

Increasing access to breast cancer prevention services among rural populations in Brazil



Zoë Greenwald
2015 McBurney Fellow
McGill Institute for Health and
Social Policy

Project Overview

Student name: Zoë Greenwald

Department: Epidemiology, Biostatistics and Occupational Health
 Organization: Barretos Cancer Hospital – Institute of Teaching and Research

Location: Barretos, Brazil

Mentor: Dr. Eduardo Franco

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About the McBurney Fellowship Program

Through McGill's Institute for Health and Social Policy, the McBurney Fellowship Program supports students in international service programs related to health and social policy in Latin America. McBurney Fellows serve abroad in organizations working to meet the basic needs of local populations. One key aspect of this fellowship is its mandate to make a significant contribution to improving the health and social conditions of poor and marginalized populations through the delivery of concrete and measurable interventions. Students and their mentors identify issues, make connections with local organizations, and develop a strategy for the fellowship. The views expressed in this document are the opinions of the fellow, and do not necessarily reflect the opinions of the IHSP.

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INCREASING ACCESS TO BREAST CANCER PREVENTION SERVICES AMONG RURAL POPULATIONS IN BRAZIL

Fellowship Rationale

My project was the first collaboration between the McGill University Division of Cancer Epidemiology and the Barretos Cancer Hospital, in São Paulo state, Brazil. The Barretos Cancer Hospital of Brazil has implemented mobile units (MUs) to proactively reach vulnerable populations and provide essential screening and health promotion services. The MU cancer screening program is designed to screen for four types of cancer: breast cancer, cervical cancer, prostate cancer and skin cancer. My Fellowship focused on evaluating the impact of the mobile unit breast cancer screening program.

The BCH mobile unit uses mammography to screen for breast cancer among 40,000 women per year in São Paulo state. The mobile unit screening program began in 2002, and has been increasing in size each year. The staff of the BCH - Cancer Prevention & Research Institute conducted research projects to evaluate the performance and impact of the breast cancer screening program during its early years. This work provided evidence on which to ground the expansion of the program. In 2011, the hospital opened a new cancer prevention center in a city called Fernandópolis, approximately 200 km away from Barretos. With this new cancer prevention center, their program nearly doubled in size. Women referred from the mobile units for follow-up of abnormal mammograms reported to the closest cancer prevention center – either the original center in Barretos, or the new site in Fernandópolis.

The staff of the cancer prevention and research institute of the Barretos Cancer Hospital have largely shifted away from breast cancer screening research projects in order to focus on maintaining their high-volume program while training mammography technicians, community health care workers and other support staff. No research projects have been conducted using data from the mobile unit mammography program from beyond 2010.

With the rationale of measuring the performance of the program during a period of transition and growth, my Fellowship involved working with members of the cancer prevention and research institute to investigate outcomes of the breast cancer screening program in recent

years, from 2011–2015. My key objectives were to provide evidence of the impact of the program and to report on performance measures, such as number of women screened and number of cases of breast cancer detected. By including data from four mobile units operating in all areas of São Paulo state, I aimed to evaluate whether the program was operating consistently in all regions, including the Fernandópolis area, where the program was more recently implemented. We hoped to improve the program by identifying areas of strength and weakness and generating information that would permit policy makers to make evidence-based decisions when considering expanding access to mammography screening to other regions in Brazil.



Objectives

My project sought to provide evidence of the impact of the Barretos Cancer Hospital breast cancer screening program, by using existing data from medical health records for the period of 2011-2015.

The first research objective was to estimate the coverage of the breast cancer screening program among 108 cities of three Regional Health Departments in the state of São Paulo. The second research objective was to describe the performance of the mobile unit breast cancer screening program by quantifying the total number of exams, recall rate (proportion of exams with results requiring follow-up visits), number of biopsies, biopsy positive predictive value and detected cases of cancer; measuring the effectiveness and efficiency of the referral system and

factors associated with delays in follow-up of abnormal results; and investigating the short-term health outcomes and occurrence of a stage-shift in breast cancer diagnosis.

Background/Context

Barretos Cancer Hospital is one of the largest non-governmental organizations devoted to cancer care and prevention in the world. It has revolutionized the availability of cancer prevention and treatment services in Brazil by establishing the Barretos Cancer Hospital network. Dr. Paulo Prata founded the Barretos Cancer Hospital in 1967 with the core philosophy of attending to the poor population and focusing on caring and compassion for patients, family and caregivers. The patients seen at the Barretos Cancer Hospital come from across the country and access cancer prevention services and treatment free of charge. The Brazilian Public Health System (Sistema Unico de Saúde – SUS) also provides care for patients free of charge, but services through the public system are limited – covering only basic services – and waiting times can be very long. The other alternative patients have to receive treatments more immediately is to pay out-of-pocket for private health care. The Barretos Cancer Hospital provides an opportunity for patients to receive the best treatment options, free of charge and with minimal delays.

In Brazil, breast cancer is the most common cancer among women with approximately 67,316 new cases of breast cancer and 16,412 deaths due to breast cancer occurring in 2012 (IARC Globocan, 2012). Mammography screening works by detecting breast cancer at earlier disease stages, when a cure is more likely and has been shown to reduce mortality due to breast cancer by 20% (Goetzche, 2010). However, access to mammography is limited or non-existent in many parts of Brazil.

Through conversations with the Director of the Barretos Cancer Hospital, I gathered the following background information on what motivated the creation of the cancer prevention program: in the early 2000s, the need to increase access to mammography services to women in rural regions was noticed by clinicians at the Barretos Cancer Hospital. The inequality in access to breast cancer prevention services was evident because women residing in rural areas were being referred to the hospital with very late stage cases of breast cancer, once symptoms had begun, and the cancer had spread to many parts of their bodies. In these cases, the chances of survival were slim. In contrast, women in urban areas who had access to mammography services were more likely to have a breast cancer detected at an earlier stage, before symptoms arose, at which point clinical action could be taken effectively and women stood the chance of surviving and going on to lead long and healthy lives. To combat inequalities in access to breast cancer prevention services, the Barretos Cancer Hospital implemented a mobile unit mammography program that serves women ages 40-69 years in 108 municipalities in the northern, mostly rural regions of São Paulo state.

Activities

During the course of my four-month Fellowship, my activities were centered around extracting data from the medical health records and analyzing that data to present results of the operations of the program. The initial phase of my work was to meet with all project stakeholders and communicate my project aims. This included meeting with the Director of the Institute for Teaching and Research (who was my key supervisor on site), the executive director of the cancer prevention department, the clinicians responsible for the breast cancer screening program and the Information Technology (IT) managers responsible for the electronic medical health records. Towards the end of my first month of the Fellowship, my supervisor from McGill, Dr. Eduardo Franco, came to Barretos for a series of meetings, at which our project aims were solidified. The final step in launching the project was to write my research protocol in Portuguese and have it approved by the ethical committee of the hospital. Once my protocol was approved, all systems were a go and I was ready to get my hands on the data and begin the program evaluation.

However, extracting the data from the electronic medical records system, SIS-ONCO (an abbreviation of “sistema oncologia”, or in English, “cancer system”) proved to be more complicated than anticipated. The mobile unit screening program was of a larger scale than I, or my collaborators, had realized. From 2011–2015, over 120,000 women were screened on the mobile units and these women collectively completed about 260,000 examinations. The IT specialists at the hospital were not familiar with extracting this volume of data from the system and I spent about two months of my Fellowship working with different versions of datasets until we arrived at a final dataset. The majority of my time was spent in my office at the hospital managing large datasets and organizing data from the four mobile units into a single unified database that contained information on all women screened by the program. Throughout my Fellowship, I had regular meetings with collaborators in order to clarify various aspects of the program and to trouble-shoot issues I was having with data management.

During the final month of my Fellowship, I had the opportunity to travel with the mobile unit. I joined the clinical team of the mobile unit for a day trip to a neighbouring town called Guaraci. The population of Guaraci is 9976 and it is home to 1472 women aged 40-69 who are eligible for mammography screening on the mobile unit (Brazilian Census 2010). Through informal in-depth interviews with the community health workers in Guaraci, I gained a nuanced understanding of how women are recruited to the program. During a period of observation of the mobile unit staff, I was also impressed by how efficiently the program runs in practice. A single radiology technician can complete a patient’s mammogram in five to six minutes (this includes two x-ray images of each breast). Ten patients are screened per hour and 60 patients are screened over the course of one radiology technician’s six-hour shift. A second radiology technician reports to Guaraci to cover the afternoon/evening shift. On average, 120 women are screened per day on the mobile unit. The experience of observing the operations of the mobile unit in action helped me put my work into context and also realize the key role the screening program plays in increasing awareness of breast health among the populations served.

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During the last week of my Fellowship, I had the opportunity to present my project to a group of collaborators and staff of the prevention and research institute of the hospital. I prepared a PowerPoint presentation in Portuguese and presented my objectives, methods and the preliminary results of my work to a group of 20 individuals in a small amphitheatre of the hospital. It was very valuable to share the findings and to get feedback from my peers.

Challenges and Successes

The four months I spent at the Barretos Cancer Hospital allowed me to design the research project in order to best serve the needs of the host institution. Before arriving in Barretos, my research project aimed to investigate cancer prevention programs for four types of cancer: breast, cervical, prostate and skin cancer. After arriving in Barretos, I discovered that the breast cancer prevention program had the greatest need for a research project to investigate program performance and provide evidence to document the impact the program was having on the local population. The program was operating on a very large scale, averaging 40,000 screening mammograms per year during the 2011–2015 period, without recent epidemiologic evidence to document the performance standards. Furthermore, due to the volume of women screened, the breast cancer program provided the richest data source for a collaborative research project in cancer prevention. The current outcome of the Fellowship is the development of a database containing information on mammography, ultrasound, biopsy and pathology exams in a study population of 122,640 women who participated in the mobile unit program from 2011-2015. Preliminary analyses have generated valuable findings which were disseminated during presentations to the Barretos Cancer Hospital Research team on November 27th, 2015, and to the McGill University Division of Cancer Epidemiology on December 8th, 2015. A summary of preliminary outcomes is as follows: median program coverage rates (2011-2014) are 35% among women ages 40-49 and 55% among women 50-69. Key performance measures include 122,640 women accessing mammography screening on the mobile unit among whom 656 cases of breast cancer were diagnosed. The average recall rate (proportion of screening mammograms with abnormal results requiring follow-up visits) was 11.2% during the first screening round, 6.3% during the second screening round and 4.6% during the third screening round. Biopsies were performed on 2,455 women, and the positive predictive value of a biopsy exam was 18.3% among women ages 40-49, 29.6% among women ages 50-59 and 42.9% among women ages 60-69. In the coming months, this database will be analyzed to respond to the specified objectives in depth.



Questions Raised

My Fellowship raised many questions regarding the way clinical information is managed and stored at the hospital. Extracting the data was much harder than any of my collaborators had imagined. All of the data I used was routinely-collected data and should have been easily accessible for the clinicians to probe and draw conclusions regarding program operations. However, the way the data is stored in the system is not user-friendly or conducive to research. In order to increase research capacity at the institution, the management would need to unify the two separate systems that are currently in use and make some major changes to the ways that patient files are organized. Though this was an issue that many of my colleagues suggested I raise with the hospital management, it was not one which could be resolved without significant time and thought on the part of all hospital workers. What worked well during my Fellowship was having regular meetings with collaborators and circulating meeting agendas and post-meeting minutes in order to keep everyone on the same page. I was originally motivated to organize meetings in this way so that they could be productive for myself and colleagues. In retrospect, I've realized that the big advantage of taking meeting minutes was to archive our conversations and have the meeting minutes as documents to reflect upon during subsequent work. My time in Barretos was a whirlwind during which I met many people and had many work-related conversations, including during formal meetings and informal chats over "cafezinhos" (coffees) or lunch. I found that keeping written records of these conversations really helped orient my research, link together ideas and hold everyone accountable to completing tasks on time.

What did you learn?

This research project greatly contributed to my academic and professional development. The project is the subject of my thesis for a Master's of Epidemiology program and therefore a core component in my epidemiologic training. Through this applied learning experience I practiced data management skills and learned new techniques to describe and analyze large quantities of data. I also gained experience in implementation research. The goal of implementation research is to reduce the gap between scientific evidence and current practices. By investigating the operations of the mobile unit breast cancer screening program in Brazil, I better understood the process of how evidence on best practice for mammography screening was synthesized by the team at the Barretos Cancer Hospital and used to inform their breast cancer screening program. From a professional standpoint, I developed skills in effective communication for project planning and management. This included attaining conversational fluency in Portuguese to facilitate collaboration with colleagues who did not speak English. I was able to network at scientific conferences in Brazil and become acquainted with key leaders and stakeholders in Cancer Prevention in Brazil, including the Vice-President of the National Cancer Institute of Brazil (INCA).

Community Implications and Further Work

Measurement is increasingly critical for work in global health. The work I did to assess the effectiveness of the breast cancer prevention program provided essential information that can be used to improve the program. The results of my project provide solid analytics that can be used to advocate for resources and investments that are needed to maintain and improve the program.

In the long-term, I hope that my project will set a precedent for future use of the routinely collected clinical data. It helped demonstrate that by regularly reporting on performance measures such as annual case detection rates in the future, operational characteristics of the program (e.g. how well it works) can become more transparent.

How might your fellowship make a difference for the people you worked with?

The Barretos Cancer Hospital is home to a team of strong clinician-researchers who are



dedicated to providing care to those most in need. The primary responsibility of the hospital's staff is to treat patients, and many clinicians struggle to allocate time to research. My collaborators benefitted from increased knowledge and evidence to support the breast cancer prevention program. The Barretos Cancer Hospital has a very strong research group dedicated to cervical cancer prevention, however research support in the area of breast cancer was limited. This project generated new and compelling evidence on which to base program decisions. For example, we learned more about what causes delays in the referral system: including the patient's age, education level and the distance from her hometown to the fixed hospital site. Knowledge of these barriers will help the program leaders design interventions to address these barriers, such as

increased support from community health workers in the regions where delays are most common. Additionally, my host supervisors will benefit from the research project by co-authorship in publications and an increased awareness of their program within the international scientific community.

Dr. Eduardo Franco, McGill Faculty Mentor, benefitted from this project via an expansion of the global health research agenda at the Division of Cancer Epidemiology. As the director of the Division of Cancer Epidemiology and Chair of the Department of Oncology, Dr. Franco has sustained a multi-disciplinary research program in cancer epidemiology at McGill for over 25 years. This project represents a new avenue of research in breast cancer prevention in low and

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middle-income countries, which is in line with global health research agendas at McGill University. Dr. Franco will benefit by receiving co-authorship on all published works. Furthermore, this project enriched our collaborations with researchers at the Barretos Cancer Hospital and may lead to future research collaborations.

What would the next steps be to translate your findings into policy action (if not already happening)?

I am planning to submit two original research articles reporting on the results from my fieldwork. The first article will describe the screening coverage rates in the northern region of São Paulo state. This may translate into policy action by identifying regions where screening coverage is particularly low and further support from the public health system in Brazil (Sistemat Unico de Saúde, SUS) is needed. The second article will describe the impact of the program and compare the staging of breast cancer cases detected through the screening program to those detected outside of the screening program. This research will show the potential short-term impacts of the mobile unit screening program and will document how the program works in practice. This may translate into policy action by increasing the transferability of this screening method to other parts of Brazil, or similar demographic settings internationally where women in rural areas face geographic and socio-economic barriers to accessing mammography screening services.

I will also make a submission to the International Agency for Research on Cancer to present at their annual conference in June of 2016. The theme of the conference, “Global Cancer: Occurrence, Causes and Avenues to Prevention”, matches our project goals and a presentation at this conference would disseminate results to audiences of policy-makers, clinicians and researchers who may be facing similar issues of inequality in access to cancer prevention services in their home communities.

Program Evaluation

Any advice for future Fellows?

- 1) Install DuoLingo (<https://www.duolingo.com/>) on your phone and computer! I found this was the biggest aid in learning Portuguese and was even more helpful than watching tele-novelas with subtitles, or attending a 10-week Portuguese course at the YMCA for that matter.
- 2) Take your time to really get to know your collaborators and identify who will be your strongest partners during your Fellowship.
- 3) Enjoy your time outside of work. It will help you contextualize the culture, and make the most out of your experience. That being said, don't forget to take lots of pictures!

Any suggestions for how to improve the program?

I really enjoyed the pre-departure training session, so I would definitely recommend including that in future rounds of the Fellowship program. The program really strikes me as a well-designed program that is adaptable to each Fellow's needs and desire. For the time being, I have no constructive criticisms.

Was your project part of a larger/ongoing program? If so, what are the next steps? If not, would you recommend this placement/organization to someone else?

I was the first Fellow to be placed at the Barretos Cancer Hospital. A big strength of this organization is that they are highly specialized and a center of excellence for oncology care in Brazil. With that in mind, a fellow could only be of use in a service-based Fellowship in the future if they have either medical training or a post-graduate education in a specialized field in medical research - such as epidemiology. What worked for me in this internship was the connection via Dr. Franco. If a student is supervised by him in the future, a similar fellowship may be possible.