THE KNOWLEDGE OF BASIC GENETIC TERMS AND AVAILABLE TERMINOLOGY IN THE SOUTH AFRICAN SOTHO LANGUAGES.

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DECLARATION

I, Matshela Andrew Mpe, herewith declare that the work on which this dissertation/thesis is based is my own original work and that neither the entire work nor any part of it has in the past, is currently being, or will be in future submitted for another similar degree at the same or at any other university.

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24 July 2023

DEDICATION

I dedicate this work to firstly to myself. When I started this degree, I was doubtful of my capabilities. I have witnessed my growth over the years. It was a really tough adjustment before it got better. I am glad I never gave up because I cannot imagine doing anything else for a living. Secondly, this is for my mother, grandmother and little sister. When the going got tough, I wasn't sure how long I could sustain the effort without breaking in two; you guys were the glue that kept it all together. Last, but not least, all the Sotho languages speakers across the nation. May this work serve as foundation of all the future great work we will achieve together and establish genetic services in the Limpopo province.

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ABSTRACT

The use of indigenous terms during a genetic counselling session has the potential to foster a better understanding between a genetic counsellor and patient. However, it is unknown if there are specific terms for commonly used English genetic terminology in the South African indigenous languages. Furthermore, the genetic terms, knowledge and understanding of basic genetic concepts in the indigenous populations is not well-documented in the South African population.

This study aimed to investigate the knowledge and understanding of basic genetic terms in the indigenous South African Sotho-Pedi-Tswana ethnolinguistic group and to explore the available common terms, sayings, and expressions. This study employed a sociolinguistic qualitative descriptive research design to investigate the study aim. Data was collected using interviews through three focus group discussions.

The total number of participants was 16 Sesotho language group speakers comprising of 3 males and 13 females from a mixture of both rural and suburban areas. All participants were enrolled as students at University of Cape Town in non-health science and non-science faculties.

Content analysis was used to extract the available terms and phrases used to describe genetics and inheritance concepts. Thematic content analysis was used to analyse the data from the verbatim transcripts according to three main categories: (1) terms and concepts, (2) understanding of genetic terms and (3) terminology usage.

The findings reveal that there are terms and expressions available for commonly used genetic concepts and conditions commonly seen in genetic counselling. These include terminology for genetic conditions such as albinism and concepts such as inheritance and consanguinity. Participants highlighted how and when specific terms are used in their home languages and which terms were found to be offensive. Contrary to English, the Sotho-Pedi-Tswana language, like other indigenous South African languages, use more descriptive language to describe concepts.

In conclusion, this study has shown that there are genetic terms or phrases that are used for common English genetic terminology in the Sotho language group. Furthermore, there is a basic understanding of genetics within their communities which genetic counsellors can use as a basis when counselling. Common genetic terminology in South African indigenous languages can be included in genetic counselling sessions to reduce communication barriers, increase rapport and minimize the need for a translator while maintaining multicultural sensitivity.

Keywords: Genetic Terminology; Genetic Counselling; Language Barriers; Multicultural Sensitivity

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INTRODUCTION

South Africa is a multi-ethnic nation that initially consisted of eleven official languages; nine of them are indigenous, which are mainly divided into Nguni-Tsonga (SiSwati, Xitsonga, isiXhosa, isiNdebele and isiZulu) and Sotho-Makua-Venda languages (Setswana, Sesotho, Sepedi, and Tshivenda) (Statistics South Africa, 2019). On the 3rd of May 2023, the National Assembly amended section 6 of the constitution by recognising and approving the South African Sign Language as the 12th official language (Oliphant, 2023). The Sotho-Pedi-Tswana ethnolinguistic group comprises of Sepedi (Northern Sotho); Setswana (Western Sotho) and Sesotho (Southern Sotho) (Nurse & Philippson, 2003).

In the context of healthcare, the multi-ethnic nature of the South African population presents different worldviews, namely the biomedical model, based on scientific knowledge; and traditional healing model, based on indigenous knowledge (Mokgobi, 2014). When consulting a health care professional, patients take with them a specific worldview that is mostly influenced by either the indigenous, cultural or religious context of their background (Summerton, 2006). The healthcare professionals also have their own cultural or religious belief systems regardless of whether they provide healthcare based on biomedical healing paradigms (Summerton, 2006). Therefore, the existence of these diverse worldviews presents unique aspects of how human health is viewed and understood. This phenomenon is known as medical pluralism (Moshabela et al., 2011). Language and communication between a healthcare professional and patient becomes particularly important to bridge the differing views of human health (Johnson et al., 2004).

English is the commonly spoken language among health professionals in South Africa, which then introduces challenges when serving a multicultural society, particularly reduced quality of healthcare services delivered to a patient that does not fully understand or know the language (Levin, 2006a). South Africa thus presents a unique landscape for genetic counselling due to the ethnic diversity of its population, the different associated languages, and socio-economic challenges (Penn, 2007). The diversity of the languages creates a challenge in terms of communication between individuals. The language used during a genetic counselling session is a common barrier between a patient and a genetic counsellor (Delikurt et al., 2015).

Genetic counselling services are available to all eligible individuals of different demographic origins and ethnic backgrounds in South Africa (Morris et al., 2015), however, the access to the service been (Jenkins, 1990) and continues to be limited due to resources. Furthermore, the sessions are efficient only if they are conducted in a common language that is well understood by both the counsellor and the counselee (Browner et al., 2003). English is the main language used in the genetic counselling sessions and many native South Africans do not understand English (Deumert, 2010). In addition to difficulty in conversing in English, they do not understand the “language of genetics” used by the genetic counsellors (GCs) even when put in the most simplified way (Delikurt et al., 2015).

This lack of understanding of genetic terminologies in English has raised awareness for genetic counsellors to provide efficient, culturally sensitive counselling services that accommodate all the ethnic groups of South Africa. To achieve this, GCs first need to have a basic understanding of how well genetic literature has been established and used in each ethnic group (Solomon et al., 2012). Additionally, GCs and healthcare professionals in general need to be self-aware and have cultural humility regarding the different belief systems, which are shaped by culture, in different ethnic group (Kleinman & Benson, 2006; Rust et al., 2006; Curtis et al., 2019). This will assist them in creating efforts to accommodate indigenous knowledge in their counselling sessions (Cohen, Fine & Pergament, 1998). By doing so, multicultural sensitivity will be established and the language barriers between the counsellor and counselee can be minimized.

LITERATURE REVIEW

The literature is presented according to the following as it relates to the study:

- Genetic counselling: An overview
- Public Understanding of genetics and genetic literacy
- Cultural competency in the South African setting
- Biomedical worldview and traditional healing worldview: conflicting paradigms
- Language barriers: South African setting
- The Sesotho Languages: Linguistic and demographic history
- Terminology development of Sotho languages

Genetic counselling: An overview

Genetic counselling is a process that aims to assist patients that are affected by a genetic condition to understand its genetic contribution and adapt to living with the condition (National Society of Genetic Counselors’ Definition Task Force et al., 2006). This includes the provision of medical facts and dealing with the psychosocial issues that are as a result of the condition (Resta et al., 2006). This is done by providing the client with well-researched and up-to-date information regarding the condition (Resta et al., 2006). Genetic counsellors serve to explain and counsel the patient about the condition and the inheritance pattern. This is explained to the patient at a level that they can comprehend often with the aid of diagrammatic illustrations (Kromberg et al., 2013). The recurrence risks of the genetic condition to children and other family members is provided to the counselee and genetic testing may be offered to other family members when appropriate (Delikurt et al., 2015). Furthermore, the genetic counsellor addresses any other questions or concerns that the patient may have developed during the session (Kromberg, Sizer & Christianson, 2013).

A significant aspect of adapting to a challenging and life-altering condition is how the patient feels upon receiving the information. Therefore, genetic counsellors also provide a safe space for patients to express their emotions and give them support (Morris et al., 2015). Additionally, they respond appropriately to patient psychosocial needs and accommodate various cultural, indigenous and religious views, a concept called multicultural sensitivity (Weil, 2001). In most cases, patients may feel overwhelmed after receiving a diagnosis. Most of them have shown to feel better with reduced anxiety after receiving a genetic counselling service. This also helps patients to better adapt to the condition (Peshkin et al., 2016).

At the end of the session, the patient may also be given information sheets that summarize the condition for the patient to read. This helps to reinforce the information since the counselling sessions are limited to an hour and some patients may not recall all the information later (Baker, Schuette & Uhlmann, 1998). Part of the genetic counselling process is patient follow-up after the session and referrals to a relevant support group for emotional support (Michie et al., 1997). In the support groups, the patients learn how others cope with the conditions and other practical ways of managing the condition (Biesecker, 2001). Patient follow ups include calling the patient after the session to hear how they are coping emotionally with the condition. This includes checking whether they are actively engaging with the suggested support groups, although a long-term follow-up is not routine (Biesecker, 2001).

Public understanding of genetics and genetic literacy

Globally, researchers found that in order for genetics to advance in both its clinical and research aspects in the field of medicine, the public need to have a basic understanding of genetic literacy (Lanie et al., 2004). This will in turn improve the quality of the data they collect and also improve the clinical practice through patient interaction and counselling (Sachs, Taube & Tishelman, 2001).

A review published by Condit (2010) covered the scope of public understanding of genetics and its influence on human health. In the review, Condit (2010) covered existing academic research that has been conducted in the past 15 years. It mainly targeted participants' understanding of genes and the role they play in the human body. It was found that people who participated in similar studies only understood the concept of genetics as being something to do with heredity and some family members sharing some degree of resemblance (Richards & Ponder, 1996; Vries et al., 2005; Lucke et al., 2008).

Some people were able to explain that they know that some of the health conditions they see around their communities are influenced by genes and the environment (Richards & Ponder, 1996). However, they did not understand the mechanisms behind the causes (Lanie et al., 2004). Some believe that a miscarriage of a baby with a congenital defect is the body's way of knowing that the baby would not have been compatible with life as we know it (Bowling et al., 2008). For people that are from areas where culture plays a huge role and science is less prominent, the information that is provided by a health professional is less likely to be taken into consideration or is rejected or questioned (Khdair, Al-Qerem & Jarrar, 2021). Therefore, the public understanding in terms of genetic testing is generally considered to be poor (Lanie et al., 2004).

Very little research has been conducted in South Africa on the availability and usage of genetic terms in the local languages (Kromberg et al., 2013; Levin, 2006; Shingwenyana, 2020; Solomon et al., 2012). Therefore, this creates a need for research to be conducted to explore the understanding of the concepts of genetics and available terminologies as used in the languages of indigenous groups in South Africa (Deumert, 2010).

The need to have terms in different languages are currently being addressed in Africa. The Indigenous Linguistic and Cultural Concepts of Heritability and Comprehension of Genomics Research in Nigeria (INDIGENE) was established as part of H3Africa (h3africa.org). This study aims to explore the linguistic and cultural concepts and fundamental genetic terms. So far, the study has identified words, proverbs, sayings, and other linguistic expressions that are used to explain the understanding of genetic concepts among the Yoruba population, which is a language predominantly spoken by people from Southwest Nigeria. The H3Africa website also stated that different researchers around Africa are now contributing to the study and exploring genetic terms in their respective ethnic groups. Current definitions can be accessed on indigenestudy.bioethicsenter.net.

Cultural competency and safety in health care setting

In order for healthcare professionals to effectively meet the medical and psychosocial needs of a multicultural society, efforts must be made for them to be culturally competent (Wang, 1994). Cultural competence is defined as the conscious awareness, acknowledgement and understanding of various cultural and religious beliefs that exist in target populations receiving healthcare (Gradellini et al., 2021).

However, the sustainability of cultural competency, which by definition, is individualistic, would be guaranteed by cultural safety, in which regulatory health institutions and organisations actively participate and are held accountable for continued provision of a healthcare service system that is equitable for all and reflective of the demographics of a nation (Curtis et al., 2019). Cultural safety in the interpersonal space gives power to the receiver of healthcare to decide whether or not the service would be beneficial to them (Ramsden, 2002).

In the South African setting, a few English-speaking health professionals have mastered the African languages, but the majority are still ignorant of the cultural diversity that surrounds them (Penn et al., 2010a). Hence, the language services are still poorly established, even more so in clinical genetics, despite the need being highlighted by the constitution (Levin, 2006a). This has highlighted the overall poor cultural competence of practising healthcare professionals.

Multiple studies have shown that the language barriers between health professionals and patients mostly result in patient dissatisfaction due to misunderstandings of the information exchange during consultations (Drennan, 1998). This also directly affects the quality of care that patients receive because they do not go back for check-ups nor follow medical advice (De Maesschalck, Deveugele & Willems, 2011).

In an effort to address and improve the cultural competency of healthcare professionals, University of Cape Town Faculty of Health Sciences in collaboration with the Department of African Languages Development established isiXhosa Health Science Programme for medical students (Deyi & Xhalisa, n.d.) as IsiXhosa is the second most spoken language in the Western Cape (Pascoe & Smouse, 2012). The programme was integrated into the curriculum of medical students and it became compulsory for students to learn isiXhosa as an effort to enhance their multilingual awareness and improve the clinical care received by isiXhosa-speaking patients.

In 2009, Hellenberg and colleagues introduced the Language Immersion Project, which mandated medical students to visit and spend time with either a local isiXhosa or Afrikaans speaking health professional for up to two and a half weeks of their specified clinical rotation. The programme also required the medical students to socially interact with their health professional host’s family and the community at large and learn about their culture under the strict rule that isiXhosa or Afrikaans is the only language spoken. Hellenberg later reported that immersing the medical students in an intense environment not only improved their linguistic skills, but also confidence in their clinical skills, awareness of cultural diversity, sensitivity and humility (Omar Y, 2014).

Biomedical worldview versus traditional healing worldview: conflicting paradigms

The diversity of the South African population in the context of language, culture, religion and belief systems presents different worldviews of healthcare, namely the biomedical model, which is rooted in western, scientific knowledge; and traditional healing model, which is rooted in indigenous, non-scientific knowledge (Moshabela et al., 2011). For instance, in the south African setting, a mother tongue or home language is usually related to ethnicity, cultural beliefs and traditional practises that are related to healthcare (Flint, 2008). Notably, the relationship between healthcare providers rooted in each paradigm is partly characterised by mistrust and conflicts (Flint & Payne, 2013). However, it is more complex and multifaceted than this.

When a black individual goes to seek healthcare services from westernized health professionals, they take with them, to some degree, a worldview of health that is largely influenced by their upbringing and social construct, which include culture, tradition and indigenous knowledge (Moshabela & Zuma, 2016), and in the South African context, medical genetics is based on the British tradition (Jenkins, 1990). Therefore, it is possible that a patient may not consider the biomedical explanations of genetic conditions. Mishler (1984) makes a point in that there is a suppression of the voice of the patient by the voice of medicine, which implies that the complex explanations provided by healthcare professions do not align with the everyday experiences of the patient (Barry et al., 2001).

The healthcare providers rooted in biomedical paradigm have made their criticism of the traditional healing model which have a non-evidence based approach publicly known, while the healthcare providers rooted in traditional healing paradigms have remained relatively silent (Mokgobi, 2014). This has led to patients disclosing biomedical information when consulting to a traditional health practitioner, but information from traditional health practitioner is unlikely to be disclosed when consulting a biomedical health practitioner. It is suggested that this is due to instructions by traditional health practitioners because they have a difficult time understanding why biomedical practitioner do not approve of their methods (Moshabela & Zuma, 2016).

Much of the current literature calls for both paradigms to work towards an improved and efficient healthcare system . However, the fundamental differences of both paradigms presents a hierarchical classification of knowledge, with biomedical knowledge being viewed as superior to the traditional healing paradigm. This continues to create conflicts and tension (Nyika, 2007). Thus, Moshabela (2011) makes the arguments that there is a need to view it as “the diverse ways in which illness can be perceived, understood and treated”.

Nonetheless, there is still a call for the two paradigms to be collectively implemented for the common good of healthcare. However, for this to be a reality, there first need to be mutual respect and acknowledgement of the fundamental principles of the two paradigms. Parties from both sides need to work towards a merged model that provides a holistic experience of healthcare. This model is called the bio-psycho-socio-spiritual model (Stoner, 2011).

Language Barriers: South African setting

Genetic counselling was established in South Africa in 1988 during the Apartheid era. At that time, the services were accessible mainly to Caucasians ranging from middle and upper socio-economic status (Kromberg & Krause, 2013). The services were then made available to a small population of Black South Africans at Chris Hani Baragwanath Hospital located in Soweto (Morris et al., 2015). However, since 2008, the services expanded and became available in Red Cross Children's Memorial Hospital and Groote Schuur Hospital through the University of Cape Town; Tygerberg Hospital through Stellenbosch; University of the Free State in Bloemfontein; and KwaZulu Natal in Durban (Kromberg, Sizer & Christianson, 2013).

There are other informal genetic clinics that are run by paediatricians with special interest in genetics, namely in University of Pretoria, Gauteng and in Polokwane Provincial Hospital, Limpopo and Durban, KwaZulu-Natal (Kromberg, Sizer & Christianson, 2013). The available genetic counselling services do not reflect the demographics of South Africa as some provinces still lack these services (Jenkins, 1990). This has contributed to the reasons why English and Afrikaans are the two main languages used in genetic counselling and that the majority of genetic counsellors in South Africa are English and/or Afrikaans first language speakers (Kromberg, Sizer & Christianson, 2013).

In terms of language, the communication barriers go beyond the fluency of the English language and requires an understanding of the key terminologies that are commonly used in a genetic counselling session (Levin, 2006a). Some genetic counsellors usually reduce communication barriers by inviting a trained translator to the session. However, less that 2% of health consultations are assisted by trained interpreters (Penn, 2007). To compensate for the lack of trained interpreters, cleaners, secretaries, nurses and other professionals are often called upon, which results in the increased risk of errors in the accuracy of translations due to the unfamiliarity of health concepts (Hunt & Swartz, 2017). Some genetic counsellors make an effort to learn the most common words of the people they mostly encounter (Taira, 1999).

Many studies have reported high levels of patient dissatisfaction where the doctor and the patient do not speak the same language (Taira, 1999). To address this issue, a study by (Levin, 2006b) aimed to identify obstacles that negatively affect access to healthcare by the Xhosa-speaking patients in South Africa. Data collection was done by designing and administering a questionnaire to a group of 53 Xhosa-speaking participants at Red-Cross War Memorial Children's Hospital. The questionnaire was used to explore what the participants thought are the obstacles to optimal access of effective healthcare. The results revealed two main factors, which are the socioeconomic status and language barriers.

According to Levin (2006b), patients were reported to be worried about not fully understanding what the medical practitioners are saying to them during consultations. More alarmingly, there is an increasing misunderstanding of medical diagnoses, use of medication and follow-up appointments by Xhosa-speaking patients as a direct result of language differences (Deyi & Xhalisa, n.d.). The study has also suggested that there is an existing strong association between language barriers and quality of care (Schlemmer & Mash, 2006a). This is because most patients refrain from asking for clarity from health professionals during consultations not only due to language barriers, but also cultural beliefs and power dynamics between patients and healthcare professionals (Levin, 2006a). Furthermore, there is evidence that the healthcare professionals are less likely to check whether the patient understands the medical jargon used in consultations (Watermeyer, Thwala & Beukes, 2021).

A study by Schlemmer and Mash (2006) explored the nature of problems faced by patients and health professionals as a result of language barriers at Hottentots Holland Hospital (HHH) located in Cape Town. The staff members spoke English and Afrikaans and the majority of patients spoke isiXhosa. After data analysis, it was found that language barriers created a negative environment between the staff and patients due to miscommunications. This directly resulted in patient dissatisfaction and negative attitude development between the two groups. The study then recommended that the staff should undergo training of basic Xhosa and that the hospital must also employ trained interpreters to overcome the language barriers.

It has been documented that an average health care professional cannot speak and/or understand the indigenous South African languages with the exception of nurses (Drennan, 1998). Crowford (1999) conducted a survey to document challenges that interfere with access to efficient healthcare services. In particular, the interpreting roles of nurses and the use of medical jargon in relation to disease concepts were investigated. It was found that Xhosa names were not pronounced correctly in the waiting room. This gave most patients anxiety prior to the consultation session. Moreover, the nurses were not willing to do the interpretation, therefore translators with no medical background/training were used (Crawford, 1999). This decreased the quality of the translation due to the lack of knowledge. The study further encouraged healthcare professionals to learn basic communication such as greetings in at least one indigenous language.

Levin (2006a) then conducted a similar study that aimed to explore whether patients understood the medical terms used by doctors to explain respiratory diseases, and to investigate the terminology used by patients in their indigenous language. The study sample consisted of 33 Xhosa-speaking participants at Red Cross Memorial War Children's Hospital and eight Medical Doctors that are first language English speakers. The results revealed that although there were some basic similarities in definitions of the terms that are available in both languages, patients did not understand many of the medical terms that the doctors used. Additionally, the Xhosa words used by patients were not in the vocabulary of the doctors and some English terms were not available in the patients' Xhosa vocabulary (Solomon et al., 2012).

Penn (2007) reported that employing a generally trained interpreter in the clinical genetics setting did not maximize the efficiency of the provision of health service. The author conducted research into other factors which could contribute towards the success of medical consultations. The factors identified the lack of specific medical terminology, training of the interpreters, and the disease context in terms of its cultural vocabulary and the perceived stigma. The study concluded that there is more efficient communication and patient satisfaction when the interpreter has received tailored illness-specific training. In some cases, these types of translators are not available for genetic counselling and available general translators are used instead (Browner et al., 2003).

The Sesotho language group: Linguistic history and demographics

The Sesotho languages are divided into three main groups, namely Sesotho, Setswana (Southern Sotho) and Sepedi (Northern Sotho). Sesotho is predominately spoken in Lesotho, Goldfields and the Vaal Complex in the Free State province (Letsoalo, 2019). Sesotho-speaking people represent approximately 4% of the South African population. The purest form of Sesotho can be traced in the Vaal complex, around Sharpeville, Van der Bijl Park, Sasolburg and major areas of Free State (Makwala, 2020).

It is possible to hear and distinguish some dialects among the Sesotho-speakers. Examples include *Sekgolokwe*, which is spoken in areas such as Harrismith, Bethlehem, Bergville and a part of Qwa-Qwa called Tsheseng (Snail, 2011). It is a dialect which derives words from both Sesotho and isiZulu. Another dialect which is also spoken is spoken in the abovementioned areas is known as *Setlokwe* (Snail, 2011). The descendants of Sotho-speaking people who lived in the former Transvaal can be traced in great numbers in the Pretoria area, including Mamelodi, one of Pretoria's Townships and also Potchefstroom, Orkney, Krugersdorp, Randfontein, Hammanskraal and Ga-Rankuwa (Smith, 1967).

The majority of the Setswana-speaking people are from Bophutaswana, a homeland for Batswana, which was situated between the Northern Cape and former Northern Transvaal (today known as North-West Province) and used to stretch across the border of Botswana and South Africa (Monyakane, 2016). When one listens to their language, there is undeniable proof that even Sesotho broke away from this language (Matšela & Mochaba, 1986). There is little to no linguistic difference between South African Setswana speakers and the those living in Botswana (Makwala, 2020).

Amongst many others Setswana dialects, there is one called *Serolong,* which is spoken in Bloemfontein and the whole Southern Free State and ThabaNchu (Snail, 2011). The other dialects like *Sengwato, Setlhaping, Setlokwe*, *Sehurutshe* are so linguistically close that it requires a Setswana speaker to distinguish (Monnig, 1967).

The remaining group of the Sesotho speakers are the Sepedi-speakers (Northern Sotho). The Bapedi inhabited the former Transvaal, but they are concentrated in areas North of Pretoria and across Northern Transvaal [modern day name: Limpopo] (Makwala, 2020). The homeland for the Bapedi was known as Lebowa (Smith, 1967). Most of the Bapedi reside in and around Pietersburg (now known as Polokwane), which was planned to be capital of that homeland (Smith, 1967).

The Sepedi language also has different dialects such as *(Ki) lobedu*, a dialect found in the vicinity of Mooketsi, Duiwelskloof and Tzaneen, but most people who speak this dialect are found in an area known as Modjadji (Monyakane, 2016). Another dialect known as *Setokwa*, is concentrated in places like Soekmekaar and some parts of Polokwane (Snail, 2011).

There is another dialect called *Sepulana* in Bushbuckridge and Phalaborwa (Snail, 2011). Sepedi is the main dialect on which the modern Sepedi is based and the speakers of it are found in lands called Ga-Sekhukhune, Jane-Furse and Middleburg. The written/official Sepedi in education curriculum draws most of its vocabulary from this dialect (Letsoalo, 2019). There are other dialects of Sepedi within the Province with no official names; however, they are spoken in the major areas of the Limpopo province such as Ga-Mothapo, Ga-Molepo, Ga-Matlala, etc. (Rakgogo & van Huyssteen, 2018).

The close relatedness of the languages is such that there are no impediments of communication between all their speakers (Makwala, 2020). Problems of communication can be observed between a speaker of Setswana or Sesotho with isiXhosa or isiZulu speakers who in their lives have never been exposed to the Sesotho languages, or the other way round, and in such cases there is a need for the employment of interpreters (Smith, 1967). This is common practice throughout South Africa in multi-lingual places (Letsoalo, 2019).

Terminology development of the Sotho languages

This study is based on the knowledge and understanding of terminology that describes concepts of genetics and inheritance. In order to execute this, there must first be a clear understanding of what terminology is. According to (Sager, 1990), terminology is defined as the study of activities concerned with the collection, description, processing, and presentation of usage of one or more languages. Sager (1990) then added that "*see it as the art of analysing terms in context and the systematic study of naming and labelling concepts with the aim of developing vocabulary for a given field"* (Duranti, 1997). Many South African languages have terminologies that are developed and borrowed from English and Afrikaans. This is because the languages were neglected for many decades and thus were not given an opportunity to advance (Letsoalo, 2015).

The South African indigenous languages were left underdeveloped as technology continued to advance (Letsoalo, 2015). This underdevelopment is noticed in other fields such as politics and economics, amongst others. The racial segregation during the Apartheid era played a major role in this. Letsoalo (2015) identified a gap that revealed the need to update the vocabulary of South African indigenous languages in various fields. This was done by conducting a study that sought to investigate possible systematic approaches to develop terminologies in Sepedi. The approach of this study paves a way to develop terminologies that provide meanings which are consistent and correlate with modern times (Letsoalo, 2015).

Another issue Letsoalo (2015) identified with this approach was that there is no clear system established to disseminate available developed indigenous terminologies. This poses a challenge because the speakers of a particular indigenous language must be able to gain access to those terminologies so that they can be practised and passed on from one generation to the next. Developed indigenous terms are routinely circulated through the internet, and thus they are accessed mainly by language practitioners. The best way in which the public can gain access to and use the recent terminologies of their language is for glossaries to be made publicly available as soon as possible to minimize the time lag (Letsoalo, 2015).

In addition to the need to establish a glossary of genetic terminologies, it was noticed that there were publications that assessed any aspect of genetic literacy in South Africa. Shingwenyana, (2020) conducted a study that aimed to explore patient's recall and understanding of genetic vocabulary in the context of Down Syndrome. It was shown that on average, patients demonstrated a good understanding of Down Syndrome. Some were able to list some clinical features associated with Down syndrome while some were able to give isiZulu terms that define inheritance. Solomon et al. (2012) conducted a study to review the understanding of genetic inheritance in the context of haemophilia. The study concluded that patients generally have a low understanding regarding clinical manifestations, treatment and management of haemophilia due to doctors using medical jargon and general language barriers (Solomon et al., 2012).

RATIONALE

Genetic Counselling is a health service that should be accessible regardless of one's ethnic and demographic background. Genetic counselling is still a relatively young and developing field in South Africa. It is now slowly reaching new demographic areas as time progresses and more people across South Africa are learning what Genetic counselling entails. English is the main language used in Genetic counselling sessions.

One of the biggest challenges that genetic counsellors face when counselling patients of different ethnic and cultural backgrounds is the language barrier. This language barrier can result in the message being sent by the counsellor not being the same message received by the patient. This can cause frustrations due to misunderstandings, and the counsellor having to attempt several times to elucidate a certain medical concept to the patient (De Maesschalck et al., 2011). Additionally, when the counsellor and patient do not share the same language, then a trained translator has to be present. In some cases, the communication through a translator not only has the potential to disrupt how the patient interprets the information provided, but also the rapport building between the health care professional and patient (Browner et al., 2003). This can have a negative effect on the overall genetic counselling session.

Therefore, this research aimed to identify common indigenous terms used to describe concepts of genetics and inheritance which can be used in genetic counselling when the patient does not understand or speak English. The data will be used to compile a list of those terms and their descriptions in indigenous languages in order to minimize the language barriers. It is hoped that this study will be used as a tool to foster an environment where counsellor and patient can effectively communicate about the medical and genetic aspects of the condition, as well as establishing good rapport in the session. Furthermore, this will allow the establishment of empathy, which will then increase the efficiency of the counselling sessions. Having a glossary comprising of genetic terminologies could potentially minimise the need to use a translator for a more effective session.

PURPOSE OF THE STUDY

Aim

The aim of the study is to investigate the knowledge and understanding of basic genetic terms in the South African Sotho-Pedi-Tswana ethnolinguistic group and to explore the available common terms, sayings and expressions.

Objectives

- To assess the participants’ knowledge and understanding of genetic literature and inheritance concepts.
- To explore the terms, sayings and expressions used in the different Sotho languages to describe genetics and inheritance.
- To compile a list of genetic terminology or phrases in the different languages that can be used in Genetic Counselling

CHAPTER TWO: METHODOLOGY

INTRODUCTION

In this chapter, the methodological design and framework that was used for the study is outlined. The study population and research setting, the nature of the sample, participant recruitment and data collection as well as the methods used for data analysis are described. Furthermore, the validity and reliability of the study as well as ethical matters that were considered are noted.

STUDY DESIGN

There are two broad categories of research designs, namely qualitative and quantitative. Quantitative research is associated with an objective approach towards data collection that is then represented numerically and analysed statistically (Goertzen, 2017). A qualitative research approach attempts to understand the participants' perspectives in the context of their experiences, beliefs, and behaviours. Furthermore, qualitative research is subjective and gives the participants a voice, and the non-numerical data generated is interpreted to make meaning (Pathak et al., 2013). This study aims to document the available genetic terminology and how the terms are used in different ethnolinguistic communities, hence a qualitative approach was chosen for this study.

The study design drew from the principles of sociolinguistics and cultural competency. Sociolinguistics is a field in sociology that studies the relationship between language and society; it looks at how language and its variability is used within different contexts of social interactions (Holmes, 2013). This is supported by cultural competency theory, which in the context of healthcare, is defined as the acquisition of knowledge and understanding of different social and cultural backgrounds of patients as a means of achieving effective communication and improved health services (Betancourt et al., 2003). These paradigms are chosen because they are in line with how the existing languages are structured and how they are used in society, specifically in the interactions between patients and genetic counsellors. This approach as outlined above is thought to be best suited to enable the accurate documentation of the available genetic terminology to understand the context of usage of the terms.

Focus group interviews are best suited in this approach as it will acquire data from participants who have first-hand knowledge of genetic terms available in the Sotho languages, which is in line with sociolinguistics as it allows participants to provide insights following an open-ended guide (Gilchrist, 1992). Interviews in the form of focus group discussions was selected because according to McLafferty (2004), focus group discussions have shown to be an efficient way of gaining an in-depth understanding of social issues (Nyumba et al., 2018), and contrary to individual interviews, focus group discussions allow the potential for storytelling by multiple opinions presented in each session, thus being particularly suitable as it will encourage discussion among interviewees (Colucci, 2007).

RESEARCH SETTING

In this study, the target pool of participants were registered University of Cape Town (UCT) Students. UCT had 30 392 registered students in the 2021 academic year, of which 26 614 were South Africans. The institution has six faculties; namely Commerce, Engineering, Science, Health sciences, Law and Humanities (UCT Fact Sheets, 2022).

The South African UCT students are from different parts of South Africa, including both rural and urban areas. Therefore, South African UCT students were thought to be an ideal sample as they are linguistically diverse, consisting of a mixture of individuals from different areas where the languages from the Sotho-Pedi-Tawana ethnolinguistic group is spoken. It was anticipated that the participants will have first-hand knowledge of the words in the languages. In addition, they were an ideal and accessible community to represent general knowledge on genetics.

PARTICIPANT SAMPLING

Purposive sampling was employed to recruit the participants. Purposive sampling is a sampling method that is used to identify information-rich individuals in a particular area of study that is directly related to the specific phenomenon of interest (Palinkas et al., 2015). Only students enrolled in non-science and non-health science faculties were recruited because they do not have direct exposure to the scientific (biological) terms to describe genetic terminologies at a university level and are thus more likely to provide terms that are used by the lay Sotho language speakers.

Penn (2010) investigated cultural beliefs of grandmothers regarding childhood genetic conditions, and the sampling was convenience with ethnicity not taken into consideration. Shingwenyana (2020) assessed patient re-call of genetic vocab after the participants received formal genetic counselling, and the sample included all native ethnic groups. Levin (2006) investigated the use of medical terminology and how it affected the communication between healthcare professionals and isiXhosa-speaking patients who do not understand English. Thus, this study specifically chose Sotho-speaking participants as there is no previous study that investigated the Sotho-specific terminology to describe genetic concepts.

RESEARCHER POSITIONALITY

The researcher's positionality as a first language Sepedi speaker was a major contribution to the interest of undertaking the research in the Sotho language group. The researcher grew up in a rural area of the Limpopo province and witnessed common genetic conditions such as Down Syndrome not being given recognition and a lack of resources in local clinics.

This led to the researcher thinking that there is perhaps a significant number of individuals that have undiagnosed genetic conditions in rural areas that do not have access to medical genetic and counselling services. Thus, as a step towards gradually developing a genetic service in Limpopo, it was thought to be imperative to conduct a study that investigates the knowledge of basic genetic terms in the Sotho Language speakers. In this study, South African students that are first language speakers of Sesotho, Setswana or Sepedi and registered in the faculties of Commerce, Engineering & Built Environment, Law and Humanities, were recruited in the study. Furthermore, there are not many differences between the three languages; and the researcher is fluent in all of them, the need for a translator for the interviews was eliminated. Additionally, the co-supervisor of this study also belongs to the Sotho-Pedi-Tswana ethnolinguistic group.

In this study, all participants were from different parts of the country, including both rural and urban areas. Each focus group discussion session included a combination of all the respective Sotho-Tswana-Pedi ethnolinguistic groups as mentioned above. This did not pose any linguistic challenge as the researcher understood all the three languages.

Inclusion Criteria

First language speakers of Sesotho, Sepedi and Setswana that:

- Are registered UCT students over the age of 18 years.
- Are registered in the faculties of Commerce, Engineering, Law and Humanities.
- Have access to internet connection and have an active Microsoft Teams account.

Exclusion Criteria

- Any South African below the age of 18 and individuals who are not first language speakers of any of the Sotho-Pedi-Tswana ethnolinguistic group.
- Any South African UCT student registered in the faculty of science or health sciences.

PARTICIPANT RECRUITMENT

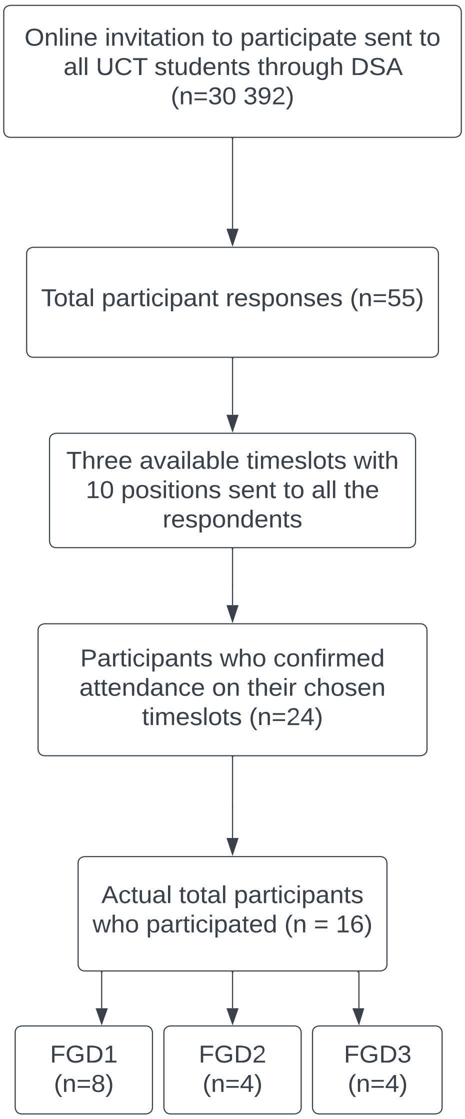

Figure 1. Flow-diagram illustrating the summarised recruitment strategy.

An online invitation was sent out to all UCT students using the mailing list of the Department of Student Affairs (DSA) (Appendix C). The invitation described the scope and aim of the research, along with a compensation fee of R150 per participant. Those that met the criteria and were interested in participating emailed the researcher and expressed their interest. The available timeslots were sent out to all respondents to select a date through a Doodle poll (doodle.com). After all the timeslots were filled, an informed consent form (Appendix B) was sent to all the respondents. Each respondent emailed the signed form back to the researcher. The Microsoft Teams meeting links for the focus group interviews were sent to all respondents.

The ideal number of participants in a focus group discussion is six to eight (Krueger, 2014b). Although this is the ideal number, some studies have as few as four participants and some studies have as high as fifteen participants (Fern, 1982). One potential obstacle is that there is no guarantee that all participants will be present for the focus group discussion (O.Nyumba et al., 2018). To address this potential for under recruitment, an over-recruitment of between 10-25% of participants is recommended. Therefore, a total of ten participants is considered to be sufficient to accommodate the potential shortage and can be well managed (Krueger, 2006).

To ensure that enough people attend the focus group, a total of ten participants were recruited per focus group timeslot. Although all participants confirmed attendance, some did not join the focus group discussion.

The interview timeslots were scheduled one week apart from each other to allow time to reflect on each interview and provide an opportunity to make any modifications to the interview guide for the next focus group discussion.

DATA COLLECTION/ RESEARCH PROCEDURE

Key informant interviews (KII) were conducted based on a focus group interview approach (Gilchrist, 1992). The key informants, which are the first language speakers of the Sotho-Pedi-Tswana ethnolinguistic group, were invited to share their ideas in a facilitated manner, thus the focus group discussion method was adopted. A focus group discussion is defined as a type of interview where a researcher designs a prompt for a selected group of participants to generate large and rich amounts of data that address a specific topic of interest (McLafferty, 2004). The interview prompt was developed as per the researcher's experience in genetic counselling practice and based on the aims and objectives of the study.

Focus groups were used instead of individual interviews because they encourage active participation through the communication of participants and sharing of ideas, which in turn results in rich and diverse data being generated (Nyumba et al., 2018). The popularity of focus group discussions as a qualitative data collection technique increased in the early 80's and has become a popular way that researchers strategically use as a bridge between scientific research and local knowledge (Cornwall & Jewkes, 1995). Focus group discussions in sociolinguistics are perceived to be a reliable alternative to individual interviews in participatory research because it offers a good platform for understudied paradigms and worldviews (Orr, 1992), in this context, available genetic terminologies.

Thus, focus group discussions were found to be the most appropriate data collection methodology to meet the aims and objectives of this study. This technique forms the core component of this research project because it gives the platform for pre-existing knowledge of genetic terminologies and inheritance concepts to be explored and discussed by participants who speak languages and dialects belonging to the Sotho-Pedi-Tswana ethnolinguistic group from various areas across the country. Focus group discussions have been found to be effective in providing a platform for a cultural group of participants to reflect on different aspects of their social realities by allowing different ideas to be discussed simultaneously, furthermore, focus group discussions of participants from the same ethnic group enhances participation and in-depth discussion of ideas (Hughes & DuMont, 1993).

An important aspect that determines the efficiency of a focus group discussion is the participants' willingness to fully engage with each other (Kitzinger, 1994). To ensure this, the researcher provided the background, explained the aims of the research and provided context to ensure that the participants understood the study and expectations prior to each focus group. Rapport on video calling can be difficult to build especially among strangers (Weller, 2017), therefore at the beginning of each focus group discussion, each participant was provided with an opportunity to introduce themselves and provide a brief background of where they come from, their first language and the faculty they are registered in. This fostered familiarity allowing them to be more comfortable.

Data was collected through focus group interviews using a question guide (Appendix D). The interview guide had 13 questions consisting of open ended and non-directive questions and probes that focused on the available genetic terms and indigenous concepts of heredity. In each focus group discussion, the participants discussed their understanding of DNA, gene, inheritance and the available terminologies in their respective home languages. Furthermore, terms and expressions used to describe common genetic conditions such as Albinism and genetic concepts such as consanguinity were discussed.

Questions were adapted as necessary and additional probing was used given the structured nature of the interview. All questions in the interview guide were in English, however, the participants were given the freedom to provide their responses in either English, their home language or mix the languages, which further encouraged participation and thus increased the richness and depth of the data collected. At the time of the interviews, the focus groups were held online using Microsoft Teams due to the COVID-19 social distancing regulations still in place at the University. Furthermore, it was a more flexible and convenient way for all the students to join the focus group discussion as they did not have to travel to a particular venue.

All three focus group discussions were audio recorded using Microsoft Teams. The first draft of the transcripts obtained from Microsoft Teams contained errors due to the mixing of languages during the discussions. The researcher then corrected the transcripts for analysis.

The focus group discussions have to be conducted until the results generated no longer change or no new information emerges, and this is known as data saturation (Krueger, 2014b). In this study, data saturation was reached by the end of the third focus group discussion as no new information surfaced after its completion. Given the small sample size and the one-time encounter nature of the focus group discussions, a research topic cannot be fully exhausted within a single session (Vaughn, Schumm & Sinagub, 1996). Therefore, it is recommended to conduct a minimum of three sessions for a simple research topic (Matthews, Baird & Duchesne, 2018). Hence in this study, three focus group discussions were conducted.

DATA ANALYSIS

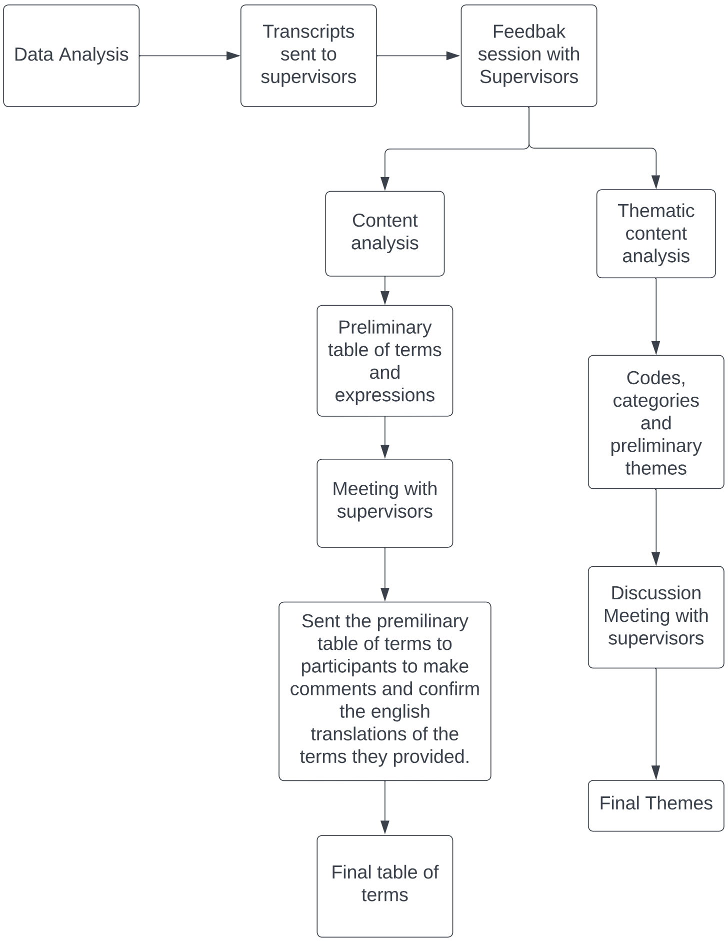

Figure 2: Flow diagram illustrates the data analysis strategy from the three focus group discussions.

Each transcript was listened to shortly after the focus group discussion to take note of the data and interactions to determine if any adjustments to the interview guide were needed.

The same approach was repeated for the second recording. After all three focus group discussions were completed, the recordings were listened to again and short notes and reflections were made in a research notebook for discussions with supervisors. This allowed the researcher to process and internalize the information output from each focus group recording and thus be able to identify similarities and differences.

TRANSCRIPTION & TRANSLATION

Each recording was then transcribed verbatim using the transcript provided by Microsoft Teams as a basis. A verbatim transcript is used to capture the participants own words, specific use of language and the corresponding verbal and non-verbal cues (Hennink & Weber, 2013). Each transcript was read multiple times to familiarise with the data as part of the data analysis process. For research rigour, the transcripts were then submitted to supervisors to read; and meetings arranged for discussion and feedback.

The data was analysed in two ways, content analysis and thematic analysis. Thematic content analysis and content analysis are different, as used in this dissertation. Joffe (2012) points out that thematic analysis originally emerged from content analysis, but it developed into a separate approach with its own unique research goals. This evolution over time contributes to the confusion between the two method. More specifically, the theoretical thematic content analysis was employed as it permits coding for a specified research question (Braun & Clarke, 2006).

Content analysis involves the organization of collected data into categories to uncover patterns that would otherwise not be detectable by listening to the recordings (O.Nyumba et al., 2018). This was specifically used for the available terminology in each language. The terms were extracted as they are and were translated to English. A table consisting of terms and expressions and their English translations was thus compiled. To demonstrate the characteristics of the languages, direct literal translations were provided and not necessarily what is implied in the indigenous languages (see Table 1 in Results Chapter). To increase rigour, the preliminary English translations were shared with the participants after preliminary analysis to make comments as a collaborative effort to validate the words and spelling in each language and dialect. When a researcher shares the analysed data with the participants in qualitative research, the process is known as member checking, and is used to validate the results (Birt et al., 2016). The table was uploaded on google sheets and a link was shared with all participants with exclusive access through their personal email addresses. Furthermore, some participants made a note that as part of their review process, they consulted with their parents and grandparents regarding the accuracy of the spelling of terms of each dialect.

Thematic analysis was employed to explore the context of the terminology usage, which included qualitative data regarding sociocultural perceptions and beliefs about genetic conditions. Thematic analysis is defined as a qualitative method of generating codes to identify specific patterns that arise from the collected data (Braun & Clarke, 2012; Vaismoradi, Turunen & Bondas, 2013) This process is initiated by data coding which is accomplished in two phases: The first phase, initial coding, is where numerous codes are generated from the transcripts without placing any limitations; diagrams are drawn to link similar ideas to generate meaning. The researcher lists all emerging ideas and identifies frequently used words which are then used as guidance to emerge preliminary themes (Charmaz, 2006). The second phase is known as focused coding where the researcher combines, eliminates or subdivides the generated codes and careful attention is given to recurring ideas that connect to the codes. The codes that are associated with similar ideas are then grouped in the categories which will ultimately describe the corresponding themes (Charmaz, 2006; Krueger, 2006). Figure 2 above illustrates the specific steps the researcher took to analyse the data.

RESEARCH RIGOUR & TRUSTWORTHINESS

Rigour in the context of qualitative research is crucial as it forms the basis of establishing trust and integrity of the research findings such that they are reliable and valid (Thomas & Magilvy, 2011). Trustworthiness is defined as the degree to which the results of a study can be believed, and it is measured by the following four pillar developed by Lincoln & Luba (1985) as indicated by Macfarlane, Zhang & Pun (2014):

- Credibility – how believable the results are from the participants' perspective.
- Transferability – the ability to replicate the same study and obtain similar results with different respondents.
- Dependability – the reliability of the conducted research and ever-evolving context.
- Confirmability – the ability of the research to identify positional viewpoint, biases and pre-conceptions

The researcher ensured rigour by:

- Following a structured approach of data collection and transcription.
- Re-checking the verbatim transcripts to ensure correlation between the transcripts and audio recordings.
- Regular confidential meetings with both supervisors to discuss the systematic way of analysing the collected data. (See Figure 1).
- Using direct quotes from the verbatim transcripts as evidence to support the statements made in the research findings.
- Reverting back to research participants to provide them an opportunity to comment and make suggestions on the research findings.
- Researcher self-reflection to ensure that both his personal and linguistic biases do not influence the data.

ETHICAL CONSIDERATIONS

Ethical Approval

The research protocol was submitted and approved by the Department of Pathology Departmental Review Committee and the University of Cape Town Health Sciences Research Ethics Committee. HREC number: 554\2021 (Appendix A).

Informed Consent

Informed consent refers to when a researcher has provided a potential participant with enough information in order to voluntarily make an informed decision on whether or not to take part in the study (Fields & Calvert, 2015). All respondents who agreed to take part in the study were emailed a copy of the informed consent document which explained the study's aims and objectives, and how the data would be collected (Appendix B). They all signed the form prior to participation and have their own personal copy. The research procedure was then verbally reiterated prior to the commencement of each focus group discussion to ensure that all participants have a consensus and they were given an opportunity to seek clarity on the research.

Privacy And Confidentiality

The privacy and confidentiality of the participants was respected by upholding the following:

- All confidential and identifying documentation were stored separate from the data.
- Audio recordings of the interviews and focus groups were removed from the recording device after uploading it to the computer and saved on a password protected computer
- The researcher himself did the translation of the audio recordings.
- The collected data was de-identified and participants were given anonymous participant codes.
- The raw data was shared with the supervisors only in order to help with the structuring of tables of terms and identification of the corresponding codes and themes.

Other Considerations: Risks And Benefits To Participants

- Potential benefits:

Although this may not benefit the participants directly, a compilation of translated genetic terms and definitions of the Sotho-Pedi-Tswana Ethnolinguistic group will be developed and made publicly available. This will help to minimize the language barriers of genetic counselling and make the sessions more efficient and of higher quality. Furthermore, each participant received R150.00 as compensation for their time and contribution.

- Potential harm

Some of the interview questions had the potential to induce stress for a participant that has a family member or a friend that is affected with a genetic condition. This could have potentially evoked emotions during the interview process. However, this was explained to all participants before consenting to be part of the study and that should there be a need, the participant would be referred for genetic counselling or other services as required. Although there were some participants who mentioned family members with genetic conditions, none of the participants expressed the need for further referrals.

CHAPTER THREE: RESULTS

INTRODUCTION

In this chapter the findings of the study are documented. It begins with the sociodemographic information of the participants followed by the results. Participant codes (P-codes) are used to distinguish between participants' contribution to the data without revealing individuals' true identities. FGD stands for "focus group discussion" and 1, 2 and 3 refers to the different focus groups conducted.

The results are presented in two parts, with part one being the themes that were identified during data analysis illustrated with excerpts of the verbatim-transcribed audio recorded interviews. The themes provide insight into sociolinguistic context of the terms, which include the social perception, cultural beliefs and understanding of genetic conditions.

Part two is the documentation of all the indigenous terms provided by the participants of the Sotho-Pedi-Tswana ethnolinguistic group. The table demonstrates the expressions and phrases related to inheritance. There are terms available to describe some of the well-known genetic conditions seen in respective communities including commentary on how they should be used.

PARTICIPANT DEMOGRAPHICS

The participants were from different rural and urban areas where their languages and different dialects are spoken, thus there was a good demographic representation. Notably, there was an unbalanced gender representation, with one male in each focus group discussion. The majority of the participants were Sepedi speakers (n=8). All the Sepedi speaking people are from Limpopo; all the Setswana speaking people (n=3) are from North-West; the Sesotho speakers are divided, with three from the Free State; one from Limpopo and one from Gauteng. Thirteen participants were enrolled for undergraduate degrees and three participants in postgraduate studies. Twelve participants are in the faculty of commerce; two participants in the faculty of humanities; one participant in the Law Faculty and one participant from Engineering & The Built Environment.

A summary of the participant's sociodemographic information is reflected in the table below.

P-code	Faculty	Gender	Qualification	Language (First Language)	Demographic origins	Age
Focus Group Discussion 1						
FGD1P1	Commerce	Male	Undergraduate	Sepedi	Limpopo, Mafefe	21
FGD1P2	Commerce	Female	Undergraduate	Sepedi	Limpopo, Polokwane	23
FGD1P3	Commerce	Female	Undergraduate	Sepedi	Gauteng, Pretoria	20
FGD1P4	Commerce	Female	Undergraduate	Sesotho	Free State, QwaQwa	24
FGD1P5	Commerce	Female	Undergraduate	Sepedi	Limpopo, Ga-Mashashane	20
FGD1P6	Commerce	Female	Undergraduate	Setswana	Northwest, Mafikeng	23
FGD1P7	Commerce	Female	Postgraduate	Sesotho	Gauteng	31
FGD1P8	Commerce	Female	Postgraduate	Sepedi	Limpopo, Burgersfort	22
Focus Group Discussion 2						
FGD2P1	Humanities	Female	Undergraduate	Sepedi	Limpopo, Jane Furse	20
FGD2P2	Humanities	Male	Undergraduate	Setswana	Northwest Rustenburg	19
FGD2P3	Commerce	Female	Undergraduate	Setswana	Northwest, Zeerust	23

FGD2P 4	Law	Female	Undergraduate	Sesotho	Free State, Bloemfontein	23
Focus Group Discussion 3						
FGD3P 1	Commerce	Female	Undergraduate	Sesotho	Free State, Bloemfontein	18
FGD3P 2	Engineering & The Built Environment	Male	Undergraduate	Sepedi	Limpopo, Dennilton	22
FGD3P 3	Commerce	Female	Undergraduate	Sesotho	Limpopo, Polokwane	19
FGD3P 4	Commerce	Female	Postgraduate	Sepedi	Limpopo, Ga-Rampheri	28

Table 1: Demographic details of research participants.

INTRODUCTION TO THE THEMES

In addition to the terms, the participants also made comments regarding the societal perspectives and usage of the terms. Thus, following the direct extraction of the terms from the verbatim transcripts, there was additional qualitative data that provided context to the terms. Through an in-depth analysis and careful study of the transcripts, four main themes were identified as illustrated in the figure below, and there is overlap on some of the themes.

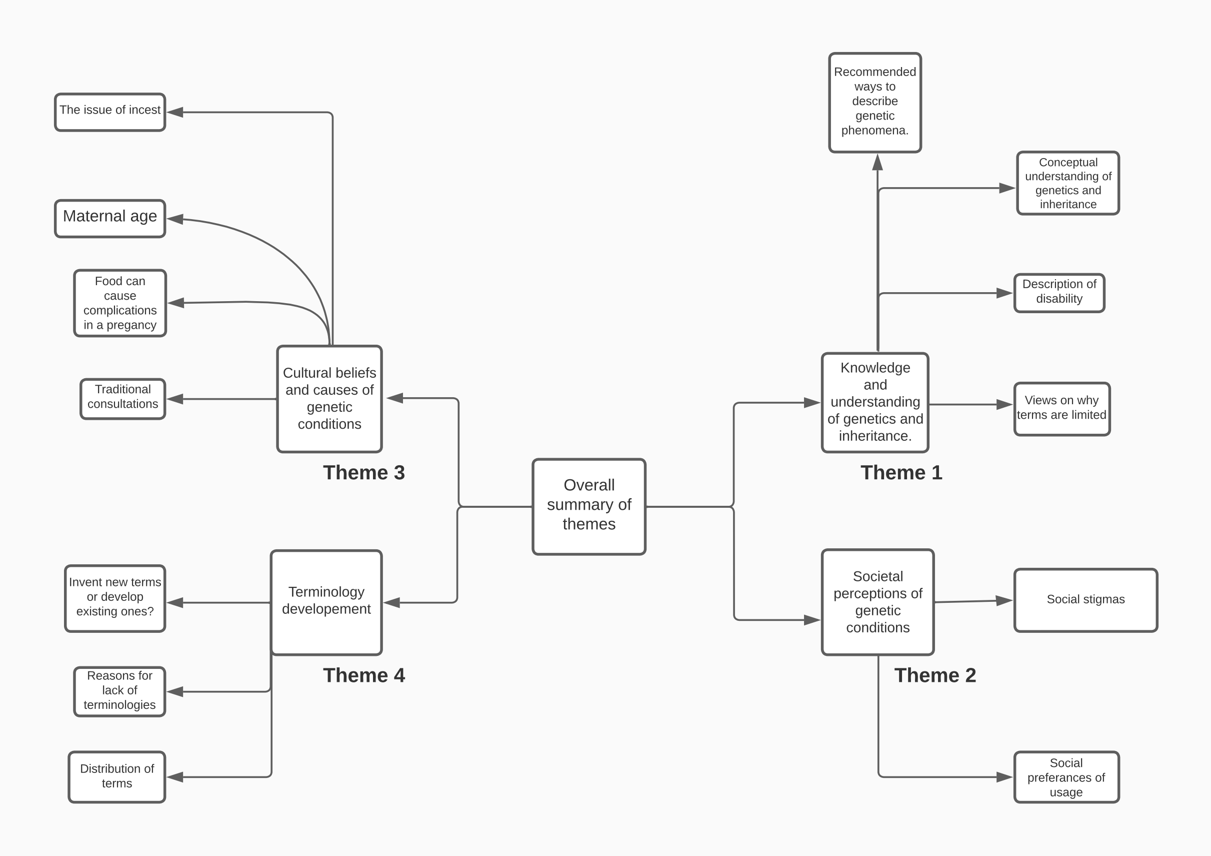

Figure 4: Overall structure of themes.

Theme 1: The knowledge and understanding of genetics and inheritance

All the focus group discussions began with the researcher asking the participants to provide existing terminologies used to describe basic genetic terms such as inheritance, gene and DNA. This question led to the discussions on the knowledge and understanding of genetics and inheritance. In the discussions the following subthemes were identified:

- Conceptual understanding of genetics and inheritance.
- Description of disability and recommended ways to describe genetic phenomena.
- Views on why indigenous terms are undeveloped.

Subtheme 1: Conceptual understanding of genetics and inheritance

All participants understood the concepts of genetics and inheritance and explained that there are words in their language to describe them. The different ethnolinguistic groups provided terms in their respective dialects that literally translate to “inheritance” . However, there are no available terms to describe concepts such as “gene” and “DNA”. The participants provided metaphoric phrases that describe their understanding of inheritance and further provided examples by using physical familial traits.

The concept of inheritance was shown to be understood as involving physical familial traits. *FGD3P4* used the word “Sepopego” (Sepedi) which directly translates to “shape” which in this context refers how an individual is built.

> *“OK. Can I get in? I think its complex because…mostly we are referring to things we see. Ba tlo re “lefa”[they will say ‘inheritance’].. but for genes, I’m not sure if that is appropriate? OK. You can say o bopegile go swana le mmage le papage.[he/she is built like his/her mother and father] goba [or] O mo abetše mmala or mosepelo [he/she has inherited skin colour or walking style] , etc.” -FGD3P4*

This shows that there is an awareness of something or attributes within individuals that shows that they are related. It was further elaborated that the familial physical features are evidence that an individual comes from a specific ancestral lineage.

> *Sa le wa utlwa [Have you ever heard] in the family like when they describe maybe ngwana o tshwana le malome wa gagwe [A child like looks like his/her uncle], or o tseetse malome wa gage ka something [or took after his/her uncle with something], then we say its hereditary – FGD2P2*

There is also an understanding that although genetics explains familiarity and shared common ancestry, the participants also explained that it can also explain why relatives have or are predisposed to certain illnesses.

> *"It can be like everything for example. I know with diseases like ke nale [I have] low blood pressure. So Mama likes saying "o latile rakgolo wa gago" [you took after your grandfather] in terms of that." -FG2P4*

FGD1P7 understood DNA to be "blood in the family", and also acknowledged that there is no specific term. Although "maadi" directly translates to blood, figuratively it means "something in the blood or DNA". FGD1P7 further elaborates that DNA is what connects a person to their lineage.

> *"OK, what I understand about DNA.. it's just that our languages are not developed, but ke gore nkare ke "maadi" [but I would say it's like blood. ('Maadi')"] – FGD1P7*

> *"But what I understand is that it's what makes you unique as an individual, and also..nka reng? [what can I say?] Connects you to your lineage. But ka Sesotho ha kena a specific term [in Sesotho I do not have a specific term.]" - FGD1P7*

FGD1P8 provided an example of having a similar nose as the father. The community understands that there is something running in their blood that is responsible for the inheritance of the observed familial traits and resemblance, as seen by the quote below.

> *"When I hear the word 'gene', what comes to mind is your family traits like otla kreya ba re ke nko ya papage [you will hear someone saying it's their father's nose]." - FGD1P8*

Subtheme 2: Descriptions of disability and recommended ways to describe genetic phenomena

When asked to provide an explanation of an individual they have observed who has a genetic condition, all participants reached a consensus that the individual would generally be regarded as "disabled". There are only two phrases with varying spellings (language-specific) that are used to describe disability across all three languages, namely "Segole" (Sepedi and Sesotho) or "Sehole" (Setswana) which both directly translate to "disabled" and "Ga a itekanela" (Sepedi and Sesotho) or "Ha a itekanela" (Setswana) which means that "the person has not developed completely" with specific reference to intellectual disability.

> *"It's the same for rona [It's the same for us] Any word.. you can use the two. So, for example, someone with schizophrenia, right, normally we say 'ga a itekanela' it's like a mental disorder. Even when someone can't walk properly we say 'ga a itekanela'. So you can interchange." – FGD2P1*

> *"Yeah even in Sesotho ke [it is] 'segole' or 'ha a itekanela'." – FGD2P3*

“Segole/Sehole” and “Ga a itekanela/Ha a itekanela are thus used as umbrella terms to describe people with disability as a spectrum. For instance, the participants gave examples such as schizophrenia; people with speech impairment; people who have normal intellectual capacity but cannot walk and use wheelchairs; and people who have both physical and intellectual disabilities. There are no specific terms provided by participants that distinguishes a disability that has a genetic cause versus one that is due to other causes such as teratogen exposure, environmental factors and/or deformities.

> *“You can have a physical disability and that can be like joint with like mental issues as well... not be like mentally fully grown. I don't know how to explain that essentially but it could be like a certain illness.. and even though we don't understand it because I feel like we don't necessarily ask like what's the real name and what does it do, like re no bona gore motho ona [we just see that this person] is on a wheelchair.” – FGD2P4*

> *“Or if someone is on a wheelchair but also can’t speak, you know, like lingos not coming out properly or whatever the case may be, so you can say ‘ga a itekanela’ [it’s a disability] because for example like you have to take care fully of this person. You know, I mean like it's a mental thing because the illness became a mental thing as well in the long run. So I think that it would you could call it whatever is fitting at the time.” – continued by FGD2P4*

The two phrases are reported to be used interchangeably, however, the participants also pointed out that the former is more associated with physical disability and it is considered to be a rude way of describing people while the latter is a more empathetic and polite word. There is no distinction in relation to the actual cause of the disability. Additionally, there were comments by other participants that “segole” is derogatory and “ga a itekanela” is a kinder way and it shows empathy and politeness towards the affected individual.

> *“Le ka Sepedi ke ‘segole’ [even Sepedi it’s ‘segole’]. But if we are just trying to be or make it seem kind, we say ‘ga a itekanela’.” – FGD2P1*

> *“Yeah, and when you say ga a itekanela, it’s more like they can’t stand for themselves. Meaning they require extra assistance, so it’s not derogatory.” – FGD3P1*

The participants agreed that all the three indigenous languages seem to use a more descriptive approach towards observed phenomena that is uncommon within communities. The participants said that if one describes the physical features and behaviour of an individual affected with a genetic condition, then people are more likely to understand what condition you are referring to, even if there is no specific term for it. Using Down Syndrome for instance, the participants say that you would have to describe features such as short stature, relatively smaller head and ears, intellectual disability, require special needs education and the fact that they all ‘look’ the same regardless of racial differences, as the participants described in the quotes below:

> *“Most children with Down Syndrome, maahlo a bona a wele [their eyes are down slanting]. Le sefahlego sa bona se wele [even their faces are down slanted/ lowly placed]. Mostly ge ba bolela ba raga leleme [mostly they stutter when they talk] and then gantšhi ba tšea nako gore ba understand di instruction [they take time to understand instructions].” – FGD3P4*

> *“Uh, go ya ka nna [uh, according to me], ngwana wa Down syndrome o no belegwa a sa itekanela [a child with Down Syndrome is born disabled/ underdeveloped]. Ga a kwe gabotse [The child cannot hear properly] and everything else that was said.” – FGD3P3*

With reference to the quote above by FGD3P4, “raga leleme” translates to “kicking the tongue” in English, however, in Sepedi it means to “stutter”. This is another example of how the Sotho languages often use metaphors to describe certain phenomena.

Subtheme 3: Views on undeveloped terms

The participants mentioned that one of the reasons why genetic syndromes do not have indigenous terms could possibly be due to the low prevalence in communities, and so the community members would collectively regard it as an “insignificant” issue that is of low priority. Another reason was thought to be that although individuals with Down syndrome, for example, may look different, they are still able to perform basic human abilities such as walking, social engagement and understanding basic instructions. Therefore, some community members may view it as a normal variant that does not need to be labelled.

> *“Yeah, I think that is the problem, in my years of living in [hometown], all my years growing. I’ve only seen one person with Down syndrome, and I have been alive for a very long time!”- FGD1P6*

> *“I think one of the reasons why they hardly talk about Down syndrome is because “bana ba teng le bona” [the children also have] they have the same abilities and are born after nine months. Although physically we see some differences, but they can perform basic human abilities so maybe that is why they did not give it a label.” – FGD2P2*

A participant commented that another reason why terms are limited could possibly be because of their age-group as participants and therefore might not have the full knowledge, and probably exposed to the more colloquial versions of the language given that the age range of the participants in this study was 18-30 years. Additionally, there was no consultation with the elderly prior to the commencement of the focus group discussions. Therefore, it could be because some of them were not exposed to the formal version of their indigenous languages when growing up since elders generally did not openly have conversations regarding genetic conditions.

> *"Do you think that because we are so young, we actually don't know these names. And they actually do exist? Do you think this would exist more within like, you know. I don't want to say traditional things, but traditional medicine rather? In that sense then maybe we don't know traditional medicine well enough. And now those names are sort of faded away in our everyday conversations." – FGD2P3*

Another reason could be because some participants were raised in suburbs and townships where the "diluted" version of their mother tongue is spoken. *FGD2P1* commented that the elders, particularly in the rural areas (villages) where a "purer" form of their mother tongue language is still being spoken, are aware of some of the commonly observed genetic conditions and they possibly have their own way of explaining them and effort should be made to engage with them to find out the extent of the indigenous knowledge.

> *"That is why I was saying earlier today that if we go to the villages and ask the grandmothers about this, they know them, but there are no terms to describe them. Umm so and it's just the thing of avoiding the conversations. Hence there is not so such…. I mean, if we were to go deeper and ask really old people about the terms, maybe they have names for these things but we don't know… we wouldn't know because we're not exposed." – FGD2P1*

Theme 2: Societal perceptions of genetic conditions

As the participants were providing the available terms, another discussion emerged around the sociolinguistic and demographic context of each terminology provided. This included the varying societal perceptions of the terms, with comments regarding the appropriateness and utility of the terms in the following manner: existing social stigmas and social preferences of term usage.

The negative perception towards genetic variation is hugely linked to the treatment by the community members, thus parents who have children with genetic conditions tend to hide and disconnect them from community members. One of the participants reported that some of the affected children are deprived from any form of social interactions with other members of the community.

> *"We know for sure there is one with Down syndrome.. but you won't see her. They would hide her. You wouldn't see her at all!. You would just hear her cry only. They didn't even take her to the mall." – FGD1P6*

Despite the limited understanding of genetic conditions, there are existing negative stigmas towards rare diseases and a poor tolerance of genetic variation in communities. An example was made by a participant when dwarfism was being discussed and some of the terms used to describe it being a way of mocking the affected individuals.

Notably, the participants discussed that although some terms exist, not all of them, are socially preferable. Some of the terms are even deemed to be unspeakable. An example of a quote by a participant is below. The participant described that the word *segatamarokgwana* literally means someone who steps on their trousers as they are too short, as being derogatory. Therefore, the participants highlighted that some terms should be used with caution. FGD2P1 discusses about how they feel about the terminology used for dwarfism.

> *"Yes there is another word used by some people to describe dwarfism. Ba are ke [they would say] 'segatamarokgwana'… but that's not a nice word hey. I thought it was inappropriate. I never actually used that word. It's wrong wrong wrong wrong." – FGD2P1*

Another derogatory terms that are well-known are "Lekgwehle" (Sepedi), "Lekgwama" (Sesotho) and "Leswafi" (Setswana) used to describe people with albinism. Notably, all the terms, although different, are deemed derogatory by the albinism community as reported by the participants. On that basis, the offense may stem from the tone of usage by the community members that treated them harshly historically, but it wasn't a point of discussion by the participants.

Theme 3: Cultural beliefs and causes of genetic conditions

The participants spoke about the existing common beliefs regarding the causes of genetic conditions in the communities. This aspect came up as the participants were discussing why there are no terms to describe the individual genetic conditions that are observed in communities. The following were the subthemes that emerged from the discussion:

- The issue of incest
- Food can cause problems in pregnancy
- Maternal age
- Traditional consultations

Subtheme 1: The issue of incest

When the question of whether a blood relatives union can result in a child with a genetic condition was brought up, there was a divide of participants in responses. Some mentioned that incest is strictly forbidden as it is believed that the children, mostly males, would be "cursed" with intellectual disability and in some cases, dysmorphism. In addition, as described earlier, "maadi" translates to 'blood". However, in this context it refers to blood relatives. This is another example of how the Sotho terms are figuratively used, and depending on the context, have a different meaning.

> *"Bana ba maadi ba belega morwa wa segole [siblings will give birth to a disabled male]." – FGD1P8*

This hinted a basic understanding that incest can result in some of the observed genetic conditions and a crude understanding of inheritance patterns, and it was mentioned that the observed disabilities tend to affect males significantly more than females. Incest is also recognised at different levels: father and daughter, and two cousins as described by *FGD1P7* and *FGD3P2* respectively below. It was also mentioned that the other reason is because of lack of remorse when practicing incest, which hinted a spiritual (ancestral) curse being a recognised component.

> *"In a certain family in my village, incest was being practiced. The father was sleeping with his daughters. From that, the entire generation, it's a curse in that family. The children are all mentally disturbed. It is also believed that the mental disability stems from the father, because apparently he was not even ashamed." – FGD1P7*
>
> *"It depends on the relatedness. It's a different story if ke di [if it is] siblings, and it's another when it is cousins" – FGD3P2*
>
> *"I have cousins that are disabled. Normally, my mom just tells me akere papage le mmage ke batswala [it's because their mother and father are cousins]. So yes I agree." – FGD2P1*

Notably, the above quote by FGD1P7 not only describes the conceptual understanding of consanguinity, but also what some community members believe to be the cause of disability. In addition, while FGD3P2 mentioned that there are different levels of incest, however, there is no further elaboration on which level of incest is associated with an increased risk of having a child with a disability.

However, some participants mentioned that incest is traditionally practised in some families where they want to preserve and keep the wealth (i.e. livestock) within the family. Furthermore, the participants said that they have never seen a case where a blood relative union, no matter how closely related, has resulted in a disabled child, and thus concluded that is it a myth and something that could happen to any couple, blood related or not.

> *"Just to comment mo tabeng ya incest [on the issue of incest], ke mabarebare [it is hearsay]. In previous times, a lot of people, batswadi ba rena ke kgale ba nyala bo motswala ba bona [our parents used to marry their cousins]. E le setšo gore swanetše ba hlokomele bana if motswadi a bajwa so swanetše ka gae gore kgomo e boele ka gae [It was tradition that 'the cattle should return to the corral/kraal so that the children would be properly taken care of in the event that one of the parents dies]. Ene bana ba no tšwa*

> *ba le 15 ba le gabotse [All 15 of the children would turn out just fine with no disabilities]. Ke nagana gore ke mabarebare [I think that it is hearsay]. Ke myth [It's a myth]." – FGD3P3*

Subtheme 2: Food products can cause complications in pregnancy

There were also discussions by the participants that pregnancies are generally regarded as sacred by the grandmothers, and so the pregnancy would be kept a secret until approximately 6 months where the development of the baby is deemed to be advanced enough, and therefore at minimal danger. Additionally, to ensure the safety of the developing baby, there are specific food items that are historically believed to cause different complications with the pregnancy. Examples of food products include eggs and citrus.

It was not specified whether the disabilities are regarded to have a genetic aspect or not. It was made clear that some food products are encouraged to be avoided because they increase the risk of complications with the pregnancy. Recommended food products that are nutritious to the developing baby include sorghum porridge, and white porridge is discouraged. However, there are also food products that can use maternal illnesses. These include citrus and spinach which are believed to cause maternal meningitis and ulcer respectively.

> *"I know with spinach and tomatoes, my sister wasn't allowed to eat them because di tlo mo gokela seokolela [it would cause her to have a heartburn and/or ulcer]. She also wasn't allowed to eat cheese.* Ne *a e ja bogobe bja mabele [she would only eat sorghum porridge]." – FGD2P2*

> *"It's also believed that citrus can cause meningitis. It's mostly about food and what to avoid." – FGD1P8*

Subtheme 3: Maternal age

There has also been observations that complications in pregnancies occur more frequently in women of older age. It was further elaborated by participants that any woman of any age can have a child with a disability, however, the trend is seen more amongst women that are approaching menopause. It is reported that some elders are not shocked when an older woman has a child with Down syndrome or any other disability as they would comment that they knew it was a possibility.

> *"I was raised by my grandmother, so they do have these conversations. Like she would say 'ngwana wa mang mang ga a itekanela because mme wa gage o bile le yena a le o mo golo' ['this person's child was born with a disability because the mother had them when she was old']." – FGD2P2*

As such, women are often encouraged by elders to have children when they are in their twenties or thirties as it is believed to be the best time to increase the chances of having a healthy child. When a woman becomes pregnant after her thirties, there is a worry that she could have a child with a disability. Although the elders have no scientific basis to explain this phenomenon, they rely on observations, experiences and indigenous knowledge that was taught and passed on orally from one generation to the next.

> *"I haven't heard it being spoken of directly, but I think it's always emphasized that it's so much better for you to have a child when you are young like in your twenties to thirty's. That's when it is apparently the perfect time. And then after thirty years it's like.. OK, like now you need to have kids, you need to hurry up." – FGD2P4*

Subtheme 4: Traditional consultations

It was clearly stated by the participants that traditional healers are aware and acknowledge that they cannot cure or reverse conditions that are deemed to be genetic, but an attempt is made regardless. During the consultation, they can determine if the child's disability was due to an underlying genetic cause (often called a natural disability) or if there is witchcraft or/and supernatural influences. If it is concluded that it's a natural disability, then there is nothing that can be done. However, if it is a witchcraft or spiritually related, the traditional healers would then provide the parents with herbs along with specific instructions of usage.

> *"if they take you to a traditional healer, I feel like maybe the person will determine if you are bewitched or it is a natural disability. If they determine that the disability is the result of witchcraft, then attempts will be made to reverse it by go arametša [steaming with traditional medicines]; wa tlola [ask/consult with the ancestors]... basically they give you herbs and tell you how to use them, but if it's genetic, then the herbs provided will not work.' – FGD1P8*

Some community members are reported to routinely consult a traditional healer even though they are aware that there is a little to no chance that any difference will be made, but an attempted effort by the traditional healer brings, to some degree, comfort knowing that they tried all options to reverse the disability of their child, which helps the parents to adapt and mentally cope with the life-long circumstances.

> *"I think with down syndrome, although they can't name it, the traditional healers know it. They routinely go and attempt but there is a known history that it is incurable." – FGD3P4*
>
> *"I agree. Ba no nyaka go leka mahlatse [they usually just want to try their luck], but there is less disappointment if it doesn't work, but the parents get closure." – FGD3P2*

Although there were no specific herbs mentioned, the methods used by traditional healers involve steaming with hot water using the prescribed herbs, drinking a certain dosage of the herbs, using some of the herbs when bathing and distributing the herbs around the yard to protect the household from witchcraft.

> *If they determine that is a disability as a result of foul play (witchcraft), then attempts will be made to reverse it by "go arametsa [steaming with water]"; "wa tlola" [applying on skin].. basically they give you herbs and tell you how to use it "Ditaelo" [specific sacred procedures] – FGD1P2*

Theme 4: Terminology development

Following the in-depth exploration of the available terms and phrases, the discussion led into reasons why terms are limited were dissected. Having recognised how limited the available terms are, the participants began discussing among themselves different methods on how this gap was be addressed, thus the idea of terminology development was presented towards the end of each focus group discussion. The participants suggested different approaches towards development of terms. The strategies are discussed below in the following subthemes:

- Reasons for lack of terminology.
- Inventing new terms versus developing the existing ones.
- Distribution of developed terms.

Subtheme 1: Reasons for lack of terminology

The participants raised a point that given the historical context of systemic oppression of the Black population, many of the indigenous languages were did not have new terms as technology advanced. This then led to very few terminologies being created to describe scientific concepts. In addition, the participants felt that the traditional approaches were not given a platform to work together with the western-oriented techniques. Hence, the traditional healing model, which is based on indigenous knowledge, is not well documented. For instance, FGD2P2 questioned the extent of medicinal properties of herbs and their usage as the indigenous knowledge is not publicised.

> *"But you can find that maybe sometimes it's not a medical condition but it's a traditional condition... but because we Africans have not been given a platform to really express. How can you know if traditional herbs cure?" – FGD2P2*

In the historical context of the education structure during the Apartheid era, the medical textbooks would use pictures of white individuals as illustrations to describe different types of diseases and illnesses while not including those of other affected ethnic groups, hence the quote below by FGD2P4 highlights that there was no access to educational information, thus leaving the black population uniformed and therefore having misconceptions that some of the genetic conditions are for white people only. This is one of the major contributions that led to why South African indigenous languages are generally not developed as mentioned by FGD1P7 in Theme 1. Hence, the currently used terminology is limited.

> *"They say it's a disease of white people because of access to information or resources, because I mean if people had social media back in the day, you know, they'd see that, you know, there's a large group of people that have this or that condition." - FGD2P4*

Subtheme 2: Inventing new terminology versus developing the existing ones.

Having recognized that there are actually limited terms and phrases to describe genetic phenomena, the participants discussed to the need to explore avenues to address the gap in genetic terminology. Some participants supported the idea of inventing new terminology, motivated by the development and preservation of the indigenous languages and not always having to resort to the English language especially in the age of attempting to decolonise society.

> *"We have to consider that it's very essential for us to come up with our own words. Not everything has to be according to the Western view, like we are already on the barrel of decolonizing our societies." – FGD2P2*
>
> *"Yeah it's a good idea to have words in our own languages rather than just English all the time." – FGD1P6*
>
> *"I'm all for preserving our languages, and I feel very strongly about this because it's important for us to do so as Black people." – FGD1P7*

However, some participants felt that inventing new terms would be a long and tedious process. Thus, it was suggested that the already existing terminologies in English should be "borrowed" and developed to come up with combined English-indigenous terms in a way that people can understand. Notably, the participants acknowledged that this method would present challenges in terms of translations and making sense of each borrowed word as one cannot re-invent a language, but it was deemed necessary because times are changing at a rapid rate and adaptations should be made accordingly.

> *"What are we translating? Is it translatable? In terms of invention, I believe there is no way we can invent the technological terms now because in Sepedi a di go [in Sepedi they are not available], so inventing them, it will still end up following… nka e bea bjang? [how can I put it?] re tlo e sothofatša mara re tseba gore aego ka Sepedi [we will use borrowed English words and combine with our own languages knowing that it's not available in Sepedi]." – FGD3P4*

> *"If we overcomplicate it by coming up with new terms, I think we might end up losing them.... if there is a way we can borrow a word from English and still make it make sense, I don't see the necessity to make up new words." – FGD1P4*

> *"Lenna kea dumellana le bona [I agree with everyone], right now okase thome language wa e re-inventer [you cannot start to re-invent a language]. There is lot of things not available in Sepedi… e ka ba morwalo [it would be a huge burden]. That is why re na le maadingwa [that is why we have borrowed words]. I would suggest combining the words of English and Sepedi in a sentence to bring about meaning. Using italics could also work. But in the long run, the newer generations are more educated, we could just borrow certain words until we could generate new terminologies, not that we should make it a priority. As long as there are means for people to understand the meaning. Thank you." – FGD3P4*

Subtheme 3: Distribution of terms

Although different opinions were raised regarding the approach of using pure terms as opposed to hybrid words; the participants have a consensus that terms to describe genetic phenomena need to be developed and made available publicly. The suggested ways to distribute the terms through mediums such as radio and television. A participant also mentioned that a smartphone application could be developed that will enable people to gain access to the indigenous genetic terms and their description, and that it would be mentally stimulating and practical for the current generation. Additionally it was suggested that workshops with healthcare professionals should be held where community members teach them the indigenous terms and how they are used in an effort to further enhance their cultural competence and improved multicultural awareness.

> *"We live in a digital age, right? Creating an app that say for example you have certain condition and you don't know what it is in your home language and you want to know specifically in your language. Maybe start having an app that has, you know, certain conditions in their respective languages" – FGD2P4*

> *"Then you're going to have to create a workshop for doctors who work in areas where our languages are spoken. This will be difficult because doctors don't have time, but they need to make space for that and say okay we need to learn these new terms." - FGD2P4*

Educating the public was also highlighted to be crucial. Suggestions included forming community engagement activities such as social events and community meetings with different community members and their respective leaders. This would particularly be aimed at the elders withing the communities. The community engagement activities would include focus group discussions on available genetic terms, their associated social stigmas and how to resolve past and present conflicts. For the younger generation, the use of social media platforms to create awareness was recommended. Once the terms are developed, they should also be included in primary and high school indigenous language curriculum.

> *"I think ba ka ya fela [I think they can just go] to the communities. Older people baya kerekeng [go to church]... or host something in the community as awareness. People in the communities have conditions but can't describe them. So, they would be interested to know." – FGD3P1*

> *"Le nna ke dumela le go ruta batho [I also agree with educating the people]. Tuto yona is the main thing you can do [Education is the main thing you can do]. Including it in the curriculum in Sepedi language to enrich it. Collaborating and engaging with people. Generalizing someone's illness must come to an end." – FGD3P3*

TABLES OF TERMS

All the provided terms, sayings and expressions are presented below along with their English translations in all the three languages. Notably, there are differences in the same concept depending on both the language and dialect . For example, on the language level, a term that refers to "inheritance" is "o fusitse" in Sesotho; "o kgotsitse" in Setswana and "O tšeetše." In Sepedi, however, within the same language, in Sepedi for example, inheritance can be referred to as either "o tšeetše"; "o abetše" and "Lefa" depending on the dialect spoken in different rural and urban areas. Where there are no specific terms, descriptions are used metaphorically to bring about meaning.

	Indigenous terms, phrases and expressions		
English term	Sesotho	Setswana	Sepedi
Inheritance	O futsitse	O kgotsitse O foditse	O tšeetše O abetše Lefa
DNA/gene	Maadi [Blood]	-	Sebopego [How someone is created/shape] Mmopego [variant of Sebopego]
Dwarfism	-	-	Dikgopana

			Segatamarokgwana*
Albinism	Leswefe Makgwama	Leswafi	Lekgwehle* Lehwefe
Disability	Sehole [Disabled]* Ha a itekanela [Not fully developed] Bofokodi [Mental Disability]	Segole [Disabled]* Ha a itekanela	Segole [Disabled]* Ga a itekanela
Consanguinity	-	"Bana ba motho ba belegwa morwa wa segole." [Blood relatives give birth to a disabled son]	Bana ba kgwale ba tsebana ka mereto. [Related to people recognising blood relations with their totems – meaning is unclear but is it a common saying]
Vitiligo	Mollo wa badimo [Fire of the ancestors]	-	-
Fontanelle	Hlogwana	Hlogwana	Tlhogwana
Traditional methods	Ke ile go hlola [I went to consult] Go alafa [To cure/heal]	-	Go fotha [To disperse traditional medicine around the home / yard] Go tlola [To consult]

			Go arametša [To steam- usually with herbal medicine]

Table 2: Summary of indigenous terms related to genetics and inheritance.

The terms with asterisks were highlighted by the participants to be derogatory in their social context and thus not preferable. The table also shows that there are different terms and phrases used to describe the same concept.

Note/Key:

T: English translations

C: Social commentary by the said participant

Participant no	**Language**	**Dialect**	**Inheritance**	**DNA/Gene**	**Dwarfism**	**Disability**	**Albinism**	**Consanguinity**	**Traditional Consultations**
FGD1P1	Sepedi	-	-	-	-	-	Lekgwehle	-	-
FGD1P2	Sepedi	Setlokwa	-		-	-	Lekgwehle . *(Rude word..not socially accepted)*	-	-
FGD1P3	Sepedi	-	O tseetše motho T: *you took after someone.*	-	-	-	Leswafa	-	-
FGD1P4	Sesotho	-	Lefutso O e nyantse mo letsweleng T: *You got it from breastfeeding.*	-		Ha a itekanela T: *He/she is not equal* O nale bofokodi bo itseng T: *He/She has a certain mental problem*	Leswefe	-	Ke ile go Hlola T: *I went to consult.* Go alafa T: *To heal*
FGD1P5	Sepedi	-	O futsitse	-	-	-	-	-	-
FGD1P6	Setswana	-	O kgotsitse	-	-	-	Leswafi	Kea tseba gore goba le ngwala le your relatives has consequences. T: *I know that having a child with relatives*	-

								has consequences	
FGD1P7	Sesotho	-	-	Maadi T: *Blood* What makes you unique as an individual What connects you with your leanage Bana ba kgwale ba tsebana ka mereto. T: ?	-	Segole *(commonly used but derogatory)* O nale bogole ba.. *(more socially accepted)*	Leswefe	-	-
FGD1P8	Sepedi	-	O tšeetše	Family traits or features	-	-	-	Bana ba madi ba belega morwa wa segole T: *Blood relatives give birth to a disabled son.*	Go arametśa T: *To steam* Go fotha T: *To spray* Go tlola T: *To apply substances on the body* Wa nwa T: *To drink*
FGD2P1	Sepedi	Serwa	O tšeetše O latile T: *You followed*	-	Dikgopana T: *Short people* Segatamaro-Kgwana T: *A person that steps on their pants*	Segole Ga a itekanela *Kinder one, but can use both)*	-	-	-
FGD2P2	Setswana	-	O tseetse	Something that you are born with.	-	Segole Ha a itekanela *Note: can used interchangeably*	--	-	-
FGD2P3	Setswana	Sehuruti	O foditse	-	-	Segole	-	-	-
FGD2P4	Sesotho	-	O futsitse	-	-	Segole Ga a itekanela	-	-	-
FGD3P1	Sesotho	-	O e kereile T: *He/she got it from*	-	-	Ha a itekanela Segole (*derogatory*)	Leswefe.	-	-

			E tswa go.. T: *It came from..* O futsitse						
FGD3P2	Sepedi	Sehananwa	O abetše	Selo se se direlang gore batho ba fapane.” T: *Something that makes people different.*	-	Segole Ga a itekanela	Maswafa	-	-
FGD3P3	Sesotho	-		Selo sa go feletela baneng T: *Something that gets passed down to children*	-		Makgwama		-
FGD3P4	Sepedi	-	O abetše Leabela Lefa	Sebopego Mmopego T: *Shape or form*	-	Segole O golofetše	Lehwefe Lekgwehle	-	-

Table 3: Table of terms describing concepts of genetics and inheritance with their English translations (prior to proofread and validation by participants).

Note/Key:

T: English translations (highlighted in yellow)

C: Social commentary by the said participant (highlighted in grey)

Participant no	Language	Dialect	Inheritance	DNA/Gene	Dwarfism	Disability	Albinism	Consanguinity	Traditional Approach
FGD1P1	Sepedi	-	-	-	-	-	Lekgwehle	-	-
FGD1P2	Sepedi	Setlokwa	-		-	-	Lekgwehle. C: *(Rude word..not socially accepted)*	-	-
FGD1P3	Sepedi	-	O tseetše motho T: *you took after someone.*	-	-	-	Leswafa	-	-
FGD1P4	Sesotho	-	Lefutso O e nyantse mo letsweleng	-		Ha a itekanela T: *He/she is not mentally*	Leswefe	-	Ke ile go Hlola T: *I went to consult.* Go alafa

			T: *You got it from breastfeeding.*			*equal to others* O nale bofokodi bo itseng T: *He/She has a certain disability*			T: *To heal*
FGD1P5	Sepedi	-	O futsitse	-	-	T: *it is a hereditary thing*	-	-	-
FGD1P6	Setswana	-	O gotsitse	-	-	-Go sa itekanelang mo tlhaloganyong T: To have a mental disability	Leswafi	Kea tseba gore goba le ngwana le your relatives has consequences. T: *I know that having a child with relatives has consequences*	-Go itlhatlhoba Go ikekola T: To consult Go alafa T: *To heal*
FGD1P7	Sesotho	-	-	Maadi T: *Blood* What makes you unique as an individual What connects you with your leanage Bana ba kgwale ba tsebana ka mereto. T: ??	-	Sehole C: *(commonly used but derogatory)* O nale bogole ba. T: has a disability *C : (more socially accepted)*	Leswefe	-	-
FGD1P8	Sepedi	-	O tšeetše	Family traits or features	-	-	-	Bana ba madi ba belega morwa wa segole T: *Blood relatives give birth to a disabled son.*	Go arametśa T: *To steam* Go fotha T: *To steam.* Go tlola T: *To apply substances on the body* Wa nwa T: *To drink*
FGD2P1	Sepedi	Serwa	O tšeeletše T: You took from O latile T: *You followed*	-	Dikgopana T: *Short people* Segatamaro-Kgwana	Segole Ga a itekanela C:	Leshobe	-	-

					T: *A person that steps on their pants*	*Kinder one, but can use both)*			
FGD2P2	Setswana	-	O tseetse	Something that you are born with.	-	Segole Ga a itekanela C: *Note: can used interchangeably*	--	-	-
FGD2P3	Setswana	Sehuruti	O foditse	-	-	Segole	-	-	-
FGD2P4	Sesotho	-	O futsitse	-	-	Segole Ha a itIkanela	-	-	-
FGD3P1	Sesotho	-	O e kereile T: *He/she got it from* E tswa go.. T: *It came from..* O futsitse	-	-	Ha a itekanela Sehole C: (*derogatory*)	Leswefe.	-	-
FGD3P2	Sepedi	Sehananwa	O abetše	Selo se se direlang gore batho ba fapane." T: *Something that makes people different.*	-	Segole Ga a itekanela	Maswafa	-	-
FGD3P3	Sesotho	-		Selo sa go feletela baneng T: *Something that gets passed down to children*	-		Makgwama		-
FGD3P4	Sepedi	-	O abetše Leabela Lefa	Sebopego/Mmopego T: *Shape or form*	-	Segole O golofetše	Lehwefe Lekgwehle	-	-

Table 4: Validated of terms referring to concepts of genetics and inheritance with their English translations (validated by participants).

CHAPTER FOUR: DISCUSSION

INTRODUCTION

The aim of the study was to investigate and document available genetic terminologies and expressions used to describe genetic concepts, and this was achieved. Interestingly, the participants also provided their views and perceptions on the development of terms, social acceptability of these terms and existing stigma in both rural and sub-urban communities. The genetic terms provided and their social context of usage will contribute to a more efficient genetic counselling session by enhancing the cultural competency and safety of genetic counsellors that work in areas where the Sotho languages are predominately spoken. The terms provided by participants are limited due to their unavailability in the Sotho languages. Therefore, the participants suggested that more terms need be developed with anticipated challenges and benefits. This chapter provides more insight to the results obtained in consultation with existing literature.

DISCUSSION

Language barriers disrupts effective communication between a healthcare professional and patient (Schlemmer & Mash, 2006b). Effective communication is defined as the exchange of information in a way that is understood by both individuals (Brooks & Heath, 1985). The results of this study show that although there is a basic understanding of genetic concepts, the terminology is limited. This creates another challenge because genetic counsellors tend to use genetic terms in a session which are considered as jargon by patients who have poor understanding of the language of genetics. Similarly, Delikurt et. al (2015) reported that in additions to conversing in English, patients do not understand the language of genetics used by genetic counsellors even when put in the simplest form.

A study by Levin, (2006) found that isiXhosa patients from rural areas not only have a hard time understanding the generally used medical jargon by the managing clinicians, but also the English language. This then resulted in poor rapport and overall patient dissatisfaction in the absence of a trained interpreter. This is supported by (Deumert, 2010) who found that some patient go to the extent of being silent and withholding crucial medical history because they are anxious of their linguistic limitations. Thus, language barriers evidently has potential detrimental effects on overall patient health care.

To the researcher’s knowledge, this is the first study in South Africa that investigated the knowledge and understanding of genetic terms specifically targeting the Sotho-speaking South Africans. Another existing study in the South African context in relation to genetic literacy was by Shingwenyana (2020) which assessed patient recall, understanding and vocabulary of genetic concepts. However, Shingwenyana's target sample included participants of all South African indigenous groups. Shingwenyana (2020) reported overall good recall and understanding of genetic concepts. It is however worth noting that Shingwenyana (2020) targeted participants who already received formal genetic counselling; whereas this study targeted participants who have not been exposed to the science-based biological terms that describe genetics and inheritance concepts.

This study has shown that although there is a basic understanding of concepts of genetics and inheritance, the availability of terms in the Sotho languages describing them are limited. The study has also shown that Sotho languages are descriptive in their nature rather than having a single term for one concept. The limited genetic terms coupled with language barriers would likely result in ineffectiveness of genetic counselling in practice. A similar finding in a systematic review by Delikurt et al., (2015) showed that in European countries, the patients have experienced difficulties in understanding the "language of genetics" used by in a genetic counselling session, even in the most simplified form.

When discussing terminology development, one of the participants asked "what are we translating? It is translatable?", which highlights one of the major differences in the worldviews of biomedical and indigenous knowledge models as explored in the literature review. Furthermore, when asked to provide a term for Down syndrome, one of the participants said that there is no term, however, the condition would be understood if the physical features of it are accurately described to community members. The reason for the lack of indigenous terms to describe genetic conditions could be because the traditional healing model is based on a more descriptive approach in contrast to the biomedical model, which is based on scientific explanations, which often use specific terms (Flint, 2015).

There is an existing trend of limited awareness and understanding of genetic conditions in different communities, which could possibly explain the overall poor understanding. For instance, Solomon (2012) conducted a study among isiXhosa speaking caretakers of children with haemophilia to assess their understanding of the inheritance pattern and pathology of the condition. The study found that there is little to no factual understanding of what causes haemophilia and how it is transmitted. Furthermore, there was an impression from the participants that the healthcare providers also did not understand the pathology of haemophilia because the treatment of the affected boys was evidently not effective. This resulted in poor uptake of management of the condition at home.

As seen in Table 1, one of the participants describes DNA as "maadi" [blood], which was further elaborated that it metaphorically means that DNA is something that one carries in their blood or something that runs in the family. Another participant described it as "sebopego" [to be formed/shaped], which metaphorically means that DNA is understood to be the building blocks of an individual and what makes people unique. This illustrates that Sotho languages tend to use a more indirect approach to describe concepts which often require interpretation.

In the United States of America, a study by Lanie et al., (2004) reported, out of 44 participants they interviewed, 25% of participants understood the word “genetic” having to do with an individual’s appearance and structure. This was shown to be linked to the lack of scientific basis of genetics as many participants commented that they first heard the word “gene” or “genetic” from the mediums such as TV talk shows and social gatherings. The study has also shown that the repeated social exposure has led participants to feeling comfortable using both terms in contexts where it may not be applicable – a phenomenon known as the “illusion of knowing” as described by Park (2001). Thus, this aligns with the need for public education and community engagement activities as suggested by the participants as part of developing genetic terms.

When discussing reasons why terms to describe genetic concepts are limited, one of the participants pointed out that that it could be linked to different cultural beliefs and myths, with witchcraft being one that stands out. It was reported that it is uncommon to hear members of the community openly talking about a genetic condition in fear of the “curse” following their household. Penn et al. (2010) reported that behaviour such as laughing at someone with a disability or genetic condition is believed to result in bearing a child with a similar disability. These attitudes could contribute to the reasons for having limited genetic terminology because the community members refrain from engaging in open social discussions due to misconceptions, stigma and fears regarding genetic conditions.

Consanguineous unions or incest has been practiced in different societies and cultures around the world (Shawky, Elsayed, Zaki, El-Din, et al., 2013). Several studies have reported that different genetic conditions have been observed in communities where consanguineous unions are strongly preferred (Bittles, 2001). Similarly, This aligns with the findings of this study as participants mentioned that consanguinity is believed to be associated with some of the observed disabilities, including those that are thought to be genetic. Some participants provided scenarios where a consanguineous union resulted in some children with physical dysmorphisms and intellectual disabilities.

A participant gave an example of a father who had children with his daughter and all the male offspring were born disabled. Penn et al., (2010) conducted a study that explored the perspectives of grandmothers from different South African ethnic groups with regards to traditional beliefs of the causes of genetic conditions. The study reported that consanguinity is recognised as a possible cause of a genetic condition, and an example of “sleeping with your brother” was given by the grandmothers as a major risk factor. Furthermore, the grandmothers reported that males tend to be more significantly affected than females, as also reported by the participants in this study. This is supported by (Shawky, Elsayed, Zaki, Nour El-Din, et al., 2013) who reported consanguinity as a cause of children having X-linked recessive conditions in 31% of the participants.

Other participants explained that their elders recognise maternal age as a cause of some of the observed congenital disabilities. Penn et al.,(2010b) also reported that age is a contributing factor that causes various congenital abnormalities. However, both Penn’s study and participants of this study report that there is no clarity on whether the disability is genetic or not. The participants of this study reported that it is recognized that not every woman of advanced maternal age (AMA) will give birth to a child with disability, which suggests that they understand that it is an increased risk and that it is not definitive.

Another cause of congenital disability described was teratogen exposure. The participants explained that the elders have a list of specific food products to avoid which may interfere with the development of the foetus. This included food products that may result in maternal illness, which then affects the developing foetus. In a study by Penn et al. (2020) study, it was similarly reported that the consumption of culturally forbidden food products such as eggs and tripe would result in genetic conditions or disabilities.

The participants discussed that the cultural beliefs of genetic conditions have fuelled the overall poor tolerance towards genetic variation and existing social stigmas in communities. For instance, albinism is one of the most stigmatised genetic condition, with various reactions across South Africa. Kromberg (2018) reported that Black people living in urbanized areas tend to have a more positive response than those living in rural areas due to increased social exposure. However, statistics by Kromberg et al., (1987) show that an individual affected with albinism is significantly less likely to marry another affected individual, with approximately 5 marriages out of every 20 women and 28 men.

There are also beliefs that the body parts of a person with Albinism are valuable to witchdoctors, and they thus live their lives in fear within their communities. A study by Kajiru & Nyimbi, (2020) also reported that in Tanzania, people with albinism are dehumanised and that mixing their body parts with certain medicines is believed to bring wealth.

There are several terms provided by the participants which people living with albinism deem to be offensive as seen in Table 1. The terms provided are different due to the different dialects but have the same meanings. In a study by Taylor et al., (2021), one of the participants mentioned that a baby with albinism was called “Mujjini”, which is a Ugandan term for “demon”. She said that because she gave birth to a “demon” the community now hates her home. In the same study, another participant said that her family members say that she has brought a ghost into their household. A study by Braathen & Ingstad, (2006) in Malawi reported, if one comes across a person living albinism and you do not spit to the ground, then you will have a child with albinism.

The different negative attitudes regarding albinism stem from different sources which fuel it to be poorly tolerated by different societies.

Sociocultural perceptions of another genetic condition, Fragile X Syndrome (FXS), have been studied in a rural community in Cameroon (Karen, 2021). The study found that the participants had a good understanding of how fragile X syndrome manifests itself, and thus provided two terms, “Rheurheu” and “Peuh,“ which mean “alienated” (mild intellectual disability) and “madness” respectively. The former term was found to be better tolerated as the caretakers felt that the affected individuals needed some degree of assistance to improve, while the latter was socially unaccepted because no intervention will make the situation better.

The limited available terms to describe concepts of genetics highlighted the need for the indigenous terms to be developed. This was also a general recommendation in a study by Alberts & Mollema, (2013) having recognised the gap between technological advances and the lack of terms in the South African indigenous languages to describe them. A study by Mmanape (2020) sought to develop Sepedi terminologies for technical linguistic terms to be used in higher learning for the first-language speakers. This was done by searching for commonly used English terms and translating them to be included in Sepedi dictionary as a means to enrich the vocabulary. Some of the participants of this study recommended that after the terms are developed, they would have to be publicly made available and easily accessible.

CHAPTER FIVE: CONCLUSIONS & RECOMMENDATIONS

INTRODUCTION

In this chapter, the conclusions are drawn based on the findings of the study and previous literature regarding the knowledge and understanding of terms that describe genetics and inheritance concepts. The themes providing context of the usage of the terms are concluded. In addition, strengths and limitations of the study are discussed, practical implications are suggested, and recommendations for future research are made.

CONCLUSIONS

This study found that there is existing knowledge and understanding of basic genetic terms and inheritance in Black communities, both in rural and suburban areas. There are available terms in the Sotho-Pedi-Tswana ethnolinguistic group that literally translates to “inheritance”. Some participants highlighted the metaphoric or descriptive phrases that explain the concepts of inheritance. Furthermore, there are existing terms to describe some of the commonly observed genetic conditions such as albinism and dwarfism. However, for disabilities that do not have direct terms, the study found that the Sotho-Pedi-Tswana languages use a descriptive approach to describe the physical syndromic features of the conditions.

The study also found that for conditions that do not have terms, they would generally be classified under “disability”, which is an umbrella term. There is very limited knowledge on distinguishing disabilities that are due to genetic aberrations, teratogen exposure, and physical deformities. However, there is awareness of genetic conditions and a basic understanding of genetics showing that knowledge does indeed exist, but understanding of and language to describe it is poorly developed. The participants highlighted that this could be linked to poor tolerance of genetic variation by community members due to existing myths that are believed to be the cause, resulting in less conversations being held.

In addition, the study gained insight in relation to the sociolinguistic context of the terms provided by the participants. This included cultural beliefs and myths around the causes of genetic conditions, which included predisposing factors such as age, consanguinity, prenatal exposure of specified food products and witchcraft. It was also found that traditional healers acknowledge that they cannot cure congenital disabilities. The study also revealed the social perceptions of genetic conditions which is directly linked to the cultural beliefs. This is important for genetic counsellors to have awareness of when counselling a patient from the Sotho-Pedi-Tswana ethnolinguistic group because it will provide an opportunity for clarification of misconceptions.

PRACTICAL IMPLICATIONS

This study determined that there is a basic understanding of genetics within Sotho-Pedi-Tswana ethnolinguistic group. Therefore, genetic counsellors can use this information as a basis when counselling. The common genetic terminology in South African indigenous languages can be included in genetic counselling sessions to reduce communication barriers, increase rapport and minimize the need for a translator while maintaining multicultural sensitivity. Part of maintaining multicultural sensitivity would be for the genetic counsellors to know which terms to use as it was highlighted by the participants that some terms are derogatory. Therefore a list has been complied that can be used in genetic counselling sessions. Lastly, the study highlighted the need for genetic counsellors to be culturally competent and practice genetic counselling by incorporating cultural humility in their work.

STRENGTHS

- All the members of the Sotho-Pedi-Tswana ethnolinguistic group were present in all three focus group discussions.
- This is the first study in South Africa that assessed the genetic literacy of the Sotho-Pedi-Tswana ethnolinguistic group.
- The researcher and co-supervisor are Sepedi first language speakers.
- After the terms were extracted from the verbatim transcripts, the participants were given a chance to review the terms and correct the spellings (dialect-sensitivity) and the literal English translations.

LIMITATIONS

Age of participants

- As discussed in chapter two, *FGD2P4* mentioned that there could be more terms available, but their age group would not have possibility been exposed to them as it is a rarely discussed topic in the communities.

Gender Imbalance of participants

- There was only one male in each of the three conducted focus group discussions. Gender specificity was not part of the sampling method, however, it is possible that the males in each focus group may have felt overwhelmed to participate fully, and thus withholding some of the information relevant to the study.

RECOMMENDATIONS

- This was a pilot study. Further research needs to go into exploring the knowledge and understanding of basic genetic terms and available terminology in the Nguni languages, Tshivenda, Xitsonga.
- The future study sample must include the elders of the native communities that have up to high school as their highest education as they are more likely to provide a more in-depth knowledge based on their relatively longer experiences and wisdom.

- Each provided term must be examined by the leaders of the communities and an agreement of usage must be reached in formal meetings.

POTENTIAL IMPLICATIONS FOR HEALTH POLICY

Section 6 (2) of The South African National Health Act of 2004 states that “the healthcare provider concerned must, where possible, inform the user a contemplated in subsection (1) in a language that the user understands and in a manner which considers the user’s level of literacy. This study highlights the challenges of the use of medical jargon that is presented in a way that the patient can understand, and the investigating the knowledge of genetic terms in the patient’s home language may alleviate language barriers.

Subsection (d) continues to state, “every health care provider must inform a user of benefits, risks; costs and consequences generally associated with each option; and the user’s right to refuse health services and explain the implications, risks, obligations of such refusal.” This subsection speaks to the patient’s constitutional right to informed consent and decision making. However, informed choice requires full comprehension of the jargon used during the consenting process with the healthcare provider. It is hoped that the genetic terms provided will aid in elucidating the informed consent process in genetic testing and genomics research.

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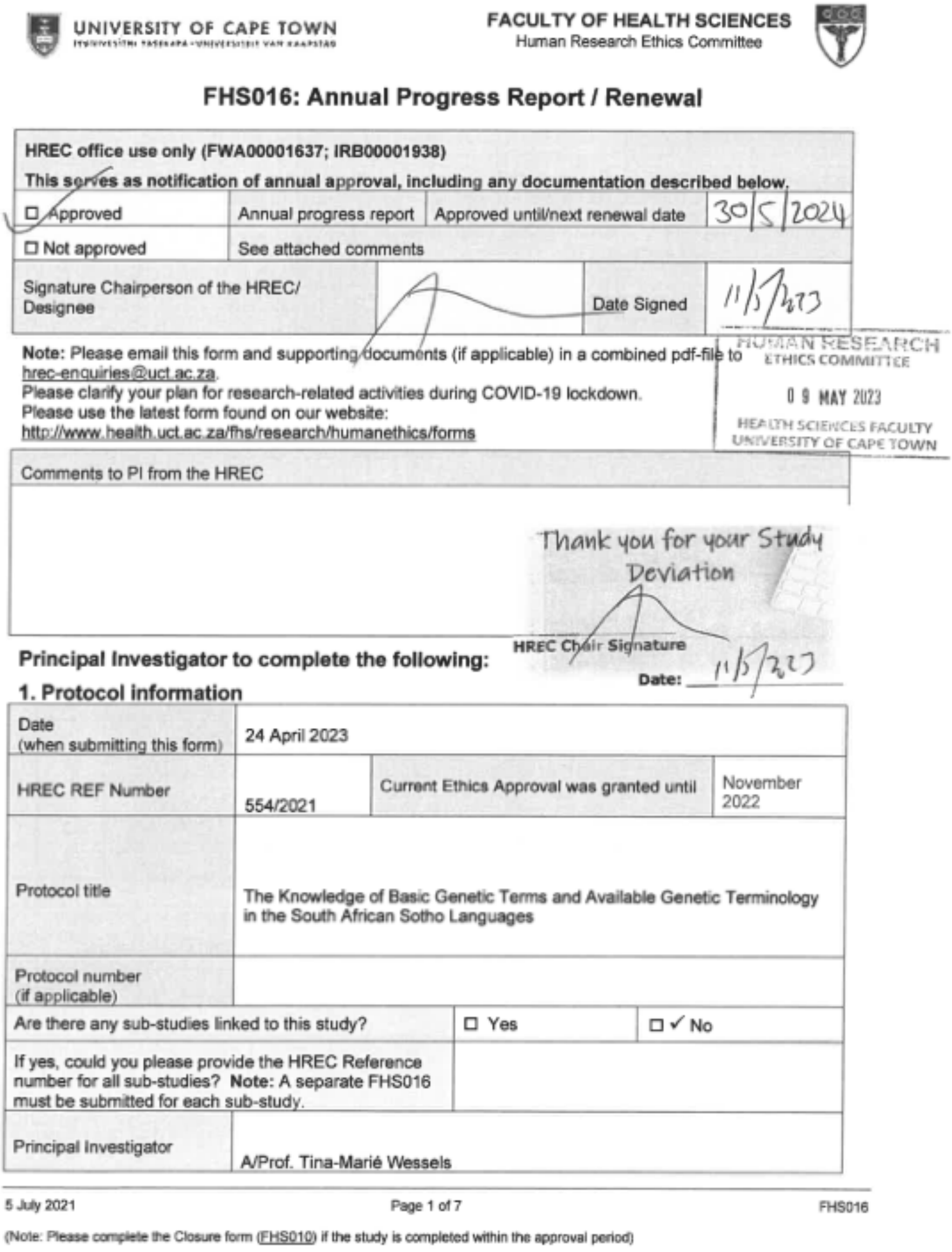
APPENDICES

Appendix A: HREC Approval



UNIVERSITY OF CAPE TOWN

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938)			
This serves as notification of annual approval, including any documentation described below.			
☑ Approved	Annual progress report	Approved until/next renewal date	30/5/2024
☐ Not approved	See attached comments		
Signature Chairperson of the HREC/ Designee		Date Signed	11/5/2023

Note: Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za.
Please clarify your plan for research-related activities during COVID-19 lockdown.
Please use the latest form found on our website:
http://www.health.uct.ac.za/fhs/research/humanethics/forms

HUMAN RESEARCH
ETHICS COMMITTEE
09 MAY 2023
HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN

Comments to PI from the HREC

Thank you for your Study Deviation

HREC Chair Signature

Date: 11/5/2023

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	24 April 2023		
HREC REF Number	554/2021	Current Ethics Approval was granted until	November 2022
Protocol title	The Knowledge of Basic Genetic Terms and Available Genetic Terminology in the South African Sotho Languages		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?	☐ Yes	☐ ✓ No	
If yes, could you please provide the HREC Reference number for all sub-studies? **Note:** A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	A/Prof. Tina-Marié Wessels		

5 July 2021 Page 1 of 7 FHS016

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

APPENDIX B: DSA Invitation to Participate

Title: The Knowledge of Basic Genetic Terms and Available Genetic Terminology in Indigenous South African Languages.

I am a Genetic Counselling student at the University of Cape Town, and I am conducting this research study to obtain my Master's Degree.

My study aims to explore linguistic and cultural concepts used to describe heritability of traits and diseases including words, concepts, proverbs, and other expressions used to express knowledge and understanding of transmissibility or heritability of character traits and diseases of the South African Sotho group, which consists of the Sesotho, Setswana, and Sepedi People.

Focus group discussions will be used to collect data. The interviews for the study will be conducted in English through a video call (i.e., Microsoft Teams). The Microsoft Teams link will be sent to the participants, and they will be able to join using their UCT email addresses. The focus group discussion (interview) is expected to take approximately 60 to 90 minutes, and will be video recorded in order for the data to be transcribed after the session.

The researcher and supervisors of this study will make sure that confidentiality is strictly maintained in all paperwork and data collected throughout the course of the study. This means your name or other identifying information will not be made known to anyone not directly involved in the study.

Participation in the research interviews is purely voluntary. If you no longer wish to participate in the study at any point, you can contact the researcher and supervisors (contact details below) and your data will be withdrawn from the study. Be assured that the withdrawn data will be deleted and will not leak.

Should you have any questions about this project, please feel free to contact any one of us. Please see details below.

Researcher:

Andrew Mpe - 021 404 6235 / 072 944 1407 / email: MPXMAT003@myuct.ac.za

Supervisors:

A/Prof. Tina-Marie Wessels : tina.wessels@uct.ac.za

Ms Malebo Malope : MLPMAL005@myuct.ac.za

UCT ethics committee at 021 650 1236 or

hrec-enquiries@uct.ac.za

APPENDIX C: Information sheet and Consent Form

Title: The Knowledge of Basic Genetic Terms and Available Genetic Terminology in Indigenous South African Languages.

I am a Genetic Counselling student at the University of Cape Town, and I am conducting this research study to obtain my Master's Degree.

My study aims to explore linguistic and cultural concepts used to describe heritability of traits and diseases including words, concepts, proverbs, and other expressions used to express knowledge and understanding of transmissibility or heritability of charactertraits and diseases of the South African Sotho group, which consists of the Sesotho, Setswana, and Sepedi People.

Focus group discussions will be used to collect data. The interviews for the study willbe conducted in English in-person or through video call (if every participant has access) On average, each interview and will last 60 to 90 minutes and will be audio- recorded.

The researcher and supervisors of this study will make sure that confidentiality is strictly maintained in all paperwork and data collected throughout the course of the study. This means your name or other identifying information will not be made knownto anyone not directly involved in the study.

Participation in the research interviews is purely voluntary. If you no longer wish to participate in the study at any point, you can contact the researcher and supervisors (contact details below) and your data will be withdrawn from the study. Be assured thatthe withdrawn data will be deleted and will not leak.

Should you have any questions about this project, please feel free to contact any oneof us. Please see details below.

Researcher:

Andrew Mpe - 021 404 6235 / 072 944 1407 / email: MPXMAT003@myuct.ac.zaSupervisors:
A/Prof. Tina-Marie Wessels: tina.wessels@uct.ac.zaMs
Malebo Malope: MLPMAL005@myuct.ac.za
UCT ethics committee at 021 650 1236 or
hrec-enquiries@uct.ac.za

Statement of participation

1. I have agreed to participate in the above-mentioned research project which is supervised under the authority of the Division of Human Genetics at the University of Cape Town.

2. I am aware that my participation in this study is voluntary and if I chose to withdraw from the study my decision will be fully accepted with no consequences.

3. I have received information about the study, including the aims and objectives. Ihave been allowed sufficient time to decide to participate in the research study.

4. I understand that the interview will be done in person or via video call (approximately 60 to 90 minutes) at a time that is agreeable for me, the participant and researcher.

5. I was given an opportunity to ask any questions that I may have about the studyand confirm that I understand the scope of the study and that I may ask any additional questions I may have for the duration of the study.

6. With the assurance of anonymity and confidentiality, I agree that the results obtained from the study may be used for publication.

7. I am aware that I will be paid a maximum amount of R150.00 for participating inthis study.

8. I agree to the interview being audio recorded. All audio recordings will be safely stored away in locked cupboards and information stored on a password- protected computer. I understand that only the researcher and supervisors will have access to the anonymised data.

9. I hereby give my consent to participate in this study and that I am doing so at myown free will.

10. I have the researcher and the HREC’s contact details in the event that I would like to contact them regarding further questions about this study.

Name and Surname of Participant	Signature	Date
Andrew Matshela Mpe	Signature	Date

APPENDIX D: Focus Group Interview guide

1. Tell me about your ethnic/tribal background.

Probing: Where are you and your family originally from?

What language do you mainly speak at home?

2. Have you ever heard of the term Gene or Genetics? If so:
   - How would you describe it?
   - Is there any word(s) in your home language that is used that refers to it?
   - Probing: What do you think causes resemblance in some of the family members?
3. What is your understanding of the saying “We are made of DNA”? Tell me more about it.
4. What other terms related to heredity or genes/DNA used in your language do you know of?
5. How would you describe them in your home language?
6. What are the available phrases, proverbs or sayings that are used instead of terms that describe a phenomenon related to genetics and inheritance?
7. Are there any members in your family or community that you know of that have disabilities?
   - What conditions do some of the members have?
   - What are the available terms in your home language would be used to describe them?
   - What do you think caused them to be the way they are
8. What other conditions related to the ones you mentioned above do you know of? What terms or sayings in your language are used to describe/identify them?
9. What are the names of the procedures that traditional doctors in your culture use to treat a person with a genetic condition?

10. What sayings and expressions in your culture are used to describe a way in which a genetic condition can be prevented?

11. Have you or your family ever heard of the term “Genetic counselling”? If yes:

- What does it mean/refer to?
- Have you ever been referred to a genetic counselling session?
- How was your experience?
- What challenges did you encounter in the session?
- How did you find it helpful for you?

12. Was there ever a case in the community where there is/was only one child in an entire family with a rare condition? If yes:

- What do you think caused it?
- What are the available term(s) used to describe it?

13. What do you understand about the following terms:

- Dominance & Recessiveness
- X-linked inheritance
- Autosomal inheritance

14. What saying or expression is there in your home language that refers to each of the abovementioned terms?