

The incidence of renal cancer in Polish National Cancer Registry: is there any epidemiological data we can rely on?

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Introduction The Polish National Cancer Registry (KRN) is the most commonly used sources of data on the incidence of cancers including renal cancer in Poland. Until today, the accuracy and completeness of these data has never been verified.

Material and methods The aim of this study was to assess the completeness and reliability of data on the incidence of renal cancer published by the KRN. KRN data on newly diagnosed cases of renal cancer in Poland (for the whole country) and separately in subjectively selected provinces between 2009 and 2011 were retrospectively compared to the data received from the National Health Fund (NFZ) on the number of radical and partial nephrectomies performed due to renal cancer in the same time frame and regions.

Results The concordance between the analysed two sources of data was 86%. Calculated ratio of the number of cases in the KRN database to number of cases in the NFZ database in selected provinces were as follows: 109% in Lubuskie, 60% in Mazowieckie, 123% in Podkarpackie and 66% in Podlaskie. No significant differences were observed between analyzed years (89% in 2009, 88% in 2010, 82% in 2011). The number of unreported cases of renal cancer in KRN was lower among male patients comparing to female patients (concordance: 78% vs. 72%).

Conclusions The incidence of renal cancer published by KRN is underestimated, thus KRN does not seem to be a fully reliable source of epidemiological data. Due to the fact that this data is crucial for the planning of the health policy in Poland, improving urooncological reporting should be a priority for the health system managers.

Key Words: cancer registries ◊ renal cancer ◊ data completeness ◊ Polish National Cancer Registry

INTRODUCTION

Renal cell carcinoma (RCC) accounts for almost 90% of all kidney malignances and 2% of all cancers. There were 88,400 new cases of RCC and 39,300 kidney cancer-related deaths estimated in the European Union in 2008 [1]. Its incidence (age-standardized) is the highest in Western countries and is estimated to be 5.8 per 100,000. Simultaneously, the mortality rate is 1.4 per 100,000 [2]. During the last two decades, there has been a moreover 2% annual increase in incidence rate among men and women in all regions and ethnic groups [3, 4].

The data on the incidence of renal cancer in Poland is published yearly by the National Cancer Registry (KRN). All newly diagnosed cases should be reported to the KRN by medical staff (including medical secretaries, physicians), hospital administration and municipal workers. This can be done through the KRN website or the hospital system by transferring data using the Extensible Markup Language statement (XML) or the Electronic Platform of Public Administration Services (PUAP) form. KRN is the only cancer registry in Poland, thus scientists, politicians, physicians, patients and finally public opinion base on its data. Ipso facto, it is essential that the KRN

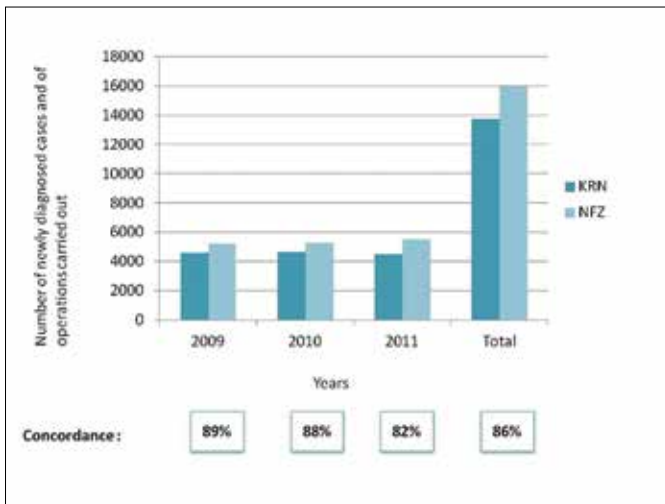


Figure 1. Number of newly diagnosed cases of renal cancer according to KRN and the number of radical and partial nephrectomies carried out according to NFZ information in the whole country.

data should be reliable. Until today, this was neither verified nor questioned and the data was interpreted as fully complete. The aim of this study was to assess the completeness and hence reliability of the data on the incidence of renal cancer published by KRN.

MATERIAL AND METHODS

Data published by the KRN on newly diagnosed cases of renal cancer in the years 2009–2011 were retrospectively compared to the data received from the National Health Fund (NFZ) on the number of radical and partial nephrectomies performed in the same time period. The analysis covered the whole country, as well as four provinces separately – Mazowieckie, Podlaskie, Podkarpackie and Lubuskie. Only surgically treated cases from the NFZ database were included into the analysis (coded as open or laparoscopic renal surgery groups according to system of homogenous groups of patients [JGP]), and all the surgical procedures were performed for the diagnosis of renal cancer (coded as C64, according to ICD–10). Results are presented as the ratio of the number of

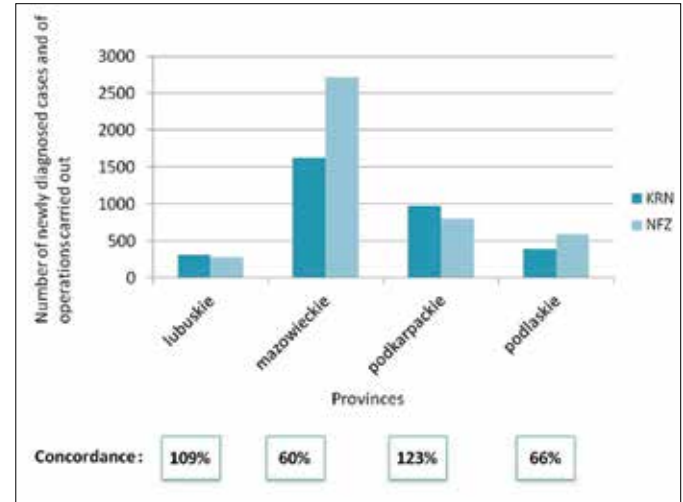


Figure 2. Number of newly diagnosed cases of renal cancer according to KRN and the number of radical and partial nephrectomies carried out according to NFZ information in selected provinces in years 2009–2011.

cases in the KRN database to number of cases in the NFZ database.

RESULTS

Significant differences between the two analysed databases were noticed. They are all presented in Table 1 and Figures 1 and 2.

Significantly higher concordance between KRN and NFZ data was observed among male patients compared to female patients (78% vs. 72%). The concordance among men and women was 82% and 78% in 2009, 79% and 71% in 2010, 66% and 71% in 2011, respectively.

DISCUSSION

Cancer registry is a systemic collection, analysis, storage, reporting and interpretation of data concerning cancer epidemiology. It seeks to collect data on all new cases of cancer occurring in the country. Its role is to describe the extent and nature of the cancer burden in the country and assist in the

Table 1. Absolute numbers of new cases of renal cancer included in KRN and NFZ databases and the concordance between these two data sources

	Whole Country	Lubuskie	Mazowieckie	Podkarpackie	Podlaskie
2009	4599 vs. 5186 (89%)	95 vs. 103 (92%)	557 vs. 820 (68%)	339 vs. 267 (127%)	129 vs. 201 (64%)
2010	4644 vs. 5277 (88%)	120 vs. 84 (143%)	524 vs. 932 (56%)	353 vs. 286 (123%)	135 vs. 200 (68%)
2011	4515 vs. 5484 (82%)	92 vs. 95 (97%)	544 vs. 936 (57%)	285 vs. 242 (118%)	125 vs. 188 (67%)
Total	13758 vs. 15947 (86%)	307 vs. 282 (109%)	1625 vs. 2715 (60%)	977 vs. 795 (123%)	389 vs. 589 (66%)

establishment of public health priorities. Furthermore, it helps in assessing and monitoring the effectiveness of cancer control activities and can be used for etiological studies. It is essential for the Cancer Registry to develop its own internal quality control checks. Data stored by the cancer registry is an important resource for cancer epidemiologists. Cancer incidence rates can be calculated and compared accordingly to many types of variables including sex, age and province, for example. Accumulated data over a long period of time can be used for time-trend studies [5].

We performed a study aimed at the assessment of the accuracy of the data published by the Polish National Cancer Registry (KRN). The study revealed that urooncological reporting in Poland is not perfect and that the KRN is not a fully credible source of data on the incidence of renal cancer. The data obtained from KRN and NFZ on the incidence of renal cancer differ and are not coherent with each other.

When analyzing recently published data, one must remember that not all patients with newly diagnosed renal cancer undergo surgical treatment. Despite advances in diagnostic methods and the incidental diagnosis of many tumors, metastatic lesions are present in 20–30% of all the patients and significantly affect the prognosis [6–9]. There is also a group of patients disqualified from surgical treatment [10], whom are also not included into the analysed NFZ data. This fact suggests that the underestimation of the incidence of the renal cancer published by the KRN may be even greater than described above. However, we also need to consider the possibility that the patient was not diagnosed and treated in the same year. Nevertheless, the number of newly diagnosed cases does not differ significantly between years. We decided to identify patients in the NFZ database by the number of performed procedure instead of disease diagnosis. This should prevent multiple considerations of the same patient in our analysis, as, in contrast to the number of hospital stays, surgery is performed only once. However, we cannot exclude a possibility of mistakes in NFZ coding.

One of the main reasons for discrepancies observed within this study can be that healthcare professionals do not fill the necessary form. Not reporting a new case of cancer to the KRN does not cause any consequences neither for a physician nor for a hospital. The cancer registry provides an efficient and economical method of ascertaining cancer occurrence in interventional trials and cohort studies, as long as patients are properly identified and case matching can be performed. Cancer registry is an essential part of a rational program of cancer control and can be used for etiological studies, health care planning

Table 2. *Cancer Registries Networks*

Association of Nordic Cancer Registries
Groupe des Registres de Langue Latine
International Association of Cancer Registries
Italian Network of Cancer Registries
Gesellschaft der epidemiologischen Krebsregister in Deutschland
National Institute for Cancer Epidemiology and Research – Switzerland
United Kingdom Association of Cancer Registries
European Network of Cancer Registries
Northern America Association of Central Cancer Registers

and patient care. We must also remember about primary and secondary cancer prevention, including cancer prevention programs. Improving the quality of urooncological data reporting may improve cancer prevention and therefore should become a priority for health care system managers.

Every country has its own cancer registry. Furthermore, there are a lot of cancer registry networks connecting individual national cancer registries. Some of the biggest ones are presented in Table 2.

Data they receive is the same or similar to the that received by KRN. There are two methods for measuring data accuracy: reabstracting and test case studies. Reabstracting actual cases is beneficial because it reflects the true quality of data currently in the registry. The advantage of case studies is the relative simplicity and adaptability of the approach [11]. In Germany, the basis for the evaluation of data completeness is the ratio of incidence to mortality (M/I-Index). It is assumed here that diagnosis and survival prospects of cancer patients within Germany do not differ fundamentally and that regionally differing cancer risks can thus be approximated by official cause of death statistics.

Many authors tried to assess the completeness and accuracy of the data in cancer registries [12–15]. Results differ from each other depending on the country and the time when the study was performed. According to Tingulstad et al., the overall completeness of reporting ovarian cancer in Norway to the Cancer Registry was 99.6% during the period of 1987–1996 [12]. Harvey et al. reports that the deficiency in the reporting of prostate cancer was less than 1% in Norway [16]. Bakken et al. suggest that data from the Norwegian Patient Register are comparable to the Cancer Registry of Norway. The degree of correspondence between the registers was lowest with regard to cancer of the gastrointestinal system (C18 colon cancer and C19–21 cancer of the rectosigmoid junction, rectum, or anus) [17]. On the other hand, MacDonald et al. suggest that The National Health Service Central Register (NHSCR) records are incomplete, as 22% of ovarian and fallopian tube cancer cases were

not registered in England and Wales [14]. Computerization makes it possible to increase satisfactory data completeness. A computerized Cancer Registry is able to automatically generate data from the hospital electronic medical records system. This can reduce healthcare costs and increase efficiency [18]. In a study by Paolo Contiero et al., a completeness figure of 98.7% indicates that the automatic procedure is a valid alternative to manual methods for routine case generation [19]. In another study by Kyllonen et al, the Finnish Cancer Registry, which is a computerized registry, achieves more than 99.9% coverage of all eligible cases [20]. Computerization makes it possible to capture all cancer cases in the registry. Our study is not free of limitations. First, we compared statistics from the KRN and NFZ without analyzing any medical data, death certificates or histopathology reports. Such analysis would bring clear

information about clinical significance of observed discrepancies. Second, the analysed time period covers the years 2009–2011, so it concerns the past ipso facto. However, the KRN has not published data for 2012 and 2013 yet.

CONCLUSIONS

Urooncological data reporting in Poland is not perfect and the KRN is not a fully credible source of data on the incidence of renal cancer. As the cancer registry objective and role is to assess the extent of cancer problem in the country, it should become a priority to improve the reliability of KRN data by, for example, enabling KRN and NFZ cooperation with mutual data transfer. Changing this situation should be of major importance for the health system administrators.

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