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## THE EXPERIENCES OF RELATIVES OF COVID - 19 PATIENTS DURING HOSPITALIZATION IN THE ICU IN MACHAKOS COUNTY AND REFERRAL HOSPITAL, MACHAKOS COUNTY, KENYA

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### ABSTRACT

**Background:** COVID-19 disease had a significant influence on the wellbeing of the patients and their relatives. Diagnosis of Covid-19 during the pandemic was majorly associated with increased family stigma and increased emotional and psychological stress among patients as well as relatives. Patients who were admitted into intensive care unit left major stress and pressure on their relatives. However, there is limited focus on the needs and wellbeing of relatives of patients admitted into ICU due to Covid-19. Thus, this study sought to explore the experiences of relatives of patients diagnosed with Covid-19 admitted into intensive care unit in Machakos County and Referral Hospital.

**Methods:** The study's research design was descriptive qualitative using a phenomenological approach. Purposive sampling technique was employed where Relatives of COVID - 19 Patients During Acute Hospitalization in in the intensive care unit in Machakos County and Referral Hospital were recruited. A total of 10 participants were included in the study. Data was collected from participants using an in-depth interview guide and participant observation. The interviews were audio-taped and transcribed verbatim and common themes identified iteratively. Data analysis was done thematically.

**Results:** There were four major themes that were identified and eight sub-themes. The themes identified include reminiscence of ICU admission process, commitment and passion for care, isolation and restricted access as well as hope and resilience. The reaction to the news of ICU admission of loved ones was characterized by a feeling of helplessness, stress and shock. The healthcare providers at the facility were highly committed and willing to assist amid restricted environment. Individual based experience was characterized by emotional confusion and unmet need to participate in care. Coping measures that were effective included support from healthcare providers, family and friends as well as accepting the situation.

**Conclusion and recommendations:** There were major challenges in communication and unmet needs of participating in care process. The high emotional confusion, stress and shock that most of the relatives felt define the need to improve commitment to the needs and wellbeing of patients as well as their relatives. This can be done through encouraging relatives of patients admitted in ICU to express their emotions and provide resources for professional counselling or support groups.

**Key Words:** Covid-19, Pandemic, Patients Experience, Machakos County

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## INTRODUCTION

The impact of the Corona Virus Disease 2019 (COVID-19) pandemic continued to expand globally, as health systems continued to be exposed. The disease had a significant influence on the lives of both patients and their relatives. The disease, which was first identified in Wuhan, China, in 2019, spread significantly fast and was declared a pandemic by the World Health Organization (WHO) in the same year. A year later, after the first case, the WHO reported 400 million confirmed cases with more than 5 million deaths. This abrupt surge made the demand for ICU and ventilators to aid patients in breathing significantly high. This crisis strained healthcare systems, leading to some patients being unable to access the much-needed care. The lack of proper care led to caregivers of the patient report different experiences.

Existing studies demonstrate that caregivers of patients in the ICU require physical, emotional, and psychological support since it is often stressful and increases symptom burden to the patient's relatives (Kiwunuka et al., 2020). The increased risk of undesired outcomes such as death and unexpected complications of the illness also causes significant stress to the patient's relatives (Frivold *et al.*, 2016). The severity in the health outcomes of relatives with patients in the ICU have been reported in various studies. According to a research by Bolosi *et al.*, (2018) conducted in Greece, 38% of relatives of patients in ICU had significantly high levels of depressive symptoms on day one of the admission. The rate rose to 58.3% by day seven.

The role played by family members in care of patients in ICU has been significant and thus considering the Covid19 period when the laws regarding patient visitation were reviewed created a major gap in care delivery among respondents. Some of the challenges that have had influence on experiences of relatives include literacy level, communication especially with care providers and emotional wellbeing (Kentish-Barnes et al., 2021).

Hospitals during the Covid-19 period played a major role in negatively influencing the wellbeing of relatives since there was significant increase in the level of distress since relatives were unable to have contact with their relatives but relayed on information shared by their healthcare providers (Bhanot et al., 2021). During the period when a patient is admitted in the ICU, family separation has been identified as a major challenge as the hospitals continue focus on controlling the spread of Covid-19 (Bartoli et al., 2021).

Kiwunuka et al. (2020) stated that separation of relatives during the pandemic has been difficult and has been largely associated with disruptive behaviour. Families have been forced to develop strategies and approaches which would help in management of the needs and wellbeing of patients. Family play a major role especially to the recovery process of the patient and thus, it is imperative to focus on building a strong platform to improve focus on their needs and wellbeing.

Change on the lifestyle of family members especially when a family member is admitted resulting from highly contagious disease such as Covid, the lifestyle of family member is disrupted and anxiety sets in among family members (Chen et al., 2021). Therefore it is imperative to focus on the emotional wellbeing of family members who are having extreme challenge in coping with the situation created by Covid 19 (Bartoli et al., 2021). Relatives have been having higher concerns regarding the wellbeing of their patients admitted in ICU which have been largely characterized by anxiety, loss of control, frustration and depression (Devlin et al., 2020).

The fact that there is reduced chance of a COVID-19 patient admitted in ICU to survive has increased the level of anxiety and stress among relatives of patients admitted in ICU. Thus, assessment of their experiences forms an integral part of their recovery since they are able to discuss their experiences. The situation has been made difficult by the implementation of the COVID-19 prevention guidelines which focus on restricted

visitation. Many of family members are unable to access their loved ones in ICU due to high chance of infection (Kentish-Barnes et al., 2021).

In Kenya, as of November 2021, there have been approximately 254, 862 confirmed cases and 5,333 deaths. However, it is understood that these statistics might not be a true reflection of the COVID-19 situation in the country due to limited capacity to test general population. Kenya has been struggling with containment of Covid-19 as well as management of the condition due to limited ICU beds and oxygen supply with only around 58 percent of ICU hospitals in the country having oxygen. The number of beds available for Covid-19 patients vary significantly across different counties with some of the counties reporting less than 20% bed capacity in ICU.

However, the surge of the disease meant that there were influx of patients seeking emergency care. It was affirmed that only 22 of the 47 counties in Kenya had at least one ICU which in turn created a major gap in care delivery. However, there has been less consideration on the experiences of patients who were admitted in ICU to help understand the extent of the problem and how it influenced their commitment to deliver quality care (Barasa et al., 2020). During this time, relatives of patients who need ICU care have been faced with diverse challenges. However, these issues have not been effectively investigated in local context exhaustively which prompts the need for understanding the needs of relatives and their experiences. Kenyatta University Teaching and Referral Hospital was turned into a Covid-19 center where many of the patients seeking ICU care in Nairobi county and neighbouring counties were transferred.

### **Problem statement**

Covid-19 has presented a different perspective especially in healthcare setting where there was no restriction. Hospital context is a high-risk area where the spread of infection is easy. The Covid-19 is a highly infectious disease which has had detrimental influence on individual wellbeing across all sectors (Fonseca *et al.*, 2019). The rate of admission has been significantly high considering high rate of exposure. As a result of high level of spread, visitation have been restricted and interaction reduced significantly between relatives of patients and healthcare providers compared to prior situation (Gordon et al., 2021). New care guidelines have been adopted which have been difficult for relatives especially considering no patient visitation policy and limited interaction with healthcare providers. However, the experiences of relatives in relation to care of their relatives admitted in ICU due to Covid-19 have not been fully investigated creating a gap in striving to create an improved focus on improved quality of care delivery despite the existing challenges brought about by Covid-19 pandemic. Therefore, to help understand the wellbeing of relatives of patients with covid-19 admitted in ICU, this study seeks to investigate the experiences as well as coping strategies based on the existing situation.

### **Research Questions**

- How does the recollection of events influence emotional distress among relatives of patients diagnosed with COVID-19 during acute hospitalization in the intensive care unit at Machakos County and Referral Hospital?
- What physical experiences contribute to emotional distress among relatives of patients diagnosed with COVID-19 during acute hospitalization in the intensive care unit at Machakos County and Referral Hospital?
- What psychological experiences are associated with emotional distress among relatives of patients diagnosed with COVID-19 during acute hospitalization in the intensive care unit at Machakos County and Referral Hospital?
- How do relatives' perceptions of care received influence their emotional distress during the acute hospitalization of a patient with COVID-19 in the intensive care unit at Machakos County and Referral Hospital?

## **Objectives**

The broad objective of the study was to explore the experiences of Relatives of COVID-19 Patients During Acute Hospitalization in the intensive care unit in Machakos County and Referral Hospital. The study was guided by the following specific objectives;

- To explore the effect of recollection of events on emotional distress among relatives of patients diagnosed with COVID-19 during acute hospitalization in the intensive care unit at the Machakos County and Referral Hospital.
- To examine the physical experiences contributing to emotional distress among relatives of patients diagnosed with COVID-19 during acute hospitalization in the intensive care unit at Machakos County and Referral Hospital.
- To investigate the psychological experiences associated with emotional distress among relatives of patients diagnosed with COVID-19 during acute hospitalization in the intensive care unit at Machakos County and Referral Hospital.
- To assess how perceptions of care received influence emotional distress among relatives of patients diagnosed with COVID-19 during acute hospitalization in the intensive care unit at Machakos County and Referral Hospital.

## **LITERATURE REVIEW**

### **Theoretical Framework**

Neuman's health systems model is a health systems model developed by Betty Neumann. This theory is based on a person's relationship to stress, response and reconstitution factors which are mainly progressive in nature. Thus, this system presents a broad and holistic system-based method to nursing and maintains a certain level of flexibility. It emphasizes on response to actual or potential environment. The model views an individual as an open system that is susceptible to stressors in the environment. The variables that are investigated in this case include physiological, psychological, socio-cultural, spiritual as well as developmental. The key underlying concepts that exist in this case include human being, environment, health, nursing and open system. Thus, this theory is appropriate in this context considering that it helps understand the underlying differences in explaining individual wellbeing and development. The experiences that relatives have when seeking to visit their relatives admitted in ICU are influenced by the guidelines and processes that are implemented within care context. Communication presents a crucial factor that helps in offering a stronger platform for successful level management of the existing diverse needs. The uncontrolled system is different, and there is no limit to the source of information as well as the changes that are likely to be made. Therefore, this theory presents an understanding of the structure of the organization and approach that is adapted to maintain a stable performance level.

## **LITERATURE REVIEW**

### **Emotional Distress Arising from Recollection of Events**

Global studies have shown a significant association between the admission of a relative to the ICU and profound emotional burden. These studies have demonstrated that families often experience shock, disbelief, and an immediate sense of helplessness whenever their patient is transferred to the ICU. For relatives of the COVID-19 patients, these intense reactions were pronounced by the sudden hospitalization of their kin, which created a psychological change of course in their lives. A study by Bartoli et al. (2021) noted that the abrupt ICU admissions disrupted the emotional preparedness and deepened the trauma of the relatives, especially when the admissions came with limited or unclear communication from healthcare professionals. This resulted in emotional, physical, and psychological detachment, which led to significant feelings of powerlessness among relatives.

The distress was worsened when communication was not forthcoming from health service providers. With visitation severely restricted during the pandemic, relatives of the COVID-19 patients were not able to offer their desired help and support to their loved ones directly. According to Tringali et al. (2021), most families received intermittent medical updates via telephone, a method that many found inadequate for capturing the full picture of the patient's condition. The lack of their physical presence made it difficult for family members to trust the care their relatives were receiving.

A study by Jetliner et al. (2020) substantiated these findings when they observed that families reported fragmented and sometimes contradictory updates and had no specific facility-allocated service provider to offer updates. In such contexts, even small discrepancies create mistrust and reinforce perceptions of exclusion from the care process. For family members, the recollection of these events not only affected them emotionally, but they also exacerbated uncertainty, fear, and isolation by the health systems.

### **Physical Experiences Contributing to Emotional Distress**

Existing studies demonstrate evidence that physical experiences surrounding ICU admissions during the COVID-19 pandemic period contributed directly to emotional distress in family members. One of the most cited themes in our reviewed literature was the stigmatization of families with COVID-19 patients. Studies observe that in many settings, especially those in developing countries, families with COVID 19 patients were shunned by community members due to the fear of getting infected. A USA-Based study by Chen and colleagues established that family members perceived themselves as socially avoided, oftentimes blamed for the spread of the infection (Chen et al, 2021). Their findings are in agreement with an Indian study by Bhanot et al (2021), which observed that patients and their kin were stereotyped as careless and negligent and that they were the cause of the spread of the disease. Whereas these stereotypes were unjustified, they imposed a psychological burden on the families of COVID-19 patients and raised communal fear and misinformation.

Similarly, a 2021 study conducted in China by Yuan and colleagues observed that having a family member diagnosed with COVID-19 significantly increased the risk of stigmatization. Their study observes that relatives of COVID-19 patients experienced a significant increase in stigma and social isolation stemming from the fear of infecting other people and subsequently increasing the chances of death within communities. The experience of being avoided, denied social support, and being left to handle the care burden alone under the suspicion of being infected created a hostile environment, which in turn increased the psychological strain (Yuan et al, 2021)

Other than the psychological and physical burden, the day-to-day logistical burden introduced a heavy emotional toll on families of COVID-19 patients. Studies suggest that family members of COVID-19 patients often face long waiting times, challenges with getting medication for their patients, and the lack of comfortable waiting areas. These challenges were more pronounced in low- resource settings like Kenya. These challenges were worsened by COVID-19 restrictions, such as visitation restrictions, which denied relatives a chance to be present at their patients' bedside, further disconnecting them from their loved one's condition and exacerbating emotional exhaustion (Villalobos et al, 2018). According to Villalobos et al. (2018), in such environments, meaningful interaction between health service providers and families of the COVID-19 patients becomes critical, not just for communication but also for the reduction of the feeling of isolation and hopelessness.

### **Psychological Experiences Associated with Emotional Distress**

The combination of restricted access, intermittent, and inconsistent information created a volatile emotional environment. According to studies, psychological experiences of relatives of ICU patients are commonly characterized by anxiety, fear, stress, and, in some cases, emotional disintegration (Bartoli et al, 2021). In their study, Bartoli and colleagues established that families are often forced into self-isolation while their loved ones are hospitalized. This leads to intense anxiety and a sense of dre hopelessness. They cite that relatives of

COVID-19 experience psychological distress related to the inability to provide the support or witness care process.

Several studies have cited anxiety and fear as common psychological experiences among family members of COVID-19 patients. These studies identified media reports on the death rates, facility reports about the shortage of supplies such as the lack or shortage of oxygen, and ICU bed crises as common sources of distress among relatives (Tringle et al, 2021). Other studies cite disconnect between public and social media narratives and the real-time information from hospitals and global bodies such as the WHO as the main drivers of distress among families of COVID-19 patients. These reports opine that the disconnect led the families to constantly contemplate the worst-case scenarios, thus the spiralling fear Hochendoner et al. (2021).

A study by Kiwanuka et al. (2022) cites the absence of visitation rights and uncertainty of the patient's outcome as one of the main causes of psychological stress. They observe that seeing a loved one intubated and unresponsive, often through glass doors, photos, or videos, caused families psychological trauma and that these experiences, compounded by the lingering emotional pain, were psychologically unbearable. A study by Hochendoner et al. (2021) agrees with these findings and further observe that the lack of supportive interaction with health service providers weakened the relational infrastructure necessary for the family's resilience.

A study by Barnes et al. (2021) reported loneliness and separation as the primary cause of emotional distress among family members of COVID-19 patients. According to their study, family members of patients described the ICU process as "void: both emotionally and socially. Studies opine that separating critically ill patients from their families, especially when the prognosis is poor, only intensifies the feelings of abandonment and grief. (Kentish-Barnes et al. 2021). According to Kentish-Barnes and colleagues, this separation was dehumanizing, especially since the separation made it impossible for family members to provide their loved ones with comfort and presence, which family members thought was necessary for the patient's recovery. This emotional detachment contributed to the emotional pain that lingered beyond the ICU stay (Kentish-Barnes et al. 2021).

### **Perceptions of Care and Their Relationship to Emotional Distress**

The way families perceive the care being provided for their loved ones has a significant influence on their emotional reaction. During the COVID-19 season, these perceptions were mostly driven by their interaction with healthcare staff, the quality of information they received about their patient, and how well involved or excluded from the care of their patient.

In developed nations, the use of technology such as video calls and tele-health platforms helped bridge the feeling of exclusion from care. Pedrosa et al. (2020) observed that the presence of digital tools helped to stay updated, even when they were physically distant from their kin. Such experiences were not possible in resource-strained settings, which lacked such infrastructure, thus leading to families feeling excluded from the care of their loved ones. Chen et al. (2021) found that in the U.S., families, to a great extent, appreciated the dedication of health workers but felt reluctant to "burden" providers further. This revealed a tension between trusting the health systems to take care of their patient and the guilt of not being there to render the much-needed love and support. Similarly, Devlin et al. (2020) observed that the ability of a facility to provide truthful feedback with empathy led to higher levels of satisfaction, even when family members were restricted from accessing their patients. These findings are contrasted by those of Hart and Taylor (2021), who established that inconsistent communication, especially in overwhelmed ICUs, led to emotional distancing and a feeling that relatives were not an integral part to the care processes.

It is on such account that Kiwanuka et al. (2022) emphasizes the need for interdisciplinary nurse-led interventions. His study establishes that such programs enhance caregiver-family communication, addresses the unique emotional needs of the family, and involves families in the care process of their kind while

truthfully and empathetically communicating patient updates to the family. However, during the COVID-19 period, most settings, especially in public hospitals, such initiatives were not available. This made families to feel excluded, uninformed, and emotionally unsupported. These negative perceptions heightened distress and eroded trust in the health system.

### **Coping Mechanisms Used by Family Members**

Studies demonstrate a wide array of coping mechanisms employed by family members. Common themes include faith-based approaches and problem-solving strategies. Koukouli et al. (2019) describe coping as “the capacity to manage environmental challenges while maintaining emotional and cognitive function.” In the ICU hospitalization context, coping was mostly situational, driven by cultural beliefs, gender roles, previous ICU experiences, and individual resilience.

A 2018 study by Villalobos et al. (2018) conceptualized coping into two broad categories: the "pile-up" model, which assesses each stressor independently, and the holistic model, which sees coping as a continuous, defined mechanism. In each case, the quality of coping was influenced by the relationship families had with the healthcare system. Monica et al. (2019) used the Villalobos model and found that avoidant coping and denial were significantly associated with increased psychological distress, whereas social support and structured communication improved family resilience to cope with distress.

A study by Chhetri and Thulung (2018) observed that the needs of family members are complex and warrant targeted interventions. They recommended that ICU nursing should extend beyond the patient and seek to structurally support the family emotionally. This proposition aligns well with that of De Beer and Brysiewicz (2017), who found that both problem-focused and emotion-focused strategies are important in improving the way caregivers adjust to the admission of their patients within the ICU. They posit that if started early in the hospitalization process, the strategy enhances emotional coping and alleviates the psychological burden of families and caregivers.

Despite these findings, during the COVID-19 period, studies demonstrate that, in many settings, there was little to no structured support to help families cope emotionally, physically, or psychologically to the admission of their patients in the ICU, forcing relatives to rely on informal mechanisms such as prayer, mutual family support, and hope. While effective in some cases, these approaches often left individuals feeling vulnerable and, in most instances, having unresolved trauma and long-term emotional distress.

## **METHODOLOGY**

### **Research Design**

The study's research design was descriptive qualitative using a phenomenological approach. This approach seeks to understand experiences from an individual perspective where it is imperative to improve efficiency through understanding what was the perceived experience and how it is experienced (Fateel & Neill, 2015). The researcher deemed phenomenological research design as important for this study since it will give room for the opportunity to learn from the experiences and feelings of others (who, in this case, are the relatives and family members of the ICU patients). Qualitative method was appropriate for this study because individual perceptions and experiences are varied and in-depth individual interviews provide rich information regarding intensive care survivors' experiences during acute hospitalization.

### **Study setting**

The study was conducted at Machakos County and Referral Hospital Intensive Care Unit. The hospital is a 450-bed facility with state-of-the-art amenities. The hospital is well equipped to offer Oncology, Trauma & Orthopaedics, and Renal among other services, 15-bed Intensive Care Unit (ICU) and 12-bed High Dependency Unit (HDU). The hospital was the main Covid-19 referral facility in which many Covid-19 positive patients were admitted in the county.

## **Study Population**

The study population included family members/ relatives of COVID-19 patients admitted to the ICU at Machakos County and Referral Hospital.

## **Inclusion and Exclusion Criteria**

### ***Inclusion Criteria***

The study included family members or guardians who are above 18 years of age who were coming to the hospital to visit or check the well-being of their relatives who were patients diagnosed with COVID-19 and admitted to the ICU and also who consented voluntarily.

### ***Exclusion criteria***

Family members/relatives of patients who may not voluntarily consent to participate in the study, and those below 18 years.

## **Sample size**

The sampling criteria for qualitative research studies recommend a sample size of 5 to 20 people (Gentles et al., 2015). The sample size is chosen by data saturation (Guest, Namey, and Chen, 2020; Saunders et al., 2017). In this study, sampling was done until the attainment of saturation and ended when no fresh information or ideas were unearthed. When choosing on sample size, researchers considered the complexity of particular instances as well as practical constraints such as time and money (Rubel and Okech, 2017).

## **Sampling technique**

A purposive sampling method was used to identify study participants. Eligible participants are invited to take part in the study. Purposive sampling is a non-probability sampling method in which subjects are chosen depending on population characteristics and the aims of the study.

## **Screening and selection of the participants**

The principal investigator accessed the ICU admission registry to identify patients admitted as a result of COVID-19 and complications relating to COVID-19. From the list, the principal investigator was able to obtain a list of next of kin or frequent family members who were in contact with the hospital in seeking to know about the patient's progress as a result of the restricted visitation policy that has been implemented. The PI then extracted their numbers and used them for research purposes only. The participants were recruited into the study as they came to check on the well-being of their relatives admitted to the ICU, follow-up clinics, and counselling following the loss of their loved ones. Only those who consented participated in the study.

## **Data collection instruments**

Data was collected from participants using an in-depth interview guide. The tool was created by a researcher and was subjected to peer review and expert opinion by experts in the field in order to ensure that it was accurate and valid. During interviews, the instrument was used to collect qualitative data. A sound recorder was used to record the interviews.

## ***Establishing Rigor and Trustworthiness***

To ensure that the study is credible, transferable, dependable, and that it conformed to the expected rigor of a qualitative study, several strategies were employed during the research process.

To ensure that the study was credible, multiple strategies were applied. First, the researcher continued conducting in-depth interviews until data saturation was reached. This ensured that there was a comprehensive understanding of participants' experiences. After data collection, the participants were given a chance to review and validate the accuracy of their transcribed interviews. Afterwards, the collected data was analyzed and reported. The report was then sent to the supervisors who ratified before being presented for defense. The defence team which comprised of supervisors and qualitative research experts discussed the emerging themes



and interpretations as documented and gave corrections. This helped in reducing researcher bias and enhanced the credibility of the study findings.

The researcher ensured that the study was transferable by giving a detailed description of the research context, participant characteristics, and a detailed presentation of findings with supporting quotes. Further, the researcher gave a detailed overview of the study location (Machakos County and Referral Hospital ICU) and explicitly explained the participant selection criteria. This was meant to help readers to assess the applicability of findings to similar contexts. Rich and detailed narratives of participants' experiences were provided to allow for informed judgments about transferability to other settings.

To ensure that the study was dependable, the researcher maintained a comprehensive audit trail by documenting each research decision. First, the interview guide was reviewed by research experts. After approval, the interview guides were pretested to ensure consistency in data collection. All methodological changes and analysis processes were explicitly explained. All interviews were audio-recorded and transcribed verbatim by the researcher. These audio recordings were verified for consistency and accuracy.

A reflective approach was adopted by the researcher by maintaining a reflective journal in which she documented her personal biases, assumptions, and reactions throughout the research process. The researcher then individually verified transcripts. This served as a cross-check mechanism. The study made use of NVivo 12 software for data analysis. This provided a systematic approach to coding and theme development, creating a clear audit trail of analytical decisions. Supervisor review of the coding framework and emerging themes provided external validation of the analytical process.

These multi-layered strategies helped the study ensure that the findings accurately represented the lived experiences of relatives of COVID-19 patients admitted to the ICU, while maintaining the desired methodological rigor needed in qualitative phenomenological research.

### **Data collection procedure**

Eligible patients selected were invited to participate in the study. The details of the research were explained to the participants while considering the benefits as well as potential risks of participating in the study. Once consent is obtained, the researcher took the participant to a secluded and quiet place for privacy and easy interaction, as well as allow for the recording of the session. The researcher established trust with the participants during the in-depth interviews by demonstrating respect, listening intently, and clarifying any issues that are unclear. After obtaining consent from participants, interviews were audio-taped. Audiotaping was used to confirm that information is accurate. Interview is conducted on each participant only once. Data gathering was conducted until the saturation point is reached. Field notes are created as a result of the researcher's observations during the in-depth interviews. The credibility, transferability, and dependability methodologies are used to ensure trustworthiness.

### **Data Management**

The data management plan entails the description of the data entry and cleaning, data analysis and data storage

### **Data Cleaning**

The audio recorded data was transcribed daily after the interviews. All transcript printouts, any field notes or documents, and the patient's demographic information was gathered and labelled appropriately.

### **Data processing and analysis**

The transcribed data and documented notes were arranged and filed immediately, as per the study objectives. This was to ensure there was no mix up during data analysis. Thematic analysis was used to make sense of the data as per each objective. During the interviews the researcher noted non-verbal cues on a note book that serves as the research log. Each participant was given a unique code depending on the position and the date of

the interview and the interview recordings were saved in a password protected file in the researcher's computer to avoid any unintentional loss.

The researcher familiarized herself with the data by replaying and listening through all the audio-recorded interviews several times. Transcription of the original recordings was done verbatim by a trained and qualified transcriber together with the researcher. An independent transcription was done by the researcher to verify consistency of data in the transcripts as one of the verification processes to enhance trustworthiness. The data was then exported into Nvivo 12 for qualitative data analysis which involved code generation. Different categories were identified and assigned codes so as to describe the content. As an analytic strategy content analysis of data was done inductively through line by line manual coding process.

The researcher read through the transcripts thoroughly then underline words that appear commonly under each research question. The words are then coded. Constant comparisons were made both during the interpersonal conversation of the interview as well as from field notes to develop patterns or themes from the codes, either from the words used or the most regularly offered phrases, while taking notice of the language, beliefs, and opinions of the participants. Eventually, the themes were defined and connected to the study objectives to find implication and interpretation.

### **Data Storage**

All interview notes, transcript print outs and audio recordings were anonymized by allocating continuous numbers to each participant. They were then locked away in a filing cabinet immediately. The keys to the filing cabinet were only be handled by the principal researcher to ensure confidentiality. Any soft data entered in the computer was password protected and only accessed by the principal researcher.

## **RESULTS**

### **Emotional Distress and the Recollection of Events**

The first objective of this study was to investigate the caregivers' memory of the recollection of events and the emotional distress they experienced during the ICU admission of their kin. All ten respondents reported their initial emotional response as intense, overwhelming, and, in many cases, traumatizing. Respondents cite memories of shock, fear of impending death, powerlessness, and disorientation, particularly because of the unpredictability of patient outcomes of COVID-19 and isolation measures.

### **Emotional Shock and Disbelief**

One hundred percent (100%) of the participants were in a state of profound shock when they were informed that their relative was being transferred to the ICU. The first response was one of immediate disbelief, which was usually followed by physical manifestations of unease like trembling, crying, or even feeling faint. Most families were unprepared emotionally and practically for the sudden weakening of their relatives.

The anxiety was exacerbated by the fact that the general population viewed COVID-19 as a fatal illness, especially at the beginning of the pandemic when the death rates seemed high, and the treatment regimen was still developing. In their immediate fear, participants often cited media reports and community stories regarding the increasing number of COVID-19 deaths.

*I was horrified as I did not know what has occurred. COVID was killing people. So, I was shocked. My young brother is a victim..."* (Participant 1, Male, 40s, Brother of Patient - Patient survived)

*"It happened suddenly. My wife works and lives in different places... I was speechless and I did not know what to think.* (Participant 3, Male, 30s, Husband of Patient - Patient survived)

The aspect of surprise was especially traumatic in the case of participants whose family members had been self-treating COVID-19 at home and appeared to be improving. Some of the participants reported that their

relative seemed to be doing well, only to suffer a sudden decline that required emergency hospitalization and further ICU admission.

### ***Fear of Death or Death Outcomes.***

Eighty percent (80% of respondents) associated ICU admission with imminent death. This association was entrenched in culture and social beliefs about intensive care units. The majority of respondents held the belief that the ICU is a place where individuals go to die and not to get better. It was no longer a mere fear but a physical, close-up fear which impaired the rational capacity of the participants to think clearly or make a rational decision.

*I thought that my mother was simply going to die. But she never died."* (Participant 2, Female, 20s, Daughter of Patient - Patient survived)

For participants who lost their relatives, this initial fear was prophetic as it subsequently led to the development of complex emotions of guilt. They felt that they had an intuition regarding their relative's death, but even with this knowledge, they were powerless and unable to avert the eventuality.

*Eventually, we lost her. She failed to pull through it.* (Participant 8, Female, 20s, Granddaughter of Patient - Patient deceased)

The psychological threat of death was enhanced by the observations of other families in similar situations, which established the communal dread of ICU admissions during the COVID-19 era. A number of respondents stated that they had seen other families getting bad news or bodies being taken out of the hospital, which further exacerbated the fear that their relative would be the same.

### ***Feeling of Powerlessness and Helplessness***

Seven out of the ten participants (70%) reported a sense of utter helplessness against the critical condition of their relative. Such helplessness was complex and included their inability to offer physical comfort, to be involved into the decisions about care, or even to have sufficient information about the state of their loved one.

These feelings of powerlessness were increased by the COVID-19 protocols which restricted family access to the ICU patients. The participants talked about being turned into mere spectators as they relied on healthcare providers to inform them about the situation of their patients and could not take on their usual caregiving roles.

*The only thing I could do was to see him through the window, greet him, nothing more. I was much surprised and concerned.* (Participant 7, Male, 50s, Brother of Patient - Patient survived)

The feeling of powerlessness was not only limited to the immediate medical context but covered a wider context including family welfare, financial implications, and the long-term effects of the disease. The cascading effects of hospitalization of their relative on the functioning and stability of the family overwhelmed many participants.

### ***Gap in Information and Communication Failure***

Half of the participants (50%) cited poor initial communication regarding the condition and prognosis of their relative. The absence of straightforward and timely information was also a contributing factor to their emotional distress since uncertainty could be harder to deal with than the bad news relayed in a kind and understanding manner.

*Firstly, they did not explain anything.* (Participant 4, Female, 30s, Wife of Patient - Patient survived)

Respondents reported having received ambiguous or conflicting information, usually on consecutive shifts by different healthcare providers. Such discrepancy in information induced more anxiety and loss of trust in the

healthcare system. Other participants said they needed to assemble information from several sources or had to use information overheard to know the state of their relative.

The communication barrier was especially problematic in the critical first 24-48 hours of ICU admission. This is the time when families needed clear information to digest the situation and prepare other family members, coordinate the caregivers' occupational duties, and plan sufficiently for logistical plans.

### **Physical Experiences and Emotional Distress.**

The second objective of this study was to explore the physical experiences of the members of the family and how it influenced emotional distress. Themes of stigmatization, limited access, logistical exhaustion, and material burden were found throughout the interview. These experiences led to a situation in which the systemic and social failures contributed to emotional distress.

### **Community Isolation and Social Stigma.**

Eighty percent (80%) of respondents (N=8) expressed that they had experienced social stigma and isolation by the community after the diagnosis and ICU hospitalization of their relative with COVID-19. This stigmatization took different forms such as subtle avoidance of people by neighbors and friends, as well as blatant discrimination and blame.

*Friends did not accept me, and neighbors did not want to see us. People feared us."* (Participant 2, Female, 20s, Daughter of Patient - Patient survived)

*"Even the neighbors... they were not able to visit our house to greet us... they believed that we had COVID too".* (Participant 8, Female, 20s, Granddaughter of Patient - Patient deceased).

*"Friends rejected me and neighbors avoided us. People feared us."* (Participant 2, Female, 20s, Daughter of Patient - Patient survived)

It was evident that stigma and isolation were not limited to the immediate circles but were extended to the community. This influenced the interaction of the study respondents within the community and in their social circles, such as workplaces. Respondents further noted that they felt marked or labeled. Some reported that they had heard people talking about them in hushed voices. Others reported that they had seen people stare at them when they were moving about in their community. This labelling led to respondents experiencing more stress, especially when the participants needed community support the most.

The stigmatization was especially heavier when participants felt that their families had taken adequate precautions and that they were not infected due to a negligent attitude. The personal responsibility implication of the disease provided further layers of shame and guilt to their already crushing burden of feelings.

Respondents cited that in some instances, the community maintained their perception of the families infected by the disease long after the relative recovered or died. This, they say, affected long-term relationships and status in society exacerbating the stigma. This continuing social aftereffect was felt long after the immediate medical crisis had passed.

### **Limited Physical Access and Visitation Controls.**

Nine (90%) of the ten respondents cited physical access limitation of their hospitalized relative as one of the most emotionally distressing parts of the ICU experience. Although such restrictions are medically justified to prevent infection, they had a significant psychological impact on people, causing a sense of abandonment.

*"We were told to keep off. It was not an experience of the best kind."* (Participant 6, Male, 50s, Father-in-law of Patient - Patient survived)

*"They even did not give me the opportunity to see him... they just said that he was doing well,"* (Participant 4, Female, 30s, Wife of Patient - Patient survived)

The failure to offer physical comfort, hold hands, or just be with their loved one contravened strongly cherished cultural and personal convictions about family obligations in sickness. Numerous participants said they felt like they were not doing their job as a family member because they could not care for their family member.

Further, respondents observed that restriction guidelines, such as the limitation on visitation, imposed further stress on the study participants. Especially those whose family members had died in the ICU, as they were denied the chance to provide a befitting send-off or to at least be present during the last moments of the life of their kin. This lack of closure led to complex grief experiences and persistent feelings of guilt and helplessness.

Respondents observed that anxiety was further exacerbated by the COVID-19 restrictions. They observed that visitation restrictions meant that families could not see the quality of care being provided, and added more anxiety about whether their relative was being given the proper attention and treatment. They mentioned that since they were not allowed to make direct contact, they solely depended on reports given by healthcare providers. This, they say, was not always sufficient.

### ***Logistical Burden and Material Strain.***

Other than the emotional burden, seven out of the ten study respondents (70%) indicated that they had significant logistical challenges. Respondents cited the long distances that they had to cover to get to the hospital, getting accommodation closer to the hospital, balancing between work and family, and the complexity of the hospital systems.

*"I was forced to purchase gloves and find oxygen. It was so hard. We were not well off financially."*  
(Participant 8, Female, 20s, Granddaughter of Patient - Patient deceased):

The logistical burden was especially pronounced among individuals who lived far from the hospital and had to cover several trips to and from the hospital to get updates on their patients or bring supplies. Some respondents complained of having to stay in uncomfortable places outside the hospital, sleep in their vehicles, or arrange for local accommodations which also stretched their budgets.

Respondents also cited challenges with balancing a variety of roles while taking care of sick relatives. They observed that working and looking after the needs of the ICU patient was physically exhausting and added to the already heavy emotional stress. Others said that they felt pulled in different directions and could not take care of any other duty in a satisfactory way.

Hospital procedures and requirements were also reported as a stressor to participants, especially those who had low formal education or had had no prior experience with patients in the ICU. They observed that caregivers had to expend a significant mental and emotional effort to cope with the bureaucratic hospital demands, master medical terms, and communicate with various departments amidst scanty or no information about their patients.

### ***Financial Hardship and Procurement of Resources.***

Sixty percent (60%) of those interviewed (n=10) had experienced a high level of financial stress due to the ICU admission of their relative. This strain included direct medical expenses, transportation expenses, accommodation expenses, and opportunity expenses of lost time spent in income-generating activities.

The participants indicated the need to buy personal protective equipment, drugs not in the hospital pharmacy, and essentials to take care of their relative. Such unforeseen costs left families already facing low income levels because of the economic impact of COVID-19 in a financial crisis.

*I began to do typing jobs on the internet so that I could get money to buy food. It was very stressful."*  
(Participant 2, Female, 20s, Daughter of Participant - Patient survived)

The economic implications were not only in the short run but also in the long run. Respondents cited debts, loss of savings, and the inability to provide for other family demands as some of the long-term implications of the ICU admission. This created a significant financial burden on the families of the patients. A section of the participants also said that they had to make some tough decisions to determine what was more important between relatively important options, such as whether to go to the hospital or to buy food to feed other family members. Further, respondents who had relatives who needed longer ICU care reported that the cumulative financial burden was too much to bear, and they were faced with extra pressure on the stability and well-being of their family in the long run.

### **Psychological Experiences related to Emotional Distress.**

The third objective sought to understand the magnitude of the psychological burden felt by family members during their patient's ICU stay. During this investigation, it was established that depression, fear, survivor's guilt, interrupted routines, role strain, and insufficient mental health support were major themes that left a complicated terrain of psychological vulnerability.

#### ***Depression and Emotional Breakdown***

Episodes of psychological breakdown that are commonly characterized by deep sadness, hopelessness, and despair were described by nine out of ten participants (90%). These depressive effects were not just the responses to the immediate crisis but the sign of a more profound psychological imbalance that influenced the basic well-being and future orientation of the participants.

*"I felt like my life had ended. He was the breadwinner, and I had nothing."* (Participant 4, Female, 30s, Wife of Patient - Patient survived)

Depression was marked by constant negative thoughts, failure to enjoy formerly pleasurable activities, and feeling that life had lost its meaning. Some of the participants reported that they were emotionally numb, out of touch with the relationships they were acquainted with, and had no positive vision of the future.

In the case of participants whose relatives eventually passed on, the depression was frequently onset during the ICU stay and exacerbated after death. Nevertheless, participants whose relatives survived also reported perennial depressive symptoms with regards to the trauma of the moment and the constant worry about the health and stability of their relative.

Physical symptoms that were frequently associated with the depression included loss of appetite, sleeping disorders, fatigue, and somatic complaints. Some of the participants mentioned that they were physically ill due to the stress, had headaches, stomach issues, and general malaise, which further incapacitated their coping capacity.

#### ***Anxiety and Persistent Fear***

Every respondent (100%) described their relative's stay in the ICU as being accompanied by severe anxiety. This anxiety was expressed in different ways, such as panic attacks, constant worry, intrusive thoughts on possible negative outcomes, and hyper-vigilance on the condition and prognosis of their relative.

Specific events like receiving a phone call from the hospital, shifts in the visiting processes, or delays in receiving information on the status of their relative usually increased their anxiety. Respondents reported that they were in a state of constant alert and could not rest or concentrate on other things.

*"I was not able to focus in the workplace... I was always in the hospital."* (Participant 5, Male, 35s, Son of Patient - Patient survived)

Respondents noted that even positive news from the hospital only gave temporary relief, and worry came back after a short while. The uncertainty surrounding COVID-19 and the absence of an apparent cure led to a constant state of uncertainty that created anxiety.

Others reported certain phobias with regard to the ICU experience. Respondents cited being afraid of hospitals, medical equipment, or even phone calls. These phobias caused more obstacles to normal functioning and social isolation.

### ***Identity Crisis and Role Disruption.***

Sixty percent of the respondents (60%) reported a major disturbance in their normal family and social roles, which resulted in identity confusion and further psychological pressure. This was especially high among participants who were primary caregivers, breadwinners, or who were key decision-makers in the family.

*"No one else would provide for the family unless I provide. It was a heavy burden."* (Participant 2, Female, 20s, Daughter of Patient - Patient survived)

Young adult participants transitioned suddenly to adult roles and demands. Something they did not feel prepared for, including family budgeting, taking care of younger siblings, or decision-making regarding medical care. This premature taking on of the adult roles caused more stress and a feeling of inadequacy.

When the survival of an ICU patient was in question, spouses were particularly disturbed in terms of their identity and future plans. The reality of being a widow or widower, a single parent, or the sole family provider caused existential anxiety about respondents' ability to cope with the demands.

It was also evident that the role disruption influenced the personal identity of the participants in the non-family context. Most of them talked about how their normal interests, ambitions, and self-image were no longer applicable in the light of the crisis, and that they felt displaced.

### ***Sleep Problems and Focus Problems***

Eighty percent (80%) of the respondents complained of severe sleep deprivation when their relative was admitted to the ICU. Such disturbances included a problem of falling asleep, waking up frequently, nightmares about the state of their relative, and waking up in the morning anxious.

*"I could not sleep, I went to hospital all the time. I focused on the patient's physical condition and mental health, as well as on her family."* (Participant 9, Female, 25s, Niece of Patient - Patient deceased)

Practical considerations like uncomfortable sleeping conditions when staying close to the hospital, being disrupted by medical equipment when they were allowed to visit the patient, and the necessity to be available in case of an emergency, frequently complicated the sleep patterns of the respondents.

Seven participants (70%), reported issues with concentration, stating that they had problems concentrating on work, household chores, or even talking to the family. This mental disturbance impacted their capacity to operate well in their business roles and duties.

This state of sleep deprivation and concentration issues led to a cyclical effect of degrading dysfunction that resulted in reduced ability of the participants to deal with the constant stress of having their relative admitted to a hospital.

### ***Lack of Professional Psychological Support.***

A majority (7 out of 10) of the participants (70%) indicated that they were not provided with any professional psychological support during their relative's ICU stay. Whereas a few participants reported having a few moments of short supportive conversations with individual nurses, they were not included in any structured psychosocial care programs.

*"One particular nurse saw me being depressed, and she made time to speak with me and gave me some hope."* (Participant 2, Female, 20s, Daughter of Patient - Patient survived)

Lack of professional mental health services meant that the participants were to cope with psychological distress using personal resources, family support, or spiritual/religious coping mechanisms. Although these informal supports proved to be helpful at times, they were not always enough to counteract the severity and the complexity of the psychological issues the participants had to deal with.

Some reported that they would have liked to have professional counselling or support groups, but they had no idea that such could or should be offered to family members. The absence of information concerning the needed psychological support services marked a missed opportunity where healthcare workers could proactively engage in mental health needs of the patient caregivers.

The lack of psychological support also implied that participants had no instructions on how to work through their traumatic events, instil effective coping mechanisms, or anticipate the long-term psychological effects of their ICU experience.

### **Perception of Care Received and Emotional Distress**

The fourth objective examined the perception of the participants about the care received by their relatives and the impact of these perceptions on the emotional experiences of the participants. From this objective, five themes emerged, and they included: Staff compassion and indifference, lack of communication, trust in medical care, and improvement suggestions. These themes showcased the respondents' perceptions of the hospital's administration, healthcare workers' efforts, and systemic challenges.

#### ***Staff Attitudes and Interpersonal Interactions.***

All ten respondents (100%), rated the attitudes and behaviors of the healthcare staff, with the perception being deeply appreciative to deeply disappointed. This flexibility of the interactions between the staff turned out to be a decisive factor in the overall emotional experience of the participants and their confidence in the healthcare system.

*"Some were kind, others were rude. I couldn't even ask questions properly."* (Participant 2, Female, 20s, Daughter of Patient - Patient survived)

From the study responses provided, it was evident that respondents who reported experiencing kind, caring personnel members indicated that they felt more optimistic, encouraged, and confident about the care of their relative. This set of respondents appreciated the time that the staff members spent explaining the procedures, answering questions patiently, and recognizing the emotional distress experienced by the family.

On the other hand, those who experienced indifferent or dismissive staff members said they felt dehumanized, ignored, and not involved in the care of their relative. These adverse exchanges exacerbated their pre-existing anxiety and developed further resentment and mistrust which lingered beyond the ICU hospitalization.

The difference in the attitude of staff members seemed to be associated with the personal differences in personality, workload stress, and perhaps with the training in the family-centered care methods. Respondents mentioned that there are members of staff who were seen to be at ease with families and others who appeared to be awkward or avoidant.

Some of the participants noted that the nursing staff tended to be more approachable and communicative compared to the physicians, who were often viewed as being too busy, too distant or too fixated on medical instead of psychosocial issues.

#### ***Inconsistency in communication and gaps in information.***

Eight participants (80%) indicated that they had serious issues with the consistency in communication, especially concerning the shift changes and handover procedures. These communication issues caused misunderstandings, anxiety, and distrust. This worsened their ability to emotionally process the condition of their relative.



*“Whenever I came across a different person, information did not flow well.”* (Participant 2, Female, 20s, Daughter of Patient - Patient survived)

Whenever being given updates on the state and condition of their relative in ICU, participants reported receiving delayed communication, conflicting information, or no communication at all from the various healthcare staff members. Such discrepancies in information flow were a problem because families could not comprehend the prognosis of their relative and act accordingly.

The communication issues were especially painful when they concerned important information regarding treatment choices, prognosis, or visiting practices. According to the participants, ineffective communication showed that their concerns and the right to know the condition of their relative were not respected.

Otherwise, some respondents blamed communication issues as staff deficiencies, excessive workload, or poor handover practices instead of intentional ignorance of family requirements. Nevertheless, their emotional welfare was heavily affected irrespective of the causes.

There were no appointed family communication coordinators or formal update processes, so the exchange of information was informal and relied on personal staff initiative, rather than an organized process.

### ***Confidence and Trust in Medical Care.***

Nine out of ten respondents (90%) indicated that they had complex feelings regarding their trust and confidence in the medical care that their relative received. Although a majority eventually came to believe that healthcare providers were doing the best they could, this belief was frequently tempered by the notion that there was a lack of resources, competence of staff, or, capacity of the system.

*“I had no other choice. I had to trust them to do their best.”* (Participant 4, Female, 30s, Wife of Patient - Patient survived)

The perceived competence and confidence of individual staff members, access to the required equipment and medications, and the openness of communication regarding treatment decisions and prognosis played a role in determining the level of trust in the participants.

Some respondents showed hesitant trust as they admitted that they had limited options but they hoped that their relative would get proper care even when the system constraints were apparent. This qualified trust left a constant worry on whether their relative was being given the best care.

Those who had relatives who survived tended to be grateful and more confident about the healthcare system and those who had relatives that had died sometimes asked whether alternative care could have yielded different results. Nevertheless, the majority of them acknowledged the issues that healthcare providers have to deal with during the pandemic.

Participants had a strong impression of staff honesty and transparency, which influenced the trust relationship. Those respondents who believed that employees were transparent on issues and restrictions were more confident than those who believed that information was being concealed or under-reported.

### ***Resource Constraints at the System-Level.***

Six participants (60%) mentioned the particular system-level resource limitations that interfered with the care of their relatives and their own emotional experience. Limitations such as the lack of ICU beds, oxygen, drugs, and PPE were the most common among respondents.

*“There were no beds, I just had to wait and pray.”* (Participant 7, Male, 50s, Brother of Patient - Patient survived)

The respondents reported that they were requested to buy medications, oxygen, or personal protective gear. These were supposed to be provided by the hospital. Such demands imposed more financial strain and created doubt on the quality of care provided to their relatives.

This apparent resource shortage also introduced anxiety regarding whether or not their relative was getting the best treatment or whether care was being rationed because of the limitation in the supply. Other participants were concerned that their family member would not get any life-saving interventions because of the lack of equipment.

Whereas respondents acknowledged resource constraints and the difficulties the healthcare system underwent in the pandemic, they believed that families should not be left to purchase the necessary medical supplies. They opined that the logistics and mental strain was already severe on the family and adding an extra financial burden exacerbated the already strained stress on the families.

Respondents also cited that the low staffing levels, heavy workload leading to staff burnout, and staff stress influenced by the resource constraints apparently reduced staff individual attention, and subsequently led to dissatisfaction with quality of care provided.

### ***Care Improvement Suggestions.***

Seven participants (70%) had specific recommendations on how to enhance the ICU experience of families. These recommendations were based on their observation of the gaps that they had witnessed and their conceptualization of how to deal with the systemic and interpersonal issues.

*"They ought to leave the immediate friends of the patient to visit them. That would help so much."*  
(Participant 4, Female, 30s, Wife of Patient - Patient survived)

The most frequent recommendation was that of altered visitation policies which would enable limited family access and still uphold infection control measures. Respondents proposed that with proper protective gear, one specific family member could visit without causing the family much distress and without affecting safety.

Others recommended enhanced communication standards with assigned family liaisons. They opined that periodic, scheduled updates, irrespective of patient condition changes was necessary and better information on hospital procedures and expectations to families.

Some of the respondents also recommended that hospitals ought to offer simple services to the families, including the provision of comfortable waiting places, or the availability of accommodation and food options in the area, as well as the provision of advice on the services available. Others suggested that hospitals should provide counselling services for families, particularly during extended ICU stays or when patient outcomes were poor.

### **Cross-Cutting Themes and Integrated Findings**

In addition to the specific objectives, multiple cross-cutting themes were identified that had an impact on emotional distress on the full range of participants and added more knowledge on the systemic and personal forces that contributed to the ICU experience of families.

#### ***The Focal Position of Communication in Affective Well-being.***

Communication emerged as a critical factor that to which all the elements of the emotional experience of the participants were attributed. Effective communication reduced anxiety, fostered trust, and allowed families to cope with traumatic experiences. Ineffective communication increased distress, raised confusion, and led to a lack of confidence in care.

Communication was considered to be effective when it was regular, honest, empathetic, and respectful of family concerns. Whenever these elements were present, participants said that they felt more supported and capable of managing the critical illness of their relative. On the other hand, communication failure had a

cascading effect such as anxiety, mistrust, feelings of exclusion, and complex grief processing. Lack of transparent and consistent communication made the families fill the knowledge gaps by their fears and assumptions.

#### ***The Overlap of Physical and Emotional Distress.***

This study established that emotional distress of the family members was significantly associated with the physical experiences such as restricted access, material hardship, and logistical challenges. These barriers played a pivotal role in the emotional distress experienced by the respondents, making it difficult for families to process and cope with their relative's admission. The physical distress experienced by families due to their experience with the ICU admission meant that emotional healing should include physical requirements such as rest, nutrition, safety, and comfort. It was observed that physical exhaustion, financial strain, and social isolation led to families lacking emotional resilience.

#### ***The Influence of Hope and Meaning-Making.***

Participants showed extraordinary ability to have hope and meaning-making in spite of the overwhelming challenges. Some of the participants were able to preserve their psychological stability with the help of spiritual beliefs, family solidarity, and personal resilience. But hope was weak and had to be cultivated by good relationships with the professionals, by being informed about how things were going, and being able to play a significant role in the care of their relative. Without these supports hope might soon be turned into despair.

#### ***The Long-term Effect of ICU Experiences***

Although the present study was specific to the acute ICU experience, the stories of the respondents indicated that the psychological effects were much further than the hospital discharge or death. The study established that trauma attributable to ICU admission, the pressure of attributable to family role disruption, and the challenge of navigating the rigid healthcare system had long-term implications on family functioning and individual well-being. Respondents whose family members survived reported having continued anxiety over their health and potential death, while those who lost their loved ones reported complicated grief processes, which were shaped by their exclusion from end-of-life care and their traumatic memories of their ICU experience.

#### **Summary of Key Findings**

This study has demonstrated that the multidimensional distress experienced by family members following the admission of their relative in the ICU due to COVID-19 was much more than the worry about their sick relative's outcome. It is evident that the perceptual, psychological, emotional, and physical aspects of distress among these families were connected and that they mutually supported each other, thus creating complex challenges that needed a multifaceted family and systems-based approach to mitigate.

These results prove that family members are not merely onlookers of the ICU care but are deeply invested participants whose own well-being greatly affects their ability to support the recovery of their relative and cope with the experience in a positive manner. The lack of systematic care about the needs of the family resulted in unnecessary suffering and the lack of therapeutic interventions.

The research also found out that participants have a lot of resilience and coping capacity which implies that proper support would improve the natural protective factors and minimize the risk of long-term psychological complications. The suggestions obtained based on the experience of participants give effective recommendations on how family-centred care can be enhanced in the ICU context, especially when it comes to emergency situations related to a public health crisis.

## CONCLUSION AND RECOMMENDATIONS

### ***Recollection of Events and Emotional Distress.***

The recollection of events by relatives of patients admitted to the ICU exhibited the emotional pain experienced by relatives. Most respondents' description of the ICU was akin to death. Several respondents recalled how they felt scared, shocked, and helplessness when they heard that their loved one was being transferred to the ICU. These findings echo several studies that attest to the psychological toll experienced by families when one of their kin was being admitted to the ICU especially during the COVID-19 pandemic period

The findings in this study echo those of Azoulay et al. (2020) who found that as many as 35 percent of relatives of patients in the ICU suffered acute stress disorder within the first week of admission. This was especially pronounced in cases where information was poorly communicated or the patients were in a critical state. Their findings echo well with the emotional paralysis that was reported in our study, where the participants noted that they felt overwhelmed, disoriented, and mentally unprepared to encounter the reality of ICU protocols and isolation measures.

Another factor stood out from the current study was the element of suddenness and unpredictability of the patients' outcome. In a longitudinal study by Kentish-Barnes et al. (2021) it was stated that families had an increased likelihood of having post-traumatic stress symptoms when the ICU admission was unexpected or when prognosis communication was vague. This is aligned with the experiences in the present study, where the majority of participants were shocked by the fact that the condition of their relative was worsening rapidly as well as them being left out of the discussion of care. The quote *"I was shocked because I was not aware of what had happened... COVID was killing people"* shows how such drastic changes worsened emotional instability.

The associations of ICU admission and fatal outcomes was also a recurring theme, irrespective of the actual prognosis. Rose et al. (2021) share their perspectives in a mixed-methods study, claiming that family members were triggered to think of death every time the word ICU was mentioned, even when recovery was probable. Our data reflected this statement in the statement, *"I thought that my mother was just going to die. But she never died."* indicating dissonance between perception and clinical outcome.

Notably, the ethical issue that the present study supports with its findings is the inability to prepare or assist families appropriately in such instances. Hart et al. (2022) argue that the lack of organized family involvement, especially in emergency admissions to ICU, is an infringement on ethical principles of inclusion and informed consent, especially when the family is seen as an outsider to the crucial decision-making. In this study, this was portrayed by the statements such *"I could only watch him through the window... nothing more."* These statements are indicative of powerlessness and invisibility as expounded by the study participants.

With regard to policy, the study findings point to a need for the establishment or enhancement of quality of communication structures between families of patients admitted in the ICU and the host facilities, especially when physical presence of family members is restricted. Also, the study observes that emotional shock experienced by the respondents can be alleviated through formal facility notification systems and psychological support offered to family members in order to be able to process the events in a better way (Wendlandt et al., 2021).

Overall, the recollection of events by the relatives before and after admission of their kin to the ICU in this research served not only as memory, but as an emotional wound, an exclusion, fear, and systemic opacity.

These results are in agreement with several global studies and indicative of a need for immediate ethical and procedural review of critical care policy in the time of a public health emergency.

### ***Physical Experiences and Emotional Distress.***

The physical experiences reported by the participants of this study, such as the inability to access the ICU, logistical burden, social stigma of the community, and subpar accommodation, played a major role in their emotional suffering. These results are consistent with the general worldwide evidence that physical marginalization and infrastructure constraints are major stressors to ICU families, especially in times of health crises like the one experienced with the COVID-19 pandemic.

In the present research, almost all of the participants reported being physically denied access to their hospitalized family member. This limitation, which was required on the basis of infection control, was felt as alienating in an emotional sense. The participants said they felt helpless when they were not allowed to offer the most basic care or support, and some of them said that they could only see their loved ones through the window or at a distance. Such experiences are reported in other studies on COVID-19 ICU family experiences. Research conducted by Montauk and Kuhl (2020) was a multicentre study that discovered that the physical separation caused by infection prevention measures caused strong emotions of guilt, frustration, and helplessness in relatives, who perceived themselves as not part of critical caregiving functions.

Distress was also caused by physical fatigue and discomfort. In our research, the participants described how they slept outside the hospital, were in long lines, and were economically overburdened by the expense of medications, PPE, and meals. A Kenyan study by Ochieng et al. (2021) confirmed these findings by stating that families of critically ill patients tend to bear the burden of organizing logistics, finding, and transporting medications in under-resourced health systems. This burden is further worsened by the absence of facilities like waiting bays, emergency accommodation, or social work support.

Another aspect that increased physical and emotional exhaustion was stigmatization by the community. Eight of ten participants in our study said that they were isolated or shunned by friends and neighbours, especially when they reported that their relative had tested positive to COVID-19. These results are consistent with a study by Tembo and Higgins (2020) who found that stigma related to the admission of an infectious disease - and, in particular, during pandemics - may spread to family members, influencing their mental and psychological health and position in the community. This aspect of social exclusion increases the emotional burden of caregivers who already feel uncertain and grieved.

These physical experiences (social isolation, infrastructural gaps, and logistical fatigue) intersected to produce an extraordinarily disturbing real world. Even the most basic caregiving chores were daunting. Kynoch et al. (2021) found that the absence of basic physical and systemic support weakens the emotional resilience of relatives. Families are subjected to a multiplied pressure of not being able to cope because they lack comfortable areas to wait, clear information on patient progress, access to transportation, and supplies.

At an ethical level, these findings question the assumption that relatives are only observers of care. As a matter of fact, they are stakeholders who bear the trauma of their embodiment. At the hospital policy level, this would require the incorporation of family-inclusive infrastructure in the ICU planning. The facilities should reflect special caregiver shelters, explicit drug acquisition instructions, and psychological assistance to waiting families (Gonzalez et al., 2020). Moreover, in times of pandemics, new models that could reduce the psychological impact of physical distancing might include mobile check-ins, family liaison officers, and remote video updates (Rose et al., 2021).

Finally, though often treated as secondary to clinical care, this study observed that physical circumstances experienced by family members was central to the emotional and psychological distress reported by the families of ICU patients. Their experiences are an indication of both structural weaknesses in the critical care system in Kenya and the human price of excluding families from therapeutic settings, especially in a crisis.

### ***Psychological Experiences and Distress of Emotion.***

This study found that psychological agony was one of the overarching themes of the experiences of family members who had a relative admitted to the ICU amid the COVID-19 pandemic. The respondents talked about various mental health issues, such as anxiety, depressive symptoms, sleep disturbances, inability to focus, emotional meltdown, and long-term fear. They were not merely the responses to the acuity of the condition that the patient presented with, but also the indicators of insufficient emotional support mechanisms at the hospital level and the isolating impact of pandemic-related measures.

The psychological effect that has been mentioned in this paper is in line with tendencies in the rest of the world. A systematic review by Sarigiannis et al. (2021) found that family members of patients in the ICU have greater chances of experiencing anxiety, depression, and post-traumatic stress disorder (PTSD) especially when a loved one is in the critical care unit or dying. These risks were revealed to be escalated by the COVID-19 pandemic, with hospitalizations being sudden, unpredictable disease courses, and restricted physical access - all of which are reflected in the respondents of this study.

Based on a participant who said, *"I felt that my life was over. He was the breadwinner and I had nothing"*, it is evident that respondents felt a mixed feeling of anticipatory grief and existential despair. This emotional spiral is congruent with other studies. For instance, a study by Kentish-Barnes et al. (2021) determined that in instances where survival at the ICU was not guaranteed and the social role of the relatives was destabilized, the latter tended to report emotional disintegration. This theme was especially high in our research, especially among the women and young adults who had to take up new caring or financial responsibilities without the presence of their spouse or parent in the hospital.

The lack of organized psychological support was also a cause of concern, almost universally across the respondents. In the current study, seven of ten respondents said that they had not received any counselling or mental health support when they were in the ICU. Some of them were talking about brief, friendly talks with nurses, but they were not frequent and were not built into official psychosocial care routes. This observation is consistent with the results provided by Azoulay et al. (2020), who reported that the lack of specific family support structures in ICUs - particularly in times of increased pressure, such as the COVID-19 may expose relatives to severe psychological issues in the long term.

The strategies of coping were personalized and in most cases spiritual. Some respondents said that they resorted to prayer, faith, or religious community members as their main sources of strength. One of the respondents pointed out that... *"it was my faith that kept me safe. The healing of God came to pass,"* which indicated a kind of psychological strength, but which, however strong, also indicated the absence of emotional support of the institution. This observation is supported by studies by Moreno-Moral and Faubel (2022), who add that spirituality can offer essential internal resources to relatives of ICU patients, yet it should not be used instead of professional mental health support.

These results impose some significant ethical and institutional inquiries. During crisis situations, particularly in cases of pandemics, the healthcare system tends to be patient-centered in a very narrow way. Nonetheless, this paper confirms that family members are psychological co-sufferers and need to have formal care mechanisms. Rose et al. (2021) suggest that hospitals use best practice models, which suggest Family Support Teams (including psychologists, chaplains, and trained social workers) that can provide organized coping support in the ICU.

The absence of psychological support services to relatives in the ICU indicates a serious health systems gap in the Kenyan situation, as viewed through the policy lens. Although there are protocols that govern the treatment of patients within critical care facilities, the same cannot be stated about family-centred mental health care. This is a symptom of a wider lack of attention to the mental health of caregivers in most low- and

middle-income countries (LMICs) whose mental health allocation is less than 1 percent of the overall health expenditure (WHO, 2022).

Finally, relatives in this study were characterized by profound vulnerability, unmet emotional needs, and excessive dependence on personal resilience. These results resonate with the international data and indicate that hospitals and policy-makers should not consider family members as marginal observers, but as being part of the ICU care ecosystem, which requires a structure and professional psychological care.

### ***Perception of Received Care and Emotional Distress.***

Study respondents to this study reported a broad range of perceptions on the nature of care received by their relatives while in ICU. This ranged from gratitude towards the efforts of individual staff members, all the way to deep dissatisfaction with the inefficiencies of the system. These perceptions were highly interwoven with emotional distress and they influenced the way in which the participants processed the illness of their loved one and the institutional response to the illness. The interpersonal and structural subjective assessment of care was found to be a critical determinant of the psychological outcome of relatives.

One of the significant observations from this study was the diverse view with which care was perceived. On the one hand, some of the participants praised certain nurses in terms of their empathy, reassurance, and even silent support. Conversely, others complained that they were being neglected, side-lined or forgotten without any explanations. The literature captures these sentiments quite well. Azoulay et al. (2020) conducted a study in a multicounty ICU during COVID-19 and discovered that levels of anxiety and depressive symptoms were, to a significant degree, mediated by the perceptions of the families on whether or not they were handled with respect and transparency. On the same note, according to the findings of de Boer et al. (2022), relatives who perceived ICU staff to be responsive and emotionally present were more likely to perceive the ICU experience as neutral or even positive - irrespective of the outcome.

Eight of ten participants in our study reported inconsistent communication, referencing changes of shifts or conflicting information or vague updates. This frustration is best typified by the quote; *“Every time I found a different person, and information didn’t flow well.”* This breakdown in communication is not specific to the Machakos County and Referral Hospital. According to a systematic review conducted by Kentish-Barnes et al. (2021), poor information-sharing practices were found by relatives in various settings as one of the major contributors to post-ICU psychological trauma. The inconsistency, unreliability, and absence of honesty and compassionate dialogue were discovered to aggravate the sense of powerlessness and fear.

A significant institutional concern was the perceived scarcity of resources, including oxygen, drugs, or ICU beds. Some of the respondents in this study mentioned that they were requested to purchase gloves, seek oxygen, or finance medications, which increased their emotional and financial pressure. The same reflections can be traced in the results of Sub-Saharan Africa and other LMICs. According to Ochieng et al. (2021), the lack of funds and workforce in Kenyan state hospitals often forces the family to cover the resource shortage, which puts them at risk of economic disaster and mental trauma. This situation was worsened by the COVID-19 pandemic, which put a strain on the already stressed health systems by increasing the demand for ICU services (Barasa et al., 2020).

Interestingly, most of the participants had some trust in the care system as they believed they were doing their best even with the apparent constraints. Such duality - disappointment with the loopholes in the system and the understanding of human work – can be seen in other literature. A qualitative study by Rose et al. (2021) participants distinguished between institutional failure and individual heroism and tended to value frontline staff and decry the circumstances under which they had to operate.

These findings have multidimensional implications. Ethically, the lack of clear and consistent communication and the absence of family input is unethical and does not comply with fundamental principles of informed engagement and relationship respect (Hart et al., 2022). Policy-wise, the results demand the formulation of

family communication guidelines in ICUs, such as the hiring of liaison officers or social workers, whose responsibilities would be to make sure that families do not feel left alone emotionally. Also, hospitals must institutionalize feedback systems that enable families to share their experiences, not only to ensure quality, but also as a healing process.

Lastly, it is impossible to ignore the context of COVID. The pandemic placed an unprecedented burden on healthcare providers and institutions and reduced their ability to engage emotionally with the families. Nevertheless, as Wendlandt et al. (2021) have it, the crisis is not to be used as an excuse to strip compassionate care. Rather, they ought to hasten innovations, including virtual updates, systematized briefing, and specific family support personnel, which protect the dignity of the patients and their loved ones.

Overall, the current research confirms that the perceived quality of care - competent, respectful, indifferent, and inadequate - directly affects the emotional state of relatives of patients in ICU. The evidence base of the call to reorient the ICU practice that acknowledges the family not as an outer unit, but as an essential part of patient-centred, trauma-informed care.

## **CONCLUSION**

This paper examined the first-hand experience of relatives of family members who were admitted in the Intensive Care Unit (ICU) of the Machakos County and Referral Hospital during the COVID-19 pandemic. It attempted to explore the emotional, physical, psychological, and perceptual aspects of distress experienced by relatives using a qualitative approach. The results provided a complex view of the effects of the ICU care, especially during the high-pressure environment of the pandemic on both the patients and their families. This conclusion is a summary of the key findings and is consistent with the objectives of the study and summarizes them into coherent thoughts which can be added to the scholarly and practical discussion of the issue of critical care and family involvement.

The first important observation was that the memory of events relating to ICU admission provoked the participants with severe emotional distress. The majority of respondents talked about the experience of receiving the news about the ICU transfer as traumatic and full of panic, helplessness, and the fear of death. These emotional reactions were not just one-time emotional reactions, they constituted a mental script which the respondents used to grieve, to feel anxious and their recollection of the sickness. Although the long-term psychological outcomes were not directly measured in this study, it is reasonable to assume that the unresolved recollection trauma can be one of the factors leading to post-ICU emotional dysfunction, particularly when the relatives were not involved in early care conversations.

Secondly, the study concluded that physical experiences of the family members, in particular, the absence of visitation, community stigmatization, and logistical burden, contributed to the worsening of their emotional pain. Physical restrictions of seeing their loved ones added to feelings of helplessness and loss. Along with that, the material strain of supplying medications, personal protective equipment, and support of other dependents put caregivers under physical and financial stress. These stressors, though not necessarily spoken as the core issues, constituted a consistent environment to the emotional stories of the participants, implying that physical displacement and social ostracism were major contributors to the psychological sufferings.

Thirdly, participants also expressed a background of psychological vulnerability that remained all through the ICU experience. The prevalence of fear, anxiety and emotional breakdown was also widespread especially in families that were devoid of social or emotional support. Spirituality and self-motivation helped some of them to stay resilient but lack of organized psychosocial support left many people alone. Based on this, it can be concluded that the lack of institutional mental health support services could have restricted the ability of these families to effectively process trauma or be able to recover on time.



Lastly, the perception of received care was varied and emotional. Some of the participants commended the efforts and compassion of ICU employees, but others reported bad communication, lacking regular updates, and absence of involvement in decision-making. These ambivalent impressions were not necessarily technical judgments concerning the medical competence, but emotional judgments with regard to trust, fairness and human dignity. It is necessary to mention that the perception of the quality of care affected the way in which the participants recollected and retold the whole experience in the ICU. Where care was interpreted as caring, even in bereavement; where it was interpreted as dismissive or unclear, distress was enhanced.

## **RECOMMENDATIONS**

This section provides practical and policy-relevant recommendations based on the findings of the study. It is grounded on the experiences of participants in an attempt to enhance the ICU care experience of the family members. Although the scope of the study was small, the insights obtained serve as a plausible basis of reforms both at the institutional and the strategic levels. The following recommendations are in line with the initial research goals and contain both the identified needs and the implied priorities depending on the trends in the narratives of the participants.

Considering the emotional trauma that is caused by the memory of the events, it is suggested that hospitals should establish the framework of family notification and engagement practices upon hospital ICU admission. These must involve clear communication that is compassionate, education about what ICU care involves and questions that families can pose. Although the given interventions were not directly tested in this study; the stories imply that shock and confusion that the relatives experienced might have been alleviated by more deliberate early-stage communication. Short-term psychological first aid at admission may also be an option in the institutions to alleviate the emotional load of the abrupt changes in ICU.

When it comes to the physical experience of family members, the hospitals are supposed to invest in infrastructure and logistics that would minimize the strain on caregivers. This involves the establishment of sheltered waiting areas to family members, virtual visitations where they are not allowed to access the facilities due to physical limitations, and equitable provision of medicines and basic necessities. On policy level, it is possible to have minimum standards in the area of family accommodation and participation in health emergencies in the community. Although the participants do not consistently insist on these changes, their accounts of exhaustion, marginalization, and stigmatization give a decent ground to promote these changes.

The introduction of psychosocial services to the ICU care is highly encouraged in order to deal with the psychological discomfort of the family members. This may be as a hospital-based support officer in the family, a regular check-up by trained counsellors or a referral channel to external mental health services. According to the results, the majority of the participants were forced to use personal beliefs or family strength because of the lack of institutional emotional support. Although spiritual coping is a good thing, it cannot replace professional assistance, particularly in high stress settings, such as critical care units. These suggestions are deduced out of the unanimous lack of such services in the participant experiences.

Finally, to enhance the impressions of care and minimize emotional injury, the ICU teams must consider active and uninterrupted, respectful, and inclusive communication with family members. This includes effective handover practices across shifts, family communication schedules and use of the language that is accessible. The institutions can also take into consideration the idea of the feedback mechanism wherein family members can share their concerns or gratitude during and after ICU stays. Though the participants did not insist on formal grievance systems, their remarks regarding inconsistency and exclusion imply that formalized means of communication might enhance trust and minimize the psychological trauma that may occur even after the event.

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