#### **ORIGINAL ARTICLE**



## Lived Experiences of Family Members of Patients Admitted to the Intensive Care Unit at the Adult University Teaching Hospital, Lusaka, Zambia

Cynthia Stephen Phiri<sup>1,3</sup>\*, Emmanuel Musenge<sup>3</sup>, Priscar Sakala-Mukonka<sup>2</sup>

<sup>1</sup>Natuseko Health Centre, Kabwe, Central province, <sup>2</sup>Lusaka College of Nursing <sup>3</sup>School of Nursing Sciences, University of Zambia

#### ABSTRACT

**Background:** Family members of patients in the Intensive Care Unit (ICU) play a crucial role in the care and support of their loved ones. Understanding their experiences, challenges, and needs is essential for providing effective family-centred care in the ICU setting. This study therefore sought to explore the lived experiences of family members of patients admitted to the ICU at the University Teaching Hospitals-Adult Hospital in Lusaka, Zambia.

**Methods:** This study utilized descriptive phenomenological design. Twelve participants were purposively sampled, and data was collected through semi-structured, face-to-face interviews. Thematic analysis was used to identify notable patterns and themes within the narratives of the participants.

**Results:** Thematic analysis revealed four key themes: (1) emotional impact, (2) Communication challenges, (3) support systems, and (4) the

healthcare system experience. Emotional impact emerged as a significant theme, highlighting feelings of fear, anxiety, and stress due to uncertainty and the critical condition of their loved ones. Communication challenges were also prominent, with participants expressing difficulties in understanding medical information and feeling excluded from decision-making processes. Coping mechanisms revealed reliance social support, spirituality, and practical strategies to navigate the stress of having a loved one in the ICU. Lastly, the healthcare system experience revealed mixed experiences, with some family members expressing satisfaction with care provided, while others reported feeling overwhelmed and neglected.

**Conclusion:** The findings highlight the importance of improving communication by providing regular updates regarding the patient's condition, provide adequate support, and involving family members in decision-making processes are essential for enhancing family-centred care.

#### Corresponding author:

Cynthia Stephen Phiri,

Email; phiricynthias@gmail.com

*Keywords:* Family-centred care, Intensive Care Unit, experiences, challenges, coping strategies, Emotional impact

© This is an Open Access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/4.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.



This article is available online at: http://www.mjz.co.zm, http://ajol.info/index.php/mjz, doi: https://doi.org/10.55320/mjz.52.2.628 The Medical Journal of Zambia, ISSN 0047-651X, is published by the Zambia Medical Association

#### INTRODUCTION

The Intensive Care Unit (ICU) is a critical care environment where patients with life-threatening illnesses or injuries receive specialized medical treatment.<sup>1</sup> While the primary focus is on patient care, the ICU experience significantly affects the lives of family members. Research consistently demonstrates that family members of ICU patients experience a range of profound emotional and psychological consequences, including anxiety, depression, and post-traumatic stress disorder (PTSD) stress due to the severity of the patient's condition and the unfamiliarity of the ICU environment. Admission to ICU often occurs suddenly and members of the family think of a possibility of their loved one dying or being severely disabled.<sup>2,3</sup>

Family members of ICU patients have unique support needs that should be addressed to promote their well-being<sup>4</sup>. These needs encompass emotional support, information resources, assurance and opportunities for involvement in the care process. Identifying and addressing these needs through tailored interventions and support programs can alleviate stress and enhance the overall experience for family members.<sup>5</sup> Structured interventions and approaches to support family members of critically ill patients are needed both to mitigate the impact of the crisis of critical illness and to prepare family members for decision-making and caregiving demands.<sup>6</sup>

The process of decision-making and the involvement of family members in the care of ICU patients are complex and emotionally challenging.<sup>7</sup> Family members may face difficult decisions regarding treatment options, resuscitation preferences, and end-of-life care. Their experiences related to decision-making and involvement in the patient's care play a crucial role in shaping their overall experience<sup>6</sup>. Understanding their perspectives could guide healthcare providers in offering appropriate support, shared decision-making models, and palliative care options.<sup>8</sup>

Family-centred care in the ICU has gained significant attention in recent years due to its

positive impact on patient outcomes and family well-being.<sup>9, 10</sup> Family-centred care refers to a partnership approach to health care decisionmaking between the family and health care provider.<sup>11</sup> Research findings consistently support the notion that involving and engaging families in the care process leads to improved patient satisfaction, reduced anxiety and stress levels among family members, and better communication between healthcare providers and families. A study by Davidson et al highlighted that family-centred care interventions in the ICU were associated with decreased lengths of stay and reduced healthcare costs.<sup>3</sup> Additionally, a systematic review by Kynoch et al emphasized the importance of family involvement in decision-making, providing emotional support, and facilitating the transition from ICU to home.<sup>12</sup> These findings underscore the significance of implementing family-centred care strategies in the ICU, ultimately leading to better patient outcomes and enhanced family experiences. Understanding how families make sense of their experience in the hospital is instrumental to develop hospital-based guidelines and protocols to implement the family-centred care.

Effective communication and information provision are vital components of family-centred care in the ICU.<sup>10, 13</sup> Family members often desire clear and timely information about the patient's condition, prognosis, treatment options, and care plans. Inadequate communication can lead to increased stress and dissatisfaction among family members.<sup>3</sup> Studies have highlighted the need for improved communication practices and family involvement in decision-making to enhance the overall experience for families.<sup>14,15,16</sup>

While research on the experiences of family members of ICU patients has grown globally, limited research has specifically focused on the Zambian context. The researcher did not come across any published information from the Zambian context describing the lived experiences of family members specifically in the context of the University Teaching Hospital- Adult Hospital (UTH- Adult) ICU. Without a comprehensive understanding of their lived experiences, healthcare providers may struggle to provide appropriate support and tailored interventions to address the unique needs of these family members. Therefore, this research sought to explore the lived experiences of family members in the ICU setting at UTH- Adult ultimately contributing to the enhancement of care and support for both patients and their families.

## METHODS

#### **Study Design**

This study utilized a descriptive phenomenological design to explore the lived experiences of family members of patients admitted to ICU. This qualitative approach was chosen to gain an in-depth understanding of participants' emotions, challenges, and coping mechanisms during their loved one's ICU stay. The phenomenological method allowed for the collection of rich, first-hand narratives that reflect the subjective realities of family members.

#### **Study Setting**

The study was conducted at the UTH- Adult in Lusaka, Zambia, a tertiary-level healthcare facility providing critical care services to patients with life-threatening conditions. The ICU at UTH- Adult is one of the largest and most advanced in the country, accommodating critically ill patients requiring intensive medical interventions and close monitoring.

#### **Study Population and Sampling**

The study population comprised family members of patients admitted to the ICU at UTH- Adult. Purposive sampling was used to select participants who met the following inclusion criteria:

- Immediate family members (e.g., spouses, parents, adult children, or siblings) actively involved in the patient's care and decision-making.
- Aged 18 years and above.

Exclusion criteria included:

• Family members of patients who had been admitted for less than 48 hours.

Sample size was determined based on data saturation, meaning recruitment continued until no new themes emerged from the interviews. A total of 12 participants were included in the study.

### **Data Collection**

Data were collected through semi-structured, faceto-face interviews conducted in a private setting within the hospital. The interviews were guided by open-ended questions that explored the emotional experiences of family members during the ICU stay, communication with healthcare providers, challenges encountered in the ICU environment, coping mechanisms and support systems utilized.

Data was collected between February and March 2024 at the ICU. The ICU nurse in-charge was first informed of the study and asked to help identify the family members who had been admitted for more than 48 hours to ICU. The researcher approached the identified family members to check if they met the inclusion criteria and informed them about the study. An information sheet outlining the purpose of the study, the risks and benefits and the voluntary nature of participation in the study was provided. If the participate, they were asked to sign a consent form.

Interviews were audio-recorded with participants' consent, lasted approximately 30–45 minutes, and were conducted during visiting hours. Field notes were also taken to capture non-verbal cues and contextual details.

#### Data Analysis

Thematic analysis was conducted using NVivo software to identify patterns and themes within the data. The analysis six-step framework of familiarization with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and writing the report.<sup>17</sup>

#### Trustworthiness of the Study

To ensure the rigor and credibility of the findings, this study adhered to Lincoln and Guba's trustworthiness criteria, including credibility, dependability, confirmability, and transferability.<sup>18</sup>

Credibility was established through prolonged engagement and peer review to enhance the trustworthiness of the data and interpretations. Dependability was ensured by maintaining an audit trail, documenting all research decisions, coding processes, and methodological steps to enhance consistency and transparency. Confirmability was reinforced through reflexive journaling, allowing the researcher to acknowledge and minimize potential biases throughout data collection and analysis. Lastly, transferability was supported by providing detailed descriptions of the study setting, participant characteristics, and findings to allow future researchers to determine applicability in similar contexts. These strategies enhanced the reliability and validity of the study's qualitative approach.

#### **Ethical Considerations**

Ethical approval was obtained from the University of Zambia Biomedical Research Ethics Committee (UNZABREC) REF.NO.4682-2023 and written permission from National Health Research Authority (NHRA) registration number NHRA- 936/15/02/2024, and thereafter by the hospital management. Participants provided written informed consent, and confidentiality was maintained by anonymizing personal identifiers in transcripts and reports. Participation was voluntary, and individuals could withdraw at any stage without consequences.

#### RESULTS

Table 1 shows that the age of participants ranged from 26 to 62 years, with the majority falling within the 40-55 age range. Over half of the participants (58.3%) attained at least secondary education, while one-third (33.3%) had tertiary education qualifications. Participants were engaged in various occupations, including nursing, business, farming, teaching, and accounting. Participants have different relationships with patients admitted to the ICU, including spouses, children, siblings, and parents. The length of time spent by patients in the ICU varied, ranging from 3 to 11 days. Lastly, all participants identified as Christian, indicating a religious similarity within the sample population.

Participant	Age	Education	Occupation	Relationship to Patient	Days in ICU
P1	26	Tertiary	Nurse	Spouse	4
P2	55	Primary	Business	Child	5
P3	50	Primary	Farmer	Parent	4
P4	48	Secondary	Business	Sibling	3
P5	62	Tertiary	Accountant	Parent	11
P6	53	Secondary	Business	Spouse	5
P7	51	Primary	Farmer	Child	7
P8	45	Primary	Business	Sibling	5
P9	40	Secondary	Farmer	Parent	3
P10	47	Tertiary	Teacher	Child	3
P11	27	Tertiary	Business	Sibling	5
P12	34	Secondary	Business	Child	4

 Table 1: Demographic Characteristics of the Participants (n = 12)

#### Themes and Subthemes that Emerged

In an exploration of the narratives provided by family members of patients admitted to the ICU, four key themes emerged each with subthemes, reflecting the core aspects of their experiences (Table 2).

# Table 2: Themes and Subthemes that emergedfrom the Study

#### P1 "I am terrified of losing my partner. Every beep of the machines makes my heart race with fear."

Participants also spoke about the impact of the ICU environment on their emotional well-being. One participant remarked, "*The constant noise and activity in the ICU adds to my stress. I am also not able to spend adequate time with my father because the visiting time is very limited.*" (P7)

Number of Theme	Major Theme	Subtheme	Potential Codes	
Theme 1	Emotional Impact	Anxiety and Stress	Fear, Worry, Stress, Anxiety	
		Coping Mechanisms	Support Seeking, Religious Coping	
Theme 2	Communication Challenges	Information Access	Understanding Medical Jargon, Communication with Healthcare Providers	
		Decision-Making	Treatment Decisions	
Theme 3	Support Systems	Family Dynamics	Roles and Responsibilities, Conflict Resolution	
		External Support	Financial Challenges, Financial Assistance	
Theme 4	Healthcare System Experience	Perception of Care	Quality of Care	
		Emotional Support	Compassion, Empathy	

#### **Theme 1: Emotional Impact**

The theme of emotional impact emerged as a significant aspect of the lived experiences of family members of patients admitted to ICU. Participants expressed a range of emotions that they experienced during their loved one's ICU stay, highlighting the profound emotional toll that the experience had on them.

One participant described the emotional strain, stating, P10 "It is overwhelming. Ifeel like I am on an emotional rollercoaster, with highs and lows every day." Many participants, who expressed feelings of anxiety, fear, and helplessness as they witnessed their loved one's critical illness echoed this sentiment.

Some participants also expressed a sense of helplessness. One participant stated, "I feel so powerless, I watch my mom in pain and there is nothing I can do to help."

Family members of patients admitted to the Intensive Care Unit (ICU) employed various coping mechanisms and sought support to deal with the emotional strain and stress of their loved one's critical illness. Participants described sources of support that played a crucial role in helping them navigate this challenging time.

Many participants leaned on their family and friends for emotional support, with one participant stating, "My family is my support during this time. They listen to me, comfort me, and help me stay strong."

Another participant shared, "Talking to friends who have been through similar experiences has helped me feel less alone and more understood."

For some participants, religion and spirituality were sources of comfort and strength. One participant mentioned, "*Praying gives me a sense of peace and helps me feel like I am doing something to help my wife. As it is now, I just put everything in God's hands to intervene in our situation*" (P6)

However, individuals vary in their reliance on religious coping, with some finding comfort and reassurance in their faith traditions, while others struggle to reconcile their beliefs with the challenges they face. P11 said:

P11: "I struggle to find comfort in religion. Sometimes, I question whether my prayers are heard or not because the condition doesn't seem to get better."

#### Theme 2: Communication Challenges

Communication challenges emerged as a prominent aspect of the experiences reported by family members of ICU patients. Family members of patients admitted to the ICU faced several communication challenges that impacted their experiences and ability to cope with their loved one's critical illness. These challenges stemmed from various factors, including the complexity of medical information, limited communication channels, and emotional strain.

Many participants expressed difficulty understanding the medical information provided by healthcare providers. One participant stated:

"The medical terminology used by the doctors is like a foreign language to me. It makes me feel lost and confused."

Another participant mentioned, "I wanted more detailed explanations about my daughter's condition and treatment plan, but I didn't know how to ask for them." Lack of information and limited communication channels are significant challenges faced by family members of patients in ICU. Many family members express frustration over not receiving enough information about their loved one's condition and treatment plan. For example, one participant noted,

"I feel like I am in the dark most of the time. I don't understand what is happening or what the doctors are doing. They were not updating us on the progress of our patient, so we have to make our own judgement." (P9)

Participants highlighted the limited communication channels available to them, particularly due to restricted visiting hours and limited access to healthcare providers. One participant stated, "I felt frustrated by the lack of communication. I wanted more updates about my husband's condition, but I couldn't always be there to ask."

Another participant shared, "I wish there were more opportunities to talk to the doctors and nurses. It is hard to get information when they are busy. When we come to visit, we expect to be updated on how our patient is doing."

The emotional strain of having a loved one in the ICU also affected communication. Participants described feeling overwhelmed, which hindered their ability to process information and communicate effectively. One participant stated, "I was so emotional that I couldn't think straight. It was hard to communicate my concerns clearly when my mother was just transferred to ICU. She seemed like she was in a lot of pain and had so many machines connected to her."

Despite these challenges, there were also instances of positive communication experiences that enhanced their understanding, comfort, and overall satisfaction with the care provided.

Some participants noted instances where healthcare providers communicated clearly and empathetically, which helped alleviate their anxiety and uncertainty. One participant stated, *"The nurses took the time to explain things to me in a way that I could understand. It made me feel more confident in the care my father was receiving."*  Participants appreciated receiving regular updates and information about their loved one's condition and treatment plan. One participant mentioned, "*The nurses kept me informed about any changes in my son's condition, which helped me feel more involved in his care.*"

Another participant stated, "The doctors took the time to explain the treatment options and possible outcomes, which helped us to make informed decisions as a family about our mother's care." (P2)

#### Theme 3: Support Systems

Family members of patients admitted to ICU often took on various caregiving roles and responsibilities to support their loved ones during their critical illness.

Many participants assumed the role of the primary caregiver, responsible for coordinating care, advocating for the patient, and making decisions about their treatment. One participant stated, "*I feel like it is my responsibility to be there for my sister, no matter what because I want to make sure she receives the best possible care.*"

P6 "Despite the challenges, caregiving allows me to demonstrate my love and commitment to my wife."

While caregiving was a fulfilling experience for many participants, it also came with challenges and burden. One participant stated,

"It is physically and emotionally draining to be the primary caregiver. I have to be at the hospital throughout the day and my brother takes over at night. There are no waiting areas for us to sit comfortably, we have to sit at the benches outside the emergency department and sometimes we are not allowed to be there during the day."

Participants expressed the need for support and resources to help them fulfill their caregiving roles effectively. One participant stated,

"I wish there were more resources available to help me navigate my role as a caregiver. Support groups for caregivers would have been helpful. It would have been nice to connect with others who were going through similar experiences." Financial challenges often accompany the emotional and physical strains experienced by family members of patients admitted to ICU. Participants in this study described the financial burden of medical expenses, transportation costs and food. One participant stated, "*The medical bills are overwhelming*. Some of the medication and laboratory tests have to be done outside the hospital at private laboratories, which is quite expensive. We have to make sacrifices and cut back on expenses to afford the treatment."

Another participant mentioned, "Day to day expenses such as food and transportation is quite high especially that we came from Southern Province, and we do not have relatives in Lusaka. It is a stressful time financially."

Despite these challenges, participants also highlighted the assistance they received from various sources, such as healthcare providers, social services, and community organizations.

One participant shared, "The hospital helped us navigate the financial aspects of care, connecting us with resources for financial assistance through a social worker."

Another participant stated, "Our church made monetary contributions to help us with the medical bills and other expenses. It was encouraging to see the support they gave us."

#### Theme 4: Health Care System Experience

Participants expressed a range of experiences regarding the quality of care received within the healthcare system. Participants described both positive and negative experiences with the healthcare team.

Many participants praised the healthcare team for their professionalism, expertise, and compassionate care. One participant stated,

"The nurses went above and beyond to make sure my son was comfortable and well-cared for. The care he has been receiving is beyond our expectations. We were referred from a different hospital, but I would say the care here is so much better." Despite the positive experiences, some participants also described negative interactions with the healthcare team. One participant stated, "Some of the nurses were dismissive of my concerns and seemed too busy to give me the attention I needed."

Participants emphasized the key role of compassion in healthcare, detailing its profound impact on patients' experiences and overall well-being. Participants shared both positive and negative experiences regarding compassion in healthcare.

P 11 mentioned, "When healthcare providers showed empathy, it made me feel more comfortable asking questions and seeking support. It was reassuring to know that they were there for us."

While many participants in this study highlighted positive experiences of empathy from healthcare providers, some also described negative experiences that lacked empathy. Participants expressed frustration and disappointment with healthcare providers who appeared indifferent or unresponsive to their emotional needs.

One participant stated, "Some of the nurses seem cold and uncaring. They don't seem to understand how stressful and overwhelming the situation is for us. There was a day when I came to visit my father and I noticed that one of the tubes had come out, I told one of the nurses and she told me that they knew what they were doing. She was even listening to loud music on the phone with other nurses."

#### DISCUSSION

The themes of emotional impact, communication challenges, coping mechanisms, and the healthcare system represent the experiences encountered by family members of patients admitted to ICU.

#### **Theme 1: Emotional Impact**

The theme of emotional impact emerged prominently in this study, particularly concerning the experiences of anxiety and stress among family members of patients in the ICU. The emotional impact on family members of patients admitted to the ICU is deep and complex, reflecting the composite interaction of fear, worry, stress, and

anxiety. Participants articulated a pervasive sense of fear, stemming from the unpredictability of their loved one's condition and the stark reality of the ICU environment. The constant presence of medical equipment and the clinical setting often intensified this fear, which evoked feelings of powerlessness and vulnerability. Moreover, participants expressed deep-seated worries about their loved one's health, prognosis, and the uncertain trajectory of their recovery journey. These findings resonate with several studies examining the emotional experiences of family members in similar contexts. The findings of Bailey et al revealed that family members experience extreme psychological distress characterised by anxiety, depression and even signs of post-traumatic stress disorder.<sup>19</sup> Similarly, De Beer and Brysiewicz in South Africa revealed that family members frequently expressed the emotional challenge of seeing the changed and helpless state of the patient. Seeing the patient in this state connected to tubes and machines was described as shocking and frightening, instilling feelings of helplessness.<sup>20</sup>

Participants in this study described various coping mechanisms that they employed to deal with the stress, uncertainty, and emotional turmoil of having a loved one ICU. Family members engaged in various coping mechanisms, including seeking social support and drawing strength from religious beliefs. Many participants relied on their social support networks, leaning on friends and family members for emotional sustenance and practical assistance. This outcome is expected as Zambian culture emphasizes strong social bonds during times of severe illness or loss of a family member. This is consistent with findings by Kalolo et al., in Malawi, which found that family members often valued the support from health care workers and other people including friends and family to cope with the stress of having a loved one in the ICU.<sup>21</sup>

Religion served as a source of strength and solace for many family members, providing a framework for making sense of their loved one's illness and finding meaning in their experiences. Participants drew on spiritual practices, such as prayer and reading scriptures, to cultivate a sense of connection to a higher power and navigate feelings of uncertainty and distress. However, individuals varied in their reliance on religious coping, with some finding comfort and reassurance in their faith traditions, while others struggled to reconcile their beliefs with the challenges they faced.

Similar studies have also identified religious coping mechanisms used by family members of ICU patients. For example, a study by Leong *et al.* in Malaysia reported that spiritual distress was common among ICU patients and family members. Thus, religious support such as praying with the patient, discussing religious topics, and fostering religious growth were regarded as a source of encouragement and hope.<sup>22</sup> Another study by Harlan et al reported that family members commonly depended on social and spiritual support. Family members sought out staff or members of their faith community for support.<sup>23</sup>

These findings highlight the significant emotional burden faced by family members of ICU patients and the importance of implementing effective support interventions within healthcare settings. Healthcare providers should prioritize providing empathetic support, facilitating open communication, and offering resources for coping and resilience building. Recognizing and addressing the diverse coping needs of family members, including religious and spiritual support, can enhance their overall well-being and satisfaction with the caregiving experience. By addressing these emotional needs, healthcare providers can contribute to holistic and patient-centred care for both patients and their families in the ICU setting.

#### Theme 2: Communication Challenges

Communication challenges emerged as a significant theme in this study, reflecting the experiences of family members of patients in ICU. Family members in this study clearly articulated the need for information and regular updates regarding the patient's condition. However, many participants faced various difficulties regarding communication

with healthcare providers, which had a significant impact on their experience and ability to provide support to their loved ones. Participants expressed struggles in comprehending medical terminology, feeling overwhelmed and excluded by complex terminology. This lack of comprehension contributed to heightened stress and feelings of helplessness, as participants struggled to navigate the details of their loved one's medical condition. Additionally, communication with healthcare providers was fraught with obstacles, including perceived one-sidedness and rushed explanations, leaving participants feeling unheard and dismissed. Lack of information and limited communication channels were significant challenges faced by family members. Many family members expressed frustration over not receiving enough information about their loved one's condition and treatment plan. Another common issue was the limited communication channels available to family members. Restricted visiting hours and limited access to healthcare providers, which hindered communication. These findings are consistent with previous research examining communication challenges among family members of ICU patients. A study by Curtis et al. reported that ineffective communication led to misunderstandings and increased stress among family members.<sup>24</sup> Additionally, a study by Davidson *et al.* found that family members often felt excluded from decisionmaking processes and lacked clear information about the patient's condition and prognosis.<sup>10</sup>

Despite these challenges, positive experiences emerged, with some participants highlighting instances of transparency, clear communication and empathy from certain healthcare providers. This suggests that communication challenges in the ICU may vary depending on individual experiences and interactions with healthcare providers. Consistent with this study's findings, <sup>25, 26</sup> found that family members had positive communication experiences, which included clear and empathetic explanations from healthcare providers, regular updates on the patient's condition, and opportunities for families to ask questions and be involved in care decisions. These findings underscore the critical need for improved communication strategies and support interventions for family members of ICU patients. Healthcare providers should prioritize clear and empathetic communication, ensuring that information is conveyed in a manner that is easily understandable and sensitive to family members' emotional needs. Strategies such as regular updates, clear explanations, and open dialogue can help address communication challenges and enhance the overall experience of family members in the ICU.

#### Theme 3: Support Systems

Participants articulated feelings of overwhelming burden and exhaustion as they navigated the demands of caregiving alongside other responsibilities. However, amidst these difficulties, participants also recognized the value and significance of their caregiving roles, finding purpose, unity, and strength in supporting their loved ones. Family members required support to be able to cope with the situation of having a relative admitted to the ICU. Families identified several sources of support, primarily from their own family members, friends and their communities. Similarly, a study by McKiernan and McCarthy reported that several different sources of support were identi?ed by families, these were primarily their own family, nursing staff, and some form of spiritual support. Family members supported them by being present at the bedside, assisting with transportation, household chores and childcare<sup>27</sup>

Financial burdens emerged as a significant challenge faced by family members of patients in the ICU in this study. Participants described the financial strain caused by medical expenses, transportation costs and food costs. These financial burdens added an additional layer of stress and uncertainty to an already challenging situation. Similar studies have also highlighted the financial challenges faced by family members of ICU patients. For example, a study by Olorunfemi & Nwozichi in Nigeria reported that critical illness imposed substantial financial burdens on the participants and increased self-reported levels of stress.<sup>28</sup> Another study by Blok *et al* showed that several family members with anxiety expressed concern about housing and financial security and stress due to medical bills and costs related to the patient's hospital stay such as accommodation and food.<sup>29</sup>

To address these financial challenges, participants in this study mentioned various sources of financial assistance, such as hospital financial aid programs, community fundraisers, and support from family and friends that helped ease their financial burden. These findings are consistent with studies,<sup>30,31</sup> which found that financial assistance programs could help alleviate some of the financial burdens faced by families of ICU patients.

However, despite the availability of financial assistance programs, accessing these resources can be challenging. Participants in this study mentioned lack of awareness about available resources as barriers to obtaining financial assistance. This highlights the need for improved communication and support from healthcare providers to help families navigate the financial aspects of critical care.

Financial burdens are a significant concern for family members of ICU patients. Healthcare providers should be aware of these challenges and proactively offer support and information about available financial assistance programs. Addressing these financial burdens can help reduce stress and improve the overall experience of families in the ICU.

#### Theme 4: Healthcare System Experience

The study findings revealed mixed experiences regarding the quality of care provided by the healthcare system in the ICU. While some family members expressed gratitude for the professionalism, expertise, and compassionate approach of healthcare providers, others reported dissatisfaction due to perceived neglect and inadequate communication. Participants who had positive experiences highlighted instances where nurses and doctors provided clear explanations, showed empathy, and reassured them about their loved one's condition, which helped build trust and reduce anxiety. Conversely, some participants in this study reported feeling ignored or excluded from the care process, particularly when healthcare providers failed to provide timely updates or involved them minimally in decision-making

Comparing these findings with other studies, a study by Moleli *et al* found that family members of ICU patients expressed similar concerns about the quality of care and trust in healthcare providers.<sup>32</sup> They highlighted issues such as communication gaps, lack of empathy, and perceived neglect, which eroded their trust in the healthcare system. Similarly, a study by Kehali *et al.* conducted in Ethiopia reported that some family members of ICU patients lost trust in the health care delivery system and the health professionals due to previous experiences of losing a family member in an ICU.<sup>33</sup>

In contrast, a study by Haave *et al.* in Norway reported that families were satisfied with a large portion of the ICU stay.<sup>34</sup> Participants in this study cited satisfaction with the nursing care and with the overall treatment for both the patient and for the family itself. Similarly, a study by Min *et al.* in South Korea reported that most of the family members were satisfied with the ICU care and decision-making process.<sup>31</sup> Additionally, a study by McKiernan & McCarthy in Ireland showed that participants described having feelings of con? dence in the care given. Being assured of best possible care was attributed in part to the provision of honest information.<sup>27</sup>

Compassion and empathy emerged as critical components of the experiences of family members of ICU patients in this study. Participants frequently highlighted how acts of kindness and understanding from healthcare providers alleviated their emotional distress, fostered trust, and enhanced their overall satisfaction with the care process. However, instances of perceived indifference or lack of empathy also contributed to heightened feelings of frustration and helplessness, demonstrating the profound impact that provider attitudes can have on family members during such critical times. These findings align with studies conducted in other contexts. For example, a study conducted in the United States by Curtis *et al.* emphasized that empathy in healthcare communication significantly reduced the psychological burden on families and contributed to higher levels of satisfaction with ICU care.<sup>24</sup> Additionally, studies show that patients and their loved ones have consistently highlighted the utmost importance of compassion, including attributes like empathy, respect, and kindness, during their healthcare experiences.<sup>35,36</sup>

#### LIMITATIONS OF THE STUDY

Several limitations were encountered during this study, which warrant acknowledgment. Firstly, the study's sample size was relatively small, consisting of a specific group of participants from a single healthcare facility. This may limit the transferability of the findings to broader populations of families of ICU patients. Despite this, similarities in the experiences of family members are consistent with international studies. Furthermore, the study was conducted within a specific cultural context, which may influence the experiences and perspectives of participants, which may limit their applicability to other settings. Future research should aim to address these limitations by incorporating larger and more diverse samples, utilizing mixed methods approaches, and exploring the experiences of families of ICU patients across different cultural settings.

#### CONCLUSION

The themes of emotional impact, communication challenges, support systems, and the healthcare system experience underscore the complexity of the experiences encountered by these individuals. The deep emotional impact on family members, compounded by fear, worry, stress, and anxiety, underscores the need for comprehensive support structures and coping mechanisms. Communication challenges within the healthcare system highlight the importance of clear, empathetic communication and the involvement of families in decision-making processes. Lastly, the healthcare system's impact on patient experiences underscores the critical role of compassion, empathy, and trust in fostering positive outcomes and patient-provider relationships. This study reiterates that admission of a loved one to ICU is a stressful event in the lives of family members. This study's findings emphasize the need for a comprehensive and holistic approach to supporting family members of ICU patients. By addressing emotional, communication, and healthcare system challenges, healthcare providers can improve the quality of care and support provided to these individuals during a critical and challenging time.

#### ACKNOWLEDGEMENTS

I would like to thank all the participants of this study, whose willingness to share their experiences provided valuable insights into the challenges faced by families in the ICU setting. Your openness and honesty are greatly appreciated. I would also like to extend my thanks to the healthcare providers and staff at the Adult University Teaching Hospital for their cooperation and support throughout the data collection process. Your dedication to patient care and commitment to improving services for families in the ICU are commendable.

#### **FUNDING STATEMENT**

Funding for review/development of this study was supported by the Fogarty International Centre of the National Institutes of Health, U.S. Department of State's Office of the U.S. Global AIDS Coordinator and Health Diplomacy (S/GAC) and the President's Emergency Plan for AIDS Relief (PEPFAR) under the Award Number R25 TW011219 under the project title: Strengthening Health Professional Workforce Education Programs for Improved Quality Health Care In Zambia (SHEPIZ) Project. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

#### **CONFLICTS OF INTEREST**

Authors declare no conflicts of interest.

#### **AUTHOR'S CONTRIBUTIONS**

- **1.** Cynthia Stephen Phiri- conceptualized the study, developed the research design, and led the data analysis process, including the coding and thematic analysis.
- **2. Emmanuel Musenge-** Conceptualization, contributed to data collection, transcribing, interpretation of the findings and helped in drafting and revising the manuscript.
- **3. Priscar Sakala-Mukonka-** assisted with the literature review, provided critical feedback on the analysis and interpretation of the data.

#### REFERENCES

- Marshall JC, Bosco L, Adhikari NK, Connolly B, Diaz JV, Dorman T, et al. What is an intensive care unit? A report of the task force of the World Federation of Societies of Intensive and Critical Care Medicine. *J Crit Care*. 2017 Feb;37:270–6. doi: 10.1016/j.jcrc.2016.07.015.
- Foster M, Whitehead L, Maybee P. The parents', hospitalized child's, and health care providers' perceptions and experiences of family-centered care within a pediatric critical care setting: A synthesis of quantitative research. *J Fam Nurs*. 2 0 1 6 F e b ; 2 2 (1): 6 – 7 3. d o i : 10.1177/1074840715618193.
- McAdam JL, Fontaine DK, White DB, Dracup KA, Puntillo KA. Psychological symptoms of family members of high-risk intensive care unit patients. Am J Crit Care. 2012 Nov;21(6):386–93. doi: 10.4037/ajcc2012582.
- 4. Alsharari AF. The needs of family members of patients admitted to the intensive care unit. *Patient Prefer Adherence*. 2019;13:465–73. doi: 10.2147/PPA.S197769.
- Scott P, Thomson P, Shepherd A. Families of patients in ICU: A scoping review of their needs and satisfaction with care. *Nurs Open*. 2019;6(3):698–712. doi: 10.1002/nop2.287.
- 6. White DB, Angus DC, Shields AM, Buddadhumaruk P, Pidro C, Paner C, et al. A

randomized trial of a family-support intervention in intensive care units. *N Engl J Med.* 2018 Jun 21;378(25):2365–75. doi: 10.1056/NEJMoa1802637.

- 7. Klaas N, Baliki O. Family satisfaction with involvement in decision making in the intensive care unit: A scoping review. *medRxiv*. 2024 Mar 11. doi: 10.1101/2024.03.11.24304110.
- Kon AA, Davidson JE, Morrison W, Danis M, White DB; American College of Critical Care Medicine, American Thoracic Society. Shared decision-making in ICUs: An American College of Critical Care Medicine and American Thoracic Society policy statement. *Crit Care Med*. 2016;44(1):188–201. doi: 10.1097/CCM.00000000001396.
- Olding M, McMillan SE, Reeves S, Schmitt MH, Puntillo K, Kitto S. Patient and family involvement in adult critical and intensive care settings: A scoping review. *Health Expect*. 2016;19(6):1183–202. doi: 10.1111/hex.12402.
- 10. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. *Crit Care Med*.
  2 0 1 7 ; 4 5 (1) : 1 0 3 2 8. doi: 10.1097/CCM.0000000002169.
- Kuo DZ, Houtrow AJ, Arango P, Kuhlthau KA, Simmons JM, Neff JM. Family-centred care: current applications and future directions in pediatric health care. *Matern Child Health J*. 2012 Feb;16(2):297–305. doi: 10.1007/s10995-011-0751-7.
- Kynoch K, Chang A, Coyer F, McArdle A. The effectiveness of interventions to meet family needs of critically ill patients in an adult intensive care unit: A systematic review update. *JBI Database Syst Rev Implement Rep.* 2016 Mar;14(3):181–234. doi: 10.11124/JBISRIR-2016-2477.
- 13. Fernández-Martínez E, Mapango EA, Martínez-Fernández MC, Valle-Barrio V. Family-centred care of patients admitted to the intensive care unit in times of COVID-19: A systematic review. *Intensive Crit Care Nurs*.

2 0 2 2 ; 7 0 : 1 0 3 2 2 3 . d o i : 10.1016/j.iccn.2022.103223.

- 14. Cussen J, Van Scoy LJ, Scott AM, Tobiano G, Heyland DK. Shared decision-making in the intensive care unit requires more frequent and high-quality communication: A research critique. *Aust Crit Care*. 2020;33(5):480–3. doi: 10.1016/j.aucc.2019.12.001.
- Edward KL, Galletti A, Huynh M. Enhancing communication with family members in the intensive care unit: A mixed-methods study. *Crit Care Nurse*. 2020;40(6):23–32. doi: 10.4037/ccn2020595.
- 16. Newcomb A, Liu C, Smith G, Lita E, Griffen MM, Mohess D, et al. Family survey of understanding and communication of patient prognosis in the intensive care unit: Identifying training opportunities. *J Surg Educ*. 2020 Nov-D e c; 77(6): e 154 e 163. doi: 10.1016/j.jsurg.2020.08.009.
- 17. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2 0 0 6; 3 (2): 7 7 1 0 1. doi: 10.1191/1478088706qp063oa.
- 18. Lincoln YS, Guba EG. *Naturalistic Inquiry*. Beverly Hills, CA: SAGE Publications; 1985.
- 19. Bailey JJ, Sabbagh M, Loiselle CG, Boileau J, McVey L. Supporting families in the ICU: A descriptive correlational study of informational support, anxiety, and satisfaction with care. *Intensive Crit Care Nurs*. 2010 A p r; 2 6 (2): 1 1 4 – 2 2. d o i: 10.1016/j.iccn.2009.12.006.
- 20. Leong EL, Chew CC, Ang JY, Lojikip SL, Devesahayam PR, Foong KW. The needs and experiences of critically ill patients and family members in intensive care unit of a tertiary hospital in Malaysia: A qualitative study. *BMC Health Serv Res.* 2023 Jun 13;23(1):627. doi: 10.1186/s12913-023-09660-9.
- 21. Harlan EA, Miller J, Costa DK, Fagerlin A, Iwashyna TJ, Chen EP, et al. Emotional experiences and coping strategies of family members of critically ill patients. *Chest.* 2020 O c t ; 1 5 8 (4) : 1 4 6 4 - 7 2 . doi:

10.1016/j.chest.2020.05.535.

- 22. Curtis JR, Treece PD, Nielsen EL, Gold J, Ciechanowski PS, Shannon SE, et al. Randomized trial of communication facilitators to reduce family distress and intensity of end-oflife care. *Am J Respir Crit Care Med*. 2016 Jan 15;193(2):154–62. doi: 10.1164/rccm.201505-09000C.
- 23. Frampton SB, Guastello S, Lepore M. Compassion as the foundation of patient-centered care: The importance of compassion in action. *J Comp Eff Res.* 2013;2(5):475–83. doi: 10.2217/cer.13.54.
- 24. Lown BA, Rosen J, Marttila J. An agenda for improving compassionate care: A survey shows about half of patients say such care is missing. *Health Aff (Millwood)*. 2011 Sep;30(9):1772–8. doi: 10.1377/hlthaff.2011.0539.
- Iglesias J, Martín J, Alcañiz M, Ezquiaga E, Vega G. The psychological impact on relatives of critically ill patients: The influence of visiting hours. *Crit Care Explor*. 2022;4(2):e0625. doi: 10.1097/CCE.00000000000625.
- 26. Kentish-Barnes N, Cohen-Solal Z, Morin L, Souppart V, Pochard F, Azoulay E. Lived experiences of family members of patients with severe COVID-19 who died in intensive care units in France. JAMA Netw Open. 2021;4(6):e2113355. doi: 10.1001/jamanetworkopen.2021.13355.
- 27. McKiernan M, McCarthy G. Family members' lived experience in the intensive care unit: A phenomenological study. *Intensive Crit Care Nurs*. 2010 Oct;26(5):254–61. doi: 10.1016/j.iccn.2010.06.004. PMID: 20674362.
- 28. Olorunfemi O, Nwozichi CU. Hermeneutic phenomenology of lived experience of family caregivers of critically ill patients sustained by healthcare technologies in Benin City, Nigeria. *MGM J Med Sci.* 2022 Oct;9(4):465–71. doi: 10.4103/mgmj.mgmj\_185\_22.
- 29. Blok AC, Valley TS, Weston LE, Miller J, Lipman K, Krein SL. Factors affecting psychological distress in family caregivers of critically ill patients: A qualitative study. *Am J*

*Crit Care*. 2023 Jan 1;32(1):21–30. doi: 10.4037/ajcc2023593. PMID: 36587003; PMCID: PMC10066878.

- 30. Olding M, McMillan SE, Reeves S, Schmitt MH, Puntillo K, Kitto S. Patient and family involvement in adult critical and intensive care settings: A scoping review. *Health Expect*. 2016 Dec;19(6):1183–202. doi: 10.1111/hex.12402. PMID: 27878937; PMCID: PMC5139045.
- 31. Min J, Kim Y, Lee JK, Lee H, Lee J, Kim KS, Cho YJ, Jo YH, Ryu HG, Kim K, Lee SM, Lee YJ. Survey of family satisfaction with intensive care units: A prospective multicenter study. *M e d i c i n e (B a l t i m o r e)*. 2018 A u g; 97 (32): e11809. doi: 10.1097/MD.00000000011809. PMID: 30095649; PMCID: PMC6133602.
- 32. Moleli N, Maputle SM. Experiences of family members regarding caring for patients in intensive care units in Limpopo province, South Africa. *Health SA Gesondheid*. 2018;23:1–7.
- 33. Kehali H, Berhane Y, Gize A. A phenomenological study on the lived experiences of families of ICU patients, Addis Ababa, Ethiopia. *PLoS One*. 2020 Dec 1 8; 1 5 (1 2): e 0 2 4 4 0 7 3. doi: 10.1371/journal.pone.0244073. PMID: 33338068; PMCID: PMC7748272.
- 34. Haave RO, Bakke HH, Schröder A. Family satisfaction in the intensive care unit: A cross-sectional study from Norway. *BMC Emerg Med.* 2021 Feb 15;21(1):20. doi: 10.1186/s12873-021-00412-8. PMID: 33588760; PMCID: PMC788544.
- 35. Frampton SB, Guastello S, Lepore M. Compassion as the foundation of patientcentered care: The importance of compassion in action. *J Comp Eff Res*. 2013;2(5):475–83. doi: 10.2217/cer.13.54.
- 36. Lown BA, Rosen J, Marttila J. An agenda for improving compassionate care: A survey shows about half of patients say such care is missing. *Health Aff (Millwood)*. 2011 Sep;30(9):1772–8. doi: 10.1377/hlthaff.2011.0539. PMID: 21900669.