The impact of the COVID-19 pandemic on the grief and bereavement of the Eersterust community

by

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GLOSSARY

AIDS	Acquired immune deficiency syndrome
ANC	Antenatal care
AUC	Area under the curve
BDI	Beck's depression inventory
CFR	Case fatality ratio
COSUP	Community orientated substance use program
COVID-19	Corona virus disease 2019
DMP	Data management plan
DSM-V	The Diagnostic and Statistical Manual of Mental Disorders, Fifth edition
ECHC	Eersterust Community Health Centre
HIV	Human immunodeficiency virus
HREC	Human research ethics committee
ICD-11	Eleventh revision of the International Classification of Diseases
ICRM	Ideal clinic realisation and maintenance
ICU	Intensive care unit
NHI	National health insurance
NICD	National Institute for Communicable Diseases
NPOs	Non-profit organisations
PIN	Participant Identification Number
PGD	Prolonged grief disorder
PGS	Pandemic grief scale
PHC	Primary Health Care
PPE	Personal protective equipment
SAMRC	South African Medical Research Council
UCT	University of Cape Town
US	United States
WBOT	Ward-based outreach team
WHA	World Health Assembly

ABSTRACT

Introduction: Strict lockdown regulations during COVID-19 could have led to emotional distress and affected grief. Feelings of distress and guilt can increase when one is unable to care for dying loved ones or get support during changed death rituals. Those that suffer from abnormal grief should be identified and managed promptly.

Aim: To explore how COVID-19 lockdown regulations impacted on grieving of public health users of the Eersterust community.

Objectives: To determine 1) the incidence of bereavement during the COVID-19 pandemic, 2) the changes in social norms of bereavement, and to 3) explore the individual effects of the changes in norms on members of the community.

Methodology: A cross-sectional mixed methods descriptive study was conducted in two phases. Phase 1 consisted of a survey with n=399 health care users, which included the validated pandemic grief scale (PGS). Bereaved individuals from phase 1 participated in phase 2 which consisted of a focus group discussion, individual interviews and qualitative data derived phase 1 questionnaires.

Results: 106 participants (26.6%) experienced loss between 1 March 2020 and 31 August 2021. Significant associations were shown for changes of funerals practices and less support received (p=0.023). The pandemic grief scale (PGS) found a complicated grief incidence of 1.9%, whilst 18.5% of participants expressed counselling needs. Five themes emerged from the qualitative data analysis: Hospitalised loved one, saying goodbye, travel, coping and funerals.

Conclusion: The "bereavement curve" was flatter than anticipated, yet lockdown regulations affected the loss experienced. Changes to all aspects of dying, death, and funerals deprived the bereaved from the comforting experiences rituals used to offer. The altered ceremonies left many dissatisfied, although participation was helpful in managing loss. The community's awareness regarding availability of mental health services were poor, but many had received counselling and support from their churches during their bereavement.

1. INTRODUCTION

1.1. Background

Lockdown, isolation, and social distancing became part of the world's daily vocabulary since the discovery of a novel virus in Wuhan, China, in December 2019. The Corona virus is transmitted through personal contact and respiratory droplets which rapidly led to a pandemic affecting the global community (1). South Africa was not safe from the pandemic as the government declared a national state of emergency and instituted stringent lockdown regulations on 27 March 2020. The harsh regulations caused severe disruptions to the country's economic and health care systems as well as the ordinary citizens social habits. The aim of the regulations was to allow medical services adequate time to prepare for the first surge of those who would fall ill to the COVID-19 virus and delay that surge for as long as possible ("flattening the curve")(2).

In health care, essential services were allowed to continue without too much change, but some of the allied health services in the public sector were diluted, and some even suspended. Of the suspended services included mental health outpatient facilities, during higher levels of lockdown. Strict infection control measures also lead to non-essential personnel, including mental health practitioners such as psychiatrists and psychologists, being discouraged to visit confirmed or suspected infected individuals in hospital, despite their need for mental intervention (1).

The pandemic broadly affected the way in which the sick, dying, and bereaved were cared for (3). Due to the focus on COVID-19, other medical conditions had delays in diagnosis and appropriate management leading to potentially avoidable complications. Visiting hours at hospitals were cancelled and worried family members had to rely on busy medical staff to keep them updated telephonically on their loved one's health status. People died alone, with less choice on where and how, and often without an opportunity to say their goodbyes (4). To avoid transmission after death, bodies were transferred and buried by trained burial teams. When not being able to comfort family members or be with dying loved ones, feelings of grief, distress, and guilt can drastically increase (1).

On the 31st of March 2020 a guideline from Dr T Pillay, the then Acting Director-General of Health, went out to the Heads of Health Departments; Heads of Health Establishments and/or Facility Managers of designated, in Terms of the Mental Health Care Act 2002, as Psychiatric Hospitals, Care and Rehabilitation Centres, Residential Mental Health Facilities run by Non-Governmental Organisations, Private Psychiatric Hospitals and Contracted Mental Health Facilities; Health District Chief Directors; Health care providers (public and private); and Mental Health Review Boards (5). This document was named the "GUIDELINES ON MENTAL HEALTH INTERVENTIONS DURING THE COVID-19 DISASTER" and stated that mental suffering was foreseen and that facilities must provide basic emotional and practical support to affected individuals, families, and staff in need. Despite this good intentioned guideline, the degree of actualisation of support for those who suffered due to loss is not known, as clinics may not have been equipped to manage the extent of loss and grief.

The COVID-19 pandemic has been associated with a sharp increase in excess deaths in South Africa. Excess deaths are defined as the difference between the expected natural deaths within a certain period (based on historic data) compared to the actual natural deaths within that period for a specific population (6). Excess deaths were a way of measuring the impact of the Covid-19 pandemic mortality in South Africa. The South African Medical Research Council (SAMRC) has compiled a report on excess deaths from the start of the COVID-19 pandemic. Until mid-February 2021, South Africa had more than 135 000 excess natural deaths over and above the 46 473 confirmed COVID-19 deaths (7). On the other hand, in the surveillance report (Week 10, 2021) of the National Institute of Communicable Diseases (NICD) the case fatality ratio (CFR) of COVID-19 was found to be 23.3% in hospitalised cases (8). Information such as this was hospital based, but the effect of these deaths on the community bereavement process' is unknown. This signifies that many more people have been left bereaved during the COVID-19 pandemic than the reported numbers of COVID-19 deaths as it was estimated that for every COVID-19 death there was nine people left bereaved (9).

1.2. Death rituals and regulations

South Africa has many different cultural groups with various important customs and beliefs around the death of a relative (10). Some of the customs are to show respect and say goodbye to the deceased, and to give condolences to the family left behind. At Christian funerals there may be a choice between burial and cremation and the ceremony may take place any time after the passing, with mourners mainly wearing black and bringing flowers. At Muslim funerals, the deceased should be buried after certain rituals are completed within 24 hours of passing with the actual burial only attended by men. At Hindu funerals cremation has to take place before the next dusk or dawn and mourners mainly wear white. Certain cultures have rituals with the aim to let the spirit of the deceased safely travel from the living to the spiritual world or afterlife, such as the African ancestral spiritual beliefs. Each ritual having to be completed to ensure this passage, as the spirit is seen as unstable soon after death and can become confused and trapped if not handled correctly (11).

Unfortunately, during the COVID-19 pandemic many of these customs were in direct violation of restrictions and carried the risk of viral transmission. Having large numbers of the community at the gatherings, having extended social events over several days with family travelling freely from far, having interactions with the corpse at home, night vigils, alcohol being shared amongst the funeral attendees and alcohol being used to reward the gravediggers, the custom to only obey the wishes of the deceased, and a custom to only wash hands at the conclusion of the ceremony at the grave site (11) were such customs posing risk.

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On 16 July 2020 the President of South Africa, Cyril Ramaphosa addressed the nation with the following statement (11):

“We are now in a war. We are in a war zone and our rights will inadvertently be affected and restricted for our own survival …”

Regulations put in place dictated harsh restrictions on social gatherings including these customary activities of South Africans when a loved one passes away. Social norm adaptations were promptly needed when lockdown regulations took effect. Funerals were labelled as super-spreader events (11) and the regulations around funerals remained very strict throughout all levels of lockdown.

Whilst death ceremonies, rituals and funerals usually aim to show respect, honour the deceased, and say goodbye, as stated above, it also has a therapeutic effect on the bereaved. It leads to better acceptance of the death and a chance to get or offer social and psychological support (12), but when these practices are hindered it disrupts the grieving process, creating feelings of confusion, guilt, regret, and fear (3). Not adhering to rituals and customs could lead to these feelings becoming unresolved, with many expected to suffer from complications of grief in the future (4). In an article published during the COVID-19 pandemic by the American psychiatrists Goveas and Shear, it was stated that the grieving process in older adults was dominated by the pressure of adherence to the lockdown regulations (13), thus weakening the reality of their bereavement. To counteract the effects of changes to customs and rituals, the bereaved must now find new ways to feel connected and have personal, meaningful expressions of their grief (14).

In some countries, COVID-19 highlighted the lack of bereavement counselling and support (3, 9). It was also recognised that palliative and psychological strategies should have been combined to support families during the pandemic (4), slogans such as “First, we worked at flattening the curve, now the urgency is to get ahead of the ‘bereavement curve’”(3), were used. Bereavement is expected to be one of the long term COVID-19 effects, which if left untreated, will further burden health and social services (9).

In South Africa, despite the recognition of the need to integrate palliative care into the health system, these services including bereavement care, is still most often provided by hospices, faith-based institutions and other Non-profit Organisations (NPOs) (15). During lockdown, these organisations were unable to work at full capacity and often did not accept new clients. This was in contrast with

the increased demand on these services as the community was becoming more affected not only by the pandemic, but also by serious illnesses such as cancer, now diagnosed at more advanced stages.

1.3. Palliative care and bereavement

In 2014, the World Health Assembly (WHA) approved the Resolution 67.19: "Strengthening of palliative care as a component of comprehensive care throughout the life course". This resolution has prompted the establishment of the South African Steering Committee on Palliative Care, whose aim was to develop 'responsive, appropriate' services ensuring universal access to palliative care on an equitable basis (16). The National Policy Framework and Strategy on Palliative Care 2017-2022 lead to palliative care being incorporated into the planned National Health Insurance (NHI) of South Africa (17).

Palliative care encompasses the most holistic approach in managing major life altering events. It considers the medical, psychosocial, and spiritual aspects of suffering (16), improves quality of life and has found to paradoxically increases life expectancy. Palliative care services include the essential provision of bereavement care that aims to minimise the elevated risks to mental health, morbidity and mortality associated with grief and loss (18). An estimated 50% of all South Africans who die could benefit from palliative care and should have access to the services (16), including bereavement support. Despite the recognition of the need to integrate palliative care into the health system, is still mostly provided by hospices and other non-profit organisations (NPOs) (15). These organisations do not have the capacity to support all those in need, thus widely accessible palliative care can only be achieved if the Primary Health Care (PHC) services are strengthened. Despite the hope of implementing palliative care in PHC, it is acknowledged that integration will not be achieved instantly (15) with the subsequent availability of bereavement counselling also expected to take time.

The journey to improved access to palliative care at PHC level in South Africa is dependent on several strategies and policies to realise. Although palliative care is planned to be incorporated into

the National Health Insurance (NHI) as mentioned above, the integration of palliative care in PHC depends on the PHC re-engineering concept of the Ideal Clinic Realisation and Maintenance (ICRM) Program. This program focus on providing all needed health services to all South Africans through an optimally functioning PHC (17). When in place, this strong platform of PHC will provide the building blocks for palliative care integration.

The COVID-19 pandemic has challenged most health systems since early 2020, thus the planned PHC strengthening, improved availability and accessibility of services (such as palliative care), has suffered greatly (2). Although bereavement care often lags other aspects of palliative care (3), South Africans will have better access to bereavement support once palliative care services becomes widely available.

1.4. Bereavement, grief, and complicated grief

Bereavement is the experience of losing a loved one, whilst grief is the natural response to this loss. Acute grief is penetratingly painful and disruptive, and it feels unbearable (13). Acute grief is normal, and the person finds a way to normalise again. Although most individuals eventually adjust to the loss, some bereaved individuals fall into a state of unrelenting and incapacitating mourning which lead them to suffer from the physical and psychological consequences, such as depression, post-traumatic stress disorder, and complicated grief (1).

Prolonged Grief Disorder (PGD) according to DSM-V and ICD-11 is the "Syndrome of persistent and pervasive yearning, longing, or pre-occupying thoughts and memories of the deceased, accompanied by other evidence of grief-related emotional pain, causing significant distress or impairment in functioning, and lasting at least 6 months and exceeding the timeframe expected by social, cultural, religious norms" (18). The terms abnormal grief, complicated grief and prolonged grief are often used interchangeably, but in this study, there will be mainly made reference to abnormal grief as the problematic form of grief. Those who are not able to say goodbye to loved ones have a higher risk of

abnormal grief (1). During the COVID-19 pandemic bereaved individuals were COVID-exposed themselves needing isolation, which lead to feelings of fear and worry about themselves whilst grieving the loss of family members. Traumatic or sudden loss during public health emergencies or disasters has higher risk to have abnormal bereavement outcomes than less sudden losses. Other risk factors include, low self-esteem, previous mental health problems, low socioeconomic status, a lack of social support, and a lack of economic resources (1). Consequences of untreated PGD include increased medication use, poor job retention, psychological disorders, and increased mortality. If identified earlier, early intervention can reduce this suffering (19).

1.5. Chapter summary

The COVID-19 pandemic hit South Africa with full force in 2020, leading to panic and regulations (2). Seemingly harsh regulations were instituted to flatten the curve, but excess deaths increased as did the number of bereaved. Mental health suffering was foreseen and attempted to be prevented, but measures to prevent the spread of the virus were at the detriment of other health priorities. Progress made on programs such as the National Policy Framework and Strategy on palliative care 2017-2022 and the ICRM program to extend palliative care into better functioning primary health care facilities were lost (2). Strict social distancing and funeral rules needed customs to be modified and the effects on the bereaved are expected to lead to the "bereavement curve" (3).

2. LITERATURE REVIEW

This chapter reviews the available literature regarding the prevalence of prolonged grief disorder (PGD) in adult bereavement, general bereavement outcomes in South Africa, as well as what is known thus far of the bereavement outcomes of the COVID-19 pandemic. Literature was also reviewed regarding the effect of funeral custom changes on the bereaved and how palliative care availability affects grief and bereavement support.

2.1. Literature search

A systematic search was conducted to identify relevant literature on grief and bereavement, as well as the effects of pandemics on bereavement. Literature on funeral customs were sought as well as on palliative care and grief. The COVID-19 pandemic necessitated new knowledge being rapidly generated and the literature on COVID-19 are evolving. From the literature review on COVID-19 grief and bereavement it is apparent that most studies were conducted within a short period of time. The terms “fast-tracked article”, “rapid review” and “mini review” are found to describe most of the studies during the researcher’s period of literature review.

The search was undertaken using keywords in a Boolean structure to search for literature in PUBMED, Clinical Key, Medline, and Google Scholar. The keywords and phrases used to conduct a thematic search included: “complicated grief”, “abnormal grief", "prolonged grief", "pandemics", "bereavement practices", "funeral customs”, “burial practices”, “palliative care”, “COVID-19 pandemic”, “lockdown regulations”, “South Africa”, “bereavement counselling”. Keywords were combined using Boolean operators AND, OR and NOT. Apart from electronic searches, the reference lists of the relevant studies were also searched for further relevant studies, after which the leading authors in this area were searched for possible articles.

The results were again sorted by reading the title and abstract and saving them according to their relevance to the themes of the planned literature review. A fair amount of research material was found for certain aspects, as the subject of COVID-19 being a very current issue globally. Research articles from South Africa and the rest of Africa was sought but found to be few. Additional local resources used were publications from the South African Research Council and webpages about the local community.

2.2. Prevalence of Prolonged grief disorder

In the systematic review and meta-analysis done by Lundorff et al. in 2017, the prevalence of Prolonged Grief Disorder (PGD) in adult bereavement were established (20). They modelled that an estimate that 10% of bereaved individuals are at risk to develop complex grief reactions needing specialised care and that 30% of the bereaved needs group support. These results were confirmed by Sealey et al. (21) and Von Gunten (22) in their respective review publications.

Several factors in Lundorff et al.'s systemic review is worrisome. Selection criteria only allowed 14 studies to be included and due to the methodology differences and poor representativeness of these studies, the results need to be interpreted carefully, with further population-based epidemiological research needed. The important outcome of this review (also reflected in Sealey et al. and Von Gunten's reviews) is that if resources for bereavement care is spread over all people bereaved, wastage of resources occur, as many people will be getting support that they do not need (20, 23).

In 2015, Sealey et al. published the scoping review of bereavement risk assessment models and applied it to palliative care (21). A reasonable public health model (three-tiered model) to utilise resources responsibly with services meeting the needs of bereaved family was to be developed (21). Three groups were identified namely the 'universal bereaved' (all bereaved), the 'selective' group (those having risk factors for complicated grief) and the 'indicated' group (those with signs and symptoms of complicated grief) (21). This review again stressed the importance of avoiding general

bereavement support but rather provision of support to those who due to their distress needs help but are not likely to seek it themselves (21), the challenge remain on how to identify this group. This review could also not clarify how to identify them.

Another review article was published in The American Journal of Geriatric Psychiatry on the effectiveness of palliative care, including bereavement care by Von Gunten in 2012 (22). It sheds light on the topic of evidence with regards to effectiveness of palliative care. Despite having few studies to include in his review, Von Gunten found palliative care to be effective and cost effective (22). In his emotive conclusion (in deductive reasoning more than statistical proof) he points out that the lack of implementation of palliative care is because no incentive (money making system) exists to effect practice changes (22). Thus, palliative care is likely to continue to be implemented slowly despite evidence thereof (22). On bereavement he concluded that, talking to patients and their families near the end-of-life, result in better quality of life and better bereavement outcomes (22), but the statistical benefit is not produced in his study. The question becoming apparent from the review articles discussed above, is how can those with risk of abnormal grief be identified accurately and timeously?

Guldin et al. conducted a cohort study in 2011. They first developed a screening tool with a predictive value that can be used 8 weeks after a bereaved person's loss to identify if they may develop PGD six months after their loss (19). They then used this tool in a cohort study within a suitable clinical setting. The screening tool consisted of the Beck's depression inventory (BDI) combined with a single question item, namely: "Even when my loved one was dying, I felt a sense of purpose in my life". This tool displayed the best sensitivity (80%) and specificity (75%), as well had a positive predictive value of 70% and a negative predictive value of 85%, compared to other explored tools (19). The study performed well with sufficient size of participants, although they were mostly recruited from a palliative care network which could have led to bias. The researchers were also concerned about the age group (not as many older individuals) and sex (less females) representation in the study (19). The tool also needed further clinical validation. Their results on the occurrence of prolonged grief were

less than what other studies suggested. They found 7% to be high risk and 23% moderate risk (19), both groups needing intervention as stated earlier.

2.3. Bereavement outcomes in South Africa

No results on bereavement outcomes, regardless of palliative care access, could be found from South Africa. Studies dating back to 2007, mainly described HIV/AIDS bereavement, although a very helpful complicated grief intervention model was written by the South African authors Drenth, Herbst and Strydom in 2010 (24). Their article comprises of both an in-depth literature study on abnormal grief, as well as a new intervention model, development of a tool to manage patients suffering from complicated grief. Their literature review demonstrated the lack of publications on this matter, but also concluded that about 10% of bereavements are abnormal. The intervention tool was not scientifically tested but could serve as a framework for the management of affected individuals. The writers had hope of validation of the tool in the future, but no subsequent studies were published.

2.4. What we know about bereavement outcome during COVID-19

"First, we worked at flattening the curve, now the urgency is to get ahead of the 'bereavement curve."(3)

Risk factors for complicated grief was apparent in the current pandemic – Sudden loss and limited social support being prominent occurrences. The COVID-19 pandemic predicted an increase in people seeking help as each death left an estimated nine persons bereaved; this needing proactive intervention to prevent further suffering (3). Several studies with different aims and methodologies have been published during 2020 and early 2021 on the impact of COVID-19 on grief and bereavement. Lessons from previous pandemics and natural disasters is valuable to assist in predicting what the bereavement outcome would be.

2.4.1. Lessons from previous pandemics

At first the effects of the recent COVID-19 pandemic being unknown; researchers looked at the impact of previous pandemics on bereavement. Mayland et al. published a rapid review article in August 2020 on previous infectious diseases pandemics effects on bereavement (25). They included

only 6 studies; 4 of which was qualitative, one observational and the other a systematic review. They found recurring themes of multiplicity of loss, uncertainty of life, fear, disconnection, and choice restriction. Disruption in social norms, rituals, mourning practices, place of burial and inaccessible site of graves was seen to influence outcome of grief. According to this study, innovative ways are needed to promote communication and connectiveness as well as to adapt rituals, whilst maintaining respect for culture and faith during the COVID-19 pandemic. Psycho-social interventions driven by communities and formal mental health services are important to manage the widespread psycho-social stress (25).

In a review article written in May 2020, Gesi et al. evaluated previous studies that was done on complicated grief after natural disasters and intensive care unit (ICU) deaths. There is not much revealed on the method in conducting the study, but the aim was to relate natural disasters and ICU deaths' bereavement to the COVID-19 pandemic to help bereaved during the acute phase of grief and recognise those at risk to develop abnormal grief (4).

After natural disasters, it was found that the suddenness of death with compounding factors such as fear for own safety, and multiple losses led to increased risk (4). The prevalence of abnormal grief varied greatly from 9 – 80% (4). Such a variation show that studies included were very heterogenous and considered many different factors.

In the ICU setting losses were found to be traumatic as family were unable to visit and had no time greet (4). The prevalence of abnormal grief here varied from 5 - 52% (speculatively the same reasons for large variation as stated above), being influenced by factors such as poor communication, death whilst intubated, and not being present at the time of death (4). The bereaved tend to blame themselves for not trying harder to be there and to take care of patients' dignity and comfort (4).

They found that funeral rituals are important for coping with loss in that taking part in arrangements leads to better grief outcomes (4). Factors that can help the bereaved are to keep connectiveness throughout, communication by medical personnel, family involvement in shared decision making, and effective social support (4).

Measures instilled to curb transmission of infectious diseases was also detrimental to successful grieving such as social distancing, and rules against public funerals (4).

2.4.2. Current pandemic bereavement knowledge

In the article written by Morris, Moment, and Thomas, they clarified that bereavement care is part of the palliative care movement, and that COVID-19 highlighted the lack of universal bereavement care in health facilities (3). The "universal" access to bereavement does not suggest "blanket" bereavement care; studies discussed earlier warned against (20, 21, 22, 23). It rather means that bereavement care is non-existent in some areas, and it should be generally available so that those who need it have access. Palliative care provides the framework for caring for patients and their families in the most difficult circumstances.

This *fast-tracked* article published in August 2020 provides suggestions from the available palliative care tools and previous results from bereavement research (3), that can be used from before a patient's death. These tools can help health care workers to provide support to families before and after the death of a patient and prevent poor bereavement outcome. No new research is published in this article, and the validity of the article rest on the references used. The palliative tools include communication skills, trusting relationships with connectiveness, and care planning processes (3).

2.4.3. Grief from losses other than COVID-19

Although it is expected that grief will be worse during the lockdown than before the pandemic, as lockdown factors created a high risk for complications (less social support and decreased death rituals); a study in the Netherlands by Eisma and Tamminga (14) showed no significant differences in non-COVID related deaths.

The quantitative study published in December 2020 (14), collected data from a voluntary-response cross sectional self-screening online survey on 1600 non-COVID bereaved persons. The large sample was adequate, although a younger population participated with mean age of 45 years (possibly due to the online nature of the survey) and more females participated (14). The results showed no significant

differences in grief from before or during the pandemic, it did, however, show more severe grief symptoms in the recent bereaved during pandemic, than the recent bereaved before pandemic, groups (14). The dealing with acute loss most likely influenced by the substantial changes in everyday lives, including the way we mourn (14).

The study concluded that the long-term effects of the worsened symptoms of acute grief, may translate to future significant increase in complicated grief sufferers, be it loss due to COVID-19 or not (14).

2.4.4. Health care workers ability to respond.

From the health care provider's point of view, a study conducted in 2021 in the United Kingdom by Pearce et al. (9) investigated the views of health care workers in identifying the major impact of the pandemic on bereavement care by means of a descriptive cross-sectional online survey. Medical personnel described major challenges in using remote forms of support (90% of respondents never used telemedicine before) for the bereaved as they had to adapt to the need to prevent complicated grief on a large scale (9).

They concluded that COVID-19 deaths are especially traumatic being sudden and unexpected, often in ICU, with patient isolation and severe symptoms of breathlessness (9). Social distancing also has a major effect on bereavement of other causes according to this study (9). They suggested the three-tiered public health model of bereavement support to help identify those needing help (21). According to the study, further research is needed on how individuals, communities and the health and social system will respond to the greater need for bereavement care as it is one of the long-term effects of COVID-19 – although action is needed now to ensure equity of provision for all (9).

2.4.5. Preparing for COVID-19 based on palliative care principles.

In order to handle the COVID-19 pandemic rapidly and effectively a *fast-tracked* article was published in March 2020 by Etkind et al. (26) to gather evidence on how the holistic approach of hospice and palliative services have an essential role in the response to the pandemic. Palliative medicine had to ensure protocols for symptom control were available to share, they needed to extend

their capacity to train non-specialists in using the protocols, they should be available to assist with triaging cases for ICU or palliation, they needed to shift their resources to the community, start using volunteers to provide psychosocial and bereavement care and assist with support amongst staff to deal with stress, and implement the use of technology to communicate with patients and their families (26). Palliative care, with its benefit in complex decision making, and management of clinical uncertainties, could in these ways be integrated into this and future pandemic responses (26).

2.4.6. Preparing for the mental health concerns of COVID-19 bereaved

In April 2020, Sun, Bao, and Lu, submitted a letter to the editor of the journal Psychiatry and Clinical Neurosciences, to give suggestions on addressing the mental health concerns of the bereaved, which is often ignored during epidemics and/or pandemics (1). They commented that very few evidence-based bereavement support services were available to use for psychological interventions in the aftermath of the pandemic (1). The overall lack of appropriate help for the bereaved were possibly contributed to a lack of mental health awareness, stigma, or the lack of mental health allocated resources (1). In preparation for the "bereavement curve" the promotion of mental health literacy was to assist in improving coping skills and understanding of psychological issues (1). With regards to the lack of evidence-based strategies, intensive plans were needed to strengthen and modify the available data to formulate services (1). Increased resources for mental health interventions were also needed to ensure the sustainable implementation of these interventions (1). They lastly suggested that further research was needed to establish if evidence-based interventions could be implemented for the bereaved in low resource settings (1).

2.4.7. Older persons' grief

From the perspective of older individuals, deaths from other causes were continuing during the COVID-19 pandemic but many were dying alone. In a commentary article by Goveas and Shear, it was again stated how the pandemic affected the way in which the terminally ill was cared for (13). Grieving was now engulfed with all the new life stressors derived from measures needed to manage the pandemic, causing even more losses (13). The commentary brought across its value in stepping into the shoes of a few elderly people and told their stories of loss during this pandemic. COVID-19

claimed more lives of older individuals, but they are also at a higher risk to develop PGD (13). To mitigate this, health workers should remain active empathetic listeners even when needing to use telemedicine to reach patients, though it takes away the personal touch (13). It could also be difficult for some older persons to use but with repeated use they can also get more confident in using technology (13).

2.4.8. Measuring grief during the COVID-19 pandemic

In December 2020, Lee and Neimeyer published a study in which they had developed and validated a brief mental health screener, namely, the pandemic grief scale (PGS) to help identify those at risk of developing complicated grief due to COVID-19 and the lockdown (27). They suggested that the PGS be used not only for COVID-19 deaths, but also for other cause deaths during the pandemic (27).

The research was performed well with an adequate number of participants and sound statistical evidence. The tool displayed a sensitivity rate of 87%, a specificity rate of 71%, and an area under the curve (AUC) value of 0.87 (27); comparable to the screening tool described earlier by Guldin et al (19).

Limitations of the study is the use of only an online survey and convenience sampling; they suggest further studies to be conducted with a probability sampling as well as structured interviews to deepen the evaluation of the grief suffered by the participants (27).

2.5. Lockdown regulations' effect on customs surrounding death.

Cultural customs needed to be adjusted due to rules set by lockdown regulations all over the world. South Africa has many different cultural groups with various important customs and beliefs around the death of a relative (10). As funerals were labelled "super-spreader events" (11), regulations around burials remained strict throughout all levels of lockdown.

2.5.1. Changes in burial practices

A rapid but thorough literature review by Burrell and Selman published in July 2020, included 17 studies, both quantitative and qualitative, on evaluating the effect of funeral practices on bereaved relatives (12).

Mental health and bereavement outcomes were established, but the quantitative evidence was found to be inconclusive: six studies showed no benefit, whilst five studies found benefit in participating in funeral practices (12).

Some of the studies included looked at grief outcomes when the bereaved were involved in planning a funeral, but it was found not to be associated with a significant change in grief outcome (12). The mixed-method part of one particular study found that 57% felt planning helped with their grief, 28% were unsure of the effect and 15% felt it was unhelpful as funeral planning was a routine task to them (12).

In other studies, included in the review those that participated in planning the funeral reported less social isolation (12). For immigrants, being able to attend funerals in their home country reinforced a sense of belonging leading to less unresolved grief. An American study found no significant differences in grief intensity between those who did and did not attend a funeral (12).

The qualitative review gave more insight and showed that the bereaved derives benefit if they partake in the ritual in a way that is meaningful for themselves (12). Feeling in control was a key factor of whether participants identified funeral practices and rituals as helpful or unhelpful (12).

In the context of COVID-19 the restrictions on funerals may reduce support for the bereaved but will not necessarily lead to poor outcomes. Infection control measures that everyone must adhere to leads to reduced emotional expressions and physical comfort such as hugs, handshakes, and closeness and not being allowed to touch the coffin or have group meetings after the funeral may leave mourners unsatisfied.

Mental health conditions are likely to increase in the future if social support remains limited (12). To mitigate this, creativity needs to be applied to a funeral to create the needed meaningful emotional

connections and provide the sense of control (12). The palliative care provider can support family with ideas for culturally appropriate alternative ceremonies such as live streaming, recordings, sharing of songs, photos, and stories, and reading of tributes by those not able to attend (12). Further research with robust methodology were suggested to fully grasp the impact of COVID-19 on bereavement (12).

2.5.2. A South African perspective

In the South African context, literature is limited on the cultural norms of burials and especially the effects on the bereaved if these norms are limited.

An article by Bank and Sharpley in 2020 (11) stated that the South African government's "War on COVID" did not translate well in the rural areas during the first wave of infection from April to July 2020, when customary rights were suspended without clear explanation by authorities. Local traditional leaders were not consulted and informed and the communities could not get the reassurance from them why their customs now seemed to be 'causing COVID' (11).

Another article was published in November 2020 under the instruction of the Office of the Premier in the Eastern Cape Province, by Bank, Sharpley and Madini (28). The aim of the study was to establish if traditional dignified burial and funeral practices could still be effectively done whilst adhering to COVID-19 protocols (28). They observed burials in ten different municipal areas of the Eastern Cape and found that the regulations led to confusion and anger (28). Traditional practices entail the family washing and dressing the body, the body needing to move to different places for viewing and rituals; thus, the bereaved found the regulations very upsetting and interfering with these practices (28). On some occasions the body was already buried wrapped in several layers of plastic and the rituals was left incomplete - this caused confusion and anger with feelings that their loved ones where not laid to rest correctly according to their culture (28). Anxiety also accompanied the regulations as law enforcement officials were sometimes present during ceremonies (28).

The outcome of bereavement was expected to be poor and greater sensitivity to local beliefs was recommended to be uphold by local authorities and government (28).

2.6. Conclusion

In this literature review it was found that many of the research was done in a short space of time to provide rapid output on a developing problem. A “bereavement curve” is agreed to be a consequence of the world-wide COVID-19 pandemic (3). The prevalence of prolonged grief disorder amongst bereaved persons is about 10% and those who needs grief counselling are usually 30% (20). To identify the specific individuals in need of bereavement counselling as early as possible has always been challenging. South Africa has no studies on bereavement outcomes although we have developed tools on management of abnormal grief (24). A promising tool to measure grief severity during COVID-19 was developed (27) and its use was encouraged by the researchers.

COVID-19 was marked with suddenness of loss, limited support, fear, and choice restrictions that made it comparable with ICU deaths, previous pandemics, and natural disasters (4). Studies on similar situations found the bereaved to be left with feelings of guilt for not trying harder to ensure the comfort and dignity of their loved ones at the time of their passing (4). Furthermore, lockdown regulations suppressed the customs that usually aim to assist the bereaved to deal with their loss (11). Previous studies (12) were not conclusive that the inability to partake in customary rituals lead to abnormal grief.

South African articles on lockdown regulations’ effect on funerals stressed that the government should have taken inconsideration the meaningfulness of customs to different cultures and have been more sensitive when deploying law enforcement to cultural and family gatherings (11, 28).

Literature on health care workers’ readiness to respond to the COVID-19 “bereavement curve” revealed that they felt unequipped to support persons online (9) and older persons experiences also revealed that they were more isolated and needed even more empathetic listeners and repeated help and interaction with telemedicine (13).

Hospice and palliative care are associated with improved quality end-of-life care and bereavement outcomes (29)(22). Bereavement care is not universally accessible to those who need it (c).

Bereavement care is mostly a preventative tool, providing support for families before and after death (29). Sadly, bereavement research and programs lag other palliative care topics (3). To support integration of palliative care into primary care, the precise need for palliative care services, including bereavement care, needs to be proven.

3. RATIONALE FOR STUDY

To truly understand the depth of distress, it was pertinent to directly involve individuals who has suffered from the loss of a loved one during the pandemic and lockdown. The loss need not have been directly related to COVID-19, as studies has found that the bereaved from other causes of death also needed to deal with the restrictions on hospital visits, social distancing and minimalistic funeral arrangements (9).

It is uncertain if there were other studies in South Africa thus far that focused on the bereavement aspects of a local community due to the COVID-19 pandemic regulations. The extent of the expected psychological burden brought on by restriction of socialising, traveling and funerals, needed to be studied to prepare for the complications of such suffering.

The information derived may contribute to the preparedness for harsh restrictions in response to future pandemics. Other benefit from the study might be that those with abnormal bereavement are identified and provided access to appropriate counselling, thereby improving access to this important aspect of palliative care, as well as motivate for a quicker integration of palliative care into primary health care as a whole.

4. AIM AND OBJECTIVES

The aim of this study was to explore how COVID-19 and the lockdown regulations had impacted on the grieving process of the public health care users of the Eersterust community.

The study had the following objectives, to:

1. Determine how many public health care users of this community experienced loss of a loved one during the COVID-19 pandemic.
2. Determine the changes that occurred in the social norms of grief and bereavement.
3. Explore the individual effects of the changes in norms on certain members of the community.

5. METHODS

5.1. Study Design

The study design was a cross-sectional mixed methods descriptive study which was conducted in two phases. Phase 1 was an assisted paper-based quantitative questionnaire (Appendix B), with opportunities for participants to elaborate qualitatively on their experiences, whilst Phase 2 was qualitative in design and conducted by means of a semi-structured focus group and individual interviews (Appendix D).

5.2. Study site

Eersterust Community Health Centre (ECHC) was the study site. It provides primary health care (PHC), to an average monthly headcount of 7400. It provides additional services with a Mental Health Unit (with sessional psychiatrists and resident psychologists and mental health nurses), a rehabilitation team (including a social worker) and a community orientated substance abuse centre (COSUP).

The formal township of Eersterust covers an area of 6.05 km² and lies within the Tshwane Metropolitan Municipality Sub-District 6, which is on the Eastern side of the city and situated in Gauteng province. In 2011, according to the Census data (30), the population was 29 676 people living in 7 715 households. The more recent 2022 Census data did not yet publish smaller community population sizes - it is estimated that the population size has increased to around 40 877 people. It is a young population with more than 80% of people younger than 50 years and less than 3% older than 70 years. The population is made up of 84% coloured and 14% black African people, with language distribution of 77% Afrikaans, 10% English and almost 3% Sepedi speakers.

The catchment area for ECHC is much larger than the geographical site, which also includes surrounding areas such as the western parts of Mamelodi, and it is estimated that there is about 62 850 people in the catchment area of the CHC, contributing to the monthly headcount of the facility.

5.3. Study population and selection criteria

Participants in the study included interested public health care users of Eersterust CHC, who accessed the facility during the 2-week period of data collection, who was older than 18 years and were able to communicate in one of the three dominant languages in the area (Afrikaans, English, or Sepedi). Minors were excluded from the entire study. For Phase 2 of the study those who had a loss before March 2020 (before COVID-19 pandemic) and/or had a recent loss ("Less than 6 months since the loss, thus ruling out those who might be suffering from possible acute grief, which is regarded normal but may have overlapping symptoms" (31) were excluded. Most of the study population for Phase 2 were participants from Phase 1.

5.4. Sampling method and size

5.4.1. Phase 1

The sample frame for Phase 1 was a convenience sample from the public health care users that accessed ECHC during the 2-week data collection period from 16 - 27 May 2022 (10 days).A systematic sampling approach was used to collect a total of 399 questionnaires (n = 399) which was based on the actual average daily PHC headcount of 389 during the study period. The sample size was calculated by a power analysis to satisfy a confidence interval 95% and a statistically significant P-value of 5% (p = 0.05); the Andrew Fisher formula: Sample Size = $(\text{Z-score})^2$ x Standard Deviation x (1 - Standard Deviation)/$(\text{confidence interval})^2$ was used This resulted in that every ninth client entering the clinic was approached with the option to consent to join the study, which amounted to an average of around forty participants per day.

5.4.2. Phase 2

The sample frame for Phase 2 was the participants from Phase 1, but only those who had lost someone in the specified period **and** had shown interest in participating in a focus group discussion. There were 46 participants from Phase 1 that met the criteria to participate in Phase 2. Every 5^{th} willing

participant was contacted telephonically to invite them to the focus group discussion. If they were unable to attend the discussion, the process was repeated until 8-10 participants agreed.

Unfortunately, despite participants agreeing on the time and location, the focus group discussion needed to be postponed several times due to participants non-attendance. As a result, the data was collected by means of 2 individual interviews and one interview with two participants.

Further qualitative data was obtained by purposeful sampling of a community member known to have fulfilled the criteria of Phase 1 but who were not at the facility in the 2 weeks of data collection. The community member was willing and present during Phase 2 data collection, providing another individual interview.

Qualitative data was also included from the Phase 1 questionnaires of eligible participants, from the comments section taken verbatim by the interviewers.

5.5. Data collection

5.5.1. Questionnaire development

To reach the specified aims and objectives of this study, a questionnaire needed to be written. The development of the questionnaire was based on thorough literature review of similar grief and/or pandemic studies.

Tools that were studied in compiling the research aids were pre-COVID-19 screening tools for abnormal grief such as the Beck's depression inventory (BDI), a tool developed by Guldin et al. in 2011 (15), as well as a tool developed after the onset of the pandemic by Lee and Neimeyer published in December 2020 namely the pandemic grief scale (PGS) (27). The PGS was validated as a brief mental health screening tool to help identify those at risk of developing complicated grief due to COVID-19 and the lockdown (27). The authors suggested that the PGS be used not only for COVID-19 deaths, but also for other cause deaths during the pandemic (27).

Apart from the screening tool for abnormal grief, additional variable questions for Phase 1 and 2 of this study needed to be developed for the specific South African setting where unprecedented

lockdown regulations affected not only hospital visits but also burial practices, as no appropriate tools were available to use.

Phase 1's data collection questionnaire was developed to collect demographic information such as gender, age, religion, and beliefs. The questionnaire furthermore collected data concerning if any losses occurred during the COVID-19 lockdown period. If the participant had not experienced any losses during this period, the knowledge of the availability of bereavement counselling at Eersterust CHC was collected. If the participant had experienced losses; further elaboration on the losses were then sought: How many losses, what the participant's relation was to the deceased, and when it occurred within the COVID-19 pandemic. Losses related to COVID-19 was documented, the suddenness of the loss, as well as the ability to say, "last goodbyes" and if hospital visits were allowed. Flow of information from hospitals and ways of communication used when visiting were not possible were collected. Travel restrictions' impact on hospital visits and spending time with the loved one were collected as well as the ability to attend funerals in person or online. Data was also included on customs of body viewing and general thoughts on how much funerals changed due to COVID-19 rules. The ability to help with funeral arrangements, the amount of support received during the loss and the need for emotional support at the time of participation were included in the tool as well.

The general public's response to the regulations and the piloted populations remarks contributed to the questions incorporated into the tools developed, but discussions with experts in the field of grief and bereavement were held and the unavailability of appropriate questionnaires were confirmed. Experts included family physicians, palliative care specialists and psychologists.

5.5.1.1. Validity and reliability

The pandemic grief scale (PGS) was used "as is" in Phase 1 of the study, as part of the questionnaire (Appendix B), as its use was encouraged by Lee and Neimeyer (27) in their study without requiring additional consent from them. The PGS was proven a valid and reliable tool in establishing risk for the development of complicated grief. It had a sensitivity rate of 87%, a specificity rate of 71%, and an AUC value of 0.87 (27). Limitations of the PGS study was the use of only an online survey and

convenience sampling; they suggested further studies to be conducted with a probability sampling as well as structured interviews to deepen the evaluation of the grief suffered by the participants. In this grief study the qualitative data obtained serves to improve the usefulness of the PGS.

The experts involved gave input on the new questionnaire's development and evaluated the content (redundancies, absences, and misleading questions), face validity (understanding, user-friendliness, adequacy, and structure), relevance to justify items' inclusion, and adequacy of the type of response scales. The newly developed questionnaire was then presented to them and was agreed upon.

5.5.1.2. Piloting

The questionnaire of Phase 1 (Appendix B), and the content of the Interview questions of Phase 2 (Appendix D), was piloted on several colleagues that are also members of the community of Eersterust. They assessed the content, language use, interpretation of the questions used in the tools, the relevance of the questions to their community and commented on the adequacy of the response scale. Minor modifications were made, and another pilot was performed to assess whether the modifications made were adequate and acceptable before the study was conducted.

5.5.1.3. Translation

The informed consent (Appendix A) and data collection tool (Appendix B) for Phase 1 of the study was translated into the three most common languages spoken in the area, offering the participant the choice to use the language of their choice. The interviews of Phase 2 of the study were conducted in English and/or Afrikaans, depending on the participant's preference.

5.5.2. Data collection procedure

5.5.2.1. Research assistants

Four final year medical students were trained by the researcher to assist with data collection, whilst they were rotating at the facility as part of their Family Medicine training. Their training focused on the informed consent process, compassion towards the topic of loss, bereavement, and cognisance of the vulnerable populations in the Eersterust community. They were also instructed and had roleplay exercises in the appropriate way to ask sensitive questions and how to identify and manage emotional

distress by means of the distress protocol used during the study. They were fluent in English and Sepedi, but when a language preference for Afrikaans was identified, the researcher would assist in obtaining the data and similarly for participants preferring Sepedi.

5.5.2.2. Recruitment and informed consent procedure

Phase 1

Phase 1 of the research was conducted in the administration foyer of Eersterust Community Health Centre (ECHC), during the 2-week data collection period of 16/5/2022 - 27/5/2022. The National State of Disaster due to the COVID-19 pandemic was lifted on 5 April 2022, but the health care facility still had social distancing and hand sanitising practices in place.

As the public health care users entered the building after their cards have been taken in and their place in the queue secured, the described systematic sampling method was used to approach the next selected user to be part of the study, whilst they were seated (about a meter apart) in a large waiting area. The informed consent was discussed in the participant's home language as far as possible, explaining in simple and clear terms the content and aims of the study. Reassurance was given that they would still receive their anticipated care at the facility and not lose their place in the queue that day. If the potential participant seemed reluctant, they were not coerced in any way to give consent to partake in the study; only 18 selected users declined any participation. The next selected user was then approached.

It was made clear that the intention of the study was to benefit the community by making grief counselling more accessible by establishing the need and creating awareness of the available services, and if needed to increase the services. The social distancing measures that were in place and the way in which the questionnaire was completed assisted in the confidentiality of the data collection process. The participants were informed on how the results will be shared with the community and that their privacy was to be protected throughout.

After their eligibility was confirmed and they agreed to participate, the users were handed a sanitised pen to sign the consent form (Appendix A). The filling in of the paper questionnaire (Appendix B)

was assisted with by the researcher/research assistants, by each question being read and the response marked. The question to show interest in participating in the qualitative section was clarified, and a contact number taken if the participant were willing to participate in Phase 2. No personal identifier was linked to the questionnaire, if the contact number was provided, the participant's name was still not written down. Assistance was offered without any interference into the participants responses. The participants were able to elaborate in their own words on some of the questions and their answers were written down verbatim.

The participants were free to withdraw consent at any stage of the study, without any consequences towards them, however no participants withdrew from the study once consent was given. The researcher was available throughout the period to support the research assistants if they had any queries or if any difficult situations arose. There was one situation in which the distress protocol (Appendix E) needed to be used in Phase 1 of the study.

On completion, the participants were thanked for their participation and the questionnaires and signed informed consents were placed in a sealed mailbox-type box.

Phase 2

The recruitment for Phase 2 of the study took place telephonically by the researcher. Participants of Phase 1 who indicated their interest to participate in the focus group discussion, and met the criteria, were considered. The selection from interested participants followed the method as was discussed in the sampling section, until 12 participants were recruited to make up for any no-shows. Consideration was given to arrange a convenient time for participants to have the discussion in the rehabilitation hall of ECHC, originally planned for 12 June 2022 at 10:00.

Unfortunately, none of the participants that agreed on the time and place came to this meeting. The potential participants were all contacted again and their willingness to participate were confirmed with more convenient times for their interviews scheduled, which was now on their return dates to ECHC. The researcher needed to adapt to this, and the interviews were now to be mostly individual interviews and included a community member recruited by means purposeful sampling. The venue

was changed to a smaller office, as the rehabilitation hall was not needed, and the resident psychologist could not be there for all the interviews.

The interviews started by informing the group/individual participant of the aim of the study and verification took place that every participant has understood and signed the informed consent (Appendix C) for Phase 2 of the study. Social distancing and the wearing of face masks were ensured during all interviews. The interviews were recorded on a secure electronic recording application on a mobile device. The participants were allocated numbers which was mentioned when they started to talk; their names were never used during the interviews.

The data collecting tool for Phase 2 (Appendix D) was a framework of topics, that were discussed by means of open-ended questions and active listening. The discussion was semi-structured by allowing the participant to come forward with their own experiences of the loss of a loved one during lockdown. The interviews lasted around 60 minutes and ended by a few summarising and supportive remarks. The interviewer remained sensitive throughout and mitigated any sign of emotional distress, implementing the distress protocol (Appendix E) where it was needed. The participants had the option to withdraw consent to participate in the study at any time. None of the participants needed to withdraw once the interviews started.

The participants were encouraged to schedule an appointment with the psychologist if needed, they were also given the contact details of the local pastors that offered their counselling services to the community.

5.6. Data storage

5.6.1. Phase 1

After completion, the questionnaires of Phase 1 were placed in a sealed, mailbox type box and stored in a locked office with access only to the researcher. It was placed in a locked office at the end of each day and over the weekend. It was only opened by the researcher after the 2-week collection period.

Each questionnaire was coded with a unique participant identification number which was a numerical sequence for reference purposes. All the data from the questionnaires was meticulously transferred to a Microsoft Excel spreadsheet from which it was further analysed.

The paper questionnaires were then placed back into the box, sealed again, and stored securely. The data will be stored for at least five years in a locked cabinet, with the consent forms kept separately from the questionnaires to ensure continued anonymity.

5.6.2. Phase 2

The audio recorded data from Phase 2 was transferred from the mobile device to audio files on the researcher's password protected computer from where it was transcribed by the researcher verbatim to a Microsoft Word document. The audio file sizes combined were 147MB. Data backups to the UCT OneDrive cloud storage were made as new data were stored during collection phases. This was stored with the data from Phase 1 as described above.

5.7. Confidentiality, sharing and costs

Confidentiality was continually protected during the study, and although data will be made public when the study is completed there will be no personal identifiers included. The informed consent (Appendix A, C) included information regarding data sharing, which emphasised that each individual's privacy would not be exposed in the results. On conclusion of the study, the data will be stored at the secure data repository, namely ZivaHub, where the completed dataset will be accompanied by keywords, a short description taken from the abstract and relevant paragraphs on the data process taken from the methods section.

No data costs are anticipated as the data is expected to be less than 10GB, and the UCT system will be used to curate the data. The electronic data generated is stored on a password protected personal computer of the researcher, on a separate hard drive as well as on the trusted password protected cloud service of the University of Cape Town (OneDrive linked to the researcher's student account).

A UCT data management plan (DMP) was also submitted to fulfil in the requirements of the university.

5.8. Data analysis

5.8.1. Phase 1

The data from the questionnaires was transferred to a Microsoft Excel spread sheet and analysed by means of descriptive statistical analysis in the program STATA. Data was analysed for regression patterns and comparisons. Cross tabulations were done between several indicators within the data. Support for appropriate analysis was sought from Biostatistical services from the University of Cape Town.

5.8.2. Phase 2

The audio recorded data obtained from the focus group discussion was transcribed verbatim by the investigator, during which the investigator was familiarised with the data. Qualitative contributions from Phase 1 were also taken from the questionnaires and prepared for analysis.

Using qualitative software (NVivo 14.23.1), thematic content was identified from the data by means of coding and a list of key themes and sub-themes emerging from the data were constructed, creating the thematic index. The themes were correlated with the study aims and literature review. The study objectives guided the selection of relevant themes, looking to identify topics, issues, similarities, and differences in the participants' contributions to the discussion.

5.9. Ethical considerations

5.9.1. Ethical guidance

The study was conducted after written approval was received from the Human Research Ethics Committee (HREC) of the Faculty of Health Sciences at the University of Cape Town (Appendix F),

G50 Old Main Building, Groote Schuur Hospital, Observatory, Cape Town; telephone number 021 650 1236. Annual review was also granted by the HREC.

Furthermore, as the proposed site was a Gauteng provincial health facility, the appropriate permission to conduct the study on the premises was sought and obtained (Appendix G). This included the submission of the study proposal to the National Health Research Database.

The study followed the Declaration of Helsinki (last update: October 2013) (32), which ensured that all ethical principles related to research with human subjects were adhered to.

5.9.2. Potential vulnerabilities and mitigation

Potential vulnerabilities that were foreseen were that the patient may experience a distressing emotional trigger when discussing their loss. A distress protocol was used (Appendix E) if any participant shows signs of distress throughout the data collection process, but especially during the Phase 2 interviews. This ensured that if the topic of loss caused significant emotional distress for any participant, it was handled compassionately. The distress may have prevented continuation of the interview and left the participant unsatisfied. Participants were assured that they may stop the interview at any time and was offered the help they needed from the mental health psychologists, but still having the option to continue the interview. The informed consents (Appendices A and C) included a section about the possibility of experiencing these distressing events. There was one situation in which the distress protocol was used in Phase 1 of the study when a participant showed distressing emotional signs, but the participation could be completed after the distress protocol was applied.

As a palliative care practitioner, the researcher is trained in complex conversations and ECHC had both social workers and psychologists as a part of the team that assisted in providing support.

5.9.3. Justifying the use of a focus group discussion

In the past, the general hypothesis has been that sensitive issues should not be discussed in groups, as the participants could be vulnerable and feel exposed. The necessity of research covering sensitive

topics can justify research methods such as focus group interviews, as was seen in the 2007 study by Jordan et al (33). They concluded that one should be conscious of the potential burden placed on participants when talking about topics that are upsetting and could trigger emotional responses, although valuable information can be gained (33).

Group discussions create an environment where the mutual topic, can encourage participants to share their experiences as well as obtain emotional relief. Focus group interviews offer benefits to both the researcher as well as the participants. It is more time-conserving as each participant does not need to be interviewed individually with less time needed to transcribe the audio recording. The mutual feeling of shared loss can generate hope with the participants not feeling alone in their loss. Therefore, despite the intent to obtain 'data' from the interview, it does offer the participants a therapeutic benefit and could lead to future support within a community. It is, however, important for the interviewer to always remain very sensitive to any emotional distress needing to implement the distress protocol (34).

During the study the process of informed consent remained vital, providing information to all the participants that feelings of loss may come to the fore when discussing their experience of their grief and bereavement. Showing appreciation for their contributions to the study was stressed and opportunities were offered for counselling should participation have stimulated emotions or thoughts they wished to discuss further.

5.10. COVID-19 adherence and prevention

In line with UCT's Faculty of Health Sciences Human Research Ethics Committee's recommendations in reducing the risk of COVID-19 transmission during studies involving humans, the study abided with the regulations and practices needed to prevent transmission.

The study did not encourage persons to come to the CHC, but recruited clients that came on their own account. The focus group discussion of Phase 2 was done when the risk of transmission was low, after the state of disaster was lifted by the government of South Africa on 4 April 2022.

5.10.1. Screening for COVID-19 symptoms

Each person entering the CHC was screened for symptoms of COVID-19 and directed to the designated area if any symptoms were present. The screening tool contained contact details in case retrospective tracing needed to be done. The risk to the researcher and assistants were low as clients was screened already by the time they are approached for the study. Participants in Phase 2 was also screened for COVID-19 symptoms before participation.

5.10.2. Social Distancing

Social distancing at Eersterust CHC was enforced since March 2020 which ensured adequate spacing between the seats and queues throughout. The recruitment of participants took place where they were distancing from other clients in the administration blocks with the researcher and assistants that kept their distance on approaching them for participation. In Phase 2 of the study, spacing was also attended to and participants sat in a well-ventilated room suitable for the number of people present.

5.10.3. Face masks

The use of face masks was not mandatory by the time of data collection. If participants wished to use face masks for their own protection, they were free to be used, especially since the mandatory use of facial masks were only recently lifted.

5.10.4. Hand washing and sanitising.

Sanitising remains at the centre of preventing the spread of COVID-19 and other infections. On entering the premises everyone's hands were sanitised. The researcher and assistants each had hand `sanitiser to sanitise themselves as well as the participants hands before handing a cleaned pen to sign the paper-based consent. Due to the assisted questionnaire procedure, the participants did not need to touch any other surfaces.

6. RESULTS

6.1. Phase 1

This chapter provides all the results obtained in the quantitative phase of the study. The results are given in three parts: Part 1 gives the demographic data, Part 2 includes all the responses on the completed questionnaires and results of certain cross tabulations, and Part 3 is the results of the willingness of participants to be included in the qualitative phase of the study.

6.1.1. PART 1 Demographic data

Part 1 of the tool (Appendix B) collected demographic information namely gender, age, religion, and beliefs. Most participants were female (n = 258; 64.7%), between 50 and 59 years old (n = 102; 25.6%) and Christian (n = 364; 91.2%).

Table 1: Demographic information

		n	%
Total		399	
Gender	Male	141	35.3
	Female	258	64.7
Age	20-29	50	12.5
	30-39	78	19.5
	40-49	66	16.5
	50-59	102	25.6
	60-69	76	19.0
	70-79	24	6.0
	>80	3	0.8
Religion	Christian	364	91.2
	Muslim	7	1.8
	Other	5	1.2
	None	23	5.8
Beliefs	Ancestral	113	28.3
	None	286	71.7

6.1.2. PART 2

Part 2 consists of the questionnaire collected data concerning loss, during the COVID-19 lockdown period and the results of certain cross tabulations.

Questionnaire data

Hundred and six of the participants (26.6%) experienced loss between 1 March 2020 and 31 August 2021. If the participant had not experienced any losses during this period, the other question that needed to be answered by all participants was regarding their knowledge of the availability of bereavement counselling at Eersterust CHC. The majority of the participants (74%) (n = 295) did not know if counselling was offered at the facility, with only 19% (n = 76) being aware of such a service and 7% (n = 28) responding that no such service exists.

Further elaboration on the losses with regards to how many losses experienced, what the participant's relation was to the deceased, and when the losses occurred within the COVID-19 pandemic is detailed in Table 2. Of the close relationships, siblings were lost most (n = 39; 30%), followed by parents (n = 21; 16.2%). In the relationship category defined as 'Other', friends accounted for the most losses (n = 9, 20.4%). Thirty percent (n = 39) of losses occurred during the Lockdown level 3, followed by Adjusted level 1, where 20.8% (n = 27) of losses occurred. The lockdown levels with their corresponding dates and length of implementation can be found in Appendix H, at the end of the study document.

Table 2: Detail of losses.

	Response	n	%
Experienced loss	Yes	106	26.6
	No	293	73.4
Multiple losses	Yes	22	20.8
	No	84	79.2
Number of multiple losses	2 losses	20	90.9
	3 losses	2	9.1
Relationship with person lost	Parent	21	16.2
	Child	7	5.4
	Sibling	39	30.0
	Spouse	8	6.1

	Response	n	%
	Other	55	42.3
Defining other relationships	Aunt/Uncle	7	15.9
	Boyfriend	1	2.3
	Brother-in-law	3	6.8
	Cousin	7	15.9
	Cousin's child	2	4.6
	Grandchild	1	2.3
	Parent-in-law	2	4.6
	Friend	9	20.4
	Future child-in-law	1	2.3
	Grandparent	8	18.1
	Grandparent-in-law	1	2.3
	Niece	2	4.5
Relationship with multiple losses	Parent	3	14.0
	Child	1	4.5
	Sibling	7	32.0
	Brother-in-law	1	4.5
	Cousin	2	9.1
	Cousin's child	1	4.5
	Daughter-in-law	1	4.5
	Father-in-law	1	4.5
	Friend	1	4.5
	Grandfather-in-law	1	4.5
	Grandmother	1	4.5
	Great grandmother	1	4.5
	Uncle	1	4.5
Lockdown level at time of loss (Also see Appendix H)	Level 1	9	6.9
	Adjusted level 1	27	20.8
	Level 2	7	5.4
	Adjusted level 2	1	0.77
	Level 3	39	30.0
	Adjusted level 3	23	17.7
	Level 4	5	3.8
	Adjusted level 4	11	8.5
	Level 5	8	6.1

Table 3 displays further results pertaining COVID-19's impact on the losses. Losses directly related to COVID-19 accounted for 39.2% of losses, 53.8% of losses were sudden or unexpected, and 65.4% of participants did not have time to greet their loved one. A total of 80 (61.5%) loved ones were admitted to hospital before their passing, with 70% of participants indicated that hospital visits were not allowed; 18.7% said adequate information about the condition of their loved one was not

communicated, whilst 32.5% were partly informed. Other ways of communication were used by 27.5% of participants when visiting were not possible.

Interprovincial and international travel restrictions limited 12.3% of participants in greeting their loved one and 10.8% in attending the funeral. Overall, 82.3% could attend the funeral, 76.2% in-person and 6.1% online. The usual custom of body viewing was found to be 92.5% among the participants, whilst this custom could only be implemented to some extent in 34.5% of funeral services during the study period. Funerals changed a lot according to 53.1% of participants due to COVID-19 rules, whilst 10.7% did not notice any changes. The ability to provide help with funeral arrangements was limited; 48.8% could still help as much as they wanted to, 15.4% could help less than they wanted to, whilst 27.7% could not help at all, although they wanted to.

Support received during the loss felt to be inadequate for 44.6% of participants. If the loss did not occur due to COVID-19, 88.6% still felt their loss to be important. The need for current emotional support were indicated by 18.5% of participants needing to deal with the passing of their loved one.

Table 3: Results pertaining COVID-19 impact on greeting loved ones, customs, and funerals.

	Response	n	%
COVID related death	Yes	51	39.2
	No	79	60.8
Unexpected loss	Yes	70	53.8
	No	60	46.2
Time spent before passing	Yes	45	34.6
	No	85	65.4
Place of death	Hospital	80	61.5
	Home	45	34.6
	Care facility	1	0.8
	Other	4	3.1
Hospital visits allowed	Yes	9	11.3
	No	56	70.0
	Not able to visit	15	18.7
Kept informed about condition	Yes, sufficiently	39	48.8
	Yes, partly	26	32.5
	No	15	18.7
Alternative communication used	Yes	22	27.5
	No	50	62.5
	Not applicable	8	10.0

	Response	n	%
Travel restrictions preventing last visit before passing	Yes	16	12.3
	No	114	87.7
Able to attend funeral	Yes, in person	99	76.2
	Yes, online	8	6.1
	No	23	17.7
Travel restrictions affecting ability to attend funeral	Yes	14	10.8
	No	19	14.6
	Not applicable	97	74.6
Usual custom to view body	Yes, mostly	98	92.5
	Yes, sometimes	1	0.9
	No	7	6.6
Restrictions on viewing body	Yes	54	41.5
	No	45	34.6
	Not applicable	31	23.9
Changes to funerals	Yes, a lot	69	53.1
	Yes, somewhat	23	17.7
	No	14	10.7
	Did not attend	24	18.5
Support availability during loss	Yes	72	55.4
	No	58	44.6
Non-COVID loss, still felt important	Yes	70	88.6
	No	9	11.4
Ability to help with funeral arrangements	Yes, as much as wanted to	63	48.5
	Yes, less than wanted to	20	15.4
	No, not able to help	36	27.7
	No desire to help	11	8.4
In need of counselling	Yes	24	18.5
	No	106	81.5

The pandemic grief scale (PGS) was incorporated into the questionnaire to be answered by those who have experienced a loss during the study period (n = 106), and had questions regarding the participants thoughts, feelings, or behaviours during the past two weeks.

The responses (as seen in Table 4) were mostly “Not at all” (Scoring 0) ranging from 91.5% to 94.3% to the questions “I wish to die to be with my loved one”, “I have confusion over my role in life because of the loss”, “Nothing seems to matter because of the loss”, “Positive memories about the deceased are difficult”, and “Life is empty, meaningless, and not worth going on without the deceased”. “Several days” scored 1, “More than half the days” scored 2 and “Nearly every day” scored 3 points; a participant could obtain a maximal score of 15 for the PGS.

Table 4: Results of the pandemic grief scale questionnaire.

	Response	n	%
I wish to die to be with my loved one	Not at all	97	91.5
	Several days	8	7.5
	More than half the days	1	1
	Nearly every day	0	0
Confusion over my role in life because of the loss	Not at all	98	92.5
	Several days	7	6.6
	More than half the days	1	0.9
	Nearly every day	0	0.0
Nothing seems to matter because of the loss	Not at all	98	92.5
	Several days	5	4.7
	More than half the days	2	1.9
	Nearly every day	1	0.9
Positive memories about the deceased are difficult	Not at all	99	93.4
	Several days	5	4.7
	More than half the days	1	0.95
	Nearly every day	1	0.95
Life is empty, meaningless, and not worth going on without the deceased	Not at all	100	94.3
	Several days	4	3.8
	More than half the days	2	1.9
	Nearly every day	0	0.0

The scores achieved by the participants are noted in Table 5. Two participants scored 7 or more points, which is regarded as complicated grief on the scale. The complicated grief incidence for the study was found to be 1.9%. The mean score obtained was 0.5 (SD = 1.4).

Table 5: Scores on pandemic grief scale (PGS)

Score	n	%
0	89	84.0
1	7	6.6
2	3	2.8
3	1	0.9
4	3	2.8
5	1	0.9
6	0	0
7	1	0.9
8	0	0
9	1	0.9
>9	0	0

Cross tabulations

The PGS that was used to establish if any participant suffered complicated grief yielded a low number of positive results (1.9%). Due to this low incidence, none of the other study questions showed statistically significant associations cross tabulated with this indicator for abnormal grief, although some associations are mentioned below.

The Pearson Chi-squared test of independence was performed to assess associations of certain pairs of categorical variables. Where the assumption of expected counts greater than 5 were violated in more than 20% of cells, the Fisher's exact test is reported. Cramer's V is reported as the measure of the strength of association (i.e., the effect size).

Significant associations found:

1. Sudden loss and limitations on hospital visits.

The association of an unexpected loss of a hospitalised loved one was cross tabulated with the limitations placed on hospital visits. It was found that unexpected losses were significantly associated with permission to visit loved ones such that a smaller proportion (n = 2; 4.65%) of those with an unexpected loss were allowed to visit compared to those who had a more anticipated or expected loss (n = 7; 18.92%). It also showed that a substantial proportion of in-patient losses experienced as unexpected were unable to visit their loved one (n = 14; 32.56%) compared to those who had a more anticipated or expected loss (n = 1; 2.7%) with $p < 0.001$. These results showed a moderate size effect with a Cramer's V of 0.4145.

2. Sudden loss and time spend with loved one.

Another association sought was how many expected and unexpected losses had time spend with their loved one prior to the passing, and if this resulted in differences in the need for counselling. With cross tabulation it was found that the association was statistically significant with $\chi2(1) = 14.3142$, $p < 0.001$ and Cramér's V = 0.3318. The proportion of persons that were able to spend time with their loved one were much larger in the group that expected the loss (n = 31; 51.67%) than the proportion

that did not expect the loss (n = 14; 20.0%). The H0 were rejected in favour of the alternative hypothesis (Ha).

The subsample that was not able to spend time with their loved one (n = 85) was considered for the next cross tabulation of expected and unexpected loss against the need for grief counselling. Need for counselling in the group of unexpected death was larger (n = 15; 26.79%) compared to the group of expected death (n = 3; 10.34%). Although not having a p-value below the 5% significance level, the result did show some association at a 10% level of significance with a small effect (p = 0.079, Cramér's V = 0.1908).

3. Changes experienced in funerals and support received.

A significant association was found with regards to funeral proceedings experienced to be very different from before and the amount of support received, (p = 0.023). Those that felt the funeral were very different also felt less supported (n = 29; 52.37%), whilst those that felt that the funeral was the same felt unsupported to a lesser extent (n = 2; 18.18%).

4. Religious groups and funeral customs.

The experiences participants from different religions had regarding the changes in funeral customs were evaluated and found to be statistically significant (p = 0.015), although having a Cramer's V of 0.2538 indicating a small effect. The various religious groups felt that their usual customs changed a lot (Christian, n = 52, 53.06%; Muslim, n = 3, 100%).

No significance found:

1. COVID-19 related loss and complicated grief / need for counselling.

The association of a COVID-19 related loss against the need for counselling and complicated grief was sought. The associations were not statistically significant, but what could be noted was that both individuals identified with complicated grief on the PGS experienced COVID-19 related losses, in contrast where none of the 65 participants without a COVID-19 related loss developed complicated grief. A slightly larger proportion of individuals that experienced a COVID-19 related loss needed

counselling (n = 9; 21.95%) compared to individuals that did not experience a COVID-19 related loss and needed counselling (n = 11; 16.92%).

2. Age and amount of support received / need for counselling.

The different age groups and the amount of support received were cross tabulated, as well as the different age groups with the need for counselling. The two age groups that experienced the least support during their grieving period compared to previous losses were the 50- to 59-year-old group (n = 19; 61.29%) and 30- to 39-year-old group (n = 9; 52.94%). Only a small proportion of these age groups needed grief counselling (50- to 59-year-old group (n = 7; 22.58%) and (30-to 39-year-old group (n = 3; 17.65%)). The age group with the most need for grief counselling was the 40- to 49-year-old group (n = 4; 33.33%). These cross tabulations were not statistically significant with p = 0.223 (age vs lack of support) and p = 0.717 (age vs counselling needed).

3. Complicated grief and closeness of loved one.

Although not statistically significant at the 5% significance level, some association of the closeness of the loved one and the complicated grief incidence was seen with a p = 0.075 and a Cramér's V of 0.3118 (moderate size effect). The two participants that displayed complicated grief in the study had both lost their parents showing an association to losing parents compared to losing other relatives.

4. Sudden inpatient loss and need for counselling.

There were also no association between having an unexpected inpatient loss and the need for counselling (p = 0.117). Although a larger proportion (n = 12; 27.91%) of unexpected losses needed counselling than those with expected losses (n = 5; 13.51%), the H0 was not rejected and most participants in both groups did not need counselling (unexpected (n = 31; 72.09%) and expected (n = 32; 86.49%)).

5. Kept informed by hospital and need for counselling.

Similar proportions of participants required counselling across the three levels of being kept informed of their loved ones' condition in-hospital, namely sufficiently informed (n = 7; 17.95%), partly

informed (n = 7, 26.92%) and not informed (n = 3; 20%). The results showed no association between being kept up to date by the hospital and the need for grief counselling (p = 0.681) or abnormal grieving (p = 1).

6. Alternative ways to make contact in-hospital or online funeral attendance and need for counselling.

No statistically significant associations were found for the association to see if alternative ways to make contact with loved ones in-hospital or funerals attendance online made a difference in the struggle with grief, compared to those who did not make contact with loved ones and did not attend the funeral in any way (p = 0.931). A larger proportion of cases that were able to make contact in other ways, needed counselling (n = 5; 22.73%) compared to cases that were not able to make contact in other ways (n = 10; 20%). A higher incidence of complicated grief was also not associated with the usage of alternate ways to make contact (p =0.375).

7. Attendance of funerals and need for counselling.

Attendance of funerals in person or by online platforms was cross tabulated with the need for counselling and the incidence of complicated grief. The results showed that the H0 cannot be rejected in favour of the alternative hypothesis (Ha) as p = 0.259 for the association of funeral attendance and the need for counselling. Although this is true, it was found that none of those who attended an online funeral service needed counselling (0%), whilst those that attended in-person, a small proportion needed counselling (n = 18; 18.18%) and a larger proportion of those not attending a funeral in anyway needed counselling (n = 6; 26.09%), albeit not statistically significant. Indications of complicated grief showed no association with funeral attendance (p = 1.00). The two cases that displayed complicated grief both attended the funerals in person.

8. Travel restrictions and not able to greet.

Although interprovincial and international travel restrictions made it difficult to greet a loved one before their passing or attend the funeral, it did not lead to an increased need for counselling (P values 0.719 and 0.866, respectively). The two participants identified with complicated grief did not

experience limitations in travel to see their loved one before passing and were both able to attend their loved one's funeral.

9. Help provided at funeral and need for counselling.

A cross tabulation between being able to assist with funeral arrangements and the need for counselling were not found to be statistically significant (p = 0.357). Those that felt they would have liked to be more involved in the funeral and needed to have counselling (n=8; 27.59%) were a larger proportion than those who were able to help at the funeral and needed to have counselling (n = 6; 12%). The two participants that were identified with complicated grief had participated less in the funeral proceedings than they wanted to. The one participant helped less than would have wanted and the other could not help with funeral arrangements at all.

10. Other associations sought.

Associations sought but found not to be significant were that those with multiple losses (n = 4; 18.2%) did not struggle more with their grieving process than those with a single loss (n = 16; 19.1%; p = 0.926); and that the level of lockdown in which a loved one passed away did not affect the severity of the grief to lead to the need for counselling (p = 0.587).

Restrictions prohibiting the usual custom to view the body affected 41.33% (n = 31) of participants, whilst 58.67% (n = 44) of those used to viewing the body was able to view, be it with certain restrictions.

6.1.3. PART 3

Part 3 of the questionnaire established if the participants who lost a loved one were willing to participate in a group discussion and thereby take part in Phase 2 of the study. N = 47 (44.3%) were willing to be contacted, whilst n = 59 (55.7%) did not give their consent to be contacted again.

6.2. Phase 2

Phase 2 results were obtained from:

- Three individual interviews
- One group discussion (with 2 participants)
- Qualitative data from 83 questionnaires obtained from Phase 1

Data saturation was reached with the interviews, discussions and comments from questionnaires obtained when no additional themes or insights emerged from the data obtained. Two individual interviews were conducted in English, whilst the group discussion and other interview was conducted in Afrikaans as per the participants requests.

6.2.1. PART 1 Interviews and group discussion

Interview participants demographics

The interview participants were allocated numerical identification numbers (2-1 to 2-5). All participants were female and Christian, two had ancestral spiritual beliefs (2-4; 2-5), and their ages varied from 24 years (2-2) to 62 years (2-5) of age.

Interview and focus group participants' background.

Participant 2-1 lost her nephew whom she raised as her own son in March 2021, due to complications of substance abuse. He passed away in hospital and she were able to spend time with him before he passed on, the hospital enabled them to go and greet him a final time.

Participant 2-2 lost both her parents-in-law in 2021, but only her father-in-law within the study period (in January 2021). It was a sudden, unexpected death due to a myocardial infarction, diagnosed at the time of passing in the resuscitation area of a crowded private Emergency unit. She did not manage to say her final goodbyes.

Participant 2-3 lost her sister (due to cancer) in September 2020, her nephew (due to COVID-pneumonia) and her daughter's fiancée (due to an overdose on a substance) on the same day in June 2021. All three losses were unexpected, as her sister's cancer diagnosis was hidden from the family. She did not manage to greet any of her loved ones at the end.

Participant 2-4 lost 3 siblings, a sister-in-law, and a close family friend in July 2020 all due to COVID-19 which they contracted at a funeral they all attended together. She was also very sick due to

COVID-19 during this time and was in isolation whilst hearing of each one's passing and thus not able to greet them. She planned a memorial service at their church a year from their passing.

Participant 2-5 lost her husband due to COVID-19 in December 2020, on the day he was due to go on pension as a hospital ordinary worker. He was admitted to ICU, but the family was allowed access to greet him before his passing.

6.2.2. PART 2 Qualitative data from questionnaires

Qualitative contributions to this phase of the study were also obtained from eight questions in Phase 1 of the study. The comments were written down verbatim on the research questionnaire at the time of being administered by the research assistants:

Table 6: Qualitative data from Phase 1

Questionnaires with Qualitative data (n = 83)	
Question in Phase 1	Number of comments in NVIVO
Q10: If your loved one passed away in hospital, were you kept up to date about their condition?	23
Q12: Did cross-provincial travel restrictions prevent you from seeing your loved one soon before their passing?	8
Q14: Did cross-provincial travel restrictions prevent you from attending the funeral of your loved one?	10
Q16: Was it possible to have the body at home or view it at the funeral home?	12
Q17: How were the funeral proceedings different compared to your usual customs?	67
Q18: Did you get as much support from your friends and family as compared to previous losses?	24
Q19: Did you feel your loss was still as important if the loss was not due to COVID-19 in this COVID-pandemic?	3
Q22: Do you currently need emotional support to deal with the loss of your loved one?	18

6.2.3. PART 3 Themes

Thematic content was identified from the semi-structured interviews and comments. A list of key themes and sub-themes emerging from the transcribed discussions were constructed, creating the *Thematic index*. The themes and subthemes that became apparent were:

Table 7: Themes and subthemes

Theme	Subthemes
1. Hospitalised loved one	1.1. Communication 1.2. Visiting inpatients
2. Saying goodbye	
3. Travel	
4. Coping	4.1. Blaming COVID 4.2. Unexpectedness 4.3. Aggravating factors 4.4. Belief system 4.5. Seeking help
5. Funeral	5.1. COVID rules (Social distance, Customs, Time limitations, Number restrictions) 5.2. Support (Social and emotional, Financial)

Theme 1: Hospitalised loved one.

During the pandemic many participants had to deal with their loved ones being admitted to hospital before their passing. Obtaining information about their condition from the hospital were challenging and visiting them without formal hospital visiting hours even more so.

1.1 Communication

The health facilities' ability to communicate with family members were not perceived to be completely honest to some participants, leaving them unprepared when hearing of their loved one's deterioration and passing. Even if kept up to date with the condition of their loved one, the information was not always truthful as the person was often sicker than was broad across on the phone calls by the hospital personnel.

"I was shocked when she passed, as I was told she was doing better." (PIN 208)

"To some extent I was angry at the whole medical team, for I thought they could have said to me, for every time I spoke to someone, they said she is okay, she is okay, but I felt they didn't speak the truth." (2-3)

Close family often felt adequately informed by the hospital, but friends and other family members did not have access to the updates. The obstruction in communication was poor passing of information from close family members to others and not keeping close friends in the loop too. Close friends were left out from communication during the period of illness as well as excluded from funerals when families decided on who could attend limited-numbered services.

"Kept very well up to date." (PIN 173)

"The hospital only responded to requests." (PIN 197)

"Family didn't share information with friends." (PIN 368)

"They only called the person who took him to the hospital, he was informed every day." (2-4)

1.2 Visiting inpatients

Hospital visiting hours were cancelled, which made access to hospitalised loved ones very difficult during COVID-19.

"I tried visiting the first one, but no one was allowed. Then I started calling, I couldn't go to hospital." (2-4)

Exceptions were made when patients deteriorated, as some of the participants did get an opportunity to visit and greet their loved one.

Depending on the level of lockdown or the enforcement of the rules at the particular facility, some participants managed to visit their loved ones and followed them to their different locations within the hospital.

"*The next morning something told me I should go early. When I got there at 6am, I told them I want to go in now... The previous evening, I called, and they confirmed that she had a bed, she is in a ward, but they couldn't tell me where…, when I got there, I still found her in casualties. Then I did what I could and eventually they got a bed." … That was the Tuesday, then the Wednesday, I visited again*." (2-3)

Theme 2: Saying last goodbyes.

The opportunity to greet sick loved ones were hampered by the pandemic. On deterioration in hospital the participants gave accounts where they were contacted and given the opportunity to see their loved one.

"…our dad he write down, they give him a paper and he write down, and they took out the pipe and he say he loves us and he miss us, it was the last words we heard him talk." (2-5)

Others passed away during the height of waves of COVID-19 infection with very strict regulations in place, where no exceptions were made to greet the dying person. In the case of one particular participant (2-4) she was bound to isolation at home due to COVID-19 infection herself.

"No one could go there close to the end to say goodbye. That, and that alone, is killing me. For all of them, the five of them, that is killing me, just to say goodbye…." (2-4)

"I could not greet them, as I was also positive." (2-4)

The challenge was not only to greet the hospitalised loved ones before their passing, but also to get the family together and spend time with the body after passing as per cultural customs. These customs needed to give way to new protocols aimed at limiting the spread of COVID-19.

"The funeral undertakers needed to be called straight away to come and fetch the body immediately due to severity of COVID." (2-2)

"…… like before, the day with our son he passed in hospital. Usually at hospital they gave each one a chance to come in and look, two or three persons at a time, that was not possible now, you could not call everyone to come." (2-1)

Theme 3: Travel

Travel restrictions affected anyone wanting to travel out of their 'current' province and country during lockdown. The exact restrictions being dependant on the level enforced at that time. Those needing to

travel to visit their dying loved one or attend their funeral had several obstacles to face. Permits, COVID-19 tests, and affordable transportation were not easy to arrange. These challenges mostly affected those who lost family in our neighbouring countries such as Zimbabwe, Namibia, and Mozambique. As if these mentioned obstacles were not challenging enough, several participants also alluded to their fear of the authorities that also influenced their decision not to attend funerals in their home countries.

"We must bury John[1] here, we can't take John to Venda, you see the COVID time." (2-5)

"…but needed to obtain permits, COVID test, and it was scary to travel with police stops." (PIN 50)

"Finances made it difficult to travel to Zimbabwe." (PIN 154)

Theme 4: Coping

The inability to accept the circumstances of the loss presented as obstacles to move on from the loss for many of the participants. The obstacles to coping were 'blaming' COVID, being unprepared for the suddenness of the losses and other aggravating factors unique to the pandemic.

4.1 Blaming COVID

As a new entity creating havoc in the lives of many, COVID was blamed for many things. In the context of this grieving study, it was found that when COVID-19 or consequences related to its regulations were given as a reason for a problem, it alluded that the participant has not yet completely coped with the loss of their loved one.

One such problematic situation COVID-regulations created, was that a non-COVID ambulance wanted a COVID-test before attending to a call, causing a delay in getting medical attention. That experience aggravated participant 2-3's trauma of her sister's last illness. COVID made it more difficult to get anyone to hospital, despite the illness they might have had.

[1] Pseudonym used.

"My sister became sick, her daughter phoned me, they phoned the ambulance. The ambulance refused to take her, they first needed a COVID test, then we took her with own car to private hospital." (2-3)

Persons working in the healthcare setting were at higher risk to contract COVID-19. There were specific guidelines to protect high-risk individuals (those with chronic illness and more advanced age) working in healthcare from working directly with possible contaminants. By the time participant 2-5's husband aged 64 contracted COVID-19, he was taken back to his usual post in Infection Control (out of the safer pharmacy) due to staff shortages (leaves over December), shortly before he was to go on pension.

"Because if maybe it was not for COVID he would be still alive now." (2-5)

"Angry at the disease for taking him but also that he was placed in a high-risk area when he was not supposed to be there, you can almost feel you want to blame the hospital. Yes, for he was drinking the tablets for high blood, he was just to go on to pension he was sixty-four, they took him there to work in a dangerous place." (2-5)

Participants felt that COVID took a lot away from them. The regulations were enforced on all, even if the deaths were not related to COVID-19. This made participants feel robbed of the sanctity period after their loved one's passing, not being able to do all the usual things they would have done, if it was not for COVID.

"Something that was also very cold to me in that Corona-time was that even though he did not pass from Corona, you still had to make your arrangements accordingly, …., you were limited with your things. So, Corona took a lot a lot from us, it took from life itself, the things you are used to, like having the whole family at the funeral, having everyone with you, to be with you, to mourn with you to comfort you…" (2-2)

COVID also left long lasting effects of fear. Even after the national state of disaster was lifted and the use of face masks no longer enforced, the lingering fear of its devastation still keep this participant from moving on in her everyday life.

"At the moment I am not okay with COVID. I am still scared." (2-3)

4.2 Unexpectedness

COVID-19 came with a rapid onset of symptoms and sometimes unexpected deterioration in certain cases, leaving very little time for the loved ones to be prepared for losing the person. The unexpectedness of their loss was a topic that was explored with the participants; someone could be fine one moment and much worse a moment later. Preparing for such a scenario is not possible, especially at the start of the pandemic before the characteristics of the virus were fully known.

"The first one was sick for a week, the other two was sick for days, the other two were also sick for less than 5 days." (2-4)

"…but no one was seeing he's got COVID, …, I saw the fire on the chest I said John, John*! …, you are not okay, are you okay? I was afraid. He said '*jam*', I am just feeling hot…... When he came back, he said Sarah*[2]*, you can't believe, I never pick up even something, but I am so tired, I doesn't know why. Now I say marra this thing was hiding, … you know death when it's coming, he makes your brain becoming stupid, …. I told him lovey, let me take you to the doctor, he said no tomorrow I will be better, but tomorrow he was worse …."* (2-5)

Participants that lost loved ones unexpectedly but not due to COVID-19, also struggled to cope with their loss. Compounding factors were multiple losses within a short period and the limited or half-true communication from healthcare providers working with their admitted loved ones.

"But I didn't expect that she will die, I thought perhaps it was Influenza or so." (2-3)

"In my mind I thought all is still okay, she is not going to pass, she is now at the hospital, and I got the doctor and the doctor put an IV in and said her vitals were okay." (2-3)

"It was the same with my sister's son, I still saw him, I only left morning hours from the hospital, he was in the COVID tent, I knew there was medical help, I was reassured. And I was still dealing with

[2] Pseudonym used.

his things at the hospital when I got the message, my future son-in-law was lying at the shop dead." (2-3)

"It still bothers me, they told me he will be okay, you can go home Ma'am, then not even half an hour then he is gone. I don't know why this happens, but I know there is a lot of pressure on the medical personnel." (2-3)

4.3 Aggravating factors

Each participant shared the detail of the circumstances in which their loved ones passed away and how the lockdown regulations of COVID-19 affected their experience. Some had more traumatising events than others, and certain of these events can be seen as aggravating factors leading to their inability to cope with their loved one's death.

Family dispute regarding bringing in alternative medication and ventilation, with subsequent passing of the loved one, can lead to feelings of anger or regret, which impedes one's coping with the loss.

"Our family disagreed on going on ventilator and bringing Ivermectin into hospital." (PIN 137)

Participant 2-5 shared several aggravating factors that may impede her ability to move on from her husband's death, namely, that he was not supposed to have worked in a high-risk department of the hospital; that the rules set for a notice month was unfair in her husband's case; that the doctors working in her husband's vicinity where not attentive enough; the possibility that the doctor that was caring for him on 31 December was intoxicated; and the unfairness of dying on the day you are supposed to have gone on pension.

"I say:' John what your boss make you do?', he was working Infection Control before; 'He take you again to that job? Ramaphosa said people of 65 they must stay because they are target, …they took you to the chemist, now they took you back?'" (2-5)

"They said he haven't got leave or a sick leave because they say it is the law because he was going for the pension, marra there were few doctors at hospital and every morning they would greet him, but no one was seeing he's got COVID." (2-5)

"The thing that makes my heart very sad, I hear that the doctor was making a mistake, by the 31st, seven of the people died, it looks like he was drinking or what?" (2-5)

"That day he was supposed to get the pension he passed away, after being two weeks in hospital." (2-5)

Life also continued whilst needing to deal with the loss of a close loved one. Participant 2-3 needed to stop helping with funeral arrangements of her sister to support her daughter with other life-changing news.

"In that time, when my sister passed, … I got another shock, my daughter was at the clinic, she called me and needed me to come to her, I said I can't, we are busy with the funeral arrangements, but I came ….and I got another shock: she had HIV, then I just shut down…I had to give her my support and I withdraw from the funeral arrangements." (2-3)

Participant 2-4 was very weak and in isolation from COVID-19 herself with her loved ones worried that she will also not survive the illness like the other five family members in the same period. Hearing her family talk of their passing, when they did not know she could hear them, and hearing them telling each other how they think she will not make it, is still traumatising her.

"And ah… I was helpless, I could not say, "please, what are you saying?", I could hear them…, I was quiet in my bed. I only discussed this so much with my twin sister four months after, 'I could hear you, when you said my brothers and sisters has passed on and I must not know', she said: 'Did you hear me?' I said: 'I heard you from the first one to the last one, and I heard you when you told our brothers that if they don't come today, they would not find me the next day'." (2-4)

Talking about their loss, participants were also keen to share how they managed to cope with their feelings of loss and despair. Spiritual anchoring has been a way to cope for many, others had comfort

in seeking help and one participant planned a memorial service for her loved ones a year from their passing.

4.4 Belief system

Religious and spiritual beliefs were important to all participants in Phase 2 of the study. All interview participants were Christian and especially participants 2-4 and 2-5 expressed their faith to have been the reason why they managed to cope thus far. Their belief system helped them to come to terms to why they lost their loved ones.

"I told myself if it was not the purpose of God, my husband would survive, he never passed on due to the carelessness of the doctor, but he passed because God, He know the time." (2-5)

"Even now, it is not the life, it is not 100%, it is only that I am a believer." (2-5)

The church provides them the space and opportunity to talk to others regarding their pain, thereby working through their trauma towards coping and healing.

"When I talk to the people, I feel a little bit better, in the church." (2-5)

Participant 2-4 is also drawing on her religion when she says that she survived the illness for a reason. She found a way to honour those that lost their lives, whilst she will get an opportunity to greet them through a memorial service.

"I thought only a professional could help me, not anyone, …we were together at the same funeral before I became sick. Even now every day when I pray, I say: 'God, I thank you, please show me the work I must do for them, because I believe you didn't save me for nothing'." (2-4)

"In my culture and religion, a funeral is very important, in fact, a day before this 6th of August I want to visit their gravesite – it will be the first time, just to say bye-bye to all of them." (2-4)

4.5 Seeking help

Some participants from the interviews and qualitative data of Phase 1 have already sought help by means of counselling.

"I am seeing the psychologist on the 18th and started on an antidepressant last week. I did tell the nurses I am worried about my memory, and they referred me. I thought perhaps I am depressed, as the children are saying, 'Mommy is not doing what you should be doing, the children are afraid to come close to you'. Sister taken me to the doctor and that is how I am now going to see the psychologist." (2-3)

"I did go for counselling," (PIN 222) and *"I am currently seeing a psychologist."* (PIN 347)

Others found informal support by talking to their friends and family also helpful to deal with their loss.

"They say to me I must stop always when I saw the people, talking how much pain I have with John I mustn't talk, it is passed, it is passed I mustn't talk, I say: "when I talk, I feel healed when I talk about what happened, really I feel better"." (2-5)

Participant 2-4 is also providing support to other bereaved by staying in touch despite their different outlook on their experiences. Talking to other bereaved helped her to realise that not being able to attend the funerals did not necessarily cause a worsened outcome for herself.

"That woman, she can't be all right even today, I speak to her almost every single day on the phone, she says: "Lizzy[3]*, I think yours is worse, because you couldn't even bury them". I said to her: "You saw their burials, but you are also crying about what you saw, so, there is no difference my friend"."* (2-4)

[3] Pseudonym used.

Theme 5: Funeral

Lock down regulations aimed at funerals affected many bereaved. Grieving whilst taking new rules in account left mourners feeling emotionally cold and less supported.

5.1 COVID rules

5.1.1 Social distance:

Social distance is contrary to what is needed by those who lost someone they loved. The bereaved needs closeness, hugs, and community. Participants mentioned how little comfort they got when needing to keep their distance due to COVID-19 rules. A recurrent comment was that the funeral events had a cold atmosphere and left the attendants 'cold'.

"No hugs, little comfort." (PIN 12) and *"Difficult not to touch each other."* (PIN 155)

"Herch stood outside the house, no one were allowed to go close to the grave." (PIN 370)

"Cold funeral, not very engaging, had people standing in street and body drove by…." (PIN 101)

5.1.2 Customs:

Customs surrounding death in a family are part of all cultures; the aim is usually to honour the deceased by showing respect to them and their loved ones. Many rules during lockdown inhibited the customs to such an extent that the ceremonies lost their intended purpose.

Spending time with the body right after the passing of the loved one, was not possible by rushed calling of the funeral undertakers and family that could not all come together.

"Usually at hospital they gave each one a chance to come in and look, two or three persons at a time, that was not possible now, you could not call everyone to come." (2-1)

Having the body at the house or viewing the body at the funeral home was also restricted, participants felt unsure it the correct person was buried.

"The funeral undertakers did not give option to see body." (PIN 156)

"Was a very cold funeral, no closure from it, not being sure who was in the coffin and who was buried." (PIN 163)

An alternative offered was that the body could be driven past the house whilst everyone would stand in the street, the gesture thoughtful, but still cold. The choice between having a burial or a cremation felt constrained; some participants mentioned they were pushed towards having their loved ones cremated.

"… not very engaging, had people standing in street and body drove by, were advised to cremate despite wanted to bury him." (PIN 101)

Family could not start closing the grave themselves, as is part of many families' customs.

"Undertaker pushed the ground over the coffin." (PIN 47)

The services to honour the deceased and support the bereaved were in some cases not held at all, such as pre-funeral memorials and after-tears functions; church services were replaced by short functions at the grave site, if at all allowed.

"No memorials the week leading up to the funeral." (PIN 56)

"Cremated without family present, no service held at church or at the graveyard." (PIN 374)

"Only able to go to the graveyard, tradition to fellowship together after the service was a loss, to not be able to eat and drink together, very cold funeral, takeaway meals." (PIN 176)

Traditional customs like slaughtering cattle to provide food for all the attendants whilst celebrating the deceased were not allowed.

"We were unable to slaughter a cow and praise him according to the culture. The meat would have gone to waste." (PIN 41)

Although strict and many regulations were in place for a long period, some of the participants felt that the funerals they had for their loved ones still had the elements they needed to deal with their loss and make their event meaningful.

"Cremation was done, as aunt wished to have." (PIN 167)

"Rest of funeral was very much the same, the family could carry casket. Funeral was not that cold." (PIN 404)

"Funeral had all aspects they needed." (PIN 18)

Other participants acknowledged that the regulations were simply ignored, or exceptions were allowed by the local authorities. This tendency was more commonly mentioned by participants who had funerals held in rural areas as well as when more well-known community members passed on.

"It was just the same as other funerals, it was in the rural area called Seskororo." (PIN 4)

"Funeral was in the Northern Cape, not that much different than before COVID." (PIN 174)

"Despite the regulations, more people attended, it was a ZCC funeral." (PIN 97)

"He was well known in the community, thus still had very many visitors, despite the rules." (PIN 52)

5.1.3 Time limitations:

Lockdown rules for funerals limited people from spending time together, in order to prevent spread of the virus. Participants experienced limits on the time they could spend together as 'hurried family time', providing little comfort. These restraints were not just for COVID-19 related deaths as it affected most funerals.

"Very short at home, very short at gravesite." (PIN 78)

"…even though he did not pass from Corona, you still had to make your arrangements accordingly, you had to have a certain number of people, you don't know who to choose, …, everyone couldn't go to the church, you were limited …. So, Corona took a lot a lot from us, it took from life itself, the things you are used to, like having the whole family at the funeral, having everyone with you, to be with you, to mourn with you, to comfort you…" (2-2)

"Could not catch up on family time." (PIN 16)

"…they pushed us to have the funeral within a certain time, it didn't really give you time to cry. 30min at home, 30min in church, 30min at grave site, nothing longer than that. Then the family had to leave immediately thereafter…." (2-2)

5.1.4 Number restrictions*:*

Restrictions on the number of attendees at funerals differed depending on the level of the lockdown. The smaller number of attendees meant less extended family and friends attending. Those needing to choose who can come and who should be excluded where particularly stressed by that responsibility. Friends felt left out, as some of them were closer to the deceased than some family members that were allowed to attend.

"Too few people could attend and only family," (PIN 86) and *"was hurting that everyone could not be there."* (PIN 230)

"Because we are a large family, we are 7 children, we all had kids with kids and very large family. So, who do you restrict as only 50 people could go to the funeral, so how do you say who can be at the funeral and who cannot?" (2-3)

"Support was less, if you are used to the coloured community, when we cater for a funeral, it is usually about a 1000 people, now for Corona you had to cater for 50 people. 50 people is basically

just your sister and her children, your brother, and his children, that was not the broader family." (2-1)

Another factor causing anxiety were police presence at the funerals overseeing if the regulations such as quotas, were followed.

"The Police was counting the people and enforcing the rules." (PIN 139)

Not only did the rules prohibit many people gathering, but food would also have been too much if the rituals involving animals were followed through during lock down.

"We were unable to slaughter a cow and praise him according to the culture. The meat would have gone to waste." (PIN 41)

"Only 25-50 people allowed, had to send some away, no catering or venue needed." (PIN 325)

5.2 Support

5.2.1 Social and emotional

Participants noticed a change in the amount and expression of social and emotional support. The lack of physical touch and inability of the whole family to travel to be with them isolated many.

"Restrictions prevented adequate support." (PIN 20)

"No hugs, little comfort." (PIN 12)

Some of the participants expressed a bitterness in the way they remember their support, that only a few friends are true, and that other people did not even notice their loss.

"Now we know who the real caring friends are." (PIN 51)

"People were dying like flies; nobody was worrying about your loss." (PIN 368)

When the losses were due to COVID-19 the support were experienced as even less. The possibility was real that the infection could be spread at that funeral, but the participants also felt stigmatised and thereby also received less emotional support.

"The other thing that is killing me is, my blood sisters and brothers could not attend that funeral, cause I was also lying there, they were afraid to go." (2-4)

"Had less support due to the death caused by COVID." (PIN 56)

Funerals were coined "super spreader events" by authorities and this lead to reduced attendance in general despite limitations on numbers. Reasons given to families for not attending funerals for deaths caused by any reason were often fear of infection. Current COVID-19 infection and self-isolation periods also kept many away from funerals they would have usually attended.

"People told us straight: "We are afraid to come, you know it is Corona"." (2-2)

"With us personally we got a lot more messages, "sorry to hear of the loss at home, but you know it is corona" or "we had corona in the house"." (2-1)

"Do you think we wanted to go to those people's houses? Although you feel you are supposed to be there? Those that were your neighbour's, and they were actually close to you." (2-2)

Some of the bereaved participants expressed their respect and understanding for those choosing not to come out to funerals during the pandemic.

"For the support of my loss the people only called, no one came to visit me, even my own children. People were afraid for this bad disease. I didn't feel bad about my own sister or children not coming to my house. I said: "We cannot all die"." (2-4)

"But if you consider the circumstances in that time and all the cases of COVID, you didn't want to expose people to a lot of others, that also came to sympathise, you had to understand if someone wasn't comfortable to come. I could understand that, going through COVID myself, I could understand." (2-2)

Certain participants expressed that they were not able to provide as much support as they would have wanted to give.

"I was in bed during all of their funerals, I couldn't walk. I should have run their funerals." (2-4)

"I wanted to provide more support." (PIN 13)

Support received was expressed as adequate by some participants, appreciating enough support from their family, friends, and congregation members. Support also came in innovative ways using technology such as to send supportive messages on digital platforms.

"My son's friends did support me very well." (PIN 159)

"Church, pastor, even now still supporting me." (PIN 404)

"The church and spiritual community supported a lot, made use of Event Wall to get people's condolences posted. Eventwall.live on Facebook." (PIN 137)

5.2.2 Financial

The burden of funeral costs in most cultures in South Africa are shared by the larger family. They are dependent on the contribution of each member, but now not receiving this made the stress of paying for the funeral much more for the organising family members. With less people attending, less felt obliged to contribute.

"Financial contributions were also much less." (PIN 59)

"My brother came and helped me; they say I am going to pay them after ... You know our funerals is little bit expensive, we not just drinking tea and bread, we cook we buy the cow and the transport." (2-5)

The financial cost of traveling to their home countries prevented many of the foreign participants to support their families in person in event of a death at home. The participants also reported less emotional support for themselves when being isolated in South Africa after losing a loved one abroad.

"Finances made it difficult to travel to Zimbabwe." (PIN 154)

"Little support in SA, no family here." (PIN 72)

7. DISCUSSION

7.1. Introduction

The aim of this study was to explore how COVID-19 and the lockdown regulations had impacted on the grieving process of the public health care users of the Eersterust community. The objectives were to determine how many public health care users had experienced loss of a loved one during the COVID-19 pandemic, determine the changes that occurred in the social norms of grief and bereavement and how these changes affected members of the community. The objectives were explored by means of a mixed methods study conducted towards the end of the COVID-19 pandemic in South Africa. In this chapter the results will be discussed and reviewed against the available literature.

7.2. Prevalence of loss during the COVID-19 pandemic

7.2.1. Loss experienced by health care users during the COVID-19 pandemic.

Just more than a quarter (26.6%) of participants in this study had lost a loved one from any cause during the period of 1 March 2020 to 31 August 2021. During this period, South Africa's lockdown regulations, in various levels, were in place and was a source of distress for most South Africans. The Eersterust community did experience loss in the form of death of loved ones, but they also experienced loss in what the regulations took away from their ordinary lives: their routines and general practices.

With the CHC's actual headcount of 3891 during the 10-day data collection period, if the quarter of them left bereaved were to be calculated the number would amount to roughly 970 persons left bereaved during the 18-month period. Natural deaths occurred at a lower incidence before the pandemic (7), although the pre-pandemic prevalence of loss in this community is not known.

There is no data to extrapolate how many excess deaths there were in a specific community, but Eersterust facility did keep track of the known COVID-19 positive cases tested at the facility and their

outcome regarding mortality. It is expected that the results of loss can be extrapolated for the larger community of Eersterust due to the sample size calculated.

In this study, COVID-19 related deaths were reported as the cause of death in almost 40% of losses, and other causes of death thus contributed to the majority of losses during the height of the pandemic in this community.

7.2.2. Prolonged grief incidence

In order to be able to respond to the bereavement needs of the community, the study aimed to determine if abnormal grief or prolonged grief disorder (PGD) occurred at a higher incidence than before the pandemic. Though there is no specific data of the incidence of PGD specifically for the community of Eersterust and South Africa before the advent of COVID-19, several studies elsewhere in the world found that the incidence of PGD is around 7-10%, whilst about 23-30% of bereaved individuals need some kind of support or counselling (19, 20, 21, 22). The incidence of abnormal grief in the current study was found to be significantly lower than the studies mentioned in the literature review; only 1.9% of participants suffered from PGD using the pandemic grief scale (PGS) (27) as measuring instrument and only 18.5% of participants indicated a need for counselling, at least six months after their loss(es) occurred.

The study validates the PGS as a tool in a South African setting and use of it will improve the identification of those truly in need of bereavement therapy due to the COVID-19 pandemic and can thereby assist health care management to allocate resources, and not too over invest in the development of services that might already be able to handle the need. To illustrate this, the following example is used: If the more conservative need for counselling incidence of 23% is used for the ±970 health care users left bereaved at Eersterust CHC, the projected need for counselling is about 225 users, but if the rate obtained in this study is used for the projection (18.5%), 180 users is in need of counselling. When projecting the incidence of PGD, 70 users will need more intensive treatment for abnormal grief on the conservative side of the usual incidence (7%), but only 20 when using the PGS (1.9%) as used in this study. These findings show, as Sealy et al. described (21), that if those that are

in need of grief therapy can be accurately identified, resources will not be wrongfully allocated in a blanket approach of bereavement where everyone gets counselling or therapy regardless of the grade or complexity of their need. Using a validated and sensitive tool such as the PGS, those left with bereavement needs after the pandemic can be identified without wastage of valuable resources. This tool would unfortunately not be adequate for identifying abnormal grief outside pandemic situations.

The question that however arises is why the community of Eersterust is somehow less affected by COVID-19 grief than anticipated? Many communities in South Africa are subjected to struggles throughout their lives. Constant trauma due to poverty, violence, and drug-abuse are common, communities have seen the devastating deaths due to HIV/AIDS just a few decades ago. COVID-19 came along as another burden to carry, causing another scar but seemingly not too deep to cope with, for most. Desensitisation due to chronic (multiple and ongoing) trauma in a community is a possible reason for this finding (35). The numbers of abnormal grief might be more in developed countries where life was overall more peaceful and comfortable before the pandemic came to disrupt it. Further comparisons with other low to middle income countries and their rate of PGD could shed more light on the reasons for this finding. This is especially important in order to not underestimate the bereavement needs of South Africans, as this could lead to a continued neglect of bereavement within the realm of palliative care (3).

7.2.3. Risks factors for worsened grief outcomes.

In anticipation of the 'bereavement curve' (3) several studies tried to determine the possible factors that could lead to an increased risk of abnormal grief (4,9,25). Sudden loss, ICU deaths, limited support, limited time spend with loved one to say goodbye, and limited hospital visits were thought to contribute to more severe experiences of loss.

In contrast to the literature in anticipation of this curve, this study in Eersterust found that although less hospital visits did take place and emotional support often felt to be less after a loss compared to previous losses, most of these factors did not seem to contribute to worsened grief outcomes in this community. Statistically significant findings were only obtained when the suddenness of a loss was

taken into account with the inability to visit an in-hospital loved one or spend time with the loved one. None of the other factors lead to a statistically significant increased incidence of abnormal grief or need for counselling. Compounded loss, such as having multiple losses within a short period, also did not lead to more severe grief symptoms in this community.

Contrary to the Eersterust community, recent studies conducted in the United Kingdom on COVID-19 bereavement found clear evidence of increased PGD due to the pandemic, especially related to factors such as the inability to visit hospitalised loved ones, and lack of social support (36)(37).

The relationship with the deceased is worth mentioning specifically in that the two participants that suffered from PGD both lost their parents, but the relationship with the person lost was not found to be significant in the quantitative section of the study. Theories such as attachment anxiety and attachment avoidance may play a role regarding the individuals' reasons for grieving a specific person abnormally (38). The loss of friends was the third most frequent loved one lost and those that lost friends often noted that they were excluded from the funeral proceedings due to them not being family, although they often felt much closer to the person in life than blood relatives. This caused friends to struggle to deal with not being informed of hospitalisation status and included in funeral arrangements.

7.2.4. Poor knowledge of available support services

Knowledge of the availability of mental health services at health care facilities is important in order to have a community utilise the services fully. The study by Sun, Bao, and Lu (1) reiterated the importance of mental health awareness in order to improve general literacy regarding coping skills and psychological issues.

The study has found that health care users of Eersterust CHC were not aware of the available mental health unit with bereavement counselling already in place at the facility at the time of the study, with almost 80% that did not know of the service. The service was not openly advertised, and its operations were restricted during the initial lockdown level by not taking in new clients. The staffing was also diluted as the health care workers employed there were used in other departments such as PPE

distribution, which could have been some factors that prevented access. It is important to note that access to mental health care in the CHC is by referral from the primary health care services only. The community can thus not present themselves for services such as grief counselling directly.

Irrespective of the access route, this does not absolve the fact that the vast majority of the participants did not know there was an option of such services. The study thus found that Eersterust CHC failed to inform and advocate the provision of basic emotional and practical support during the of the pandemic to the extent of informing about available mental health services, as urged in the document issued early in the pandemic by Dr T Pillay, the then Acting Director-General of Health (5). Some of the reasons mentioned above could account for it, but other factors such as ability or cost to travel could also have hindered access. Faith-based institutions such as churches, have given support to many participants in providing counselling and some mentioned that they rather sought help at church than at the health facilities.

7.2.5. Demographic findings discussion

Although the community of Eersterust has a young demographic distribution with almost equal gender distributions (30), the age groups that were utilising the health facility during the study period were mostly older than 50 years and close to two thirds of the participants were females. This fits with expectations that health facilities are utilised by older individuals that are more prone to chronic conditions and that females are more frequent utilisers due to the type of services offered (39), such as family planning and antenatal care (ANC).

Another reason why younger persons might not be reflected in the results may be because the ANC users are using another entrance to the facility. This could have led to some skewing of the results, but it is not expected to have changed the results significantly, as screening for general well-being and mental health is also done during ANC.

Goveas and Shear's (13) findings about the elderly feeling overwhelmed by adherence to the regulations of the COVID-19 pandemic could not be seen in Eersterust population as the aged are not accessing the clinic directly. The community of Eersterust is integrated in ward-based outreach team -

so called ‘WBOT’ - programs which utilises home based care for the elderly and this age group could have been missed with randomisation, although the population is known to have a small number of elderly persons (<3% being older than 70-years) (30).

There are no specific data on the religious distributions in Eersterust, but the study found that 90% of the CHC’s health care users stated that they are Christians. Almost 30% of participants had ancestral beliefs, demonstrating that many Christians has both Christianity and ancestral traditions that they adhere to, as is common in South Africa and is not contradictory in the African tradition (40). As a suburb with historical township demographics (that has grown into a more fixed brick-and-mortar community), many workers utilising the facility still have their homestead in the rural areas, but the topic of certain African traditions not being able to be fulfilled for the funerals during COVID-19, such as described in the article by Bank (11) did not feature strongly in the study. A few participants mentioned that they were not able to take their loved ones for burial in the rural Eastern Cape, but none were concerned of the spiritual unrest of their loved ones due to not completing the rituals.

Their faith has been a reason many participants have managed to cope and get to terms with their loss. It helped them to accept that their loved ones would not have passed if it was not the right thing to happen, and that they survived for a reason. Faith-based institutions such as churches, have given support to many participants in providing counselling and some mentioned that they rather sought help at church than at the health facilities. This could also be a reason why few persons knew of bereavement help at the CHC as they are used to turning to their faith in matters concerning loss. This demonstrates that cooperation within the community by using volunteers to provide psychosocial support and bereavement care can assist in implementing palliative care principles in pandemic situations as was recommended by Etkind et al. (26).

7.3. Changes to social norms and customs pertaining to grief and bereavement.

7.3.1. Hospitalisation and saying goodbye.

The number of deaths in hospital reported in this study were about 20% higher than the 43.2% that was published in the 2016 Statistics South Africa report for the place or institution of death

occurrence (41). COVID-19 contributed to close to 40% of deaths of loved ones in this study, and most of these passed in hospital, which could explain the difference from the 2016 report to some extent.

A higher number of persons passing in hospital did not in itself affect the community of Eersterust, but rather the difficulty or inability to gain access to the admitted person and get honest communication from the hospital regarding the status of their loved one. Although the quantitative part of the study shown no statistically significant impact due to not being informed, the qualitative part did contribute a lot to demonstrate how the community was affected by thinking their loved one was doing fair in hospital and then suddenly hearing of their deterioration and passing.

The suddenness of the loss with the inability to visit was significant and this compared well with the literature, such as in the study by Pearce et al. which predicted that with sudden and unexpected deaths, often in ICU, together with patient isolation, bereavement was going to be affected (9).

Although exceptions were made so that some participants could reach their loved ones to say goodbye, those that were themselves very sick and in isolation felt helpless for very long needing to cope with their own illness and loss. Similarly, to the study by Gesi, one participant blamed herself for not trying harder to be there to take care of her loved ones' dignity (4).

7.3.2. Funeral custom changes effect on community.

Hospital access, whether telecommunication or visitation, was not as challenging to the Eersterust community as the regulations placed on funeral customs. The literature predicted that COVID-19 would cause a disruption in social norms, rituals, and mourning practices, influence the place of burial, and influence the outcome of grief based on previous pandemics (25). It was found to be true regarding the disruptions as from the moment of their loved one's passing, the newly bereaved experienced regulations being placed on many of these aspects such as the preparation of the body, funerals attendance by invitation only and time limitations placed on ceremonies and the gathering afterwards. This left the community with the feeling of being robbed, and emotionally discontent. The enforcement of social distancing as a regulation lead to further feelings of isolation and with little

comfort gained when they were in need of closeness, hugs, and a sense of community. When alternative rituals were performed, it brought mixed feelings amongst participants, some felt satisfied that all elements were represented while others still felt empty and unfulfilled.

This study has shown a significant association with regards to the funeral proceedings experienced as very different compared to before, as well as the amount of support experienced. Those that said funerals were very different, felt least supported and dissatisfied. This was found to be even more explicit when the losses were caused by COVID-19. However, less support did not lead to increased need for grief counselling. This finding was aligned with the findings of Burell and Selman who also concluded that reduced support during the grieving period did not necessarily lead to poorer outcomes, although it left individuals dissatisfied (12).

The cold atmosphere experienced at funerals was especially true when police officers were present to ensure that rules were enforced. There was bitterness in the community when exceptions to regulations were allowed, as was seen in Bank's study (11), when well-known persons in the community passed away. Contrary to Bank's study though, participants in this study who attended rural funerals in another province (Limpopo), stated that the rules were more relaxed there than in the city.

It is a frequent expectation to financially contribute towards a funeral of a family member in the African culture (40). The study found participants reporting financial contributions to be much less and cause stress for the families that were responsible to bear the costs of the undertakers and ceremonies. Choosing who were allowed to attend funerals placed an added burden on grieving families and not having the usual emotional support of neighbours and friends made it even more difficult.

Most of the participants in the study were able to partake in the funeral arrangements to the extent of their liking, with 27.6% that would have liked to be more involved and needed counselling, which was not statistically significant. The decreased level of involvement thus did not show poorer grief outcomes. In the qualitative part if this study though, significant expressions of distress was found in

those who could not assist at funerals as much as they would have liked too. This discrepancy between quantitative and qualitative parts of the study, was also found by Burrell and Selman. They found with the qualitative research that the bereaved who participated in funeral arrangements and found ways in which the rituals had meaning for them, benefitted from participating (12), although quantitative sections were equivocal.

COVID-19 and the regulations created due to it were blamed for many problems faced by participants. Individuals cope differently with adverse events in their lives. Those that blamed COVID-19 for all problems and complications that followed in their lives, showed that they still struggled with the adjustment to their loss. Götmann published a study on engagement-and disengagement-related coping strategies that revealed that problem-solving was positively related to well-being, whereas negative coping strategies often shows with behaviour such as blaming (42). Some of the problems COVID-19 were blamed for in this study were that it made it more difficult to get any kind of timeous medical care, led to risks at the workplace and left a participant with long lasting symptoms of fear for her and her family's safety. The need for intervention or counselling can be identified in this way and the individual referred to the facility's service or faith-based institution if preferred.

7.4. Moving on and coping with loss

An array of ways in which individuals in the Eersterust community managed to move on from their painful experiences and cope with their losses despite the pandemic and its consequent regulations were identified by this study. By being involved in the funeral arrangement of even organising a memorial service for family who could not be visited in hospital and whose funerals could not be attended, different participants have found peace and comfort and in their own survival of COVID-19. Driven by the notion that the loss of their loved ones was the correct time for them to pass and their faith helping them to realise this and by embracing support from the church, individuals has not struggled with prolonged grief. Although not seeking formal help from the government healthcare facility, many has been speaking about their pain and losses to friends and their religious leaders,

thereby many participants in this study have already shown to be on the path of recovery. Yet the notion should be challenged whether they had coped so well with their losses due to coping skills learnt from other ongoing social crisis like drugs, violence, and socio-economic stresses.

7.5. Strengths and limitations of the study

Some strengths of the study identified:

- A large sample size of n=399
- A mixed methods study was conducted
- Robust analyses were performed using software as well as biostatistical expertise

A few limitations were identified as the study was conducted and written up.

- Sampling limitations

Female users that are ANC clients utilising the maternal obstetric unit entrance to the facility could have been excluded from randomisation as well as older individuals that are part of the WBOT-program does not attend the CHC, were underrepresented in the study, although the community has a very small percentage of elderly citizens.

- Previous counselling

The questionnaire did not inquire whether any outside emotional support was obtained after bereavement. That could have influenced the expressed need of support by the community.

- Counselling available elsewhere.

Community resources outside health care, providing bereavement counselling were not identified before the study commenced. If known, data could have been collected on the community's knowledge, preference and access to those services compared to the health care services.

- Ancestral beliefs

Despite 28.3% of participants in the quantitative phase indicating Ancestral spiritual beliefs, this topic was not explored explicitly. Additional exploration of this topic is needed in the South African context.

- Poor uptake / attendance of focus group

Although a bigger focus group discussion was planned, it was enforceable as none of the twelve participants that agreed on the date and time attended the initial scheduled meeting. Due to the modification of the original sampling plan, it may have reduced the richness of the data.

8. CONCLUSION AND RECOMMENDATIONS

The COVID-19 pandemic hit South Africa with great force in 2020, leading to panic and the implementation of regulations. It was marked with suddenness of loss, limited support, fear, and choice restrictions that made it comparable with ICU deaths, previous pandemics, and natural disasters. Regulations caused a halt on progress made on programs such as the National Policy Framework and Strategy on palliative care 2017-2022 and the ICRM program to extend palliative care into primary health care facilities.

Strict social distancing and funeral rules were imposed by the regulations and subsequently customs needed to be modified. The effects on the bereaved were expected to lead to a "bereavement curve". Bereavement research and programs lag behind progress made by other palliative care topics. To support integration of palliative care into primary care, the precise need for palliative care services including bereavement care needed to be shown. This study contributes to the knowledge of bereavement in South Africa and specifically grief and bereavement of the community of Eersterust.

The study found that the apparent "bereavement curve" was flatter than anticipated in this community after the worldwide COVID-19 pandemic hit South Africa, but the community was still greatly affected by the lockdown regulations.

The aim of the study was to explore how COVID-19 and the lockdown regulations had impacted on the grieving process of the public health care users of the Eersterust community. The objectives were to determine how many public health care users had experienced loss of a loved one during the COVID-19 pandemic, determine the changes that occurred in the social norms of grief and bereavement, and determine how these changes affected members of the community in their grieving.

The study found that 26.6% of health care users lost someone close to them within the first eighteen months of the COVID-19 pandemic. The study furthermore established that despite the high number of losses, the incidence of prolonged grief disorder as well as those with the need for counselling were

lower than anticipated. Two factors found to influence this were pre-exposure to loss and trauma in the community and resilience due to their own coping mechanisms. The study found that the awareness of the community regarding mental health services provided at the CHC was poor, with less than 20% of participants being aware that the facility offered grief counselling. Looking for help at the health facility was not frequent, and many participants had already received counselling and support from their churches during their bereavement period.

The study then further determined changes that occurred in the social norms of grief and bereavement due to the regulations placed on funerals and other death rituals during the COVID-19 pandemic. The study found that the changes were very prominent: from hospital admission due to any illness, through to all aspects of death rituals. The lockdown rules enforced to curb the spread of COVID-19 by ensuring social distancing, took away the comforting experiences funeral rituals used to offer the bereaved. The alternative or altered rituals and ceremonies, despite having all the necessary elements, still left many feeling emotionally unsatisfied. Despite the changes in the grief and bereavement practices, there were also no statistically significant increase in PGD or need for counselling.

The study further explored how the abovementioned changes impacted specific members of the community. Discussions with the community members collected knowledge on the perspective of individuals' grief experiences as affected by the COVID-19 pandemic and the lockdown regulations.

Information relayed to families from hospital staff when loved ones were admitted were experienced as incomplete and to some extent 'dishonest' according to the participants when sudden deterioration followed soon after a call of reassurance. Saying 'last goodbyes' were mostly allowed but those who were unable to, due to their own isolation or illness, struggled more to manage their feelings of inadequacy. Social distancing and time limitations stood out amongst other COVID regulations for being enforced rigorously, even when the person did not pass from COVID-19 and left participants feeling disgruntled. Participation in rituals - despite limited - were helpful in managing their loss, but some participants still had problems with acceptance of the circumstances leading up to their loved one's loss, blaming factors that could not be controlled.

Most participants managed to move on from their loss, many by focusing on their faith, sharing their pain with their friends and by finding other ways to celebrate their loved ones' lives. One participant needing counselling due to severe anxiety has been identified and is getting the help needed.

Conducting qualitative research in the community contributed to the depth of the knowledge obtained from the rest of the study by adding on the emotional significance the COVID-19 regulations had on the members of the Eersterust community.

Recommendations

- Campaigning is suggested to create awareness of the mental health services and availability of bereavement counselling at the health facility and the community services offered.

- WBOT to be trained to screen for mental health and abnormal grief amongst elderly and other home-based patients.

- The incidence of abnormal grief in this study was found to be less than what developed countries extrapolated in the early studies of COVID-19 bereavement. Studies are needed in grief and bereavement in South Africa and other developing countries in order to better understand the reasons for differences found in the lower incidence of PGD. This is important to not underestimate the bereavement needs of South Africans, as this could lead to a continued neglect of bereavement within the context of palliative care.

- Interventions using locally available resources to manage abnormal grief and bereavement should be thoroughly researched, applied, and evaluated for their effectiveness. Further studies into the reasons for the seemingly better resilience and coping of the Eersterust community after their losses is suggested.

- Community specific statistical analysis of COVID-19 related losses is another study suggested, as this data was collected by Eersterust CHC during the pandemic.

- African ancestral beliefs with an overlap with Christianity is a topic that became apparent from the demographics of this study. This aspect could be explored more in the future, in order to understand the dual belief system better and draw better comparisons to studies such as those from the Eastern Cape.

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10. APPENDICES

APPENDIX A Phase 1 Informed Consent (English / Afrikaans / Sepedi)

APPENDIX B Phase 1 Data Collection tool: Questionnaire (English / Afrikaans / Sepedi)

APPENDIX C Phase 2 Informed Consent

APPENDIX D Phase 2 Data collection tool: Focus Group Interview

APPENDIX E Distress protocol

APPENDIX F HREC Ethical approval

APPENDIX G Permission from study site

APPENDIX H Additional tables

APPENDIX A (English)

A: Phase 1 PARTICIPANT INFORMATION AND INFORMED CONSENT

The Questionnaire

Study title: The impact of the COVID-19 pandemic on the grief and bereavement of the Eersterust community.

Principal Investigator: Dr Delene Murray, Medical Doctor, Eersterust Community Health Centre.
Supervisor: Dr Liesl Visser, Senior Family Physician and Senior Lecturer.
Institution: School of Public Health and Family Medicine (Interdisciplinary Palliative Care & Medicine), University of Cape Town.
Study site contact information: Dr Delene Murray at 012 806 1300, C/O Hans Coverdale East and P.S Fourie Street, Eersterust.

STUDY IDENTIFICATION	COVID-19 BEREAVEMENT
PARTICIPANT IDENTIFICATION NUMBER	

Date of informed consent discussion:

Day	Month	Year

Dear Prospective Research Participant,

1) **Introduction**

You are invited to participate in a research study. I am doing this research to complete the Master's degree in Palliative Medicine at the University of Cape Town. This document gives information to help you decide if you would like to participate. Before you agree to take part, you should fully understand what is involved. If you have any questions, which are not fully explained in this document, do not hesitate to ask the investigator. You should not agree to take part unless you are completely happy about completing the questionnaire.

Bereavement is the experience of losing a loved one, whilst grief is the natural response to this loss. Acute grief can be intensely painful, disruptive, and feel unbearable. Acute grief is normal, and you find a way to have a new normal.

According to the DSM-V (a manual for the assessment and diagnosis of mental disorders) and the ICD-11 (the latest International Classification of Diseases, which follows a method to classify diseases,

injuries, and causes of death) is Prolonged Grief Disorder (PGD) the "Syndrome of persistent and pervasive yearning, longing, or pre-occupying thoughts and memories of the deceased, accompanied by other evidence of grief-related emotional pain, causing significant distress or impairment in functioning, and lasting at least 6 months and exceeding the time-frame expected by social, cultural, religious norms." Consequences of untreated PGD include increased medication use, poor job retention, psychological disorders, and increased mortality. If identified earlier, early intervention can reduce this suffering. It is estimated that 10% of bereaved individuals are at risk to develop complex grief reactions which may need specialised care and 30% needs group support.

2) **The nature and purpose of this study**

The aim of this study is to explore how COVID-19 and the lockdown regulations had changed the grieving process of the Eersterust community. We would like to know how many people suffered the loss of a loved one and if you did, how much your usual way of mourning and saying goodbye had to change, so that we can better plan to support the community in their grief.

3) **Explanation of procedures and what can be expected of participants**

This study involves answering some questions on if you did or did not experience the death of a close loved one during the COVID-19 lockdown. A close loved one is a parent, child, spouse, sibling, or another very close family member. We are especially interested if you lost someone like this due to any cause, in the period March 2020 to August 2021. Filling in a questionnaire will take approximately 15 minutes. There are three assistants available to help you complete the questions. Your name will not be written on the questionnaire to ensure that your answers are kept private. The completed questionnaire will be placed in the clearly marked box where it will be sealed and kept safe. The researcher will make sure that only people working on the study will have access to it.

The questionnaire consists of three parts:

Part 1: Demographic information which involves answering some questions about your age, your sex, and your religious affiliation. This will help the researcher to see if there are associations between these factors and the people in the community's experience of loss.

Part 2: A questionnaire to determine how many people visiting the clinic during these 2 weeks lost a loved one during the lockdown, how they were able to say goodbye and how they were able to perform their usual customs. There are also questions that are asked to find out how many people suffer already from longer and more severe grief than is usually expected. If you did not lose someone, you will not need to answer all the questions but can still participate.

Part 3: A section to ask if you are willing to take part in a focus group discussion (a group of 8 -10 people) to explore your own experiences around losing a loved one during the lockdown period. Further information about this will be given if you decide to participate in this discussion group.

4) **Risk and discomfort involved**

We do not think that taking part in the study will cause any physical risk. We do however foresee some emotional discomfort since we will be asking questions about the loss of your loved one. If questions feel too personal or make you uncomfortable, you do not have to answer them. You are also allowed to stop participating in the questionnaire at any time. The researcher will support and refer you for

counselling if the questions upset you. If this happens, you will keep your place in the queue today and receive the service you came for.

5) **Possible benefits from the study**

You might not benefit directly from being part of this study, although you might feel better after thinking about your experiences. Your participation, however, will help us to better understand the effect the COVID-19 regulations on the community's experience of loss and grief. The information you give may help the researcher improve bereavement support and counselling for more people in the community that have been affected.

6) **Ethics approval**

The proposal for this study was submitted to the Human Research Ethics Committee of the Faculty of Health Sciences at the University of Cape Town, G50 Old Main Building, Groote Schuur Hospital, Observatory, Cape Town; telephone number 021 650 1236 and written approval has been given by that committee, REF: 542/2021. The study will follow the Declaration of Helsinki (last update: October 2013), which guides doctors on how to do research in people. The researcher can give you a copy of the Declaration if you wish to read it. Without this approval, the study is not allowed to take place.

7) **Voluntary participation**

The decision to take part in the study is yours and yours alone. You do not have to take part if you do not want to. You can also stop at any time without giving a reason. If you decide not to take part in the study, it will not affect you in any way. You will still receive your usual care and treatment from the clinic.

8) **Information**

If you have any questions concerning this study, you are welcome to contact Dr Delene Murray at Eersterust CHC on 012 806 1300.

9) **Confidentiality**

All records from this study will be kept confidential. All results will be published or presented in such a way that it is not possible to know who the participants are.

10) **Compensation**

You will not be paid to take part in the study. There are no costs involved for you to be part of the study.

11) **Consent to partake in this study**

I confirm that the person requesting my consent to take part in this study has told me about the nature and process, any risks or discomforts, and the benefits of the study.

- I have also received, read, and understood the above written information about the study.
- I have had adequate time to ask questions and I have no objections to participate in this study.
- I am aware that the information obtained in the study, including personal details, will be anonymously handled, and presented in the reporting of results.

- I understand that I will not be penalised in any way should I wish to discontinue with the study and my withdrawal will not affect my care at the clinic.
- I am participating willingly.
- I have received a signed copy of this informed consent agreement.

_____
Participant's name (Please print)

_____ _____
Participant's signature Date

_____
Researcher's name (Please print)

_____ _____
Researcher's signature Date

AFFIRMATION OF INFORMED CONSENT BY AN ILLITERATE PARTICIPANT

I, the undersigned, _____ have read and have explained fully to the participant, named _____, the participant informed consent document, which describes the nature and purpose of the study in which I have asked the participant to participate. The explanation I have given has mentioned both the possible risks and benefits of the study. The participant indicated that he/she understands that he/she will be free to withdraw from the study at any time for any reason and without jeopardizing his/her standard of care. I hereby certify that the participant has agreed to participate in this study.

_____
Participant's name (Please print)

_____ _____
Participant's Signature or Mark Date

_____
Investigator's Name (Please print)

_____ _____
Investigator's Signature Date

_____
Name of the person who witnessed the informed consent (Please print)

_____ _____
Signature of the Witness Date

APPENDIX A (Afrikaans)

A: Fase 1 DEELNEMER-INLIGTING EN INGELIGTE TOESTEMMINGSDOKUMENT

Die Vraelys

Studie titel: Die impak van die COVID-19 pandemie op die hantering van rou en verlies op die Eersterust-gemeenskap.

Hoof ondersoeker: Dr Delene Murray, Mediese praktisyn, Eersterust Gemeenskapsgesondheid-sentrum (ECHC).
Toesighouer: Dr Liesl Visser, Senior Huisarts en Senior Lektrise, Universiteit van Kaapstad.
Institusie: Die Skool van Publieke Gesondheid en Huisartskunde (Interdissiplinêre Palliatiewe sorg en geneeskunde), Universiteit van Kaapstad.
Kontakbesonderhede: Dr Delene Murray by 012 806 1300, h/v Hans Coverdale Oos en P.S Fourie strate, Eersterust.

STUDY IDENTIFICATION	COVID-19 BEREAVEMENT
PARTICIPANT IDENTIFICATION NUMBER	

Datum van ingeligte besluitneming bespreking:

Dag	Maand	Jaar

Geagte voornemende deelnemer,

1) **Inleiding**

Jy word uitgenooi om deel te neem aan ‘n navorsingstudie. Ek doen ‘n navorsingsprojek ten einde die vereistes van ‘n Meestersgraad in Palliatiewe Geneeskunde by die Universiteit van Kaapstad te voltooi. Hierdie dokument verskaf inligting om jou te help besluit of jy aan die studie wil deelneem. Voordat jy instem om deel te neem, moet jy verstaan wat die studie alles behels. Indien jy enige verdere vrae het, kan jy gerus die ondersoeker kontak. Voordat jy nie heeltemal tevrede is nie, moet jy nie toestemming gee om deel te neem nie.

Verlies is die ervaring om 'n geliefde aan die dood te verloor, terwyl rou die natuurlike reaksie op hierdie verlies is. Akute rou kan intens pynlik, ontwrigtend wees en ondraaglik voel. Akute rou is normaal, en jy vind oor tyd 'n manier om 'n nuwe normaal te hê.

Volgens die DSM-V ('n handleiding vir die assessering en diagnose van geestesversteurings) en die ICD-11 (die jongste Internasionale Klassifikasie van Siektes, wat 'n metode volg om siektes, beserings en doodsoorsake te klassifiseer) is “Prolonged Grief Disorder” (PGD) die "Sindroom van aanhoudende en deurdringende verlange, of indringende gedagtes en herinneringe van die oorledene, vergesel met ander bewyse van rou-verwante emosionele pyn, wat aansienlike nood of inkorting in funksionering

veroorsaak, en wat ten minste 6 maande duur en die periode wat deur sosiale, kulturele, godsdienstige norme verwag word, oorskry." Gevolge van onbehandelde PGD sluit in verhoogde medikasiegebruik, swak werksbehoud, sielkundige versteurings en verhoogde mortaliteit. As dit vroeër geïdentifiseer word, kan vroeë intervensie hierdie lyding verminder. Daar word beraam dat 10% van bedroefde individue die risiko loop om komplekse rou-reaksies te ontwikkel wat gespesialiseerde sorg kan benodig en 30% het groepsondersteuning nodig.

2) **Die aard en doel van die studie**

Die doel van die studie is om vas te stel hoe die COVID-19 pandemie en Suid-Afrika se inperkingsregulasies die manier van rou in die gemeenskap van Eersterust verander het. Ons wil weet hoeveel mense het verlies ervaar en ook hoe die hantering van rou verander het, sodoende wil ons beter beplan hoe ons die gemeenskap kan help om verliese te verwerk.

3) **Die prosedures en wat van deelnemers verwag word**

Indien jy aan die studie sou deelneem, sal jy 'n vraelys invul rondom of jy 'n nabye geliefde aan die dood afgestaan het gedurende die eerste jaar van COVID-19 se streng inperkings. 'n Nabye geliefde is 'n ouer, kind, lewensmaat, broer/suster of 'n ander baie naby familie-lid. Ons stel belang of jy so iemand aan die dood afgestaan het in die tyd vanaf Maart 2020 tot Augustus 2021. Dit maak nie saak waaraan die persoon gesterf het nie (COVID-19 of ander oorsake). Dit sal ongeveer 15 minute neem om die vraelys te voltooi en een van die navorsingsassistente sal jou help om jou antwoorde in te vul. Jou naam sal nie op die vraelys geskryf word nie, om sodoende jou antwoorde privaat te hou. Die voltooide vraelys sal dan in 'n gemerkte boks gesit word, wat geseël en veilig gehou sal word. Die navorser sal seker maak dat slegs die persone wat aan die studie werk toegang tot die vraelys het.

Die vraelys bestaan uit drie dele:

Deel 1: Demografiese inligting oor jou geslag, ouderdom en geloofsoortuiging.

Deel 2: 'n Vraelys om te bepaal hoeveel mense wat die kliniek besoek, het tydens die eerste jaar van grendeltyd iemand naby aan hulle aan die dood afgestaan. Daar is ook vrae oor of hulle hulle geliefdes kon gegroet het en of die manier van begrafnis en ander tradisies aangepas moes word. Ander onderwerpe in die vraelys gaan oor hoeveel mense alreeds erger en langer rou tydperke ervaar as wat normaalweg verwag word. Indien jy nie iemand verloor het nie, hoef jy nie al die vrae te antwoord nie, maar jy kan steeds aan die studie deelneem.

Deel 3: Hierdie deel vra of jy belang sou stel om deel te neem aan 'n fokusgroep-bespreking (Fase 2 van die studie) van tussen 8 tot 10 mense, waar julle 'n kans sal kry om julle eie ervarings rondom die verlies van geliefdes te deel. Verdere inligting sal aan jou gegee word indien jy besluit om deel te neem aan hierdie besprekingsgroep.

4) **Risiko en ongemak betrokke**

Daar is geen fisiese risiko betrokke indien jy aan ons studie deelneem nie, jy sal deurlopend jou plek in die tou behou. Daar word egter voorsien dat die emosionele aard van die onderwerp wel in sommige deelnemers emosionele ongemak kan veroorsaak. Indien enige van die vrae te persoonlik voel of jou te

ongemaklik maak, hoef jy dit nie te antwoord nie. Jy kan ook enige tyd tydens die studie jou deelname onttrek. Die navorser sal jou ondersteun en verwys vir berading indien die vrae jou sodanig ontstel. Indien dit sou gebeur, sal jy steeds jou plek in die lyn behou en die dienste ontvang waarvoor jy vandag na die kliniek toe gekom het.

5) **Moontlike voordele indien jy sou deelneem**

Jy mag dalk nie direk voordeel trek as jy deelneem aan die studie nie, alhoewel jy beter mag voel nadat jy weer oor jou ervarings gedink het. Jou deelname gaan baie help dat ons die impak van die COVID-19 regulasies op die gemeenskap se ervarings van hul verlies en rou beter verstaan. Sodoende kan ons beter ondersteuningsdienste aan meer gemeenskapslede beskikbaar stel om hulle verliese te help verwerk.

6) **Etiese goedkeuring**

Hierdie navorsingsvoorstel is ingehandig by die Menslike Navorsings-Etiek Kommittee van die Fakulteit Geneeskunde aan die Universiteit van Kaapstad, G50 Old Main-gebou, Groote Schuur Hospitaal, Observatory, Kaapstad; telefoonnommer 021 650 1236. Skriftelike toestemming om die studie te doen is ontvang vanaf hierdie kommittee. Die studie volg die Verklaring van Helsinki (laaste opdatering: Oktober 2013), wat navorsers lei om veilig navorsing oor mense te doen. Die navorser kan vir jou ‘n afskrif van die Verklaring gee indien jy dit sou wou lees.

7) **Vrywillige deelname**

Die besluit of jy aan die studie gaan deelneem is jou eie. Jy hoef nie deel te neem indien jy nie wil nie. Jy kan ook enige tyd jou deelname onttrek sonder om te verduidelik waarom. Indien jy besluit om nie deel te neem aan die studie nie, sal dit geensins jou sorg by die kliniek beinvloed nie.

8) **Inligting**

Indien jy enige verdere vrae het, kan jy gerus vir Dr Delene Murray (die navorser) kontak by Eersterust CHC, telefoonnommer: 012 806 1300.

9) **Vertroulikheid**

Al die vorms en inligting wat uit die studie vloei sal vertroulik gehou word. Die resultate van die studie sal op so ‘n manier opgeskryf word, dat dit onmoontlik sal wees om te weet wie aan die studie deelgeneem het.

10) **Vergoeding**

Jy sal nie betaal word om aan die studie deel te neem nie en daar is geen kostes vir jou om deel te neem nie.

11) **Toestemming om deel te neem aan die studie**

Hiermee bevestig ek dat die persoon wat my toestemming vir die studie vra, my al die inligting oor die aard, proses, risiko’s, moontlike ongemak en voordele verduidelik het, indien ek sou deelneem aan die studie. Ek het die inligiting gelees, verstaan dit en het ook ‘n afskrif van die skriftelike inligting ontvang.

- Ek het genoeg tyd gehad om vrae te vra en het geen probleem om deel te neem aan die studie nie.
- Ek is bewus daarvan dat die inligting wat deur die studie versamel word, insluitende persoonlike inligting, altyd anoniem sal bly.

- Ek verstaan dat ek nie benadeel sal word indien ek besluit om nie verder aan die studie deel te neem nie, hierdie besluit sal nie my sorg by die kliniek beinvloed nie.
- Ek neem vrywillig deel.
- Ek het ‘n ondertekende afskrif van hierdie ingeligte toestemmingsdokument ontvang.

_____
Deelnemer se naam (Drukskrif)

_____ _____
Deelnemer se handtekening Datum

_____
Navorser se naam (Drukskrif)

_____ _____
Navorser se handtekening Datum

BEVESTIGING VAN INGELIGTE TOESTEMMING DEUR ‘N ONGELETTERDE DEELNEMER

Ek, die ondertekende, _____ het volledig gelees en verduidelik aan die deelnemer, genaamd _____, die ingeligte toestemmingsdokument, wat die aard en doel van die studie beskryf en ek het die deelnemer gevra vir sy/haar deelname aan die studie. My verduideliking het ook die moontlike risiko’s en voordele van die studie ingesluit. Die deelnemer het aangetoon dat sy/hy die inligting verstaan en verstaan dat sy/hy enige tyd van die studie mag onttrek sonder enige nagevolge. Ek verklaar hiermee dat die deelnemer toestemming verleen om aan die studie deel te neem.

_____
Deelnemer se naam (Drukskrif)

_____ _____
Deelnemer se handtekening of merk Datum

_____
Navorser se naam (Drukskrif)

_____ _____
Navorser se handtekening Datum

_____
Naam van getuie teenwoordig

_____ _____
Handtekening van getuie Datum

APPENDIX A (Sepedi)

A: Phase 1 TLHAHISOHISO EA BATHO-NAKO LE TUMELLANO E TSOANG PELE

Lenane la lipotso

Sehlooho sa thuto: Kameho ea kelello ea seoa sa COVID-19 sechabeng sa Eersterust, haholoholo mesarelo le ho shoeloa.

Mofuputsi e Moholo: Ngaka Delene Murray, Ngaka ea Bongaka, Setsi sa Bophelo sa Sechaba sa Eersterust (ECHC).

Mookamedi: Ngaka Liesl Visser, Ngaka ya Lelapa e Phahameng le Morupelli e Moholo.

Mekhatlo: Sekolo sa Bophelo ba Sechaba le Bongaka ba Lelapa (Tlhokomelo ea Bongaka ea Bongaka le Bongaka), Univesithi ea Cape Town.

Tlhahisoleseling ea sebaka sa boithuto: Ngaka Delene Murray ho 012 806 1300, C / O Hans Coverdale East le P.S Street Street, Eersterust.

ITHUTOANG BOITSEBISO	COVID-19 HO AMOHUOA
YA MONKAKAROLO EO O BOITSEBISO NUMERO	

Letsatsi la puisano ea tumello e nang le tsebo:

Khoeli	Letsatsi	Selemo

Morupeluoa ea tlang ho etsa lipatlisiso,

1. Selelekela

U mengoa ho nka karolo phuputsong ea lipatlisiso. Ke etsa lipatlisiso tsena ho phethela lengolo la Masters ho Palliative Medicine Univesithing ea Cape Town. Tokomane ena e fana ka tlhaiso-leseling ho u thusa ho etsa qeto ea hore na u ka rata ho nka karolo. Pele o lumela ho nka karolo, o lokela ho utloisisa ka botlalo se amehang. Haeba u na le lipotso, tse sa hlalosoang ka botlalo tokomaneng ena, u se ke oa tsilatsila ho botsa mofuputsi. Ha ua lokela ho lumela ho nka karolo ntle le haeba u thabile ka botlalo ka ho tlatsa lenane la lipotso.
Ho shoeloa ke phihlelo ea ho lahleheloa ke moratuoa, athe ho sareloa e le karabelo ea tlhaho tahlehelong ena. Ho sareloa ho tebileng ho ka ba bohloko haholo, ho ferekanya, le ho ikutloa ho sa mamellehe. Ho sareloa ho matla ke ntho e tloaelehileng, 'me u fumana mokhoa oa ho ba le tloaelo e ncha.

Ho ea ka DSM-V (bukana ea tlhahlobo le tlhahlobo ea mafu a kelello) le ICD-11 (ea morao-rao ea Sehlopha sa Machaba sa Mafu, se latelang mokhoa oa ho arola mafu, likotsi le lisosa tsa lefu) ke lefu la nako e telele la ho sareloa. (PGD) “Boloetse ba ho hlololheloa ho sa khaotseng le ho ata, tlholohelo, kapa mehopolo le mehopolo ea mofu e sa khaotseng, e tsamaeang le bopaki bo bong ba bohloko ba maikutlo bo amanang le ho sareloa, bo bakang tsieleho e khōlō kapa ho holofala ha ho sebetsa, le ho tšoarella bonyane likhoeli tse 6. le ho feta nako e lebeletsoeng ke litloaelo tsa

sechaba, tsa setso, tsa bolumeli.” Liphello tsa PGD e sa phekoloeng li kenyelletsa tšebeliso e eketsehileng ea meriana, ho se bolokehe mosebetsing, mathata a kelello le ho eketseha ha lefu. Haeba ho tsejoa pejana, ho kenella kapele ho ka fokotsa mahlomola ana. Ho hakanngoa hore 10% ea batho ba shoetsoeng ba kotsing ea ho ba le maikutlo a rarahaneng a saretsoeng a ka hlokang tlhokomelo e khethehileng 'me 30% e hloka tšehetso ea lihlopha.

2. Mofuta le sepheo sa thuto ena

Morero oa phuputso ena ke ho lekola hore na COVID-19 le melaoana ea ho notlela e fetotse mokhoa oa ho sareloa oa sechaba sa Eersterust. Re rata ho tseba hore na ke batho ba bakae ba lahlehetsoeng ke moratuoa mme haeba u etsahetse joalo, tsela eo u tloaetseng ho siama ka eona le ho re salisa hantle e tlameha ho fetoha, hore re tle re tsebe ho rera hantle ho ts'ehetsa sechaba mesarelong ea bona.

3. Tlhaloso ea lits'ebetso le se ka lebelloang ho bankakarolo

Phuputso ena e kenyelletsa ho araba lipotso tse ling mabapi le hore na u kile oa ba le lefu la moratuoa nakong eo COVID-19 e koaletsoeng. Moratuoa ea haufi ke motsoali, ngoana, molekane, ngoan'eno, kapa setho se seng se haufi sa lelapa. Re thahasella haholo haeba o lahlehetsoe ke motho ea joalo ka lebaka lefe kapa lefe, nakong ea Hlakubele 2020 ho isa Phato 2021. Ho tlatsa lenane la lipotso ho tla nka metsotso e ka bang 15. Ho na le bathusi ba 3 ba teng ho u thusa ho qeta lipotso. Lebitso la hau le ke ke la ngoloa lenaneng la lipotso ho netefatsa hore likarabo tsa hau li bolokoa e le lekunutu. Lenane la lipotso le tlatsitsoeng le tla beoa ka lebokoseng le tšoailoeng ka ho hlaka moo le tla tiisoa le ho bolokoa le bolokehile. Mofuputsi o tla etsa bonnete ba hore ke batho feela ba sebetsang phuputsong ba tla e fumana.

Lenane la lipotso le na le likarolo tse tharo:

Karolo ea 1: Tlhahisoleseling mabapi le palo ea batho e kenyeletsang ho araba lipotso tse mabapi le lilemo tsa hau, thobalano le bolumeli ba hau.

Karolo ea 2: Lenane la lipotso ho fumana hore na ke batho ba bakae ba etelang tleliniking nakong ea libeke tsena tse 2 ba lahlehetsoeng ke baratuoa nakong ea ho notlela, hore na ba atlehile joang ho salisa hantle le hore na ba atlehile ho etsa litloaelo tsa bona tse tloaelehileng joang. Ho boetse ho na le lipotso tse botsoang ho fumana hore na ke batho ba bakae ba seng ba hlokofalitsoe ke mesarelo e melelele le e matla ho feta kamoo ho lebelletsoeng. Haeba u sa lahleheloa ke motho, ha ho hlokahale hore u arabe lipotso tsohle.

Karolo ea 3: Karolo ea ho botsa hore na u ikemiselitse ho nka karolo moqoqong oa sehlopha se tsepamisisang maikutlo (sehlopha sa batho ba 8 -10) ho lekola boiphihlelo ba hau ba ho lahleheloa ke moratuoa nakong ea ts'ebetso. Lintlha tse ling tse mabapi le sena li tla fanoa haeba u nka qeto ea ho nka karolo sehlopheng sena sa lipuisano.

4. Kotsi le pherekano li ameha

Ha re nahane hore ho nka karolo phuputsong ho ka baka kotsi efe kapa efe mmeleng. Leha ho le joalo re bona esale pele ho se utloise bohloko maikutlong kaha re tla be re botsa lipotso mabapi le ho hlokahalloa ke moratuoa oa hau. Haeba lipotso li ikutloa li le teng haholo kapa li u utloisa bohloko, ha ua tlameha ho li araba. U boetse u lumelloa ho emisa ho nka karolo lenaneng la lipotso ka nako efe kapa efe. Mofuputsi o tla u tšehetsa le ho u romella bakeng sa tlhabollo haeba lipotso li

u koatisitse. Haeba sena se etsahala, o tla beha sebaka sa hau moleng kajeno mme o fumane ts'ebeletso eo u e tliselitseng.

5. Melemo e ka bang teng ho tsoa boithutong

O kanna oa se rue molemo ka kotloloho ka ho ba karolo ea thuto ena, leha o ka ikutloa o le betere kamora ho nahana ka boiphihlelo ba hau. Ho nka karolo ha hau, leha ho le joalo, ho tla re thusa ho utloisisa hantle phello ea melaoana ea COVID-19 holima boiphihlelo ba sechaba sa tahlehelo le mesarelo. Tlhahisoleseling eo u fanang ka eona e ka thusa mofuputsi ho ntlafatsa ts'ehetso ea batho ba shoetsoeng le tlhabollo ho batho ba bangata sechabeng ba anngoeng.

6. Kamohelo ea melao ea boitšoaro

Tlhahiso ea thuto ena e ile ea romelloa ho Komiti ea Boitšoaro ea Lipatlisiso tsa Botho ea Lefapha la Saense ea Bophelo bo Botle Univesithing ea Cape Town, G50 Old Main Building, Groote Schuur Hospital, Observatory, Cape Town; nomoro ea mohala 021 650 1236 mme tumello e ngotsoeng e fanoe ke komiti eo. Phuputso e tla latela Phatlalatso ea Helsinki (ntlafatso ea ho qetela: Mphalane 2013), e tataisang lingaka mabapi le mokhoa oa ho etsa lipatlisiso bathong. Mofuputsi a ka u fa kopi ea Phatlalatso haeba u lakatsa ho e bala.

7. Ho nka karolo ka boithatelo

Qeto ya ho nka karolo phuputsong ena ke ya hao mme ke ya hao feela. Ha ua tlameha ho nka karolo haeba u sa batle. U ka emisa nako efe kapa efe ntle le ho fana ka lebaka. Haeba o nka qeto ya ho se nke karolo thutong, e ke ke ya o ama ka tsela efe kapa efe. O ntse o tla fumana tlhokomelo le kalafo ea hau tse tloaelehileng tliliniking.

8. Tlhahisoleseling

Haeba o na le lipotso mabapi le thuto ena, o amohelehile ho ikopanya le Ngaka Delene Murray ho Eersterust CHC ho 012 806 1300.

9. Lekunutu

Lirekoto tsohle tsa thuto ena li tla bolokoa e le lekunutu. Liphetho tsohle li tla phatlalatsoa kapa li hlahisoe ka tsela eo ho seng thata ho tseba hore na bankakarolo ke bo mang.

10. Matšeliso

O ke ke oa lefshoa ho nka karolo phuputsong ena. Ha ho na litjeo tse amehang hore u be karolo ea boithuto.

11. Tumello ea ho nka karolo thutong ena

Ke netefatsa hore motho ea kopang tumello ea ka ho nka karolo phuputsong ena o mpolelletse ka sebopeho le ts'ebetso, likotsi kapa ho se utloisehe leha e le hofe, le melemo ea thuto

• Ke amohetse hape, ke balile, hape ke utloisisitse tlhaiso-leseling e ngotsoeng kaholimo ka boithuto.

• Ke bile le nako e lekaneng ea ho botsa lipotso 'me ha ke na khanyetso ea ho nka karolo boithutong bona.

• Ke a tseba hore lesedi le fumanweng phuputsong, ho kenyeletswa le dintlha tsa motho ka mong, le tla sebetswa le sa tsejwe mme le hlahiswe tlalehong ya sephetho

• Ke a utlwisisa hore nke ke ka otlwa ka tsela efe kapa efe ha nka lakatsa ho emisa ka thuto mme ho tlohela ha ka ho tla ama tlhokomelo ya ka tliliniking.

• Ke nka karolo ka boithatelo.

• Ke fumane kopi e saennoeng ea tumellano ena ea tumello e nang le tsebo.

_____
Lebitso la monkakarolo (Ka kopo printa)

_____ _____
Tshaeno ya monkakarolo Letsatsi

_____
Lebitso la mofuputsi (Ka kopo printa)

_____ _____
Saena ea mofuputsi Letsatsi

TLHOKOMELISO EA TSEBISO EA MOTSOALLE OA TSEBISO

'Na, ea saenneng ka tlase, ke balile' me ke hlaloselitse monka-karolo ka botlalo, ea bitsoang _____, monka karolo ea tsebisang tokomane ea tumello, e hlalosang mofuta le sepheo sa thuto eo ke kopileng monkakarolo ho nka karolo. Tlhaloso eo ke faneng ka eona e boletse likotsi le melemo ea thuto. Morupeluoa o bonts'itse hore oa utloisisa hore o tla ba le bolokolohi ba ho ikhula thutong nako efe kapa efe ka lebaka lefe kapa lefe ntle le ho beha tlhokomelo ea hae e tloaelehileng kotsing. Ke tiisa hore monkakarolo o lumetse ho nka karolo phuputsong ena.

_____
Lebitso la monkakarolo (Ka kopo printa)

_____ _____
Ho saena kapa ho tšoaea monkakarolo Letsatsi

_____
Lebitso la Mofuputsi (Ka kopo printa)

_____ _____
Tshaeno ea mofuputsi Letsatsi

_____
Lebitso la motho ea pakileng
tumello e nang le tsebo tsebiso (Ka kopo printa)

_____ _____
Tshaeno ea paki Letsatsi

APPENDIX B (English)

B: Phase 1 DATA COLLECTION TOOL

Questionnaire

STUDY IDENTIFICATION	COVID-19 BEREAVEMENT
PARTICIPANT IDENTIFICATION NUMBER	

PART 1: Demographic information

Gender	Male		Female		Other	

Age	<20		20-29		30-39		40-49		50-59		60-69		70-79		>80	

Religion	Christian		Muslim		Hindu		None		Other	

Beliefs	Ancestral spirits		None		Other	

PART 2: Questionnaire

1. Did any of your loved ones (parent, child, spouse, sibling, close family member) pass away between March 2020 and August 2021?

YES		NO	

If you answered <u>NO</u> to question 1, please answer ***question 21***. You do not need to answer any of the other questions.

2. Did you lose more than one loved one?

Yes		How many?	2		3		>3	
No								

3. When did your loved one/s pass away? (month/year)

   _____/_____

4. Who was this person/s of you?

Parent		Child		Sibling		Spouse		Other	

If Other, please specify _____

5. Was the passing directly related to COVID-19, the illness?

YES		NO	

6. Did the passing of your loved one come unexpectedly / suddenly?

YES		NO	

7. Were you able to spend time with and greet your loved one before they passed?

YES		NO	

8. Where did your love one pass away?

Hospital		Home		Care facility		Other	

- If your loved one <u>did not</u> pass away in hospital**, please go to *question 12*.**

9. If your loved one passed away in hospital, were you allowed to visit?

YES		NO		Was unable to visit / N/A	

10. If your loved one passed away in hospital, were you kept up to date with their condition?

YES, sufficiently		YES, partly		NO	

COMMENT:

_____

11. If you were not allowed to visit in hospital, did you use other ways to make contact? (e.g., Social media with video calling, voice notes, photos)

YES		NO		Was able to visit / N/A	

12. Did cross-provincial travel restrictions prevent you from seeing your loved one soon before their passing?

YES		NO	

13. Were you able to attend the funeral/memorial?

YES, in person		YES, online		NO	

14. Did cross-provincial travel restrictions prevent you from attending the funeral/memorial?

YES		NO		Was able to attend / N/A	

15. Is it your custom to have the body at home or view the body at the funeral home?

YES, mostly		YES, sometimes		NO	

16. Was it possible to have the body at home or view the body at the funeral home?

YES		NO		Not applicable / I did not attend the funeral	

17. Were the funeral proceedings different compared to your usual customs? (Other than social distancing, masks, and sanitising)

YES, a lot		YES, somewhat		NO		I did not attend the funeral	

COMMENT: _____

18. Did you get as much support from your family and friends during this loss compared to previous losses (before COVID-19 regulations)?

YES		NO		I had no previous losses	

COMMENT: _____

19. If your loved one **did not** pass away from COVID-19 or its complications; did you feel that your loss was still as important as others who lost someone from COVID-19?

YES		NO		My loved one passed due to COVID-19	

COMMENT: _____

20. Were you able to help with the funeral arrangements?

YES, as much as wanted to		YES, less than wanted to		NO, not able to at all		No desire to help with arrangements	

21. Is there bereavement counselling available at Eersterust CHC?

YES		NO		I do not know	

22. Do you feel that you currently require emotional support to deal with the passing of your loved one?

YES		NO	

COMMENT:

_____

Over **the last 2 weeks**, how often have you experienced the following thoughts, feelings, or behaviours related to your loss? (Question 23 - 27)

23. I wished to die to be with the deceased.

Not at all		Several days		More than half the days		Nearly everyday	

24. I experienced confusion over my role in life or felt like my identity was diminished because of the loss.

Not at all		Several days		More than half the days		Nearly everyday	

25. Nothing seemed to matter much to me because of this loss.

Not at all		Several days		More than half the days		Nearly everyday	

26. I found it difficult to have positive memories about the deceased.

Not at all		Several days		More than half the days		Nearly everyday	

27. I believed that without the deceased, life was either meaningless, empty, or could not go on.

Not at all		Several days		More than half the days		Nearly everyday	

PART 3: Willingness to participate in group discussion.

28. Do you want to be part of a research discussion group that will discuss your loss and grieving further?

YES		NO	

If you agree to partake in a focus group discussion of 8-10 participants about your experience after the passing of your loved one amidst the COVID-19 pandemic, please supply a telephone number (and alternative number) to be contacted on _____ /_____.
Participants will be randomly selected.

Thank you for your time and participation.

APPENDIX B (Afrikaans)

B: Fase 1 DATA INSAMELINGSINSTRUMENT

Vraelys

STUDIE	COVID-19 ROUPROSES
DEELNEMER IDENTIFIKASIE NOMMER	

DEEL 1: Demografiese inligting

Geslag	Manlik		Vroulik		Ander	

Oud.	<20		20-29		30-39		40-49		50-59		60-69		70-79		>80	

Godsdiens	Christen		Moslem		Hindu		Geen		Ander	

Geloofsoortuigings	Voorvader geeste		Geen		Ander	

DEEL 2: Vraelys

29. Het enige van jou nabye geliefdes (ouer, kind, eggenoot, broer/suster, ander baie naby familie) afgesterf vanaf Maart 2020 en Augustus 2021?

JA		NEE	

Indien jy NEE geantwoord het op vraag 1, antwoord nou **vraag 21**. Jy hoef geen ander vrae te beantwoord nie.

30. Het jy meer as een geliefde verloor?

JA		Hoeveel?	2		3		>3	
NEE								

31. Wanneer het jou geliefde/s afgesterf? (maand/jaar) _____

32. Wie was die persoon/persone van jou?

Ouer		Kind		Broer/Suster		Eggenoot		Ander	

Indien Ander, spesifiseer asseblief _____

33. Is die sterfte veroorsaak deur COVID-19 die siekte?

JA		NEE	

34. Het die sterfte van jou geliefde skielik of onverwags gebeur?

JA		NEE	

35. Kon jy groet en tyd met jou geliefde spandeer voor die afsterwe?

JA		NEE	

36. Waar het jou geliefde afgesterf?

Hospitaal		Huis		Versorgingseenheid		Ander	

- Indien jou geliefde **nie in die hospitaal gesterf het nie**, gaan asseblief na **vraag 12.**

37. Indien jou geliefde in die hospitaal gesterf het, kon jy hom/haar besoek?

JA		NEE	

38. Indien jou geliefde in die hospitaal gesterf het, is jy ingelig gehou oor sy/haar toestand?

JA, volledig		JA, gedeeltelik		NEE	

Opmerkings:_____

39. Indien jy nie toegelaat is om te besoek nie, kon jy op ander maniere in kontak bly met jou geliefde? (bv., Sosiale media met video oproepe, stemboodskappe, foto's)

JA		NEE		Kon besoek / Nie van toepassing	

40. Het die trans-provinsiale reisverbod veroorsaak dat jy jou geliefde nie kon sien kort voor hul afsterwe nie?

JA		NEE	

41. Kon jy die begrafnis/roudiens bywoon?

JA		NEE	

42. Het die trans-provinsiale reisverbod veroorsaak dat jy nie die begrafnis/roudiens kon bywoon nie?

JA		NEE		Kon die begrafnis bywoon / NVT	

43. Is dit jou gebruik om die liggaam tuis te hê of te gaan besoek by die begrafnisondernemer?

JA, meestal		JA, soms		NEE	

44. Was dit moontlik om die liggaam tuis te bring of te gaan besoek by die begrafnisondernemer?

JA		NEE		Nie van toepassing	

45. Het die begrafnis anders afgeloop as wat dit sou voor die beperkings ingestel is? (Behalwe vir sosiale afstand handhawing, maskers en handsanitering)

JA, baie anders		JA, redelik anders		NEE, andersins dieselfde	

Opmerkings: _____

46. Het jy dieselfde mate van ondersteuning van jou sosiale netwerk gekry as met vorige verliese (voor COVID-19 regulasies)?

JA		NEE		Geen vorige verliese	

Opmerkings: _____

47. Indien jou geliefde aan ander oorsake as COVID-19 gesterf het, het jy gevoel dat jou verlies net so belangrik was soos COVID-19 verwante sterftes?

JA		NEE		My geliefde het gesterf as gevolg van COVID-19	

Opmerkings: _____

48. Kon jy help met die begrafnis reëlings?

JA, soos wat wou		JA, minder as wat wou		NEE, kon glad nie help nie		NVT/sou nie help nie	

49. Is daar rou ondersteuningsdienste by Eersterust CHC?

JA		NEE		Ek weet nie	

50. Het jy tans die behoefte aan emosionele ondersteuning om die verlies van jou geliefde te hanteer?

JA		NEE	

Opmerkings:

_____

Hoe gereeld het jy die **afgelope 2 weke** die volgende gedagtes, gevoelens of gedrag ervaar wat met jou verlies verband hou? (Vraag 23 - 27)

51. Ek wou sterf om by die oorledene te wees.

Nooit		Sommige dae		Meer as die helfde van die dae		Amper elke dag	

52. Ek het verwarring oor my rol in die lewe ervaar of gevoel dat ek minder werd is as gevolg van die verlies.

Nooit		Sommige dae		Meer as die helfde van die dae		Amper elke dag	

53. Niks het vir my meer saak gemaak nie, weens hierdie verlies.

Nooit		Sommige dae		Meer as die helfde van die dae		Amper elke dag	

54. Ek het dit moeilik gevind om positiewe herinneringe rondom die oorledene te hê.

Nooit		Sommige dae		Meer as die helfde van die dae		Amper elke dag	

55. Ek het gevoel dat sonder die oorledene, die lewe betekenisloos en leeg was, en dat ek nie kon aangaan nie.

Nooit		Sommige dae		Meer as die helfde van die dae		Amper elke dag	

DEEL 3: Bereidwilligheid om deel te neem aan groepsbespreking vir studie

56. Wil jy deel wees van 'n kleiner groep waar jou persoonlike ervarings van die verlies en rou verder bespreek sal word?

JA		NEE	

Indien jy instem om deel te neem aan die fokus-groep bespreking van 8-10 deelnemers oor jou ervarings, gee asseblief die telefoonnommer waarop ons jou kan kontak: _____.
Deelnemers sal lukraak gekies en in kennis gestel word.

Dankie vir jou tyd en deelname

APPENDIX B (Sepedi)

DATA COLLECTION TOOL
Phase 1: Lenaane la dipotso la

ITHUTOANG BOITSEBISO	COVID-19 HO AMOHUOA
YA MONKAKAROLO EO O BOITSEBISO NUMERO	

KAROLO EA 1: Babapatsi ba u fumane boitsebiso bo

Bong	E motona		E motshehadi		Tse ling	

Lilemo	<20		20-29		30-39		40-49		50-59		60-69		70-79		>80	

Bolumeli mokgatlo	Mokreste		Mamosleme		Hindu		Letho		Tse ding	

Litumelo	Meea ea balimo		Letho		Tse ding	

KAROLO EA 2: Lenaane la dipotso la

1. Na leha e le ba baratuoa ba hao (motsoali, ngoana, molekane, ngoan'eno,haufi Setho sa lelapa) o hlokahala pakeng tsa nakong ea Hlakubele 2020 ho isa Phato 2021?

Ee		Che	

Haeba u arabile ka Che , potsong ea 1, ka kopo araba ***potso ea 21***. Ha ho hlokahale hore u arabe e 'ngoe ea lipotso tse ling.

2. Na u lahlehetsoe ke moratuoa a fetang a le mong?

Ee		Ba bakae?	2		3		> 3	
Che								

3. Moratuoa oa hao o hlokahetse neng? (khoeli / selemo) _____
4. Motho eo / wa hao e ne e le mang?

Motsoai		Ngoana		Ngoan'eno		Molekane oa Hao		A mang	

Ha Other, ka kopo qaqisa _____

5. Ne e ntse e feta amana ka ho toba COVID-19, ho kula joang?

Ee		Che	

6. Na ho hlokahala ha moratuoa oa hau ho ile ka tšohanyetso / ka tšohanyetso?

Ee		Che	

7. U kile ua qeta nako u e-na le motho eo u mo ratang le ho mo lumelisa pele a feta?

Ee		Che	

8. Eo u mo ratang o hlokahetse kae?

Setsi sasepetlele		Lapeng		Tlhokomelo ea		Tse ling	

Haeba moratuoa oa hau **a sa hlokahala sepetlele**, ka kopo ea ***potsong ea 12***.

9. Haeba moratuoa oa hau a hlokahala sepetlele, na u ile ua lumelloa ho mo etela?

Ee		Che	

10. Haeba moratuoa oa hau a hlokahala sepetlele, na u ne u lula u tseba ka boemo ba bona?

Ee, ho lokaneng		Ee, karolo e 'ngoe		Che	

MAIKOTSO:

_____

11. Haeba u sa lumelloa ho etela sepetlele, na u sebelisitse mekhoa e meng ea ho ikopanya? (Mohlala, Mecha ea phatlalatso e nang le ho letsetsa video, lintlha tsa lentsoe, linepe)

Ee		Che		Ba khonne ho etela	

12. Na lithibelo tsa maeto a liprofinse li u sitisitse ho bona moratuoa oa hau kapele pele ba feta?

Ee		Che	

13. O khonne ho ea lepatong / sehopotsong?

Ee		Che	

14. Na lithibelo tsa maeto a liprofinse li u sitisitse ho ea lepatong?

Ee		Che		Ba khonne ho ea	

15. Na ke tloaelo ea hau ho ba le setopo lapeng kapa ho shebella setopo ntlong ea lepato?

Ee, haholo-holo		Ee, ka nako e 'ngoe		Che	

16. Na ho ne ho khoneha ho ba le setopo lapeng kapa ho shebella setopo ntlong ea lepato?

Ee		Che		Ha e ea sebetsa	

17. Na linyeoe tsa lepato li ne li fapane ha li bapisoa le litloaelo tsa hau tse tloaelehileng? (Ntle le ho its'etleha sechabeng, limaske le ho itlhoekisa)

Ee, ho joalo haholo		Ee, ho joalo ha nyenyane		Che	

Maikotso: _____

18. Na u kile oa ikutloa u ts'ehetsoe ke ba leloko la hau ea hau ea sechaba nakong ea tahlehelo ena ha e bapisoa le tahlehelo e fetileng (pele ho melao ea COVID-19)?

Ee		Che		Ke ne ke se na tahlehelo	

				ea pejana	

TLHOKOMELISO:

_____

19. Haeba moratuoa oa hau a sa ka a hlokahala ka lebaka la COVID-19 kapa litlamorao tsa eona, na u ile oa utloa eka tahlehelo ea hau e ntse e le bohlokoa joalo ka tahlehelo / lefu la COVID-19?

Ee		Che		Moratuoa oa ka o fetile ka lebaka la COVID-19	

TLHALOSO: _____

20. Na u khonne ho thusa ka litokisetso tsa lepato?

Ee, joalo ka ha o ne o batla		Ee, ka tlase ho ho batla		Che, o sa khone ho hang		Ha ho na takatso ea ho thusa ka litokisetso	

21. Na ho na le tlhabollo ea batho ba shoetsoeng e fumanehang Eersterust CHC?

Ee		Che		Ha ke tsebe	

22. Na u ikutloa hore ha joale u hloka tšehetso ea maikutlo ka hlokahala ha moratuoa oa hau?

Ee		Che	

TLHALOSO:

_____

Libekeng tse 2 tse fetileng, ke hangata hakae u bileng le maikutlo a latelang, maikutlo, kapa boitšoaro bo amanang le tahlehelo ea hau? (Potso ea 23-27)

23. Ke ne ke lakatsa ho shwa hore ke be le mofu.

Ho hang		Matsatsi a ‘maloa		Matsatsi a fetang halofo		Hoo e ka bang letsatsi le letsatsi

24. Ke ile ka ba le pherekano mabapi le karolo ea ka bophelong kapa ka ikutloa eka boitsebiso ba ka bo fokotsehile ka lebaka la tahlehelo.

Ho hang		Matsatsi a ‘maloa		Matsatsi a fetang halofo		Hoo e ka bang letsatsi le letsatsi

25. Ha ho letho le neng le bonahala le le bohlokwa ho nna ka lebaka la tahlehelo ena.

Ho hang		Matsatsi a ‘maloa		Matsatsi a fetang halofo		Hoo e ka bang letsatsi le letsatsi

26. Ke ne ke thatafalloa ke ho hopola lintho tse ntle ka mofu.

Ho hang		Matsatsi a ‘maloa		Matsatsi a fetang halofo		Hoo e ka bang letsatsi le letsatsi

27. Ke ne ke lumela hore ntle le mofu, bophelo bo ne bo se na morero, bo se na morero, kapa bo ne bo ke ke ba tsoela pele.

Ho hang		Matsatsi a ‘maloa		Matsatsi a fetang halofo		Hoo e ka bang letsatsi le letsatsi

KAROLO 3: Ikemiselitse ho ba le seabo puisano ea sehlopha

28. Na u ka rata ho ba karolo ea sehlopha hore se tla tšohla phihlelo ea hao saretsoeng ka ho eketsehileng?

Ee		Che	

Haeba u lumela ho nka karolo lipuisanong tsa sehlopha se senyenyane sa barupeluoa ba 8-10 ka boiphihlelo ba hau kamora ho hlokahala ha moratuoa oa hau nakong ea seoa sa COVID-19, ka kopo fana ka nomoro ea mohala eo u ka ikopanyang le eona ho _____. Barupeluoa ba tla khethoa ka mokhoa o ikhethileng.

Ke leboha nako ea hau le ho nka karolo.

APPENDIX C

C: Phase 2 PARTICIPANT'S INFORMATION AND INFORMED CONSENT

The focus group discussion

Study title: The impact of the COVID-19 pandemic on the grief and bereavement of the Eersterust community.

Principal Investigator: Dr Delene Murray, Medical Doctor, Eersterust Community Health Centre.

Supervisor: Dr Liesl Visser, Senior Family Physician and Senior Lecturer, University of Cape Town.

Institution: School of Public Health and Family Medicine (Interdisciplinary Palliative Care & Medicine), University of Cape Town.

Enquiries and Contact information: Dr Delene Murray ECHC at 012 806 1300, C/O Hans Coverdale East and P.S Fourie Street, Eersterust.

Date of informed consent discussion:

13	June	2022
Day	Month	Year

Dear Prospective Participant,

1) Introduction

You are invited to participate in a research study. I am doing this research to complete the Masters' degree in Palliative Medicine at the University of Cape Town. This document gives you information to help you decide if you would like to participate. Before you agree to take part in this study you should fully understand what is involved. If you have any questions, which are not fully explained in this document, do not hesitate to ask. You should not agree to take part unless you are completely happy about what we will be discussing during the focus group discussion.

2) The nature and purpose of study

The aim of this study is to explore how COVID-19 and the lockdown regulations had changed the grieving process of the public health care users of the Eersterust community.
This part of the study will be a focus group discussion. A focus group is where a few people – usually about 8 to 10 – get together with the researcher to discuss a specific topic. The discussion will be arranged at a time that is convenient to you and will take place at Eersterust CHC, Rehabilitation Hall.

3) Explanation of procedures and what will be expected of participants.

If you agree to participate, you will be asked to join in a focus group discussion which will take about 60-90 minutes. You and the other participants will be asked a few questions about your personal experience on how the COVID-19 regulations influenced your dealing with the passing of your loved one, as well how much bereavement support you still need. With your permission, the discussions will be recorded on a recording device to ensure that no information is missed. The researcher (Dr Delene Murray), Ms Lucinda Risseeuw, (a clinical psychologist), Ms Emma Shabangu (Counsellor) and the other participants will be part of the interview.

4) Risks and discomforts involved.

Participation in the study will not cause any physical risk. We do, however, foresee some emotional discomfort since we will be discussing the loss of your loved one. You do not have to share anything that you are not comfortable with. During the discussion, you may find that some questions are sensitive, for instance, questions about how you experienced your loss during the COVID-19 lockdown and how much it may still be affecting you. If questions feel too personal or make you uncomfortable, you do not have to answer them. You are also allowed to stop participating in the discussion at any time. If you need any psychological support or counselling during or after the focus group discussion, you will be able to see one of our qualified professionals. Your discussion and opinion as expressed during the group will be kept confidential and your response will not be linked to your identity when the results are written up. Your identity will not be revealed in any report or discussion that will follow the study.

5) Possible benefits of the study

There is no direct benefit by being part of this study, although you might feel better after sharing your personal experience. Your participation will, however, help us to better understand the effect the COVID-19 regulations on the community's experience of loss and grief. The information you give may help the researcher improve bereavement support and counselling for more people in the community that has been affected.

6) Compensation

You will not be paid to take part in the study. There are no costs involved for you to be part of the study, apart from travelling to the clinic.

7) Voluntary participation

The decision to take part in the study is yours and yours alone. You do not have to take part if you do not want to. You can also stop at any time during the interview without giving a reason. If you decide not to take part in the study, it will not affect you in any way. You will still receive standard care and treatment at the clinic.

8) Ethical approval

This study was submitted to the Human Research Ethics Committee of the Faculty of Health Sciences at the University of Cape Town, G50 Old Main Building, Groote Schuur Hospital, Observatory, Cape Town, telephone number 021 650 1236 and written approval has been given by that committee. The study will follow the Declaration of Helsinki (last update: October 2013), which

guides doctors on how to do research in people. The researcher can give you a copy of the Declaration if you wish to read it.

9) Information on who to contact.

If you have any questions concerning this study, you can contact Dr Delene Murray at Eersterust CHC on 012 806 1300.

10) Confidentiality

We will not record your name anywhere and no one will be able to connect you to the answers you give. Your answers will be linked to a made-up code, or a pseudonym (another name) and we will refer to you in this way in the data, any publication, report, or other research output. All records from this study will be regarded as confidential. Results will be published in medical journals or presented at conferences in such a way that it will not be possible for people to know that you were part of the study.

The records from your participation may be reviewed by people responsible for making sure that research is done properly, including members of the Human Research Ethics Committee. These people are required to keep your identity confidential. Otherwise, records that identify you will be available only to people working on the study, unless you give permission for other people to see the records.

Although all participants of the focus group discussion will be requested to keep the entire discussion confidential, the researcher cannot guarantee that they will do so. I therefore request that you decide what information you are willing to share with the group.

11) Consent to participate in this study.

- I confirm that the person asking my consent to take part in this study has told me about the nature and process, any risks or discomforts, and the benefits of the study.
- I have also received, read, and understood the above written information about the study.
- I have had enough time to ask questions and I have no objections to participate in this study.
- I am aware that the information obtained in the study, including personal details, will be anonymously processed, and presented in the reporting of results, without disclosing my identity.
- I understand that I will not be penalised in any way should I wish to discontinue with the study and my decision will not affect my treatment and care.
- I am participating willingly.
- I have received a signed copy of this informed consent agreement.

_____ _____

Participant's name (Please print) Date

_____ _____

Participant's signature Date

_____ _____

Researcher's name (Please print) Date

_____ _____

Researcher's signature Date

I understand and give consent that the focus group discussion will be audio recorded.
(Circle your answer)

YES / NO

APPENDIX D

D: Phase 2 DATA COLLECTION TOOL

STUDY IDENTIFICATION	COVID-19 BEREAVEMENT
PARTICIPANT IDENTIFICATION NUMBER	

Focus group interview.

Guided conversation with 8-10 participants around three themes:

- Changes in norms
- Personal experience of loss during lockdown
- Access to counselling and support

Interview format

Introduction	• Introduction of self, psychologist, and participants • Reason for invitation explained. • Informed consent process done (Appendix C) • Time allocated for discussion 60-120min. • Confidentiality statement • Storage of data • Distress protocol explanation (Appendix E)
Ice breaking question	1. Tell me about the circumstances of the passing of your loved one in the period March 2020 – August 2021? (Covid related, Hospitalisation, Funeral arrangements)
Open-ended questions (not all will be used if conversation is naturally unfolding)	2. How did the COVID-19 restrictions affect your experience of the loss? (Isolation rules, fear of illness, last goodbyes, funeral arrangements) 3. How supported did you feel? (Social support and organisation support) 4. How are you coping currently? (Need for further counselling and support)
Closing statements	Summary, reminder on confidentiality request Appreciation for participation

APPENDIX E

E: The Distress Protocol

As the study involves the emotive topic of grief and bereavement the potential harm that is foreseen is that participants may experience a distressing emotional trigger when discussing their loss. The distress may prevent continuation of the interview and leave the participant unsatisfied. The distress protocol is to be used if any participant shows signs of distress throughout the data collection process but especially during the focus group interview. This will ensure that if the topic of loss causes significant emotional distress for any participant it is handled compassionately.

The informed consents (Appendices A and C) include sections about the possibility of experiencing these distressing events. The participant will be assured that they may stop the interview at any time and be offered the help needed from the mental health psychologists, but still having the option to continue the interview.

As soon a participant shows signs of emotional turmoil such as shedding tears, trembling voice or withdrawal from conversation, the investigator will approach the participant and follow these steps:

1. Take him/her to a quiet separate place.
2. Ensure trust, privacy, and confidentiality.
3. Put participant at ease with active listening techniques.
4. Give opportunity to express feelings if wants to talk about it.
5. Discuss if wants to continue with participation or withdraw consent.
6. If not keen on discussing emotions at current time, options given to meet with someone at the Mental Health Unit (Clinical psychologists or social worker)

As a palliative care practitioner, the researcher is trained in complex conversations and ECHC has both social workers and psychologists as a part of the team.

F: HREC approvals

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room 45 E-52-E-Floor- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-submissions@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

22 April 2022

HREC REF: 542/2021

Dr L Visser
Division of Family Medicine
Email: lvisser@gmail.com
Student:delenemurray@gmail.com

Dear Dr Visser

PROJECT TITLE : THE IMPACT OF THE COVID-19 PANDEMIC ON THE GRIEF AND BEREAVEMENT OF THE EERSTERUST COMMUNITY
(MPHIL DEGREE – DR DELENE MURRAY)

Thank you for your response letter, addressing the issues raised by the Faculty of Health Sciences Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19, our letter dated 02 February 2022 provides guidance found on our website:
http://www.health.uct.ac.za/fhs/research/humanethics/forms

Approval is granted for one year until the 30 April 2023.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

The HREC acknowledge that the student: Dr Delene Murray will also be involved in this study.

Please quote the HREC REF 542/2021 in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

pp **PROFESSOR M BLOCKMAN**
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637. Institutional Review Board (IRB) number: IRB00001938 NHREC-registration number: REC-210208-007
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2020), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

UNIVERSITY OF CAPE TOWN
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FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938)			
This serves as notification of annual approval, including any documentation described below.			
☑ Approved	Annual progress report	Approved until/next renewal date	30.11.2024
☐ Not approved	See attached comments		
Signature Chairperson of the HREC/ Designee	Signed by candidate	Date Signed	11/11/2023

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

HUMAN RESEARCH ETHICS COMMITTEE
- 9 NOV 2023
HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN

Comments to PI from the HREC.

Form FHS007: Amendment – study staff

HREC office use only (FWA00001637; IRB00001938)			
☐ Approved			
This serves as notification that all changes to the study staff and documentation described below are approved.			
Chairperson of the HREC signature/ Designee	Signed by candidate	Date	11/11/2023

Note: Please note that incomplete amendment submissions will not be reviewed.
Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za.

HUMAN RESEARCH ETHICS COMMITTEE
- 9 NOV 2023
HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN

Please clarify your plan for research-related activities during COVID-19 lockdown.

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	7 Nov 2023
HREC REF Number	542/2021
Protocol title	The impact of the COVID-19 pandemic on the grief and bereavement of the Eersterust community.
Protocol number (if applicable)	
Principal Investigator	Dr Liesl Visser
Department / Office Internal Mail Address	lvisserdr@gmail.com

1.1 Does this protocol receive US Federal funding?	☐ Yes	√☐ No

2.1 Staff changes (tick ✓)

Are new personnel being added to this research?	✓☐ Yes	☐ No
Are current personnel being removed from this research?	☐ Yes	✓☐ No
Is the principal investigator for this research being changed? If yes, please attach revised conflict of interest and PI declaration statements. (Refer: sections 7 and 8.3 in the New Protocol Application Form - FHS013)	☐ Yes	☐ No

Do the consent and assent forms need modification to reflect these staff changes? If yes, please attach copies of the revised forms, with all changes highlighted or tracked and listed in the documents for approval.	☐ Yes	√☐ No

2.2 Amended study staff details

Title, first name, surname	Department/Division	E-mail	Role of new staff member
Dr Lindsay Farrant	**FaCE / IPCM**	**Lindsay.farrant@uct.ac.za**	**New PI and supervisor**
Dr Liesl Visser		**lvisserdr@gmail.com**	**Continuing as supervisor but no longer a UCT staff member**

3. List of documentation for approval

Please list below all staff documentation such as CVs, declarations, GCP certificates and revised consent forms which need approval. This information must correspond to all 'yes' answers in 2.1 above. This form will be signed and returned to the PI as notification of approval. Please add extra pages if necessary.

FHS016

4. Signature

My signature certifies that I will maintain the anonymity and/ or confidentiality of information collected in this research. If at any time I want to share or re-use the information for purposes other than those disclosed in the original approval, I will seek further approval from the HREC.

Signature of PI	Signed by candidate	Date	07 November 2023

G: Permission from study site

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Enquiries: Dr. Manei Letebele-Hartell
Tel: +27 12 451 9036
E-mail: Troy.Mashabela@gauteng.gov.za

TSHWANE RESEARCH COMMITTEE: CLEARANCE CERTIFICATE

DATE ISSUED: 10/05/2022
PROJECT NUMBER: 27/2022
NHRD REFERENCE NUMBER: GP_202204_064

TOPIC: The impact of the COVID-19 pandemic on the grief and bereavement of the Eersterust community

Name of the Lead Researcher:	Dr Liesl Visser Dr Delene Murray
Facilities:	Eersterust CHC
Name of the Department:	University of Cape Town

NB: THIS OFFICE REQUEST A FULL REPORT ON THE OUTCOME OF THE RESEARCH DONE AND

NOTE THAT RESUBMISSION OF THE PROTOCOL BY RESEARCHER(S) IS REQUIRED IF THERE IS DEPARTURE FROM THE PROTOCOL PROCEDURES AS APPROVED BY THE COMMITTEE.

DECISION OF THE COMMITTEE: APPROVED

Signed by candidate

.....
Dr. Mpho Moshime-Shabangu **Date**...10/05/2022.....
Deputy Chairperson: Tshwane Research Committee

.....Signed by candidate.. **Date:** 2022.05.10
Mr. Mothomone Pitsi
Chief Director: Tshwane District Health

Annexure 1

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DECLARATION OF INTENT FROM THE PHC MANAGER FOR TSHWANE PROVINCIAL CLINICS

I give preliminary permission to **Dr Liesl Visser** to do his or her research on **"The impact of the COVID-19 pandemic on the grief and bereavement of the Eersterust community"** In **Eersterust CHC**

I know that the final approval will be from the Tshwane Regional Research Ethics Committee and that this is only to indicate that the clinic/hospital is willing to assist.

Other comments or conditions prescribed by the PHC Manager to the Researcher are

The researcher to have an entry meeting with potential facilities before starting with the data collection.

Signed by candidate

Mr M. Makhudu
Primary Health Care: Tshwane
Date: 3/5/2022

H: Additional tables

Table 4: Lockdown levels with dates (43)

Lockdown level	Dates level applied	Total nr of months
Alert level 5	26 March 2020 - 30 April 2020	1
Adjusted alert level 4	28 June 2021 - 25 July 2021	1
Alert level 4	1 – 31 May 2020	1
Adjusted alert level 3	29 December 2020 - 28 February 2021 16 June 2021 - 27 June 2021	2,5
Alert level 3	1 June 2020 - 17 August 2020 26 July 2021 - 12 September 2021	4
Adjusted alert level 2	31 May to 15 June 2021 13 September 2021 - 30 September 2021	1
Alert level 2	18 August 2020 - 20 September 2020 1 June 2021 - 15 June 2021	1,5
Adjusted alert level 1	1 March 2021 – 30 May 2021 1 October 2021 - 4 April 2022	9
Alert level 1	21 September 2020 - 28 December 2020	3
National state of Disaster lifted.on 5 April 2022		**24**

The National state of Disaster lasted for 24 months after its implementation on 26 March 2020. Various levels of lockdown were created by the South African government based on various factors to reduce transmission and ready medical facilities (43).