

COMMENTARY

Cancer Registration in the Peoples Republic of China

Kuang-Rong Wei^{1&}, Wan-Qing Chen^{2&*}, Si-Wei Zhang², Zhi-Heng Liang¹, Rong-Shou Zheng², Zhi-Xiong Ou¹

Abstract

The current situation of cancer registration in China was systematically reviewed. So far, cancer registration in China has been making a great progress in the following aspects: the number of cancer registries and covered population have increased dramatically; a registration network has been established and completed gradually; regulations and rules improved remarkably; more attention is being paid by every level of government; a lot of registration software has been created and financial support ensured. However, we are still facing some problems and challenges, such as no stable groups of registrars, shortage of training opportunities, poor data quality, insufficient utilization and lack of multidisciplinary mechanisms, so that the cancer registration system still needs to be enhanced and improved. Along with the development of economy, science and information technology, methods and patterns of cancer registration is changing. It is to be expected that cancer registration will be automatic, nationwide and integrated with community healthcare in the near future.

Keywords: China - cancer registration - achievements - future aims

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Introduction

As cancer hazardness and prevention importance are gradually aware of worldwide (Ahmedin et al., 2011), more and more attention are paid to cancer registration (Yang, 2005). But before cancer registration could be done exactly and efficiently, current status, existing problems and issues of cancer registration should be analyzed thoroughly and dealt with properly. Moreover, Chinese cancer registration had never being introduced in review form abroad before. Hence, for Chinese cancer registration could be done better and be well known by foreign countries, it was systematically reviewed according to current available related documents, data, reports, papers, meeting summary and problems met frequently in practical works.

Current status of Chinese cancer registration

As of June 2011, there were 195 cancer registries covering about 190 million people and 13 percent of population in China (Chinese Health Ministry Disease Prevention and Control Bureau et al., 2011). Compared with corresponding figures in 2008, when there were only 95 cancer registries covering 120 million people and 8 percent of population in China (Chinese Health Ministry Disease Prevention and Control Bureau et al., 2009; 2011), the number of cancer registries and covering population in China had increased greatly. And the goals set in 2009, which cancer registration covering population in China

should reach 10 percent (Huangpu, 2010), had been overachieved. Chinese cancer registration was flourishing and full of vitality as a whole right now. Chinese Health Ministry (CHM) and National Center of Cancer Registration (CNCCR) even hoped that there will be 300 cancer registries in China covering 30 percent of Chinese population in the near future. Following characteristics could be seen of Chinese cancer registration now.

More attention being paid by leaders at all levels

As the importance of cancer registration was increasingly aware of by leaders at all levels such as CHM, Chinese National Office of Cancer Prevention and Control (CNOCCP), CNCCR, provincial/municipal/county health departments and Centers for Disease Control and Prevention (CDC) and hospitals, more and more attention were paid to cancer registration. CHM was stipulating next 10-year national cancer control and prevention program and several other cancer control project, among which cancer registration would play a key role, and also building up a long-term collaborative mechanism with the departments of Public Security, statistics, Civil Administration and Social Security now. CNCCR and CNOCCP believed that setting up a national cancer registering system and network, through which Chinese urban and rural cancer incident and mortality status could be reflected, cancer burden nationwide and in different Chinese areas could be represented, data quality about 10 percent of Chinese population could meet national quality requirements, and data quality of

¹Zhongshan Cancer Registry, Zhongshan, China, ²Chinese National Office for Cancer Prevention and Control, Beijing, China
[&]Equal contributors *For correspondence: mrchenwq@yahoo.com

50 Chinese cancer registries could meet international requirements and be received by Cancer Incidence in Five Continents and Globocan, was the main target of Chinese cancer registration in the future (Chen, 2011). Hence, they attached very much importance on stipulating and improving national cancer registration regulations and rules, data quality and application, personnel training and education, performance evaluating and supervising. Conference was held annually to summarize cancer registration works nationwide, to find out and deal with existing problems and issues, and to arrange next year work. Each provincial health department and CDC followed suit, laying down their own cancer registration regulations and rules, setting up and completing their own administrative and professional organizations, enhancing personnel training and education, supervising and assessing their own cancer registration work regularly. As of the end of 2010, there were 95 counties/cities in Jiangsu Province which launched cancer registration and covered 80.32 percent of its population. In 2008, Health Department of Fujian province established a cancer information registration and notifying network, asked all general hospitals over level two and tumor hospitals in the province to notify cancer data, and treated cancer registration as one of their performance indicators. Liaoning and Fujian province even planned to launch cancer registration in their whole province in 3-5 years (Chinese Health Ministry Disease Prevention and Control Bureau et al., 2011).

National registration network being set up gradually

From 2008, CFM began to fund cancer registration. Thereafter, almost every province in China launched cancer registration and set up corresponding administrative (Health Department) and professional (CDC) organizations. A three-levels cancer registration network composed of by municipal CDC, county CDC and hospitals or by cancer institutes, town hospitals and community health stations, and a three-level cancer follow-up and comprehensive-intervening network composed of by municipal CDC, county/regional CDC and community health station or town hospitals, were built up gradually in the areas where cancer registration had begun (Pan et al., 2009). Meanwhile, a national cancer registration and notifying network was basically set up in China, which was lead administratively by CHM and professionally by CNOCP/ CNCCR, guaranteed and promoted Chinese cancer registration (Chinese Health Ministry Disease Prevention and Control Bureau et al., 2011).

Regulations and rules being improved continuously

Since 2002, CNOCP/ CNCCR continuously improved the regulations and rules on cancer data collecting, checking, notification, applications, personnel training and performance-assessing gradually. It was required that cancer data of last year and three years ago (2009 data was reported in 2012) should be annually reported by the ending of January (for data of last year) or by June 15th (for data of three years ago), and every five-years cancer data (2003-2007 data were reported last year)

by June 15th every five-years to CNCCR respectively. Every five-year data were also required to report to IARC/ IACR by CNCCR every five-year. Publishing annual (the latest one was 2011 Chinese Cancer Annual Report) and every five-years (the latest one was 2003-2007 Cancer Incidence and Mortality in China) cancer reports by CNCCR had slowly become the norm and guideline for Chinese cancer registration. What had CNCCR done had become an example of all Chinese cancer registries and was driving the development of Chinese cancer registration.

Personnel training enhanced, and staff ability elevated

Along with cancer registration being paid more attention, organization being built up, regulations and rules being improved, especially performance continuously being supervised and assessed, personnel training and education had become top-priority. Recently, different training courses on cancer registration such as data quality auditing, ICD coding, patient follow-up and registration software were sponsored by CNOCP/ CNCCR in different places such as Zhongqing, Taiyuan, Hefei and Dalian city respectively, all related professional personnel were asked to participate the training courses. Most Chinese provinces, cities and areas where cancer registration had already started also hosted different training courses every year, all related staffs were required to attend the courses and take exams after courses, and the proportion of staff who passed exam should be over 95 percent (Chinese Health Ministry Disease Prevention and Control Bureau et al., 2011). Guangdong provincial Health Ministry/CDC held cancer registration training courses in Guangzhou in 2010 and in Zhuhai in 2011 respectively. Shenzhen, Zhuhai and Zhongshan city of Canton also held training courses. Thus, staff professional abilities were greatly elevated.

Cancer registration software becoming increasingly important

For simplifying and improving cancer registration, many cancer registration softwares were developed by CNCCR and some Chinese cancer registries. Among them, software for dealing cancer and death-causes data developed by Henan province on IBM-PC (XT) in 1985 was the first in China, and was popularized to and applied in 21 Chinese provinces and cities by CHM's Information Statistics Center (Lu, 2007). In 2002, CANREG4 developed by IARC/IACR was translated into Chinese version and used in Chinese cancer registries by CCCR (Zhang, 2002), Shanghai Cancer Registry also developed its own cancer notifying computer management system (Lu, 2002). In the same year, in order to improve cancer registration pattern and completeness and to reduce clinical doctor burden, Dalian Cancer Registry developed its cancer registration system, and thereafter continuously modified and applied it in all Dalian hospitals over level two (Zhao et al., 2008; Zhang, 2009). In September of 2003, Beijing Cancer Registry developed and adopted its cancer monitoring information system (Li et al., 2003; 2005), and in 2009 upgraded it so it could automatically find cancer cases, fill report card, check and analyze

cancer data (Guo et al., 2008; 2010; Wang et al., 2010). In the ending of 2006, Guangzhou Cancer Registry also developed its cancer registration and network-notifying system (Yu et al., 2007; Cao et al., 2009; Pan et al., 2009). At the same year, Yuhuatai district of Nanjing City in Jiangsu province developed its cancer registration and cancer burden assessing system, which could link with community health information network and integrate cancer registration with community healthcare routine works. What had they done not only facilitated cancer registration, but also improved community healthcare service, and was a valuable exploration (Zhou et al., 2009). Otherwise, cancer registries in Jiangsu province and Shenzhen Cancer Registry all had developed their own cancer registration software (Zhou et al., 2010).

But it was not a good way for each cancer registry developed its own registration software, as some problems and issues such as data uneasy to merge, software un-compatible and uneasy to be popularized, wasting resource might exist. Hence, Professor Wang Qin-sheng from Tianjin Cancer Registry introduced a cancer registration software in 2011 Chinese national cancer registration conference in Fuzhou city, which was collaboratively developed by him and CNCCR and named as "Chinese Cancer Registration Data Management and Analytical System", hoped it could unify Chinese cancer registration and analytical software and be popularized nationwide (Chinese Health Ministry Disease Prevention and Control Bureau et al., 2011). Zhongshan Cancer Registry of Canton suggested automatic cancer registration software should be developed so that cancer data collection, collating, checking, coding and analysis could be done automatically by software (Liang et al., 2010; Wei et al., 2009; 2012), and Zhongshan Cancer Registry had realized cancer data automatic collection now (Liang et al., 2012).

Cancer data application being enhanced greatly

The purposes of cancer registration are to collect and analyze cancer data, find out cancer epidemiological traits and provide scientific information for cancer prevention and control.

First report in which cancer data registered by cancer registries was used and titled as Cancer Incidence and Mortality in Chinese Pilot Cities and Counties in 1988-1992, was published by CNOCCP in 2001. Thereafter, four other related monographs titled respectively as Cancer Incidence and Mortality in Chinese Pilot Cities and Counties in 1993-1997, Cancer Incidence and Mortality in Chinese Pilot Cities and Counties in 1998-2002, Chinese Cancer Incidence and Mortality: 2003-2007 and Guideline for Cancer Registration in China were also in succession published by CNOCCP (Yang, 2005; Zhang et al., 2009). CNOCCP printed its first annual cancer report in 2008 (Chinese National Office of Cancer Control and Prevention et al., 2008) and the latest one in 2011, as of now five annual cancer reports had been published by CNOCCP. Survival analysis had also been carried out in some Chinese cancer registries with long history and good data quality, and cancer survival data of Shanghai, Tianjin and Qidong Cancer Registries were accepted by IARC's SurvCan (R. Sankaranarayanan et al., 2011). Meanwhile,

most Chinese cancer registries had also been analyzing their cancer data, writing and publishing related papers, reports and monographs, such as Harbin Cancer Registry published Cancer Incidence and Mortality in NanGan Districts of Harbin City: 1992-2007 in 2010 (Chinese Health Ministry Disease Prevention and Control Bureau, et al., 2011), Shanghai Cancer Registry published Shanghai Cancer Incidence, Mortality and Survival (1973-2000) in 2007 (Gao et al., 2007) and Cancer Nomenclature and Coding Manual in 2009 respectively, Zhongshan Cancer Registry published Cancer Incident Geographic Distribution in Zhongshan in 2000-2004 in June 2012 (Wei et al., 2012). Annual Cancer Reports were also printed by Shanghai, Guangsu (Chen et al., 2009), Guangzhou and Zhongshan Cancer Registry. Zhongshan Cancer Registry compiled its first annual cancer report in 2000, and was the first Chinese registry who printed annual cancer report.

Until now, Chinese Shanghai, Beijing, Tianjin, Qidong, Cixian and Zhongshan Cancer Registry etc had systematically analyzed their cancer data and published many papers.

Cancer registration methods changed quietly and remarkably

Along with the development of economy, technology, informatics, hospital informationization, changing of hospital staff remuneration-allotting system and traditional ideas, increasingly working load, especially along with welling up of registration software, cancer registration methods and patterns were changing quietly and remarkably. Passive registration method was being used less and less, active method was being used more and more, automatic registration pattern emerged gradually. Traditional passive registration methods were substituted by modern passive registration ways, cancer data was directly notified to registry through network by clinical doctors in some registries such as Guangzhou and Shenzhen (Zhou et al., 2010). And traditional active registration methods were replaced by modern active registration methods too, cancer data was found and downloaded directly in initial page of electrical patient record in some registries such as Beijing and Dalian (Zhang et al., 2007; 2009). Zhongshan Cancer Registry had completely adopted active registration method for almost 10 years, and was exploring and using automatic registration method now which was the first Chinese cancer registry to do so (Wei et al., 2009; Liang et al., 2010; Ma, 2010).

Regular financial supports by CFM can be got.

The fund for maintaining cancer registries in China before mainly came from following sources: self-raising, local authority and registry's affiliation. It could be one, two or all sources. From the ending of 2008, for improving Chinese healthcare and disease prevention and control system and enhancing Chinese cancer registration, CFM began to provide regular special funds to each Chinese cancer registries (Zhang et al., 2009; Chen, 2011). And some provincial financial ministries also provided supporting funds to their own registries according to local requirements.

Existing Problems and Issues

Although as of now, Chinese cancer registration had made great progress, there was still a long way to go comparing with excellent-performing cancer registries such as SEER cancer registries in USA (Chen, 2011). In short words, following problems and issues existed and needed to be dealt with urgently about Chinese cancer registration (Meng et al., 2009).

Data quality should be improved

As far as 2010 cancer data quality was concerned, there were only 38 of 48 Chinese cancer registries which should report 2007 cancer data to CNCCR with good data quality, their data quality met the requirements of CNCCR and were included in 2010 Chinese Annual Cancer Report. DCO proportions of most cancer registries were on the low side, MV percentage and M/I ratios of some registries were too low (some even as low as 6.32 percent and 0.07 respectively) or too high, indicating that missing report of new or death cases might existed. O&U (Others and Unknown) percentage of individual registry was even as high as 78%. And consistent errors among age/site/histology, site/histology, diagnosing basis/histology and ICD coding errors also occurred in some registries data (Chinese Health Ministry Disease Prevention and Control Bureau et al., 2011). Moreover, as of 31 January 2011, there were still 10 cancer registries which did not notify data to CNCCR at all and 14 registries which only notified part of their data to CNCCR in 195 Chinese cancer registries which should reported 2010 cancer data to CNCCR, although without any explicit quality requirements by CNCCR.

Close long-term collaborative mechanism among different organization lacking

Although CHM, CNOCCP/CNCCR all had fully realized that cancer registration involved many organizations such as Statistical Bureau, Public Security, Civil Administration and Social Security etc, and a close long-term collaborative mechanism should be set up among them, but until now no such mechanism had been established and it had affected Chinese cancer registration obviously.

Staffs changed job quickly, and it lead to low staff ability and poor data quality

As cancer registration was not attached importance to by some Chinese leaders, troublesome and bored, most staffs had low income and were not full-time staffs, so staffs often changed their jobs quickly, even all registrars changed their jobs in one year in some registries. And the newcomers were not familiar with cancer registration, not trained well and even not trained at all. So cancer registration was badly influenced (Meng et al., 2009). Truth was that staffs who had been working for a long time were experienced, achieved lots and were very good examples for other staffs.

Personnel training should be enhanced.

As Chinese cancer registration developed quickly, and

staffs easily change their jobs, so personnel professional training was very important. But reality was that quite some Chinese registrars did not well understand cancer registration, were not familiar with its methods and working flow. Some registrars even had never been trained, only with the help of Manual for Cancer Registration to do work. Meanwhile, experienced trainers were relatively short of, training methods and ways were not very efficient and need to be improved and enhanced.

Reward and punishing regulations and rules not effective

As of now, there were no effective reward and punishing regulations and rules for Chinese cancer registration. Hard-working and good-performing staffs often felt unfair and discouraging, because they should be praised and awarded according to their performances, but often not. And this badly harmed their enthusiasm and positivity. In some places rewards were even awarded to not-good performers.

Cancer registration was still not paid much attention by some leaders

Some leaders at all levels were not paying much attention to cancer registration. They seldom cared about it, even when asked to resolve problems and issues they often shirked responsibility, evaded doing a duty or just leaved them unsettled. But when prompted by superior leaders, they usually asked registrars to finish impossible tasks in very short time, and this made cancer registrars felt very frustrated (Chen, 2011).

Data not being fully utilized

Among 213 Chinese cancer registries now, only 4 had ever published annual cancer reports, a few had made survival analyses or systematically analyzed their registered data, most registries did not utilized their cancer data fully.

Cancer registries unevenly distributed geographically and could not represent Chinese national cancer burden

In 2009, Chinese cancer registries mainly located in Jiangsu, Liaonin, Zhejiang and Guangdong provinces, there were no cancer registry in Chinese western areas such as Xinjiang, Tibet, Qinhai and Ninxia, only one or two cancer registries existed in each of other provinces. As of July 2011, although almost every province in China had launched cancer registration and cancer registries distributed geographically increasingly evenly, but still not even enough. For example, there were only few areas in many Chinese provinces which had begun cancer registration, but in 2006 in Jiangsu province, 26.97 percent of its population and 24.74 percent of its areas had been covered by cancer registration, which surpassed any other Chinese provinces (Ding et al., 2006), and as of 2011, 80 percent of its population covered by cancer registration (Chinese Health Ministry Disease Prevention and Control Bureau et al., 2011). Moreover, old cancer registries all located in regions with high incidence of certain cancer, such as Linzhou, Cixian Shexian and Yanting cancer registries all located in high esophageal cancer incidence area, and Guangzhou, Sihui and Zhongshan cancer

registries all located in high nasopharyngeal carcinoma incidence areas. And cancers types in these old registries might not be sufficiently diverse and varied greatly from other registries. Thus, Chinese cancer registries now probably could not represent real Chinese cancer burden.

No laws about cancer registration had been enacted

Cancer registration in many countries such as in USA, England, Norway, Australia and Korea was guaranteed by law (Li et al., 2010), but in China it was only carried out voluntarily before and now warranted by the requirements of CHM/provincial health departments. Although cancer registration had been paid much more attention now, compared with foreign countries, policies about cancer registration in China were still not enough, still short of relative laws. And this hindered Chinese cancer registration further development (Chen, 2011).

Outlook

Along with the development of economy, science, technology and hospital informationization, increasingly awareness of cancer hazardness and attention by leaders at all levels, cancer registration will play more and more important role in cancer control and prevention, and will develop toward the following directions:

Cancer registration methods will change gradually and automatic registration ways will be paid attention increasingly

In the past 53 years since China launched cancer registration, its ways and methods in China had being changed gradually. Based on cancer registration software, hospital informationization and public health information platform Chinese cancer registration will become more simple, convenient and humanistic, cancer data collecting, collating, coding and analysis will be automatic (Ma, 2010).

Cancer registration covering population and areas will extend substantially

As the development of economy and hospital informationization, and welling up of cancer registration software, cancer registration had become more and more convenient and simple, therefore, Chinese cancer registries will cover more and more population and areas, some provinces with sound economy and advanced technology will begin cancer registration in their whole provinces firstly.

Cancer registration will closely integrate with community healthcare works

Cancer patients are followed up by the staffs of community health stations, hence, cancer registration should closely integrate with community healthcare work. Cancer registration system developed by Yuhua Tai Districts of Nanjing city in Jinagsu province suggested that integration of cancer registration with community healthcare work not only facilitate cancer registration, but also drive the development of grass roots healthcare (Zhou et al., 2009).

Hospital-based cancer registration will be attaching increasingly important

Hospital based cancer registration data can show how many, what kind of and how effective cancer patients were diagnosed and treated in the registered hospital, so this data is very important for hospital executives and cancer experts. For evaluating the effects of healthcare service and better hospital administering, some general and tumor hospitals with good management and healthcare service and long-term developing strategic vision, will initiatively launch hospital-based cancer registration (Sun et al., 2010; Chen, 2011).

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