An exploration into the lifeworld of patients with cluster headache in South Africa

By

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This work is submitted in partial compliance with the requirements for the Master's Degree in Health Sciences: Chiropractic at the Durban University of Technology

I, Tanya Tschirpig, declare that this dissertation is representative of my own work in both conception and execution (except where acknowledgements indicate to the contrary).

____ 30 March 2023 .

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Approved for final submission

__ _______ 4 April 2023 .

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PhD: Health Sciences
M.Tech: Chiropractic
Advanced Diploma: Management Sciences (Business Administration)

DEDICATION

For Mel Klingenberg – thank you for showing me what bravery was, before I ever knew that it was something I would need to know myself.

For every cluster headache sufferer – I dedicate this to you. May your voices be heard, and may you be cared for in a way that you deserve.

ACKNOWLEDGEMENTS

While I feel like I have poured every drop I could into the completion of this project, I know that the cup I was pouring from was filled by the wonderful humans that have helped me get to this point. Words cannot express my gratitude for all the support with which I have been blessed.

I begin with expressing my gratitude to the Ada and Bertie Levenstein Scholarship Foundation for the financial contribution that has allowed me to complete my studies. Thank you for making this possible.

To my supervisor, Dr Desiree Varatharajullu, your faith in me is something I will never be able to say thank you for enough. It has been such a privilege to work with and learn from you. Thank you for the trust you expressed in my ideas and the work I presented to you, for the guidance at every point, and the insurmountable patience you had every time I panicked unnecessarily about a minor detail. Your support is the reason that this work gets to exist.

To my teachers and lecturers, too many to name, I want to acknowledge how much your work impacted who I am today. Many of you saw potential in me before I believed it was there — I hope that I can become the person you seem to see.

To my family: Mama, you have been the most beautiful example of the kind of human I aspire to be. Thank you for extending that love to me forever more, and wiping my tears every time I doubted myself. Papa, I do not know a single person who works as tirelessly and with as much love as you. I want you to know that I see how you take care of your family and will always be grateful for the opportunities you have given me. Mama, Papa, Chantelle, *und* Ivan, *ich habe euch unendlich lieb*.

To all my friends who cheered me on during this process: know your encouraging voices are always on my mind and very dear to me. I am so proud of us.

Sarah, your gentle encouragement and every cup of coffee you offered over this time is acknowledged and appreciated.

Heidi, my special, you have been inexpressibly helpful. Thank you for your unwavering faith in my ability to ‘figure it out’, but being a listening ear while I did so out loud. You asked ‘how my research was going’ exactly the right number of times.

To my mentor, Taylor, for filling my clinical cup every month, instilling hope for revolution in healthcare in me, and reminding me what I was working towards when I felt ready to abandon every hope.

Simone, thank you for making me pick a lane; I am happy I get to be here. I will forever be indebted to you for teaching me to have the audacity to believe in myself — thank you for walking this entire journey alongside me.

To every participant in this study, I want to extend my sincerest gratitude for opening your world to my inquisition and telling your stories in such a vulnerable manner. Without your willingness to share your suffering with this stranger, none of this would be possible.

ABSTRACT

Background: Cluster headache is an excruciatingly painful condition that greatly affects the lived experience of those who suffer from it.

There is a general paucity of information on the condition, and with little literature about headaches in the African continent; this is a novel investigation into the experience of cluster headaches within the South African context using an explorative and qualitative approach.

Aim: The aim of this study was to describe and reflect on the lifeworld of individuals' with cluster headaches within a South African context.

Methodology: the study was a qualitative study exploring the lifeworld and experiences of eight South Africans with cluster headache. Data were collected using in-depth semi-structured interviews. Transcriptions were systematically reviewed to find common themes and subthemes using appropriate qualitative methodology.

Results: The participants were equally distributed with regard to gender; there were four male and four female participants within an age range of 20 to 62 years. Of the eight participants, six were white, one Indian and one black. All but one patient had the episodic sub-type. Only one participant utilised the public healthcare system. Five main themes emerged: a) the inexplicable intensity of the pain, b) the reality of a disease-experience outside of head pain c) anxiety as a complexly recurring reaction, d) the perceptions of healthcare sought-out, and e) the value of a diagnostic label.

Conclusion: The interpretation of results revealed that individuals with cluster headache perceived to have a massive impact on most aspects of their life, with emotional and psychological ramifications being significant. These experiences were exacerbated by misdiagnosis and mismanagement, as well as the perception of the impacts of a variety of stigmas. Cluster headache individuals in this cohort expressed a desperate need for empathetic care alongside more effective and

accessible treatments and desire for more awareness of the condition within the medical field.

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ABBREVIATIONS

CAM therapies	Complementary and alternative therapies
CH	Cluster headache
MOH	Medication overuse headache
MH	Migraine headache
TTH	Tension-type headache
SPG	Sphenopalatine ganglion

CHAPTER ONE

ORIENTATION TO THE STUDY

1.1 INTRODUCTION AND BACKGROUND

Cluster headache (CH) is a relatively rare primary headache, characterised by frequently recurring, brief but excruciating hemi-cranial headaches, with ipsilateral associated cranial autonomic features (Headache Classification Committee of the International Headache Society 2018: 41).

The burdens of CH have been shown to have a dramatic effect on an individual's overall wellbeing and affect multiple facets of the lives of those affected (Palacios-Ceña *et al.* 2016: 1171). The condition has made appearances on lists that cite some of the most painful conditions in existence (Burish *et al.* 2020: 120). Some accounts describe it as one of the worst pains known to man (Rossi *et al*. 2016: 181), to the extent that they have gained the nickname of 'suicide headaches' due to the associated pain intensity (Rizzoli and Mullally 2018: 21) and the resulting risk of morbidity by suicide (Trejo-Gabriel-Galan *et al.* 2018: 802).

Among the top ten most frequent reasons for seeking out chiropractic care, 'headache' as been shown to be a frequently reported reason in sixth place (Beliveau *et al.* 2017:6); a critical review by Moore, Sibbritt and Adams (2017: 3) found that the prevalence of chiropractic use in populations with headaches was up to 22%. For this reason, it is reasonable to assume that chiropractors may come across CH patients seeking relief and knowledge on the disorder is required.

Chiropractic aligns itself with the biopsychosocial model of healthcare, where a 'whole-person" approach is taken in patient management (Gliedt *et al.* 2017: 1). Qualitative data, having shown to promote health and quality of life (Willis *et al.* 2016: 1185), lends itself well to informing this holistic approach to patient care.

The purpose of this study will be to describe and interpret the lifeworld of patients with CHs within a South African context, and to utilise this data to find areas that have the potential to be pragmatically addressed to improve the care received by chiropractic and other healthcare providers and enhance the lived experience of CH sufferers.

1.2 PROBLEM STATEMENT

Research suggests that CHs can considerably modify patients' lifestyle (Palacios-Ceña *et al.* 2016: 1172) even outside of active bouts (Abu Bakar *et al.* 2016a: 87).

For many years, CHs have been overlooked by researchers (Martelletti and Mitsikostas 2015: 1), resulting in a general paucity of information surrounding the condition. There is also little to no research regarding the experiences of South Africans with CH.

With little illustrative data that demonstrates the lived experience of having CH, studies that quantitatively investigate disability and impact of CH (Lampl *et al.* 2016: 1; Kim *et al.* 2019; D'Amico *et al.* 2020) have little transferability into practice and treatment.

1.3 AIM OF THE STUDY

The aim of this study will be to describe and reflect on the lifeworld of patients with cluster headaches within a South African context.

1.4 OBJECTIVES OF THE STUDY

- Explore the lifeworld of those with cluster headaches in South Africa.
- Investigate the influences that result in the experiences and challenges that those with cluster headaches in South Africa experience.
- Determine areas that could be addressed by healthcare professionals, that could contribute to an improved lived experience of cluster headache patients in South Africa.

1.5 RESEARCH QUESTIONS

- What is the lifeworld of a patient with cluster headaches in South Africa?
- What are the apparent and nuanced influences that result in this experience?
- What are the perceived personal, social, occupational, and emotional impacts of cluster headache?

1.6 RATIONALE FOR THE STUDY

Chronic conditions have multifaceted effects on individuals’ lives, with their impact extending beyond the patient themselves, but also to all those they encounter (Megari 2013: 141). Individual headaches alone are painful and can be disabling (Andre and Cavers 2021: 425), but headache disorders, characterised by recurrent headaches, may become severely burdensome and debilitating (Pohl *et al.* 2019).

Cluster headache is one such disorder, and considered a relatively rare primary headache disorder of the trigeminal autonomic cephalalgia type (Headache Classification Committee of the International Headache Society 2018:41). It is described as severe, unilateral, recurrent “attacks” of pain in a trigeminal distribution that last between 15 to 180 minutes and recur up to eight times a day (Headache Classification Committee of the International Headache Society 2018:41). Associated with the pain are ipsilateral cranial autonomic features, such as conjunctival injection, rhinorrhoea, miosis and ptosis (Headache Classification Committee of the International Headache Society 2018: 2021).

This headache disorder reduces patient well-being and quality of life in a variety of ways, as well as carrying a significant socioeconomic burden (D’Amico *et al.* 2020: 809). While most targeted research has taken place to understand the pathophysiological underpinnings of the disorder targeted at addressing the need for effective treatments (D’Amico *et al.* 2020: 809), CH patients have also expressed their desire for empathy and adequate understanding (Palacios-Ceña *et al.* 2016: 1179-1180). Addressing this need of theirs can simultaneously assist with the enhancement of the efficacy of care outside of the empirical success of treatment (Barry *et al.* 2001: 487) and can be achieved by making use of lifeworld-led care

(Hemingway 2011) – a model of care on the rise in holistic treatment that has proven effective for reparations, compassion, improved wellbeing, and dignity for all concerned (Galvin *et al.* 2020: 1).

A critical review of the current evidence of CH up to the year 2019, conducted by D'Amico *et al.* (2020), confirmed that, though evidence of reduced wellbeing and quality of life with CH existed, most of this evidence was conducted with quantitative methods of assessment and little evidence depicts descriptions of patient experience. With the emphasised need for information on the lived experience of CH to tailored care for these individuals, (D'Amico *et al.* 2020: 816) exploration of the CH lifeworld is necessitated using research with a qualitative design.

Invisible illnesses that involve chronic pain generally have large effects on health in a physical and mental capacity and place patients at increased risk of suicidal ideation (Pederson, Gorman-Ezell and Hochstetler-Mayer 2017: 184). Some accounts of CH have described it as the worst pain afflicting mankind (Rossi *et al*. 2016: 181; Rossi *et al.* 2018: 57).

Pain is under-treated and under-managed globally (Bateman 2015: 621), but in developing nations, the treatment of infectious disease is often the priority of the primary care sector (Woldeamanuel and Cowan 2017: 308). While the treatment of pain as a human right is gaining traction (Brennan, Lohman and Gwyther 2019: 61), South Africa's burden of disease is of the infectious kind – though it is also inundated with injury and violence requiring treatment, maternal and paediatric illness, as well as non-communicable diseases (Fairall *et al.* 2016).

With pain minimally considered as a condition in and of itself, but rather as a symptom of another, treatment of pain is negatively affected even into the priorities of training (Bateman 2015: 622) – making one of the greatest barriers to good pain-care being a knowledge deficit within the country (Lourens, Parker and Hodkinson 2021: 1). Without evidence one can only assume how this training is affecting CH patients in their plight for help.

The South African context is unique, for it is a country with a myriad of differences within (Shutte *et al.* 2018: 467). It contains the first and third world – the developed and the developing – made of individuals with varying gender, race, ideas, values, cultures, religions, levels of education, financial statuses, and ways of life (Shutte *et* *al.* 2018: 462). Here, healthcare is sought from a variety of places, such as traditional healthcare practitioners, complementary and alternative medicine (CAM), and allopathic doctors (Rasweswe *et al.* 2021: 1). Since it is well known that a broad and multidisciplinary approach is required to address the scope of pain's dimensions (Brennan, Lohman and Gwyther 2019: 64), the transdisciplinary access warrants investigation.

Exploring the lifeworld of those with CHs in South Africa will hopefully reveal information that can lend itself to the development of solutions to problems within their lifeworld and healthcare they receive (Vagle 2018).

1.7 SIGNIFICANCE OF THE STUDY

Chiropractors are portal-of-entry healthcare providers internationally (Cupler *et al.* 2021: 138) and are commonly consulted by patients in the treatment of headaches (Beliveau *et al.* 2017: 6; Rhee and Harris 2017: 44). Furthermore, in seeking treatment, research has noted dissatisfaction with orthodox treatments among CH patients, which often results in the exploration of CAM (Andersson, Persson and Kjellgren 2017: 60), of which chiropractic treatment is a popular choice (Bekkelund, Ofte and Alstadhaug 2014: 114). With suicide being considered a global public health crisis, there has been a call for chiropractors to recognise their ethical responsibility as part of a primary care team in the recognition and prevention of mental health crises and suicidality in practice (Cupler *et al.* 2021: 138). Due to the likelihood of chiropractic exposure to a patient with CH, as well as the proven resulting risk of morbidity by suicide in these patients (Trejo-Gabriel-Galan *et al.* 2018: 802), this becomes ethically significant: misdiagnosing, mismanaging or not addressing CHs adequately can be considered demoralising, dangerous, unethical, and unnecessary (Koo *et al.* 2021:8).

Including the lifeworld view builds a better understanding of the patient's experience, which can improve the efficacy of medical consultation (Barry *et al.* 2001: 487), as well as foster a better physician-patient relationship (Palacios-Ceña *et al.* 2016: 1172). A study by Koo *et al.* (2021) found the increased risk of suicidality in CH patients to be greatly associated with demoralisation and feelings of hopelessness. A key element to reducing demoralisation and hopelessness, and thus a strategy in reducing suicidality in CH patients, is improving CH care by gaining a better understanding of the patient perspective (Andre and Cavers 2021: 425). Since headache experiences are highly unique and individualistic (Palacios-Ceña *et al.* 2016: 1172), and the experience of pain is also a highly subjective and multidimensional (Koyama *et al.* 2004: 12950), the use of qualitative data to help shed light on the full pain experience, can be an invaluable contribution in pain therapeutics (Webster and Harden 2013: 1811).

Using qualitative research to address the ‘what’, ‘how’ and ‘why’ questions, an in-depth and rich understanding of the experience within its context can be developed (Myers 1997: 241). While this is not as generalisable as quantitative research typically is, it is ideal information to use when designing health interventions that are targeted at a particular population or a specific context (Tuckerman, Kaufman and Danchin 2020: 819). Furthermore, the Afro-sensed approach argues that the African contexts and spaces should be considered as opportunities of value in the discovery of knowledge, particularly in the development of coping practices (Rasweswe *et al.* 2021: 3). For these reasons, evidence from low-income and middle-income countries, such as South Africa, can be justified to be of value to not only its own people, but potentially also the global population.

For many years, CHs have been overlooked by researchers (Martelletti and Mitsikostas 2015: 1), resulting in a general paucity of information surrounding the condition. Lifeworld research can guide lifeworld led care for these patients in South Africa and beyond, which will be one of the firsts for this population.

1.8 OUTLINE OF THE THESIS

CHAPTER ONE:

This chapter serves as a preliminary introduction and provides insight into the aims, objectives, rationale and the significance of the research study.

CHAPTER TWO:

The second chapter exhibits an extensive review of the current literature relating to the study. Within this literature review, elements of the study are deconstructed and elaborated on.

CHAPTER THREE:

In this chapter, the procedures, model, and design of the methodology developed and utilised to perform the research will be discussed in detail.

CHAPTER FOUR:

This chapter presents the findings of the study.

CHAPTER FIVE:

In this chapter, the results of the study are interpreted and explicated, with an emphasis on the relation to the research aims and objectives.

CHAPTER SIX:

The final chapter concludes the research. A summary of the study and its findings will be included, along with a depiction of the study's limitations and recommendations.

1.9 SUMMARY OF THE CHAPTER

This chapter serves as an introduction to the research by providing a context to the study and exhibiting its intentions. Within it, the background to the research, research problem, study aim and objectives, research questions, rationale of the study, structure of the dissertation and an outline of the upcoming chapters were expanded upon. The following chapter will elaborate on the current literature relating to the study.

CHAPTER TWO

LITERATURE REVIEW

2.1. INTRODUCTION

This chapter serves as a depiction of the literature available relating to CHs and identifies the gap in the literature that pertains to the lived experience of the condition, especially by those in the South African context. Sources for this review were obtained from PubMed, Google Scholar, EBSCO-Host and ScienceDirect.

2.2. BACKGROUND

Headaches are a common complaint across all populations; they occur with a high lifetime prevalence of 96% (Rizzoli and Mullally 2018: 17) and carry an equally large associated personal and global burden (Saylor and Steiner 2018: 182).

Burden from headache presents itself in the form of pain, disability, reduced quality of life as well as economic and financial loads (Saylor and Steiner 2018: 182). Though these burdens are high, with headache disorders ranking fourteenth of the global reasons of disability-adjusted life years (Stovner *et al.* 2019: 106), headache disorders generally have negligible mortality associated with them, resulting in them being poorly acknowledged.

Most studies have shown that those that do seek medical assistance for management of headaches often note a desire for improvement in the care they receive (Takeshima 2004: 18; Harpole 2005: 1048; Bekkelund, Ofte and Alstadhaug 2014: 114; Steiner *et al.* 2019: 58). A recent study conducted in South Africa found that up to 68.9% of participants did not feel they received good quality or patient-centred healthcare (Padayachee *et al.* 2020: 6317). There is currently a paucity of literature available that provides an indication of the patient experience of any treatment related specifically to headaches in South Africa.

In recent years, in an attempt to improve the experience of patient-centred care for headaches, science has begun making use of patient-led research (McGinley *et al.*

2022: 262) to assist in the identification of unmet patient needs (de Wit *et al*. 2019: 1095). Cluster headache researchers did take heed, and qualitative studies about the CH experience have started surfacing (Palacios-Ceña *et al.* 2016, Andre and Cavers 2021). However, the condition has a long history of taking a backseat to other headache conditions in terms of research (Martelletti and Mitsikostas 2015: 1) and thus a paucity of information still exists, leaving valuable information regarding CH in an African context wholly untouched.

2.3. OVERVIEW OF HEADACHES

Headaches are defined as "pain located in the head, above the orbito-meatal line and/or nuchal ridge" (Headache Classification Committee of the International Headache Society 2018: 209).

Currently, over 200 specific headaches are recognised in the International Classification of Headache Disorders, 3rd Edition (ICHD-3). They can broadly be divided into primary and secondary categories. In addition, the International Classification of Headache Disorders, 3rd Edition (Headache Classification Committee of the International Headache Society 2018: 164) also includes a third section for 'painful cranial neuropathies, other facial pains and other headaches' for cranial and head pain that does not suit the classification criteria within the first two categories.

Primary headache disorders are characterised by recurrent episodes of head pain symptomatology that have no known underlying cause (Headache Classification Committee of the International Headache Society 2018: 211). The most common primary headache disorders are migraine, tension-type headache (TTH), and CH (Stovner *et al.* 2019: 106). Secondary headaches are attributed to an underlying cause or disorder (Headache Classification Committee of the International Headache Society 2018: 211), usually resulting in traction or inflammation of pain-sensitive structures of the cranium (Rizzoli and Mullally 2018: 18). These headaches are classified by their underlying cause of pathology, for example, 'of vascular disease' or 'due to intracranial pathology' (Headache Classification Committee of the International Headache Society 2018: 4).

Roughly, 90% of headache presentations to primary care providers are attributed to a primary headache disorder. Most headache management also occurs appropriately at a primary care level (Steiner *et al.* 2019: 58). Alongside managing the most common primary headaches, the goals of primary care intervention for headaches are also to be able to identify any red flag symptoms for secondary headaches that may have dire consequences if not recognised and treated timeously, in order to refer for specialist examination if indicated (McNeil 2021: 40). Regardless of referral, it is recommended that the primary care physicians continue to manage the patient after specialist visits (Starling and Dodick 2015: 410).

The Global Campaign against Headache' identified the headaches of importance to the primary sector as migraine headache (MH), tension-type headache (TTH) and medication overuse headache (MOH) due to them making up the bulk of headache-burden (Steiner *et al.* 2019: 59), along with CH. Cluster headaches are rarer, but of incredulous pain levels, and require better recognition at primary care level in terms of diagnosis, followed by referral to specialist care (Steiner *et al.* 2019: 57).

2.4. THE EPIDEMIOLOGY OF HEADACHES

Headaches have a lifetime incidence of about 96% (Rizzoli and Mullally 2018: 17). Approximately 90% of these are estimated to be primary headaches, of which up to 75% are hypothesised to be a subset of migraine (Ebell 2006: 2087).

According to the Global Burden of Disease Study in 2019, 52% of the populations studied had an active headache disorder of any type, and 15.8% of the global population have a headache every day (Stovner *et al.* 2022: 2). This latest review also reiterated that migraine and headaches that occur for more than 15 days per month occur more commonly in females, as was previously seen in earlier studies (Stovner *et al.* 2022: 2).

Headache epidemiology is seen as an immature discipline and epidemiological studies in the field have notable variations in their methodological undertakings. Most publications that provide data are from high-income countries (Stovner *et al.* 2022: 2). Information regarding the prevalence of headache is rare from the African continent (Haimanot 2003: s47) – a recent narrative review found only 27 published epidemiological studies for Sub-Saharan Africa, of which none were found for South Africa (Stovner *et al.* 2022: 2). With little epidemiological evidence, little is also known about the impact and burden of headache in these countries.

A small, unpublished study conducted at Durban University of Technology (DUT) in South Africa assessed the prevalence and impact of headaches in health sciences students; it found that 75% of students in the Faculty of Health Sciences at the institution suffered from headaches (Prangley 2010). Migraine prevalence in this cohort was 31% and TTH was 30% (Prangley 2010: 38), which can be seen as elevated when compared to global prevalence of migraine at 24% and TTH at 26% (Stovner *et al.* 2022: 3) – it is unsure whether this deviation is due to geographical differences, a student cohort or other factors. A further study conducted at the DUT confirmed that rates were similar across faculties (Basdav, Haffejee and Puckree 2016: 2). Both studies found high prevalence of migraine and TTH and no CHs were identified.

With a previous lifetime prevalence of less than one in every 1000 (0,1%) for CH (Manzoni 1998, as cited in Martelletti and Mitsikostas 2015: 1; Wei, Ong and Goadsby 2018: 3), it is relatively rare in comparison to more commonly known headaches such as migraine and TTH – which occur in up to two in three adults (Cleveland Clinic 2021: para. 4 line 2-3) – making its absence from epidemiological studies a less surprising fact. However, in 2015, an Open Thematic Series dedicated to CH and other rare headaches was introduced in *The Journal of Headache and Pain* where CH was presented as a *quasi*-rare disorder instead – 'quasi' meaning 'apparently, but not really' (Martelletti and Mitsikostas 2015: 1). A review in 2004 found that epidemiological studies indicated that CH may actually occur in one in every 500 in certain populations and that even this may not be an accurate representation as the condition is very commonly misidentified due to lack of physician awareness (Russell 2004: 279).

No epidemiological studies of CH have been conducted in South Africa, where the population is vastly different to those where people were of European descent only, or largely, were included, and it is thus not known if these prevalence statistics are applicable to this context. A more applicable study conducted in rural Ethiopia, for example, found a prevalence of up to 1.3% (Mengistu and Alemayehu 2013). While CH have been shown to be present in the African and African-American population (Haimanot *et al.* 1995, Wheeler and Carrazana 2001, Mengistu and Alemayehu 2013); studies have shown that the condition's diagnosis is further delayed in those that are African-American woman due to gender and race (Wheeler and Carrazana 2001), which may be of significance in the South-African context as well.

With the South African population over the age of 18 estimated to be around 40 million in 2022 (based on predictions by the United Nations) (World Population Review 2022), 0.1% amounts to roughly 40 000 people with CH. While this is an incredibly crude estimate, it is clear that a large amount of the population may indeed have this condition and it should not be discarded as unimportant based on 'rarity'. Though its societal and economic burdens may not be comparable to that of other primary headaches, it is of devastating pain and personal burden (Martelletti and Mitsikostas 2015: 1), which should be enough reason to increase available knowledge and improve care.

2.5. HEALTHCARE IN SOUTH AFRICA

2.5.1 The South African Context

South Africa, a dominant country of sub-Saharan Africa, is one with an unique context (Shutte *et al.* 2018: 462); its population is extremely diverse and co-exists with significant disparities (Howell 2019). The heterogeneity of the population includes, but is not limited to, the variety of gender, race, ideas, values, cultures, religions, levels of education, financial statuses, and ways of life (Shutte *et al.* 2018: 462). The diversity of its people is mirrored by the diversity in their choices of seeking healthcare, from traditional healthcare practitioners, complementary and alternative medicine (CAM), and allopathic doctors (Rasweswe *et al.* 2021: 1). Traditional medicine remains a primary source of care in South Africa for a significant portion of the population – particularly when caring for inflammatory and pain-based conditions (Aremu and Pendota 2021: 1).

While South Africa treasures equality in its Constitution, the oppression and division of its history still haunt the country in present time (Howell and Shearing 2017). A distinct socioeconomic line affects the healthcare its population seeks and receives (Gordon, Booysen and Mbonigaba 2020: 2) with the population either accessing care from the public, government-funded sector, while the affluent make use of more costly private healthcare (Young 2016: 4).

Furthermore, because infectious disease is often the priority in developing nations (Woldeamanuel and Cowan 2017: 308), there are insinuations that pain care is not well prioritised during training (Bateman 2015: 622), resulting in a national knowledge deficit (Lourens, Parker and Hodkinson 2021: 1), which, in turn, affects patients with pain conditions regardless of which sector they seek care from.

2.5.2 Headaches in South Africa

It is no secret that the South African healthcare system has been inundated with challenges over the last 30 years. It has taken major strain from what has been termed ‘four colliding epidemics’ – namely HIV and TB, chronic and mental illness, injury and violence, as well as maternal, neonatal and child mortality (Achoki *et al.* 2022: 471). Additionally, the Covid-19 pandemic has placed an already overburdened and under-resourced healthcare system under even greater strain (Kelly *et al.* 2021).

With clear priorities that are required to be addressed, South Africa’s research strategy is aimed at addressing those issues (South Africa, Department of Health 2021). Furthermore, it has previously been hypothesised that headaches may be majorly under-researched, underdiagnosed and undertreated in Africa as a whole, due to more demanding socio-economic problems making headache appear like a trivial condition (Haimanot 2003: s47). This explains the lack of epidemiological studies conducted on headache in Southern Africa, as well as the lack of research available that speaks to the impact of headache on the population, and the accessibility and efficacy of treatment that is offered. While treatment guidelines in South Africa are largely based on the World Health Organization's recommendations (South Africa, Department of Health 2020: xvii), the guidelines for pain are limited, with no recommendations for the treatment and management of any headache type in a South African context.

With little to no headache studies illuminating the headache experience in South Africa, the study that investigated the prevalence and impact of headaches at DUT

(Basdav, Haffejee and Puckree 2016) provides some relevant input. A large prevalence of headaches was reported again, echoing that this is, among the student population at the very least, a significant occurrence in South Africa. The study indicated that students with primary headaches felt that their headaches negatively affected their daily life, studies and social activities. Furthermore, it was seen as a negative influence on their moods, concentration and personal care activities. Those with headache felt afraid of letting people down and indicated that they experienced the additional feeling of ‘being a burden on others’ which resulted in feelings of frustration. It is necessary to investigate if such feelings also occur in other parts of the population.

South Africa’s Sustainable Development Goals include the aim to ‘”ensure healthy lives and promote well-being for all at all ages”, with an aim to “promote mental health and well-being” and the “provision of accessible, quality essential health-care services…and medicines” (South Africa, Department of Statistics 2019: 41). With the above on headache impact taken into consideration, it is clear that effective treatment of primary headaches would indeed promote well-being in the country’s population.

2.6 THE HEADACHES OF IMPORTANCE TO THE PRIMARY CARE SECTOR

In March 2004, ‘The Global Campaign Against Headaches’ was officially launched. The campaign was led by the UK charitable nongovernmental organisation (NGO) ‘Lifting the Burden’, in collaboration with other organisations such as the World Health Organization and academic institutions, with the goal to reduce the effects of headache on society worldwide. In 2007, Lifting the Burden collaborated with the European Headache Federation to develop principles that may aid the management of headache disorders in the primary healthcare sector. The three headaches that were outlined to be of importance at that time were MH, TTH and MOH, as these three made up the bulk of headache burden globally. In addition to these, CH was added to the conditions relevant to the primary sector (Steiner *et al.* 2019: 57). This decision was not made due to the frequency of the occurrence of this headache, but rather due to the known severity of the condition. It is not necessarily expected that all management of CH take place at a primary-care level, but rather that awareness of the condition is high so that it is not misdiagnosed and thus to speed up specialist referral so that treatment can ensue. In part of the recognition of CH, a knowledge base of other trigeminal autonomic cephalalgias and orofacial pain, such as trigeminal neuralgia, will naturally be required in order to differentiate the conditions from each other at presentation.

The idea of taking a patient's lived experience into account to improve the quality of their care is no longer a foreign one (Gaille 2019: 339). The experience that the patient holds can be seen as a source of knowledge of the disease, and thus a valuable resource for a practitioner to tap into when managing a patient. Investigating this wealth of knowledge for the experiences of headache patients revealed that patients with chronic headache grew frustrated with the 'invisibleness' of their condition as they felt it contributed to the trivialisation of their experience (Lonardi 2007: 1620).

In a systematic review of the research on the lived experience of patients with chronic headaches, it was revealed that among the impacts of these conditions, a persistent feeling of concern clouding their life was common (Nichols *et al*. 2017: 5). Like other pain conditions, chronic headache caused strain on relationships and was a major driver of daily decisions, overall having a large impact on individuals' lives (Nichols *et al.* 2017: 2). For example, it is known that chronic MH and MOH include the increased likelihood of psychiatric co-morbidities, such as anxiety, depression and personality disorders (Yang *et al.* 2019: 202). While CH is also a chronic recurring pain and headache condition, and it can thus be partially assumed that some of this information may be true here as well; most chronic headache studies of a qualitative nature have been conducted on chronic MH, chronic TTH and MOH.

2.6.1 Migraine

Migraine is considered a common neurological condition, or neurobiological disorder, with heterogeneous presentation (Headache Classification Committee of the International Headache Society 2018: 18) and is the primary contributor to disability burden among headache disorders (Steiner *et al.* 2020: 1). A migraine is multiphasic in presentation: prodromal, aura, headache and postdrome (Dodick 2018: 4).

Typical characteristics of a MH are described in the ICHD-3 as unilateral presentation of moderate or severe pulsating pain that lasts between four to 72 hours (Headache Classification Committee of the International Headache Society 2018: 41), is aggravated by physical activity and associated with nausea, and/or photo-phobia and phonophobia (Burstein, Noseda and Borsook 2015: 6619). The headaches may be accompanied by prodrome and/or postdrome symptoms, as well as cranial autonomic symptoms and symptoms of cutaneous allodynia (Headache Classification Committee of the International Headache Society 2018: 41). The presentation may also present with or without a complex of neurological symptoms, termed an aura (Dodick 2018: 5). An aura occurs in roughly 30% of those with MH (Dodick 2018: 5).

The neurological symptoms of an aura are unilateral and fully reversible, peripheral, or central neurological symptoms usually preceding typical migraine symptoms (Headache Classification Committee of the International Headache Society 2018: 18). Though these symptoms usually precede a headache, they may continue into the headache phase of a migraine attack or begin after head pain has commenced (Eriksen *et al.* 2004: 565). Aura symptoms can be visual, sensory, speech or language-related, of brainstem origin (dysarthria, vertigo, tinnitus, hypacusis, diplopia, ataxia and/or a reduced level of consciousness), include motor weakness or be of retinal origin (Headache Classification Committee of the International Headache Society 2018: 22).

Prodromal symptoms can precede MH by hours to days; they include various combinations of fatigue, yawning, difficulty concentrating, neck stiffness, nausea, photophobia, phonophobia, blurry vision, and pallor (Headache Classification Committee of the International Headache Society 2018: 19).

Postdrome symptoms, if present, follow once the headache has resolved and can last for up to 48 hours; symptoms include difficulty concentrating, feeling tired or weary, as well as neck stiffness (Headache Classification Committee of the International Headache Society 2018: 19).

Presentation of MH is considered either episodic or chronic. A diagnosis of chronic migraine is made in patients who have a headache on 15 or more days, for more than three months, of which at least eight days per month the headache has features of a MH (Headache Classification Committee of the International Headache Society 2018: 24).

The one year prevalence of migraine is estimated at around 15% at a global level (Ashina *et al.* 2021: 1487), and 10.4% in Africa, at a continental one (Woldeamanuel and Cowan 2017: 307). The condition is more common in females than in males, most common in young females (Ashina *et al.* 2021: 1487), and has a higher prevalence among Caucasians (Khan *et al.* 2021: 2*)*.

Migraine has shown to have a large global and personal burden (Headache Classification Committee of the International Headache Society 2018: 18). In fact, The Global Burden of Disease Study (2019) found migraine as the second leading cause of disability overall in both genders of all ages, and the leading cause of disability in females between the age of 15 and 49 years of age (Steiner *et al.* 2020: 1). The substantial economic burden on society (Buse *et al.* 2011: 4) is likely a driving factor for the large amount of research regarding migraine that is published.

Since 1900, a total of 48 825 papers with migraine as the topic were published (as per the Web of Science on 1 January 2021) (Khan *et al.* 2021: 3). The understanding of pathophysiological mechanisms of the disorder is thus advancing rapidly, and with it, the scope of potential treatments (Charles 2018: 175).

While the aetiology of migraine is complex, it is thought to be the result of a combination of genetic and non-genetic/environmental factors that interact to produce the disorder (Sutherland *et al.* 2019: 72). The pathophysiological mechanisms underpinning the condition are also incompletely understood, but advancements are developing rapidly.

In the past, it was largely theorised that migraine was a vascular disorder, and that pain was due to vasoactive changes of the cranium – this has since been ruled out as the primary cause of disorder or pain (Ruschel and De Jesus 2021). Both structural and functional alterations occur in the brains of those with migraine (Burstein, Noseda and Borsook 2015: 6623); it is now suggested that primary neuronal impairments cause a cascade of intra and extracranial change that result in migraine (Ruschel and De Jesus 2021). The different phases of migraine (prodrome, aura, headache, postdrome) are understood to have characteristic pathophysiological processes (Charles 2018: 175). The headache itself is thought to be due to activation of the trigeminovascular pathway (Noseda and Burstein 2013), with focus on calcitonin gene-related peptide (CGRP) as a mediator (Charles 2018: 176). Unravelling mechanisms behind migraine phases, as well as molecular roles, such as that of CGRP, in the pathophysiology, expands the potential armamentarium that is available for the therapeutic purposes of migraine.

Migraine treatment encompasses preventative and symptomatic regimes. Goals of preventative treatment is to reduce frequency and severity of attacks (Starling and Dodick 2015: 408) and prevent the progression to chronic migraine or the development of medication-overuse headaches (Ha and Gonzalez 2019: 18). A 2019 publication provides a synthesis of evidence for the prophylaxis of migraine, ranging from non-pharmacological intervention such as supplementation, trigger mitigation, cognitive behavioural therapy and biofeedback, to pharmacological prophylactic regimen (Ha and Gonzalez 2019), which provides good guidance for clinical application. This is in addition to a paper by Starling and Dodick (2015) that provides a review of and tools for the better care of patients with chronic migraine.

Symptomatic, or as needed, medication for migraine is intended to relieve pain and/or associated symptoms of an attack and is generally comprised of triptans, non-steroidal anti-inflammatories and antiemetics (Gilmore and Michael 2011; Marmura, Silberstein and Schwedt 2015; Mayans and Walling 2018). A major risk of acute medication is headache transformation into chronic migraine, or MOH. Thus, if treatment is necessary more than two or three times a week, prophylaxis is recommended (Mayans and Walling 2018: 245).

Currently, research on anti-CGRP drugs, as well as ditans and gepants has shown great promise for new anti-migraine drugs and is representative of the large strides in migraine research and treatment that are being made (Argyriou *et al.* 2022: 485).

While these developments of novel treatment options are exciting for patients, there are other aspects of healthcare for migraineurs also requiring attention. A study investigating the common experiences of patients with migraine described a strong relationship between the experiences of pain with experiences of invalidation, unsatisfactory healthcare, and a patient perception of a poor quality of life (Heidari *et al.* 2022). Access issues to care, primarily the availability of suitable providers and the costs of care and medication were also significant themes that influenced their experience.

2.6.2 Tension-Type Headaches

Tension-type headaches are commonplace and considered the most frequently occurring primary headache (García-Azorin *et al.* 2020), with a review of epidemiological studies showing prevalence estimates ranging between 30% and 70% (Bendtsen and Jensen 2006: 306). The ICHD-3 describe TTH as mild to moderate, tight or pressing pain that usually presents bilaterally (Headache Classification Committee of the International Headache Society 2018: 35). TTH can last minutes to days.

Though this description is quite obviously distinct from the report given in MH in the ICHD-3, the primary diagnostic challenge with TTH is the differentiation between them and migraine without aura, largely due to their common co-occurrence (Chen *et al.* 2018*)*. Some papers even suggest that they are not different clinical entities (Vargas 2008: 433, Turner *et al.* 2015: 1200), which is a large driver for neurophysiological studies to differentiate between their different underlying pathological mechanisms. Regardless, currently the following information extracted from the ICHD-3 can be considered to differentiate TTH from a MH without aura in a clinical setting: Pain with TTH does not worsen with routine physical activity compared to that of a MH, which is aggravated by movement. Tension-type headaches are also typically not associated with nausea, which is a common associated symptom of MH. Photo- or phonophobia may occur in TTH, though, if both occur, the diagnosis would be MH and not TTH. A detailed clinical history is thus required to make accurate diagnosis (Waldman 2019: 12).

There are three subtypes of TTH recognised in the ICHD-3: infrequent (less than one headache day per month); frequent (one to 14 headache days per month), and chronic (15 or more headache days monthly). The impact of these subtypes on quality of life are massively contrasted, and so is their need for medical attention (Magazi and Manyane 2015). Infrequent TTHs are generally self-managed (Loder and Rizzoli 2008: 90), while the need for care and the degree of disability increases with headache frequency (Kim *et al.* 2015), meaning that frequent TTH can be associated with considerable disability, but that chronic TTH is considered the most debilitating subcategory.

The underlying pathophysiology is thought to vary between subtypes (Magazi and Manyane 2015). Pain from TTH was initially assumed to be primarily psychogenic (Tsuboi 2002: 202) but further studies have shown that there may be a neurobiological basis (Chowdhury 2012: S83); the exact pathophysiology is yet to be fully understood but it is thought that peripheral factors, such as alterations in the muscular and vascular systems, interact with upregulation of pain perception in the central nervous system, while genetic risk factors are also thought to play a considerable role (Mungoven, Henderson and Meylakh 2021). Central pain mechanisms and genetic risk factors are believed to play a bigger role in the development of the chronic subtype (Bhoi, Jha and Chowdhury 2021: S119). While frequent TTH can be disabling in its own right, chronic TTH is associated with significant disability and high degrees of disability (Headache Classification Committee of the International Headache Society 2018: 35).

As with migraine, treatment for TTH can be either for acute pain or as prophylaxis, and may be pharmacological or non-pharmacological in nature. As a result of no one pathological mechanism having been outlined for TTH, it is suggested that symptomatic treatment as the sole management be avoided and that the patient be empowered to explore as many management options as they desire (Bentivigna *et al.* 2021: 797*).*

Often those with fewer episodes of TTH self-medicate with well-known over-the-counter NSAIDs without reporting to a physician (Bhoi, Jha and Chowdhury 2021: S117). If it is not done carefully, for example using for more than 10 days in a month, using combination analgesic medication often, or medication with the addition of caffeine, codeine, sedatives or tranquillisers, it increases the risk of MOH development (Fischer and Jan 2022).

It is recommended that those with frequent attacks or high levels of disability receive prophylactic treatment to reduce the risk of MOH and increase quality of life. The most common recommendation for TTH is the use of amitriptyline, but other drugs such as mirtazapine, muscle relaxants and anticonvulsants are also available (Kahriman and Zhu 2018).

Non-pharmacological interventions include cognitive behavioural therapy, sleep hygiene, relaxation and biofeedback training, as well as the monitoring of meals (Probyn *et al.* 2017). It is also common for physicians to recommend the use of a ‘headache diary’ as this can track the progression or improvement of episodes, the intake of acute medication, as well as habits and events that may be underlying triggers needing to be addressed (Kahriman and Zhu 2018).

There is some research that lends itself to the use of manual therapy for the treatment of TTH, where cranio-cervical training and modalities such as transcutaneous electrical nerve stimulation, acupuncture, hot and cold therapy and massage may assist in pain management (Kamonseki *et al.* 2020).

As in migraine research, the use of CGRP receptor agonist medication is of current interest as potential treatments for TTH, but clinical trials are still required. Other current areas of interest for the treatment includes the use of NOS inhibitors that are currently being researched (Pradhan, Bertels and Akerman 2018).

Compared to MH, qualitative research about TTH is sparse. This may be due to the fact that, generally speaking, the severity of pain is less in those with TTH. Of the research that is available, it also appears that this affects the experience of TTH as compared to those with MH. In a study conducted in 2013, Jonsson *et al. n*oted that those with the chronic subtype of TTH were markedly less distressed when compared to those that experienced MH, stating that while those with MH described fear around their pain, those with TTH described the headache to be ‘disturbing’.

With the stark contrast between the experience of MH and TTH, the question about the applicability of qualitative research on chronic headaches is accurate enough to extend to those with CH. Migraine and TTH are often described as similar clinical entities, but even here the experiences are so vastly different; this makes it abundantly clear that there is a need for the exploration of the CH experience so that this can be contrasted with the information that is available, with respect to the other primary headaches of importance.

2.6.3 Medication Overuse Headaches

Medication overuse headaches (MOH) are colloquially often called ‘rebound headaches’ (Munksgaars, Madsen and Wienecke 2019: 405). These headaches typically occur in patients who already have another primary headache disorder, such as TTH or migraine, and use analgesic medication in an attempt to reduce their symptoms. Unfortunately, this can lead to drug-induced headache and a vicious cycle ensues that can become a major contribution in the progression of headache disorders from their episodic form, to their chronic (Wakerley 2019: 399). Medication overuse headache can result in great disability and requires careful medical management, and often an interprofessional approach (Fischer and Jan 2022).

Medication overuse headache is classified as a secondary headache due to its identifiable underlying cause – the use of analgesics (Headache Classification Committee of the International Headache Society 2018: 122). The type of medication that is involved in the development of MOH largely specifies the subtype of the headache; the eight subtypes are MOH induced by ergotamine, triptans, analgesics including paracetamol, aspirin and other non-steroidal anti-inflammatory drugs (NSAIDs), opioids, combination analgesics, unspecified multiple drug classes and others (Headache Classification Committee of the International Headache Society 2018: 122)

The general criteria for MOH, according to the ICHD-3, is a headache occurring on 15 or more days per month in a patient who has a pre-existing headache disorder and is regularly taking and overusing one or more drug to symptomatically manage said primary headache disorder for three or more months (Headache Classification Committee of the International Headache Society 2018: 122).

The epidemiology of MOH is largely unknown as it has been redefined recently (Fischer and Jan 2022). Prevalence estimates in the general population range from 0.5 to 2.6 percent (Shahbeigi *et al.* 2013: 1162), while at headache centres, patients with chronic daily headache have reported MOH in a massive range between 11 and 70 percent. Some countries, such as Russia (Ayzenberg *et al.* 2012: 373) and Iran (Shahbeigi *et al.* 2013: 1160), also have larger prevalence estimates (7.6 and 4.6 percent respectively), making it clear that there is a need for the study of MOH in a variety of populations. No statistics for MOH are available for the South African context.

The reason that MOH is a headache of importance in primary care is largely due to its contribution to disability levels in those with already disabling primary headaches. In the 2016 Global Burden of Disease, where migraine disability was listed as the second largest cause of disability, it is largely considered that this is in part due to MOH that is concomitantly occurring in these patients (Stovner *et al.* 2022: 2).

This condition is considered to be a neurological one, though its pathophysiological mechanisms are not well understood. Some studies have shown that central sensitisation plays a major role (Lai and Wang 2018). Both functional and structural changes of the central nervous system have been demonstrated, as well as an increased upregulation of vasoactive pro-inflammatory mediators (Vandenbussche *et al.* 2018: 50). Studies also show that there is likely a large genetic risk to the development of the condition (Waung *et al.* 2020: 887).

As mentioned previously, MOH are considered to occur secondary to another headache; in other words, patients with MOH will have had previous experience or diagnosis of migraine, TTH or other headaches before experiencing MOH. These headaches generally begin increasing in frequency and intensify until they develop from episodic primary headaches to MOH. Usually, the MOH mimics the headache they had previously, but they also commonly change over time (Fischer and Jan 2022). Patients with MOH often report neck pain, along with headaches occurring in the morning – this may be due to drug withdrawal occurring overnight, or due to poor sleep quality (Tepper 2017).

Associated with MOH may be skin hypersensitivity, as well as autonomic and/or gastrointestinal symptoms, such as nasal injection, tearing, nausea, vomiting and diarrhoea, with a physical exam revealing no deficits (Fischer and Jan 2022).

Medications that often cause MOH include ergotamine, triptans, NSAIDS, acetaminophen and opioid medication, all of which are prescribed and used to treat primary headaches like MH and TTHs (Aleksenko, Maini and Sánchez-Manso 2021).

Medication overuse headache is largely preventable with education of appropriate medication dosing (Fischer and Jan 2022). Treating MOH, is however, not as simple and requires withdrawal of the culprit medication, treatment of withdrawal symptoms, prophylactic treatment for the initial primary headache, so that the need for acute medication can be reduced, as well as other options for symptomatic treatment made available to be used when acute management does become necessary (Fischer and Jan 2022). The key to treatment of MOH is patient motivation, as withdrawal has been said to be brutal on them. It is important that they understand that the use of analgesics in their current situation is lowering their quality of life (Negro *et al.* 2017: 32); with this knowledge in place, successful withdrawal rates of MOH are between 50 and 70 percent after a year (Vandenbussche *et al*. 2018: 50). Neurology and psychiatric consultations may be needed in certain cases, but generally, a supportive team that address concerns throughout the stages of treatment improves the experience of MOH (Westergaard *et al.* 2016: 15)

Patients with MOH report the chronicity of the headaches as ‘unbearable’ and ‘threaten to ruin their life’, but medication withdrawal to improve the condition is complicated by taking acute medication as they feel they have no other choice. In addition, there is also skepticism of prophylactic medication that would assist in the reduced need for acute treatment (Jonsson *et al.* 2013). Since both chronicity and pain intensity are factors mentioned that contribute to life disruptions and disability in this condition (Westergaard *et al.* 2016: 17), it raises the question as to what factors may be at play with those experiencing CH.

2.6.4 Trigeminal Autonomic Cephalalgias

Trigeminal autonomic cephalalgia (TAC) is the third major category of primary headaches in the ICHD-3. There are a four main headache disorders that fall within this category, namely cluster headache (CH), paroxysmal hemicrania (PH), short-lasting unilateral neuralgiform headache attacks (SUNHA), and hemicrania continua (Headache Classification Committee of the International Headache Society 2018: 41). Of these, CH is the most common type (Kandel and Mandiga 2022).

As the name suggests, TACs are all suspected to involve the fifth cranial nerve, the trigeminal nerve – a nerve providing both sensory and motor supply to the face (Huff and Daly 2021). Studies suggest that the activation of the trigeminal-parasympathetic reflex is responsible as part of the conditions’ pathophysiology (Benoliel 2012: 107).

‘Autonomic’ in ‘TAC’ refers to secondary ipsilateral cranial autonomic features that occur in this cluster of conditions due to sympathetic dysfunction (Wei and Jensen 2018: 346). These cranial autonomic signs include conjunctival injection, lacrimation, nasal congestion, rhinorrhoea, facial sweating, miosis, ptosis and swelling of the eyelid (Headache Classification Committee of the International Headache Society 2018: 41).

All of the TACs present with severe, unilateral episodes of orofacial pain, along a branch of the trigeminal nerve (Headache Classification Committee of the International Headache Society 2018: 41). Clinically, the four different conditions can be broadly differentiated from each other by the time of each pain-attack, though there are other features that set each of them apart as well (Ravishankar 2018).

Table 2.1 provides a brief summary of the different TACs and highlight some of their differences.

Table 2.1: A summary of features and differences of the trigeminal autonomic cephalalgias

	Cluster Headache	**Paroxysmal Hemicrania**	**SUNHAs** **(Short-Lasting Neuralgiform Headache Attacks)**	**Hemicrania Continua**
Time of attack (Ravishankar 2018)	15 to 180 minutes	Two to 30 minutes	One to 600 seconds	Continuous
Other features	Most common TAC (Kandel and Mandiga 2022). More common in men than women (Allena *et al.* 2019). Marked restlessness or agitation with attacks (Wei, Ong and Goadsby 2018: 3)	Diagnosis confirmed with absolute response to indomethacin (Bose *et al.* 2015).	Two subtypes: -SUNCT (SUNHA with conjunctival injection and tearing) -SUNA (SUNHA with cranial autonomic features) Both are very brief headache attacks that may be triggered by cutaneous stimuli (Cohen 2022)	Side-locked pain that is continuous for three months that responds well to indomethacin (Bose *et al.* 2015).

The pathophysiology of these entities involves the hypothalamus, the trigeminovascular complex and parasympathetic fibres with a crucial role of the sphenopalatine ganglion via the trigeminal autonomic reflex (Hoffman and May 2018). However, the understanding of TACs was relatively superficial, therefor treatment and management options for the conditions have not always been very specific –though recent advances made regarding underlying pathological mechanisms are providing hope for development of more targeted treatment in both pharmacological and neuromodulatory realms (Wei and Jensen 2018: 346).

One fact worth highlighting concerning pain in TACs, is that though the involvement of the trigeminal nerve is alluded to in the name, it alone does not explain the pain that occurs in these conditions. This is proven by studies showing that activation of the trigeminal nerve can occur in those with CH and not cause pain (Matharu and May 2008: 135), and surgical lesioning on the trigeminal nerve does not resolve TAC pain for all (Jarrar *et al.* 2003: 1361).

2.7 CLUSTER HEADACHE

Cluster headache is the most common of the TACs (Kandel and Mandiga 2022). Though it is considered rare in comparison to MH and TTH, it has also been termed a ‘quasi-rare’ disorder (Martelletti and Mitsikostas 2015: 1); this statement insinuates that its rarity has been exaggerated/overestimated and that it is an underrecognised condition. In part, this could be due to their frequent misdiagnosis – with the condition having a six year diagnostic delay, even though it is considered to have a very stereotypical presentation (Lund *et al.* 2017: 1069).

2.7.1 Clinical Presentation of Cluster Headache

The condition attained its name due to headaches occurring in ‘clusters’ or bouts called periods or cycles, with individual headaches usually termed ‘attacks’. The attacks typically last between 15 minutes to three hours – often occurring at predictable times (Tepper 2017: 757). They are also known to follow a circadian pattern, with a high prevalence of nocturnal attacks and recurrence in a seasonal pattern (Hoffmann and May 2018: 75).

Each CH attack consists of severe pain in the orbital, supraorbital and temporal regions, or any combination of these. Singular attacks are strictly unilateral, and usually remain on the same side for most, though studies have shown that few do experience side-shift within a cycle of attacks, and a few between cycles (Bahra, May and Goadsby 2002: 356).

The severity of this pain is in part what sets CH apart from other primary headache conditions; cluster headache has made appearances on lists of the most painful health conditions (Burish *et al.* 2021: 120) with accounts of it being considered to be ‘one of the worst pain known to man’ (Rossi *et al.* 2016: 181; Burish *et al.* 2021: 120). Other depictions of its severity include its colloquial name “suicide headaches”, and previous studies describing it as “worse than childbirth”. A study using a survey to determine the pain intensity of CH found that the majority of participants rated their pain at 10 out of 10 on the numerical pain rating scale; when compared to other conditions that are considered intensely painful, such as nephrolithiasis and pancreatitis, CH surpassed them in comparative pain intensity (Burish *et al.* 2020: 122).

Attacks are associated with the cranial autonomic features (ipsilateral conjunctival injection, lacrimation, nasal congestion, rhinorrhoea, forehead and facial sweating, miosis, ptosis and/or eyelid oedema) and can occur at a frequency of about one every other day, to about eight attacks in a single day.

Additionally, a symptom that occurs in 80% to 90% of patients is “restlessness or agitation” (Torelli, Beghi and Manzoni 2005: 471) –this symptom is very contrasting to other headaches, such as MH, where restlessness would likely aggravate symptoms. Reports of this restlessness include those with CHs pacing, rocking back-and-forth or even banging their head to distract themselves from the pain (Tepper 2017: 757).

Cluster headaches have been divided into two subtypes – Episodic CH and Chronic CH. A diagnosis of Episodic CH is made if the CH attacks occur in periods lasting from seven days to one year, separated by periods of remission that last at least three months before the next period of attacks begin. On the other hand, if headache attacks occur for longer than a year at a time and period of remission are absent or shorter than three months, then the diagnosis of Chronic CH is given. Episodic CHs are more common, while Chronic CH occur in 15% to 20% of this population (Kandel and Mandiga 2022).

Patients with episodic CH may go on to develop the chronic form of the condition, while about a third of patients who initially presented with the chronic presentation may remit to the episodic type over time. The natural history of CH is difficult to predict, though anecdotally, full remission may occur with age, or time between cycles may increase, thus reducing the time of active CH (Bahra, May and Goadsby 2002: 357).

2.7.2 Epidemiology of Cluster Headache

Due to the relative rareness of this condition, epidemiological and prevalence studies on CH are difficult to conduct with high certainty and accuracy; studies show large variations of total prevalence as well as differences of distribution among different races and genders. The most commonly used statistic is that CH has a lifetime prevalence of about one in every 1000 (or in 0.1%) of the population – this statistic comes from a meta-analysis conducted by Fischera *et al.* in 2008 – another indication of the lack of research in this field.

Cluster headache, very unlike MH and TTH, are more predominant in males over females. Historically, it was thought that this predominance was very large, but a downward trend in male to female ratios have been observed, with the current male-to-female ratio appearing to be around 2.5:1 (Lund *et al.* 2017: 1073). Though overall, it is believed that CHs are more common in males, some studies have shown that females dominate the chronic subtype (Weaver-Agastoni 2013: 811).

The age of onset for CH is usually between the ages of 20 and 40 years (Headache Classification Committee of the International Headache Society 2018: 42) –with an increased risk to the development of the condition if there is an established family history. Those with a first-degree relative with CH are up to 18 times more likely to develop CH compared to those without (Kandel and Mandiga 2022). A systematic review and meta-analysis of the prevalence of familial CHs estimated that the percentage of those with CH that had familial history was around 6.27% (O'Connor *et al.* 2020: 37).

2.7.3 Aetiology and Risk Factors of Cluster Headache

There is no single clear reason for the development of CH. The cases of familial CH do show that there is a potential genetic link, but no definite genotype has been isolated. There is, however, research underway that aims to establish underlying genetic risk factors; the most recent discovery indicates that the HFE H63D variant may be regarded as a disease modifier of CH, though more research is necessary to determine its full role (Papasavva *et al.* 2022).

Besides familial occurrence, there are a few established risk factors to the development of CH, including being of male gender, having a history of surgery or trauma to the head or brain (Lambru and Matharu 2012). It has also shown that former and current smokers are more common in the CH population, and that these patients had worse CH presentation than those that were considered 'never-smokers' (Lund *et al.* 2019). Having said that, smoking cessation did not necessarily improve current symptomatology (Ferrari *et al.* 2013) suggesting that the relationship between CH and smoking is not necessarily a causal one.

Very rarely, CHs may occur as secondary headaches, as complication of, for example, inflammation, neoplasm or infection –it is recommended that all those with a suspected diagnosis of CH undergo neuroimaging to rule out secondary causes that may require treatment (Long, Zhu and Wang 2021).

2.7.4 Pathophysiology of Cluster Headache

As previously stated, no single cause for CH is yet to be determined. Some genetic pathways have been hypothesised to be involved in disease pathophysiology, though no single gene has been named causative.

The condition is thought to be due to an interplay between peripheral and central systems, particularly an interaction of aberrant activity in the hypothalamus, trigeminovascular system and the autonomic nervous system (ANS) (Kandel and Mandiga 2022). Multiple neurotransmitters have also been implicated to be involved in the process of a CH attack. Though this process is not fully understood, a hypothetical schematic of the pathophysiology of CH put together by Hoffman and May (2018) illustrates a possible interaction that could explain the phenomena. This is depicted in **Figure 2.1.**

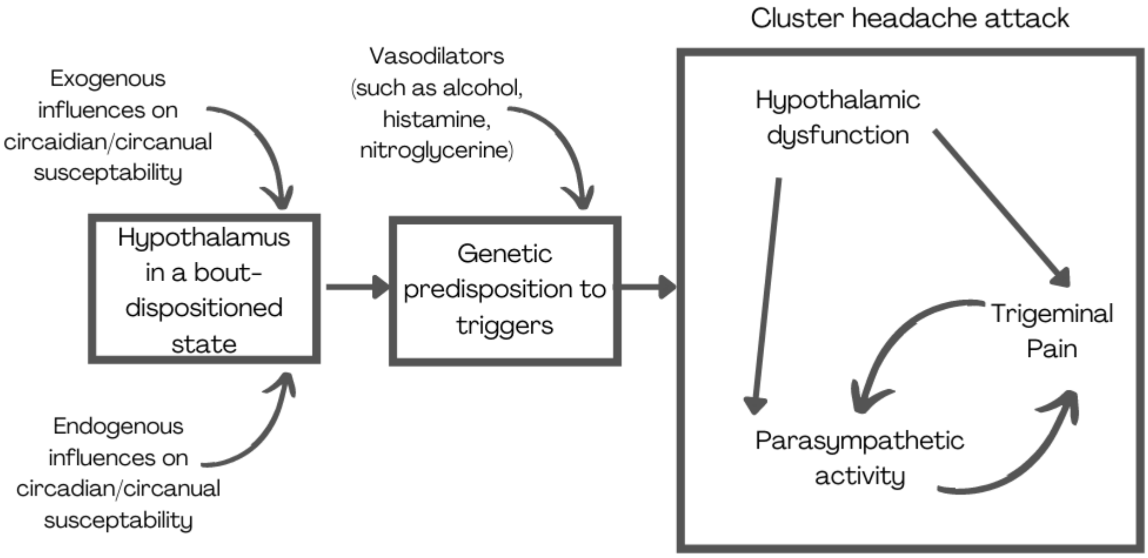

Figure 2.1: A schematic presentation of the hypothetical pathophysiology of cluster headache (Adapted from Hoffmann and May 2018)

It is understood that a hypothalamus in a permissive state will allow individual attacks to be triggered. The predisposition for the hypothalamus to allow such attacks to occur is hypothesised to be related to exogenous and endogenous influences, such as light exposure and melatonin levels respectively, on the hypothalamus' circadian/circannual control.

Vasodilators, including alcohol, histamine triggers and nitro-glycerine can trigger attacks. These triggers are theorised to be as a result of unique but undiscovered genetic variances. However, attacks only occur when a patient is in an active bout, or cycle.

Once an attack has been triggered, this hypothalamic dysfunction influences trigeminal and autonomic communication, setting into motion the cascade that ultimately leads to the orbital/trigeminal pain and cranial autonomic features of a CH.

Neuroimaging and the role of the hypothalamus in initiating cluster headache attacks

Neuroimaging has revealed the role of several areas of the brain involved in the areas of the brain that process pain to be at play in CH pathophysiology (Buture *et al.* 2019: 269). Changes in the temporal lobe, hippocampus, insular cortex and cerebellum, as well as the right amygdala, right caudate and right pallidus have been demonstrated – though these changes have been explained as neuroplastic changes occurring due to disease burden and pain states rather than causative changes (Naegel *et al.* 2014: 415, Király *et al.* 2018: 664).

In particular, neuroimaging has highlighted the role of the hypothalamus (Buture *et al.* 2019: 664). Structurally, the hypothalamus has recently been shown again to be of likely relevance as studies have indicated it to be enlarged in patients with CH when compared to migraine (Arkink *et al.* 2017: 1040), while functional brain studies have revealed changes in activation of the hypothalamus and pain modulatory areas (Chou *et al.* 2017: 1161). Interestingly, it is of note that stimulating the hypothalamus does not induce an episode of CH pain and in fact, some research suggests that stimulation of the hypothalamus can abort an attack (Leone *et al.* 2010). The exact mechanisms by which the hypothalamus is involved in CH is not fully understood. As the hypothalamus is involved in numerous physiological processes, a myriad of hypotheses of its involvement exists (Vollesen *et al.* 2018: 89).

Diurnally, CH exhibits a relationship with nighttime and annually with daylight hours. Studies suggest a complex relationship as sleep quality improves between clusters, but remains pathological (Barloese 2021: 156). It is, for example, hypothesised that the supra-optic nucleus that is found within the anterior hypothalamus, and is considered the ‘endogenous biological clock’, may provide an explanation for the circadian and circannual presentation of CH (Arkink *et al.* 2017).

The trigeminal autonomic reflex and parasympathetic activation

The trigemino-autonomic reflex is a physiological reflex that is driven by activation from the brainstem (Möller and May 2019: 438) and prompts parasympathetic activation such as vasodilation and lacrimation as a consequence of trigeminal stimulation (Möller, Schroeder and May 2018: 888). It is thought to be peripherally and centrally driven: centrally by structures such as the hypothalamus which then generates parasympathetic outputs through branches of the facial nerve, such as the major petrosal nerve that innervates the lacrimal glands (Möller, Schroeder and May 2018: 890).

The cranial autonomic features of CH can be largely explained by this parasympathetic output, but like with the hypothalamus, the exact trigger of the trigeminal autonomic reflex is not fully understood (Kandel and Mandiga 2022).

The trigeminovascular system and its role in vasodilation and pain

Another pathophysiological aspect of CH attacks is the activation of the trigeminovascular system. Though the hypothalamus is supposed to play a role in the initiation of an attack (May and Burstein 2019: 1710), it is unsure how the hypothalamus and the trigeminovascular system interact to cause the pain, though it is suspected that the trigeminal autonomic reflex may be involved in its activation.

The trigeminovascular system is a functional network of neuronal fibres from the trigeminal nerve, and the cephalic blood vessels that they innervate (Huff and Daly 2021). The afferent neurons are primarily from the ophthalmic division of the trigeminal nerve, but also include afferents from the upper cervical fibres (Ruthirago *et al.* 2018: 159). These pseudo-unipolar neuron’s cell bodies converge to form the trigeminal ganglion and innervate vasculature of the pia and dura mater, cerebral vessels and large venous sinuses (Edvinsson *et al.* 2020: 65).

It is thought that vasodilation is linked to the pain experience during an attack (Kandel and Mandiga 2022). When the trigeminovascular system is activated, perivascular afferent nerves cause vasodilation (Kandel and Mandiga 2022) and this is understood to be mediated by the release of CGRP (Belin, Ran and Edvinsson 2020: 30). This molecule, that is also found to be elevated in migraine patients (Vollesen *et al.* 2018: 89), is thought to be involved as it is both vasodilatory and modulates nociception of the trigeminal neurons (Iyengar *et al.* 2019: 659).

The link between CH attacks and CGRP is an important one, as anti-CGRP treatments have shown some success for migraine management (Caronna and Starling 2021), and are thus a worthwhile avenue in the exploration of treatment for CH.

2.7.5 Treatment of Cluster Headaches

The treatment and management of CH consists of two phases: acute treatment to abort attacks, as well as prophylactic treatment that is meant to reduce the number of attacks a person experiences. Treatment can further be divided into pharmacological and non-pharmacological approaches. Considering that both the increased duration of pain attacks, as well as the frequency are associated with disability in CH (Sohn *et al.* 2020: 2428), both acute and prophylactic regimes may be needed for individuals with CH in order to improve the quality of life.

No treatment has been designed specifically to combat CHs, but both prophylactic and abortive medication have been found by chance (Andersson, Persson and Kjellgren 2017: 60) –meaning any drug currently prescribed is done so off-label. Unfortunately, the condition is also known to be resistant to many conventional regimes (Hoffman and May 2018). Ultimately, as with other conditions, treatment regimes should be individualised and planned based on goals, personal efficacy and risk-reward ratio (Kwon *et al.* 2022: 711).

Not all treatments that are utilised by patients are of high quality evidence or scientifically validated at all (Bilchik 2004: 157). Not only is medication with a low level of evidence trialled in practice daily because of low levels of evidence and high disease burden, but unvalidated treatment use is often prompted by desperation

(Andersson, Persson and Kjellgren 2017: 62). Iit is important that information regarding their use is also available, as it is ethically important for practitioners to have enough information to guide patients safely (Pilecki *et al.* 2021).

Palacios-Ceña *et al.* (2016: 1179) reported that patients had multiple difficulties with healthcare treatment, including their awareness of the lack of knowledge that practitioners held about CH and its treatments. Patients reported better experiences when they perceived a physician to treat their disease in ways that they preferred. Another discomposing experience was that they felt they were being ‘bounced from practitioner to practitioner’ without clear care.

From the above, it is plain that there is benefit in a practitioner’s full understanding of the scope of treatments available for CH so that care regimes can be discussed with patients in detail, and appropriate referrals can be made, leading to streamlined healthcare.

Though there are some publications guiding management, particularly pharmaceutical, of CH, available (Kingston and Dodick 2018; Wei, Khalil and Goadsby 2019; Brandt *et al.* 2020), these guidelines do not generally contain any information regarding the ease or difficulty of access to the treatment, their costs, or patient choices, opinions and experiences surrounding them. This may further widen the rift that is perceived between patient and practitioner, as there is little information for healthcare providers regarding the preferential choices for CH treatment outside of objective recommendations.

2.7.5.1 Prophylactic Treatment for Cluster Headache

The goal of prophylactic treatment is to reduce the number of attacks that occur, the length for which they occur and bring down pain intensity of individual attacks.

An effective prophylactic regime ultimately reduces the amount of rescue medication that is required, which in turn reduces the risk of the development of MOH, which would further complicate cases (Dodick and Freitag 2006). From this, it is clear that prophylactic treatment has a clear role in the adequate management of pain.

2.7.5.1.1 Pharmacological Prophylaxis of Cluster Headache

Multiple drugs can be prescribed for CH prophylaxis: Verapamil, lithium and topiramate are the most popular choices historically, but galcanezumab (a drug developed as an anti-CGRP) is also being trialled more recently (Brandt *et al.* 2020).

These four drugs are discussed as follows:

<u>i. Verapamil</u>

Verapamil, a drug of the calcium-channel blocker class, is considered the drug of choice, though there is a scarcity of randomised control of the efficacy of the drug in those with CH. The proposed mechanisms of action of verapamil includes an influence on circadian rhythm, and/or an effect on CGRP release (Petersen *et al.* 2019).

A recent review in 2019 by Petersen *et al.* found five studies of relevance with three being open label studies and two being randomised control trials. Results between the studies varied, as well as between the efficacy of the drug in those with episodic versus chronic CH subtypes. For example, in the trial by Blau and Engel (2004), 94% of episodic CH experienced total suppression of attacks with verapamil, while only 55% of those with the chronic subtype experience reprieve. In the chronic subtype, men and women also showed a difference in response, as 69% of men responded to verapamil prophylaxis, while only 20% of women experienced the same effect. Though the data are minimal, these five trials have deemed verapamil generally safe and efficient for the preventative treatment of CH (Petersen *et al.* 2019). It is to be noted that this does not mean that verapamil has no side effect profile, for instance, ECG monitoring is mandatory for those on verapamil treatment (Brandt *et al.* 2020).

<u>ii. Lithium</u>

Lithium for the treatment of CHs was first trialled in 1977 with success in the entire cohort of five CH participants (Ekbom 1977). The mechanism of action of lithium for its aid in CH is unsure, however, past discoveries of its effects have been used to theorise its function. Lithium has shown to alter platelet serotonin and histamine levels (Medina, Fareed and Diamond 1980), which are both powerful vasodilators and have both been linked to the pathophysiology of CH attacks (Anthony and Lance 1971; Alstadhaug 2014). Other studies point towards its chronobiological effects, as it has shown to affect serotonin levels in the hypothalamus (Wang and Friedman

1988), have immediate action on REM sleep (Kupfer *et al.* 1970: 37) as well as reduce melatonin amplitude and cortisol levels (Chazot *et al.* 1987: 222). More studies, especially of a more recent view, are needed to determine its exact mechanisms.

Again, few trials are available regarding the use of lithium for CH. The plasma levels of lithium are always tested during lithium therapy so dosing may be adjusted to keep it within a therapeutic index; this, however, complicates trials as pre-established plasma lithium levels influence results of drug efficacy. A one-week trial of lithium at a plasma level of 0.5 to 0.6mmol/L for episodic CH showed poor results (Bussone *et al.* 1990, Steiner *et al.* 1997), but a trial of lithium at plasma levels of 0.7 to 1.2mmol/L, some chronic CH participants did experience reprieve within two weeks, and a portion of those with episodic CH experienced relief (Ekbom 1981). Some studies also suggest that lithium therapy is more effective in those with the chronic CH subtype and as such, this deserves further reappraisal (Brandt *et al.* 2020) It is clear that more trials of different doses in different CH cohorts are necessary to establish true efficacy of lithium therapy in these patients.

When lithium is prescribed, its side effect profile may outweigh the benefits in some patients, leading to discontinuation of the drug. Side effects include nausea, dizziness and tremor along with the potential risk of hypothyroidism and kidney dysfunction with long-term use (Gitlin 2016: 27).

iii. Topiramate

Topiramate is only recommended if treatment with verapamil and lithium both fail (Brandt *et al.* 2020). The mechanism of action of the drug is also unknown, but theorised to be mediated by gamma-aminobutyric acid (GABA) (Huang *et al.* 2010: 285), which has been found to be involved in signalling pathways in the pathophysiology of CH (Kandel and Mandiga 2022).

Only open-label case series and trials exist for the use of topiramate for CH, revealing that side effects, such as paraesthesia, mood swings and speech disturbances, were a major deterrent (Huang *et al.* 2010: 286). However, there is some evidence for its usefulness as a prophylactic as some studies did show that some of both, episodic and chronic, subtypes benefit from its intake (Wheeler and Carrazana 1999, Láinez *et al.* 2003, Huang *et al.* 2010). Further research is needed to determine the true mechanism of action, as well as the efficacy and safety of topiramate in those with CH.

<u>iv. Galcanezumab</u>

Galcanezumab is an antibody to CGRP, one of the molecules linked to vasodilation and pain in headache disorders. It has shown some efficacy in migraine management and one trial has shown promise of the drug for those with episodic CH (Goadsby *et al.* 2019), though no information exists regarding the use of galcanezumab for the chronic subtype.

2.7.5.1.2 Non-Pharmacological Prophylaxis of Cluster Headache

<u>i. Trigger management</u>

Cluster headache attacks can be set off by certain triggers when individuals are ‘in a cycle’/’bout’ and thus susceptible to these triggers (Hoffman and May 2018). As with most disorders, triggers for CH attacks are individualised. It is common for vasodilators to trigger attacks –this means that histamine-mediating triggers, as well as the consumption of alcohol, nitroglycerin or other vasodilatory agents need to be managed, reduced or avoided where possible in those susceptible (Weaver-Agostoni 2013: 124). Another common time for CHs to occur is during sleep. This trigger is mostly endogenous and not necessarily avoidable, but there is some evidence suggesting that those with CH that also have insufficient, erratic or disordered sleep may have more attacks (Pergolizzi *et al.* 2020: 368). There may be some benefit to the management of sleep patterns as part of managing sleep as a trigger of attacks.

Other triggers, such as watching television, stress, sexual activity and hot weather (Kandel and Mandiga 2022) would have to be established by each patient individually and can then be addressed through patient counselling surrounding lifestyle changes if necessary.

<u>ii. Vitamin D3</u>

Vitamin D3 may be implicated with CHs due to their diurnal and seasonal patterns, though no concrete evidence can be found in the literature to support its role in pathophysiology of CH, nor in its treatment.

The absence of evidence, however, is not the evidence of absence –in fact, the research surrounding Vitamin D for the treatment of CH is making steady progress (Dell'Isola *et al.* 2021).

Anecdotal evidence of the efficacy of Vitamin D3 supplementation for the management of CH attacks is common. A survey conducted in 2014 reported that up to 80% of those supplementing with 10 000 UI/d of cholecalciferol (Vitamin D) experienced a reduction in the frequency, severity and duration of attacks during periods of supplementation (Batcheller 2014).

Following this survey, a small study was conducted to assess the potential of a Vitamin D deficiency in the CH population (Sohn *et al.* 2018). The results of this study suggested that Vitamin D deficiency is commonplace in the CH population. Besides its significance as a subtle seasonal influence, this was simply a preliminary study and did little but signified that more research may be warranted.

The preliminary data from the study by Sohn *et al.* (2018) and the reports from patients (Batcheller 2014), along with data that suggest that Vitamin D may play a significant role in primary headache prophylaxis (Dell'Isola *et al.* 2021) prompted the conduction of a randomised, double-blind, placebo controlled clinical trial examining the use of high-dose Vitamin D in the prevention of CH by Mark J. Burish at the University of Texas Health Science Centre in Houston. This trial is estimated to be completed by September of 2023 and will provide the much-needed evidence for Vitamin D supplementation in the CH population that is needed.

iii. Melatonin

The hormone melatonin is another molecule implicated in circadian rhythm and has been found to play a role in CH pathophysiology (Johnston and Skene 2015). The production of melatonin is produced endogenously by the pineal gland: light acting on the suprachiasmatic nuclei within the hypothalamus inhibits its release. The external light-dark cycle thus plays a role in melatonin production, synchronising it to the circadian cycle (Johnston and Skene 2015). Normally, melatonin levels peak at night due to the reduction of light inhibition; in CH patients within an active bout, that endogenous melatonin peak has been shown to be significantly reduced or even absent (Bruera *et al.* 2008) and thus hypothesised to be the potential reason for sleep-triggered attacks.

Some studies on the use of exogenous melatonin supplementation for the prevention of CH to combat the lack of the nocturnal melatonin surge have been conducted. Information available is of low quality evidence, but a small study found that a portion of episodic CH found significant improvement in frequency when 10mg of Melatonin daily was taken orally and introduced early within an active cycle (Leone *et al.* 1996). Further case studies also reported some reprieve by those with the chronic subtype (Leone *et al.* 1996).

A large attraction to the management of CH with melatonin is the low side effect profile and general safety of the drug (Leger *et al.* 2015, Anderson *et al.* 2016). However, when examining the total available evidence for exogenous melatonin for the treatment and management of CH, data are insufficient to make broad recommendations, though further studies are warranted in this area to confirm the role of melatonin administration for CH (Liampas *et al.* 2020).

2.7.5.1.3 Neuromodulatory, Surgical and Invasive Prophylaxis of Cluster Headache

Surgical therapy is usually a last resort option for those with symptoms that are refractory to other prophylactic treatments after exhausting all available options (Belvis *et al.* 2019: 76). Various procedures that attempt to address and interrupt different aspects of the pathophysiological process exist and their efficacy and safety profiles all differ (Franzini *et al.* 2019). While not all of these surgical procedures are major, there is debate over whether any surgery, even minor, is unnecessarily invasive, or if a ‘once off surgery’ is less invasive than the continued long-term use of prophylactic and acute medication (Shevel 2007). This duality should be taken into consideration when options are presented to patients.

Neurosurgeries can be largely divided into procedures that are ablative or stimulatory, while another type of surgical procedure often used is one of microvascular decompression (Ogbuji and Kopell 2021). Novel neuromodulatory devices and implants to certain areas are also becoming available (Pietzsch 2018). It is important to note that none of them offer guaranteed results or cure of the condition. Some of the more common procedures are discussed below:

i. Sphenopalatine ganglion-targeted treatments

The sphenopalatine ganglion (SPG), which is an extracalvarial ganglion, contains sympathetic, parasympathetic and sensory neurons that terminate in the trigeminal ganglion (Piagkou *et al.* 2012: 340). It may play a pivotal role in the presentation of CH, which is why it has long been a target of potential relief of this condition (Fontaine *et al.* 2018: 375)

The SPG can be accessed through the nasal mucosa, transorally and percutaneously from beneath the zygomatic arch (Tolba, Weiss and Denis 2019: 35). SPG blockage and ablative treatments involve fluoroscopic needle placements via one of these approaches. It is proposed that blocking pathways from the SPG assists with pain relief as it interferes with the parasympathetic flow from the ganglion that is involved in the condition's presentation (Piagkou *et al.* 2012).

i.a. Blockage or ablation of the sphenopalatine ganglion

During an SPG block, local anaesthetic is injected. This is offered as a procedure alone, or as a pre-ablation diagnostic tool (Tolba, Weiss and Denis 2019: 34). During an ablation, nerve fibres are severed using pulsed radiofrequency, traditional thermal "burning", electrical current, surgical instrumentation (like a gamma-knife) or with chemical-injection rhizotomy. Ablation of the SPG aims to extend any pain relief that a blockade provided for those that had favourable responses (Tolba, Weiss and Denis 2019).

i.b. Stimulation of the sphenopalatine ganglion

Sphenopalatine ganglion neurostimulation involves the trans-oral insertion of a microstimulator that targets the SPG. The device can be controlled by a handheld remote. Patients are encouraged to apply on-demand SPG stimulation for about 15 minutes as soon as an attack is felt, as well as prophylactically when no symptoms are present. A study on a cohort of 95 participants (majority being chronic) revealed that 55% of chronic patients had a reduction in frequency by more than 50%, and 32% of all participants were acute responders (Barloese *et al.* 2018: 812). This study suggests that SPG stimulation may be a viable option for treatment resistant CH participants, as it even showed that the majority of participants were able to reduce or completely stop all other preventative medications.

ii. Other neurostimulation

Other non-invasive neuromodulatory targets include transdermal vagus nerve stimulation, supraorbital stimulation and occipital nerve stimulation, all having some evidence for the prophylactic and acute treatment of CH to some extent (Magis and Schoenen 2011, Evers and Summ 2021, Magis *et al.* 2007).

ii.a. Occipital nerve stimulation

Rationale for occipital nerve stimulation (ONS) comes from the convergence of dural afferents from the ipsilateral posterior hypothalamus with fibres of the greater occipital nerve. Given the hypothalamus' implication in CH (Buture *et al.* 2019: 269), it was believed that ONS had the potential to influence CH (Franzini *et al.* 2009). Multiple open-label studies showed significant efficacy of ONS (Magis *et al.* 2007; Burns*,* Watkins and Goadsby 2009; Fontaine *et al.* 2011), but did not control for placebo. Wilbrink *et al*. (2021) conducted a small trial of ONS at low versus at high intensity and found that both significantly reduced the frequency of attacks. They suggest that further research surrounding the most significant ONS protocol and its exact mechanism of action be conducted.

ii.b. Vagus nerve stimulation

The rationale for vagus nerve stimulation (VNS) in the treatment of CH is due to the strong parasympathetic activation that can be seen with an attack (Piagkou *et al.* 2012). The mechanism of action is thought to be by inhibition of afferent vagal signals to the trigeminal nucleus as well as modulation of neurotransmitter release (Oshinsky *et al.* 2014). Vagus nerve stimulation can be conducted using a non-invasive device named the gammaCORE (O'Connell *et al.* 2021). Multiple case series have suggested that it may have a role in the prevention of attacks (Nesbitt *et al.* 2015, Gaul *et al.* 2017). This has however not been confirmed with any randomised controlled trials. Vagus nerve stimulation has also been studied for acute treatment of attacks. A double-blind, randomised, sham-controlled trial showed that there was no significant response difference between the VNS group and the sham group (Silberstein *et al.* 2016), suggesting its role as an adjunctive prophylactic device may be larger, than as an abortive one.

ii.c. Deep brain stimulation

Deep brain stimulation developed as the first neuromodulatory treatment after functional imaging that suggested pathogenic pathways were conducted. Targets of stimulation vary, but are popularly the posterior hypothalamus and ventral tegmental area (Akram *et al.* 2017). Multiple case series have presented DBS as an effective method of reducing frequency of attacks in those with chronic CH (Nowacki *et al.* 2020), but it is not considered successful enough as an abortive option (Leone *et al.* 2006).

It is important to note that although the meta-analysis by Nowacki *et al.* (2020) of available case series found a 75% response rate, the results of the first randomised, placebo-controlled, double blind trial of DBS of the ipsilateral hypothalamus found no significant improvements between active and sham stimulation (Fontaine *et al.* 2010). Furthermore, DBS is far from without risk. In the above mentioned trial, three major adverse events had occurred, including subcutaneous infection, transient loss of consciousness and micturition syncope (Fontaine *et al.* 2010). Additionally, a pilot study on hypothalamic DBS reported an intracerebral bleed occurring due to implantation of this device (Schoenen *et al.* 2005). These events make it clear that DBS is far from a risk-free procedure and is thus reserved for CH patients severely disabled and usually refractory to a multitude of other, less invasive and generally safer treatment options.

iii. Microvascular Decompression

Microvascular decompression is an invasive surgical technique that requires a craniectomy. The intention is to remove vasculature that may be compressing neurological structures or nerves. The role of microvascular decompression in a cluster is not as well defined as in trigeminal neuralgia. A small case series of three patients ligated the pterygopalatine artery and placed a temporal muscle graft between the SPG and the artery. Of the three, none had any success, suggesting that microvascular decompression was likely of little use to the CH population (Oomen *et al.* 2011).

iv. Maxillary Artery Cauterisation

A single case series of this procedure has presented this procedure as a novel and minimally invasive technique with major potential in the treatment of CH (Shevel 2013: 677). The procedure involves the cauterisation of the maxillary artery and terminal branches of the carotid artery from an intra-oral approach.

Feasibility of the procedure was explained as such:

The role of the SPG in CH presentation, and as a target of treatment is well established (Fontaine, Santucci and Lanteri-Minet 2018: 375). The tertiary portion of the maxillary artery supplies the SPG (Morton and Khan 1991: 205). In migraine, where vasodilation is partially considered to be responsible for pain through neuropeptide release (Mason and Russo 2018: 233), an effective treatment is that of vasoconstriction via triptans (Nicolas and Nicolas 2022). Vasoconstrictive therapy, such as triptans and ergotamine have also been shown to be helpful abortive options in CH (Law, Derry and Moore 2010), suggesting that vasodilation may play a role in, not only migraine headache pain, but also CH pain as well.

Vascular migraine patients had previously shown to benefit from terminal carotid cauterisation (Shevel 2007: 451), suggesting that cauterisation of vasculature may be a treatment option for headaches with vasodilatory components. It was thus hypothesised permanent closure of the maxillary artery, due to its proximity and role to the SPG, could be beneficial as a treatment form for those with CH. In the series, four out of five patients reported complete cessation of their CH immediately, with no return of attacks on follow-up (varying times of follow up), while one patient had no relief from the procedure (Shevel 2013: 681). To our knowledge, no follow-up literature or further studies have been published on this procedure.

2.7.5.2 Abortive Treatment for Cluster Headache

Abortive medication for CH is given to reduce the duration of an attack. The presentation of CH attacks presents some challenges to finding treatments that work effectively. For example, the time from onset to peak of an attack is relatively short (less than 15 minutes) and attacks themselves usually do not last more than 180 minutes which means that any chosen agent would have to act extremely fast to be effective. As such, this makes certain routes of administration less likely than others (Kingston and Dodick 2018: 9). Oral administration works less efficiently than parenteral routes for speedy medication delivery (Kim and De Jesus 2022). Options frequently used to administer medication for CH abortion thus include intranasal, inhalation or injection (Kingston and Dodick 2018: 9).

2.7.5.2.1 Pharmacological Abortive Treatments of Cluster Headache

i. Triptans

Triptans are a well-studied group of medications within the context of the treatment of migraine headaches (Tepper and Milson 2003; Dodick 2004). The safety and tolerability of these drugs for MH are well established, resulting in information from these studies often being utilised when these drugs are used for CH.

The mechanism of action of triptans is a central and peripheral processes (Tepper, Rapoport and Sheftel 2002). Direct vasoconstriction, as well as indirect vasoconstriction by inhibition of neuropeptides like CGRP of trigeminal nerve endings in larger cerebral blood vessels, is thought to be one mechanism, while it is also thought that neuronal inhibition within the hypothalamus may be another contributor (Pomeroy and Marmura 2013; Law, Derry and Moore 2013).

Triptans can be highly effective for treating acute attacks of CH. The route of administration is a large factor in the efficacy of all medications, including triptans, in abortion of CH attacks. Subcutaneous injection is favoured, followed by intranasal or sublingual administration, while oral administration is not considered appropriate for this use (Kwon *et al.* 2022).

Available triptan types in suitable formulations include sumatriptan (subcutaneous or intranasal), zolmitriptan (intranasal) and rizatriptan (sublingual wafer). Currently, studies show that subcutaneous sumatriptan is superior for the treatment of CH attacks, followed by intranasal zolmitriptan in cases where injections are not tolerated or attacks are lengthy (longer than one hour), as intranasal administration does take longer to be effective (Brandt *et al.* 2020). No information published in the medical literature regarding the use of rizatriptan for CH was found. Additionally, the use of triptans was associated with a need for less acute medication overall (Law, Derry and Moore 2013). This is positive, as the greater the need for abortive therapies, the larger the likelihood of adverse effects and MOH occurring is (Kwon *et al.* 2022: 1411). However, it is still important to note that the use of triptans is still considered to be associated with some adverse effects when compared to placebo (Kwon *et al.* 2022: 1411), though these were generally mild or moderate and rarely led to discontinuation of use (Law, Derry and Moore 2013).

The use of triptans for CH was trialled at previously determined ‘safe doses’. While this is theoretically good news, that CH can be treated within previously established safe doses, it means that there are limitations of the efficacy of triptans due to currently recommended ceiling doses (Law, Derry and Moore 2013). During an active bout, it would be plausible for the need of abortive medication to be much larger than this maximum dosage recommendation (Law, Derry and Moore 2013), however this frequent dosing could lead to toxicity leading to an increase of adverse effects and/or MOH (Kwon *et al.* 2022: 1411). Brandt *et al.* (2020) reported that, even though the current guidelines recommend that maximum dosage of subcutaneous sumatriptan should be no more than two injections per day, patients with CH use multiple daily for extended periods in daily practice. In this review, they mentioned multiple case reports in which triptans were used in doses above recommendations without serious adverse effects, changes on ECG or the development of MOH (Ekbom *et al.* 1992; Kallweit and Sandor 2011; Leone and Cecchini 2016). The true safety of such practices have not yet been evaluated.

Adverse effects of triptan use that may influence the experience of their use include chest pain, distal paresthesias, somnolence and pain at injections site and the development of MOH (Brandt *et al.* 2020). The risk of severe adverse effects varies between the triptan type, and increases with dosage (Kwon *et al.* 2022: 1411); these effects could include arrhythmias, myocardial infarctions and strokes, but are estimated to occur in less than 1% of patients (Nicolas and Nicolas 2022). For this reason, however, they are not recommended for any patients with histories of previous cardiovascular incidents (Negro, Koverech and Martelletti 2018: 520).

ii. Ergotamine and dihydroergotamine

Ergotamine is now rarely used for the treatment of CH due to its association with severe adverse effects such as myocardial infarction, limb ischemia and fibrotic changes in the tissues (Meyler 1996: 7), but is one of the oldest agents used for its treatment (Brandt *et al.* 2020).

Randomised controlled trial showed that when compared to placebo, intranasal dihydroergotamine was not superior in the abortion of attacks; it did however reduce the intensity, which means that it is not rendered a useless option for all CH patients

(Andersson and Jespersen 1986: 53), though very limited and up to date research is too sparse to draw conclusions.

In comparison to intranasal dihydroergotamine, intravenous dihydroergotamine has clearer efficacy: 3 consecutive days of intravenous (IV) administration was shown to have success rates between 57% and 100% in four different open-label studies (Mather *et al.* 1991; Mathew 1997 and Nagy *et al.* 2011). Compared to regular ergotamine, IV dihydroergotamine has a less serious adverse effects profile, with reports of nausea, leg cramping being the most commonly experienced (Nagy *et al.* 2011: 1830)

2.7.5.2.2 Non-Pharmacological Abortive Treatments of Cluster Headache

i. Oxygen Inhalation

The use of high-flow 100% oxygen gas inhalation via a non-rebreather mask during the initial stages of an attack has been reported as an effective abortive measure in the literature since 1940 (Alvarez and Mason 1940: 108). The mechanism of action is not clear, but it is thought that it plays a role in reducing neuroinflammation of the trigeminovascular system and its ability to cause vasoconstriction in cerebral vessels (Guo *et al.* 2019: 229).

Flow rates of oxygen need to be high for the treatment to work; rates of 6 to 15 litres per minute are suggested (Guo *et al.* 2019: 229), and rebreather masks have also been found to be superior when compared to simple masks (Petersen *et al.* 2017: 220). Further studies on oxygen flow rates, tools of administration and inhalation times are required.

The data on the rate of successful treatment of CH with oxygen vary between 56 to 82% (Pearson *et al.* 2019, Lademann *et al.* 2016); along with its low risk and adverse effects profile, this makes oxygen a competitive option for CH abortion compared to or alongside triptans. Unfortunately, roughly 20% of those with CH do not find reprieve with oxygen inhalation (Pearson *et al.* 2019: 235). Predictors of non-responsiveness to oxygen are no history of smoking, lingering pain between attacks (also called interictal pain) and attacks longer than 3 hours (Backx *et al.* 2010: 1533). Though no single therapy works or is medically appropriate for everyone, 100% oxygen inhalation is safe, shows efficacy and does not interact with other medications. For this reason having oxygen as a safe abortive option is good to have, particularly when attacks are frequent or other options are contraindicated, such as in pregnancy (Guo *et al.* 2019). Unfortunately, oxygen is only reimbursed for in 50% of countries, even though it is commonly considered as a first line treatment (Pearson *et al.* 2019). In South Africa, the Medical Schemes Act, 131 of 1998 provides a list of “diagnosis and treatment pairs” that comprise a list of ‘prescribed minimum benefits’ (PMBs) that medical schemes are legally required to cover for their beneficiaries (Council for Medical Schemes 2020: para. 1 line 1); other than these PMBs, what schemes pay for is dependant from scheme option to scheme option.

2.7.5.3 Transitional Treatment for Cluster Headache

Transitional therapy is indicated in times in which there is an acute increase of attack frequency, such as when a new active bout begins, to induce remission periods for those with chronic CH or when new prophylactic treatment in being initiated or up titrated to an effective dose (Schindler and Gottschalk 2019: 93). Transitional treatments are intended only to be used for short periods, usually until long acting treatment becomes effective, and are not suitable for continuous monotherapeutic use (Kingston and Dodick 2018: 12).

Greater occipital nerve injection is the most proven transitional treatment option. Other options include high dose prednisone (Brandt *et al.* 2020). A single case report for the use of oral frovatriptan was found, with some success reported, but no further studies conducted (Siow, Pozo-Rosich and Silberstein 2004).

2.7.5.4 Other and Developing Treatments for Cluster Headaches to Note

2.7.5.4.1 Psychedelic Agents and Illicit Substances

Though treatments for CH are available, none are designed specifically for CH which is a condition known to be resistant to many of these conventional therapies (Hoffman and May 2018) and, as with all conditions, some people may encounter other barriers to treatment. When treatments continue to fail, and challenges arise, online forums have been found to be a commonplace as sites for the exchange of information regarding the use of alternative treatments and mechanisms (Andersson, Persson and Kjellgren 2017: 65). Many state that this advice on treatments is sought out because of desperation.

On these online forums and other forms of communications between CH sufferers, a large variety of alternative and anecdotal treatment substances are discussed, including, during desperate times, illegal – and very possibly dangerous – psychoactive drugs such as psilocybin, lysergic acid diethylamide (LSD) and related psycho-active tryptamines (Andersson, Persson and Kjellgren 2017: 60).

Legal access to psychedelics for therapeutics purposes remains challenging, as they remain a controlled substance in most countries (Pilecki *et al.* 2021) and South Africa is no different. Currently, psilocybin remains prohibited for use, possession, manufacturing or supply (South Africa, Department of Justice and Constitutional Development: 22). Many using psychedelics are doing so on their own, rather than waiting for legal access; it can thus be argued that information regarding their use is important for practitioners to know, so they may provide support for those using psychedelics with the goal of harm reduction as their ethical duty (Pilecki *et al.* 2021).

i. Psilocybin and other psychoactive tryptamines

Psilocybin is a prodrug-molecule found in certain species of mushrooms. It is metabolised into the active compound psilocin that is presumed to be responsible for the effects in the CNS (Passie *et al.* 2002: 357). The main mechanism of action that accounts for its behavioural effects is thought to be by agonistic activity at the 5-hydroxytryptamine 2A receptor, though it does not account fully for its effects (Winter *et al.* 2007: 472).

Psilocybin is considered an illicit substance but has shown remarkable safety when administered under medical supervision (Gukasyan *et al.* 2022: 151). It has low physiological toxicity and relatively low risks of abuse (Fantegrossi, Woods and Winger 2004: 153), making it an exciting option to explore.

Most evidence for psilocybin is anecdotal, but some other promising literature has been published. A case study published in 2006 interviewed people with CH that had used psilocybin or LSD as treatment. 22 of 26 psilocybin users reported that psilocybin aborted their attacks, 25 of 48 reported that it aborted their cluster period and 18 of 19 reported that it extended the period of remission (Sewell, Halpern and Pope 2006: 1920). Additionally, in 2015 a survey investigated the use of conventional and alternative medications in 496 CH patients and found that, along with other hallucinogenic substances, psilocybin was perceived to shorten cluster bouts and dongate remission, which further reinforced the need for the investigation and exploration of this potential treatment (Schindler *et al.* 2015: 372). Furthermore, it appeared as though infrequent use of low dose psilocybin that produced no hallucinogenic properties was also efficacious (Schindler *et al.* 2015: 372).

Showing enough promise, psilocybin is currently being studied for its efficacy in the treatment of CHs. In the trial, the Heffter Research Institute is comparing low dose, high dose and placebo regimens. Results have not yet been published.

ii. Lysergic acid diethylamide

Lysergic acid diethylamide, or "LSD", is another illicit substance that has received no official research due to its legal status for many years, and is now receiving reappraisal. A case study that interviewed people that had used, or were currently using LSD for the treatment of their CH, revealed that seven of eight LSD users reported termination of their active bout, and 4 of 5 reported that their remission period was longer with the use of LSD (Sewell, Halpern and Pope 2006: 1920).

Another open, non-randomised case series conducted in 2010 revealed that 2-bromo-lysergic acid diethylamide (BOL-148), a non-hallucinogenic analogue, showed promise as a preventative agent for CHs. Even in those previously refractory to other standard treatments responses varied, but three single doses of this agent within 10 days terminated active cluster-bouts, reduced the frequency and intensity off individual attacks, assisted in changing chronic CH to the episodic subtype for some participants and extended periods of remission for many months (Karst *et al.* 2010: 1140). Success with this non-hallucinogenic agent, BOL-148, suggests that the mechanism of action is unrelated to its effects on hallucinogenic receptors – an exciting finding for potential future therapeutic options. Like ergotamines, it is thought that the effects on serotonin-receptor-mediated vasoconstriction is responsible for its efficacy (López-Giménez and González-Maes 2018: 45-73).

LSD is currently being researched as a treatment option at the University Hospital, Basel in Switzerland. An oral LSD regimen of LSD is being compared with placebo in 30 CH patients; results are expected to be released in 2023.

iii. Ketamine

Ketamine is a non-competitive N-methyl-D-aspartate (NMDA) receptor antagonist that is primarily used as an agent during general anaesthetic (Rosenbaum, Gupta and Palacios 2021). It also lends itself to a variety of non-anaesthetic treatments of many other medical disorders, including, but not limited to, treatment resistant major depression, acute and chronic pain disorders, seizure treatment and headaches (Pribish, Wood and Kalava 2020). For many of these, research is still growing, including the use of ketamine for the treatment of CH. In a study conducted in 2016, 29 CH participants received low-dose intravenous ketamine at two-week intervals; this suspended attacks for months at a time in patients with episodic CH and showed efficacy is 50% of those with the chronic subtype (Granata *et al.* 2016: 286).

Another study conducted on 17 chronic CH participants delivered a single ketamine infusion along with magnesium sulphate (Moisset *et al.* 2020: 2537). 13 of the 17 participants had positive responses, with reduction in the number of the daily cluster attacks. The primary adverse effect reported was sedation. Neither of these studies, however, were placebo controlled. The promising results suggest that further studies of ketamine infusions may be worth investigating with randomised, double-blinded and placebo-controlled trials.

Further to the prophylactic use of intravenous ketamine, intranasal ketamine showed some promise as an acute treatment for individual attacks (Petersen *et al.* 2022: 26). About half of participants in this open-label trial preferred ketamine over other abortive options, such as sumatriptan and oxygen inhalation. This demonstrated proof of concept and prompted further investigation and trialling.

2.7.5.4.2 Intranasal Lidocaine

The use of intranasal lidocaine is attractive due to it acting as a blocking agent at the SPG (Bakbak *et al.* 2012: 64). Various papers (consisting of studies as well as case series and case reports) have shown varying degrees of efficacy, but the mechanism of administration and dosing were inconsistent (Kittrelle, Grouse and Seybold 1985; Robbins 1995; Costa *et al.* 2000; Bakbak *et al.* 2012).

In 1985, a study concluded that the use of a cocaine solution was beneficial as an abortive adjunct (Barré 1982: 69). Cocaine, like lidocaine, is a local anaesthetic; lidocaine, however, has no rewarding or addictive properties, making it a much more ethical and safe alternative to explore (Wildsmith and Jansson 2015: 143).

Lidocaine as an intranasal treatment has been shown to be an efficient method of pain management for patients who arrive at the emergency department with the complaint of headache (Mohammadkarimi *et al.* 2014: 331-335). Its ease of administration and quick onset make it an adjunctive option for the abortive treatment of CHs as well.

2.7.5.4.3 Energy Drinks

Scientific literature on the use of ‘energy drinks’, such as Red Bull or Monster, is to our knowledge, non-existent. Nevertheless, Al-Ansari and Robertson (2019: 2890-2892) reported that 17% of a cohort of over 2000 of their participants mentioned treating their headaches with caffeine or energy drinks. The combined use of caffeine and taurine (as is found in most energy drinks) was also mentioned in an investigation into the use of alternative medication (Andersson, Pearson and Kjellgren 2017: 60).

2.7.5.4.4 Antihistamines

Though CH are believed to be triggered by histamine during active bouts due its vasodilatory properties, and has even previously been known as a ‘histamine headache’, antihistamine therapy is not commonly recommended or considered useful. However, isolated cases of antihistamine therapy being effective do exist (Neubauer, Kuhar and Ravnik 1997).

2.7.5.5 The Role of Opiates and NSAIDs in the Treatment Of Cluster Headaches

Cluster headache patients have a higher risk of addictive behaviours and suicide. In fact, de Coo *et al.* (2019: 630) reported that those with CH had higher rates of drug abuse and use of illicit substances than those with other headache types, as well as chronic pain patients. Regardless of this information, they are twice as likely to be prescribed high-risk medications (Choong *et al.* 2017: 1363). Amongst these high-risk medications, opioids are one, of which more than 40% of CH patients have been found to have a prescription for, even though they are not currently recommended by any treatment guidelines for CH (Choong *et al.* 2017: 1359).

Insight into drug-dependency in this population revealed that only drugs that had some analgesic properties were being abused, such as opioids, anxiolytics, hypnotics, cannabis and sedatives (Choong *et al.* 2017: 1364); this suggests that CH pain may be poorly managed resulting in self-medication.

Non-steroidal anti-inflammatory drugs (NSAIDs) are some of the most commonly available drugs to treat headache (Lanza, Chan and Quigley 2009: 728), and its use as attempted self-medication is likely underestimated (Choong *et al.* 2017: 1363). Additionally, NSAIDs are prescribed to nearly 33% of CH patients within one year of diagnosis, though as with other orally administered drugs, they are generally ineffective for acute CH treatment (Kingston and Dodick 2018: 10) and are thus not included in any treatment guidelines.

It appears that NSAID and opioid use may stem from the desperate desire to assist with analgesia, though the overuse and misuse of either can lead to other complications such as gastrointestinal side effects for chronic NSAID users and drug-dependency and suicide for those that take opioids (Choong *et al.* 2017: 1363).

Choong *et al.* (2017: 1370) found that CH patients who had access to non-opioid abortive therapy prescriptions were less likely to require emergency department care. They reiterate that prescription pattern should focus on making effective acute pharmacological (e.g. triptans) and nonpharmacological (e.g. oxygen) available instead of offering NSAIDs and opioids as what appear to be the merciful options – not only are these prescriptions ineffective, but they are not without risk and likely can do more harm than good.

2.7.5.6 The Role of Complementary and Alternative Medicine for the Treatment and Management of Cluster Headache

Any form of treatment, including chiropractic care, that is used alongside or in place of allopathic or conventional medicine can be considered complementary or alternative, respectively (Sharp *et al.* 2018).

In a study conducted by Palacios-Ceña *et al.* (2016: 1180), patients felt that there was a widespread ignorance about their condition which, when coupled with a common diagnostic delay, often led to them to seek out alternative therapies under complementary and alternative medicine (CAM). Between 29% and 63% of CH patients have reported use of CAM (Rossi *et al.* 2008: 225; Bekkelund, Ofte and Alstahaug 2014: 112). Some of these treatment options, such as the use of psilocybin and LSD, have already been mentioned. As stated before, the reason people usually turn to CAM, especially psychedelics, is due to a sense of desperation (Hoffman and May 2018).

In general, CAM is sought out as a last resort due to dissatisfaction with allopathic care (Gaul *et al.* 2009), studies also show that CAM is often utilised due to personal belief systems of the patient or due to the desire to get treatment with fewer adverse effects (VanderPluym 2016). For CH specifically, current evidence shows that the exploration of CAM for these patients is usually due to their disappointment in orthodox treatments (Andersson, Persson and Kjellgren 2017: 60*).*

Besides the complementary measures of psychedelics and nutritional supplementation that have already been mentioned, other complementary treatments that are mentioned in the literature include, but are not limited to the use of intranasal capsaicin, daith piercings (a type of ear piercing that has been insinuated to be helpful in the prevention of MH), manipulation based therapies such as chiropractic, acupuncture, massage, aromatherapy, reflexology, craniosacral therapy and hyperbaric oxygen administration, caffeine, vigorous aerobic exercise, thermal therapy and injection of botulinum toxin.

CAM is perceived as effective by a minority of patients, between 8% and 37% (Bekkelund, Ofte and Alstahaug 2014: 112; Rossi *et al.* 2008: 225) but the clinical review of the literature suggests that there is a major lack of evidence to support the use of CAM for the treatment of CH (Millstine, Chen and Bauer 2017). CAM will continue to be relevant as long as modern medicine has gaps in its ability to treat every ailment which means that for all conditions including CH, complementary caregivers will have to expand their knowledge to assist patients who do present to them. There is also a need for cooperation among health professionals and those working in CAM fields for the benefit of the patient.

2.7.5.6.1 The Role of Chiropractic in the Treatment and Management of Cluster Headache

Headache management by chiropractic is substantial (Moore, Sibbritt and Adams 2017: 3), and it remains a commonly consumed form of CAM for the treatment of headaches (Beliveau *et al.* 2017: 6). In fact, Moore, Sibbritt and Adam (2017) reported that the prevalence of chiropractic use on those with headaches is up to 22%. It is thus not surprising to know that chiropractic treatment is a popular choice when CH patients do seek out CAM care (Bekkelund, Ofte and Alstadhaug 2014: 114), nor outrageous for chiropractors to be required to be knowledgeable on the condition.

Chiropractors are considered primary-care physicians or portal-of-entry healthcare providers internationally (Cupler *et al.* 2021) and is a field that generally claims to align itself with the biopsychosocial model of healthcare, where a ‘whole-person” approach is taken in pain care (Gliedt *et al.* 2017: 1). Suicide is considered a global public health crisis; there has been a call for chiropractors to recognise their ethical responsibility as part of a primary care team in the recognition and prevention of mental health crises and suicidality in practice (Cupler *et al.* 2021: 138). The combination of a high likelihood of chiropractic exposure to a patient with CH, their commitment to holistic healthcare and the proven resulting risk of morbidity by suicide in this population makes it ethically significant for chiropractors to be equipped with information surrounding CH (Trejo-Gabriel-Galan *et al.* 2018: 802). Misdiagnosing, mismanaging or not addressing CHs adequately can be considered demoralising, dangerous, unethical, unnecessary and can increase the risk of suicidality (Hattle 2020; Koo *et al.* 2021: 8).

There is a dearth of literature assessing the efficacy of chiropractic treatment or spinal manipulation specifically as a modality for CH, nor the experience and opinions of CH patients on chiropractic specifically. While the treatment of CH by chiropractic adjustment or other similar physical therapy is unlikely to be a major source of revolutionary relief for CH patients, considering the low reports of efficacy for CAM therapies, chiropractors that do come into contact with CH patients still have a role to play as holistic primary care physicians (Bekkelund, Ofte and Alstahaug 2014: 114; Rossi *et al.* 2008: 225). Previous research has explicitly noted that care for CH in primary care settings needs to be beyond clinical treatment provision (Andre and Cavers 2021: 426). Patients need more than effective treatments, drug prescription and disease education. They crave understanding and empathy from their physicians and care that extends to supporting a patient's ability to self-manage their condition and to the psychosocial impacts that it has (Palacios-Ceña *et al.* 2016: 1179-1180; Andre and Cavers 2021: 420) which is a role that chiropractors may indeed be fit to play provided they have sufficient knowledge regarding the condition. Qualitative data, having shown to promote health and quality of life (Willis *et al.* 2016: 1185), lends itself well to informing CAM care in situations such as these.

2.7.6 Previous Studies on the Impacts and Experiences of Cluster Headaches

Although primary headaches are often considered benign conditions, research shows that they can provoke suicides and that those at the highest risk of suicide attempts are individuals living with CHs (Trejo-Gabriel-Galan *et al.* 2018: 802). Research shows that patients with CH have a substantial headache-related disability (Abu Bakar *et al.* 2016a: 68); quantitative analysis on the quality of life of those with CH showed that it had a significant impact even with appropriate treatment (D’Amico *et al.* 2020: 816). Further studies demonstrated that these impacts could still remain when episodic CH patients were outside of active bouts (Palacios-Ceña *et al.* 2016: 1172). More recently, a CH specific quality of life scale was developed (Abu Bakar *et al.* 2016b: 1-9) which has shown some promise in being sensitive to changes in status and being able to track the effects of the disorder on patient's lives, as well as the deductive efficacy of treatment (Cappon *et al.* 2020).

Two previously conducted qualitative studies on the experience of CH patients were found. The first qualitative study was a Spanish study conducted by Palacios-Ceña *et al.* (2016: 1171-1182) at a headache treatment centre and included interviews of 20 male CH patients. The second, by Andre and Cavers (2021) took place in the UK and included 15 participants, both male and female. Both studies revealed that the areas that CH affected were widespread and included social, psychological, and economic grievances, and shed light on some of the challenges that these patients face. By providing a further comparison, this South African study may be able to highlight which common themes are experiences that do occur due to the nature of the condition itself, versus the degree of input that external factors (such as laws, education, culture and healthcare access) have on the experience.

It is already known that there are large direct and indirects costs involved in this condition (specialist visits, diagnostic test costs, visits to the emergency room, the cost of medication as well as days impacted or lost at work or study) (Negro *et al.* 2020). The severe, recurring and sometimes unpredictable nature of the headaches may cause a considerable modification of a patient's participation in daily life and altered involvement in personal and occupational roles (Abu Bakar *et al.* 2016a: 68). How these changes affect participants can be elucidated with further studies such as this.

Cluster headache patients express a major struggle to find adequate and correct medical care (Hattle 2020), and have felt as though their condition was misunderstood, trivialised and that the general lack of awareness around the condition by medical professionals negatively affected their well-being (Andre and Cavers 2021: 426). Further exploration into their experience with medical care is warranted so these areas can be addressed with accuracy.

Another study conducted in the UK, explored the perceptions and experiences of general practitioners and neurologists in the treatment of CH. The study revealed two important factors; firstly, although practitioners were at least partially aware of some of the impacts of CH they did not necessarily feel equipped to treat them adequately or with ease and secondly, many of these perceived challenges were implicated by the specific and unique medical system within which the study occurred (the NHS) (Buture *et al.* 2020). This does bring up the question of the challenges that CH patients perceive in accessing medical care within a South African context, as it seems to suggest that the challenges, and thus the solutions, may be unique to the healthcare context.

Statistics suggest that a significant amount more of those with CHs, compared to control, have lifetime active suicidal ideation (47.0% vs 26.7%); furthermore, a large portion admit to the use of illicit and potentially dangerous substances out of desperation (Andersson, Persson and Kjellgren 2017: 62). Misdiagnosing, mismanaging or not addressing CHs adequately can be considered demoralising, dangerous, unethical and unnecessary (Koo *et al.* 2021: 8). As such, understanding more about the context within which these occur will allow for holistic management solutions to be developed, that is uniquely targeted at the challenges of this, clearly proved to be vulnerable, population.

2.8 SUMMARY OF THE CHAPTER

Review of the available literature reveals that though the scientific information and the qualitative data in CH is expanding, there are still significant problems with regards to adequate care experienced by these patients (Andre and Cavers 2021: 426). Although the impact of other headache conditions is large (GBD 2016 Headache Collaborators 2018); the impact of CH is severe which is illuminated by their reduced quantitative scores in quality of life studies, psychological grievances and comorbidities, increased rates of suicide and ventures into potentially dangerous and illegal substances (Abu Bakar *et al.* 2016b: 1; Andersson, Persson and Kjellgren 2017; Ji Lee *et al.* 2019; Song *et al.* 2019; D'Amico *et al.* 2020; Koo *et al.* 2021: 2). The seeking of comfort and empathy, along with information regarding alternative treatment options, from internet sources, support groups and forums in this population is large which highlights that current medical systems are failing these patients (Andersson, Persson and Kjellgren 2017; Buture *et al.* 2020; Hattle 2020; Andre and Cavers 2021: 426; Koo *et al.* 2021: 8).

The South African context is unique, and the experiences that patients have with healthcare services are hypothesised to be different to those from other nations.

Headache studies in the South African population are very scarce, thus, exploring the lifeworld of those with CHs in South Africa and reflecting on it will hopefully reveal information that can lend itself to the development of attainable solutions and improvements in the healthcare received that are relevant to the specific population and potentially to others across with CH the globe (Vagle 2018).

The chapter to follow discusses the research design and methodology employed to execute this study

CHAPTER THREE

METHODOLOGY

3.1 INTRODUCTION

This chapter will concern itself with the elaboration of the methodology employed in this study, while focusing on tools and techniques used to collect and analyse data.

3.2 RESEARCH DESIGN

A research design guides the process of a study from the conceptualisation of its purpose to the final presentation of analysed data (Abutabenjeh and Jaradat 2018: 238). It can be seen as the outline of a plan that allows for appropriate decisions regarding details of data collection and analysis by keeping the purpose of the study in mind (O'Sullivan *et al.* 2007: 248). A thorough design helps a study be planned and conducted in a way that will obtain relevant results (Burns and Grove 2001).

This study used an open and reflective lifeworld approach (an approach to traditionally qualitative research of phenomena). The theoretical framework that was compiled to assist with data collection is discussed below; it is largely based on defining 'the lifeworld' using Habermas' theory of communicative action, and Bronfenbrenner's ecological systems theory. Data were collected from participants who reside in a variety of areas within South Africa.

Because there is a link between philosophies that a researcher holds, and the framework they utilise to shroud their investigation (Creswell and Poth 2018), research paradigm and theoretical framework aspects are discussed before the 'methods' portion of the research design, as it was used as a basis to make decisions regarding the design.

3.3 RESEARCH PARADIGM

A research paradigm can be described as a set of philosophical principles or beliefs that implicate all choices that are made in the research design (Johannesson and Perjons 2014; Kivunja and Kuyini 2017: 26).

3.3.1 Interpretivism

In Chapter One, the purpose of the study was stated to be “to shed light on the lifeworld of patients with CHs within a South African context’ – which involves the acquisition of a rich understanding of their lived experiences. Interpretivism, also known as ‘constructivism’ or ‘the qualitative research paradigm’ (Guba and Lincoln 2005), enables researchers to construct a deep understandings of life experiences, and of people within various settings (Taylor and Medina 2013), which made it the appropriate paradigm for this research study to occur within.

To understand interpretivism, one must first understand the various components of the paradigm. According to Saunders, Lewis and Thornhill (2019), a paradigm may be deconstructed into three elements, namely: ontology, epistemology, and axiology (**Figure 3.1**).

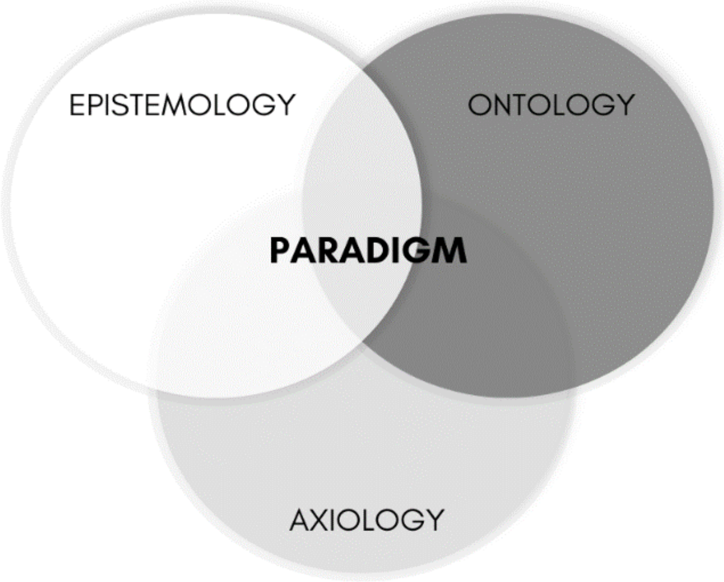

Figure 3.1: A schematic depiction of the components of a paradigm (Adapted from the description by Saunders, Lewis and Thornhill 2019)

3.3.1.1 Ontology

The branch of philosophy concerned with the ‘nature of reality’ is called ontology. The ontological stance taken here was one of relativism, with the central idea of inseparability. Relativism is the idea that reality is created in the mind, and unique to everyone (Moon and Blackman 2014: 1167). The belief is thus that multiple realities can co-exist (Creswell and Poth 2018). Inseparability is the idea that, although reality is relative to the individual, no individual human beings can be fully separated from the world they exist within (Hamauzu, 2018).

3.3.1.2 Epistemology

Epistemology is the philosophical ‘study of knowledge’ (Killam 2013), including the stance that is taken on what information is considered to be ‘of value’, ‘true’ and ‘valid’ (Moon and Blackman 2014). Epistemology also concerns itself with the way in which information is acquired (Kivunja and Kuyini 2017).Similar to the ontological position that reality is relative to the individual’s context, the epistemological view of interpretivism is one of subjectivity: there is an assumption that truth and knowledge are based on people’s experiences and their understanding of them (Ryan 2018: 45).

This stance implies that by interacting with different participants, the multiple realities can be explored (Okesina 2020: 59), but that the information acquired is subjective to the researcher’s context. The data are made meaningful and constructed into knowledge by the researcher, who, ontologically speaking has a reality that, though also unique, is inseparable from the shared reality between the researcher and participants.

The concept of subjective knowledge is described well by the words of Dahlberg and Dahlberg (2020: 460): “Human experience is born from the world, directed to the world, and must be understood with the world”. In other words, researchers must aim to investigate subjective and objective dimensions, as well as the relationship between them, rather than remove their subjective perspective from the process, in order to obtain meaningful information.

3.3.1.3 Axiology

In research, an axiological stance determines the role of a researcher's values during the research process (Creswell and Poth 2018). In an interpretivist paradigm (**Figure 3.2**), the axiological stance is said to be a 'balanced' one (Kivunja and Kuyini 2017), which is to say that the researcher recognises the value-laden nature of the research. These values and biases are openly declared and discussed (Creswell and Poth 2018), but it is ultimately assumed that there will be a degree of subjectivity within the interpretations made by the researcher (Saunders, Lewis and Thornhill 2019).

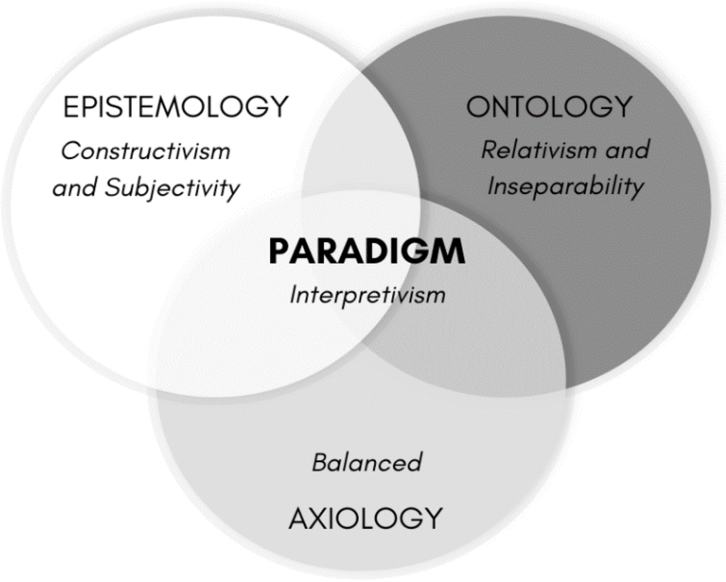

Figure 3.2: A schematic depiction of the components of the chosen paradigm (interpretivism) (Adapted from Figure 3.1)

3.4 THEORETICAL FRAMEWORK

The definition of a theoretical framework for the purpose of this study is taken to be 'a set of interconnected concepts and premises taken from existing theory and combined by a researcher with the intention of developing a scaffolding for the study' (Varpio *et al.* 2020: 989). Use of theory in the shaping of a study is relevant to its quality (Kelly 2010: 285). Portraying how theory shapes a study is done by defining key concepts of each, showing how they link to each other and how they relate to attempting at fulfilling the aim of the study (Varpio *et al.* 2020: 989). The research paradigm that has been explicated above forms a part of the theory that constructs this scaffolding.

With the purpose of the study in mind, grounded by the principles of the paradigm outlined above, a lifeworld-led approach was selected to guide methodological design. A lifeworld-led approach aligns itself with the wave of lifeworld-led healthcare, which is said to be a humanising healthcare model (Dahlberg, Dahlberg and Nyström 2008, Galvin *et al.* 2020: 1). In this model, healthcare providers are encouraged to hold information about patients' experiences within their wealth of knowledge, as it allows for them to provide well-informed support needs (Dahlberg, Todres and Galvin 2009: 270). The focus on the promotion of patient wellbeing is largely done by placing value on subjective experiences (Hemingway 2011; Galvin *et al.* 2020: 7), meaning the study naturally involved the collection of data of a qualitative nature.

3.4.1 Qualitative Research

Qualitative research is constructed around data that are non-numerical in nature, which allows for the exploration of complex human experiences (Houghton *et al.* 2013: 13). It gives participants a voice to better explain health-related issues and is typically useful when a contextual understanding of a population is sought (Hennink, Hutter and Bailey 2020: 11).

In healthcare sectors, this kind of information is valuable for a variety of reasons, particularly when seeking understanding to provide more humanising care with the ability to improve these areas by informing intervention and future policy (Doyle *et al.* 2020: 453; Galvin *et al.* 2020: 7).

In this study, the use of transcribed interviews between the researcher and participant were considered the primary source of data.

3.4.2 The Open and Reflective Lifeworld Approach

Developments in the approaches to qualitative inquiries have resulted in the suggestion of 'open and reflective lifeworld research' to be of use in the healthcare sector by producing studies that can satisfy the need for both, meaning-rich and scientifically rigorous data by tapping into a wealth of phenomenological and hermeneutical (Dahlberg and Dahlberg 2020: 458).

3.4.2.1 Principles of the Approach

Though a publication by Dahlberg, Dahlberg and Nyström (2008) aimed to outline some essential ideas around open and reflective lifeworld as an approach to qualitative research and a later publication by Dahlberg and Dahlberg (2020) further articulated some methodological principles of the approach there is to our knowledge, a paucity of literature that provides a step-by-step method to research studies with this approach. It is for this reason that methods were so highly influenced by deeply understood principles and philosophies.

The principles that were discussed by Dahlberg and Dahlberg (2020) were highlighted with the intention of creating a strong theoretical basis for this approach to research to form further methodological constructions. These principles are elaborated on below, based on the explanations given by Dahlberg and Dahlberg (2020) as the pioneers of this approach:

3.4.2.1.1 Inseparability, Objectivity and Subjectivity

Briefly described already as a key principle within the paradigm, the concept of inseparability illuminates the common ground between objectivity and subjectivity.

It is clear that because of the tenant of inseparability, there is no need to erase a researcher's subjectivity. This is not seen as second-rate, but rather as an opportunity to investigate the relationship between the subjective and objective.

The methodological principles of this were that the researcher could not, but thankfully was not expected to, choose between objectivity and subjectivity. It was also required to find a way in which the space between objectivity and subjectivity could be explored.

3.4.2.1.2 Bridling Openness

In most qualitative research, the task of 'bracketing' is used to mitigate the tainting of findings with a researcher's presuppositions. This approach, however, suggests that a researcher's preconceptions and personal experiences are *not* bracketed because their pre-understandings are essential to their ability to 'understand' and thus create meaning. In its place, it is recommended that the attitude, "the world is as it seems" should be bracketed.

The attempt to remove the subjective (presuppositions) is thus discarded and instead replaced with *the goal of an astute awareness* around 'how the world is, shows itself and how that information is meaningful'. This altered approach is known as 'an attitude of openness'.

However, to prevent the understanding from evolving randomly or too quickly, the researcher must 'restrain' or 'keep an eye on' the understanding they develop with this awareness. This is done by the art of bridling – which is to be *present* and query our understanding of phenomenon as they form. These questions open the door for many possibilities of understanding. These two acts are employed together, called "bridling openness". Being aware of the impact one's own lived experience has on the research, is precisely how a researcher can move between the subjective and objective domains.

3.4.2.1.3 Description Versus Interpretation

The ability to utilise principles from both phenomenological ("descriptive") and hermeneutical ("interpretive") approaches derives from this: The idea that description and interpretation were never in opposition. The stance is that even original phenomenology inconspicuously included the ontological idea of inseparability, resulting in descriptions within a context, which implies that there is no difference between the knowledge obtained from meaningful descriptions versus interpretations. Findings are thus represented as a structured description of meanings.

3.4.2.1.4 Essences

'Essences' is the term used to encompass 'structured meanings'. They can be equated to the main interpretations made from data. The scientific goal of a study is for findings to be able to be extrapolated to both individual situations and more globally (such as to groups with differences to that of the studies cohort). Findings are said to be required to have "texture" and "structure" to meet these requirements, respectively.

The grouping of meanings into 'essences or main themes provides structure to findings, that allows for them to be applicable to larger groups and those with differences to the study's cohort. By elaborating on these main themes with individual variations and subthemes, texture is added to the findings, which allows for the findings to be applicable to individuals

3.4.2.2 The Concept of the Lifeworld

The concept of ‘lifeworld’ was born in 20th century philosophy and social theory, initially mentioned in publications by Edmund Husserl and Alfred Schütz and later by social theorists such as Jürgen Habermas (Harrington 2006: 341). Continuous development of theory left the concept generally ill defined, due to poor congruency of the concept between authors. To Husserl, the ‘lifeworld’ was seen as the subjective understanding of the world that scientists innately possess, which is in turn used to make objective information meaningful (Harrington 2006: 341). To Schütz, the concept was understood as the reality of ordinary individuals and was thought to be constructed by their interactions with others (Harrington 2006: 341).

In Habermas’ publication, the lifeworld was described as a world shaped by everyday communication and interaction (communicative action), where the interactions had power to result in social evolution (Harrington 2006: 341). Dahlberg and Dahlberg (2020) proposed that what is to be taken from these is the essential idea of ‘inseparability’ between researcher, participant, and the world they exist in. Habermas ‘Theory of Communicative Action’ included the construct of a two-part society made up of ‘the lifeworld’ of the individual and ‘the system’ within which they exist (Roderick 1986). The interaction between the two is best explained in **Figure 3.3** adapted from Froggatt *et al.* (2011: 265).

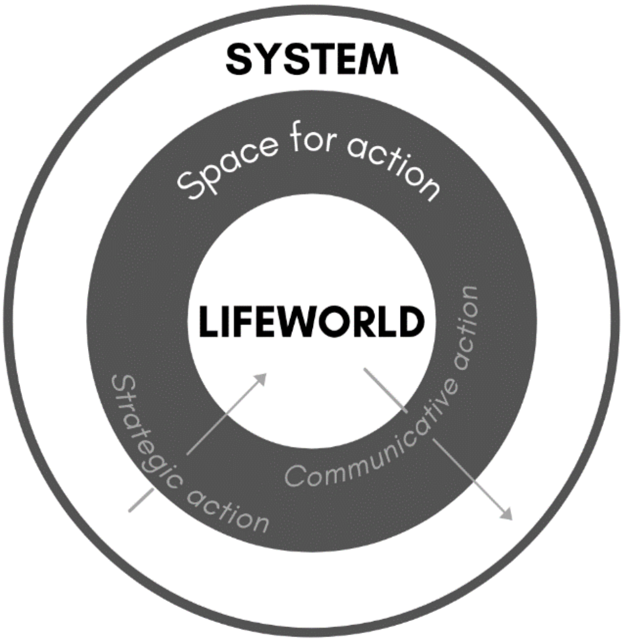

Figure 3.3: A schematic depiction of the dualistic relationship between 'the lifeworld' and 'the system', adapted from Froggatt et al. (2011: 265)

Understanding the lifeworld as part of this construct allows for the potential for systemic change to occur via the space for action. The exploration of the lifeworld in this study occurred within this model. The critical concept of 'inseparability' was naturally applied, as in this model; 'the lifeworld' and 'system' are dynamic and co-constructive.

3.4.2.2.1 Constituents of the Lifeworld

Though this provided an understanding of a model within which to investigate the lifeworld, the outline of the lifeworld was still vague, beside its essence being 'a subjective experience of human life'. To explore the lifeworld, more information regarding the constituents that required investigation was needed.

This need was met with the inclusion of 'Bronfenbrenner's Ecological Systems Theory'. This theory echo's the key concept that individual and contextual systems exist separately and interactively (Eriksson, Ghazinour and Hammarström 2018: 416); in other words, their interdependence is co-constructive, as is the ontological view of Habermas' theory of communicative action, and the open and reflective lifeworld approach.

Bronfenbrenner's ecological system's theory classifies complex components of existence into a tangible model (Pask *et al.* 2018: 1082) that allows for guidance of investigation, without taking a stance that results in isolation of each aspect. A schematic of the model is included in **Figure 3.4**.

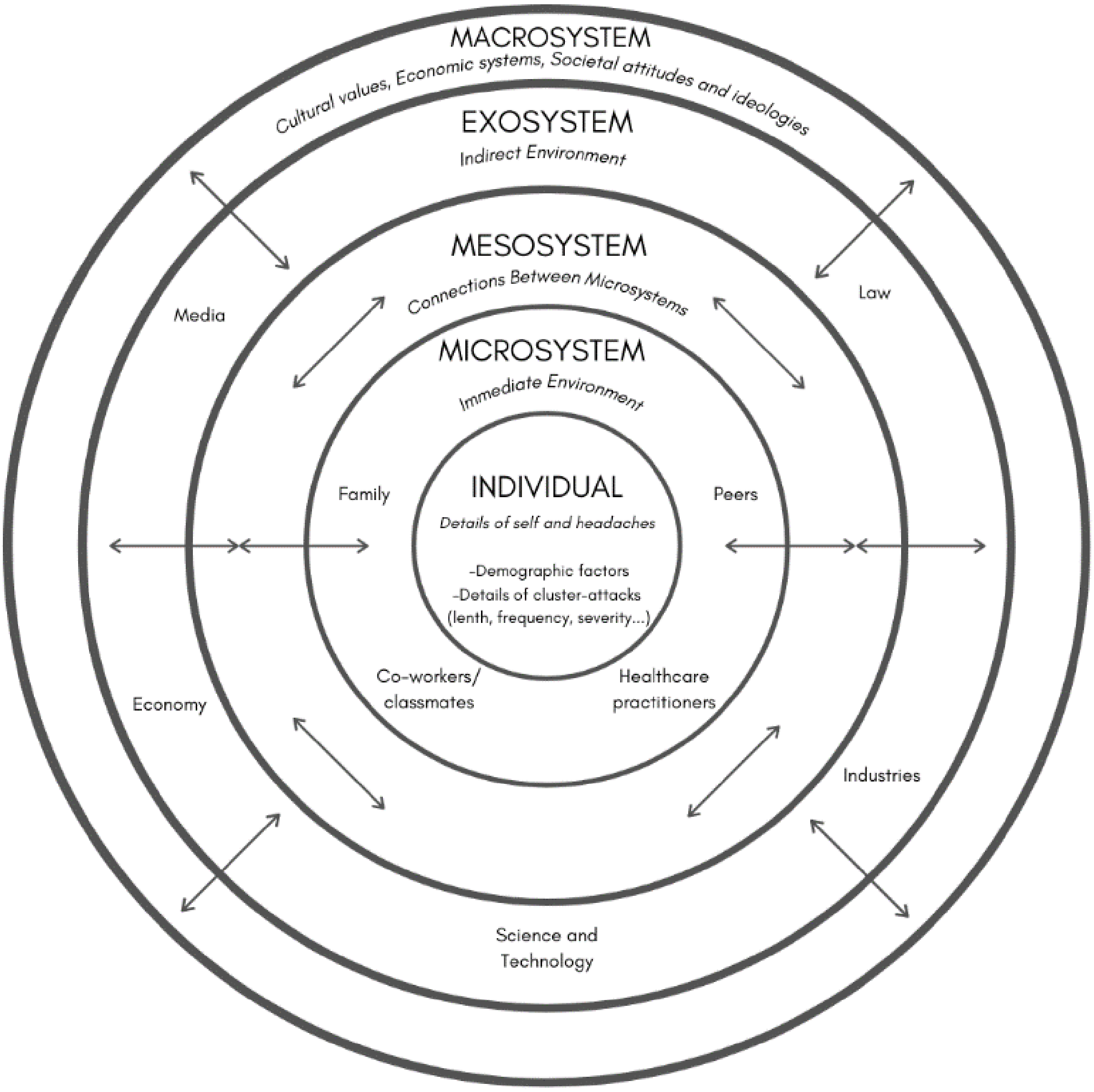

Figure 3.4: A schematic depiction of Bronfenbrenner's Ecological Systems Theory (adapted from Pask et al. 2018)

The components of macrosystem and exosystem were taken to be part of the outer system that was depicted in Habermas' theory of communicative action and was thus seen as the context that is inseparable from the individual's lifeworld. The components 'mesosystem', 'microsystem' and the 'individual' were taken to be components of the 'lifeworld' that was under investigation by this study. This model was later utilised in the conceptualisation of research data-collection tools.

3.5 RESEARCH SETTING

The research setting is the place where data are collected. Data were collected from South African participants via electronic media that offered video-call (such as Skype, Zoom or similar electronic communication that could provide closed communication for the interaction). Platforms were chosen on a case-to-case basis, dependent on what was available and convenient for both parties. Electronic media was chosen to allow for a broader reach to participants living with CHs nationally, as it allows for the participant and researcher to communicate from distant locations. It is also useful as a form of encouraging social distancing due to Covid-19. Though face-to-face interviews are common in qualitative research, video conferencing is considered as a viable option for conducting interviews (Nehls, Smith and Schneider 2015: 140).

3.6 POPULATION

3.4.1 Study Population

The population refers to the entire group about which some information is sought (Banerjee and Chaudhury 2020). A sample of participants is selected from the population (Kumar 2014). The research population for this study comprised of those with a diagnosis of episodic or chronic CH residing in South Africa, 18 years and above.

3.4.2 Population Size

Epidemiological studies suggest that this rare condition affects about 0.1% of the population (Wei, Ong and Goadsby 2018: 3). The estimation of the total population over the age of 18 in South Africa is taken from the estimations provided by the United Nations on World Population Prospects to be 39,806,445 people. 0.1% of 39,806,445 results in an estimate population size of 39 806 people.

There is, however, no epidemiological data specific to South Africa that can confirm this estimation nor is a formal database of diagnosed CH patients in South Africa available to verify the amount with known diagnoses. Therefore, the available population in reach for the study is much smaller and limited to those that have joined popular support groups as this is where the advertisements of the study were placed.

3.7 SAMPLING PROCESS

When conducting research, a portion of a population, termed a ‘sample population’ is chosen, as having an entire population participate is usually not feasible (Elfil and Negida 2017). The process of generating this sample population is termed ‘the ‘sampling process’. Purposeful sampling was utilised for sample selection. With purposeful sampling, the researcher utilises their judgement in identifying and selecting information-rich cases as participants based on the qualities the participant possesses that hold relevance to the study (Etikan, Musa and Alkassim 2016: 2). It is useful in making the most effective use of a limited population (Palinkas *et al.* 2015). The sample was thus chosen to include those that have first-hand experience with CHs as they will be able to answer the research questions by providing insight into the condition from a personal perspective.

The researcher additionally made use of snowball sampling. This refers to the recruitment of future study participants through existing study subjects and improves access to subjects with difficult target characteristics (Naderifar, Goli and Ghaljaie 2017).

3.8 SAMPLE CHARACTERISTICS

3.8.1 Inclusion Criteria

- Participants who are 18 years and older.
- Participants who have been previously diagnosed with CHs by a medical professional and scored greater the eight points on the CH Screening Questionnaire (CHSQ) (Appendix A)
- Participants who are currently a South African resident or have resided in South Africa for the duration of at least one CH cycle.

3.8.2 Exclusion Criteria

- Participant who refuses to provide informed consent.

3.9. SAMPLE SIZE

An estimated six to eight participants is usually sufficient to provide homogenous sampling, while between 12 and 20 is estimated to reach redundancy (Kuzel 1992). These figures are within the parameters of a similar qualitative study (Palacios-Ceña *et al.* 2016: 1174) where 20 participants were interviewed before saturation occurred. Vasileiou *et al.* (2018) recommend utilising the saturation parameters of previous studies to make appropriate evaluations on sample size estimation.

A minimum of eight participants were to be included, with data collection continuing until data saturation occurred. Data saturation was said to have occurred when no new similarities or differences were identified through data collection (Aldiabat and Le Navenec 2018). Data collection was terminated when data saturation was achieved after the 8th interview.

3.10 PARTICIPANT RECRUITMENT

Potential participants were invited to participate in the study through a series of advertisements/recruitment posters (Appendix B) posted particularly on online social support groups with permission from their relevant administrators (Appendix C and Appendix D). They were also recruited with snowball sampling.

3.11 RESEARCH TOOLS

Research tools are the instruments used by a researcher in the process of data-collection and are required to be suitable to collect the specific information required (Pandey and Pandey 2015: 70).

3.11.1 The Cluster Headache Screening Questionnaire

The Cluster Headache Screening Questionnaire (CHSQ) (Appendix A) is a self-administered questionnaire that was developed by Chung *et al.* (2019) to screen for the presence of CH. Chung *et al*. (2019) assessed the validity of the scoring model and were able to verify that the CHSQ is a dependable screening tool that can quickly and accurately detect the presence of CH. In its conceptual study, a cut-off of eight points was calculated to be the most appropriate, where the CHSQ has a sensitivity of 83.3% and a specificity of 99.3% (Chung *et al.* 2019). The CHSQ was administered to each interested participant to confirm the likelihood that their diagnosis was accurate to 'CH', as this was needed for their information to be most relevant to the study.

3.11.2 Semi-Structured Interview Guide

Semi-structured interviews were conducted using an interview guide (Appendix E). The development of an interview-guide for a semi-structured interview followed the framework proposed by Kallio *et al.* (2016) with the aim to produce a rigorous research tool, which contributes to the trustworthiness of the study. Kallio *et al.* (2016: 2961) states that there are five interrelated phases in the development of a semi-structured interview guide:

I. Justifying the use of semi-structured interviews
II. Investigating and using existing literature
III. Formulating a preliminary guide
IV. Pilot testing the guide
V. Refining the guide to its final form

Semi-structured interviews make use of open-ended questions in a particular order where responses to the open-ended questions can be further probed. This was decided to be suitable for this study as it allowed the participant to respond freely and expand on their answers which provides the information on their lived experience that is required, while providing some structure and homogeneity to the interviews (Morse 2012).

While Artino *et al.* (2014: 436-474) recommends using previously published guides, no guides with the purpose of investigating the lifeworld exist – thus no existing guide was used in its absolute existing form. However, permission was obtained from the corresponding author of Palacios-Ceña *et al.* (2016) to adapt the questions used in their study (see Appendix F and G). The preliminary guide was then created by adapting these questions and formulating other relevant ones in a way that was aimed at investigating the levels in Bronfenbrenner's Ecological Systems theory.

3.11.3 Demographic Datasheet

A demographic data sheet was also used to collect basic demographic data of participants (Appendix H) before the interview commenced. This is to ensure that some information was available during data analysis, as demographic data are a useful set of information that adds to context **(Table 3.1).**

The development of the interview guide and demographic sheet as useful tools were directed at the exploration of the different 'levels' or 'systems' of the lifeworld as per Bronfenbrenner's ecological system's theory.

Table 3.1: A depiction of the incorporation of theory in the development of research tools

Level of Bronfenbrenner's ecological system's theory	Level within Habermas' Theory of Communicative Action	How was this addressed in the research?
Individual	Lifeworld	-Demographic Information. -Investigation of personal headache experience.
Microsystem	Lifeworld	-Investigation of relationships and experiences of daily life.
Mesosystem	Lifeworld	Probing, data analysis and the development of researcher understanding may reveal relationships between facets of experiences.
Exosystem	System	-Participant's perception of the exosystem based on their experience may present itself during the interview. -Context is also considered during Part 2 of Data Analysis.
Macrosystem	System	-Participant's perception of the influences by the macrosystem of their experience may present itself during the interview. -Context Considered during Part 2 of Data Analysis.

The theory was utilised to construct the six main open-ended questions of the interview guide. A summary of these questions, and the aspect of Bronfenbrenner's Ecological Systems Theory that it addresses is given in **Table 3.2**.

Table 3.2: A summary of the main questions used in the interview guide

Question number	**Question**	**Facet of experience it aimed to address/ *[aspect of Bronfenbrenner's Ecological Systems Theory]***
Question 1	Describe your experience living with cluster headaches.	Personal symptomology and experience of the headache *['individual']*
Question 2	Please describe the coping mechanisms you use for your headaches.	Mechanisms that are used by the individual to manage the headache as part of their personal headache experience *['individual].*
Question 3	Discuss the areas of your life that have been impacted by your headaches.	The participant's experience of the facets of their immediate environment that have been impacted by CH *['microsystem'].*
Question 4	Explain how your daily life has changed because of cluster headache.	Information on CH influences within their immediate environment, as well as the participant's perception of how these impacts come about *['microsystem' and 'mesosystem'].*
Question 5	Please describe your understanding of your diagnosis and its treatment and management.	Revelations surrounding the patient's perceptions of impacts on their disease and the influences they perceive on their treatment *['individual', 'microsystem', 'mesosystem', 'exosystem' and macrosystem'].*
Question 6	Describe your journey with the healthcare professionals you have encountered with your headache.	Illumination of healthcare experiences and the delineation of aspects that CH patients perceive would improve their experience with the healthcare sector *['individual', 'microsystem', 'mesosystem', 'exosystem' and 'macrosystem'].*

3.12 PRE-TESTING OF THE DATA COLLECTION TOOLS

A pilot study or feasibility study is a pre-test technique which is used to develop and test the adequacy of the research instrument, identify any logistical issues which may occur during the actual test and assess whether the research protocol is realistic and workable (Van Teijlingen and Hundley 2001). It is suggested as part of the framework by Kallio *et al.* (2016: 2961) that was used in the development of the interview guide for a rigorous research tool.

Once provisional approval was obtained from the Durban University of Technology (DUT) Institutional Research and Ethics Committee (IREC), a pilot study was conducted to assess whether the questions were appropriate, easy to understand and applicable. The pilot study was conducted on one CH sufferer. The participant was required to complete a letter of information (Appendix I), complete a consent form (Appendix J) and a code of conduct form (Appendix K), and was excluded from participating in the main study. Any recommendations suggested were made on the semi-structured interview guide.

3.13 DATA COLLECTION PROCESS

Once full ethical approval was obtained from the DUT IREC, potential participants were invited to participate in the study through a series of advertisements/recruitment posters (Appendix B), posted particularly on online social support groups with permission from their relevant administrators (see Appendix C and D).

All interested participants were first screened with the CHSQ (Appendix A). The screening questionnaire was self-administered by the potential participants after being sent to them via e-mail, returned to the researcher, and then scored. Those with a score above eight were notified that they were eligible to continue to the interview. The participants who expressed an interest and consented to an interview were liaised with individually to set up a suitable date for their interviews.

Before the interview, a letter of information (Appendix L) and an informed consent form (Appendix M) were also emailed to the participant to read, sign and return, along with the demographics sheet (Appendix H). The researcher gave a verbal explanation of the study to the participant before commencing with the interview to ensure that the participant was aware and understood the interview process. Participants were also informed that the interview was audio recorded and that they were able to withdraw at any time should they feel uncomfortable.

Probing questions were taken from the suggestions on the interview guide, but also informed by the understanding that the researcher was developing during each interview, as guided by the philosophical principles outlined in 3.3 and 3.4.

Thereafter the interviews were transcribed verbatim by the researcher.

All information regarding all participants was regarded as strictly confidential. The privacy and identity of all participants was protected by assigning them pseudonyms (this applies to both interview data and demographic sheets).

3.14 DATA ANALYSIS

Two-part analysis of the data, as guided by Dahlberg and Dahlberg (2020: 462), was conducted. The first part of analysis dealt with empirical data, while the second part of analysis allowed for input of secondary and external data sources to be included in the interpretation, for further understandings to be developed.

3.14.1 Part One of Data Analysis

Thematic analysis was conducted, using Tesch's method as a guide, with the assistance of NVIVO as a digital mechanism in coding for thematic data analysis. Steps in the analysis of qualitative data by Tesch (1990: 142-145) are summarised as follows:

The interviewer carefully read through all the transcriptions to familiarise themselves with the data and begins searching for topics. Similar topics were grouped and abbreviated as codes were used in finding similarities within all data. The researcher remained open to the emergence of new topics as more data were read and analysed. Grouping of related topics allowed for the development of categories and subcategories, or recurring 'themes', which served as an organising system for the data by placing data into appropriate categories. The data were then interpreted within each category to allow for reporting and write up of findings.

3.14.2 Part Two of Data Analysis

The second part of analysis comes at the recommendation of Dahlberg and Dahlberg (2020) as 'a third way' approach to qualitative investigation. Its purpose is to build upon the foundations of the first part by the utilisation of external sources, since "meaning is infinite" (Dahlberg and Dahlberg 2020).

Most of these sources were chosen by the researcher after 'part one' with the goal being the incorporation of theory or other appropriate information in relation to the phenomenon that could assist with the illumination of aspects of the phenomenon that remain vague or elusive (Dahlberg and Dahlberg 2020: 463) after the analysis of the empirical data.

This external data also included the addition of demographic data collected before the interviews, as well as information that could provide illumination on the meso-system and exosystem, based on information elucidated from the transcripts.

3.15 ETHICAL CONSIDERATIONS

3.15.1 Ethical Approval

Ethical approval for this study was granted by the Institutional Research and Ethics Committee (IREC) of the DUT (Ethics Reference Number: 240/21) (Appendix N).

3.15.2 Ethical Principles

Participation in the study was on a voluntary basis, with no coercion used to gain participation and no monetary or any other form of remuneration received by participants. Before commencement, participants receive a letter of information and informed consent that they were required to read, sign and return. Participants were assured that they could decline to participate and were free to withdraw from participation at any point.

All participant information is regarded as confidential, and participant identities were protected with the implementation of pseudonyms. The research and interview data were only accessible by the researcher and research supervisor. Hard copy data and password-protected electronic data (on USB) will be stored at the DUT Chiropractic Department for five years, after which all the data will be disposed of or deleted.

The four cardinal principles of ethics – autonomy, beneficence, non-maleficence, and justice (Artal and Rubenfeld 2017: 108) – were taken into account:

3.15.3 Autonomy

Autonomy means self-governance, which refers to a person’s ability to make decisions about their own well-being (Jahn 2011: 225). To respect this, participants were given an explanation of the research as well as a letter of information before informed consent was signed.

3.15.4 Beneficence and Non-Maleficence

Beneficence (promoting participant well-being) and non-maleficence (inflicting the least possible harm) promote acting in the best interest of the participant (Artal and Rubenfeld 2017: 108). As this study was interview based, participants were at no risk of being physically harmed because of the study, but participants were still given the option to withdraw from the study at any point.

3.15.5 Justice

The principle of justice accounts for fairness in the distribution of burdens, benefits and resources and requires that legislation is upheld in the making of decisions (Jahn 2011: 225). This principle was upheld, as no participant was turned away from the study due to race, background or gender.

3.16 TRUSTWORTHINESS

Trustworthiness of qualitative research refers to the integrity of the study's findings and requires credibility, dependability, confirmability and transferability as the main criteria that need to be met (Connelly 2016: 435). The development of an open reflective lifeworld research design was specifically born from the need to construct research that is both scientifically rigorous and reflectively open (Dahlberg and Dahlberg 2020: 463).

3.16.1 Credibility

Credibility is the believability of a source and thus the results of the study (Connelly 2016), and includes the appropriateness of the data collection and analysis to address the focus of the research (Graneheim and Lundman 2004: 109). To establish credibility, participants with various perspectives were interviewed to contribute to a richer viewpoint. Furthermore, interviews were conducted until saturation occurred to allow for sufficient data to be analysed and the researcher returned to the transcriptions regularly to examine the data rigorously several times in order to ensure adequate coverage of themes.

3.16.2 Transferability

Transferability is the degree to which the findings of a study can be transferred to other scenarios (Graneheim and Lundman 2004: 109). Transferability is subjective to the reader, but facilitation thereof by clear description of the studies context and details of the participants under data analysis will assist in that verdict. Detailed accounts are a part of the study and enhance transferability. Additionally, a lifeworld-led approach aimed to allow for research to be transferable by relating to, both, essential meanings and individual variations in experiences, by means of grasping essences (Dahlberg and Dahlberg 2020).

3.16.3 Dependability

Dependability is described as the reliability or stability of the data outcomes over time and in various conditions (Connelly 2016: 435). The data were collected within a narrow timeframe, to ensure comparability between data from different participants; data of experiences of a phenomenon is generally dependable over time.

3.16.4 Conformability

Conformability is the impartiality of study; it is the degree to which findings are repeatable and is comparable to objectivity in quantitative research (Connelly 2016: 435). Interviews were transcribed verbatim and detailed notes of research decisions were made and reviewed throughout the study to ensure a methodological audit trail. The data were also rechecked by the supervisor.

Furthermore, though the intention in lifeworld-led research is not to be wholly objective, ‘bridling openness’ (an attitude that prompts the questioning of one’s own understanding of a phenomenon) is used whereby the researcher moves between subjectivity and objectivity by being aware of their personal pre-understandings (Dahlberg and Dahlberg 2020).

3.17 SUMMARY OF THE CHAPTER

This chapter discussed the research paradigm and philosophical underpinnings of the research design and process in great depth. Ethical consideration, and trustworthiness of the study were also included. The ensuing chapter will present the findings of the study.

CHAPTER FOUR

PRESENTATION OF RESULTS

4.1. INTRODUCTION

This chapter will present the results of the eight semi-structured interviews that were conducted with South African CH sufferers.

Some basic information regarding the participants is outlined in **Table 4.1**.

Table 4.1: Outline of demographic information of participants of the study

Participant	Age	Gender	Race	Episodic vs Chronic	Healthcare system use
1	28	female	white	chronic	private
2	33	male	white	episodic	private
3	62	male	white	episodic	private
4	36	female	white	episodic	private
5	41	female	white	episodic	private
6	37	male	white	episodic	private
7	37	male	indian	episodic	private
8	20	female	black	episodic	public

4.2 MAJOR THEMES

After analysing the data, the following six major themes were elucidated:

Theme 1: The inexplicable intensity of the pain

Theme 2: The reality of a disease experience outside of head pain

Theme 3: Anxiety as a complexly recurring reaction

Theme 4: Perceptions of healthcare sought-out

Theme 5: The value of a diagnostic label

Within each major theme, sub-themes were also identified. The five major themes and their associated sub-themes that were extracted from the data are presented in **Table 4.2.**

Table 4.2: Outline of themes and subthemes

	Description of theme or sub-theme
Theme 1	**The inexplicable intensity of the pain**
Subtheme 1	*Barriers to conveying the true reality of pain to others*
Subtheme 2	*The limitations of traditional ways to describe pain*
Subtheme 3	*Comparisons to other headaches being ill-received*
Theme 2	**The reality of a disease experience outside of head pain**
Subtheme 1	*Changes in sleep*
Subtheme 2	*Impact on work and functioning*
Subtheme 3	*Differences in recreational activities*
Subtheme 4	*A plethora of emotional and psychological impacts*
Theme 3	**Anxiety as a complexly recurring reaction**
Subtheme 1	*Fear of a condition with associated morbidity*
Subtheme 1	*Background anxiety during interictal periods*
Subtheme 2	*Anxiously waiting for the next attack during active bouts*
Subtheme 3	*Generalised fear of having pain attacks in public*
Theme 4	**Perceptions of healthcare sought-out**
Subtheme 1	*The perception of the doctors asked for help*
Subtheme 2	*Experiences of delayed diagnosis, mis-diagnosis and self-diagnosing*
Subtheme 3	*Experiences of inefficient and inaccessible treatments*
Subtheme 4	*An undeniable financial burden*
Theme 5	**The value of a diagnostic label**
Subtheme 1	*Reassurance that the condition is not lethal*
Subtheme 2	*Finding hope for treatment with the new information*
Subtheme 3	*Having the words to help explain the condition to others*
Subtheme 4	*Diagnosis opens the door to supportive communities*

4.3 PRESENTATION OF THEMES AND SUBTHEMES

This section will provide a presentation of the study results in the form of expansion on the previously mentioned themes and subthemes (**Table 4.2**). Information from the transcripts is provided to substantiate these results.

4.3.1 Theme 1: The Inexplicable Intensity of the Pain

When asked to describe their pain with cluster attacks, participants used vivid imagery to try and convey the sensations through imagery, expressing that they have difficulty explaining what the attacks truly felt like.

Examples of the imagery used include:

"*I used to describe it almost as if it felt like there was a creature inside your head that was trying to get out…like claw its way out"* (Participant 1).

"The worst pain I ever felt. I've had a kidney stones so I would say it feels like I'm having a kidney stone in my left eye" (Participant 2).

"It was almost… uhh, you know they call it the beast?... it feels as if this beast is attacking you and you have absolutely no defence" (Participant 3).

"I've got two kids, two natural births. I'll do that any day of the week compared to these" (Participant 4).

"If you could imagine what it would feel like to have a hot flat red pick stuck in your temple repeatedly and then your eye..it feels like you just want to scoop your eye out to get rid of that" (Participant 5).

"It feels like there's a sosatie stick in my brain and its trying to push out through my skull…it's terrible" (Participant 7).

"It's almost like I have a piece of metal inside my head and someone is moving a magnet just tracing along my head and the piece of metal moves and attaches itself to the magnet but cannot free itself from my head…it's like there is something eating my eye…trying to escape" (Participant 8).

Most participants shared the sentiment that it was incomparable to other pain, as seen in statements like *"there is no pain that you [can compare it to that] even closely describes what it feels like*" (Participant 5).

Overall, the transcripts echoed a shared view of a pain level that surpassed any other pain they could even imagine which was expressed through statements such as *“it's the worst pain I’ve ever felt…there cannot be a headache worse than this”* (Participant 2) and *“I work with pain to a certain degree and know people that have gone through very bad, very painful experiences, and they’ll always say that cluster headaches is the worst pain they’ve ever had”* (Participant 6).

4.3.1.1 Barriers to Conveying the True Reality of Pain to Others

Associated with the difficulty of describing the true severity of their situation was participants’ avoidance of talking about the condition to others. Participants felt that others simply did not understand and rationalised the experience as *“everyone has had a headache before so they sort of think they know what it is and that they don't quite get that yours is very different from all the ones that they've ever had” (Participant 2).*

Another participant expressed this sentiment as *“they say they also get headaches every now and again, you know it's not the same thing”.*

At large, participants did not feel like explaining to others was a pleasant experience, and was something that was avoided in part due to their perception that, because of the lack of understanding, *“it looks [to others] as if you're dramatising a normal headache’* (Participant 3).

This was echoed in other transcripts with statements such as, *“talking with people is a waste of time…”* (Participant 2), *“it doesn't sink in any way so you just sort of stay away from too much detail”* (Participant 2) and *“I tried to avoid having to discuss the effects of cluster headaches…that's why I did that on that time, and I did it on plenty other occasions”* (Participant 3, explaining why he had told someone he would be late due to a flat tire and not told the truth about having a cluster attack).

There appeared to be a general consensus that only other CH sufferers can truly comprehend the experience, which was one of the reasons that participants felt grateful to be in support groups. This will be further discussed in 4.3.5.4.

Another reason for not telling others about their struggles was that describing the pain:

> *“makes them feel like they need to feel guilt”* (Participant 1).

This attitude seemed to extend to medical professionals as well: *“I don't want pity or sympathy, but just [for them] to understand” (*Participant 6*).*

4.3.1.2 The Limitations of Traditional Ways to Describe Pain

It was clear that participants had some difficulty expressing their true pain experience and, thus, the data were re-assessed to look for the areas that participants felt failed to explain their experience adequately. Three means of expression were found to have been insufficient to participants, namely the use of language, making comparisons to other pain experiences, and the use of traditional pain scale.

The quotes “*The pain is just indescribable …*”(Participant 5) and “*the actual sensation of pain … I can’t explain it. It's not something you can compare to anything else*” (Participant 4), depicts just how participants felt language and comparison failed to be enough, while *“I know they talk about a 10 scale but I would say that it's more than a 10 out of 10. I don’t think a 10 justifies it”* (Participant 6) makes it clear that a numerical pain rating scale does not even feel sufficient.

4.3.1.3 Comparisons to Other Headaches Being Ill Received

Personal pain experiences facilitate empathetic responses when relating to someone else in pain (Jackson, Melzoff and Decety 2005). In what appears to be an attempt to empathise with those that have CH, strangers and loved ones often liken their own experience with headaches to that of the experience of the participants.

“If I tell someone that I get CH they say they also get headaches every now and again. You know, it's not the same…” (Participant 4).

This type of comparison is often followed by well-intended, but tactless suggestions such as *“you should drink more water”* (Participant 3)*.*

“I’ve had people telling me that I must put my feet in Listerine and some of the weirdest things. I must go see a chiropractor and I must go see a homoeopath… and I must try aromatherapy and acupuncture…” (Participant 5).

Though some participants revealed an understanding as to the intention behind this action with the quotes of “*maybe it's because everyone’s had a headache before so* *they sort of think they know what it is"* (Participant 2), the general feeling of participants was one of disdain towards the comparison.

Participants feel that the comparisons highlight prompt comparisons that emphasise someone's lack of understanding.

"You know some people want to help but it's just that irritation of them not understanding what it is you're going through" (Participant 5).

An extension of these experiences is the disdain for the name 'Cluster *headaches'* as a whole – as it facilitates this comparison to other headaches, and is something they wish to avoid. A participant revealed: *"I've stopped using the term headache and now say it's a neurological condition"* (Participant 5) simply to avoid this.

4.3.2 Theme 2: The Reality of a Disease Experience Outside of Head Pain

While pain is an undeniably large portion of the CH experience, participants expressed that there was more to living with this condition than the pain alone.

"Don't get me wrong, the attack itself is a terrible thing to go through -but for me… the worst part is the day after" (Participant 4).

Transcripts showed that being in an active bout felt like *"it flips your whole life around"* (Participant 2) – essentially having the ability to change any normal day activity as expressed here:

"I had to be careful of where I was doing, be careful of what I was doing, at what intensity I'm doing it, who I'm with, and driving. You know driving a vehicle, I can't be driving alone" (Participant 3).

Some of these experiences that reappeared throughout the transcripts as common themes are discussed below:

4.3.2.1 The Effects of Cluster Headache on Sleep

Changes in sleep were common in most participants. The transcripts revealed two major effects:

First, a subgroup of participants avoided sleep in an attempt to avoid the imminent pain attacks that sleep was bound to set on. Fear of pain was a motivating factor to avoid sleep; Participant 5 mentioned, *"I'm scared to go to sleep".*

"I tried to stay awake as long as I could. That was a way of coping with, not the intensity, but the regularity of them ... if you don't do that and just think 'bugger that, I'm going to go to sleep when I want', you're just going to have an extra headache" (Participant 3).

"I mainly get my attacks at night so I tend to not sleep much … I try to keep myself busy with watching TV or reading, I read a lot, so I don't fall asleep" (Participant 6).

On the other hand, some participants found that the consistent attacks of sleep caused by the persistent wakeful periods after being awoken by pain, resulted in an increase of sleep or sleepiness overall.

I sleep a lot more when I am in cycle. So for example on a weekend, I wouldn't take a nap in the afternoon now, whereas when I'm out of cycle, I wouldn't do this because I'm not tired. You know, I'm exhausted from all the attacks." (Participant 4).

"I might be more tired than I would normally be when I'm out of cycle because maybe my sleep gets broken and things" (Participant 7).

Participant 6 explained the duality of the situation*: "Sleep is a definite trigger, but I'm in a difficult space because the more tired I get, the more sleep deprived and also the more likely I am to get an attack. So it's an up and down at night, but I try to avoid sleep as much as possible."*

One participant mentioned that he always tries to maintain a steady sleep schedule, even outside of active bouts, as changes in this have triggered cycles in his past: "*I think my cycle is brought on by, uhhh, disturbances in my sleep pattern … so I try not to stay awake till too late"* (Participant 7).

A major source of distress caused by these sleep disruptions and alterations is the resulting fatigue that many participants revealed to be a large and impactful struggle secondary to pain, when in an active bout.

"*I feel, you know, like I'm not doing what I'm supposed to…out of cycle its not a problem – I can do all that in a day without any stress, but in cycle, then I'm tired and irritable"* (Participant 4).

“I couldn’t attempt classes. I couldn’t do much, really, in terms of school. I couldn't concentrate. And when I tried to concentrate, I don't know, I forget what I was studying or what I was doing because of the brain fog and everything” (Participant 8).

Regardless of how sleep impacted the individual specifically, it appears that there is an obvious association of CH and sleep disturbances and alterations.

4.3.2.2 Impact on Work and Functioning

The fatigue mentioned in 4.3.2.1 is the largest cause of impairment.

Fatigue in the workplace was associated with an impairment of accuracy and efficiency, according to participants, which had further individual impacts.

One participant was able to make accommodations in order to address the times when his cycle would result in work-affecting fatigue, that they termed *‘inefficiencies and a lack of concentration’* (Participant 3).

"My last boss ... You know as you go up in the job, your job becomes more expensive and all that type of thing so I used to phone and say ‘please I’m in a cycle and I’m still working getting up at a normal time and working until 5 o'clock and I’m not going to be able to do any calculations’. I prefer not to and if I do any – just check and double check.” (Participant 3).

“I still don't get as much done because after the attack you're exhausted. It feels like you've run a marathon… and if I do get an attack at work…I am absolutely useless” (Participant 5).

“I’ve never really taken off work due to a CH. It's more the fact that I haven't slept the whole night so I can carry on with my work…but it's making it a lot more difficult and tiring and causes me some stress to keep on working and have to be on top of things but while being tired” (Participant 6).

Not all participants were lucky enough to have work accommodate them.

One participant mentioned that *“I had a cycle that lasted much longer than normal and it actually came to the point where my job was discussing medically boarding me because I was taking so much time off work because I couldn’t cope with no sleep”* (Participant 4).

"I wasn't studying as much as I should have. I even cancelled a module because it was really stressful" (Participant 8).

In part, this was due to the aforementioned sleep alterations as the same participant explained:

I'd be woken up at around maybe 3am so I'm up from 3am to 7am, I'm only able to sleep at 7am and wake up at 12pm – so I had to change a lot of things and I wasn't able to attend classes" (Participant 8).

Participant 4 also experienced disruption during their studies due to CH:

"When I was a student I missed a few exams because of it".

Interesting to note, is that participant 4, who experienced threat to her ability to work, found relief during the "work from home" Covid-19 period, explaining that:

"*There are days where I might not feel up to going to the office and facing people and having to get to work and putting on a smiley face and everything's fine. Where now I can sit here and my hair is all messed up in front of my computer and push through. So I haven't actually in the last three years taken a single day off work because of clusters"* (Participant 4).

Though fatigue was a major contributor to the work-related impairment, there were other factors that impacted employment. Participant 3 noted

"I could no longer work as a bartender and I could no longer shoot (photos) weddings – because no bride wants a photographer coming with an oxygen tank to their big day. It makes them feel like they need to feel guilt".

Another factor that impacted work was the unpredictability of pain attacks. Depending on job type, these effects can obviously vary, but participant 2 explained that there was anxiety related to:

"*having to reschedule your whole life"* and that *"I've generally…had to cancel appointments with patient bookings and stuff which obviously affects me financially because I work on a commission basis".*

4.3.2.3 Differences in Recreational Activities

Besides work and study-related activities, recreational activities were also affected.

The changes to recreational activity were mostly short-term, and occurred primarily during active periods.

> *"I had to be careful of where I was going be careful of what I was doing, at what intensity I'm doing it, who I'm driving with"* (Participant 3).

One aspect of the reduction is recreational activity was due to a preference for proximity to home and abortive treatment access:

> *"I mean everything, dude, I don't really leave like a 10km radius of my house because if I happen to have an attack I need to be able to rush back to my oxygen tank. Unless I have my like portable one in the car but having to…it's like having an extra limb that's massive so I think that was a big change"* (Participant 1).

> *"I used to make sure my schedule is very sort of local and close. Fairly close to my house like within… I wouldn't go further than about 20 minutes from my house – I like proximity to my oxygen"* (Participant 2).

Sport and exercise activities were an affected area for some during headache times, like for participant 2, who explained the effect of sleep on exercise:

> *"I think I exercise a bit less because if I have a rough night I don't get up early because I always exercise around five in the morning. That doesn't happen in those few weeks because I'm just irregular with it"* (Participant 2).

Additionally, participant 3, who was affected differently depending on his use of abortive agents that day:

> *"I would never do anything that I knew that if I get a headache I've got to get out…I wouldn't put myself in …even playing golf, I don't play golf. If I had a headache and had taken an injection then I could play a round of golf after that but other than that, no"* (Participant 3).

Another cause for sport avoidance was it being a potential trigger:

> *"So if I ever ran anything between 8 and 12km I got a headache so it was the intensity of it I suppose"* (Participant 3).

Another common event that was avoided was those involving alcohol.

> *Having to not be able to go out. Being able to party was a big one – I used to be a big partier"* (Participant 1).

“Other than that, I played sports but I didn’t go into the bar. Not that I couldn't stay away from alcohol, it's just that I was so scared to go in there and the smell of alcohol. I remember at one stage … I thought I got a headache because I smelled alcohol. That smell was so intense that it felt to me…that's how hard it could get me. I smelt it and then I got a big headache” (Participant 3).

“It affected my life in every way… emotionally, physically…I couldn't do the things that I used to do, the things I normally do, Couldn't go to the bar, couldn't go out with friends…it was hell” (Participant 8).

A few participants expressed the effect changes in ability to engage in activity ultimately having an effect on relationships:

“We’ve had one or two family events…I remember one function from my toddler, my toddler is two and a half now. So he had a little school function where I had to leave a bit had to rush home and they then had to catch a lift to get back…back home…so I couldn't be there” (Participant 2).

“It definitely affects relationships. I’m not keen to go out anywhere when I'm in cycle even though… I don’t have attacks during the day, typically. So I could go down to the restaurant or whatever if I wanted to but because I'm not feeling well and I’m feeling tired and then I don’t interact with people like I normally would out of cycle” (Participant 4).

Not all participants, however, expressed the same profound impact of CH on activities:

“When the headaches come I just try to deal with it. And when it's gone then I just get on, get on with life. You know I don't try and think about it and stress….I just try and continue as normal, so I just carry on with my week, like I cycle and I do MMA and stuff” (Participant 7).

4.3.2.4 A Plethora of Emotional and Psychological Impacts

During analysis of the transcriptions, it was noted that a variety of emotions were presented by participants, relating to a plethora of aspects of the CH experience.

Some of the recurring emotions and psychological impacts are discussed as follows.

4.3.2.4.1 Anger and Agitation

One of the first reactions that was noted by the participants was one of agitation and anger.

Participant 1 experienced this anger as

"misplaced anger because it's just like 'why is this happening to me?'" and being *"angry with the world for no real reason"* and noted that "*relationships change when you fight with everybody around you*" (Participant 1).

Another presentation of this anger relating to interpersonal erosion appeared as

"Shame the poor kids get shouted at a lot more because I've got a shorter fuse so things that normally don't bother me… it would set me off and I'd be fighting with them. And they look at me like 'but mom, that's not a problem normally, and now all of a sudden it's a thing'" (Participant 4).

Three other instances of agitation were noted: agitation as a symptom, agitation towards the condition as a whole, and agitation towards people who were not understanding.

I go through periods of ups and downs where I'm fighting a lot of aggression" (Participant 6).

"I feel aggravated, but I don't know what to do…I feel emotional…its destructive to my life" (Participant 8).

"So people tend to downplay it. So my family, especially my dad, I think I grew frustrated with him. I started moving away from him. Not just him, my family members" (Participant 8).

4.3.2.4.2 Hopelessness, Defeat and Suicidality

Another commonly mentioned feeling was one of being trapped due to pain and a lot of resulting hopelessness.

Some participants were able to be very candid about those feelings, such as, *"there are times where I just feel defeated and hopeless"* (Participant 6), while others expressed this much more graphically, as participant 3 did when explaining *“it's this feeling of being bound with this… with spikes for six weeks. You can’t get away from the pain. There is absolutely nothing you can do, and suddenly these headaches disappear and it feels as if someone has released you”.*

Similarly, participants expressed *"feeling like you're out of control constantly"* (Participant 1), and feeling “*desperate, like all of us are”* (Participant 3). Participant 4 felt “*like my body is letting me down”.* These experiences echoed in participant 7’s quote: *“You feel like…there's nothing you can really do…except just shake your head and scream and, I don't know, cry until the pain goes away”.*

It appears that from this hopelessness, breeds a more dangerous situation: one of depression and suicidality.

“Not being able to escape from them makes you feel like ‘Why should I carry on?’” (Participant 1).

“The hopelessness, it's like ‘will this ever stop? Is it going to stop?’ I get to a point where I just can't do this anymore. You're emotionally exhausted, physically exhausted. It's just like I say you get to a point where you say ‘I'm done, I cant anymore’” (Participant 5).

In fact, depression and suicidality was something that some participants spoke of with a frank tone of voice.

“I fell into depression. I really wasn't seeing the point of living anymore if I'm just in bed the entire time. I wasn't able to do the things I used to do. I wasn't myself anymore… so I’d say at one point I did consider suicide” (Participant 8).

“I was contemplating suicide because I just couldn’t see going through all of it again and again and again” (Participant 4).

While suicidality was not something all felt they experienced, it was something they seemed to be easily able to empathise with, having their own experience with defeat relating to the condition and its pain.

"I think having it be a condition thats knows as suicide headaches, it almost feels like its already blanketed onto you that there are many people who have passed away from these attacks, not because they will kill you but not being able to escape from them makes you feel like ‘why should you carry on?’. I think that's a big

mental barrier that a lot of people who have clusters should learn to just like… but it's difficult” (Participant 1).

“I’ve never considered suicide but I think if I was chronic…I don’t know if I’d feel the same” (Participant 3).

“I’ve never gotten to a point where I would say that I will get to a suicidal point, but its just that … feeling of helplessness. Even though you know it's going to end – because my cycles are usually between eight to twelve weeks at a time… you know it's going to come to an end but… it's a point where it's like I can't, I just can't do anything. It's like the moment you start feeling a shadow coming on or you start feeling that twitching in your eyes you are already exhausted…you start freaking out” (Participant 5).

4.3.3 Theme 3: Anxiety as a Complexly Recurring Reaction

Having anxiety associated with pain is not a novel discovery; what this study did reveal is that the anxiety that was coupled with their CH is linked to very tangible experiences that participants had, rather than an absent emotion that they experience as a side effect of a condition.

The recurrently mentioned experiences that occurred in which participants had anxious reactions are discussed as follows.

4.3.3.1 Fear of a Condition with Associated Morbidity

One significant source of anxiety was, when the pain first occurred, and no diagnosis or understanding was yet held, that the severity of pain was caused by a lethal or otherwise serious condition.

“None of us knew what was going on. We all actually assumed it was, like, maybe a tumour possibly” (Participant 1).

“She said ‘what's going on with you?’ and I said ‘I don’t know, I think there’s something seriously wrong’” … “That's when I went through and had my first CAT scan and there was nothing wrong” (Participant 3).

“My husband was concerned that you know, maybe a tumour, maybe it's an aneurysm, maybe there’s something wrong else in my head that keeps coming up” (Participant 5).

4.3.3.2 Background Anxiety During Interictal Periods

Multiple participants expressed the desire to live their life without having their condition affect every aspect of them.

“In general, I try to be as positive as I can and not think about it until it happens, which isn't always easy” (Participant 4).

“I try to block it out and not think about it when I’m not in a cluster” (Participant 6).

“I try not to be negative about the whole thing…So you don’t want to be like, miserable and stuff…When the headaches come, I just try to deal with it, and when it's gone, I just get on with my life. I try to continue as normal” (Participant 7).

This is easier to be done during inter-ictal periods, but what was revealed is that even without pain, the condition’s existence plagued participants regardless – anxiety of active cycles was a common theme amongst interviewee’s. Participants expressed the pain being on their mind, or in the back of their head, even during breaks in their cycles.

“I didn’t forget about the pain, even when I wasn’t feeling it up here, it was very constant [thoughts about CH]” (Participant 1).

“A lot of when it's behaving it is always in the back of your head and sometimes it just pops up in your mind to remind you that it might come back…it creates anxiety and dread thinking ‘this is going to happen again’... I do get a lot of flashbacks and then start doing the maths in my head about when is this about to start again, or when can I expect it to start” (Participant 6).

“It's gonna come again and you just have to wait for it to come again” (Participant 7).

One participant felt exposure to known triggers easily set off anxiety around its oncoming:

“You never know when it's going to come so you're always anxious. As soon as I start feeling maybe a bit down or stressed at work or whatever then I start worrying about it” (Participant 4).

Other triggers for anxiety surrounding cycles recurrence was that of other headache-type symptoms appearing. These feel like threatening omens to participants. Speaking of experiencing mild headaches out of cycle, Participant 5 spoke*: “You know, then you get a panicky feeling like ‘its coming’ but then nothing happens.”,* which was a thought reiterated by the quote, *“I’d say fear that it could come back because sometimes I just get a migraine from maybe stress or whatever, and I think that migraine will just stay for a month and become an episode of CH” (*Participant 8*)*

4.3.3.3 Fearful Anticipation During an Active Bout

During active cycles, the fear that participants expressed became more targeted towards the impending next attack. While the degree of anxiety experienced between participants was variable, it was evidently present nonetheless.

Participant 2 felt that *“living with it is obviously fine in the two years where I don’t have symptoms, but in those six weeks, I think it’s sort of like my anxiety levels go up a bit because you’re always expecting it to hit you…”,* while the fear was more intensely expressed by another participant as *“in a nutshell, I live in constant fear… so lucky for me, I’m episodic so I don't have that worry of you know living with it constantly, but when Im in cycle, it's a constant fear of the next and the next ”* (Participant 5). Another participant echoed the depth of the in-cycle anxiety *“[If I have a shadow], so a mild indication that I’m going to be getting a headache … it's not too severe… it's just like the anxiety that kills you”* (Participant 7).

The anxious anticipation seemed to induce planning for abortive actions. For example, participants 1 and 2 required access to their oxygen therapy

“I don't really leave like a 10km radius of my house, because if I happen to have an attack, I need to be able to rush back to my oxygen tank” (Participant 1).

“In the moment you just know ‘okay so where's my oxygen I need to get to the oxygen within the next 10 minutes’…I used to make sure my schedule is very sort of local and close…I wouldn't go further than about 20 minutes …if I’m in the middle of that sort of period. So I think that’s the other thing – like proximity to my oxygen” (Participant 2).

While participant 3 would pre-emptively have their medication accessible.

"And lights of course, no lights on anywhere. And I was even just scared to put lights on to take my pills so I'd put them out already" (Participant 3).

4.3.3.4 Generalised Fear of Having Pain Attacks in Public

Further to fear of imminent attacks, some participants noted anxiety of these attacks occurring in public. This anxiety did seem to be a major contributing factor to the isolation that occurred for participants during CH periods, and was influenced by the characteristic sudden-onset that the attacks have.

"You'll be fine one minute and next thing you're in a full blown attack so you don't want to go out. I'm scared to go to the shops because it has happened before that I'm shopping in spar and everything is fine and the next minute Im standing at the counter trying to pay and it looks like somebody beat me up so you just try and avoid things" (Participant 5).

"If I go somewhere I don't like to be in public spaces. Always to get a terrible cluster headache in a public space" (Participant 6).

Reasons for this fear were individualised, and sometimes deeply personal:

"I was always very anxious about having an attack in public and feeling unsafe because you're suddenly out of control. I specifically can't see very well when I'm having an attack, or speak" (Participant 1).

"Um, it's a horrible feeling. I can give you an example. In 2018, I had a very bad cycle in a period of over four days. I only had 6 hours of sleep so I was extremely sleep deprived. I had one attack on the next… at a constant shadow…eventually I went to the pharmacy close to my house and I walked in and I was crying and I was standing at the pharmacist and I was begging him to give me something and the way people were looking at me it was, like you know, what is wrong with this person. It's like I'm standing there in tears, I'm emotional, I'm in pain. People don't understand. So that is always what comes to mind when I think about going out in public is the way people were looking at me. I was like, kind of like this feeling that I was a drug addict and I was in the pharmacy trying to get some kind of things and they don't understand what is actually happening" (Participant 5).

"I'm kind of all over the place and it's embarrassing but I don't like people to see me when I'm in that situation… During an attack I tend to be really agitated. I will

be pacing around. I'll be hitting the walls, uhm, banging my head against the walls or the door frame just to try and get to distraction. Having cold-cold showers in the winter, ice-blocks until it hurts more or tries to have it hurt more than the headaches I have caused quite a free bruises and slits on my head sometimes just by how hard I bang my head just to get a distraction from the pain… But people always want to help, which sometimes is quite difficult. They take offence when you're sort of like 'listen i just need to deal with this'. Afterwards people always feel bad for you and then you feel bad…it does strain the relationship… I feel very vulnerable when I get attacks and that's why it's difficult to be in a position with people around me" (Participant 6).

4.3.4 Theme 4: Perceptions of Healthcare Sought-Out

Participants revealed information about the healthcare they received for their condition both indirectly and in response to direct questions. The opinion appeared to be that the care is known to be poor and inefficient, and those that felt like they received adequate care were aware that this was not a universal experience.

Multiple aspects contributing to these experiences that recurred in the transcripts are discussed below:

4.3.4.1 The Perception of the Doctors Asked for Help

The perception that participants had of the professionals that treated them was highly individualised, though some similarities were able to be drawn out.

One common subtheme was the perception that their doctors were unimpressed when presented with a CH patient to manage; similarly, participants perceived that they were unimportant to their practitioners.

Participant 6, for example, stated that *"I do feel that people are… when they get confronted – the neurologist – and think cluster headache, they do seem to be a little bit irritated. I can see it's not the kind of patient they like to manage…Maybe it's an irritating kind of patient to have because you don't know what's going to help and they're probably going to keep on complaining. You're not going to be able to get them better necessarily".* Contrastingly, participant 7 perceived his doctor as "*conceited"* when he appeared too confident in his treatment prescriptions, stating *"He seems like someone who thinks he knows everything. I suppose he is a*

Professor of Neurology in South Africa so you would understand why he has that kind of attitude but he was very kind of confident that whatever medication he was going to prescribe for me, and the injections in my neck…that it was going to work and all of that stuff and I think that's one of the reasons I stopped going to him because I feel like someone that thinks he knows everything but he didn't actually know everything". Participant 4 mentioned *"to some… a lot of times, I feel like I'm just a number…there's no real interest in you as a person and what you are going through".* Further to this sentiment, like participant 4, others also perceived a lack of empathy, and felt like they were being *"brushed off":*

"It's almost like – not all of them but a lot of them – have this attitude of 'it's just a migraine' and 'everyone gets them' so like kind of almost brushing you off a bit… it's not always understanding" (Participant 5).

"It was really bad. The first time I saw a doctor for my headaches it was during exam season so when I get there I tell him that I'm having really bad feelings and he tells me that they're just migraines…and he just dismisses it" (Participant 8).

"I wish they had listened, I really wish they had listened. Just take some time to listen, most just dismiss it or don't just rush… because the diagnosis is just there, just listen to my symptoms" (Participant 8).

Participants expressed their disappointment in their perception of professional's empathy, often stating that they wished that they "understood" what they were going through more, or that they felt very "dismissed". For example, when asked directly what they wished their healthcare practitioners knew, participant 4 explained: *"The pain is unbearable. Like, I wish they would – I don't know. I feel like Dr [retracted], he's just like, ugh, you've got cluster headaches, here's some tablets, it'll go away. You know, it's not that simple!"*

Participants 3 and 8 both explained how being dismissed by healthcare practitioners was worrisome, because they were craving help from them, and didn't know where else to look if they weren't assisted by their medical doctors:

I'll tell you one thing, and it may sound selfish, whatever, but I would have appreciated it if one of them … had phoned me … I didn't get that from my GP, neurologists, secretary, at all. When, the first time that the cortisone was prescribed ... I was given them, there's the dosage, get on with it. No one followed up, so ... the *follow up of "this person is really concerned". It's almost clutching, I'm probably sounding to you, I'm clutching at any straw I can for support with this beast because although your people at home know you're getting these things, they can do nothing. But when you start getting to the health professionals and that, they're a bit closer to some kind of ... you know, it's almost like a person drowning and you were just looking for anything to hold on to so that this thing doesn't overwhelm you completely. That's how I feel about them not coming back to me: 'Do they really care? And if they don't care, how am I going to get out of this?'"* (Participant 3).

"Very dismissive. It's like they didn't want to listen, they didn't want to hear anything about it. I was almost like they were ganging up against me, in a way that's just how it felt. And it made me feel really helpless because these are the only people that can help me, because there are professional doctors. So if I'm not seeking help from you guys, where am I supposed to get help" (Participant 8).

The perception of a lack of understanding, however, was not limited to an understanding of their pain and subpar empathy, but extended to another common perception that participants held of their doctors – that they lacked knowledge, and that this led to inadequate diagnosis and treatment of the condition.

"It actually seems like most people with clusters know more about it than any doctor we've been to, and honestly, I can still say that to this day. Like all of us know more about this than any doctor and that's really friggin sad" (Participant 1).

"Sometimes they are understanding but it has happened before that I have seen a doctor, just a GP, to try and get a script for oxygen and I actually had to explain what cluster headaches were, they did not know what it was" (Participant 5).

"I think most people don't really know how to manage cluster headaches according to the literature. I was fortunate enough, some of the barriers I could overcome because I am a medical professional myself. So just to get access to oxygen is extremely difficult, especially if you are being managed by a GP that does not have knowledge to properly manage the situation…" (Participant 6).

Ultimately, participants did not feel adequately supported.

Another common thread was the perception that some of the more highly specialised physicians were untrustworthy and out to exploit a vulnerable population.

Participants 1, 3, 5 and 6 had all been to a specific headache clinic and expressed multiple concerns around the practices there.

“I ended up going to the headache clinic in Johannesburg where Dr [retracted] diagnosed me with cluster headaches….I mean he’s notorious in the industry as being a terrible doctor. Most cluster headache patients would never go near him with a 50 foot pole…And I mean their goal is, they’re like a cult, man. They’ve got people on instagram who find cluster headache sufferers and they send them a message to be like ‘I found a cure for your cluster headaches’ you have to go see Dr [retracted] [retracted] ... he claims it's the cure for cluster headaches. He claims it to all CH patients. He’s like ‘I have the cure. Come to me and you will never have another cluster headache again’. So I almost fell into that trap and it felt very shifty so I went online, found a bunch of CH groups and spoke to them about it.. They were like ‘stay away from Dr [retracted] he's mad!’ so I immediately stopped going to him” (Participant 1).

“I cannot [say too much] for fear of being found out of saying these things directly, but I went to him once…and I was desperate, like all of us are…My wife at the time was absolutely against it. She said ‘I’ll go with you, I will hear what he’s got to say but he’s not touching you, he’s not picking up a knife’, because she’d heard other stories” (Participant 3).

“For me the biggest impact was the headache clinic…It cost a fortune…I was there for four days….for them to do tests… and then at the end of it being misdiagnosed… you see this world renowned neurologist and he tells you you suffer from tension migraine and gives you a stupid plate in your mouth that gives you blisters and actually made it worse…You go with it and then you realise it's not working so you start thinking to yourself ‘does this guy really know what he’s talking about? Does he understand? Is he just out to make money?’. You know, that's the feeling that I had afterwards. I just felt that he was out to make money, He is still out to make money off people that have a real condition. Honestly they’re just looking for someone to help, someone to understand what they’re going through, and they're just bagging money on them” (Participant 5).

“It wasn't a very pleasant experience…He ended up not making the correct diagnosis. And they diagnosed it as tension headaches and I have too much tension

in my neck muscle and I have to wear a certain brace in my mouth which was expensive so it's sort of fun to make this diagnosis and make this brace for you and uhm yeah they just hear what they want to hear” (Participant 6).

This was, however, not the only specialist that concerns were expressed over. Participant 4, for example, had sought help from another ‘headache specialist’ and explained it to be a traumatic experience that had a “profound personal impact” on them:

> *“Dr [retracted]… I walked into his office. I had to pay cash…he literally saw me for 10 minutes. He did an ekg and asked me like 20 questions and then he told me to come back the next day. I went back the next day and he told me ‘oh you've got stress headaches’. Okay well, it's not the first time I've had that diagnosis, and I don't agree with it so what else can we do…he then asked me how many pain pills I take and I told him well, when I'm having headaches I take about 100 pills a month and then he said ‘well, you’re addicted to medication so I'm not going to treat you any further’. And he refused to see me until I stopped taking the medication. And I stopped taking the medication but I never went back to him because I felt like he wasn't trying to help. He was just judging me… An appointment like that had a very profound personal impact on me because my mother was a drug addict. A real drug addict. Having to grow up with that and then being accused of that after not being that was terrible for me…”* (Participant 4).

Though not experienced in specialist care, personal comments by healthcare professionals who were missing the mark were also made to Participant 8: *“I was called fat. I was told I had an allergy. I was asked all sorts of questions…”,* and participant 1 expressed gender based discrimination: *“Most other doctors who I’ve gone to question that I even have clusters because I’m a woman”* (Participant 1).

Many did acknowledge that they know that professionals could not be perfect or know everything, but the desire for more informed care continued.

> *“It's unrealistic to expect everyone to have all of the knowledge, so I understand why there was a long period where I wasn't diagnosed, but maybe if I had been asked different questions I could have given different answers and gotten a diagnosis sooner”* (Participant 4).

“You're a doctor, you should know this. I'm not saying they should know in detail, but you should know what it is if you're a doctor, not let the patient explain to you…I'm coming to you for help” (Participant 5).

4.3.4.2 Experiences of Delayed Diagnosis, Mis-Diagnosis and Self-Diagnosing

Some of the common experiences mentioned by the study participants revolved around misdiagnoses and the difficulties in finding answers. The experiences are elaborated on in this section, along with the quotes from transcriptions to substantiate this. Preceding this, some of common experiences have been condensed and tabulated in **Table 4.3**, to easily demonstrate some of the shared experiences of the group.

Table 4.3: A summary of experiences mentioned by participant, relating to delayed-, mis- and self-diagnosis of cluster headaches

	Mentioned at least one misdiagnosis	Made a self-diagnosed	Is healthcare professional themselves	Visited a h/a clinic or h/a specialist	Misdiagnosed at the headache clinic / by specialist
Male					
Participant 2		x	x		
Participant 3				x	
Participant 6	x	x	x	x	x
Participant 7		x			
Female					
Participant 1	x	x		x	
Participant 4	x	x		x	x
Participant 5	x	x		x	x
Participant 8	x	x			

Many, but not all, participants experienced misdiagnosis for a considerable time before having their condition explained accurately. As previously mentioned, participants perceived a lack of knowledge being a barrier, here in terms of receiving a diagnosis:

“So I went to go and see a few GPs. I actually didn't know where else to go. None of them knew what I was talking about” (Participant 1).

“I’ve seen neurologists, I’ve seen headache specialists…if I move or change medical aid or whatever then I might see this doctor and we start the whole process do blood tests and scans and then they send me to a neurologist and then ‘oh you’ve got migraines, oh you’ve got stress headaches, oh you’ve got this, you’ve got that’. So I’ve been through the mill quite a few times with a few different types of doctors…It took a very long time for me to even get a diagnosis…in the end it was actually my primary doctor because I kept on going back to him… He mentioned cluster headaches and that’s when I started researching and you know, the more I read about it, the more I was like, well, this is what's happening to me” (Participant 4).

“I first went to a GP and then…I went to St John's clinic…and she tried referring me to a headache clinic inside Chris Hani Hospital…It was really frustrating because it took a very long time for me to get help” and *“You know when I went to Bara (Chris Hani) I don’t know what's happening in that hospital whether it's the doctors fault or whatever but all patients are checked outside. Your checkup is outside so you don't sit in a room with the doctor and just have a full body check out, it's outside and you're always sent back home. I don't know how many times I had to go back to bara to be taken seriously. To this day I've never really sat with a doctor in a room and had a full examination so I think their system needs to improve”* (Participant 8).

Participant 2 was one of the participants who was diagnosed promptly, acknowledging:

> *“I was lucky. I was really, really one of the lucky ones. The people knew what it was… I think they listened to me and they seemed like they knew what I was talking about, whereas I think sometimes that’s not the case for many people. But I was lucky, I felt happy with the management or that sort of interaction all around”* (Participant 2).

This this further confirms that the difficulty in obtaining diagnosis is a well known one within the community.

The two participants who were interviewed were medical professionals themselves and able to obtain diagnosis from exposure to class material and other professionals in the medical field due to proximity:

“In terms of me getting the diagnosis, I’m very fortunate that I went to my GP and she immediately said she thinks it's CH… and then I got diagnosed mainly because I was a student and there was someone lecturing on this… I think she was a neurologist. So I just went and asked her, ‘listen, these are my symptoms. You were talking about the headaches, is that it?’ and she said ‘yes, absolutely, textbook’. So in terms of diagnosis, I was lucky. It was spot on from the start” (Participant 2).

“I actually made the diagnosis myself. I did study medicine and when we talked about all the different kinds of headaches I realised that I had this diagnosis” (Participant 6).

Many other participants diagnosed themselves. These self-diagnoses were often following years of desperation and then followed by confirmation from medical professionals, as was expressed by Participant 5:

“I’ve been getting them since I was 15…[but] only properly diagnosed in 2018. I’ve been told that it was tension headache, its migraines, its tension migraines, its sinus, so eventually I started doing my own research”.

“I’ve never had a doctor diagnosing me and explain it to me. I’ve just been doing my research and reading on the groups and analysing my symptoms and just self-diagnosing based on that so I've never really had anyone explain as a professional to me” (Participant 8).

Participant 1 explained a shared sentiment amount participants well here:

“I did some googling, because that's what our generation likes to do, and I found that I seemed to match quite a lot of the symptoms”

Those without medical backgrounds sought out information about their symptoms and self-diagnosed by researching on the internet. It was also mentioned that this self-diagnosis and internet research was not necessarily well received by physicians. Participant 8 explained a time that she tried to explain that she felt she might have CH and not migraine as she was being told, but was told “‘*all kinds of patients that come to me about their google searches’”,* and was then fully *“dismissed”.* Participant 5 even knew well enough that physicians had this distaste, and altered her approach to the physician carefully when presenting her information, symptom and suspicions, in order to not be dismissed as quickly- *“I didn't want to go telling* *him ‘I found this on Google’ you know, that's the last thing you want to tell a doctor”* (Participant 5).

4.3.4.3 Experiences of Inefficient and Inaccessible Treatments

Preceding the discussions about specific themes, a summary of the groups of treatments tried, used and mentioned by participants can be found in **Table 4.4**. This information will hopefully provide some context to information that will be presented thereafter.

Table 4.4: A summary of treatments that have been mentioned to be explored by the participants

	Energy Drinks	***NSAIDs or Opioids***	***Prescription prophylactic medication***	***Oxygen***	***Psychedelic mushrooms (psilocybin) or LSD***	***Triptans***	***Other***
Participant 1	*x*		*verpamil,* *Trazadone* *pregabaline*	*x*	*Mushrooms* *LSD* *CBD*		*x* *'Epilepsy medication' – presumably Topamax*
Participant 2	*x*	*x*	*trepiline*	*x*		*Maxalt*	
Participant 3	*x*	*x*	*trepiline*		*Mushrooms*	*Suma-triptan*	
Participant 4	*x*	*x*	*x*	*x*	*Mushrooms*		*Vitamin D3 regimen*
Participant 5	*x*	*x*		*x*	*Mushrooms*		
Participant 6	*x*			*x*		*Maxalt*	
Participant 7	*x*	*x*		*x*	*Mushrooms*	*Maxalt*	*Sinol*
Participant 8	*x*	*x*					

Treatment of CH is notoriously difficult, and this was confirmed by the variety of experiences that participants shared about their journeys in pursuit of pain relief.

Many treatments that are used to treat other headaches do not work for CH, which was well reported by participants.

"I think a few panados and hope for the best, which obviously didn't work at all" (Participant 2).

"I used to take migraine kits and I'm like but this stuff is not working, its not doing anything" (Participant 5).

Some participants explained that they even continued to take medication that they knew would not help, simply due to desperation and fear of pain.

"I never took nothing, I couldn't. I couldn't face a full two, three hours of this…" (Participant 3).

"I started with regular paracetamol. It wasnt really helpful at all. I find myself taking three grandpas in one go trying to lessen the pain as much as I knew it wouldn't help. I don't know, I just had to" (Participant 8).

Participant 6 who explained his mismanagement when he was misdiagnosed further confirmed the importance of an accurate diagnosis:

"I had seen help before I knew what was wrong and wass just very wrongly managed. I even was at the headache clinic in Joburg and they also didn't make the correct diagnosis… I understand there is a big paucity of knowledge in all medical fields where people don't really know much about it. When a patient suffers from it, they don't understand actually the helping and treating of the patient." Additionally, participant 1 explained her difficulty with obtaining the correct medication because of sex-influenced hesitancy to diagnose her, correctly, with CHs: *"And so I go through like, multiple different medications until they finally decide that I do actually have clusters. It's not just a man's disease"* (Participant 6).

Another desperation-induced behaviour that was described by at least half of the participants was one that has also previously been described in the literature (Andersson, Persson and Kjellgren 2017): the use of psychedelic and illicit substances for pain management in CHs.

"I have tripped on acid (LSD) but it makes me nervous, so I microdose instead" (Participant 1).

"I just couldn't take it, it was too much, so I started the mushrooms" (Participant 4).

"My last two cycles I have been microdosing [on psychedelic mushrooms] as well" and *"the psychedelics obviously, you know that seemed to have helped me …that's obviously a bit more tricky and not quite legal so that's what we're resorting to"* (Participant 5).

"...the mushrooms are a big thing so I've been using mushrooms as well" (Participant 7).

The barriers and difficulties to the construction of an effective treatment plan described by participants were multiplex, and while inefficacy of drugs pre-diagnosis was a problem, inefficacy of prescribed medication post-diagnosis was equally problematic, along with their associated side-effect profiles. This often led participants to feel sceptical about new treatments, as described by Participant 7:

"*With all of the things, it's like it works then it doesn't know if its working so there's that really you know you're 100% sure that's gonna work".*

The problems that participants experienced with some of their treatment prescriptions are elaborated on in their statements from the transcriptions:

"I started this epilepsy medicine… and it really didn't work for me dude. It sent me, it made me feel like I was going crazy which really, like it really made me not be and I still suffer from it now. I can't really string sentences together very well. I stutter quite badly. My brain…huh?" (Participant 1).

"So one of them was Maxalt, which is a sort of triptan, which is classically a migraine medication but that made no difference to me." (Participant 2)

"The trouble with oxygen, strangely enough, is it feels to me like – no oxygen, I've got the headache solid non-stop for an hour and then it sort of slowly turns and gets less and less and less for the next hour or so…the funny thing about oxygen is it feels like its just pressing pause on the headaches actually… it's like okay, cool, the headache is gone in 10 minutes, but then an hour later I just wake up and it's back just as strong as before. So that's the oxygen, it's like a temporary stop" (Participant 2).

"I did try trepiline as well, that the doctor prescribed and it felt like it actually did work in that cycle, but then the next cycle it didn't work at all and made like no difference so that was a little frustrating" (Participant 2).

"I tried some other pain medication…I think one of them was Perlexiss or something like that – that gave me high blood pressure so I stopped taking that" (Participant 4).

"So you get your hopes up and you think 'oh, this is going to help me and then it doesn't'. You're back where you started, you're back in pain, you're back feeling miserable. And there's no hope inside" (Participant 4).

"The prophylactic actually seems not to work for me so I'm mainly using abortives and I definitely need to overuse a lot more than one should" (Participant 6).

"I don't know, you take trepiline, you get tired as hell, you can't function, whatever" (Participant 7).

"I had the injection a few times…and again, it's like sometimes it worked and my cycle ended, sometimes I'd go for like two injections, but then I stopped going for it because one year I went for the injection and the next day I got such a severe headache and then my cycle just continued. So I just figured that this injection is just like everything else, you know, it works and sometimes it doesn't" (Participant 7).

"Last time I went to the hospital I was put on prednisone. That was really helpful… then I moved to trolic… I was still the same but when my dosage decreased I could feel some heaviness behind my eye and sharp pain…" (Participant 8).

In addition to their inefficacy, some difficulty with using drugs at safe dosages was also expressed:

"You know, even if I took it… I remember asking the pharmacist 'can I take two at a time' and he laughed at me. He was like 'are you serious', and I'm like the one doesn't do anything whatsoever" (Participant 2).

"Well…a lot of these drugs… you have a maximum dose that you could take in 25 hours… I know very well the consequences… but you sort of don't care…" (Participant 6).

Another complicating matter was accessibility to treatment; this was also a multifaceted problem, encompassing access to prescriptions due to cost and effort of consultation or acquisition of medication, lack of practitioner knowledge about alternate prescriptions (such as for oxygen), and national restrictions on the availability of certain medications.

Participant 5, 7, and 8 mentioned the difficulties of actually attaining treatment, due to administrative processes (such as going to physicians, organising oxygen equipment, obtaining letters of recommendation) being overwhelming:

"I just found the whole process was just a bit of a schlep" (Participant 5).

"... now go to a hospital to get a letter of recommendation or whatever letter for medical aid … it's such a mission just to get an injection" (Participant 7).

“It's such a mission to get prescription for maxalt and then you have to pay for this stuff out of pocket and it's not cheap …” (Participant 7).

“I would say within myself I just started giving up … whenever I have a follow up, check up, I’d be too lazy to go ... I wouldn't want to go. That it almost hindered me from getting treatment” (Participant 8).

In particular, the barriers to using oxygen to treat cluster attacks was a common theme. Participant 1 and 2 both mentioned the oddity of lugging a tank around:

“I could no longer shoot (photograph) wedding because no brides wants a photographer coming with an oxygen tank to their big day” (Participant 1).

“Put it (the oxygen tank) in the car going on holiday with a massive oxygen tank” (Participant 2).

Other factors that influenced the precurance of oxygen treatment included lack of practitioner knowledge on how to prescribe and obtain oxygen for patients, the cost of oxygen (discussed in 4.3.4.4.) and access limitations at the time of the Covid-19 pandemic.

“There’s not really a lot of people that are experts in the field. There's definitely a lot of barriers to get proper treatment…I think most people don't really know how to manage cluster headaches according to the literature. I was fortunate enough, some of the barriers I could overcome because I am a medical professional myself. So just to get access to oxygen is extremely difficult, especially if you are being managed by a GP that doesn’t have knowledge to properly manage the situation… There's a lot of barriers, I imagine for the people that dont have the benefits that I do” (Participant 6).

“They were out because of it was the middle of a covid wave, so oxygen was hard to come by” (Participant 2).

“Then obviously covid happened and then there was just a complete shortage of oxygen so I couldn't get oxygen from the place that I used to get it …”

“My wife does like charity work… and was assisting people in our area with covid packs, including oxygen … so she had access to oxygen during the covid period” (Participant 7).

Another topic that did come up, though not often, but may be worth the mention, was some disappointment by physicians lack of holistic treatment presentations:

“There are the treatments we give patients, but why don’t we even mention the treatments patients give themselves, you know, because I treat myself much more often than a doctor treats me. So that I thought was a little tone deaf, because they never spoke in the article about energy drinks … surely it deserves a mention” (Participant 2).

“These other things are so much more convenient and there’s a chance that they work and it’s going to cost me a quarter of what the neurologist is going to prescribe so why not give me those options?” (Participant 7).

Here, it also feels worth the mention, that all eight participants used energy drinks as an abortive treatment with at least some success, which is a treatment that is usually shared among sufferers on CH forums and support groups and rarely presented as an option by practitioners.

The frustration at the lack of presentation of treatments extended into that of lack of oxygen presentation as well for participant 2, who explained that:

“No doctor, nor the neurologist suggested oxygen, which I found interesting, because it’s like, why the hell wouldn't you suggest it because it's the cleanest way and very quick relief so I googled it and saw that oxygen was one of the things on the list” (Participant 2).

On the other hand, participant 1 expressed some disappointment in care of psychedelics and illegal treatment:

“It would be really cool if any doctor would be willing to do a trial or like, what will work into the whole understanding why psilocybin or LSD works for our condition”.

The last important aspect of this sub-theme is that in acute pain settings, such as the hospital emergency room, another cause of inadequate treatment is lack of dedicated and specific protocol that is appropriate and time-sensitive. Only two of the eight participants who had sought acute pain relief from the emergency room discuss as follows:

"Also in an emergency setting, because when you get to the point where you go to the emergency room they say wait but they don't understand the urgency of having to try and trying to help with this" (Participant 6).

"So when I went to hospital I knew that I just wanted oxygen right? Because apparently.. I never tried oxygen before this experience. But from every- all the reading and stuff that I've done, I knew that oxygen we had the best chance of getting rid of the headache. So when I went to the hospital I told the nurse, 'listen, I suffer with cluster headaches and I just need to get oxygen' and then they made me fill out paperwork and give them my medical aid details … that tool like half an hour, 45 min or something. And then when all that was done, they took me to casualty and gave me oxygen and within 15 to 20 minutes, after 3 hours of suffering, the headache was gone. I mean, yeah that was my experience – it was terrible" (Participant 7).

It is worth mentioning that participants also sought out advice and guidance on treatment options from support groups and internet sources. This is further discussed in 4.3.5.4.

4.3.4.4 An Undeniable but Variable Financial Burden

Many chronic illnesses have a considerable financial burden. This is especially true in cases such as South Africa, where privatised care makes the cost of treatment the sole responsibility of the patient, and where the population have a variety of socioeconomic backgrounds that influence their quality of life.

Transcriptions revealed a varying degree of burden among participants with varying financial factors that were patient-background and condition-detail dependent.

When asked about barriers to treatment, participant 1 answered:

"Money. Distance. I live in a small town … and my neuro is in Cape Town and it takes me like an hour and a half to get to him and then it's like 2 grand just to see him, and that's minus any medication" (Participant 1).

This quote explains the multifactorial financial burdens that existed well; some main financial burdens mentioned throughout transcripts were the cost of doctor's consultations, transport to consultations, testing required and then the continuous cost of abortive and prophylactic treatments.

“I mean, oxygen for somebody on my side of the spectrum, that there are many on the more chronic side of the spectrum, they spend up to like, easily six grand a month on oxygen alone” (Participant 1).

“... some of the oxygen places are super expensive and then in the middle of the covid wave oxygen was hard to come by and you had to buy a big one …” (Participant 2).

“At first I was using Maxalt … but they are very expensive, and you only get like four in a box so R700 for a pop is not very economical if you have three/four attacks a night” (Participant 4).

“It can become quite expensive. For example, with the oxygen. Um, this is without doctor’s visits and just like being in cycle um oxygen is about R350 and on the bad cycle, those bottles can last you maybe three days, if you’re lucky. So three to four days your R350 out. Uhm, the monsters that I buy … up to six a day when Im in cycle … you know R15 a tin, becomes quite expensive and that not even the doctors fees, Then my last neurologist the whole, exploding the hospital stay and the tests done in the hospital – just the neurologist was about R8 000 just for his visit and consultation in 2018 … can be quite bad” (Participant 5).

“I went and got a few quotes to have it refilled and it was like R1600 for that oxygen tank … it lasted maybe three or four headaches … so I felt like, you know what, if i was really balling then maybe id keep a stash of oxygen tanks at home, but it's a bit expensive … plus with oxygen tanks you have to rent them” (Participant 7).

“Transport was an issue too sometimes” (Participant 8).

Another influencing factor for those with the episodic subtype is some difficulty in accurately predicting active bouts – this influenced participants ability to plan for the expenses.

“I mean, if you could plan it, you know, if I could budget for it then maybe it wouldn’t have such a big impact but if my cycle starts, like now, it started in the middle of January, I wasn’t expecting it … so now I have to get medication, I have to get the vitamins I need … even if it's just the Monsters of Red Bull, you know it’s R10 a can, but if you go through four, five cans a day, that's R50 a day that most people

don't have extra in their budget, you know. You live according to your means" (Participant 4).

"Having to buy pain medication is expensive … I had to pay cash for my doctor's visits and all of that. Just the Vitamin D3 regimen … it's an expensive thing to do. It's about a R1000 for one course" (Participant 4).

"All of us live on a budget, so when it starts you really start stressing about, you know, you need to figure that in you need to calculate that into the budget. You need to calculate an additional two, three grand in your budget this month, whatever you're going to need and if there's a doctor's fee or say it's quite stressful, especially if you're not planning on it" (Participant 5).

Alongside these complaints, many of those making use of medical aid in the private healthcare sector complained of its inadequate ability to assist with the condition.

"Gosh, the fact that there is no like medical aid in the country that will cover the costs …Yeah, dude, so I mean, some medical aid would be [retracted] amazing" (Participant 2).

"Just the vitamin D3 regimen to buy that – which is just vitamins…it's an expensive thing to do…and it's not covered by medical aid even if you have medical aid" (Participant 4).

Participant 2 also reminded us of the financial impact of CHs in terms of its threat of loss of income, as discussed in 4.3.2.2.:

"I had to cancel appointments with patient bookings and stuff which obviously affects me financially because I work on a commission basis" (Participant 2).

Those that were well-equipped to deal with the financial burden, were aware that it could have the potential to be very expensive for others without the same privileges, highlighting the variability of financial burden in a country with such variable socioeconomic backgrounds, but also the clear degree of cost, if it is even significant for those in good financial positions.

"I was very fortunate, I have very good medical aid" (Participant 3).

"Look for me … I can definitely afford it, but I can definitely imagine that it can be a problem for some people because it can be very expensive" (Participant 6).

4.3.5 Theme 5: The Value of a Diagnostic Label

Diagnosing conditions accurately is important in order to be able to provide specific and most effective treatment.

Since many participants expressed a difficulty in obtaining an accurate diagnosis, they were asked how a diagnosis eventually assisted and/or affected them. The common themes amongst participants are discussed in the following sections.

4.3.5.1 Reassurance That Condition is Not Lethal

Due to the severity and degree of pain that they felt, as well as overall ‘strange’ (when compared to other, more common and well known headache disorders) presentation, a significant portion of participants felt their life may be in danger, or that they may be suffering from a dangerous or lethal condition, as discussed in 4.3.3.1. Receiving a diagnosis that explained their symptoms was a significant help in reassuring them that this was not the case. The fact that their symptoms did not mean they were in danger was appreciated.

“The label actually helps to go, ‘this is like a well known phenomenon, it's not like there is something sinister happening’” (Participant 2).

“Just putting your mind at ease a bit” (Participant 5).

4.3.5.2 Finding Hope for Treatment with the New Information

Since participants are not fully satisfied with the treatment they receive from healthcare professionals, many often need an accurate label to do research for alternative treatments.

“When I’m not in a cluster … I’m just more energetic so then I start planning, reading, thinking about ‘if I go get a cluster again’ motivates me to find sort of ways that I may try to improve the situation… it's sort of a way to run from this, to lessen the anxiety of when I do think about it” (Participant 6).

Participant 4 explained that

“Most of the treatment that I’ve used was stuff that I found on the internet that people recommended ”

Without the correct diagnosis, these treatments that are discussed by fellow CH sufferers would not be accessible.

4.3.5.3 Having the Words to Help Explain the Condition to Others

Many said they had a hard time explaining their experience, symptoms and conditions to others. Having a name (a ‘diagnosis’) to use as an explanation was of assistance here and helped them with communication when needed.

This was good for their social life, their work life as well as in healthcare realm when seeking treatment, as it made it easier to discuss

“I think that's where the guilt also comes from … in a lot of patients' own minds because so few doctors know what this condition is. A lot of your time is being misdiagnosed and being sure. And you also start to question in your own mind, ‘is this actually real?’ even though you know it's real. It's happening to you … Am I really feeling these things? Because nobody seems to know what I’m talking about? Does my family think I’m lying? Until you eventually get diagnosed, a lot of this guilt goes away with the acceptance of ‘oh my gosh, yes, somebody knows what I’m talking about!’” (Participant 1).

“Its nice to have a label so thats its not just a headache, you know? If someone was interested, I would say, just, if you wanted to, just go read and you will understand. Google, whatever, a youtube video clip, in the middle of a cluster headache” (Participant 3).

“I would definitely if I do go see a doctor be sort of demanding and explain that I can't wait for the next available day, this is an emergency I need to see someone” (Participant 6).

“It's a relief being able to tell someone ‘okay this is what I'm suffering from’ and it is a relief to know that it is not just a migraine … it’s really great to me that I can explain it to someone and tell them that no this is what's going on because I think it's also helpful when I go to the doctor or when I'm explaining to a friend what's going on” (Participant 8).

4.3.5.4 Diagnosis Opens the Door to Supportive Communities

It appeared to be common for participants to find community in support groups after doing research once a diagnosis had been made (either self-diagnosis or by a professional). Having support (people that ‘truly understand’) and others to assist with alternative treatment were the two main reasons mentioned that these communities were appreciated.

"All of a sudden you can find the WhatsApp groups and find the Facebook groups and actually find community and not feel so alone" (Participant 1).

"I've got a very good support system … but they can't understand" (Participant 4).

"Even though I've got a very very strong support system, just being able to speak to somebody even though they can't do anything about it at that time, but just having that rant … and they say, they tell you, 'I know what you're feeling, I know what you're doing' and you know that they actually really do know what you're going through" (Participant 5).

"I don't know anybody else, haven't met anybody else. So it does help to know there's people that actually understand … people just don't understand … it also helps, and also advice, like drinks and stuff that help other people. It's very helpful…Somewhere where you know people understand what you're going through" (Participant 6).

"I use it [support groups and forums] more for information, more than support" (Participant 7).

4.4 SUMMARY OF THE CHAPTER

This chapter presented the findings of the data collected through this study. Each theme and its associated subthemes was expanded upon and presented with supportive excerpts from the interview transcripts. The chapter to follow will be used to discuss the findings presented in Chapter Four and provide insight by utilising existing theories to interpret some of the findings.

CHAPTER FIVE

DISCUSSION OF RESULTS

5.1. INTRODUCTION

This chapter will interpret and discuss the results that were presented in the previous chapter. They will be interpreted within a more contextual framework, according to the methodological design, using outside sources to elucidate information gained from the transcripts. The results and interpretations will also be compared and contrasted to findings in comparable literature, and any potential explanations for notable differences, if any, will simultaneously be discussed.

5.2. OVERVIEW OF THE RESEARCH DISCUSSION

The aim of this study was to describe and reflect on the lifeworld of patients with CHs within a South African context. After the semi-structured interviews explored this, the following five themes were identified and outlined in the previous chapter:

Theme 1: The inexplicable intensity of the pain.

Theme 2: The reality of a disease experience outside of head pain.

Theme 3: Anxiety as a complexly recurring reaction.

Theme 4: Perceptions of healthcare sought-out.

Theme 5: The value of a diagnostic label.

These themes and their sub themes are discussed, compared and contrasted with the pertinent literature, as well as explained and substantiated using further literary information. Finally, this chapter will serve as an exposition of the researcher’s interpretation of the results and showcase ways in which the themes can be connected to reveal information that may not have presented itself at first glance. This will be aided by secondary literature and other sources that allow for the informed building of a comprehensive context. One such is the demographic data on each participant that were collected, which is to be discussed alone, as well as serve as secondary information for the contextual interpretation of the themes within the South African construct.

5.3. RECOGNISING CONTEXTUAL GAPS

As per methodological design, as previously discussed in Chapter Three, supporting media and literature was consciously selected to help construct a fuller picture. This literature should not only add to the understanding, but also substantiate and provide potential explanations for any understandings that revealed themselves to the researcher during the data collection process.

During the initial interpretation process, it was noted what areas required further reading to flush out a larger understanding of the exosystems and macrosystems, so as to interpret the lifeworld with more depth. The information gained from these areas allows the researcher to make interpretations that are more informed.

The areas that were noted as necessary for the researcher to have a good understanding on are expanded upon below:

5.3.1 Information Gathered for the Macrosystem

The macrosystem involves the largest, intangible influences of a system. Examples include cultural values, economic systems, societal attitudes and ideologies.

It was noted that there was a need to draw on information related to the South African socioeconomic effects on healthcare access, societal and cultural values and behaviour in relation to pain and illness, as well as the impact of gender and race with regards to healthcare experiences and at large within the South African experience.

5.3.2 Information Gathered for the Ecosystem

The exosystem, also called the ‘indirect environment’, is the direct interface between the ‘system’ or ‘context’ and what is considered the lifeworld. Examples included are science and technology, media, law and industry.

It was noted that influences that impacted participants, which necessitated further exploration, for interpretation’s sake were the South African healthcare industry, information regarding drug availability and provision, medical aid provision for CH, and scientific advances on CH treatments, both locally and globally.

5.4. SCRUTINY OF THE DEMOGRAPHIC DATA

The use of demographic data is commonly used in research to assess risk-factors and their role in the determination of health outcomes. It is also suggested that contextual characteristics (such as demographic details, in context) can provide useful information in an attempt to understand health disparities (Hillemeier *et al.* 2003). For this reason, the role of age, gender, sex and healthcare access were scrutinised, to assess their potential contextual roles in the lifeworld of those with CH.

Age and Sex

Considering the typical age of onset of CH being between 20 and 40 years (Headache Classification Committee of the International Headache Society 2018: 42), the participant age range can be considered a good reflection of the population.

Given that the sample was split equally between male and female participants, the information received does allow for a well-rounded understanding from both sexes. It is an interesting oddity that as many females were available for the interview process, considering CH is historically known to be very predominant in men; the abundance of female participants may however be considered reflective of the downward trend in the male to female ratio that has been observed in recent epidemiological studies (Lund *et al.* 2017). Only one participant had the chronic subtype of CH – this was unsurprising, considering that episodic CHs are far more common (Barloese *et al.* 2018).

Ethnicity and healthcare sector

While the age and sex parameters of the participants reflect the population well, looking at other demographic features reveals some interesting information. The ethnicity and racial prevalence of CH is not well studied, though there have been some suggestions that diagnosis may be delayed in part due to ethnicity (Wheeler and Carrazana 2001), there is no literature that strongly supports any notion that CH would be more common in the white population that in a population of any other ethnicity.

Given this information, and the fact that the 2017 census estimate of the South African population is that 81% of the population is made of black South Africans, compared to 8% whites and 3% Indian, the fact that six of the eight participants are white, is incongruent. Not only does this make generalising information gained through the interviews difficult to generalise to the entire South African population accurately, but also raises the question of *why* so many white participants were interviewed.

Invitation to participate in the study was made public to anyone on CH support groups. In theory, this would make accessing those with CHs easier. What was not considered was subtheme 4 of theme 5 (‘Diagnosis opens the door to supportive communities’); A common thread in the interviews that were held was that support was often found post diagnosis, as the ‘label’ allowed for information that equipped them to seek out others with their condition. This means that those without access to diagnosis, and thereby not having accessed support, were not accessible for inclusion in the study. While this would not necessarily be a problem with all conditions, unfortunately CH is a condition that is well documented to have a large diagnostic delay (Frederiksen *et al.* 2020) and this was not considered when considering appropriate sampling strategies.

Considering all seven non-black participants who were diagnosed had access to privatised healthcare, there appears to be a likelihood that socioeconomic status and ethnicity in South Africa may very likely be resulting in the misdiagnosis and under-diagnosis of CH in these South African populations. This is because access to private healthcare is a clear indication of socioeconomic status in South Africa, and echoes the disparities that are ever-lasting from the country’s apartheid era (Howell and Shearing 2017). This is because in South Africa, racial capitalism is rampant; this is an economic system where, due to South Africa’s long history of racial inequality, capitalism is intertwined with racial discrimination, resulting in a direct impact of race and socioeconomic status on healthcare access (Neely and Ponshunmugam 2019).

The lack of accessible diagnosed individuals from CH support groups that accessed healthcare from the public sector, potentially coinciding with the lack of people of colour in the cohort, leads us to question if perhaps South Africa’s public healthcare sector is even more ill-prepared than the private sector to diagnose individuals with CH, potentially due to its preoccupation with infections disease (Woldeamanuel and Cowan 2017: 308) and general lack of resources (Chopra *et al.* 2009; Mayosi and Benatar 2014) that does not allow for it to be equipped to treat complex pain conditions.

There are, of course, additional reasons that may explain the lack of racial diversity that need to be considered. For example, with the little evidence available, it is possible that CH is indeed more common in those of Caucasian descent. Unfortunately, with the bias of research on those of Eurasian descent it is impossible to draw any conclusions in this aspect. Additionally, another reason for the underrepresentation of people of colour, also linked to a reason that they may be undiagnosed, is due the degree of reliance on traditional health care, more so in the poorer communities (Oyebode *et al.* 2016).

5.5 DISCUSSION OF THEMES AND SUBTHEMES

5.5.1 Theme 1: The Inexplicable Intensity of the Pain

It is not surprising that CH were described to be immensely painful, considering the condition has been titled ‘the worst pain afflicting mankind’ before in several publications (Rossi *et al*. 2016: 181; Rossi *et al.* 2018: 57). In fact, a study by Burish *et al.* (2021: 120) compared the average maximal pain ratings of multiple conditions known to cause immense pain, and CH was once again rated as the most painful of the subset, scoring a 9.7 on the Numerical Rating Scale. The pain following this was labour pain, with a sizable drop to a score of 7.2, followed by pancreatitis and nephrolithiasis. Migraine headaches rated 8th on the list with an average score of 5.4. The results of this study echo these findings, with the intensity of pain having been emphasised by every single participant. To participants, CH pain surpassed that of any other they could fathom, with comparisons to nephrolithiasis and labour both mentioned in an attempt to explain the intensity.

5.5.1.1 Barriers to Conveying the True Reality of Pain to Others

Articulation of pain is not an easy feat, considering that all pain is subjective (Wideman *et al.* 2019). Overall, an avoidance amongst participants to disclose their reality to others was noted. This avoidance, termed ‘self-concealment’, is explained by Pohl *et al.* (2019: 4) to be positively associated with a higher ictal burden of disease in those with CH, which is not unlike the effects of self-concealment in other pain conditions, as discussed by Uysal and Lu (2011). Self-concealment has been linked to be a cardinal factor in poor health care prognosis and its further exploration may benefit the CH community.

This study deduced four major barriers to pain expression from the results, namely an innate difficulty to accurately portray the degree of pain, the perceived inability of anyone without CH themselves ability to understand, participant intolerance to others’ attempts at empathy involving comparisons to other headaches as well as participant avoidance of disclosure due to distaste for other’s emotional reactions to the information.

The difficulty of expressing pain severity is discussed in section 5.3.1.2. Briefly, it entails the concept of “pain defying language” (Smith 2007), but the desire to express it as such regardless, because of our innate need to be understood in order to accurately foster empathy. The perception that only a fellow CH-sufferer could truly understand is a reiteration of previous qualitative studies conducted investigating CH experiences (Palacios-Ceña *et al.* 2016).

Like other qualitative research conducted in Spain (Palacios-Ceña *et al.* 2016), as well as a more recent investigation from the United Kingdom (Andre and Cavers 2021), this study found that those with CH are generally irked when an attempt at empathy from others involves a comparison to other headache conditions, suggesting that this is not impacted by global cultural differences.

Lastly, avoidance of discussing CH with others due to emotional reactions and entanglements of such a discussion was highlighted as a barrier. Aside from the belief that others were unable to understand their situation, the two scenarios discussed by participants were the avoidance of ‘causing awkwardness or guilt in others’, and ‘not wanting to be pitied’. The self-concealment motivational model by Larson *et al.* could explain this behaviour by categorising this avoidance as “an anticipation of shame and vulnerability” that promotes the intentional seclusion of personal information from the awareness of others.

5.5.1.2 The Limitations of Traditional Ways to Describe Pain

Having been asked to describe their experience with CH, participants had a difficult time expressing the true reality of the pain they face during attacks. Participants grasped at very emotive words, trying to conjure imagery that would convey the reality of the ordeal, as well as explaining that comparisons and pain scales felt scant and lacking. The importance of this difficulty in pain expression is multifactorial: first, it may be a contributing factor to poor psychological health in the population, and second, a barrier to receiving adequate care.

In his writings, *"The Importance of Being Understood",* Morton (2003) discussed the philosophical benefits of "being understood". The primary inference made is that the importance of mutual human understanding comes from a need for safety; we seek to predict the behaviour of others, and attempt to do so by conceptualising their internal processes that govern their actions. In addition, there is the simultaneous need, not just *to understand,* but also *to be understood* – a reciprocal demand for mutual intelligibility – as human survival also calls for others to be able to predict your actions, in order for them to meet your needs. It is thus conjectured that the ability to make oneself understandable is a human need, and at that, one that those with CH struggle to meet.

Unmet psychosocial needs or psychosocial stressors such as this one, can be a source of emotional distress and mental illness that not only increase the experience of suffering, but also further limit one's ability to manage illness adequately and accessing appropriate healthcare resources (Yarcheski *et al.* 2004).

Many publications have noted multiple hindrances to general pain care, including a study conducted in the Western Cape, where the perception of patients was that their self-reports of pain was exaggerated and not considered trust-worthy (Lourens, Parker and Hodkinson 2021: 5). Difficulty with expression of pain was noted here to be linked to drug-seeking behaviour, intoxication, language, culture and religious factors, further causing difficulties with pain assessments. This study presents a novel finding that CH pain may be misunderstood based on the condition's quiddity itself, rather than due to an individual's social, educational and cultural differences alone but is a hindrance to the proper care required nonetheless.

5.5.1.3 Comparison to Other Headaches Being Ill Received

Social comparison of health conditions can have a multitude of consequences (Arigo, Suls and Smyth 2014), but research on the implications of pain comparison is still in its infancy. The effects of comparison of self-perception have previously been seen to be fairly variable (Wills 1981; Arigo 2012; Forgeard *et al.* 2020) and highly context dependent (Arigo, Suls and Smyth 2014).

The reaction of participants in this study is not unlike that of participants in Palacious-Ceña *et al.* (2016) where it was expressed annoyance over comparison of their pain to migraines. Participants feel that comparisons underscore their pain and are perceived as 'empathetically insufficient', which naturally has affective consequences.

The researcher hypothesises that these comparisons foster further concealment. Reiterating Morton's (2003) conjecture that there is an innate need to make oneself understandable, it can be assumed that CH sufferers may feel that inadequate and underscoring comparisons are to blame for their feelings of contempt to comparison. They would understand that the comparison is the frame of reference that others perceive them. By knowing that they cannot meet the expectations of these comparisons, they are subjected to the stigmas of the incorrect perceptions that others have of them, as well as the feeling that their reactions may be considered to be 'over dramatic'. Concealment may be a reaction to this, in an attempt to avoid such stigmas and judgements (Bean *et al.* 2022).

Although there was an overarching understanding that the comparisons were being made to empathise and connect, overall, participants felt that CH pain was more severe than any other condition they had experienced, to the point that even 'headache' in the condition's name felt insufficient, and prompted further unwarranted and inaccurate comparison from others.

With participants in this and previous studies expressing dissatisfaction of likening CH to others, what are perceived by them as 'more trivial' headache conditions, it may be worth questioning if it is possible to avoid comparison by changing the condition's name. Could stigma be avoided and make CH sufferers more comfortable if an alternate name meant that the initial impressions of others' is not perceived so negatively by CH sufferers when they choose to reveal their condition and thus foster improved social wellbeing, and indirectly result in better health outcomes?

5.5.2. Theme 2: The Reality of a Disease Experience Outside of Head Pain

Subsequent to the desire discussed in 5.2.1.3. of wanting CH to be considered “more than a headache”, participants in this study discussed the influence of their condition in multiple areas of life that were not related directly to the pain itself.

In 2019, Pohl *et al.* confirmed what was previously discussed in the qualitative study by Palacios-Ceña *et al.* (2016: 1171-1182) that the burden of CH extended into inter-ictal periods, and was related to social, psychological and economic spheres of life.

Further exploration into disability, quality of life and socioeconomic burden of CH indicated that there is a need for supplemental information on the burden that CH has on these aspects (D’Amico *et al.* 2020: 816). This study reveals some initial details regarding mechanisms that influence disability, burden of disease and quality of life outside of the condition’s pain intensity, namely sleep disruption and workplace environment, which may be worth investigating.

5.5.2.1 Changes in Sleep

Known as a chronobiological disorder (Barloese 2021: 153) with circadian and circannual influences (Hoffman and May 2018), CH is well known to be associated with sleep.

The relationship between attacks and sleep has previously been discussed to be bi-directional in CH (Barloese 2021: 159), which was confirmed by the narratives of the participants in this study. Sleep is a common trigger of CH, thereby resulting in nocturnal attacks, which derange sleep; disturbed sleeping patterns may lead to more frequent CH attacks and a resultant vicious cycle that is difficult to balance.

The three reactive behaviours towards sleep were noted in this cohort: a) an attempt to regulate sleep to avoid derailment triggering active cycles and attacks, b) the avoidance of sleep during an active cycle in an attempt to avoid nocturnal sleep-triggered attacks, and c) an increase of daytime sleepiness due to night time disruptions by attacks.

Behaviours of the attempt at pain-avoidance are noted to be anxiety-fueled; the fear of sleep resulting in nocturnal attacks simply trumps the desire for rest, resulting in the sleep avoidance and its indirect consequences on the individuals' life – effects that were a cause of notable distress to participants. The fatigue that is expressed as such is one of the mechanisms by which lack of sleep affects the life of those with CH.

It is known that even in healthy individuals, sleep disruption is associated with multiple health consequences of both short- and long-term duration (Medic, Wille and Hemels 2017). Deficits in sleep quantity and quality, both which are noted in this population, can affect stress reactivity, pain regulation, dysregulated emotional and cognitive health, worsen mood disorders, impact memory, reduce performance and reduce overall quality of life alongside the risk of secondary health conditions that it increases (Medic, Wille and Hemels 2017).

The researcher proposes that the loss of sleep alongside the psychosocial influences surrounding it may be worth exploring in relation to impact on, burden of and quality of life in relation to CH due to its far-reaching consequences. A conclusion that echoes the sentiment of Barloese (2021), who noted that there might be a large missed opportunity in the treatment of CH through a chronobiological lens, which is to date, not featured in any treatment recommendations or guidelines.

5.5.2.2 Impact on Work and Functioning

A review of literature has found that the impact of CH on career can be very significant due to a variety of interrelated CH impacts (Freeman *et al.* 2022); however, echoing other studies, this study found workplace impacts to be highly heterogeneous (Jensen, Lynberg and Jensen 2007).

In this particular cohort, workplace inefficiency stemming from CH-related and the resultant fatigue appeared to be a primary source of stress in this realm. Considering deficits in sleep impact memory and cognition, it is not surprising that function at work and participation in education-related activities were affected.

Another suggested impact on work- and school-related function was the unpredictability of the attacks. Though CH is a condition with a traditionally rhythmic nature, unpredictability was a commonly occurring theme that was also noted in a Spanish cohort (Palacios-Ceña *et al.* 2016: 1171-1182). The perception of unpredictability appears not to be tied strictly to the timing of the attack, but rather that there is always a possibility that an attack may impair their daily life, and the way that is impacted is unpredictable depending on their surroundings.

In fact, the workplace environment of participants did appear to be a contributing factor to the impact that CH had on participants; those that were able to fare better also seemed to be able to access accommodations or have more flexible working patterns – such as the ability to work from home. This correlates with observations made by Jensen, Lynberg and Jensen (2007), that job burden may be correlated with the ability to adjust working patterns.

Conversely, the lack of ability to accommodate to the workplace,or vice versa, was associated with the threat of job-loss, as well as decreased earnings, thus, confirming the presence of indirect cost of CH as an economic burden of disease to be present in many sufferer's lives and to be of significance in a South African context as well (Gaul *et al.* 2011; Negro *et al.* 2020). As mentioned in Chapter Four, Covid-19 had an unpredictably positive impact on one participant as this was correlated to the new flexibility they gained due to the work-from-home accommodations that were made available at this time.

The available literature on workplace accommodations and interventions for migraine showed that workplace education reduced absenteeism, and increased productivity, along with some evidence of benefits with occupational health referrals (Begasse de Dhaem *et al.* 2021). The researcher proposes that a similar investigation of the workplace environment and its impact on the economic burden and productivity of CH could reveal information to improve socioeconomic outcomes in this population.

5.5.2.3 Differences in Recreational Activities

Another recurring theme from the transcriptions was that of an overall alteration in ability to resume activities. While prominently, these were those of a recreational or social kind, it also extended to the avoidance of activities of daily living, such as getting ready in the morning to leave the house and driving vehicles. This information correlates well with the details used to develop the Cluster Headache Quality of Life Scale (Bakar *et al.* 2016), where both 'restrictions of activities of daily living', as well as 'impact on mood and interpersonal relationships' are considered to be prominent factors contributing to quality of life.

The relational changes of interpersonal relationships in this cohort seemed to be of minimal concern. Many saw family as supportive. They felt that friendships and work relationships were more at risk of being strained, but that overall this effect was usually temporary and would not halt once they were out of cycle again. The largest impact on social behaviour was the reduction activity with social group activities during active bouts due to withdrawal and avoidance of public spaces.

Reduction is participation of activities, whether relating to activities of daily living or to recreational participation, corresponded with three major factors: fatigue or tiredness, desiring proximity to home and the avoidance of alcohol. The mention of alcohol as a significant social impact in this study was contrary to that of Palacios-Ceña *et al.* (2016: 1179). It is hypothesised that this is likely due to the high levels of alcohol use in South Africa where alcohol consumption has been shown to be one of the highest in the world (Marx *et al.* 2021).

The desired proximity to home appeared to be a secondary desire, stemming from the preference of being close or having access to abortive treatments. Not being able to access these desired treatments was a source of distress to participants. This behaviour is supported by previous evidence: Palacios-Ceña *et al.* (2016: 1179) found that patients tend to develop coping strategies for which they have little explanation, and that the inability to carry them out was associated with intensification of pain. The resultant withdrawal was explicitly associated with social strain, suggesting a relationship between the tendency to isolate and the access to support.

It is noted that these behavioural changes are seasonal – only taking place during active cycles. Unfortunately, any break down in relationships due to these changes, can be more permanent. It is also of concern to those with the chronic subtype of CH considering they would have a significantly shorter reprieve of symptoms within which to nourish and/or repair any relationships or habits that are impacted. From these deductions, it can be extrapolated that the change in ability and behaviour facilitates isolation and increases the psychosocial load of the condition on a patient’s lifeworld.

5.5.2.4 A Plethora of Emotional and Psychological Impacts

The International Association for the Study of Pain defines pain as being an unpleasant sensory *and* emotional experience (Raja *et al.* 2020: 1977). This alone makes the presence of emotional and psychological reactions to CH unsurprising. Additionally, a variety of negative affective responses in CH has been described in the literature (Freeman *et al.* 2022). The emotional reactions discussed were those that occurred due to the pain itself, or reactions to the dysfunction that the condition caused.

a) Anger and agitation

The investigation of anger, particularly in conjunction to pain conditions is still in development, but some findings have shown a general bidirectional relationship between the two (Rausa *et al.* 2019: 2367) with the leading model being one of opioid dysfunction (Bruehl *et al.* 2009: 487). Anger is reported as more frequent in those with chronic pain (Fernandez and Turk 1995; Sturgeon *et al.* 2015) and has been shown to be more likely to affect the severity of chronic pain than anxiety, sadness and other related emotions (Vickers and Boocock 2005).

Sommer *et al.* (2019) defines anger across the three dimensions of ‘quality’, ‘quantity’ and ‘form’ – an emotion that is innately unpleasant but can present as a feeling, mood or attitude to a varying degree and frequency. These characteristics explain the variety of expressions of anger that were detected in the transcripts – from irritation to frustration to aggression.

To better understand anger, two major models that separate anger experience from anger expression are used for most anger research. First is the state-trait model developed by Spielberger (Spielberger 2010) that separates anger into a reaction or response to a situation that is highly likely to fluctuate (state anger), versus the proneness or tendency to experience anger as seen in a personality dimension (trait anger). Additionally, anger is investigated by assessment of ‘anger-in’ and ‘anger-out’ reactions (Spielberger 1985), namely the suppression and outward expression of feelings of anger respectively. Along with this model comes the investigation of emotional regulation and its impact on pain intensity.

Anger and related affective responses have been noted in multiple investigations into CH (Palacios-Ceña *et al.* 2016: 1181; Rossi *et al.* 2018: 57), however only two studies have exclusively investigated anger in CH (Luerding *et al.* 2012; Rausa *et al.* 2019).

Rausa *et al.* (2019) found that state anger in CH patients was elevated when compared to state anger in migraine patients during active periods. This information provides a very limited view into the experience of anger and its significance in the lives of those with CH.

What is unclear from the transcripts is the influence of state or trait anger in terms of expression during CH attacks. Using a frustration-aggression model, one can understand aggression as an inevitable result of frustration — is the aggression that participants mentioned fighting during pain attacks a separate entity to the 'agitation' that is commonly described as a symptom of CH or is the 'agitation' an expression of anger that has simply manifested itself into aggression in this particular person?

Leurding *et al.* (2012) studied aggressive behaviour (a form of anger expression) in those with CH and found no significant aggressive behaviours in those with CH when compared to migraine, besides self-aggression (in terms of penance, rather than physical mutilation – i.e. anger-in behaviour); however, it is well understood that South Africans are reaping the consequences of a violent past, one which includes a culture of anger and gender-influenced aggression (Masango 2004). One must therefore question whether this lack of aggression can also be applied to the South African context. This is unclear from the results of this study and justifies further research in order to fully understand these concepts and their relationship both to each other, as well as to their unique cultural contexts.

Regardless of aggressive behaviour, when speaking of anger, some participants in this study felt that though the anger they felt was towards their condition and the fact that they have to experience so much pain, that it influenced their relationships because misplaced anger-out expressions towards loved ones occurred instead.

Given the vast information about anger that can still be investigated and its bidirectional role with pain, the investigation of the relationship of anger with CH may be worth exploring in depth as a way to understand its role in emotional and functional impairment in CH and if its assessment and regulation may be a valuable therapeutic strategy. Anger, and the strategies used to regulate/control its expression may also impact relationships with friends, family and healthcare providers (Sommer *et al.* 2019), as expressed by the participants in this study, giving further reason to explore the entity, as this could impact overall quality of life and response and access to treatment options.

b) Hopelessness, defeat and suicidality

Psychiatric comorbidity of trigeminal autonomic cephalalgias, such as CH, is not well studied, though evidence of increased psychiatric burden to at least some extent has indeed been noted (Robbins 2013). Like other primary headache disorders, CH has a significant incidence of separate psychiatric comorbidities such as bipolar disorder (Robbins 2013) and an increased likelihood of lifetime incidence of depression (Louter *et al.* 2016): 1996. Considering the condition is also colloquially called ‘suicide headaches’, the theme of suicidality appearing during interviews is relatively unsurprising. Multiple studies have proven the rate of suicidal tendency to be common, but actual attempts remain relatively low (Rozen and Fishman 2012; Robbins 2013: 110). It may be easy to assume that psychiatric comorbidity is to blame for the suicidality in this group of patients; however, a study by Koo *et al.* (2021: 8) presented suicidality to be associated with a state of demoralisation rather than depression in those with CH.

Depression and demoralisation are similar but separate entities. Both share a feeling of deep hopelessness; however, in depression there is lack of motivation to take the appropriate course of action, while demoralisation occurs due to the uncertainty of any appropriate course of action to take, even though the motivation to do so exists (Koo *et al.* 2021: 3).

These two major themes relating to defeat were presented in Chapter Four: the experience of a desperation to escape pain and a lack of ability to do so resulting in a sense of hopelessness, along with the common occurrence of this ‘inability to escape’ to prompt suicidal ideation. Furthermore, multiple participants (with episodic CH) explained that they were able to avoid acting on suicidal thoughts due to their knowledge of symptom-free periods existing. A reprieve of symptoms was presented to be the primary source of hope for this cohort, and appeared to be directly linked to their personal perspective of suicide.

Since the link between suicidality and demoralisation is known, the assistance of symptom reprieve on moral and overall hope can be justified by understanding the interaction of emotions that appear to occur in order to form a case of suicidality. The sense of desperation to access an ‘escape from pain’ (course of action) met with failure of reprieve breeds hopelessness that would result in the sense of demoralisation that predicts suicidality. The findings of Koo *et al.* (2021) echoed by this cohort but the hope of inactive periods provides relief from demoralisation resulting in lowered act of self-injury and suicide.

There is a need to delineate if this experience is different between chronic CH and episodic CH patients. It could be hypothesised that chronic CH sufferers may suffer with higher degrees of hopelessness as a result of their shortened episodes of pain-free days but the reality of a difference is unknown.

5.5.3 Theme 3: Anxiety as a Complexly Recurring Reaction

Pain experiences are known to lead to affective states of anxiety (Crombez *et al.* 1999; Hirsh *et al.* 2008). The anxiety and fear that presented in the transcripts were clearly linked to several recurring experiences of pain or pain-related dysfunction.

5.5.3.1 Fear of a Condition with Associated Morbidity

Several participants and/or their loved ones experienced significant anxiety that the pain they felt was dangerous, and presented a threat to their life. This feeling was ameliorated by testing not revealing any obvious causes of lethality, and further reduced when a diagnosis was delivered as it provided a deeper sense of understanding.

When an individual is presented with an actual or perceived threat of death, they are at risk of developing posttraumatic stress disorder (PTSD) (Holbrook *et al.* 2001; Heir, Blix and Knatten 2016: 307). This study presents the narratives of participants to be clear indications of perceived threat, and suggests that the episodes of severe pain, particularly when undiagnosed, can be interpreted as severe threatening and, thus, as traumatic incidents. Other symptoms of PTSD (Kerig, Mozley and Mendez 2020) that may meet the criteria for a diagnosis of PTSD in this cohort include, but are not limited to intrusive thoughts; avoidance behaviour; changes in mood (such as hopelessness and anxiety) and cognition (brain fog), as well as signs of arousal and reactivity (such as anger outbursts) that together are resulting impairment or dysfunction in everyday life. Since PTSD can cause significant impairment (Jellestad *et al.* 2021), its identification and subsequent role may be of value to this community.

Although there is evidence that PTSD may develop as a result of medical illness and its treatment (Tedstone and Tarrier 2003), there is currently no evidence of its occurrence and potential role in CH. It is unsure whether there is an association between being undiagnosed and the way in which these medical events are experienced. One can, however, deduce from the transcripts that participants of this study did find comfort in having an answer, ‘label’, or ‘diagnosis’, rather than experiencing their attacks of pain with uncertainty.

5.5.3.2 Background Anxiety During Interictal Periods

It has previously been discussed that CH carries a burden even outside of active periods (Pohl *et al.* 2019: 2) The anxiety that participants expressed in this study reinforces the impact of CH overall, as it causes significant rumination during interictal periods. Though there is an attempt to live as though they do not have CH at all during pain free episodes, the knowledge that the pain will occur with the next active cycle, results in anxiety even during these pain free times.

According to patient narratives, it appeared as though anxiety is specifically set off by symptoms similar to CH episodes (like the occurrence of other head pains) as well as being surrounded by known triggers of CH attacks (such as alcohol).

Interictal anxiety has been named a significant component of interictal burden for migraine headaches (Lampl *et al.* 2016: 1), and has recently been outlined as an independent source of the escalation of disease burden in CH (Pohl *et al.* 2019: 5) as well. Given its contribution to burden, and participant expression of its presence, it may prove useful to investigate what kind of behaviour this anxiety results in, and if it is a driver of poorer treatment outcomes. This should lend itself to an understanding of how anxiety can be better managed in order to improve QoL outside active bout for CH patients.

Given that the inter-ictal anxiety in the transcripts off this study revealed that the interictal anxiety revolved around triggering active cycles and pain attacks, the researcher hypothesises that a better management plan for when the cycles do come may be of assistance in this realm, by giving the patient a higher degree of control over their fear (the pain).

5.5.3.3 Anxiously Waiting for the Next Attack During Active Bouts

Awaiting ‘the next attack’ during an active headache period, though similar to awaiting the first attack of a new active period during an inter-ictal period, presented with some minor differences to the former.

Unlike interictal anxiety, where the anxiety pertains to the fact that an attack has the *potential* to occur, ictal anxiety comes with a higher degree of certainty that the next headache attack *will* be occurring. This certainty appeared to be the driving factor for pain-relief preparation.

In a cross-sectional study of patients with CH, Pohl *et al.* (2019) found that on headache-free days, two-thirds of respondents were anxious about their next attack, and about half of them had some form of accessible treatment to attempt to rebuke the next attack, should it happen.

Similar to this finding, the participants in this study discussed a sense of anxious anticipation for the next attack, as well as mechanisms they would put in place to try to treat it. Many keep stock of energy drinks and ice packs as part of their acute management, while one participant discussed having his medications pre-prepared for him. It is noted that the need to be close to abortive medicines and oxygen tanks for oxygen inhalation treatment, as well as the desire to express pain-related agitation, further increased isolation by keeping participants close to or at home for proximity-sake.

5.5.3.4 Generalised Fear of Having Pain Attacks in Public

Jürgens *et al.* (2011) studied impairment in chronic CH and found that a third of their cohort showed signs of agoraphobia. Agoraphobia can be defined as extensive anxiety that occurs when one is placed in a public or crowded space with perceived or actual difficulty to escape to one's home, or another safety-associated space (Balaram and Marwaha 2022). Socialisation may reduce and isolation by proxy increase further due to the presence of this agoraphobia.

Transcripts revealed multiple instances of the avoidance of public spaces as much as reasonably possible to avoid attacks from occurring in public. The suddenness and unpredictability of attacks were two major mediating factors of this fear. Both male and female participants had a sense of embarrassment associated with having public attacks. A very subtle but further gender-related underlying cause of agoraphobia has been noted and may warrant further investigation. Female participants who discussed reasons for fearing attacks in public mentioned being anxious about their own safety and about being caught off guard and helpless, while the male participant was more occupied with the fear of his behaviour (in the form of agitation and aggression) being witnessed.

The difference though subtle, could easily be explained by the international gender difference in safety perceptions that have been described (Wrigley-Asante 2016; Polko and Kimic 2022), along with the reality that South Africa is notorious for fostering an unsafe habitus for women, as can be substantiated with South Africa's crowning spot on the Woman's Danger Index (Fergusson and Fergusson 2019). Additionally, there is the possibility of sex-related differences of pain expression being at play, rather than gender-socialisation factors alone (Reidy *et al.* 2009 Bartley and Fillingim 2013: 52).

The different underlying reasons for agoraphobia cannot be said to be of gender-related origin with certainty from a few quotes alone and would need to be investigated further to ascertain its presence as well as its contributing role in disease experience.

Regardless of gender-based factors, agoraphobia was noted in both sexes and does require attention from the viewpoint that it may be reducing relational successes and patients' ability to work; it may therefore be a useful target for holistic management.

5.5.4 Theme 4: Perceptions of Healthcare Sought-Out

In 2006, over a decade before the initiation of this study, Kernick, Matharu and Goadsby (2006: 486) wrote that CH remained, at that time, "underdiagnosed and undertreated", and that the needs of patients were being left unmet. From the transcripts, it is clear that the participants felt that this narrative still held true for them.

It is noted that those whose care was not experienced as poor, attributed their access to treatments to three main factors: a) they received timeous and accurate diagnosis, b) they were healthcare professional themselves and thus had better access to professionals and/or treatment and/or understanding of pain, c) they had access to healthcare because of good medical aid coverage. These participants were still of the opinion that navigating the healthcare system with CH came with massive challenges, and felt that their experiences were likely outlying positive, rather than the norm.

Like participants in Palacios-Ceña *et al.* (2016) and Andre and Cavers (2021), South African CH sufferers perceived a lack of practitioner knowledge and understanding about CH. Receiving an accurate and timous diagnosis is an important part of any good management plan, as it guides good clinical decision making with regards to treatment and thus precedes good healthcare outcomes (Committee on Diagnostic Error in Health Care 2015) – an experience that was not afforded to those CH sufferers interviewed in this study.

Overall, participants expressed a desire for sincerity in clinical interactions, with empathy for, or belief and understanding of their pain. These wishes align with stigma-induced challenges that those with chronic pain experience (Bean *et al.* 2022); The perceived scepticism in social circles extends into their perception of healthcare professionals feeling like their pain is disbelieved and attributed to other stigmatising causes such as ‘drug seeking’. Stigma has been correlated with greater degrees of depression, disability and reduced social support and qualitatively associated with higher degrees of self-concealment.

5.5.4.1. The Perceptions of the Doctors Asked for Help

Physicians were described by participants as ‘lacking’ in two departments: empathy and knowledge. Many left their interactions feeling dismissed, brushed off and unimportant to practitioners, and as though their cases were an annoyance to them. Similar perceptions were echoed by CH participants in Palacios-Ceña *et al.* (2016: 1179), suggesting that there is a gap in efficient communication between patient and professional that is resulting in this deficit.

Participants made it clear that they were desperately craving help in the form of empathetic and informed healthcare, as they felt physicians were their last hope. Leaving healthcare appointments with a lack of effective treatment in addition to a perceived lack of empathy from the physician increased their sense of hopelessness and was a clear contributing factor to the demoralisation.

Previous literature investigating the professional perception of CH found that general practitioners in England felt pressured by patients to be referred to secondary care to a neurologist (Buture *et al.* 2020: e517), while the study investigating patient perceptions in Spain (Palacios-Ceña *et al.* 2016) showed that referral to secondary care was perceived as a relief.

Contrary to these narratives, specialist care was not experienced positively by participants in this study; specialists were perceived as untrustworthy, uncaring, not knowledgeable enough and many questioned if they were being exploited. One participant also mentioned that, considering he was not satisfied with his treatment (even though his diagnosis was thankfully accurate), he perceived his practitioner as overconfident and arrogant.

Specialist care was sought due to desperation (for a diagnosis or for effective treatment) though dissatisfaction was unanimous in this cohort. Of the six participants who sought out specialist care, three were misdiagnosed.

The four of the six participants who had visited a specialist headache clinic did discuss their various dissatisfactions. Those that were correctly diagnosed discussed being warned about a surgical procedure offered here by others in the CH community, while those that were misdiagnosed lamented the loss of their time and money and expressed severe disappointment not only for being misdiagnosed at this level of care, but also for receiving resulting care that was expensive and inefficient.

The difference in experience of specialist care by South African participants may be due to the way the country's privatised healthcare system allows for access to specialised care without prior referral from primary care. This means that secondary care is not necessarily thought of as inaccessible as it may be in other countries with socialised healthcare, which may account for the reduction of relief. The experiences of meagre care that were discussed, as well as the use of what is assumed to be maxillary artery cauterisation and the use of intra-oral device appliance for headache may necessitate further investigation into specialist knowledge and perceptions of CH to improve care in this sector of South Africa's healthcare, considering the scant evidence of their use in the literature.

A hospital-based study by Voiticovschi-Iosob *et al.* (2014) found that the primary specialists consulted for CH prior to diagnosis were neurologists, primary care physicians, ENT specialists and dentists. It is interesting to note that the majority of secondary care in this cohort of participants discussed care from a maxillofacial surgeon, whereas specialist care in CH is generally associated with neurologist-guided care. It may be of use to investigate underlying reasons for this choice of specialist and the resulting satisfaction based on difference is approach from the different fields.

5.5.4.2 Experiences of Delayed Diagnosis, Mis-Diagnosis and Self-Diagnosing

The participants of this study perceived a deficit in practitioner knowledge. This perception can be appreciated, considering five of the eight participants had initially been misdiagnosed, while the same ratio of participants also received these misdiagnoses at secondary-care level.

A majority of seven of the eight participants discussed initially making a self-diagnosis before finding more ‘official’ answers; these self-diagnoses were prompted by immediate need for answers evoking a need to research, being in the field of healthcare and having answers more-easily available as well as desperation from being misdiagnosed and a deep longing for answers.

It is interesting to note that participants who made an initial self-diagnosis by researching about their symptoms on the internet felt that it was or would be frowned upon by their physicians. A systematic review by Farnood, Johnston and May (2020) found that the opinion of physicians on this matter was split between those that felt that it was a good option for patients to have access to ways to look after themselves versus those that felt that the utilisation of the internet by patients in this way reflected on the patient’s perceived degree of trust in their expertise. felt that self-diagnosis, especially when coming from having done research.

Cluster headache is frequently unrecognised or misdiagnosed which impacts care due to the consequent treatment regime. Assessing misdiagnosis in this cohort shows a clear bias toward female misdiagnosis, given that all four females had experienced misdiagnoses, while only one male patient had experienced the same. This reflects the opinion of Wheeler and Carrazana (2001), who described inappropriate diagnosis appearing to be commonplace because of the misconception that CH very rarely occurs in women. Given that the exploration of female phenotypical differences of CH is in its infancy and contradictory in its findings (Lund *et al.* 2017; Allena *et al.* 2019), it is understandable that there is some confusion. More physician awareness and education of CH diagnostics and the reduced female to male ratio being seen in recent years may be valuable to this population to reduce this specific reason for delay.

Exploring the role of stigma in healthcare is very apt for a South African environment, as a country forced by apartheid claiming to be in the process of ‘nation-bulding’ post this divisive era. It is well known that there are racial disparities in many areas of healthcare (Penner 2013), and the role of ethnicity in misdiagnosis and delayed diagnosis in CH has also previously been discussed (Wheeler and Carrazana 2001). It is noted that very little information, besides the stigmatising role of gender, can be drawn from this small cohort that has very poor diversity. Hypothetical roles of race and ethnicity, as well as their interplay with socioeconomic status in South Africa in terms of access to healthcare.

5.5.4.3 Experiences of Inefficient and Inaccessible Treatments / A Need for Urgency

A broad scope of treatments that have been tried in the quest for pain relief were mentioned by participants – from over the counter medication to prescriptions to illegal and experimental treatments.

The use of medication that was ineffective for CHs was associated with desperation-induced self-medication (such as NSAIDs and opioids), along with prescription patterns inconsistent with current recommendation, either due to incorrect diagnosis or practitioner misinformation regarding effective drug therapy. Buture *et al.* (2019) discussed the role of misdiagnosis with mismanagement, which was reinforced by participants in this study. Additionally, the cohort discussed mixed results even to medications that do align with current evidence and recommendations when they were correctly diagnosed.

Participants often took medication regardless of their inefficacy in a misguided, but desperate attempt of pain avoidance. Overmedication may have effects that are not negligible, such as toxicity or secondary medication-overuse headache, which would in themselves negatively impact a patient’s quality of life, giving us reason to want to reduce desperation-induced behaviour by improving pain-care for this population.

Another difficulty experienced by participants is managing side-effect profiles of medications that they were offered. Recent systematic review found that although pharmacological treatments were associated with a significant reduction of attack frequency and duration, it did reveal what was mentioned here – an increase in adverse effects that needs to be considered when the risks and benefits of medications are discussed (Kwon *et al.* 2022: 1411).

It is often in online-community spaces that many participants were exposed to the use of psychedelics, particularly psilocybin, as a treatment method. Similar to the findings of Andersson, Persson and Kjellgren (2017), the use of these psychoactive substances was usually a last-resort for participants. This is a clear indication that other treatments that had been available had failed significantly and is once again, a reverberation of the desperate situation of CH patients. Despite the ongoing international interest in psilocybin's medicinal uses, it is at this time, the acquisition, use, possession, manufacture and supply of psilocybin is prohibited in South Africa. The use of illicit substances increases social inequity and is known to increase discrimination in healthcare settings (Pauly *et al.* 2015); It is for such reasons that multiple United Nation programmes recommend for the decriminalisation of activities related to personal drug use (Guterres 2017). Like in other countries, the prohibition of substances hampers scientific study considerably which is resulting in a direct delay in the study of the inclusion of psychedelics safely and effectively into CH treatment regimes, leaving patients to their own resorts. (Dos Santos *et al.* 2021) calls for "urgent dialogue between science, health systems, society and politics" to reduce the challenges of inculpating the use of psychedelics and preventing their clinical integration into health systems to more effectively and ethically treat patients.

Inaccessibility of treatment was, according to transcripts, certainly not limited to psychedelics: the difficulty in accessing sumatriptan and oxygen, among others, was bemoaned as well. Study has shown that rural health facilities experience more difficulties in terms of access to necessary medication (Zuma 2022), which raises concern as primarily private healthcare was observed in this study, meaning that it is likely that those with CH have even bigger challenges than those already discussed here.

Participants who wanted to use oxygen inhalation as part of their treatment regime discussed a variety of difficulties with its use. The cost of it makes it an inaccessible option to many and it is a commodity not covered by medical aid programmes in South Africa. They also felt that there were difficulties in obtaining prescriptions in the first place, ranging from practitioner ignorance on prescription recommendations and regulations, to the effort of obtaining such prescriptions not being worth the relief they receive when compared to the cost it holds. Additionally, the coronavirus pandemic made oxygen a rare commodity (Groenewald *et al.* 2022) that affected access to it even further.

There was a direct cry for more holistic management by participants, wishing for a more open and collaborative approach when options are presented to them. Many felt they were not explained what types of options were available to them, which was a large contributing factor to the deviation of seeking care-advice from other CH patients, such as on support groups. This includes not being told about oxygen inhalation, no mention of energy drinks as a common abortive agent and the use of psychedelics in the condition.

The last significant discussion about the treatment experiences of this population is that of the experience of seeking care in emergency care settings for CH. The two participants who did present to the emergency room did so out of desperation in a quest for oxygen when they were unable to manage the pain themselves. As found in other studies, the current protocol for headaches is not entirely suitable for the treatment of CH (Crawley and Brady 2016). It is also known that pain is a neglected problem in low-resource settings, making the ill experiences plausible within South Africa’s state of affairs (Goucke and Chaudakshetrin 2018). It may be worth investigating ways to make emergency room visits more effective for this population both nationally and internationally.

5.5.4.4 An Undeniable Financial Burden

The financial burden of CH is both direct and indirect (Negro *et al.* 2020), as well as personal and societal (Petersen *et al.* 2022: 26-35). From the transcripts, some of the most common direct personal impacts were deduced to be the cost of doctors appointments, the cost of testing undergone in the diagnostic process, the cost of travel to healthcare facilities as they are often not locally equipped, and finally the cost of treatment modalities. Finally, the costs of privatised healthcare was complicated by the lack of coverage by medical aid schemes for many CH-related health costs, such as oxygen inhalation therapy.

By law, medical aid schemes are required to cover any condition listed as a Prescribed Minimum Benefit (PMB). PMBs cover an estimated 270 conditions with 26 chronic conditions (Council for Medical Schemes 2020). Cluster headache is not one of these. In order for members to have benefits that cover CH, it would need to be enlisted as a PMB. Without this, it will remain a condition that is covered subject to member savings, depending on scheme policy.

It is important to note that these burdens have not been quantitatively assessed in South Africa, and are not reflective of the experience that those making use of public healthcare would be experiencing.

5.5.5 Theme 5: The Value of a Diagnostic Label

Diagnostic labelling is a practice that healthcare practitioners undertake in order to explain a set of symptoms, and is usually done for clinical or research purposes (Werkhoven, Anderson and Robeyns 2022). Another definition of 'diagnosis' provided by Ilgen, Eva and Regehr (2016) is it being a process of 'making meaning' from data.

Diagnostic labelling can have both positive and negative psychological consequences (Sims *et al.* 2021). It is largely accepted that the criticism and defence of providing patients with diagnostic labels needs to be contextualised, as its benefits can be highly variable between different conditions and individual patients.

From the interviews held with CH patients in this study, it is easy to see that diagnostic understanding held therapeutic and social value and should, therefore, be considered as important to provide.

Four primary benefits of receiving a diagnosis, or 'a label', discussed by participants in their interviews are discussed as follows.

5.5.5.1 Reassurance That the Condition Is Not Lethal

Those with undiagnosed CH experienced significant anxiety that their pain was an indication of something potentially dangerous or lethal that has not yet been discovered. Participants felt relieved receiving the diagnosis of CH as it helped reassure them that they were not suffering from a potentially lethal condition.

5.5.5.2 Finding Hope for Treatment with the New Information

In addition to feeling relieved about their diagnosis, participants explained that they used their label to search for complementary and alternative treatment options. The use of a label in this search is helpful, as the efficacy of suggestions and support that may be found can be facilitated by the label. The treatment of CH is starkly different from that of other headache disorders, making this information very relevant as it largely alters treatment access and therefore is expected to provide improved therapeutic response.

5.5.5.3 Having the Words to Help Explain the Condition to Others

Participants felt relief in being able to explain their experience or set of symptoms, with a term or phrase. The ability to improve social communication in this cohort appeared to be associated with having a diagnostic term to use.

Considering social difficulties have been described with one aspect being a difficulty in relaying pain this would appear to have the potential to improve social relationships for those with CH. The association between social burden of CH with a diagnosis versus experiencing the symptoms of CH without a diagnosis has not been studied, but it appears from this argument that there may be an association.

5.5.5.4 Diagnosis Opens the Door to Supportive Communities

Diagnostic labels were used to find other CH sufferers. The desire for a supportive community was associated with the desire for others that truly understand the experience, as well as the use of communities for treatment advice. The use of support communities in this South African cohort was similar to the narratives discussed in previous investigations (Palacios-Ceña *et al.* 2016: 1179; Andersson, Persson and Kjellgren 2017), suggesting that these are desires not necessarily altered by international differences, but rather by patient’s access to these communities, very likely through access to a diagnosis (or at the very least a suspected self-diagnosis).

5.6 THE CONCEPTUAL LIFEWORLD OF A SOUTH AFRICAN CLUSTER HEADACHE SUFFERER

Below is a graphic conceptualisation of the lifeworld experiences of those with CH is South Africa as synthesised by the researcher that attempts to showcase the interconnectedness of sub themes and challenges faced.

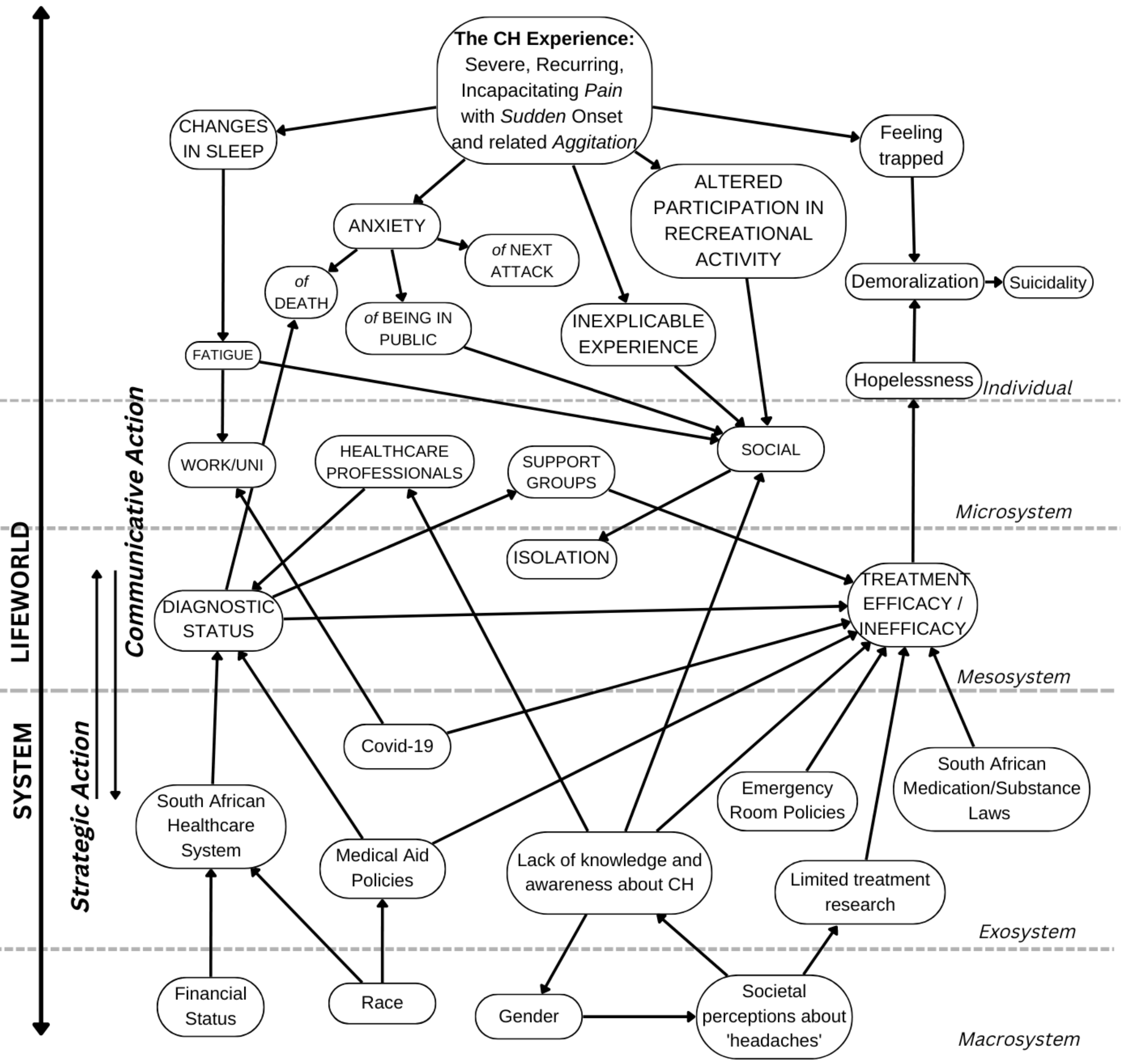

Figure 5.1: A conceptual portrayal of the lifeworld of those with cluster headache in South Africa as reconstructed by the researcher into the framework described in chapter 3

5.9 SUMMARY OF THE CHAPTER

In this chapter, the findings of the study were discussed, resulting in an interpretation of the lifeworld of those with CH in South Africa. The results were compared and contrasted to previous research of a similar scope and supporting literature was used to explain any differences or interpretations that were made. Using the theoretical framework that was discussed, the information that had been sourced was then synthesised into the framework in order to conceptualise a model of their lifeworld. Overall, the interpretation aligned with that of previous studies on CH, showing that participants were having difficulty with the symptoms of their disorder itself, but also in social realms and with accessing adequate healthcare which broadly reduced their quality of life. Multiple influences contribute to poor diagnostic experiences and inefficient treatment, which are major factors contributing to the lived experience of CH that have potential to be modifiable. This is also the first study that illustrates the signs of PTSD in this condition, which warrants further research.

The following chapter summarises the findings of the research and provides strengths, limitations and recommendations of the study.

CHAPTER SIX

CONCLUSION

6.1 INTRODUCTION

This chapter is a reiteration and summary of the aims of this study. In this chapter, the research questions devised in the first chapter will be addressed. Finally, the study's strengths and limitations will be discussed, preceding a reflection from the researcher and the recommendations that can be made from the results of the study.

6.2 SUMMARY OF THE STUDY

The aim of this study was to describe and reflect on the lifeworld of patients with CHs within a South African context with the objective to understand the experience, its influences and identify ways in which the experience can be improved. The research questions were formulated to address this aim.

6.2.1 Research Question One: What is the Lifeworld of a Patient with Cluster Headache in South Africa

The participants of this study expressed a desperate situation of severe, incapacitating pain that, with its sudden onset, felt unpredictable and resulted in massive changes to their lives since the beginning of their journey with the disease. Many discussed a long and difficult journey to diagnosis, while the majority expressed an even longer journey to finding relief. Social difficulties were experienced with an increase of isolation occurring during active periods, as well as serious strain experienced in work environments. The participants perceived that both their social circles, as well as their healthcare professionals overall had a poor understanding, if any, of their condition and that more knowledge and awareness of CH would improve their experience. Unanimously patients craved understanding and empathetic care, but instead many found themselves inefficiently managed and left feeling unimportant. It was clear that they were desperate for reprieve from their pain, and when not able to source this, they became hopeless and eventually demoralised. All participants mentioned reaching out to support groups; the role of support groups was one of kinship with others that were capable of understanding their experiences, while simultaneously seeking support and advice regarding treatments in hope of relief.

6.2.2 Research Question Two: What are the Apparent and Nuanced Influences That Result in This Experience?

From the transcripts, there were several apparent influences that obviously affected the experience of the participants such as their diagnostic status and the efficacy of their treatment (which are very interconnected). These in turn were influenced by other apparent influences from the exosystem including, but not limited to, the state and functioning of the South African healthcare system, current medical aid policies on treatment and care coverage, policies for treatment in emergency rooms, the limited research available on effective treatment for CH and South African substance and medication laws that hamper access to certain treatment options. The more nuanced influences on the experience of their lifeworld were found within what was classified as the macrosystem and included factors such as race, gender, and socioeconomic status and their interconnectedness with society's perceptions of headaches.

6.2.3 Research Question Three: What Are the Perceived Personal, Social, Occupational, and Emotional Impacts of Cluster Headache?

Participants perceived a large impact on many aspects of their life because of CH. Personally, participants felt that their whole life was ‘turned on its head’ when they began being symptomatic. The emotional ramifications were broad, anger and frustration that sometimes led to social difficulties, to a deep sense of hopelessness when they are unable to escape from their pain and the majority of participants experienced the psychological result of demoralisation. Overall, participants felt that family was supportive to the best of their ability, but some did experience strain in social relationships (family included) when they felt they were not believed. Active periods led to times of isolation, which impacted social behaviour, but most participants did not feel that this impacted the quality of their relationships. All participants did experience difficulties in their work environment due to CH, but the perceived impact varied widely; generally, all experienced a lack of concentration during active periods, while most perceived some disruption in their occupational routine and abilities, and some experienced a threat to employment and income.

6.3 STRENGTHS OF THE STUDY

The qualitative nature of this study allowed for narratives of first-hand experience to be collected, which provided insight into the experiences of CH sufferers in South Africa. The thorough and robust theoretical framework that was constructed on firm philosophical principles validates the methodology and guided decision making from data collection, through to analysis and interpretation in a way that can be substantiated by the literature and supports the studies trustworthiness. The studies cohort in combination with its framework allowed for information unique to the South African context to be revealed alongside more global impacts of CH that likely occur in any population.

6.4 LIMITATIONS OF THE STUDY

The study has limited generalisability for a multitude of reasons, including the lack of racial diversity in the cohort and the bias towards those of a higher socioeconomic status. Though information about the lack of diversity can be withdrawn from the study, and helpful information regarding the potential of insufficient diagnostic access in lower socioeconomic settings of the country was alluded to, these are simply deductions made and have not been substantiated. This also means that the experiences of those that received their care from the public health sector do not have their personal narratives represented in this study and therefore this narrative cannot be fully generalised to everyone with CH in South Africa.

The study was also only conducted on those with CH in South Africa, which has a unique context and is not necessarily fully comparable to other countries – therefore those with CH may have different experiences that would need to be taken into consideration. However, the grouping of meaningful sub-themes into larger main themes allowed for the creation of essences, which does allow for information to be more applicable to larger groups.

6.5 RESEARCHER'S REFLECTIONS

Reflection is considered a metacognitive process where the researcher analyses their own thought processes and is usually practised in qualitative research in an attempt to legitimise results (Mortari 2015). This kind of reflection aligns with the principle of 'bridled openness' of a lifeworld-led approach to qualitative research, which requires an astute awareness around knowledge development and questioning of interpretations in order to allow for multiple understandings to develop. In this framework, it is this reflectivity that allows the researcher to move between subjective and objective interpretations of the data ethically.

The researcher was inspired to research this condition after witnessing its impact on a family member of theirs. Furthermore, the researcher has their own experiences with chronic illness and pain, and had a difficult journey navigating healthcare, which sparked their interest in qualitative research, as they started developing an appreciation for the need for understanding in healthcare. They knew that they would have to work on avoiding bias from misconstruing the study, but were surprised with the ease of this matter throughout the research – until they had to interpret the results and realised that they found certain subjects easier to write about than others, as well as had preconceived ideas about the types of themes that would be revealed. To allow for a more authentic view of the participant to show through, rather than accidentally manipulating information to create themes that would fit these preconceived ideas, the researcher regularly had to check in with themselves and reflect on what a certain theme meant to me and find ways to help them compare their perception to the more objective transcripts. Ultimately, they kept reminding themselves that in order to best help this community find a voice, they needed to elevate their stories and experiences, and avoid, to the best of the researcher's ability, the need to misconstrue any information, even accidentally, to fit their own narrative.

During the developmental process of this study, the researcher faced one particular challenge that resulted in an incredibly long and frustration-filled delay in the research process, but ended up being the one they perceive to have taught them the most about the nature of qualitative research.

They knew that the study they wanted to conduct would have to be one of qualitative nature, and that they would likely be conducting interviews in the process, but while going through the approval process of the concept paper, the justification of the methodology was questioned. The researcher then set to work to understand how they could justify it, and found that there was a wealth of knowledge regarding theoretical frameworks that the researcher was yet to tap into, available. They used this time to gain an in-depth understanding of the variety of approaches and philosophical underpinnings of qualitative research methods and allowed myself to explore a variety of models until they finally found some that they could adapt to meet my research goals. The researcher feels that though this delayed the research process significantly, it was the most mentally expanding aspect of the research process and that they have gained knowledge that is invaluable, and is grateful for the opportunity to have gained such an extensive understanding.

In addition to the personal gain of knowledge that the researcher gained from the assimilation of literature on an array of methodological concern in qualitative research, they are happy to have spent the time they did in understanding its concepts and assimilating the frameworks they did, as it proved to be helpful in guiding decision making at every point of the study. Engaging with the constructed framework and allowing it to guide the expansion of their understanding of the context within which they exist in turn has allowed them to learn so much about South Africa, their beloved home, and the intricacies of a healthcare system they will soon integrate into. They feel that this has opened their heart and mind to a diversity of experiences and dynamics that they were not equipped to understand before. The researcher hopes that this, in conjunction with the skills of developing an understanding of a disease or disorder in context that this has taught them, will help them have a deeper sense of empathy and understanding with future patients when they present with conditions that they have no personal experience with, and ultimately allows them to help patients in the solution-finding process.

As the researcher conducted the interviews, they felt that participants were grateful and excited to be given a voice. They could tell that the information being shared with me was intimate and important to them. The information they shared was very dear to the researcher and they felt a strong desire to do the population justice with portrayal of their experiences, which, though at times made things challenging, was ultimately a positive pressure to conduct rigorous work.

The most challenging aspect of this project, though a great sign for this population, is that in the time that the researcher began conceptualising their research, to the point of the write-up of dissertation, the available literature had rapidly grown and updated, which meant that the researcher had an ever-growing literature pool to utilise and update. Though difficult to keep-up with at times, the new information was resourceful to the study and allowed for much more in-depth comparison of results.

6.6 RECOMMENDATIONS

The exploration of the lifeworld in this study was done within the theoretical framework of Haberman’s theory. This allows us to make recommendations that change the larger systems in place that can in turn affect the lifeworld through ‘strategic action’. Furthermore, one is able to reflect on the individual, micro- and meso-system roles in creating these systematic changes through ‘communicative action’ and suggest strategies that will ultimately improve the lived experience of the individual within their lifeworld.

6.6.1 Recommendations of Communicative Action

Communicative action aims to mobilise potential change by directing information, through communication, from within the lifeworld to the system (Froggatt *et al.* 2011: 265).

The results of this study itself can be considered a communication to the system requiring change. Further to this, the researcher suggests the following to encourage systematic change:

- Mixed media patient advocacy should be encouraged to create more awareness and allow for patient narratives to be heard. Media such as art, story telling, video and film, prose and social media may be used to generate public knowledge and cognisance of the condition.
- Advocates may further be encouraged to use their voices to encourage change by writing suggestions and requests they may have to relevant policy

makers. Relevant parties may include, but are not limited to research institutes, medical aid schemes, ministers of health and deans of healthcare institutions.

- Further to these generalised forms of communication that can be suggested to evoke change, it was also made clear from the transcripts that a majority of patients in this cohort had negative experiences with healthcare professionals on their journey. They may benefit from knowing that they may lodge any complaints to relevant regulatory boards that may decide to investigate if they deem it to seem necessary.
- Reasonable workplace accommodations should be put in place for those with cluster headaches to enable them to continue having an effective role in the workplace environment. The South African constitution calls for the accommodation of diversity in the workplace, with Section 6 of the Employment Equality 55 of 1998 states that "no person may unfairly discriminate, directly or indirectly, in any employment policy or practice, on one or more grounds, including race, gender, sex, pregnancy, marital status, family responsibility, ethnic or social origin, colour, sexual orientation, age, disability, religion, HIV status, conscience, belief, political opinion, culture, language, birth or on any other arbitrary ground" (South Africa, Department of Labour 1998: 10). However, the onus is on the employees and employers to develop appropriate and fair systems. The researcher recommends that employees with cluster headaches use the current law to their advantage and make reasonable arrangements, such as working from home during active headache periods if possible.

6.6.2 Recommendations of Strategic Action

Strategic action mediates purposeful change and occurs as measures within systems change that affect the lifeworld (Froggatt *et al.* 2011: 265).

The onus to make changes within the systems that affect the lifeworld is on the individual components/institutions themselves, but advocacy may improve the likelihood of these changes being made. The following are suggested policy reform that may improve the lived experience of those with cluster headache in South Africa:

- Emergency room protocol for headache presentation may benefit from a re-evaluation. Current protocol does not allow for effective management of acute pain attacks, primarily because of long wait times in those that are diagnosed. It is suggested that options for more rapid access to oxygen inhalation be considered and implemented to allow for faster pain abortion.
- PMB coverage of cluster headache would greatly benefit those with cluster headache to be able to afford necessary medical care. PMB management of chronic conditions is limited to a very small list of 26 conditions (Council for Medical Schemes 2020) that would require national policy changes to occur for cluster headache to be included. While this is unlikely to be feasible at that level, there may be more hope in targeting medical aid schemes to include cluster headache as a covered chronic condition, regardless of its PMB status.
- The researcher suggests a re-evaluation of health and allied health headache curricula on cluster headache to ensure that information is accurate and up to date. Information should allow for accurate identification as well as a good understanding of the experience. Furthermore, it is suggested that this understanding be fostered by making use of lifeworld-based information and knowledge such as this, and incorporating patient narratives where possible.

6.6.3 Recommendations for Clinical Practice

While the above changes are based in action of large systems, there are changes that can be made at an individual practitioner level. These changes are suggested by the researcher based on the patient narratives presented and may help improve the healthcare experience of those with cluster headaches in South Africa.

- Navigate the presentation of information from the internet with tact and empathy. Understand that a patient presenting such information is likely doing so because they are seeking answers; furthermore, internet usage has become immensely popular and its use for seeking out medical information is no different – incorporating this knowledge with grace would be considered culturally appropriate healthcare.
- It is recommended that practitioners learn about and take a trauma-informed care approach with patients, such as working within the ‘BITTEN’ theoretical

framework (Selwyn *et al.* 2021: 636). This will help them better understand the experience of engagement that patients are having within the healthcare system. Practitioners should aim to express empathy during appointments, making an effort not to make patients feel rushed or burdensome. Additionally, it may be beneficial to follow-up on known or suspected cluster headache patients after appointments, as this was mentioned to be an actionable way that ‘care’ from practitioners was perceived.

- The presentation of a full scope of treatment and management options to patients is important; brushing up on the variety of options that patient’s and their related evidence and risks/benefits is thus recommended. The researcher suggests that pharmacological and non-pharmacological options are explained to patients along with individual pros and cons of the options so that the patient may make an informed choice. It may also be helpful for patients to be aware of what options they have available to try if the initiated one is deemed to be ineffective, inappropriate or inaccessible. It may be helpful to point patients with cluster headache towards support groups who can provide relevant coping mechanisms and information about alternative treatments.
- The researcher recommends that practitioners familiarise themselves with the efficacy of oxygen inhalation for cluster headache as a first line abortive mechanism, as well as its prescription processes. As oxygen is not a usual prescription, it is understandable that many physicians are unsure about its prescription, but this is a barrier to pain care for those that need it and can easily be addressed to make the option available to those who need it.
- Based on the findings of this study, the researcher recommends that practitioners screen patients with cluster headache for signs of demoralisation and PTSD. This is because demoralisation is a risk factor for suicidal intent and/or behaviour in this population and would need to be addressed for the patient’s safety. Additionally, if signs of PTSD can be recognised, they can also be addressed timeously by providing patients with the relevant referrals and support, which in turn promotes patient well being and safety.

6.6.4 Recommendations for Further Research

Multiple areas that require further research were noted in this study, including areas where there is a clear paucity of knowledge and areas where further exploration or confirmation is needed. Based on these findings, the following areas of further research in this realm is recommended:

- The study population was not very diverse, particularly with regards to the race of participants. It is recommended that a larger-scale study is conducted so that information from this study may be confirmed and therefore be more generalisable to the population.
- The role of the name of the condition on its perception and its treatment should be investigated.
- The comparison of occurrence and degree of demoralisation in the CCH versus the ECH population requires investigation.
- Further studies should focus on the public health sector, as this has not been fully investigated. Furthermore, epidemiological research on the occurrence of cluster headaches, and headaches at large, in the black African population is vital as there is a large paucity of their representation in the literature.
- A study into the potential presence and incidence of PTSD in the cluster headache population is recommended by the researcher.

6.7 CONCLUSION

This lifeworld exploration provided a novel look into the life experiences and perceptions of these experiences of those that suffer with CH in South Africa, as well as touching on the factors that influence these. The results of the study indicate that CH patients in South Africa struggle with receiving timely diagnoses and effective treatment, which leads to a decay in social and work environments due to the nature and severity of their headaches and has severe and potentially life-threatening emotional and psychological repercussions. Overall, participants expressed desperation for more efficacious and empathetic care and treatment that helps them experience a life that is less impacted by the presence of their disorder.

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APPENDICES

Appendix A: The Cluster Headache Screening Questionnaire (CHSQ)

Part A: Questionnaire

Please answer the following questions by marking ('x') the applicable option in the relevant square.

	Never	Rarely	Sometimes	Frequently
1. Headache improves within 3 hours				
2. Headache is accompanied by conjunctival injection and/or tearing on the headache side				
3. Headache is accompanied by sense of restlessness or agitation				
4. Headache is unilateral on the right or left side				
5. Headache is accompanied by nasal congestion and/or rhinorrhea on the headache side				

*Sometimes = less than half the time

Frequently = half the time or more

	No	Yes
6. Headache is repeated intensively for over a week		
7. Headache limits you from doing what you need to do		
8. Headache recurs more than three times weekly		
9. Male		

Part B: Scoring

	Never	Rarely	Sometimes	Frequently
1. Headache improves within 3 hours	0	0	0	3
2. Headache is accompanied by conjunctival injection and/or tearing on the headache side	0	0	0	3
3. Headache is accompanied by sense of restlessness or agitation	0	0	0	3
4. Headache is unilateral on the right or left side	0	0	0	1
5. Headache is accompanied by nasal congestion and/or rhinorrhea on the headache side	0	0	0	1

	No	Yes
6. Headache is repeated intensively for over a week	0	2
7. Headache limits you from doing what you need to do	0	1
8. Headache recurs more than three times weekly	0	1
9. Male	0	1

The total score of the CHSQ ranged from 0 to 16.

A participant is considered eligible to continue with the study when scoring 8 or above.

Development and validation of the CHSQ is credited to: Chung, P.W., Cho, S.J., Kim, B.K., Kim, S.K., Lee, M.J., Choi, Y.J., Park, J.W., Kim, B.S., Oh, K., Moon, H.S., Song, T.J., Kang, D., Cho, J., Chung C.S. 2019. Development and Validation of the Cluster Headache Screening Questionnaire. *Journal of Clinical Neurology*, 5(1):90–96. doi:10.3988/jcn.2019.15.1.90

Appendix B: Recruitment Poster

DUT
DURBAN
UNIVERSITY OF
TECHNOLOGY

DEPARTMENT OF
CHIROPRACTIC

DO YOU SUFFER FROM CLUSTER HEADACHES?

If so, research is being conducted on the lived experiences of those with cluster headaches in South Africa

As a participant in this study, you would be invited to participate in one-on-one interviews, either in person or over Skype to discuss your experiences with and the effects of cluster headaches on your life.

Your participation would involve *one* interview, of approximately

20–40 minutes.

For more information or queries about this study, or to volunteer for this study, please do not hesitate to contact me.

Researcher: Tanya Tschirpig 074 342 1225 / tanya.tschirpig@gmail.com

Appendix C: Permission Letter to the Administrator of the Cluster Headache Support Group

DUT
DURBAN
UNIVERSITY OF
TECHNOLOGY
INSTITUTIONAL
RESEARCH
ETHICS
COMMITTEE

Dear Ms M. Kryney

I hereby request permission to place an advertisement on the “Clusterheads SA” support group in order to recruit participants to conduct research as a Master’s Student at the Durban University of Technology Chiropractic Day Clinic.

The title of the research study is: Living with cluster headaches (CH): An exploration into the lifeworld of patients with CH in South Africa.

This study aims to explore the experiences of patients with cluster headaches in South Africa in order to add to the literature of the condition and improve the care they are able to receive.

Please find attached a copy of the research proposal. Should you require further information about this study, please contact me.

Kind regards,

____

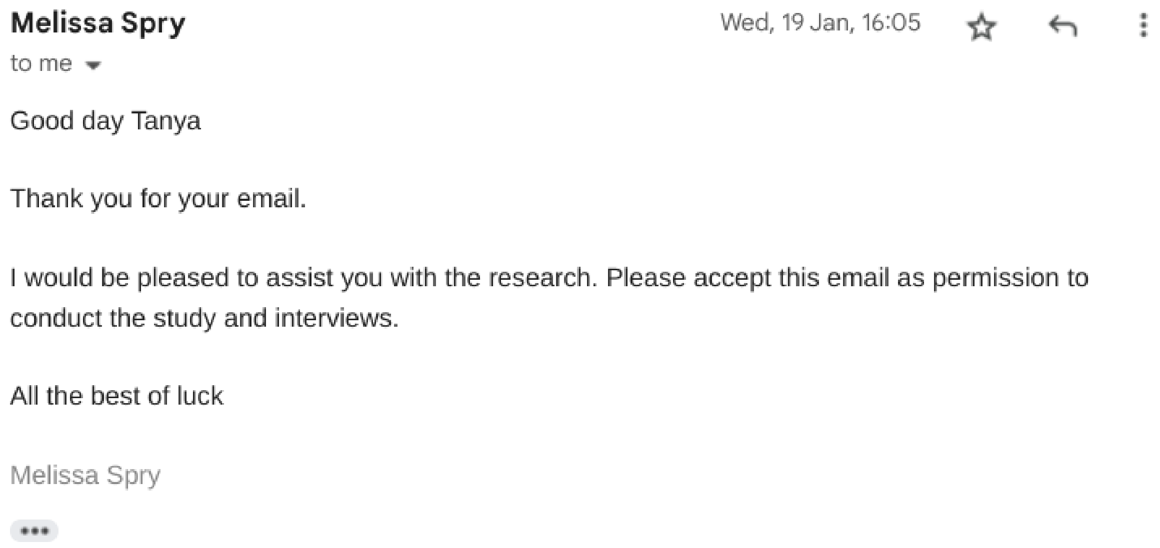
Tanya Tschirpig

Student Number: 21711332

Cell Number: 074 342 1225

Email: tanya.tschirpig@gmail.com

Appendix D: Permission to Advertise on Cluster Headache Support Group Granted



Melissa Spry

Wed, 19 Jan, 16:05

to me

Good day Tanya

Thank you for your email.

I would be pleased to assist you with the research. Please accept this email as permission to conduct the study and interviews.

All the best of luck

Melissa Spry

Appendix E: Interview Guide

Describe your experience living with cluster headaches.

Probes: What does the condition look like in you? How would you describe the pain? How do you feel during cluster attacks? And asymptomatic periods?

Please describe the coping mechanisms you use for your headache.

Probes: is there anything you do during attacks? Do you have specific strategies in place? How do attacks impact you?

Discuss the areas of your life that have been impacted by your headaches.

Probes: such as work, home, family, social, financial; how have they been impacted? What do these impacts mean to you? Comment on the impact of and changes due to CH in your relationships (work, friends and family).

Explain how your daily life has changed because of cluster headache.

Probes: What are the most relevant changes you have had to make in your life because of CH? Did making these changes impact you emotionally or otherwise?

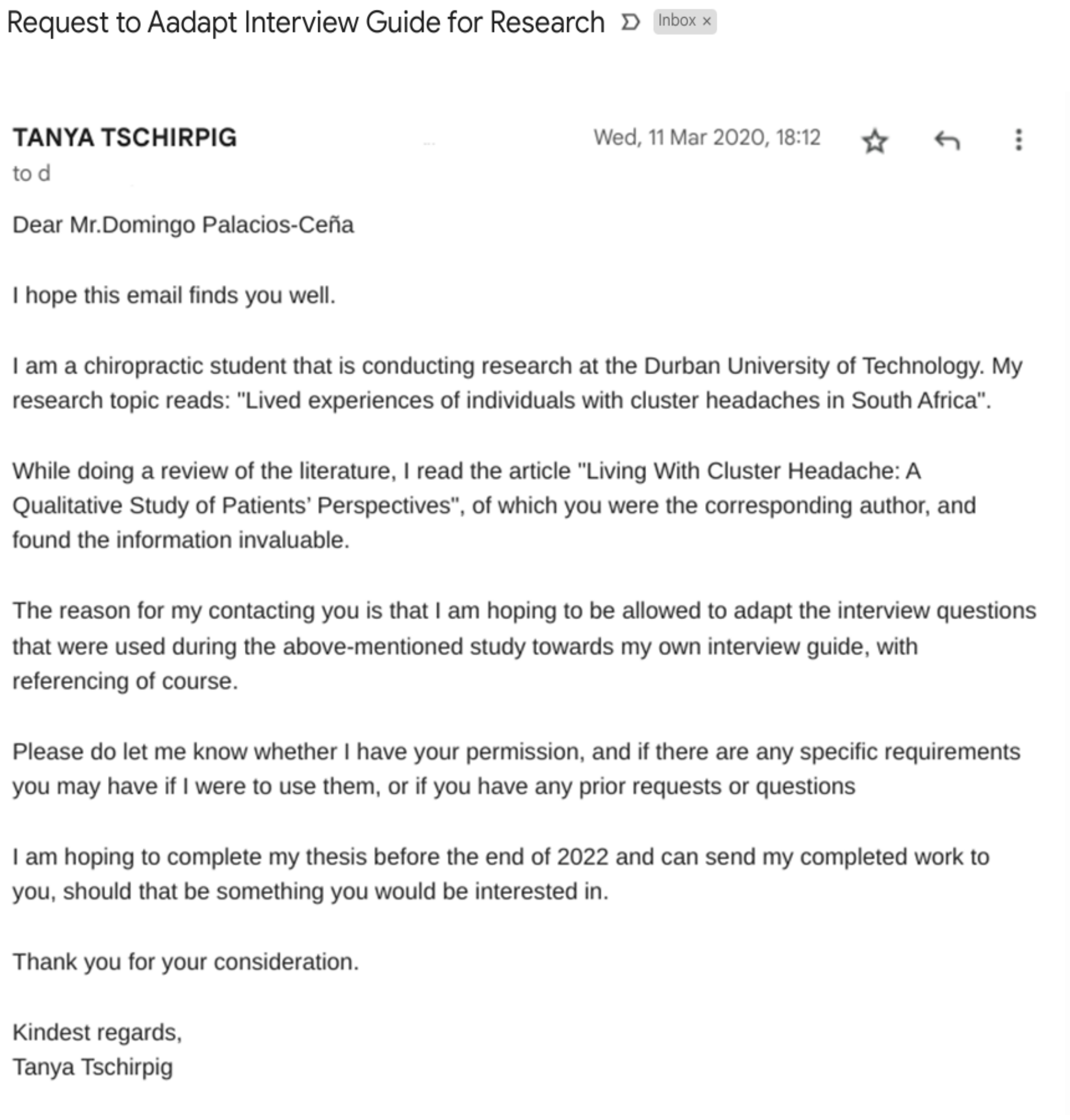
Please describe your understanding on the diagnosis, treatment and management of your headaches.

Probes: Comment on your experience with each of the above areas. What types of treatments have you tried, adhered to and how do you feel about it/them? Is there any aspect of treatment that has been prescribed to you, or that you have tried, that you consider to be the most relevant? Or that you feel you would like to comment on?

Describe your journey with the healthcare professionals you have come into contact with for your headache.

Probes: What type of professionals have you encountered for CH? Comment on your perception of the professionals you have encountered. What did you feel their knowledge and attitudes were? Is there anything you wish they knew, or a way they would behave that would improve your experience?

Appendix F: Permission Request for Adaption of Interview Questions



Request to Aadapt Interview Guide for Research

TANYA TSCHIRPIG Wed, 11 Mar 2020, 18:12
to d

Dear Mr.Domingo Palacios-Ceña

I hope this email finds you well.

I am a chiropractic student that is conducting research at the Durban University of Technology. My research topic reads: "Lived experiences of individuals with cluster headaches in South Africa".

While doing a review of the literature, I read the article "Living With Cluster Headache: A Qualitative Study of Patients' Perspectives", of which you were the corresponding author, and found the information invaluable.

The reason for my contacting you is that I am hoping to be allowed to adapt the interview questions that were used during the above-mentioned study towards my own interview guide, with referencing of course.

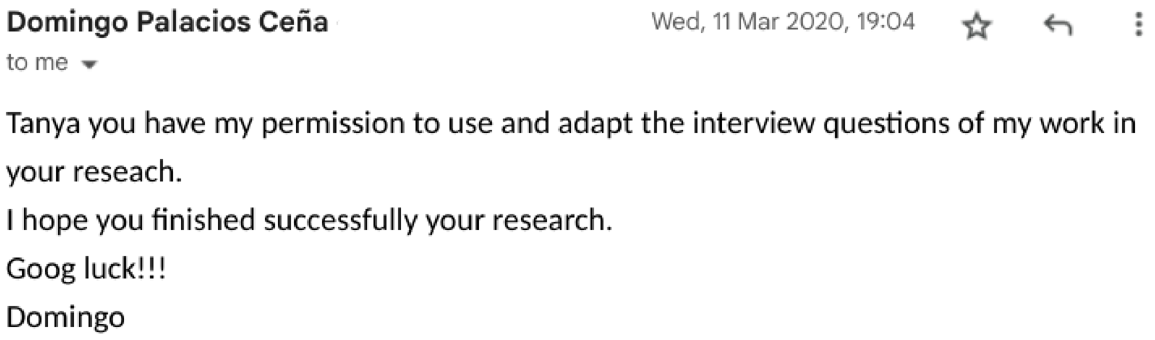
Please do let me know whether I have your permission, and if there are any specific requirements you may have if I were to use them, or if you have any prior requests or questions

I am hoping to complete my thesis before the end of 2022 and can send my completed work to you, should that be something you would be interested in.

Thank you for your consideration.

Kindest regards,
Tanya Tschirpig

Appendix G: Permission for Adaption of Interview Questions Granted



Domingo Palacios Ceña
Wed, 11 Mar 2020, 19:04
to me

Tanya you have my permission to use and adapt the interview questions of my work in your reseach.
I hope you finished successfully your research.
Goog luck!!!
Domingo

Dr. Domingo Palacios Ceña, Nursing Bachelor Degree, Humanities BD, Health Sciences PhD.

Appendix H: Demographic Data Sheet

DUT
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UNIVERSITY OF
TECHNOLOGY

INSTITUTIONAL
RESEARCH
ETHICS
COMMITTEE

Participant Name: ______________________________

Age	18-29	30-39	40-49	50-59	60-69	70-79	80+
Sex	Male		Female		Other		
Race	Black/African	Coloured	White	Indian	Asian	Other (please specify):	

Appendix I: Letter of Information for the Pilot Study

DUT
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INSTITUTIONAL
RESEARCH
ETHICS
COMMITTEE

Dear Participant,

I would like to take this opportunity to welcome you to my research study.

Title of the Research Study: Living with cluster headaches (CH): An exploration into the lifeworld of patients with CH in South Africa.

Principal Investigator/s/researcher: Tanya Tschirpig, B.Tech Chiropractic

Supervisor: Dr D. Varatharajullu, M.Tech Chiropractic

Brief Introduction and Purpose of the Study: This study will identify, explore and describe the lived experiences of patients with cluster headaches (CH) in South-Africa. Participants will be interviewed on various aspects of their experiences in order to gain a full-bodied understanding of the many facets that collectively constitute their lives. Data will be collected by conducting audio-recorded interview sessions, which will be for approximately 20 to 40 minutes. Any South African cluster headache sufferer that it is willing to participate is eligible for the study.

Aim: The aim of this study will be to describe and interpret the lifeworld of patients with CHs within a South African context. This data may be used to find areas that have the potential to be pragmatically addressed in order to improve the healthcare received and the lived experience of these patients.

Research questions:

1. What is the lifeworld of a patient with cluster headaches in South Africa?
2. What are the essential and nuanced influences that result in this experience?
3. What are the perceived personal, social, occupational and emotional impacts of cluster headache?

Risks or Discomforts to the Participant: There are no risks/discomforts involved from your participation in this study.

Reasons of Potential Withdrawal from the Study: This study may be terminated early under particular circumstances such as non-compliance, illness or government rulings avoiding personal contact between people. You may withdraw from the pilot study at any time should you wish to do so. I, as the researcher, under certain circumstances, may decide to withdraw you from the pilot study.

Benefits: Findings of the study will add to the body of knowledge on cluster headaches which may have an impact on practitioner insight into the condition, which will hopefully improve their ability to efficiently treat patients with cluster headaches, thus possibly indirectly benefiting you as a participant of this study.

Remuneration: No remuneration will be awarded to you for participating in this study and participation in this research study is completely voluntary.

Costs of the Study: You, as a participant, shall not incur any costs by participating in this research study.

Confidentiality: The details and information obtained through the interview process will be treated with utmost confidence. With the exception of the letter of information, no personal identification details are required. Your identity will only be known by the researcher and research supervisor. You may withdraw from study at any time.

Research-related Injury: Due to the nature of the study, injury is unlikely to occur.

Persons to Contact in the Event of Any Problems or Queries

Please contact the researcher Tanya Tschirpig on 074 342 1225, my supervisor Dr D.

Varatharajullu on 031 373 25833 or the Institutional Research Ethics Administrator on 031 373 2900. Complaints can be reported to the Director: Research and Postgraduate Support, Dr L Linganiso on 031 373 2577 or emailed to researchdirector@dut.ac.za

Appendix J: Informed Consent for the Pilot Study

Full Title of the Study: Living with cluster headaches (CH): An exploration into the lifeworld of patients with CH in South Africa

Names of Researcher/s: Ms Tanya Tschirpig and Dr D. Varartharajulu

Statement of Agreement to Participate in the Research Study:

- I hereby confirm that I have been informed by the researcher, ____________________ (name of researcher), about the nature, conduct, benefits and risks of this study – Research Ethics Clearance Number: ______________________________,
- I have also received, read and understood the above written information (Participant Letter of Information) regarding the study.
- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

____________________ ____________ __________

____

Full Name of Participant **Date**
Time **Signature/Right Thumbprint**

I, ____________________(name of researcher) herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

____________________	____________	______________
Full Name of Researcher	**Date**	**Signature**
____________________	____________	______________
Full Name of Witness (If applicable)	**Date**	**Signature**
____________________	____________	______________
Full Name of Legal Guardian (If applicable)	**Date**	**Signature**

Appendix K: Code of Conduct and Confidentiality Statement

This form needs to be completed by every member of the pilot group prior to the commencement of the interviews.

As a participant of this pilot study I agree to abide by the following conditions:

1. All information contained in the research documents and any information discussed will be kept private and confidential. This is especially binding to any information that may identify any of the participants in the research process.

2. None of the information shall be communicated to any other individual or organisation with the exception of the researcher and supervisor.

3. The information gathered by the researcher will be made public in terms of a dissertation and journal publication. The researcher will ensure that any participants in the pilot study and main study remain anonymous and confidential.

4. The interviews will be voice recorded and the data will be transcribed verbatim. The transcribed data will then be stored in the Chiropractic Department on a USB for a period of five years after which electronic data will be deleted and any paperwork will be shredded.

5. All data generated from this study (including the recording) will be kept for a period of five years after which electronic data will be deleted and any paperwork will be shredded.

________________________________	________________
Full name of participant	**Signature**
________________________________	________________
Full name of witness	**Signature**
________________________________	________________
Full name of researcher	**Signature**
________________________________	________________
Full name of supervisor	**Signature**

Appendix L: Letter of Information

Title of the Research Study: Living with cluster headaches(CH): An exploration into the lifeworld of patients with CH in South Africa

Principal Investigator/s/researcher: Ms Tanya Tschirpig, B.Tech: Chiropractic

Co-Investigator/s/supervisor/s: Dr D. Varatharajullu, M.Tech: Chiropractic

Brief Introduction and Purpose of the Study: This study will identify, explore and describe the lived experiences of patients with cluster headaches (CH) in South-Africa. Participants will be interviewed on various aspects of their experiences in order to gain a full-bodied understanding of the many facets that collectively constitute their lives. Data will be collected by conducting audio-recorded interview sessions, which will be for approximately 20 to 40 minutes. Any South African cluster headache sufferer that is willing to participate is eligible for the study.

Dear Participant,

I am a 4th year student at DUT doing research for my Master's degree in Chiropractic.

I would like to invite you to participate in my research.

What is Research? Research is a systematic search or enquiry for generalised new knowledge. It involves the collection, organisation, and analysis of information to increase understanding of a topic or issue.

Outline of the Procedures: If you meet the inclusion criteria, are willing to participate, and have signed the informed consent form, an interview will be set up at your convenience. It will be approximately 20 to 40 minutes in duration and will take place at a location convenient for you – likely using an online or digital platform to abide by social distancing measures.

Risks or Discomforts to the Participant: There are no risks/discomforts involved from your participation in this study.

Explain to the participant the reasons he/she may be withdrawn from the study:

You, as the participant, may withdraw from the research study for any reason, without penalty. You may be withdrawn from the study by the researcher, if you do not meet the full inclusion criteria.

Benefits: Findings of the study will add to the body of knowledge on cluster headaches which may have an impact on practitioner insight into the condition, which will hopefully improve their ability to efficiently treat patients with cluster headaches, thus possibly indirectly benefiting you as a participant of this study.

Remuneration: No remuneration will be awarded to you for participating in this study and participation in this research study is completely voluntary.

Costs of the Study: You, as a participant, shall not incur any costs by participating in this research study.

Confidentiality: The details and information obtained through the interview process will be treated with utmost confidence. With the exception of the letter of information, no personal identification details are required. Your identity will only be known by the researcher and research supervisor. You may withdraw from study at any time.

Results: The results of the study will be submitted as part of the researcher's Master's thesis; there is potential for the results to be published as a journal article. This article can be shared with you digitally, if you wish.

Research-related Injury: Due to the nature of the study, the possibility of injury is unlikely.

Storage of all electronic and hard copies including tape recordings: All participant information will be regarded as confidential, and their identities will be protected with the implementation of pseudonyms. Research and interview data will only be accessible by the researcher and research supervisor. Hard copy data and password-protected electronic data (on USB) will be stored at the DUT Chiropractic Department for five years, after which all the data will be disposed of or deleted.

Persons to contact in the Event of Any Problems or Queries:

Please contact the researcher Tanya Tschirpig on 074 342 1225, my supervisor Dr D. Varatharajullu on 031 373 2533 or the Institutional Research Ethics Administrator on 031 373 2375.

Complaints can be reported to the DVC: Research, Innovation and Engagement Prof S Moyo on 031 373 2577 or moyos@dut.ac.za.

Appendix M: Informed Consent

DUT DURBAN UNIVERSITY OF TECHNOLOGY
INSTITUTIONAL RESEARCH ETHICS COMMITTEE

Full Title of the Study: Living with cluster headaches (CH): An exploration into the lifeworld of patients with CH in South Africa

Names of Researcher/s: Ms Tanya Tschirpig and Dr D. Varartharajulu

Statement of Agreement to Participate in the Research Study:

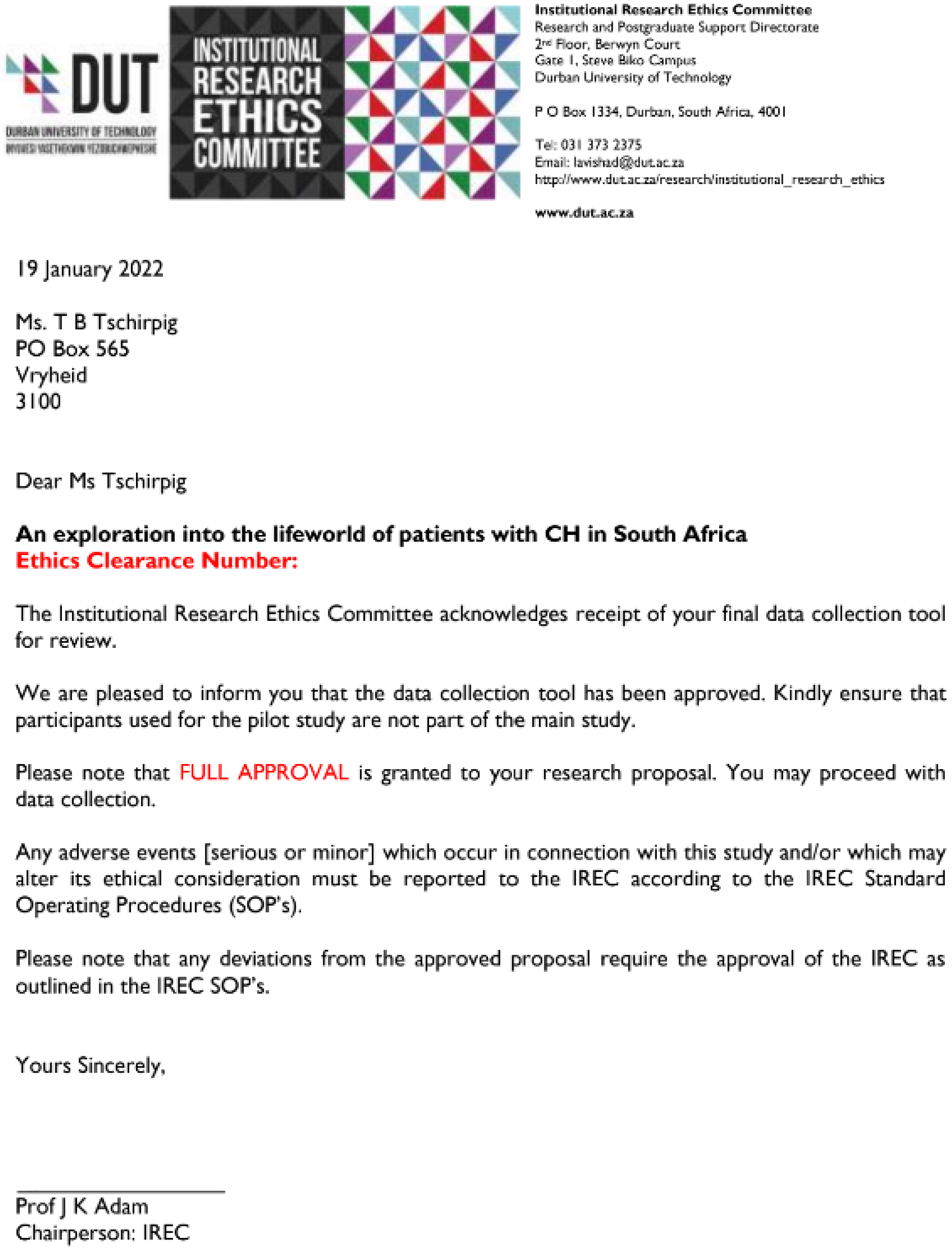
- I hereby confirm that I have been informed by the researcher, ________________________ (name of researcher), about the nature, conduct, benefits and risks of this study – Research Ethics Clearance Number: ____,
- I have also received, read and understood the above written information (Participant Letter of Information) regarding the study.
- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

______________________	____________	___________	________________
Full Name of Participant	**Date**	**Time**	**Signature/Right Thumbprint**

I, ____________________(name of researcher) herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

___________________	_____________	_________________
Full Name of Researcher	**Date**	**Signature**
___________________	_____________	_________________
Full Name of Witness (If applicable)	**Date**	**Signature**
___________________	_____________	_________________
Full Name of Legal Guardian (If applicable)	**Date**	**Signature Thumbprint**

Appendix N: IREC Approval



DURBAN UNIVERSITY OF TECHNOLOGY
INYUVESI YASETHEKWINI YEZOBUCHWEPHESHE

INSTITUTIONAL RESEARCH ETHICS COMMITTEE

Institutional Research Ethics Committee
Research and Postgraduate Support Directorate
2nd Floor, Berwyn Court
Gate 1, Steve Biko Campus
Durban University of Technology

P O Box 1334, Durban, South Africa, 4001

Tel: 031 373 2375
Email: lavishad@dut.ac.za
http://www.dut.ac.za/research/institutional_research_ethics

www.dut.ac.za

19 January 2022

Ms. T B Tschirpig
PO Box 565
Vryheid
3100

Dear Ms Tschirpig

An exploration into the lifeworld of patients with CH in South Africa
Ethics Clearance Number:

The Institutional Research Ethics Committee acknowledges receipt of your final data collection tool for review.

We are pleased to inform you that the data collection tool has been approved. Kindly ensure that participants used for the pilot study are not part of the main study.

Please note that FULL APPROVAL is granted to your research proposal. You may proceed with data collection.

Any adverse events [serious or minor] which occur in connection with this study and/or which may alter its ethical consideration must be reported to the IREC according to the IREC Standard Operating Procedures (SOP's).

Please note that any deviations from the approved proposal require the approval of the IREC as outlined in the IREC SOP's.

Yours Sincerely,

Prof J K Adam
Chairperson: IREC