RESEARCH PERSPECTIVE

Challenges and Opportunities to Conduct Cancer Care Research in China: Experience from a Pilot Project

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Abstract

Background: Cancer has become the leading cause of death in China. Effective cancer control and population science research programs are desperately needed in China. The China Medical Board (CMB) funding has provided us with an opportunity to build a research team specializing in cancer care utilization and access research and demonstrate the usefulness of the accrued data. The CMB-funded project will describe patterns of cancer screening, incidence, and treatment in Shandong Province in China and enable the researchers to understand possible causes of disparities in cancer control in China.

Findings: Although CMB projects do not provide salary support for affiliated American faculty, they do provide Chinese scholars in the U.S. an excellent opportunity to help improve health care in China. There are many challenges and opportunities in health care service and utilization research in China. For example, public data for cancer care research does not exist. We had to acquire secondary data from several governmental organizations andreconciled regional variations in data management. After acquiring all the data, we could create the most comprehensive cancer access, utilization, and outcomes research database to date in China and possibly expand this research in Shandong and other provinces. Students and analysts need to be trained to ensure the confidentiality of data linked to personal identifiers of patients and providers. At the same time, users need to learn how to manipulate and analyze large scale, messy, secondary data.

Discussion: We hope that the key findings will identify innovative scientific opportunities to improve cancer control and reduce inequities in communities. We intend to prepare manuscripts and reports in Chinese to disseminate findings to communities, policy makers, health care providers, and the scientific community. From the policy perspective, this study is a demonstration project drawing policy makers' attention to the importance of comprehensive cancer prevention and control data collection, both for accurate assessment and informed decision making with a high likelihood to effect desired change.

Keywords: China; Cancer Care; Health Policy; Research Data

Background

Dr. Yao: I am a health services and policy researcher primarily interested in cancer care and based in the U.S. My current research is supported by the National Cancer Institute and the Komen Breast Cancer Foundation and focuses on cancer care in older American patients. I initiated my research in cancer care in China as a PhD student when I was at The Pennsylvania State University but could not find any cancer related public data. During my last semester of PhD training, I saw the call for applications for Health Policy and Systems Sciences Open Competition projects on the China Medical Board (CMB) website. The project required a principle investigator from one of 17 Chinese universities. I was doubtful that any Chinese researchers would be interested in writing a CMB proposal with a PhD candidate from the US and did not know any health policy researchers in these 17 universities. However, **the China Health Policy and Management Society (CHPAMS)** monthly emails listed Shandong University's recruitment information and contact person, Dr. Xiaojie Sun. I contacted Dr. Sun who was very interested in collaborating. We exchanged several emails and had phone discussions, which became the basis for future collaborations.

We wrote and submitted the letter of intent or pre-proposal at the end of March 2013. CMB received 119 pre-proposals and in May we were notified that we were one of 25 teams invited to submit a full proposal in June. In order to make the team stronger, I invited several cancer care researchers and physicians to serve as consultants and Dr. Sun invited administrators at local cancer hospitals to join the research team. Reviewers liked our ideas and research design but were skeptical about the feasibility of the data collection because no published studies have used a similar data collection plan in China. We provided additional data acquisition and analysis information in the revision and were notified in December that they would receive $150K to study "Patterns of Cancer Screening, Incidence, and Treatment and Disparities in China."

Cancer in China

Cancer is the number one killer in China, the most feared and most expensive health condition. Evidence from well-designed studies reveals the heavy population burden; cancer has become the leading cause of death in China (374.1 per 100,000 person-years) [1]. Both cancer incidence and mortality in China are increasing [2]. The most recent data show that 13% of deaths in China were caused by malignant neoplasm and every minute, six people in China are diagnosed with cancer [2]. However, relatively few resources have been dedicated to cancer prevention and control research. In contrast, in the United States, the Division of Cancer Control and Population Sciences was established in 1997 to enhance the US National Cancer Institute's (NCI) ability to alleviate the burden of cancer through research in epidemiology, behavioral sciences, health services, surveillance, and cancer survivorship. Since that time, the division has grown and evolved into the model for cancer control research. Most NCI designated cancer centers in the US have a cancer control and prevention research program that aims to generate basic knowledge about how to monitor and change individual and collective behavior and cancer care practice. This provides a path for knowledge translation into practice and policy rapidly, effectively, and efficiently. This project aims to promote similar pervasive cancer prevention and control research in China, tailored to the needs and context in China.

The project officially started in January 2014. The project has two phases: a pilot phase and a main study. The one-year pilot study aims to examine the completeness and accuracy of population based secondary data. In addition, the pilot study includes the development and testing of a survey questionnaire for patient interviews. This paper reports the challenges and opportunities the study has faced thus far.

Findings

CMB encourages collaboration between Chinese and overseas researchers

CMB is a highly focused independent American foundation targeting its grant and support activities to "carefully selected Asian institutions", especially a small number of Chinese universities. CMB encourages overseas researchers to establish relationships directly with CMB-affiliated Chinese and Asian institutions. They believe that all 11 funded projects in the 2013 cycle have a research team that crosses country boundaries. Since CMB supports very few Chinese institutions, oversea researchers may have a hard time finding a collaborator if he or she wants to initiate a CMB project, especially if he or she has never worked with Chinese researchers before. **The China Health Policy and Management Society (CHPAMS)** can possibly play a role to facilitate communication between China-based scholars and overseas researchers.

CMB grant is relatively small for soft-money faculty

We have to use $150,000 (total cost) to cover the expenses of a three-year research project requiring both primary and secondary data collection. Compared to an NIH grant, we are using an R03 grant amount to do an R01 project. Although Dr. Sun is actually running the project, Dr. Yao has to spend substantial time in designing the study and assisting with research implementation. For those in a soft-money faculty position, CMB grant money will not cover salary and may not be a cost-effective way to get tenured in a medical school in the U.S. However, cancer care policy research is really important and urgent in China and could save lives. We hope that our research will lead to policies directed to reducing cancer care disparities, improving quality of care, and controlling treatment costs. Other funding sources may also support American faculty to study health policy in China, but the amount of funding is not significantly larger than the CMB grant. In order to cover my salary, I have to apply for other grants to study American healthcare issues at the same time.

The review process is smooth and efficient

We received brief comments about our pre-proposal. Those comments were encouraging but not very helpful in developing the full proposal. Three reviewers provided comments on their full proposal. Reviewers' comments were encouraging, but only one reviewer provided detailed comments and suggestions besides the scores on significance, innovation, and feasibility. We basically addressed all the reviewers' concerns by adding more information and references to the revision. It took about 10 months from drafting the pre-proposal to receiving the grant notification. We did not need to deal with the burdensome paperwork that NIH requires. CMB sent the award funding on time so we could allocate funds to kick off the project right away. We feel the whole process was transparent, smooth, and efficient. CMB announced the review results on their Weibo account. Proposal templates were provided when the call was announced, which we found very helpful. Readers can refer to the 2013 October issue of *China Health Review* for more information about the review process. Three grantees have provided their opinions from the perspective of China-based faculty.

The key to success: two committed collaborators

We had not worked jointly when we decided to write the proposal together. We had many virtual meetings through Skype and QQ while writing the proposal. We both committed to designing a rigorous study. Dr. Yao wanted to introduce his cancer care research into China, and Dr. Sun had to evaluate feasibility and discuss the project with many other researchers and administrators in China to find an effective way to implement the research. Although this is a three-year project, we are determined to develop and promote cancer care and policy research in China. We plan to offer our data and data analysis training to other Chinese researchers in the third year. With Dr. Sun's help and guidance, Dr. Yao has learned a lot in the past year about the Chinese health care system and the way to conduct academic research in China. Although most Chinese speaking researchers in the US were born and raised in Mainland China, they may lack basic knowledge about China healthcare since China is changing so fast. Commitment to rigorous health care research has kept our heads up and feet on the ground.

Cancer care is understudied in China

Cancer incidence and mortality rates have been analyzed in China, while the patterns of cancer screening, treatment, and disparities have not been rigorously examined. China National Cancer Center (CNCC) is a bureau (*jú*) level non-government organization affiliated with the National Health and Family Planning Commission (NHFPC). To our knowledge, CNCC, established several years ago, has not done much population based cancer care research through either extramural or intramural programs. Although cancer care physicians in cancer hospitals and general hospitals are motivated to do research and to publish, they are more likely to be involved in basic and clinical science research. Not many health services and policy researchers in China study cancer care, because they need to have substantial clinical knowledge of cancer or collaborate closely with cancer doctors. We are optimistic that we can find physician collaborators in China as long as we can help them publish in highly ranked clinical science or health care journals.

Data acquisition is the most difficult job

There is no public data at all for cancer care and policy research in China. We identified all possible cancer related data sources, which were mostly collected for administrative purposes rather than for research. We then found the data source owner organizations and used the personal connections in Shandong to establish a working relationship with these owner organizations. We are collecting data from five rural counties and one metropolitan area, since there is not a provincial level organization that can provide data from all study regions. We collaborate with three or four organizations in each county or city. In addition, we have found regional variations in data management. Same data may be managed by different organizations in different places. Dr. Sun has to spend enormous amount of time and efforts on trust building for the research collaboration. Obtaining secondary data from government organizations is difficult from any position on the career ladder. It is not easy for a full professor, a center director, or a dean. Dr. Yao has consulted a well-known faculty who returned to China a decade ago from the US. There is no better way than requesting data while conversing around the dining table. It is extremely difficult to acquire data in a province or an area if the researcher does not have any personal connections in healthcare related sectors. If we can demonstrate the value of cancer care research through this project, it may be possible to get political support for data acquisition from the provincial government or the central government in the future. For example, we could create the largest cancer care research database in the world if Shandong provincial government supports us to collect data from the entire Shandong province (100 million population). This vision motivates the whole team to work diligently.

Data safety and analysis are challenging

We will receive data with personal identifiers and information about the providers. Since the data will only be stored and analyzed in China, this study received expedited review in Virginia Commonwealth University and full review in Shandong University. Dr. Yao has trained students to ensure the confidentiality of individuals included in the data. It is also important to consider the privacy of providers, because unless cancer physicians and hospitals' privacy is protected, it could compromise their willingness to cooperate in the future. None of us has ever used cancer related data from so many organizations. Although Dr. Yao has rich experience with similar large data sets in the US, we expect the incoming data will be different in terms of structure, completeness, and regional variations. Dr. Yao has discovered several limitations in the data. For example, the stage of diagnosis is missing for most cancer patients in the cancer registry data. Therefore, we have to find other data sources to supplement the registry data. In addition, we do not have skilled data analysts or research assistants to do statistical programming. Junior faculty members in China are normally not eligible to formally mentor PhD students. Their mentees are master level students who often lack rigorous training in programming, data analyses, and statistics or econometrics. They have limited experience with messy, large secondary data. The bright side is that the data will include patients younger than 65 who are excluded from US studies because of data limitations. Also data owners are making efforts to improve the data quality and completeness.

Publish or perish

Both American and Chinese universities require research faculty to publish in reputable English journals. We think it is relatively hard to publish non-US studies in US-based health policy or clinical journals such as *Medical Care, Health Affairs, Health Services Research, Journal of Clinical Oncology*, and *Cancer*. We may have a better chance of publishing the results from this study in UK-based journals such as some BMC journals, which are not popular journals for American health policy researchers. Similarly, we expect that our research will only have a slim chance of being accepted as oral presentations at premier health policy research conferences such as AcademyHealth Annual Research Meeting and clinical conferences such as American Society of Clinical Oncology Annual Meeting. Sometimes publishing in English journals is not directly aligned with the non-academic goals of a research projects in China. We want to identify innovative scientific opportunities to improve cancer control and reduce inequities in communities experiencing an excess burden of cancer. We want to disseminate findings to communities, policy makers, and health care providers and to the scientific community. The key findings of this project will be submitted to the NHFPC through some of Dr. Yao's ex-colleagues. In order to accomplish these goals, we want to write Chinese articles and reports. Dr. Yao is not confident that Chinese publications will help his career development but believes that it is the right thing to do.

Example results from the pilot survey data

We collected both primary and secondary data in this project. We also conducted a survey on the lasting effects of treatment on employment, finances, health insurance coverage, and life in general. The pilot survey in Feicheng county of Shandong revealed that most breast patients were diagnosed when cancer symptoms were present, while most breast cancer patients in the US were diagnosed through screening. [3] We have also asked cancer survivors if the cancer experience had any positive impact on their life (Table 1). It seems that US survivors responded more positively to the cancer experience than survivors in Feicheng, China [4]. Chinese cancer patients may be sicker than US survivors after diagnosis and treatment.

Table 1. Positive Response to Cancer Experience

Have any of the following been positive things about your experiences with your cancer, its treatment, or the lasting effects of that treatment?	Feicheng, China (N=148)	US (MEPS data, N＝1,419)
It has made me a stronger person	35.1%	58.8%
I can cope better with life's challenges	44.6%	59.4%
It became a reason to make positive changes in my life	23.0%	57.2%
It has made me have healthier habits	54.1%	61.7%

Conclusions

Cancer has become the leading cause of death in China. The patterns of cancer screening, treatment, and disparities have not been rigorously examined. In addition, cancer care costs remain unexamined with relatively rigorous methods in China. We believe that effective cancer control and population science research programs are desperately needed in China, which motivated us to collaborate on promoting cancer care and policy research. CMB provides a good opportunity to build up a research team specializing in cancer care research. Although CMB projects do not provide salary support for American faculty, they provide Chinese scholars in the US an excellent opportunity to help improve health care in China. From the economic perspective, health care research in China may have a greater impact on people's wellbeing than in the United States if the effect of research on health has reached the point of diminishing returns in the US.

This project will clarify the pattern of cancer screening, incidence, and treatment in China and facilitate our understanding of possible causes of disparities in cancer control. We will identify new and innovative scientific opportunities to improve cancer control and reduce inequities in communities experiencing an excess burden of cancer. Disseminating the data and methods of data analysis in the Chinese community will invite others to do the same. From the policy perspective, this study is a demonstration project drawing policy makers' attention to the power and utility of data collection on cancer prevention and control. We hope interests from the academia and the government will lead China to increase cancer control and population science research. There are many challenges and opportunities in this type of research project. First, China lacks of public data for cancer care related research. We had to acquire several different types of secondary data from multiple governmental organizations. We also found regional variations in data management. Once we acquire all the data, we could create the most extensive cancer care research database in China to date and possibly expand this research in Shandong and other provinces. Since we receive a lot of data with personal identifiers of patients and providers, they trained students and analysts to ensure data confidentiality. We have also discovered limitations of the data. We have to train students and analysts to use large scale, messy secondary data. It is relatively hard to publish non-US studies in US-based health policy or clinical journals. Despite of all these challenges, we hope that the key findings will identify innovative scientific opportunities to improve cancer control and reduce inequities in communities. We also intend to write Chinese articles and reports to disseminate findings to communities, policy makers, and health care providers and to the scientific community.

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