost of non-quality*. *Total Quality Management* 2000;11:1095-2003.
- 18- Giakatis G, Enkawa T, Washitani K. *Hidden quality costs and the distinction between quality cost and quality loss*. *Total Quality Management* 2001;12:179-85.
- 19- Centers for Disease Control and Prevention. State cancer registries: status of authorizing legislation and enabling regulations—United States, October 1993. *MMWR Morb Mortal Wkly Rep*. 1994;43:71-75.
- 20- Al-Zahrani A, Baomer A, Al-Hamdan N, Mohamed G. Completeness and validity of cancer registration in a major public referral hospital in Saudi Arabia. *Ann Saudi Med*. 2003 Jan-Mar;23(1-2):6-9.