Exploration of the Genetic Assistant Position in the Provision of Genetics Services

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A Thesis submitted to the Faculty of Graduate Studies of

The University of Manitoba

in partial fulfilment of the requirements of the degree of

MASTER OF SCIENCE

Department of Biochemistry and Medical Genetics

Genetic Counselling Program

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Winnipeg, Manitoba, Canada

ABSTRACT

Genetic counsellors (GCs) are healthcare professionals with specialized training in genetics and counselling. There are approximately 4,000 certified GCs in North America; however, this is not sufficient to satisfy the demand for services. Approximately 25% of clinical GCs' time is spent on tasks other than clinical care. Based on the concept of skill-management, clinics could increase the time that GCs have to provide clinical care by reassigning tasks that do not require their specialized training to other employees. Accordingly, some institutions have integrated genetic assistants (GAs): non-clerical staff who perform many of the "behind-the-scenes" responsibilities otherwise assigned to GCs. Despite integration of GAs in clinical and laboratory settings throughout North America, there is only one published study about GAs.

Due to the paucity of literature about GAs, this study employed a mixed methods design to explore the GA workforce and the impact of GAs on genetics service provision. Individuals who worked as or with GAs were invited to participate in a survey; a subset of the survey participants were also interviewed about their experiences. Data from the local genetics clinic in Winnipeg was used to examine the relationship between patient volume (e.g., clinical productivity) and staff mix.

The survey and interview data revealed that the scope of the GA position is inconsistent and still evolving. GAs primarily work autonomously, but need adequate training, supervision, and continuing education to be successful. The majority of GAs intend to pursue a career in genetic counselling and thus tend to stay in the position short-term. Most participants reported that integrating a GA reduces genetics providers' roles and responsibilities, allowing them to spend

more time on tasks for which they have specialized training; accordingly, integration of GAs results in increased productivity and improved patient care. Preliminary analysis of the clinic data also suggested that integrating GAs leads to increased GC productivity.

Taken together, the results of this study highlight GAs as an evolving workforce who are vital to improving both productivity and quality of care. Future research efforts should focus on developing competencies for GA positions and further exploring the impact of GAs on productivity.

ACKNOWLEDGEMENTS

Thank you to my supervisor, Jessica Hartley, for your mentorship, supervision, and numerous contributions to the research and this document. I appreciate all the time that you have given to this project, as well as your mentorship for my professional development as a genetic counsellor. Thank you to my committee members, Shannon Chin, Dr. Michelle Liu, and Dr. Christine Kelly, for sharing your knowledge and expertise in your respective areas of interest. I was able to use several different methodologies for this project – each of you were instrumental in carrying out these methodologies and interpreting the results.

I am tremendously appreciative of the financial assistance that I received through the University of Manitoba Graduate Fellowship (Department of Biochemistry and Medical Genetics), the Manitoba Graduate Scholarship, and the Canada Graduate Scholarship from the Canadian Institutes of Health Research to support me over the course of the genetic counselling program.

Throughout my time in the program, I worked with many clinical supervisors who provided support and guidance. Additionally, I had the opportunity to get to know the five other Genetic Counselling students: Taryn Athey, Emily Bonnell, Selina Casalino, Rachelle Dinchong, and Ashleigh Hansen. Thank you for the help, support, fun, and laughter that we shared throughout the program. I am so lucky to have met you all and formed these lasting friendships.

Thank you to my family and friends, especially Jason, Michelle, Justin, Mom, and Pops, for your support over the course of my university education. I could not have done it without your love and encouragement.

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LIST OF ABBREVIATIONS

ABGC	American Board of Genetic Counseling
ABMG	American Board of Medical Genetics
ACGC	Accreditation Council for Genetic Counseling
CAGC	Canadian Association of Genetic Counsellors
CCMG	Canadian College of Medical Genetics
GA	Genetic Assistant
GC	Genetic Counsellor
MD	Doctor of Medicine (Physician)
NSGC	National Society of Genetic Counselors
OTA	Occupational Therapist Assistant
PA	Physician Assistant
PSS	Professional Status Survey
PTA	Physical Therapy Assistant

CHAPTER 1: BACKGROUND/LITERATURE REVIEW

1.1. History of the Genetic Counselling Profession

Genetic counsellors (GCs) are health care professionals who have specialized training in both medical genetics and counselling. Although the profession of genetic counselling emerged in the 1970s, the act of providing genetic counselling to patients and their families began much earlier (Walker, 2009). In order to understand the current state of the genetic counselling profession and the workforce, it is essential to consider where it began.

1.1.1. Origins of Genetic Counselling

1.1.1.1. Eugenics Model

The eugenics model of genetics dates back to the late 1800s. Sir Francis Galton, a Victorian scientist who studied heredity and environment as it relates to human traits, is considered to be the father of eugenics (Gillham, 2001; Reed, 1974). Galton first introduced the term "eugenics" in 1883 in his book entitled *Inquiries into Human Faculty and its Development*. The primary focus of the eugenics model was improving the human race by promoting reproduction among individuals with desirable traits and restricting reproduction among others (Walker, 2009).

Genetics clinics opened in Germany and Denmark during the 1930s for the purpose of offering marriage advice to couples (Paul, 1997). In the 1940s, the United States and Britain opened genetics clinics, the first of which were the Dight Institute at the University of Minnesota, the Hereditary Clinic at the University of Michigan, and the medical genetics program of the Bowman Gray School of Medicine at Wake Forest University (Turner, 2012). These early clinics were rooted in eugenics principles. Typically, geneticists (first non-physician PhD geneticists,

and then physician geneticists) would provide disease recurrence risks to families, with the aim of avoiding recurrence in any future pregnancies; since diagnostic genetic testing was not available at the time, the only way to avoid recurrence was to stop having children (Walker, 2009).

The eugenics model has been the target of major criticisms from both scientific and social perspectives. Scientific criticisms of eugenics include poor study design and methodologies, oversimplification of complex diseases (e.g., intellectual disability and mental illness), and ignorance of environmental contributors to disease (Allen, 2011). The major criticism from a social perspective concerns the unfortunate ways in which eugenics was used in history. As examples, early eugenics measures included mandatory sterilization, the Immigration Restriction Act, and euthanasia of individuals considered to be "genetically defective" (Walker, 2009). Furthermore, the eugenics model assumed that all individuals would make the decision to not have any future children when presented with a recurrence risk for a genetic condition; this is in direct opposition to the concepts of non-directiveness and facilitative decision-making that are major tenets of modern-day genetic counselling (Weil, 2000).

Though the eugenics model has fallen out of favour among both the scientific community and the general public, modern-day genetic counselling emerged from this early model and is still seen as associated with a eugenics perspective by some. For example, genetics professionals support and advocate for the rights of two groups with contrasting needs, priorities, and perspectives: 1) parents pursuing reproductive options to avoid having a child with a genetic condition, and 2) individuals with genetic conditions. Some argue that genetics professionals do

not balance their responsibilities to both of these patient groups, which has resulted in a tenuous relationship between the disability and genetics communities (Madeo, Biesecker, Brasington, Erby, & Peters, 2011). Due to the unfortunate and detrimental history of the genetics field, as well as current concerns raised by representatives of the disability community, it is imperative that genetics professionals work in collaboration with this community to ensure that their values are preserved and reflected in the practice of modern-day genetic counselling.

1.1.1.2. Birth of Genetic Counselling

In 1943, Dr. Tage Kemp (a Danish geneticist) coined the term "genetic hygiene" in his book, entitled *Arvelighedslaere* (as cited by Reed, 1974). In 1947, Dr. Sheldon Reed (a PhD biologist and geneticist at the Dight Institute) proposed the term "genetic counselling" as a replacement for "genetic hygiene" and other terms that were being used at the time, such as "genetic consultation" and "genetic advice". Dr. Reed described genetic counselling as "a kind of genetic social work without eugenic connotations" (Reed, 1974, p. 335). He first presented the term "genetic counselling" to the Dight Institute Advisory Committee in December 1947; the term subsequently appeared in their bulletins and continues to be used in the current age of genetics.

By 1968, there were 101 genetics clinics in the United States and 4 genetics clinics in Canada (Turner, 2012). Genetics clinics continued to open across the world; by 1974, there were 387 locations providing genetics services in the United States and 890 locations worldwide (Reed, 1974).

1.1.1.3. Physicians as Genetic Counsellors

Initially, genetics services were provided by PhD geneticists; these individuals were typically trained as zoologists, human biologists, or population geneticists and did not have medical training (Herrmann & Opitz, 1980). Due to their educational background, PhD geneticists tended to be more interested in learning and discovering new information rather than providing care to the individual (Kenen, 1984).

In the 1950s and 1960s, significant advances were made in the field of genetics. Such advances included identifying the correct human chromosome complement (n=46), elucidating the cytogenetics behind common aneuploidy syndromes (i.e., Down syndrome, trisomy 18, trisomy 13, Klinefelter syndrome, and Turner syndrome), and the ability to identify carriers for certain hemoglobinopathies and metabolic diseases (Walker, 2009). Consequently, the scientific community recognized that there were potential clinical applications of genetics services (e.g.,. preventing births of individuals with congenital anomalies). This led physicians with an interest in genetics to begin providing genetic counselling (Herrmann & Opitz, 1980; Kenen, 1984). Many believed that physicians were the most appropriate individuals to provide genetic counselling, as explained in the following quote from the Dight Institute's Bulletin No. 6: *"The function of a counselor in human genetics has been inherited mainly by the physician, which is as it should be, for the problems are very often medical as well as genetic"* (as cited by Reed, 1974).

As opposed to PhD geneticists, physicians focused on providing care to individual patients (Kenen, 1984). However, they typically followed a paternalistic approach; most geneticists (such

as Drs. Lee Dice and Sheldon Reed) assumed that patients would make "rational choices" (from a eugenics point of view) if genetic information was available to them (Turner, 2012). The majority of physicians viewed counselling as an obligation, rather than an integral component of the clinical encounter (Stillwell, 2015). However, some physicians incorporated elements of modern-day genetic counselling in their session. For example, the genetic counselling provided by Dr. Reed differed from other medical services in that he established a caring and respectful relationship with his patients (Resta, 1997).

1.1.2. Establishing and Growing a Genetic Counselling Profession

1.1.2.1. First Genetic Counselling Training Programs

In 1971, the Genetics Training Committee of the National Institute of General Medical Sciences reported that a 68% increase in geneticists was needed by 1988 in order to fulfill demand for genetics services in the United States (as cited by Marks & Richter, 1976). As a means to overcome the shortage of practicing geneticists, Dr. Melissa Richter and Joan Marks (MSW) (1976) proposed formal Masters level training for a genetic associate position. They defined the genetic associate as "a new health professional who works under the supervision of a medical geneticist as a member of the genetics team" (Marks & Richter, 1976, p. 388). At the time, the program was opposed by those who felt that only individuals with medical or doctorate level training could provide genetic counselling (Stern, 2009).

Despite opposition from geneticists, the first Master of Science program in Genetic Counselling was established at Sarah Lawrence College in 1969 under the direction of Dr. Melissa Richter (Stern, 2009). The initial proposal for the program was based in eugenics; however, the focus

was re-directed towards individual decision-making and patient-centred care, which remain foci of genetic counselling today. Following leadership by Dr. Richter, Joan Marks (MSW) became the program director and incorporated a psychosocial focus into the training, which remains a key component of modern-day genetic counselling practice.

The training program at Sarah Lawrence College was rooted in feminist values. Dr. Richter was an advocate for women's education, especially for returning students who had previously left post-secondary education to raise a family (Stern, 2009). Additionally, the program began during the movement towards reproductive freedom, a time during which women gained access to contraception, prenatal genetic diagnosis, and termination (Stern, 2009; Stillwell, 2015; Walker, 2009).

1.1.2.2. Genetic Counsellor Title

Early GCs had a variety of titles, including genetic associate, genetic assistant, genetic nurse, genetic social worker, and research assistant (Herrmann & Opitz, 1980; Zeesman & Creighton, 2000). The GCs often referred to themselves as "genetic counsellors"; however, geneticists and genetic counselling training programs usually did not afford them this title (Kenen, 1984). Physicians opposed this title since the GCs did not have medical training (Heimler, 1997). Dr. Charles Epstein presented this viewpoint in a 1973 publication:

> *"To me, the term 'genetic counselor' connotes one who is capable of giving genetic counseling, with all that it entails. It is my contention, and I am prepared to be proven wrong, that except in the rarest of instances, non-medically trained individuals are not so prepared. . . . Basic geneticists (PhD), public health nurses, social workers, or genetic associates . . . are certainly capable of providing valuable assistance and of carrying out many of the functions that are part of the overall counseling situation. . . . I do not regard these individuals as 'genetic counselors' . . .*

> *associates, assistant, aides, collaborators, yes; counselors, no!"* (as cited by Heimler, 1997)

Despite opposition, when early GCs were establishing a professional society, they decided to name the profession "genetic counselling" to avoid diminishing the value of GCs (Heimler, 1997; Kenen, 1984).

1.1.2.3. Establishing a Professional Society

Early GCs recognized the need to establish an independent professional society, in order to help create a "separate professional identification" (Heimler, 1997, p. 321). The idea of a professional society for GCs first arose during the early 1970s and was discussed more formally near the end of the decade (Heimler, 1997). Many early GCs contributed time and monetary donations between 1978 and 1979, which led to incorporation of the National Society of Genetic Counselors (NSGC) in New York on Oct 1, 1979. The society published results of its first membership survey in December 1981, at which time there were 238 full members (Begleiter, Collins, & Greendale, 1981). A Code of Ethics for genetic counsellors was adopted in 1992 (Benkendorf, Callanan, Grobstein, Schmerler, & FitzGerald, 1992). The society also developed its own journal, *Journal of Genetic Counseling*, which was first published in March 1992 (Heimler, 1997) and is still in press today.

In the 1980s, two Canadian GCs (Susan Zeesman and Susan Creighton) learned about NSGC and contacted others about establishing a similar communication network in Canada (Zeesman & Creighton, 2000). In response to widespread interest, a newsletter (*CROSS-OVER*) was created and distributed to GCs across the country. In the mid-1980s, the Canadian College of Medical Genetics (CCMG) identified a need to define the roles of GCs (called genetic associates at the

time). Fifty-two GCs met in Toronto in 1987 and agreed to pursue establishment of a professional society within Canada to ensure their voices were heard. As a result, the Canadian Association of Genetic Counsellors (CAGC) became an official not-for-profit organization on February 9, 1990. The society assembled a *Canadian Directory of Genetic Support Groups* and continued distribution of *CROSS-OVER*, in addition to making many other contributions to the genetics community.

1.1.3. Boundaries Between Physicians and Genetic Counsellors

Genetic counselling has been a constantly evolving profession since its inception. Early GCs often worked with pediatric geneticists (Balkite & Smith, 2009). Their primary role was to support physicians by performing tasks that were of low priority to the physicians and that did not require their specialized Masters level training. Examples of such tasks included obtaining records, typing letters, obtaining histories, and preparing pedigrees (Stillwell, 2015). In a report based on a 1972 Workshop on Genetic Counseling, Fraser (1974) delineated the roles of a GC compared to a geneticist. GCs at the time would collect medical and family histories, while the geneticists would review the collected histories and any relevant literature, order tests and consultations, and estimate the recurrence risk for a genetic condition.

Over the last 35 to 40 years, the roles assigned to GCs and geneticists in North America have shifted (Ormond, 2013), leading to changes in the boundaries and relations between these two professions (Leeming, 2013; Zeesman & Creighton, 2000). This change was driven by an increase in both the workload of geneticists and the number of tests available in the 1980s. For example, routine availability of diagnostic prenatal procedures (i.e., amniocentesis, chorionic

villus sampling, and ultrasound) allowed for integration of GCs in prenatal settings, in addition to expansion of some GC roles (Balkite & Smith, 2009; Paul, 1997; Stillwell, 2015). GC autonomy varied according to their relationship with the geneticist on their team, as well as the setting in which they were working (Stillwell, 2015). However, as time went on, GCs achieved greater autonomy and consequently, recognition as a profession (Adams, 2010; Leeming, 2013).

Modern genetics clinics are usually comprised of medical geneticists, GCs, and administrative professionals, at minimum. Medical geneticists usually possess an MD or DO degree and have completed a residency or fellowship in medical genetics (American Board of Medical Genetics and Genomics, 2017; Canadian College of Medical Geneticists, 2007; Pagon, Hanson, Neufeld-Kaiser, & Covington, 2001; Walker, 2009). Medical geneticists in North America are certified by the American Board of Medical Genetics and Genomics (ABMG) or Canadian College of Medical Genetics (CCMG) (Walker, 2009). GCs possess a Masters level degree from an accredited Genetic Counselling program. GCs in North America are certified through the American Board of Genetic Counseling (ABGC) or CAGC. In North American clinics, both medical geneticists and GCs have patient appointments; most GCs see patients independently and manage their own patient load. However, certain tasks must be performed by a physician, including physical examinations and making clinical diagnoses. GCs have formal education in psychosocial skills and incorporate these skills in their patient interactions, which is another major distinction between GCs and medical geneticists (Resta, 2006). Participants in a study that explored the value of GCs reported that GCs add a patient-centred approach, communication and counselling skills, understanding of psychosocial, legal, and ethical issues, and increased availability to patients (Paneque et al., 2017). Differences stated between GCs and geneticists

were the indications and complexity of appointments, formal training in counselling and non-directiveness, and level of autonomy. Beyond GCs and medical geneticists, numerous other positions are being incorporated in genetics clinics to meet demand for services and best serve patient populations.

1.1.4. Who are Genetic Counsellors Today?

1.1.4.1. Current Definition and Competencies

In 2006, the NSGC Genetic Counseling Definition Task Force published our current definition of genetic counselling, as follows:

> "Genetic counselling is the process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease. This process integrates the following:
>
> - Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence.
> - Education about inheritance, testing, management, prevention, resources, and research.
> - Counselling to promote informed choices and adaptation to the risk or condition."

The ABGC first developed practice-based competencies for genetic counsellors in 1996 (Fine, Baker, & Fiddler, 1996). Several revisions have occurred since; the most recent version was assembled by the Accreditation Council for Genetic Counseling (ACGC) and contains 22 practice-based competencies that are needed to successfully practice as a GC (Doyle et al., 2016). These competencies are used to guide training program curricula and evaluate the skillset

of practicing GCs. The competencies are divided into four primary domains: 1) genetics expertise and analysis, 2) interpersonal, psychosocial, and counselling skills, 3) education, and 4) professional development and practice.

The CAGC created its own list of practice-based competencies for GCs practicing in Canada (Ferrier et al., 2013). The Canadian competencies are divided into three domains: 1) counselling and communication, 2) genetic expertise, and 3) professionalism and ethical practice. Alongside the practice-based competencies, the CAGC also assembled a list of knowledge-based competencies (which were updated in 2018); the Canadian certification examination is based on these competencies, as are many other initiatives of the CAGC (e.g.,. practice guidelines and training programs) (Canadian Association of Genetic Counsellors, 2018). The nine units are: 1) epidemiology, population, and basic human genetics, 2) clinical genetics, 3) molecular genetics, 4) cytogenetics, 5) biochemical genetics, 6) cancer genetics, 7) genetic screening, 8) prenatal diagnosis, and 9) genetic counselling.

1.1.4.2. Accredited Training Programs

In 1980, the ABMG became responsible for approval of clinical training sites, review of student's logbooks, and certification of GCs (Walker, 2009). However, there was rapid growth in the number of genetic counselling programs in North America (Walker et al., 1990). As a result, the ABGC was incorporated in 1993 and assumed two main activities: 1) certification of GCs, and 2) accreditation of genetic counselling programs (Walker, 2009). In 2012, these responsibilities were divided between two organizations: the ABGC remained responsible for

GC certification, while the ACGC was established to manage program accreditation (Accreditation Council for Genetic Counseling, 2019b).

As of spring 2019, there were a total of five Canadian programs (four of which are accredited) and 45 accredited American programs in genetic counselling (Accreditation Council for Genetic Counseling, 2019a). Current genetic counselling programs are at the Masters degree level. They include three core components: 1) clinical training, 2) didactic instruction, and 3) research and other scholarly activities. Programs are designed based on the standards for accreditation, which are reviewed and updated every five years (Accreditation Council for Genetic Counseling, 2019b). Genetic counselling programs focus on training their students in the core competencies for GCs. (Accreditation Council for Genetic Counseling, 2015). Upon graduation from an accredited program, graduates are eligible to write the ABGC and CAGC certification examinations (American Board of Genetic Counseling Inc., 2019b; Canadian Assocation of Genetic Counsellors, 2018).

1.1.4.3. Genetic Counsellor Workforce

As of 2018, there were more than 4,000 GCs who were certified through the ABGC (American Board of Genetic Counseling Inc., 2019a). The NSGC had over 3,600 members and the CAGC had more than 340 members (National Society of Genetic Counselors, 2018b).

Every two years, the NSGC surveys its membership and publishes a Professional Status Survey (PSS)[1]. This report includes information about demographics, salary and benefits, work environment, service delivery and access, professional life, and satisfaction. The 2018 PSS surveyed a total of 4,780 GCs who were: 1) a member of the NSGC, 2) a member of the CAGC, and/or 3) diplomates of the ABGC (National Society of Genetic Counselors, 2018b). They received responses from 2,543 GCs (53% response rate). The majority of the respondents to the 2018 PSS were female (95%) (National Society of Genetic Counselors, 2018a). Over 90% of the GCs identified as white or Caucasian. The GC workforce was relatively young, which reflects the recent evolution of this profession: 70% of genetic counsellors were under 40 years of age and more than 80% graduated from a genetic counselling program after the year 2000.

1.1.4.4. Genetic Counselling Settings

According to the 2018 PSS, the majority of individuals worked in a full-time position (88%) and about one-third worked remotely at least some of the time (National Society of Genetic Counselors, 2018e). Just over half of the GCs provided direct patient care (59%), while 25% provided non-direct services, and 16% provided a combination of both direct and non-direct services. The most common work settings (i.e., settings that 10% or more GCs reported working in) were: university medical centres (30%), diagnostic laboratories (commercial, non-academic) (18%), public hospital/medical facilities (17%), and private hospitals/medical facilities (14%). The most commonly reported areas of practice were cancer (46%) and prenatal (32%), followed by pediatrics (23%) and general genetics (23%).

[1] CAGC conducted an independent PSS of its membership until 2018. Since then, CAGC members are included in the NSGC PSS.

1.1.4.5. Genetic Counsellor Shortage

It is widely recognized that there is a shortage of genetics providers, including GCs. A workforce study predicted that the shortage of GCs providing direct patient care in the United States would persist until 2024, based on a balance of one GC per 100,000 civilians (Hoskovec et al., 2017). In order to achieve a balance of one GC per 75,000 civilians, the shortage would persist until approximately 2030.

The persistent shortage of GCs has been attributed to several factors. First, there are a limited number of graduates from accredited genetic counselling programs in North America. While there are currently 49 accredited programs (Accreditation Council for Genetic Counseling, 2019a), there are always more applicants to genetic counselling programs than spots available. Abacan et al. (2019) estimated that there are more than 1,200 applicants to American and Canadian programs and yet only 400 spots in American programs and 25 in Canadian programs. Despite the fact that most of these applicants have high grade point averages and Graduate Record Examination scores, the programs can only accommodate approximately one-third of the applicant pool (Pan, Yashar, Pothast, & Wicklund, 2016). In a mixed-methods study conducted in 2011, American program directors identified six barriers to the expansion of genetic counselling programs: 1) lack of funding, 2) inability to meet accreditation requirements (e.g.,. not enough qualified supervisors), 3) availability of clinical rotations, 4) shortages of faculty and research supervisors, 5) lack of diversity among applicant pool, and 6) inadequate physical space (e.g.,. student rooms) (Pan et al., 2016). Despite these barriers, 73% of program directors felt that programs should increase in size (the remaining 23% were undecided).

Second, GCs have adapted their skills to a broad range of positions outside of traditional clinical positions. GCs first entered non-traditional work settings (primarily in genetics laboratories) in the 1990s; some of these GCs worked as liaisons between patients or providers and the laboratory, while others were employed within business or marketing departments (Balkite & Smith, 2009). Currently, GCs work in laboratory, industry, research, education, and public health settings, in addition to traditional clinical positions (Stoll, Kubendran, & Cohen, 2018). In the 2018 PSS, approximately one-third of respondents reported working in settings outside of medical facilities (21% in laboratory settings and 15% in other settings) (National Society of Genetic Counselors, 2018e). In fact, due to the significant number of GCs employed in laboratory settings, the ACGC now requires genetic counselling programs to include curriculum about and observation of activities in a genetics laboratory (McWalter et al., 2018). The primary reason that GCs have easily assimilated into other work settings is that their genetics knowledge and formal training in the four core competencies (i.e., communication, critical thinking, interpersonal skills, and ethics) can be applied to a variety of positions (Balkite & Smith, 2009; McWalter et al., 2018). As a result, GCs have more opportunities to advance their career than ever before, including through promotions within academic settings, administrative and leadership roles, and career ladders in clinical and industry settings (Baty, 2018).

Last, there is an ever-increasing demand for genetics services. In the 2018 PSS, 40% to 55% of GCs providing direct patient care reported a moderate or significant increase in new patients since 2016 (results varied among service delivery models, e.g.,. phone, in-person, web-based/video, or group counselling) (National Society of Genetic Counselors, 2018d). Furthermore, the majority of GCs reported that the number of returning patients either stayed the

same or increased over those two years. In the same report, approximately 20% of GCs reported that new patients waited over one month for the third "next available" appointment with a GC alone. Approximately 50% reported wait times greater than one month for the third "next available" appointment with both a GC and a geneticist. Similarly, a 2015 needs assessment study found that over 30% of geneticists had wait times greater than three months for routine appointments, compared to 10% in a 2005 study (Maiese, Keehn, Lyon, Flannery, & Watson, 2019). In the same study, 21% of other genetics providers (including GCs, metabolic dietitians, registered nurses, physician assistants, and laboratory specialists) reported wait times longer than three months for appointments with themselves. The respondents also reported a total of 100 open positions for medical geneticists and 200 open positions for GCs across their institutions, which further compounds issues with wait times and caseloads.

1.2. Health Workforce/Health Human Resource Theory

The area of health workforce or health human resources addresses issues related to personnel shortages, training, certification, and professional regulation. Based on the purposes of the present study, this review will focus on workforce shortages and health human resource strategies to manage such shortages. However, one should not overlook the fact that health workforce theory involves multiple integral components beyond the distribution of labour.

1.2.1. Health Human Resources

Health human resources pertains to the clinical and non-clinical staff that are involved in the provision of both individual and public health interventions (World Health Organization, 2000).

Health human resources are an integral component of the Canadian health care system (Birch & Bourgeault, 2007). In fact, in most health care systems, human resources are one of three main health system inputs (the other two being capital and consumables) and typically constitute two-thirds of recurrent health expenditures (World Health Organization, 2000). For these reasons, health human resources is not an independent factor, but rather is intertwined with the success of policy initiatives, access to health services, and quality of patient care. Accordingly, human resources is an important topic of consideration when planning health care delivery (Birch & Bourgeault, 2007).

1.2.2. Workforce Shortages

Zurn et al. (2004) described several categories of workforce imbalances or shortages. First, workforce shortages can be defined in two different ways. A shortage may be identified when the available workforce cannot meet employers' demand for skills (i.e., presence of unfilled positions). Shortages may also be defined based on pre-determined criteria, such as the amount of care that patients are expected to receive or the ratio of health care providers to population size (e.g.,. one provider per 1,000 patients). Second, workforce imbalances can be static or dynamic. A static shortage is unchanging, which can be due to a variety of factors, such as lengthy education requirements or a limited number of training programs. On the other hand, dynamic shortages change rapidly as a result of a competitive labour market. Third, workforce shortages can be quantitative or qualitative. A quantitative shortage is one where there are no personnel to fill vacancies, while a qualitative shortage is one where there are personnel to fill vacancies, but the personnel do not fulfill certain qualities that the employers desire. Last, Zurn et al. (2004) provided the following typology of workforce imbalances: profession/specialty

imbalances, geographical imbalances, institutional and services imbalances, and gender imbalances.

Many factors can drive health workforce shortages. Such factors can include societal trends – for example an aging workforce, early retirement age, and reduction in work hours (Dubois & Singh, 2009). Increased demand for labour and associated health care services, as well as a decreased supply of a professional/occupational group can also lead to shortages (Zurn, Dal Poz, Stilwell, & Adams, 2004). Furthermore, the health care model, current health policies, available resources, and external global factors can also influence workforce imbalances (Zurn et al., 2004).

1.2.3. Strategies to Manage Workforce Shortages

Staff-mix refers to the number and type of personnel, while skill-mix focuses on the roles, responsibilities, and activities that the workforce is trained/educated for and capable of performing (Dubois & Singh, 2009). Despite these differences, both strategies aim to identify the best composition of professionals and other staff to efficiently deliver health care services (Dubois & Singh, 2009). Accordingly, staff-mix or skill-mix can be altered to cope with workforce shortages.

1.2.3.1. Staff-Mix

As described by Dubois and Singh (2009), staff-mix relates to several different characteristics of a workforce. First, staff-mix can include the number of personnel in a health care setting, which influences workload and amount of time spent engaged in patient contact. Second, one can

consider qualifications, such as the proportion of staff with certain education, training, and/or credentials. Third, staff-mix can pertain to the amount of experience within the workforce (e.g.,. proportion of junior versus senior staff). Last, staff-mix can also relate to representation of disciplines or specialties; this is especially relevant in the context of multi-disciplinary teams, which are becoming increasingly popular in a variety of health care settings. One criticism of the concept of staff-mix is that it focuses on proxy measurements of skills (such as education level, profession, and amount of experience), rather than actual skills and roles within the workforce (Dubois & Singh, 2009).

1.2.3.2. Skill-Mix and Skill-Management

The priority of skill-management is to identify the optimal skill-mix in a health care setting, in order to ensure that professionals and other staff are best using their education/training, skills, knowledge, and experience; this leads to optimization of the workforce and hopefully, better patient care (Dubois & Singh, 2009). Skill-management can involve a variety of strategies to balance demands for health care services with the current workforce conditions. Examples of these strategies include role enhancement, role enlargement, role substitution, and role delegation, which are each detailed by Dubois and Singh (2009) and briefly explained here. Role enhancement involves the expansion of a group's skills, enabling them to assume new roles that were previously performed by individuals of higher professional status. These roles are still within the group's scope of practice, but are not routine; because role enhancement requires the application advanced knowledge and skills, it represents what has been referred to as "advanced practice" in some health care professions (Cancer Care Ontario, 2006). In contrast, role enlargement refers to the expansion of a group's activities to encompass roles that were

previously performed by individuals of equal or lower professional status. Role substitution is the process through which a group extends their scope of practice across typical professional/occupational boundaries. Last, role delegation enables professionals to delegate tasks to other staff at a different status level (usually lower).

Administrators may ultimately decide to review skill-mix in a health care setting for a range of reasons; these can include unfilled vacancies/workforce shortages, technological advances, changes in professions/occupations, the need for professional/occupational standards and/or training, improvement or maintenance of quality of services, and productivity increase, among others (Buchan, Ball, & O'May, 2000). In response to health workforce shortages, there has been significant research into alterations of skill-mix. In fact, one study found that interest in skill-mix (measured by number of publications) significantly increased in the late 1990s compared to previous years (Buchan & Dal Poz, 2002). Prior to 2000, most research studies focused on skill-mix in the contexts of the nursing workforce and substitution of nurses in place of physicians (Buchan et al., 2000). Recently, more studies have explored skill-mix in relation to other professions and occupations. When faced with workforce shortages, skill-mix review is usually undertaken in the context of exploring new ways to meet needs through either role substitution, the creation of new positions, or the introduction of new cadres (Buchan et al., 2000; World Health Organization, 2000). For this reason, role substitution is explored in more detail below.

1.2.3.3. Role Substitutions

Horizontal and vertical role substitutions refer to professionals or other staff assuming tasks that were previously performed by other workers (Nancarrow & Borthwick, 2005). Horizontal

substitution involves redistributing roles to providers who have a similar level of training and expertise as those who traditionally performed them but are in different disciplines (e.g.,. shared roles between occupational therapists and physiotherapists) (Dubois & Singh, 2009; Nancarrow & Borthwick, 2005). In contrast, vertical substitution involves reassigning tasks to staff that do not have the same level of training and expertise as those who traditionally performed the role (Dubois & Singh, 2009; Nancarrow & Borthwick, 2005). In most cases of vertical substitution, roles are reassigned to staff with less training and expertise (e.g.,. rehabilitation services assistants); however, vertical substitution may also involve the transfer of tasks to individuals with a higher level of training and expertise, such as in the case of midwifery where doctors medicalized a role traditionally performed by community women (Nancarrow & Borthwick, 2005).

Role substitutions have been incorporated in numerous health care settings, involving a variety of health care professionals. The reason behind such substitutions is often because professionals are performing tasks that do not require their specialized training; in order to address workforce shortages, such tasks can be assigned to staff of lower professional status, allowing highly trained staff to allocate more time to tasks that do require their specialized training (Nancarrow, 2004). For example, in a 1998 literature review, Richardson et al. summarized the findings of more than 20 studies that collected data on tasks performed by physicians (primarily family physicians), which could instead be performed by other staff. Reports from these studies indicated that 25% to 70% of physicians' tasks could be delegated to others.

1.2.3.4. Impact of Altering Skill-Mix

Altering skill-mix, such as through role substitutions, can impact the professionals who relinquish certain roles, the workers who assume these roles, and the relationships between these two groups. Abbott (1988) felt that professions were constantly engaged in disputes over boundaries, given the overlapping and neighboring nature of professional/occupational boundaries (as cited by Nancarrow & Borthwick, 2005). Role overlap and changing roles can challenge the identity of a profession, which may cause conflict and subsequently lead to low morale and poor working relationships (Dubois & Singh, 2009).

In some cases, professionals may be uncomfortable with or resistant to role substitutions. For example, in a report on the integration of an occupational therapist assistant in a European setting, occupational therapists were reluctant to let go of some of the roles that they traditionally performed. For some, this was because the roles being reassigned (primarily patient interactions) were the very reason why they entered the profession (Mackey & Nancarrow, 2004). In other cases, professionals may feel threatened by role substitution. In fact, role substitution has also been referred to as "encroachment" (Nancarrow & Borthwick, 2005), the connotation of which explains why some conflicts can arise between different professional/occupational groups when substitution occurs. Furthermore, re-assignment of tasks may reinforce institutional and professional hierarchies. In his 1954 book, Hughes described division of labour based on "dirty work", whereby those of higher professional status re-assign less desirable, nuisance tasks or "dirty work" to staff of lower status. In such scenarios, the professionals retain tasks that are "an essential, symbolically-valued part of [their] work" (Hughes, 1954, p. 122). This reassignment increases the status gap between the professionals and other, non-professional staff.

It should be noted that conflicts do not always arise as a result of role substitution. For example, in a study of intermediate care teams in the European setting, Nancarrow (2004) found that various professionals (i.e., physiotherapists, occupational therapists, nurses, and social worker) were not threatened by role substitutions. This was perceived to be related to confidence in one's own role and possessing an understanding of others' roles. However, because professional boundaries are intertwined, changes in the role of one group of professionals will usually, in turn, impact others' roles and professional boundaries (Nancarrow & Borthwick, 2005).

1.3. Adaptation within Health Professions to Manage Workforce Shortages

Throughout the history of Westernized medicine, there have been shortages of health care providers. More recently, the global health workforce shortage of physicians, nurses, allied health professionals, support workers, and administrators has been widely recognized (Dubois & Singh, 2009). As explained in the previous section, institutions can take a variety of approaches to manage shortages of health care providers, including alteration of skill-mix through skill-management. One example of a skill-management strategy is role substitution, which has been used in the contexts of primary health care provision, as well as allied health professions (including genetic counselling).

1.3.1. Physician Assistants

The physician assistant (PA) position emerged in the United States in the 1960s (Cawley, 2007). The position arose in response to a shortage of general practitioners during the 1940s and 1950s (Cawley, 2007; Cawley, Cawthon, & Hooker, 2012). The PA position was designed on the basis of role substitution; PAs were envisioned as "physician extenders", individuals who could

perform tasks that had previously been performed by physicians (Cawley et al., 2012). Programs were often designed to meet the needs of certain communities, such as increasing access to primary care in rural areas or among underserved populations (Cawley, 2007; Cawley et al., 2012). In order to allow PAs to enter the workforce quickly, early programs were typically two years in length; these programs also did not have any educational prerequisites, though students typically had an extensive medical background through work as a nurse or in the military (Cawley, 2007). In the early stages of PAs, physicians were largely in support of the position, since these individuals were supervised by a physician who could therefore control their activities (Cawley et al., 2012). Over time, physicians recognized the benefits of employing PAs, specifically: benefits to the employer (e.g.,. higher quality of life, increased earnings, opportunity for collaboration, more flexibility, and opportunity to expand one's practice), benefits to the patient population (i.e., better access and continuity of care) and benefits to the healthcare system (i.e., shorter wait times and increased access for previously underserved regions/populations) (Taylor et al., 2013).

The implementation of PAs in Canada began in response to a number of issues within the health care system, namely long wait times, significant chronic diseases, an aging population, a need for mental health services, and health inequities (Fréchette & Shrichand, 2016). There is actually an extensive history of PAs in the Canadian military since the 1960s; however, they were not implemented in the public health care system until much later (Jung, 2011). The first civilian programs were established in 2008 at the University of Manitoba and McMaster University, though the University of Manitoba program is currently the only Canadian program at the Masters degree level (Fréchette & Shrichand, 2016). In contrast, the majority of training

programs in the United States are a Masters degree level, which was decided due to the academic rigor of the program and the applicant pool (most already had Bachelor's degrees) (Cawley, 2007).

The PA workforce is quite large in the United States compared to in Canada, likely owing to its earlier introduction, the presence of more training programs, and unstable funding for physician assistant positions in Canada (Fréchette & Shrichand, 2016). At the end of 2018, there were over 130,000 certified PAs in the United States (National Commission on Certification of Physician Assistants Inc., 2019). In comparison, there were only approximately 500 PAs in Canada as of 2016 (Fréchette & Shrichand, 2016). Despite these differences, the role of PAs is synonymous – to expand the delivery of medical services through role substitution. The PA position could be likened to a GC position, since both often require Masters level training and allow graduates to take on roles that were traditionally performed by a physician.

1.3.2. Rehabilitation Assistants

1.3.2.1. Occupational Therapy Assistants

Similar to PAs, assistant positions have been implemented in rehabilitation services to meet service inadequacies. Occupational therapists first emerged in the 1920s (Salvatori, 2001). Several decades later, in the 1950s, there was an unmet need for occupational therapists as they began providing rehabilitation services to World War II veterans (Haynes & Loesche, 2017; Salvatori, 2001). The shortages were most significant in psychiatric settings and led to the creation of occupational therapist assistant (OTA) positions. In the 1990s, the demand for occupational therapy services further increased as the prevalence of disability and chronic

diseases rose (Salvatori, 2001); as such, the opportunities for OTAs also expanded (Clynch, 2017). Today, OTAs are employed in a wide range of settings in which occupational therapists also work. They are currently defined as "individuals who have the job-related competencies to support occupational therapists in delivering occupational therapy services" (Canadian Association of Occupational Therapists, 2018, p. 3) and accordingly receive direct supervision from occupational therapists.

As with PAs, formal training for OTAs began much earlier in the United States than in Canada (late 1950s in the United States versus 1990s in Canada) (Clynch, 2017; Salvatori, 2001). Currently, there are 36 training programs for OTAs or rehabilitation therapy assistants in Canada (Occupational Therapist Assistant & Physiotherapist Assistant Education Accreditation Program, 2013) and over 100 OTA training programs in the United States (The American Occupational Therapy Association Inc., 2019). Most OTA training programs confer a two-year associate degree. At this time, there are significant career prospects for OTAs – in 2016, the United States Bureau of Labour Statistics estimated a total of 46,800 OTA positions (Bureau of Labor Statistics: United States Department of Labor, 2019a).

1.3.2.2. Physical Therapy Assistants

The physiotherapy profession first emerged in the early 1900s (Clynch, 2017). Approximately two decades later, the need for physical therapy services increased exponentially. Outbreaks of poliomyelitis in the 1940s and 1950s led to an increased need for physiotherapy services for rehabilitation of affected individuals (usually children) (Carpenter-Davis, 2003; Clynch, 2017). Furthermore, veterans from World War II required rehabilitation for the injuries they sustained

(Clynch, 2017). In response to demand, informal training for physical therapy aides (later called physical therapy assistants or PTAs) began in the 1950s (Carpenter-Davis, 2003). In these early days of PTAs, new rehabilitation and treatment facilities were opened and Medicare was created, which led to further increases in demand.

As the use of physiotherapy services became more common, the scope of practice extended beyond treatment for poliomyelitis and war injuries to also include individuals with cardiopulmonary and orthopedic conditions (Carpenter-Davis, 2003). To alleviate the resultant shortage of physical therapists, formalized training programs for PTAs emerged in the late 1960s (Clynch, 2017). When PTAs became capable of performing many roles without constant supervision (as a result of their formal training), physiotherapists expressed concerns that PTAs would absorb most of the patient interactions (the very reason many of them entered the profession) or would perform inappropriate roles (Clynch, 2017). While there is still some debate about the appropriate use of PTAs, there is also significant literature about the PTA occupation and workforce.

At this time, PTAs are defined as "trained personnel who assist in the provision of physiotherapy services under the direction and supervision of a registered/licensed physiotherapist" (National Physiotherapy Advisory Group, 2012, p. 6). Current PTA training programs are typically two-year associate degree programs. There are 38 training programs in Canada (Occupational Therapist Assistant & Physiotherapist Assistant Education Accreditation Program, 2013) and over 350 programs in the United States (American Physical Therapy Association, 2019). As with OTAs, there are also many positions for PTAs; the United States Bureau of Labour Statistics

estimated that there were 140,300 PTA and aide positions in the United States in 2016 (Bureau of Labor Statistics: United States Department of Labor, 2019b).

1.3.3. Genetic Assistants

The last several Professional Status Surveys demonstrated that GCs in clinical settings spend approximately 25% of their time on tasks other than direct patient care (National Society of Genetic Counselors, 2016, 2018d, 2019). In order to counteract the workforce shortage, some clinics and laboratories applied the concept of role substitution and created a new position, called a "genetic assistant" (GA or GAs for plural)[2]. GAs were expected to take on some of the roles traditionally performed by GCs that do not require specialized training, such as clinical coordination tasks (e.g.,. obtaining medical records, coordinating testing, and screening and accepting patient referrals). Accordingly, GAs are non-clerical clinic staff who do not provide direct clinical care, but rather perform many of the "behind-the-scenes" coordination and administrative responsibilities that would otherwise be assigned to a GC.

To date, there has been one published study about GAs (Pirzadeh-Miller, Robinson, Read, & Ross, 2017). The authors surveyed GAs and GCs who worked with GAs at two academic cancer genetics programs in the United States (University of California, San Francisco and University of Texas Southwestern Medical Center), which implemented GAs in 2011 and 2012. All of the GCs reported an increase in patient care of productive time utilization. GCs also described other changes to their daily workflow, such as opportunities to provide mentorship, streamlining of

[2] This position has also been given other names, such as "genetic counselling assistant" or "genomic medicine assistant"; for consistency, it will be referred to as "genetic assistant" (GA or GAs for plural) throughout the text.

processes, and increased patient volume. In fact, analysis of clinic data revealed an increase in total patient volume; each genetic counsellor now reported an average of 10.3 new patients per week in 2015 (one GA for every three genetic counsellors), compared to an average of 6.5 new patient appointments per week in 2011 (no GAs). Most (90%) of the surveyed GCs thought that the GA position should be a pathway to becoming a GC, though 72% also felt that it could be a terminal position. Themes related to the career path of GAs included that it is a stepping stone career, that it has limited growth, that it is not unique enough from administrative professionals, and that it has high turnover. 86% of surveyed GAs were interested in entering the genetic counselling profession. They reported that the GA position prepared them for the following: genetic counsellor workflow, behind-the-scenes work, cancer genetics knowledge, qualification for genetic testing, comfort with patient interactions, pedigrees, multi-tasking, and presentations.

At the 2018 NSGC Annual Conference, one attendee presented a poster on GAs (Hnatiuk, Noss, Mitchell, & Matthews, 2018). They surveyed genetic counsellors (both those who work with GAs and those who do not) through the NSGC listserv (n=271). They reported that GAs allow GCs to spend more time on their workload and core competencies, see more patients, and increase efficiency. In clinical practice, GCs reported that GAs increase efficiency, timeliness, number of patients seen, and amount of work done within genetic counselling core competencies, as well as relieve the volume of administrative tasks. Participants had some concerns about the GA role, including undefined scope of practice, potential legal issues, high turnover, lack of supervision and training, and potential for devaluation of GCs. The GCs tended to agree on the appropriateness of GA tasks and felt that administrative tasks were more

acceptable for GAs to perform than clinical tasks. However, the authors found that GCs who do not work with GAs tend to overestimate what GAs can do within the clinical setting.

Despite the lack of publications about GAs, there is evidence that many genetics service providers have integrated them into their practice. In the 2018 Professional Status Survey, 307 (21%) genetic counsellors providing direct clinical care reported working with at least one genetic counselling assistant (National Society of Genetic Counselors, 2018e). Of GCs working in a mixed role (i.e., a position that includes some contact with patients, in addition to other roles that do not involve patient interactions), 96 (31%) reported working with at least one GA.

Among GCs providing direct patient care, 22% were dissatisfied with the number of patients or cases they were assigned because they felt the volume was excessive (National Society of Genetic Counselors, 2018c). Additionally, 39% of GCs providing direct patient care were dissatisfied with the administrative responsibilities of their position (too many) and 35% were dissatisfied with the secretarial or administrative support available (too little). Similarly, among genetic counsellors working in non-direct patient care roles, 16% were dissatisfied with administrative responsibilities (too many) and secretarial/administrative support (too little). Among GCs working in mixed roles, 10% felt there were too many patients or cases, 30% felt there were too many administrative responsibilities, and 28% felt there was too little administrative/secretarial support. Taken together, these findings demonstrate the need for additional support for GCs.

CHAPTER 2: STUDY OVERVIEW

2.1. Overview of Program of Genetics & Metabolism (Winnipeg)

The Program of Genetics & Metabolism in Winnipeg, Manitoba, Canada is situated at the Health Sciences Centre (Winnipeg Regional Health Authority, n.d.), one of the major tertiary care hospitals in the city. As the only genetics program in the province of Manitoba, it provides genetics services to the entire Manitoba population, in addition to northwestern Ontario, and western Nunavut. As of 2010, this geographic region was greater than three million square kilometers in size and home to over 1.2 million Canadians (Hartley, Greenberg, & Mhanni, 2011).

In 1999/2000, the clinical responsibilities of GCs employed in this program included face-to-face patient counselling and a variety of clinic coordination responsibilities (S. Chin, personal communication, Jan. 15, 2018). In response to personnel shortage and unfilled GC positions, the program hired its first GA in 2005. Since 2005, a total of 14 GAs have been employed within this program. Currently, the program has five GA positions, which are integrated across specialties in the clinic. The clinic also includes a variety of other staff, including medical geneticists, genetics residents, GCs, a dietitian, a nurse, and administrative professionals.

2.2. Rationale

Given the shortage of GCs, it is imperative that genetics providers consider other ways in which they can meet the demand for services. Implementing GAs in genetics services is an example of one such strategy. Currently, there is only one published study about GAs (Pirzadeh-Miller et al., 2017). Although this research provided a good introduction to the GA position, it was limited to

two centres in the United States and focused on GAs working in cancer genetics. Furthermore, there are no publications that describe the GA workforce across Canada and the United States, despite evidence that there are at least 400 GCs working with GAs (National Society of Genetic Counselors, 2018e).

Due to the sparsity of published data about GAs, the current study employed a comprehensive mixed methods design to investigate the GA workforce and their impact on the provision of genetics services across Canada and the United States. Survey and interview data were collected from a variety of genetics health care workers and complemented by the rich and complete data from the Program of Genetics & Metabolism in Winnipeg, Canada, to characterize the workforce, explore the GA position, evaluate the clinical benefits and limitations of employing a GA, and describe the ways in which implementation of GAs shapes the professional work of others.

2.3. Research Questions

1. Who makes up the GA workforce?
2. How are GAs integrated in genetics teams (including roles and responsibilities, fit, and attitudes)?
3. How does implementation of GAs shape the clinical roles, professions, and productivity of others within genetics services?

2.4. Research Aims

The objectives of this study were to:

1. Describe the demographics, training, roles, responsibilities, and number of GAs,
2. Explore the attitudes of other health care workers towards GAs,
3. Describe the ways in which GA implementation shapes the roles and responsibilities of other health care workers in the clinic/laboratory,
4. Detail the impact of GA implementation on the professions of genetic counselling and medical genetics, and
5. Utilize retrospective health service data from the local genetics clinic to evaluate the impact of GAs on patient volume.

CHAPTER 3: METHODS

3.1. Study Design

The study followed a convergent parallel mixed methods design where qualitative and quantitative data were collected and analyzed separately, then brought together for interpretation (Fetters, Curry, & Creswell, 2013). A sequential explanatory design (quan → QUAL) was nested within one prong of the parallel design (Figure 3.1). In this prong, the quantitative portion of the study (a survey) was performed first and used to identify issues that could be explored further through qualitative methodology (interviews); therefore, emphasis was placed on the results obtained through the qualitative portion of the study (Fetters et al., 2013). The respective survey, interviews, and productivity analysis are explained in separate sections below.

The study was approved by the University of Manitoba's Bannatyne Campus Health Research Ethics Board (REB approval number HS21791/H2018:192) and the Health Sciences Centre Research Impact Committee (RIC approval number RI2018:058).

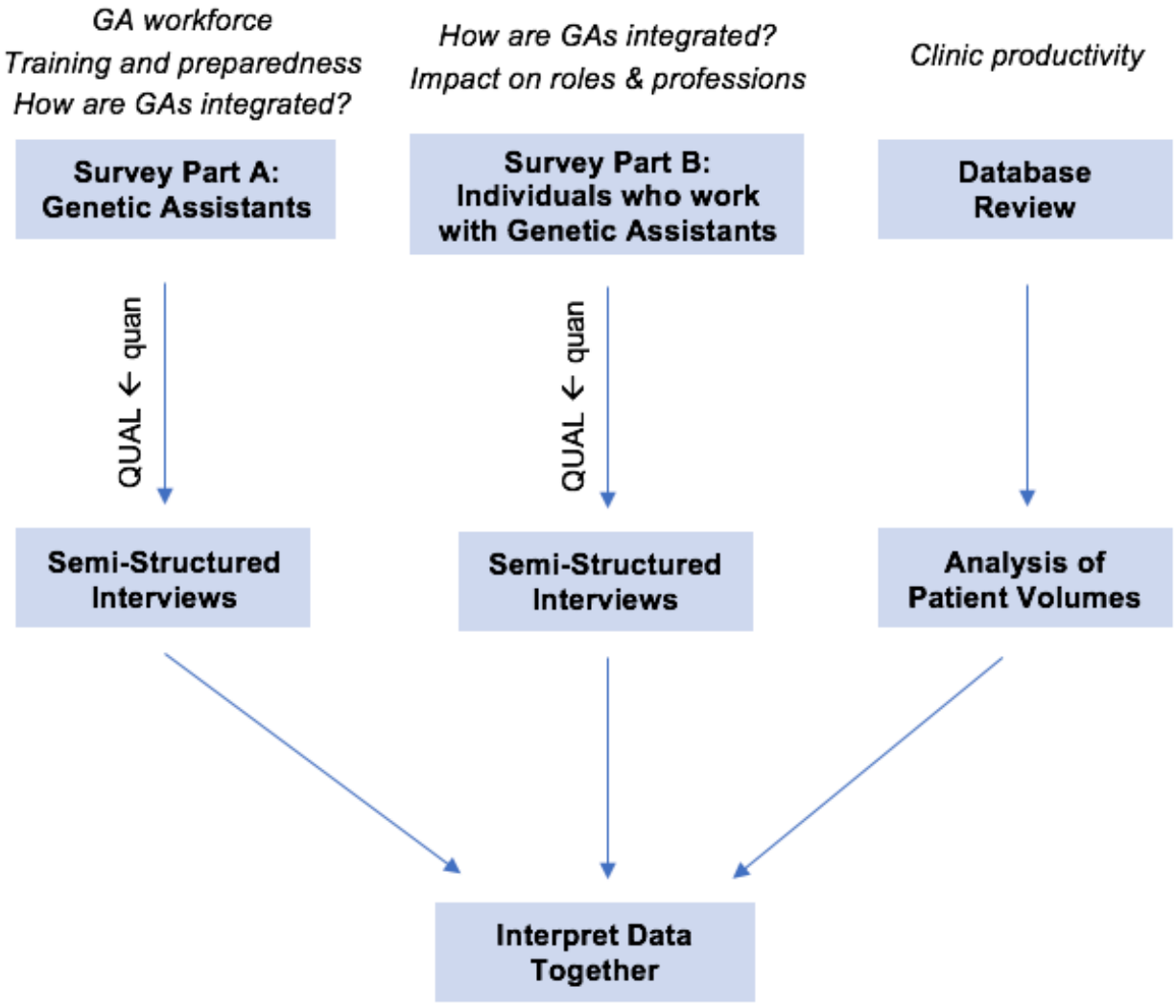

Figure 3.1. Study design

3.2. Survey

3.2.1. Participants

The study population included two groups of individuals: 1) individuals who currently work or previously worked as a GA for a minimum of six months in Canada or the United States between 2000 and 2018, and 2) individuals who currently work or previously worked with a GA as a GC, medical genetics resident, medical/clinical geneticist, laboratory/molecular geneticist, or administrative professional for a minimum of six months in Canada or the United States between 2000 and 2018. Individuals who met either or both of the above inclusion criteria were eligible to participate in the study.

3.2.2. Recruitment Procedures

Information about the study was distributed via e-mail listservs to members of the Canadian Association of Genetic Counsellors and the National Society of Genetic Counselors. Reminder e-mails were distributed two to four weeks following the initial invitation to participate. Responses were collected from June 2018 to February 2019. Recruitment of participants (other than genetic counsellors) relied on snowball sampling; the invitation to participate requested that recipients forward the study information to others who might meet the inclusion criteria. We were unable to calculate a response rate since the total number of individuals directed to the survey is unknown.

3.2.3. Instrumentation

The survey was administered through the REDCap secure web-based application hosted at the University of Manitoba (Harris et al., 2009). The survey was divided into two parts:

- Part A was completed by past and present GAs. The survey questions pertained to demographics, human resource information, training and preparedness for their position, their career path, and their roles and responsibilities in the clinic or laboratory.
- Part B was completed by GCs, medical genetics residents, medical/clinical geneticists, laboratory/molecular geneticists, and administrative professionals who currently work or previously worked with a GA. The survey questions collected respondent demographics, human resource information about their positions and the GAs' positions, training and preparedness of the GAs, GA roles and responsibilities in the clinic or laboratory, and the impact of GAs on one's own roles and responsibilities.

The majority of the survey questions were single-answer multiple choice. There were also several multiple-answer multiple choice and open-ended questions. Each part of the survey was expected to take approximately 15 minutes to complete.

Aspects of the survey instrument were developed based on the 2016 NSGC PSS and the questionnaire used in Pirzadeh-Miller et al. (2017). The survey was piloted for length and clarity with an individual who previously worked as a GA, a health care administrative professional, a medical resident, a physician, and an allied health professional; these individuals were not eligible to participate in the research study. The complete survey can be found in Appendix 1.

3.2.4. Data Analysis

Survey information was exported from REDCap (Harris et al., 2009). Descriptive statistics were generated for multiple choice questions. Means, standard deviations, and ranges were generated for quantitative information. Comparisons were made between the following groups: 1) GA

participants and participants who work with GAs, 2) Canadian and American participants, and 3) clinical GAs and laboratory GAs. Comparisons between categorical variables used two-sided chi-squared tests or two-sided Fisher's exact tests (when at least 20% of the cells had an expected frequency less than 5). Associations between binary variables and ordinal or continuous variables (that did not follow a normal distribution) were examined using two-sided Mann-Whitney U tests. A nominal p-value of 0.05 was used for all analyses. All data management and quantitative analyses were performed using SAS ® software, Version 9.4 of the SAS System for Windows. Copyright © 2016 SAS Institute Inc. SAS and all other SAS Institute Inc. product or service names are registered trademarks or trademarks of SAS Institute Inc., Cary, NC, USA.

The responses to open-ended questions were coded based on content using Dedoose ("Dedoose Version 8.1.8, web application for managing, analyzing, and presenting qualitative and mixed method research data," 2019), a qualitative analysis software.

3.2.5. Description of Genetic Assistant Positions by Region

The final survey question asked participants to indicate the clinic/laboratory/site of employment at which they most recently worked with GAs and the number of GAs that were employed at that site. In order to maintain anonymity of the participants, the responses to this survey question were not linked to any other survey responses. A heat map was constructed that combined the total number of GAs within each of the six regions as defined by the NSGC (see Appendix 2 for regions).

3.3. Interviews

3.3.1. Participants

Individuals who completed the survey were invited to contact the student principal investigator by phone or e-mail if they were interested in participating in an interview. When the survey was initially distributed, only individuals who worked with GAs were invited to participate in an interview, while GAs were invited to contact the student principal investigator if they were interested in participating in future research studies. However, in order to optimize recruitment, the research protocol was later revised to include interviews with both GAs and individuals who worked with GAs. At that time, GAs who indicated they were interested in participating in future research studies were contacted and invited to participate in an interview. One additional invitation to participate in interviews was distributed through both the CAGC and NSGC e-mail listservs to improve the response rate.

Accordingly, potential interview participants included two groups of individuals: 1) individuals who currently work or previously worked as a GA for a minimum of six months in Canada or the United States between 2000 and 2018, and 2) individuals who currently work or previously worked with a GA for a minimum of six months in Canada or the United States between 2000 and 2018. Individuals who met either or both of the above inclusion criteria were eligible to participate in an interview.

3.3.2. Selection Criteria

All individuals interested in participating in an interview were contacted by email with additional information about the interview. They were also asked to complete several screening questions

(Figure 3.2), which were used for purposive maximum variation sampling (Patton, 2015). Rather than selecting a representative subset of the survey participants, the aim was to interview participants from various geographic regions in both Canada and the United States who have worked with/as GAs for variable lengths of time, in order to collect a broad range of perspectives and experiences. Several individuals who expressed interest in participating in a research interview were lost to follow-up. Interviews were performed until saturation was reached on the major research questions. Saturation was determined by a lack of new emergent themes and was later verified during the data analysis process.

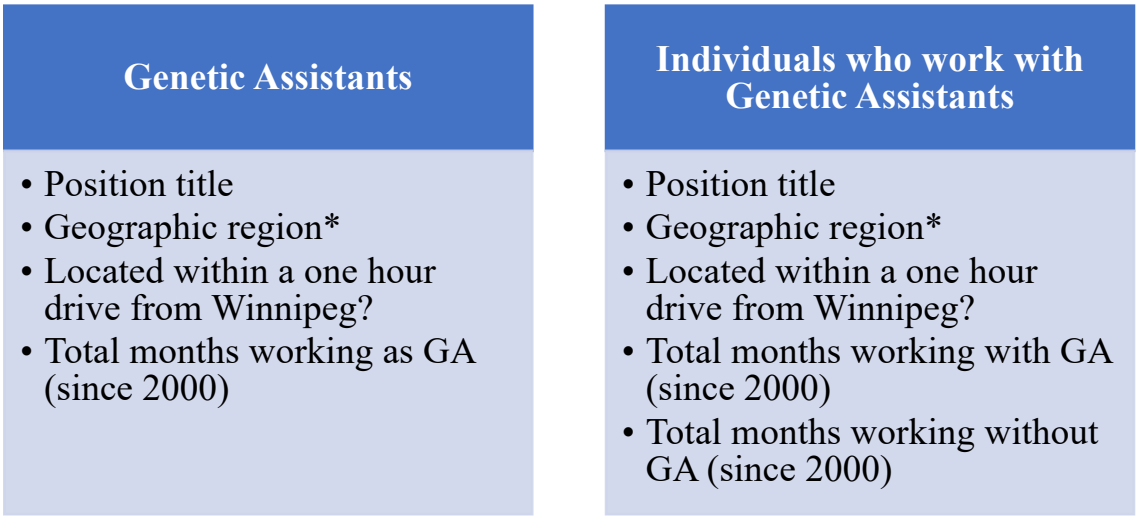

Figure 3.2. Interview screening questions for GAs and individuals who work with GAs
*Geographic regions were Canada: Atlantic, Central, Prairies, or West Coast; United States: Northeast, Midwest, South, or West.

3.2.3. Instrumentation

A semi-structured interview guide was developed based on several themes that emerged from the survey responses. The same key concepts were included in the interview guides used with the GA participants and the participants who worked with GAs, though there were some

modifications to the wording of the questions. The interview guide was reviewed by the supervisor and one committee member and subsequently piloted with an individual who previously worked as a GA.

All interviews were performed by the student principal investigator. At the beginning of each interview, additional information about each participant's experience working as or with a GA was collected (Figure 3.3), as these variables may have influenced the participant's experiences.

Genetic Assistants	Individuals who work with Genetic Assistants
• Are you currently working as a GA? • How long have you worked/did you work as a GA? • Was your GA position in a clinic or laboratory? • Were you the first GA in that genetics service? • Did you work alone or with other GAs?	• How long have you worked in your current position? • Do you currently work with GAs? • Do/did you work with GAs in a clinic or laboratory? • Were GAs already working in the genetics service when you started your position or were they later integrated into the program? • Did you work with one single GA or multiple GAs at one time? • Have you worked with more than one GA?

Figure 3.3. Initial interview questions regarding each participant's experience working as or with a GA

The overarching research question was:

What is the experience of GAs and those working with GAs in genetics clinics and laboratories?

The interview guide interrogated three main research themes, as follows:

1. *How does a GA impact others' roles and responsibilities within the clinic?* This section of the interview guide addressed portrayal and understanding of the GA position, roles and responsibilities of a GA, and patient interactions that a GA engages in.
2. *How are GAs integrated into the genetics team?* This section of the interview guide addressed fit/integration, workplace culture, attitudes towards GAs, recognition and value of GAs, independence level of GAs, and job satisfaction/engagement.
3. *How would having GA as a long-term career impact the clinic or laboratory?* This section of the interview guide addressed whether there is potential for the GA position to become a long-term career path, as well as the impact that this would have on the clinic/laboratory and other professions within the genetics service.

The complete interview guides can be found in Appendices 3 and 4.

3.2.4. Interviews

Interviews were conducted at a location of each participant's choosing in the Winnipeg area, by telephone, or through BlueJeans, a secure teleconferencing software ("BlueJeans," 2019). The interviews were audio-recorded. They were transcribed using intelligent verbatim transcription by either the student principal investigator or a professional transcriptionist from the company, Transcript Heroes ("Transcript Heroes Transcription Services Inc.," n.d.). The transcripts and quotes provided in this document were anonymized by: removing names and locations, referring

to all assistant positions as “GA” positions (rather than using the official job title), and replacing pronouns with “the GA” or “he/she”.

3.2.5. Qualitative Analysis

Dedoose, an online computer assisted qualitative data analysis software (CAQDAS), was used to manage and analyse all qualitative data collected from the interviews (“Dedoose Version 8.1.8, web application for managing, analyzing, and presenting qualitative and mixed method research data,” 2019). During first cycle coding, a combination of concept and in vivo codes were assigned to the transcripts (Miles, Huberman, & Saldaña, 2018). Concept codes are words or short phrases that summarize the broad meaning of the data, while in vivo codes are words or short phrases used by the participants. Codes were organized and collapsed throughout the first cycle coding process. During second cycle coding, cross-case thematic analysis (which involves identifying and interpreting patterns that are common to many participants) was employed to generate themes and sub-themes (Patton, 2015).

To establish internal reliability, the student principal investigator and supervisor independently reviewed and coded the first four interviews using the same codebook. They met to review the assigned codes and resolve any discrepancies. The student principal investigator coded the remainder of the interviews and modified the codebook as required.

3.2.6. Reflexivity

Reflexivity was incorporated throughout the research process. The student principal investigator’s thoughts and experiences were documented through field notes during the

interview stage and memos during the analysis stage. As such, comments on reflexivity are integrated throughout the Results and Discussion sections.

3.4. Productivity Analysis

3.4.1. Collected Information

The Shared Health (formerly Winnipeg Regional Health Authority) Program of Genetics and Metabolism at the Health Sciences Centre in Winnipeg, Manitoba, Canada maintained a database of all genetics patients until the introduction of a new electronic medical record system in 2018. Two datasets that spanned from January 2000 to December 2017 were collected from the program's database (Shire):

- Patient Counts: The first dataset contained patient counts by genetics provider initials and appointment outcome (e.g.,. attended or did not attend appointment) for each specialty. A separate list provided by the clinic indicated staff type by staff member initials (e.g.,. "AB" is a geneticist, or "BA" is a GC). Patients that did not attend their appointment were removed from the patient counts. Patient counts were grouped by staff type to maintain anonymity of individual patient counts.
- Program Appointments: The second dataset was a list of all appointments in the program. This dataset included unique ID numbers assigned by Shire in a sequential order each time a new patient is entered in the system, as well as patient birthdate, appointment date, appointment type, and patient type. Appointments for procedures (i.e., amniocentesis, chorionic villus sampling, cordocentesis, and ultrasound), fetal assessment, or laboratory testing were removed, as these patients were seen by a genetics provider (geneticist or GC) during a separate appointment. Historic cancer genetics appointments that were

added to Shire retrospectively were also removed because the ID numbers did not correspond to the sequential pattern of the other ID numbers in the system.

3.4.2. Estimating Referral Numbers

Since Shire did not contain a referral date for each new patient, the Program Appointments dataset was used to approximate the number of new referrals to the genetics program per month. The first ID number assigned at the beginning of each month was inferred by identifying the first inpatient appointment for a newborn that month (using birthdate and appointment date), based on the assumption that newborn inpatients are not subject to a wait time for genetics assessment. All ID numbers assigned until the first inpatient appointment for a newborn the following month were used to approximate the number of new referrals during the time period.

For example, if a baby assigned ID "50001" was born on January 1, 2000 and had an appointment on January 2, 2000, we would infer that the first ID number assigned in January 2000 was 50001. If a baby assigned ID "50101" was born on February 1, 2000 and had an appointment on February 3, 2000, we would infer that the first ID number assigned in February 2000 was 50101. From this, we could estimate that there were 100 new referrals in January 2000.

3.4.3. Staff Mix

The genetics clinic is composed of a mix of medical geneticists, GCs, GAs, and administrative staff, with varied staff mix varied over time. For the purposes of this study, the number of administrative staff was not collected. The Patient Counts dataset was used to determine the number of geneticists and GCs employed during each month. The supervisor and a committee

member who has been employed in the clinic since the beginning of the study period checked these timelines for accuracy and provided the full-time equivalent (FTE) for each GC position. All geneticists with at least one weekly clinic were considered to be 1.0 FTE. The supervisor and the same committee member mentioned above also provided the timeline for GA positions, as this information was not available from the database.

3.4.4. Data Analysis

Patient volume was defined as the number of patients seen per genetics provider FTE per month. The trends in patient volume and number of referrals per month were visualized with scatter plots. Patient volume was examined at specific time points during which new GA positions were incorporated in the clinic.

Linear regression models were used to preliminarily examine the association between total number of patients per month and GA FTE, with adjustments for geneticist (MD) FTE, GC FTE, and the number of referrals to the clinic (see equation below). Number of patients seen per month by GCs and number of patients seen per month by geneticists were considered both together and separately.

$$Patients = \beta_0 + \beta_1 GA\ FTE + \beta_2 MD\ FTE + \beta_3 GC\ FTE + \beta_4 Referrals$$

CHAPTER 4: SURVEY RESULTS

4.1. Participants

A total of 164 GAs met the inclusion criteria and completed the demographic questions, at minimum (Figure 4.1). Of these, 87 (53.0%) currently work as GAs, 60 (36.6%) previously worked as GAs, and 17 (10.4%) did not indicate their current job status. Seventeen GA participants have worked in more than one position (10.4%). Eleven of these GAs worked in two different positions, three worked in three different positions, and two worked in four different positions; one GA did not indicate the total number of positions that he/she has worked in.

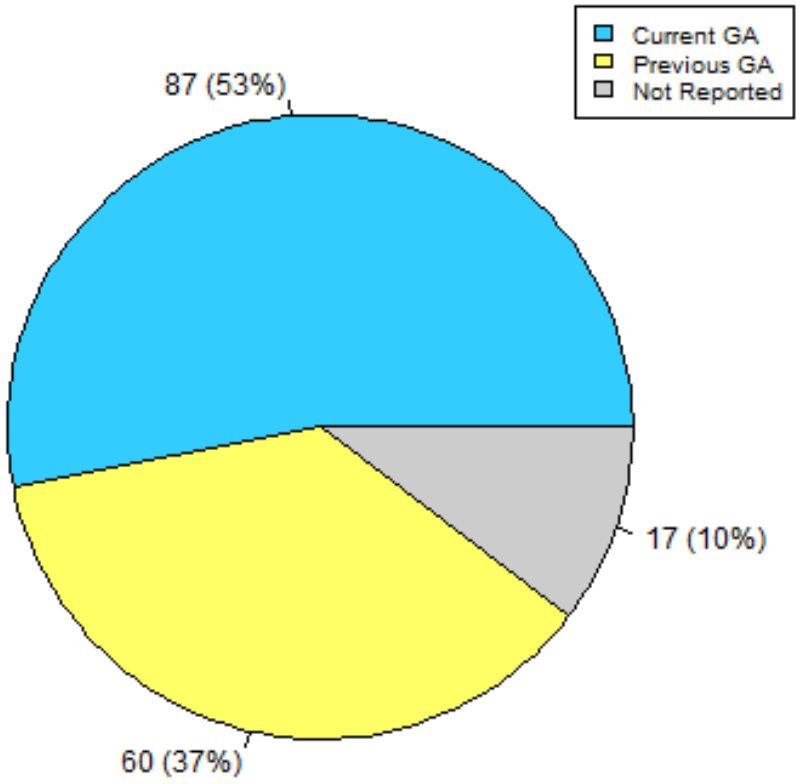

Figure 4.1. Current job status of GA participants (n=164)

A total of 139 individuals who currently work or previously worked with a GA met the inclusion criteria and completed the demographic questions, at minimum (Figure 4.2). These participants included 113 (81.3%) GCs, 1 (0.7%) medical genetics resident, 6 (4.3%) medical/clinical geneticists, 2 (1.4%) laboratory/molecular geneticists, and 2 (1.4%) administrative professionals. Fifteen (10.8%) participants did not provide information about their position. Survey responses are presented in aggregate to avoid identification of any participants.

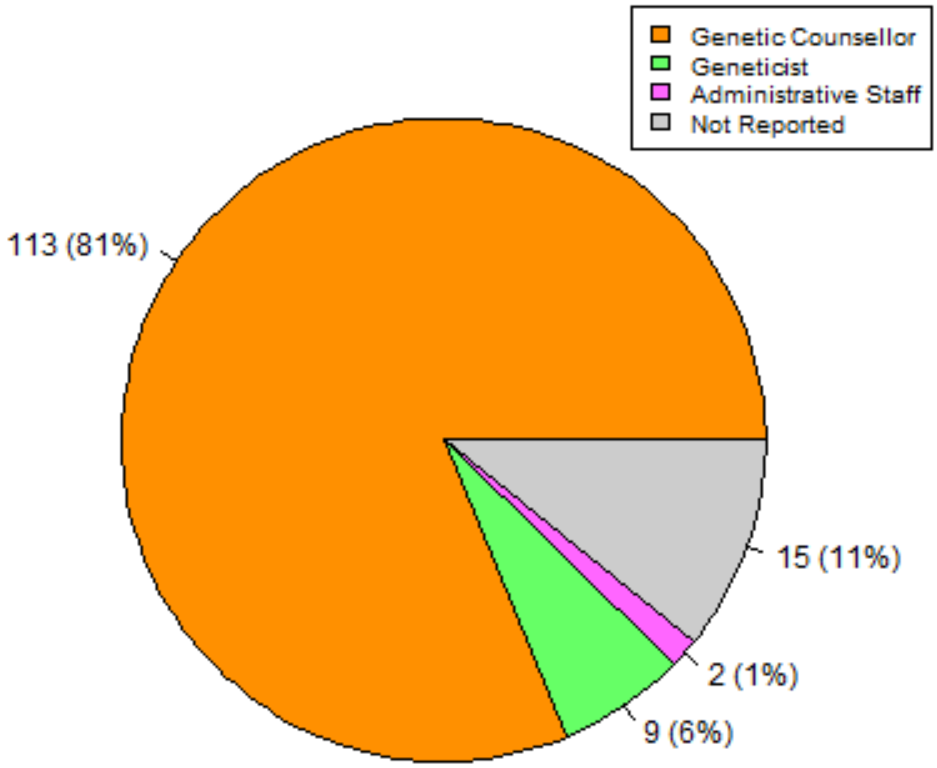

Figure 4.2. Position of participants who work with GAs (n=139)
Geneticist includes medical/clinical geneticists, laboratory/molecular geneticists, and medical genetics residents.

4.2. Demographic Information

Table 4.1 summarizes demographic information reported by both groups of participants. The majority of participants were female (90.9% of GAs and 93.5% of participants who work with GAs; p=0.39). Approximately half (85/164, 51.8%) of the GA participants are currently 25 years of age or younger, with an additional 31.1% (51/164) of GA participants currently between 26 and 30 years of age. In contrast, more than half (82/139, 59.0%) of the participants who work with GAs were over 30 years of age (p<0.0001). For both groups, approximately 80% of the respondents were from the United States and approximately 20% were from Canada (p=0.09); three participants worked with GAs in both Canada and the United States.

Table 4.1. Demographic information reported by GA participants and participants who work with GAs (n=164 and n=139, respectively)

Demographics	**GAs n (%)**	**Works with GAs n (%)**	**p-value**[a]
Gender			
Female	149 (90.9)	130 (93.5)	0.39
Male	15 (9.2)	9 (6.5)	
Current Age			
18-25	85 (51.8)	13 (9.4)	
26-30	51 (31.1)	44 (31.7)	<0.0001
31-35	18 (11.0)	31 (22.3)	
36 or older	10 (6.1)	51 (36.7)	
Country			
Canada	26 (15.9)	28 (20.1)	0.09
United States	138 (84.2)	108 (77.7)	
Both Canada and United States	0 (0)	3 (2.2)	

[a] The p-values for gender, current age, and country were calculated using the following statistical tests, respectively: chi-square test, Mann-Whitney-U test, and Fisher exact test.

4.3. Educational Background

The majority of GAs (128/155, 82.6%) reported having an undergraduate degree (Table 4.2); half of these were in biology (64/128, 50.0%) and approximately one-quarter (36/128, 28.1%) were in genetics or psychology/social science. An additional six participants (3.9%) reported having a Masters or Doctoral degree, five of which were in genetics.

Table 4.2. Educational background reported by GA participants (n=155)

Educational Background	**n (%)**	**Major**	**n (%)**
No College/University	1 (0.6)	–	–
Some College/University (no degree awarded)	17 (11.0)	Biology Genetics Psychology/Social Science Other[a]	7 (41.2) 4 (23.5) 1 (5.9) 5 (29.4)
Diploma/Certificate	1 (0.6)	Psychology/Social Science	1 (100.0)
Diploma/Certificate + Undergraduate	1 (0.6)	Other[b]	1 (100.0)
Associate + Undergraduate	1 (0.6)	Other[c]	1 (100.0)
Undergraduate	128 (82.6)	Biology Genetics Psychology/Social Science Other[d]	64 (50.0) 21 (16.4) 15 (11.7) 28 (21.9)
Masters	5 (3.2)	Biology Genetics	1 (20.0) 4 (80.0)
Doctoral	1 (0.6)	Genetics	1 (100.0)

[a] Biomedical sciences, biochemistry, business management, biology/psychology, and health sciences.
[b] Applied counseling and bioanthropology
[c] Health sciences
[d] Included biobehavioral health, bioinformatics, biomedical science, biotechnology, business, epidemiology, health sciences, human biology, microbiology, neuroscience, philosophy, political science, and public health.

The majority of participants who work with GAs reported that they require GAs to have an undergraduate degree (88/122, 72.1%) (Table 4.3). 103 of 122 (84.4%) have worked with a GA that meets this requirement at minimum; this is similar to the proportion of GAs that reported having at least an undergraduate degree. Interestingly, 21.3% of participants reported that they have worked with a GA with a Masters or Doctoral degree.

Table 4.3. Educational requirements and backgrounds of GAs, as reported by participants who work with GAs (n=122)

Education	Requirement n (%)	Highest Level n (%)
No College/University	6 (4.9)	0 (0)
Some College/University (no degree awarded)	10 (8.2)	8 (6.6)
Diploma/Certificate	1 (0.8)	1 (0.8)
Associate	1 (0.8)	1 (0.8)
Undergraduate	88 (72.1)	77 (63.1)
Masters	0 (0)	22 (18.0)
Doctoral	0 (0)	4 (3.3)
Unsure	16 (13.1)	9 (7.4)

4.4. Human Resource Information

Most GA participants started the position early in their career (141/164, 86.0% between 18 to 25 years of age) (data not shown). With respect to job title, the majority of GAs in the United States were called “genetic counselling assistants” (99/136, 72.8%), while the majority of GAs in Canada were called “genetic assistants” (16/24, 66.7%) ($p<0.0001$) (Table 4.4). Other titles included genomic medicine/clinical genomics assistant, coordinator (genetics, genetic testing, or genetic counselling), research assistant, volunteer, student intern, medical secretary, assistant (department, administrative, or clinical), and specialist (clinical administrative, genetic counselling assistant, genetic counsellor support, or support).

Table 4.4. Human resource information reported by GA participants

Position Information	United States n (%)	Canada n (%)	p-value[a]
Position Title	**n=136**	**n=24**	
Genetic assistant	8 (5.9)	16 (66.7)	<0.0001
Genetic counselling assistant	99 (72.8)	7 (29.2)	
Other	29 (21.3)	1 (4.2)	
Hourly Wage[b]	**n=135**	**n=23**	
$10 or less	8 (5.9)	0 (0)	
$11-15	40 (29.6)	3 (13.0)	
$16-20	59 (43.7)	3 (13.0)	—
$21-25	20 (14.8)	2 (8.7)	
$26-30	3 (2.2)	9 (39.1)	
More than $30	0 (0)	3 (13.0)	
Unpaid position[c]	5 (3.7)	3 (13.0)	
Hours per Week	**n=136**	**n=24**	
1-10	13 (9.6)	3 (12.5)	
11-20	20 (14.7)	8 (33.3)	0.007
21-30	6 (4.4)	3 (12.5)	
31-40	90 (66.2)	10 (41.7)	
41+	7 (5.2)	0 (0)	
Work Setting	**n=137**	**n=24**	
Public hospital/Medical facility	36 (26.3)	22 (91.7)	
Private hospital/Medical facility	20 (14.6)	0 (0)	
University medical facility	44 (32.1)	2 (8.3)	<0.0001
Diagnostic laboratory (non-commercial)	6 (4.4)	0 (0)	
Diagnostic laboratory (commercial)	26 (19.0)	0 (0)	
Private practice	4 (2.9)	0 (0)	
Other	1 (0.7)	0 (0)	
Specialty[d]	**n=136**	**n=22**	
Cancer	79 (58.1)	11 (50.0)	0.48
Pediatric genetics	43 (31.6)	9 (40.9)	0.39
Laboratory	37 (27.2)	1 (4.5)	0.02
Prenatal	25 (18.4)	8 (36.4)	0.09
Adult genetics	19 (14.0)	9 (40.9)	0.005
Metabolics	16 (11.8)	4 (18.2)	0.49
Neurogenetics	15 (11.0)	3 (13.6)	0.72
Cardiology	13 (9.6)	2 (9.1)	1.00
Other[e]	9 (6.6)	0 (0)	0.36

[a] The p-values for title, hours per week, work setting, and specialty were calculated using the following statistical tests, respectively: Fisher exact test, Mann-Whitney-U test, Fisher exact test, and chi-square/Fisher exact test. A p-value was not calculated for hourly wage given that the wages are in different currencies.

[b] Hourly wage was reported in each country's currency.

[c] Unpaid positions included volunteer, co-operative, and internship positions.
[d] Multiple responses were permitted (i.e., respondents could select all that applied), therefore totals do not equal 100%.
[e] Includes clinical genomics (i.e., whole-exome/whole-genome sequencing), cytogenetics, pre-conception, and research.

Among American respondents, the most common hourly wage was $16.00 to $20.00 (59/135, 43.7%), followed by $11.00 to $15.00 (40/135, 29.6%). The most common hourly wage for Canadian respondents was $26.00 to $30.00 (9/23, 39.1%). A total of 12 Canadian GAs (52.2%) reported an hourly wage of $26.00 or more, while only 23 American GAs (17.0%) reported an approximately equivalent hourly wage of $21.00 or more (based on an exchange rate of 0.30 in October 2018) (Bank of Canada, 2018).

Most American participants reported working 31 to 40 hours per week (90/136, 66.2%), while the weekly work hours were more variable among Canadian participants with eight of 24 (33.3%) participants reporting 11 to 20 hours per week and 10 (41.7%) reporting 31 to 40 hours per week ($p=0.007$). The mean number of hours worked per week by American and Canadian GAs were 33.1 (SD: 12.0, range: 4-60) and 25.6 (SD: 12.1, range: 6-40), respectively ($p<0.0001$ using a Mann-Whitney U test).

Almost all Canadian GAs reported working in public hospitals/medical facilities (22/24, 91.7%). Responses from American GAs were more variable, with most respondents working in public hospitals/medical facilities (36/137, 26.3%), university medical facilities (44/137, 32.1%), or commercial diagnostic laboratories (26/137, 19.0%) ($p<0.0001$). The work settings reported by individuals who work with GAs were not significantly different from those reported by the GAs (Appendix 5).

Among Canadian respondents, the most common specialties that GAs reported working in were cancer (11/22, 50.0%), pediatric genetics (9/22, 40.9%), adult genetics (9/22, 40.9%), and prenatal (8/22, 36.4%). The most common specialties reported by American GAs were cancer (79/136, 58.1%), pediatric genetics (43/136, 31.6%), and laboratory (37/136, 27.2%). The specialties in which individuals reported working with GAs were not significantly different from the specialties reported by the GAs (Appendix 5).

Eleven of 22 (50.0%) and 46 of 136 (33.8%) GAs from Canada and the United States, respectively, reported working in more than one specialty. GA participants who worked in pediatric genetics, prenatal genetics, adult genetics, metabolics, neurogenetics, cardiology, and other specialties were significantly more likely to work in multiple specialties than a single specialty (Figure 4.3). Among participants working in cancer or laboratory genetics, there was no significant difference in the proportions who reported working in these specialties alone compared to those who reported also working in multiple specialties.

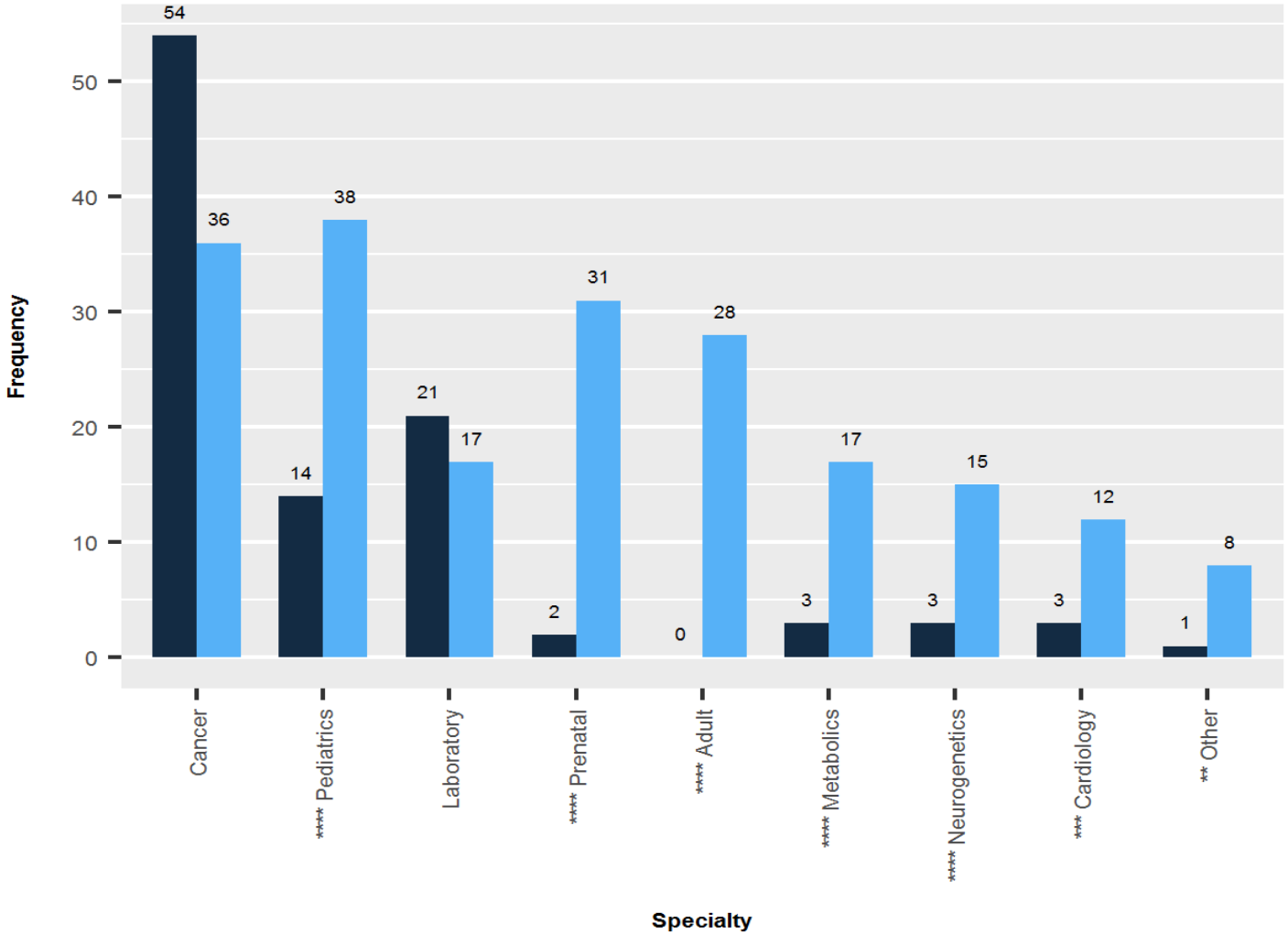

Figure 4.3. Specialties reported by GA participants who work in single versus multiple specialties (n=158)
Black bars represent GAs who work in a single specialty. Blue bars represent GAs who work in more than one specialty. Asterisks indicate a significant difference between proportions of GAs who work in that specialty only and GAs who also work in other specialties. (** $0.01 > p \geq 0.001$, *** $0.001 > p \geq 0.0001$, **** $0.0001 > p$)

Approximately half of GA participants have worked in the position for one year or less (79/137, 57.7% of American participants and 12/24, 50% of Canadian participants) (Figures 4.4 and 4.5). Of 137 American GAs, 20 (14.6%) worked in the position for more than two years; in contrast, 10 of 24 Canadian GAs (41.7%) worked in the position for more than two years. When treated as a continuous variable, number of months working as a GA was not significantly different between Canadian and American participants (p=0.19 using a Mann-Whitney U test).

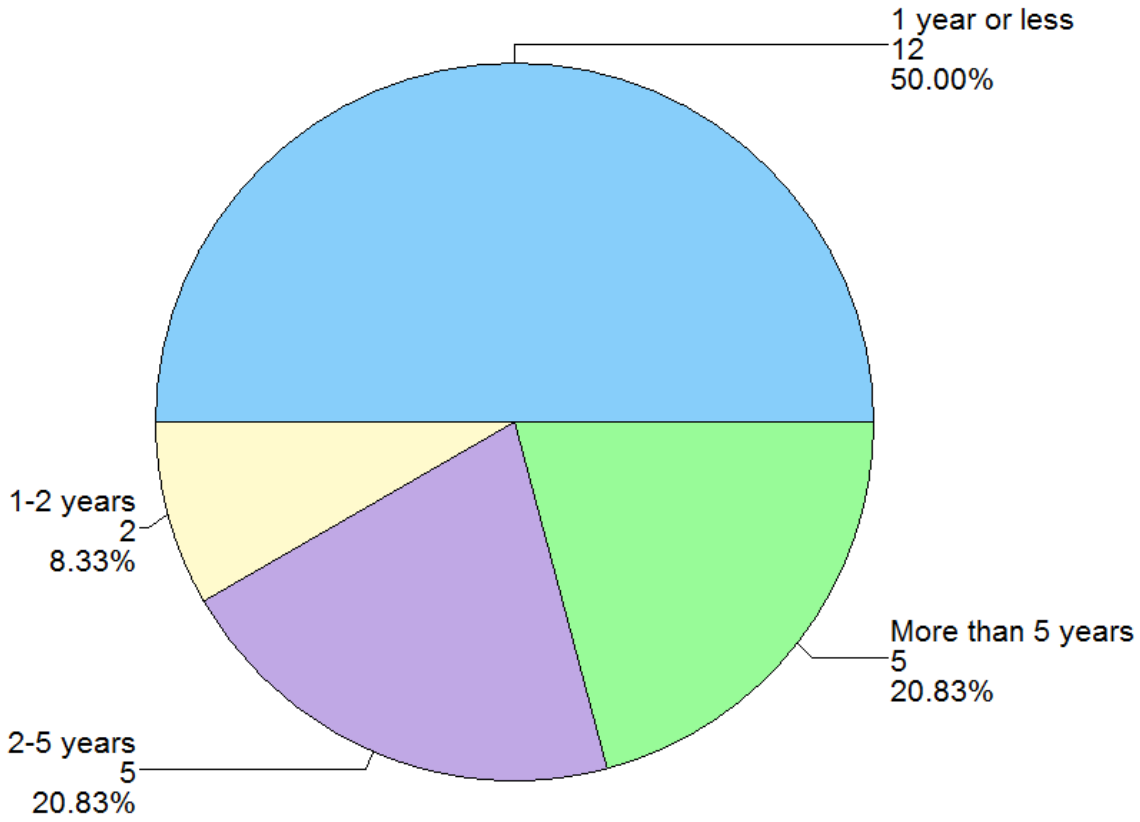

Figure 4.4. Length of time working as a GA among Canadian GA participants (n=24)

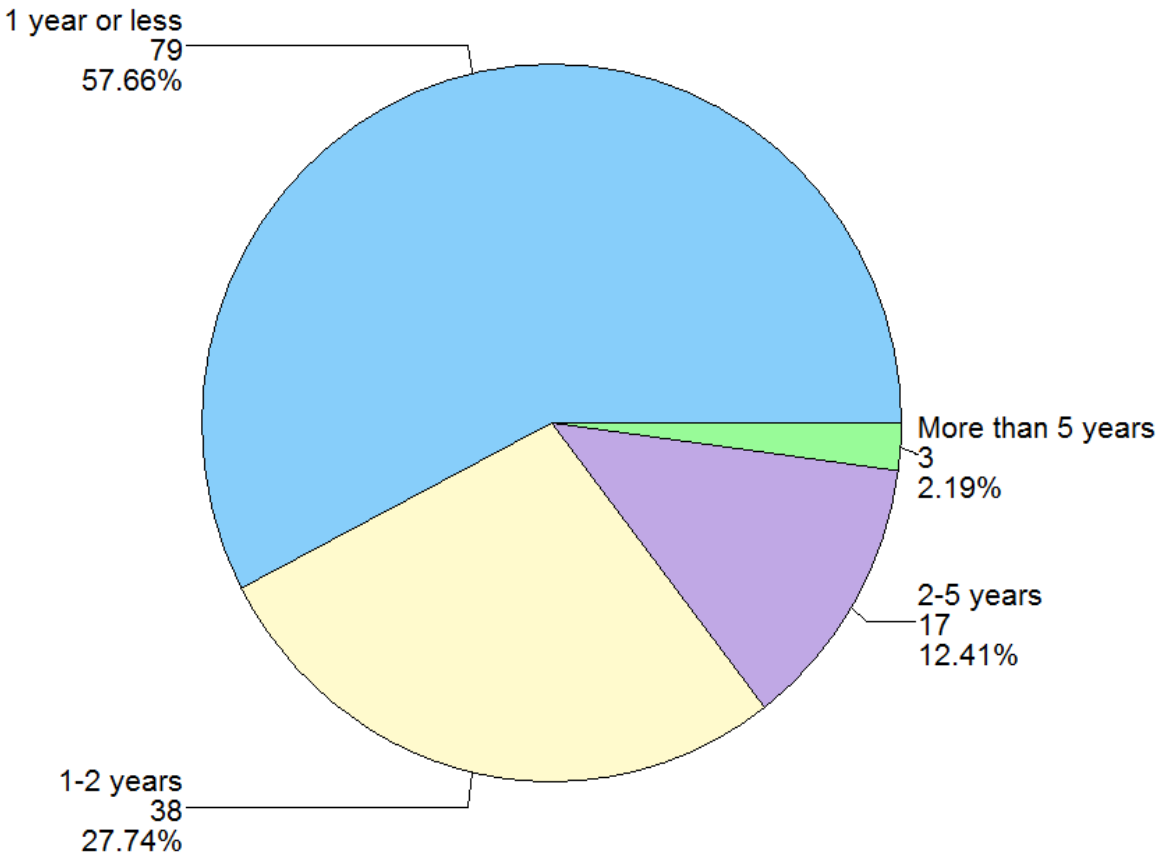

Figure 4.5. Length of time working as a GA among American GA participants (n=137)

The majority of participants have worked with a GA for more than one year (67/98, 68.4% of American participants and 19/24, 79.2% of Canadian participants) (Figures 4.6 and 4.7). Of 98 American participants, 11 (11.2%) have worked with a GA for over five years; in contrast, 10 of 24 Canadian participants (41.7%) have worked with a GA for over five years. When treated as a continuous variable, number of months working with GAs was marginally higher among Canadian participants than American participants (p=0.05 using a Mann-Whitney U test).

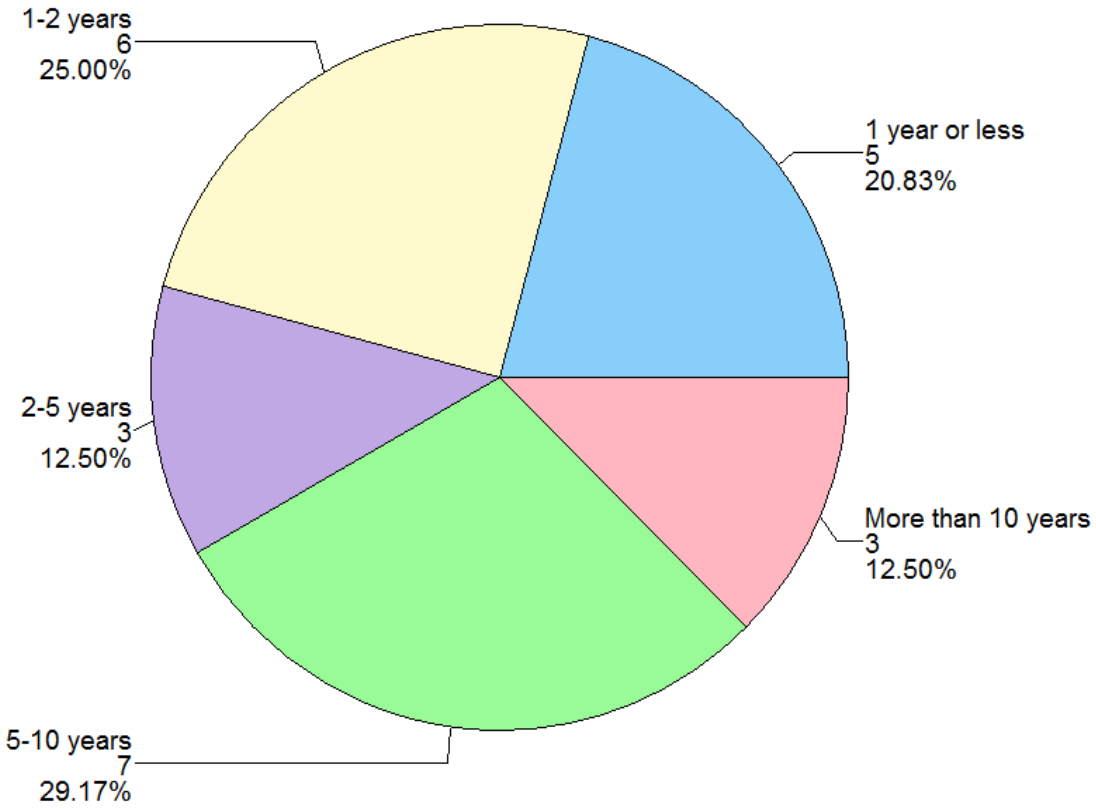

Figure 4.6. Length of time working with GAs among Canadian participants (n=24)

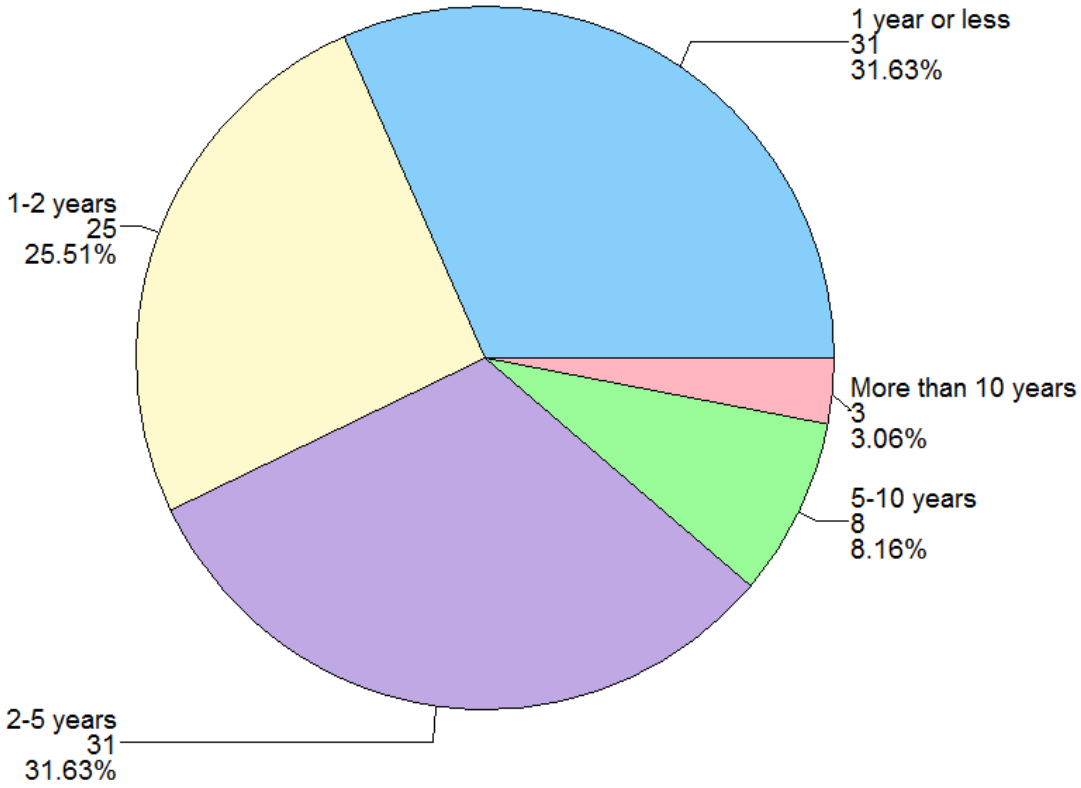

Figure 4.7. Length of time working with GAs among American participants (n=98)

4.5. Career Plan

Of the 87 participants who were currently employed as a GA at the time of the survey, 20 (23.0%) planned to continue working as a GA, 61 (70.1%) planned to attend university or college, and 26 (29.9%) planned to work in a different position (Figure 4.8). Of those who planned to attend university or college, 51 (83.6%) were attending or planning to attend a genetic counselling program; other education plans included medical school, Masters in Public Health, clinical research coordination, and other degrees in genetics/genomics. Among those who planned to work in a different position, most indicated that they hoped to work as a GC (16/26, 61.5%), with the remainder of respondents currently undecided or planning to pursue a non-clinical profession.

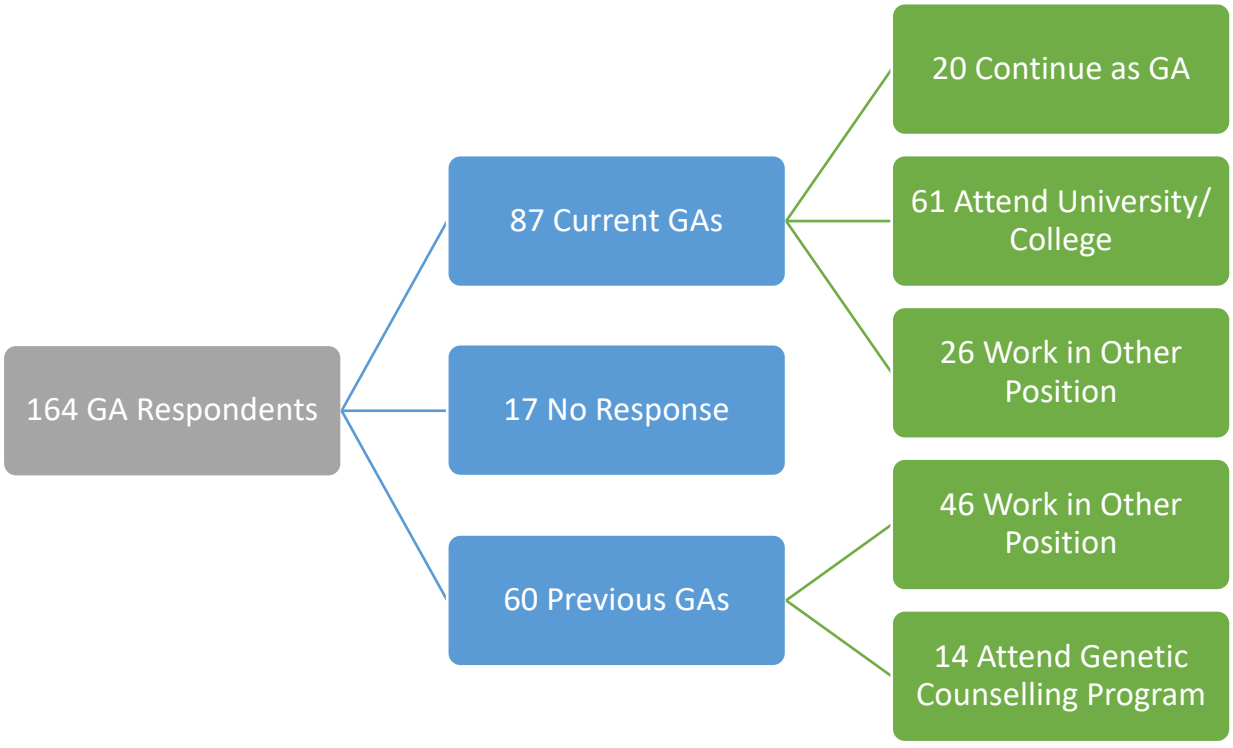

Figure 4.8. Desired career trajectory of GA participants (n=164)

Approximately 31% of Canadian respondents indicated that they planned to continue working as a GA compared to 22% of American respondents (p=0.53 using a Fisher exact test). 74% of American respondents indicated that they planned to attend university/college as compared to 46% of Canadian respondents (p=0.01 using a chi-square test); furthermore, 27% of American respondents indicated they planned to work in a different position as compared to 46% of Canadian respondents (p=0.26 using a Fisher exact test). Among those who planned to attend university/college or work in a different position, all respondents (n=77) felt that their work as a GA helped to prepare them for these career plans.

Of the 60 participants who were not employed as a GA at the time of the study, 46 (76.7%) worked in a different position, with most respondents working as a GC (n=40); those who were not working as a GA or GC (n=6) reported a variety of positions, including work in the fields of education, research, youth support, disability, and networking. The other respondents (n=14) were all enrolled in genetic counselling programs. When asked about the reasons for leaving their position as a GA, most participants (49/60) cited enrollment in or graduation from a genetic counselling program; however, other reported reasons included graduation from an undergraduate program, unfulfilled career goals, the need for a paid position, life changes (e.g.,. marriage or moving), a lack of upward mobility in the GA position, and the need for a more flexible schedule.

4.6. Roles

The proportion of GAs who performed specific roles were comparable between clinical and laboratory settings for approximately half the roles (Figure 4.9); specifically, these roles were

data entry, administrative tasks (e.g.,. scanning, copying, filing, organization, and ordering supplies), case preparation (e.g.,. preparing chart and obtaining relevant medical records), acting as a liaison with other health professionals or agencies (e.g.,. gathering information and making referrals), shipping genetic testing (e.g.,. boxing samples), identifying and providing patient resources, research activities (e.g.,. preparing ethics applications and assisting with data collection), preparing results letters based on gene test results, and calling patients with abnormal results. Compared to laboratory GAs, GAs working in a clinical setting were significantly more likely to have a role in contacting patients for follow-up information, collecting and/or drawing family histories, completing test requisition forms for genetic testing, assisting with clinic flow (e.g.,. receiving patients), screening and tracking referrals, coordinating genetic test coverage (i.e., contacting insurance companies or relevant government agencies), preparing letters of medical necessity or application forms for patient testing, calling patients with negative gene test results, scheduling patients for genetic visits and/or with other specialists, and calling patients with variants of uncertain clinical significance results. On the other hand, GAs working in a laboratory setting were significantly more likely to be involved in tracking genetic testing and offering genetic testing than GAs working in a clinical setting.

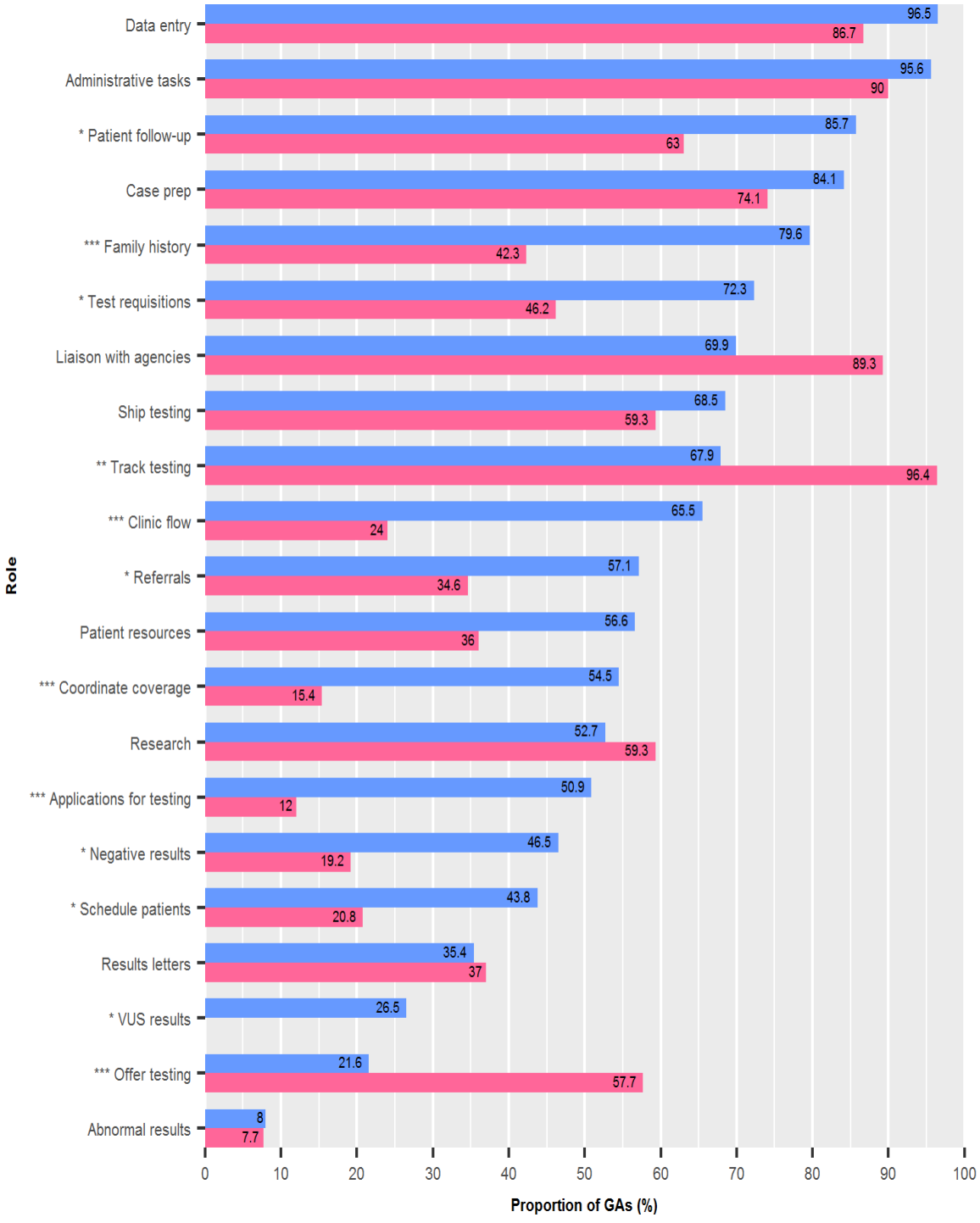

Figure 4.9. Roles performed by GAs who work in clinical versus laboratory settings, as reported by GA participants

Blue bars represent GAs who work in a clinical setting. Pink bars represent GAs who work in a laboratory setting. Full roles are listed in Appendix 1. Asterisks indicate a significant difference between their reports. (* $0.05 > p \geq 0.01$, ** $0.01 > p \geq 0.001$, *** $0.001 > p \geq 0.0001$)

Roles that were performed by at least two-thirds (67%) of GAs, regardless of setting, were: data entry, administrative tasks, case preparation, liaising with other providers and agencies, and tracking genetic testing. Additionally, at least two-thirds of GAs working in a clinical setting reported involvement in: patient follow-up, collecting and/or drawing family histories, completing test requisition forms, and shipping genetic testing. There were no other roles that at least 67% of GAs performed in a laboratory setting.

Despite the fact that most GAs reported involvement in administrative tasks, the majority also reported other administrative support in the genetics service besides themselves (151/161, 93.8%). However, a lower proportion of participants who work with GAs reported other administrative support (102/123, 82.3%).

GAs and participants who work with GAs had many similar perceptions about the roles of a GA (Figure 4.10). Exceptions were that a significantly higher proportion of GAs than participants who work with GAs reported that the GA role includes drawing family histories, liaising with providers and agencies, tracking genetic testing, assisting with clinic flow, and identifying and providing patient resources. For most tasks in the laboratory setting, reports of GA roles were similar between GA participants and participants who work with GAs (Figure 4.11). However, a slightly higher proportion of participants who work with GAs reported that GAs screen and track referrals than GAs themselves. On the other hand, significantly more GAs than participants who work with GAs reported that offering genetic testing is part of the GA role.

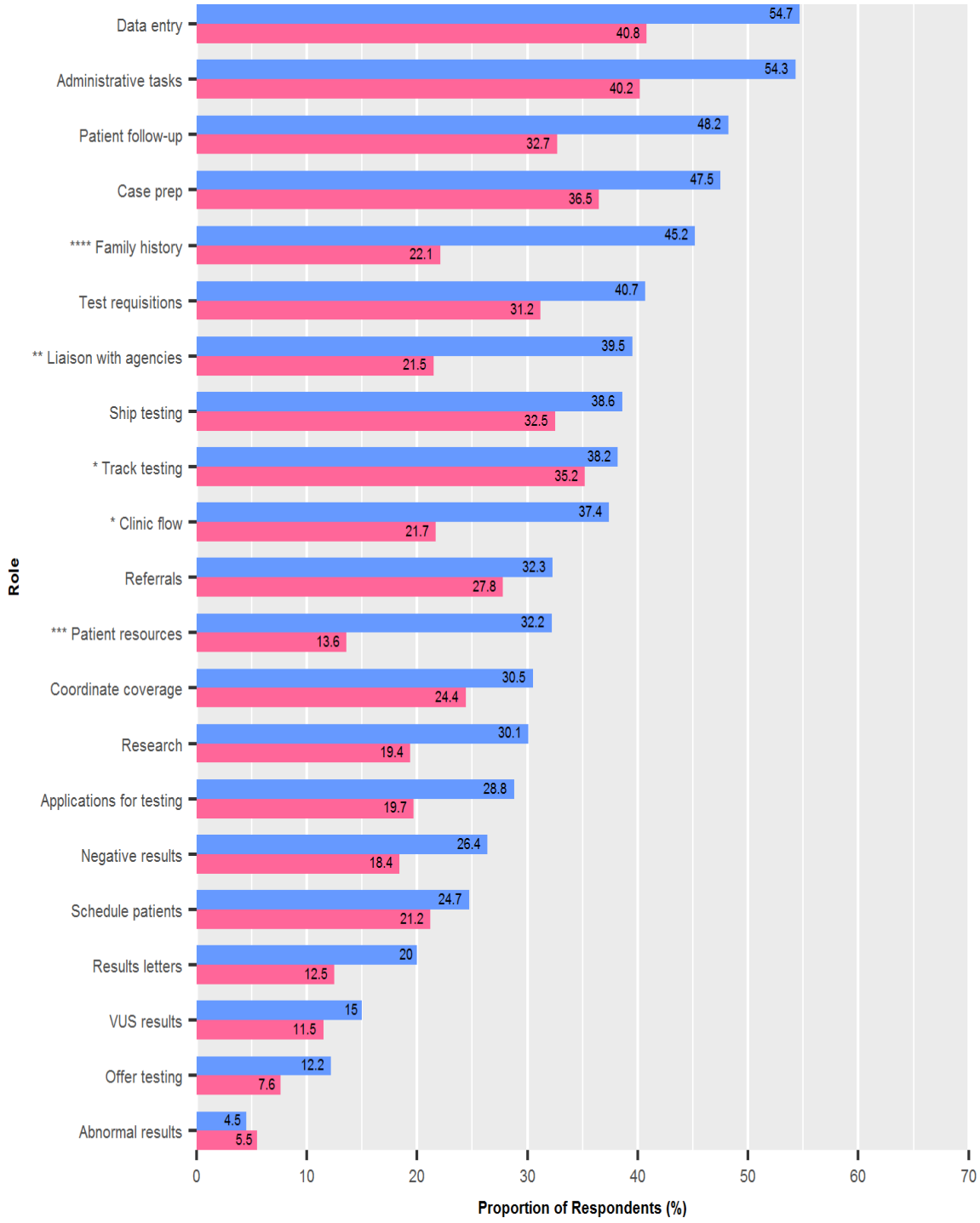

Figure 4.10. Roles performed by GAs who work in clinical settings, as reported by GA participants and participants who work with GAs
Blue bars represent GA participants. Pink bars represent participants who work with GAs. Full roles are listed in Appendix 1. Asterisks indicate a significant difference between their reports. (* $0.05 > p \geq 0.01$, ** $0.01 > p \geq 0.001$, *** $0.001 > p \geq 0.0001$)

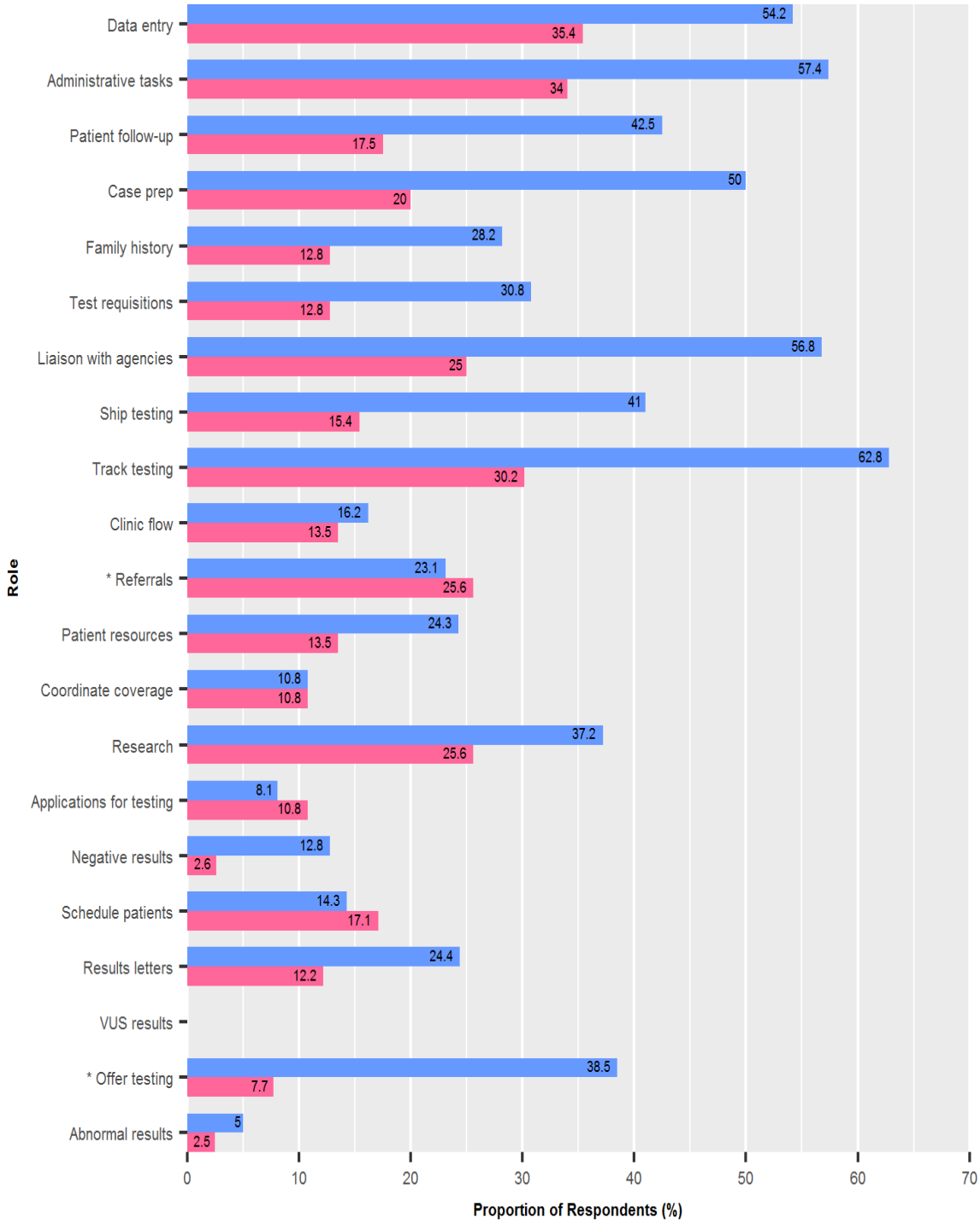

Figure 4.11. Roles performed by GAs who work in laboratory settings, as reported by GA participants and participants who work with GAs
Blue bars represent GA participants. Pink bars represent participants who work with GAs. Full roles are listed in Appendix 1. Asterisks indicate a significant difference between their reports. (* $0.05 > p \geq 0.01$, ** $0.01 > p \geq 0.001$, *** $0.001 > p \geq 0.0001$)

Overall, GA participants and participants who work with GAs agreed on whether most roles are appropriate for GAs to perform (Figure 4.12). However, significantly more GAs than participants who work with GAs reported that the following tasks are appropriate for GAs to perform: administrative tasks, collecting and/or drawing family histories, identifying and providing patient resources, preparing results letters, calling patients with variant of uncertain clinical significance results, offering genetic testing, and calling patients with abnormal results.

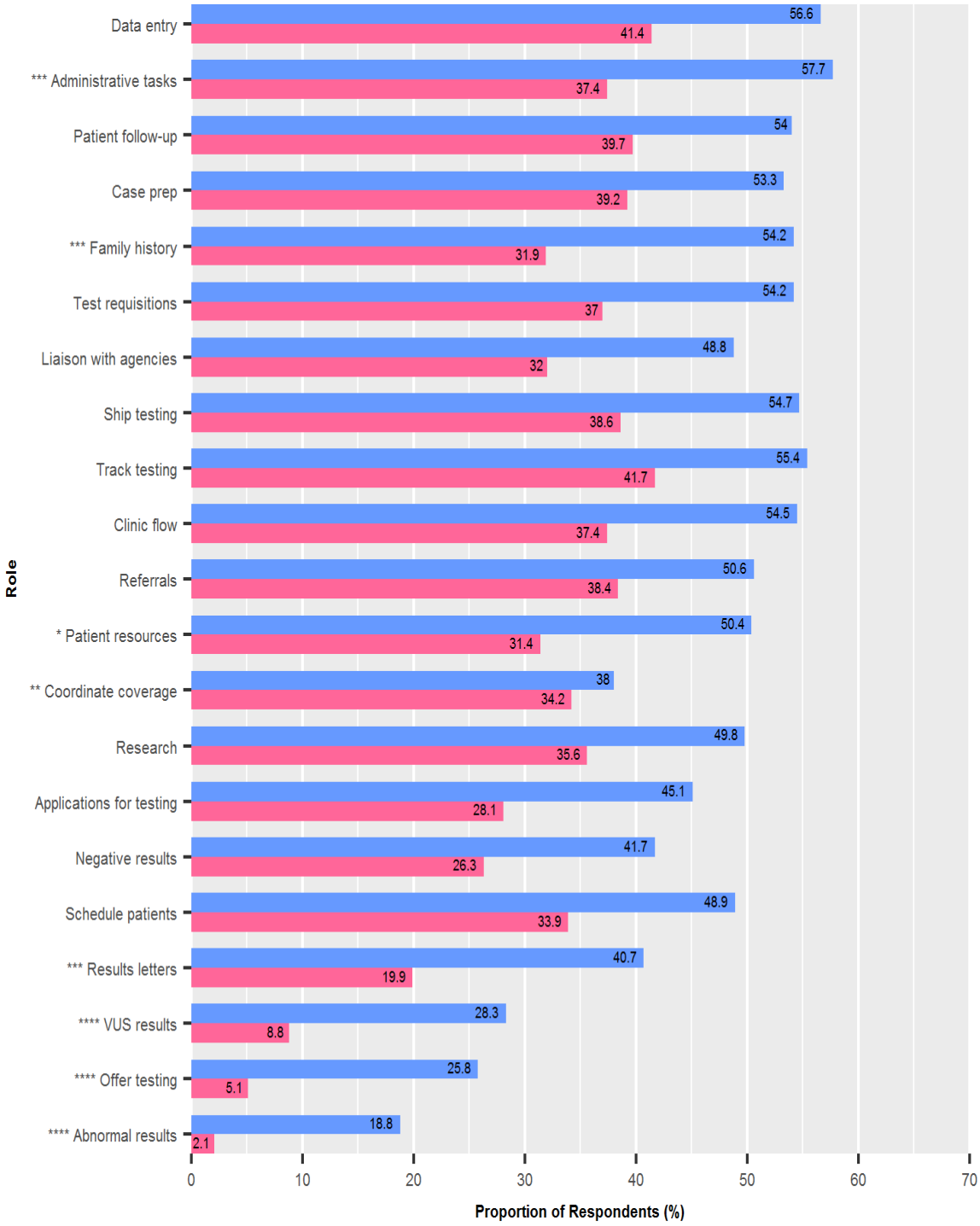

Figure 4.12. Appropriate roles for GAs, as reported by GA participants and participants who work with GAs

Blue bars represent GA participants. Pink bars represent participants who work with GAs. Full roles are listed in Appendix 1. Asterisks indicate a significant difference between their reports. (* $0.05 > p \geq 0.01$, ** $0.01 > p \geq 0.001$, *** $0.001 > p \geq 0.0001$)

4.7. Training and Preparedness

The majority of the GA participants felt that their prior education prepared them for the training and focus of their position (134/155, 86.5%). The GAs who felt that their prior education did not prepare them for the position primarily reported either that they did not have a strong background in genetics or that the responsibilities of their position did not require their knowledge of genetics (e.g.,. required more administrative experience). Additionally, some respondents expressed that aspects of their GA position could only be learned through on-the-job experience, rather than through post-secondary education.

Similar to above, the majority of participants who work with GAs felt that the GAs' prior education prepared them for their position (107/121, 88.4%). There were six respondents who felt that the GAs' prior education did not prepare them for the training and focus of the position; they explained either that the GAs lacked the necessary skills for the position (e.g.,. critical thinking and organization) or that their training did not align with the roles of the position (e.g.,. lacked clinical context or human genetics knowledge). The remaining eight respondents were unsure about whether the GAs were prepared for their positions based on their prior education.

Almost all GAs were provided with some form of training (either in advance or on-the-job) for their position (143/155, 92.3%); a similar proportion of participants who work with GAs reported that GAs were provided with training (112/122, 91.8%). On average, the mean hours of training provided were 69.9 hours (SD:109, range: 1-900) and the median hours of training provided was 40 hours (Table 4.5). The training hours reported by participants who work with

GAs were not significantly different from those reported by the GAs themselves (p=0.17 using a Mann-Whitney U test).

Table 4.5. Amount of training received by GA participants (n=118)

Amount of Training[a]	n (%)
1 day	16 (13.2)
2 days	15 (12.4)
3 days	17 (14.0)
4 days	9 (7.4)
1 week	20 (16.5)
1-2 weeks	17 (14.0)
2-3 weeks	10 (8.3)
3-4 weeks	5 (4.1)
>4 weeks	9 (7.4)

[a] Amount of training was calculated based on a 40-hour work week.

Of the GAs who received training, 114 (83.2%) felt that it prepared them for the responsibilities of their position. Many respondents who felt that the training did not prepare them primarily attributed this to the fact that some knowledge comes with working experience in the position rather than through training. Some respondents reported that they were the first GA in that position, therefore a training protocol was not established at the time that they were hired. Other reasons why respondents felt that their training did not prepare them included the dynamic/evolving nature of their responsibilities and policies/protocols, an inadequate length of training, and receiving training from someone who was inexperienced. However, one GA described continual learning as being one of the things she/he enjoys most about her/his position:

> *"Because there is such a diverse patient population and clinical presentation with our referrals, there is no way anyone could learn everything they need to know in four days. I continue to learn every day and that is part of the reason why I love this job. If I knew how to do everything, I feel that my role would become so monotonous. The real challenge is trying to figure out how to order new tests or finding innovative ways to communicate with patients that don't have phones. To continue to submit*

letter after letter to get a patient coverage for a new therapy or to justify why a patient needs an expensive medication that will improve their quality of life – this is what I love doing."

A higher proportion of participants who work with GAs felt that the training prepared them for the responsibilities of the position (93/100 respondents, 93%). However, those that felt the training did not prepare GAs provided the following explanations: the centre did not have a formal process established, training did not cover the clinic workflow, GAs need hands-on training/experience, and not enough time was allotted or available for training.

GAs reported receiving training from a variety of individuals (Figure 4.13). Almost all GA participants (134/140, 95.7%) received at least some of their training from a GC. Over half of GAs (86/140, 61.4%) received at least some of their training from another GA. Between one-third to one-half of GAs reported receiving at least some training from a medical/clinical geneticist (59/140, 42.1%), a clinic manager (50/140, 35.7%), and/or coursework or training modules (50/140, 35.7%). Other individuals who provided training to the GAs included administrative staff, administrators, program assistants, human resources, nurses, research coordinators, laboratory technicians, and other employees from the same organization. The proportions of participants who work with GAs that reported training by each of these individuals were not significantly different from the proportions reported by GAs themselves ($p=0.88$ using a chi-square test) (Appendix 6).

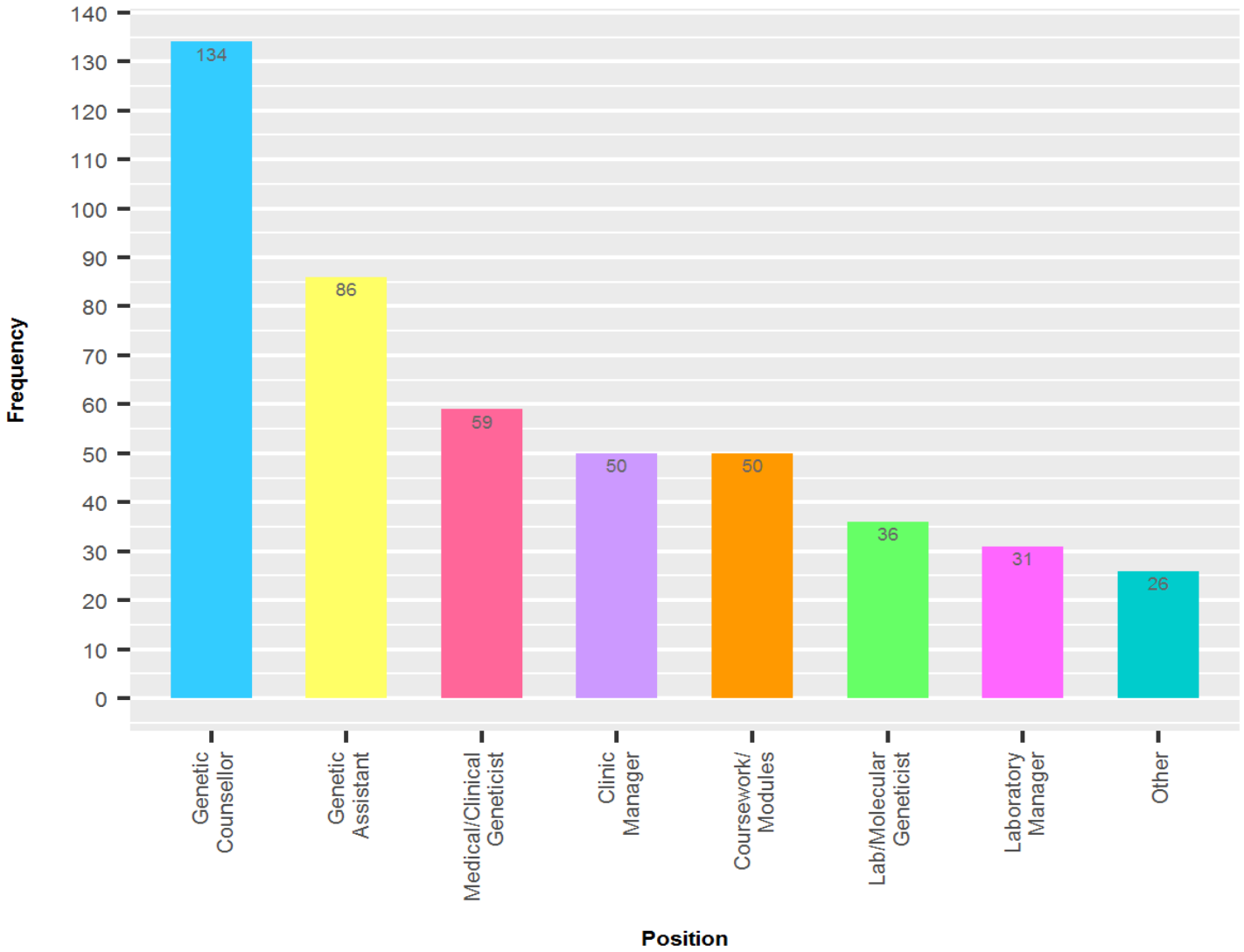

Figure 4.13. Individuals involved in training of GAs, as reported by GA participants (n=140)
Multiple responses were permitted, therefore the total is greater than the sample size

Approximately half of the participants who work with GAs reported that they were involved in the training of GAs in some capacity (68/122, 55.7%). The types of training that they provided could be divided into three main categories: 1) knowledge in subject area, 2) skills training and practical knowledge, and 3) institutional policies and procedures. Specific roles within these three categories are provided in Figure 4.14. Participants also provided information about the methods that they used to train GAs. These responses included: providing on-the-job training, reviewing cases, assisting with navigation of unusual circumstances, providing mentorship, answering questions, overseeing training, providing continuing education, shadowing, and supervising day-to-day tasks.

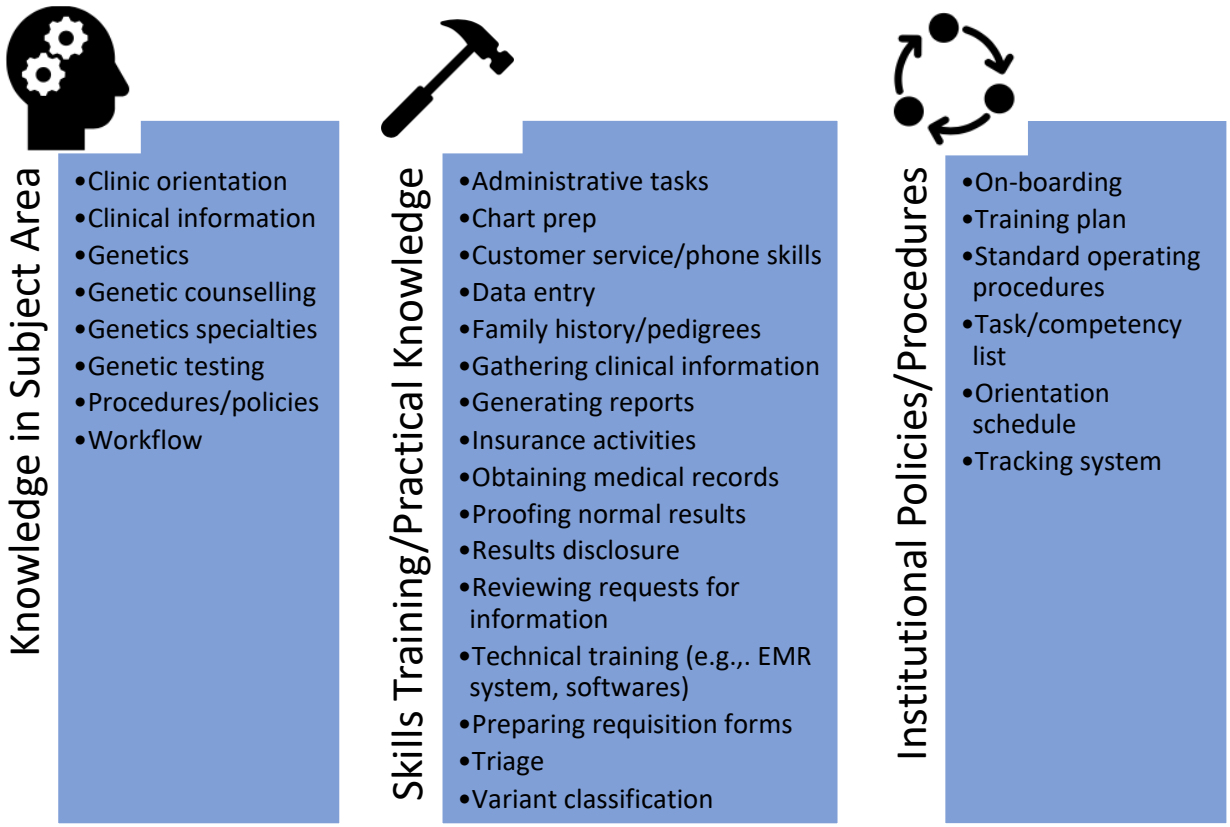

Figure 4.14. Types of training provided to GAs by participants who work with GAs

The GA participants were asked to describe training that they feel would help other individuals to prepare for work as a GA (Figure 4.13). Their training recommendations could be divided into three main categories (two of which were similar to the categories of training provided by participants who work with and train GAs): 1) knowledge in subject area, 2) skills training and practical knowledge, and 3) previous experiences. Specific recommendations within these three categories are provided in Figure 4.15. Similar to the participants who work with GAs, GA respondents also provided recommendations about the various methods that should be used to deliver training to GAs. These responses included providing on-the-job training, observation, shadowing with GAs and/or GCs, training by GAs and/or GCs, and providing continuing education (e.g.,. conferences, workshops, or presentations).

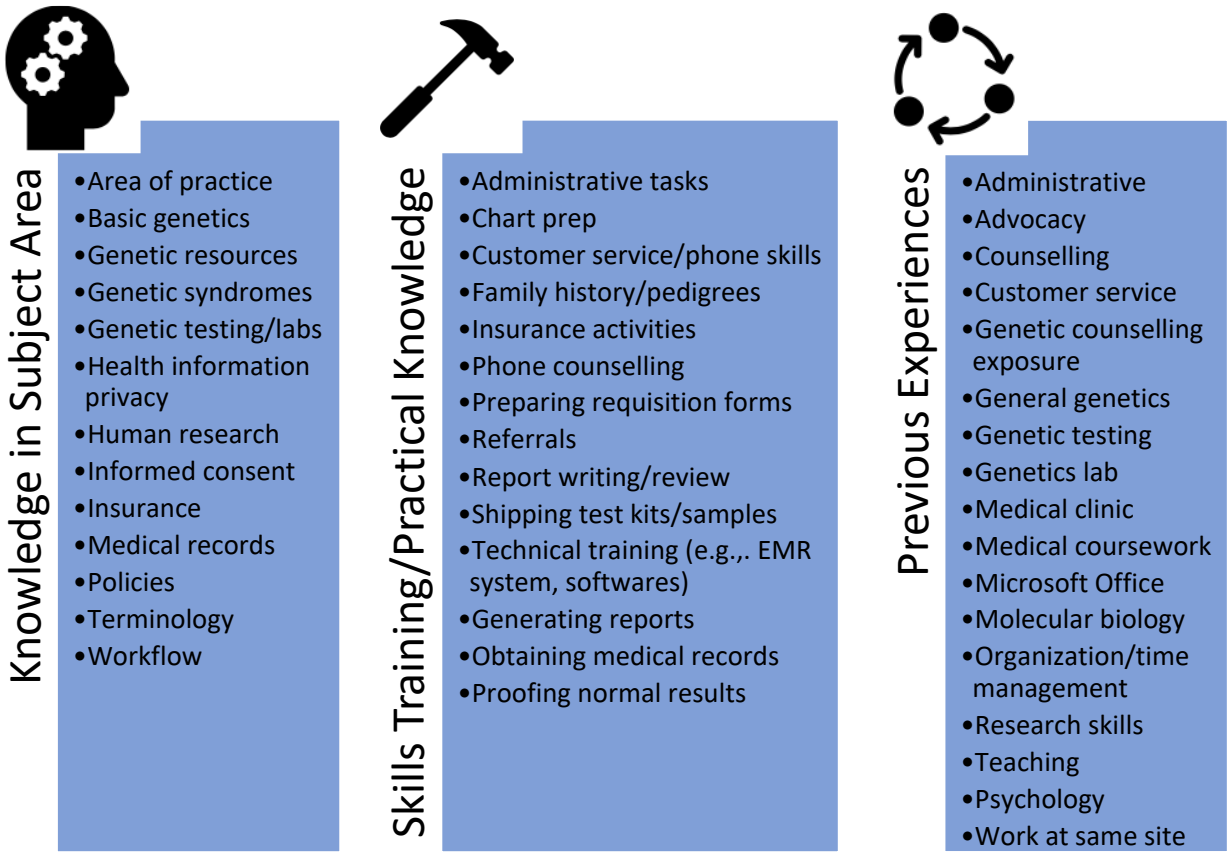

Figure 4.15. Training recommendations made by GA participants

4.8. Supervision

Virtually all GA participants felt that they received sufficient supervision in their GA position (147/148, 99.3%). Similarly, the majority of participants who work with GAs felt that GAs received sufficient supervision (107/111, 96.4%). One respondent who felt that the GAs did not receive sufficient supervision indicated that there is no system in place for supervision and training responsibilities at his/her site. Another respondent attributed insufficient supervision to the fact that the GCs do not have time to provide enough direct supervision to the GA.

The proportions of individuals from whom GAs received supervision (Figure 4.16) were similar to the proportions of individuals from whom GAs receiving training (Figure 4.13). Again, almost all GA participants (132/140, 94.3%) received at least some supervision from a GC. Approximately half of GAs received at least some supervision from a medical/clinical geneticist (57/140, 40.7%) and/or another GA (55/140, 39.3%). Approximately one-third of GAs received supervision from a clinic manager (45/140, 32.1%). Other individuals that provided supervision to the GAs include administrative staff, administrators, directors, other physicians, supervisors, and other employees from the same organization. The proportions of participants who work with GAs that reported supervision by each of these individuals was not significantly different from the proportions of GAs ($p=0.50$ using a chi-square test) (Appendix 6).

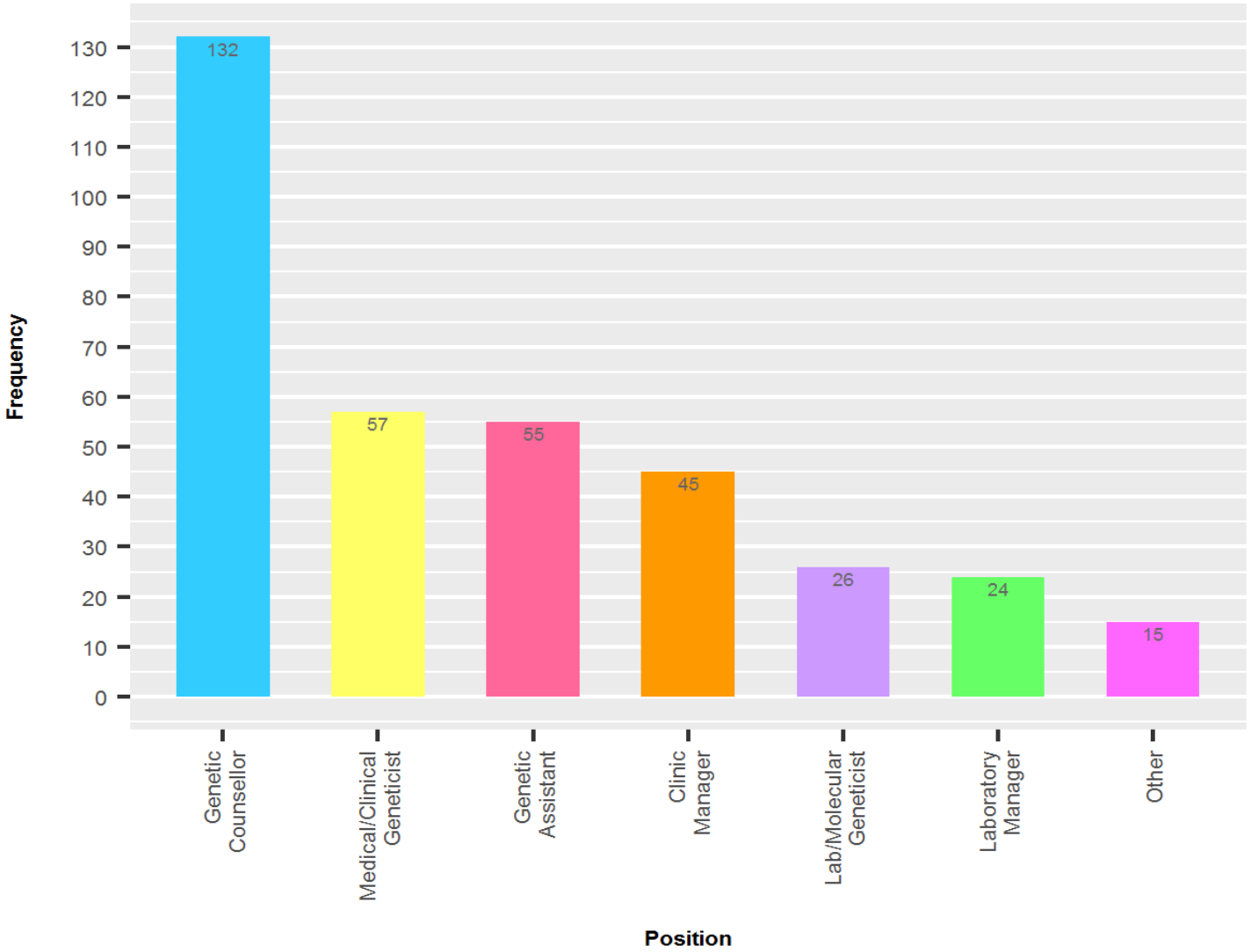

Figure 4.16. Individuals involved in supervision of GAs, as reported by GA participants (n=140)
Multiple responses were permitted, therefore the total is greater than the sample size

Supervision types are defined in Table 4.6. The most common type of supervision reported by the GA participants was intermittent supervision (92/148, 62.6%) (Table 4.6). General and general direction supervision were both reported by approximately 40% of GAs. Less than 10% of GA participants reported receiving direct supervision. The types of supervision reported by participants who work with GAs were generally comparable to those reported by the GAs themselves. However, a significantly higher proportion of those who work with GAs reported that GAs receive general supervision (68.8%) than the GAs themselves (45.3%) ($p=0.0002$). Of the participants who work with GAs, 55 of 112 (49.1%) provided direct supervision to GAs.

Table 4.6. Types of supervision provided to GAs, as reported by GA participants and participants who work with GAs (n=148 and n=109, respectively)

Supervision Type[a]	GAs n (%)	Work with GAs n (%)	p-value[b]
Direct Supervision Supervisor is present at all times and gives specific instructions/oversees all tasks.	13 (8.8)	18 (16.5)	0.06
General Supervision Supervisor provides continuing or individual assignments by indicating what is to be done, limitations, quality and quantity expected, deadlines and priorities (e.g.,. assignment of general clinic tasks in team meetings). Employee takes initiative for recurring assignments.	67 (45.3)	75 (68.8)	0.0002
Intermittent Supervision Supervisor provides specific protocols, priorities, and deadlines, and assists the employee with unusual situations that do not have clear objectives (i.e., employee follows established clinical protocol and seeks supervisor's assistance as needed).	92 (62.6)	66 (60.6)	0.79
General Direction Supervisor provides assignments in terms of broad practice, precedents, policies, and goals (i.e., employee makes autonomous decisions about clinical responsibilities). Work may be periodically reviewed by the supervisor.	61 (41.2)	44 (40.4)	0.89
Other Responses were: no supervision (acted as clinic manager) and support from distance	2 (1.4)	0 (0)	—

[a] Multiple responses were permitted (i.e., respondents could select all that applied), therefore totals do not equal 100%.

[b] The p-values were calculated using chi-square tests. A p-value was not calculated for other supervision, given that these responses are not comparable.

The primary mentors for GAs were GCs (99/148, 66.9%) or other GAs (32/148, 21.6%) (Figure 4.17). However, some GAs also reported seeking the most assistance with clinical responsibilities, support, and mentorship from medical/clinical geneticists (6/148, 4.1%) and clinic managers (6/148, 4.1%). Other sources of mentorship included administrative staff, a supervisor, and a research coordinator. The sources of mentorship for the GAs that were reported by participants who work with GAs were not significantly different (p=0.27 using Fisher exact test) (Appendix 7).

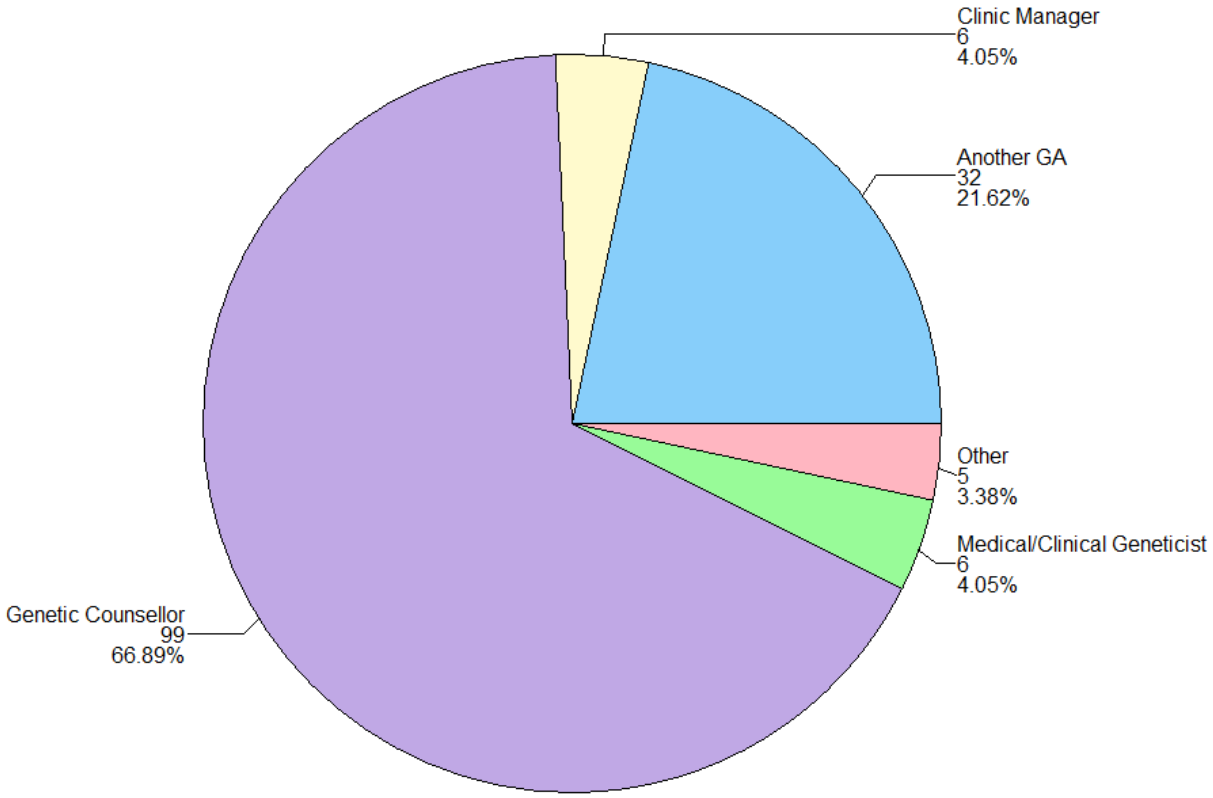

Figure 4.17. Primary sources of mentorship reported by GA participants (n=148)

4.9. Impact of GAs

When asked to assess/hypothesize the impact of GAs on their own roles, the majority of participants who work with GAs (76/101, 75.3%) indicated that working with a GA reduces the number of roles and responsibilities that they have (Figure 4.18). When asked which additional roles and responsibilities they would have to perform without a GA, they provided a wide range of responses (Figure 4.19).

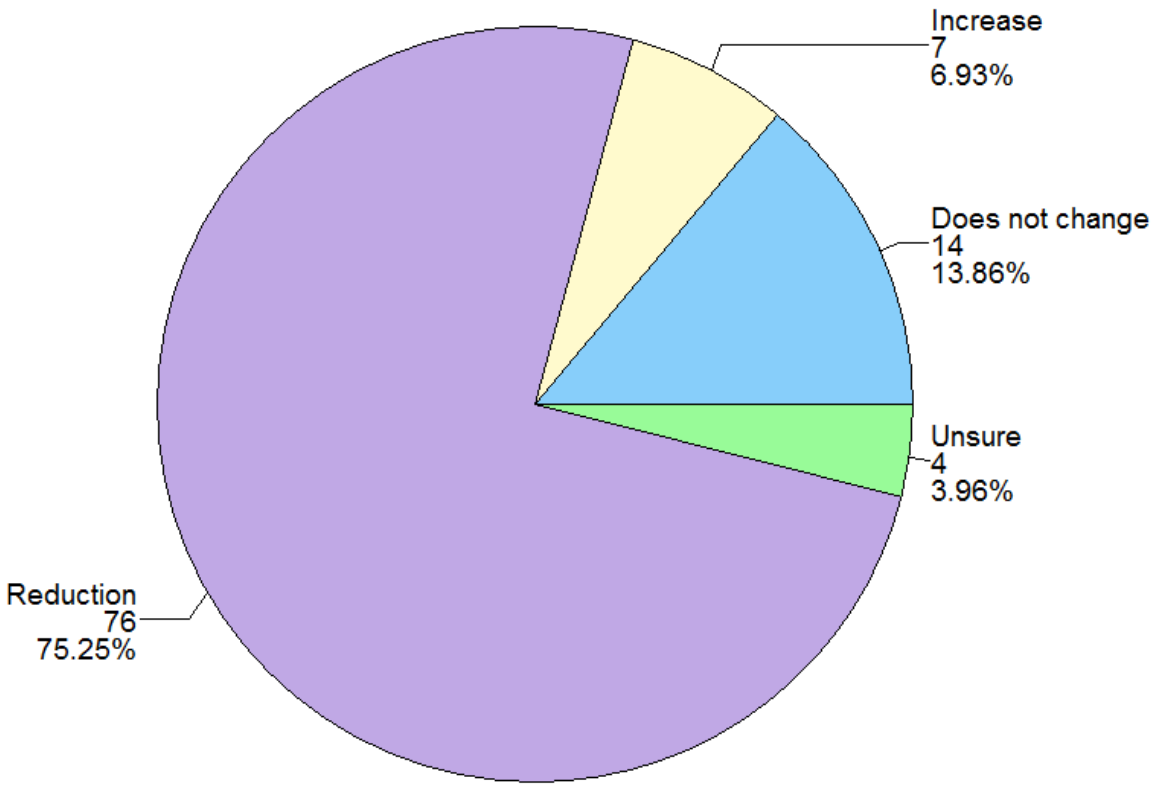

Figure 4.18. Impact of GA integration on the number of roles and responsibilities assigned to participants who work with GAs (n=101)

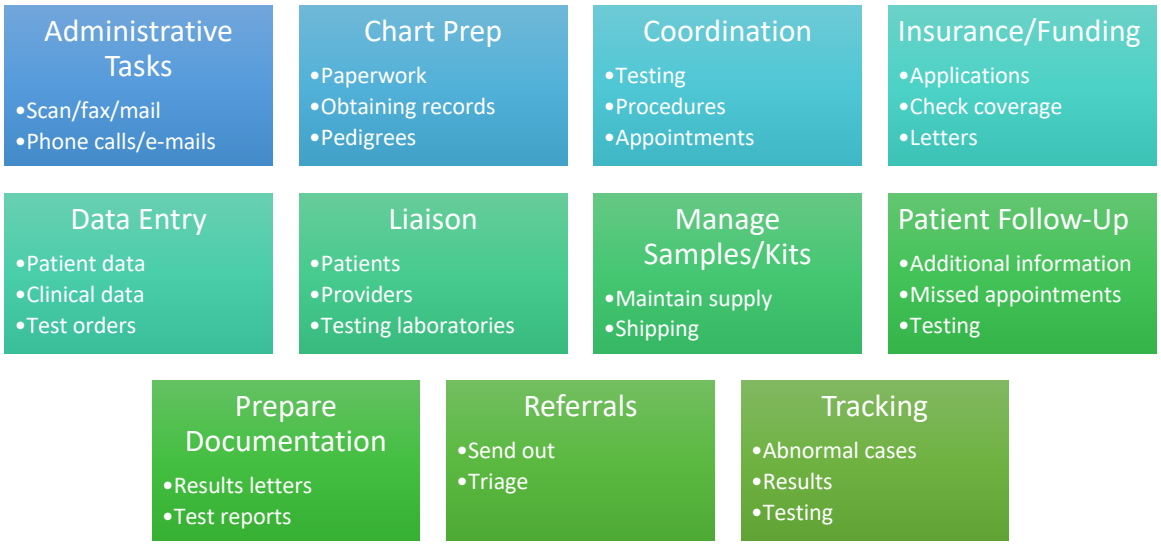

Figure 4.19. Roles and responsibilities assigned to participants who work with GAs when there are no GAs employed in the genetics service

Only a small proportion of respondents (7/101, 6.9%) reported that working with a GA increases their roles and responsibilities. Additional roles and responsibilities when working with a GA included data entry, supervision and training of GAs, drafting reports, screening reports, implementing screening programs, and leading tumor boards. However, one participant who indicated that working with a GA increases her/his roles and responsibilities commented that it *"increases the number [of roles and responsibilities]… but decreases time spent… thereby impacting GC efficiency and programmatic development goals"*.

The majority of participants who work with a GA (87/100, 87%) indicated that working with a GA allows them to spend more time on tasks that they have specialized training for (Figure 4.20). The participants provided numerous examples of these tasks (Figure 4.21). Interestingly,

four participants (4%) felt that working with GAs decreases the amount of time that they can spend on tasks that they are trained for, though specific reasons were not provided.

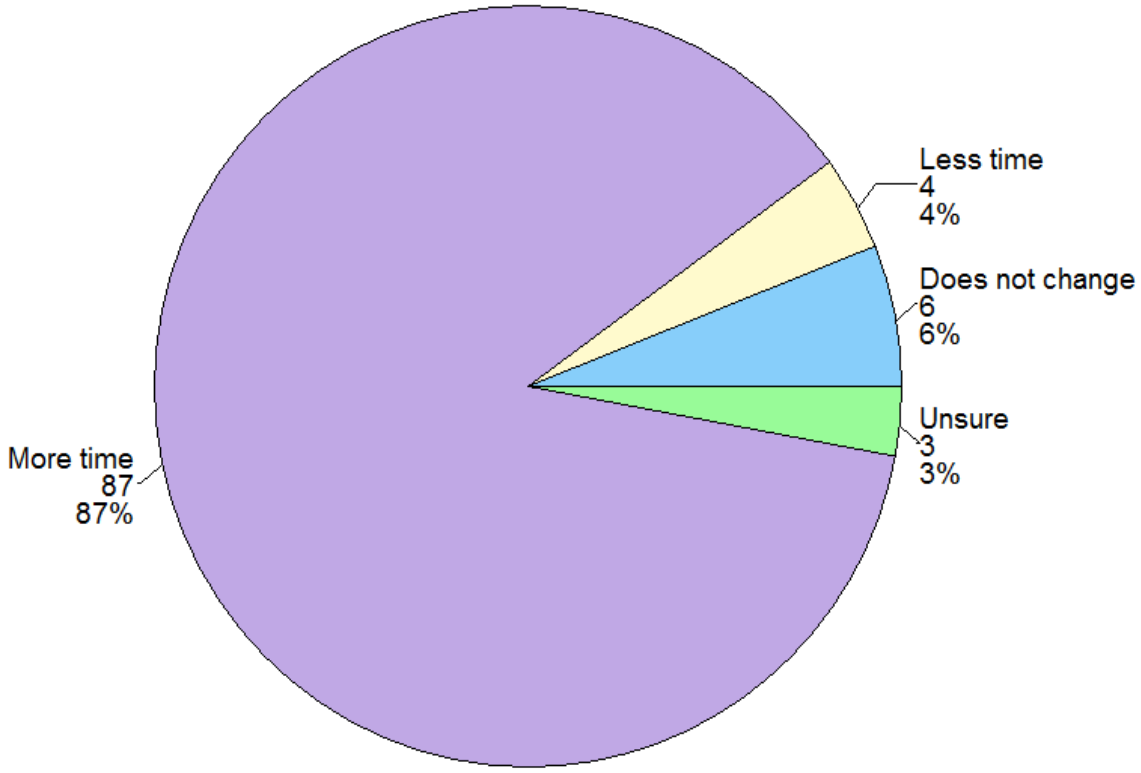

Figure 4.20. Impact of GA integration on the amount of time that participants who work with GAs can spend on tasks for which have specialized training (n=100)

Figure 4.21. Tasks that participants who work with GAs reported spending more time on when GAs are integrated in the genetics service
The code cloud shows codes assigned to long-answer responses from participants. Font size indicates the relative frequency of each code compared to the other codes.

Among 82 participants who work in a clinical setting, 52 (61.2%) felt that working with a GA allows genetics providers to see more patients, while 24 (28.2%) felt that working with a GA does not impact the number of patients seen (Figure 4.22). Only one respondent (1.2%) reported that working with GAs results in genetics providers seeing fewer patients. Correspondingly, among 19 genetic providers who work in a laboratory setting, 17 (89.5%) felt that working with a GA increases productivity in laboratory service provision (Figure 4.23). A small number of respondents (2/17, 10.5%) reported that working with GAs does not impact laboratory productivity. No respondents reported that GAs decrease laboratory productivity.

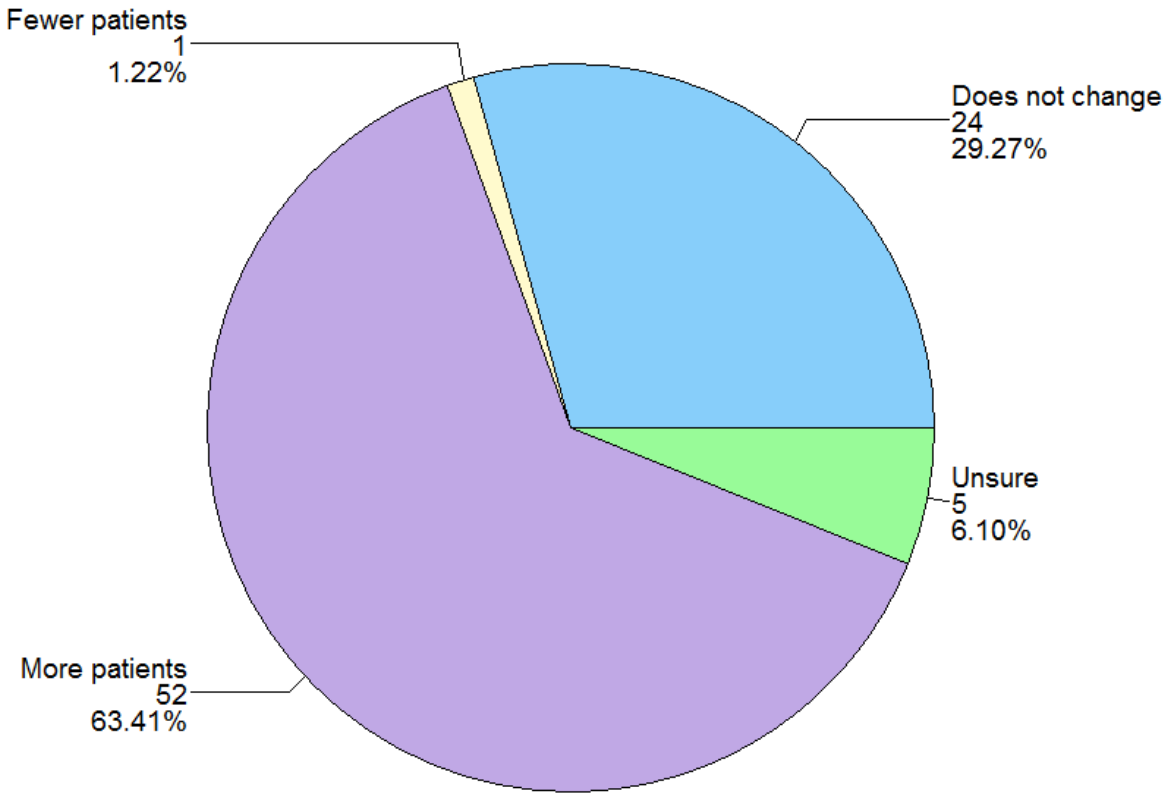

Figure 4.22. Impact of GA integration on clinical productivity (i.e., number of patients seen by physicians and GCs), as reported by participants who work with GAs in a clinical setting (n=82)

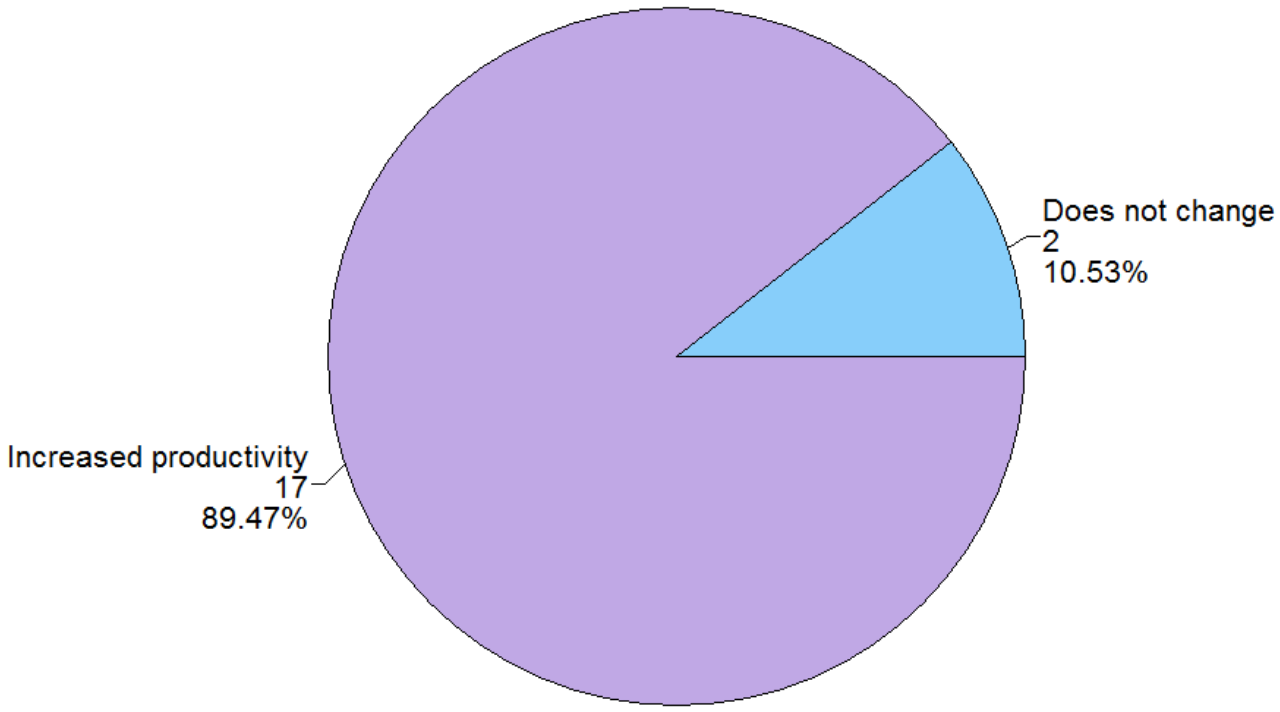

Figure 4.23. Impact of GA integration on laboratory productivity (i.e., laboratory service provision), as reported by participants who work with GAs in a laboratory setting (n=19)

When asked to comment on their work setting particularly (both clinic and laboratory settings), 95 of 102 (93.1%) participants felt that adding more GAs to their work setting would increase productivity (Figure 4.24). Three respondents (2.9%) did not think having a GA would impact productivity and four were unsure of the impact (3.9%). No respondents indicated that adding more GAs to their work setting would reduce productivity.

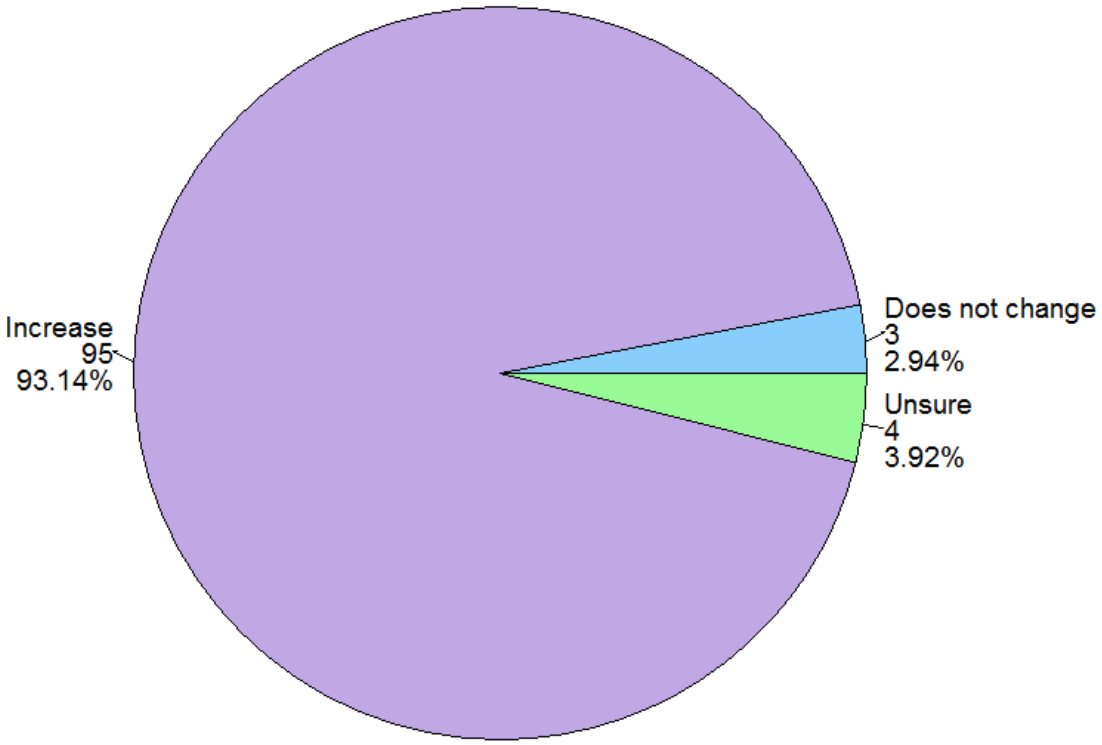

Figure 4.24. Hypothesized impact of additional GAs on productivity, as reported by participants who work with GAs (n=102)

4.10. Enumeration of GA positions

The participants reported a total of 144 GAs that were employed at the time of the survey (Figure 4.25). NSGC region 4 had the highest volume of GAs, while NSGC regions 1 and 3 had the lowest volume of GAs.

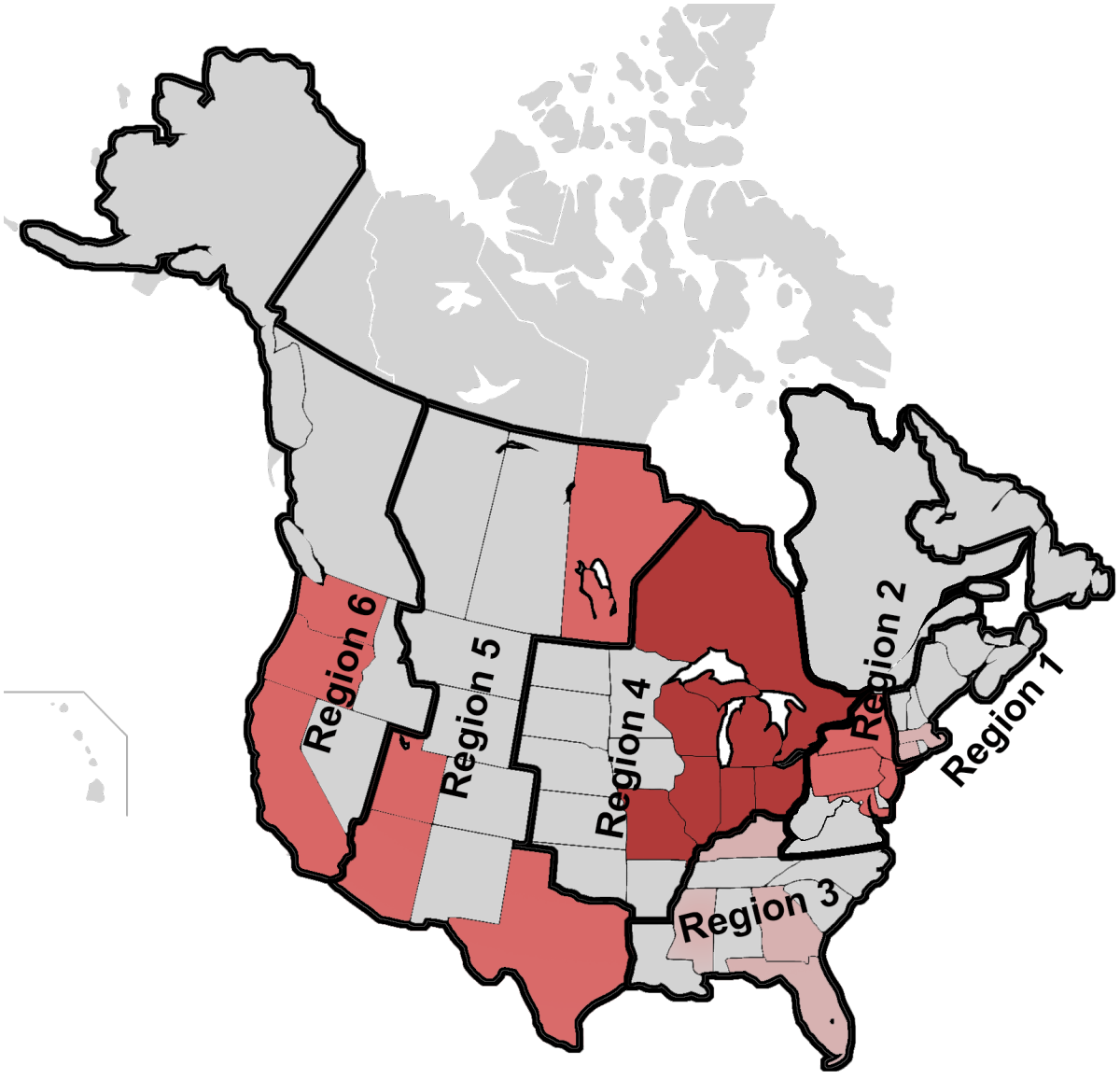

Figure 4.25. Heat map of GA positions by NSGC region (see Appendix 2)
Shades of pink/red represent the total number of GA positions across the region; light pink indicates 1 to 15 GA positions, bright pink indicates 16 to 30 GA positions, and red indicates 31 or more GA positions. Grey indicates a province/state that did not report any GA positions.

CHAPTER 5: INTERVIEW RESULTS

5.1. Participants

A total of eight GAs and six GCs who worked with GAs were interviewed. Four participants were interviewed in person, one by telephone, and nine via BlueJeans. The interviews ranged in length from 29 to 91 minutes, but the majority were 30 to 40 minutes in length. After the 14 interviews were completed, saturation was reached on the first two research questions (i.e., impact on others' roles and responsibilities and integration in the genetics team) and the participants were divided on the third research question (i.e., potential for long-term GAs).

Three of the GAs worked in Canada and five worked in the United States (Table 5.1). Most worked in a clinic setting, though two GAs worked in a laboratory and one worked in research for part of his/her position. Experience as a GA varied widely among the participants (ranging from 1 to 13 years). Five of the GAs were employed as a GA at the time of the interview and three were not. None of the GAs were the first in the genetics service they worked in and all but one participant worked with other GAs. Position titles included genetic assistant, genetic counselling assistant, genomic medicine assistant, and genetic counselling volunteer; however, to maintain anonymity of the participants, all quotes use the terms "GA" or "GAs".

Half of the GCs worked in the United States and half worked in Canada (Table 5.2). All GC participants worked in a clinic setting. Length of time working with a GA was quite variable, ranging from 0.5 to 17 years. All of the GCs worked with a GA at the time of the interview. GAs were already working in the genetics service when half of the GCs started their position, while GAs were later integrated for the other half of participants. Half of the GCs worked with more

than one GA at a time, and most (five of six GCs) had worked with more than one GA during their career.

Table 5.1. Characteristics of the GA participants

Participant	Location	Setting	Months as GA	Current GA	First GA in service	Worked with other GAs
GA1	Canada	Clinic	95	No	No	Yes
GA2	Canada	Clinic	48	No	No	Yes
GA3	United States	Laboratory/Clinic	158	Yes	No	No
GA4	Canada	Clinic	43	Yes	No	Yes
GA5	United States	Clinic	11	No	No	Yes
GA6[a]	United States	Clinic/Research	24	Yes	No	Yes
GA7	United States	Laboratory	20	Yes	No	Yes
GA8	United States	Clinic	20	Yes	No	Yes

[a] Did not provide permission to quote

Table 5.2. Characteristics of the GC participants

Participant	Location	Setting	Months with GA	Months without GA	Currently working with GA	GAs at start of position	>1 GA position	>1 GA ever
GC1	United States	Clinic	7	35	Yes	No	No	No
GC2	United States	Clinic	192	12	Yes	No	Yes	Yes
GC3	United States	Clinic	34	9	Yes	Yes	No	Yes
GC4	Canada	Clinic	31	141	Yes	No	No	Yes
GC5	Canada	Clinic	80	0	Yes	Yes	Yes	Yes
GC6	Canada	Clinic	104	8	Yes	Yes	Yes	Yes

5.2. Themes

Five major themes emerged through analysis of the interview data (Table 5.3). The majority of the themes were related to the main research questions from the interview guide, though new themes also emerged.

Table 5.3. Major themes from the interviews

Major Themes
The evolving nature of the GA position
You can't be autonomous on your own
The career divide
GAs in the eye of the beholder
"Once you have one, you will never want to go back"

5.2.1 The Evolving Nature of the GA Position

Every participant referred to the evolving nature of GA positions in some way. Some participants described their initial expectations about the role of a GA and how this changed over time. Many participants discussed factors that may influence the evolution of the GA position, specifically clinic structure and resources, experience and demonstrated competence in the position, and evolution within the field of genetics itself. Additionally, some of the participants described concerns/issues that may arise as a result of this evolution, including role overlap and loss of traditional roles.

Evolution of GA Role

Specifically, evolution of the GA position involved GAs taking on new roles and responsibilities over the time that they worked in the clinic or laboratory. Often times, GAs assumed roles and responsibilities that were traditionally performed by a GC; however, some GAs also took on roles that were normally performed by other employees (e.g.,. administrative professionals).

> *"One GA first started in my office as a work study student. Just basically doing the administrative stuff. And then eventually training him/her to call patients and talk to them over the phone."* (GC2)

> *"Right now, as a GA, I am taking on things that have previously been done by GCs that I'm honestly surprised I've been able to have taken on because I don't have a Masters. So I actually was surprised that I am able to call clients and say, 'Hey, this test probably isn't most appropriate. You should consider this [test].'"* (GA7)

> *"Over time we've distributed more and more, or delegated more and more, of our responsibilities to the GAs that seemed like administrative tasks"* (GC6)

> *"There was also an administrative assistant . . . And he/she did a lot of the answering phone calls initially for the clinic. And then we also had support in the sense of scheduling appointments. However, by the end of my time there . . . I ended up manning our clinic phone line and answering those calls. And then I also, because of some wait list issues and scheduling problems, ended up scheduling patients as well."* (GA5)

Initial Expectations

Given that the GA position is new and ill-defined, participants had varied perceptions of a GA's role prior to working with/as a GA. Several participants did not have concrete expectations about the specific roles and responsibilities of a GA; however, a few of these participants expressed some understanding that the primary role of a GA was to support the genetics service and the providers working in that service.

> When asked what his/her understanding of the role of a GA was when he/she first started work at the clinic: *"Zero understanding. . . . Where I trained, there were no GAs and this was my first job out of training, so I didn't really have any expectations about what they would do."* (GC5)

> *"I didn't have a whole lot of understanding of the role. It was fairly new to me. Just that I would essentially be assisting a geneticist and a clinic. . . . Just kind of assisting with whatever they needed in their clinic, with their patients, preparation. But really didn't have a good understanding of what the role would be once I started. So that was more after I started."* (GA2)

Interestingly, one of the GAs explained that even his/her employer did not have a good understanding of the role of a GA. As with some of the examples above, he/she had a basic understanding that he/she would be supporting the GCs. Beyond the roles included in the job posting, his/her job has evolved over time.

> *"When I started, even my boss didn't quite understand where I was going to be needed. So it's been evolving over time and I've definitely taken on more tasks. So I knew that I would be assisting the GCs in their daily work, but the range of that scope was unclear to me. I had a job description and I understood what was posted when I applied to the position. . . . So those were clear in my head, but it seemed like there was still a lot to be defined when I started and it's definitely been an ever-evolving position."* (GA7)

On the other hand, some of the participants were already familiar with the role of a GA prior to working as or with one. For example, one GC based his/her expectations about what a GA would do on his/her knowledge about what GAs did in other clinics.

> *"I had heard of GAs before and understood that their role was to help with administrative tasks, like filling out forms, helping with letters, like mailing and addressing letters, calling insurance companies, helping with the insurance side of things, sometimes helping with intakes for patients. And I had heard of a group that has them call out results as well – negative results"* (GC1)

Another GC had previously worked as a GA for a short period of time and therefore had some experience with the roles of a GA.

> *"I had also worked very short-term as a GA in [city] years ago . . . I basically did a coverage of a leave for a GA a couple times. So I worked for two month stints a couple times, so . . . I definitely had a vague idea of it."* (GC3)

When asked about their initial expectations of the GA position, some participants (both GAs and GCs) simply described the duties that a GA was expected to perform, rather than their perceptions of the role. It was not clear whether these participants' responses reflected their initial understanding of the role or if this was more representative of their current understanding of the role.

Influences

The participants described several factors that they perceived to influence shifts in the roles and responsibilities of GAs. All of the GCs explained that the roles and responsibilities of GAs are, at least in part, dictated by the structure of the work setting. For example, one participant summarized some of the institutional factors that may influence the ways in which roles and responsibilities are assigned to different employees:

> *"A lot of things, both man power hours, and clinic structure, and the way referrals are booked in triage, a lot of things change how we end up allocating resources."* (GC5)

Another GC provided a specific example of the impact of staff mix on the roles of a GA. After the GA in this example took on additional clinical tasks (e.g.,. collecting family histories), his/her role later reverted to be more administrative in nature (e.g.,. scheduling and collecting forms) because new GAs were added to the clinic.

> *"The primary role initially of the GA's job was mostly booking patients and then ultimately turned into a sort of more data management role [and he/she] could take phone pedigrees. And then more recently . . . we had hired GAs . . . They are paid employees, but they're on short term contracts with us rotating through from the [university]. And their jobs are more clinically driven . . . So our third GA is now primarily doing chart prep start to finish."* (GC6)

Several GCs described how GAs' roles and interactions with other employees may differ depending on which specialty they are working in.

> *"With clinical staff, I think it depends on how the clinic is set up and what the structure is like. But for instance, the metabolic GAs are a lot more involved with their clinic staff and a lot more involved with the GC and the geneticists . . . My understanding is that the cancer GA works a lot more with the GCs and is more in support of the referral triage service, rather than one-on-one direct assistance. . . . And then the prenatal GA doesn't interact as much with either GCs or geneticists . . . [The] prenatal GA is more helping to make sure that the screening program stuff goes smoothly . . . although we've used the prenatal GA in different ways. So the prenatal GA has often been a support for the GCs on-call."* (GC5)

Few GAs commented on the ways in which clinic structure and resources impacted their roles and responsibilities. However, given that most GAs work in these positions for short periods of time, they may be less aware of the factors that influence changes in or the introduction of GA positions.

On the other hand, multiple GAs described evolution of a GA's roles and responsibilities in response to new projects or goals of their institution. Therefore, as a clinic's/laboratory's programs evolve, the GA position may simultaneously evolve to meet staffing needs.

> *"We're still in the very beginning processes of that research. And I'm hoping that I will be able to be more involved with it as the steps unfold. So there's still a lot that's unclear about where my role is going to be, but I'm hoping to be more involved with that."* (GA7)

> *"I think, even just over time as I worked there, the expectations changed, as well as the department grew, and as different areas needed different supports."* (GA2)

> *"I think the program itself was designed to sort of develop during the year . . . There was an intentional shift of trying to make it more of a mentoring program. So there was the development of a set of rotations through some of the different areas that are associated with our clinic."* (GA8)

A GA's roles may also evolve to cope with significant inefficiencies in the clinic. This could include strategies to address lengthy waitlists, backlogged work among other employees, or cross-coverage for vacancies or absences.

> *"So [the GAs] had limited contact with the patients . . . And then it really started changing in the last two or three years actually, where there was so much backlog and cases that we just weren't able to get through them. And so I started looking at different models and it evolved . . . So at first, they would show a video and then that was basically informing the patients of some basic genetic information. And then I would come in and do the pre-test [counselling]. And then it came to the point that that was too much. So I educated them to actually do the pre-test [counselling], show them the video, and then actually gave them the basic information. And I was still doing disclosures over the phone. And then it evolved where they were disclosing all negatives over the phone for me. And I was doing in-person disclosures for the positives. . . . And that's pretty much where we are now."* (GC2)

> *"[The GA] will do the secretary's work, when needed. So when the secretary's overwhelmed or not in the office, the GA'll take over that role, which is really helpful because previously when the secretary was off, I did it, right? I checked the fax, I checked the phone, I answered the phone. And now the GA can do that. So that's very helpful."* (GC4)

Another factor in the evolution of the GA position (which was mentioned by half of the GCs and a couple of GAs) was related to experience and competence in the position. As GAs demonstrated competence in their assigned duties and became comfortable with their roles, other employees felt comfortable assigning them additional responsibilities. These duties seemed to primarily involve interactions with patients (e.g.,. contacting patients with results or obtaining consent for genetic testing).

> *"Over time, maybe even if he/she is here longer, we may start to assign the GA even more roles. For example, consenting patients to genetic testing. I do that, but as maybe the GA stays on in the clinic and just gets more and more experience, that's something that he/she can actually do is consenting patients. So I think there's room for growth. But you obviously can't throw that all on him/her within the first six months of being here"* (GC4)

> *"As we grew more comfortable within the role, the physicians and GCs that I work with felt more comfortable giving me more responsibility. So calling out certain*

> *results, calling patients to arrange follow-ups, and doing some of the booking myself if the secretaries weren't around. Just taking on some extra."* (GA4)

For this reason, some GCs recommended that other institutions should assign GAs straightforward tasks when first incorporating them into the genetics service. As the GAs become more comfortable in the position and demonstrate competence in their assigned duties, they can take on patient interactions.

> *"Start slow. I think start with phone calls and bookings before getting into greater responsibilities like preparing charts. Because it's a steep learning curve . . . And so they do need to learn about the clinic flow before they can actually do some of the more clinical-like paperwork."* (GC6)

> *"Be prepared to evolve, have the position evolve. It's ok to start out with them doing [a] limited amount. Because I would never have been able to go from seeing patients all the time to switching to what we do now. It was an evolution in their role. So if you're having a GA in the clinic for the first time, I would start slow and then evolve their role with patients over time."* (GC2)

Interestingly, a couple of the GAs felt that the evolution of the GA position reflected evolution within the field of genetics. Accordingly, GAs may be integrated into other areas of genetics (e.g.,. research) or may require additional training of GAs to stay up-to-date with advances in the field.

> *"There's consistent learning to be done. It's an ever-evolving position. And as the GCs take on more work, hopefully the GAs will be able to as well. So even within the year and a half that I've been here, it's ever-evolving. And I think it's so newly established that there's going to be so many new sectors that [GAs] can be involved in. Like a clinical GA, or a research GA, or a lab GA, or even intersection between those three different things."* (GA7)

<u>Concerns</u>

A few of the participants explained that the evolving nature of the GA position can lead to role overlap between GAs and other employees (e.g.,. administrative professionals or GCs). Conflicts

may arise if other employees fear being replaced by a GA if there are not clear boundaries between the roles assigned to each position.

> *"If you got a secretary who was very strict about union rules, you might run into trouble with [a GA] doing some admin work. . . . Like photocopying is a secretary's job, and it's in the job description and in your union, and nobody is supposed to do that job. . . . In some offices, I have heard it can get a bit sticky and the secretaries might complain and say, 'No, no, no. That's my work. You're not allowed to give that to the GA.'"* (GC4)

> *"I think GCs sometimes felt a little bit miffed, I would say. Like they felt like sometimes GAs might be taking away from their value and their role and so there was a bit of conflict there. But it wasn't an open conflict, it was more of an overarching cloud that just kind of sat there . . . and then needing to have that role or that specific task clarified that it was their job. . . . And I think, from a GC's perspective, perhaps that might jeopardize their job or their role, because if it's not clear boundaries between [a GA and a GC], then what's the value of having one or the other, right?"* (GA2)

Alternatively, one GA described a positive experience with role delineations in his/her work setting. This example demonstrates that clearly defining the roles of each employee leads to positive working relationships and more efficient work practices.

> *"I think everyone had a really good understanding of what their role was. And I feel like it worked really well. . . . I just think everyone knew what their job was and knew who to ask for help."* (GA1)

Accordingly, it is imperative that each institution clearly defines the roles and responsibilities of GAs prior to implementing them in the genetics service. However, GAs and other employees in the service should also be prepared for the GA position to evolve over time, as explained by one GC.

> *"Have the roles that you want them to do identified, but let them know that there might be additional roles or might require some flexibility."* (GC1)

Along similar lines, one GA emphasized the importance of a clear definition of the GA role, as well as an understanding of other employees' roles. Clear role delineations make it easier to determine who is responsible for any new tasks that may arise.

> "*I think it would be valuable to have a clear outline of what is your role, what is your job, what are the tasks that you are responsible for, when do you pass those on? . . . I think having just a clear job description. So whether it's an employee handbook or some type of thing like that, where these are a list of your duties. And you might have other things that are assigned. Also having knowledge on what is a GC's specific role? And what is an admin role? And then how do they all fit together? I think that's important too because there could be gaps in there that there's an expectation that one of those roles fills, but it's not clear."* (GA2)

Although the participants recognized that the GA role is still evolving, some of the GCs provided examples of specific tasks that they were not comfortable with a GA performing. These were tasks that extended beyond a GA's background knowledge or training. In these examples, it seemed that assigning these types of tasks to a GA could compromise the quality of patient care.

> *"We had one time when the GA did call out a very simple result and the family actually had a lot of questions and was frustrated that he/she couldn't answer them. So we reversed that and said, 'You know what? Let's not have you call out results.' That's a role that we just want to keep."* (GC1)

> *"In this job, the GA does all of the pedigrees for us before we even see the patient. The GA does that over the phone. And that's something that I was really surprised to see happen because I think pedigree taking is such a big part of your initial contact and building rapport. . . . I remember when I first started working here and I overheard him/her doing some pedigrees over the phone. I remember thinking . . . just word choice and things that you would learn in a genetic counselling training program that he/she hasn't learned yet. . . . So I think I'd rather GAs not do that part. Simply because, it's not like you can't learn how to take a pedigree, but there's these nuances that you learn from actually going through the program of just how to speak about certain sensitive things or whatever it may be, that I think it may be more of a GC role."* (GC3)

> *"There's a lot of variants of uncertain significance stuff that comes up. And the GA's job actually involves calling the patients if the variants get re-classified one way or the other, which I think is definitely a GC role. . . . I think we learn how to do that, and not having gone through a GC program, there's just more chance for*

> *miscommunication or not being able to answer the questions the patient has. It just seems a little bit outside his/her scope."* (GC3)

One GC also mentioned his/her dissatisfaction with a GA performing tasks that are usually assigned to administrative professionals.

> *"The GA also ends up doing a lot of admin stuff because our secretary is super busy. So some of that overflows onto his/her job, like faxing and filing. He/She ends up just doing a lot of that, which I'm not super happy about because it is basically like we're overpaying him/her to do that."* (GC4)

A couple of GCs highlighted the importance of ensuring that other employees are aware of which tasks are appropriate and inappropriate for GAs to perform.

> *"We absolutely respect that they are assistants and they can't provide genetic counselling."* (GC6)

> *"So just one thing I guess that I would say, advice to maybe GCs or geneticists, is what GAs aren't. So I've seen experiences where people turn to the GAs kind of as their personal assistants in a way, or asking them to do things that aren't GA roles. Like I had a colleague who asked the GA if he/she could organize a folder of research papers that he's/she's printed out because all the staples were out and it was messy. And I was pretty disgusted that he/she asked the GA to do that . . . so I would just want to clarify to people that they are not a personal assistant, they're not a secretary, they're not an admin person in that sense. And to just remember to respect it as its own position."* (GC3)

Additionally, several GCs expressed dissatisfaction with losing some of the roles that they traditionally performed themselves. These roles primarily involved patient interactions. While it may be essential to reassign some of these roles to GAs, these examples demonstrate that other employees may be resistant to letting go of some of their roles.

> *"This was born out of necessity. And it was hard for me to let go at first. . . . Especially building the rapport with the patients. So ideally I told them that I would like to stop in and say hello and talk to each patient. . . . Taking a little bit back, some of that contracting. . . . Just being more openly visible. That's something that I would like to take back."* (GC2)

> *"I like being involved with all aspects of the case, from start to finish. So I'm not totally sure this is my favourite set-up."* (GC3)

However, as illustrated above, GCs' feelings about a GA performing a certain task may change over time. One GC summarized this perfectly when explaining how his/her attitudes towards appropriate roles for GAs had changed since completing our survey (Appendix 3) approximately six months earlier.

> *"When I answered your survey, some of the questions, like I think one of them was whether you would have a GA disclose results, that kind of thing. And my answers have changed since the survey. . . . Six months ago, I wouldn't have said you would have a GA disclose a positive test result over the phone. But they actually tell the patient there's a positive result [now]"* (GC2)

5.2.2. You Can't Be Autonomous On Your Own

Both the GAs and the GCs described the GA position as being primarily autonomous; however, they also discussed six factors that appear to equip GAs to carry out their work independently. Adequate training and on-the-job learning lay the foundation for GAs to function independently. Appropriate supervision and regular feedback ensure that GAs feel supported. Last, continuing education and additional learning opportunities (specific to each GA's interests) increase engagement and may also provide training and background knowledge to help prepare those GAs who plan to apply to genetic counselling programs.

Autonomy

Most of the GAs explained that they themselves generally worked autonomously. Similarly, half of the GCs described the GAs as working autonomously. Both groups of participants explained that GAs usually train with or work alongside another employee when they start in the position;

once GAs demonstrate competence in their work and feel comfortable, they begin to work independently.

> *"I am definitely mostly independent. When I work remotely, I am my own supervisor. My actual direct boss works at a completely different site than I do. So there is a lot of trust that the GAs are getting their job done, which is great because I don't necessarily like being micromanaged. So I trust myself to manage my time, get my work done. . . . I am my own manager, in a sense, because I don't have someone sitting over my shoulder telling me that I need to get my stuff done."* (GA7)

> *"Definitely in the beginning, I would say the first six months, I was definitely asking a lot of questions and asking for a lot of help with all different levels of the genetics team. But as I became more comfortable in the processes of working day to day, I think I was able to work pretty independently. Anything new, I always asked for help. . . . There wasn't direct supervision at all"* (GA1)

> *"Once the GA is comfortable to call patients on their own to take pedigrees, then they do with minimal supervision. So we're always around, but they do work autonomously."* (GC6)

In line with working autonomously, a couple of GCs explained that the GAs prioritize their work independently. While supervisors may provide GAs with specific tasks or deadlines, the GAs ultimately organize their time and choose which tasks to prioritize.

> *"We let the GA prioritize his/her work. . . . He/She knows that all of our red charts are prenatals, are urgent. So anytime a red chart comes into our office, that takes priority. The GA organizes his/her own workday, in terms of how he/she prioritizes his/her work. And then I'll give the GA deadlines, as necessary. For example, I need these stats done by a week today."* (GC4)

> *"I'd say he's/she's somewhat independent. So we have him/her rotate with the different GCs on different days. So he/she has a schedule. . . . We give him/her tasks. But between those things, he/she can do what he/she wants. And if someone is asking him/her to do a task that deviates from his/her normal schedule, he/she has the independence to decide whether he/she does that or not."* (GC1)

As GAs gain clinical knowledge, they may also be able to assist in working up cases independently, as explained by one GA below.

> *"When you first start the job itself, I think in the description [it] says that there's a huge part of autonomy and be[ing] able to work things out for yourself. Well, you're not really, because you have other people in the department that are there to help you out when you need it. But taking the initiative to send the referrals. And if it's stated in the letter that we were going to do this, this and this . . . having been in this role for over three years, I'm not going to go back and double check. . . . I'm just going to do it"* (GA4)

Training and On-the-Job Learning

Only one participant (GC6) mentioned formal training that is provided to GAs at his/her institution; the GAs complete the same hospital orientation as all other employees. It was not clear whether GAs at other institutions completed formal hospital training at the outset of their positions.

> *"Our GAs who have come on since I started do go through the entire process of, for example, patient interaction and confidentiality modules through the hospital. So they do the regular orientation, and then with us they do on-the-job training. So a lot of it is observation of the GCs to get started and then once the GA is comfortable to call patients on their own, to take pedigrees, then they do with minimal supervision."* (GC6)

When other participants were asked about the training provided to GAs, they typically described GAs observing other employees in the genetics service (usually GCs) and/or receiving mentorship from other GAs.

> *"So in terms of learning to draw pedigrees we (the GC) would call a patient and put the patient on speakerphone . . . And then draw the pedigree. And then the GA would be in the room watching to learn how to do it. And then, I think we probably did a few phone calls with the GA doing it and the GC in the room watching. And then, once we felt comfortable that the GA was okay to do that by himself/herself, then he/she ran with it . . . Doing that for all aspects of patient tasks."* (GC4)

> *"In terms of training, I worked really next door to the GCs, so they were really available for questions. I had a manual of instructions and guidance in terms of how to do certain things or how to document in medical records and that sort of thing. So that was all available. And then just direct training through either a GC, or if the other GA was there, he/she would also help me as well if I had any questions."* (GA5)

> *"The GA that was in the role before me was there for four half days with me, for one week, and then I was on my own. Luckily, there are other GAs in the program so a lot of it was learned experience on-the-job and they were there to support me and answer questions that I had that a physician may not know. . . . Having coworkers that know and deal with the same things on a daily basis was a great support."* (GA4)

Half of the GAs expressed that the training they received was limited or inadequate. In some cases, the inadequacies described were related to specific tasks or roles. In other cases, GAs expressed that the training they received was inadequate overall.

> *"I remember feeling overwhelmed with the [pedigree program] entry at first and the training for that was a little inadequate. Myself and one of the other GAs are actually working to revise the training on that for this incoming year. Some people have spent a little bit too long in what I might call [pedigree program] purgatory, where they're waiting to be cleared from having to send their copies of their entered pedigrees onto a mentor."* (GA8)

> *"I was involved in a lot of research. Which I don't feel is generally part of the scope of a GA. But at that time we didn't have a lot of funding for genetic tests so the geneticists were trying to do everything possible to help their patients and so a lot of that involved a research route. . . . So some of those days really cut into my regular GA roles because research, at that point, wasn't something I was comfortable with. It was new and I had to navigate my way through that."* (GA1)

> *"My orientation was not clear in the beginning. Other than I was matched up with a mentor. And that was instrumental I think, more so than meeting with the geneticist"* (GA2)

Often, the GAs recalled feeling unprepared for their interactions with patients and/or providers. However, throughout their time in the position, they gained the necessary skills and became confident handling these types of interactions.

> *"I still remember my first family history questionnaire . . . was a very sharp, snappy old woman and it couldn't have gone worse for me. I was a very nervous 17-year-old freshman kid"* (GA3)

> When asked if he/she felt prepared for the patient interactions that were a part of his/her position: *"Maybe not initially, but I think it's something that I was becoming*

> *more comfortable with throughout the position. And I think maybe it took a little bit of time in the beginning, but I think the ability to talk to patients on a regular basis . . . I was able to become comfortable with that."* (GA5)

> *"It was a little nerve racking at first, but over time, you gain the confidence and you feel that you have all the skills you need to make those types of calls [to providers]."* (GA7)

To this end, a few participants expressed a desire for more formal training. They each provided examples of what such training might involve, including: referral indications, types of genetic disorders, clinic workflow, roles of other staff in the genetics service, insurance (at institutions in the United States), and managing patient emotions. This training could be delivered in a variety of formats, such as review with a GC, an employee handbook, orientation meetings, and/or workshops.

> *"I think I wish we had done a little more formal training with him/her. . . . I think it would involve going through different types of genetics indications, maybe a few case examples, going through the flow of clinic, how it works, the role of the GC versus the geneticist. Maybe a little background on insurance issues and what's required from that. We did train our GA with some casual training about the workflow of clinic and how genetics appointments work or how genetic testing works. But I wish we had gone more into how insurance works."* (GC1)

> *"Having some sort of resource, or reference book, or page for the quick things that can come up. And then if there are certain topics that a GA needs to know really offhand. . . . Having that as a homework assignment for your orientation. . . . I think a clearer orientation process . . . Having some sort of mini intro to each area. So a mini intro with a GC . . . Meeting with the geneticist and then meeting with the admin that might be directly supporting your area. Maybe even meeting with the director or any other management that's involved . . . Having some sort of a group meeting with the other GAs where they each describe what their role is and how it might connect back to what you do."* (GA2)

> *"Maybe if there were a workshop of some kind. Or even some additional training that could have been offered on the side to deal with [patient emotions]. . . . For people who are just starting in the role, I think it's important to address not only your psychological health, but how to manage patient emotions and being careful with your wording as well."* (GA4)

However, most of the GAs and all of the GCs acknowledged that some knowledge and skills are gained over time in the GA position and cannot simply be acquired through formal training at the beginning of a GA's employment.

> *"Just like anything in your life – the more you do it, the more you get used to it. It kind of becomes second nature."* (GA3)

> *"You learn things as you go along and you bite off what you can handle at that time. So I think if you keep up with information as it comes, you acquire quite a bit over time."* (GA1)

A couple of participants described a significant "learning curve" for GA positions. Interestingly, they both attributed this to the fact that there are no formal training programs for GAs.

> *"There's a really big learning curve and there isn't really a specific training program that teaches you how to be a GA."* (GA2)

> *"It's a steep learning curve, at least for us, because these individuals have not had any formal training as GAs – we're doing on-the-job training."* (GC6)

Supervision and Feedback

While most participants reported that GAs primarily worked autonomously, they still emphasized the need for appropriate supervision and support. About half of the GAs acknowledged and appreciated for the support provided by their supervisors (usually GCs). They often described how available their supervisors were to them, even if they were not in the same physical workspace as the GAs; this is especially important because many GCs and geneticists see patients outside of their office (i.e., in other clinic space, which may be at the same or different institution). However, one GA (GA6) explained that GCs may be limited in how available they can be to GAs due to having busy schedules and heavy workloads.

> *"I feel like I have people available to me all the time. . . . So my direct boss is so helpful and, even though he's/she's not involved in my daily tasks, he/she is always there if I do need something. . . . And if I have a question about anything, I'll reach*

> *out and they're more than happy to answer and get me involved. . . . I never feel like someone is not going to be able to answer my question. . . . They're just a quick phone call away or quick instant message. Even though we're not physically close, I have no problem feeling like someone's available for me if I need. . . . I love that the GC's are always happy to help me learn and help me with anything that I might need."* (GA7)

> *"I've come to appreciate that regardless of whether or not they're actually physically in the office, doesn't mean I can't get a hold of them if I really need to. And so that's always been a really great feeling."* (GA4)

Similarly, several of the GCs described themselves as readily available to the GAs who they work with. This included being easily accessible by phone/e-mail, available to answer questions, and willing to assist with patient interactions.

> *"I am very available for the GA. I get back to him/her immediately when I see an email from him/her. Or when he/she calls, I prioritize that."* (GC1)

> *"The GA comes to [name] and I all the time with questions. And we are always available, unless we're with a patient, or on the phone, or something obvious. But our door is always open and he/she just comes in whenever. That's never a problem."* (GC4)

> *"We have to definitely step in here and there when there are cases that, once they're on the phone for example, need more clarity from a GC. We've just had to train our GAs to recognize who those patients are and to be confident that it's okay to pass on to a GC whenever necessary"* (GC6)

In opposition to the majority of respondents, one GC and one GA described situations in which they felt that the GAs received limited or inadequate supervision.

> *"I feel very available. We're close, there's easy communication . . . But the GA's not supervised really. He/she is pretty independent, but I don't think in a good way necessarily because I think people in that role need direction . . . I feel like he/she doesn't have that person available necessarily all the time."* (GC3)

> *"In terms of supervision, I don't know if there was really anything direct. There wasn't scheduled check-ins where we had one-on-ones and figured out how you're doing. . . . Supervision would be more relating to who you shared an office with and them giving you tidbits of info. Or if your current work task might involve a GC, they might just give you information."* (GA2)

One GC explained that the level of supervision needed may differ between GA positions, depending on the GA's roles or the specialty that he/she is working in. Therefore, it is important that each institution bases supervision guidelines on their GAs' workloads.

> *"I think it depends on that GA's specific niche. I think there are definitely some roles that are very independent and some roles that do require a lot more help. And not because of the individual, but just because the nature of the job. So for instance, the maternal serum screen coordination bit is very routine, for instance. So that role has not as much supervision, and they might only ask the GC if there's something that falls out of the ordinary. . . . As individual support for the geneticists they work with, for instance, that might require a lot more direction just because every patient is unique. So there might be a few things that they can anticipate the geneticist will ask, but they might not be able to anticipate everything."* (GC5)

In addition to discussing the supervision provided to them, a couple of GAs discussed the experience and impact of receiving feedback in their position. One GA (GA6) sought ongoing feedback from his/her supervisors and felt that this helped to develop his/her skills and advance in his/her career. Alternatively, another GA stated that he/she received minimal feedback and felt that more consistent feedback would have helped him/her to achieve higher performance in the GA position.

> *"Feedback wasn't something that I got a lot of – whether it was because I was doing a good job or just because it was not part of the natural way of the department. Annual reviews would happen . . . But other than that, it was just muddling through things a little bit. . . . So just having whoever it is that you're reporting to giving you an indication like, 'This isn't something typically you would do', or 'You're doing a really great job at this, but I would really like you to do it this way', that kind of thing. Rather than finding out after everything was done"* (GA2)

A couple of GCs also discussed the amount and type of feedback provided to the GAs who they work with. One GC provided ongoing feedback to the GAs, while the other GC acknowledged that the GA he/she worked with did not receive any feedback. As such, there does not seem to be a standard for how and whether GAs receive performance feedback.

> *"We do acknowledge them [during] regular check-ins – the GAs do have to be evaluated . . . so we're constantly checking in to let them know where they're at in terms of progress and expectations. Encouraging them to continue to do things the way that they're doing them when they're doing them well, give them feedback when they might need a little redirection. And then always just reinforcing that handle what you can handle, let us know if we're overwhelming you."* (GC6)

> *"The GA doesn't get feedback, he/she doesn't get mentorship. So not like the GA's on his/her own, but he's/she's not supervised really."* (GC3)

Continuing Education and Additional Learning Opportunities

The majority of the GAs brought up continuing education during their interviews. As explained by several GAs, continuing education and training may enhance engagement among GAs. Furthermore, it may better prepare GAs who are planning to pursue a career in genetic counselling.

A couple of the GAs described continuing education opportunities that were available to them during their GA positions.

> *"For every eight hours . . . we're encouraged to do one hour of enrichment, and that can be going to the Medical Genetics Grand Rounds, that can be going to the weekly clinic meeting, or that can be shadowing."* (GA8)

> *"[The GC's] specialty is within hemoglobinopathies. And he's/she's had multiple training sessions for the GAs to really inform us of the types of orders that come through. And so we're learning to verify those right now."* (GA7)

Several other GAs explained that continuing education opportunities were not available to them, but suggested that this should be incorporated into GA positions.

> *"I think it was on the survey . . . 'Do you think it would be good for GAs to have tutorials on certain things? Would that be helpful?' And I think it would. . . . We don't get fun things like conferences to go to, but maybe there could be some good educational things that we could do. . . . And it might help keep [GAs] there longer."* (GA1)

> *"I think that for GAs, just even having lists of things that would be relating to that area and then providing those regular opportunities. So maybe it's learning about teamwork – so something relating specifically to what they do. Or maybe it's an area in a specific science – so whether it's genetics, or metabolics, or prenatal care – having mini-sessions. The department allowed you to go and see presentations within the hospital, but often times you had to factor that into your working time. And so if you wanted to see presentations that week, but you had 500 million other things, it was pretty much impossible for you to participate in that and your work performance not suffer. So making sure that your performance wasn't going to suffer from pursuing more education that was being promoted by the department."* (GA2)

No GCs mentioned continuing education for GAs; this was surprising, given that continuing education is an important component of GCs' own professional development. While they did not discuss continuing education opportunities for the GAs, GCs did discuss their willingness to offer additional learning opportunities to the GAs based on their interests. For GAs who are considering a career in genetic counselling, this could include shadowing patient sessions or taking family histories.

> *"We are very receptive to the fact that they are often interested in just exploring genetic counselling as a career. If they're caught up in their work, we'll give them shadowing opportunities to see patients in the clinic with us."* (GC6)

> *"Our previous GA, I used to get him/her to do pedigrees in-person when the patient came. . . . We were doing it a lot for our previous GA because he/she was trying to get into school. And so we tried giving him/her that experience of drawing pedigrees and getting that information from the patient."* (GC4)

A couple of GAs also reflected on having these additional opportunities for learning, which were based on their own personal interests.

> *"I was able to shadow a lot, so I saw a lot of appointments with the GCs. And that was really helpful for me to see those appointments and have a good understanding of what that looked like ahead of time, before going into my training program."* (GA5)

> *"Sometimes I was provided opportunities to be part of a patient conversation where they were being given a diagnosis, and I was given the opportunity to provide that information with supervision. So outside the scope of what a GA would normally do*

> *. . . I love the excitement of learning new things and being given opportunities to grow and learn about other aspects of the department that I'm working for, so that gives me a better perspective on what's happening and what's going on. . . . It was a really great learning opportunity and I actually value those now in my current work."* (GA2)

5.2.3. The Career Divide

After interviewing the participants, it appeared that there was a divide in desired career paths among GAs. Half of the GAs interviewed were attending, applying to, or planning to apply to Masters of Genetic Counselling programs at the time of their interviews. The other half of participants either chose different career paths or planned to remain employed as a GA. Those who planned to pursue a career in genetic counselling typically worked in the position for a shorter period of time (thus termed "short-term GAs") compared to those who were not pursuing genetic counselling (termed "long-term GAs").

The survey results demonstrated that the GA position is primarily a "short-term" position. Interview participants identified several factors that may influence this trend (Figure 5.1). Most described the position as the ideal "stepping stone career" for individuals planning to pursue a career in genetic counselling. For this reason, many GAs and GCs seem to form a "mutually beneficial" relationship. Participants also provided examples of barriers that may prevent many GAs from remaining in the position long-term. On the other hand, whether individuals who did not plan to pursue genetic counselling continued working as a GA or left the position to pursue a new career path appeared to be related to their career values.

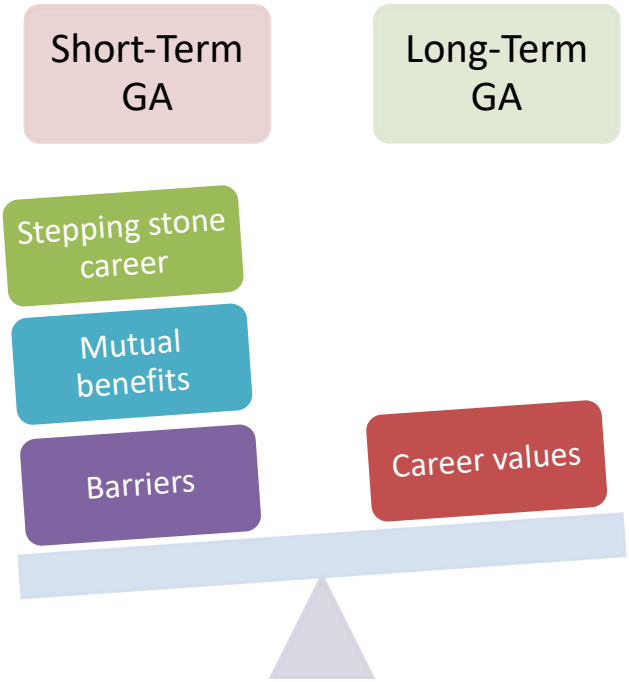

Figure 5.1. Factors associated with the career divide between short-term and long-term GAs The factors on the left are factors that influence individuals to work in a GA position for a short period of time, while the factors on the right are factors that influence individuals to work as a GA for a longer period of time.

Stepping Stone Career

The majority of the participants (both GAs and GCs) identified that the GA position often serves as a "stepping stone career" for those planning to apply to genetic counselling programs. For this reason, there is often high turnover and a short length of employment among those in GA positions.

> *"I think it's such a good stepping stone for people going into genetic counselling or medicine."* (GC1)

> *"I know most GAs want to get into genetic counselling school. So it's a super high turnover rate and . . . I don't think that will change. Every once in a while you get somebody who wants to stay in a position and then it's great. But I think it will always have a high turnover rate for that reason."* (GC4)

The GAs who planned to become GCs highlighted the knowledge and experience that they gained through their work as a GA. During their time in a GA position, participants were able to become more familiar with the role of a GC and gain experience working in a genetic counselling setting. They may even learn some skills that GCs learn through their Masters curriculum (e.g.,. taking family histories or interacting with patients), giving them an advantage when entering a training program.

> *"I just am in the best place for where I want to go. It doesn't get any better than assisting GCs if you want to be a GC yourself"* (GA7)

> *"My advice [to other GAs] would likely be: take advantage of every opportunity you're presented with. It's a unique circumstance in which a lot of individuals aren't exposed to the field of genetic counselling before attending a program. And so really just becoming familiar with the way that GCs work, the way that they function in a health care system, and just gaining as much knowledge and experience as possible. Because those opportunities are really invaluable and something a lot of other individuals don't have the opportunity to do."* (GA5)

> *"I think the ability to talk to patients on a regular basis . . . really gave me a leg up coming into a program and being able to just understand how that interaction with patients worked. And so, when I started in my rotations and sitting down in front of a patient for the first time, it didn't feel as unnatural because I've had those conversations in the past and have been able to talk to patients in that way."* (GA5)

Mutual Benefits

A number of the participants described a mutually beneficial relationship between GCs and GAs who are planning to pursue a career in genetic counselling. The GAs relieve some of the GCs' workload (section 5.2.5) and the GCs provide the GAs with mentorship.

> *"It was extremely supportive. I think the fact that it was so beneficial for them to have us around, I think they really invested time in training us, and supporting us, and providing all the resources we needed. And I think as GAs, our interests and appreciation for the training really was beneficial for them. It created this environment where it's this . . . mutually beneficial relationship. And so it was supportive on both ends."* (GA5)

Some participants explained how the mentorship provided by GCs serves as acknowledgement of the GAs' contributions to the genetics service. Additionally, some centres have unpaid GA positions, in which the volunteers obtain experience in a genetic counselling setting, mentorship, and support in exchange for their work.

> *"I think that they typically fit in quite seamlessly. I definitely feel . . . that they feel valued in their roles. They know that we rely on them a lot, that they're also learning a lot, so it's definitely a two way street."* (GC6)

> *"Even though we're not being financially compensated, I think everybody that's doing it really feels that their skills are being used appropriately and that they're really getting something out of it."* (GA8)

Barriers

When asked to identify barriers that might prevent someone from working in a GA position long-term, the participants provided a wide range of factors that might be involved (Figure 5.2).

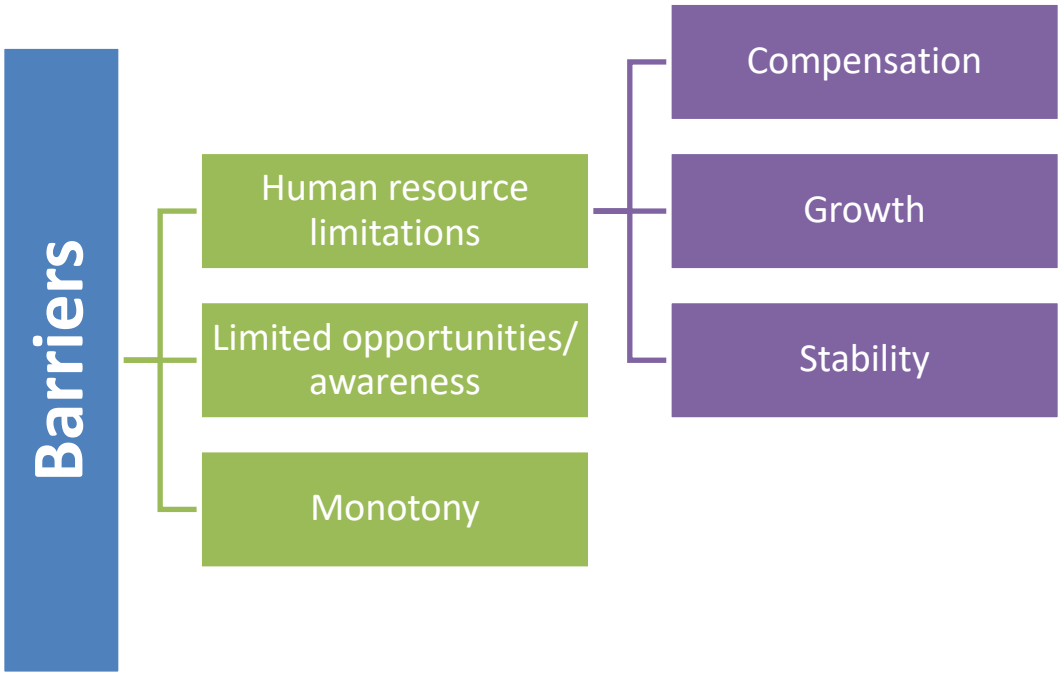

Figure 5.2. Barriers that prevent GAs from working in the position long-term, as reported by interview participants

About half of the participants referred to human resource limitations of GA positions. For example, these positions may have limited compensation (in terms of salary and/or benefits).

> *"It would be similar to other probably graduate diploma type positions where there's always the financial issue. We do actually pay our GAs quite well but it's not a GC salary and I think that they would understand that."* (GC6)

> *"In our office, the senior GA is a permanent employee. And the other GA is a temporary [position], even though it's . . . a 40-hour a week position. It's funded differently so they don't get benefits."* (GC2)

A few participants identified that GAs have limited opportunities for upward mobility, both in terms of job title and pay scale. While there may be multiple levels of GA positions, this is likely the only type of upward mobility in this position. A couple of participants described this as a "ceiling" that GAs may reach after a certain amount of time in the position.

> *"We do have the two levels – we have a senior GA and then we have the basic one. But once you get to the senior GA level, there's not really a step up."* (GC2)

> *"Probably not much potential for growth in salary or professional roles. There might not be much room for promotions. I think you could maybe create a couple levels and promote that way, but I think there would probably be a glass ceiling there."* (GC1)

A couple of GCs also described instability of GA positions, which may be a barrier to retaining GAs long-term. For example, a GA position may be term, casual, or contract, rather than a permanent position. Additionally, it may be one of the first positions to be removed if: 1) there are budget constraints, or 2) the GC workforce expands enough to meet the demand for services.

> *"These positions are almost always, from what I've seen, they are a contract position. . . . And I don't know if this position will ever become a permanent position. I don't think it will because I think the managers just always want that opportunity. The reason the GA was kind of hired in the first place is because we couldn't hire a GC, right? So I think they kind of want to always keep that option open to get rid of that position, if all of a sudden there's ten GCs that want to come here."* (GC4)

> *"Other barriers would be just things out of their control . . . if there's changes to budget, or clinic structure, or things like that."* (GC5)

Some of the participants also explained that there are limited GA positions at this time. Furthermore, there is limited awareness about the field of genetic counselling and even less awareness about the GA career path.

> *"Right now, my understanding is that the GA position is not that common. And a lot of people who are wanting to get their Masters are having trouble finding GA positions. It's a highly coveted position for people wanting to be a GC."* (GA7)

> *"The way to become a GA is a little bit nebulous. So I think maybe people don't expect that that's going to be their career path, probably because they don't know about it in the beginning"* (GC5)

A couple of participants envisioned that creating more GA positions will help to raise awareness about the position and recruit individuals who want to remain in the position long-term. Furthermore, creating more GA positions will allow more people to obtain experience prior to attending genetic counselling training programs and may help to grow the profession of genetic counselling itself.

> *"Having some sort of pipeline of trying to open up student GA positions at different clinics. So that way you potentially catch someone's interest. . . . The student would be reimbursed a certain amount of money for their hard work. And then after they graduate, potentially becoming a fulltime GA or going to genetic counselling school. They already have the training while they're in school. Something like that I think would be pretty awesome, in terms of genetic counselling clinics or programs potentially targeting people and helping them out."* (GA3)

> *"We're trying to take a focus of diversity and inclusion . . . We want to make sure that a diverse group of people has an opportunity to explore genetic counselling so that they can consider it as a field. And so we're trying to look at what are some of the barriers and what are some of the difficulties that make it difficult for someone to do that. And I could certainly see a role like GA, because it's paid, being a way that some people might be able to get the experience prior to going to genetic counselling. But it's my understanding that there's just not a lot of GA opportunities out there."* (GA8)

> *"I would definitely recommend people trying to get more GAs on board. . . . The more GA positions then that are available, maybe more people get interested and get drawn to the [GC] profession, which then obviously helps grow the profession."* (GC3)

Last, several participants (both GAs and GCs) indicated that a GAs' engagement in the position may be limited by the monotony of the work. Therefore, after they have become proficient in their work, they may want to take a new position where they will meet new challenges and continue learning.

> *"Given the kind of duties that we do around our clinic as GAs . . . I'm not sure that most people would end up being satisfied doing just that long-term."* (GA8)

> *"I think it can be a little bit monotonous, I guess. To just do organizing, and paperwork, and coordinating."* (GC5)

Career Values

Four of the GAs interviewed worked in the position long-term (ranging from approximately 3.5 to 13 years). These individuals did not plan to pursue a genetic counselling degree at the time of their interviews, though some had previously considered this.

> *"I had actually applied a couple times for genetic counselling and, of course, it's very difficult to get in . . . That was before the GCs got their big raise. And so I [would] get debt going off to school somewhere. I'm going to come back and make maybe three dollars more. . . . And all of the stress and everything of going through the application and interview process? . . . So I ended up going into education instead."* (GA1)

> *"I love my job. And I have considered possibly going back to school, and getting my Masters, and being a GC, but this job right now makes me very happy."* (GA4)

In contrast to the GAs that planned to pursue a career in genetic counselling, the GAs who worked in the position long-term expressed a variety of reasons for either staying in or leaving the position. Essentially, long-term GAs seemed to base their decisions about whether to stay in or leave the position upon their career values, which are "evaluations of the desirability of different kinds of job attributes" (Sortheix, Dietrich, Chow, & Salmela-Aro, 2013, p. 467).

A couple of these GAs discussed team culture and the ways it related to their career decisions. For one GA, the close relationships that he/she had formed with other employees and a sense of dedication and loyalty to the institution were the reasons that he/she stayed in the position long-term.

> When asked what he/she enjoyed about the GA position: *"Mostly it's the people. If my work environment was not as happy and I didn't get along with most of the people, then I don't think I would still be here. . . . I've always been pretty loyal when it comes to anything I set my mind out to do. . . . I consider myself pretty dedicated and once I start something, it takes a lot to get me to leave."* (GA4)

In contrast, another GA cited a clash between his/her values and those at the institution as the reason for ultimately leaving the position.

> *"Eventually [I] kind of figur[ed] out that I didn't really feel appreciated in my current role, in that I was taking on a lot of initiative and a lot of extra work and . . . it [was] not being recognized in any way. Not even to me personally. And so that recognition piece was a big part of what was lacking, I think, in that workplace. So it wasn't necessarily the immediate culture of my peers, but it might have been the overall culture of the department"* (GA2)

> *"When it came down to wanting to get more education in an area that was related to what I was doing, I didn't have the program's support. . . . It was either: you don't pursue any further education and stay, or I was essentially told I had to resign from my position. . . . I'm kind of a life-long learner and so my intention throughout my working career is to continue to educate myself. And so a workplace that doesn't value that continued learning in a flexible way, to me wasn't something I wanted to invest in."* (GA2)

One GA, who has worked in the field for over 13 years, referred to the meaning that he/she draws from helping others throughout the interview. It seemed quite clear that this was his/her primary reason for choosing a life-long career as a GA.

> *"It's just really cool that you have the ability to do something like this for somebody else – potentially saving not only their life and their relatives', but also do[ing] it without expecting anything in return. That's just very rewarding when you're able to do something like that for somebody else. I'm very fortunate that I've been able to do that for my entire adult life"* (GA3)

The last GA cited a need for more creativity as one of the reasons why he/she left the GA position. However, he/she described a sense of happiness while working in both the GA position and his/her current career.

> *"I needed more of a creative outlet. I found, at times, I was a bit bored."* (GA1)

> *"I was happy while I was there, and I'm happy now that I've left."* (GA1)

5.2.4. GAs in the Eye of the Beholder

When participants described the workplace culture at their respective institutions, they identified a number of factors that influence the way in which GAs are treated by others within the genetics service. Participants described a variety of ways in which GAs' contributions are acknowledged, as well as the role of upper management in establishing and expressing such acknowledgements. They also described different types of relationships between GAs and other employees; specifically, GAs were treated as "part of the team", formed close bonds with other GAs, and felt supported by others (both in their personal and professional lives). Last, it became apparent that individual employees may hold different attitudes about the value of GAs, which are conveyed through the ways in which they embrace a GA's unique perspective, as well as through unspoken, yet clearly evident hierarchies within the genetics service.

Value and Recognition

All of the GCs indicated that they value the work of the GAs. The impact of GAs and the reasons why they value GAs are explored in more detail in section 5.2.5; however, the following quotes demonstrate that the GAs are valued both for the ways in which they support GCs and geneticists, as well as for the quality of the work that they produce.

> *"I do feel that the other clinicians really value their work. I do feel that the geneticists and the GCs who work directly with GAs really find them useful."* (GC5)

> *"Everyone is very happy to have the support of our GAs. We really wouldn't function very well without them, I think at this point, considering how long we've had them support us."* (GC6)

> *"I think everyone just adores the GA because he/she makes our clinic flow so much easier and does so much great work. And he's/she's just really fantastic at it. He's/She's just learned really quickly and does a really good quality job on everything."* (GC1)

Similarly, most of the GAs felt that their work was valued by others and that they were making a meaningful contribution within the genetics service.

> *"Everybody always just seems so happy to have us around."* (GA4)

> *"Well, they definitely needed me. If I was gone for a day, they often needed to ask other GAs for getting a requisition, . . . scheduling an emergency follow-up that needed to be seen as a priority. So I think we were definitely missed if we weren't there. So I did feel that our job was valued."* (GA1)

> *"I really look forward to it every week. And when I first started my regular work life . . . it was just really nice to have my GA position every week, where I knew for sure that the work that I was doing was appreciated and . . . that it was definitely helping."* (GA8)

In fact, a couple of participants provided examples where upper management was planning to remove a GA position and GCs or geneticists advocated to keep it, which clearly demonstrates the value that others place on the GA position.

> *"Before I became a permanent staff, there was a period where they were talking about deleting my position because it was casual. And some of the physicians I work with had to put up a huge fuss about that position being gone and not having me around."* (GA4)

> *"The idea was, when we hired [a new GC], that [the GA] position would go. And I had a hissy fit and they're going to actually keep the GA on, as far as I know."* (GC4)

In addition to providing support within the genetics service, many participants (both GAs and GCs) described the GAs as mentors or sources of information to other employees.

> *"They often sent new people to me for [clinical database], so I guess maybe they thought I had a pretty good understanding of documenting everything in [clinical database] and teaching others how to use it. So I often found volunteers, new GAs, they would have me show them around [clinical database]."* (GA1)

> *"One of the GAs that's been in the position for quite a number of years . . . has definitely learned a lot. He's/She's done a lot. He/She has a lot of education. He/She was the one that you would go to when you first started if you had a question about how to do this, or where to send that, and how does this process work? He/She knew all the ins and outs. He's/She's definitely been a great resource."* (GA4)

Interestingly, a couple of the GCs acknowledged that they utilized the GAs who had worked in the institution longer than they did for information and mentorship. This truly exemplifies the value of GAs, especially those who work in the genetics service long-term. Taken together, the examples provided by the GAs and GCs demonstrate that individuals recognize and make use of the unique skills that each GAs possess (in at least some institutions).

> *"When I started, I relied on the GAs that I worked with a lot as a resource. Because they knew a lot more about how the [provincial] health care system worked, they knew a lot more about what the referral processes were like, and that sort of thing. So I relied on them a lot for that kind of support."* (GC5)

> *"I learned pretty quickly how valuable GAs are and how they come in with a different set of skills. And especially with our GA, [name], who was here much longer than I was, understanding of the cancer centre and who is who in the cancer centre. . . . He/She has been here longer than many of us."* (GC6)

Given that the majority of the participants spoke about the value of the GA position, participants were asked how each GA's contributions were acknowledged. Participants provided examples of different types of acknowledgement that a GA might receive, which primarily included common courtesies, outward acknowledgements, and formal celebrations.

Several GAs described the types of common courtesies that others within the genetics service used to recognize their work. These common courtesies included thanking the GAs for their work, exchanging pleasantries, and approaching the GAs with a positive attitude. Similarly, one GC described treating the GA he/she worked with as any other colleague by making "small-talk" and asking about his/her personal life. While the GC acknowledged that this made it difficult to assign tasks to the GA, he/she indicated that approaching the GA with a positive and respectful attitude allows them to maintain a collegial relationship.

> *"I always get a thank you, which feels really nice."* (GA7)

> *"There was one of our GCs, recently, who had broken his/her arm and had to have surgery and so was limited in his/her writing ability. So he/she had various GAs working as a scribe for him/her for a couple of weeks. And he/she thanked everybody, even people like myself who didn't actually sit in clinic with him/her, but who had volunteered to"* (GA8)

> *"[Employee] was really good with that – he'd/she'd always have a joke or a smile on his/her face in the morning. Sort of took the time to say hi."* (GA1)

On the other hand, a couple of GAs indicated that they did not receive acknowledgement in the form of common courtesies and wished that these could have been incorporated by other employees in the genetics service, especially by acknowledging the heavy workload assigned to GAs.

> *"Please and thank you would be nice."* (GA1)

> *"Saying that thanks or acknowledging the huge workload that this person has. Saying, 'I totally understand, I'm sorry to interrupt, but I really need [you] to do this'"* (GA2)

Most commonly, participants referred to outward acknowledgement (or lack thereof) of a GA's contributions to the genetics service. More than half of the GAs felt that they received due outward acknowledgement from others at their institutions.

> *"The GCs are always singing praises about the GAs, even though the reality is we don't do a whole lot, as GCs on their own. But one of the GCs I work with in metabolic issues, he's/she's very thankful that he/she has me to help support him/her within his/her role as a GC in Metabolic Clinic. So he/she doesn't keep that to himself/herself. He/She makes it known that he's/she's very happy to have us around."* (GA4)

> *"It was one of the first times in my life where I [ever] received such positive feedback. I think because they were so appreciative of what we were doing for them, they were more than happy to express that"* (GA5)

In contrast, a couple of GAs expressed that they did not receive fair acknowledgement for their contributions within the genetics service. This primarily related to the volume and scope of their work going unrecognized.

> *"Sometimes I feel, as a GA, we did a lot of things that GCs did, but yet we weren't seen in the same way. And I know that they go through a Masters program and do a lot of different training. But sometimes I felt like we were doing a lot of the same stuff. . . . We didn't see patients directly in a clinical setting, but we did a lot of phone counselling. I think sometimes as GAs we felt that we almost didn't get as much as a GC in appreciation. And didn't have the same perks. So we didn't get to go to fun conferences, and we weren't recognized as high as GCs were, and obviously weren't paid as much as them. But sometimes we felt like our workload was as much as a GC and similar scope of what they did."* (GA1)

> *"I was taking on a lot of initiative and a lot of extra work, and it [was] being unnoticed or it [was] not being recognized in any way. Not even to me personally. . . . It might have been the overall culture of the department in that everyone worked really hard, but no one really recognized that or celebrated that in any way."* (GA2)

As with the GA participants, over half of the GCs described the ways in which they outwardly acknowledged each GA's contributions. In some cases, this was through direct feedback to the GA. Other times, the GCs also discussed the GAs' contributions with other employees at the institution (e.g.,. employees in other clinics or upper management).

> *"Well, I hope he/she feels valued and appreciated. I think we tell the GA all the time how great he/she is."* (GC4)

> *"Just reminding them that they're really the key to the success of our clinic, so making sure that they feel valued."* (GC6)

> *"They do work very closely with the breast navigator. . . . I do talk them up to him/her as well."* (GC2)

In contrast, a couple of GCs indicated that they and other employees at their respective institutions may not acknowledge GAs very well and could potentially improve upon this.

> *"I don't think we are that good at recognizing the GA. . . . And we sometimes don't remember to check in or that kind of stuff. . . . . It's hard to say because, overall, everyone is so happy with him/her and appreciative. It's just we don't actually seem to take the time to say that."* (GC3)

Last, a couple of GAs described small tokens of appreciation that they received from others in the genetics service. These included small gifts or group events/outings.

> *"They give us a small Christmas gift. . . . They give us a party at the end of the year. And we're invited to the centre-wide barbecue at the beginning of the year and some of the other events. We did [go] out for drinks with the GCs and they picked up the tab on that. . . . Little appreciations here and there."* (GA8)

> *"So I believe they started a Genetic Assistant Appreciation Day . . . Now it's just become a random day and the GCs usually do something nice for us."* (GA4)

As evident from the examples above, acknowledgment and recognition usually comes from the other employees that the GAs directly interact with in their day-to-day work (e.g.,. GCs and geneticists). However, several participants also described the role that upper management plays. In some institutions, upper management acknowledged the work of the GAs, while in others, upper management "set the stage" for a lack of recognition.

> *"His/her official boss, even though he/she doesn't work directly with him/her, is my boss, the medical geneticist. And in his/her review that happened recently, he/she was just complimented so much about everything he/she does."* (GC1)

> When describing changes in the ways his/her contributions were recognized: *"I think different leadership changed that. So I don't know that initially the leadership that*

> *was in place was very good at that value piece. At understanding and taking into account what people were doing, where they came from, and using those experiences to benefit."* (GA2)

Relationships

The majority of the GAs described feeling like a "part of the team" within the genetics service at their respective institutions. Similarly, most of the GCs echoed this sentiment. In some examples, participants referred to personal relationships between different employees (e.g.,. between GAs and GCs). In other examples, they used "team" language to refer to the way in which different employees worked together in a collaborative fashion.

> *"We fit in like they regard us as part of the team, we're not just assistants to them. . . . We are the people who allow them to do their job. But we're involved as if we do their job as well."* (GA7)

> *"They've done a great job of making us feel like we're part of the team – and that was really something that I remember echoing several times last year, during my first year in the cohort – that they really made us feel like an integral part of the work."* (GA8)

> *"I'd say we worked very collaboratively. It's very much a team in the sense that I'm basically working directly with the geneticist, but I have to talk on a regular basis with secretaries for booking, people doing dictation, with the patients, and with other GAs as well, if they had a resource that I needed. So I feel like we all worked very collaboratively together."* (GA1)

> *"We're a team. . . . Our offices are substandard. So I'm in the same room with the GAs all day. And they're in the same room with me all day. And it's small. So we're a very close-knit team, and we get along very well, and we work well as a team"* (GC2)

In line with the team environment described by the majority of participants, many GAs described others as being supportive. Participants described the supportive nature of their relationships with other employees on both professional and personal levels. For example, two GAs both

described ways in which other employees were supportive of the GAs' professional goals, as well as major events in their personal lives.

> Professional goals: *"They want us to be successful and they're very encouraging towards all of us who are planning to apply [to genetic counselling programs]"* (GA8)
> Personal events: *"I find it to be, just in general, really [a] pretty warm culture and good communication, celebrating different little things that are going on in people's lives, and very supportive."* (GA8)

> Professional goals: *"It was just how accommodating they were with me going through school. I did my education degree while I was working. So that was three years where I was going to school all day Saturday and all day or Wednesday evenings. And then I had practicums twice a year. So I used all my vacation up first, and then it was usually about a month each year that I needed to ask for a leave of absence. . . . But I think they saw the value in keeping someone trained and experienced, and they worked with me rather than against me after that. And so I found them just so supportive and accommodating to help me reach my dreams. Which meant me leaving the clinic. But I think they just respected that and I'm so grateful for that."* (GA1)
> Personal events: *"When I was pregnant . . . so Genetics had a little baby shower for me. And we recognized weddings and that sort of thing. So I think there was a good culture in that sense."* (GA1)

A few of the GAs also described close relationships between themselves and other GAs that they worked with. GAs may be especially likely to bond with each other if they are both at the same places in their careers; for example, one GA formed relationships with other GAs at his/her institution who were also going through the process of applying to genetic counselling programs. It was not clear whether the participants who did not describe their relationships with other GAs did not form such relationships, or simply did not work closely with other GAs.

> *"There [were] two GAs who would have been there anywhere from one to four years prior to me and they were just really instrumental . . . I'm still friends with them now and we still have that great relationship and that understanding of what we went through together in the department."* (GA2)

> *"The other GAs and I get together sometimes one-on-one, go to lunch, go for coffee. I invited some of the GAs over to my place so that we could all work on applications back in the fall"* (GA8)

Attitudes

A couple of the GAs brought up the topic of whether their previous experiences were recognized and valued within the team. Their responses were in direct contrast to one another. One GA described the ways in which he/she felt that GCs and upper management valued his/her experiences and welcomed his/her suggestions for improving their services. The other GA explained that his/her unique experiences were not recognized, and as a result, was not used to his/her full potential.

> *"Things are just going really well and I appreciate the fact that a lot of the different thoughts and ideas that I'm bringing to the team are actually being acted upon. And it sounds like they value my experience too."* (GA3)

Although most participants described the GAs as being a "part of the team", several participants portrayed a hierarchy within the genetics service during their interview. For example, one of the GAs described the different hierarchical levels within his/her work setting, which were based on each employee's education level and position within the genetics service. The geneticists were very clearly at the top of the hierarchy. Below the geneticists were GCs, followed by GAs, and then administrative professionals. Another GA provided an example of how this hierarchy manifested in the work setting when describing the working relationship between geneticists and GAs.

> *"[There's] sort of a hierarchy, right? The geneticists all worked very closely together, and the GAs were more on a social level with the GCs, and the secretaries kept to their group."* (GA1)

> *"I think sometimes people just think you're a work mule, so you're there to throw papers on your desk, and the next day they should be done, and that was the expectation. And so definitely that experience was privilege in the department, depending on what level you were dealing with. So it tended to be geneticists – some of them, not all, I want to be specific. Some of them were just really standoffish and just like, "Here's the work, here's what I want you to do, and I'll be back tomorrow*

> *morning for it". And that could have been at 3:00 on a Thursday or something. And so I think in terms of that, it was difficult to manage"* (GA2)

One of the GCs described the general hierarchy within the hospital system and how GCs fit into this hierarchy. However, in this example, he/she also revealed an individual bias, which places GAs below GCs within this hierarchy.

> *"If everyone had a GA, I think that that would elevate us in the eyes of other providers, as well. So I know that still a lot of people see GCs as people who can coordinate genetic testing and do the insurance stuff. And that is so not our forte. So I see that if GAs became more ubiquitous, I think that would elevate everyone. . . . It would help other medical professionals see us for what we really are good at and not just as coordinators. In the hospital, there's a very clear hierarchy. . . . I walk around with our medical geneticist with my little binder. And I think even that visual, me with the attending with all my paperwork and stuff, makes me be seen a little bit as her assistant. That's not how I feel he/she treats me at all, but I think people can see me as that sometimes."* (GC1)

To this end, one GA provided several recommendations on how to avoid establishing a hierarchy within a genetics service. These included recognizing each individual's unique contributions and the value of each role within the service, as well as being open to learning from other employees.

> *"Having opportunities to connect as a team and not segregate different areas just because of their qualifications, or degrees, or that sort of thing. And recognizing that that clinic is a team and without each individual area, that clinic wouldn't work. And so if everyone in that clinic would recognize how important each of those areas are, that clinic would run just that much more smooth[ly]."* (GA2)

> *"Don't underestimate anyone else in your department. So everyone has a place and everyone has a role, and without each person's role, the department just doesn't function. And so thinking that your job is more important than anyone else's and vice versa is not going to be beneficial to your learning."* (GA2)

One GC denied any hierarchy in the genetics service that he/she worked in. However, he/she acknowledged that this may not be the case in all institutions and referenced the historical hierarchy between geneticists and GCs within genetics services.

> *"Our clinic is really respectful of our GAs, [but] you don't know that every clinic's GCs or geneticists are going to be that way. As a GC myself, I've had clinics where (especially when I was training as a GC student) for example, a geneticist didn't see the value of a GC. So you probably could see the same thing happen with a GC not seeing the value of a GA."* (GC6)

5.2.5. "Once You Have One, You Will Never Want to Go Back"

The impact of GAs on others' roles, responsibilities, and professional identity within genetics services was one of the three main research themes in the interview guide. The overarching roles of GAs, as well as the impact of GAs on other employees and the patient population, is summarized in Figure 5.3.

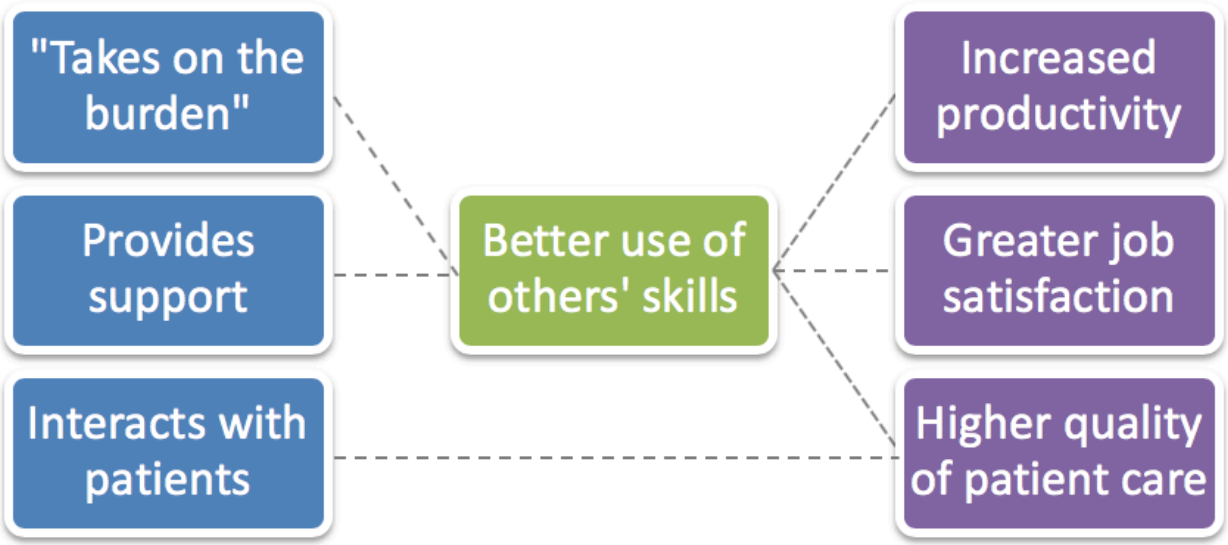

Figure 5.3. Overarching roles of GAs and the impact of these roles on genetics service provision The blue boxes indicate GA roles, the green boxes indicate the impact of these roles on GCs' skills, and the purple boxes indicate the downstream effects of making better use of GCs' skills.

Roles of the GAs

All of the GCs and the majority of the GAs described one of the main functions of GAs as "taking on the burden" of tasks that would otherwise be assigned to GCs. Some participants used

phrases (such as “taking on the burden” or “taking something off the plate of a colleague”) or sweeping statements to describe this overarching role of GAs.

> *“A big portion of that was just taking, not that it was nonsense time away from the GCs, but it was more so alleviating some of that workload from them, really making it possible for them to focus on direct patient care. And so answering those logistical questions or some of the case prep things and allowing them to really focus on the counselling and the testing discussions”* (GA5)

> *“In terms of the geneticists, just taking away a lot of those [menial] tasks that they would not have time, or not have put enough attention to. Just because of the sheer numbers of patients they’re seeing, other responsibilities that they might have, research, all that kind of stuff, other things that might be involved. So taking away the simple things . . . And with the GCs, I think having them be able to really see more patients, and do direct counselling, and be involved in all of that . . . because they’re not having to do all of these little [menial] tasks.”* (GA2)

Other participants provided examples of specific tasks that a GA takes on, which were previously performed by another employee. Often times, GAs alleviated some of the workload of GCs; however, GAs also assumed the burden of tasks that were previously performed by administrative professionals or geneticists. Describing these tasks as “burdensome” implies that such tasks take a significant amount of time to complete and are not an aspect of the job that GCs particularly enjoy.

> *“There’s this huge administrative aspect of genetic counselling where GCs don’t only have to worry about patient stuff, but all this administrative stuff gets dragged into the position as well. And I know a lot of GCs are like, ‘I just want to do patient stuff. I don’t care about this other stuff.’ So having a GA there to really help out with that”* (GA3)

> *“We decided that it would help us see more patients if we wrote a basic template letter that the GAs actually submit. And that really helped because having to write all the letters was a big time consumer for me.”* (GC2)

> *“And certainly us (being those who are able to do the clinic prep), I know certainly eases the load some for the GCs. At least some of their prep work and things are prepared . . . It may make it a little easier.”* (GA8)

> *"We have admin assistants who used to do some more of the scheduling of these patients. And it's still a little bit split. But the GA does take some of that burden of scheduling. And then for us (the GCs), he/she definitely takes on the role of calling them with logistics and insurance questions. Or if they're calling to ask about how long the test is going to take, if it's ready yet, he/she will call them back. So that's really lightened our burden with those types of interactions with patients on the phone."* (GC1)

A few participants provided examples that demonstrate these tasks often require time, rather than significant effort or specialized knowledge. Such examples include following up on outstanding paperwork (e.g.,. "Release of Information" or ROI forms) and contacting other providers for additional information required by the genetics service.

> *"Doing ROIs is the most annoying part of my job. And I think that a lot of my time could be saved if I didn't have to do that. I guess just things that are relatively routine and don't require a lot of effort. It just needs somebody to do it."* (GC5)

> *"I think sometimes the hardest part of getting in contact with the provider is just getting them on the phone. When you call the lab, you have to get the right office number. And even then, the doctor, or nurse, or medical assistant might not be available, so they'll kick you back and forth to a different phone line, or you'll have to leave a message. So that takes a lot of time itself. So that opens the GC's schedule up immensely."* (GA7)

Half of the participants summarized the role of a GA in more general terms, explaining that GAs provide support within the genetics service. Sometimes, participants described a general sense of providing support within the clinic. How "support" is defined may vary between cases, meaning that a GA may perform different tasks depending on the medical genetics work-up for a particular patient. Interestingly, a few participants explicitly stated that this support extends beyond performing administrative tasks; which may be these participants' way of differentiating the GA role from that of an administrative professional.

> When asked how he/she would describe his/her role: *"Supportive. I think it's one of those duties as assigned [positions]. So it just depended on what the diagnosis was or what direction we were heading with their diagnosis."* (GA2)

> *"I see their role as being somebody who supports the clinic, but not just in an administrative way."* (GC5)

> *"I think it changes the way in which clinics may function. Having that support is something I think is common in other areas of medicine. And so I could see maybe genetic counselling taking on more of the models of physicians or something where they have individuals under them to take on not just the administrative tasks, but the clinic support as well, and patient care."* (GA4)

Sometimes, participants provided support to specific individuals (e.g.,. GCs or medical geneticists) or in particular services (e.g.,. referrals or insurance).

> *"I'd say just really support for the GCs.*" (GA5)

> *"The prenatal GA has often been a support for the GCs on-call. And so, a lot more similar to cancer genetics where the GA is more for support of the referral services, not so much support of the clinic itself, other than in their other role as clinic support for the doctor."* (GC5)

> *"It's really nice having someone to support you, and know what's going on with the patients, and deal with the stuff that maybe isn't your favourite part of genetic counselling. Honestly, for me, especially coming here and having to learn about insurance and all that stuff has been crazy. And so having someone that can just tell me, 'Ok, this person needs this, this. This one's taken care of.' – it's awesome. Not that I'm saying their only job is to make it easier for me, but that was helpful"* (GC3)

<u>Impact of GAs on Genetics Service Provision</u>

Most of the GCs explained that integration of GAs allows them to use their skills better. As detailed above, GCs' day-to-day job duties previously included straightforward tasks that did not require their specialized training nor are in their scope of practice; now that GAs have taken on the burden of such tasks, GCs can make better use of their Masters-level education and unique skillset in medical genetics and counselling.

> *"I see it as our skills being used for what they're supposed to be used for."* (GC1)

> *"I have more time to focus on researching my patient's conditions. I'm in pediatrics so I see a lot of really rare, crazy stuff. So we're constantly learning about new*

conditions. So I have more time to dig into that. More time to focus on letters, and getting those done in a timely manner, and getting them done well." (GC1)

"It gives me more time to research difficult cases and work on other things like switching or changing our database, developing the family history questionnaire, doing all that stuff to continue moving us forward in terms of being able to provide care to the patient population here." (GC2)

A couple of GAs also recognized that their work in the genetics service allowed GCs to dedicate time to tasks for which they have specialized training. One GA and one GC described how team members value GAs because of the resultant changes in the workloads of GCs.

"My work is important to the team because, before the GAs came, the GCs were doing a lot of the meticulous work that a person with a Master's shouldn't be doing. So I do feel I'm very valued because I allow the GCs to take on more appropriate tasks per se." (GA7)

"We were really hurting before. Just getting really bogged down by administrative tasks and insurance issues. So I think everyone just adores the GA because he/she makes our clinic flow so much easier and does so much great work." (GC1)

Most participants felt that integration of GAs also increased productivity in the genetics service. In clinical settings, this meant that GCs were able to see more patients. In laboratory settings, this meant that GCs were able to spend more time on other tasks in their job description (e.g.,. meetings with laboratory clients).

"This is very informal information from [clinical database], but I was able to see 70 more patients in a year, in the year that we had the GA than in the year we didn't have a GA. There's been a lot more patients and it's really because I cut out all that paperwork. So when we got files, we would draw the pedigree, we would phone the patient to expand it, we would get the records – we would do all of that. And now that information, it just comes to us in the file and the patient is ready to be seen. Probably for every cancer patient, it probably cuts out two, three hours of work that we need to do." (GC4)

"If I did not have a GA and I was, for example, obtaining a full pedigree in person without having that prepped ahead of time, probably a one-to-one patient appointment would take me an hour and a half, I would think, in session to obtain that pedigree, run computer models if I needed to for breast cancer risk assessment,

> *all that. And instead, we're able to see patients one-on-one in about 45 minutes or so. . . . So the volume of patients has increased for us with less paperwork. I think it's definitely lowered the amount of time that I have to spend in clinic [with] individual patients"* (GC6)
>
> *"When I'm taking on tasks that the GCs have previously done, it opens up more time for them to take on other tasks. So they might be able to travel more, do more client visits, focus on more research."* (GA7)

Most participants felt that GAs have a more significant impact on the work of GCs compared to geneticists. This is likely because straightforward tasks would either be done by a GC or a GA, rarely by a geneticist. However, one GA (who worked directly with a geneticist) also felt that she enabled medical geneticists to manage an increased patient load.

> *"Overall, I think it has definitely improved efficiencies. I can't see physicians being able to see more than three patients alone if they didn't have the support of a GA. There's just no way. Having to do all the extra calling and the ordering themselves, it would be very difficult. And especially those physicians that are doing more than just one or two clinics a week. That would be impressive. So I mean, I don't doubt their dedication, but they would probably burn out faster"* (GA4)

Participants also felt that by reassigning straightforward tasks to GAs, GCs are able to spend more time providing direct patient care. While this may translate to an increase in patient volume, it can also improve the quality of patient care because GCs have more time to spend in appointments, can redirect the focus of the appointment to more advanced genetic counselling skills (e.g.,. psychosocial counselling, which are unique skills that only GCs are trained in), and make appropriate follow-up calls or appointments.

> *"In addition to being able to see more patients, I feel like I can spend more time with patients as well. . . . I don't feel rushed. And I feel I could spend more time with patients. And I can follow-up with patients. I can phone them the following week and see how they're doing. 'Do you have any questions?' Whereas before, honestly, I couldn't do that. So I feel like it's really enhanced patient care as well."* (GC4)
>
> *"It definitely helped with a lot of follow-up stuff. Again, we could maybe focus a bit more on the actual patient session. And then in terms of referrals, or follow-up of*

> *negative results, or coordination of logistical things, all that was taken care of by the GAs, which was awesome. So again, it opens it up maybe a little bit more for the GCs to just be the counsellors"* (GC3)

Many of the GAs identified patient interactions as a significant component of their job. A few of the GAs provided examples of the ways in which they themselves improved quality of patient care through these patient interactions.

> *"So the goal was to determine, 'Okay, does the patient meet criteria for genetic testing?' before the appointment . . . We had patients travel from sometimes five, six hours away just to meet with us, so if we could get that information ahead of time, we'll tell them they don't meet criteria for genetic testing. But that's actually [good] news information for the patient and that way we would save them the time, money, and effort to travel down to the [workplace]."* (GA3)

> *"I think the important part that I took from it was creating a relationship with the patient, so that there was some sort of trust there. And understanding that sometimes the physicians are really busy and they might not just be able to spend an hour talking about a certain topic. So having someone that they could call with questions. . . . It would allow for them to feel like they were getting treated and getting the feedback that they needed from appointments. Or even before that, if that call went to a physician or someone else in the department, they may not get a call back for several days."* (GA2)

A few participants also explored the impact that long-term GAs might have on the quality of patient care. Having the same GAs in the genetics service over time can provide continuity of care, which may ultimately result in better rapport, trust, and care for patients.

> *"We have a lot of patients that [are] in and out of our clinic for years, right? So having that continuity of care with the same GA, the same geneticist is helpful too."* (GA1)

Beyond increased productivity and improved quality of care, two GCs felt that making better use of GCs' skills results in higher job satisfaction. No GAs identified increased GC job satisfaction as a benefit of integrating GAs; however, this may be because they are not aware of the GCs'

experiences prior to GA integration, or are not familiar with these perceptions of their colleagues.

> *"It would cull better job satisfaction because we're using our skills better. It would allow us to do things that elevate our professional goals."* (GC1)

> *"I'm actually spending my time [on] what I went to school for, right? I didn't go to school for two years and do a Masters Degree to chase a lost blood sample . . . So I feel like job satisfaction also goes up when you have GAs in the clinic."* (GC4)

Overall, the participants focused on the positive ways in which GAs impact genetics services. However, a couple of participants recognized that GAs could also negatively impact the work of GCs. One GA explained how GCs have to assume additional work training and mentoring new staff.

> *"Some people have spent a little bit too long . . . where they're waiting to be cleared from having to send their copies of their entered pedigrees onto a mentor. . . . That's additional work on the mentor."* (GA8)

Additionally, when one GC described the supervisory relationship between GAs and GCs, it was apparent (though not explicitly stated) that this does require the GC to devote significant time to training and supervision.

> *"Among the six GCs, we rotate among supervisory roles, so the person calling to take the phone pedigrees works with one particular GC to give those pedigrees back to be reviewed . . . And then another person [is] assigned to supervise chart prep . . . It is our responsibility to double-check things, like computer models and that the appropriate test is being ordered."* (GC6)

A couple of participants did refer to the independence level of GAs and the impact that this has on productivity. Because most GAs work relatively independently, the supervisory roles assigned to GCs are likely minimal and not significant enough to offset the time gained by reassigning straightforward tasks to GAs.

> *"I think most GAs work very independently and it helps with productivity."* (GA1)
>
> *"I feel they're an extension. . . . Instead of being micro-manager, I'm a macro-manager."* (GC2)

Multiple GCs emphasized their overall satisfaction with working with GAs. Each explained that they could not imagine having to integrate these burdensome tasks back into their workflow and that GAs are integral to the success of the clinic.

> *"I think they're an integral part of the process and the clinic. And I can't imagine not having them."* (GC2)
>
> *"Once you have one, you will never want to go back. . . . Just because we're having so much more fun doing our job, right? And seeing patients and doing the things that we want to do. . . . I can just say honestly, once you have one, you will never go back. Like, you will never want to go back."* (GC4)
>
> *"I don't think we can really imagine working without GAs. Even though I don't work directly with a GA, I still, like I said, work alongside them. And I can't really imagine picking up the burden of the work that they're currently carrying"* (GC5)
>
> *"If I were to go back to having to do bookings, inputting all of my own pedigrees into [pedigree program], to do all of my own chart prep, it would absolutely change my workload for sure. So they're taking on big pieces of GC prep and so it's . . . the key to the success of our clinic."* (GC6)

CHAPTER 6: PRODUCTIVITY ANALYSIS RESULTS

6.1. Clinic Description

6.1.1 Staff Mix

The number of geneticists (MDs) in the clinic remained relatively constant over the study period (Figure 6.1). MD FTE ranged from 4.0 to 7.0 during the study period, with constant FTE from November 2004 to October 2014. In contrast, the number of GCs increased over the course of the study period (Figure 6.2). GC FTE fluctuated between 5.0 and 6.0 from 2000 to 2009 and between approximately 6.0 and 8.0 from 2009 to 2017. GCs were employed in the disciplines of medical genetics, prenatal, metabolics, and cancer. It is important to note that board-certified GCs were not always employed in the GC positions. Early in the study period, a clinic coordinator and registered nurses were employed in two GC positions as the program was unable to recruit board-certified GCs to these positions; however, these positions were consistently filled by board-certified GCs from 2009 to 2017.

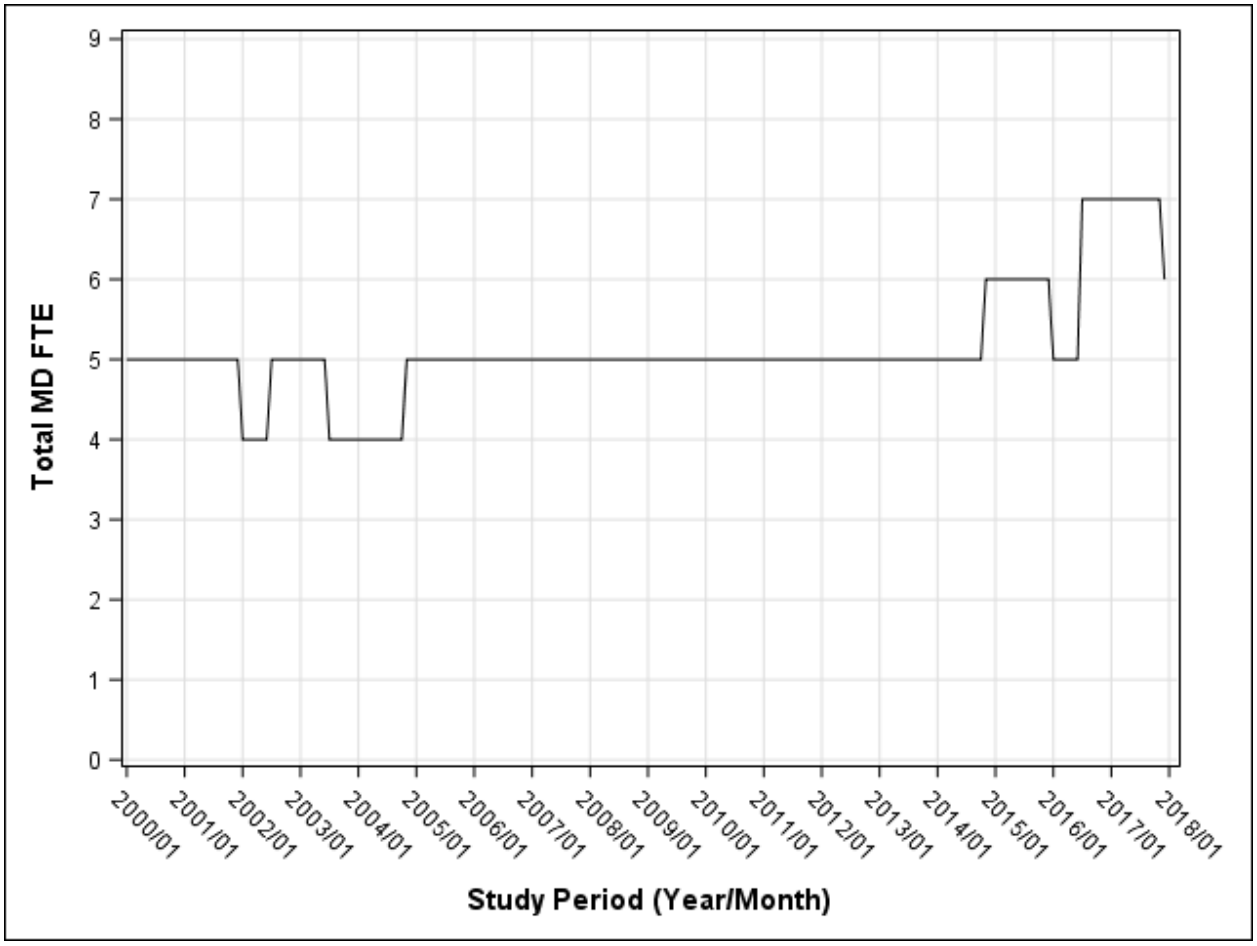

Figure 6.1. FTE of MDs employed in the clinic during the study period

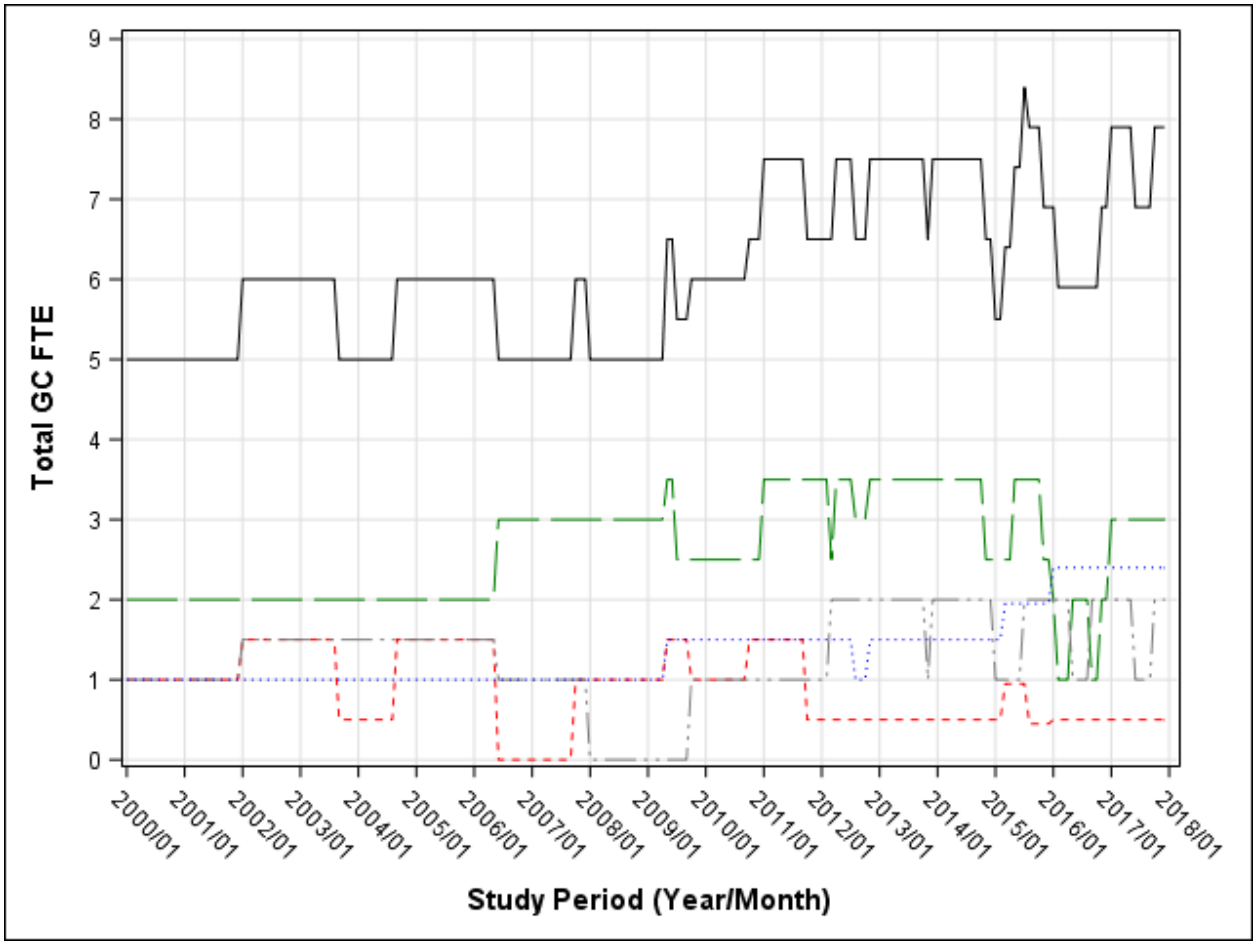

Figure 6.2. FTE of GCs employed in the clinic during the study period
Black solid line indicates total FTE, red short dashed line indicates medical genetics FTE, green long dashed line indicates prenatal FTE, grey dashed/dotted line indicates metabolic FTE, and blue dotted line indicates cancer FTE.

GAs were first introduced in the clinic in 2005 via a trial 0.5 FTE position (Figure 6.3). In August 2006, the funding from an unfilled GC position was re-allocated to create three GA positions; these GAs worked directly with MDs. From 2006 to 2016, the GA FTE gradually increased from 3.0 to 4.93. The last GA position added to the clinic was a 0.4 FTE position in November 2015.

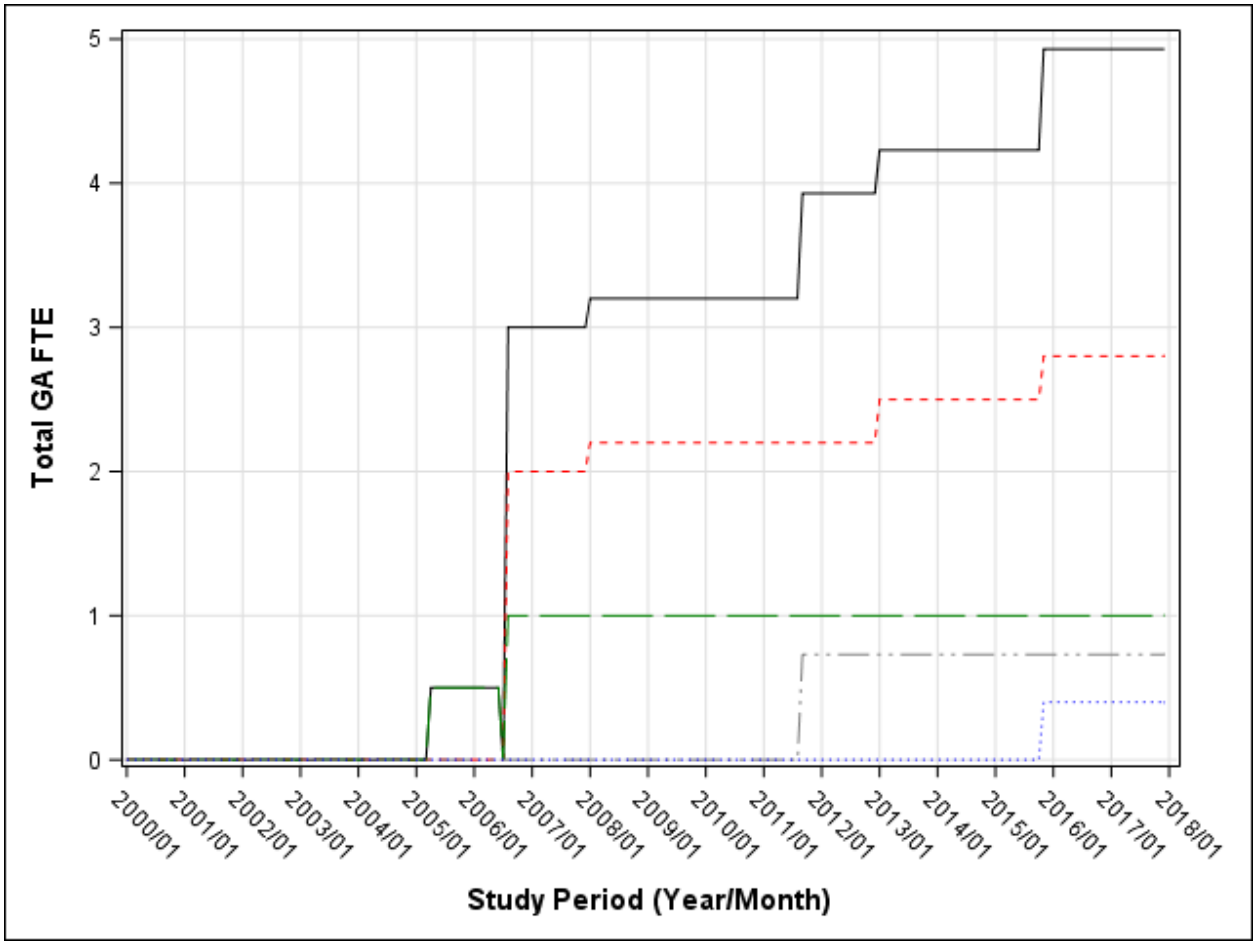

Figure 6.3. FTE of GAs employed in the clinic during the study period
Black solid line indicates total FTE, red short dashed line indicates medical genetics FTE, green long dashed line indicates prenatal FTE, grey dashed/dotted line indicates metabolic FTE, and blue dotted line indicates cancer FTE.

6.1.2. Trends in Referrals

The genetics clinic received a gradually increasing number of referrals over the study period. Annual referral numbers ranged between approximately 2200 and 3650 (Figure 6.4). Monthly referral numbers ranged from approximately 100 to 450 (Figure 6.5). It is important to note that referral criteria changed throughout the study period; in 2017, the clinic used more stringent referral criteria as compared to the criteria used at the beginning of the study period.

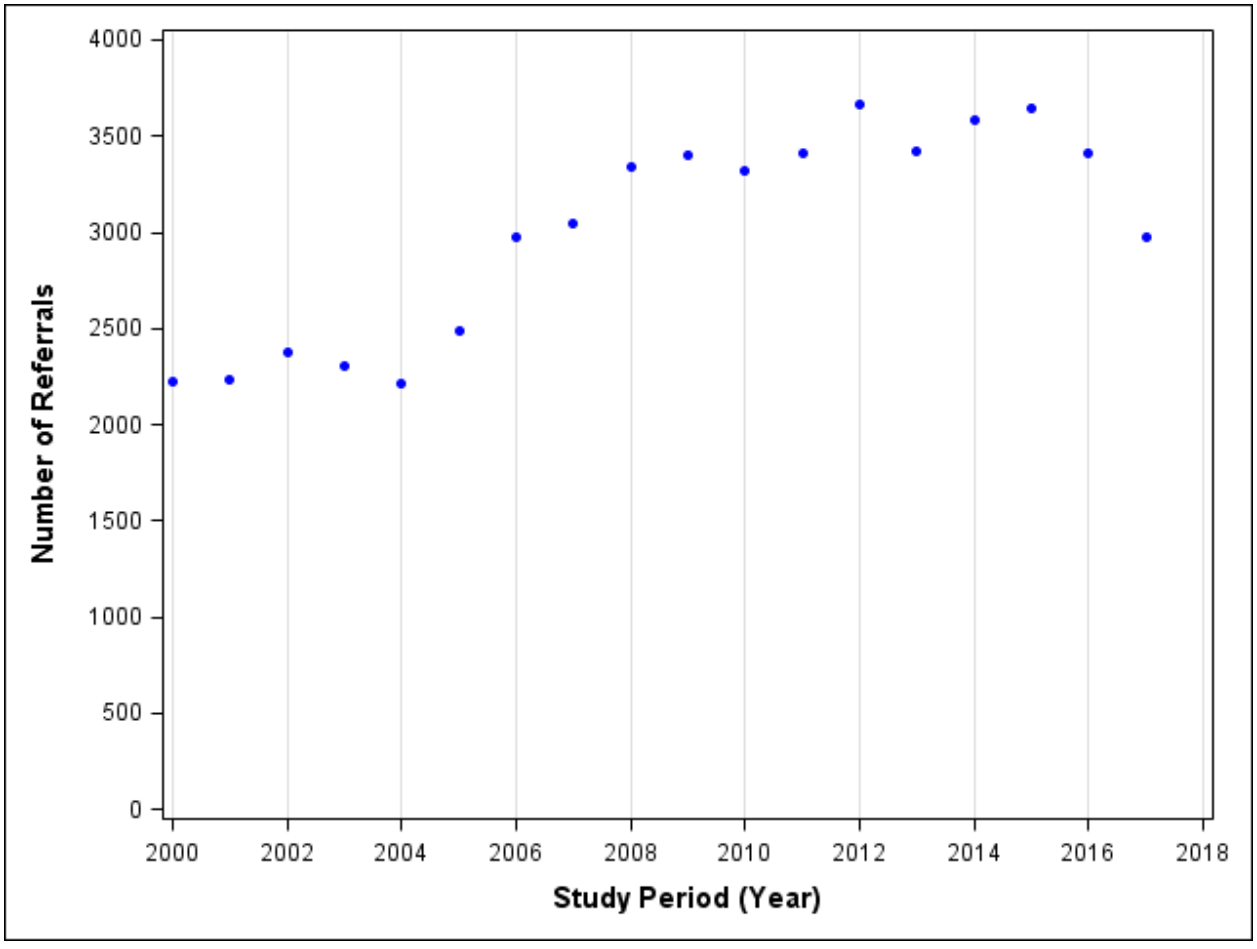

Figure 6.4. Annual number of new referrals to the clinic during the study period

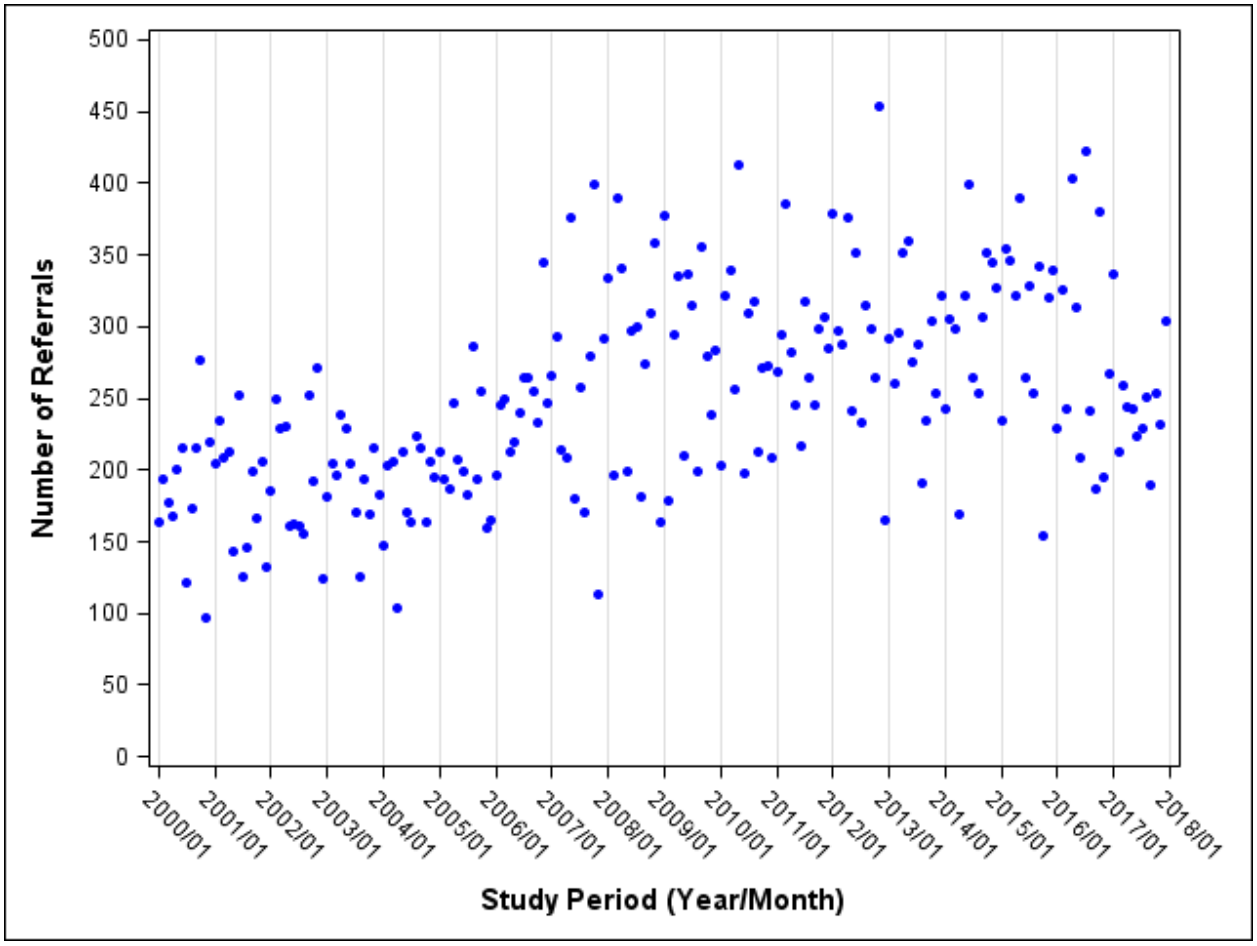

Figure 6.5. Monthly number of new referrals to the clinic during the study period

6.2. Effect of GA Addition on Clinic Productivity

6.2.1. Trends in Patient Volume

Patient volume is reported as the number of patients seen per provider FTE per month. Visualization of patient volume revealed an increase in the number of patients seen following integration of three full-time GAs (Figure 6.6). Patient volume appeared to increase over the following two years. After 2009, patient volume remained constant with 1.0 FTE providers seeing approximately 30 to 40 patients per month.

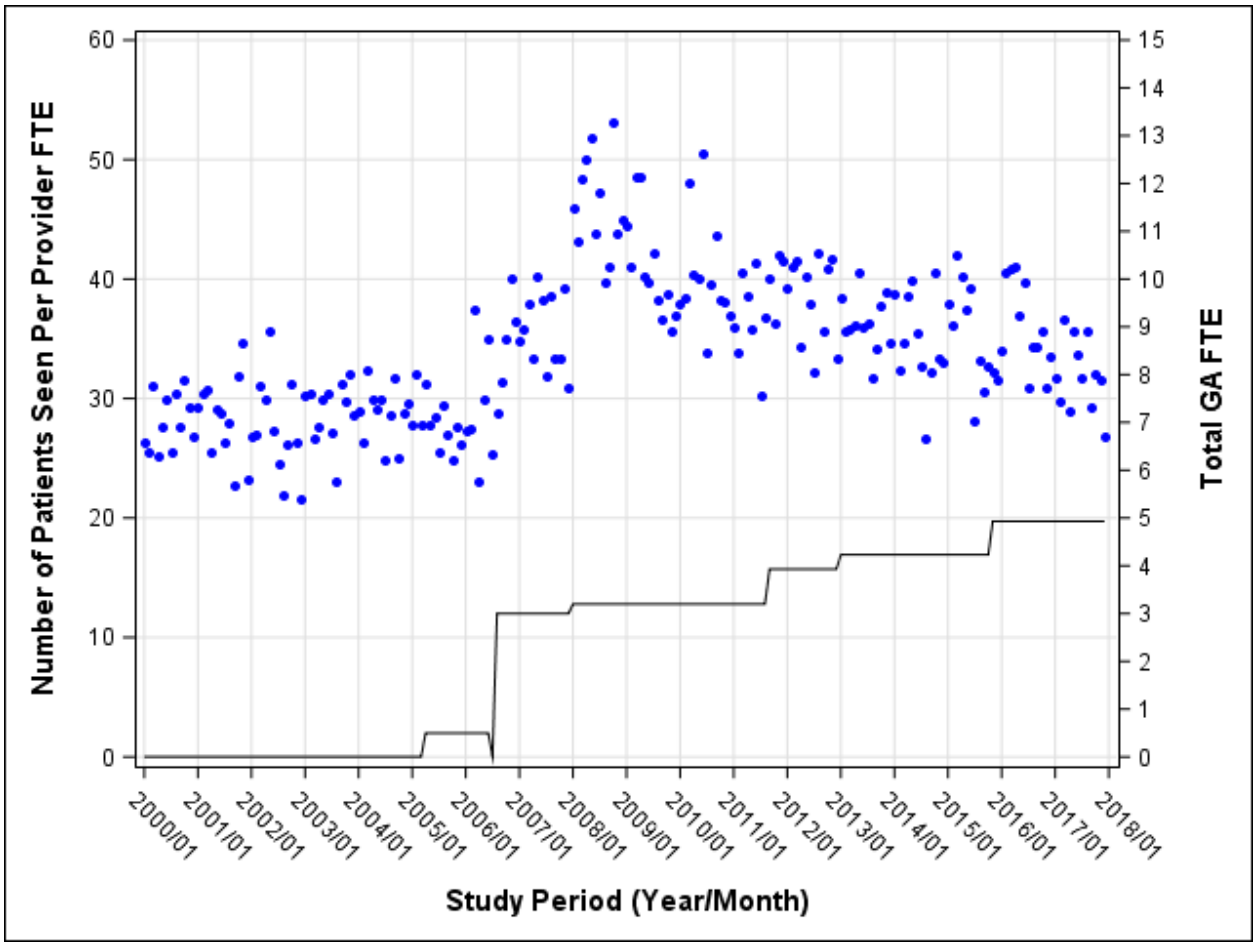

Figure 6.6. Average number of patients seen per provider FTE (MDs and GCs combined) by month during the study period (indicated by blue dots and left y-axis). Black line indicates GA FTE during the study period (right y-axis).

MD patient volume remained stable for the majority of the study period (Figure 6.7). MDs typically saw between 45 and 75 patients per month, both before and after GA integration. However, MD patient volume began to decline in 2014. MDs typically saw 40 to 60 patients per month between 2014 and mid-2016, and 30 to 40 patients per month from mid-2016 to the end of the study period. The reason for this decline in patient volume is not clear.

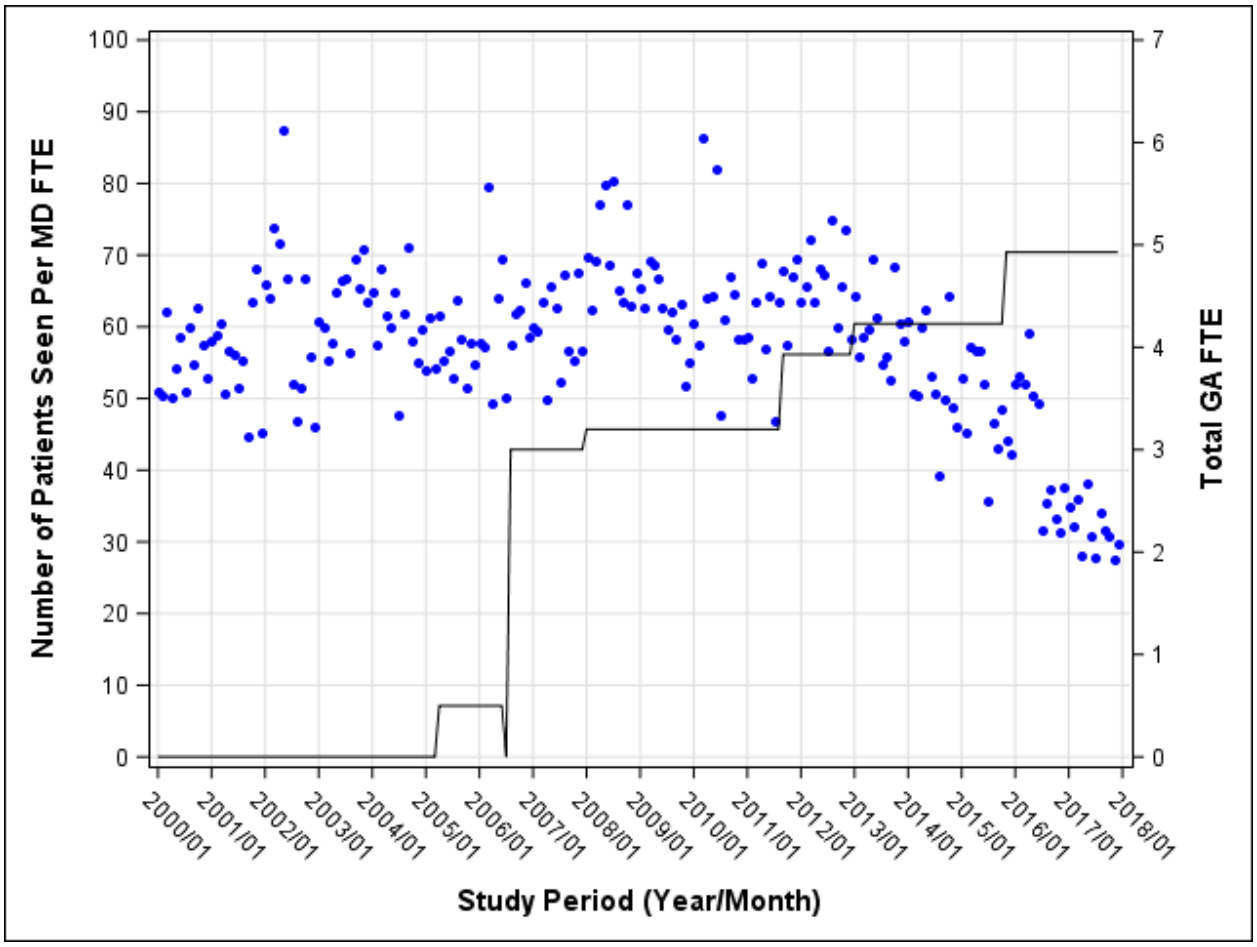

Figure 6.7. Average number of patients seen per MD FTE by month during the study period (indicated by blue dots and left y-axis). Black line indicates GA FTE during the study period (right y-axis).

The increase in patient volume was more pronounced using GC patient volume only (Figure 6.8) compared to patient volume for MDs and GCs together (Figure 6.6). Prior to GA integration, 1.0 FTE GCs typically saw fewer than ten patients per month. After GA integration, the patient volume increased to between 15 and 25 patients per month. In November 2015, a 0.4 FTE cancer GA who worked specifically with GCs was integrated in the clinic, at which time GC patient volume further increased to approximately 25 to 35 patients per 1.0 FTE position per month.

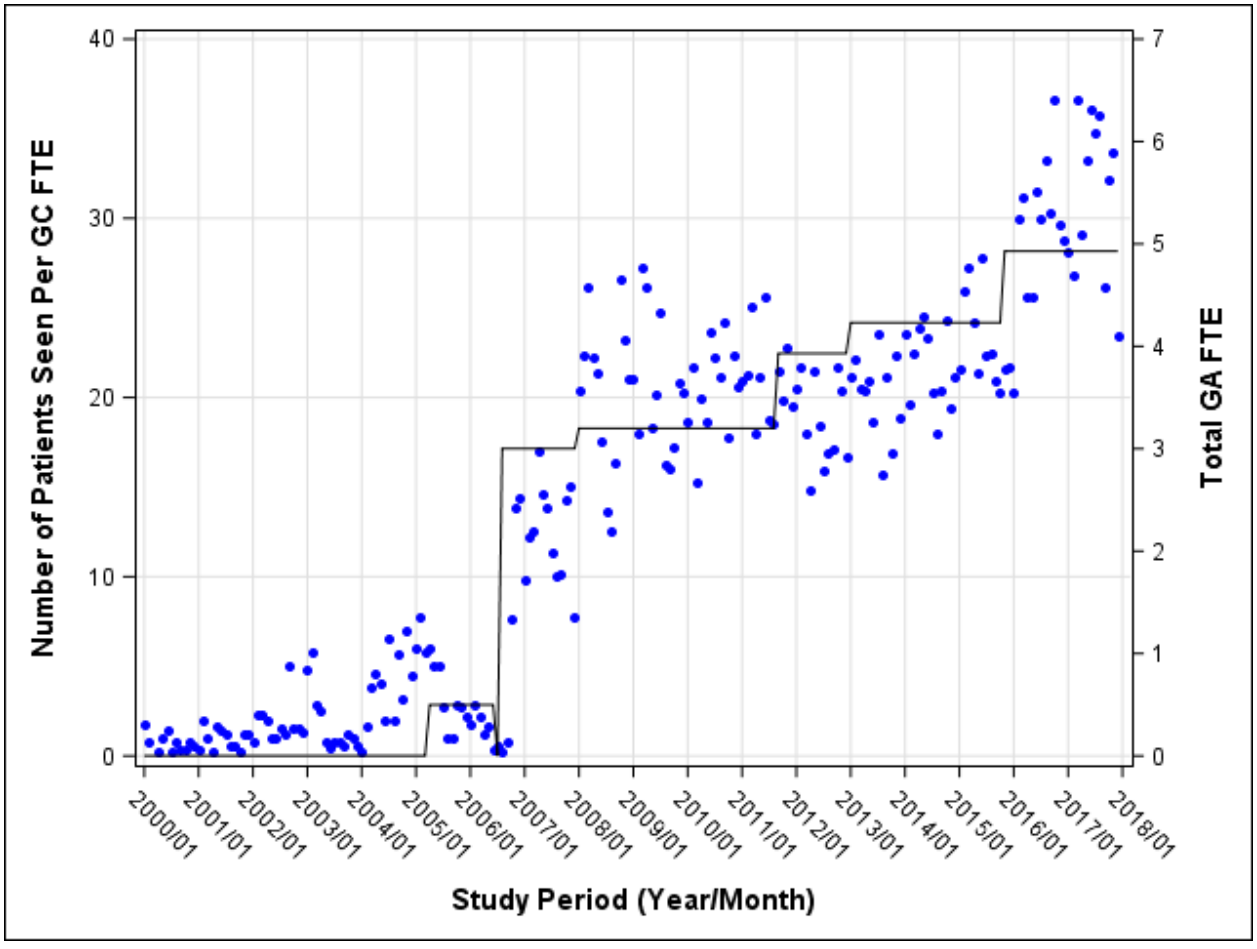

Figure 6.8. Average number of patients seen per GC FTE by month during the study period (indicated by blue dots and left y-axis). Black line indicates GA FTE during the study period (right y-axis).

Similarly, visualization of patient volume for prenatal GCs demonstrated an increase in the number of patients seen following integration of a 1.0 FTE prenatal GA (Figure 6.9). As seen with the overall clinic data, 1.0 FTE prenatal GCs typically saw fewer than ten patients per month before GAs were integrated. After a prenatal GA was hired in 2006, patient volume for the prenatal GCs increased, whereby 1.0 FTE prenatal GCs were seeing 10 to 40 patients per month. During 2016, there were eight months in which patient volume increased to 40 to 90 patients per month. Some of this variation may be explained by a shift in clinic policy, where prenatal GCs began to see patients who previously would have been seen by an MD. It may also be attributed to open positions, which necessitated other GCs to take on prenatal patients within their existing FTE to keep up with the demand for this time-sensitive specialty.

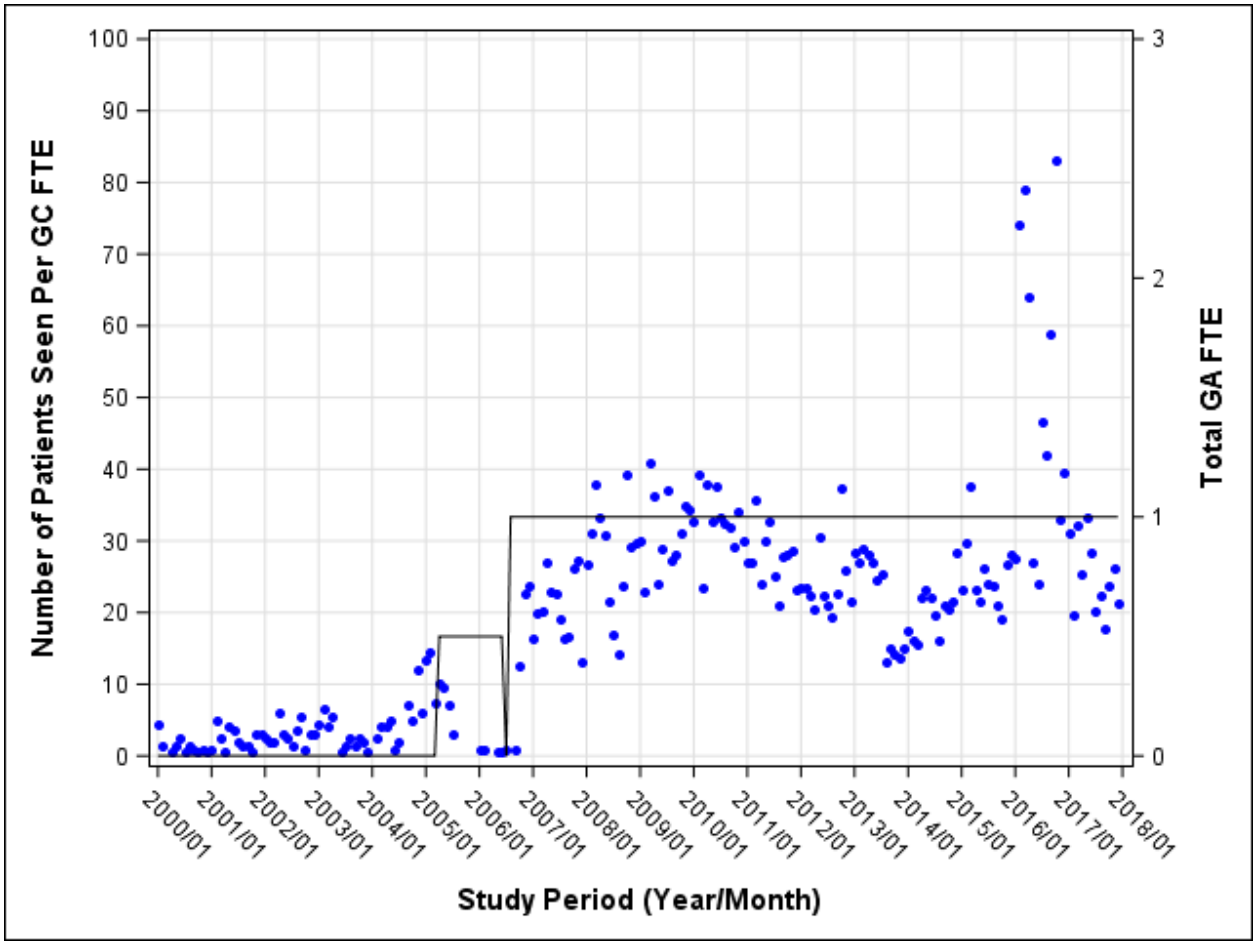

Figure 6.9. Average number of patients seen per prenatal GC FTE by month during the study period (indicated by blue dots and left y-axis). Black line indicates prenatal GA FTE during the study period (right y-axis).

6.2.2. Statistical Analysis of Patient Volume

Monthly patient counts for all providers, as well as for MDs and GCs separately, were significantly associated with GA FTE using linear regression models (Table 6.1). A model of patient counts across all providers (i.e., MDs and GCs) estimated the average number of patients seen per month to be 302 when there are no GAs, an average FTE complement of both MDs and GCs, and an average number of referrals to the clinic. Holding provider FTE and number of referrals to the clinic constant, each full-time GA added to the clinic was estimated to increase the monthly patient count by 33.

The model for MD patient counts estimated the mean number of MD patients seen per month to be 276, when there are no GAs, an average FTE complement of both MDs and GCs, and an average number of referrals to the clinic. With a constant complement of providers and constant number of referrals, each full-time GA was estimated to only increase MD patient counts by six.

A model of GC patient counts estimated the average number of GC patients per month to be 26, when there are no GAs, an average FTE complement of both MDs and GCs, and an average number of referrals to the clinic. If provider FTE and number of referrals remains constant, each full-time GA added to the clinic was estimated to increase monthly GC patient counts by 27; accordingly, adding a single GA to the clinic would double monthly GC patient counts.

A similar analysis for the prenatal clinic (i.e., prenatal patient counts among prenatal GCs) was significantly associated with prenatal GA FTE. Without GAs, and with an average complement of MDs and prenatal GCs, as well as an average number of clinic referrals, prenatal GCs were estimated to see 13 prenatal patients per month. However, each full-time GA added to the prenatal specialty was estimated to increase monthly prenatal patient counts by 56 (assuming constant MD and prenatal GC FTE, as well as a constant number of referrals).

Models were not constructed for the medical genetics and metabolics specialties due to minimal patient volumes early in the study period and positions that were shared across disciplines. A separate model was not constructed for cancer genetics, given that there was only a single GA integrated in this area of practice near the end of the study period.

Table 6.1. Associations between patient counts and GA FTE (n=216)

Patient Counts	Intercept	GA FTE		MD FTE		GC FTE		Referrals	
	β (SE)	β (SE)	p-value	β (SE)	p-value	β (SE)	p-value	β (SE)	p-value
MD + GC patients[a]	302 (7.1)	33.4 (2.6)	<0.0001	-4.7 (5.5)	0.40	7.5 (3.8)	0.05	0.2 (0.05)	0.004
MD patients[a]	276 (6.2)	6.0 (2.3)	0.009	-22.4 (4.9)	<0.0001	-10.3 (3.4)	0.003	0.2 (0.05)	0.001
GC patients[a]	26.4 (3.7)	26.6 (1.4)	<0.0001	17.2 (2.9)	<0.0001	18.3 (2.0)	<0.0001	-0.001 (0.03)	0.84
Prenatal GC patients[b]	12.6 (3.3)	56.2 (4.7)	<0.0001	0.8 (2.0)	0.67	6.4 (2.5)	0.01	0.06 (0.02)	0.003

[a] Model was adjusted for MD FTE, GC FTE, and number of clinic referrals
[b] Model was adjusted for MD FTE, prenatal GC FTE, and number of clinic referrals

CHAPTER 7: DISCUSSION

8.1. GA Workforce and Characteristics of GA Positions (Aim 1)

8.1.1. Demographics and Background

The majority of the GA participants in the present study were female, 30 years of age or younger, lived in the United States, and had an undergraduate degree at minimum. Overall, the demographics were similar to those published by Pirzadeh-Miller et al. (2017) about their GA participants; however, their sample was restricted to 14 GAs. The present study, however, is the first to describe the demographics and background of the GA workforce across North America, providing a more comprehensive picture.

Demographics of the GA participants in this study were also similar to the demographics of GCs reported in the 2018 PSS; 95% of GC respondents were female, 70% were under the age of 40 (proportion under the age of 30 is not readily available), and 89% worked in the United States (National Society of Genetic Counselors, 2018a). It is not surprising that the demographics of the GA participants are similar to those of GCs in North America, given that the majority of GAs planned to pursue a career in genetic counselling.

The genetic counselling profession has been criticized for its lack of diversity (Mittman & Downs, 2008; Stern, 2009). These criticisms are substantiated by the demographics reported in the PSS, specifically the extremely high proportion of Caucasian females, as well as the lack of representation of the disability community (only 1% of GCs). The homogeneous nature of the genetic counselling community is likely based on several factors, including: 1) shared personal characteristics that draw individuals to the genetic counselling profession, and 2) a certain socio-

economic status that allows individuals to explore career options and access the necessary mentorship, training, and education.

Some participants proposed that the GA position may be a way to draw more individuals to the profession of genetic counselling. Taking this one step further, the GA position may provide an avenue to increase diversity among GCs, as explained by one interview participant:

> *"We're trying to take a focus of diversity and inclusion . . . We want to make sure that a diverse group of people has an opportunity to explore genetic counselling so that they can consider it as a field. And so we're trying to look at what are some of the barriers and what are some of the difficulties that make it difficult for someone to do that. And I could certainly see a role like GA, because it's paid, being a way that some people might be able to get the experience prior to going to genetic counselling. But it's my understanding that there's just not a lot of GA opportunities out there."* (GA8)

Based on this reasoning, creating additional GA positions might recruit more long-term GAs to the field, as well as draw more individuals to the field of genetic counselling through paid work exposure. However, access to the field would still remain limited to only those with significant financial means. As reported by the survey participants, GA positions typically require an undergraduate degree and correspondingly, are limited to those who have the opportunity to pursue post-secondary education. Furthermore, some GA positions offer limited compensation or are completely unpaid, which may make it difficult for an individual to work as a full-time GA, unless he/she has financial support from another individual, such as a parent or partner. Access to genetic counselling education would also remain limited based on the overarching programmatic structure; genetic counselling programs are generally very expensive and, given that they accept few students, often require relocation to a new province or state.

Co-operative positions or work-study programs could enable students to gain exposure to GA positions, while also providing them with the means to finance their post-secondary education, as proposed by one interview participant:

> *"But I think having some sort of pipeline of maybe trying to open up student GA positions at different clinics. So that way you potentially catch someone's interest . . . The student would be reimbursed a certain amount of money for their hard work. And then after they graduate, potentially becoming a fulltime GA or going to genetic counselling school. They already have the training while they're in school."* (GA3)

Institutions that employ GAs could also help to improve access to genetic counselling programs by providing scholarships/return of service agreements or employing genetic counselling work-study students. Survey and interview data suggested that some institutions are beginning to implement these strategies; however, it would require nation-wide efforts in order to truly ensure that those who demonstrate dedication to the field of genetic counselling have the opportunity to pursue this career.

8.1.2. Training

Most GA participants felt that their prior education prepared them for the training and focus of the GA position. Given that most GAs entered the position with an undergraduate degree, the study findings suggest this is a sufficient educational requirement for GA positions.

In general, the survey respondents reported that the GAs received adequate training and supervision. Despite this, many participants also explained that some skills can only be gained through on-the-job experience. This is likely due to a myriad of indications and unique patient circumstances that one can encounter in the field of genetics. While there is no simple way to prepare GAs for every possible situation they might encounter, it is possible to provide them

with the resources they need to be successful. This includes adequate training materials (with guidelines on which individuals and/or resources to consult when new situations arise), as well as appropriate supervision and mentorship.

Although the GA participants reported adequate training, they did still provide numerous suggestions for the training of future GAs. These could be divided into categories: 1) content knowledge (also includes knowledge of policies and procedures), 2) skills development, and 3) experiential learning, which align with cognitive learning theories described in the clinical education literature (Conn, Lake, McColl, Bilszta, & Woodward-Kron, 2012). This demonstrates that the GA position lends well to development of training modules or programs based on a clinical education approach. Interestingly, John Hopkins University recently released an online "Genetic Assistant Training Program" that is designed to build an individual's knowledge base in clinical genomics, as well as demonstrate how to apply clinical genomics concepts to duties typically performed by GAs (John Hopkins Medicine, 2019). However, there is little information available about the foundations of this program, such as how the curriculum was developed or how the roles and responsibilities of a GA were determined.

Competency based frameworks have been embedded in clinical education for many years (Morcke, Dornan, & Eika, 2013). In fact, the curriculum design and accreditation standards for genetic counselling programs centre around the practice-based competencies for GCs (Accreditation Council for Genetic Counseling, 2015) and a framework for student evaluation based on these competencies has been proposed (Guy, 2016). Accordingly, the most effective educational approach may be to first establish GA competencies or scope of practice and

subsequently develop training materials, such as handbooks or online training modules. Since the GA cohort is distributed across the continent, online training modules that incorporate both knowledge acquisition and skills training (such as that developed by John Hopkins University), coupled with experiential learning in some fashion (i.e., local or remote observation/practice), may be the most effective way to disseminate training materials to a cohort distributed across the continent, while also ensuring that all GAs meet a minimum training standard.

8.1.3. Roles and Responsibilities

Overall, the results of this study demonstrated that the scope of the GA position is variable at this time, leading to inconsistencies in the roles and responsibilities that are assigned to GAs both within and across institutions. For example, there were few roles that at least two-thirds of GAs reported performing, even when GAs were separated by clinical or laboratory setting. Additionally, many participants described the GA position as ever-evolving, which means that the roles and responsibilities of many GAs may change throughout their time in the position, even if they are only employed as a GA for a short period of time.

These inconsistencies in roles and responsibilities have the potential to cause a variety of issues within genetics services. First, there is a potential for role overlap (as identified by some of the interview participants), which could lead to conflicts in the workplace, dissatisfaction, and a reduction in productivity. Second, basing a GA's roles and responsibilities solely on clinic structure and resources may lead to GAs operating outside their knowledge base and training, which could ultimately compromise patient safety. Some interview participants (both GAs and GCs) described feeling uncomfortable when such roles were assigned to GAs. Third, GAs may

be unable to distinguish between tasks that they have the knowledge and training to perform, and tasks that fall within a GC's scope of practice; this was illustrated by the higher proportion of GAs compared to GCs that felt certain complex tasks were appropriate for a GA to perform (e.g.,. identifying patient resources, preparing results letters, disclosing variant of uncertain significance and abnormal results, and offering genetic testing). These inconsistencies and the potential issues that may result from an ill-defined scope of practice highlight the need for the development of GA competencies. Similarly, the previous study about GAs found that some participants were concerned about GAs working without a defined scope of responsibilities, further demonstrating the need for GA competencies (Pirzadeh-Miller et al., 2017).

Among the GAs who reported performing less common and arguably more complex roles (e.g.,. preparing results letters and disclosing variant of uncertain significance and abnormal results) were those who have worked in the position for many years (though approximately half of the GAs who reported performing these roles had worked in the position for one year or less). This is in line with qualitative reports describing that GAs assume additional roles after they gain experience and demonstrate competence in those initially assigned. Taken together, these observations support the development of either defined position levels (i.e., GA1 and GA2 classifications) or advanced practice competencies, which would allow for role expansions among GAs who are employed in the position long-term. There is a wealth of literature on advanced practice in healthcare; the literature primarily focuses on advanced nursing practice, but also includes other professions. In fact, the Canadian Association of Medical Radiation Technologists created an Advanced Practice Framework in 2015. Based on the literature, they identified four key principles of advanced practice, namely: 1) improving patient outcomes, 2)

critical thinking and ability to make complex decisions, 3) increased autonomy, and 4) leadership, advocacy, and mentorship (Canadian Association of Medical Radiation Technologists, 2015). While these principles may be most applicable to provision of direct patient care, they could also be applied to those supporting the provision of patient care, such as GAs. However, given that advanced practice competencies are not yet developed for the genetic counselling profession, it is unlikely that this would be pursued for GAs in the near future.

8.1.4. Enumeration of GA Positions

The survey participants reported a total of 144 GA positions across North America. It is likely that the survey participants did not represent every institution that employs GAs; therefore, the true size of the workforce is probably larger. Furthermore, due to the high turnover rate associated with the GA position, there are many other individuals who previously worked as a GA and now work in another career; given that GA positions serve as a "stepping stone" to genetic counselling, as reported by the interview participants, it is likely that most individuals who previously worked as a GA are now employed as GCs. While the GA workforce is small, this study demonstrates that there are motivated individuals willing to participate in research to advance our knowledge about GA positions. Furthermore, this research provides evidence that many institutions have already incorporated GA positions in their genetics service provision model.

Compared to other assistant positions in allied health (e.g.,. occupational therapy assistants and physical therapy assistants), the GA workforce is quite small (Bureau of Labor Statistics: United States Department of Labor, 2019a, 2019b). However, the GA position is very new; most survey

respondents (83%) had worked with GAs for less than five years. Contrariwise, the OTA and PTA positions first emerged in the 1950s to 1960s (Carpenter-Davis, 2003; Salvatori, 2001); therefore, those workforces have had significantly more time to grow. Furthermore, the OT and PT professional workforces themselves are larger, as well as more widely recognized and known to the public than the GC workforce. Accordingly, it is expected that assistant positions in rehabilitation services would be more prevalent than those in genetics services.

The distribution of GA positions may be related to the distribution of GC positions, whereby areas that have more GCs employ more GAs. Survey respondents reported the highest number of GA positions in NSGC region 4; according to the 2018 PSS, region 4 had the highest proportion of GCs (28%) (National Society of Genetic Counselors, 2018a). NSGC regions 1 and 3 reported the fewest GA positions and also had the lowest proportion of GCs in the PSS (7% and 12%, respectively). Region 5 also had a low proportion of GCs (13%), yet a moderate proportion of GAs; however, Manitoba and Texas may have been some of the first places to integrate GAs into their genetics service provision models (as explained in this study and the study by Pirzadeh-Miller et al., 2017) and therefore may employ more GAs in comparison to other provinces and states. Regions 2 and 6 both contain a moderate proportion of GCs (22% and 19%, respectively) and reported a moderate proportion of GAs.

8.2. Attitudes Towards GAs (Aim 2)

Overall, the GCs expressed appreciation and recognition of the value of GAs, based on their impact within their respective genetics services. Most GCs felt that the GAs were “part of the team” and the GAs themselves echoed this sentiment. However, when discussing workplace

culture, attitudes, and relationships, evidence of hierarchical systems within some genetics services also emerged.

Braithwaite et al. (2016) define a hierarchy as "a layered social structure which conceptualises superior and subordinate relationships transitively, in rank order . . . In healthcare, the 'clinical pecking order' is one key example". Given that healthcare teams involve individuals from various training/educational backgrounds and occupational/professional groups, hierarchies are bound to occur. As explained by Green et al. (2017) using a variety of examples from both healthcare and aviation, some hierarchies have negative effects (e.g.,. a lack of teamwork or negative working relationships), while other hierarchies may have positive effects (in the context of a student-supervisor relationship, a hierarchy can enable effective communication and a higher quality of patient care).

Because most participants in the present study did not speak directly about the hierarchical system within their work setting, it is difficult to interpret the effect on their workplace cultures. However, it is worth nothing that a continual process of role substitution seems to be intertwined with the long-standing hierarchical system embedded inherent in genetics services. Each time a new position is introduced to the genetics clinic/laboratory, "burdensome" tasks are reassigned to the position that is of lower status according to educational background and credentials. The reallocation of "burdensome" and potentially less desirable tasks to others within the workplace may reinforce the hierarchy system, as individuals of higher professional status exert their authority to choose which tasks they will perform and which will be assigned to other employees. This is in line with Hughes' (1954) depiction of the reassignment of "dirty work" to

staff of lower status, which ultimately increases the status divide between certain providers and other healthcare workers.

Additionally, there is historical evidence of a hierarchical system within genetics services. For example, physicians were initially opposed to the GC position. As a result, most early GCs were assigned tasks that did not make use of their specialized Masters level training (Stillwell, 2015). While most GCs now see patients independently and manage their own workloads, this systemic hierarchy may still be embedded within genetics clinics. As other positions are added (such as the GA position), they may be integrated within this dated hierarchy framework according to their level of training and education.

8.3. Impact of GAs (Aims 3 to 5)

The majority of study participants described GAs as making a positive and significant impact on the provision of genetics service. Most survey participants reported that integrating GAs resulted in other employees having fewer roles and responsibilities, as well as more time to dedicate to the tasks for which they have specialized training, which could lead to increased professional satisfaction among GCs. Furthermore, many survey participants reported that GAs result in increased clinical and laboratory productivity. Interview participants echoed these sentiments by describing an overarching role of GAs to be "taking on the burden" of tasks normally assigned to other employees, especially GCs. Allowing GCs to spend more time on tasks for which they have specialized training was seen as making better use of their unique skillsets. Ultimately, interview participants agreed with survey participants that integration of GAs result in increased productivity. However, they also described improved quality of patient care, an outcome that was

not measured in the survey; interestingly, this arose both as a result of increased GC time for direct patient care, as well as through GA's direct interactions with patients. Last, the productivity analysis suggested that integrating GAs increases the number of patients seen by GCs, which supports the findings from the survey and interview data.

The primary rationale for integrating GAs in genetics services was that they could assume some of the roles traditionally performed by GCs (i.e., role substitution), allowing GCs to spend more time providing direct patient care. Both the quantitative and qualitative data collected in this study confirm that GAs are in fact "living up" to these expectations. This is also consistent with the findings from the previous GA study, which revealed an increase in total new patients seen and average weekly volume of new patients per GC as GAs were added to the clinic (Pirzadeh-Miller et al., 2017). In the previous study, smaller GC to GA ratios resulted in increased productivity; the smallest GC to GA ratio (3:1) led to a 58.5% increase in new patients seen compared to having no GAs in the clinic.

While the impact of GAs on the productivity of GCs was evident, the impact of GAs on medical geneticists (if any) was less clear. The productivity analysis revealed only a slight change in geneticist productivity with each GA added to the clinic. Furthermore, the majority of interview participants expressed that GAs impact GCs significantly more than they do medical geneticists. Most of the geneticists who participated in the survey reported that GAs increase productivity; however, their responses could be based on impact in the overall work setting, rather than on their own workloads. Nonetheless, the results from the productivity analysis and the observations from the interviews may be explained by the history of genetic counselling itself. PhD and

medical geneticists began as the sole providers of genetic counselling. However, due to a shortage of medical geneticists, the GC profession was born. Initially, GCs performed tasks that were of low importance to the physicians and did not require a GC's specialized training (e.g.,. obtaining records and preparing pedigrees) (Stillwell, 2015). Over time, GCs gradually became more involved in providing genetic counselling, though many also retained administrative, organizational, and/or clinic coordination responsibilities. GAs were introduced to assume many of these ancillary responsibilities from GCs and as such, have likely not assumed many roles and responsibilities that were previously performed by a medical geneticist themselves; instead, GAs may be providing support to medical geneticists in lieu of GCs.

Some of the GC interview participants expressed discomfort with GAs performing certain roles, as well as displeasure with losing some of the roles that they traditionally performed themselves. The ways in which some GCs described their experience of losing traditional roles as a result of changing professional boundaries is a perfect illustration of why role substitution has also been referred to as "encroachment" (Nancarrow & Borthwick, 2005). The GCs' experiences are also consistent with previous reports of the impact of altering staff-mix. For example, after PTA training was formalized, physiotherapists became concerned that: 1) PTAs would assume most patient interactions (which many physiotherapists enjoyed engaging in themselves) and 2) PTAs would take on inappropriate roles (Clynch, 2017). Similarly, some occupational therapists were reluctant to relinquish patient interactions to occupational therapist assistants since they entered the profession with the intent of undertaking these interactions themselves (Mackey & Nancarrow, 2004). Furthermore, early GCs were restricted in the roles that they performed (Stillwell, 2015); this was (at least in part) due to the fact that geneticists did not think GCs

should provide genetic counselling (Epstein, 1973, as cited by Heimler, 1997). Accordingly, other staff members' discomfort is not unique to role substitution in the context of the GA position. However, some GCs may be comfortable with the roles assigned to GAs provided that there is adequate supervision to ensure that the activities are performed appropriately; this is similar to the reasons that physicians were supportive of PA integration in the early days of the profession (Cawley et al., 2012). As the GA position becomes better defined, GCs will likely become more comfortable with the roles assigned to and performed autonomously by GAs.

Interview participants were asked to comment on whether long-term GAs would ultimately change other professions within the genetics team, especially the genetic counselling profession. Many participants had a difficult time answering this question. It may be difficult for individuals to identify any changes to the GC profession for two main reasons: 1) the GA position is still new in many institutions, and 2) the role of GAs has been gradually evolving over time. Those that did respond to the question were divided on whether the presence of long-term GAs would impact the profession of genetic counselling, as opposed to the daily workflow of GCs. It is reasonable to assume that widespread use of GAs may shift daily duties, roles, and responsibilities to be primarily focused on those that use the practice-based competencies for GCs. Additionally, as described by one interview participant, widespread integration of GAs may elevate the status of GCs among other health care professionals. However, when considering the defining characteristics of a profession, it is more difficult to envision a significant change in the professional identity of GCs resulting from the integration of GAs. Furthermore, the GA position seems more likely to remain a stepping stone position than to become an independent occupation. Accordingly, at this time, it seems that the integration of

GAs is unlikely to alter the professional identities of medical geneticists and GCs as drastically as GCs altered the profession of medical genetics.

Taken together, the findings in the present study provide overwhelming support of the assertion that GAs improve productivity within genetics services. However, further research is still needed. While the preliminary linear regression models suggested that integrating GAs in a clinical setting leads to higher GC productivity, more sophisticated statistical analyses are needed to confirm these findings. Given the difference in salary between GA and GC positions, further research may also include a cost-benefit analysis to determine the mix of GCs and GAs that leads to optimal productivity.

8.4. Genetic Assistant: A Profession?

It is important to note that not every occupation is a profession. There is an entire body of literature about what constitutes a profession and the ways through which professions are born. A wide range of definitions for professions have been published. Many definitions include the presence of professional associations, specialized training and education, expert knowledge, provision of services, a scope of practice, and a code of ethics; furthermore, more recent definitions also focus on the high level of power that many professions have (Adams, 2010).

Some have considered whether the GA position should become a profession or simply remain an occupation. This was asked of interview participants through the following questions: “Can you envision the GA position as a permanent/long-term career path? Why or why not?” The majority of participants felt that the GA position is a stepping stone position as opposed to an independent

profession, though the researchers do not wish to diminish the fact that working as a GA can be a terminal career path for some individuals. Nonetheless, the interviews yielded more reasons why GAs would work in the position short-term, as opposed to long-term. These reasons included human resource limitations (i.e., compensation, potential for growth, stability), monotony of the work, and that it is an ideal stepping stone position to a career in genetic counselling, which lends well to a mutually beneficial relationship between GCs and GAs. Similarly, Pirzadeh-Miller et al. (2017) found that most GAs used the GA position as a stepping stone to a career in genetic counselling (12/14 respondents or 86% applied to genetic counselling programs).

While it may become a terminal position (and thus an occupation) for some, it is unlikely to become a profession by definition, given all that that entails. If the GA position is more likely to remain defined as an occupation rather than a profession, some might question whether it is worth investing resources to develop competencies and educational curricula. The researchers in this study would argue that it is certainly worthwhile. One of the primary reasons for this is that GAs are involved in the provision of genetic health services, like other occupations with specific training (e.g.,. medical secretaries or medical assistants). Accordingly, it is imperative that GAs function within a defined scope of practice and have sufficient training, knowledge, skills, and experience to perform their roles and responsibilities.

8.5. Study Design

8.5.1. Mixed Methods

When selecting a mixed methods design for this study, the researchers adopted a pragmatist approach. They recognized that by combining quantitative and qualitative methods, they were

mixing two very different theoretical paradigms. For the quantitative portions of the study, the researchers worked from a post-positivist epistemology; post-positivists strive to find truth based on empiric evidence, while recognizing that knowledge gained is subject to a variety of intrinsic and extrinsic influences (such as errors in observation or a researcher's interpretation of the research findings) (Fox, 2008; Patton, 2015). For the qualitative portions of the study, the researchers worked from a constructivist epistemology, which aims to understand how individuals have constructed their knowledge and reality through social interactions and what the implications of these perceptions are (Costantino, 2008; Patton, 2015). Importantly, this theory recognizes that realities differ between individuals or groups of individuals and asserts that there is no one universal, discoverable truth.

Despite the differences between these theoretical perspectives, an approach using both methods provided rich, complimentary data to explore the GA position. Quantitative methodology yielded a comprehensive description of the GA position and the impact of GAs in the provision of genetics services. Qualitative methodology allowed further exploration of the survey data (e.g.,. training and supervision) and provided thorough depictions of the experiences of working as or with GAs. Since one of the fundamental principles of genetic counselling is constructing an understanding of each patient within the context of his/her unique situation (Weil, 2000), it would be unreasonable to assume that all employees in a genetics service have the same views and experiences. For this reason, it was appropriate to work from a constructivist perspective, which does not try to find one collective experience shared by all participants, but rather recognizes that each individual constructs their own reality and knowledge based on his/her unique experiences and social interactions (Costantino, 2008; Patton, 2015). Furthermore,

utilizing both quantitative and qualitative methods produced data in a format accessible to multiple stakeholders. Genetics employees (e.g.,. GCs and geneticists) will likely appreciate a combination of quantitative and qualitative data about the experience of integrating GAs, while healthcare administrators may prefer productivity data. To this end, the rationale and benefit of employing a mixed methods design in the present study is summarized well by Greene and Caracelli (1997), who said that mixed methods designs lead to "more comprehensive, insightful, and logical results than either paradigm could obtain alone" (as cited in Hesse-Biber, 2017).

8.5.2. Triangulation

The study design incorporated two types of triangulation to improve the credibility of the research (Denzin, 1978). Methodological or mixed-methods triangulation was incorporated by using multiple methodologies (i.e., surveys, interviews, and clinical data) to explore the impact of integrating GAs in a clinic or laboratory (Patton, 2015). Data triangulation was utilized by collecting the perspectives of multiple people from different viewpoints (i.e., surveying and interviewing both GAs and individuals who work with GAs) (Patton, 2015). While other methods to improve the credibility of qualitative research (e.g.,. member-checking or multiple analysts for all transcripts) were not employed in the present study, the use of both methodological and data triangulation enhances the quality of the research findings.

8.5.3. Researcher Positionality

In qualitative research, it is widely recognized that the researcher's position influences every aspect of the research study. Positionality is the term used to describe the "stance or positioning of the researcher in relation to the social and political context of the study" (Rowe, 2014, p. 628).

The student principal investigator in this study is a female in her late 20s, who has a Masters level education and is pursuing a career as a healthcare professional. She did not have any personal experience working as a GA; however, she did work with several GAs at the Shared Health Program of Genetics & Metabolism during her clinical training. The supervisor of the present study also worked with GAs in the Shared Health Program of Genetics & Metabolism, prior to her current position as director of a healthcare professional program. Accordingly, the researchers may have brought their perceptions about the demographics, roles, training, supervision, and impact of GAs to the research project. These perceptions likely shaped development of the research questions, the survey, and the interview guide, as well as the way in which the student principal investigator conducted the interviews.

The student principal investigator was in contact with all interview participants and conducted all of the interviews. Most of the interview participants were female, were approximately 20 to 50 years of age, either had or were pursuing Masters level education, and worked in healthcare. Consequently, commonalities between the student principal investigator and the interview participants may have resulted in a relatively equal power dynamic and facilitated rapport building, even for interviews conducted by telephone or video-conferencing. Additionally, the student principal investigator had past professional interactions with several of the interview participants. This may have resulted in these participants speaking more candidly during their interviews, although some participants may have felt less comfortable sharing their true opinions and experiences with the interviewer.

8.6. Limitations

8.6.1. Response Rate

While it was not possible to calculate a response rate for the survey since a snowball sampling strategy was employed, a response rate can be approximated using data from the 2018 PSS, which was completed by 53% of North American GCs (2,543 of 4,780 GCs). In 2018, 403 GCs reported that they worked with a GA (National Society of Genetic Counselors, 2018e). Accordingly, one can assume that there are at least 403 GCs in North America who work with a GA. If the proportion of GCs who work with GAs is similar between those who responded and those who did not respond to the PSS, there would have been approximately 760 GCs across North America who worked with GAs in 2018.

Based on these numbers, the sample of 113 GC participants in the present study likely represented between 15% and 30% of the GCs across North America who work with GAs. The present study required participants to have worked with a GA for a minimum of six months, whereas the PSS did not specify any requirements; thus, some of the GCs who reported working with GAs in the PSS may not have been eligible to participate in the present study.

8.6.2. Interview Format

The purposive sampling strategy in this study depended on including participants from across North America. Accordingly, it was not possible to perform all interviews in person. Participants who lived within one hour of Winnipeg were given the choice of an in person interview or an interview via teleconference; all four participants in the Winnipeg area chose in person interviews. The 10 remaining interview participants were interviewed via teleconference.

In the literature, telephone interviews have typically been viewed as inferior to in person interviews. In her review of the literature about telephone interviews, Novick (2008) found that concerns about telephone interviews were primarily related to an absence of visual cues and the resultant potential for loss of nonverbal data, loss of contextual data, and loss/distortion of verbal data. Another primary concern about telephone interviews is diminished rapport, which may lead participants to be less open with the interviewer. On the other hand, telephone interviews may also have some advantages over in person interviews, including increased privacy and better accessibility for participants, as well as lower expenses for the research team (Musselwhite, Cuff, McGregor, & King, 2007; Sturges & Hanrahan, 2004). Studies that evaluated the impact of interview mode (e.g.,. telephone versus in person) on data quality have yielded variable results (Novick, 2008); therefore, there is not clear evidence whether telephone interviews are truly inferior to in person interviews.

In this study, two of the in person interviews were approximately 10 to 15 minutes longer than the majority of the interviews conducted via teleconference; however, the longest interview (91 minutes) was actually conducted through teleconference. Despite some differences in the lengths of the interviews, the quality of the data did not seem to differ. One potential explanation could be that shared characteristics between the interviewer and the interview participants facilitated rapport building, even when the interviewee and interviewer were not face-to-face. While it is possible that conducting interviews via teleconference in the present study may have resulted in lower quality data as compared to data that could be collected in person, this was a necessary component of the study design that could not be overcome easily or affordably.

8.6.3. Productivity Analysis

While the clinical data allowed a preliminary evaluation of the impact of GAs on clinical productivity, the dataset had several limitations:

1) Information about wait times was not available. One of the potential outcomes of incorporating GAs in a clinic is reduction in wait times; however, since the dataset did not contain a referral date for most patients, wait time could not be calculated.
2) Some variables of interest were not directly available from the dataset and were instead approximated by proxy variables. For example, the number of referrals per month was not available and was best approximated by the sequential ID numbers assigned to new patients. Additionally, employee records were not incorporated in the dataset; instead, employment timelines were generated based on the staff codes in the patient count dataset and information provided by members of the research team who were long-standing employees within the clinic.
3) Historic cancer genetics appointments that were added to Shire retrospectively were removed from the dataset used to estimate the number of new referrals to the genetics program. The appointments that were removed constituted approximately 60% of the total cancer appointments, with the majority of appointments removed (98%) occurring between 2000 and 2014. Accordingly, the estimated number of new referrals may have been lower than the true number for the years 2000 to 2014. However, since the dataset lacked referral dates for the patients, the information available was used to best approximate the number of new referrals.
4) In the metabolics specialty, there were joint clinics where both physicians and GCs met with the patients. These patients would have only been included in the physician patient count;

therefore, patient counts may not be representative of the number of patients that metabolic GCs truly saw per month.

5) Data entry errors are a well-documented occurrence within clinical, research, and administrative databases. The datasets used in the present study may contain data entry errors; however, most errors would be difficult to detect without comparing the collected data to each patient's paper chart.
6) The genetics clinic in Manitoba is a complex model, compared to some other genetics clinics. Multiple GA positions were integrated between 2005 and 2015, rather than a single position. The allocation of GC positions within different specialties was variable; for example, a GC position may have begun as 1.0 FTE prenatal and later changed to a split position (e.g.,. 0.5 FTE prenatal and 0.5 FTE medical genetics). There were also some vacancies in GC positions and subsequent shifts of FTE to different disciplines for coverage, which led to fluctuations in GC FTE throughout the study period and made for a more complex dataset. Additionally, clinic policies were in flux throughout the study period (which is typical of most clinical programs). One example of such a change was described in the productivity results (i.e., prenatal GCs began to see patients for referral indications that previously would have been seen by an MD). Another example of a policy change is when referrals for a certain indication (e.g.,. certain connective tissue disorders) are no longer accepted. Changes in the clinic policies may have resulted in changes in the number of referrals and/or patient counts; unfortunately, such policy changes are not easily tracked and cannot be adjusted for in this type of statistical analysis.
7) Because linear regression models were used to analyze the data, the results should be interpreted with caution. A linear regression model does not account for characteristics of

longitudinal data, such as autocorrelation: correlation between observations at different time points (in this case, different months throughout the study period) (Everitt & Skrondal, 2010). Additionally, it is not theoretically appropriate to compare the patient volume prior to the integration of GAs and post-integration, as this does not account for any trends in the pre-integration data. Due to these limitations, future analyses will use an interrupted time series analysis to account for the longitudinal nature of the data.

One potential solution to overcome some of the limitations of the productivity analysis would be to use data from a simpler clinic model. Such a dataset would include information about wait times, a shorter time period (and thus fewer policy changes), fewer or more consistent GC positions, and incorporation of a single GA position. A statistical model could be developed using data from the clinic in Manitoba and then applied to the second clinic for proof-of-concept.

8.7. Future Directions

This research is expected to pave the way for numerous other studies on the GA position, especially research aimed at addressing training, integration, and the impact of GAs in both clinical and laboratory settings. Two future research projects are outlined below.

8.7.1. Competencies for GAs

Due to inconsistencies in the roles and responsibilities of GAs, now is the ideal time to develop competencies for the GA workforce. The Delphi method is "a structured mechanism to attain insights and perspectives from people with a specific expertise on a topic or issue in order to inform decision making about policy and practice" (Brady, 2016, p. 61). It can be applied to a

variety of contexts, such as public policy, management and organizational structure, conflict resolution, and strategic planning. Modified Delphi methodologies have also been used to develop competencies for a wide variety of health care professions, including occupational therapists (Holmes & Scaffa, 2009), nurse practitioners (Sue Hoyt et al., 2010), and even GCs (Eubanks Higgins et al., 2013; Hampel et al., 2009).

In a Delphi study, a group of experts (usually under 50 in total) are recruited based on pre-determined criteria (Hsu & Brian A. Sandford, 2007). Typically, three to five waves of questionnaires are completed by the experts and are analyzed with thematic analysis to identify consensus on the research question (Brady, 2016; Hsu & Brian A. Sandford, 2007). The first questionnaire is used to gather initial data about the research question and the second is used to allow participants to provide feedback on one another's responses (Brady, 2016). Subsequent questionnaires are based on the responses to the previous questionnaires, allow the experts to revise their opinions, and are used to reach a final consensus (Hsu & Brian A. Sandford, 2007).

Accordingly, the Delphi method could be used to develop competencies for the GA workforce. The expert panel would include: 1) GCs who have considerable experience working in the field and working with GAs, 2) GAs who have considerable experience in the position, and 3) researchers who have studied the GA workforce. Because the questionnaires can be completed electronically, the study could include participants from across North America. The questionnaires would be used to determine primary competency domains, as well as the competencies that fall within each domain (similar to the competencies that have been developed

for GCs). These competencies could then be applied to GA job descriptions and development of training modules.

8.7.2. Time-Series Analysis of Clinic Data

The results in this study provided preliminary evidence that integration of GAs increases GC productivity (i.e., patient volume) in a clinical setting. However, the linear regression models used did not account for the longitudinal nature of the data and thus should be interpreted with caution.

Future research will use an interrupted time-series segmented regression model (ITS) to analyze the impact of new GA positions on patient volume between 2000 and 2017. This model will allow for examination of clinic productivity during three periods: 1) prior to the addition of the GA positions, 2) during the "step-wise" implementation of GA positions, and 3) within a "steady state" of five GA positions. The ITS model will examine the association between staff mix and number of patients seen per provider, while adjusting for an increase in patient referrals.

An ITS model is the most appropriate way to analyze the dataset, given that the initial trend in patient volume was presumably "interrupted" by the integration of GAs. Adding GAs to the genetics clinic should have allowed GCs to see more patients; this likely resulted in a change in both the gradient (slope) and level (y-intercept) of the initial trend in patient volume. Accordingly, the ITS model is an appropriate statistical method as it is capable of modeling these changes in trend (Bernal, Cummins, & Gasparrini, 2017). The ITS method can also be extended

to include multiple interruptions (i.e., implementation of additional GA positions at various time points), which further substantiates that it is well suited to analysis of this clinical data.

8.8. Significance

This is the first study to describe the GA workforce across North America. The data collected provides a strong depiction of who GAs are, where they come from, and where they end up. This study provides a glimpse into the roles and responsibilities typically assigned to GAs, as well as the training and supervision provided for such roles. Qualitative methodologies generated a rich description of how GAs are integrated in genetics services and the impact of GAs on the workload of other health care workers. Last, the study provides preliminary evidence supporting a relationship between GA implementation and GC productivity. Taken together, this work highlights the strengths of integrating a GA in a genetics clinic or laboratory, while also illuminating opportunities for further research.

This exploration into the impact of GAs in genetics services can be used as evidence to: 1) sustain current models at institutions that employ GAs, and 2) advocate for the integration of GAs at institutions that currently do not have these positions (Bourgeault, 2013; Murphy & MacKenzie, 2013). More broadly, this study contributes a new example of role substitution and altered staff mix to the health workforce literature. Most importantly, in a time of workforce shortages, this data can be incorporated in plans to meet the ever-growing demand for genetic counselling services.

CHAPTER 8: SUMMARY

The present study provides a detailed description of the GA workforce, rich depictions of the experiences of those who work as or with GAs, and compelling evidence about the impact of GAs on productivity.

The survey data revealed that the demographics of GAs were similar to those of GCs, which likely reflected the fact that most GAs plan to pursue a career in genetic counselling. The roles performed by GAs were quite variable, reflecting the current lack of GA competencies or scope of practice. Most GAs received training and felt that it prepared them for the position; however, GAs also provided a wide range of training recommendations for the future. Most individuals who work with GAs reported that GAs reduce their roles and responsibilities, allow them to spend more time on tasks for which they have specialized training, and increase productivity (both in clinical and laboratory settings). The participants reported a total of 144 GA positions across North America, with the most positions in region 5 (according to the regions defined by the National Society of Genetic Counselor). Cross-case thematic analysis of the interview data identified five major themes, specifically: the evolving nature of the GA position; factors needed for GAs to work autonomously (including training, supervision, and continuing education); the career divide between short-term and long-term GAs; other staff members' values about, attitudes towards, and relationships with GAs; and the positive impact of GAs on the work of GCs. Last, data from the local genetics clinic in Winnipeg suggested that integration of GAs in a clinical setting increases GC productivity, but has limited impact on medical geneticist productivity.

Taken together, these results show that GAs are a growing workforce that is being integrated in clinics and laboratories across North America. Data from all three arms of the study provide overwhelming evidence that GAs increase productivity in the provision of genetics services by allowing others to make better use of their skills and allocate more time to providing patient care. This research identified numerous avenues for future research, most notably: a need for development of GA competencies and/or scope of practice, as well as more formal statistical analysis of the impact of GAs on clinical productivity.

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APPENDICES

Appendix 1. Survey

Part A: Screening Questions

If you answer NO to screening question 1, a command box will indicate that the survey will end. In this case, please select "End the survey now" to proceed to screening questions for Part B of the survey.

Since the year 2000, have you ever been employed as a Genetic Assistant (GA) or Genetic Counsellor Assistant (GCA) in Canada or the United States (full-time or part-time)?

a. Yes
b. No

If you answer NO to screening question 2, a command box will indicate that the survey will end. In this case, please select "End the survey now" to proceed to screening questions for Part B of the survey.

Since the year 2000, were you employed in a single GA/GCA position for at least six (6) months continuously?

a. Yes
b. No

Since the year 2000, have you held more than one GA/GCA position in Canada or the United States (full-time or part-time)?

a. Yes (please specify)
b. No

Please base your responses on the most recent GA/GCA position in which you were employed for at least six (6) months.

Section 1: Demographics

What is your gender identity?

a. Female
b. Male
c. Transgender female
d. Transgender male
e. Gender variant/non-conforming
f. Not listed (please specify)
g. Prefer not to disclose

What was your age when you began working as a GA/GCA?

a. 18-25
b. 26-30

c. 31-35
d. 36 or older

What is your current age?
a. 18-25
b. 26-30
c. 31-35
d. 36 or older

In what country did you work as a GA/GCA?
a. Canada
b. United States
c. Both Canada and the United States

Section 2: Position Demographics

What was your position title?
a. Genetic Assistant
b. Genetic Counsellor Assistant
c. Other (please specify)

How many months did you work in your most recent GA/GCA position?

Which specialty/specialties was your most recent GA/GCA position a part of? (check all that apply)
a. Cancer
b. Prenatal
c. Pediatric Genetics
d. General Genetics
e. Adult Genetics
f. Cardiology
g. Metabolics
h. Neurogenetics
i. Laboratory
j. Other (please specify)

Which of the following represents your most recent hourly wage in the GA/GCA position (in your country's currency)?
a. $10 or less
b. $11-15
c. $16-20
d. $21-25
e. $26-30
f. More than $30
g. Unpaid position (e.g.,. Volunteer/Co-operative/Internship)

How many hours do/did you work per week in your most recent GA/GCA position?
In what work setting was your most recent GA/GCA position?

a. Public hospital/Medical facility
b. Private hospital/Medical facility
c. University medical facility
d. Diagnostic laboratory – Non-commercial
e. Diagnostic laboratory – Commercial
f. Health maintenance organization
g. Private practice
h. Other (please specify)

Was there other administrative support within the clinic where you held your most recent GA/GCA position (e.g.,. secretary, clerk, administrative professional)?

a. Yes
b. No

How did you discover your most recent GA/GCA position?

a. Contact through a genetic counsellor
b. University/College professor
c. Genetic counselling program director
d. Advertisement
e. Volunteering in a clinic
f. Other (please specify)

Section 3: Training/Preparedness/Background:

What was your educational background prior to the GA/GCA position? (check all that apply)

a. No college/university
b. Some college/university (no degree awarded)
c. Diploma/Certificate
d. Associate Degree
e. Undergraduate/Bachelor's Degree
f. Master's Degree
g. Doctoral Degree
h. Associate Degree
i. Other (please specify)

(For each response B-I) What was your major/program?

a. Biology
b. Genetics
c. Psychology or other social science
d. Other (please specify)

Did you feel your prior education prepared you for the training and focus of the GA/GCA position?

a. Yes

b. No (please explain)

Were you provided training either in advance or on the job specific to your most recent GA/GCA position?

a. Yes
b. No

Please describe training that you feel would help individuals to prepare for work as a GA/GCA.

(If yes) The following list includes individuals from whom you may have received training for your most recent GA/GCA position. Please rank these individuals in order of most training provided (1) to least training provided (maximum 8). Do not provide a rank for any individuals from whom you did not receive training.

a. Another GA/GCA
b. Genetic Counsellor
c. Medical/Clinical Geneticist
d. Laboratory/Molecular Geneticist
e. Clinic Manager
f. Laboratory Manager
g. Coursework/training modules (please specify)
h. Other (please specify)

(If yes) Approximately how many hours of training were provided for your most recent GA/GCA position?

(If yes) Did you feel the training you received as a GA/GCA was enough to prepare you for the responsibilities of the position?

a. Yes
b. No (please explain)

The following list includes individuals by whom you may have been supervised during your most recent GA/GCA position. Please rank these individuals in order of most supervision provided (1) to least supervision provided (maximum 7). Do not provide a rank for any individuals from whom you did not receive supervision.

a. Another GA/GCA
b. Genetic Counsellor
c. Medical/Clinical Geneticist
d. Laboratory/Molecular Geneticist
e. Clinic Manager
f. Laboratory Manager
g. Other (please specify)

How were you supervised in your most recent GA/GCA position? (check all that apply)

a. <u>Direct Supervision:</u> Supervisor is present at all times and gives specific instructions/oversees all tasks.

b. General Supervision: Supervisor provides continuing or individual assignments by indicating what is to be done, limitations, quality and quantity expected, deadlines, and priorities (e.g.,. assignment of general clinic tasks in team meetings). Employee takes initiative for recurring assignments.
c. Intermittent Supervision: Supervisor provides specific protocols, priorities, and deadlines, and assists the employee with unusual situations that do not have clear objectives (i.e., employee follows established clinical protocol and seeks supervisor's assistance as needed).
d. General Direction: Supervisor provides assignments in terms of broad practice, precedents, policies, and goals (i.e., employee makes autonomous decisions about clinical responsibilities). Work may be periodically reviewed by the supervisor.
e. Other (please describe)

From which individuals did you seek the most assistance with clinical responsibilities, support, and mentorship in your most recent GA/GCA position?

a. Another GA/GCA
b. Genetic Counsellor
c. Medical/Clinical Geneticist
d. Laboratory/Molecular Geneticist
e. Clinic Manager
f. Laboratory Manager
g. Other (please specify)

Did you feel the supervision provided to you as a GA/GCA was sufficient?

a. Yes
b. No (please explain)

Section 4: Career/Life Plans:

Are you currently employed as a GA/GCA?

a. Yes
b. No

(If yes) What are your career plans/goals? (check all that apply)

a. Continue working as a GA/GCA
b. Attend university/college (please specify degree and educational program)
c. Work in a different position (please specify position)

(If answer A-C) Do you feel that your work as a GA/GCA prepared you for your career plans/goals?

a. Yes
b. No (please explain)

(If no) What do you currently do?

a. Attend university/college (please specify degree and educational program)
b. Work in a different position (please specify position)

c. On leave (parental, medical, leave of absence)
d. Unemployed

(If no) What was your primary reason for leaving your GA/GCA position?

Section 5:

Please select one of the following options per role:
-Role PERFORM(ED) that you feel/felt adequately TRAINED or qualified for
-Role PERFORM(ED) that you do/did NOT feel adequately TRAINED or qualified for
-Role NOT PERFORMED that you feel/felt you have the POTENTIAL to perform
-Role NOT PERFORMED that you feel/felt you NOT have the POTENTIAL to perform

a. Administrative tasks (e.g.,. scanning, copying, filing, organization, ordering supplies)
b. Data entry
c. Assisting with clinic flow (e.g.,. receiving patients)
d. Screening and tracking referrals
e. Scheduling patients for genetic visits and/or with other specialists
f. Liaison with other health professionals/agencies (e.g.,. gathering information, making referrals)
g. Case preparation (e.g.,. preparing chart, obtaining relevant medical records)
h. Obtaining and/or drawing family history/pedigree
i. Contacting patients for follow-up information
j. Offering genetic testing
k. Completing test requisition forms for genetic testing
l. Preparing letters of medical necessity/application forms for patient testing
m. Coordinating genetic test coverage (i.e., contacting insurance companies or relevant government agencies)
n. Shipping genetic testing (e.g.,. boxing samples)
o. Tracking genetic testing
p. Calling patients with negative gene test results
q. Calling patients with variants of uncertain clinical significance
r. Calling patients with abnormal results
s. Preparing results letters based on gene test results
t. Identifying and providing patient resources
u. Research activities (e.g.,. preparing ethics applications, assisting with data collection)
v. Other (please specify)

Are you interested in being notified about the option to enrol in future research studies on the training, roles, and education of genetic assistants?

If you wish to be contacted about future research studies, please contact Angela Krutish at _____ or_____. Your contact information will not be linked to any of your survey responses and will be accessible only to the Principal Investigator, Jessica Hartley, and her research team.

Part B: Screening Questions

If you answer NO to screening question 3, a command box will indicate that the survey will end. In this case, please select "End the survey now".

Since the year 2000, have you ever worked in a genetics clinic/laboratory with a Genetic Assistant (GA) or Genetic Counsellor Assistant (GCA), while working as a Genetic Counsellor, Medical Genetics Resident, Medical/Clinical Geneticist, Laboratory/Molecular Geneticist, or Administrative Professional (e.g.,. Secretary, Clerk) in a genetics clinic/laboratory in Canada or the United States?

a. Yes
b. No

If you answer NO to screening question 4, a command box will indicate that the survey will end. In this case, please select "End the survey now".

Since the year 2000, in this position, have you worked with Genetic Assistants or Genetic Counsellor Assistants for at least six (6) months?

a. Yes
b. No

Section 1: Demographics

What is your gender identity?

a. Female
b. Male
c. Transgender female
d. Transgender male
e. Gender variant/non-conforming
f. Not listed (please specify)
g. Prefer not to disclose

What is your current age?

a. 18-25
b. 26-30
c. 31-35
d. 36 or older

In what country do/did you work with a GA or GCA?

a. Canada
b. United States
c. Both Canada and the United States

Section 2: Position Demographics

Since the year 2000, how many months (in total) have you worked with a GA/GCA in any position?

Since the year 2000, how many months (in total) have you worked without a GA/GCA in any position?

*If you have held more than one position in a genetics clinic/laboratory setting: Please base your responses to the remainder of the questions on the most recent position in which you worked with a GA/GCA for six (6) months or more.

In which of the following positions were you employed?

a. Genetic Counsellor
b. Medical Genetics Resident
c. Medical/Clinical Geneticist
d. Laboratory/Molecular Geneticist
e. Administrative Professional (e.g.,. Secretary, Clerk, Administrative Assistant)

Which specialty/specialties did you work in? (check all that apply)

a. Cancer
b. Prenatal
c. Pediatric Genetics
d. General Genetics
e. Adult Genetics
f. Cardiology
g. Metabolics
h. Neurogenetics
i. Laboratory
j. Other (please specify)

Which specialty/specialties did the GAs/GCAs work in? (check all that apply)
*If you worked with more than one GA/GCA: Please check all specialties in which GAs/GCAs were employed.

a. Cancer
b. Prenatal
c. Pediatric Genetics
d. General Genetics
e. Adult Genetics
f. Cardiology
g. Metabolics
h. Neurogenetics
i. Laboratory
j. Other (please specify)

In what work setting did you work with a GA/GCA?

a. Public hospital/Medical facility
b. Private hospital/Medical facility
c. University medical facility
d. Diagnostic laboratory – Non-commercial
e. Diagnostic laboratory – Commercial
f. Health maintenance organization
g. Private practice
h. Other (please specify)

Was there administrative/clerical support within the clinic/laboratory where you worked with a GA/GCA (e.g.,. Secretary, Clerk, Administrative Professional)?

a. Yes
b. Yes (myself)
c. No

Section 3: Training/Preparedness/Background

What was the educational requirement for GAs/GCAs at your clinic/laboratory?

a. Not sure
b. No college/university
c. Some college/university
d. Diploma/Certificate
e. Associate Degree
f. Undergraduate/Bachelor's Degree
g. Master's Degree
h. Doctoral Degree
i. Other (please specify)

What was the highest level of education of any GA/GCA that you worked with?

a. Not sure
b. No college/university
c. Some college/university
d. Diploma/Certificate
e. Associate Degree
f. Undergraduate/Bachelor's Degree
g. Master's Degree
h. Doctoral Degree
i. Other (please specify)

Based on their educational background, do you feel that the GAs/GCAs were prepared for the training and focus of the position?

a. Yes
b. No (please explain)
c. Not sure

Were the GAs/GCAs provided with training, either in advance or on the job?

a. Yes
b. No
c. Not sure

(If yes) The following list includes individuals who may be/have been involved in training GAs/GCAs. Please rank these individuals in order of most training provided (1) to least training provided (maximum 8). Do not provide a rank for any individuals who were not involved in training GAs/GCAs.

a. Another GA/GCA
b. Genetic Counsellor
c. Medical/Clinical Geneticist
d. Laboratory/Molecular Geneticist
e. Clinic Manager
f. Laboratory Manager
g. Coursework/Training Modules (please specify)
h. Other (please specify)

(If yes) In total, approximately how many hours of training were provided for the GA/GCA position?

(If yes) Do you feel the training that was provided to GAs/GCAs was enough to prepare them for the responsibilities of the position?

a. Yes
b. No (please explain)

Were you involved in training GAs/GCAs?

a. Yes (please specify in what capacity)
b. No

The following list includes individuals who may be/have been involved in supervising GAs/GCAs. Please rank these individuals in order of most supervision provided (1) to least supervision provided (maximum 7). Do not provide a rank for any individuals who were not involved in supervising GAs/GCAs.

a. Not sure
b. Another GA/GCA
c. Genetic Counsellor
d. Medical/Clinical Geneticist
e. Laboratory/Molecular Geneticist
f. Clinic Manager
g. Laboratory Manager
h. Other (please specify)

How were the GAs/GCAs supervised? (check all that apply)

a. <u>Direct Supervision:</u> Supervisor is present at all times and gives specific instructions/oversees all tasks.

b. General Supervision: Supervisor provides ongoing or individual assignments by indicating what is to be done, limitations, quality and quantity expected, deadlines, and priorities (e.g.,. assignment of general clinic tasks in team meetings). Employee takes initiative for recurring assignments.
c. Intermittent Supervision: Supervisor provides specific protocols, priorities, and deadlines, and assists the employee with unusual situations that do not have clear objectives (i.e., employee follows established clinical protocol and seeks supervisor's assistance as needed).
d. General Direction: Supervisor provides assignments in terms of broad practice, precedents, policies, and goals (i.e., employee makes autonomous decisions about clinical responsibilities). Work may be periodically reviewed by the supervisor.
e. Other (please describe)

Did you provide direct supervision to GAs/GCAs?

a. Yes
b. No

From which individuals did the GAs/GCAs seek the most assistance with clinical responsibilities, support and mentorship?

a. Another GA/GCA
b. Genetic Counsellor
c. Medical/Clinical Geneticist
d. Laboratory/Molecular Geneticist
e. Clinic Manager
f. Laboratory Manager
g. Other (please specify)

Did you feel the supervision provided to GAs/GCAs is/was sufficient?

a. Yes
b. No (please explain)

Section 4: Roles

Please select one of the following options per role:
-Role PERFORMED by a GA/GCA that you feel is APPROPRIATE
-Role PERFORMED by a GA/GCA that you feel is NOT APPROPRIATE
-Role PERFORMED by a GA/GCA that you feel they have the POTENTIAL to perform
-Role NOT PERFORMED by a GA/GCA that you feel they DO NOT have the POTENTIAL to perform

a. Administrative tasks (e.g.,. scanning, copying, filing, organization, ordering supplies)
b. Data entry
c. Assisting with clinic flow (e.g.,. receiving patients)
d. Screening and tracking referrals
e. Scheduling patients for genetic visits and/or with other specialists
f. Liaison with other health professionals/agencies (e.g.,. gathering information, making referrals)

g. Case preparation (e.g.,. preparing chart, obtaining relevant medical records)
h. Obtaining and/or drawing family history/pedigree
i. Contacting patients for follow-up information
j. Offering genetic testing
k. Completing test requisition forms for genetic testing
l. Preparing letters of medical necessity/application forms for patient testing
m. Coordinating genetic test coverage (i.e., contacting insurance companies or relevant government agencies)
n. Shipping genetic testing (e.g.,. boxing samples)
o. Tracking genetic testing
p. Calling patients with negative gene test results
q. Calling patients with variants of uncertain clinical significance
r. Calling patients with abnormal results
s. Preparing results letters based on gene test results
t. Identifying and providing patient resources
u. Research activities (e.g.,. preparing ethics applications, assisting with data collection)
v. Other (please specify)

Section 5: Experience Working with Genetic Assistants
The following questions ask you to assess your work environment with and without a GA/GCA. If you have never worked without a GA/GCA, please hypothesize what the impact on your roles might be if you did not work with one.

How does working with a GA/GCA impact the number of roles and responsibilities that you have within the clinic/laboratory compared to working without one?

a. Reduces the number of roles and responsibilities
b. Increases the number of roles and responsibilities
c. Does not impact the number of roles and responsibilities
d. Unsure

(If a) Which roles and responsibilities do you have to perform when there is no GA/GCA on your team?
(If b) Which additional roles and responsibilities do you have to perform when working with a GA/GCA that you would not otherwise have to?

How does working with a GA/GCA impact your specific roles and responsibilities within the clinic?

a. I spend more time on tasks that I have specialized training for
b. I spend less time on tasks that I have specialized training for
c. No change to the amount of time spent on tasks that I have specialized training for
d. Unsure

(If a) Which tasks are you able to allocate more time for?
(If b) Which tasks do you allocate less time for?

If you work in a clinical setting: How does working with a GA/GCA impact clinic productivity/efficiency?

a. Genetics providers (physicians/counsellors) see more patients
b. Genetics providers (physicians/counsellors) see fewer patients
c. Genetics providers see same number of patients
d. Unsure

If you work in a laboratory setting: How does working with a GA/GCA impact laboratory productivity/efficiency?

a. Increased productivity in laboratory service provision
b. Reduced productivity in laboratory service provision
c. No change in productivity in laboratory service provision
d. Unsure

How would having more GAs/GCAs employed in your work setting impact productivity?

a. Increased productivity
b. Reduced productivity
c. No change in productivity
d. Unsure

The following information is only being collected to estimate the number of GA/GCA positions in Canada and the United States. This information will not be linked to any of your other survey responses. The name of the clinic/laboratory/site of employment at which you work(ed) will only be used to remove duplicate responses from the same centre and will not be reported in study findings.

Name of clinic/laboratory/site of employment

Number of GAs/GCAs employed at the above-named clinic/laboratory/site of employment

Would you be willing to participate in a follow-up interview to explore your experiences working with a GA/GCA?

If you are interested in participating, please contact Angela Krutish at _____ or _____. Interviews will be approximately 30 minutes in length and will be conducted either in the Winnipeg area (at a location of your choosing) or through video-conferencing.

Appendix 2. NSGC regions (National Society of Genetic Counselors, 2018a)

NSGC Region	Provinces and States	
1	Connecticut	Newfoundland and Labrador
	Massachusetts	Nova Scotia
	Maine	Prince Edward Island
	New Hampshire	Rhode Island
	New Brunswick	Vermont
2	District of Columbia	Quebec
	Delaware	Virginia
	Maryland	West Virginia
	New Jersey	Puerto Rico
	New York	Virgin Islands
	Pennsylvania	
3	Alabama	Mississippi
	Florida	North Carolina
	Georgia	South Carolina
	Kentucky	Tennessee
	Louisiana	
4	Arkansas	North Dakota
	Iowa	Nebraska
	Illinois	Ohio
	Indiana	Oklahoma
	Kansas	Ontario
	Michigan	South Dakota
	Minnesota	Wisconsin
	Missouri	
5	Alberta	New Mexico
	Arizona	Saskatchewan
	Colorado	Texas
	Manitoba	Utah
	Montana	Wyoming
6	Alaska	Idaho
	British Columbia	Nevada
	California	Oregon
	Hawaii	Washington

Appendix 3. Interview guide for GAs

I would like to start off by finding out more about your genetic assistant position.

- Are you currently working as a GA?
- How long have you worked/did you work as a GA?
- Was your GA position in a clinic or laboratory?
- Were you the first GA in that genetics service?
- Did you work alone or with other GAs?

Research Question	Key Concepts	Interview Questions
How does a GA impact others' roles and responsibilities within the clinic?	Portrayal of GA position	When you started your job as a GA, what was your understanding of the role? (General roles and responsibilities? Distinction between your role and others in the genetics service? Interactions with others in the genetics service?) Did this change as you worked in the clinic/laboratory? How?
	Roles/responsibilities	How did your position as a GA alter the roles and responsibilities of others in the genetics team? Were there any roles/responsibilities that you felt should have been reassigned (either from others to you, or from you to others)? (Recall specific example?)
	Patient interactions	Please describe the typical patient interactions that you engaged in (if any). (Types/setting? Indication? Role? Preparedness? Supervision/training? Satisfaction?) Did your direct interactions with patients change the roles and responsibilities of others in the genetics team, specifically their interactions/time spent interacting with patients?

How were you integrated into the genetics team?	Fit/integration/Culture	How did you fit into the genetics service? (Any problems/difficulty with integration?) Can you describe the workplace culture in the genetics service? In what ways did you interact with other members in the genetics service? How would you describe your working relationships with others in the genetics service? For example, how available were they to you? Did any team members serve as a mentor to you? What were the attitudes of other team members towards the GAs?
	Recognition/Value	How do you think your contributions are valued/recognized by others in the genetics service?
	Independence	Please describe your independence level as a GA. (Supervision? Assigned roles/responsibilities? Initiative? Preparedness? Training/supervision? Recognition? Satisfaction?)
	Job satisfaction/engagement	Overall, how satisfied and engaged were you with your position as a GA? What factors most strongly influenced your satisfaction/engagement level?
How would having GA as a long-term career impact the clinic?	Career path	Can you envision the GA position as a permanent/long-term career path? Why or why not? What barriers do you envision might prevent GAs from remaining in the position long-term?
	Evolution of professions of GAs and others in the clinic (professional evolution)	How would having long-term GAs impact the clinic/laboratory? Do you feel that having long-term/permanent GAs would change the professions of GCs/MDs/PhDs/administrative staff? In what ways?

- What advice would you give to someone starting out in this career path?
- Is there anything you would like to add about your experience working as a GA?

Appendix 4. Interview guide for individuals who work with GAs

I would like to start off by finding out more about your work with genetic assistants.

- How long have you worked in your current position?
- Do you currently work with GAs?
- Do/did you work with GAs in a clinic or laboratory?
- Were GAs already working in the genetics service when you started your position or were they later integrated into the program?
- Did you work with one single GA or multiple GAs at one time?
- Have you worked with more than one GA?

Research Question	Key Concepts	Interview Questions
How does having a GA impact clinical roles and responsibilities within the clinic/laboratory?	Portrayal of GA position	When you started your job as a ___/When GA(s) were first integrated in your workplace, what was your understanding of the role of a GA? (General roles and responsibilities? Distinction between their role and others in the genetics service? Interactions with others in the genetics service?) Did this change as you worked with GAs? How?
	Roles/responsibilities	How did having a GA alter your roles and responsibilities within the program? What about others' roles (GCs, MDs, admin staff)? Were there any roles/responsibilities that you felt should have been reassigned (either from the GAs to you/another staff, or from you/another staff to the GAs)? (Recall specific example?)
	Patient interactions	Please describe the typical patient interactions that GAs engaged in (if any). (Types/setting? Indication? Role? Preparedness?) Supervision/training?) Did the GAs' direct interactions with patients change the roles and responsibilities of others in the genetics team, specifically their interactions/time spent interacting with patients?

How were GAs integrated into the genetics team?	Fit/integration/Culture	How did the GA(s) fit into the genetics service? (Any problems/difficulty with integration?) Can you describe the workplace culture in the genetics service? In what ways did you interact with the GAs? How would you describe your working relationships with the GAs? For example, how available were you to them? Did you act as a mentor?
	Attitudes	What was your general attitude towards the GA(s)? What were other staff members' attitudes towards the GA(s)?
	Recognition/Value	How are the GAs' contributions valued/recognized by others in the genetics service?
	Independence	Please describe the independence level of the GA(s). (Supervision? Assigned roles/responsibilities? Initiative? Preparedness? Training/supervision? Recognition? Satisfaction?)
	Job satisfaction/engagement	How satisfied were you with the level of engagement/participation of the GA in the genetics team?
How would having GA as a long-term career impact the clinic?	Career path	Can you envision the GA position as a permanent/long-term career path? Why or why not? What barriers do you envision might prevent GAs from remaining in the position long-term?
	Evolution of professions of GAs and others in the clinic (professional evolution)	How would having long-term GAs impact the clinic/laboratory? Do you feel that having long-term/permanent GAs would change the professions of GCs/MDs/PhDs/administrative staff? In what ways?

- What advice would you give to those considering adding a GA to their genetics team?
- Is there anything you would like to add about your experience working with GA(s)?

Appendix 5. Work setting and specialty of GA positions, as reported by GA participants and participants who work with GAs

Position information	GAs n (%)	Work with GAs n (%)	p-value[a]
Work setting	**n=161**	**n=124**	
Public hospital/Medical facility	58 (36.0)	28 (22.6)	0.10
Private hospital/medical facility	20 (12.4)	21 (16.9)	
University medical facility	46 (28.6)	44 (35.5)	
Diagnostic laboratory (non-commercial)	6 (3.7)	1 (0.8)	
Diagnostic laboratory (commercial)	25 (15.5)	25 (20.2)	
Private practice	4 (2.5)	2 (1.6)	
Other[b]	2 (1.2)	3 (2.4)	
Specialty[c]	**n=158**	**n=120**	
Cancer	90 (56.9)	55 (45.8)	0.07
Pediatric genetics	52 (32.9)	35 (29.2)	0.50
Laboratory	38 (24.1)	29 (24.2)	0.98
Prenatal	33 (20.9)	26 (21.7)	0.87
Adult genetics	28 (17.7)	28 (23.3)	0.25
Metabolics	20 (12.7)	14 (11.7)	0.80
Neurogenetics	18 (11.4)	12 (10.0)	0.71
Cardiology	15 (9.5)	15 (12.5)	0.42
Other[d]	9 (5.7)	9 (7.5)	0.54

[a] The p-values for work setting and specialty were calculated using the following statistical tests, respectively: Fisher exact test and chi-square test.

[b] Other work settings reported by individuals who work with GAs were: a non-profit medical facility, a sperm/egg bank at a private company, and a government hospital system.

[c] Multiple responses were permitted (i.e., respondents could select all that applied), therefore totals do not equal 100%.

[d] Other specialties reported by individuals who work with GAs were: assisted reproductive technology, clinical genomics (i.e., whole-exome/whole-genome sequencing), pre-conception, and research.

Appendix 6. Individuals involved in training and supervision of GAs, as reported by GA participants and participants who work with GAs

Position[a]	GAs n (%)	Work with GAs n (%)	p-value[b]
Training	**n=140**	**n=104**	
GC	134 (95.7)	103 (99.0)	0.12
GA	86 (61.4)	77 (74.0)	0.04
Medical/clinical geneticist	59 (42.1)	49 (47.1)	0.44
Clinic manager	50 (35.7)	48 (46.2)	0.10
Coursework/modules	50 (35.7)	33 (31.7)	0.52
Lab/molecular geneticist	36 (25.7)	31 (29.8)	0.48
Laboratory manager	31 (22.1)	26 (25.0)	0.60
Other[c]	26 (18.6)	18 (17.3)	0.80
Supervision	**n=140**	**n=107**	
GC	132 (94.3)	101 (94.4)	0.97
GA	55 (39.3)	37 (34.6)	0.45
Medical/clinical geneticist	57 (40.7)	37 (34.6)	0.33
Clinic manager	45 (32.1)	43 (40.2)	0.19
Lab/molecular geneticist	26 (18.6)	10 (9.3)	0.04
Laboratory manager	24 (17.1)	19 (17.8)	0.90
Other[d]	15 (10.7)	10 (9.3)	0.72

[a] Multiple responses were permitted (i.e., respondents could select all that applied), therefore totals do not equal 100%.

[b] The p-values were calculated using chi-square tests.

[c] Other individuals who provided training to the GAs (as reported by individuals who work with GAs) included administrative staff, other physicians, human resources, supervisors, medical assistants, research staff, clinic coordinators, and other teams within the same organization.

[d] Other individuals who provided supervision to the GAs (as reported by individuals who work with GAs) included administrative staff, human resources, supervisors, and research staff.

Appendix 7. Primary sources of mentorship for GAs, as reported by GA participants and participants who work with GAs

Position	GAs n (%) n=148	Work with GAs n (%) n=112	p-value[a]
GC	99 (66.9)	86 (76.8)	
Another GA	32 (21.6)	15 (13.4)	
Medical/clinical geneticist	6 (4.1)	6 (5.4)	0.27
Clinic manager	6 (4.1)	4 (3.6)	
Other[b]	5 (3.4)	1 (0.9)	

[a] The p-value was calculated using Fisher's exact test.

[b] The response from the participant who works with GAs was no primary mentor (i.e., mentored by GCs, GAs, and geneticists equally).