Chronic Pain After Total Abdominal Hysterectomy in Rwanda: Prevalence and Associated Risk Factors

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Background:

Chronic pain is an ongoing health concern experienced by millions of people worldwide with many patients feeling large ongoing effects of the condition on their ability to participate in activities of daily life (ADL). According to a study conducted in Singapore in 2018, risk factors for post-surgical chronic pain may include the type of anesthesia administered, perioperative pain, the amount of opioid pain medication given and psychological factors such as ongoing anxiety and depression [1]. Another important risk factor is the type of surgical route used for the hysterectomy, which could include: laparoscopic, vaginal or abdominal methods. Many studies have shown that the use of laparoscopic and other minimally invasive methods over abdominal methods leads to a noted decrease in surgical complications and recovery time. As such, minimally invasive procedures have increased in popularity in recent years despite their higher cost and the relative paucity of surgeons trained to use these methods in low-income countries [2]. In western countries such as the United States, it has been found that the prevalence of chronic pain post-hysterectomy ranges between 5-32% with the large range attributed to the varying definitions of pain used in each study [3]. In Rwanda however, there is as of yet no published data regarding chronic pain following total abdominal hysterectomy (TAH), the country's surgical route of choice for the procedure. It is known that Rwanda uses techniques that could make patients more susceptible to chronic pain post-procedure, such as the use of general anesthesia and an abdominal surgical route. Therefore, a study on the prevalence of chronic pain in Rwanda and the risk factors

predisposing patients to experiencing post-surgical pain is an endeavor that has the possibility to reduce morbidity significantly.

Research Question and Rationale:

Our project, developed and directed by Dr. Claudine Uzamukunda, entitled, "Prevalence and Factors Associated with Chronic Pain After Abdominal Hysterectomy" is being conducted at the Centre Hospitalier Universitaire de Kigali (CHUK) and began in the summer months of 2019. Our study aims to identify the number of women who underwent an elective TAH between the months of January 2015 to December 2018 and who subsequently experienced chronic pain symptoms. Moreover, through both a demographic study and personal phone calls with patients, the study aims to identify key risk factors leading to the instances of chronic pain post-procedure. As chronic pain is central to our study, it is important to define its character to produce more specific responses. Therefore, this study defines chronic pain as the persistence of pain three months after surgery. With our goal of increased understanding of chronic pain prevalence and risk factors post elective TAH at CHUK, our study aims to help promote further pain studies in women's health in Rwanda to aid future health care professionals in counseling patients on expected postoperative course and instigating preventative measures.

Methods:

Our research was planned as a retrospective cohort study with a target of 75 to 125 total participants. To be eligible, patients had had to have undergone an elective TAH at one of two major public hospitals in Rwanda between January 2015 and December of 2018. With the help of Dr. Claudine Uzamukunda, the primary investigator for the project, it was determined that data collection and entry would be separated into three main phases. The vast majority of data collection occurred at the Centre Hospitalier Universitaire de Kigali (CHUK), with a minor contribution from the public hospital of Butare (CHUB):

Phase 1 – Identification of Eligible Patient Population:

Upon arrival at CHUK, we were directed to the hospital archives where we requested access to the patient entry logs for the various surgical specialties at CHUK. These logs were kept as written entries in bound notebooks with handwritten details for each patient undergoing surgery at CHUK. Information such as the unique hospital ID number of each patient, the type of surgery, and the indication, urgency, and date of the procedure were included for each entry. Each notebook contained approximately 4 -6 months of data. One of the main challenges for this phase of the project involved tracking down the notebooks in order to ensure that all of the available data over the 2016-2018 period was included. Although the vast majority of the data was found, one notebook, which contained data from early 2016, was not able to be tracked down.

Relevant data from the handwritten entry logs was sorted and transferred to an Excel spreadsheet created by the project team in order to easily classify and refer to data. The data collected from eligible patients included:

(1) **Name and age of the patient**
(2) **Date of surgery**
(3) **Indication for the procedure** (ex. Uterine fibroids, myoma, cervical cancer)
(4) **Unique hospital identification number**

At times the same patient was booked into the operating room for multiple procedures on different days, requiring us to identify and eliminate double-entries in our data collection spreadsheet. Furthermore, it was difficult at times to decipher the handwritten data, especially patient ID numbers – which was critical information for the next phase of

our project. If there was uncertainty about a specific number in a patient's file, potential alternatives to the number in question were listed in our data collection set.

Phase 2 – Consultation of Archives and EpiInfo Data Collection

According to the CHUK operating room records, approximately 300 patients underwent an elective TAH from 2015 to 2018. The number of eligible patients identified exceeded expectations, and it was decided that the sample size of the project should be enlarged given the probability of a high rate of non-response during Phase 3 of the project.

Once the complete list of patient names and identification numbers was compiled, the electronic medical record (EMR) database employed by providers at CHUK was used to identify the archive record number of eligible patients. This number is used by the CHUK archives in order to classify and locate the hard copies of a patient's full medical record. It is distinct from the patient identification numbers. Patient information in the EMR was also used to correct and/or update data errors accumulated during Phase 1 of the project. At times, patient information collected during Phase 1 did not align with that found in the EMR and approximately thirty eligible patients were therefore lost due to inability to follow-up.

A separate data form including only the patient names and archive numbers was created to hand to the professional archivist at CHUK. Using this list, the hard copies of the full medical records of each eligible patient were collected. Once the full medical records were made available, data was gathered and entered into a data collection form created for the project in EpiInfo, a data management and analysis software created by the CDC

specifically for public health workers. Information gathered during this stage of the project included:

(1) **Demographic Data:**

a. Patient's home province and district

b. Patient's listed phone number

(2) **Perioperative History:**

a. Preoperative pain history and pain medications used prior to surgery

b. Type of anesthesia used intraoperatively (General vs. Spinal)

c. Presence of acute pain postoperatively and pain prescriptions received upon discharge.

During this phase of the project, there were again a few discrepancies between the data contained in the medical records of patients and the information collected during Phase 1. For a number of patients, the decision was made intraoperatively to not complete the TAH as planned, often due to the identification of undue risk for the patient (i.e. heavy bleeding, cancer spread beyond the surgical site). Furthermore, a minority of patients had no personal or family/friend phone number listed within their medical records, making it impossible to follow up with them during Phase 3 of the project.

Phase 3 – Patient Follow Up

After extracting data from the medical records of eligible patients in Phase 2, approximately 200 patient EpiInfo files and phone numbers had been collected. The next phase of the project involved using patient phone numbers to follow up directly with them regarding their pain status. Information to be collected and recorded in EpiInfo during this phase of the project involved:

(1) **The presence, intensity, quality, and location** of pain 3 months after the procedure
(2) **The effect of pain** on the patient's ability to work and/or perform daily tasks

The major limitation during this stage of the project involved communication. Only the lead researcher in the project spoke conversational Kinyarwanda, the most widely and often only spoken language throughout Rwanda, especially in rural districts. As such, phone call scheduling was dependent on the availability of the lead researcher, with the rest of the team taking on a supportive role by quickly sifting through data to provide timely information on the phone number, demographics, and pain history of the patients being called. Furthermore, this supportive role included filling EpiInfo patient records with data as it was collected during the phone call.

If a patient did not respond to the initial phone call, this was marked down under their name in the data collection sheet. Patients who did not respond were called once a day over three consecutive days before being listed as "Lost to follow up" according to project protocol. The response rate of patients during Phase 3, which had been predicted to be about 25%, was significantly higher than expected with approximately 50% of patients responding to phone calls by the third attempt. At times the phone numbers listed in the

patient records belonged to a spouse, neighbor, or friend and it often took a significant effort to track down patients in order to collect data directly from them.

Results:

The project at CHUK is still ongoing with plans for Dr. Uzamukunda to follow up with the remaining patients by phone in order to continue collecting data. As of August 2019, quantitative analysis of data is still pending. Our project identified over 130 patients who had undergone an elective TAH at CHUK between January 2015 and December 2018.

Conclusions:

Qualitatively, this project has helped in the achievement of numerous goals. First, by working closely with Dr. Uzamukunda, the project advanced an ongoing effort at CHUK to develop a formal academic research course to help anesthesiology residents meet research and publication requirements set by the University of Rwanda. In 2016, there were nine anesthesiology residency slots filled in Rwanda [4]. In a country of over 12 million, this means that there continues to be a serious shortage of trained anesthesiologists in the country. The development of an academic research program at CHUK will allow graduate anesthesiologists to serve as mentors for future physicians undertaking projects that investigate how to efficiently use the limited health care resources available in Rwanda.

Secondly, our project highlighted the hurdles within the archival and record system at CHUK which make it difficult to track down eligible patients for a study population. The data collected from handwritten OR entry logs during Phase 1 of the project was at times very difficult to obtain, since some books were missing or stored out of order. Although the majority of the log books for 2015 through 2018 were eventually identified and used, there were a few months during this stretch for which data

could not be found. Undertaking the research process with CHUK mentors such as Dr. Uzamukunda helped physicians at the hospital to identify the areas in which logistical challenges were impeding study protocols. The identification and rectification of these hurdles represents a significant achievement in the ongoing development of an academic research department at CHUK.

Personal Statement:

I originally was compelled to apply for the HGMA award due to my passion for women's health and a yearning to experience global public health work firsthand during my time as an undergraduate. As a nursing student, I have participated in many discussions about the complexities of the word "health" and how the well-being of each individual is impacted by a variety of social determinants such as environment, income, race and gender. Through these discussions and my time in clinical, I have become fascinated with the role gender plays in healthcare specifically and I quickly developed the firm belief that women's health is global health. Women are the caretakers of the world. By raising children, the future of society, women become the building blocks of communities. Yet, women are often restricted from learning key information about their bodies and are restricted of the ability to make their own healthcare decisions. However, women need to be allowed the space to make choices about their bodies on their own accord. Knowing this to be true and with a desire to understand women's health in the setting of global public health work, I set out for Rwanda. Over the eight weeks spent there, I experienced both the ups-and-downs of health research and cross-cultural communication, as well as felt the overwhelming amount of strength and kindness of every Rwandan I met.

The first lesson I learned about global health work is to be flexible. Well thought out plans will most definitely be changed; however, the work can always get done. Americans observe a very strict adherence to time management and productivity. We expect efficiency. In Rwanda, on the other hand, time is viewed more loosely. Appointments are made in a general time frame and time spent with others is enjoyed, rather than constantly watching the clock. Although different, one viewpoint is not necessarily better than the other. Thus, Marc and I had a learning curve in the beginning of our stay in Kigali. We had to learn how to shift our thinking to that of Rwandan time and to balance pushing for more work versus letting tasks occur in due process. For example, one of the main sources of our data collection was patient admission files to the women's surgical unit. These files were key holders of

information such as which patients received an abdominal hysterectomy, admitting diagnosis, and patient ID numbers so that we could go to the archives later in our research. Yet, these files were not easy to find and involved coordination between the anesthesiology residents we were working with and other organizational staff. Rather than becoming frustrated by the time it took to get these files, Marc and I learned to focus on the available files and used our extra time to help other research projects in the program. Moreover, we expanded the number of years included in our study to make up for a few months of missing patient files that were never found.

Although just a small example of the realities of global research, time management became a significant learning curve this summer. As much as this caused frustration, I also grew as a collaborator, research partner and cross-cultural community member. Furthermore, I learned that public health research is not always about finding the clear-cut answers and the perfect statistics. Our project on post-operative chronic pain will most likely produce minimal amounts of significant statistical data. However, the wider program that this project takes part in contributes considerable good to CHUK, Kigali and more broadly Rwanda. Twenty years ago, there was only one anesthesiologist for all of Rwanda. Today, through this program and the help of many people, Rwandans and otherwise, the number of anesthesiologists has grown to dozens. This project was both my first experience with research and the first time for Claudine, our head researcher. We learned together and grew together. I hope that the conclusion of this project will empower Claudine to keep cultivating her interest in the effects of chronic pain through further research and practice. UVA's presence in Rwanda each summer allows the residents to perform their clinical work, while continuing their research. With the help of collaborations, such as the one with UVA, the anesthesiology program is able to grow in its abilities and expand in numbers year after year; therefore, increasing anesthesiology care and research for the benefit of physicians and Rwandans alike.

Rwanda is a unique country for many reasons. One of them being the state of women's rights compared to other countries globally. According to the World Economic Forum in 2015, Rwanda is ranked 6th overall in minimizing their gender gap. An amazing accomplishment, especially seeing that the United States is ranked a disheartening 28th [5]. Moreover, the country currently has more women in their parliament than any other, with a staggering 64% of parliament members being women [6]. This large focus on women's rights stems from the country's rebuilding after the genocide. In 1995, after the horrific events took place and the country began the long process of healing, forgiveness and growth, the country's remaining population consisted of about 70% women. Therefore, when President Paul Kigame took office and the new constitution was written, women were included in both the drafting process and mandated to have at least 30% of parliamentary seats [7].

Through statistics alone, Rwanda stands as a shining light for women's rights and gender equality in Africa and abroad. During my time in the country, I experienced these benefits firsthand through the lead researcher of my project, Claudine. A third-year anesthesiology resident, Claudine works full time while also raising her two young sons. Both she and her husband work full time jobs and she commutes an hour every day by bus to get to CHUK. With each conversation and interaction, I was amazed by Claudine's work ethic, energy and positivity through any situation. Although women's opportunities in Rwanda have improved, there are areas for growth. Women have more job opportunities; however, there are still many ideologies supporting men as the superior sex. Furthermore, many citizens live in very rural areas, working on farmland. Women and their families lack access to healthcare providers, clean water and education, while their rural location makes it harder for philanthropic and government groups to aid in change. Nowhere in the world are women truly seen as equal to men. Humankind has created an unequal distribution of power that persists across all nations, and Rwanda is no exception. One of the best endeavors is to shed light on these inequities with aspirations for change. I hope that the chronic pain after abdominal hysterectomy project can fuel the

further investigation into pain and its effect on the daily lives of people of all genders. Women are often the main caregivers of the family and when they are disabled by pain, the whole family is affected. By aiding women, we aid all genders.

It's hard to put into a few words the effect that this summer has had on my personal viewpoints, actions and aspirations. This experience has led me to dream of obtaining a master of public health and a renewed desire to connect health issues experienced in Rwanda, the United States and across the globe. Yet, in all honestly, I now realize how little this project is about myself and the benefits I've personally seen from this award. Programs like the Hannah Graham Memorial Award allow connection. They bring thinkers from across the globe to find commonality whether this be through hobbies, interests, experiences or desires for change. With only twenty-five short years since the genocide, Rwandans have shown me the importance of forgiveness. They demonstrate how to look beyond one's own anger and fear and instead look towards a better tomorrow filled with peace. Rwandans are a shining example of humility to the world. I will be always grateful to everyone with UVA's Center for Global Health and most importantly Mr. and Mrs. Graham for this experience. I only hope that one day I can pay it forward.

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