

The experiences of laboratory, research, and industry-based genetic counsellors in South Africa – a qualitative study.

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**UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG**

A research report (in the format of a “submissible” paper) submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Medicine (Genetic Counselling) by Research and Coursework

Johannesburg, 2025

19 June 2025

RE: Research report submitted to the Faculty of Health Sciences, University of Witwatersrand, by Ms Reagan Chidrawi in partial fulfillment of the requirements for the degree of Master of Science in Medicine (Genetic Counselling)

Dear examiner,

Thank you for agreeing to examine the research report submitted by Ms Reagan Chidrawi (student number 2272705) entitled, "The experiences of laboratory, research, and industry-based genetic counsellors in South Africa – a qualitative study." This research report is being submitted by the candidate in the format of a "submissible" paper as per the Style Guide for Thesis, Dissertation and Research Report (updated March 2016) by the University of Witwatersrand Faculty of Health Sciences. This research report contributes 30% towards the final mark of the MSc (Med) Genetic Counselling for which the candidate is enrolled.

The candidate and her supervisors have chosen to submit the paper to the international journal of Genetic Counseling. The submissible paper below is therefore written according to the author guidelines outlined by the journal. These guidelines have been attached for reference in the appendices section of this document. The only deviation from these guidelines is that the manuscript has been presented as one complete document (including tables and figures) for ease of marking, rather than being submitted separately.

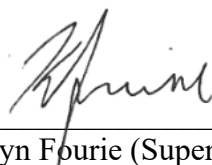
The research protocol has also been attached as an appendix for the purpose of providing an extended literature review and further contextualization of the study. The protocol has already been assessed and approved by the Faculty of Health Sciences Post-Graduate Assessors committee and is therefore not for examination.

Please refer to the Table of Contents for a complete list of the contents provided in this research report.

Yours sincerely,



Reagan Chidrawi (Candidate)



Katryn Fourie (Supervisor 1)



Monica Araujo (Supervisor 2)

Declaration

I, **Reagan Chidrawi**, declare that this Research Report (in the form of a “submissible format”), is my own, unaided work. It is being submitted for the degree of Master of Science in Medicine (Genetic Counselling) by Research and Coursework at the University of Witwatersrand, Johannesburg. It has not been submitted before to any other degree or examination at any other University.



Reagan Chidrawi

Student number: 2272705

19th day of June 2025 in Johannesburg

Contribution of Candidate

Student's contribution to the article(s) and agreement of co-author(s)

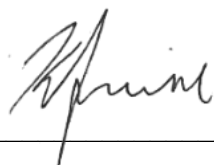
I, Reagan Chidrawi, student number 2272705, declare that this Research Report, entitled, “The experiences of laboratory, research, and industry-based genetic counsellors in South Africa – a qualitative study,” is my own work and that I contributed significantly towards the research findings presented in the paper intended for publication below.



Signature of Student

19/06/2025

Date



Signature of Supervisor 1

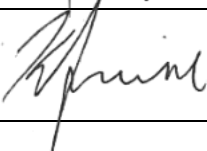


Signature of Supervisor 2

20.06.2025

Date

Agreement by co-authors: By signing this declaration, the co-authors listed below agree to the use of the article(s) by the student as part of her Research Report.

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Presentations arising from this research project

1. Faculty of Health Sciences Faculty Research Day, 5th September 2024 (oral presentation)
2. Genetic Counselling South Africa (GCSA) Research Showcase 2024, 21st November 2024 (virtual oral presentation)

Abstract

Having first emerged in the 1970s, genetic counselling is a relatively young profession in South Africa (SA). Historically, genetic counsellors (GCs) in SA have been employed through academic and public institutions, with only a few practicing privately. However, recently there has been a noticeable shift in the employment trends of genetic counsellors worldwide and in SA, transitioning away from traditional roles and gravitating toward non-traditional practice. It is, therefore becoming more common to find counsellors employed in laboratory, research, and industry settings. These roles typically involve far less direct patient care, redefining the role of a GC. Although this trend has been researched elsewhere, mainly in the United States of America (USA), it is yet to be explored locally. Therefore, this qualitative study aimed to explore the perspectives and experiences of non-traditional genetic counsellors (NTGCs) employed in laboratory, research, and industry-based settings in SA. Using semi-structured interviews, this research gathered data from qualified GCs employed outside of traditional practice. Reflexive thematic analysis revealed three themes: “No choice but to pivot”, concerning the scarcity of traditional job opportunities within the field in SA; “Quality of life,” which illustrates the high levels of job satisfaction reported by GCs in non-traditional roles; and “Professional identity,” reflecting the maintenance of a genetic counselling identity due to a transferable skillset, despite working in non-traditional roles. These findings offer new insights into an unexplored topic and offer an in-depth understanding of the NTGCs based in SA, their motivations that drive this trend, and the evolving professional landscape of genetic counselling in SA. They address the scarcity of traditional employment opportunities for qualified GCs, advocate for the integration of non-traditional role exposure into training and highlight the potential to guide workforce policies to address the employment gap.

Acknowledgements

I would like to express my gratitude to my supervisors for their invaluable support, guidance, and input into this project, from design to analysis. Your encouragement allowed me to delve into qualitative research, a field of research I have grown to appreciate and enjoy. Through this project, I had the privilege of interviewing genetic counsellors across the country, an experience that has contributed to my personal and professional growth. Thank you for your support and belief in my abilities throughout this process.

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List of abbreviations

GC – genetic counsellor

GCSA – Genetic Counsellors South Africa

HPCSA – Health Practitioners Council of South Africa

NHLS – National Health Laboratory Service

NSGC – National Society of Genetic Counselors

NTGC – non-traditional genetic counsellor

PSS – Professional Status Survey

SA – South Africa

USA – United States of America

Research report in the form of a “submitable” paper

To be submitted in the Journal of Genetic Counseling.

Research article

The experiences of laboratory, research, and industry-based genetic counsellors in South Africa – a qualitative study.

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Abstract for journal submission

Having first emerged in the 1970s, genetic counselling is a relatively young profession in South Africa (SA). Historically, genetic counsellors (GCs) in SA have been employed through academic and public health institutions, with only a few practicing in private healthcare. Recently there has been a noticeable shift in the employment trends of genetic counsellors worldwide and in SA, transitioning away from traditional roles and gravitating toward non-traditional practice. It is, therefore becoming more common to find counsellors employed in laboratory, research, and industry settings. These roles typically involve far less direct patient care, redefining the role of a GC. Although this trend has been researched elsewhere, mainly in the United States of America (USA), it is yet to be explored locally. Therefore, this qualitative study aimed to explore the perspectives and experiences of non-traditional genetic counsellors (NTGCs) employed in laboratory, research, and industry-based settings in SA. Using semi-structured interviews, this research gathered data from qualified GCs employed outside of traditional practice. Reflexive thematic analysis revealed three themes: “No choice but to pivot”, concerning the scarcity of traditional job opportunities within the field in SA; “Quality of life,” which illustrates the high levels of job satisfaction reported by GCs in non-traditional roles; and “Professional identity,” reflecting the maintenance of a genetic counselling identity due to a transferable skillset, despite working in non-traditional roles. These findings offer new insights into an unexplored topic and offer an in-depth understanding of the NTGCs based in SA, their motivations that drive this trend, and the evolving professional landscape of genetic counselling in SA. They address the scarcity of traditional employment opportunities for qualified GCs, advocate for the integration of non-traditional role exposure into training and highlight the potential to guide workforce policies to address the employment gap.

Keywords: non-traditional genetic counsellor, employment trends, laboratory, driving forces, professional identity

What is known about this topic

Genetic counsellors are not only fulfilling traditional roles but are employed in other sectors such as research, laboratories, and industry. This trend has been explored in the United States of America and Canada mainly, but lacks exploration in other parts of the world, such as South Africa, where it is similarly well established.

What this paper adds to the topic

This paper presents qualitative data on the lived experiences of genetic counsellors working in non-traditional fields in South Africa, such as laboratories, research, and industry. Although the trend is evident in the field, there is a lack of research into the perspectives and experiences of these professionals, which is crucial to understanding the motivations behind this career shift. This paper addresses that gap by taking an in-depth approach to explore and offer insights into the broader employment landscape for genetic counsellors in South Africa.

1. Introduction

Having first emerged in the 1970s, genetic counselling is a relatively young profession in South Africa (SA). Historically, genetic counsellors (GCs) in SA have been employed through academic and public health institutions, with a small number practising in private healthcare (Kromberg et al., 2013). However, in recent years, there has been a noticeable shift in the employment trends of GCs worldwide, including in SA, transitioning away from traditional roles and gravitating toward non-traditional practice (Cohen et al., 2017; Schwartz et al., 2023; Strohmeyer et al., 2023a; Waltman et al., 2016; Wessels et al., 2024). It is, therefore, becoming more common to find GCs employed in laboratory, research, and industry settings. Although this trend has been explored elsewhere, mainly in the United States of America (USA) and Canada, it is yet to be explored in SA. Therefore, there is a need to provide context to the local genetic counselling profession and the changing landscape of employment opportunities for GCs, focusing on the experiences of non-traditional genetic counsellors (NTGCs).

1.1. Employment trends

A traditional genetic counselling role involves patient-centred care, encompassing responsibilities such as pre- and post-test counselling, assessing family history for risk calculations, providing education on testing options, inheritance patterns, management options, and counselling to promote autonomy in making informed choices (Resta et al., 2006). These roles are typically performed within clinical settings, such as private and state hospitals. According to the 2024 National Society of Genetic Counsellors Professional Status Survey (NSGC; PSS), 56% of genetic counsellors in the USA work in a direct patient care position, defined as “a role that primarily involves counseling patients,” and categorised as a traditional role. These GCs also contribute to research, education and teaching, scientific writing, and program development. However, GCs are increasingly employed outside of traditional practice. As documented by the PSS, GCs in the USA work in laboratories, universities, biotechnology and pharmaceutical industries, non-profit organisations, and government. These roles performed within these areas are categorised as non-traditional practice, therefore they do not involve direct patient care and account for 26% of GCs’ roles in the USA. The remaining 16% possess mixed roles which combine elements of both traditional and non-traditional practice (National Society of Genetic Counselors, 2024).

1.2. The non-traditional genetic counsellor

Advancements in genomics, the growing accessibility of genetic testing, and the limited genetic proficiency among non-genetics professionals have broadened employment opportunities for GCs beyond traditional roles (Swanson et al., 2014). This shift has brought increased attention to the evolving roles of GCs in non-traditional practice, and due to the increasing number of GCs employed in laboratory and industry, these individuals were termed “NTGCs” (McWalter et al., 2018). Christian et al. (2012) first delineated these roles in Canada and the USA, which investigated laboratory GCs working in customer liaison, administration, result communication, report writing, and policy development. Follow-up studies have expanded on these roles, and found GCs involved in a range of duties, some of which include next generation sequencing analysis and result interpretation, variant interpretation, and research grant writing (Cohen et al., 2017; Field et al., 2016; Swanson et al., 2014; Waltman et al., 2016).

1.3. Experiences of non-traditional genetic counsellors

Having outlined NTGCs’ roles and responsibilities, their experience in and perspectives of non-traditional roles have been further investigated in the USA (Cohen & Tucker, 2018; Schwartz et al., 2023; Strohmeyer et al., 2023). This included factors driving GCs out of traditional practice, how prepared they felt going into a non-traditional role, their professional identity, and their job satisfaction. Leaving the traditional field was previously stigmatised as “moving to the dark side” in the USA – a narrative shared amongst GCs in traditional practice (McWalter et al., 2018). Consequently, GCs hesitated to leave traditional practice due to negative stereotypes, including the belief that they were driven by money, not considered “pure”, and did not have “real jobs” (Schwartz et al., 2023), impacting their professional identity. Despite this, GCs have left traditional practice due to high workloads and feeling undervalued, wanting to pursue personal growth opportunities, better-earning potential, and the chance to learn new skills (Cohen & Tucker, 2018; Field et al., 2016; Rabideau et al., 2016). Among those who still work in traditional roles, 33% said they think about leaving their jobs at least once a month. This was associated with working in a hospital (clinical) environment that involves direct patient care (Cohen et al., 2017). Most NTGCs have felt underprepared for their non-traditional role, due to a drastic shift in duties and the technical nature of the work, saying that more exposure to these opportunities in their training would have been beneficial to prepare them. (Field et al., 2016; Schwartz et al., 2023; Strohmeyer et al., 2023a). However, they note that their flexibility and the adaptability facilitated an easy transition and there is recognition that skills learnt in genetic counselling training serve as an asset for this transition (Schwartz et al.,

2023). With this, NTGCs had high job satisfaction, with reasonable and flexible work hours contributing to this, as well as opportunities for growth (Cohen et al., 2017; Field et al., 2016).

1.4. The landscape of genetic counselling in South Africa

Although extensive literature explores the experiences of GCs in non-traditional practice internationally, there is a paucity of literature in SA. The genetic counselling profession was established over 35 years ago in SA and is regarded as a niche field, with only 56 GCs registered with the Health Practitioners Council of South Africa (HPCSA) from 1995 to April 2024, according to a recent audit (Gomes et al., 2024). Becoming a GC in SA requires a minimum of seven years of training. This pathway includes a relevant four-year Honours undergraduate degree, followed by a Master's (MSc) in Genetic Counselling. The Master's is accompanied by a mandatory 24-month internship accredited by the HPCSA, designed to provide sufficient clinical exposure to qualify as a GC (Wessels et al., 2024).

Of the 56 registered GCs, 46 are actively registered – with 28 (61%) GCs practising in the country and the remaining 39% having emigrated. Of those practising locally, 18 work in the private sector and ten in the public sector. In the public sector, GCs fulfil traditional roles and are employed by universities including the University of Witwatersrand and the University of Cape Town, as well as the Department of Health and the National Health Laboratory Service (NHLS). Genetic counsellors often hold joint appointments across institutions, and attend various genetic clinics weekly, including cancer, prenatal, and general clinics (Kromberg et al., 2013). Additionally, GCs employed in the public sector are involved in teaching, training, and supervising students, as well as part-time research and genetic testing analyses. In the private sector, traditional GCs run their own practice and usually collaborate with one or two specialists from who they obtain referrals. These roles remain largely patient-facing unless they hold a mixed role.

It is known that NTGCs in SA are employed by research programs or commercial laboratories that offer genetic testing, with the first laboratory GC employed by a private laboratory in 2013 (Wessels et al., 2024). The Genetic Counsellors South Africa (GCSA) group keeps a record of all GCs and their employment, and according to the GCSA secretary, there are currently 12 GCs that fit the definition of a NTGC (M. Duvenhage, GCSA secretary, personal communication, 2024). Some possess mixed roles that involve both traditional and non-

traditional practice, which constitutes private genetic counselling services (Wessels et al., 2024).

1.5. Relevance of this study

Our understanding of the NTGC remains based on global studies, emphasising the need for local investigation. Without comprehensive research on the topic, the parallels between the experiences of NTGCs in SA and those globally remain uncertain. Therefore, the aim of this study was to explore the perspectives and experiences of NTGCs counsellors in SA, to establish the landscape of the genetic counselling profession in SA and the employment opportunities available within the country.

2. Methods

2.1. Design

This study employed a qualitative research design which is well-suited for exploring the nuanced perspectives and lived experiences of NTGCs, offering depth and context to achieve the study's aim (Patton, 2002). A phenomenological approach was chosen as this is an unexplored area of research in SA, offering comprehensive insight into the profession. Reflexive thematic analysis was selected for its flexibility and effectiveness in capturing the perspectives of NTGCs (Braun et al., 2023). Research ethics approval was granted by the University of Witwatersrand Human Research Ethics Committee (Medical) M240611 MED24-04-566.

2.2. Recruitment

Non-traditional practice, as adapted from definitions in previous studies, was defined as employment outside of clinical settings such as state and private hospitals. Eligible participants were over the age of 18, proficient in English, held a Master's degree in Genetic Counselling, registered with the HPCSA, and, at the time of the interview, were employed for at least six months in a non-traditional role (laboratory, research, industry), spending over 50% of their time in this role if mixed. Those with less than six months experience may not have had sufficient time to gain relevant experience and provide valuable insights. Genetic counselling interns and HPCSA-registered counsellors who currently practise abroad were not included in this study. Participants were recruited using purposive sampling via the Genetic Counsellors of SA (GCSA) listserv, as HPCSA-registered genetic counsellors are affiliated with this group. Invitations to participate included an overview of the study and a Google Forms link to provide

the participants' contact information. Thereafter, eligible participants were contacted privately via email by the first author (RC), and interviews were subsequently scheduled.

2.3. Data collection

The first author, a genetic counselling student, conducted 9 individual, semi-structured interviews with participants. This method of interviewing was chosen to allow participants to speak freely and for unexpected themes to emerge. An interview guide was developed by the first author based on relevant literature that explored similar topics and areas of interest (Christian et al., 2012; Field et al., 2016; Schwartz et al., 2023; Strohmeyer et al., 2023). It was comprised of eight open-ended questions with follow-up prompts regarding topics such as job description, leaving a traditional role, preparedness, experience in the field, and reflection on a traditional role (Appendix A). One pilot interview was conducted with a registered GC at the National Health Laboratory Service to test the guide and develop interview skills. Interviews were conducted either in-person or virtually via Zoom, with the average interview length being 40 minutes (Table 1). Interviews were recorded on two devices (one being Zoom if virtual) and verbal and written consent was obtained at the start of each interview. While the nine participants did not represent the entire group who met the inclusion criteria, the sample was considered sufficient to gain meaningful insight into the phenomenon, particularly given the small population of GCs in SA. Data saturation was reached across key themes (Marshall, 1996).

2.4. Analysis

Automated interview recordings generated from Zoom were cross-checked against the first author's audio recording, and transcribed verbatim on Microsoft Word. All identifying data was removed or anonymised to ensure participant confidentiality. Reflexive thematic analysis was conducted according to guidelines from Click or tap here to enter text.. An inductive coding strategy was chosen to allow themes to emerge directly from the data and to ensure the analysis remained grounded in participants' experiences, allowing the data to guide the development of findings Braun et al. (2023). To ensure validity, all three authors independently coded the first two interviews. Through a collaborative effort, the authors generated a code book which was used by the first author to code subsequent transcripts. Any new codes that emerged during this process were added to the codebook following discussion with the authors. Using the percentage-based method, intercoder reliability of 75% was achieved. This is a numerical measurement of the consistency or agreement between coders, and is used to assess the

reliability of the analysis, with percentage agreement being an adequate method (O'Connor & Joffe, 2020). Three main themes were identified, redefined and finalised throughout the process and continuous group discussions were held between the researcher and supervisors to crosscheck themes. Bias bracketing was practiced throughout the analysis process to minimise the influence of pre-existing assumptions. This was done by the first through regular reflexive journalling and discussions between the authors, allowing for ongoing reflection on potential biases.

2.5. Positionality statement

The first author is a white female genetic counselling student at the University of Witwatersrand, with academic and clinical exposure to the genetic counselling landscape in SA. The second and third authors are qualified female GCs employed by the NHLS, bringing professional experiences from public and private practice. All authors remained aware of their professional lenses and engaged in ongoing reflection to ensure that findings remained grounded in the participants' narratives.

3. Results

3.1. Participant demographics and employment information

For this study, the terms 'industry' and 'laboratory' are used interchangeably, with industry being the umbrella term. Going forward, the term 'laboratory' will be used to encompass both. In total, nine participants with either mixed or exclusively non-traditional roles were interviewed during this study and had an average of approximately 4 years' total experience in non-traditional practice (Table 1). This study represents 75% (9/12) of GCs outside of traditional roles in SA, and matches, if not exceeds, the sample size of other studies (Cohen & Tucker, 2018; Schwartz et al., 2023; Waltman et al., 2016), strengthening the value of the insights generated.

Table 1: Participant demographics and interview information.

Category	Number of participants (N=) or mean (range)
Total number of participants	9
Type of interview	
In person	1
Online via Zoom	8
Average interview length	40min 52s (24min 04s - 60min 04s)
Type of role	
Exclusively non-traditional	4
Research	3
Laboratory and industry	1
Mixed	5
Research	2
Laboratory and industry	3
Average experience in non-traditional role (years)	4 years 3 months (10 months – 9 years 4 months)

*Due to the small sample size, descriptive statistics are reported as mean and range to provide clearer representation of the dataset. Furthermore, demographic data has been intentionally limited to protect participant anonymity, given the small, highly interconnected group of GCs in SA.

The duties of GCs in exclusively research and laboratory settings are summarised below (Table 2). Those who have a mixed role reported spending approximately 30% of their time doing traditional genetic counselling in private practice, which entailed risk assessment, counselling, and admin-related work after each consultation. This included writing letters and motivations to medical aids, billing, and writing appropriate referral letters. In private practice, GCs are not employed by private hospitals as such, but rather own their own practices and consult with specialists in private healthcare settings (Wessels et al., 2024).

Table 2: Non-traditional genetic counsellors' roles and responsibilities in research and laboratory-based positions.

Employment setting	Research	Laboratory and industry
Roles and responsibilities	• Recruitment • Pre- and post-test counselling • Supervision • Data keeping and collection • Community engagement • Research projects • Variant interpretation • Writing research reports	• Gatekeeping of test requests • Advising on availability of tests • Advising clinicians on test selection • Writing content for company websites • Explanation of results

*Based on data obtained through individual participant interviews.

In this study we opted to use the word ‘non-traditional’ rather than ‘non-clinical’ to describe GCs in these environments, as many non-traditional roles may still be perceived as clinical in nature, despite not being patient facing. However, participants use the words ‘traditional’ and ‘clinical’, as well as ‘non-traditional’ and ‘non-clinical’ interchangeably. Therefore, these terms are considered synonymous and should be interpreted as such.

3.2. Themes

The data is summarised by three main themes: “No choice but to pivot,” “Quality of life,” and “Professional identity,” which are discussed in detail below.

Theme 1: No choice but to pivot

This theme relates to participants’ motivation for leaving a traditional role. Limited job availability in traditional settings has been the main driver of this trend, as all newly qualified GCs had to find alternative work after their internship. This reality for GCs is expressed by participants who said:

“There weren't like particular posts that were advertised that I could be like, ‘Okay I'm making a choice now between being employed as a medical scientist or as a genetic counsellor’ – there weren't any posts.” – P7

“There's such limited genetic counselling positions in the whole of South Africa, that [position] seemed to be the next step for me, and so I think it's almost forced, but yeah, I think it's basically forced and not necessarily planned or unplanned. It's forced.” – P2

Given the ‘forced’ nature of the transition, participants were asked how prepared they initially felt going into a non-traditional role. Their feelings were based on their internship exposure; those with relevant experience felt more equipped and applied that knowledge in their current role. For instance, participants working in research had prior involvement in either the same or similar projects, easing their transition compared to those without. Some upskilled themselves by taking courses in variant interpretation. Others felt unprepared, needing to learn new systems and figure out work dynamics, which highlights acclimatising to a new role – something that anyone might feel unprepared for. However, many participants noted that their genetic counselling internship taught them how manage high workloads and stress effectively. Given that many newly qualified GCs enter non-traditional roles directly, it is important to evaluate whether the internship sufficiently prepares them for these roles. Participants’ preparedness is shown by the quotes below:

“I felt very prepared and very equipped, and there's so many aspects that are required that I feel I completely fit in, and there's a need that I find myself being able to fill that gap.” – P3

“Not even remotely [prepared], not at all. But it's fine, you learn as you go. So the first few weeks were like, quite intense like, it's a sharp learning curve.” – P5

“[It was] the internship training, I think, who really gave me the upper hand in the sense that I could manage a lot of stress.” – P4

Additionally, some participants noted uncertainty about the expectations of their role, as both they and their employer were unclear about what their position entailed. While these organisations recognised that GCs could add value to the team, they had a limited understanding of exactly what that value was and, hence what their job description was. This was reflected by the following quotes:

“I think in the beginning I struggled because there isn't like a lecture on how to be a Research Genetic Counsellor.” – P1

“They hadn't had a genetic counsellor before, nobody really knew what to expect or what the role should look like or I started without a job description as an example, because they didn't know.” – P8

Although stepping into a non-traditional role initially brought feelings of unpreparedness and anxiety, all participants described how specific skills acquired in their genetic counselling training have greatly enabled them to adapt. Participants mentioned active listening and effective communication as skills that have been essential in their role and, in fact advantageous. They raised the importance of simplifying complex genetic information for diverse audiences; patients, laboratory scientists and technicians, and referring clinicians. They further expressed that these skills have set them apart from non-genetic specialists and could not imagine another individual fulfilling their role.

“You have to identify certain mechanisms that people use during communication, and also, like, pick up a lot about the person and how best you can help them in their situation so that they make informed decisions. So, you also have to be like managing the anxiety, managing the uncertainties that come with all this, and the genetic counselling skills come in very handy at that point” – P3

“You're speaking with patients to really listen, to hear what are they saying, not just the words that they're using, but you know, body language, all of the other things that go along with that and then being able to simplify things because sometimes things can just be overcomplicated from a lab perspective.” – P8

Overall, this theme speaks to the forced nature of the movement of GCs into non-traditional practice given a lack of job availability in clinical settings. However, GCs voiced their appreciation for their genetic counselling training that enabled them to adapt quickly to their role, which they perceived to be advantageous when compared to other professionals.

Theme 2: Quality of life

This theme explores participants' overall well-being in their non-traditional role, reflected by their level of job satisfaction and opportunities for professional and intellectual growth.

Most participants noted that they experienced a shift in work stress when moving into a non-traditional role, related to a change in work dynamics. Traditional roles were described as high-stress environments and subsequently, they felt less stressed and “calmer” in a non-traditional environment, where stress is “manageable”. However, some participants explained the stress in non-traditional roles – particularly private laboratories – was more related to logistical pressures and the demanding nature of managing critical samples. The shift in responsibilities and associated stressors were raised by the following participants:

“Research is not as high paced as the clinical space and so there was time to learn a lot of things.” – P2

“I think every workplace essentially would cause, you know, like these different stresses. But I do feel, that I have more time for myself now as an individual which I really appreciate...It's calmer...Different stresses, but yeah, a little bit less frantic.” – P4

“It's different stress. I was gonna say it's less stressful, but I think it's a different stress, because of all the things I'm trying to do at the same time.” – P5

Flexibility was an aspect of a non-traditional role that was raised by participants and contributed to their job satisfaction. This was particularly evident in those who worked in a mixed role, who could control their schedules in private practice, those who worked part time in laboratories, and those who worked independently in research. This aspect was of high importance for those who were parents and had children, being able to do the “school run” and watch sports games. For others, the flexibility meant running their own schedule in research and the laboratory, and managing their own time, something that would not be as easily possible in a traditional setting. Participants’ flexibility is depicted by the quotes below:

“I'm a mom. I've got young kids, so being able to have that work-life balance, and for me to be able to organise that myself, rather than working for someone who's telling me I need to be here during these hours. And you know, I think to have that flexibility is nice, and the research as well again, that you work very much independently. So you have a lot of flexibility.” – P6

“What this role has allowed me, which I sometimes overlook until I am reminded by colleagues that are in different roles and positions, is it allows me flexibility, which I think goes a very long way at different points in your life.” – P8

A challenge that most participants who had a mixed role expressed was that managing this can get overwhelming and hamper their quality of life as they have less time for themselves. Participants' feelings are shown by the quotes below:

“So there's a lot of sacrifice that comes into doing all of these things, but I think that's just purely because I have now these two things that I have to juggle and like, I said, they're very intensive if you just have...if it was just the research job I had, it would have been much easier of a life, I guess, when it comes down to personal kind of quality of life.” – P9

“I think having the luxury of being able to do both is has really been beneficial, and I'm very grateful for that. But I would say, juggling both is hard – finding that balance. For example, my research day that I've dedicated to doing research and university-based work, there'll always be moments where you get a phone call because there's a clinic emergency, or an email will pop in with results that urgently need to be delivered. So separating it and kind of keeping it in two different separate boxes is quite hard on a day-to-day basis.” – P6

Those with a mixed role felt this fulfilled both sides to them and gave them the balance of both traditional and non-traditional genetic counselling. This is demonstrated by the quotes below:

“I think I have a love for both [research and traditional genetic counselling], but I also think that both areas really complement each other. I think having the luxury of being able to do both is has really been beneficial, and I'm very grateful for that. The research now I think you know I'm kind of doing it because I'm passionate about it, and I enjoy it.” – P6

“I think that for a lot of us, and I know for me, like you become a genetic counsellor because you want to talk to people, and then you go into a lab and you're not seeing patients...So you're sitting behind a desk and behind a computer which is not really the kind of profession that you wanted to be in, so I think that's why I see patients privately.” – P5

“I’m very, very happy to have this, because I feel like if it was only the research position it would become, become a bit too much for me, I think, because it doesn’t have necessarily as much of that patient interaction on a regular basis, or as much of the core roots of what a genetic counsellor would do.” – P9

In contrast, participants who did not have a mixed role longed for patient interaction, an element described as “missing” from their current job. This is shown by the following quotes:

“I think the only thing that makes it a less enjoyable role is the decrease in patient contact, which is something that I would prefer to have.” – P2

“Now for the position that I’m in, I can see the result, for example, or I can deliver it to who it needs to go to, but I don’t see how it is conveyed, or how it is delivered to a patient. So it’s good that you know that there is an end in the job aspect of, I did my job, but that ending point of delivering or explaining results is lacking, I must say.” – P4

Some participants also raised the issue of financial instability and inadequate pay for GCs in the country. This is shown by the following quotes:

“So I definitely enjoy all of those different things and the only thing that I would say kind of hampers that a little bit is the financial aspect of it.” – P7

“I think that the pay is really poor. I don’t think that they pay genetic counsellors well all round – [in] the labs, [and in] universities.” – P5

However, participant 2 had a different perspective, and explained:

“However, I think I do realise that with the stress levels that come with the job, so does the pay. And so obviously, that is something that I am, I want to say, missing out on in my role, but I am not sure that that is the worst thing to happen, is that I think I am willing to lose out on that money and have a better quality of life.” – P2

Participants noted that opportunities for professional growth enhanced their job satisfaction and quality of life. This is demonstrated by the following quotes:

“It's just satisfying for me whether [I'm] doing it as a researcher or as a counsellor but the fact that I can communicate and educate and help people to understand and make choices, you know, and raise awareness, and all of that about such an important field.” – P3

“I'm always acquiring new skills, doing courses that I never would have done if I only had my role in genetic counselling. So that's the rewarding part for me is always like learning new things, and meeting new people in different spaces, and kind of trying to bring those things like seeing where they can meet each other halfway.” – P7

Although participants enjoyed their non-traditional role and saw opportunities for growth, some still desire to work in a traditional setting, under specific conditions. For some, they would consider moving into a traditional setting if the work was purely clinical genetic counselling. Others aimed to own a private practice and described their current job as an intermediary step for this. Some felt content with their mixed role and what it offered for them. Others felt they were meeting a need and were not considering moving into a traditional role completely. These varying perspectives are shown below:

“I think I'm not opposed to it. I think I'm more inclined to it. However, I think just strictly clinical is something that I want, and not a mixture of this and that...I'm not sure how the rest of the genetic counselling profession feels, but I think if there were more clinical genetic counselling vacancies or positions to hold, I think there'd be a lot more people within those roles.” – P2

“Well based on where I am at right now, based on that, I feel more happier in in what, in the setting in the setting that I am now, I feel like I would rather continue contributing in the community engagement work, you know, in the sense of being the centre of community of communities and engaging people in terms of research and education focus groups, raising awareness.” – P3

Expanding on this decision, some participants would consider moving into a purely traditional role as they feel the description of a “traditional GC” in South Africa is changing and shared advice for newly qualifying GCs. This is demonstrated by the following quotes:

“I think even the traditional roles are expanding so I definitely would consider moving into the clinical sort of traditional role, because I think in the future, even in the new future, it's not going to look the same as it looks. Now, I think that transition is slowly happening... And whatever I'm doing now will definitely, I think, be applicable and add value to any future clinical role that I might undertake.” – P7

“I suppose a lesson going forward for other genetic counsellors who are just qualifying that like, don't close yourself off to other areas in terms of our skill set and what we can do.” – P6

This theme reflects the high levels of job satisfaction that NTGCs have in their role, primarily driven by flexibility and personal time. However, all participants who possessed exclusively non-traditional roles expressed a strong desire to work in a clinical setting if given the opportunity. In contrast, participants with mixed roles highly valued both traditional and non-traditional aspects to their role, despite the challenges of balancing both.

Theme 3: Professional identity

This theme evaluates how participants perceive and define their identity in non-traditional environments. Terms such as, “medical scientist”, “genetic application specialist”, “laboratory genetic counsellor”, “research associate”, “research genetic counsellor”, and “research coordinator” were used to describe their job title in their non-traditional role. However, participants expressed that they inherently view themselves as GCs, which was important to them, and therefore these titles did not reflect their sense of self. For example, some participants described their job title as merely a label that the laboratory provides to characterise their scope of practice, a way to determine their compensation, and reflects a lack of clinical work. All participants expressed that the deviation between these job titles and their sense of self was largely due to organisational structure and does not define how they view themselves as GCs. Participants voiced:

“I think a genetic counsellor maybe intrinsically implies that you do clinical service, which I do not do so I think when I have to talk with the doctors or when someone calls me, I still introduce myself as I am the genetic counsellor working at [company].” – P4

“Yes, absolutely so, definitely as a genetic counsellor, and I think there would be few other health professionals that could fulfil that role because I rely very heavily on my genetic counselling training and skills and knowledge.” – P8

“I don't like seeing myself as a research coordinator as such. I like seeing myself as a genetic counsellor, because that's what I want to be... If you are a genetic counsellor, you don't want to necessarily, or I don't want to necessarily be just something else.” – P9

Although not extensively explored in this study and not a general feeling shared amongst participants, one participant shared their perception amongst colleagues. This was due to a shift in roles and responsibilities in a non-traditional space, for example a reduction in patient-facing duties and a change in work schedules. Participant 1 shared:

“I identified as a genetic counsellor, but there were instances where I was probably like made to feel like I'm not a genetic counsellor, and I think, ‘cause I worked closely with my with genetic counsellors that were purely clinical.” – P1

A key concept that arose from participants was the broad professional identity of GCs in South Africa. Some participants described this identity as “wearing different hats,” inherently shaped by their role as generalists. Participants expressed:

“At this point all of us are super generalists. Jumping from a mTOP to a cancer patient every day.” – P4

“So a Jack of all trades, really in terms of which I think most of us are as genetic counsellors.” – P6

Participants also felt a constant sense of duty to the profession, advocating for the role of GCs in healthcare. They emphasised the importance of their role, stating that “we matter and what we do matters,” highlighting their ongoing struggle with the government and other healthcare professionals to secure recognition, placements, and adequate pay. Participants noted:

“It's like this two-edged sword, because on the one hand, we know that there is a lack or scarcity of genetic counsellors, but, on the other hand, no one's making use of us.” – P7

“I just don't think we're valued.” – P5

“Getting others to see the value of genetic counselling – it's rewarding but it's draining too.”

– P6

This theme highlights how participants feel a strong sense of identity as GCs despite working in non-traditional fields and holding job titles that differ from that of a traditional GC. These terms are described as merely labels provided by employers, but it is important for them to still feel and be known as a GC. Overall, this theme represents the challenges GCs face with their identity in non-traditional roles.

4. Discussion

The growing availability and accessibility of genomic testing has created expanded opportunities for GCs worldwide, broadening their expertise beyond traditional roles (Swanson et al., 2014). It is therefore becoming more common to find GCs employed in research, laboratory, and industry settings. While this trend has been explored for approximately 12 years in the USA and Canada (Christian et al., 2012; Field et al., 2016; Schwartz et al., 2023), there is a lack of data in SA, albeit an observable trend of GCs employed in non-traditional roles (Gomes et al., 2024; Wessels et al., 2024). Therefore, this research provides context to this shift by exploring the perspectives and experiences of NTGCs in SA, through semi-structured interviews and reflexive thematic analysis. Our study provides an important perspective on the genetic counselling profession in SA by including the perspectives of NTGCs, highlighting the distinct differences of this trend between countries where data is available.

In SA, NTGCs are either employed by research programs, or private laboratories that offer genetic testing (Wessels et al., 2024). While most of the NTGCs in other studies have full-time positions in non-traditional practice (Cohen et al., 2017; Field et al., 2016; Schwartz et al., 2023; Strohmeyer et al., 2023b), our study revealed that around half of the NTGCs interviewed have mixed roles rather than exclusive ones, maintaining traditional genetic counselling in their own private practice, reflecting the unique landscape of genetic counselling in SA.

In the USA and Canada, GCs have moved out of traditional settings due to a variety of factors. These include seizing the right opportunity at the right time, feeling ready for change, and seeking to expand their knowledge and skills (Field et al., 2016), as well as pursuing better

salaries and benefits, addressing feelings of underappreciation, and handling challenging work environments (Cohen & Tucker, 2018). Additionally, GCs have moved to explore new opportunities for growth and be involved in start-up business ventures (Rabideau et al., 2016), as well as expand their skillset in a clinical setting but subsequently found themselves in other areas such as research and sales (Davis et al., 2020). These findings illustrate how GCs in the USA have often made planned, intentional choices to move into non-traditional roles, driven by active job-seeking and the availability of desirable job opportunities.

In contrast, our study revealed a starkly different scenario in SA, as none of the NTGCs interviewed reported moving into non-traditional roles by choice or serendipity. Instead, they felt ‘forced’ into these roles due to the persistent lack of traditional job availability in a clinical setting. This is because the implementation of genetic counselling in SA remains limited. With only 28 practicing GCs in SA, the country operates at 5% capacity: 2% in the public sector and 24% in the private sector (Gomes et al., 2024). With that, no new traditional genetic counselling positions have been created in government health departments i.e. the public sector since 2000 (Wessels et al., 2024). Additionally, the 2030 Human Resources for Health Strategy does not include provisions for expanding genetic counselling capacity (Gomes et al., 2024). Therefore, GCs who want to practice traditionally must wait for a post to be vacated, and even then, it is often frozen or terminated. As a result, GCs often seek employment in private healthcare where they start their own practices when feasible, or they move abroad. Since 1995, 62% of the total qualified GCs in SA have emigrated and are practising abroad (Gomes et al., 2024).

Nonetheless, NTGCs reported high levels of job satisfaction, with key contributors being a change in work dynamics and subsequent decreased stress levels, flexibility, and the ability to integrate traditional and non-traditional genetic counselling in a mixed role. They experienced a shift in work-related stress when moving into a non-traditional role, as traditional roles were described as fast-paced, high-stress environments, particularly in the state healthcare system due to the number of activities one is expected to perform. For instance, preparing for multiple genetic clinics within one week and the subsequent administrative tasks that follow, lecturing and supervising students, attending several weekly clinical meetings, and coordinating genetic counselling training courses. Hence, NTGCs felt calmer, with more time for themselves to develop personally. In laboratories, NTGCs explained their stress to be more logistics related. For example, dealing with the demanding nature of couriering precious chorionic villus samples as soon as possible, ensuring the correct sample is delivered to the correct laboratory,

and constantly keeping up to date with the available tests. Overall, GCs described this shift in stress and calmer environment to contribute positively to their quality of life. For those in mixed roles, while their passion for traditional work remains strong, they highlight significant professional growth enabled by their non-traditional role. They described being able to build their skills, take new courses, and gain exposure to technologies and sequencing – opportunities often limited in a traditional environment. Therefore, they feel their non-traditional role has expanded their professional career.

However, NTGCs also identified challenges that negatively impact their job satisfaction and overall quality of life, which included decreased patient contact, balancing a mixed role, and financial instability. One common aspect between our study and those globally is that patient contact or the lack thereof was not a deciding factor as to whether GCs wanted to move into non-traditional roles and is often reported as one of the factors that is least liked about their non-traditional job (Christian et al., 2012; Cohen et al., 2017; Field et al., 2016). Patient care ranked as one of the three best attributes of traditional jobs (Christian et al., 2012), and was similarly valued by NTGCs in SA, who felt the lack of patient care made their role less rewarding. Many expressed pursuing genetic counselling to talk and engage with people, only to find themselves in an opposite work environment. For instance, some wished to be involved in delivering test results and not just explaining them to clinicians, and hence most desire to move back into a traditional role. The setting of this, however, impacted their decision, as most NTGCs wanted to focus solely traditional genetic counselling, and did not want additional tasks, such as teaching and research, which are typically expected in traditional (i.e. public sector) roles in SA. In contrast, roles in the private sector generally do not require these additional duties. This speaks to the broad identity of GCs in SA, varying between state and private healthcare, largely due to the duties one is expected to perform. Subsequently, private practice often becomes the only avenue to maintain a connection to traditional genetic counselling. This explains why over half the NTGCs in this study possess mixed roles, initially entering non-traditional practice out of necessity and later incorporating traditional practice into their careers. Overall, while NTGCs have high job satisfaction, their desire to work in traditional settings is unsurprising, as many were forced into non-traditional roles without the opportunity to pursue traditional work after completing their internship.

Given the ‘forced’ nature of the transition, participants’ preparedness for a non-traditional role varied, with their training providing the foundation for it. In SA, the Master’s in Genetic

Counselling curriculum comprises medical genetics, practices, and principles of genetic counselling (<https://www.wits.ac.za>; <https://www.uct.ac.za>). Thus, while variant interpretation and laboratory tutorials, for example, are included in the training, the syllabus focuses strongly on counselling skills rather than non-traditional role exposure (Wessels et al., 2024). Therefore, NTGCs did not feel prepared for their role initially given the lack of direct patient care of the role, new systems, and different work dynamics. This included, for example, the various tests that are offered in private are more diverse than those in the state healthcare system and so they needed to expand their knowledge. However, there is recognition of some exposure to these duties in training, contributing to their preparedness and mainly having to deal with new dynamics in their non-traditional role. Despite this, many participants expressed confidence in their unique skillset, believing that their training equipped them with strengths – such as communication, critical thinking, and empathy – that made them particularly well-suited to these positions. In other studies, this feeling of unpreparedness appeared to be more prevalent as GCs have noted their Master’s in Genetic/Genomic Counseling did not prepare them for a non-traditional role, needing assistance with variant interpretation, genetic testing concepts, test proficiency, and business-related managerial skills (Field et al., 2016; Schwartz et al., 2023; Strohmeyer et al., 2023b). They further emphasised that increased exposure to these roles during their training would have been helpful and felt that courses such as ‘Business 101’ and ‘A crash guide for switching from clinical to lab/industry’ would have better prepared them (Strohmeyer et al., 2023). As with our findings and those from Zetzsche et al. (2014), some NTGCs in our study felt uncertain about what was expected of them in their non-traditional role, as did the organisation, highlighting a need for a defined role establishment in non-traditional practice.

Despite this, one of the key advantages highlighted by NTGCs was their effective communication skills and active listening. This was particularly evident in tasks such as ensuring informed consent and autonomy during recruitment for research projects, efficiently gatekeeping test requests, and explaining complex results at commercial laboratories. This transferable skillset enables NTGCs to make a great interface between the laboratory, patients, and employees, enabling effective team dynamics in non-traditional roles broadly. This skill set is not unique to South African NTGCs but a hallmark of those worldwide. Previous studies also identified communication as a key skill, with NTGCs describing the quality that “sets us apart” (Christian et al., 2012; Cohen et al., 2017; Davis et al., 2020; Schwartz et al., 2023). Their communication, active listening, understanding, empathy, flexibility, and adaptability

forms a skillset that facilitates an easy transition into non-traditional roles initially, but also makes them valuable team members in non-traditional settings.

Our study highlighted that NTGCs in SA maintain a significant connection to their GC identity in non-traditional roles, despite being forced into their role and holding alternative job titles, as well as acknowledging a lack of direct patient care. Further, NTGCs find it unimaginable for another professional to fulfil their role, given their utilisation of valuable skills acquired in genetic counselling training. In previous American-based studies, while 95% of GCs also maintain their identity in a non-traditional role, the remainder do not for various reasons. Among these, some GCs felt the title “genetic counsellor” to be misleading, as they are not involved in direct patient care, and therefore it misrepresents their role by giving other professionals the impression that they “talk to patients every day” (Strohmeyer et al., 2023). Others deliberately chose not to identify as a GC in their job title, perceiving it as limiting. They felt it lowered expectations of senior leaders and reduced their salary bracket, defining their skillset as merely patient-focused, and in turn, reduced respect for their role (Strohmeyer et al., 2023). For this reason, other laboratory GCs have referred to their identity as “genetic *consulting*” rather than “genetic counselling” to avoid confusion (Schwartz et al., 2023). Other GCs have also struggled with their identity, questioning whether they can call themselves GCs if they do not see patients (Zetsche et al., 2014).

However, similar to our findings, other GCs have acknowledged their role as different to traditional GCs but continue to identify as a GC because it aligns with how they’ve always viewed themselves (Stenberg et al., 2024). Additionally, they expressed great pride in their title, explaining that it represents a core foundation from which they were taught and a skillset that has been applied in various ways (Means et al., 2020; Stenberg et al., 2024). Furthermore, NTGCs describe their identity as broad and view themselves as generalists – professionals who consult a diverse range of genetic cases in clinical environments. Their generalist identity, a hallmark of genetic counselling in SA, equips GCs to handle variety and subsequently enables them to adapt to alternative career paths and facilitate smoother transitions into non-traditional roles. The difference in professional identity abroad and locally could stem from the unique landscape of genetic counselling in SA and the limited opportunities available for GCs compared to the USA. In SA, a smaller workforce, limited traditional roles, and the need for adaptability means that NTGCs maintain strong ties to their GC identity despite being employed in a non-traditional role. This contrasts with the USA, where a more established

workforce allows for greater role diversity and specialisation, leading some choosing to no longer identify as a GC in a non-traditional role.

While the metaphor, ‘moving to the dark side,’ has been illustrated by previous studies and has been a long-standing concern in the American GC community (McWalter et al., 2018; Strohmeyer et al., 2023), it was not raised in ours. Although one participant expressed a feeling that their identity was not that of a GC, it was not a general theme across participants, and so while it was not intentionally analysed, the theme never emerged organically either. This difference seen in the South African genetic counselling community could be because NTGCs did not choose to move into non-traditional roles. The choice often brings judgement, which may explain why GCs in the USA indeed felt judged, ashamed, impure, and perceived as money-driven by traditional GCs when making the transition (Schwartz et al., 2023; Strohmeyer et al., 2023), and some felt their placement in the genetic counselling program was wasted (Hippman et al., 2016). Some have, in fact, avoided transitioning into non-traditional roles out of fear of losing their identity and sense of belonging within profession (Davis et al., 2020).

With only 28 practising counsellors in the country, the field is considered niche. Therefore, by sharing similar employment struggles after their internship, GCs can relate to and emphasise with each other, creating a highly supportive environment that further encourages mutual support and minimises judgement. This illustrates why GCs in SA, including NTGCs, have a strong sense of duty to advocate for the genetic counselling profession in the country, highlighting its significance and value in healthcare. This collaborative effort is seen in support groups, such as the GCSA, social media advocacy through various genetic counselling pages, and the use of messaging platforms for professional communication and assistance. They discuss the constant challenge within the healthcare system of gaining recognition, adequate placements, and fair pay, all of which impact their sense of fulfilment. Although this advocacy represents GCs’ passion for the profession, it has an emotional toll and is described as draining as they constantly strive to be valued in the healthcare system. While this has been found in Cohen & Tucker (2018), it may also be unique to SA given the lack of genetic counselling awareness and implementation (Gomes et al., 2024).

Although some NTGCs expressed the desire to move back into a traditional setting, they provided hopeful advice for newly qualifying GCs, stating that the identity of a GC in SA is

already changing and may look different in the future. Therefore, they advise GCs to be open to diverse work settings and not feel restricted with their qualification, as they possess a highly transferable skill set that can be easily translated into a non-traditional setting. This provides hope to newly qualifying GCs in the country, ensuring the degree remains highly valued and provides options for employment in diverse settings given the current situation for genetic counselling in SA.

5. Research recommendations

Since our study focussed on NTGCs' perspectives and experiences, it may be insightful to evaluate that of the GCs working in traditional practice, outlining how they feel toward the profession and those who work in non-traditional roles. Additionally, the study excluded the 16 GCs that have emigrated, and thus exploring their motivations may add to the findings of this study. Future genetic counselling training should incorporate non-traditional role exposure to a larger extent, given that the reality for most GCs in SA is to move into these roles upon completion of their internship. This will allow those to feel more prepared for their role, but also to establish networks in these areas of work.

6. Limitations

Most participants' form of clinical work experience was that as a trainee in their internship, which could mean that their comparison to their first actual job was not quite the same as comparing two different jobs that they have held, seen in previous studies. However, given the employment situation for GCs in SA, we felt this comparison was adequate. Our study did not include the 16 GCs that have emigrated, which could have added depth to the theme, "No choice but to pivot." However, we felt that it did not provide context to the profession in SA as such, and therefore chose to exclude them.

7. Conclusion

Our study highlights the evolving role of genetic counsellors (GCs) in South Africa (SA), with particular focus on non-traditional genetic counsellors (NTGCs). While much of our current understanding of NTGCs is drawn from American studies, this research provides context to the unique nature of South African NTGCs and the collective struggles they face. While GCs in the USA move into non-traditional practice by choice and have a subsequent negative connotation associated with that move, our study illustrates that GCs in SA are in fact 'forced' into non-traditional practice, due to a lack of choice given the shortage of traditional

employment. Consequently, most newly qualified GCs are pushed to make pragmatic decisions regarding their employment, changing their career trajectory. Thus, NTGCs experience similar struggles which minimises judgement around this trend. Nonetheless, NTGCs remain proud to identify as GCs in non-traditional practice, with overall high job satisfaction and feel they are meeting a need. Their unique skillset makes a great interface in the laboratory and facilitates ethical practice in research projects, therefore they advise newly qualifying GCs to stay open-minded as to where their skillset can be applied, as this has asset been translatable in a variety of work settings.

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Statement of Ethics

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Conflict of Interest Statement

The authors, RC, MA, and KF declare that they have no conflicts of interests.

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Author Contributions

K. Fourie and M. Araujo designed the study. R. Chidrawi collected all data and completed the analysis. Through a collaborative effort, all three authors contributed to the design of the code book.

Data Availability Statement

All de-identified data and materials can be made available upon request.

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Appendices

Appendix A: Supplementary Tables and Figures

Appendix B: Ethics Clearance Certificate

Appendix C: Approved Research Protocol

Appendix D: Turnitin Report and Plagiarism Declaration

Appendix E: Journal of Genetic Counseling Author Guidelines

Appendix A: Supplementary data

1. *Interview guide*

1. Can you describe your current role as a genetic counsellor?
 - What are your primary responsibilities in your role?
 - How would you describe your level of job satisfaction?
 - Do you identify as a genetic counsellor in your job title?
2. Please describe previous roles, both non-laboratory (or industry/research) and laboratory-based, that you've held as a genetic counsellor prior to your current position.
 - Reflecting on your role as a clinical genetic counsellor, what aspects of your role did you find rewarding, if any?
 - In contrast, did you face any challenges working in clinical practice?
3. How did you find yourself in this role?
 - Did you ever think about leaving your clinical role?
 - Was it a planned move?
 - Did you feel you made the right decision at the time?
4. What was your experience of the transition from a clinical to a non-traditional setting?
 - How did you feel amongst your colleagues?
 - Did you feel prepared for your role?
 - How did you feel leaving a clinical setting?
5. How prepared did you feel for this role?
 - How did you cope with your role initially?
 - Were there any challenges you encountered?
6. How do you feel your genetic counselling background impacted your current role?
 - Are there advantages of being a genetic counsellor?
7. How would you describe your quality of life now compared to when you had a clinical role?
 - Does it differ significantly?
 - In what way has it changed?
8. Do you ever think about working in clinic again?

2. Demographic questionnaire:

Participant code: _____

Name (s)	Surname	DOB (dd/mm/yyyy)
Race		Gender
Please indicate the highest qualification you've obtained, specifying the academic institution and year of qualification.		
Qualification (list all)	Institution	Year
Please list all previous employment positions you have held, specifying the position title and the number of year's experience in that role.		
Position title (e.g. laboratory manager)	Organization name (e.g. NHLS Braamfontein)	Year (e.g. 2010-2015)

3. Participant information sheet

STUDY INFORMATION DOCUMENT

Study title: The experiences of laboratory, research, and industry based genetic counsellors in South Africa – a qualitative study.

To whom it may concern, my name is Reagan Chidrawi and I am currently in my first year of the MSc (Med) Genetic Counselling program at the University of Witwatersrand and the National Health Laboratory Service. I am currently doing research on genetic counsellors that are employed outside of clinical practice, i.e. laboratory, research, and industry based genetic counsellors in South Africa. What is referred to as the ‘traditional’ role of a genetic counsellor involves patient-focused roles within clinical settings, such as pre- and post-test counselling, assessing family history for risk calculations, providing education on testing options, inheritance, and management options, and counselling to promote autonomy to make informed choices. In South Africa, the role of a traditional genetic counsellor is well understood. However, the role of non-traditional genetic counsellors has been explored mainly in the United States of America (USA) but remains unexplored in a local setting. In this study we want to provide context to the Genetic Counselling profession in South Africa and the changing landscape of employment opportunities for genetic counsellors, focusing on the experiences of non-traditional genetic counsellors. We would like to evaluate the motivations, experiences, and impact of this shift to better understand it and to highlight the importance of the exposure to non-traditional opportunities in genetic counselling training programs. Without comprehensive research on the topic, the parallels between the experiences of non-traditional genetic counsellors in South Africa and those globally, such as in the USA, remain uncertain. Given the disparities in economies, employment opportunities, and healthcare infrastructures, investigating this matter will be insightful and may highlight the subtle nuances and implications within different contexts. Therefore, the aim of this study is to determine the experiences of non-traditional genetic counsellors employed in laboratory, research, and industry settings in the unique context of South Africa. We are inviting you to take part in a research study if you feel you meet the requirements and would like to be a part of this study.

Overview of study logistics

This is a qualitative study; therefore, the researcher will be conducting one-on-one, face-to-face, semi-structured interviews with the participants. The interview will be conducted at a

place that is convenient for the participant, in a quiet and confidential space. The interviews will be roughly 1 hour long and will be conducted using an interview guide with questions related to the research topic. If an in-person interview cannot be held, one-on-one interviews will be held via Zoom. The interview guide will entail questions regarding the participants experience as a genetic counsellor thus far in their career, exploring motivations, feelings, and perceptions about both traditional and non-traditional work environments. The study will begin in July and end in December 2024. Interview transcripts will be transcribed verbatim and used as the basis for analysis, specifically reflexive thematic analysis.

Participant confidentiality

All information will be stored in a password protected file, and all personal information will be treated in the strictest confidence and will only be available to the Principal Investigator (PI) of the study. Confidentiality of the participant will be kept by anonymising the participants with participant codes, i.e. P1 for participant 1. Additionally, no names, identification numbers, cell phone numbers, workplaces or any other identifiable information will be made publicly available. No individual will be identified by name in any report or publication arising out of the study. All data collected in the course of the study will be securely retained for two (2) years, if a scientific publication arises from the study and six (6) years, if there is no publication. Thereafter it will be destroyed accordingly.

The Participant will be given pertinent information on the study while involved in the project; after the results are available, the participant should be offered a free results summary, on request. Refusal to participate will involve no penalty or loss of benefits to which the Participant is otherwise entitled. The Participant may discontinue participation at any time without penalty, or loss of benefits to which the Participant is otherwise entitled; that there is no requirement to provide a reason for withdrawing and any data collected on such a person will in default be destroyed, unless the Participant specifically consents to its retention.

Contributions to the Genetic Counselling profession in South Africa

Although there is no direct benefit to the participant when partaking in this study, there is the benefit that this study will contribute to the overall understanding of the Genetic Counselling profession in South Africa. The traditional genetic counsellor, who typically works in clinical settings, is well understood in South Africa. This study aims to expand that understanding to include non-traditional genetic counsellors who are currently employed in laboratory, research,

and industry-based environments. The output of this study aims to provide context to the Genetic Counselling profession in South Africa. Where possible, it aims to elucidate the transition from traditional to non-traditional environments and provide insight into this global employment trend.

Ethical approval

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg (**M240611 MED24-04-566**). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.

For further information please contact:

Principle Investigator:

Reagan Chidrawi | T: 0763308006 | E: 2272705@students.wits.ac.za

Supervisors:

Katryn Fourie | T: 011 489 9243/9223 | E: katryn.fourie@nhls.ac.za

Monica Araujo | T: 011 489 9902/9223 | E: monica/araujo@nhls.ac.za

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Paul Ruff, who may be contacted via any one member of the secretariat. The telephone numbers for the Committee secretariat are 011 717 2700/1234/2656/1252 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za, Rhulani.Mukansi@wits.ac.za, Mapula.Ramaila@wits.ac.za and Iain.Burns@wits.ac.za.

Thank you for reading this Study Information Sheet.

4. Participant informed consent form

Participant Consent Sheet

Project Title: *The experiences of laboratory, research, and industry based genetic counsellors in South Africa – a qualitative study.*

1. I have been given a Participant Information Sheet which explains the nature and processes involved in this study, which is attached hereto;
2. I was given time to read it, or had it read to me, in the language I best understand;
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory;
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be;
5. I understand that there will be no immediate benefit to me, should I agree to participate, nor will I receive any payment; conversely, participation will not cost me anything but my time;
6. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons; if that happened, any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained
7. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study I am free to speak to any of these contacts.

Consent Sheet for Audio Recording of Study Participation

Project Title: *The experiences of laboratory, research, and industry based genetic counsellors in South Africa – a qualitative study.*

I hereby consent to audio recording of the interview;

1. For face-to-face interviews, I hereby consent to the recording of the audio.
2. For interviews held via Zoom, I hereby consent to the recording of the audio through the Zoom platform.

I understand that:

- The recording will be stored in a secure location (a locked cupboard or password protected computer) with restricted access to the researcher and the research supervisors.
- The recording will be transcribed and any information that could identify me will be removed,
- The recordings will be erased within either (a) two (2) years of the publication of the research findings, or (b) six (6) years, if no publications arise from this research
- Anyone wishing to access this information in the future will first have to obtain the approval of the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg
- Direct quotes from my interview, without any information that could identify me, may be cited in the research report or other write-ups of research.
- *In accordance with the provisions of the **Protection of Personal Information Act 4 of 2013** (as amended), I hereby consent:*
 - *To my personal information (hereinafter 'data') being collected, processed, shared and stored in accordance with the research protocol/proposal as approved by the Wits HREC (Medical);*
 - *To my anonymised data being shared, processed, and transferred by third parties and between third parties, and where relevant beyond the jurisdictional borders of South Africa;*
 - *To all findings and results flowing from my anonymised data being broadly shared and published at the conclusion of the research.*

Name of Participant: _____

Date: _____

Place: _____

Signature or mark _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____

Contact details:

Reagan Chidrawi, Principal Investigator, telephone no. 0763308006 or e-mail at 2272705@students.wits.ac.za.

Katryn Fourie, Supervisor, on telephone no. 011 489 9243/9223, or e-mail at katryn.fourie@nhls.ac.za

Monica Araujo, Supervisor, on telephone no. 011 489 9902/9223, or e-mail at monica.araujo@nhls.ac.za

Professor P Ruff, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, who may be contacted via any one member of the secretariat. The telephone numbers for the Committee secretariat are 011 717 2700/1234/2656/1252 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za, Rhulani.Mukansi@wits.ac.za, Mapula.Ramaila@wits.ac.za and Iain.Burns@wits.ac.za.

Appendix B: Ethics Clearance Certificate



R14/49 Miss Reagan Chidrawi M240611

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M240611

NAME: Miss Reagan Chidrawi
(Principal Investigator)

DEGREE: MSc Genetic Counselling

STUDENT/STAFF NO: 2272705

DEPARTMENT: School of Pathology
Human Genetics
NHLS

PROJECT TITLE: The experiences of laboratory, research, and industry based genetic counsellors in South Africa - A qualitative study

DATE CONSIDERED: 21/06/2024

DECISION: Approved unconditionally

CONDITIONS:

NOTE: Ethics Online System ref no MED24-04-566

SUPERVISOR: Mrs Katryn Fourie and Miss Monica Araujo

APPROVED BY: Paul Ruff
Paul Ruff Aug 27 2024 14:09 GMT+2
Prof P Ruff, Chair, HREC (Medical)

DATE OF APPROVAL: 29/07/2024 **EXPIRY DATE:** 29/07/2029

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to Committee. I agree to submit a yearly progress report in July each year until study is closed. Failure to submit annual report will result in ethics clearance certificate suspension. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in June and will therefore be due in the month of June each year. Unreported changes to the application, invalidate the clearance given by the HREC (Medical). Email signed copy of this ethics clearance certificate prior to commencing with the study hrec-medical.researchoffice@wits.ac.za

Reagan Chidrawi

Principal Investigator Signature

27 August 2024

Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix C: Approved Research Protocol



Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Ms Sandra Munesar
E-mail: Sandra.munesar@wits.ac.za

13 August 2024
Person No: 2272705
PAG

Miss R Chidrawi
9 Mimosa Avenue Cedar Lakes
Fourways
2191
South Africa

Dear Miss Reagan Chidrawi

Master of Science in Medicine: Approval of Title

We have pleasure in advising that your proposal entitled *The experiences of laboratory, research, and industry based genetic counsellors in South Africa - a qualitative study* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely



Ms Sandra Munesar
Faculty Registrar
Faculty of Health Sciences





CANDIDATE'S SURNAME: Chidrawi		FIRST NAME/S: Reagan	STUDENT NUMBER: 2272705
CURRENT QUALIFICATIONS: BSc(Hons) Genetics			
TEL: 0114691523	CELL: 0763308006	E-MAIL: 2272705@students.wits.ac.za	FAX:
DEGREE FOR WHICH PROTOCOL IS BEING SUBMITTED: MSc(Med) Genetic Counselling			
PART-TIME OR FULL-TIME: Full-time			
FIRST REGISTERED FOR THIS DEGREE:	TERM: 1	YEAR: 2024	
DEPARTMENT: Human Genetics			
TITLE OF PROPOSED RESEARCH: The experiences of laboratory, research, and industry based genetic counsellors in South Africa – a qualitative study.			
CANDIDATE'S SIGNATURE:			DATE:
SUPERVISOR 1 (NAME & SURNAME): Katryn Fourie			% Supervision 50%
SUPERVISOR'S QUALIFICATIONS MSc(Med) Genetic Counselling			
SUPERVISOR'S DEPARTMENT Human Genetics			
SUPERVISOR'S ADDRESS / TEL / E-MAIL: Room 15, First floor, Jack Metz building, Cnr Hospital and De Korte st, Braamfontein [T]: 011 489 9243/9223 [E]: katryn.fourie@nhls.ac.za			
SUPERVISOR 2 (NAME & SURNAME): Monica Araujo			% Supervision 50%
SUPERVISOR'S QUALIFICATIONS MSc(Med) Genetic Counselling			
SUPERVISOR'S ADDRESS / TEL / E-MAIL: Room 6, First floor, Jack Metz building, Cnr Hospital and De Korte st, Braamfontein [T]: 011 489 9902/9223 [E]: monica.araujo@nhls.ac.za			
SUPERVISOR 3 (NAME & SURNAME):			% Supervision
SUPERVISOR'S QUALIFICATIONS			
SUPERVISOR'S ADDRESS / TEL / E-MAIL:			

SYNOPSIS OF RESEARCH:

Introduction

Genetic counselling is a profession that is relatively young both globally and in South Africa. Historically, genetic counsellors in South Africa have been employed through academic and public institutions, with only a few practicing privately. Recently there has been a noticeable shift in the employment trends of genetic counsellors worldwide and in South Africa, transitioning away from conventional or traditional roles and gravitating toward non-traditional practice. It is, therefore, becoming more common to find counsellors employed in laboratory, research, and industry settings, redefining the role of a genetic counsellor. Although this trend has been explored elsewhere, mainly in the United States of America (USA), it is yet to be explored in South Africa.

Justification for study:

This research will elucidate a previously unexplored topic in South Africa, providing insight into the experiences of non-traditional genetic counsellors. Without comprehensive research on the topic, the parallels between the experiences of non-traditional genetic counsellors in South Africa and those globally, such as in the USA, remain uncertain. Given the disparities in economies, employment opportunities, and healthcare infrastructures, investigating this matter will be insightful and may highlight the subtle nuances and implications within different contexts. Therefore, there is a need to provide context to the genetic counselling profession and the changing landscape of employment opportunities for genetic counsellors globally, with a particular focus on the experiences of non-traditional genetic counsellors.

Aim:

To explore the perspectives and experiences of non-traditional genetic counsellors employed in laboratory, research, and industry based settings in South Africa.

Methodology:

This study will employ a qualitative methodology. Semi-structured interviews using an interview guide with open-ended questions will be conducted with qualified genetic counsellors in South Africa that are currently employed outside of clinical practice. Reflexive thematic analysis using coding and generating themes will be employed to evaluate the experiences and perspectives of non-traditional genetic counsellors, and to provide insight into the rationale behind this transition.

Expected outcomes:

This study will provide insight into a previously unexplored topic in a local setting, potentially elucidating crucial aspects regarding the scope of practice of genetic counsellors in South Africa. Moreover, its findings may assist in policy decisions regarding genetic counselling training.

WITS ETHICS NOT REQUIRED:

Yes ☐ No ☒

WITS ETHICS PENDING:

Yes ☐ No ☒

WITS ETHICS APPROVED:

Yes ☐ No ☒

(circle appropriate symbol)*

IF Y SUPPLY ETHICS
CLEARANCE CERTIFICATE AS
ATTACHMENT AND INCLUDE
ETHICS NUMBER HERE:

***Please note the final human ethics clearance certificate or animal ethics certificate must be available prior to starting research**

As supervisor/s, I/we confirm that I have read the protocol which has been submitted for assessment.

SIGNATURE OF SUPERVISOR/S:		
SIGNATURE PG OFFICE STAFF 	REGISTERED YES..... NO.....	STAMP



The experiences of laboratory, research, and industry based genetic counsellors
in South Africa – a qualitative study.

Reagan Chidrawi

2272705

MSc(Med) Genetic Counselling

Supervisor 1:

Katryn Fourie

MSc (Med) Genetic Counselling, Genetic Counsellor and Lecturer, Clinical and Counselling
Section, Division of Human Genetics, School of Pathology, Faculty of Health Sciences,
University of the Witwatersrand

Supervisor 2:

Monica Araujo

MSc (Med) Genetic Counselling, Genetic Counsellor and Lecturer, Clinical and Counselling
Section, Division of Human Genetics, School of Pathology, Faculty of Health Sciences,
University of the Witwatersrand



PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I **Reagan Chidrawi** (Student number: **2272705**) am a student registered for the degree of **MSc(Med) Genetic Counselling** in the academic year **2024**.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.
- I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

Signature: 

Date: **2 April 2024**

1. Background literature analysis/ critique

1.1. Introduction

Genetic counselling is a relatively young profession both globally and in South Africa. Historically, genetic counsellors in South Africa have been employed through academic and public institutions, with a small number practicing privately (Kromberg, Wessels and Krause, 2013). Recently there has been a noticeable shift in the employment trends of genetic counsellors worldwide and in South Africa, transitioning away from traditional roles and gravitating toward non-traditional practice (Waltman *et al.*, 2016; Cohen, Tucker and Delk, 2017; Schwartz *et al.*, 2023; Strohmeyer *et al.*, 2023). It is, therefore, becoming more common to find counsellors employed in laboratory, research, and industry settings. Although this trend has been explored elsewhere, mainly in the United States of America (USA), it is yet to be explored in South Africa. Therefore, there is a need to provide context to the genetic counselling profession and the changing landscape of employment opportunities for genetic counsellors, focusing on the experiences of non-traditional genetic counsellors.

1.2. The genetic counselling workforce

Genetic counselling goes together with advancements in genomics and the era of precision health, leading to diversification in the roles of genetic counsellors. As of 2023, 53% of genetic counsellors in the USA work in direct patient care, as documented by the National Society of Genetic Counsellors Professional Status Survey (NSGC; PSS) (National Society of Genetic Counselors, 2023). Recently, there has been a noticeable trend of genetic counsellors moving out of clinical practice and obtaining employment in non-traditional settings. This is supported by the fact that 27% of genetic counsellors in the USA are employed in non-direct patient care and 20% in a mixed role (National Society of Genetic Counselors, 2023). A notable observation is that due to the limited exploration of this trend outside of the USA, American statistics have been used in this argument. The section below explores traditional and non-traditional genetic counsellors, focusing on roles and responsibilities, employment patterns, and overall job satisfaction.

1.2.1. Employment trends

1.2.1.1. The traditional genetic counsellor

What is referred to as the 'traditional' role of a genetic counsellor involves patient-focused roles within clinical settings, such as pre- and post-test counselling, assessing family history for risk calculations, providing education on testing options, inheritance, and management options, and counselling to promote autonomy to make informed choices (Resta *et al.*, 2006).

According to the latest PSS, genetic counsellors in the USA are employed in laboratories, universities, biotechnology and pharmaceutical industries, non-profit organisations, hospitals (private and public), and government (National Society of Genetic Counselors, 2023). In the USA, genetic counsellors commonly engage in research, direct patient care, education and teaching, scientific writing, and program development (National Society of Genetic Counselors, 2023). Of the counsellors involved in direct patient care, the three main roles included direct patient care, student supervision, and education and teaching (National Society of Genetic Counselors, 2023). In South Africa, genetic counsellors are employed in academic clinical centres and private healthcare (Southern African Society for Human Genetics, 2024).

1.2.1.2. The non-traditional genetic counsellor

Laboratory and industry (LI) genetic counsellors have varied roles and responsibilities outside of clinical practice, which are tightly bound to increased employment opportunities. Christian *et al.* (2012) first delineated these roles in Canada and the USA, describing the genetic counsellors' role in customer liaison, administrative work, result communication, and student supervision (Christian *et al.*, 2012). Subsequent research by Waltman *et al.* (2016) found that customer liaison and test result interpretation accounted for more than 50% of LI genetic counsellors' duties. Additionally, only 24% of LI genetic counsellors participated in face-to-face counselling, which only took up 7.3% of their time (Waltman *et al.*, 2016). Further research showed that examining and interpreting exome sequencing results, assessing the clinical significance of variants, managing bioinformatic data concerning genetic testing, recruiting for new positions such as genetic counselling assistants, and being involved in research were some of their main duties (McWalter *et al.*, 2018). More recently, LI genetic counsellors work in commercial laboratories, working in sales, marketing, or as variant specialists (Schwartz *et al.*, 2023). Their duties encompass variant interpretation, grant writing, designing and writing reports, and customer service (Schwartz *et al.*, 2023). In the USA, LI genetic counsellors focus on education and teaching, laboratory report writing and support, and customer liaison (National Society of Genetic Counselors, 2023). Additionally, LI genetic counsellors are involved in contacting patients regarding test results, obtaining family history for better interpretation, and dealing with customers regarding test interpretation (Waltman *et al.*, 2016). Evidently, LI genetic counsellors bridge a gap between the laboratory and clinicians (Schwartz *et al.*, 2023), and possess a transferable skillset, which is often advantageous in a laboratory setting (Christian *et al.*, 2012; Schwartz *et al.*, 2023; Strohmeyer *et al.*, 2023).

1.2.2. Job satisfaction

Approximately 86% of genetic counsellors in the USA are either satisfied or very satisfied working in their current profession (National Society of Genetic Counselors, 2023), consistent with the previous year's statistics (National Society of Genetic Counselors, 2020, 2021, 2022). More specifically, job satisfaction among LI genetic counsellors is high (Christian *et al.*, 2012; Field *et al.*, 2016; Waltman *et al.*, 2016; Schwartz *et al.*, 2023; Strohmeyer *et al.*, 2023). The highest-ranked contributors to job satisfaction were autonomy, liaison with other clinicians, and support from laboratory directors (Christian *et al.*, 2012). In contrast, advancement opportunities, research opportunities, total workload, and salary were the least ranked areas of satisfaction (Christian *et al.*, 2012). Through qualitative analysis, the major themes that best described what LI genetic counsellors most enjoyed about their role include the level of respect, flexible and regular work hours, the ability to use their expertise in the laboratory and be a valuable resource, as well as the variety of new learning opportunities (Christian *et al.*, 2012; Field *et al.*, 2016). Furthermore, helping multiple patients in a laboratory setting was preferred over intense dealings with only a "handful" of patients in the clinic (Strohmeyer *et al.*, 2023). Genetic counsellors in LI settings felt to be valuable members of the laboratory team due to increased autonomy and independence in their role (Strohmeyer *et al.*, 2023), and felt recognised, valued, and accepted by their colleagues (Schwartz *et al.*, 2023).

1.3. The non-traditional genetic counselling trend

1.3.1. Factors influencing the movement out of clinical practice

As this trend has become more noticeable, it has led to investigating the driving forces compelling genetic counsellors to leave clinical practice. It was reported that it was not necessarily direct patient care that drove genetic counsellors out of a clinical setting since counsellors ranked this as one of the best aspects of their job, but rather a high workload and feeling undervalued (Cohen and Tucker, 2018). It was also described that the "brain drain" of counsellors to industry exacerbates the workload on remaining counsellors (Cohen and Tucker, 2018). Notably, counsellors who moved into non-traditional settings dealt with significantly less direct patient care, and the common factors for moving among these individuals were salary and flexibility (Cohen, Tucker and Delk, 2017). Among the genetic counsellors who still work in clinics, 33% said they think about leaving their jobs at least once a month (Cohen, Tucker and Delk, 2017). Further, an investigation of the rationale behind genetic counsellors moving out of clinical practice revealed that it was not necessarily because they didn't enjoy

their job, but rather they found newer opportunities for personal growth (Rabideau *et al.*, 2016). Some genetic counsellors found that they could impact more individuals by working in a start-up company that explored microarray testing and its availability (Rabideau *et al.*, 2016). Others found that they could contribute to the growth of a new start-up company using their counselling skills in a laboratory setting (Rabideau *et al.*, 2016). Field *et al.* (2016) also describe that the reasons for genetic counsellors moving into the biotechnology and pharmaceutical industries were due to earning potential, the inclination to work in an area of expertise, and to learn something new. Notably, wanting to work with less direct patient care was not found to be one of the contributing factors (Field *et al.*, 2016). With the increase in genetic testing available, the movement of genetic counsellors to a non-traditional setting might be anticipated. It may reveal that there are, in fact, greater job opportunities for genetic counsellors in the industry, but it remains a challenge for remaining counsellors in the clinic (Cohen and Tucker, 2018).

1.3.2. The experiences of non-traditional genetic counsellors

1.3.2.1. Moving to the dark side

Leaving the traditional genetic counselling field was previously stigmatised as “moving to the dark side” (McWalter *et al.*, 2018). Some genetic counsellors felt hesitant and nervous to leave clinical practice due to the negativity and stereotypes within the field (Schwartz *et al.*, 2023). One such stereotype was that genetic counsellors moving to non-traditional roles were only money-driven and not considered ‘pure’ (Schwartz *et al.*, 2023). It was also perceived that genetic counsellors working in clinical practice were superior with “real jobs” (Strohmeyer *et al.*, 2023). Subsequently, LI genetic counsellors felt guilty, judged, or ashamed for choosing to accept research-based jobs and employment in a non-traditional area (Strohmeyer *et al.*, 2023). Additionally, these counsellors felt their placement in the genetic counselling program was wasted (Hippman, Davis and Counselors, 2016). However, this stigma seems to have dissipated slightly as of 2018, which is potentially due to the dramatic increase in job availability from genomic advancements, thereby normalising the transition (McWalter *et al.*, 2018).

1.3.2.2. Identifying as a genetic counsellor

By redefining the role of a genetic counsellor, it becomes intriguing to observe whether these individuals still identify as a genetic counsellor in their new role. It was found that 94.5% of genetic counsellors in the USA employed in a LI role still identify as a genetic counsellor professionally, and of that, 51.3% display the term within their job title (Strohmeyer *et al.*, 2023). In addition, 5.5% of genetic counsellors did not describe themselves as genetic

counsellors professionally, with most participants stating that it did not accurately define their job specifications (Strohmeyer *et al.*, 2023). This was elaborated by Schwartz *et al.* (2023), who found that “genetic counsellor” referred strictly to those in direct patient care, and LI genetic counsellors were providing “genetic consulting” rather than counselling. The term “genetic counsellor” was found to be confusing and somewhat limiting because it lowered the expectations of higher leaders and created preconceived ideas of their expertise that were much lower than their capabilities (Strohmeyer *et al.*, 2023). By not identifying as a genetic counsellor, these individuals felt that their salary bracket increased (Strohmeyer *et al.*, 2023).

1.3.2.3. Preparedness for a non-traditional role

The preparedness of LI genetic counsellors varies. Some LI genetic counsellors state that there should be adequate and sufficient exposure to other career opportunities in training besides those that are clinical, since around 60% of LI genetic counsellors in the USA felt inadequately prepared for their LI role (Schwartz *et al.*, 2023; Strohmeyer *et al.*, 2023), needing assistance with variant classification, genetic testing concepts and test proficiency (Schwartz *et al.*, 2023). Field *et al.* (2016) also found that 72% of LI genetic counsellors in the USA did not feel their Master’s degree prepared them enough for a laboratory role. It was suggested that learning about clinical trials, drug development, and sales and marketing would have been beneficial (Field *et al.*, 2016; Waltman *et al.*, 2016). However, Schwartz *et al.* (2023) revealed that LI genetic counsellors valued their communication skills in their new role, as they can speak to any individual from any background. The flexibility and adaptability of LI genetic counsellors facilitated an easy transition to non-traditional roles (Schwartz *et al.*, 2023). While LI genetic counsellors may have felt underprepared regarding their proficiency in laboratory work, there is recognition that the communication and interpersonal skills inherent in genetic counselling training serve as an asset in transitioning to a non-traditional role.

1.4. Rationale

The landscape of the genetic counselling profession is experiencing an employment shift globally, and in South Africa, as genetic counsellors are moving out of traditional, clinical practice and into non-traditional, commercial laboratories, research, and industry settings. While the experiences, perspectives, and motivations of non-traditional genetic counsellors have been explored in the USA, providing valuable context for this trend, such insights remain largely unexplored in the unique context of South Africa. Moreover, our understanding of the non-traditional genetic counsellor remains based on global studies and statistics, emphasising the need for local investigation. This urges the exploration of the motivations, experiences, and

impact of this shift to better understand it, and to highlight the importance of the exposure to non-traditional opportunities in genetic counselling training programs. Without comprehensive research on the topic, the parallels between the experiences of non-traditional genetic counsellors in South Africa and those globally, such as in the USA, remain uncertain. Given the disparities in economies, employment opportunities, and healthcare infrastructures, investigating this matter will be insightful and may highlight the subtle nuances and implications within different contexts. Therefore, the aim of this study is to explore the perspectives and experiences of non-traditional genetic counsellors employed in laboratory, research, and industry based settings in the unique context of South Africa.

2. Aims and objectives

2.1. Aim

To explore the perspectives and experiences of non-traditional genetic counsellors employed in laboratory, research, and industry based settings in South Africa.

2.2. Objectives

1. To recruit registered genetic counsellors in South Africa who are currently employed in a non-traditional field and who report spending more than 50% of their time in this role.
2. To explore the experiences of non-traditional genetic counsellors employed in laboratory, research, and industry based settings.
3. To assess the perspectives of genetic counsellors working outside of traditional roles within laboratories, research, and industry.
4. To elucidate the motivations behind genetic counsellors transitioning from clinical practice to non-traditional roles, providing insights into their rationale.

3. Methods

3.1. Study population

The study will employ purposive sampling – a widely used method in qualitative research aimed at recruiting information-rich participants who are experienced or knowledgeable in the research area to provide insightful information (Patton, 2002). Registered genetic counsellors in South Africa who currently work predominantly (more than 50% of their time) in non-traditional areas and meet all the inclusion criteria requirements will be recruited. According to the knowledge of the researcher's supervisors, who are experienced individuals in the Genetic Counselling field, there are approximately 15 genetic counsellors in South Africa who

fit the inclusion criteria and could be potential participants. The secretary of the Genetic Counsellors South Africa (GCSA) committee has permitted the researcher to send an introductory email via the GCSA mailing list to all registered genetic counsellors in South Africa, inviting these individuals to participate in the study. The email will include a link to a Google form which will stipulate the inclusion criteria for this study, and those who would like to participate in the study will then be asked to consent to being contacted and fill out their contact details. Interview logistics will be arranged with the participants.

3.1.1. Inclusion criteria

Individuals over the age of 18 who meet all the following criteria:

- Is a HPCSA registered Genetic Counsellor in Independent practice.
- Holds a Master's degree in Genetic Counselling, either MSc(Med) or M(Med)Sc.
- They are currently employed in a non-traditional environment i.e. laboratories, research, and industry.
- Spend more than 50% of their time in a non-traditional work environment.

3.1.2. Exclusion criteria

- Genetic counsellors in South Africa who are currently employed in clinical practice and spend more than 50% of their time within clinical practice.
- Genetic counsellors who have been employed in a non-traditional environment for less than six months.
- Genetic counsellors who are registered in South Africa but are employed in a different country.
- Genetic counselling trainees who have not yet completed their training.

3.1.3. Sample size

A suitable sample size for qualitative research is one that can effectively address the research topic. Therefore, a small sample size is considered appropriate since the quality of the data is valued more than the quantity, and hence, in-depth exploration is prioritised over generalisability (Marshall, 1996). Thus, qualitative research focuses on sampling information-rich cases that provide depth and understanding to the research topic (Marshall, 1996; Braun and Clarke, 2021). Data saturation will be considered as the project progresses, and this is when novel themes and categories stop presenting from the data (Marshall, 1996; Patton, 2002). The sample size for this project was determined based on the proposed guidelines of qualitative research (Marshall, 1996; Patton, 2002), and precedents set by similar studies. Therefore, between 5-10 participants is expected and will be adjusted accordingly if necessary.

3.2. Data collection

This study will utilise qualitative research methodology. This approach is used to explore complex human issues and phenomena (Marshall, 1996), such that to gather meaning, experience, and perspective from the view of the participants (Braun and Clarke, 2012). It is advantageous in its capacity to elucidate the intricacies and patterns of human behaviour that can be challenging to quantify with quantitative methodologies (Patton, 2002). Since this project focuses on the experiences of non-traditional genetic counsellors, qualitative methodology will enable an in-depth exploration of the experiences and perspectives of these individuals, offering the ability to address unexpected topics of interest.

3.2.1. Semi-structured interviews

Qualitative data collection is most commonly done through interviews (Beeson, 1997), which facilitate deeper insights beyond preconceived notions, addressing possible bias inherent in structured surveys (Patton, 2002). Therefore, individual, face-to-face semi-structured interviews will be held with participants to explore this topic. An interview guide with open-ended questions and prompts that explore the topic will be used to conduct the interviews. This guide has been designed by the researcher and is tailored to explore themes from previous literature (Christian *et al.*, 2012; Waltman *et al.*, 2016; Schwartz *et al.*, 2023; Strohmeyer *et al.*, 2023), providing the participants freedom to express themselves openly. The advantage of semi-structured interviews is they allow for unexpected topics to emerge from the data and enable the researcher to obtain information from the perspectives of the participants without introducing bias in predetermined questions (Patton, 2002), contributing to the richness of the data. The interview guide will be trialled within the Division of Human Genetics prior to the participant interviews i.e. practiced with registered genetic counsellors. Any feedback, suggestions, or requests for changes will be incorporated into the guide accordingly. Thereafter, interviews will be arranged with the participant in a convenient and private place. Interviews will primarily be conducted face-to-face; however, if an in-person interview is not feasible, one-on-one interviews will be held via Zoom to ensure flexibility and accessibility for all participants. At the interview, the participant will be asked to sign a consent form that provides information regarding the use of quotes and phrases provided by the participants, as well as consenting to the session being audio-recorded. Each interview will be conducted by the researcher – who at the time is studying a MSc (Med) Genetic Counselling – individually and will be approximately one hour long with the understanding that it may vary depending on each participant. The interviews will be conducted in English since the inclusion criteria specify that participants must have a Master's degree in Genetic Counselling, which in South Africa is only

offered in English; therefore, all participants have sufficient English literacy. Each interview will be audio-recorded with two devices to ensure no loss of data. The recordings of each interview will be kept in a password-protected file with limited access to the researcher.

3.3. Data analysis

Each interview will be manually transcribed to generate a verbatim transcript, serving as the primary data for analysis. The data will be stored in a password-protected file with access limited to the researcher. The study will employ reflexive thematic analysis, which is a widely used method in qualitative data interpretation and serves as the foundation for the identification and analysis of patterns or themes in a given dataset (Braun and Clarke, 2012). It has shown to be an effective method used in exploring qualitative datasets (Braun and Clarke, 2012), such as those in previous studies exploring the roles of laboratory genetic counsellors and had favourable outcomes (Cohen, Tucker and Delk, 2017; Schwartz *et al.*, 2023). A qualitative research analysis software program, MAX-QDA, will be utilised. MAX-QDA digitalises this process and is specifically designed to assist coding and data analysis (MAXQDA, 2024). Each transcript will be examined, and codes will be identified inductively using this software package. A code is a label assigned to a specific piece of text that has relevance to the research topic (Braun and Clarke, 2012). These codes will be grouped and form part of a greater theme, which entails a specific pattern found in the data. Major themes drawn from the data will then be used to form the basis of the evaluation of the experience and perspectives of non-traditional genetic counsellors in South Africa, providing context to the nature behind this employment shift.

3.4. Validity and reliability

Validity refers to the accuracy of the findings and ensures that the participants' perceptions are clearly and precisely presented (Noble and Smith, 2015). To ensure the validity of the research, the researcher will collaborate with this study's supervisors during the process of coding. Transcripts will be coded independently, and group discussions will be held where codes are crosschecked and compared. Any questions regarding these codes or any other research-related matters can also be discussed. Practising critical reflexivity empowers researchers to effectively examine the assumptions tied to their subjectivity, especially those that may arise during the research process (Noble and Smith, 2015). Validity can be strengthened through personal reflexivity, along with constant and repetitive analysis of the data and emerging themes which increases the credibility of the data (Leung, 2015; Noble and Smith, 2015).

Reliability refers to the “trustworthiness” and dependability of the research findings, ensuring that the results can be corroborated by others in similar circumstances (Leung, 2015; Noble and Smith, 2015). It involves consistency of the data collection and analysis procedures, and accounting for any personal and research biases (Leung, 2015). To maintain this, an interactive approach will be taken where continuous group discussions will be held throughout the research process, interview questions will be continuously workshopped and piloted until the commencement of the interviews, and supervisors’ inputs will be continuously considered. Body language, non-verbal vocalisations, and subtle nuances will be noted in field notes during the interview which will enhance the rigour and reliability of the research.

4. Ethics

Ethics approval from the Human Research Ethics Committee (HREC) (Medical) of the University of Witwatersrand is necessary for this study and has been submitted on 19 April 2024. The project will only commence once Ethics approval from HREC is obtained. Individuals meeting the inclusion criteria will be recruited without coercion or persuasion. Participants will be required to sign a written consent form prior to the commencement of the interviews, that provides information regarding the use of quotes and phrases provided by the participants, as well as consenting to the session being audio-recorded. According to South Africa’s Protection of Personal Information Act (POPIA), confidentiality will be maintained throughout the research project. Confidentiality of the participants will be upheld by deidentifying participants using participant codes e.g. P1 for participant 1, and all identifiable information will be anonymised. All data will be stored in a password-protected file with limited access to the researcher. Apart from the above-mentioned considerations, the study holds minimal risk.

5. Timeline

Table 1: Timeline for proposed project in 2024.

Task	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec
Literature review											
Preparing protocol											
Protocol assessment											
Ethics application											

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Appendix D: Turnitin Report and Plagiarism Declaration



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				SQUIRE for quality improvement studies CONSORT for RCTs GCIRS for genetic counselling intervention and outcome studies
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