Qualitative Exploration of Experiences of Cognitive and Emotional Changes in COVID-Encephalopathy Patients

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Abstract

Background: Encephalopathy is one of the severe complications that has been documented in COVID-19. Very little data is available regarding the cognitive and emotional outcomes in this condition although encephalopathy from other causes has been linked to lasting difficulties. Recovery from brain injury is complex and studies of subjective personal experiences play an important role in understanding the process.

Aim: This study explored the personal experiences of cognitive and emotional changes in COVID-encephalopathy patients, including the difficulties they face daily.

Design & setting: Adopting a qualitative methodology, participants were recruited from Groote Schuur Hospital in Cape Town and from Durban.

Method: Findings regarding cognitive and emotional changes were interpreted and classified according to the diagnostic principles of clinical neuropsychology which acknowledges brain-behaviour relationships. Interviews with five participants were conducted face-to-face. Thematic analysis was conducted to identify reoccurring patterns and themes in the data.

Results: The findings of the study reveal that even after the patient has been discharged from the hospital they continue to experience psychological and physical challenges. Main findings included: the effects of fatigue in COVID-encephalopathy participants and the *'problematic and depressing task'* of managing the cognitive and emotional changes; living with fear uncertainty; hospital-related-trauma. The findings further illustrated multiple losses in memory, concentration, attention, and motivation levels. Participants described these changes as interfering with their ability to lead normal lives.

Conclusion: This study has created awareness, especially for healthcare workers and family members, regarding the difficulties these patients face on a daily basis. Crucial to all of this, is ongoing support by primary care professionals and family members during recovery and rehabilitation. Additionally, physical rehab, regular counselling, resting, and having a healthy diet could also play an important part in assisting these patients.

Key words: Encephalopathy; COVID-19; COVID-encephalopathy; cognitive; emotion; post-acute COVID-19; clinical neuropsychology

Introduction

On the 11th of March 2020, the World Health Organisation (WHO) classified the COVID-19 outbreak as a pandemic (Hao et al., 2020). The virus has since claimed many lives and altered others, physically, neurologically, and psychologically (Nalleballe et al., 2020). Clinical manifestations can range from mild to severe (Nalleballe et al., 2020). Common manifestations include fever, dry cough, fatigue, headache, and sore throat, however the virus can also cause complications that can be fatal, for example acute respiratory distress syndrome (Almeria et al., 2020). Many patients experience psychological distress which can lead to PTSD, depression, and anxiety (Sun et al., 2021). Furthermore, as the research accumulates, more neurological manifestations of the virus are being identified (Almeria et al., 2020; Liotta et al., 2020).

Neurological Manifestations

Common neurological manifestations of the COVID-19 virus include headaches, confusion, strokes, giddiness, sleep disorders, seizures and encephalopathy (Liotta et al., 2020; Nalleballe et al., 2020; Niazkar et al., 2020; Wilson et al., 2020). Studies have also shown that patients’ cognition and emotions may also be severely affected due to the aforementioned damage (Almeria et al., 2020; Wilson et al., 2020; Yang et al., 2020). Several theories exist on how the virus causes neurological symptoms. These theories look at direct CNS infiltration, post infectious autoimmune responses, cytokine network dysregulation and peripheral immune cells transmission to describe neurological manifestations (Hao et al., 2020; Liotta et al., 2020; Nalleballe et al., 2020). The virus can also travel to the brain via the olfactory system, which can cause the brainstem to be affected and in turn cardiac and respiratory functions become inflamed and dysregulated (Garg et al., 2021).

Framing Encephalopathy

One of the significant and severe neurological manifestations of COVID-19 is encephalopathy which is characterised by generalised brain dysfunction and presents patients with unique challenges, cognitively and emotionally (Garg et al., 2021). Encephalopathy is associated with adverse long-term clinical outcomes and can lead to serious disabilities (Liotta et al., 2020). Encephalopathy is one of the major presentations of COVID-19 illness (Alturi, 2021). And there are multiple aetiologies of encephalopathy (Garg et al., 2021). These include toxic, metabolic, sepsis, inflammatory and anoxic-ischemic (CCCHC Clinic, 2017). Encephalopathy is an inflammation or infection of the brain and presents itself symptomatically through fevers, headaches, a modified mental state, seizures, neurological deficits, and reduced consciousness (Roos, 2014). Encephalopathy in actual fact, is a prevalent symptom of multiple organ dysfunction (i.e., acute respiratory insufficiency, hepatic, or cardiac failure) because the body becomes unsuccessful in maintaining the normal functioning of the brain (Garg et al., 2020). Encephalopathy patients are often confused and present with behaviour abnormalities and flu like symptoms including nausea, myalgia, diarrhoea, vomiting and respiratory illness (Roos, 2014). Encephalopathy can lead to disability and sepsis and is associated with higher rates of mortality in COVID-19 patients (Liotta et al., 2020).

Many critically ill COVID-19 patients have severe inflammatory responses to the virus which causes hypoxic or metabolic changes in the body (Garg et al., 2021). These changes are thought to be responsible for the presentation of encephalopathy in COVID-19. Although it is still not clear whether COVID-19 patients experiencing encephalopathy, specifically, report lingering cognitive deficits, it has been established that many severely ill COVID-19 patients do (Wilson et al., 2020). These deficits include problems with memory, attention, executive functioning, and processing of information (Wilson et al., 2020). This leads to repercussions for patients and their functioning but also for those who look after them (Almeria et al., 2020). Not being able to work has a big effect on the finances of patients and their socioeconomic statuses (Grønkjær et al., 2018). Not only is cognition affected, but patients are also impacted psychologically (Sun et al., 2021). Thus, although there are currently no reports of cognitive deficits in COVID survivors who are presented with encephalopathy specifically, there is reason to believe that these patients will also experience numerous setbacks, social isolation, and a dependency on others (Grønkjær et al., 2018). For example, prior studies show that emotional reactivity and regulation are impaired post-encephalitis (Salas et al., 2014). Post-encephalitis patients have also reported problems with memory, concentration, executive function, processing speed, visuo-spatial deficits and communication (Grønkjær et al., 2018; Hopkins et al., 2004; Iwashyna et al., 2010).

What we know about cognitive changes in encephalopathy comes almost entirely from quantitative approaches. There are few studies that document the subjective accounts of mental changes in patients with encephalopathy, and there no qualitative studies to date on neuro-cognitive outcomes in COVID-19 patients that would shed light on the challenges that should be considered when designing effective rehabilitation programs (Fabrellas et al., 2020; Grønkjær et al., 2018). Although quantitative studies account for what domains of cognition are affected, how these deficits translate into difficulties in everyday life is lacking. Literature in the ‘neuro-covid and covid-encephalopathy’ field has rapidly emerged with impressive sample sizes but it is comprised using solely quantitative instruments (Hao et al., 2020; Sun et al., 2021).

Moreover, this research has been situated in high income areas that have been under-representative of cultural, gender and ethnic diversity (Borno et al., 2020). Individuals from minority backgrounds are twice as likely to die from COVID-19 and research data is not uniformly collected when it comes to race with black patients’ disease burden being underrepresented (Borno et al., 2020; Wilson et al., 2020). Yet the COVID-19 virus is not discriminatory and affects individuals of all cultures, races, and genders (Sun et al., 2021). By studies only adopting quantitative approaches, the “insider” perspective or the patient-experienced perspective is missed (Grønkjær et al., 2018). To aid the rehabilitation of these patients, qualitative research is needed to create an understanding of the difficulties these patients face in everyday living.

Qualitative Research in the Field of Neuropsychology

According to Sacks (1998), “The patient’s essential being is very relevant in the higher reaches of neurology, and in psychology, for here the patient’s personhood is essentially involved, and the study of disease and identity cannot be disjoined” (p. 6). Therefore, some authors argue that purely quantitative measures cannot capture the scope of experience and the extent of suffering endured by brain injury patients (Salas et al., 2017). Instead, rehabilitation efforts that are guided by a neuropsychoanalytic approach may be particularly appropriate for the emerging cohort of COVID-encephalopathy patients (Coetzer et al., 2018). The main features of this approach would emphasise personality and emotions, a person’s self-awareness, the self, relationship and systemic aspects, and therapeutic methods that use non-confrontational approaches (Coetzer et al., 2018).

Open-ended interview-based studies are well suited to achieving these ends as they provide rich descriptions of subjective understandings of how functionality in these patients has been impacted and how psychologically and cognitively, they have been affected in their unique social-cultural contexts (Hao et al., 2020). In studying brain damage, and encephalopathy, the consideration of ethnocultural factors is increasingly recognised. Different cultural factors play a role in how patients and their caregivers respond to illness (Mahoney et al., 2005). For example, in Chinese culture, there is an emphasis on fulfilling family responsibilities and if you are unable to do so, you are looked down on and face increased stigma in addition to your illness (Sun et al., 2021).

In conclusion, there is a gap in our understanding of encephalopathy in COVID-19 patients and the exact nature of mental changes experienced by this group of survivors. A qualitative study, as well as a study in a low-income area will address this gap. An attempt to meaningfully characterise and classify the experiences of these individuals must be made in order to meet the needs of patients from all social and economic backgrounds. This research has the potential to create awareness and produce tailored rehabilitation programmes that significantly impact patients' recovery (Liotta et al., 2020).

Aims and objectives

Aims:

The overall aim of this study is to document and characterise the subjective accounts of emotional and cognitive changes that took place in COVID-encephalopathy patients during the acute and subacute phases of the virus. This study aims to gain an understanding of experiences of patients from low to middle to high income areas and to create awareness, especially in healthcare workers and family members, on the difficulties these patients face on a daily basis. Also to aid in the creation of low-cost rehab programmes tailored to the specific needs of low SES groups

Main research questions:

- How do COVID-encephalopathy survivors describe changes in their cognition and emotion during the acute phase of their illness?
- What challenges are linked to the emotional experiences of these participants?
- What challenges are linked to cognitive deficits that these participants report?

Method

Theoretical framework

The brain relates to our mental lives in a way that no other organ does (Solms & Turnbull, 2002). The theoretical framework for this study was conducted from general principles that modern clinical neuropsychology is based on. The recognition of clinical neuropsychology as its own scope of knowledge has led to the establishment of neuropsychological strategies of a qualitative and quantitative nature for clinical use; experimental research in cognitive, comparative, and physiological psychology; and an analysis of the behavioural effects of lesions on the central nervous system (Meier, 1992). Basically, the field of clinical neuropsychology is built upon relationships that exist between the brain and the mind, the latter of which includes cognition and thoughts, feelings, and emotions, and behavioural control. This interaction of the brain and behaviour affects subjective experiences and information processing, that is, cognition (Martin, 2016).

When brain injuries result in the breakdown of the brain's ability to effectively process information, certain general categories of deficit arise in the way a person interacts with the world. Cognitive deficits are well described in the literature and are generally assessed objectively using standardised tests (Tranel, 2007). However, Alexander Luria, who revolutionised modern clinical neuropsychology assessment, founded the idea that a qualitative analysis is needed of the signs and symptoms in patients to evaluate their conditions and where the areas of dysfunction are in their brains (Morgan & Ricker, 2017). This study drew on this theory when interpreting patterns of problems that these patients describe on the basis that they could be indicative of cognitive deficits as a result of their illness. It was used to infer, based on the clinico-anatomical method that is informed by this framework, what deficits in the brain these patients may have.

Research design

This study employed a qualitative approach. Data was drawn from semi-structured interviews and subjective reports from participants about their experience of completing three cognitive tests. Qualitative research enables the understanding of perspectives and experiences to make sense of the world (Blanche et al., 2012). Additionally, qualitative research brings about empowerment to participants as it gives special attention to the voice of the participant over that of the researcher (Babbie & Mouton, 2007). It allows for in depth research to take place on selected issues and for an understanding to take place on the themes that emerge from these issues. As our interest was in the experiences of individuals, this method was appropriate. It was also appropriate as qualitative research develops knowledge that deals with the ‘how’ and ‘why’ questions which contributes greatly to medical service research (Kingstone et al., 2020).

Experiences were seen as realities and the study engaged with these experiences to better understand what these participants are going through and how this can inform rehabilitation (Blanche et al., 2012).

Participants

Participants were previous patients who had been hospitalised for COVID-19 related illnesses with a positive viral diagnosis of COVID-19- related encephalopathy. However, for the sake of bringing to light any unique experiences reported by COVID-encephalopathy participants, individuals who were hospitalised for COVID-19 related illnesses with no positive encephalopathy diagnosis were also interviewed with the aim of comparing experiences. This study employed non-probability, purposive sampling techniques which is a convenient recruitment method.

Participant’s time after discharge from hospital ranged between 5-12 months. Participants were recruited from low to middle socio-economic contexts, however there was no exclusion or inclusion criteria. Participants were able to communicate in English and were also deemed medically stable by a physician to participate.

No participant was excluded from the study as a result of a history of any neurological illness or learning disability. All information collected from participants will remain strictly confidential as stipulated by the Protection of Personal Information (POPI) Act. To further protect personal information, the identities of all the participants was protected by means of pseudonyms throughout the report.

Table 1 gives an account of the ages, gender/sex, home province, economic status category, classification with regards to neurological manifestations/severity of COVID they belong to and the time in which they were discharged from hospital.

Table 1

Participant Characteristics

Participant	Age	Gender/sex	Home Province	Economic class/category/status	COVID-19-related encephalopathy diagnosis	Time discharged from hospital (in months)
Annette	68	Female	Western Cape (Cape Town)	Lower middle income status	Encephalopathy present	5
Patricia	59	Female	Western Cape (Cape Town)	Middle economic status	Encephalopathy present	12
Ntsikayomzi	56	Male	Western Cape (Cape Town)	Lower middle economic status	Encephalopathy present	12
Nokuthula	25	Female	KwaZulu Natal (Durban)	Lower middle economic status	No encephalopathy diagnosed	6
Ntokozo	45	Male	KwaZulu Natal (Durban)	Lower middle economic status	No encephalopathy diagnosed	5

Data collection methods

Data was collected primarily through semi-structured face-to-face interviews (See Appendix B). Semi-structured interviews differ in that, specific questions are asked to evoke conversation that will allow the participant to express a response that they feel is most relevant and important (McIntosh & Morse, 2015), vital to this was the avoidance of closed-ended questions (See Appendix C).

Participants were then administered three cognitive assessments as stimuli to elicit feedback regarding subjective experiences of engaging in the tasks. Measures included a test of attention capacity, efficacy, executive functioning memory (attention, working memory and planning). The Digit Span Test, the memory component of The Mini Mental State Examination, and the Rey–Osterrieth Complex Figure.

Procedure

Participants were invited telephonically to take part in the study. Colleagues at Groote Schuur Hospital invited eligible patients to participate and requested permission to give us their contact details if they were interested. In Durban, participants were invited to participate by means of a WhatsApp status the researcher posted. My peer-researcher, Raine Comninos who was based in Cape Town, interviewed the 3 encephalopathy participants and I interviewed the other 2 participants who had no presence of encephalopathy in Durban.

Before the commencement of the interview sessions, participants were given a general overview of what the session would involve and asked to read through and sign the consent form. The research sessions took place at the Neuroscience Institute in Cape Town and Pentecostal Holiness Church office in Durban at the participants' convenience. The sessions strictly adhered to COVID-19 health regulations. And, so as to foster full disclosure, participants were interviewed alone, without the presence of any carer or family member who might have accompanied the participant. Protection of data was in line with the POPI Act.

In each interview the participants were asked, "I would like to know more about your experiences with the COVID-19 virus, maybe could you start by telling me when you first got sick?" (see Appendix B & C). After that, the participant' cognitive and emotional aspects of their lives were explored. During the interview, the researcher took notes and audio-recorded the session with permission from the participant. After the completion of each of the three cognitive tests, participants were asked one question “How did you find the test you just completed?” Recordings were transcribed. Participants were thanked for their participation and received payment of R100 each.

Data analysis

Data was analysed using a thematic approach which is a method that involves examining data to identify any recurring patterns or themes (Braun & Clarke, 2006). The guidelines to thematic analysis as outlined by Braun and Clark (2006), were followed. Therefore, themes were allowed to emerge naturally, and coding occurred according to themes from a clinical neuropsychological perspective, for instance cognitive domains.

Additionally, themes were later identified so as to locate cognitive deficits in the participants' relationship between their brain and cognition and to explore and also give an account on the participants’ actual accounts of their personal and subjective experiences of cognitive and emotional changes. Extracts were coded to categorise the experiences of the participants. This formed part of an inductive approach and themes were assigned and reformulated until all data was categorised appropriately. The researcher remained aware of response bias and used non-leading questions. A database was created wherein each participant's neuropsychological scores and their COVID-19 medical histories are compiled.

Ethical Considerations

Ethical approval for conducting the study was granted by the Psychology Department Ethics Committee, University of Cape Town.

Harm to Subjects

Our greatest worry was the risk of participants getting re-infected and because encephalopathy is so severe, participants might not give consent. However, all COVID-19 safety precautions were followed. Rooms were sanitised, only one session took place a day, the room was ventilated, everyone was required to wear a mask and that they sit 1.8 metres apart with a screen between them. Before entering the venue, each person's temperature was checked, screening questionnaires were completed, and hands were sanitised. In addition, participants were screened telephonically a day before their sessions. Participants unfit to travel alone were accompanied by a caregiver, however this was not mandatory or a requirement. The identities of all the participants were protected by means of pseudonyms throughout the report.

Informed Consent & Deception of Respondents

Prospective participants, during the recruitment stage, were made fully aware of what their commitment entailed. There was transparency with regards to the purpose and aims of the study and the nature of the questions. Participants were handed informed consent forms (see Appendix A) that clearly defined the goals of the study, how it will be executed, possible risks and inconveniences, how their confidentiality is guaranteed and their voluntary participation. Participants who did not understand the information in the consent form were considered ineligible.

Debriefing and Referrals

As our aim was in exploring the experiences in cognitive and emotional changes the participants experienced, the set of questions we had might have caused emotional distress to them and their family members. Hence to help mitigate that, each participant was given a list of organisations and resources (see Appendix A) which, in case they needed additional support they would contact. Furthermore, a week after the interviews, in the event that the research session/discussions negatively affected participants, participants were contacted to see if they needed any extra support.

Reflexivity

When analysing data, the researcher noted and discussed any personal biases he may have towards participants' individual traits. Any individual experiences that the researcher has had with patients that have been neurologically ill and preconceptions on emotional control and brain injuries were noted and discussed. The main goal was to be objective, neutral and unbiased. The researcher was aware of racial and gender power dynamics that can be at play during the interviews. Posing participants as the experts on what they are discussing was emphasised.

Results and Discussion

Fatigue and Long Periods of Sleep Experienced by COVID-encephalopathy Participants

Out of all the accounts/experiences narrated by participants, experiences of fatigue, lethargy and long periods of sleep accompanied by stupor were most prevalent. Annette’s and Ntsikayomzi’s accounts below represent the pain, inconvenience, agitation and upset that surfaced frequently throughout participants’ accounts of fatigue and long periods of sleep and stupor.

> *They let me go home when I got home I couldn't walk they had to take me in a wheelchair to the toilet. Oh, yes. I couldn't do nothing. I couldn't do anything. Then my sister came and bath and she came and bath me and my other daughter came in bath me…. Yeah. And I couldn't do anything for myself. When I got home I had to get in the wheelchair. They pushed me to the they must say take off the pyjama paints whatever and put me on the tub……I couldn't walk the legs were lame.* (Annette)

> *All I discovered I was paralyzed; I couldn't even walk. I couldn't even stand my my joint all my joints. couldn't work. I couldn't even speak…… Everything i was doing in bed. Nothing. I couldn't I couldn't talk I couldn't nothing…. I just saw the shadows of people, if these are people. The doctors were here. But I couldn't recognize these are doctors,*

> *these are people in fact, I just saw that. These are just shadows. Because I was I can just say I was in coma. I can just say that…* (Ntsikayomzi)

Liotta et al., (2020) found that encephalopathy can lead to disability in COVID-19 patients. Annette's and Ntsikayomzi's accounts demonstrate the before and after effect the COVID-19 virus as a result of encephalopathy has on an individual. Ntsikayomzi's narrative also points to stupor as he mentions that *I was in coma*. Participants' accounts of the fatigue they experienced and continue to experience as a result of encephalopathy (generalised brain dysfunction) resemble those identified by previous research (Sue et al., 2010). Additionally, participants describe similar deficits to patients who had encephalopathy from non-COVID causes, however the emotional and psychological changes experienced are different. Encephalopathy presents persons with acute symptoms which include lethargy, fever, delirium, and long periods of sleep (Sue et al., 2010). Moreover, encephalopathy is an inflammation or infection of the brain and presents itself symptomatically through fevers, headaches, seizures, neurological deficits, and reduced consciousness (Roos, 2014). Therefore, using the brain-behaviour relationship perspective (Solms & Turnbull, 2002), participants' reports are without any contradictions because when encephalopathy is present, an inflammation in the brain must have occurred resulting in cognitive, physical and emotional changes. The participants' frequent complaint about how when they were still at the hospital were unable to do anything, and just wanted to lie in their beds and sleep concurs with the aforementioned literature.

Annette's account reveals that even after discharge, participants continue to experience psychological and physical changes. She voices that she could not do anything, to the extent that she was unable to bathe herself. All of this proves that as a result of the fatigue she experienced, she was now unable to perform some tasks. And sadly that applied to all participants.

We noticed that in Annette's narrative that such inconveniences or inabilities lead to feelings of dependency to others. Fatigue and long periods of sleep and stupor produced a sense of loss of independence which resulted in irritation, feelings of uselessness, and sadness:

> *All I wanted to do sleep, I just, my head just wanted to stay on that pillow.*
>
> *…And I did my head want to burst, all I wanted to do is lie on the bed, with my eyes closed. And everybody just <u>had to just leave me alone</u>! Because my head was my head was terrible…* (Patricia)

This among other narratives was the most common complaint that emerged from the participants. Participants' accounts of fatigue or inability to perform simple tasks like bathing themselves was one that worried them enormously and brought about great upset and anger. Such feelings were accompanied by feelings of worthlessness, uselessness and helplessness to the point of internalising and living according those thought/feelings. Some participants, when talking about their experiences started stuttering, because of anger and upset. Changes in terms of behaviour and the way you feel as a result of brain infection or inflammation result (brain-behaviour relationship) can be devastating an burdensome.

Furthermore, during their acute and subacute phases, the only time some participants, felt better was when they closed their eyes and slept for a while (post-COVID). This change occurs when they are in the process of recovering and adjusting back to life, however they are faced with not being able to get back to their old selves.

> *But all the time my head is busy. The only time I feel relieved is if I close my eyes*. (Patricia)

Across each and every interview it became evident that the harm, trauma, grief and distress these participants face daily runs deeper than testing positive for COVID-19. Moreover, fatigue and long periods of sleep prevalence came with its effects and these effects were later seen more prevalent in the lives of the COVID-encephalopathy participants when they went back to work. Patricia’s report above concurs with that claim.

This brought about distractions, hindrances, interferences and disturbances to the participants’ functioning at their workplace. Both Patricia and Ntsikayomzi narrate such a story. Patricia, a nurse by profession diagnosed with *post exertional immunological fatigue syndrome,* a disorder that occurs generally after being exposed to stress (Lacout et al., 2020), was the most affected by the effects of fatigue and long periods of sleep and stupor. Below is her narrative;

> *This was only I couldn't cope at work……*
>
> *And if I'm sitting down, I'm fine. But if I must just get up to go fetch a file from there, bring it here, write it and go file it there. It's all this movement. But if I'm sitting here and I'm doing something, I'm fine.* (Patricia)

A professional nurse working with kids in a busy place like a hospital having to only work efficiently when she is sitting down. Imagine the distress, anger, turmoil and anxiety she went and is going through. The pain she felt that for almost 41 years in service she now has to work sitting down.

Ntsikayomzi a ticket official’s narrative of the negative effect his fatigue brought to his workplace lies below;

> *As I said if I the whole year I was not working most of the time I was sleeping most of the time I was sleeping always in bed just relaxing. Now this week I went back to work so I'm working five hours for now because they accommodate me so I'm working five hours that five hours when I come back home straight to bed.* (Ntsikayomzi).

For a whole year, Ntsikayomzi was not working as a result of fatigue, most of the time he was always sleeping (long periods of sleep). But fortunately enough, at his workplace they accommodated him and reduced his working hours but still after a year has passed. When he goes back home after working those five hours he is tired and goes straight to bed. The negative results of fatigue are further illuminated when he tells us that *"Yeah, it also affects your brain because before I, I had nothing and I noticed that it was when I came out from hospital I had to go back to work, as I'm losing money daily…"* (Ntsikayomzi) We put an emphasis on that because we want to concur with Grønkjær et al (2018) said "Not being able to work has a big effect on the finances of patients and their socioeconomic statuses." Participants' narratives resemble existing literature because encephalopathy in both non COVID- causes (Sue et al., 2010) and COVID causes presents itself symptomatically through headaches, confusion and sleep disorders (Liotta et al., 2020; Nalleballe et al., 2020; Niazkar et al., 2020; Wilson et al., 2020).

COVID-encephalopathy led to situations where the participants felt that they were no longer themselves. This resulted in the feeling of a loss of identity and dependency to others, which can be frustrating:

> *They pushed me to the they must say take off the pyjama paints whatever and put me on the tub……I couldn't walk the legs were lame.* (Annette).

Such losses and feelings (changes), even the ones mentioned earlier here, resemble what previous research identified (Grønkjær et al., 2018).

Hospital Related Trauma

Another common narrative was about the participants stay/time in the hospital. Participants voiced that their time in the hospital was not a nice experience. When asked "did you find the hospital strange or unusual?" most of them answered "I don't like hospitals", in an angrily voice, some reminisced about hospitals back when they were growing up, how much love and care the nurses' had, and the quietness. According to participants these qualities are no longer there.

Psychological implications. When going to the hospital, participants were of the opinion that once you are hospitalised because of COVID-19 chances of you coming back alive were slim. The deaths they saw when hospitalised, the extent these people sicknesses and now seeing that first-hand, the medical staff's negligence, stigma and own fears resulted in participants leaving with constant fear and uncertainty. Participants all explained that hospitals are not what they used to be and as a result went in doubting whether they will come back alive (fear and uncertainty). Here is Patricia relaying to us how she truly felt about being in the hospital.

> *And but all I remember is I just wanted to get out of the hospital. Because that wasn't it wasn't a nice feeling.* (Patricia)

Some participants blamed the nurses and doctors for the death of other COVID patients. Ntsikayomzi mentioned that permanent nurses were on holidays during his stay at the hospital, agent nurses were available and were negligent. According to Ntsikayomzi, many people died because of that. Below is Ntsikayomzi's account of that;

> *One other thing I can tell other people when, didn't die because of the COVID. They died because of that the oxygen the pipe was not tight. You know. So you were supposed to, to to safeguard the pipe that you mustn't come out. There was no it was supposed to, to do to have to have a nurse all the time around us. Maybe they will leave us more than three hours. No one, then the pipe if the pipe come out of your nose, you can't breath then the other when she comes someone is is dead because of that pipe on my thinking that oh, if the pipe was in the the nose, this person couldn't die. But he died because of this thing. So what I experienced that the nurses were scared to be inside with the COVID people. So they were just coming for 10 minutes and leave in and leave again.* (Ntsikayomzi)

Ntsikayomzi's narrative points to also the fear the nurses had. However, it also points to negligence, lack of love and care. Cases of negligence by hospitals, nurses and doctors correspond with existing literature (Adams & Adams., 2021). We have another narrative by 68-year-old Annette who tells us that hospitals have changed, when she was 13 years' hospitals were nice and the nurses were also nice.

She told us that her grandchild, who is probably 8 years said crying "they must let Mah come home, cause I know they are not treating her properly".

> *....it was a very a bad experience. But one thing I want to say to you and i never knew hospital was like that. There's no more love the nurses they just do whatever. And hospital used to be quiet that is God was 13 years old when I was in hospital.. I thought is this how hospital is supposed to be quiet. They don't even attend my hair cut my hair because it was like a Rasta hair. They don't even see that to look decent or whatever. And your family can't come in and all that. I was just laying there. I just don't no* *<u>man I must get home. Really!</u>* *I'm the one praying for the patients in hospital that God may just put love in the, in the nurse's heart to you know that. Yeah. So sad. It's very sad.* (Annette)

During the interview Annette further stated that superiors must go in hospitals and see the what goes in there. It is evident throughout the participant's accounts of their stay at the hospital that what they experienced had psychological implications. Despite the possibility that this study's aim was not to measure the presence of PTSD in participants, however possible symptoms of PTSD were noticeable in many of their accounts. Participants described fluctuating and unstable moods and feelings of confusion, social isolation (as depicted by Ntsikayomzi and Patricia), in one of Ntsikayomzi's narratives he stated that he no longer had the interest to stay with his family, he just wanted to be alone. Participants' accounts of their stay at the hospital warrants claims of PTSD, found by the (National Institute of Mental Health [NIMH, 2007f]) is in accordance to the participants' accounts the fears and trauma they now experience because of hospitals. Exposure to a traumatic event however, does not necessarily mean one will develop stress disorders (Sue et al., 2010) and so not all participants developed stress disorders.

> *So so that thing was traumatized me, even at home I used always having my my...* (Ntsikayomzi)

Many participants reported intrusive symptoms such as having painful memories constantly replayed in their heads. Not only is cognition affected, but patients are also impacted psychologically (Sun et al., 2021).

The Lack of Communication experienced by COVID patients) Many participants commonly complained about not being able to see their loved ones. In the complaints, participants added, and spoke about how when they got home, their loved ones told them that the hospital did not keep them up to date. There was just absolute silence, the loved ones had to be the ones who called for updates and sometimes they received responses late or never.

> *There was no family allowed. Not a single. Not family allowed there.* (Ntsikayomzi)

Not seeing your loved one for over a week is not something nice. Feelings of loneliness haunt you during night and day, you long and yearn to talk to someone you familiar with, face to face. And if that is not possible loneliness takes control. This happens especially if you are really sick. Your stay at the hospitals becomes more unenjoyable. Because seeing a loved one's, face gives you hope and strength. You remember that you have something to fight for, you feel loved, appreciated and special.

Mood Changes During Hospitalisation. At the same time, the participants also experienced problems with their moods as a result of the COVID-virus that infected their brains thereby causing encephalopathy. Studies show that the virus can affect the brain and leave lasting cognitive, behavioural, and emotional problems within the patient (Almeria et al., 2020; Nalleballe et al., 2020; Niazkar et al., 2020; Sun et al., 2021; Wilson et al., 2020). Therefore, the participants' reports of mood fluctuations coincide with existing literature:

> *as I said, I was not used the thing. I used to, to to to shout especially to those to the caterer to the people were bringing the food for us. So they knew that when they come in my what I will shout so I was always not in a good mood for them. Not in a good mood.* (Ntsikayomzi)

Stigma and Discrimination Experienced by COVID patients in Hospitals. Sadly, as a result of the participants' COVID status, some participants were stigmatised and discriminated against. We note and understand that doctors and nurses had to be careful when treating COVID patients, but the way in which the participants reported their stories, it was evident that it was no longer about being careful. Fear, negligence coupled with stigma and discrimination had taken over the minds of the medical staff. Proof of this is found in Ntsikayomzi's and Patricia's narration. Ntsikayomzi's narrative mentions that nurses would leave them unattended for hours and each time they came back, a person or two had died:

> *…were just put us check us and go out. Maybe they will leave us more than three hours.* (Ntsikayomzi)
>
> *the doctors didn't come near me…. So, so so. So the worst thing is that the human touch, a physio, a physio came to me…..he stood at the end of the bed. And he was supposed to give me physio doctor came every day he stood at the end of the bed that affected that human touch, that connection.* (Patricia)

Living with Uncertainty and Fear. COVID-19 had taken countless number of lives and so, that resulted in fear and uncertainty for participants during hospitalisation. One particular participant said he knew that people were dying because of COVID and so he thought he was not going to go back home alive. Ntsikayomzi told a story about how he deprived himself of sleep because he thought he was going to die. His narrative included stories about how six people died in front of him:

> *That sickness that that COVID eh... I don't wish even to to see someone with that. I was really lucky to be survived. I saw six people in my my ward. While I was there, in Somerset, six people died just in front of me, in front of me. The other thing, because I saw these guys coming in, they were better than me. But they are dying. Then I said ey and the day is coming for me also. So that thing is traumatizing. Because you you ah just waiting for your time to come. I was just waiting for my time to come. Because the guys will just pass away while we are talking. We're talking but just talking talking, you're just a guy is dropping, what is going on? The guy can't talk anymore is gone. Then I said no, man, there is nothing better than these guys. I'm not better than because these guys were better than me the time they come in here. So, meaning that I must also wait it was that time there was a higher rate of of death. Yes.* (Ntsikayomzi)

Deliberate sleep deprivation resulted in huge amounts of agitation, pain, and anxiety because persons with encephalopathy are presented with acute symptoms like long periods of sleep and stupor (Sue et al., 2010).

The ‘Problematic and Depressing Task’ of Enduring and Managing the Cognitive and Emotional Changes

Seeing that the virus has taken countless lives while reorienting others neurologically, psychologically and physically (Nalleballe et al., 2020). Living for over 51 years and now having to change, adjust and reorient yourself to suit a virus that has killed over millions of people is the most devastating thing ever. Simply because you not sure if you going to contract the virus again and all your adjustment and change efforts were in vain. It becomes very depressing and problematic to endure and manage the cognitive and emotional changes that you face. Nallebale et al (2020) stated that the virus changes peoples even neurologically and psychologically.

When changes occur to persons neurologically, psychologically and even physically, some tasks are now going to prove to be problematic fulfiling (Kingstone et al., 2020). You find it harder to control or hold back your emotions, especially persons who were admitted as a result of encephalopathy. You find it hard to do a lot of things, things which before you could do within minutes but now you need hours to perform those tasks. To have to endure and trying to come to terms with those changes is hard and may result in depression and anxiety. One participant during the interview became very emotional when talking about her experiences of the COVID-19 virus.

[cries]*…it's still very emotional talking about it.* (Patricia)

These are the emotional changes COVID-encephalopathy patients suffer from, even after they have recovered and are COVID-free. Psychologically and neurologically however, many are the alterations that occur or occurred and managing those alterations is difficult. It is worth noting that Patricia was narrating a story that happened a year ago but still cried when talking about it and in this story she stated how she was unable to manage the symptoms that still persisted even after she was COVID free. Emotionally she was still distressed and depressed.

Let us now move to another participant who 12 months after being declared COVID free, still experienced COVID like symptoms and had emotional, thought, and concentration changes. This participant had to be prescribed depression tablets because of his recurring headaches. Managing symptoms proved to be a huge task.

> *drinking pain tablets Everyday everyday to it up until I the I went to a doctor saying you are stressing you must have stress tablets. Then I bought I bought the stress tablets drinking every day before I sleep stress tablets stress and then be the guy that the doctor last my last appointment here. He said no. He your I will give you some tablets. So that because I think you were traumatized. So you are having a depression. So I must give you the tablets for depression.* (Ntsikayomzi).

Changes in Thoughts and Moods Post-COVID. Myriad are the changes these participants had or have or are trying to come to terms with (Kingstone et al., 2020).

*I thought I had an adjustment syndrome***.** (Patricia)

Patricia's thoughts were now disordered, her brain was really affected resulting in changes in behaviour, emotions and thinking. She portrayed signs of a depressed person. She kept on diagnosing herself with an adjustment syndrome/disorder, she was starting to think she is going crazy. Depression in most cases is portrayed in faulty thinking, like having irrational or unjustified beliefs (Sue et al., 2010). Precipitating that was her family members and workplace wanting her to retire. Many physicians found nothing wrong with her. Psychologists could not help her. She felt like no one understood her. Another participant when asked if there are any changes in her thoughts after COVID. She answered:

I feel I'm stuck, man! (Annette)

Annette's account also points to a depressed person as she is showing signs of dejection, worthlessness and anxiety. Annette's way of thinking, because of what she went through has changed completely. Changes in thoughts was not the only change COVID-encephalopathy patients reported. They also reported changes in moods after they had been discharged from hospital. While in the process of recovering, they experienced changes in their moods. Below is an account by Ntsikayomzi about how his mood changed;

My girl used to say to me sometimes I'm moody. I didn't notice that. I don't know but she used say I'm moody sometimes, but sometimes I'm okay. All those but there are times that I'm moving. How do I not say no? You are not. You are not you all the time? There are times we don't want to talk to you. I even decided no let me watch my TV…. you see, (Ntsikayomzi)

These changes in moods result in negative changes in relationships. Notice how Ntsikayomzi's daughter responds to his question, she says "there are times when we don't want to talk to you". Ntsikayomzi because of his sickness now secludes himself and leaves in isolation. Furthermore, in the hospital Ntsikayomzi says he used to shout at the caterers and whenever they came in, they knew he was going to shout at them. He says he was *always not in a good mood for them.* That resulted in his relationship with the caterers to be an unpleasant one. Same goes for the one with his family. A moody person is the most annoying person. So mood changes induce negative changes in relationships.

Oh! Sometimes I can really get cross with the children. (Annette)

Multiple Losses (Memory, Concentration, Intelligence, Attention, and Motivation)

These are clear and obvious signs of depression. Cognitive symptoms of depression include difficulty in concentrating and taking and making decisions (Sue et al., 2010). Behavioural symptoms of depression then symptoms like social withdrawal and lowered work productivity, little to no motivation, show anhedonia and agitation (Sue et al., 2010). All of these domains of depression make it abundantly clear that that there are some cognitive deficits/difficulties participants sustained and sustain. Further, also revealed that there are emotional changes experienced by participants. Participants were asked to describe their concentration before and after their illness. And all of them reported the same thing, *it is not like before*.

Such findings resemble those identified by previous studies "many patients experience psychological distress which can lead to PTSD, depression, and anxiety" (Sun et al., 2021). Cognitive deficits include problems with memory, attention, executive functioning, and processing of information (Wilson et al., 2020). For all these cognitive deficits to result, there brain must suffer from an infection or inflammation. Then as a result the manifestation of concentration, intelligence and motivation levels declining.

Memory Loss Suffered by COVID-encephalopathy Participants. Among common narratives, we also had memory loss being reported frequently. Most participants were experiencing or had experienced the same changes, with regards to memory loss; however, changes were expressed in different ways and affected the participants differently. Experiences were unique and personal. Even when recovering, COVID-encephalopathy participants experienced changes. Thus, after hospitalization, some participants experienced difficulties with memory. Participants reports when it came to memory loss was one that ignited feelings of pure dismay, worthlessness, worry, distress and loss of identity (Grønkjær et al., 2018).

> *And but, I was I don't know, I was just laying there and I was just feeling you know that people saying they did this and that for me, but I can't remember I didn't remember really! I wasn't… My mind was like a blank and I'm telling you it was a blank.*
>
> *No I, it's almost as if my mind is slipping away then other things is in my mind like that…*
>
> (Annette)

As found in previous research studies encephalopathy is characterised by generalised brain dysfunction, and presents patients with unique challenges, cognitively and emotionally (Garg et al., 2021). Participants' narratives contained overwhelming proof that due to generalised brain dysfunction, they were presented with unique challenges cognitively (memory loss/decline).

Annette's and Ntsikayomzi's account further describe the experience of cognitive and emotional changes, both during an episode and in recovery (post-COVID). Annette voices that she cannot remember what happened before she got admitted *"My mind was like a blank and I'm telling you it was a blank".* Even after she was discharged, she complains about her mind slipping away. Patricia's narrative below also serves as additional proof to how participant' memory and energy levels were affected during/before and after the acute and subacute phase of their sickness.

> *I can't remember much!*

> *Oohhh I can't my memory is gone. I went into the shop. This is when I realized it I went into the shop to go buy some things. And I took this packet of what was priced for nine. And I came home and undressed and I found a packet of space in my pocket and I can't up to that I can't remember putting it there. So my memory is terri...i ca.. like uhm uhm. Someone died of COVID and then the person told me the whole, you know what happened happened. And then I was trying to relay it to someone else and I just couldn't and she told me it's a second time not yesterday Sunday and I still won't be able to tell you what she told me and that is the scary part of it.* (Patricia)

Also during interviews some participants were manifesting and depicting symptoms of memory loss. And requested to be reminded what they were saying. Although it is still not clear whether COVID-19 patients experiencing encephalopathy, specifically, report lingering cognitive deficits, it has been established that many severely ill COVID-19 patients do (Wilson et al., 2020). Below and above are narratives agreeing with existing literature;

> *So anyway, so started I come to that, what was talking about now?* (Patricia)

Another participant (Annette) had to be reminded about the date of the interview for out study. And those were definite signs of a cognitive deficit.

> *But now and then it then it slipped now and then I actually had to be reminded about today. That I must be here.* (Annette)

All of these are clear signs that after one has contracted the COVID-19 virus due to generalised brain dysfunction also known as encephalopathy, loss of memory will be prevalent and take charge. This all comes back to the negative changes that occur when one's brain is damaged or an inflammation resulted.

> *…. Where my work is concerned, because I had to tell them because I'm working with children if I'm going to a mom and the moms telling me sister, listen this is wrong with the child and I go back to my seat and I forget what's going on….* (Patricia)

Lack of Concentration and Intelligence.

> *this is also the other thing i did if I'm if somebody if you give me a problem that I won't be able to solve that problem at all at all but leave me let me go and beyond be on my own in my own little alone in a room and then I can sort but ah…. But do you understand what I'm saying I have a problem also express myself you not finding the right words but you understand what I'm saying* (Patricia)
>
> *But the other weeks the memory the memory was very, very poor I think this COVID It also affects your brain. Yeah, it also affects your brain because before I, I had nothing* (Ntsikayomzi)

Ntsikayomzi's ability to read and concentrate has been altered by the virus, he says *my brain getting tired quickly*. Patricia's narrative also depict how her life had now changed, she was now no longer able to concentrate in the presence of people. Now she needs time to focus and concentrate.

Lack in Attention and Motivation. We now move to how the virus affects attention and motivation. Yet, again we have Patricia reporting how as a result of her sickness she could not even drive, she stopped driving because she attention and that affected her in a great deal.

> *My head gets to the point not like it wants to burst, but it just gets really busy and it throws me off. And i said it's got something to do with movement. Because if, if, if if I sit, if somebody was walking behind you they are instantly distracted in my head will go into overdrive or if this door open and people are walking up and down. So I musn't see movement in the car. I wasn't driving then, I stopped driving because of the movement and my husband tries my eyes is focused but i made the point of it. We used to order online but I made the point of it. I had to go to the shops. I had to do things for myself.* (Patricia)

Patricia, Annette and Ntsikayomzi report the same thing about their lack of motivation. Participants exhibiting signs of little to no motivation resemble what Sue et., (2010) found with depressed persons. Feelings of loss of identity, physical skills, and independence were most prevalent in participants' narratives.

Recovery and Rehabilitation: what would help?

Participants now had doubts and were sceptical, ambiguous and uncertain about a lot of things, particularly regarding recovery and whether rehabilitation was possible and if it is possible what will help them to recover. Such ambiguity and doubts led to participants having feelings of helplessness and fear. Such feelings would really take charge over the participant when he/she went to someone for assistance and they could not receive help. Patricia experienced this when she went to more than two physicians who were unable to assist her.

> *because I know life must get back normal you know. from Dr Redding to Dr Redding gets me an appointment with Dr Marie. I go in they had to work a full on neurological exam, they can't find anything wrong.* (Patricia)

> *The bad thing is that the doctor said they cannot do it will also will stay I will stay with this pain. You see? That is my problem. I don't know where can I get help for this also, but it changed that and this memory.* (Ntsikayomzi)

Post-COVID-encephalopathy participants also experienced insomnia.

> *That is one thing. I've got a problem with sleeping.* (Patricia)

Living with Uncertainty and Fear post-COVID.

Feelings of fear and uncertainty did not apply to participants while they were in the hospital only, those feelings followed them home. Months after being discharged from hospital, participants still experienced such feelings. Another common feeling participants shared was the **Fear of Infecting Others and the Fear of Reinfection.** Participants did not want people to come close to them. As proof we provide Ntokozo's narratives below:

> *When I came back from the hospital I did not want my family members to come in close proximity with me, as we were told that close contact can lead to the spread of the virus. So as a results I feared that I might infect my loved ones.* (Ntokozo)

The notion of living in a constant state of fear and uncertainty raises questions around psychological effects the COVID-19 virus has on persons.

Stigma and Discrimination suffered by post-COVID survivors.

Nokuthula, a participant who had no positive viral diagnosis of any neurological manifestation but was admitted for COVID reported;

> *There was this other time, when I went to the tuckshop and the people who were in the tuckshop started going away, even the person behind the counter refused to sell for me, because they knew I was a covid victim. So they thought I was going to infect them.* (Nokuthula)

Overall Functioning (Problems in Performing as Efficient as Before). Participants experienced more or less the same changes. Among narratives that were common, problems in performing as efficient as before were also common. Participants' overall functioning was disturbed; they were no longer able to function as they used to. Participants were now unable to do their daily routines. And as a result participants suffered a great deal of distress, pain, turmoil, depression and anxiety. Their emotions and cognitive capacity and domains sustained a lot of changes.

I used to be a fresh person. I was fresh. When I walk, I was just you could see this person is fresh and running, running, doing. But now….When I went to the doctor, he said the doctor the COVID really changed something because I was paralyzed. The COVID changed me I don't know, maybe it will change your again. Take me back to the person I was I d… (Ntsikayomzi)

Summary and Conclusion

Based on this study's discovery and results, findings suggest that COVID-encephalopathy patients do experience cognitive and emotional changes. The commonality in the participant's narratives and accounts strengthen this claim. However, due to the small sample size of the participants in this study, it may be said that it is not safe to make the aforementioned statement. Nevertheless, the common responses received during the interview sessions, indeed reflect changes in participants' cognition and emotions. This study shows the mind-brain relationship. Findings further reinforce and mirror the definition of encephalopathy as per (Roos, 2014). According to Roos (2014) encephalopathy is an inflammation or infection of the brain and presents itself symptomatically through fevers, headaches, a modified mental state, seizures, neurological deficits, and reduced consciousness (Roos, 2014). Post-COVID-encephalopathy participants still portrayed and presented the aforementioned symptoms, predominantly the ones underlined. Therefore, for this reason the reader was automatically invited to take an even deeper look at the long-lasting effects the virus has on a person's psychological, cognitive and emotional domains.

It then became evident that participants in this study experienced numerous setbacks, social isolation and a dependency on others (Grønkjær et al., 2018). What participants experienced opened a gap in literature; what can be done to help these participant get their lives back? Currently with the COVID-19 pandemic, there is a lack in surveillance systems to observing ill health and long-term implications of COVID-19; sufficient are only deaths reports. It is therefore, crucial to enhance reports that are have are laboratory confirmed clinical cases, this can be done through knowing how existing systems can be acclimatised or used for this purpose (Kingstone et., 2020). Patients with post-acute or long-COVID39 could then be coded and monitored as appropriate. Participants' accounts evidently showed that going back to your normal self becomes a very problematic and depressing task. Those accounts also revealed how the virus caused multiple losses. And adjusting to these changes also becomes very burdensome. Participants' inability to perform as efficiently as a before and finding it hard to manage the cognitive and emotional changes they were experiencing triggered, provoked and induced certain negative feelings in them.

Feelings like feelings of worthlessness, uncertainty, fear, guilt, and uselessness. The participants felt stuck, terrible, pain, hurt, distress, turmoil, depression, despair, worry, low-self-esteem, and hardship. Basically, participants' accounts reflected definite negative feelings about themselves. Therefore, the virus has the potential to devastate a person's sense of self. The association of the brain and behaviour impacts subjective experiences and the ability to process information, that is, cognition (Martin, 2016). Encephalopathy is harmful to people due to the way in which it defeats and sometimes destroys a person's view of the world, thinking, memory, and the cognitive domains. Moreover, it can be also be said to be detriment due to the way in which it provokes negative feelings about oneself.

For COVID-patients, accepting your COVID status and the ideas attached to it meant accepting and internalising the stigma and discrimination which they were subjected to within hospitals, families and communities. Further illustrated by the findings of this study is that participants' mental and psychological wellbeing was and continues to be in jeopardy, as a result of the experiences they experienced. For most participants living with the frequent and constant inability to function as efficiently as before, fear, uncertainty and trying to endure and manage the cognitive and emotional changes brought by the virus was and is too much participants to handle. Thus, it can be said that the virus is detriment as it has the potential to pervade, penetrate and devastate the internal world of patients. For comparison of experiences participants with no positive viral diagnosis of any neurological manifestations were invited in the study, and after comparing their experiences with COVID-encephalopathy you note that there are huge differences. Participants brought in for comparisons' sake exhibited little to no signs of cognitive deficits. In the subjective changes questionnaire

Appendix C most of their answers was a *no*, signifying no major cognitive difficulties or changes. They were able to function as they used to, they did not complain about any negative impacts they suffered as a result of the virus. Most of them, when specifically asked if what they were now experiencing was because of the COVID virus, they answered *no*. Therefore, one fact remains to true in this paper and it is Liotta's claim "encephalopathy is associated with adverse long-term clinical outcomes and can lead to serious disabilities." The real and manifest cognitive and emotional changes are those serious disabilities experienced by COVID-encephalopathy patients.

Limitations of the Study

The estimated number of participants for this study was 10-15 participants, however due to the recently enacted Act, the Protection of Personal Information (POPI) Act, the doctors (neurologists) were hesitant in giving out the participants' details and had to contact the participants first to request permission to pass on their contact details to the researcher. This limited the study as it caused delays in the data collection phase. In addition, as a result of the fear and anxiety caused by the pandemic we are continuing to face and the fact that encephalopathy is of the most severe manifestation of the COVID-19 illness some participants refused to participate and some were hesitant. I went to approximately 10 different neurologists and hospitals in Durban and not even one was able to assist me. Therefore, as a result, the estimated number of participants decreased. The type of research question this study explored deals with experiences and so qualitatively speaking this study's size of sample can be used to explore qualitative experiences. This should be noted because it may be said that the small sample of my participants is unrepresentative of all the people who contracted the virus having encephalopathy as a neurological manifestation and those without. Moreover, it may also be said that those with a positive viral diagnosis of encephalopathy compared to those with no positive viral diagnosis of any neurological manifestation, share differences. Nevertheless, this study’s aim was not to broaden or approximate findings to the general population, however to rather explore the personal, particular and distinctive experiences of individual participants (Babbie & Mouton, 2007). And so experiences were seen as realities and the study engaged with these experiences to better understand what these participants are going through and how this can inform rehabilitation (Blanche et al., 2012).

Significance

The third wave of the COVID-19 pandemic has just been recognised globally (World Health Organisation, 2021). However, there are still many unknowns when it comes to the virus (Hao et al., 2020). Current research has shed some light on the virus however the cognitive and emotional changes that result from COVID-19 are still neglected, especially in individuals from low to middle socioeconomic statuses (Borno et al., 2020). By gaining an understanding of the experiences of emotional and cognitive changes in COVID-encephalopathy patients, it will create awareness on the difficulties these patients face, and it could inform rehabilitation programmes. This study will also offer participants the opportunity to validate their experiences and know that there are possibly other patients who are going through similar experiences.

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Appendix A

Informed Consent Form

UNIVERSITY OF CAPE TOWN

DEPARTMENT OF PSYCHOLOGY

Qualitative Exploration of Experiences of Cognitive and Emotional Changes in COVID-Encephalopathy Patients

1. **Invitation and Purpose**

   You have been invited today to take part in this research study because we are hoping to understand more about your experiences of developing encephalopathy during your Covid-19 illness. Encephalopathy refers to an altered mental state that can be a consequence of infection and we are hoping to learn more about how it affects thinking, memory and moods. I am a research student from the Psychology department at the University of Cape Town.

2. **Procedures**

   - If you decide to participate in this study, I will interview you on your experiences of emotional and cognitive changes that have taken place due to your positive diagnosis of encephalopathy due to COVID-19. I will ask you to share your experiences from when you got sick up until the present day. By interviewing you, I hope to find out what changes you have experienced mentally, changes such as changes in memory, attention, language, moods, daily routines and lifestyle.

   - The interview will take about an hour and will be audio recorded. This will be followed by 3 exercises that assess certain types of attention, memory and thinking. During an exercise that requires you to draw something, a video recording of your hands and the page will be taken. A family member of yours will be interviewed telephonically a week after your interview.

3. **Risks, Discomforts & Inconveniences**

   - Given the fact that the study will take place in a public venue this study poses some risk of harm to you, as you might get re-infected with the COVID-19 virus by meeting with me. All COVID-19 safety protocols will be followed.

   - Potentially, through sharing your experiences with me, it could be emotionally distressing. However, you are not in any way obligated to share anything you do not feel comfortable sharing and you can decide what to share with me.

   - The interview will take about an hour and a half.
   - If you feel like you need to speak to a counsellor to further discuss your experiences, you can contact one of the following organizations: SAFMH (011781 1852/ 086 558 6909), Life-line (0861 322 322), SADAG (076 882 2775) or Cipla 24 Hour Mental Health Helpline (0800 456 789) or Durban & Coastal Mental Health (031 207 2717) or Life St Joseph's Psychiatric Hospital (031 204 1470)

4. **Benefits**

   By voicing your experiences, you will be creating awareness, especially in healthcare workers and family members, of the difficulties you and patients like you face on a daily basis. This data will also further inform rehabilitation programmes for patients like you.

5. **Costs**

   There are no costs that you will have to pay. You will receive R50 in compensation for your travel arrangements.

6. **Privacy and Confidentiality**

- Interviews will occur in a private room.

- Anything you say to me or share with me is strictly confidential. Throughout the research process you will remain anonymous and you have the right to request to withdraw any information that you have shared with me so that it is removed from the study. Information given to us by you will be in a password protected file on a password protected computer with no identifying details and separately from the consent form; or in a locked file cabinet that only members of the research team have access to. The audio and video recordings will be permanently deleted when the study comes to a conclusion.

7. **Voluntary Participation**

You may withdraw from the interview and the study at any time with no consequences. Your participation is completely voluntary. And it will have no effect in services received from the hospital.

8. **Questions and further information**

Should you wish to ask questions about your rights as a study participant, make comments or lodge complaints about the study you can contact the Human Research Ethics Committee on 0800 212 123. Further information may be requested from us, my supervisor or the Department’s administrator. See section 8.

8. **Contact details**

If you have any further questions, concerns, or complaints about the study please contact:

- Ntuthuko Ngobese (student researcher) on 061 698 4985
- Dr Donne Minne (Supervisor) at the Department of Psychology, University of Cape Town (UCT) 021 650 3417/072 800 5230
- Rosalind Adams (admin for the UCT Department of Psychology) 021 650 3417

8. **Signatures**

{Subject’s name}________________ has been informed of the nature and purpose of the procedures described above including any risks involved in its performance. He or she has been given time to ask any questions and these questions have been answered to the best of the investigator's ability. A signed copy of this consent form will be made available to the subject.

____

Investigator's Signature Date

I have been informed about this research study and understand its purpose, possible benefits, risks, and discomforts. I agree to take part in this research as a participant. I know that I am free to withdraw this consent and quit this project at any time, and that doing so will not cause me any penalty or loss of benefits that I would otherwise be entitled to enjoy.

Check box

1. I agree to have the interview ☐
2. I agree to have the interview audio recorded ☐
3. I agree for the drawing exercise to be video recorded in such a way that only my hands and the pen and paper are visible. ☐

____

Subject's Signature Date

Appendix B

Qualitative Exploration of Experiences of Cognitive and Emotional Changes in COVID-Encephalopathy Patients

1. I would like to know more about your experiences with the COVID-19 virus, could you start by telling me about the time when you first got sick?

2. While you were at the hospital, how did you find your level of contact, were you able to communicate with your family, relatives, friends and with the nurses and doctors?

3. With regards to your memory and concentration, can you tell me how the virus affected you mentally during your stay in the hospital?

4. Can you tell me about your mood when you were still at the hospital?

5. Have you told anyone about how you were during your time at the hospital?

6. In what way(s) has your life changes since you came back home? If you were to compare your life before and after you contracted the COVID-19 virus, what is different?

7. Are there any other changes you can think of, for example activities when you look at before COVID and now that you are unable to do now?

8. In what way(s) would you say your memory might have been affected since you contracted the virus?

9. Can you describe your concentration before and after your illness? Are you finding it easy to recall or remember things again? When doing things like reading or watching tv, are you able to concentrate? A few examples you can think of where you feel like you confused?

10. In what way(s) do you think your level of intelligence has changed, since you got sick?

11. Can you describe your current motivation levels?

12. In what way(s) are your thoughts nowadays different to before you had COVID?

13. How have you been finding having conversations with others?

14. What has been hardest about adjusting back to life at home?

15. In what way(s) has your general sense of wellbeing or happiness changed?

16. Can you describe any changes in your relationships that might have occurred or are occurring since you got sick (relationship strength)?

17. Are there any changes in your sleeping patterns since you got sick?

18. Are there any daily/everyday activities do you now need help to do? Any challenges you now face because of your illness?

19. Can you give me any examples of how you might find it harder to hold back or your emotions nowadays? And what your average emotional state on a day, how do you normally feel?

20. Any other difficulties controlling your emotions in terms of sadness?

21.How would you evaluate your overall functioning now compared to before you got sick?

22. What has been your biggest source of strength while you were sick?

23. Are there any experiences related to how COVID affected you, that you would like to share?
24. How did you find the task of having to complete the three cognitive assessments?

Social History Questionnaire

1. In what town and suburb do you live?

2. What gender do you identify as?

3. What is your age?

4. What is your current relationship status?

5. What is the highest level of education you have completed?

6. What is your current occupation?

7. Do you live in an urban or rural areaWhat is your work situation?

Appendix C

Subjective Changes in Cognition Questionnaire (Adapted from Kim et al., 2011; Rabin et al., 2020)

Subjective Changes in Cognition Questionnaire

Cognitive Domain	**Item Question**	**Response Choices/(Score)**
Language	Do others often have difficulty understanding what he/she is speaking about?	Yes (1)/No (0)/Don't know
Language	Does he/she experience difficulty finding the words they want to use in normal conversation?	Yes (1)/No (0)/Don't know
Memory	Does he/she struggle to remember recent events?	Yes (1)/No (0)/Don't know
Memory	Does he/she tend to repeat stories and/or questions?	Yes (1)/No (0)/Don't know
Attention	Is he/she able to focus on one thing at a time?	Yes (1)/No (0)/Don't know
Attention	Does he/she become easily distracted from the topic of an ongoing conversation?	Yes (1)/No (0)/Don't know
Executive Functioning	Does he/she have trouble performing a basic household	Yes (1)/No (0)/Don't know

	task (e.g., putting dishes away, making a cup of tea)?	
Executive Functioning	Does he/she have trouble using basic household appliances (e.g., kettle, TV, vacuum cleaner)?	Yes (1)/No (0)/Don’t know
Visuo-spatial Functioning	Is he/she prone to getting lost in familiar environments (e.g., local neighbourhoods or shopping centres)?	Yes (1)/No (0)/Don’t know
Visuo-spatial Functioning	Does he/she struggle to find the bedroom or bathroom in his/her home or familiar homes (relatives or close friends)?	Yes (1)/No (0)/Don’t know
General Cognitive Functioning	Does he/she experience any additional cognitive difficulties?	Yes (1)/No (0)/Don’t know

Appendix E

Dear Doctors

My name is _______________ and I am a research student from the Psychology department at the University of Cape Town. I am currently conducting a study which looks at **Qualitative Exploration of Experiences of Cognitive and Emotional Changes in COVID-Encephalopathy Patients**

The purpose of this study is to

- further understand how COVID-19 affects the brain

- create awareness in health workers and family members of the challenges that COVID-encephalopathy patients face for rehabilitation

I would like to ask for your assistance in identifying participants for this study.

Participants will need to be

- patients who have had to be hospitalised for COVID-19 related illnesses
- patients who have had a positive viral diagnosis of COVID-19 related encephalopathy
- 18-60 years old
- discharged within the last 5-12 months
- from low to middle socio economic backgrounds
- able to comprehend and speak English
- physically fit and stable enough to attend the interviews

Your assistance would contribute massively to further research in neurological complications associated with COVID-19.

If you have any patients that would be willing to participate, please send their contact details via email to ntuthukongobese881@gmail.com. or via phone 061 698 4985

Thank you for your time.

I look forward to hearing from you!

Kind regards

____

Appendix F

UNIVERSITY OF CAPE TOWN

Department of Psychology
Research Ethics Committee
Rondebosch, 7701
Tel: 27 21 6503417 Fax: 27 21 6504104

APPLICATION TO CONDUCT PSYCHOLOGICAL RESEARCH

1. All applications must be submitted with the documentation outlined in the attached form.
2. All documents should be submitted electronically.
3. The University of Cape Town's Department of Psychology actively supports research as an essential academic function. It is essential that all applicants consult the UCT Code for Research involving Human Subjects (available from the UCT website).
4. In the case of research involving clinical populations, drug trials, neuroimaging, and recruitment from Groote Schuur Hospital or any affiliated medical institutions, approval must also be obtained from the Faculty of Health Sciences Research Ethics Committee (FHS REC).
5. Final responsibility for the ethical and effective conduct of the research lies with the principal investigator.

HONOURS STUDENTS:

Complete this application form, and submit it to Rosalind Adams with the formal research proposal that forms part of your research methods module in the Honours programme.

MASTER'S AND DOCTORAL STUDENTS:

Complete this application form, and submit it in electronic form to Rosalind Adams attached to the research proposal you will present to a departmental thesis committee.

DEPARTMENTAL STAFF, VISITING SCHOLARS AND POST-DOC STUDENTS:

Complete this application form, and submit it in electronic form to Rosalind Adams (rosalind.adams@uct.ac.za). The application must be accompanied by a detailed proposal (maximum length 25 1.5-spaced pages).

UNIVERSITY OF CAPE TOWN
DEPARTMENT OF PSYCHOLOGY
APPLICATION FOR ETHICAL APPROVAL TO CONDUCT PSYCHOLOGICAL RESEARCH

Section A	Proposal Identification Details	To be completed by all applicants
Section B	Study Information	To be completed for all studies
Section C	Financial and Contractual Information	To be completed by all applicants
Section D	Declaration on Conflict of Interest	To be completed by all applicants
Section E	Ethical and Legal Aspects	To be completed by all applicants
Section F	Checklist	To be completed by all applicants

Section A: Proposal identification details.

1. Title of the proposal/protocol:

Qualitative Exploration of Experiences of Cognitive and Emotional Changes in COVID-Encephalopathy Patients

2. Has this protocol been submitted to any other Ethical Review Committee?	Yes		**NO**

2.1 If so, list which institutions and any reference numbers.	N/A
2.2 What was/were the outcome/s of these applications?	N/A

3. Is this proposal being submitted for ethical approval for an amendment to a protocol previously approved by this committee?	Yes		**NO**

3.1 If so, what was the previous protocol’s reference number?

N/A

4. Investigator details

4.1 Principal Investigator (if a student project, the student is the principal investigator):

Title	Initials & Last Name	Department and Institution	Phone	Email	Signature	Date
Mr	NN Ngobese	Department of Psychology, UCT	+27 (61) 698-4985	ntuthukongobese881@gmail.com	NN Ngobese	13/06/2021

4.1.1 (If different to 4.1 above) UCT Principal Investigator

Title	Initials & Last Name	Department and Institution	Phone	Email	Signature	Date

4.2 Co-investigators: (if a student project, add the supervisor's name here)

Title	Initials & Last Name	Department and Institution	Phone	Email
Miss	D Minné	Department of Psychology, UCT	0	donvanwest@gmail.com
Prof	M Solms	Department of Psychology, UCT		Mark.Solms@uct.ac.za

5. Is the study being undertaken for a higher degree?	**Yes**		No
If yes: 5.1 What degree? Bachelor of Social Science (Honours) specialising in Psychology			
5.2 Student name: Ntuthuko Ngobese			
5.3 Supervisor name: Mark Solms			
5.4 In what department is the degree? Department of Psychology			

Section B: Study Information (summarize the information contained in the proposal).

6. Who will act as participants in the study?

Participants will be patients who have been hospitalised for COVID-19 related illnesses. These patients need to have had a positive viral diagnosis of COVID-19 related encephalopathy. Participants need to be between 18-60 years of age and discharged within the last 5 months. Participants need to be from low to middle and high (just to compare experiences) socio economic backgrounds and must be able to comprehend and communicate in English. They must be deemed physically fit and stable. Participants will be excluded if they have a history of pre-morbid neurological illness, learning disabilities or intellectual impairment, as well as a history of major pre-morbid psychiatric illness.

7. Estimated duration of study:

   Once ethical clearance has been received, recruitment will immediately begin.

   Data collection: 01 July 2021 – 01 October 2021.

   Analyses and Results: 01 October 2021 – 01 November 2021.

   First draft of research report: 05 November 2021

   Hand in of research report: 18 November 2021

8. Location of study (e.g. UCT, school, hospital, etc., where you will gather data from the participants):

   King Dinuzulu Hospital, Durban

1. Recruitment: Please describe how and from where the participants will be recruited. Attach a copy of any posters or advertisements to be used.

   Participants will be primarily recruited from King Dinuzulu Hospital in Durban. Potential participants from other hospitals will not be excluded. Doctors from both hospitals will be contacted to request contact details of possible participants from the hospitals’ databases.

2. Vulnerable groups: Are there pre-existing vulnerabilities associated with the proposed participants, e.g., relating to pre-existing physiological or health conditions, cognitive or emotional factors, and socio-economic or legal status?

   Yes

If yes, explain briefly what vulnerability would entail in the study, and how you propose to safeguard participants' wellbeing.

Our greatest worry is the risk of participants and their family members getting re-infected with COVID-19 and that encephalopathy is so severe, participants might not give consent. In order to safeguard participants' wellbeing all COVID-19 safety precautions will be followed. Rooms will be sanitised, only one session will take place a day, the room will be well ventilated, everyone will be required to wear a mask and the researcher and participants will sit 1.8 metres apart with a screen between them. Before entering the venue, each person's temperature will be checked, screening questionnaires will be completed, and hands sanitised. We will further screen participants telephonically a day before their sessions. Detailed planning will take place in order to minimise as much risk as possible to participants. Participants will only be included in the study if they have been deemed physically fit and stable enough to attend the interviews by their doctors.

3. Risks: Briefly describe the research risk associated with your study, i.e. the probability and magnitude of harms participants may experience. Minimal risk means that the probability and magnitude of harm due to participation in the research are no greater than that encountered by participants in their everyday lives.

   The participants face the high risk of getting re-infected with COVID-19, however this risk is encountered by participants in their everyday lives. There is also a risk that after the interview participants will face emotional distress from voicing their experiences.

4. Costs: Give a brief description of any costs or economic considerations for participants.

   Participants will be given R50 to pay for transportation costs.

5. Benefits: Discuss any potential direct benefits to the participants from their involvement in the project.

   Participants have the benefit of being able to voice and discuss their experiences with COVID-19. They also will experience the benefit of the study creating awareness in health care workers and family members as well as in informing rehabilitation programmes.

6. Compensation: If participants are to receive compensation for participation, please provide details.

   N/A

7. Consent. Describe the process to be used to obtain informed consent. Where applicable, attach a copy of the information letter and consent form.

   The researcher will go over the consent form, get the participants to read through the form and obtain signed consent before the family member that is accompanying them leaves the room. The researcher will verify the participant's understanding of the consent form and answer any questions they may have. Key issues, for example confidentiality, the right to withdraw from the study and protection of data will be covered. The participant will be informed verbally and in writing that the session is confidential and will not be in their medical records or shared with anyone else. The researcher will ask participants for their understanding of the form and participants who feel like they do not understand the information in the consent form will be considered ineligible to participate.

8. Confidentiality. Please describe the procedures to be used to protect confidentiality of the data.

   All collected data will be transferred to the researchers' personal password-protected laptops which only the research team will have access to. Audio recordings will be transcribed word for word and no information will be left out except information that may reveal the participants' identities.

9. Does the protocol comply with UCT's Intellectual Property Rights Policy (including ownership of the raw data)?	**Yes**		No

Section C: Financial and contractual information

10. Is the study being sponsored or funded?	Yes		**No**
If yes: 10.1 Who is the sponsor/funder of the study? N/A			
10.2 Are there any restrictions or conditions attached to publication and/or presentation of the study results?	Yes		**No**
10.3 Does the contract specifically recognize the independence of the researchers involved?	Yes		No
(Note that any such restrictions or conditions contained in funding contracts must be made available to the Committee along with the proposal.)			
11. Will additional costs be incurred by the department?	Yes		**No**
11.1 If yes, specify these costs: N/A			

Section D: Statement on Conflict of Interest

The researcher is expected to declare to the Committee the presence of any potential or existing conflict of interest that may potentially pose a threat to the scientific integrity and ethical conduct of any research in the Department. The committee will decide whether such conflicts are sufficient as to warrant consideration of their impact on the ethical conduct of the study.

Disclosure of conflict of interest does not imply that a study will be deemed unethical, as the mere existence of a conflict of interest does not mean that a study cannot be conducted ethically. However, failure to declare to the Committee a conflict of interest known to the researcher at the outset of the study will be deemed to be unethical conduct.

Researchers are therefore expected to sign **either** one of the two declarations below.

a) As the Principal Researcher in this study (name: Ntuthuko Ngobese), I hereby declare that I am **not aware** of any potential conflict of interest which may influence my ethical conduct of this study.

Signature: __ N Ngobese__________________ Date: 13/06/2021____________________

b) As the Principal Researcher in this study (name: ____________________________), I hereby declare that I am **aware** of potential conflicts of interest which should be considered by the Committee:

Signature: ______________________________ Date:__________________________

Section E: Ethical and legal aspects

12. Have you read the UCT Code for Research involving Human Subjects (available from the UCT website)?	**Yes**		No

Section F: Checklist **Tick**

Application form	1 electronic copy	√
Covering letter and all other correspondence (e.g., ethics approval from other bodies, letters to parents, etc.)	1 electronic copy	√
Detailed proposal, including a 200-word summary/abstract	1 electronic copy	√
Consent/Assent form/s	1 electronic copy	√
Participant information sheet/Debriefing form (if separate from consent form)	1 electronic copy	√
Other documents (e.g., advertising posters)	1 electronic copy	√

IMPORTANT NOTES:

- All applicable sections of this application form must be filled in OR justified why not.
- All applicable signatures must be sought
- All additional number of copies must be included with application
- All incomplete applications will be returned to the applicant, leading to delays in review.

Version May 2020

Appendix G

Transcription/Quotation Information

…	Ellipsis points are use to indicate that parts of participant’s original speech have been omitted from the quotation
( )	Brackets indicate words which have been inserted into quotation for extra clarification
__	Underlining indicates emphasis in participant’s original speech