Turk J Gastroenterol 2005; 16 (3): 147-149

Can we rely on public data as a source of information for cancer registry in developing countries?

Gelişmekte olan ülkelerde kanser kayıtları için anket çalışması güvenilir midir?

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Background/aims: *Although a "hospital-based cancer registry" is important in improving patient care, a "population-based cancer registry" with emphasis on epidemiology is important in allocating health care resources and prioritizing public health programs. Because of its reliance on retrieved clinical and para-clinical documents, there is some limitation in registering all cancer incidents in this system, especially in developing countries. In this study we examined the possibility of using public data as a complementary source of information for recording cancers in a population-based cancer registry.* ***Methods:*** *Along with the annual census in rural areas, a survey was performed in Golestan province in March 2004 to identify public awareness about cancer incidents in the community. Individuals were questioned about history of cancer in their close relatives during the last two years. Those who reported cancer in their relatives were also asked to name the main organ of involvement. A similar list was retrieved from the cancer registry at the Ministry of Health in Gorgan, and cases with upper GI (esophagus and gastric) cancer diagnosis from 21 March 2002 through 20 March 2004 were selected for this study. Finally, these two lists were compared for examining accuracy of the collected data.* ***Results:*** *We included 137 cases in our study with rural residence and known addresses. Only 35 (25.5%) cases were reported by the relatives and among them only 20 (57.1%) relatives correctly reported the tumor location. Although we found a difference in accurate reporting of cancer incidents by year of diagnosis (more correct cases reported during the second versus the first year), the difference was not statistically significant between the two years.* ***Conclusion:*** *In this study, we examined the possibility of using public awareness about cancer incidents as a complementary source of information for a population-based cancer registry. We found that this approach is not ideal for reducing limitations. Therefore, we recommend a nationwide cancer registry to record all cancer-related information at the time of diagnosis. This strategy will reduce the need for performing retrospective surveys in collecting cancer-related information.*

Key words: Population-based cancer registry, hospital-based cancer registry

Amaç: *Hasta bakımını iyileştirmede, "hastane orjinli kanser kayıtları" önemli olsa da, epidemiyolojik kaygı barındıran "topluma-dayalı kanser kayıtları" sağlık harcamalarının yönlendirilmesi ve halk sağlığı programlarının öncelik sıralarının belirlenmesi açısından önemlidir. Toplanan klinik ve paraklinik dokümanlara bağımlı olunması nedeniyle bu sistem içerisinde tüm kanser vakalarının kayıt altına alınmasında, özellikle gelişmekte olan ülkeler açısından bir yetersizlik söz konusudur. Bu çalışmada, toplumsal kanser kayıtlarında, ek bir bilgi kaynağı olarak halkın kullanıp kaullanılamayacağını araştırmayı amaçladık.* ***Yöntem:*** *Mart 2004'de kırsal kesimde yapılan nüfus sayımı sırasında Golestan eyaletinde, halkın kendi yöresindeki kanser vakaları konusundaki bilinçlilik derecesini değerlendirmek amacı ile bir anket yapıldı. Kişilere son 2 yıl içinde yakın akrabalarında tespit edilen kanser vakaları soruldu. Akrabalarında kanser öyküsü bildirenlere, ayrıca kanserin hangi organa ait olduğu soruldu. Bu ankete ek olarak Gorgan Sağlık Bakanlığı kanser kayıtlarından 21 Mart 2002 ile 20 Mart 2004 arasında bildirilmiş mide ve özofagus kanseri vakalarının listesi çıkarıldı. Sonuçta, anketten elde edilen mide ve özofagus kanseri listesi ile Sağlık Bakanlığı'nın listesi karşılaştırıldı.* ***Bulgular:*** *Kırsal kesimde oturan ve adresleri bilinen 137 kanser vakası çalışmaya alındı. Bu kanser vakalarından sadece 35'i (%25.5) akrabaları tarafından bildirildi ve bunlar arasında da sadece 20'sinde (%57.1), hasta akrabaları kanserin orjin aldığı organı doğru olarak bildi. Tanı yılı ile kanseri doğru olarak bilmek arasında (yakın zamanda tanı konan kanser vakalarının doğru olarak hatırlanması şeklinde) bir ilişki var gibi görünse de bu istatistiki anlamlılığa ulaşmadı.* ***Sonuç:*** *Bu çalışma, halkta belli ölçüde kanser bilinci olduğu varsayımına dayanarak, tutulan resmi kanser kayıtlarının yetersizliklerinin, halka yönelik yapılacak anketlerle bir ölçüde giderilmesine yönelik bir yaklaşımın, ek bir yarar sağlayamayacağını düşündürüyor. O nedenle tüm kanser vakalarının tanı anında kayda geçmesine yönelik ülke çapında bir kanser kayıt sistemi gerekliliği ortaya çıkıyor. Böyle bir strateji, kanserle ilgili retrospektif bilgi toplanması gerekliliğini azaltacaktır.*

Anahtar kelimeler: Toplum temelli kanser kaydı, hastane temelli kanser kaydı

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Manuscript received: 08.03.2005 **Accepted:** 19.04.2005

INTRODUCTION

Cancer registry is one of the main sources for cancer studies (1, 2). In general, there are two types of cancer registries: "population-based cancer registry" and "hospital-based cancer registry". Based on the purpose of establishing cancer registry, each of these methods has a specific design for collecting and capturing cancer-related information. The most common method currently being used in Iran is "pathology-based cancer registry", in which all cancers are recorded based on collected pathology reports from hospitals and pathology centers. The main shortcoming of this method is lack of information about cases with clinical or para-clinical (e.g., X-ray, CT scan, or sonography) diagnosis. Pathologic evaluations are not performed on these patients and treatment centers or physician offices do not report these cases to the cancer registries. A new technique with the capacity to take into account clinically and para-clinically diagnosed cancers in cancer registries is needed to overcome this limitation.

Golestan province set up its first cancer registry eight years ago and it is now planning to establish a population-based cancer registry, which is a comprehensive method and has the required capacity to capture more cancer cases (3). In this method, information regarding possible cancers (clinical or para-clinical documents) in addition to pathology reports from confirmed cases is collected, and, after a thorough evaluation, cases with possible cancer diagnosis are registered at the cancer registry.

Although it has a broader range of investigation in registering cancers, low quality and quantity of retrieved clinical and para-clinical documents may lessen its comprehensiveness in recording all cancer incidents (4, 5). Regarding the importance of capturing all cancers in the cancer registry and lowering the possibility of missing cases with clinical or para-clinical diagnosis (6), such as those who are diagnosed at other provinces, we examined the possibility of using public awareness about cancer in the community as a complementary source of information for cancer registry. It is based on the hypothesis that some cancers are not diagnosed pathologically and the clinical or para-clinical documents may not be retrieved for these cancers by the cancer registry.

In this report, we tried to compare information regarding recorded cancers at the Ministry of Health in Gorgan with public awareness about cancer incidents in the community. If this study shows that there are unreported cancers in rural communities and relatives are aware of them, we might recommend public data as a complementary source of information for a population-based cancer registry. We chose rural residents because they are more oriented about their community and have stronger social cohesion than urban residents.

MATERIALS AND METHODS

During the annual rural census in March 2004, an open questionnaire was attached to the official census forms and all residents were asked to report occurrence of cancer during the last five years in their close relatives. If such a case existed, they were asked to locate the tumor by naming the involved organ. For the purpose of this study, we retrieved esophageal and gastric cancers recorded in the pathology-based cancer registry at the Ministry of Health in Gorgan from 21 March 2002 through 20 March 2004; only rural residents with precise address were included in this study. We then checked this information with the data collected from rural residents. Chi-square test was used for statistical comparison of accuracy of collected data with the year of registration (first year versus second year). P value of 0.05 was accepted to indicate level of significance. The required early measures were taken to keep patient medical information confidential. The Ethical Committee of Golestan University of Medical Sciences (GOUMS) approved the study.

RESULTS

Based on the collected pathology reports, a total of 217 esophageal and gastric cancers were registered in the cancer registry at the Ministry of Health in Gorgan during the two-year study period. After excluding urban residents and cases with unknown address, we investigated 137 cases to compare their information with the data collected from rural residents. Table 1 shows patients' demographic and clinicopathologic factors retrieved from the cancer registry.

A total of 137 esophageal and gastric cancers were registered during the two-year study period at the Ministry of Health, but relatives reported only 35 (25.5%) of these. Among reported cases, only 20 relatives correctly reported tumor location, which was matched with our roster from the Ministry of Health. Other tumor locations (15 cases) that we-

Table 1. Patients' demographic and clinicopathologic factors

Factors		Esophageal cancer (%)	Gastric cancer (%)
Year of diagnosis	2002-2003	37.3	37
	2003-2004	62.7	63
Mean age (SD)		65.69 (12.36)	62.59 (11.31)
Sex	Male	57.3	81.5
	Female	42.7	18.5
Tumor histology	SCC	69.1	0.0
	Adenocarcinoma	10.0	85.2
	Unknown	20.9	14.8

re incorrectly reported by the relatives were breast, lung, large bowel, and blood cancer.

There was no difference in accuracy of reporting (correct or false report) based on sex and age of the deceased person. Although relatives reported diagnosed cases in the first year with a better accuracy than in the second year (53.3% versus 46.7%), this difference was not statistically significant ($p>0.05$).

DISCUSSION

Regarding the importance of cancer registry and the need for improving recorded cancers in the population-based cancer registry, we examined the possibility of using public awareness about cancer among relatives as a complementary source of information for registering cancers. Results from this study revealed that collected information from relatives, even close relatives, is not a reliable source of information for cancer registry. This is more appreciated when we consider the collection of information from several years ago. Although we did not find a significant difference between years of diagnosis, in a larger sample size and longer retrospective study we may better appreciate this fact. This finding is in contrast with previous studies (7), which may highlight the unreliability of collected information in developing countries. This may also raise uncertainties about the accuracy of family history in the clinical setting. Therefore, it may be logical to perform similar studies to explore this possibility.

There is much work to be done regarding cancer registry in Golestan province and it may take several years before it is fully established (8). Since the Golestan province has been selected for a pilot study in cancer registry, it is prudent to set a network at the province level to systematically collect all relevant information from private or public medical centers. Recording confirmed or suspicious cancer cases on pre-designed cancer registry forms at the time of diagnosis and/or clinical evaluation would be a complementary approach for capturing cancer cases. In this way, there would be no need to perform a retrospective study, and the collected information could be shared with other cancer registries at the national level to record cancer-related information.

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