# ATHABASCA UNIVERSITY

# GRADUATE STUDENTS' EXPERIENCE WITH RESEARCH ETHICS

BY

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# A THESIS SUBMITTED TO THE FACULTY OF GRADUATE STUDIES IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF HEALTH STUDIES

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## **Approval Page**



The future of learning.

#### Approval of Thesis

The undersigned certify that they have read the thesis entitled

"Graduate Students' Experience with Research Ethics"

Submitted by

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In partial fulfillment of the requirements for the degree of

#### **Master of Health Studies**

The thesis examination committee certifies that the thesis and the oral examination is approved

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"It always seems impossible until it's done" ~ Nelson Mandela

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#### Abstract

What graduate students learn about research ethics forms their perceptions and impacts how they apply ethics principles in practice. Research Ethics Boards review and grant ethical approval for student research projects, and may provide additional support to these novice researchers. Existing literature explains how curriculum content, teaching approaches, the learning environment, and research relationships influence students' learning. However, a gap exists with regards to fully understanding students' experience with research ethics. Qualitative descriptive inquiry was used to investigate the experience of eleven masters and doctoral students in health disciplines. Semi-structured interviews provided rich description of four themes focused on curriculum, supervisor support, the ethics application process, and the students' overall experience. Suggestions are made for enhancing curriculum, deepening students' relationships with supervisors, and the role Research Ethics Boards could play in their learning. The study contributes to comprehension of research ethics by describing what graduate students' value as novice researchers.

*Keywords:* graduate students, research ethics principles, Research Ethics Board, qualitative description, constructivism

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### **Chapter I – Introduction**

Graduate students in health disciplines conducting research involving human participants must learn and apply principles of research ethics throughout their research projects. The ethics review process is an important element of students' learning, and prepares them for a research career as ethically responsible leaders and scholars (DePauw, 2009; Michael Smith Foundation for Health Research, 2007). Students first experience the research ethics process when they submit an ethics review application and receive approval to begin their investigation. As novice researchers, they are likely to need additional support as they encounter the challenges of incorporating research ethics principles into their research projects. The research ethics in order to determine what supplementary support would be helpful and who should provide it.

#### Significance of the Research

In Canada, the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, also known as the TCPS 2, expects Research Ethics Boards (REBs) to provide support as well as approval for student research projects (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2014). REBs need to understand what knowledge students' gain through curriculum and what support they receive from academic supervisors, in order to identify what additional education and support the REB might offer.

The final and seminal report on *The Health of Canadians – The Federal Role* included ten recommendations for ethics in health research, one of which focused on

effective education and training for all those involved in research (Kirby & LeBreton, 2002). To enact these recommendations, the three federal government agencies that fund research in Canada jointly endorsed the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (2014). The TCPS 2 outlines three core principles for research ethics: respect for persons, concern for welfare, and justice (Canadian Institutes of Health Research et al., 2014, pp. 6-9). These core principles are reflected in research through: autonomy, free and informed consent, privacy and confidentiality, information security, minimizing harm and maximizing benefit, inclusiveness and fair recruitment, and respect for vulnerable populations. Thus, these values are referred to as research ethics principles.

The Panel on Research Ethics provides a *Course on Research Ethics* (CORE) online tutorial focused on these principles and it is freely available to anyone, though primarily used by people conducting research with humans (Panel on Research Ethics, 2014). Many academic institutions in Canada mandate completion of this tutorial before students are approved to conduct research with human participants. Beyond this tutorial, other strategies are required to provide the support essential for graduate students as they apply principles of ethics in their research projects.

### **Purpose of the Research**

The purpose of this research project was to explore the student researcher experience with research ethics, specifically:

- What graduate students in health disciplines learned about research ethics principles;
- What perceptions of research ethics did the graduate students have; and

 What was the experience of graduate students with applying research ethics principles when they conducted health research projects?

It is hoped the findings will contribute to the limited existing literature related to graduate students' experience with research ethics and provide insights for further research.

### **Personal Connections to the Research**

Lincoln, Lynham and Guba (2011) describe the researcher as a "passionate participant" inquirer in a constructivist paradigm (p. 101). As the primary researcher for this project, I have felt passionate about facilitating the reconstruction of graduate students' involvement with research ethics. I am currently employed as a Research Ethics Leader for a health authority in British Columbia, Canada and Chair the Research Ethics Board. I also participate as a community member of a local university Behavioral Research Ethics Board and both of these career roles have influenced this research project.

My responsibilities with each of these positions includes providing ethical review for student research projects, which to date I have always viewed from a REB perspective. In these roles, I often issued provisos for graduate student projects related to: recruitment and consent, privacy and confidentiality, data security, dual role, and potential conflict of interest. These reviews led me to question what knowledge and perceptions students had of research ethics principles.

As I began the project I used bracketing, a process of identifying and then temporarily setting aside my own assumptions (Richards & Morse, 2013), to gain a fresh perspective and understanding of students' engagement with research ethics. Glesne

(2011) notes that reflexive thought leads a researcher to understand how they apply their own personal characteristics, values, and positions in the research design and in their relationships with participants. It is important that qualitative researchers identify how their background informs their interpretation and what they gain from a study (Creswell, 2013). Throughout the project I practiced reflexivity by asking questions about my research interactions, discussing these with my supervisor, and documenting them in a journal for ongoing consideration.

I carefully considered my multiple career roles in research ethics when choosing the sample population for this study. The recruitment strategy was planned to specifically refrain from targeting student researchers in health disciplines who had submitted research projects to the health authority Research Ethics Board or the university Behavioral Research Ethics Board where I am a member. I acknowledged that my connection with these REBs could be perceived as having influence or power over any participants from those populations so I avoided conducting this project in my own backyard.

However, I was also a graduate student, and in some ways in the same position of experience with research ethics as my participants. By expanding my own learning of research ethics throughout this masters program, I developed a new insider perspective regarding ethics issues and now better comprehend what it is like to apply research ethics principles in practice.

### Summary

This inquiry began with the recognition that graduate students in health discipline programs are often expected to conduct research projects as part of their studies. These

novice researchers would experience the research ethics process for the first time and learn how to integrate ethical considerations into their research practice. As a Research Ethics Leader, I wanted to explore graduate students' experience with the process and discover what additional support they needed and how it could be provided.

### Chapter II – Review of the Literature

### **Search Methods**

A wide net was cast for a broad search of the literature through Google Scholar and the Athabasca University journal database using EBSCO host. Boolean (About Technology, 2014) search statements were refined to include the terms: "graduate student\*", "research ethics or TCPS2", "thesis or dissertation", and "health research". The searches were limited to peer reviewed articles from 1998 (first publication date of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*) to 2015 and English language.

Title matches for 829 articles were reviewed for inclusion of the search terms, faculties related to health disciplines, and content focused on graduate students' experience with research ethics reducing possible matches to 38 articles for abstract review. A detailed search of three research ethics journals produced an additional four articles. A separate search focused on literature specific to REBs role with education for student researchers revealed four articles that provided additional evidence. A final search by subject headings of CINAHL® and MEDLINE/PubMed® found no new results.

A critical review of the 46 abstracts determined that 31 of the articles provided evidence relative to graduate students' experience with research ethics. The literature is international in scope with research that has been conducted in Australia, Canada, Finland, Korea, Turkey, the United Kingdom, and the United States. The literature revealed five interconnected themes related to: curriculum content, teaching approaches, learning environments, research relationships, and research ethics board processes.

### **Curriculum Content**

Graduate curricula in health faculties varied in content they include about research ethics and the responsible conduct of research. Generally, most health science institutions in Canada have not invested enough pertaining to education of research ethics even though a considerable amount of peer reviewed educational material is available nationally and internationally (McDonald, Pullman, Anderson, Preto, & Sampson, 2011). Considerations for ethics in each step of a full research ethics lifecycle, from priority setting through protocol design, implementation and culmination in knowledge translation activities, is lacking in the health professions (McDonald et al., 2011).

Students in nursing may lack theoretical knowledge of research ethics resulting in an inability to recognize ethical issues and discrepancies (Demir Küreci, Demir Zencirci & Ulusoy, 2008). For graduate students in health disciplines to really understand and respect research ethics principles, and why they should bind researchers, they also required basic ethical theory including virtue ethics, consequentialist theory, and deontological theory (Weyrich & Harvill, 2013). Students needed to develop a nuanced understanding of ethics in general in order to successfully incorporate research ethics into their work. Eisen and Berry (2002) suggested that ethics education in the biosciences should start early with students in high school, thus preparing them for a better understanding of science and its social implications before they move into undergraduate programs.

Having designated courses that addressed ethical issues and decision-making was one approach for integrating research ethics content into curricula. Schmaling and Blume (2009) suggested that knowledge gained through an ethics course affected the

relationship between the responsible conduct of research and moral reasoning for graduate students; however, they found that the two were not significantly associated. Aita and Richer (2005) claimed that researchers conducting studies with humans in health care settings must identify and understand ethical dilemmas so they can take responsibility for the impacts of their research on individuals and society.

Integrating ethical principles of research in curricula continues throughout the research process to the dissemination of findings. Arda (2012) found that doctoral students rated fraud, plagiarism, and undeserved authorship as the worst issues related to publication ethics. Scientific integrity of graduate students' publications depends on these researchers being trained in critical reading and writing skills.

### **Teaching Approaches**

Various teaching approaches have been utilized to support students as they developed a deeper understanding of responsible and ethical conduct of research. A university in Georgia offered a program in research ethics via annual workshops for medical students and a semester long course for nursing students. Teaching approaches included: didactic lectures, written assignments, group discussions, guest lectures, movies and videos, case study analysis, and peer presentations. Unfortunately, the supervisors did not use the prime setting of the research laboratory as an opportunity to extend teaching on research ethics principles (Eisen & Parker, 2004).

Teixeira-Poit, Cameron and Schulman (2011) used experiential learning to engage sociology students in critical thinking about the research process. They applied an overview of ethical guidelines, a review of a fictional case study with ethical violations, and an interactive role-play activity to enhance students' knowledge and understanding of

responsible research conduct. At Ohio University a different approach to learning was trialed with speech language pathology students by engaging them in the development of hypothetical cases to use for analyzing standards of conduct, thus making the ethical issues more relevant to them (Chapman et al., 2013).

Löfström (2012) used simulations and role-playing to help psychology students contextualize different sides of research ethics, particularly aspects that are usually invisible to research participants. They supported involving students in research early in their graduate studies, and embedding content on research ethics in their programs to facilitate application in research practice. In a second study, Rissanen partnered with Löfström (2014) to use ethical dilemmas portrayed in vignettes exploring how psychology students' identified ethical issues in research. Findings were not statistically significant for relationships between ethical sensitivity, empathy, and experience of ethical issues in the learning environment. However, their sample was small and they postulated that the majority of graduate students might not find research ethics issues interesting or important so therefore didn't participate (Rissanen & Löfström, 2014).

Finally, the use of technology may be an answer to successfully engage graduate students in wanting to learn about research ethics principles. In-class sessions combined with an online education program for nurses showed benefits for positive learning in Korea (Cho & Shin, 2014). The study proposed that mandatory research ethics training for nurses should be implemented in order to improve ethical research practice.

The National Institutes of Health in the U.S. have had training requirements for the responsible conduct of research for over twenty years but no standards have been set for the skills required to practice ethical research. Plemmons and Kalichman (2013) have

determined that despite variations in curriculum content and teaching approaches, the fundamental need is still to determine the goals of education for the responsible conduct of research; consensus has not yet been reached.

### **Learning Environments**

A key factor that influenced students' learning was a supportive environment. Bowater and Wilkinson (2012) emphasized, "It is important that a 'safe space for active involvement with the ethical issues' is provided" (p. 109). Safe spaces created in health professions programs must begin with open and trustful learning environments. Langlais and Bent (2014) assessed a small sample of health science students for their ethical predisposition and perception of the research climate in their organization. They found meaningful associations between gender, ethical predispositions, disciplinary fields and perceptions of organizational climate on ethical decision-making in research.

Minifie et al. (2011) supported the need for academic programs in communication sciences to create and foster a culture of ethical research. Ensuring regulatory compliance alone was not good enough to preserve public trust. Both the year of graduate education in which the students received research ethics training, and the method of delivery impacted which research ethics principles they perceived to be the most important. In Romania specialized training on research ethics geared at multiple levels of the students' career was proposed to be impactful and successful in sustaining learning (Loue, 2014).

Commitment from leaders within academic and practice organizations was also essential. Faculty dedication to the integration of research ethics topics, particularly those involving dilemmas was important. However, some faculty made assumptions that principles of research ethics are already well known and used in practice, and therefore

did not need to be taught (Adams, 2012). Even when students requested more opportunities to discuss research ethics, faculty were not interested in providing additional content in their research courses (Freeberg & Moore, 2012).

### **Research Relationships**

Graduate students relationship with their supervisors or mentors impacted their knowledge and perceptions of ethical practice. Research experiences, mentoring, and department climates contributed to students' self-confidence with research ethics (Fisher, Fried & Feldman, 2009). Supervisors heightened students' awareness with discussions of research ethics principles, thus reducing the complexity and frustration of the ethics review process by sharing the experience (Richards, 2010; Willis 2010). Explicit transmission of knowledge occurred when the mentor provided direct instructions or practical guidance to steer the student, and socialized them into a research community (Fisher, Fried, Goodman & Germano, 2009).

Academic institutions have an ongoing responsibility to ensure ethics and professional expectations are inherent in education in order to promote sound research practice. Commitment to academic integrity should be notable in teaching, advising, mentoring, and engagement activities integrated with research training. This dedicated focus promoted graduate students to become ethically responsible leaders and scholars whose research will benefit the public (DePauw, 2009).

### **Research Ethics Board Processes**

The last theme emerging from the literature involved students' relationships with research ethics boards. When REBs shared knowledge and negotiated a mutual process, the ethics application experience was more positive for both novice and experienced

student researchers, and strengthened their research planning (Boyd et al., 2013). Students who developed relationships with research ethics committees had a better understanding of processes governing research ethics, and used that knowledge to mitigate risks in health research (Shore, 2009; Snowden, 2014). When a student attended an REB meeting to present their research project, they showed a sense of ownership (Heasman, Preshaw, Turnock & Gray, 2009). They also learned how the ethical review could impact their project positively with recommendations that improved the research design.

Another way students engaged with an academic REB in Toronto, Canada was as a student member of the board. These young REB members then provided valuable peer mentorship for other novice student researchers with regards to research ethics principles (Walton, Karabanow, & Saleh, 2008).

These studies demonstrated the value that research ethics boards can provide to student researchers by having open communications with them, and sharing knowledge and guidance with ethics principles through the review process.

### Summary

Knowledge of research ethics and ethical theory may not be consistently embedded in curriculum requirements for graduate students in health disciplines planning to conduct research with human participants. The literature demonstrated that students wanted more education and practice with ethical dilemmas so they could integrate the learning into their research projects. Research relationships, learning environments, and contact with REBs all impacted what and how graduate students learned about research ethics principles. The literature failed to provide an in-depth understanding of the student

researcher's experience with research ethics from their perspective, and to fully explain how they integrated ethical principles into their own research practice.

### **Chapter III – Conceptual Framework**

### **Social Constructivism**

To me this means that we construct knowledge through our lived experiences and through our interactions with other members of society. As such, as researchers, we must participate in the research process with our subjects to ensure we are producing knowledge that is reflective of their reality. (Byrd, 2011, p. 103) This quote captured the essence of this research project, for as a Research Ethics Leader and REB Chair I often work with graduate students and therefore have a vested interest in understanding the reality of their experiences with research ethics.

Constructivist thinking suggests that people bring valuable existing knowledge to their interactions with others (Piaget, 1972; Vygotsky1978). A social constructivist worldview espouses that individuals extend this existing knowledge by integrating information they acquire through interactions with others (Vygotsky, 1978). In essence, people construct their own understanding of reality and meaning based on their interactions with others (Lincoln & Guba, 1985). Research grounded in a social constructivist perspective aims to understand the world that the participants' live and work in, and to learn how their experiences have contributed to their ways of looking at their world (Creswell, 2013). Constructivist researchers elicit individuals' personal ways of forming knowledge, refine these, and then come to agreements with participants (Guba & Lincoln, 1994).

Guided by constructivist thinking, I reflected on my own beliefs, assumptions, and values about the research ethics process and then opened my mind to the new information participants' shared with me. This personal grounding was the foundation

from which I explored the complexity of the students' lived experience from their perspective and reality, and thus generated meaning.

The constructivist paradigm is based on a relativist ontology respecting that there are multiple realities (Denzin & Lincoln, 2011). By sharing their knowledge, the graduate students who participated in this research project provided meaning for research ethics from their own realities, both for themselves and others. REB members and academic supervisors have their own actualities with research ethics that may expand with knowledge of the student experience. From a subjective epistemological view, the students interacted with the researcher to co-create a new understanding. The nature of this new knowledge is what Lincoln, Lynham and Guba (2011) explain as individual and collective reconstructions based on consensus. The intrinsic value of a transactional process such as this is the reconstructing of perceptions with authenticity and trustworthiness to improve praxis (Lincoln, Lynham & Guba, 2011).

Aligning with the axiological beliefs inherent in constructivist thinking, the participants' values were acknowledged, honored, and respected throughout the research activities. This intention produced an informed and sophisticated description, and interpretation of the experience at the point that it existed in the real world for these graduate students.

### Summary

The conceptual framework of social constructivism guided this research towards giving high status to participants' own views and experiences, and focused on the interactions between the researcher and participant. Their individual experiences were

collected and collated by consensus, and honoring their values allowed them to describe their own reality from their perspective.

### Chapter IV – Design

### **Qualitative Description**

Qualitative description is an appropriate method where the purpose of research is to reveal, "What is going on" and link processes between phenomena in order to expand our horizon of what we already know (Neergaard, Olesen, Andersen & Sondergaard, 2009; Richards & Morse, 2013). This qualitative approach was used to investigate graduate students' knowledge and perceptions of research ethics and how they applied them in research practice. The participants' own descriptions brought new knowledge and a better understanding of their experience.

Sandelowski (2000) proposed the use of fundamental qualitative description to provide a comprehensive summary of events in their natural state. The straight description of this study focused on presenting the data in everyday language from the participants and providing an accurate account of their experience. Unlike quantitative description, this method allows for full versus skinny description, providing meaning for participants' events (Sandelowski, 2000). In a qualitative descriptive approach the data is documented as beliefs, behaviors, and perceptions that convey what is going on for each participant from their point of view (Sandelowski, 2010).

This study was founded on the acknowledgment of existing research ethics principles (Canadian Institutes of Health Research et al., 2014), however qualitative description is utilized to explore a phenomenon with no a priori commitment to spin one theoretical view (Sandelowski, 2000). There was no plan to make the study more than mere description or to posture another qualitative methodology but indeed to produce a valued end product.

Interpretation of the data was low inference through inductive reasoning to convey the 'facts' accurately and in proper sequence in order to understand the 'who, what and where' of the phenomena (Neergaard et al., 2009; Sandelowski, 2000). Full descriptions depict the perceptions, inclinations, and sensitivities of participants, thus staying close to the data obtained (Neergaard et al., 2009; Sandelowski, 2000, 2010). There was no intention for deeper level interpretation of the data for this project, which is a limitation of this methodology. The rich, thick description provided abundant and interconnecting details allowing any reader to enter the research context (Creswell, 2013; Glesne, 2011). The advantage of qualitative description was to produce a complete and valued descriptive summary that provided knowledge of a phenomenon, which may in turn stimulate future theory-based research (Neergaard et al., 2009).

Kahlke (2014) noted that although qualitative description is a generic approach less defined and established than other methodologies, it has benefits for opening up a new way of looking at a topic. This simpler approach was chosen because it fits the research questions and few qualitative studies have been conducted on this subject matter to date. The boundaries of this study have been recognized in the novice skills of the researcher and resources for this project, yet the "big-tent" criteria for qualitative quality have been imbedded (Tracy, 2010, p. 840).

### **Research Question**

The research questions for this inquiry focused on the purpose of this study to explore and describe the students experience with research ethics.

What did graduate students in health disciplines learn about research ethics principles;

- What were graduate students' perceptions of research ethics; and
- What was the experience of graduate students with applying research ethics principles when they conducted health research projects?

### Sample

The purposeful sample for this study included students who were enrolled in, or had graduated from, a masters or doctoral program with a research thesis or dissertation in a health discipline in the past five years. Recruitment was initially targeted at universities in British Columbia and Alberta but then reached further to other universities across Canada. Current masters students were excluded unless they had already experienced the full research ethics process for their thesis project or another research project. Students who had completed course-based programs were excluded if they had no research experience.

A purposeful sample provides validity to the data when participants have information on the phenomena of interest and are willing to participate (Richards & Morse, 2013). This population was the chosen sample as they had recently conducted health research projects and would be able to provide information rich for the purpose of this inquiry. The graduates had recently experienced the research ethics process and had an interest in the topic as related to their graduate work. As a range of eight to twelve participants can provide complete and adequate data (Sandelowski, 1995), the target sample size for this study was ten participants.

### Recruitment.

Various recruitment strategies to access graduate students who had completed their university programs were considered. Access might have been available through a

local university's graduate student and alumni offices but as the university is a public institution they would be restricted from providing personal information for the purpose of contacting a person to participate in research (Freedom of Information and Protection of Privacy Act, 2015). General recruitment strategies using posters, memos, and website advertisements were doubtful to be effective in reaching the target population through these venues as most graduates had moved on with their careers and were unlikely to keep in touch with the university. Direct recruitment through professor contacts was also discussed but may have put them in a position of power over or conflict of interest if they still had working relationships with the students.

For these reasons, recruitment was carried out using social networks Facebook and Twitter. Social media has been demonstrated as an effective way to reach and recruit specific populations for research (Kapp, Peters, & Oliver, 2013; O'Connor, Jackson, Goldsmith & Skirton, 2014; Ryan, 2013). A Facebook site unique for this research project was created solely for the purpose of recruiting the targeted number of participants; no data was collected directly from the Facebook site (UBC Office of Research Ethics, Social Networking Sites, 2012).

Khatri et al. (2015) determined that recruitment through social media provides access to a larger number of potential participants and serves as a rapid recruitment method. Facebook and Twitter messaging resulted in reaching graduates from different health programs and universities thus adding diversity to the sample. Once the target number was reached, and participants had confirmed their participation, the Facebook site was closed. A Twitter account and email script unique for this research project were created for the purpose of communicating recruitment messages to health and academic

research communities across Canada. Like the Facebook page, the Twitter account was closed once recruitment was completed. I acknowledged and respected user and privacy agreements for both Facebook and Twitter social media.

The recruitment invitation included information about the research project, inclusion criteria, expectations of participation, and how the graduate student could contact the researcher if s/he was interested in participating (see Appendix B). The invitation to participate remained on the Facebook page for the duration of the recruitment period, and the Twitter account was used to send regularly scheduled tweets with abbreviated information to contacts in the research community.

On receipt of an expression of interest from a participant, I contacted the person directly via email, provided the letter of information and informed consent form (see Appendix C), and arranged an interview date and time at their convenience. Participants received a \$20 gift card for Chapters Indigo after the interview as a thank you for participating.

### Sample Characteristics.

Eleven participants representing five different academic health programs consented to participate in this project. One graduate student from community health science, two students from social dimensions of health, one student from public health, three students from nursing, and four students from rehabilitation sciences all contributed to this project. The participants attended their programs at three different Canadian universities and two universities from outside of Canada.

Seven of the participants were presently enrolled in or had completed a doctoral program and four of the students were currently in a first or second masters program,

having completed at least one ethics process with a research project. Six of the students graduated from their respective programs between 2013 and 2016, and five participants were current students, so all had recent experience with research ethics processes to draw from.

The sample population also presented diversity in the research methodologies they chose for their projects with two students using mixed methods and two students using quantitative methods. Seven graduates used qualitative methodologies with a variety of narrative, phenomenology, grounded theory, descriptive, and participatory action research approaches adding fullness to the data.

## **Data Collection**

Each participant was invited to participate in a one-hour interview conducted via phone and audio-recorded with the participant's consent. In person interviews were offered to participants who lived within one hundred kilometers of my home location if they preferred a face-to-face interview experience. The location of the interview was scheduled for the accessibility of the participant, ensuring privacy and confidentiality during the interview.

Informed consent was confirmed by having participants scan and email their signed consent forms to me prior to the interview. Consent was reviewed and acknowledged again at the start of each interview. Semi-structured and open-ended interview questions were appropriate for the qualitative description methodology being utilized (Neergaard et al., 2009) and aligned with the research questions (see Appendix D). Each interview was scheduled for one hour but flexibility allowed for more or less time to allow the participant to complete the sharing of their story.

An experienced transcriptionist was hired to transcribe the interview audiotapes. I then conducted a thorough comparison of each transcript against the audio recording. Each participant was invited to review their transcript in order to verify the accuracy of data representation and sequencing (Glesne, 2011; Sandelowski, 2000); they were also allowed to keep the copy of their transcript.

### **Data Analysis**

The spiral of data analysis starts with the data collection and interconnects with analysis and writing throughout the project (Creswell, 2013). For this project the collection of interview data continued into the thematic analysis and reporting of themes and findings. Qualitative description is conducted from a factist perspective, assuming the data to be truthful in reflecting reality (Sandelowski, 2010). Thematic analysis is an independent, reliable approach to identify, analyze and report the patterns and themes across multiple interviews in qualitative data and fits well in a constructivist paradigm (Vaismoradi, Turunen & Bondas, 2013).

Gibbs recommends reading each transcript twice in order to gather general knowledge and then focus on words representing key messages (2011a; 2011b). During the analysis, codes and themes with definitions were developed after the first reading, and later applied to the focus words after the second reading. The surfacing of repeated data noted as important by the participants, data similar to the literature, and data related to the concepts was coded and categorized. This process was data driven for authenticity and the codes and themes were reviewed for consistent application; there were no preset codes or categories to avoid any researcher bias on my part. Analysis using 'in vivo coding' is known to identify similar phrases, patterns and sequences, and extract

similarities and differences, thus providing descriptive validity (Gibbs, 2011c; Neergaard et al., 2009; Sandelowski, 2000).

The expected outcome of this process was generalizations examined in light of existing knowledge related to students' learning and application of research ethics in practice. The final rich descriptive summary re-presenting the data using themes and sensitizing concepts was sent to the participants for member reflection to confirm that it truly described their experiences from their perspectives.

### Budget

As a student researcher I was supported with funding from the Athabasca University Graduate Student Research Fund and the Access to Research Tools Award that covered the costs of the recording device, transcription, and incentives for participants (see Appendix E). I took personal responsibility for the extra costs with dissemination of the research results.

### **Ethical Considerations**

Values and ethics are intrinsic to constructivism (Lincoln, Lynham & Guba, 2011). Individual values of the researcher and participants shall be honored and negotiated during the research process (Creswell, 2013). These beliefs fit well with research ethics where the core principles of respect for persons, concern for welfare, and justice should be implicit in any research project (Canadian Institutes of Health Research et al., 2014).

An ethics application for this study was submitted to the Athabasca University Research Ethics Board as the academic institution I am affiliated with as a graduate

student (see Appendix A). Participant recruitment and data collection did not commence until ethical approval had been granted.

All participants received detailed information about the research project including risks and benefits, and protection of personal information and confidentiality. Written, informed consent was obtained from all participants prior to participation in research activities and ongoing with the return of transcripts and requests for member checking the results. All of the participants were made aware that they could withdraw from the research at any time without giving a reason and without consequence. Only the supervisor, transcriptionist, and myself had access to the identifiable data, and the transcriptionist signed a confidentiality agreement. Dissemination of the research findings would only include aggregate and anonymous data; no participant identifiers were used in reporting or publication of the results.

Throughout the project, I remained aware of my career roles in research ethics and tried to avoid any conflicts of interest or power over participants. I recruited publicly instead of directly through the two organizations where I am a member of their respective REBs. My work in research ethics was disclosed to participants during the initial contact, and reviewed again at the start of each interview to ensure that they were informed.

### Trustworthiness

Lincoln and Guba (1985) established five criteria for recognizing trustworthiness in qualitative research; three of which, peer debriefing, referential adequacy, and member checking, have been applied to this study. Tracey (2010) notes that credibility "refers to the trustworthiness, verisimilitude, and plausibility of the research findings" (p. 842).

Credibility for this investigation was attained through regular peer debriefing with my academic supervisor and thesis committee throughout the research design and implementation. These researchers shared their knowledge and expertise in qualitative research throughout the undertaking.

Referential adequacy is an activity that allows findings to be compared to the raw data (Lincoln & Guba, 1985). The audio-recordings of each interview were compared to the transcript during my first reading, and each participant was asked to review their transcript to ensure it was assessed for accuracy. Representation of an accurate description of the participants' experience in the proper sequence is essential in qualitative description (Neergaard et al., 2009; Sandelowski, 2000). At the completion of my analysis, a summary of the research findings was sent to each participant for member checking and validation of the findings. Member checking, also known as member reflection, allows for a direct affirmation of the research findings and interpretations (Lincoln & Guba, 1985; Tracy, 2010).

It was important that each participant felt free to speak and their voice was heard, giving authenticity to their story (Milne & Oberle, 2005). I used open-ended questions during the interviews to allow the participants ample opportunity to carry the conversation and feature the facts that were most significant to their experience. Probing sub-questions used by an interviewer engage participants to delve deeper, adding richness to their description (Milne & Oberle, 2005).

As a novice researcher, my preparation included learning qualitative description methodology, bracketing my prior assumptions about students' experience with research ethics, and using reflexivity to remain aware of the influence my current career roles

might have on the project. I acknowledged and documented my prior knowledge of research ethics principles, and potential for conflicts of interest or power over relationships with participants. Knowing the importance of honesty and transparency in a researcher's relationship with the participants (Tracy, 2010), I shared my position with them at the start of each interview.

Methodological journals documenting all research procedures and decisions can serve as an audit trail used to verify the research process for dependability and confirmability (Lincoln & Guba, 1985). Throughout this project I maintained a comprehensive journal to document all of the information, references, discussions and decisions related to this study.

### Limitations

Limitations for this research project included; lack of prolonged engagement with participants, triangulation of multiple data sources, or use of negative case analysis. The data collection strategy was limited to one interview interaction with each participant and did not allow for repeat conversations. Triangulation with secondary data sources of documents from participants' research ethics applications was not examined due to access issues.

Interpretation of the data was restricted to convey the 'facts' accurately and in proper sequence in the participants' own language (Neergaard et al., 2009; Sandelowski, 2000). There was no intention for deeper level interpretation of the data by the researcher, which is a limitation of qualitative description.

The sample size was appropriate for this inquiry but small for true maximum variation sampling. Thus, it is unlikely that even a rich descriptive summary would

enable transferability for those interested in the possibility of applying these results to another setting (Creswell, 2013; Lincoln & Guba, 1985).

### Summary

This research design used a qualitative description methodology appropriate to answer the research questions. A purposeful sampling technique and thoughtful recruitment strategies to protect the participants resulted in a diverse sample of eleven graduate students engaging in this project. Data were collected through an interview process and analyzed using themes and categories driven from the data. Budget impacts and ethical considerations have been discussed, and the trustworthiness of the effort established. Limitations of the research design with regards to lack of triangulation or prolonged interaction with participants, and plans for only low inference interpretation of the data have been recognized.

#### **Chapter V - Results**

The findings from the data analysis were categorized to align with the research questions and revealed four themes in support of the significance of this inquiry: what do graduate students in health disciplines learn about research ethics principles; what perceptions do they have of research ethics; and how do they experience applying research ethics principles in practice?

### **Curriculum Content**

Graduate students indicated that in both masters and doctoral level programs any curriculum content focused on research ethics was delivered through quantitative and qualitative research methodology courses. The content was usually brief with the topic discussed in one class of less than three hours course time. Some students described research ethics content that was threaded throughout a course over the semester. Principles of research ethics were explored through the examination of a REB application process, case studies, and ethics experiences shared by faculty or guest speakers. The topics often covered included; how to conduct interviews, informed consent, privacy and confidentiality for participants, vulnerable populations, risks and benefits for participants, and ethical dilemmas that may arise during research activities.

Doctoral students, depending on the health discipline, were sometimes required to complete a general ethics course delivered through a workshop session or a semester long course. Some students from both graduate levels also chose to voluntarily take additional ethics, bioethics or research ethics courses.

Participants identified that academic curriculum content devoted to research ethics does not provide enough content depth or specific instruction on research ethics

principles and how to integrate them into research practice. All of the students asked for more detailed instruction regarding the ethics application process and lessons on how to create participant documents such as letters of invitation and consent forms. Four of the eleven students believed that graduate programs should include a required ethics course. One of these students suggested that universities should heighten awareness of ethical research practice through the curriculum:

I think the awareness needs to be increased for sure. I think at the level of the university, not at the level of you know, individual health sciences departments but at the level of the university. It should be a course; it should be a required course. We are all expected to do required methods course or statistics course but nobody really talks about a required ethics course. (Participant 6)

Another participant reflected that ethics material delivered in one of her program courses was not translated for research practice, even though the basic ethics principles could be applied. She suggested that ethics content from various courses needs to be pulled together through a knowledge translation process.

### **Research Ethics Tutorials.**

The Panel on Research Ethics in Canada provides the *Course on Research Ethics* (CORE) online tutorial (Panel on Research Ethics, 2014) which many Canadian academic institutions mandate students complete before they are approved to conduct research with human participants. During this project it was noted that most of the participants were aware of the CORE tutorial and six students had completed it, five students had not. Only one current masters student had no previous knowledge of the tutorial offered by the Panel on Research Ethics. Successful completion of the CORE tutorial was a requirement

for two students during their quantitative research methods course, and three participants indicated it was a requirement for the principle investigator or co-investigator submitting the ethics application for their research projects.

Similar to the CORE tutorial provided by the Panel on Research Ethics in Canada, the U.S. Department of Health and Human Services, Office for Human Research Protections (OHRP) delivers an on-line tutorial that includes three modules related to roles, requirements, and procedures in conducting research involving human subjects (United States Department of Health and Human Services, Office of Human Research Protections, n.d.) Three of the participants in this research project had completed the OHRP tutorials as they were either attending universities in the U.S. or conducting international research.

The CORE tutorial and OHRP training programs are valuable educational resources that may complement academic curriculum in any graduate program promoting research involving human subjects. The Canadian and U.S. government agencies and departments responsible for the protection of research involving human subjects are well renowned for their education and training programs available for all researchers, including graduate students.

## **Support from Supervisors**

In order for a graduate student to be successful in a masters or doctoral program s/he needed a positive working relationship with a faculty supervisor. Ongoing, dedicated support from the supervisor was imperative if the student was going to thrive and achieve the program goals.

Six of the participants described feeling like they had sufficient support from their supervisors. Support was extended to the students through a variety of ways including: ethics application examples; dialogue on research ethics principles; being available for conversations, questions and concerns; discussing ethical implications; and providing review and feedback prior to ethics submission.

Characteristics of supervisors who were recognized as being supportive were noted as: having experience supervising graduate students; teaching and allowing for self-directed learning; encouraging critical thinking about ethics and how to apply the principles; mentorship; having significant research and field experience; and being approachable and easy to work with. Students indicated that if they had a previous relationship with a professor who later became their supervisor it added to a positive experience. Sometimes the supervisor had been their teacher for a previous research or ethics course, or the student was a research assistant for the professor with a previous project.

The other five participants indicated they did not have much supervisor support through their research journey. The supervisor would provide broad suggestions but not hands on support, or was disengaged from the process. This lack of support frustrated students and cost them time with self-learning or problem solving their way through ethics processes. One graduate student described feeling like the driver of the ethics process for her research project, reflecting that she had expected the supervisor to contribute more direction:

I have consulted my supervisor on the process as I've gone along but I would say that I'm definitely the driver. In that sense though, although she would have

reviewed my ethics application, we definitely didn't have any prolonged discussion about those elements. (Participant 10)

These students tended to turn to other committee members for support, especially if a committee member demonstrated a strong position on ethics. Some students used committee meetings to discuss the ethics review and looked to the committee members to provide suggestions. Another approach was to ask a committee member specific questions related to their area of expertise. Unfortunately, students sometimes received differing feedback from committee members that was confusing for them.

Additional gaps indicated in supervisor support were: lack of general guidance and information, insufficient experience with electronic ethics application processes, or being uninformed regarding harmonized ethics review with multiple REBs. If an academic supervisor did not truly understand the complexities of the health system and impacts on research at health care sites, the students' project suffered from multiple delays with navigation of the system and dealing with operational requests.

#### **Ethics Application Process**

Depending on the nature of the project, health research was often conducted under the auspices of at least two institutions; the academic institution that the graduate student was affiliated with, and the health institution where the research activities would be conducted. Therefore, the student researcher often required research ethics approval from more than one REB. Seven of the participants in this project submitted ethics applications to one REB, but in five of those situations the REB jointly represented both the academic and health institutions in the geographical area. Four participants had to submit ethics applications to two separate REBs.

In general, graduate students found the ethics process more complicated with health institution REBs. These REBs are responsible to protect the patients, clients and residents that are served by their healthcare organization; as well as staff, physicians, and volunteers who may participate in research. In addition, institutional approval from each health research site, department or program may be required before ethical approval is granted.

Graduate students found the health institution REB ethics application convoluted with many questions and some paper or electronic forms were difficult to work with. Some students used content from funding applications to inform their ethics applications to try and make the process easier. After the initial submission, students received provisos with requests for numerous modifications. Subsequent submissions were scrutinized for minor typographical errors, date and version changes on documents, and other minor details that did not significantly affect the ethical aspects of the project. Participants believed that REBs place too much emphasis and energy on these finer points creating extra workload and timeline delays. Some of the graduate students questioned if these issues were actual ethical considerations for their projects, or what Gunsalus et al. (2006) refer to as mission creep where REBs focus on less productive activities. If a student researcher had previous experience with an ethics application, including the forms and process, as well as familiarity with the ethics office staff, the whole process was more efficient.

Academic REB reviews were simpler and generated fewer provisos, however the graduate students learned that where ethics applications were submitted to two REBs, any modifications for one application had to also be made on the other application to ensure

they aligned. Different views surfaced between the two types of REBs, for example with acceptable recruiting and consenting procedures, and the student researchers had to figure out how to modify their research design to comply with both REB requests. One graduate student expressed her frustration with the different expectations of REBs:

And then of course the University 1 [REB] would not budge on their end because .... I thought I'd passed all the checks and balances on their own from what my supervisor saw was appropriate and all that but they were pending the decision on this end [REB 2] and then this end was pending the decision on that end so it was quite an interesting thing.... I felt I lost six months of my life and my time based on bureaucracy and I still at this point in time don't understand why...

(Participant 4)

Some graduate students experienced how the expertise of the REB members can affect the review. One participant didn't feel supported by a REB that lacked experience with international research, and another participant faced barriers to using social media data because the REB lacked knowledge in determining the privacy and confidentiality concerns. In some areas in Canada REBs are harmonizing research ethics review for multi-jurisdictional research and this impacted one students' experience with exaggerated time delays due to new processes and communication lapses.

Where student researchers could submit to a joint academic/health institution REB, their experience was supported with access to a specific contact person for student inquiries. Ethics office staff was found to be approachable and responsive in a timely way to most of their requests. Another benefit was that ethics information for a project was shared directly with the health care sites where the research was conducted. However,

these students faced the same tedious issues with pragmatic pieces of the application and the onerous job of responding to multiple rounds of provisos and re-submissions.

Electronic application systems presented another set of challenges. All users had to be registered and trained on the system including researchers, academic supervisors, and site managers responsible for operative approval. Sign off by all parties was required for each submission and subsequent amendment. Student researchers found they spent extra time training site managers on how to use the system, or following-up to get sign off on approvals. Technical difficulties were frustrating and caused system shut down or a user to lose changes before saving, thus adding time for the content to be re-entered. Participants indicated that terminology in ethics applications was geared to quantitative methodologies so they had difficulties answering some of the questions in relation to qualitative approaches. Lastly, in some instances, electronic notification of approvals was sent to the supervisor who was listed as the principal investigator and not to the student, causing a delay in communication and the student being notified.

## **Research Ethics Board Provisos.**

Research Ethics Boards (REBs) issue provisos, or a request for modifications, to the principal investigator after the initial ethical review of a research project has been performed. All of the eleven participants reported receiving provisos with respect to a number of ethical principles.

Some were questioned on their dual role as a student researcher and clinician with potential for power over their participants who were patients where they worked. Certification and confidentiality of research team members and transcriptionists needed to be explained. Provisos regarding justification of sample size, inclusion, and exclusion

criteria were common. The process for recruiting participants, and if incentives were offered, had to be clearly described and justified in their applications.

Most of the participants reported receiving provisos related to consent including: if consent was informed, the process for obtaining consent, consent form language and reading level, information for withdrawal and withdrawal of data, and wording related to funding sources. Another common proviso received was regarding data: the use of demographic data from a previous survey, how information would be anonymous or deidentified, storage and destruction of data, and clarity of data transfer.

The graduate students learned that as they responded to each proviso they gained a deeper understanding of the ethical impacts of their project and came closer to receiving ethical approval. One participant reflected on the impacts of the ethics review process:

I think it's really made me think things through a lot more than just operationalizing the project... even the process of preparing an application where you are having to think in advance of many, many details strengthens it because you start to say, "Oh, I never thought ... I've got to think about that. Exactly how are we going to operationalize that? What is that going to look like?" (Participant 10)

#### Support from Research Ethics Boards.

The graduate student participants in this project were asked what additional support REBs could have provided to them. Six participants quickly identified REB resources they had utilized such as ethics application samples, document templates, website resources, and ethics workshops. The other participants had not experienced

access to these types of resources with the REBs they applied to, and suggested that all REBs should have similar education materials available.

As novice researchers, the graduate students expressed that they wanted clear information on details of the ethics application process and timelines, including samples of forms and formatting guidelines. They commented on how they would like to see conflicting or overlapping questions removed from the application and questions revised to apply for qualitative methodologies. One participant suggested that a frequently asked questions document could provide information for common ethical issues. Other suggestions included: using video tutorials or webinars to demonstrate completion of an application: providing examples of participant materials and consent forms; and clarifying processes for confidentiality, data storage, data retention, and destruction of data.

Graduate student researchers also indicated that they would like the option to submit their application for a pre-review, and then make the suggested revisions before their submission progresses to a full board or delegated REB review. Having a designated contact person for student projects in the research ethics office, and a process for expedited review would have been effective in streamlining the process for these novice researchers. Viewing through the eyes of the participants in this study, communication could be enhanced through availability to ethics office staff, simultaneous electronic notifications to the student (co-investigator) and supervisor (principal investigator), and use of chat lines.

Finally, collaboration between academic and health institution REBs was encouraged by the students to make the ethics review process more congruent for the researcher. One participant suggested:

What are the opportunities between university and health authority REBs to meet and collaborate and talk about problems and how they see finding some of the solutions to some of these issues that we see between an external researcher doing health service research because we need them. We need that research. We want to hold the rigor as well as the ethical practice but I still think they're really, really far apart. (Participant 1)

## **Graduate Students' Perceptions and Experience**

Participants openly shared their experience with research ethics as novice student researchers. First they were asked which research ethics principles were most important to them in conducting their health research project. Secondly, they described their perceptions of research ethics, and lastly they shared how the overall experience had been for them.

#### **Important Research Ethics Principles.**

The eleven participants recognized four key research ethics principles as the most important to integrate into their research with human participants. Depending on the nature of each research project, the following principles had varying degrees of significance for each graduate student.

The first principle identified was that of fair recruitment and the potential influence of dual role of the researcher as both a student researcher and a clinician. Some students were also employed at the site where they conducted their research while others

had health professional relationships with staff at the site. They described the significance of being careful to mitigate any power over participants, being non-judgmental, developing trusting relationships with their participants and colleagues, and always being transparent and culturally safe. Student researchers tried to avoid any potential for coercion by recruiting through a third party, and respected the roles of clinical staff in health care sites with recruitment strategies that did not put them in a position of conflict of interest.

Privacy and confidentiality for participants and staff involved in the research activities was the second research ethics principle noted as most important. These graduate student researchers focused on privacy with the location of interviews and focus groups, and data security throughout the project including storage and destruction. The protection of identity for both participants and work colleagues in the dissemination of results and publications was imperative.

These novice researchers recognized and respected that they were conducting their research with vulnerable adults. The nature of their inquiries involved vulnerable target populations including: student mothers, adolescent mothers, university students, frail elderly, caregivers of spouses with dementia, parents of children receiving health services, breast cancer patients, patients with pain, and marginalized populations. In every case the student researchers distinguished their concerns for the welfare of these individuals and groups as research participants. They wanted to safeguard the balance of benefits and risks for each individual involved in their projects.

Informed consent was the fourth research ethics principle that was mentioned as most important. The student researchers wanted to ensure that participants were capable

to give informed consent, that consent was ongoing, and that the consent process was appropriate (i.e., verbal versus written, consent forms read to participants who were illiterate).

On reflection of these four research ethics principles chosen as the most important by the participants in this research project, it is clear that the three core principles of the *Tri-Council Policy Statement for the Ethical Conduct for Research Involving Humans* (2014) were at the center of their health research projects. Respect for persons, concern for welfare, and justice prevailed as common bonds in the relationship between these graduate student researchers and the participants of their research projects.

## **Perceptions of Research Ethics.**

The depth of perceptions of research ethics shared by these novice researchers, most of who had only been involved in one or two research projects, was remarkable. Most reflected on the responsibility of research ethics to protect those individuals who choose to participate in research that advances knowledge and benefits society as a whole.

I think it holds researchers accountable to being transparent and ethical and respectful and considerate to people that they're asking for information from so that it avoids treating participants as just participants. Like they're people living their life and giving their time and it's the people that are going to help you make the difference and you need to treat them well. (Participant 7)

Another participant commented:

I definitely would not have considered these things if I hadn't had some training in ethics. You know, I wouldn't have considered, "Oh okay, that's a power over

relationship and that might not be appropriate." And you know you don't want people participating only because they feel that they have to and that's not appropriate for them. And I'm not sure if I would have come up with that on my own? ... I feel like it's protective of my caregivers and I feel so strongly about them that I want them to have that. So I'm sort of pleased to provide that to them. (Participant 11)

Others described their perceptions of the impacts of research ethics processes and approval on the researcher and the research design. "It really does test a researcher to balance between the rigor of a study and the quality of a study and the respect for the population that's providing you with the data" (Participant 1). Additional perspectives pointed out that it is often complicated; detail oriented and takes a lot of time. Two students noted that the ethics process added credibility to their projects and others recognized that it was important to carefully think about, even more so than their research methods and just implementing the project.

Graduate student researchers also shared profound insights related to the importance of integrating ethics throughout their projects, not just for the sake of the REB application. "I think that's another really important piece that I have continued to take away from is that the ethics process is not just about the ethics application" (Participant 5). Participant 9 reflected, "If I do it the way I've set out to do it then it should be a high quality project because at the end of it all, it's a large waste of time and resource and effort if it's not a high quality project at the end of it."

The intensity shared in these comments, and the underlying perspectives that they illustrate, speaks to the role that REBs have to play in the review of health research.

REBs not only protect the participants, but also having a positive impact on the researchers.

#### **Overall Experience.**

At the end of each interview I asked the graduate student participants to describe their overall experience with research ethics. Most stated that is was positive, using terms like good, quite supportive, valuable, interesting, and eye opening. Timelines and the focus on tedious details were often stressful and not always easy to understand. Five participants commented that once they were familiar with the process, that they expected it to be easier the next time around with future research projects. Two students recognized that they now had much more confidence in their role as a researcher. "I think it helped me feel more confident going into my study because after all that work, I feel like I had a really good handle on what I was proposing that I do." (Participant 9)

Three of the participants, who now teach and mentor in graduate programs, indicated that they have used their experiences to imbed ethics in their lessons and coaching with other students. They have used their knowledge of research ethics principles to pay it forward to the next group of graduate student researchers.

#### Summary

The data collected from eleven interviews with novice graduate student researchers was rich in detail and complexity, and four themes emerged related to curriculum content, support from supervisors, ethics application processes and their overall experience.

Participants described the curriculum content related to research ethics in their graduate programs and how it was delivered. They provided creative suggestions for how

it could be improved and endorsed the requirement for a mandatory ethics course for graduate students in health discipline programs. They noted how training modules provided by government agencies responsible for the protection of research involving humans could be utilized more regularly in academic programs.

Half of the participants indicated they had positive relationships with supervisors who were engaged with them throughout their research journey, and identified the characteristics of this support. The other participants lacked this vital relationship, therefore looking to committee members and other resources to fill the gap.

Ethics application processes were a central theme within the data and participants elaborated on: challenges with health and academic REBs, paper and electronic application systems, REB provisos, and review and approval processes. The graduate student participants also offered numerous suggestions for additional support that REBs could provide.

Lastly, the participants described their overall experience with research ethics from their own perspective, including which research ethics principles were most important to them as they conducted their health research projects.

## **Chapter VI - Discussion**

Because ethical concerns occur at the level of the personal behavior of the research team, and in the development, implementation, analysis, and dissemination of the study results, it is imperative that researchers have an understanding of the ethical principles and guidelines that impact the research of human subjects. (Aita and Richer, 2005, p. 124)

Aita and Richer's statement speaks to the importance for all researchers to know, understand and imbed ethical principles into their research practice involving human participants. Research ethics is not merely an application submitted to a REB for review and approval. Rather, ethical research is a way of doing research that reflects the knowledge, integrity, and values of the researcher. As the previous chapter illustrated, findings from this study revealed that graduate student researchers either had or would have valued having ongoing support from the curriculum, their supervisor, and the Research Ethics Boards; both during the ethics application process and throughout their research projects. They provided important suggestions for improvements that could strengthen their experience with the research ethics process. In this section I discuss these findings and suggestions.

## **Enhancing Curriculum**

Students who embark on graduate programs in health disciplines will often be required to complete a research project as part of their studies, thus they quickly become novice researchers. The students have so much to learn about quantitative and qualitative research methods and design, statistics and analysis, writing and dissemination to become

knowledgeable about conducting research. Where do research ethics truly fit in to this busy schedule of program content and time limitations?

This descriptive inquiry demonstrated that graduate students need and want more information and focus on ethics and research ethics in their academic programs. They explained that indeed, research ethics was a topic in their quantitative and qualitative research methods courses but received a very small amount of attention. Students requested that more opportunities to learn about research ethics principles and practice with ethical dilemmas be imbedded into curriculum.

These findings align with McDonald et al. (2011) and indicate that academic institutions need to invest more resources for the education of research ethics. Basic ethical theory, virtue ethics, and moral reasoning are necessary for students to identify ethical issues, discrepancies, and how to work through them (Aita & Richer, 2005; Demir Küreci, Demir Zencirci & Ulusoy, 2008; Schmaling & Blume, 2009; Weyrich & Harvill, 2013). Curricula must also include instruction on the ethical dissemination of research findings as many graduate students publish their thesis and dissertation work.

Considerable research has previously investigated the teaching approaches and presentation formats that are effective in promoting a deeper understanding of research ethics principles (Chapman et al., 2013; Cho & Shin, 2014; Eisen & Parker, 2004; Löfström, 2012; Loue, 2014; Rissanen & Löfström, 2014; Teixeira-Poit et al., 2011). However, further research is required to define the depth of ethics content that should be covered in curriculum in order to meet the needs of the student learners. An inquiry into the effectiveness of separate courses devoted solely to ethics and research ethics

principles could contribute to curriculum planning focused on filling this void. Integration of research ethics principles must also be imbedded in research training conducted in laboratory settings.

Further research conducted with academic faculty to explore their perceptions of how much ethics content is required to meet students' learning needs, and how they can best integrate that content into curriculum, could support graduate level program development that moves the merit of ethics and research ethics to the forefront.

#### **Relationships with Supervisors**

Graduate students partner with an academic supervisor in a relationship that begins early and continues throughout their research project journey. Students described how important it was for them to have a supportive supervisor who provided guidance, information, and encouragement. These supervisors were there for them, available for consultation and discussion on the ethical implications of their projects. For students who had a supportive supervisor, their experience with research ethics was more positive because they learned through their supervisor what the curriculum failed to give them.

Other students shared that their supervisors were unavailable or disengaged, leaving them feeling frustrated and on their own. They utilized self-directed and problembased learning strategies to find answers for their ethical questions and concerns. Sometimes they turned to other committee members who were more approachable than their supervisor, or who had expertise with ethics and research practice. Unfortunately, differing advice from multiple mentors could sometimes be more confusing than helpful.

The experiences with their supervisors shared by the student participants in this project validated the context of the literature. The relationship between a graduate student

and supervisor impacts knowledge and perceptions, contributing to the student's selfconfidence (Fisher, Fried & Feldman, 2009; Tilley, 2008). Learning is most effective when the mentor provides direct instructions, practical guidance, and integrates the research ethics process into supervision (Fisher et al., 2009; Richards, 2010). Commitment to academic and research integrity should be notable in teaching, advising, and mentoring activities (DePauw, 2009). The supportive role of an academic supervisor is critical to students' success and deserves further investigation with faculty to explore their perceptions and ideas for strengthening this role.

#### **Connections with Research Ethics Boards**

All of the graduate student participants in this project recognized the role of research ethics staff and the REB in the review and ethical approval of research conducted involving human participants. Although the ethics application process was often fraught with challenges, time delays and pragmatic details, they valued receiving ethical approval for their projects. They appreciated the REB focus on the protection of research participants, and that all of the ethical considerations for their projects had to be addressed before commencing research activities. The students benefitted from the ethics review with a feeling of confidence as novice researchers, and the credibility it added to their projects.

The literature has shown that when REBs share their knowledge, students have a better understanding of the ethical review process and the experience is more positive (Boyd et al., 2013; Shore, 2009; Snowden, 2014; Tilley, 2008). Student researchers also benefit from the opportunity to attend REB meetings and talk about their projects (Heasman et al., 2009). The *Tri-Council Policy Statement: Ethical Conduct for Research* 

*Involving Humans* (2014) in Article 6.13 considers that participation by the researcher in REB discussions is helpful to both the REB members and researchers. The researcher is available to answer questions about their research and address any ethical concerns with additional information and explanation. Such discussions are an essential part of the educational role of the REB and can have a constructive influence on these next generation researchers.

This study provided evidence that REBs can have a significant role to play in supporting graduate student researchers. These novice researchers looked to the research ethics office staff to guide them with the application process and provide support for their questions related to the ethical impacts of their research. The REBs had information on research ethics principles to offer the students that they didn't find anywhere else.

Further research should explore the connections between REBs and student researchers. REBs need to acknowledge the value of their expertise with research ethics principles and how it can be shared through effective educational resources. If students have clearer information and expectations of research ethics and how to imbed the principles into their projects they will submit higher quality applications. Ethics office staff and REB members would benefit from easier reviews with fewer provisos and resubmissions.

REBs might also collaborate with faculty development activities to host joint presentations that focus on enhancing the skills of both faculty supervisors and students for integrating research ethics principles in practice. While REBs cannot take responsibility for the ethical conduct of any researcher, they can certainly provide support and education that promotes the integrity of ethical practice throughout a project, and

thus assist novice researchers to understand that the REBs' role is not just for the purpose of ethics review and approval.

## Summary

In summary, this inquiry has provided a rich, descriptive picture of graduate students' experience with research ethics. The strengths and weaknesses of curriculum content related to research ethics principles and suggestions for enhancement have been outlined. The characteristics of a supportive academic supervisor were identified and further exploration with faculty regarding their perspectives would clarify how the role of the supervisor can be most effective. Students' connections with REBs have considerable impact on their ethical research practice, and REBs need to invest in opportunities for improving educational resources provided to novice researchers.

## **Chapter VII – Conclusion**

Graduate students who conduct research involving human participants must learn and apply principles of research ethics throughout their research projects. The ethics review process is an important element of students' learning and when they submit their first ethics review application they often require additional support with incorporating research ethics into their health research projects.

Research Ethics Boards (REBs) provide ethical review and support for student projects and benefit from understanding the student experience with research ethics in order to identify what additional support they might offer. Existing literature established the effects of curriculum content, teaching approaches, learning environments, research relationships, and ethics board processes on what and how students learned about research ethics principles. However, it failed to define how the learning impacted their decision-making and experience with integrating the principles in research practice.

Qualitative description within a constructivist framework was used to explore: what graduate students in health disciplines learn about research ethics principles in curriculum; what support they receive from academic supervisors; what perceptions they have of research ethics; and how they apply ethics in research practice. Students in graduate level health discipline programs were recruited via social media and communication shared through health research networks. Eleven students from nursing, rehabilitation sciences, community science, public health and social dimensions of health participated in semi-structured interviews. Participants also assisted with member checking by verifying the accuracy of data representation in their transcripts and reviewing the findings.

Thematic analysis conducted from a factist perspective, assuming the data to be truthful in reflecting reality, identified four themes. Curriculum content including the use of research ethics tutorials, support from supervisors, the ethics application process, and support provided by REBs all have significant impacts on a graduate students' experience with ethics in conducting health research. The present study extends knowledge and understanding by describing how curriculum, supervisors, and REB's can all provide important support to graduate students as they implement their research projects. Suggestions for curriculum enhancement, the supervisor role of academic faculty, and the role of Research Ethics Boards with education were discussed.

Credibility for this research was attained through peer debriefing with the supervisory committee, recording of interviews for referential adequacy, and member checking of transcripts and findings. Limitations included lack of prolonged engagement with participants and triangulation of multiple data sources. Bracketing and reflexivity were utilized to acknowledge the influence of the researcher's career roles, and to mitigate any potential conflicts of interest or power over relationships with participants through thoughtful recruitment processes.

This inquiry into graduate students' experience has given them a voice to describe how they assimilate research ethics principles into practice. By sharing their experience, the students have strengthened their own awareness and confidence as novice researchers. Academic faculty and the research ethics community can use this knowledge to increase awareness, and address the gaps in research ethics education and processes that have been identified. Each member of the research community has an important role to play in supporting this next generation of health researchers with ethical research practice.

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## Appendix A

Research Ethics Board Approval



August 10, 2015

Mrs. Wendy Petillion Faculty of Health Disciplines\Centre for Nursing & Health Studies Athabasca University

File No: 21916

Expiry Date: August 09, 2016

Dear Mrs. Wendy Petillion,

The Faculty of Health Disciplines Departmental Ethics Review Committee, acting under authority of the Athabasca University Research Ethics Board to provide an expedited process of review for minimal risk student researcher projects, has reviewed you project, 'Graduate Students' Experience with Research Ethics'.

Your application has been Approved on ethical grounds and this memorandum constitutes a Certification of Ethics Approval. You may begin the proposed research.

AUREB approval, dated August 10, 2015, is valid for one year less a day.

As you progress with the research, all requests for changes or modifications, ethics approval renewals and serious adverse event reports must be reported to the Athabasca University Research Ethics Board via the Research Portal.

To continue your proposed research beyond August 09, 2016, you must apply for renewal by completing and submitting an Ethics Renewal Request form. Failure to apply for annual renewal before the expiry date of the current certification of ethics approval may result in the discontinuation of the ethics approval and formal closure of the REB ethics file. Reactivation of the project will normally require a new Application for Ethical Approval and internal and external funding administrators in the Office of Research Services will be advised that ethical approval has expired and the REB file closed.

When your research is concluded, you must submit a Project Completion (Final) Report to close out REB approval monitoring efforts. Failure to submit the required final report may mean that a future application for ethical approval will not be reviewed by the Research Ethics Board until such time as the outstanding reporting has been submitted.

At any time, you can login to the Research Portal to monitor the workflow status of your application.

If you encounter any issues when working in the Research Portal, please contact the system administrator at research\_portal@athabascau.ca.

If you have any questions about the REB review & approval process, please contact the AUREB Office at (780) 675-6718 or rebsec@athabascau.ca.

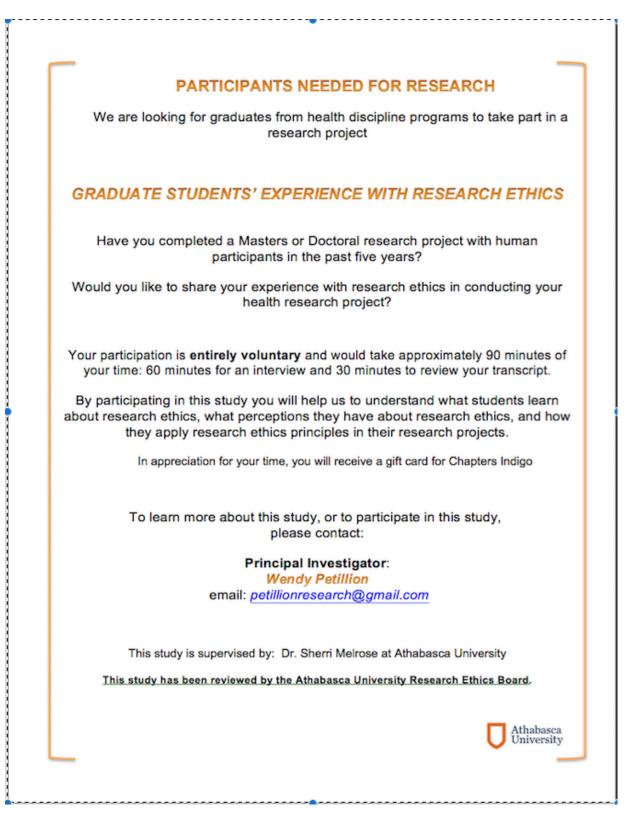
Sincerely,

Terra Murray

Acting Chair, Faculty of Health Disciplines Departmental Ethics Review Committee Athabasca University Research Ethics Board

## Appendix B

#### **Recruitment Poster**



## Appendix C

## LETTER OF INFORMATION / INFORMED CONSENT FORM

Graduate Students' Experience with Research Ethics

September 2015

Principal Investigator (Researcher):	Supervisor:
Wendy Petillion	Dr. Sherri Melrose
Graduate Student	Associate Professor
Centre for Nursing and Health Studies	Centre for Nursing and Health Studies
Athabasca University	Athabasca University
250-718-9370	1-888-281-5863
awpetillion@shaw.ca	<u>sherrim@athabascau.ca</u>

You are invited to take part in a research project entitled *Graduate Students' Experience with Research Ethics.* The information presented should give you the basic idea of what this research is about and what your participation will involve, should you choose to participate. In order to decide whether you wish to participate in this research project, you should understand enough about its risks, benefits and what it requires of you to be able to make an informed decision. Take time to read this carefully as it is important that you understand the information given to you. Please contact the principal investigator, Wendy Petillion if you have any questions about the project or would like more information before you consent to participate.

It is entirely up to you whether or not you take part in this research. If you choose not to take part, or if you decide to withdraw from the research once it has started, there will be no negative consequences for you now, or in the future.

## Introduction

My name is Wendy Petillion and I am a Master of Health Studies student at Athabasca University. As a requirement to complete my degree, I am conducting this research project to learn about graduate students' experience with research ethics in conducting health research. This project is under the supervision of Dr. Sherri Melrose and has funding support from the Athabasca University Graduate Student Research Fund.

## Why are you being asked to take part in this research project?

You are being invited to participate in this project because you have graduated from a university with a Masters or Doctoral degree in a health discipline in the past five years. You have completed a research project as part of your thesis or dissertation and have recent research experience as a graduate student.

## What is the purpose of this research project?

The purpose of this research is to describe what students learn about research ethics, what perceptions they have about research ethics, and how they apply research ethics principles in their research projects.

## What will you be asked to do?

You are invited to participate in a one-hour interview to share your experience about research ethics. The interview may be conducted in person, via phone or Skype; whichever is most comfortable for you. The interview will be scheduled at a location, day and time that is convenient for you and will be audio-recorded. Ten participants will be interviewed.

You will be asked to review your transcript for accuracy and to confirm your comments. The transcript will be provided to you in a password protected email within two weeks of your interview, and you will have one week to return it to the Researcher with any changes.

## What are the risks and benefits?

We do not think there is anything in this study that could harm you. Some of the questions we ask may seem personal and you do not have to answer any question if you do not want to.

We do not think taking part in this study will help you. However, in the future, others may benefit from what we learn in this study.

You will receive a \$20 gift card for Chapters Indigo as a thank you for participating.

## Do you have to take part in this project?

Your involvement in this project is entirely voluntary. You have the right to refuse to participate in this study. If you decide to take part, you may choose to withdraw from the study at any time by contacting Wendy Petillion. You do not have to give a reason and there will be no negative consequences for you. If you withdraw during the interview or prior to the review of your transcript, your data will be removed from the project. If your transcript has been reviewed and returned to the Researcher the data will be kept in the research project.

## How will your privacy and confidentiality be protected?

The ethical duty of confidentiality includes safeguarding participants' identities, personal information, and data from unauthorized access, use or disclosure. Your confidentiality will be respected. Information that discloses your identity will not be released without your consent unless required by law. Only the Researcher, the Supervisor, and a professional transcriptionist will have access to the data. The transcriptionist will sign a Confidentiality Agreement.

A unique code number will be used to identify your audio-recorded file and the transcribed interview. Your name and all identifying data will be removed at the time of

transcription. Participants will not be identified by name or quoted directly in any reports of the completed study.

## How will my anonymity be protected?

Anonymity refers to protecting participants' identifying characteristics, such as name or description of physical appearance. <u>Every reasonable effort</u> will be made to ensure your anonymity; you will not be identified in any publications without your explicit permission.

## How will the data collected be stored?

The audio-recorded interview will be uploaded to a private file in Drop Box for the transcriptionist. The audio-files will be deleted after the transcription. The text data and consent forms will be stored on a password-protected USB and password-protected computer in the Researcher's home office.

Your consent form and interview transcript will be kept for a period of five years after the research project is finished and the final reports have been presented. At that time, the USB and computer files will be deleted and wiped cleaned from the devices and any hard copy data will be shredded. There will be no future secondary use of this research data.

## Who will receive the results of the research project?

You may request a copy of the final results of this research project by contacting Wendy Petillion at <a href="mailto:awpetillion@shaw.ca">awpetillion@shaw.ca</a>

The final results of this research project be submitted to a scholarly journal for publication and presented at professional conferences.

The existence of the research will be listed in an abstract posted online at the Athabasca University Library's Digital Thesis and Project Room and the final research paper will be publicly available.

# Who can you contact for more information or to indicate your interest in participating in the research project?

Thank you for considering this invitation. If you have any questions or would like more information, please contact Wendy Petillion by e-mail at <u>awpetillion@shaw.ca</u> or by phone at 250-718-9370. You may also contact my supervisor by email at <u>sherrim@athabascau.ca</u> or by phone at 1-888-281-5863.

If you are ready to participate in this project, please complete and sign the attached Consent Form and return it by scanning and emailing to <u>awpetillion@shaw.ca</u>.

Thank you.

Wendy Petillion

This project has been reviewed by the Athabasca University Research Ethics Board. Should you have any comments or concerns regarding your treatment as a participant in this project, please contact the Research Ethics Office by e-mail at rebsec@athabascau.ca or by telephone at 1-800-788-9041, ext. 6718.

## **Informed Consent:**

## Your signature on this form confirms that:

- You have read the information about the research project and understand the risks and benefits.
- You have had time to think about participating in the project and had the opportunity to ask questions and have those questions answered to your satisfaction.
- You understand what the research project is about and what you will be asked to do.
- You understand that participating in the project is entirely voluntary and that you may end your participation at any time without having to give a reason, and without any penalty or negative consequences.
- You understand that if you choose to end your participation **during** data collection, any data collected from you up to that point would be destroyed.
- You understand that if you choose to withdraw **after** data collection has ended, your data can be removed from the project at your request, up to your transcript being reviewed and returned to the researcher.
- You have been given a copy of this Informed Consent form for your records.
- You agree to participate in this research project.

	YES	NO
I agree to be audio-recorded	$\bigcirc$	$\bigcirc$
I am willing to be contacted following the interview to	$\bigcirc$	$\bigcirc$
verify that my comments are accurately reflected in the		
transcript.		

Signature of Participant

Date

Principal Investigator

I have explained this project to the best of my ability. I invited questions and responded to any that were asked. I believe that the participant fully understands what is involved in participating in the research project, any potential risks and that he or she has freely chosen to participate.

Signature of Principal Investigator

Date

## Appendix D

## Interview Script

Thank you for accepting the invitation to participate in this research interview about your experience with research ethics as a graduate student. I would like to confirm that you have read and signed the *Letter of Information and Informed Consent Form*. Your participation is voluntary and you may choose to withdraw from the interview at any time. You may also choose to not answer any of the questions. The interview will take up to one hour. Do you have any questions before we begin? Let's get started.

## Interview Questions

## Demographics

- 1) What is your health discipline?
- 2) What level is your graduate education Masters or Doctorate?
- 3) Which University did you take your graduate studies at?
- 4) What year did you finish your degree?

## **Topic Questions**

- 1) What was your experience with research ethics during your graduate research program?
  - What were you taught about research ethics in the curriculum?
  - What support did you receive from your instructor or supervisor in relation to research ethics and your research project?
  - Did you identify any gaps in teaching or support as you went through the research process?
- 2) How did you apply research ethics principles in your research project?
- 3) What was your experience with the ethics application process?
  - What feedback or provisos did you receive from the REB?
  - What additional support could the REB provide?
- 4) Which research ethics principles were most important to you in conducting your health research project?
- 5) What are your perceptions of research ethics?
- 6) How would you describe your overall experience with research ethics?

## Appendix E

Budget

Budget for Research Project Graduate Students' Experience with Research Ethics		
Sony Recorder	\$90	
Transcription	\$969	
11 transcripts @ \$25/hour		
Thank you gift cards for participants	\$220	
11 x \$20		
Poster presentation	\$100	
Total Costs	\$1379	
Funding grants and awards		
AU Graduate Student Research Fund	\$1000	
AU Access to Research Tools Award	\$500	
Total Funding	\$1500	
Balance – to be used for travel to conference for	\$121	
dissemination of results		