UNIVERSITY OF CAPE TOWN

Department of Social Work and Social Development

Exploring the Experiences of South African Youth Living with Myasthenia Gravis

A minor dissertation, submitted in partial fulfilment of the Master of Social Science degree in Social Development

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Abstract

This study explored experiences of South African youth living with Myasthenia Gravis (MG). Myasthenia gravis is a rare autoimmune disease marked by skeletal muscle weakness caused by the breakdown of communication between nerves and muscles at the neuromuscular junction. The aim was to understand how MG affects emotional and physical well-being, social and family relationships as well as educational and employment prospects of young people who have been diagnosed with the disease. In addition, the study sought to understand the role of culture and religion on how youth understand and cope with MG.

Using a qualitative research design and a purposive sampling technique, eight young people from diverse backgrounds who were receiving MG treatment at Groote Schuur Hospital (GSH) in Cape Town were interviewed about their experiences of living with MG. Data collection took place through in-person interviews which were conducted at the MG clinic located within the neurology division at GSH. A semi-structured interview guide was used as a data collection instrument. Data was analysed through Applied Thematic Analysis (ATA). Findings from the study indicate that a shortage of specialist doctors, poor awareness and lack of accountability among Health Care professionals (HCPs), especially those in township communities where most participants were from, added to participant experiences of symptom progression and delayed diagnoses. Findings also suggest that MG may mentally affect youth's personal relationships as well as spousal relationships in instances where participants were married.

The research concludes that skills and knowledge gaps in public institutions led to delayed diagnoses allowing, patients' symptoms to progress while awaiting diagnoses. In contrast, services at private hospitals showed better outcomes. It is also concluded that public awareness of MG and HCPs accountability is crucial to enhance patients' health prospects and ability to cope with MG. The study recommends that patient referral procedures be better regulated with mandated time frames for HCPs to refer patients if they struggle to make a correct diagnosis. This is to reduce the occurrence of delayed diagnoses observed amongst the youth diagnosed with MG. Furthermore, provision of financial aid and grants to support youth, especially students with disabilities who are unable to study full-time or in-person are recommended.

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Glossary

ATA – Applied Thematic Analysis

AYHP – National Adolescence and Youth Health Policy

GSH - Groote Schuur Hospital

HCPs – Health Care Professionals

HRQoL – Health-Related Quality of Life

MG – Myasthenia Gravis

MG-ADL - Myasthenia Gravis Activities of Daily Living

NYP – National Youth Policy

CHAPTER 1

INTRODUCTION

This chapter is an introduction of the research project which explored the experiences of South African youth who have been diagnosed with the medical condition called Myasthenia Gravis (MG).. Myasthenia gravis is a rare autoimmune disease marked by skeletal muscle weakness caused by the breakdown of communication between nerves and muscles at the neuromuscular junction. Voluntary muscles of the body, including those that control the limbs, eyes, mouth and throat are affected leading to implications for wellbeing and functionality. The study aimed to explore the nature and the occurrence of this condition amongst young people, how it affects their family and social relationships, its impact on young people's education and employment prospects as well as the degree to which cultural and religious beliefs inform how people understand and cope with the disease. The chapter outlines the problem statement, significance of the study, research objectives, research aims, and ethical considerations and provides a clarification of terms used in this paper.

1.1 Background & Statement of the Problem

Myasthenia Gravis is an auto immune disease where antibodies block nicotinic acetylcholine receptors at the junction between the nerve and the muscle, leading to skeletal muscle weakness (Gilhus, Skeie, Romi, Lazarus, Zisimopoulou & Tzartos, 2016). The disease manifests through weakness/fatigue which can affect ocular and general muscles. This is why MG is divided into ocular and generalised MG. In ocular MG, eye muscles are affected resulting in symptoms of ptosis and/or double vision. Ptosis refers to the experience of drooping eyelids which often result from eye muscle weakness. Generalised MG affects the limbs, bulbar, respiratory and ocular muscles leading to weakness affecting the whole body (Dresser, Wlodarski, Rezania & Soliven, 2021). Muscle weakness in MG typically increases with repetitive muscle use and fluctuates over the course of a day, and from day-to-day with average muscle strength in the morning. Onset can be sudden although MG is common amongst women below the age of 49 and men over the age of 60. Young people are also affected by this condition.

The prevalence of MG in the South African context is medically well documented. Research documenting clinical manifestations and treatments for both ocular and generalised MG is available through works of scholars such as Heckmann and Marais (2020) who have researched the topic in relation to other primary health concerns within the South African context. These authors have produced work highlighting complications associated with treating MG in the South African context, where infections such as HIV and tuberculosis are highly prevalent. Heckmann, Owen and Little (2007) have also looked at racial differences in clinical manifestations of MG and found that white participants were more likely than Black participants to develop generalised MG that is not responsive to treatment. The authors also reported that there were no significant racial differences in the time between diagnoses to initiation of therapy, which led the researchers to conclude that biological factors play a role in patients' response to the immuno-suppressive therapy used in MG treatment (Heckman, Owen & Little, 2007). The findings presented by these authors provide rich contextual data which adds value to the paper. Substitute text could not be found due to data limitations.

Studies above provide insights into medical dimensions of MG, adding value to the understanding of MG from a health sciences perspective as they highlight the role of genetic and heredity factors play in the MG manifestation and treatment response. However, there is limited availability of qualitative data regarding the effects of MG on the well-being of South African youth who have been diagnosed with MG. This research hopes to fill this gap through by exploring experiences of MG amongst young people in South Africa. According to Morar, Seedat and Richards (2023), the gap between urban and rural contexts make it harder to document the occurrence of MG in South Africa. These divides shape MG reporting as samples often consist of participants from big cities. Consequently, as opposed to the global context, South Africa continues to have limited literature on MG which is a gap this study hoped to fill. This was achieved through a qualitative inquiry where semi-structured interviews and the Myasthenia Gravis Activities of Daily Living (MG_ADL) tool were used for data collection. The MG-ADL is an eight item self-reporting scale used to measure the severity of MG symptoms and the functional status of MG patients. The scale is a reliable and valid measure used to measure MG symptoms and treatment response in clinical trials and observational studies. Administering the MG-ADL does not require additional training as it is easy and quick to complete (less than 10 minutes) (Muppidi, Silvestri, Tan, Riggs, Leighton & Phillips, 2022).

1.2 Rationale and significance of the study

This study aimed to explore how South African youth experience living with MG while developing and navigating their social, academic and professional lives. Data generated from this study supports policies such as the National youth Policies (NYP) which provides for general services to improve the lives of South African youth, including those who are living with chronic illnesses such as MG. The policy outlines its aims and goals to ensure universal and inclusive youth development that promotes equal access to quality educational programmes and employability for all young people (NYP, 2020). It is this author's observation that the policy has failed to include youth with disabilities and chronic illnesses in its goals as it rarely mentions them and does not acknowledge health, educational and employment challenges faced by these young people due to limitations caused by their disabilities and medical conditions. Jacob and George (2022) also argue that South African youth continue to struggle because of contextual and structural barriers due to the NYPs failure to align its strategies and the situation faced by youth on the ground. The policy acknowledges the need to involve youth with disabilities in development programmes and transformation opportunities (NYP, 2020). However, lack of clear targets detailing how this will be achieved remains a barrier to the inclusion of youth facing a spectrum of health-related challenges such as MG. Recommendations presented in this research could help develop clearer targets that speak to specific needs of young people living with chronic illnesses and disability.

Findings presented in the study may also benefit people living with MG, their families and communities as they provide insight on coping, understanding and support strategies that may be useful when living with MG. Those living with MG can also learn various perspectives on how others understand and cope with MG, while those around them such as their families and communities can also gain insight on how others support and cope with loved ones' MG diagnoses. These findings also provide insight that will allow medical practitioners to understand needs and challenges faced by young people living with MG based on their reality or lived experiences. This could contribute towards better social cohesion and integration of youth living with MG into society and create greater awareness of the disease. HCPs could also benefit from the findings given their lack of knowledge and awareness about MG. Furthermore, the study's findings and recommendations may inform youth disability interventions aimed at improving youth health and education.

1.3 Main Research Questions

The main research questions for this study were formulated as means to explore experiences of being diagnosed and living with MG amongst South African youth. As such, the main research questions were based on young people's experiences of being diagnosed with MG, the effects of MG on their physical and mental wellbeing, the effects of MG on their family and social relationships, the effects of MG on youth's employment and educational prospects, as well as the influence of culture and religion on how South African youth understand and cope with MG.

- What are young people's experiences of being diagnosed with MG?
- How does MG affect young people's physical and mental well-being?
- How does MG affect young people's family and social relationships?
- What impact does MG have on young people's prospects in terms of their education and employment?
- How does culture and religion influence coping and understanding of MG?

1.4 Research Objectives

To achieve these outcomes young people with MG were interviewed about their experiences of being diagnosed and living with MG. Data was collected using a semi-structured interview guide and analysed using Applied Thematic Analysis (ATA). These findings are documented in chapter four. Consistent with research questions, research objectives were defined as follows:

- To explore young people's experiences of being diagnosed with MG.
- To explore how MG affects young people's physical and mental wellbeing.
- To explore how MG affects young people's family and social relationships.
- To explore the influence of an MG diagnosis on young people's employment and educational prospects.

- To determine how culture and religion influenced participants' coping and understanding of MG.

1.5 Main Assumptions

In this research people are viewed as unique individuals with unique understanding of their experiences and environments. As such, a qualitative research design was employed using a phenomenological approach. The phenomenological approach was deemed appropriate to gain deeper insight into the topic due to its focus on participants' lived experiences. The research aimed to gain insight on participants' subjective experiences and present findings based on these experiences as opposed to fitting them into existing categories.

The researcher assumed that living with MG would have a negative impact on young people's physical and mental wellbeing. It was also assumed that MG would have a negative impact on youth's social and family relationships and limit their employment and educational prospects due to the emotional and physical burden caused by the disease. Authors like Freeman, Lewis and Heckmann (2014) and Muzaffar and Rohail (2021) argued that MG is highly associated with issues of depression and anxiety. These authors reported high depression and anxiety scores observed amongst MG patients. Low social support observed amongst MG patients also affects their wellbeing and may lead to strained social and family relationships. According to Lehnerer et al (2021), education and employment limitations are common amongst MG patients due to the nature of the physical and mental strain caused by the disease. Lastly, the study assumed that coping strategies and understanding of MG would be informed by participants' cultural and religious beliefs. According to White (2015), the African traditional religion holds the belief that some medical problems cannot be treated or healed through Western interventions and therefore need spiritual forms of intervention. The author highlighted that although this point of view does not oppose medical treatment it may have negative or positive influence on people's understanding and coping strategies regarding diseases such as MG.

1.6 Clarification of Terms

Myasthenia Gravis - MG is an autoimmune neurological disorder characterised by fluctuating skeletal muscle weakness which commonly affects muscles of the face, eyes and swallowing. Onset can be sudden and result in double vision, drooping eyelids as well as difficulty walking and talking (Dresser, Wlodarski, Rezania & Soliven, 2021). According to Derrow

(2023), MG is relatively uncommon and only affects approximately 700 000 people worldwide with the prevalence of 150 to 200 cases per one million individuals (National Institute of Health, 2021). Although MG is manageable through surgery and treatment, there is no cure. From this description one can ascertain that the occurrence of this disease may vary. This is why the study aimed to explore participants' subjective experiences of MG.

South African Youth - In South Africa, the NYP (2020) defines youth as individuals aged between 14 and 35 years. The policy gives the understanding that young people are not a homogeneous group and differentiates between adolescents who fall between the ages of 14 to 17 years, and older youth who fall between ages 18 years and older. Older youth are understood as adults who are capable of making decisions. This is why this study engaged this group as participants deemed legally capable to consent to the study and give rich descriptions of their experiences of living with MG.

Wellbeing - There are different definitions of wellbeing which according to Ruggeri, Garcia-Garzon, Maguire, Matz and Huppert (2020) refer to a sustainable condition that allows one to develop and thrive while feeling good and functioning well across physical, emotional and spiritual aspects of life. This study integrates these aspects to refer to wellbeing as participants' ability to function and cope with MG while meeting the demands of daily life within the framework of their physical, emotional and spiritual well-being.

Mental Wellbeing – According to Peterson (2022), mental wellbeing refers to people's ability to strive in various aspects of life despite encountering life's ups and downs. Mental wellbeing includes how a person acts, thinks and handles emotions. Skills such as self-acceptance, desire for growth, internal happiness and many others that people can practise all form part of mental wellbeing (Peterson, 2022). The study drew on this definition to understand mental wellbeing as participants' ability to thrive while coping with psychological stresses associated to MG and other life challenges.

Education - Formal education refers to a methodological and composed training model which encompasses primary, secondary and tertiary education (Department of Basic Education, 2022). The South African constitution states that everyone has a right to basic education, including adult basic education (The Constitution of the Republic of South Africa, 1996). Education is crucial to active engagement in society and these dimensions of education were a focus to explore the educational experiences of participants in the study. Primary, secondary and tertiary education levels of were included in this study's understanding of this term. This is due to some participants' experiences of being diagnosed with MG with MG while they were engaging on attaining an education.

Employment - The South Africa's Labour Relations Amendment Act (2014) defines an employed person as anyone who works for another person or assists in conducting the business of an employer. Formal and informal employment is included in this definition. Informal employment is characterised by its casual nature, being less regulated and lack of employment benefits enjoyed by people in formal employment. Examples of informal work include street vendors or owning a small business such as a tuck shop. On the contrary, formal employment is recognised for its provision of stability as it is often long-term. It is also characterised by pension benefits and being more regulated in terms of remuneration and working hours (Labour Relations Act, 2014). Examples of formal employment include permanent, part-time, freelance, temporary work and casual work. The rights and benefits enjoyed by employees in these different types of employment differ although they are all formal with a contract of employment often recommended to protect employers and employees (Labour Relations Act, 2014). Formal employment is the lens through which employment is viewed in this paper.

Religion - This paper understands this concept through Harrison's (2015) point of view which describes religion as a perception which entails diverse sets of beliefs and principles about people's spirituality. According to Harrison (2015), this definition embraces both Western and Non-Western beliefs. South Africa is one such context that embraces diversity and freedom of religion. This is also enshrined in the country's constitution which promotes freedom of religion. Section 15(2) of the South African constitution speaks to religious freedoms and states that everyone has the right to freedom of conscience, religion, thought, belief and opinion (Constitution of the Republic of South Africa, 1996). With this, many religions are represented in the ethnic and religious diversity of the country's population. According to Statistics South Africa (2024), 80% of South Africans are Christians, 15% are not religiously associated and 5% affiliate with other religions including Muslim and Hinduism. The African traditional religion is a huge part of religion in South Africa. Although this religion is not institutionalised and has no doctrine, it promotes the development of a spiritual relationship with one's ancestors (Denis, 2006). The religion holds the belief that ancestors protect their descendants by spiritually guiding them and preventing misfortunes including diseases that may threaten them.

Culture - Spradley and McCurdy (2012) define culture as the learnt and shared knowledge used by people to generate behaviour and interpret experience. This definition emphasises the view of culture as a kind of knowledge that is learnt and taught to others, as opposed to behaviour. This knowledge encompasses people's shared beliefs and values. However, Kpakane (2018) argues that people in different cultures hold variant conceptualisation of understanding and self-representation. According to the author, many African cultures promote relational-oriented identities where individuals forge their cultural identities through spirituality, society and their inner experiences of life. These agencies inform people's understanding of health and other social issues (Kpakane, 2018). Sunday, Idemudia and Adedeji (2023) view of African culture as highly collective, with an emphasis on social connection which is the view adopted by this paper. This view is important as it was considered relevant to participants' understanding of MG, their treatment options, as well as their social and family relationships after an MG diagnosis.

Mental health - According to Parry (2023), mental health plays a crucial role in people's overall wellbeing and is therefore an essential element of health. Similar to physical health, mental health fluctuates and flows as people experience life. Good mental health means that we can recognise our full potential and thrive in everyday life (Parry, 2023). Therefore, according to Parry (2023), mental health is understood as one's ability to engage in productive activities, fulfilling relationships with others and adaptation to change and coping with challenges.

1.7 Ethical Considerations

In research there are a number of ethical principles to consider and uphold. According to Denison (2023), ethics are an important element that one needs to carefully consider in order to conduct responsible research. They ensure the validity and reliability of the findings and protect participants' rights. This is why ethical considerations are crucial as they contribute to the outcome of the study. Below mentioned ethical considerations informed this study. In this process the researcher followed various procedures. Firstly, the proposal for this study was submitted, reviewed and approved by the Ethics Review Committee of the Humanities Faculty at the University of Cape Town (UCT) with reference number SWK-REC-2022-

SR021. Since the research involved exploring a medical condition, ethical clearance was also required from the Health Sciences Faculty at UCT.

Secondly, an application for ethical clearance was therefore submitted and approved by the Human Science's Ethics committee at GSH. This was due to the nature of the study which involved a sample of vulnerable participants who are living with a medical condition. The risk associated with participants being medical patients made them physically and emotionally vulnerable to harm. Ethics approval letters can be seen in appendices 1 and 2. Once ethical approval was obtained, the researcher obtained permission from GSH to conduct the research at the MG clinics held in the neurology division at this facility. The letter of approval allowing the researcher to collect data at the clinic is attached in appendix 4.

1.7.1 *Avoidance of Harm* – Battista and Torre (2023) describe avoidance of harm as the primary principle governing the protection of research participants by clearly stating that no harm should come to research participants. This protection is extended to real world settings such as participants' communities, schools or in this research a hospital environment where research took place. According to Cresswell (2014), researchers need to anticipate the possibility of harmful, intimate information being disclosed during the data collection process. While it may be difficult to anticipate and plan for the impact of this information, the author emphasised that researchers need to prioritise and uphold the safety and protection of their research participants throughout the research process. The researcher understood the sensitivity of the research topic and that it could evoke strong emotions for participants. This is why sensitive and unclear questions unrelated to the study were avoided and participants were not pushed into answering questions that made them feel uncomfortable. Participants were asked questions that only related to the research objectives of the study. Participants were also given the freedom to choose not to answer questions that made them feel uncomfortable and were given space to calm down and asked if they wished to continue with the discussion. This occurred in events where participants got uncomfortable or emotional during the interviews. This was observed through their verbal and non-verbal cues. Some participants verbally expressed their discomfort and stated that they did not wish to answer certain questions. These questions were passed with the participants' permission. However, the researcher also paid close attention to participants' body langnage and asked for their permission to continue. For example, some questions evoked physiological responses such as fidgeting or crying. The researcher had to pause and inquire about participants' willingness to answer or continue with the interview.

Participants also had the option to be also referred for counselling in cases deemed necessary by the researcher. For example, a participant was referred for this service after they raised many issues which indicated some distress which led to the referral. The researcher arranged for the participant to be seen by the social worker at the neurology division where they attended clinic MG for treatment. Arrangements were made with the social worker to see participants who showed signs of distress and attend the clinic at GSH. These arrangements were made prior to the commencement of the research.

1.7.2 *Informed Consent-* According to Arifin (2018), a researcher needs to obtain informed consent from participants. Informed consent may be obtained in two phases which include the researcher providing potential participants with an invitation letter or a recruitment letter. This letter includes the researcher introducing themselves to participants, their interest in the topic as well as the basics of what the research process will entail. The second phase involves obtaining written consent from participants which should include the title of the research project, identification of the researcher with contact details, as well as other basic information about the research including the methodologies and procedures (Leavy, 2017). Creswell (2014) agrees with this scholar and further argued that participation in research should be seen as voluntary and that the aims, purpose and study procedures should be explained to participants. Written informed consent was obtained in this research project. A third party who is the head of the MG clinic attended by participants verbally introduced the study to possible participants who fitted the sampling criteria. Communication requesting her to introduce possible participants to the study took place through email. A detailed discussion is included in the methodology section. Participants who were interested in participating were then introduced to the researcher who explained the study aims and procedures in detail. Consent was also acquired from participants in writing prior to the beginning of each interview. The need for consent was verbally explained and participants informed of their right to withdraw from participation at any point of the interview. Consent to record was also requested through an informed consent form (see appendix 5) which included the title of the project, researcher's details as well as the main objectives, procedures and methodologies as described by Leavy (2017). The informed consent was signed by participants to confirm their participation.

1.7.3 *Deception of Respondents*- According to Arifin (2018), it is important for researchers to uphold the ethic of honesty, integrity and caring. This author argued that researchers need to be mindful and ensure that they always represent themselves and the project in a truthful manner.

This also includes being objective and non-judgemental in the language being used during the research process except for rare occasions where deception is necessary due to the nature of the research. Creswell (2014) agrees that participants need to know that they are actively participating in a study and should be given instructions that remind them about the purpose of the study. Deception was not used in this study. The researcher did not give any misleading information or withhold information about the study purpose and procedures from participants. The researcher notified participants of her condition prior to the beginning of each interview when she introduced herself to participants.

1.7.4 *Privacy*- Privacy refers to the participant's right to choose how, when, to whom and to what extent their opinions are disclosed (Arifin, 2018). Creswell (2014) argues that researchers need to anticipate the possibility of harmful, intimate information being disclosed during the data collection process. Although it may be difficult to plan for the consequences of this information, the ethical code for researchers requires researchers to protect the privacy of participants and to convey this protection to all research participants. This needs to be done in writing, verbally and practically by ensuring that a private location is used for data collection. This also needs to be accounted for when obtaining informed consent (Creswell, 2014). The researcher arranged a secluded room where data collection took place. This room was located within the clinic for convenience purposes. This was to ensure participants' privacy by making sure that conversations could not be overheard by a third party and be linked back to participants. This was reinforced by conducting the interviews in a private room at the MG clinic. This was organised by the researcher. .

1.7.5 *Confidentiality*- According to Leavy (2017), confidentiality refers to the guarantee that participants' identities will be kept anonymous and that they will be assigned fictitious names in any resulting publication. The author also argued that audiotapes should be destroyed after transcription and that transcripts should only reflect fictitious names. Any people mentioned in interviews should also be assigned fictitious names as these details might alert readers to participants' identities (Leavy, 2017). Fictitious names were not used in this research project as names were excluded.

However, a similar method where participants were assigned numbers during transcription was used. This was to ensure that participants' responses could not be linked to them. Interview recordings are stored in the researcher's UCT data management drive which is only accessible to the researcher and will be deleted within the required timeframes. Therefore, the information presented on the transcripts, and final report will not in any way be linked back to participants.

1.7.6 *Voluntary Participation-* According to Battista and Torre (2023), participants should not be forced to partake in research. Creswell (2014) emphasise that researchers should not force participants to sign informed consent forms when obtaining consent. According to him, participation should be viewed as voluntary and allow participants to withdraw their participation at any point of the research. This should be verbally explained and communicated in the informed consent forms signed by participants. In this research consent was collected in person prior to the commencement of each interview. The informed consent form detailing the purpose, methodologies and ethical considerations of the research were explained to each participant. Participants were also given an opportunity to read informed consent forms and ask for clarification before signing. Participants were also alerted of their right to withdraw their participation at any point, without consequence and were not in any manner coerced into partaking in the study.

1.7.7 *Debriefing Participants-* According to Battista and Torre (2023), debriefing refers to a follow-up session used by researchers to discover problems experienced by participants during the research process. This session provides an opportunity to elicit feedback from participants about their experiences which may inform decisions or amendments to the research or future research projects. The debriefing stage is mostly important when the study has investigated sensitive topics that may cause emotional harm (Battista & Torre, 2023). Debriefing took place immediately after data collection was concluded. The researcher asked participants to reflect on the interview to see if the process had evoked emotional distress. This was also observed through verbal and no-verbal cues. Signs of emotional distress were observed through gestures such as crying and other physiological clues. Some participants verbally communicated their need for emotional support. This opportunity was used to suggest counselling and refer them in cases deemed necessary by the researcher. Counselling was suggested to three research participants who exhibited signs of emotional distress during data collection.

One participant accepted and was referred to the social worker at the neurology department. The second participant declined to be referred and felt that they could cope on their own. The third participant was already attending counselling with the social worker. The social worker had been contacted and agreed to see research participants due to her expertise working with MG patients at GSH.

1.7.8 *Publication of Findings*- According to Cresswell (2014), findings from the study must be released to the public in written form. According to the author, it is utterly important for the details of the research to be shared with the study design so that readers can determine the credibility of the study for themselves. Details of this research and findings will be presented in a dissertation and submitted to the University of Cape Town. Participants were made aware of this publication prior to signing the informed consent. The dissertation will give an in depth report of participants' experiences based on the researcher's analysis of the data.

1.7.9 *Anonymity*- According to Battista and Torre (2023), it is the responsibility of the researcher to respect and protect the identity and anonymity of participants. Researchers usually do this by disassociating names from responses during the coding and recording process. According to the author qualitative researchers often use participant numbers and fictitious aliases for individuals and places in order to protect participants' identities. Furthermore, the author stressed the importance of putting participants' rights and wishes first in any situation that may arise regarding anonymity (Battista & Torre, 2023). Participant numbers were allocated to each participant to avoid responses being traced back to their identities. This was done during the transcription phase. All documents and audio recordings containing participants identifying information were safe-guarded and stored in the researcher's UCT data management drive and cannot be accessed by a third party. This is in line with the Protection of Personal Information Act (POPIA) code of conduct for research which stipulates that researchers must ensure that participants' personal identifying information is protected and stored in a secure access-controlled location to prevent it being infiltrated and used by third parties.

1.7.10 *Respect for Persons*- According to Barrow, Branna and Khandhar (2022), respect to persons is also known as the principle of human dignity which prescribes that researchers must protect participants' autonomy and ensure full disclosure of factors surrounding the study. This includes factors that may cause potential harms and benefits. Being autonomous refers to one's capability to deliberate about personal goals and act under the direction of such deliberation (Barrow, Branna and Khandhar, 2022). The researcher respected participants' dignity and autonomy by encouraging the participants to be contributors to the project. The most crucial element to this research was learning about participants' experiences of living with MG. Therefore, participants were encouraged to share their stories in a manner comfortable to them. Participants were also informed of their freedom to not answer certain questions or withdraw from participation at any time of the data collection process. Not imposing certain questions and topics that participants felt uncomfortable with was the researcher's efforts to maintain participants' autonomy and dignity.

1.8 Outline of the Chapters

This chapter overviewed the research project and discussed the background of the research topic, the research objectives, questions, assumptions, concepts, and ethical considerations informing the study. The following is the chapter outline of the dissertation:

Chapter two presents a literature review that overviews youth experiences of being diagnosed with MG, well-being, the effects of MG on social and family relationships, employment prospects as well as the role of culture and religion in understanding MG. The chapter also presents a discussion of the Afrocentric and ecological approaches as the two theoretical frameworks informing the research. The NYP and National Adolescent and Youth Health Policy (AYHP) are also discussed as the policy frameworks guiding the research.

Chapter three presents the research methodology which will give an overview of the research design, sampling as well as data collection and analysis. Data verification and reflexivity are included. Reflexivity is an important aspect in this research. This is due to the researcher being an MG patient with personal experiences of MG and had a keen interest in the topic herself

Chapter four provides a presentation and discussion of findings. The analytical framework for analysis and a table profiling the study participants is included in the chapter.

Chapter five presents the conclusions and recommendations based on the research findings

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

The previous chapter introduced the research and core dimensions including the problem statement as well as the significance and aims of the study. This chapter expands on the topic with a review of literature to explore the occurrence of MG in the South African context. The literature also presents findings on young people's experiences of being diagnosed with MG, the impact of MG on wellbeing, the role of culture and religion in understanding and coping with MG, the impact on their social and family relationships, as well as the impact of MG on educational and employment prospects. Furthermore, the chapter discusses Afrocentric and Ecological approaches as theoretical frameworks that guide this inquiry. Lastly, the NYP and AYHP are discussed as policy frameworks relevant to the research.

2.2 Review of literature

2.2.1 *MG in the Global Context*

A secondary inquiry conducted by Bubuioc, Kudebayeva, Turuspekova, Lisnic and Leone (2021) documented the epidemiology of MG. The authors reviewed a total of 64 studies dating up to 2019. Their findings indicate that the prevalence of MG around the globe ranges from 1.5 to 17.9 million people depending on the geographic location, with Western countries in the lead. According to Bubuioc et al (2021), studies found that the number of MG patients is increasing and has doubled over the last 20 years due to a higher MG incidence in the population of older persons, which can be attributed to better treatment, diagnoses and increasing lifespan of people living with MG. A secondary systematic review conducted by Sciancalepore et al's (2024) investigated the epidemiology of MG. A document review of literature published on MG up to February 2024 was retrieved from numerous databases using key tenns such as frequency, epidemiology, prevalence or incidence (Sciancalepore et al (2024). The authors that the global prevalence and incidence of MG has increased over the last years which they attributed to improvements in epidemiological methodologies and current diagnostic advances. The authors also observed a significant variation in MG frequencies between and within countries which they attributed to clinical responses and methodological biases.

2.2.2 *MG in the South African context*

Morar, Seedat and Richards (2023) argue that incidents of MG are harder to document in the South African context. Authors claim that this is due to racial diversity and the gap between urban and rural health services observed in South Africa. Moreover, geographical and racial divides observed in this context shape the reporting of MG incidence. Studies conducted in bigger cities like Cape Town may report higher MG incidence rates due to the nature of sample groups available in these contexts (Morar, Seedat & Richards, 2023). Heckmann and Marais (2020) conducted a primary inquiry to investigate management issues in MG patients living with MG. They concluded that MG management is difficult in patients living with other communicative diseases such as HIV. HIV is highly prevalent in South Africa; this poses a greater risk to MG patients. This is due to MG symptoms worsening within six months of commencing antiretroviral treatment.

2.2.3 *Youth and MG*

Despite limited data on this topic, a case study presented by Phiri, Noah, Borgstein, Baker, Mhemedi and Fisch (2021) on a 19-year-old Malawian lady who was diagnosed with MG highlights negative consequences experienced by youth who are diagnosed in low-income contexts such as Malawi. Authors highlight how lack of infrastructure, resources and personnel leads to delayed diagnoses and symptom progression. The case study indicates that the patient had to be transferred to a city hospital due to the lack of specialist doctors in a small town where she resided (Phiri et al., 2021). Lack of supporting equipment in the city hospital also prolonged the patient's diagnosis due to inability to complete all necessary tests. According to the authors, early stages after diagnosis are crucial. However, the patient could not commence treatment due to the unavailability of treatment required to treat her. Law et al (2021) also acknowledge challenges faced by patients during early stages of being diagnosed with MG.

A qualitative inquiry by Law et al. (2021) highlight treatment difficulties faced by MG patients and HCPs after an MG diagnosis has been made. This inquiry explored lived experiences of people living with MG and found that the fluctuating nature of the disease leads to a treatment burden. This is more so during early stages of diagnosis. According to the study' findings, the occurrence of myasthenic crises as well as adverse effects of steroids used to control the disease leads to HCPs often struggling to determine the best treatment plan (Law et al., 2021). This prolongs the recovery process for patients and the time spent seeking to determine the best treatment plan for them. As a result, both patients and HCPs are often frustrated as they seek treatments that can effectively control the disease. A qualitative inquiry using secondary data conducted by Narayanaswami et al. (2021) also highlights the frustration caused by the use of slow effect treatments to treat MG. In this inquiry authors aimed to generate an updated MG treatment guide through a review of updated literature with the hope of recommending more effective, up-to-date treatments that align with current medical advances (Narayanaswami et al., 2021). Authors emphasise the need to constantly review treatments to enable a smooth recovery for patients after an MG diagnosis.

2.2.4 *MG and youth well-being*

Most studies conducted on MG used quantitative methods. This includes the works of authors like Braz, Rocha, Vieira, Barbosa, Gomez, Kakehasi and Teixeira (2018); Fan, Xing, Yang, Wang and Feng (2020) and Muzaffar and Rohail (2021) who investigated patients' Health-Related Quality of Life (HRQoL) and the adjustment of MG patients to provide observable and measurable findings. These studies show that lower HRQoL amongst people with MG is common and that this is concurrent with depressive symptoms within this population.

A quantitative study conducted by Fan et al. (2020) revealed that HRQoL is affected by multiple aspects of people's health. These include physical, psychological, social and economic aspects of life. This inquiry used the Short-Form Health Survey to evaluate the wellbeing of patients living with MG in China. This is a 36 item self-administered questionnaire developed to assess the impact of disease on perceived wellbeing. According to the authors, the questionnaire is often used in neuromuscular research and has good validity and reliability. Social functioning, physical functioning, vitality, mental health, bodily health and general health are some of the categories the questionnaire entails (Fan et al., 2020). A similar inquiry conducted by Braz et al. (2018) using the MGQoL 15 scale yielded similar findings which claimed that HRQoL provides insight on people's perceived positions in life. This scale consists of items including chewing, speaking, swallowing and vision which are areas often affected in MG (Braz et al., (2018). According to the authors, HRQoL relates to all aspects of life, including people's goals, expectations, cultures and value systems. Hence, it informs health evaluations due to the value of data it provides on physical, mental and social functioning of patients.

In a quantitative inquiry aimed at evaluating predictors of HRQoL in MG patients, Braz et al. (2018) found that strain caused by MG limits people's physical functioning. Although this differs according to the severity of symptoms, day-to-day functioning is still affected. Hence, countries like the United States of America and Germany classify MG as a disability (Braz et al., 2018; Lehnerer et al., 2021). Fan's et al. (2020) views align with these findings as their cross-section observational study also found that patients had lower scores on the SF-36 questionnaire when it came to categories of physical and general health. As mentioned above, this is a tool used to measure the impact of MG on well-being.

Authors conclude that MG leads to poor physical well-being which is something that Muzaffar and Rohail (2021) concur with as they found evidence that routine activities such as brushing teeth, combing hair, swallowing and chewing are difficult for people living with the condition. According to Narayaswami et al (2021), MG treatments constantly need to be improved and adapted to counter symptom fluctuations experienced by patients. These authors emphasise the need for holistic treatment guidelines that account for all of wellbeing including mental wellbeing. Treatment guidelines need to account for this as patients may experience negative side effects from treatment which may affect other forms of wellbeing such as their mental wellbeing (Narayaswami et al., 2021).

According to Muzaffar and Rohail (2021), psychological well-being is a big threat to HRQoL for MG patients. This is due to high depression and anxiety scores they observed through a quantitative correlational inquiry they conducted. The inquiry was set to estimate the impact of symptom severity on psychological functioning of people living with MG. Using purposive sampling, the study engaged a total of 270 participants living with MG. Their findings show that MG negatively affects patients' psychological well-being. The results presented a link between emotional problems and the diagnosis of MG. This includes the frustration caused by the severity of MG symptoms which leads to emotional distress. A mixed methods inquiry comparing the HRQoL of people living with MG and the general population conducted by Lehnerer et al. (2021) also found that MG patients had lower mental health scores. This group presented with symptoms of depression, anxiety and fatigue due to the condition. Hence, the study concluded that people living with MG have a lower HRQoL compared to the general population.

A cross-sectional study conducted by Freeman, Lewis and Heckmann (2014) detected symptoms of moderate to severe depression and anxiety amongst MG patients. Findings from this study show that MG severity, early onset and longer duration of MG correlate with severe depression and anxiety symptoms. The study also found that those diagnosed with MG at a young age also had suicidal tendencies (Freeman, Lewis & Heckmann., 2014). According to Nadali, Ghavampour, Beiranvand and Takhtegahi (2022), issues of depression and anxiety are a major concern among people living with MG. A secondary inquiry conducted by these authors reviewed the prevalence of depression and anxiety in MG patients using a total of 38 studies. Findings detected a high prevalence of depression and anxiety amongst MG patients in comparison to other autoimmune disorders (Nadali et al., 2022).

Authors argue that HCPs need to prioritise MG patients' mental and psychiatric wellbeing in intervention strategies. This aligned with Freeman, Lewis and Heckmann's (2014) conclusion that depression screening should take place in clinics to prevent the under-diagnosis of neuropsychiatric conditions in MG patients. Other factors also hinder the wellbeing of individuals living with MG. These include economic factors which will be discussed in the following paragraph.

According to Lehnerer et al. (2021), MG creates a burden for low-income groups. Using mixed methods research these authors sought to explore and estimate MG patients' perspectives on the burden of the disease. Findings indicate that costs associated with the management of the disease created a strain on patients, especially those in the low-income group category. This is due to numerous factors such as transportation to attend check-ups and medical fees as they mostly do not have medical insurance (Lehnerer et al., 2021). Fan et al. (2020) also found financial burden to be high amongst people living with MG as 73.9% of their participants reported needing to consult a doctor more than 12 times per year. Authors conclude that despite most patients being on medical insurance, the financial burden caused by MG is a huge problem and contributes towards poor economic wellbeing amongst MG patients.

2.2.5 *Family, social relationships and MG*

According to Lehnerer et al. (2021), poor social support has negative implications for social well-being. Findings provided by these authors show that low social support is prevalent amongst people living with MG. According to the authors, more than one fifth of a total of 1660 participants reported to have low social support which had a negative impact on their mental and physical health. This highlights the need for the development of holistic intervention plans as previously argued by Narayaswami et al. (2021). Fan et al. (2020)'study also yielded similar findings which indicate that social functioning directly affects people's mental and overall well-being. This contributes towards low HRQoL which is common amongst MG patients. Despite the authors not relating this specifically to family or other social relationships, authors such as Chen et al. (2013) highlight the importance of peer and social relations as key factors in the development of coping strategies for MG. This is due to the psychological role played by these relationships in determining patients' coping and well-being.

A narrative secondary inquiry conducted by Larrosa-Dominguez and Reyes-Marti (2023) reviewed functional support in patients living with MG. Authors reviewed international literature with the aim to understand the impact of social support and networks on patients with MG. A total of 13 articles were analysed (Larrosa-Dominguez & Reyes-Marti, 2023). Authors conclude that social support is crucial for people living with MG as it generates tangible assistance and information. They suggest that emotional support helps MG patients cope with challenges and improves their HRQoL. However, they note that MG symptoms such as ptosis and slurred speech can hinder social interactions due to their negative psychosocial impact. As a result, patients may isolate themselves to avoid questions from others. Nonetheless, the authors' conclusions are consistent with Lehnerer's et al. (2021) argument that social support is crucial to the wellbeing of people living with MG.

2.2.6 *MG education and employment*

Employment and educational limitations are common amongst people living with MG (Fan et al., 2020; Lehnerer et al., 2021). This is due to the nature of the disease and physical restrictions associated with it. Lehnerer's et al. (2021) mixed methods study revealed MG as the cause for numerous employment limitations. According to the study findings, 45.8% of the participants, including youth, were reportedly unable to work while 18.6% were on occupational disability. Other participants reported having reduced working hours, not finding work and viewed professional disability as limitations to gaining employment. They related this to their physical inability to work long hours or to work at all because of MG. Fan's et al. (2020) inquiry also found that despite having moderate to high educational levels, less than a quarter (24.6%) of participants in their study worked every week. Authors also found disability-related retirement as the main reason for unemployment which supports Lehnerer's et al. (2021) argument that MG limits educational and employment prospects.

2.2.7 *The role of culture and religion in understanding and coping with MG*

According to Chen et al. (2013), perceptions of MG impact people's understanding and response to MG. A qualitative inquiry conducted by these authors engaged nine Taiwanese MG patients and used in-depth interviews to explore their experience of MG as well as their coping and support strategies. Perceptions about MG, adaptation and adjusting to MG are some of the key themes found by researchers. Their findings reveal that these themes are shaped by people's cultural and religious beliefs which informed their understanding of the disease as spiritual. According to these authors, participants' cultural and religious beliefs led them to view MG as a disease that should be treated through cultural and religious methods. However, participants also acknowledge the need to recognise the role of Western medicine in controlling MG (Chen et al., 2013).

An inquiry by White (2015) found that African traditional religion informs people's choice of treatment when they get sick. This inquiry explored the influence of African tradition and religion on the understanding of disease and health care. According to this author's findings, African tradition and religion holds the belief that some diseases result from spiritual influences and therefore should be treated using traditional or religious methods. The author argues that this arises from Africans' beliefs that God and ancestors control their lives, including their health. This point of view does not oppose Western medicine but views some health problems as spiritual and traditional which should be treated as such (White, 2015). Hence the inquiry concluded that we should seek to find common ground to bridge the gap between the Western and African traditional methods by accepting traditional methods as equally smart and recognising African traditional healing as important. In contexts like South Africa, traditional healing is legally recognised through the South African Traditional Practitioners Act, Act 35 of 2004 (White, 2015). This promotes openness and dialogue about efforts to bridge the gap and misconceptions about Western and African health methods. This is why people in this context are likely to seek both Western and traditional treatment when they encounter health problems such as MG.

2.3 Theoretical Framework

2.3.1 Afrocentric Approach

According to Shokane, Makhubele and Blitz (2018), the Afrocentric approach seeks to provide an African perspective by recognising beliefs, values, traditions, taboos and cultures that are central to African life. These authors argue that African life is communal and deeply rooted in the philosophy of Ubuntu which places great emphasis on values such as caring, kindness, tolerance, compassion and empathy towards others.

Nicolaides (2023) stressed that South African healthcare practices should build on the principles of Ubuntu to promote virtuous morality and ethics in healthcare. After all, the principle of Ubuntu influences one's way of thinking and behaviour. This also applies in communal and family living where decisions about care are based on this principle. As discussed by Lefa (2015), Ubuntu is an African way of life and impacts every aspect of people's wellbeing. This principle drives relations in African societies. This comes with the understanding that family, community and society have a specific role to play when one of their own experiences health burdens. This role is often unspoken but can be observed through acts of care, support and love. For example, Lefa (2023) argues that neighbours often take the responsibility to check on each other as a symbol of care and support for one another. This also takes place when a neighbour or a family member falls ill. As such, acts of compassion, care and humanity are often observed amongst families, friends, neighbours and community members within the African culture. As discussed earlier in the chapter, the African context has a unique perspective of understanding health and healing. In this context, disease are often treated as spiritual and traditional problems which informs people's choices about health and healing.

Findings presented in this paper support this notion by giving insight on the emotional and financial strain that this disease causes not only for those diagnosed but also their families. This approach has added to the paper's understanding that MG not only affects the person living with the disease but also affects their loved ones including family and others in their social circle. It has also contributed to the comprehensiveness of this research as individual, family and communal features of living with MG have been considered. This is based on the theory's understanding that phenomena such as MG are not individualistic but communal, that is, not only the person living with the condition is affected but also those around them. The research also considered cultural and religious factors that contribute to understanding and coping with MG.

2.3.2 Ecological Approach

In addition to the Afrocentric approach, the ecological approach also provided a valuable theoretical perspective for analysis in this research. This approach focuses on the relationship between individuals and the systems in which they exist. This relationship is seen as interdependent and determine behaviour (Hammond, 2019).

The ecological approach acknowledges that individuals are dependent on each other and their environment (Bronfenbrenner, 2017; Shokane, Makhubele & Blitz, 2018). The approach understands that individuals encounter stressors as they progress through life and that they might struggle to cope with these stressors. Coexistence between people and the environment helps people cope with stressors as they employ various coping mechanisms and draw on environmental and social resources and networks (Shokane, Makhubale & Blitz, 2018). With the understanding that these factors can cross between multiple levels and impact people differently, the ecological approach helped this research identify how multiple aspects of the environment such as friendship, family, social, welfare, health and policy structures influenced youth's experience of living with MG. The model enabled the researcher to generate the understanding that participants' environment (geographical location) and financial status influences the types of institutions they attend as well as the treatment and care received from these institutions. In essence, the environment and financial status influences participants' access to health care. Based on these factors participants views about the health care system and personnel differ based on experiences and interactions they have had with these environments. The model also informed this paper's understanding that social and spiritual environments such as religion, culture and support play a substantial role in participants' ability to cope with the stress introduced by MG and the health care provided to them. These findings are reviewed in chapter four.

2.4 Policy and Legislation

2.4.1 National Youth Policy 2020- 2030

The NYP 2020-2030 policy promotes positive youth development outcomes in South Africa. According to the NYP (2020), the policy is designed to cater for all youth while redressing previous injustices and dealing with current challenges faced by young South Africans. The policy seeks to address youth development issues according to three priority areas which include youth education, health and employment. These priority areas are identified as youth's most pressing challenges (NYP, 2020). Core issues influencing these priority areas include high dropout rates, youth unemployment, lack of skills or skills mismatch, high prevalence of HIV and other diseases amongst youth. The policy also promotes the inclusion of youth with disabilities and youth living with chronic illnesses (NYP, 2020). The NYP has helped to identify how the education, health and employment prospects of youth living with MG are affected.

It has also enabled the paper to identify types of resources participants draw on to navigate challenges they face and life aspects while coping with MG. However, this paper has identified gaps in the targets and implementation of this policy. These will be discussed in the findings chapter. Suggestions to improve the policy may also be useful to policy makers to ensure clearer targets in the future.

2.4.2 National Adolescent and Youth Health Policy (AYHP), 2017.

This policy aims to promote the health and wellbeing of young people through equitable distribution of health resources and the expansion of service delivery (AYHP, 2017). According to the policy objectives, this is to be done through creating awareness about youth challenges and developing adolescent and youth friendly health care services. Jacobs and George (2022) argue that despite the positive transformation that this policy for the health care system, very little has been achieved in executing the policy. As such, the authors argue that more needs to be done to bridge the gap between the rhetoric of the health care system on paper) and the situation in reality. Authors argue that a big gap exists between what the policy identifies as youth participation and the reality of youth involvement in the health sector. Contextual challenges, lack of institutional capability and lack of representation have been highlighted as hindrances to youth health. This policy has shaped the paper's analysis of participants' experiences of the health care system and how these experiences shape participants' view of health institutions and HCPs within these institutions. The policy also aided the paper in noting structural challenges that hinder youth with MG from being able to participate in health. These include structural barriers such as lack of skilled professionals in public health institutions which hinder youth from accessing the health care they require.

2.5 Conclusion

This chapter reviewed literature on the diagnosis of MG and how this is a challenging process especially in low-income countries due to structural and resource barriers such as policy regulations. The effect of MG on mental, physical, emotional and financial well-being has also been discussed. Lack of social support and limited educational and employment prospects amongst those diagnosed with MG have also been discussed. Then, Afrocentric and ecological models of health and well-being were discussed as theoretical frameworks that have guided this study to gain a holistic and African perspective of the experience of people living with MG amongst South African youth.

Finally, the NYP and the AYHP were discussed as policies guiding this research. The following chapter will outline the research methodology in this research including the data analysis and data verification.

CHAPTER 3

RESEARCH METHODOLOGY

The previous chapter reviewed literature on the occurrence of MG in the South African context, participants' experiences of being diagnosed with MG and the effects of MG on multiple aspects of participants' health and lives. The chapter also outlined theories and policies used to guide the research. This chapter outlines the methodology guiding the research. This includes a discussion of the research design used in this study. Sampling and data collection procedures will also be discussed. Furthermore, data analysis, data verification and reflexivity will also be discussed as important tools that informed the study findings as well as the credibility and trustworthiness of the study.

3.1 Research design

In research, different designs exist to elicit data to understand phenomena. Qualitative, quantitative and mixed methods are primary research designs. A qualitative research design was used in this study. Qualitative research uses exploratory and descriptive frameworks to study research problems and the meaning people place on social problems (Hennink, Hutter & Bailey, 2020). Descriptive qualitative research seeks to describe a problem or phenomena. The focus is on who, what, how and where in order to gain insight from participants' experiences regarding poorly understood phenomenon (Muzari, Shava & Shonhiwa, 2022).

Descriptive research inquiries include various approaches that include phenomenological research. A phenomenological approach was used to explore the essence of MG from a South African youth perspective. According to Neubauer, Witkop and Varpio (2019), phenomenology emphasises the role of the environment in shaping how people experience phenomena and how they make sense of these experiences. The approach searches for a holistic interpretation and uses inductive reasoning as it develops theory. Inductive reasoning builds knowledge by exploring and unpacking the meanings people ascribe to events, situations and experiences. People's subjective experiences are used to acquire a depth of understanding. Therefore, knowledge is based on meaning, discovery as well as communication and observation (Leavy, 2017; Muzari, Shava & Shonhiwa, 2022). This is why a phenomenological approach was useful in exploring how various aspects of life combine and shape young people's experience of living with MG. In this process reflexive notes were used to ensure that the researcher's interpretation of participants' experiences was not clouded by her biases.

The researcher could have meaningful conversations with participants which allowed room for open dialogue that enabled the researcher to gain insight through open-ended questions. This would not be possible using quantitative measures as this approach does not allow room to explore, describe or explain. This is due to the nature of quantitative inquiries which uses deductive reasoning to measure variables and test relationships which is the opposite of this study's purposes (Arifin, 2018). The main aim of this research was to gain comprehensive insight about the lived experiences of South African youths diagnosed with MG. This makes the qualitative approach a perfect fit for this study.

3.2 Population and sampling

According to Hennink, Hutter and Bailey (2020), a research population does not always refer to people. It can refer to a group of individuals or objects that are the main concentration of a scientific inquiry. Other authors such as Shukla (2020) understand a research population as the set group of all the units on which the research findings are applied. In other words, a population consists of all the units which hold the variable characteristics under study and to which findings can be generalised. Shukla (2020) differentiates between a homogeneous and a heterogeneous population found in this study. A homogeneous population refers to all units of a population being similar or identical in terms of certain characteristics. Such a population is not often observed in areas of social science. A heterogeneous population is found where all units under study differ completely or in some instances due to mental, physical or any other aspects (Shukla, 2020). The study sought to explore lived experiences of South African youth who have been diagnosed with MG as a study population. This included young people between the ages of 18 to 35 who are living with MG. This population is considered heterogeneous due to the population consisting of people with variant mental, physical, cultural, personality, contextual and biological traits which contribute to their experiences of living with MG.

The study comprised of participants from a rare group with a rare condition. This made it hard to find participants. According to Leavy (2017), when your population is large in size, difficult to contact or geographically dispersed, it becomes necessary to use a sample. Sampling took place in Cape Town which allowed for in-person interviews to take place.

South African youth who have been diagnosed with MG were sampled through the purposive sampling technique.

3.2.1 *Sampling technique*

According to Hennink, Hutter and Bailey (2020), a sample is a group of people or things chosen based on their qualities to make inferences about the population. According to Shukla (2020), researchers can apply different sampling techniques according to the objectives of the research. Different sampling methods are categorised in two groups named probability and non-probability sampling (Hennink, Hutter & Bailey, 2020; Shukla, 2020). Probability sampling takes place when a sample is selected without any bias and all members of the population have a fair chance of being selected for participation. Non-probability sampling occurs when the population units do not have a fixed chance of being selected which increases chances of bias within the sample. The purposive sampling technique was used in this research. This is a form of non-probability sampling which uses the researcher's judgement to decide which participants are best suited for participation and will provide rich data for the research (Creswell, 2014). This judgement is usually made based on the researcher's knowledge about the population and the study's purpose. Participants were sampled based on their accessibility and ability to share their experiences with the researcher. Sample characteristics outlined below determined the sample.

3.2.2 *Sample characteristics*

The main goal of sampling is to focus on specific characteristics of interest that can be found within the population. Therefore, participants included in the sample were chosen based on the following criteria: (a), must be between the ages of 18 to 35, (b), must be a South African citizen residing within the country. This is due to the study focusing on the South African experience of MG, (c), must be diagnosed with MG for at least a year. This is to ensure that participants have lived a sufficient time with the condition to provide in-depth insight on the experience of living with MG on a daily basis. The criterion also served as a precaution to ensure that participants were emotionally and physically well enough to participate, since they would have had some time to deal with the diagnosis and live with the implications of the condition. This is due to the researcher's understanding that MG can require time to manage after diagnosis. This has been validated by the works of Law et al. (2021) who argue that HCPs often take time to determine the best treatment plan for MG patients after diagnosis. This is due to patients responding differently to the steroids and medication used to treat MG. Therefore, multiple treatments may have to be administered to see which work better for each patient.

3.2.3 *Sampling procedure*

The researcher gained access to the sample through a gatekeeper. According to Babbie (2013), a gatekeeper is a third-party which acts as a go-between between the researcher and the participants. This party may also possess the authority to grant or deny access to potential research participants. The specialised MG clinic at Groote Schuur Hospital was approached to recruit participants. The clinic is located within the neurology division of the hospital where specialised MG clinics are held on the second and last week of every month. MG clinics are often held on Fridays where patients including children are seen by the division's neurologists on appointment.

The researcher approached the head of the MG clinic by email requesting permission to sample from patients attending the MG clinic in Groote Schuur Hospital. The email detailed the study objectives, methodologies and procedures to give perspective of what the researcher intended to do (see appendix 3). At first the researcher proposed putting up posters at the neurology unit to alert possible participants of the study. After reading the study objectives and methodologies, the head of the clinic offered to identify participants who fit the sampling characteristics from participants attending the clinic. Permission to collect data was then granted through a letter of approval signed by the head of the MG clinics (see appendix 4). The permission was granted on the condition that the head of the clinic would identify possible participants and introduce them to the researcher with their permission. This meant that she had to briefly introduce the research to them without the researcher present and then introduce them to the researcher with their permission if they communicated interest to participate. This is consistent with the POPIA which seeks to protect people from harm by protecting their personal information. This includes information about their medical condition. The act is fundamental in protecting people's right to privacy which is provided for in the Constitution of the Republic of South Africa (1996). The researcher organised a private room within the neurology division where interviews took place while participants were waiting to be attended or after they had been attended. A total of eight participants were included in the sample, which was influenced by data saturation in the data collection.

3.3 Data collection

According to Hennink, Hutter and Bailey (2020), data collection refers to a practice of collecting and assessing data systematically. Data collection takes place in multiple forms during a qualitative inquiry.

In this research, data collection took place through qualitative interviewing. Qualitative interviews take place in a form of face-to-face interviews, telephonic interviews or focus groups which include six to eight interviewees being interviewed in a group discussion. These interviews often include a few open-ended questions that evoke participants' views and opinions (Hennink, Hutter & Bailey, 2020). One-on-one in-person interviews were used to collect data in this study. The interviews took between 30 to 45 minutes, allowing a five minute break for participants who got too tired due to the nature of MG which can cause slurring of the speech. The interview guide (see appendix 6) included semi-structured and open-ended questions which aimed to evoke participants' opinions.

According to Leavy (2017), semi-structured one-on-one interviews are the best way for researchers to gain detailed insight on participants' views and build rapport. This is due to the understanding that human beings have unique understandings and interpretations of their environment leading to unique insights about events and experiences around them. The researcher used open-ended questions which were not leading but encouraged participants' opinions while driving the interview process. Questions were funnelled from broad to more specific questions to build rapport and unearth possible dead-logs. According to Creswell (2014), dead-logs are questions or topics that might remain unasked or be forgotten during data collection. Organising questions in a funnelled manner minimised this possibility and allowed the researcher to use probing questions to gain more insight. Furthermore, commencing the interviews with more general questions eased participants into the interview and built rapport as this method allowed them to relax.

Data were collected from eight participants and was guided by data saturation. Neaem, Ozuem, Howell and Ranfagni (2024) refer to data saturation as a stage in data collection that occurs when further data collection does not generate useful insights. The phrase data saturation means that no new supplementary data is being found Naeem et al. (2024). The researcher stopped sampling when new insights stopped emerging from the collected data. In other words, the data that had already been collected from eight participants did not yield any new information and was therefore deemed satisfactory to draw necessary conclusions. For example, participants, shared similar experiences of experiencing prolonged diagnoses and symptom progression. This was common amongst other research questions where participants shared similar experiences.

3.3.1 *Data collection instrument*

A semi-structured interview schedule was used as a data collection instrument. This is a list of predetermined questions used as an instrument to engage participants and guide the research narrative (Leavy, 2017). The schedule entailed open-ended and probing questions that guided the interview process. The main themes of the schedule spoke to research objectives and theoretical frameworks.

In addition to the structured interviews the MG-ADL (see appendix 7) was also administered during the interviews. The MG-ADL is an eight item self-reporting scale used to measure the severity of MG symptoms and the functional status of MG patients. The items on the scale are categorised in to four. Ocular, bulbar, respiratory and motor/limb impairment are the categories used to monitor patients' functionality. The scale is a reliable and valid measure that has been used in clinical trials and observational studies to measure generalised MG symptoms and treatment response. The tool is administered by clinicians and Health Care Professionals (HCPs) to monitor patients' symptoms (Muppidi, Silvestri, Tan, Riggs, Leighton & Phillips, 2022). The items in the scale are linearly scored with each item ranging from 0 – 3 with a total score range of 0 - 24. Administering the MG-ADL does not require additional training for HCPs and can also be administered by anyone as it is easy and quick to complete (less than 10 minutes) (Muppidi et al., 2022). The researcher administered the MG-ADL during the data collection phase. The tool was given to participants and they were asked to score themselves on the scale. The scale was thoroughly explained to each participant. Some participants were familiar with the tool as it is also used by doctors for monitoring their MG symptoms. This increased the credibility of research findings presented in chapter four due to the validity of the tool as a measure of MG symptoms. Administering this tool also provided verifiable evidence of participants' self-reported experiences of MG which contributes to the trustworthiness of the study.

This tool uses daily living activities as an instrument to measure MG symptoms and therefore helped the researcher to identify participants who experienced severe symptoms and were at risk of/or presented with psychiatric symptoms such as depression and anxiety. As discussed by Freeman, Lewis and Heckmann (2014), these symptoms are more prevalent in people with severe MG symptoms.

3.3.2 *Data recording*

According to Creswell (2014), tape recording is a useful technique which allows the researcher to focus on guiding the interview process, rather than note taking. The author also argued that this technique yields a much accurate and clearer record than note-taking. A more modern form of recording device which is a smart phone was used to capture the interviews during data collection. Permission to record was obtained from participants during informed consent. Interview recordings have been stored on a UCT data management drive which is only accessible to the researcher for safekeeping purposes. However, numerous issues as reported by Hennink, Hutter and bailey (2020) may arise from using audio recording devices during data collection. The author argued that participants may be unsettled by being recorded. This may lead to participants restricting their responses due to fear of being recorded. Furthermore, the author also argued that some participants may purposely misrepresent their opinions in an effort to sound good for the recording. These disadvantages were minimised by reassuring participants that there were no right and wrong answers and explaining that recordings were merely for note-taking purposes and would be destroyed once the research process was complete.

3.4 Data analysis

The Applied Thematic Analysis (ATA) approach was used for data analysis. ATA is an inductive set of steps and procedures intended to detect and examine themes from textual data in a transparent and credible manner (Guest, MacQueen & Namey, 2012). This approach draws from multiple theoretical and methodological perspectives to present stories and experiences of participants in a most comprehensive and accurate manner. The first step of ATA is familiarisation which involves transcribing audio, reading through the transcripts and taking initial notes with the purpose of getting to know the data (Guest et al., 2012). All interviews were recorded and transcribed by the researcher. Each transcript was re-read while listening to the audio to ensure correct transcription. Initial notes were taken for reflexive purposes and getting familiar with the data.

Coding is the second step of ATA which is described by Leavy (2017) as the process of allocating a word or phrase to divisions of data. According to the author, the codes should capture the overall meaning of data. Inductive coding was used in the study. This is a process where codes are generated from the data collected. The NVivo coding software was used to code all phrases that could be relevant in the interview transcripts.

The software is used solely for coding purposes and organises non-numerical data by classifying and arranging information. The third step to the ATA approach is generating themes. According to Castleberry and Nolen (2018), the researcher combines the codes identified in step two to formulate broader phrases called themes. The codes generated using NVivo coding software were analysed and grouped according to their meaning. Similar codes were grouped into themes to generate broader meaning. During this process codes that were deemed irrelevant were discarded while important codes were combined to forge a deeper meaning. For example, the codes of being dismissed and going to numerous doctors without a diagnosis were combined to generate the sub-theme of being feeling ignored by HCPs.

The fourth step of the ATA approach is the process of reviewing themes. According to Guest et al. (2012) this step is important for data analysis as it determines the accuracy of the research findings. Themes were read and re-read until they were deemed illustrative of the data collected. Themes were evaluated, rearranged with some themes being combined, split and discarded during the process. This was to ensure an accurate representation of the data collected. Memo notes were taken and used to identify patterns across data and search for links between themes. Themes were then defined and named which is the fifth step of ATA. According to Castleberry and Nolen (2018), defining themes includes determining exactly what is meant by each theme and how it helps us understand the data. These must be concise and easily understandable. Themes can be divided into sub-themes and themes. The themes were defined and named according to the meaning they generate. Writing up is the final step of ATA approach which includes the presentation of data analysis and findings in the form of an academic text (Castleberry & Nolen, 2018). This dissertation constitutes the academic text of this research.

3.5 Data verification

Leavy (2017) asserts that qualitative research findings need to be credible. This speaks to the quality of the project, the accuracy of the methodologies as well as the ability to establish trustworthiness with the readers of the findings. Credibility, transferability, dependability and confirmability are therefore important aspects of data verification (Leavy, 2017).

According to Lincoln and Guba (1985), credibility refers to the degree to which study findings can be corroborated by others. The author argued that credibility is achieved through persistent engagement which includes keeping an open mind, recognising personal biases and triangulation.

The researcher's personal biases were tracked through reflexive notes which were document during the course of the project. This was to ensure that the researcher kept an open mind, preventing her biases from influencing the research outcomes. According to Carter (2014), triangulation refers to the use of numerous sources to develop a comprehensive understanding of phenomena in qualitative research. The four types of triangulation include method, investigator, theory and data source triangulation. In this research, theory triangulation was used. Theory triangulation refers to the use of multiple theories to interpret data (Carter, 2014). The Ecological and Afrocentric approaches were used to analyse data. This gave more value to the data interpretation as more than one theoretical perspectives are taken into account.

Transferability is another important aspect of data verification which Ahmed (2024) define as the extent to which findings can be reassigned to other groups or settings. The author described transferability as synonymous with generalisability in quantitative research. Transferability is established by providing readers with evidence that the inquiry's findings could be applicable to other situations, contexts, populations and times (Ahmed, 2024). The study has provided detailed information about the research design, sampling procedures, data collection and data analysis. This information would allow researchers from other contexts to apply the study to other contexts.

According to this author, dependability of the study lies in the researcher's ability to formulate an audit trail which can allow the reproduction of the research by other researchers. This is to assure reliability (Ahmed, 2024).The study processes and methodologies are comprehensively documented in this this report. This is to enable other researchers to reciprocate the findings to other contexts. The use of a recording device during data collection has boosted the study's credibility and confirmability as participants are directly quoted in the presentation of findings. Data analysis and reflexivity notes have also been well documented to enable other researchers to confirm findings. Furthermore, the MG-ADL tool administered during data collection contributed to the credibility of the study findings. This is due to the tool being a valid measure of MG symptoms. This increases the trustworthiness of the study findings.

3.6 Limitations of the study

The study has a few limitations. Firstly, the study is not representative of the South African population due to it being a small scale study with a limited number of participants. . Secondly, the study is highly representative of women than men due to the nature of MG prevalence amongst young females as mentioned earlier in this paper. MG is typically prevalent amongst women below the age of 49 and men over the age of 60 years (Dresser, Wlodarski, Rezania & Soliven, 2021). As a result, seven of the eight study participants (87.5%) were young women which makes young men less represented and limited in providing insights in this regard. Thirdly, the scope of study participants was limited and only included youth from Cape Town in the sample. This may limit the representativeness of the study findings to youth from other South African contexts such as rural areas and other provinces. Young people living in these contexts may have completely different experiences from the study participants who live in an urban area. This assumption is deduced from Morar, Seedat and Richards (2023) argument that health care gaps exist between rural and urban contexts. Future research could address limitations about representativeness through the use of broader samples which are geographically diverse to ensure representation of all contexts.

3.7 Reflexivity

In qualitative research, the researcher reflects on their role, personal background, culture, and experiences which hold potential in shaping interpretations of themes and meanings assigned to data (Palaganas, Sanchez, Molintas & Caricantivo, 2017). A researcher is a part of the research process. Therefore, their experiences, assumptions and beliefs influence the research process. Reflexivity is an important part of ensuring rigour in qualitative research as it is a critical reflection about the researcher's position in account of the research (Palaganas et al., 2017). This is more relevant to this study as the researcher also suffers from MG which is the topic under investigation. As such, the researcher acknowledges the influence of her experiences on the research throughout the research process. According to Olmos-Vega, Stalmeijer, Varpio and Kahlke (2022), failure to account for the researcher's biases can negatively impact the knowledge built via qualitative research and those connected to it. The researcher kept a reflective journal to document her biases, emotions, and opinions throughout the research process. Notes were recorded immediately after every interview and during transcription to ensure accurate documentation of the researcher's feelings and views that could influence the research.

These stemmed from the researcher's personal experiences of living with MG and her opinions associated to the health care systems in South Africa. For example, the researcher has negative perceptions of the public health system which may affect her interpretation of participants' experience of this system. As a young person living with MG in South Africa, the researcher has experienced the hardships of living with this disease on multiple aspects. This piqued her interest in this topic as she hoped to discover how other youth diagnosed with MG navigate life with MG. The reflexive notes were used as a self-reflective tool to help distinguish the researcher's opinions from the data. The notes were also helpful in helping the researcher to analyse participants' experiences impartially, regardless of their similarities or variations to her own. Furthermore, the researcher shared her MG diagnosis with participants to build rapport and enable a free sharing environment.

3.8 Conclusion

This chapter discussed the methodology used in this study. The discussion includes a qualitative approach using phenomenology as a design chosen for the study and the motivation thereof. The population and the sampling strategy employed in the study were also discussed. This includes sample characteristics and procedures. Furthermore, the process of data collection, data collection instrument and analysis method were also highlighted. Data verification, study limitations and reflexivity were also discussed as important aspects which inform the credibility and trustworthiness of the research.

CHAPTER 4

FINDINGS AND DISCUSSION

4.1 Introduction

The previous chapter outlined the research methodology. This chapter presents the study findings and discussion. Firstly, the table outlining information on the profile of participants is presented. Secondly, is the analytic framework which provides an overview of findings. In the end a detailed presentation of findings with a conclusion is presented.

4.2 Participant profile

The study consisted of participants from unique backgrounds and geographical contexts in Cape Town. Although these participants were sampled from the same clinic in GSH, some of them had travelled from outskirts of the city, townships around the Cape Flats, while others lived a small distance away from the city centre. As highlighted by Turok (2021), the city of Cape Town is known as the most segregated city in South Africa, where social and economic disparities are apparent. As a result, access to resources differs depending on the context.

Table 4.1: Participant profile

Participant Number	**Gender**	**Age**	**Ethnicity**	**Ocular/ Generalised MG**	**Period Lived with MG (years)**	**MG-ADL Score**	**Employment Status**	**Religion**
1	Female	26	Asian	Generalised	2	3	Student	Muslim
2	Female	30	Coloured	Generalised	15	12	Employed (full-time)	Christian
3	Female	33	White	Generalised	1	11	Employed (part-time)	Christian
4	Male	23	African	Ocular	1	-	Student	Does not identify
5	Female	23	Coloured	Generalised	10	3	Employed (full-time) & student	Christian

							(online)	
6	Female	35	Coloured	Generalised	1	4	Employed (full-time) & student (part-time)	Christian
7	Female	28	African	Generalised	8	4	Employed (full-time)	Christian
8	Female	35	Coloured	Generalised	6	6	Unemployed	Muslim

A total of 8 participants, 1 male and 7 females were sampled. Their ages ranged from 23 to 35 years. 4 participants identified as Coloured, 2 African, 1 White and 1 Asian. A total of 7 participants were diagnosed with generalised MG and 1 participant with ocular MG. Their MG-ADL scores ranges from 3 to 12 with an average score of 6.14. Two participants had a score of 3, two participants had a score of 4 and the rest scored 6, 11 and 12. Two participants reported high scores of 11 and 12, indicating that they experienced severe symptoms during data collection. Participants reported experiencing slurred speech, droopy eyelid, shortness of breath and struggling to arise from a chair. These include symptoms across all item categories on the scale (that is, ocular, bulbar, respiratory and motor impairment). Participants' period of MG diagnosis ranged from 1 to 15 years, 4 participants had lived with the condition for less than 4 years and others for over 6 years. One participant's score was excluded from reported data. This participant has ocular MG and could not be tested on items related to generalised MG.

The participant profile above highlights the uniqueness of study participants in terms of context, race, beliefs and functioning ability. A measure of racial representation was achieved as all four racial groups were represented in the study. This is despite the Coloured population making up the majority of participants which can be attributed to contextual factors, this population accounts for 42.4% of the population in Cape Town's (StatsSA, 2024). More women were represented in the sample when compared with their male counterparts. This is due to the prevalence of MG as discussed by Dresser, et al. (2021) in the first chapter. The authors argue that MG is commonly observed amongst young women below the age of 49. MG onset generally affects men when they are older.

Therefore, the disproportionate representation of women over men could not be controlled. The mean MG-ADL score of 6.14 recorded indicates that participants experienced moderate MG symptoms on average. However, only two participants scored higher than 10, indicating severe MG symptoms and four participants had an MG-ADL score between zero and four, indicating mild symptoms. The researcher notes this to highlight that the MG-ADL score is subject to participant's reported symptoms during data collection. Hence this information was analysed with a subjective interpretation of the MG-ADL scores as opposed to the average score. This is due to important variations in the experience of MG symptoms and daily functioning that this paper intended to highlight, which would be ignored if the scores were only analysed as a mean.

4.3 Analytical framework

The analytic framework presented below depicts the themes and sub-themes found during data analysis.

Table 4.2: Themes and sub-themes from data analysis

Theme	**Sub-theme**
4.3.1 Delayed diagnoses	4.3.1.1 Feeling ignored by HCPs
	4.3.1.2 Symptom progression
4.3.2 Impeded ability to function	4.3.2.1 Limited physiological functioning
	4.3.2.2 Mental health and wellbeing
4.3.3 Coping Mechanisms	4.3.3.1 Family support
	4.3.3.2 Spousal support
	4.3.3.3 Social Withdrawal
4.3.4 Accessing Opportunities	4.3.4.1 Employment
	4.3.4.2 Education
4.3.5 Spiritual beliefs	4.3.5.1 Religious beliefs
	4.3.5.2 Traditional beliefs

4.3.1 Delayed diagnoses

Most of the participants reported that they experienced situations that led to delays in their diagnosis and prevented early treatment. To varying degrees, all eight study participants reported experiencing delayed diagnoses. Six of these participants lived in township areas such as Mitchells Plain, Gugulethu, Philippi and Claymont, which are located in the outskirts of the city. The most common reason for the delayed diagnosis according to participants' reports was doctors and other HCPs not being able to recognise MG symptoms to make a diagnosis. As a result, participants reported spending weeks and in some cases months being sick without a diagnosis. This was despite their efforts of seeking medical attention during the early stages of developing symptoms. Feeling ignored by HCPs and symptom progression are two sub-themes that emerged from this theme. These are discussed below.

4.3.1.1 Feeling ignored by HCPs

Six participants reported feeling ignored by HCPs when reporting their symptoms. According to these participants, doctors and nurses in most institutions did not understand their symptoms and appeared to be unaware of their condition. All study participants gave various accounts of being misunderstood by doctors who did not believe that they were telling the truth about their symptoms. In some cases, participants were misdiagnosed and repeatedly asked to return to private doctors despite the doctors' inability to accurately diagnose their symptoms. This left participants feeling ignored and in some cases exploited by HCPs. Participants also reported being neglected by HCPs, especially those in government hospitals. One participant recalled sleeping on a bench and struggling to walk without any help whilst in the care of a public hospital. Two participants who were admitted in private institutions reported receiving better care than they did in public institutions. One participant recalled being ignored and her symptoms being dismissed by doctors.

> *...during a period where I couldn't help myself I had to force to help myself cause no one could help me, I don't know if they couldn't or they didn't want to but I tried getting attention (trails) but I couldn't, I didn't get attention. So at that point where I couldn't walk and I couldn't see, my eyes was like (does a hand gesture) at the time a little I could see. So even with maybe going to the toilet like I had to basically crawl along the walls to walk. Nurses would walk past, no one would stop me, no one would be like "is everything okay", nothing like that.* (Participant 1, Female, 26)

> I *can say that uhm, honestly uhm, the private sector was a lot more helpful when you pay, you had to pay for it. The government hospitals first, my first experience coming here (Groote Schuur hospital) was very bad, uhm, I just, I had a lot of doctors dismiss my symptoms and they didn't listen to me properly.* (Participant 3, Female, 33)

> *...my aunt would take me to doctors. The ones from the township that require you to pay cash, so I kept going to them and paying until one of them referred me to Mitchells Plain Hospital, they also didn't know what it is going on with me.* (Participant 4, Male, 23)

Six participants reported feeling ignored and being dismissed by HCPs and doctors when they first experienced MG symptoms. These participants recalled negative experiences of attending public health care institutions. One participant narrated her experience of being ignored while feeling weak and struggling to walk around. The participant reported that despite her efforts to get HCPs attention for assistance, this is something she never got and was left with no choice but to crawl using hospital walls to get to the bathroom while nurses and doctors passed by without assisting her. This report not only suggests the violation of the participant's right to access quality health care, but also suggests negligence amongst HCPs and violation of participants' right to quality health care. This is consistent with Maphumulo and Bhengu's (2019) findings that misconduct amongst HCPs is common in South Africa. According to the authors, the South African Nursing Authority has faced a number of misconduct claims due to violation of patients' rights by HCPs. Authors argue that broader challenges affecting the South African health care system contribute to patients' rights not always being upheld. These challenges include lack of human resources and equipment such as beds and medical equipment (Maphumulo & Bhengu, 2019). This paper holds the view that despite these challenges, lack of accountability amongst HCPs perpetuates the cycle of patient rights violations within the health care system.

Five participants also reported experiences of being told that there was nothing wrong with them despite their symptoms. These participants reported being dismissed by HCPs who did not believe that they were ill and refused to conduct further investigations or transfer them. According to these participants, doctors did not acknowledge their symptoms as real. As a result, they could not get early treatment and had to consult numerous doctors and institutions in search for a diagnosis. Phiri's et al. (2021) argue that structural barriers such as lack of expertise and personnel such as specialists lead to patients' misdiagnosis.

Findings point to doctors not possessing the required expertise to make an MG diagnosis. However, lack of regulations governing patients' referral procedures is concerning. Participant's reports of the time it took for doctors to refer them to tertiary institutions suggest lack of clear regulation of patient referral procedures. This applied in both public and independent institutions. Reported incidents of participants' misdiagnoses while being asked to return for further treatment highlights patients' vulnerability and exposure to exploitation and negligence by doctors and HCPs.

Two participants noted a gap between private and public health care in their experiences of accessing healthcare, which highlight the difference in services in the public and private sector. Participants who attended both private and public hospitals reported having received better care in private institutions. These participants reported having felt more heard and cared for in private care. On the contrary, these participants reported feeling ignored and dismissed in public hospitals. This highlights the gap described by Lehnerer et al. (2021) and Fan et al. (2020) who argued that MG causes a heavy burden on low-income groups who cannot afford private health care. These authors argue that the high cost of medical care in the private sector excludes low-income earning patients from accessing quality health care which state institutions often fail to provide. As highlighted by participants, private care is better as patients pay substantial costs for private care. In other words, treatment is better because one pays for their medical costs. However, those who cannot afford to pay for their healthcare are forced to rely on public health institutions where HCPs and doctors may not provide the same level of service. Where participants experienced the latter, it led to more trauma experienced by participants as their symptoms progressed.

4.3.1.2 Symptom progression

Participants reported having gone through significant trauma as their symptoms worsened without a correct diagnosis. This related to both physical difficulties and emotional trauma experienced as their symptoms progressed. Seven participants reported feeling worried and anxious as they experienced more symptoms without clarity about the cause. These participants reported that they feared the unknown and that the trauma they experienced informed their views about navigating MG and the health care system. This is due to the distrust that they developed about the system and HCPs ability to care for them.

As such, participants reported that the emotional trauma they experienced through symptom progression that had a long-term effect on them in that they it was something they still carry with them. The following participant quotes express this experience

> *Emotionally there are times where I am feeling stressed, I am feeling sad or I do get snippets of what happened back then and I feel like I'm not over it, not that I'm over it but like it feels like it happened yesterday for me.* (Participant 1, Female, 26)

> *That is also something on its own where the unknown for me is stressful and like thinking am I gonna come back here, am I going to relapse. That is on my mind all the time but like I said it is a possibility and that possibility is scary for me to come back and experience that whole scenario again... every time I get sick I get paranoid. Like I need to go to the doctor, must I go to the doctor. If I go to the doctor, am I gonna end up in hospital, you know all that so anxiety is a big thing.* (Participant 6, Female, 35)

> *Even back home where I'm from I don't go to the clinic there because a lot of people don't know MG. So if I get sick I just nurse myself better and that's it.* (Participant 5, Female, 23)

Symptom progression is one of the most devastating consequences of delayed diagnoses reported by participants. Participants reported feelings of uncertainty as their symptoms worsened without knowing what was wrong. They reported feeling scared and anxious due to not knowing what would happen in the future and that looking back at their experiences of feeling weaker as symptoms progressed triggered stress and anxiety. They recalled the time they experienced symptom progression as difficult and hard to forget as they reported mentally recalling about them and sometimes getting flashbacks. One participant mentioned experiencing fear about hospitalisation or going to the doctor due to the trauma experienced when she was hospitalised due to MG. These findings can be attributed to the neglect, dismissal by HCPs or any other negative experiences that may have been experienced by these participants leading to their symptom progression. It appears that the psychological trauma from these experiences remains deeply embedded in participants' memories and informs their decisions about health care. This is due to some participants' reports that they often choose self-medicating and nursing themselves instead of going to health institutions for health issues such as flu.

4.3.2 Impeded ability to function

All study participants reported experiencing flare ups because of their condition. This was reported to take a toll on their physical and mental ability to function. Two sub-themes were evident within these themes. These include limited physiological functioning, as well as depression and anxiety.

4.3.2.1 Limited physiological functioning

Wellbeing as defined by Ruggeri et al. (2020) refers to people's ability to function and cope with the day-to-day demands of life. This includes functioning across physical, emotional and spiritual aspects of life. The nature of the occurrence of MG is characterised by fluctuating symptoms which makes it hard to predict when symptoms may persist or subside. In some cases, symptoms are triggered by numerous factors which can cause a flare. Genetics also play a role in patients' experiences and occurrence of MG. Heckmann et al (2007) discussed the role played by hereditary factors in the occurrence of MG. Authors argue that patients respond differently to MG treatment and numerous factors contribute to this. Therefore, while some patients may respond well and reach remission, others may struggle with symptom fluctuation and flares regularly.

Physical strain caused by MG is one of the direst consequences reported to impede participants' physiological functioning. All study participants reported that MG negatively affected their ability to perform certain social activities. These ranged from normal activities of daily living such as walking, to more physically demanding social activities such as hiking and sport. Participants reported that they struggled to complete activities that they enjoyed prior to their diagnoses. They also reported that the unanticipated or random occurrence of MG symptoms made it difficult for them to engage in certain activities as they cannot anticipate when their symptoms might get worse or reappear.

> *I used to go hiking and do a lot of like different sports and stuff, which I can't do anymore.* (Participant 3, Female, 33)

> *...I don't know when the speech is gonna be affected, I don't know when I can't pick up that glass to drink, you know, a little.* (Participant 2, Female, 30)

> *...depending on the weather also, you don't do well when it's too cold or too hot uhm so either way. If you wanna go for a walk you have to think, and you also can't walk*

> *alone because if you get stiffness in your muscles or you can't continue to walk you need someone to guide you basically.* (Participant 5, Female, 23)

Participants reported experiencing limited physiological functioning abilities to varying degrees. One participant reported not being able to participate in physically demanding tasks such as hiking and other sports. According to the participant these are activities that she did and enjoyed prior to her MG diagnosis. Four other participants reported experiencing physiological difficulties with their speech and other day-to-day tasks. These include tasks such as combing ones, hair, brushing teeth and holding a glass of water to drink from. A participant emphasised the difficulty of not knowing when their symptoms are going to reappear and limit their ability to function in completing these tasks is.

Three other participants reported being restricted in the types of activities they can complete due to the nature of their condition. According to these participants one needed to practise caution before performing these tasks by themselves. These included day-to-day tasks such as taking a walk. One participant stressed the need to have others around you when engaging some tasks. This is due to the knowledge that MG symptoms can be triggered at any moment, preventing one's ability to complete the task. One participant reported that severe weather conditions worsened their MG and therefore exposure to such conditions restricted their physical ability to cope. Due to a lack of literature, exploring the relationship between weather conditions and MG could not be done in this study. However, these findings align with Braz's et al. (2018) findings in that MG causes physical strain which affects people's ability to function physiologically. This is due to the unpredictable nature of the disease, which can cause symptoms to reappear at any moment, negatively affecting their motor abilities.MG fluctuates despite treatment making it impossible to predict or control the occurrence of the muscle weakness (Braz et al., 2018). This is consistent with what participants' reported when they claim that they cannot foresee when their symptoms will reappear.

4.3.2.2 Mental Health and Wellbeing

According to participants MG does not only hinder physical functioning but also strains mental wellbeing and coping. Most participants reported struggling to cope with their emotions and experiencing feelings of anxiety and stress due to not knowing what to expect and when. The experience of flares has also been reported to result in mental health challenges which manifested in depression and anxiety.

Six participants reported struggling to cope with the MG flares. Three of these participants reported experiences of being diagnosed with depression because they struggled to cope with MG. Participants also reported living with a continuous fear that they might relapse as evident the following responses.

> *I can't fully say that it's because of the MG but that is also something on its own where the unknown for me is stressful and like thinking am I gonna come back here, am I going to relapse. That is on my mind all the time but like I said it is a possibility and that possibility is scary for me to come back and experience that whole scenario again.* (Participant 1, Female, 26)
>
> *mentally I, I've had a lot of dips... and that's because I have good days and when I have good days it feels like I don't even have myasthenia I'm just living my life I'm doing everything I need to do.* (Participant 2, Female, 30)
>
> *...they even gave me medication for depression cause like no since they saw me uh-uh I wasn't coping and they even suggested I see a psychologist but I mhm, cause you see now, you see other people at your age doing certain things for their homes and for themselves and you feel like no I'm a failure now cause there's no progress in your life and stuff.* (Participant 7, Female, 28)

These participants reported feeling anxious due to not knowing if or when they might relapse or experience flares. One participant highlighted that even though she cannot fully attribute her stress to MG, she often worries about the possibility of relapsing and going back to the condition they were in before commencing treatment. Another participant reported experiencing a lot of mental lows associated to MG. She reported that this is due to the fluctuation of the disease which leads to her struggling to cope when her symptoms reappear. The participant further indicated that some days are good and allow her to function well, which causes her to struggle emotionally when the bad days come. Another participant also recalled not being able to cope with MG to a point of being diagnosed and put on treatment for depression. According to this participant, she felt left behind by her peers and felt that her life was not progressing as it should.

Muzaffar and Rohail (2021) highlight high depression and anxiety scores observed amongst MG patients during their inquiry. Authors argue that symptom severity is the most common reason for depression amongst MG patients.

Symptom severity does not only affect patients' physical wellbeing but also negatively affects their psychological functioning (Muzaffar & Rohail, 2021). The quotes presented above verify that MG hinders participants' ability to strive and function well mentally. The ecological approach was essential in the analysis of these findings due to its understanding of participants' experiences based on their socio-economic status. For example, participants living in township areas reported experiencing strain when it comes to health care access. This is informed by their geographical location which is far from the city where specialist doctors are often located. Other aspects of life such as mental health may be affected due to the worry about their symptoms or lack of counselling resources. The findings presented suggest that numerous factors including social and economic factors contribute to participants' ability to mentally cope with MG. These may include the trauma faced by participants, their experiences of being sick as well as the experience of healthcare received at the time. For example, one participant reported that she often worries about the possibility of being hospitalised and experiencing what she went through prior to her diagnosis. This suggests that that her experiences around that time may have been negative.

4.3.3 Coping mechanisms

According to Emad, Algorani and Gupta (2023), coping refers to thoughts and behaviours utilised to manage internal and external stressful conditions. Coping is understood as conscious and voluntary utilisation of acts to reduce or tolerate stress. Social coping takes form when an individual neutralises stress by pursuing instrumental and emotional support from their community which may include family, friends and the larger community (Emad et al., 2023). In this theme participants' experiences could be identified within three sub-themes from the perspective of coping. These include family support, spousal support and communal withdrawal.

4.3.3.1 Family support

According to participants, family support is the main source of social support that they depend on to cope with MG. Participants reported distinct ways in which their families provide emotional and instrumental support. One participant reported that her family had learnt about MG which enabled them to understand the nature of the condition. This enabled them to notice when she needed to rest. Another participant reported that her family emotionally supported her by accompanying her to hospital appointments.

The participant also noted the financial support that her family provides by ensuring that her financial needs are met even though she is unable to work full-time. Another participant reported that her family does not know much about MG. As a result, support is provided through reminders about medication and hospital appointments. Five other participants reported similar experiences where they had supportive family members who struggled to fully understand the nature of MG. One participant mentioned that despite her their partner filling in when she's not feeling well, he does not fully understand the condition. The following comments illustrate these experiences:

> *They are a great support system yes. They also learnt to just like me, they learnt to know what my body needs when it needs it. They also learnt that by, just by looking at me and go no she needs to rest now. no there's something wrong now. So I think I have a really great support system.* (Participant 5, Female, 23)
>
> *I'm staying with my parents now and my aunts and they have been extremely supportive like my mother has accompanied me to every appointment and they've also supported me financially, without them I'd be really really stuck because I can't work.* (Participant 3, Female, 33)
>
> *They don't pay that much attention to it. What they pay attention to is my medication. But they don't know, what can I say... they don't know what causes it, when it gets worse and things like that. So yeah, they only focus on the treatment and remind me to take it, that's all. They don't pay attention to the rest* (Participant 4, Male, 24)
>
> *On the days that I do feel down he's always there to pick up that extra shift sort of thing with the children, cleaning or whatever or just being with me if I'm emotional, if I'm down he's there but he does not understand exactly what it's about man.* (Participant 2, Female, 30)

The quotes presented above reiterate the authors' arguments in highlighting the important family plays as a support system informing the study participants' ability to cope with MG. According to Cheng et al. (2013), social support informs patients' coping strategies while living with MG. Authors argue that family, peer and social relationships are key sources of social support that people living with MG depend on to cope with the disease. These include both physical and emotional implications of MG which lead to participants' need for extra support and care from those who are close to them.

Larrosa-Dominguez and Reverte-Villarroya (2022) emphasise the crucial role social support plays in in MG patients' wellbeing and coping. According to Larrosa-Dominguez and Reverte-Villarroya (2024), social support requires the activation of social resources aimed at satisfying functional needs routinely and in crises. Authors suggest that social support is an important factor in wellbeing and coping for people living with chronic illnesses. The authors further argue that support can be received through actions provided or perceived by an individual. Subsequently, one can receive actions of support but be dissatisfied with the resources available from their social networks. Patients with low perceive social support had more difficulties undertaking daily life activities and experienced lower HRQoL (Larrosa-Dominguez & Reverte-Villarrova, 2024). This argument aligns with findings from this study which show that participants whose medical condition as understood by families had lower MG-ADL scores, indicating ability to cope with life's daily activities than participants who reported that their families did not understand MG.

Findings also suggest a variance between the types of support provided by participants' families. Five participants reported that their families provide more instrumental than emotional support. Other participants reported an experience of a balance between both. The Afrocentric theory discussed in chapter two highlighted the core value of Ubuntu as a primary moral value for the provision of care and support in the African context. Lefa (2015) argues that in the African context, support and care are provided through physical acts such as nursing a loved one when they are sick. In this context, the imbalance between emotional and instrumental support provided is not shocking due to lack of education about mental health. The Afrocentric theory could not be distinctly applied in this context. This is due to only two participants being African. However, the theory can be applied to any culture due to its values which facilitate the understanding of individuals' context. This theory was also relevant for the promotion of inclusion, especially in health care where families are often excluded from health care. The values of Ubuntu could be useful in the South African system and would promote better cohesion between HCPs and civic society, especially in public hospitals.

4.3.3.2 Spousal support

Two participants who had experiences of living with a spouse after diagnosis reported that their spouses were also affected by MG. These participants reported that despite their efforts, their spouses fell short and could not completely understand the condition. One participant reported that MG was a significant contributing factor to her divorce. This was due to her husband struggling to come to cope with her medical condition. The second participant reported that despite her spouse's efforts in researching and learning more about the condition, he struggled to understand the practicality of it and could not understand why she sometimes struggled with certain activities.

> *I'm going through a divorce now and one of the big things was that he could not handle my disease, my husband.* (Participant 3, Female, 33)
>
> *So, my husband, I think that he... he doesn't really know what myasthenia entails. Like he, he did research on it and he's seen how I handle it and how I am but I think that he doesn't fully grasp the concept of what it does and how it affects my day-to-day life, because you will find sometimes that he doesn't understand why I can't do certain things or why I choose not to do certain things, and I feel like I shouldn't have to explain that because you know that I'm living with this thing that's affecting my ability to do certain things.* (Participant 2, Female, 30)

According to these participants, their relationships took strain and, in some cases, ended after they were diagnosed with MG. These participants reported that their partners struggled to come to terms with their MG diagnoses. As a result, their relationships deteriorated and in some cases ended in divorce. Although these participants acknowledged other factors that may have led to this, MG was reported as the main contributing factor to their separation from partners. The issue being partners struggling to come to terms and cope with the MG diagnoses and consequences. For other participants despite their partners being supportive, they felt that their partners did not have a true understanding of their condition and how it affects them. Participants reported that their partners do not understand when participants struggle to do certain tasks. This may include simple day-to-day tasks which MG may prohibit participants from being able to do at times. However, participants' spouses struggle to understand as they do not truly comprehend the nature of MG and how it affects participants' functioning.

These findings are consistent with Kawaguchi, Tsuda, Tanaka, Kerstens and Daisuke's (2024) findings from a qualitative survey they conducted on MG patients in Japan. These authors found that MG patients felt that their partners or spouses did not understand the seriousness of the disease. Furthermore, MG patients did not think they were interested or wanted to understand the disease (Kawaguchi et al, 2024). This highlights the strain that can be caused by the presence of MG in spousal relationships. According to Eriksson, Wejaker, Danhard, Nilsson and Kristofferzon (2019), the number of spouses proving informal care and support for their partners living with chronic illnesses is increasing. These authors argue that the experience of one's spouse living with a chronic illness takes a mental and physical toll on the other partner. Authors argue that this may lead to feelings of frustration and emotional distress for the other partner. Eriksson et al. (2019) argue that the presence of a chronic illness affects both spouses in a relationship. In their inquiry, authors conclude that emotional and physical wellbeing of spouses caring for a partner living with a chronic illness is negatively affected. This is due to the financial, physical and psychological demands associated with demands of caring for a partner. The authors further argue that these demands take more time away from the partner who is providing care. Some participants reported that their spouses are supportive and take over household duties when they struggle from MG, this simultaneously reduces their spouses' time for themselves. Hence, they may not find the time to learn more about the condition to understand it more.

4.3.3.3 Self-isolation

Six participants reported keeping fewer social relationships than they did when they first got diagnosed with MG. These participants reported feeling disconnected from their friends, resulting in them distancing themselves from relationships. They described that they felt a shift in the bonds they shared with their friends. They also felt that they were not as close to their friends as they were prior to their MG diagnoses. Four of these participants reported not being interested in improving the state of these relationships. Instead, they reported keeping more formal relationships that come in a form of acquaintanceship or being colleagues. When probed, participants revealed that they found these relationships to be convenient as they are less demanding. Participants described that there is less pressure to engage in social events. Friendships are the opposite and open room for participants to frequently attend social events where they might struggle with some activities because of MG.

According to these participants, they do not want to be treated differently by others due to not being able to perform certain tasks that are considered part of normal functioning.

> *The friends that I had back when I was diagnosed with myasthenia I don't have them anymore. I have one friend, but we're not very close and the friends*

> *that I, I don't have friends now really. Honestly, I have colleagues and acquaintances, people that I see now and then. I don't have friends that I will go and grab a cup of coffee with or chill. I don't want people to feel sorry for me and I don't want people to treat me a certain way because they think oh she can't do that.* (Participant 2, Female, 3)

> *We did go out a lot but now it has changed, it has changed. So yeah it has man, this condition does really change your life to be honest. You don't become, you don't become the person that you were before cause you may try to think that no it's no big deal but reality tells you that no this thing is a big deal.* (Participant 7, Female, 28)

These participants reported that living with MG had changed their social lives and affected their desire to participate in social relationships. Diminished interest in social events, friendships and outings, especially those that were not familial were commonly reported by participants. According to Willard (2023), loneliness and isolation are most prevalent, which contributes further to the public health crisis, harming individuals and societal health. The author argues that relationships are a source of healing and wellbeing that enables individuals living with chronic illnesses to live more fulfilled and productive lives. People depend on relationships as a source of companionship, happiness and communion. This is why when these relationships end people may start to develop feelings of loneliness (Willard, 2023), which seems to be the case with participants in this study. Some participants reported that they still kept relationships that developed prior to their MG diagnoses. However, participants reported that these friendships had also changed since their diagnoses, with the main reason being the nature of MG which limited their ability to participate in activities enjoyed by their friends. These findings suggest that participants utilised self-isolation as a defence mechanism and coping strategy to avoid being in situations where they might struggle in the presence of others. This was also to prevent judgement and unwanted sympathy from others.

4.3.4 Accessing Opportunities

Participants reported experiences of struggling to access opportunities as a result of MG. These ranged from educational, employment and career opportunities that participants wished to access and in some cases tried to pursue, but could not complete due to the physical and psychological effects caused by MG. Two sub-theses emerged from this theme. These include education and employment.

4.3.4.1 Employment

Six participants reported being of employable age and being interested to fully participate in the job market. Of these participants, four reported being in full-time employment, one reported working part-time and one reported that she was unemployed. All these participants reported that MG hindered their ability to fully participate in the employment sector. This is despite their expressed interest and efforts in fully participating. A participant reported losing the opportunity to pursue her childhood dream of being a television presenter due to the nasal and slurred speech she experiences from MG. She also reported physical challenges she faced while working in retail. These included struggling to cope with the demand to stand all day and getting to work on some days. Another participant reported not being able to work on a full-time basis due to the fatigue caused by MG preventing her from being able to work long hours. The participant explained that this affected her financial wellbeing as she could not earn enough. Another participant reported being demoted to a less paying position after her MG diagnosis due to being unable to handle the stress related pressure of her previous position. One participant who reported that she was unemployed indicated that she was employed prior to her MG diagnosis. However, when the participant tried to go back to work after being diagnosed, she reported that she could only work three days and was forced to leave her job because her physical state did not allow her to continue. The following quotes highlight these experiences:

> *I wanted to be a tv presenter and I had the personality cause I love to talk but yeah man. I can't do that now cause what if my voice starts slurring while I'm on tv, would the people even hear me. I used to work in retail so when I worked there I had to be on my feet for the whole day and that was a struggle but also with getting to work I used to struggle because some days are hard.* (Participant 2, Female. 30)

> *I can't work full-time because of the disease. Like I used to have a full-time job uhm, I was earning like a proper salary and now I'm only working part-time because of not feeling well enough.* (Participant 3, Female, 33)

> *when I was diagnosed they moved me from that to receptionist and uhm with that came a salary deduction because they were, my boss read up about the MG and they*

> *said aah stress and all of that… just before the MG I was promoted to the accounts department and with the MG and all of that then I got demoted again.* (Participant 6, Female, 35)
>
> *I can't go back to work cause I'm getting tired. When I use my hands I'm getting tired. I did try to go to work. I only worked three days so I can't, my body can't… I was just feeling tired so I can't stand up the next morning.* (Participant 8, Female, 35)

Findings presented above suggest that MG limited participants' ability to fully participate and thrive in employment. Participants who were full-time employed reported losing their childhood dreams and facing demotions due to MG effects. Another participant reported only being able to work part-time which led to her financial security being compromised as she reported previously working full-time and earning a higher salary. One participant who reported being unemployed was also forced out of employment by MG. These findings highlight the financial burden caused by the experience of living with MG through the work and salary limitations it imposed on participants. These findings align with Liao's (2021) argument that MG has forced some individuals to quit their careers physically and emotionally not being able to work as a result of the disease. The author argues that this does not mean the end as MG patients can re-enter the job market after remission. However, this paper argues that while some participants may get to a stage of remission, this is not the case for every MG patient as remission in MG is not guaranteed (Arroyo & Torres, 2022).

These findings also align with Fan et al. (2020) and Lehner's et al. (2021) findings which highlight the financial burden caused by MG in low-income contexts. Authors found that MG patients' lives get altered due to the restricted ability to work caused by the disease. The authors emphasised that this has negative implications for patients' standard of living and wellbeing as they also faced a financial burden associated with MG management. Although most people can benefit from subsidised health services in South Africa, participants still have to carry the burden of travel costs associated with MG management.

This may apply to above mentioned participants, especially those who regularly attend MG clinics and those who live in the outskirts of the city and townships. Participants reported the need to downsize due to their inability to uphold their financial status. This had implications for their health and social wellbeing as some participants reported having to move from public to health care institutions due to not affording medication cots. Others reported that they had to financially depend on family members as they could not work full-time and earned too little to afford all their living expenses. This may have had negative implications for participants' mental health. This is due to participants' reports that they experienced feelings of frustration and stress associated with not being able to work and struggling to meet the demands of the work they do. Furthermore, the participant who reported being unemployed due to MG presented with severe symptoms of depression. Although this cannot be directly linked to her inability to work, it is believed to be a massive contributing factor.

4.3.4.2 Education

A total of five participants had experienced living with MG while in school. Three of these participants were diagnosed when they were in tertiary, one in high school and one in primary school. The participant who was diagnosed while in primary school reported that the challenges posed by her condition prohibited her from accessing education through in-person attendance at a school. As a result, she was home schooled until she completed grade 12. The participant who was diagnosed in high school reported an experience of not being able to write her grade ten exams due to being hospitalised subsequently to MG. A total of four participants reported being enrolled in tertiary institutions during data collection. Two of these participants were studying full-time (in-person) and the others online (virtually). The participants who studied in-person reported experiencing challenges which resulted in one participant being forced to drop out of university. The participant recalled not being able to cope with her studies due to constant MG-related hospitalisations at the time. She reported her efforts in trying to continue her studies numerous times and being hindered by the effects of her medical condition.

> *I couldn't go to school for a while so then we, we decided to do home schooling which is what I did until grade 12. I did home schooling cause it was more hospital than school attendance. So we had to make that big adjustment and we did home schooling instead, which I enjoyed.* (Participant 5, Female, 23)

> *when I was diagnosed with myasthenia was grade 10. That was, I think it was in the June either by the end of the year but I remember that year I didn't write exams to pass over to matric because I was sick in hospital for a long time. So the teachers at the school made a choice based on my work throughout the year that they were gonna put me over, because my work was good enough for them to say we think she would've*

> *passed anyway. So I did, I went over to grade 12, I did my matric and I passed thankfully.* (Participant 2, Female, 30)

> *So like i felt like my life became on hold, you see, cause I couldn't cope at school. I kept on trying to push and push, but then again, and then in 2016 I tried again to go back to school. But even then uh-uh cause each and every year I was in and out of hospital and then in 2016 it even got worse.* (Participant 7, Female, 28)

Education is a huge part of young people's lives which according to participants' reports was largely impacted since their MG diagnoses. Participants who reported experiencing MG during primary, high school or tertiary reported similar experiences of their education prospects being hindered by the effects of MG. Participants who were diagnosed with MG at early ages reported that they struggled to cope in the usual school environment. This was due to the effects of the MG symptoms on their physical ability to function at school. Some participants reported struggling to see on the board and other children not understanding their situation. Others mentioned that they were often too sick to go to school which led to them drop out of school to pursue alternative routes to complete their education. These include home schooling and online education. Other participants reported not being able to complete their education due to the effects of MG. These participants reported that despite their efforts, their health would not allow them to cope with the demands of attending school.

It is evident that youth's financial backgrounds play a role in developing resilience when it comes to completing their education. These findings highlight the difficulties of completing an education while living with MG. The condition makes it hard for young people to attend school on a regular basis. The physical strain of going to school and attending classes may have led to participants experiencing flares and becoming weaker and ultimately having to drop out. Alternatively, participants with the exposure and means were able to complete their studies through alternative forms of education such as home schooling and online education in tertiary. However, most South African youth do not have financial means to afford home schooling and online studies.

Furthermore, some contexts are most likely limited to little or no knowledge about alternative education such as home schooling. de Clercq (2020) argues that inequalities in South Africa still have an impact on educational outcomes to date. This author explored the persistence of educational inequalities in South Africa through an analysis of the policies and political structures as important contributors to understanding these inequities. The author concludes that although the country has improved in mending the imbalances of the apartheid era social inequalities, these imbalances still affect youth education. The ecological approach which holds the view that people's social, economic and environmental factors intersect to inform their lives is relevant in this regard with respect to participants' inability or ability to pursue alternative education depending on their contexts.

4.3.5 Spiritual beliefs

The study employed a diverse group of participants from different traditions and religions (see table 4.1). As such, participants reported that they drew on various spiritual systems to inform how they understand and cope with MG. Some participants reported that they lean on religion as a source of understanding and strength. Although participants identified with different religions, they shared common attributes which include faith and prayer. Two participants reported that they also rely on traditional belief systems which inform their view of MG and how they treat the disease. White (2015) argued that culture, religion and tradition govern people's understanding of disease in the African context. According to this author, there is a gap between African belief systems and Western beliefs when it comes to understanding and treating diseases. It was the author's view that Africans have a spiritual understanding of disease and view them in a spiritual and traditional light. Findings from this study suggest that spiritual beliefs are an integral part of participants' wellbeing, which enables them to cope and understand MG in their contextual lens.

4.3.5.1 Religious beliefs

Seven participants reported that they are associated with a religious group. These participants reported that faith, prayer and reading the bible are core elements they use to cope with MG. One participant reported that through faith and prayer she believes that things will be better and that one day she will be healed. Another participant also reported that prayer helped her find understanding when she was diagnosed with MG. This participant reported that praying strengthened her faith and belief that God listened to her prayers and gave her strength.

One participant reported that praying is not always easy, especially when her MG is on flare. However, she reported that praying during this time helps her mental wellbeing. Another participant also emphasised reading the bible and in unison with praying. This participant reported that this helped her to find herself spiritually and it was part of her spiritual journey.

> *I have like a really strong faith in God. I think it has helped me remain really positive and I'm still, and to just keep having faith and pray and believe that things will get better. So it has impacted me in a positive sense having that uhm, ultimately trust that one day I will be healed from this disease.* (Participant 3, Female, 33)

> *When MG happened mostly what we did was pray, fast and pray. Prayer makes you find understanding of why and what this is and pray that God is listening to help me through this and that's, I think that's also your faith and your belief maybe. Not just in the God that you serve but also in yourself and that, cause if you don't have anything to believe in or yeah to believe in then you won't have the strength to try.* (Participant 5, Female, 23)

> *It costs me a lot to pray, it costs me a lot to talk to God. I think that in any sickness that you have you have to believe in a higher power because you, you're not gonna make it. So for me I constantly pray, constantly ask God to help me take each day as it comes... If I'm having a good day great! but mentally I think… praying helps, praying, I just pray if it's a bad day just pray (laughs).* (Participant 2, Female, 30)

> *You read the bible, you speak to Almighty and you just find yourself within yourself. It's like a spiritual journey that you can go on.* (Participant 6, Female, 35)

The above quotes highlight the role of participants' religious beliefs in informing their understanding of MG and mental coping. According to participants, their trust in God helps them to maintain a positive outlook on life. This is despite the pain and challenges of living with the disease. As such, their faith stems from the understanding that God is the creator and controller of all things, including their illness. Similarly, prayer was reported as a means of communication that strengthened participants' faith in God. For participants this is a way for them to report and tell their wishes and troubles to God despite it not always being an easy process. White's (2015) claims that the religion as a part of the African tradition is relevant to these findings. This author argues that religion forms part of the African way of life and informs people's understanding of diseases within this context.

Therefore, diseases in this context may be viewed in a spiritual manner. This aligns with findings in this study as participants reported that they understood MG as a disease that only God can cure. This proves the significance of the Afrocentric theory in highlighting the value of traditional African perspectives and their role in understanding phenomena. However, participants still attended their hospital appointments which suggests that they acknowledged the role of Western intervention in MG treatment. This further highlights White's (2015) argument that African tradition does not clash with Western ways but the two can work well together. In this manner, the Afrocentric theory promotes social inclusion and the recognition of African perspectives as valuable.

4.3.5.2 Traditional beliefs

Two participants who identified with traditional cultural beliefs outside of religion reported that their traditional beliefs shaped their views of understanding and treating MG. One participant shared that they considered going to a traditional healer if they had not found the answers they were looking for through Western doctors. Another participant reported that their culture understands diseases in a certain manner. The participant reported that certain traditional protocols are applied when one is sick in their culture. According to the participant, this stems from the belief that when one is sick their ancestors have called them with a spiritual gift that requires them to go for initiation.

> *I was contemplating to go to a witch doctor if they couldn't figure out my problem here at Groote Schuur. It was sad, I was planning to go to a witch doctor so they could tell me what was wrong with me, you see... but the witch-doctor stuff no, I was just confused cause I didn't know what to do, so I was seeking for anything that could help me, you see.* (Participant 4, Male, 23)

> *you see moss with us as Xhosa people and stuff you'd hear that there're these things where they say no man you're supposed to do this and that, you have a gift you're supposed to go for initiation and stuff, you see.* (Participant 7, Female, 28)

> *For us no one can help you other than your creator.* (Participant 1, Female, 26)

Participants' reports suggest that although they hold traditional beliefs with unique views about diseases, they acknowledge the role of Western medicine in the diagnosis and treatment of MG.

Participants reported that in their traditional perspectives sickness is understood as something that results from one's ancestors communicating with them. Hence the occurrence of disease can be understood through consultation with a traditional healer. Other participants reported that their traditional perspectives understand the occurrence of disease as a religious problem which can be solved through religious approaches. To these participants their religion constitutes their culture and tradition and as such informs their way of life. Despite these beliefs, participants were sampled from a Western medical institution which highlights their understanding of MG as a disease that requires this type of intervention. This suggests that Western and traditional interventions do not clash. Despite the gap that still exists between these two schools of thought, common ground can be reached to bridge this gap.

This research was conducted to explore lived experiences of South African youth diagnosed with MG, and the core objectives of the study included exploring youth's experiences of being diagnosed with MG and the effects of MG on numerous aspects of youth's lives. The experience of delayed diagnoses amongst youth with MG was found to be common amongst youth from townships and outskirts of the city, suggesting a contextual gap in the provision of health care. This is consistent with the work of Phiri et al. (2021) who argues that structural barriers hinder the diagnosis of MG in some contexts. These authors found that barriers common to those reported in this study contribute towards delayed diagnoses. Lack of personnel such as specialist doctors and other structural barriers in these contexts were found to be a contributing factor. These barriers also contribute to the gap found between private and public health care provision.

The MG-ADL was used to measure participants' symptoms severity during data collection. Participants' scores were consistent with the findings that MG strains youth's physical and mental ability to cope with daily living demands. This is consistent with the findings of Fan et al. (2020) who found that MG negatively affected patients' HRQoL and had negative implications for mental wellbeing. Findings from this study are also consistent with Braz et al. (2018) and Lehner's et al. (2021) findings which indicate that MG limits individuals' physical functioning and wellbeing. Mental wellbeing was also found to be negatively affected by the presence of MG. Depressive symptoms were associated with severe MG symptoms which is consistent with Muzaffar and Rohail (2021).

Freeman, Lewis and Heckmann (2014) also observed symptoms of anxiety and depression amongst MG patients in their early inquiry. These prove the study assumptions to be correct in presuming that MG would have negative consequences for youth's overall wellbeing. Furthermore, family support was found to be a crucial factor that informs youth's ability to cope with MG while other social relationships take strain due to the burden of the disease.

These include spousal relationships which get affected by the burden of the disease on the spouse providing care, and social relationships which participants often withdraw from due to physical and emotional challenges posed by MG. Chen et al. (2013) earlier highlighted the role of social relationships in determining wellbeing and coping for MG patients. This was confirmed in this inquiry as youth with little or no social support presented with depressive symptoms. This may be attributed to limited support as suggested by Chen et al.'s (213) findings.

The Afrocentric and ecological perspectives were useful in examining MG in the South African context. These approaches provided a comprehensive understanding of MG implications, considering social, environmental and spiritual factors. Participants were found to rely on both cultural and religious beliefs to understand disease which was highlighted by the Afrocentric approach. Despite the gap in research participants belonging to the African tradition, using this approach highlighted the essential meaning of the concept of Ubuntu which Lefa (2015) referred to as an African way of life relevant to all African societies. Hence, the approach was crucial in highlighting the primary role of family as a support structure. The provision of care was also found to primarily assumed family which is consistent with Lefa's (2015) findings. As such, the need for community and family involvement in the provision of health care is a crucial missing pierce that could enhance the provision of care. This could improve relations between society and HCPs, and raise awareness about MG. Chen et al. (2013) also highlighted the importance of family and social support for MG patients.

The ecological approach also played an eminent role in highlighting how the interaction between participants' geographical location, economic status and social resources inform their access to health care. The gap between private and public health care institutions highlighted the role of economic status in determining access to health care. This is consistent with Lehnerer's et al. (2021) argument that low economic status contributes towards poor outcomes for MG patients. Furthermore, the gap observed between township institutions and institutions in the city highlights the geographical barriers to health care which can be modified through policy interventions. As such, the study has shown the importance of the ecological and Afrocentric approaches in providing a theoretical analysis of MG in the South African context. By integrating these perspectives, policy makers, HCPs and communities can develop more effective strategies to support individuals living with MG in South Africa.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

This study aimed to explore the experiences of South African youth who have been diagnosed with MG. The first objective was to explore young people's experiences of being diagnosed with MG. Findings suggest that young South Africans diagnosed with MG experienced many challenges when accessing the health care system. These included personal and social challenges, and within the public hospital sector structural and policy challenges such as lack of personnel and infrastructure in public health institutions. It was also found that participants from townships and the outskirts of Cape Town experienced severe symptom progression as it took longer for them to get diagnosed. Based on participant responses study findings also suggest that most HCPs and doctors do not know about MG or treatment issues related to it. This puts MG patients at a high risk of medication use which can cause harmful side-effects on their health. Therefore, MG awareness amongst HCPs is also needed. This would benefit both the health care system and the public as doctors and HCPs would be able to identify symptoms and refer patients earlier as well as possess the necessary information to know what medications not to give to MG patients. It is therefore to conclusion of this study that there are gaps in the provision of care in urban and township contexts, which informs the type of care received by participants in these contexts. Furthermore, the paper concludes that there is lack of accountability amongst doctors and HCPs for (a), failing to refer patients to bigger institutions upon realisation that they cannot give an accurate diagnosis and (b), repeatedly misdiagnosing patients while asking them to return for further treatment. This conclusion stems from findings of this study which found that participants commonly experienced being ignored by their doctors and misdiagnosed. It is suggested that patient referrals be more regulated through health policies.

The second objective looked to explore the effects of MG on youth's physical and mental wellbeing. The study found that youth living with MG experienced physical limitations which limit their ability to participate in physically demanding and day-to-day activities. These include challenging activities such as hiking and day-to-day activities such as walking or picking up a glass to drink. It was also found that participants experienced mental struggles associated to their MG experiences. This is due to the fluctuating nature of the disease which affects their ability to mentally cope when they experience flares.

As a result, depression was also found to be a risk factor to participants' mental wellbeing. Anxiety due to the fear that symptoms may flare up at any moment was also found to be a common threat to participants' mental wellbeing as they reported that they constantly experienced fear and worry about experiencing flare ups and the possibility of hospitalisation. Hence, the study concludes that MG has negative implications to young people's mental and physical wellbeing. This due to the mental health risks and distress the diseases evokes as well as physical limitations experienced by young people living with the condition.

The study also aimed to explore the effects of MG on youth's family and social relationships. Findings suggest that participants mainly relied on family support to cope with MG. Spousal support was also found to be crucial. According to the findings, participants with families who understand MG tend to strive emotionally and physically than those whose families do not. This suggests that family involvement and knowledge about the nature and occurrence of MG is crucial for coping. This includes family members and loved ones knowing more about the condition, how it works and being able to observe signs of fatigue in MG patients. However, in cases of married or divorced participants, participants reported that their spouses struggled to fully comprehend physical and psychological demands and challenges posed by MG. Furthermore, self-isolation was found to be common amongst MG patients. This is due to the emotional effects of the disease which was reported to diminish participants' desire and ability to engage in friendships. Based on these findings, the study concludes that family support is crucial to participants' coping. It is also concluded that spouses of people living with MG require psychological support as the disease may also negatively affect their mental wellbeing. Furthermore, the paper concludes that the effects of MG limit participants' support. Self-isolation due to limitations caused by MG limits participants' social support as they do not get to fully benefit from relationships that are not familial.

The study also aimed to explore the influence of MG diagnoses on youth's educational and employment prospects. The findings indicated that MG caused significant participation restrictions for young people. These involved restrictions to participate in employment and education as some participants reported dropping out of full-time schooling and employment due to the inability to cope with physical demands of these spaces. Some participants resorted to remote learning and employment however, this solution is not affordable for some due to socio-economic factors. Findings also indicate that MG causes strain on participants' financial wellbeing.

Participants noted that being unemployed, getting demoted and working part-time due to the effects of MG has caused strain on their financial wellbeing. As such it is concluded that MG limits youth's educational and employment prospects by restricting their participation in these spheres.

Lastly, the study aimed to explore the role of culture and religion in influencing coping and understanding of MG. Participants reports revealed that religious and traditional beliefs both shaped their understanding and treatment of MG. Participants from different religious and cultural backgrounds revealed that their culture and tradition has religious roots, therefore informs their understanding of MG as something that can be healed only by God who is their creator. Participants who were Africans revealed that their traditions perceived disease as a form of communication from their ancestors. As such, these participants understood disease as something that can truly be understood through consultation with African traditional healers even when it was not necessarily accessed. The study found that although participants' traditional and religious beliefs informed their understanding of MG, the role of Western medication is still recognised as a primary source of treatment for this disease. This confirms the argument that traditional and Western approaches can work together. The study also found that religion informed participants' mental wellbeing while coping with MG. According to participants, faith and prayer enabled them to keep positive mindsets, which enhanced their mental wellbeing.

Based on findings and conclusions from the research, the following recommendations are proposed:

In the care and diagnosis of MG, a specified period can be stipulated to HCPs and doctors for patient referral if they are unable to determine a correct diagnosis by the specified period. This would protect patients from the possibility of exploitation by doctors asking them to repeatedly go back to them when they cannot without correctly diagnosing them. Furthermore, this will also limit patients' experiences of symptom progression. These suggestions are not guaranteed to entirely solve the problem but would curb the length of time patients suffer due to symptom progression without a diagnosis. Furthermore, it would also help ensure that HCPs are held accountable. It is understandable that MG diagnoses can only be made by specialist doctors, however, the understanding of this condition by other doctors and HCPs would fast-track patients' diagnoses.

Therefore, it is suggested that other doctors should possess necessary skills to recognise neurological symptoms to make the necessary referrals.

The study suggests that it is crucial for families living with MG patients to learn about the condition. MG awareness is a key strategy that would spread knowledge to families and communities to help them to understand the condition. This is to quip them to provide the best support and understanding towards their family members who have been diagnosed. It is also suggested that there is a need for support groups for families and spouses of people living with chronic illnesses such as MG. The health system needs to be proactive in identifying mental health risks and those who are likely to be affected. Proactive solutions are also recommended to counter mental health challenges such as depression.

Policies such as the NYP could ensure that youth with medical conditions are considered for financial support to pursue education through online studying. The policy could also promote initiatives to raise awareness about the availability of alternative education methods for this youth. Remote full-time opportunities are also a method worth exploring for the benefit of individuals and youth living with chronic illnesses and disabilities in South Africa. This would lift the burden of travelling to work daily and enhance the productivity of these youth. In addition, further research is required to build awareness about the challenges faced by youth and other individuals living with MG in South Africa in accessing resources.

In light of these recommendations, the following specific strategies are recommended

- Training programmes on MG should be instituted for HPCs in public hospitals.
- Support networks need to be established for individuals living with MG and their family members.
- Policies should integrate measures to support youth living with chronic illnesses and disabilities access and utilise employment and educational opportunities.
- Research initiatives exploring experiences of individuals living with physical impairment and disabilities should be conducted to boost public awareness.
- Future research should also look into experiences of youth living with MG in rural areas.
- Specialists should be made available in secondary institutions to reduce the prevalence of delayed diagnoses.

- Further literature on the role of cultural and religious belief systems in shaping people's understanding of diseases such as MG, especially in the South African context.

This study aimed to explore the nature of the occurrence of myasthenia gravis through lived experiences of South African youth living with this condition. Through five research questions, the study explored how youth experience being diagnosed with the condition, how it affects their social and family relations, opportunities as well as their understanding of the condition. Findings suggest that youth experience delayed diagnoses leading to symptom progression. Youth were found to rely on available social structures and coping mechanisms to cope with the implications of MG. However, spousal relationships were found to be at risk of taking strain caused by the presence of the disease. A gap was also found between healthcare in private and public sectors. Furthermore, findings suggest limited access to opportunities for education and employment purposes. Lastly, cultural and religious beliefs were found to be at the core of participants understanding and coping with MG. In conclusion, MG has been found to put strain on numerous aspects of youths' lives. Hence, future research is crucial for awareness and stakeholder engagement purposes to employ the necessary support strategies for this youth.

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Appendix 1

UNIVERSITY OF CAPE TOWN

Department of Social Development

University of Cape Town Rondebosch 7701 South Africa
Phone: +27-21-650-3483
E-mail: taryn.powell@uct.ac.za

08 November 2022

Student: **Nomfundo Zime Nokulunga Gebashe (GBSNOM001)**

Outcome: **ACCEPTED**

I am pleased to inform you that ethical clearance has been given by an Ethics Review Committee of the Faculty of Humanities for your study, ***Exploring the Experiences of South African Youth Living with Myasthenia Gravis***. The reference number is SWK-REC-2022-SR021.

I wish you all the best for your study.

Yours sincerely
Dr Shanaaz Hoosain
Senior Lecturer
Chair: Ethics Review Committee

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2020), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

UNIVERSITY OF CAPE TOWN
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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, includin an documentation described below.

☑ Approved — Annual progress report — Approved until/next renewal date 30.6.2025

☐ Not approved — See attached comments

Signature Chairperson of the HREC/ Designee — Date Signed 13/6/24

Note: Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za.

Please use the latest form found on our website:
http://www.health.uct.ac.za/fhs/research/humanethics/forms

Comments to PI from the HREC

Please submit annual progress

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	10 June 2024		
HREC REF Number	788/2022	Current Ethics Approval was granted until	30/01/2024
Protocol title	Exploring the experiences of South African youth living with myasthenia gravis		
Protocol number (if applicable)	N/A		
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.	N/A		
Principal Investigator	Somaya Abdullah (Supervisor for Nomfundo Gebashe)		

Appendix 3

UNIVERSITY OF CAPE TOWN

Department of Social Development

24 March 2023

Dear Professor Heckman,

Permission to conduct research at Groote Schuur Hospital.

I am a student with the department of social development at the University of Cape Town seeking permission to conduct research at the MG clinics in the neurology department at GSH.

I am conducting research on the lived experiences of South African youth who have been diagnosed with MG. The research aims to (a) explore youth's experiences of being diagnosed with MG; (b) explore how MG affects youth's physical and mental wellbeing; (c) explore how MG affects youth's family and social relationships; (d) explore the impact of MG on youth's educational and employment prospects and (e) explore the influence of culture and religion in shaping youth's coping and understanding of MG. As such, participants will be asked questions related to these aspects of their lives.

Sample characteristics will include South African residents who are between the ages of 18 to 25 and have been diagnosed with MG for at least one year. Individuals matching this criteria will be invited to participate in the study. If they agree, they will be asked to participate in an audio recorded interview which will take place in a private space at hospital. The interviews will last for approximately 30 to 45 minutes.

Participants will be asked to give their written consent before the research begins. Their responses will be treated confidentially. Risks associated to emotional distress are foreseeable. In such cases, participants will be referred to a social worker for assistance. Participants will be made aware of their right to withdraw their participation at any time during the project without any penalty. Participants will not be paid for taking part in the study.

I therefore request your permission in writing to conduct my research at your clinics. Please let me know of you require further information. I look forward to hearing from you.

Yours sincerely,

Nomfundo Gebashe

Appendix 4

UNIVERSITY OF CAPE TOWN

DIVISION OF NEUROLOGY
Faculty of Health Sciences
University of Cape Town
Observatory, 7925
South Africa
Tel: +27 21 404 3198

12 May 2023

HSF human ethics research committee

Dear Prof Blockman

This letter is to confirm that Ms Nomfundo Gebashe, a social science student form UCT with ethics approval to approach and recruit patients in our Myasthenia Gravis (MG) clinic, has been given permission to interview patients at the clinic in a quiet room. These patients would have volunteered to stay behind after the clinic activities to speak to Ms Gebashe.

Kind regards

(electronic signature)

Jeannine Heckmann

Appendix 5

UNIVERSITY OF CAPE TOWN

FACULTY OF HUMANITIES
DEPARTMENT OF SOCIAL DEVELOPMENT

REQUEST FOR PARTICIPATION & CONSENT FORM

Date: 25 July 2022
Name of Researcher: Nomfundo Gebashe
Student number: gbsnom001

This research forms part of the qualification for a masters in social science degree in the Department of Social Development at the University of Cape Town.

Title of Study: Exploring the Experiences of South African Youth Living with Myasthenia Gravis.

Objectives of the Study:

- To explore young people's experiences of being diagnosed with MG.
- To explore how MG affects young people's physical and mental wellbeing.
- To explore how MG affects young people's family and social relationships.
- To explore the impact of MG on young people's prospects regarding their education and employment.
- To explore how culture and religion influence coping and understanding of MG.

Please read the following and sign if you agree to participate in this study.

Research Procedures: I understand that I will be participating in an interview process to explore the experience of living with Myasthenia Gravis (MG) amongst South African youth. The interview will last approximately one hour and will be recorded with your permission using a digital recorder or by taking notes. The recording will be transcribed and the transcripts and notes will be kept in a secure place. Once the research has been completed, this material will only be used for academic purposes and the transcripts will be destroyed.

Risks and Harm: emotional distress may arise as a result of participating in this research. In the event that this occurs, the researcher will refer participants for appropriate assistance.

Benefits/Incentives: I understand that this research will not benefit me directly and that I will not be paid for agreeing to do this interview. However, the information gathered through my participation will provide important insight on how youth living with MG cope with this condition and how it impacts their social relationships, employment and education. The information gathered will also provide insight on how culture and religion inform the understanding of MG in South Africa.

Participant's Rights: I understand that I am free to withdraw from participating in this study at any time, without giving any reason and that there are no consequences should I decide not to participate at any stage.

Confidentiality: I understand that the interview process will be kept strictly confidential and that information will be available to the researcher and the supervisor. Extracts from the interviews will be included in the final research report without anyone being able to link my quotes to my identity. The final report will be examined by an external examiner and the findings will be made available to participating agencies. Under no circumstances will my name be revealed in the report or any other publications related to this research.

I understand that if at any time I would like any additional information about this research, I can contact the research supervisor, Dr.Somaya Abdullah telephonically at 021 650-4219 or by email at somaya.abdullah@uct.ac.za

I confirm that I have read this consent form or the researcher has read it to me and that the study has been explained to me. I voluntarily participate in this study

____

Name of Participant

____________________________ ________________

Signature of Participant Date (dd/mm/yyyy)

____________________________ ________________

Signature of Researcher Date (dd/mm/yyyy)

Appendix 6

INTERVIEW GUIDE

1. Introduction of the interview

Thank you for your participation. I appreciate you spending your time to share your experience as a young person living with myasthenia gravis.

Your responses will help me understand your experience of living with myasthenia gravis. Please know that there are no right and wrong answers because your experience is what is really important to me. This interview will take about 30- 40 minutes of your time. However, this can be broken down to two sessions due if you feel tired and wish to continue at a different time. We will be recording your interview using an audio recorder.

All responses will be confidential as your name and identity will remain private. Please remember that you have a right to stop this interview at any time or skip any question that you do not wish to answer. Please let me know if you are confused with any questions.

Do you have any questions before we begin?

2. Demographics
    - Please tell me a little bit about yourself and your family?
      [age; where they live; employed (kind of work, part/full time) OR student (Uni/tvet or high school); highest level of schooling attained]
      [family: who do you live with]

3. Exploring young people's experiences of being diagnosed with MG
    - How long have you lived with MG?
    - When did you first experience MG symptoms? What were they?
    - What was your first reaction? Where did you first seek help?
    - Where did you first seek medical assistance? (private/public health care) (city/rural are)?
    - Lease describe the process from when you first looked for medical assistance to when you were diagnosed with MG (what happened? **technicalities**) (how was your health)
    - How would you describe the experience the health care system during the time you were awaiting a diagnosis? Was it helpful? How/ how not?
    - How would you describe your experience of the health care system after MG your diagnosis?
      - Have you experienced any problems when it comes to receiving your medication?
      - Have you experienced any problems with the health care professionals and the service provided to you (nurses and doctors)?
      - Any other issues related to the quality of health care received since diagnosis?

4. Exploring how MG affects young people's wellbeing
   [EXPLAIN & ADMINISTER THE ADL]

Physical wellbeing

- How often do you attend check-ups for MG?
- How would you describe your physical health?
- To what extent would you say that MG has affected your ability to function physically?
- Are there any activities that MG has prevented or limited you from being able to do or participate in? if yes, what are they?
- Have you noticed any changes in how you physiologically cope or respond to stressful events since being diagnosed with MG?

Mental wellbeing

- How would you describe your mental health before you were diagnosed with MG? …how about after?
- In your opinion, would you say that living with MG has affected your mental health? How?
- Do you have any coping strategies that have helped you during your struggle with MG?
  -If yes, what are they?
- Have you noticed any changes in how you cope and respond to stressful events since being diagnosed with MG?

5. Exploring how MG affects young people's family and social relationships
    - How would you describe your relationship with your family: 1) **before being diagnosed with MG**; 2) **at present** (i.e after being diagnosed with MG)
    - In your opinion, would you say that your family has been supportive in helping you cope with MG? how?
    - Do you and your family talk about the ways in which MG affects your wellbeing?
    - Would you say that your family understands the effect that MG has had on your wellbeing, if any? If not, what do you think could help them better understand from your perspective?
    - Are there things that you have had to adjust or change within your family because of MG (e.g diet, relocating)? If yes, what are they?
      -In your opinion have these adjustments affected the relationship between you and your family? If yes, how?
    - Have you noticed any changes in the relationships you have with others since being diagnosed with MG (**family, friends, colleagues/schoolmates, community**)? If yes, what are they?
    - How would you describe your ability to participate in social activities (with friends/family and in the community etc)? Has this changed since you were diagnosed with MG? if yes, how?
    - how do you experience starting new relationships with others?
        - Do you find it easy to build relationships with others (friends, colleagues, romantic etc)
        - Do you share your diagnosis in these relationships? Why/ why not?

6. Exploring the impact of MG on young people's prospects

- In your opinion, do you think that MG has impacted your ability to access education? If yes, how?

- What are some of the difficulties that you face (or have) at school due to living with MG?
- Has your school been supportive in your education journey?
- Are the any ways that you feel that the school can (could've) further support you and make learning easier for you? E.g providing extra writing time.

6.1 Employment

- Have you worked after being diagnosed with MG? if yes, where? Permanent or full-time hours?
- Do you think that having MG has impacted your ability to access employment?
- What are some of the difficulties that you have faced when it comes to employment?
- Are your employers aware of your diagnosis?
  -if yes, have they taken any measures to support you within the working environment?
- Are there times when you experience MG symptoms/complications while you are at work?
  -if yes, how do you cope or manage these?

7 Exploring the role of culture and/or religion in understanding and coping with MG

- Do you identify with any religious group? If yes, which group?
- Do you identify with any cultural group? If yes, which group?
- Would you say that your culture or/and religion have influenced how you and those around you (**family, friends, community**) understand or first understood MG? how so?
- Are there any cultural or religious values, beliefs or systems that have helped you and your loved ones cope with MG?
  -what are they?
  -how have they helped?

8. Conclusion

To conclude our conversation, I'd like to hear your opinion on how you think others around you have been affected by MG and how you think they could help support people with MG.

- In your opinion, would you say that those around you were affected by your diagnosis? If yes, how (family, friends, community)?
  -Can you think of any suggestions that could help them better cope with your diagnosis? If yes, what are they?
- In your opinion, what can families, friends and others do to support people living with MG?
- What do you think the government can do to better support and include young people living with chronic illnesses such as MG in education and employment.
- What so you think can be done to improve the health care services provided to young people with MG?

Appendix 7

Myasthenia Gravis Activities of Daily Living (MG-ADL)

- Score each activity form 0-3 and add the results to see your total score.

	0=Normal	1	2	3=Most severe	Total
Talking	Normal	Intermittent slurring or nasal speech	Constant slurring or nasal speech, but can be understood	Difficult-to-understand speech	
Chewing	Normal	Fatigue with solid food	Fatigue with soft food	Gastric tube	
Swallowing	Normal	Rare episode of choking	Frequent choking necessitating changes in diet	Gastric tube	
Breathing	Normal	Shortness of breath with exertion	Shortness of breath at rest	Ventilator dependence	
Impairment of ability to brush teeth or comb hair	None	Extra effort, but no rest periods needed	Rest periods needed	Cannot do one of these functions	
Impairment of ability to arise from a chair	None	Mild, sometimes uses arms	Moderate, always uses arms	Severe, requires assistance	
Double vision	None	Occurs, but not daily	Daily, but not constant	Constant	
Eyelid droop	None	Occurs, but not daily	Occurs, but not constant	Constant	
				Total score	

(out of 24)

Name of Participant:

Signature:

Date:

Interview Transcript: Participant 1

Interviewer: please tell me a little bit about yourself

Participant: okay, uhm…my name is XXX. I am 26 years old and I'm a current student in my 3rd year studying civil engineer.

Interviewer: okay, and where are you studying?

Participant: at CPUT, cape peninsula university.

Interviewer: okay, how long have you had MG?

Participant: I was diagnosed in… (thinks) 2 years ago, so I would say in 2021. Yes yes in 2021.

Interviewer: Okay what about your family, do you live at home?

Participant: I live at home yes, with my parents and my grandmother.

Interviewer: your grandmother?

Participant: my grandmother yes and my siblings are as well there.

Interviewer: okay, and when did you start experiencing symptoms of mg, you said 2 years ago?

Participant: 2 years ago yes…uhm I would say about two days before I felt dizzy and I had a headache… uhm at that point I just took medication for dizziness and then it didn't go away and then took my blood pressure and it was very high. And then I went to a normal GP the following day because I felt like I got worse and my high blood pressure was higher. I uhm went to the GP and they tried lowering my blood pressure by giving me medication and that didn't work. I think I spent about 2 hours there at the GP and it didn't work, and then they advised me to go to the emergency hospital Heideveld clinic.

Interviewer: is that a private or a public hospital?

Participant: it's a public clinic… they advised me to go there to take further tests on what it could be cause at that point they didn't know what was wrong… Thinks), uhm also during that time I was getting weaker where my eyes were closing and I couldn't walk but that time I didn't know, no one knew what was going on. so then I went to heideveld clinic and then …uhm they took tests through the night where the next day I think actually the doctor only could see me. Public hospital yeah (scoffs). So I spent the entire night there and the next morning the doctor only saw me. Then they took a scan, a head scan but that is as much as they could do at that hospital, and then because, I had a, I took a lung puncture at that hospital as well and that was it and then they told me that I need to go for further tests at Groote Schuur hospital.

Interviewer: mmhm

Participant: and I came through to Groote Schuur via the ambulance with them.

Interviewer: and this was on the second day you were there?

Participant: the second day yes, on the same day…came to the hospital groote schuur and I think I spent about 2 days in the trauma until I could get a ward to come in to. With, during that time yes there were tests, a lot of tests that they were doing. A lot of tests yes to find out what's going on. I think about only a week later I was actually diagnosed with mg yes, and then they started treatment. And then I was out of the hospital about 2 weeks. So I spent 2 weeks in hospital, round about.

Interviewer: and how was your experience at the hospital during that time, with staff and generally?

Participant: at Heideveld or both?

Interviewer: uhm, let's say both

Participant: okay… at Heideveld very bad. Very very bad.

Interviewer: okay, what was the problem?

Participant: the problem was… you see for me at that time I didn't know what was going on. like all I knew is I'm just, I'm not right, something is very wrong… and the way they were reacting I could say it's like "we're living you there we'll get you later on, when we can". I understand they're busy, it was in covid but the, their system wasn't right.

Interviewer: mmhmm

Participant: Uhmm, I spent a night there with no bed, no chair. There was a time there was a chair, there was a time I sat on the floor and no attention to me whatsoever. Amongst other patients I was sitting so we're all going through the same thing. Each one had their own illness and we're all just waiting on the doctor.

Interviewer: but the chair, was the hospital overpopulated or?

Participant: it was a very narrow bunk, like a bench.

Interviewer: was it because they don't have chairs, beds?

Participant: probably, there was a time I sat on a wheelchair but then they took it from me (laughs) and there was a time I came there and was on a bed but they also took it from me.

Interviewer: okay

Participant: so then I moved from a bed to a wheelchair to a bench and lay basically on a narrow bench like 2 people on that small bench. So it was very traumatising for me as well cause my experience wasn't the best at all. I would go to the bathroom maybe and vomit, I experienced nausea as well during that so I would vomit as well and … during a period where I couldn't help myself I had to force to help myself cause no one could help me, I don't know if they couldn't or they didn't want to but I tried getting attention (trails) but I couldn't, I didn't get attention. So at that point where I couldn't walk and I couldn't see, my eyes was like (does a hand gesture) at the time a little I could see. So even with maybe going to the toilet like I had to basically crawl along the walls to walk. Nurses would walk past, no one would stop me, no one would be like "is everything okay", nothing like that. So yes I vomited, I went through all of that (small laugh). That was at Heideveld, very bad experience.

Interviewer: yeah, I'm sorry to hear that.

Participant: yeah, so I came here to Groote Schuur the next day and was in the trauma unit. My experience with nurses, okay the doctors were checking up on me. There were different doctors, I don't know who was who at that point (laughs) I couldn't see obviously but there were people coming in and out. And the nurses were okay (hesitant), I would say okay, not as bad as Heideveld, my experience there. They were there but were also okay and the doctors were in and out. So I don't have anything had to say about doctors. Same when I came to the ward, the nurses were good, very good actually, very good. They would check up on me, yes I would I'd say good things about the nurses here at Groote Schuur as well as the doctors.

Interviewer: okay, there's also this (hands over the MGADL). So this is basically a form, it's an mg test, it checks how you're doing with your mg. so it asks you questions about your chewing, swallowing, breathing. So you basically rate yourself, your talking is your talking normal or do you have slurred speech.

Participant: mmh, okay.

Interviewer: can you fill that out for me please.

Participant: should I just write the number?

Interviewer: yes

Participant: do you mean intermittent slurring, is that like now and then?

Interviewer: mhhm, like occasionally.

Participant: okay, yeah… (thinks while feeling out the form) …drooping is that double vision or just wanting to close?

Interviewer: wanting to close, yes.

Participant: okay (total the score)

Interviewer: so you're doing pretty okay hey?

Participant: yeah, I did improve very much from the last time I was here, pretty much yes.

Interviewer: so how often do you attend check-ups here?

Participant: it started with every 3 months and the it went to last year six months. So I'm on 6 months now but then I'll see, from today onwards I'll see them in a year.

Interviewer: so how are you doing physically? You said you're doing well?

Participant: Physically (thinks) I'm okay, there are times where I feel like I need to take a step back…cause I do have busy days as well, not all the time but some days. And I could tell if my body…if my body is saying like "that's enough", I can tell. So there are times, like I can't over exert myself cause I could feel like tired in my legs, sitting upright. So there is a limit to how I go about things.

Interviewer: and are there other activities that maybe you struggle with, like things you used to be able to do very well maybe but now you find that you're really struggling to do those or to get around them?

Participant: uhm… maybe like being active (thinks) as in walking long distance, running…uhhm, things like that yes. Where I could maybe walk back then longer even if it was just normal walk before than what I can now.

Interviewer: okay and have you noticed any changes in how you cope with stress or?

Participant: how I cope or if I have stress? What do you mean?

Interviewer: mhhm, okay let's start with if. Would you say that you're more stressed often after being diagnosed with mg or?

Participant: I would say yes

Interviewer: okay…

Participant: but there are also other things outside of mg that also causes stress. So I can't fully say that it's because of the mg but that is also something on its own where the unknown for me is stressful and like thinking am I gonna come back here, am I going to relapse. That is on my mind all the time but like I said it is a possibility and that possibility is scary for me to come back and experience that whole scenario again.

Interviewer: mhhm, and how do you cope with stressful events?

Participant: how do I cope… (thinks)

Interviewer: would you say there's a difference between in how you used to be able to cope with stressors and you know challenging times in your life because of any problem really as opposed to now that you have mg?

Participant: I really don't know hey, like every day is different (laughs). i…every day is really different, uhm in terms of coping like I just go on by my day and if I feel sad or at that time I just, I just let myself be and grow myself out of that moment and carry on, and them I'm okay.

Interviewer: okay.

Participant: so as to, like, there are no actual measures like maybe if I could say I mean or maybe mean that, stuff like gym. I don't know that is also like a coping mechanism for some people…I don't do, I'm not very much active or I'm active in other ways I don't know. I'm walking a lot on campus (laughs) and yeah. Like I'm very busy as, when it comes to, academically as to a point where I don't have time for other things. Yeah, so that is on my mind most of the time.

Interviewer: mmhm

Participant: so there's no really room for other things.

Interviewer: okay, I hear you. So how would you describe your mental health right now?

Participant: mental health? Like on a scale or…?

Interviewer: no, it doesn't have to be on a scale, if you can just tell me, do you feel that emotionally you're okay, you're doing well or do you need help, you know with coping?

Participant: uhmm… emotionally there are times where I am feeling stressed, I am feeling sad or I do get snippets of what happened back then and I feel like I'm not over, not that I'm over but like it feels like it happened yesterday for me… uhm, yeah so I do, like I am at a point where I think about it, I know close to a time now I got admitted I wouldn't want to maybe talk about what I went through or like remind myself of what happened. Like I would refrain away from yeah talking about it.

Interviewer: okay…

Participant: like when people ask me how I am I just feel like I'm good because I think back then if I would speak about what had happened, I feel like this is the first time that I'm talking so in-depth (laughs) of like my experience. I am also a person that's like not very much open. Like I don't speak much about myself (laughs). I don't know that is just me… uhm, yeah I…what was I saying now (laughs). I forgot (laughs again).

Interviewer: you were talking about how sometimes what happened just pops up and you struggle to talk about it.

Participant: yes, that was back then. I struggled to talk about it but I feel like now I am more confident to talk about the experience that I went through. Like I'm able to share what I went through. Whereas back then I was like no, no I don't wanna talk about it because I would just cry. The words didn't come out, I would just cry. But now I feel like I'm at a much better space in terms of that. I could share what I went through and at the same I do get emotional about it. But I am better in terms of…emotionally now than back then, but it's still there, that sadness and that trauma, I don't know if I should say trauma…

Interviewer: yeah

Participant: but it is there.

Interviewer: okay, so you are processing it though?

Participant: like I'm still in that process yes of acceptance. Okay I am, I, I accepted, I am, I did accept… uhm, yes I accepted it but I, like I'm still, my emotions are still there.

Interviewer: mmhm, so now I'd like to ask you a couple of questions about your relationship with your family, if that's okay and basically just people around you like the society you live in and the community. So you live in Heideveld you said? .

Participant: I live in XXX

Interviewer: where?

Participant: xxx, Athlone.

Interviewer: oh, in Athlone, okay.

Participant: yeah.

Interviewer: so how would you describe your relationship with your family?

Participant: I'm very close. We are a lot of family members you know, we live together. We are seeing each other every day, we reach out to each other every day. So I would describe it as very close yeah. Cause we're all in each other's faces (laughs).

Interviewer: (laughs) so how would you describe the support system in your family and how they supported you when you were going through all of this?

Participant: how would I describe… we I would say they were there for me. It was also tough for them, cause when I was admitted in hospital it was covid.

Interviewer: mmhm…

Participant: so that 2 weeks I didn't see them at all. So, uhm definitely they were very worried cause no one knew what was going on, and like the doctors even sent the back and it was even a shock for them because I was a completely healthy person I never suffered from high blood pressure at all. Everything that happened that day, it was like wow, like you know where is this coming from. So to them it was also like, what could it be. There wasn't really what they'd be like "what!", like you know she had this stuff or illness it could lead this way. So it was really like hey, we don't know. And at that time I couldn't also really speak. So for me sharing the message over to them, like it wasn't…like we couldn't, we couldn't really communicate…but I would be on the phone with them every day. I tried my best with talking about what happened… now this doctor was here and I went for that test, they said this. Stuff like that, I would share that to them. So the support system was very good, from them. Yes, they were definitely by my side and they still are.

Interviewer: mhm, okay, that's good.

Participant: yeah (smiles)

Interviewer: so do you guys talk about how this illness has affected you as a family, do you have one of those conversations?

Participant: uhm… not really, I feel like back then yes maybe, uhm, but not much now. Like I try to not make this illness my life. Like, I don't wanna be identified as that person with this illness so am that person that just brushes it off and act like I'm not a person with a chronic illness… and I just try to maintain a very positive mind-set when it comes to this. Like I don't want people to be like oh! No! she is sick.

Interviewer: Yeah

Participant: like at this point I don't feel like I am sick anymore. So I don't want to be labelled as… you know her name is xxx and she has this and… so I would say like it came to a point where we're like normalised things now and we just obviously watch out for, I, I am a chronic patient obviously so we do watch out for things, you know.

Interviewer: yeah

Participant: anything can happen, right but as every day goes by I like, I live normally, go by normally as I wold before. But obviously physically I'm not the same.

Interviewer: mmhm, okay. So are there any other adjustments that you had do in your family, maybe like a change of diet, maybe you have to watch what you eat now or?

Participant: no I continue eating more, I usually eat yeah (laughs).

Interviewer: (laughs) okay, and in any other areas, besides the fact that obviously you have mg, you've come to a point where you're going about your lives the way you used to?

Participant: yeah, I, like I said, I try to go by my life every day as normal as I could be. And like I don't think there are changes much or there's a much difference from how I used to do things compared to now. There's just maybe in terms of physically being active. That's the only difference I could say.

Interviewer: okay, so how would you describe your relationship with your friends?

Participant: my friends, very good, yeah. I do have friends from university that I see every day, that I speak to every day… and both academically and socially. And then I do have other friends as well that I basically could say I grew up with in high school that I still see quite often. So I do, mmh, have a good bunch of friends, yeah.

Interviewer: so you wouldn't say that mg affected your ability to make social relationships?

Participant: no

Interviewer: That's good, so now hmm, you said you are a student?

Participant: mmhm

Interviewer: how are you coping at school?

Participant: I am… so right because I decided to study is not easy, definitely not easy, so I do struggle. I do stress a lot and like we are, like I'm really under pressure. Like we do have things we need… yeah, so the civil engineering like, it's difficult but I do enjoy it. I enjoy the work, I, but like the, the work load, it's very much. It's a lot, so my life, I'm constantly busy seven days a week trying to submit things, learn things, yeah and it is, it's very stressful. I would say that that's the most stressful part of my life right now because … yeah we only have certain chances of maybe meeting up with friends and all of that is really pressurising.

Interviewer: okay, but about access to school, are you able to, are there a lot of stairs maybe, building without lifts, things like that?

Participant: yes, there are a lot of walking distances, there are lifts and there is a lot of walking to do. Uhm, but I feel like I'm okay with it. When it comes to stairs uhm there is a bit (does a hand gesture)
Interviewer: you get tired?

Participant: yeah. I do struggle when it comes to stairs but when it's like a normal straight level, I'm okay.

Interviewer: do you feel like you have enough support at school?

Participant: yes, I do.

Interviewer: and you're not working, right?

Participant: no

Interviewer: okay, so what cultural group do you identify with, do you identify with any cultural group or religion?

Participant: Islam

Interviewer: Islam, Okay. So would you say your culture or religion has impacted how you understood mg?

Participant: yes, definitely, definitely. It has, yes.

Interviewer: how so?

Participant: so, uhm, like with obviously being ... (thinks) what's the word... diagnosed with this illness, for us we believe in our religion, like your creator will not give you anything that you cannot cope with, basically.

Interviewer: mmhmm

Participant: so, there are always... with difficulty comes ease, and I definitely went through that. I had difficulty and I am through the ease. Like I was at a point where I thought I wasn't gonna be able to see, I wasn't able to walk, chew, but currently I am doing all those things. So I would definitely, I would say faith played a big role, and my trusting in my creator played a big role.

Interviewer: mmmhm, that's good.

Participant: yeah.

Interviewer: I'm glad that you had something to you know, to believe in. it's very important

Participant: that is also very important for us as well because for us no one can help you other than your creator.

Interviewer: mmh, so in your opinion would you say that, mmh, okay you already told me how your family was also affected, it was difficult for them but do you have any suggestions that you think would help other families cope with mg. if they had a family member maybe, who was diagnosed.

Participant: suggestions (thinks)...uhm, I would definitely say to be patient with them, cause maybe the things they could do back then in terms of being physical, they can't do now. So, I'd definitely say patience and not to expect the things that they could do back then to do it now. Cause they might look okay, like "go on, carry on with your life". There is a limit to what they can do in terms of being physical.

Interviewer: mmhm, so what about the government or structures around us, do you think there's anything that maybe, like for example, the hospital. What would you like to see happen… that you think could help people with chronic illnesses like mg?

Participant: at this hospital I really feel like they did their utmost best that they could with me. I went through a lot but they did… I feel like they could do on anybody so they really did everything they could, yeah at this hospital. uhm, like I have nothing bad to say about this hospital. With Heideveld…ugh man (giggles)… (sighs), I mean if you can't even get a bed for your patient then… yeah, I don't know. I really don't know, and if your patient is looking like she's about to die and you only come see her the next day, then I don't know. Yeah.

Interviewer: yeah… thank you, that will be all. Participant:

Participant: okay

Interviewer: thanks a lot for talking to me about your experience.