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General practitioners and completeness of cancer registry

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Abstract

***Study objective*—The aim of the study was to evaluate the role of the general practitioner as a source of information for a cancer registry.**

***Design*—The study involved a random sample of respondents to a letter inviting participation which was sent to all general practitioners in a specific area. Participating doctors were visited to maximise cooperation. Data collection consisted of setting up a retrospective (prevalence) registry of cancer patients diagnosed over a 20 month period, and a prospective (incidence) register over a subsequent 12 month period. The general practitioner cancer file was then linked to the total cancer registry data base to estimate missed cases.**

***Setting*—The study took place in the catchment area of the Comprehensive Cancer Centre Middle-Netherlands (IKMN).**

***Participants*—Of 448 general practitioners in the IKMN region, 152 were willing to participate and of these 52 were randomly selected to take part (11% of all general practitioners in the region).**

***Measurements and main results*—A total of 1637 tumours were identified from the general practitioners, of which 252 (15·4%) were not included in the cancer registry. Of these, only 22 (1·3%) were not included in the registry because they had tumours diagnosed clinically in outpatients and therefore had been omitted from the usual sources of information available to the cancer registry (pathology reports, hospital discharge letters). The missed cases were mostly older patients with digestive tract tumours.**

***Conclusions*—On cost-benefit grounds it was not considered feasible to initiate an active cancer registration system among general practitioners, provided that notification of pathological examinations to the registry is complete. Limited underregistration will occur when death certificates cannot be used as an additional source of information.**

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Completeness of a cancer registry is an extremely important determinant of the usefulness of such a registry. Notification of patients to the registry usually starts with a pathology report. However, not all cancer diagnoses are based on pathological examinations. It is estimated that about 20% of the cases are not histologically verified.[1] In the Dutch health care system it is to be expected that a high percentage of the patients in whom the diagnosis of cancer was made solely on clinical grounds remain under the care of the general practitioner. It has been estimated that 8–15% of the cancer patients in the Netherlands are never referred to specialist care.[2 3] This could cause an unacceptable underregistration in the cancer registry. This paper presents the results of a study among general practitioners in the catchment area of the Comprehensive Cancer Center Middle-Netherlands (IKMN), aimed at obtaining exact data on the amount of underregistration, if the cancer registry were to be based only on pathology reports.

Methods

HEALTH CARE SYSTEM IN THE NETHERLANDS

The general practitioner in the Netherlands acts as a gatekeeper to the health care system. Everybody has a general practitioner to whom he/she has to go first when health complaints occur. A number of diagnostic tests are available to the practitioner, who then decides whether or not he will treat the patient himself or whether he will refer the patient to specialist (eg, secondary) care.

LMR AND PALGA

A national hospital discharge diagnosis register (LMR) has existed in the Netherlands for 25 years. In all patients, the diagnosis (ICD-9) at discharge from the hospital is registered. This register does *not* include those patients seen only in the outpatient department.

"PALGA" is an automated pathology register, which has been in operation for about 10 years and covers about 70% of all pathology laboratories in the Netherlands. Pathology examinations ordered by general practitioners are also included in this register.

IKMN AREA

The IKMN Regional Cancer Registry is located in the central part of the Netherlands. In the catchment area lives a population of about 1·2 million; there are 17 hospitals, one radiotherapy department, four pathology laboratories and 468 general practitioners. During the study period (1987/1988) 16 hospitals participated in the regional cancer registry.

STUDY DESIGN

The study aimed at defining the role of general practitioners as primary sources for the cancer registry. For this purpose all general practitioners in the region of the IKMN (n = 468) were sent a letter inviting them to participate in the study. From the positive responders (n = 152) a random sample of 52 practitioners was chosen to participate. These took care of a population of about 160 000 patients, 13% of the total population in the area. All participating general practitioners were visited, so that the purpose of the study and the study design could be explained in detail. The study consisted of two parts. First a retrospective ("prevalence") registry of all patients diagnosed with cancer from January 1985–September 1987 was set up. The practice administrative assistants searched the files of all the patients for this purpose. Deceased cases were included whenever possible. Secondly a prospective ("incidence") registration was performed from September 1987 until September 1988. In both instances the relevant patients needed only to be identified by the general practitioners, the actual data collection for the registry being done by members of the registry team. Data were collected on age, sex, date of diagnosis, mode of diagnosis of the tumour, localisation and morphology of the tumour and the hospital to which the patient was referred.

The general practitioner file was then linked with the total cancer registry data base, thus enabling us to estimate the number of missed cases, both prevalent as well as incident.

Results

A total of 1637 (prevalent as well as incident) tumours were registered in 1610 patients during the study period. The age and sex distribution of these patients is shown in figure 1.

Of the total number of 1637 tumours, 624 (38%) were not yet included in the cancer registry data base: "possibly missed cases". Further evaluation revealed that 252 patients (15%) should probably have been included in the registry, because these patients had been referred to hospitals which were situated within the catchment area of the registry and were participating in the registry (table I). These patients should have been notified to the registry either by means of PALGA or through the LMR. Patients referred to non-participating hospitals or hospitals outside the region could not possibly be known to the registry data base. At a later stage, when the national cancer registry system functions, these cases will be notified through that system.

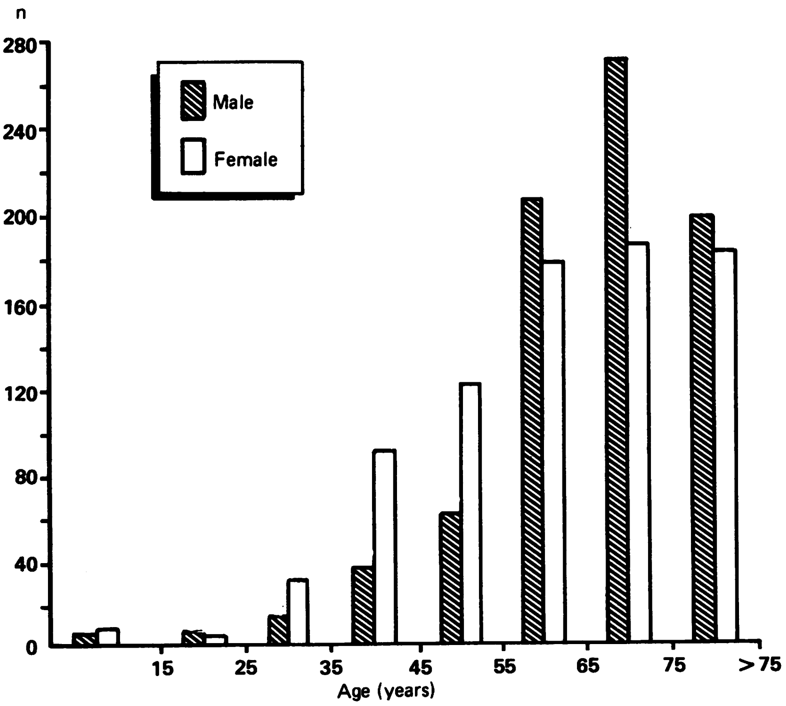

Figure 1 Distribution of all general practitioner cases by sex and age (10 year categories)

Table I Referral of patients

	Known	Unknown	Total
Participating hospitals	941	252	1193
Non-participating hospitals	63	251	314
Outside region	9	121	130
Total	1013	624	1637

Table II shows the tumour localisation of the 252 missed cases by way of diagnosis: in 202 tumours the clinical diagnosis was confirmed by pathological examination. In 50 cases, eg 3% of the total number of general practitioner cases, the diagnosis was exclusively based on clinical judgment.

It is of interest to evaluate the method of diagnosis of all 624 (see table I) unknown, possibly missed cases. Figure 2 shows the distribution of these cases among the various stages of medical care.

As explained above, all patients are first seen by a general practitioner, who then decides whether or not the patient needs to be referred. Of those not referred to secondary care (n = 12), pathological examination for confirmation of the diagnosis was ordered by the general practitioner in three cases. A total of 612 of the 624 unknown cases were referred for secondary care, and in 84% (n = 515) of these cases the clinical diagnosis was confirmed by pathological examination. Only 13 cases (2%) were treated as outpatients only, with no pathological examination to confirm the clinical diagnosis.

From fig 2 it can be seen that 22 cases (the shaded area) could only be registered because of the fact that they were known by the general practitioners. These were the cases not referred and diagnosed by the general practitioner only on clinical grounds (n = 9) and those cases who were referred but not admitted to a hospital or subjected to a biopsy procedure to confirm the clinical diagnosis (n = 13). This means that, given a reliable and complete identification via PALGA and the LMR, an "underregistration" of 1·3% (22/1637) would occur in the cancer registry, if general practitioners do not act as an information source for the registry.

Discussion

This study was organised to evaluate the role of general practitioners in the completeness of a cancer registry. The first question to be answered in that respect is, can the system we choose be regarded as a basis for future cooperation? Although the response rate of 41% on the letter of invitation to participate in the study was not very high, those who did collaborate did so without any problem. Although the "prevalence registration" caused quite a bit of work for the practice assistants, no drop outs from the study occurred. The incidence registration was considered to be no problem. In our opinion the prerequisite for the success of this study with regard to the collaboration of the general practitioners was the fact that most of the workload was indeed carried by the registry (so called "active registration"). It seems to us that possible future collaboration between general practitioners and the registry should be based on that axiom.

The results of our study were both encouraging and discouraging. They were encouraging because we found that a possible underregistration of only 1·3% would occur if general practitioners fail to act as an information source for the registry. It is of interest to know what kind of patients would be missed. Are they generally older? Do they have some type of tumour in particular? One could expect that maybe older patients (for example living in a nursing home) would less often be referred for secondary care by the general practitioners. Indeed 54·5% of the patients seen only by general practitioners were ⩾ 75 years of age, compared to 23·6% in the total study population. The age and sex distribution of the 22 "general practitioner only" cases compared to that of the total number of registered cases is shown in table III. Among the "general practitioner only" cases the tumour was located in the digestive tract in 32% (7/22). There were four lung tumours, two skin cancers, four breast carcinomas, three brain tumours and in two cases the primary tumour was unknown. It thus seems that the underregistration would cause a particular underrepresentation of older patients with digestive tract tumours.

Table II Localisation of tumours missed by the registry

			Mode of diagnosis		
	n	(%)	Histology	Cytology	No pathology
Head and neck	8	(3·2)	8	–	–
Digestive tract	38	(15·1)	22	–	16
Lung	31	(12·3)	1	–	14
Female breast	9	(3·6)	8	–	1
Gynaecological tumours	14	(5·6)	13	–	1
Urological tumours	29	(11·5)	24	–	5
Haematological neoplasms	18	(7·1)	8	9	1
Bone/soft tissue	3	(1·2)	3	–	–
Skin (basal cell carcinoma)	78	(31·0)	78	–	–
Other	24	(9·5)	12	–	12
Total	252		193	9	50

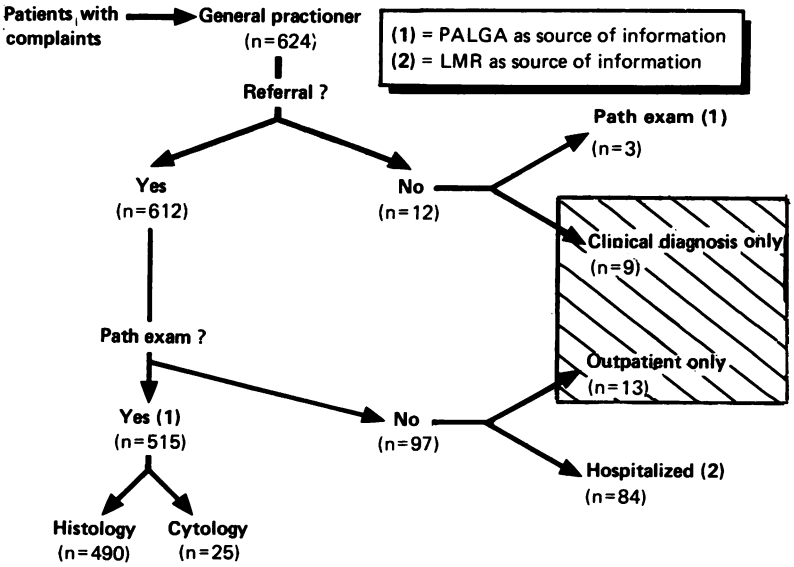

Figure 2 Diagram of the methods of diagnosis in 624 possibly missed cases (for explanation see text)

Table III Age and sex distribution of "general practitioner (GP) only" cases compared to all registered cases

	GP only cases		All cases	
Age (years)	Male	Female	Male	Female
< 15	1	–	7	9
15–24	–	–	7	6
25–34	–	1	15	32
35–44	–	1	38	91
45–54	–	1	63	123
55–64	2	–	208	180
65–74	4	–	274	198
⩾ 75	3	9	201	185
Total	10	12	813	824

Although 100% completeness is the ultimate goal of every cancer registry, a documented completeness of 98·7% can in our view be regarded as excellent. The result of our study differs from other reports concerning this problem. The Peilstation data[2] can be questioned on grounds of both methodology (recall bias by the general practitioners) and diagnostic accuracy.[4] The data of Schadé[5] are probably not generalisable, because this study was concerned only with deceased patients. Our study is, to our knowledge, the first in which general practitioner data have been collected prospectively and then compared with the actual cancer registry data base.

The question then arises as to whether the cost-benefit ratio permits the registry to collaborate with general practitioners in the way we did in this study, or whether another way could be found to ensure registration of the general practitioner only cases. The obvious solution is registration after death by means of death certificates. However, until now the Central Bureau for Statistics—the only institution where causes of death are recorded in the Netherlands—has refused to cooperate with the cancer registry!

The total project took 41·25 working days. Extrapolating to all general practitioners in our area, this means that 1·7 full time equivalents would be necessary for the first year (provided that the prevalence registry was wanted and needed). For an incidence registry only (eg, after the first year) only one full time equivalent would be required for our region with 1·2 million inhabitants. If the same system were to be implemented in all regional registries, this would mean a total of 12 additional full time equivalents, at a cost of Dfl 2·273 per general practitioner registration (compared to a "normal" registration for which Dfl 100 is paid).

The results of this study were discouraging in the sense that it became clear that—at least in the study period—the main source of information for the cancer registry (the pathology laboratories) missed, for some reason or another, 15% of the cases. Part of the problem might be explained by the fact that about one third of the missed cases were basal cell skin carcinomas (table II). We are aware of the fact that in the first years of the registry some pathologists did not include these tumours in their list of malignancies. In our region haematological neoplasms (leukaemia for example) are not diagnosed in pathology laboratories but rather by the haematologists themselves. Apparently the notification to the registry from this source did not function properly. There is however no clear cut reason why, for example, the urological and/or digestive tract tumours should not have been notified to the registry.

In summary our study showed that our registry was indeed incomplete in the first years after the start. Automatic notification to the registry by pathology laboratories (with the help of PALGA) will hopefully solve this problem for the most part. The main result of our study, however, is that the exclusion of general practitioners as a source of information for the registry would result in an underregistration of only 1.3%. It seems that cost-benefit analysis prohibits the use of a system such as the one employed in our study. To ensure registration of "general practitioner only" cases (and for obvious reasons with regard to follow up) it is mandatory that the registry should have access to death certificates.

The study would not have been possible without the help of the 52 general practitioners in the IKMN area. The registry team was very helpful and without their enthusiasm these data could not have been generated. Frits Bosman made sure that all the data in the computer were turned into understandable tables and Irma van Beuningen time and again typed the manuscript.

1 Muir C, Waterhouse J, Mack TM *et al*, eds. *Cancer incidence in five continents*, vol V. Lyon: IACR Scientific Publication No 88, 1987.
2 NIVEL. *Continue morbiditeits registratie*. Peilstations Nederland: Jaarverslag, 1984, 1985.
3 Schadé E, IJzermans CJ. Over de volledigheid van de voorgestelde landelijke kankerregistratie. *Huisarts en Wetenschap* 1985; **28**: 171–3.
4 Berkel J. Huisarts en kankerregistratie. *Huisarts en Wetenschap* 1987; **30**: 394–5.
5 Schadé E. *Overleden patiënten*. Amsterdam: University of Amsterdam, 1986. Thesis.