Prof. Wanqing Chen: the past, present and future of cancer registry in China

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Cancer registry is an information system designed for the collection, storage, management and analysis of data from cancer patient. Cancer registry provides population-based data of cancer incidence, mortality and survival, which are vital for decision making regarding cancer prevention and control. The data generated by cancer registry also enable public health professionals to understand and address the cancer burden more effectively. In this featured interview, Prof. Wanqing Chen described the past, present and future of cancer registry in China. Opportunities and challenges for cancer registry in China were also discussed.

Interviewee: Professor Wanqing Chen, MD, PhD, Deputy Director, National Office for Cancer Prevention and Control & National Central Cancer Registry (NCCR), National Cancer Center, China (*Figure 1*).

Figure 1 Professor Wanqing Chen, MD, PhD, Deputy Director, National Office for Cancer Prevention and Control & National Central Cancer Registry, National Cancer Center, China.

ATM: Prof. Chen, would you please tell us more about the history and status quo of cancer registry in China?

Prof. Chen: The cancer registry in China can be tracked back to the end of 1950s, during which we began to collect data on esophageal cancer in Lin County (or Lin Zhou), a high-risk area for esophageal cancer in Henan province.

In 1960s, epidemiological surveys were also carried out in some other areas with high prevalence of esophageal cancer. In addition, similar work was also conducted in some urban areas, particularly in major cities such as Shanghai. Though China was still an impoverished and backward country during that period, people in the urban areas paid high attention to health due to their relatively good socioeconomic conditions.

However, no nationwide data on cancer had been available up to early 1970s. During the period between 1973 and 1975, the Ministry of Health of China organized the first National Death Survey with an attempt to understand the situation of deaths across China. The survey was conducted in all the provinces in Mainland China except the Tibet Autonomous Region, covering a population of 850 million. Generally speaking, it was a nationwide all-cause mortality survey, focusing on tumors. Thus, the information of tumors across China was roughly obtained. The survey also facilitated the establishment of a preliminary cancer surveillance mechanism. However, cancer surveillance was never a priority. There was no much progress in cancer registry, which was still only carried out in high-risk areas and large cities.

In early 1990s, with an attempt to establish the cancer registry system, a second survey was conducted. It was not a whole-population survey; rather, it was conducted among one tenth of the whole population, covering over 100 million people located in 263 different sampling survey points. As a key project supported by the state, the project group carried out a 5-year survey in 11 survey points in both the rural and urban areas. Based on their findings, the first *Report on cancer Morbidities and Mortalities in Some Cities and Counties across China* was published. The dynamic observations in these 11 points have lasted till today.

The 1990s also marked by the decrease of communicable diseases and the increase of chronic diseases. We began to pay more attention on the chronic diseases, and cancer registry was gradually initiated in some other areas. At that time, no reporting system for tumors (like those already established for communicable diseases) was available, and voluntary registration remained the main practice. Cancer registry was mainly conducted in areas where tumor(s) had become a particular concern. By the end of 1990s, over 30 registration points had been established nationwide. The number of registration points was then increasing, but quite slowly.

After 2000, like its counterparts worldwide, the Ministry of Health of China began to attach greater importance to cancer registry. At that time, only 3% of the people living in China were covered by the registration points, while the global average proportion reached 10%. Therefore, the Chinese government was committed to enhance the cancer registry. In 2002, the Department of Disease Control under the Ministry of Health launched the NCCR, with its office in the National Cancer Prevention and Control Office. In 2004, the International Association of Cancer Registries (IACR), a WHO affiliated organization, expressed its considerable interests in cooperating with NCCR. In the same year, the Annual Meeting of Cancer registry was held with our great effort to make all the registration standards and procedures geared to international standards. The day I came to NCCR in 2005, I began to communicate the importance of cancer registry with the Disease Prevention and Control Bureau, Ministry of Health (DPCB), so as to seek the ways to further improve this work, particularly the financial supports. This is not just a project; rather, it is a daily work that must be regularly maintained. However, after years and even two decades of hard work, the prevalence/incidences of cancers remain unclear. In 2006, launched by Ministry of Health, a third nationwide survey was conducted with an attempt to further identify the disease distributions across the country; and more importantly, to promote the monitoring of diseases on a regular basis. Total 213 counties or cities were selected, including of 160 sampling points and cancer high risk areas. The survey was informative; however, it was cross-sectional, and the overall trends remained vague. In 2008, after years of efforts, the DPCB decided to establish a specific project for this work. As a project authorized by the Ministry of Health, it was financially supported by the Central Government, with the funds directly allocated by the Central Government to the project points. Initially there were 43 points. One year later, the number increased to 95. The coming years witnessed the increase of both funds and project points. Till last years, 249 tumor registration points had been established and 260 million people included. Quite a few new points have been established in each province. Interestingly, some provinces believe cancer registry is a valuable work, and they begin to do it also by themselves. In this sense, more populations have been covered by the cancer registry, not only in these 249 points. It is estimated about 300 million people have been covered. We are delighted to see that the Ministry of Health has paid significant attention to these basic work in the prevention and control of tumors.

ATM: With your introduction, cancer registry sounds to be a very meaningful work. Can you expand on its application in daily practice or its role in oncology?

Prof. Chen: First, cancer registry provides the basic data needed during the establishment of health policies. Tumors are chronic diseases, and their prevention and treatment are extremely challenging. Due to their diverse causes, the clinical outcome of cancer treatment tends to be poor. Thus, cancer registry is particularly important during the prevention and control of chronic diseases. There must be priorities. We need to know which tumors are highly prevalent and which not. Also, the trends of the changes in tumor prevalence/incidences are particularly informative for policy-making.

Second, unlike many other diseases, tumors are diagnosed using common international standards. The definition of onset time, the diagnostic criteria, and the pathology of tumors have been widely recognized. Some other diseases may not have such uniform standards. For instance, a patient with heart disease has suffered from chest pain for many years, and a recent CT showed ischemic lesion; then, when did his disease begin? Also, the diagnosis of a specific tumor (e.g., lung adenocarcinoma, squamous cell carcinoma, etc.) is based on "gold standard" and pathological findings, while no such "gold standard" is available for many other diseases. Second, the proportion of tumors among the chronic diseases is stable. For example, the death cause surveys have shown that tumors were responsible for about 1/5 to 1/4 of all deaths. Surveys in other countries have yielded similarly stable data. A clear understanding of the disease burdens of tumors will help us to estimate the burdens of all the chronic diseases. Thus, these data are not only meaningful for tumors but also for all the chronic diseases.

Third, the primary, secondary, and tertiary prevention measures have been adopted in China, and we need a standard to evaluate the effectiveness of these measures. Cancer registry is especially useful in this regard. For example, if the morbidity or mortality of a tumor decreases in a specific area, the local prevention and control efforts may thus be proven effective. Obviously, such evaluations must be achieved via cancer registry.

Fourth, cancer registry, as a population-based survey, is highly diverse among different areas with different risk levels. Their findings provide valuable information for etiological research. For example, if one tumor has a high prevalence in a specific area. Why? Is it caused by the local diets, geographic location, or soil micronutrient deficiencies? We can carry out further etiological studies based on the results of cancer registry.

ATM: Compared with the cancer registries in the developed countries, what's our strength and weakness?

Prof. Chen: An obvious strength is the huge population in China. China's population is large, accounting for 1/5 of the world's population. Thus, both the IACR and institutes of tumors attach great importance to China and are willing to establish close relationship with China. It may be said that a conclusion without data from China will be less persuasive. The increase in tumor burden in China means a global increase. China is a developing country; thus, a highly functional cancer registration system will provide valuable experiences for the practices in other developing countries. Furthermore, the number of tumor cases is large in China. For example, the number of esophageal cancer cases in one area in China may be even larger than that in a European country. It is sad but nevertheless provides an efficient filed for etiological studies. In these areas, it can be much easier to collect data from a large number of patients. Thus, early in 1970s and 1980s, many foreign research groups began to cooperate with Chinese institutions to carry out clinical trials and intervention tests.

However, the large population can also be a weakness in scientific research. Some European countries only have several or tens of millions people, which enable them to carry out whole-population studies. In China, however, the population of 1.3-billion makes the whole-population studies almost impossible. Also, the socioeconomic developments dramatically differ among different areas and between urban and rural areas. The medical resources may be rich in some areas but are still lacking in most areas. Also, there is still no national law to govern cancer registry. For instance, according to the *Communicable Disease Control Act of the People's Republic of China*, any communicable disease case found in a hospital must be reported. However, no such law has been available for tumors. Currently, tumor cases are voluntarily reported or reported via projects, which will unavoidably lower the data quality. Nevertheless, we have actively promoted the legislation. Last year, we tried to urge the Ministry of Health to issue a *Regulations on Cancer registry*, but unfortunately failed. In recent years the State Council has also expressed their concerns about tumor prevention and control. This morning I received a call from the Department of Disease Control explaining that the department was planning to issue a regulation on cancer registry in the form of "Instruction of Commission Chairperson". But I am not sure if such an instruction can be issued or not. Laws and regulations are urgently needed to optimize cancer registry. This is the same case in tobacco control: without legislation, all the campaigns and initials failed in China. Finally, the distribution of medical resources is dramatically uneven in China. Cancer registry may be acceptable in urban areas; in some poverty-stricken areas, however, quite a few patients give up treatment and thus omissions in reporting are common.

ATM: As data collecting is essential to the whole work, how can we guarantee and improve the data quality during the work?

Prof. Chen: Based on international standards, we have established a strict scheme to ensure the quality of the whole procedures. Of course, the data quality may be poor in some areas. To address this problem, we organize nationwide trainer's training classes annually; also, we request each province to hold local training classes. Some provinces may hold more classes. For example, with 70-80% of its populations covered by the cancer registry, Jiangsu province has its second- and third-level training classes. Also, we will carry out field supervision regularly or irregularly to identify and address problems in each procedure. Finally, we will strictly check all the annual data we received. We have established a set of data verification standards. The quality of all information must be ensured, and any information should not interfere with other data. Erroneous data might as well not have been obtained. Therefore, in our annual report, about one third of the data from the registration points have been deleted. These deleted data are poor in quality, and some of them have omitted or duplicate information. In 2013, about 220 cancer registries reported their data; however, only data from 145 points were used, and those from the remaining 165 points were deleted, so as to ensure the integrity and reliability of our final report. Globally, data for the Cancer Incidence in Five Continents (CI5) were collected every five years. CI5 has strict requirements on data quality, and therefore the inclusion (or not) in CI5 is often used as an indicator of data quality. A few years ago, only data from two or three points in China were included in the CI5 due to the poor data quality in other points. At most eight points had had their data included. For some points, although the overall data quality was still poor, the data on some a specific tumor was reliable (e.g., the data on a specific tumor in its high-risk areas) and thus included in CI5. The NCCR takes CI5 seriously. The newest version of CI5 is known as Volume X, covering data collected from 2003 to 2007, which were reported during the period between 2010 and 2012. We reported data from 26 registration points to the newest CI5, which was similar to that (n=25) for Volume IX. Encouragingly, data from 12 points were included by Volume X, compared to 5 in Volume IX. Obviously, the quality of data from Chinese registration points has remarkably been improved. In future, we will continue to improve the data quality and hopefully more data will be included in Volume XI.

ATM: Comparison of the tumor statistics between China and the United States has shown that the tumor ranking the first among the incidence of malignancies is dramatically different. Could you please explain why there is such a difference?

Prof. Chen: The overall incidence of tumors is much higher in the United States than in China. However, their cancer profiles are drastically different from ours. In the United States, prostate cancer ranks first in males, accounting for 1/5 of all malignancies; in females, the breast cancer ranks first. Although breast cancer also ranks first among Chinese women, its proportion is lower than that in the United States. Nevertheless, both the prostate cancer and breast cancer have good prognoses in the United States: The 5-year survival reached 90% for prostate cancer and 70-80% for breast cancer. In China, however, lung cancer ranks first among all malignancies in males, whereas the proportion of prostate cancer is relatively low. Also, the incidences of gastrointestinal cancers including esophageal cancer, stomach cancer, liver cancer, and colorectal cancer are also high in China, and the prognoses of these diseases are often poor. As a result, cancers in China are featured by relatively low incidences but high mortalities. This may also be explained by race. The difference in cancer profiles between China and western countries may also affect the priorities of clinical practices and scientific research. Without robust data from cancer registry, we might copy the experiences in the United States and mistakenly put our focuses on prostate cancer and breast cancer. Therefore, the data from our own cancer registry are quite informative for the policy-making. In addition, the incidences of lung cancer, breast cancer, and colorectal cancer have surged in China in recent years and thus have become particular concerns. Finally, although the incidences of gastric cancer and esophageal cancer remain high in China, there have shown decreasing trends. Thus, they will be relatively less important. These trends can also guide the policy-making.

ATM: Given the broad prospect of the work, what are your current priorities and where do you see the future direction of the work is leading?

Prof. Chen: One priority is to further expand the coverage of cancer registry in China. Although the coverage is growing, it is far being "nationally representative". Also, the registration points are not evenly distributed: most of them are located in the socioeconomically developed eastern region, and few in the western region. The western region including Tibet, Ningxia, Xinjiang, and Shanxi have fewer registration points, and the quality of data obtained from these points is often unsatisfactory. In the coming years we will establish more registration points to increase the coverage, particularly in the less covered areas.

The second question to be addressed is the "representativeness" of the data. Since whole-population registry is still impossible in China, we need to further improve the "representativeness" of our data, making the data from specific points become more representative for the whole country.

The third priority should be put on data quality. We will further strengthen quality control by training and capacity-building at local levels. One extrusive problem is that the registration is not a highly technical job but it may involve various facets; meanwhile, it is somehow boring and poorly paid. As a result, it is often hard to retain the staff. Further supports from the government are therefore required.

Finally, we need to optimize the data applications.

Data on the shelf are useless. We hope that our data can be further applied in policy-making, etiological research, and clinical practices. By doing so, we can highlight the importance of these data and thus promote cancer registry, forming a virtuous cycle.

A good trend is that the government has increasingly realized the importance of cancer registry. This year, the Department of Disease Control has proposed a budget rising to several hundreds of millions of RMB for chronic diseases, which is expected to be mainly used in the collection of basic data including cancer registry, surveillance of all-cause mortality, and surveys on hypertension. Obviously, the Chinese government has paid more attention to the basic work.

ATM: Thank you very much!

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