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Research Article

Experiences of Caretakers During Transfer of their Patients to Intensive Care Units at Mbarara Regional Referral Hospital

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Abstract

Background: The transfer of patients to the Intensive Care Unit (ICU) is a critical moment for both patients and their caregivers, often accompanied by emotional, financial, and logistical challenges. This study aimed to explore caregiver experiences during the transfer of their loved ones to the ICU at Mbarara Regional referral Hospital.

Methods: A phenomenological qualitative study design was employed to interview 10 participants selected by purposive sampling using a semi-structured interview guide. Interviews were recorded and transcribed. Thematic analysis was used give the deeper understanding of subjective experiences and views of caretakers at MRRH regarding transfer of their Patients to ICU.

Results: The findings revealed a range of emotional responses among caregivers, including distress, anxiety, fear, and post-traumatic stress. Many caregivers reported feeling excluded from decision-making processes and experiencing communication barriers with healthcare providers. Financial concerns emerged as a significant issue, with limited support from relatives and friends exacerbating the financial strain of medical emergencies. Accessibility issues, such as restricted visitation policies in the ICU, further compounded caregivers' distress and sense of isolation.

Conclusion: The findings underscore the need for healthcare providers to prioritize communication, inclusion, and support for caregivers during the ICU transfer process. By addressing the challenges, nurses and healthcare professionals can create a more supportive and collaborative care environment that meets the holistic needs of both patients and their caregivers during critical illness.

Recommendations: Enhancing communication skills among healthcare teams, providing education and support for caregivers, advocating for flexible visitation policies, and addressing the financial needs of caregivers is paramount in improving their experience.

Keywords: Intensive Care Unit (ICU); Healthcare; Distress; Anxiety

Introduction

Background

Being admitted to the intensive care unit (ICU) is a terrible experience; even though the patient may have accepted their fate by then, their loved ones haven't. They fidget around with an anticipation, while glancing through the unit's windows hoping to see how their patients are faring, even though the windows are typically drawn. Atumanya., *et al*. (2020) [4].

'The global burden of critical illness is poorly defined, and best estimates remain diagnosis-based and extrapolated. Currently, the critical illness burden is characterized in its relation to ICU admissions or specific critical illness syndromes' Crawford., *et al*. (2023) [13]. ICU transfers represent a critical aspect of healthcare delivery globally, reflecting the increasing demand for intensive care services and the need for specialized treatment for critically ill patients Caretakers play a pivotal role in supporting patients during these transitions Ghorbanzadeh., *et al*. (2021) [17], the same author stated that the care givers navigate through the complexities of the healthcare system coping with the emotional stress associated with ICU transfers.

In Africa, the demand for ICU services has been steadily rising Droogh., *et al*. (2015) [16]. However, the availability of intensive care facilities and resources often falls short of the growing need as a result, transfers of critically ill patients to ICU facilities become essential Bergman., *et al*. (2020) [5], highlighting the challenges faced by caretakers in accessing specialized care for their loved ones Conolly, C (2018) [12].

'In Sub-Sahara Africa, the burden of critical illness in low-income countries is high and expected to rise' Kifle., *et al*. (2022) [29]. The landscape of critical care is evolving with efforts to centralize resources and formalize critical care networks. Despite these advancements, issues such as limited access to ICU facilities, inadequate training of caregivers, and logistical challenges during patient transfers persist, impacting the experiences of caretakers in the region Groenland., *et al*. (2018) [18].

In Uganda, the burden of critical illness is over whelming with an un-matched resource Atumanya., *et al*. (2020) [4]. The same author found out that the demand for ICU services has outpaced the available resources, leading to a significant number of patients being transferred for specialized care. However, the transfer process itself poses numerous challenges for caretakers, including emotional distress Tunner., *et al*. (2023) [50], financial burden, and concerns about the quality of care provided in ICU facilities Conolly, (2018) [12]. Abraham., *et al*. (2020) [1].

At MRRH, which serves as a critical healthcare hub in southwestern Uganda, the experiences of caretakers during patient transfers to ICU remain under explored because the only study found related to care giving was among care givers of patients with cancer Kansiime., *et al*. (2022) [27]. Understanding the unique challenges and needs of caretakers in this setting is essential for developing targeted interventions to support them through the transition process, improve communication between healthcare providers and caretakers, and enhance the overall quality of care for critically ill patients Burns., *et al*. (2023) [8].

Transfer of patients to ICU is very key in preventing deterioration of the patients due to early interventions thus contributing a reduction in mortality Conolly, (2018) [12]. Delay in transition due to rejection from caretakers results in increased risk for in-hospital mortality, poor neglectful care and poorer adverse clinical outcomes and violations of human dignity Groenland., *et al*. (2018) [18]. More so Harris., *et al*. (2018) [20], found out prompt admission to ICU can reduce mortality.

As well, inadequate transfer is associated with poorer clinical outcomes like; patient falls, nosocomial infections and critical incidents Recio-Saucedo., *et al*. (2017) [39]. Guidelines have been developed to ensure proper transfer of patients to ICU which included; training of patients and caregivers, use of ICU checklist Conolly., (2018) [12]. Abraham., *et al*. (2020) [1]. The guidelines recommend that a full, transparent explanation of the rationale for transfer be given to patients and caretakers until they are in Agreement on the transfer to allow safe transfer NHS. (2021) [36].

However, Caretakers such as spouses, siblings, children, parents and friends experience intense stress and anxiety whenever their Patients are allocated for transfer to ICU Burns., *et al*. (2023) [8]. This is because during intra hospital transport, the caretakers have to transport their Patients through corridors and elevators, sometimes to distant areas of the hospital Bergman., *et al*. (2020) [5]. Transition stress is a mental disorder that the patients and caretakers experience when they move from one environment to another during which they need to be psychologically prepared

to face ICU care Ghorbanzadeh., *et al*. (2021) [17]. This stress will have long- and short-term manifestations and nurses must reduce it through managing the transition time, requesting patients and caretakers to ask questions for clarification, training and educating them in relation to clinical progress and any forthcoming issues.

Successful transition in care requires effective multi-disciplinary communication, comprehensive planning and shared accountability throughout the entire transition process Tunner., *et al*. (2023) [50]. Providing information and counseling to caretakers about the new plan remains vital in relieving their stress and anxiety. Poor management of the transition process has negative effects on the patients' transition, health, treatment goals and outcomes. This increases problems such as; prolonged hospital stay, high cost of care, greater degree of disability and psychological stress for the patients and caretakers, leading to avoidable deaths Ghorbanzadeh., *et al*. (2021) [17].

Caretakers often reject transfer of their Patients as transfer seems unpleasant and frightening memories stemming from moving about and sensing motions Karlsson., (2021) [28]. To caretakers, transition led to serious gap in the continuity of care as there's limited access to ICU basic needs requiring much money Ghorbanzadeh., *et al*. (2021) [17]. Caretakers also experience intense anxiety whenever transfer is announced Chauliac., *et al*. (2023) [10].

Being a caretaker is not easy and during transfer they experience being in a fragile trust that is unexpectedly withdrawn and replaced with uncertainty. Facing the unknown, they experience a need to become seekers of meaning coherence. Being a caretaker means having a need to be close but being faced with loneliness while longing for proximity and participation in care of your loved ones Karlsson, (2021) [28].

Oftentimes, organized care in the transition process has shown beneficial results to both patients and caretakers that includes; greater satisfaction with care, successful transition, better preparation for the transition and less hospital stay Chauliac., *et al*. (2023) [10].

Little is known about the experience of caretakers from MRRH towards transfer of their Patients to ICU. Such information would guide on how best they can counsel. Therefore, this study will explore the experiences of caretakers at MRRH during transfer of their Patients to ICU.

Problem statement

Transfer of patients to any new ward remain challenging to caretakers especially they want to adjust to the new ward, shifting belongings and so on Imanipour., *et al*. (2019) [22]. Providing information and Counseling to the caretaker about the new plan remain vital. The benefits of transferring the patient to ICU are well explained during this time. This helps the caretakers get prepared to move to the new place and appreciate the patient's quality service and care.

However, observation made during clinical rotation on the different wards at MRRH, some caretaker resist transfer of their patients or others accepts after a long time after having been told to transfer to ICU. Some of the given reasons mention are; patient is already dead, caretakers/relatives will not see the patient leading to delays hence compromising patient care. This has sometimes contributed to mortality. In line with research conducted by Rose, (2020) [40] and Ninise., *et al*. (2023) [37]. respectively.

Little is known about the experience of caretakers from MRRH towards transfer of their Patients to ICU. Most studies done have looked at the experience of the caretakers post ICU or transferring from ICU to another ward. Sleeuwene., *et al*. (2020) [44], and Jiayi., *et al*. (2023) [23] respectively, thus the need to conduct this study and explore the experiences of caretakers at MRRH towards transfer of their Patients to ICU1.

Study aim

To explore the experiences of caretakers during transfer of their Patients to ICU at MRRH.

Research question

What are the experiences of caretakers during transfer of their Patients to ICU at MRRH?

Significance of the study

Nursing administration

This study will provide insight into the experiences of caretakers of ICU patients, and the factors that contribute to their burden. Understanding these experiences is important for improving the

quality of care for both patients and their caretakers. This study can also inform the development of support programs and resources for caretakers of ICU patients.

Nursing education

This study will provide a better understanding of the experiences of caretakers of ICU patients. This understanding can be incorporated into nursing education programs to prepare future nurses to better support and care for the caretakers of their patients. It can also inform the development of educational resources and training materials for nurses to help them understand and manage the needs of caretakers.

Nursing practice

The findings from this study will inform the development of new or improved practices to support caretakers of ICU patients, and to help nurses understand and manage the needs of caretakers. It can also lead to changes in the way that hospitals and other health care settings approach and support the caretakers of patients.

Nursing research

This study will add to the body of knowledge about the experiences of caretakers of ICU patients. It can also identify gaps in the existing literature and lead to further research on this topic. Additionally, the findings from this study can be used to inform future research on the experiences of caretakers of patients in other settings, such as the emergency department or the general ward.

Theoretical framework

The conceptual framework for this study will adopt the Neumann's system model Akhlaghi., *et al*. (2021) [2]. This theory focuses on the interaction between the patient, environment, and health care system.

In this model, three lines surround the person in Neuman's description of the Systems Model. the outermost line, being the flexible line of defense, followed by normal line of defense and then the line of resistance Loredana. (2022) [33]. The same author further found that the care taker may be affected by various pressures. Relationships between these components emerge to shield the caretaker from the impacts of the stressor when it reaches a typical line of defense. When these factors are not strong enough, the stressor gets past the wall of protection and affects the care taker.

Variables

- Dependent variable: Care taker experience
- Independent variable: Process of transfer

Conceptual framework

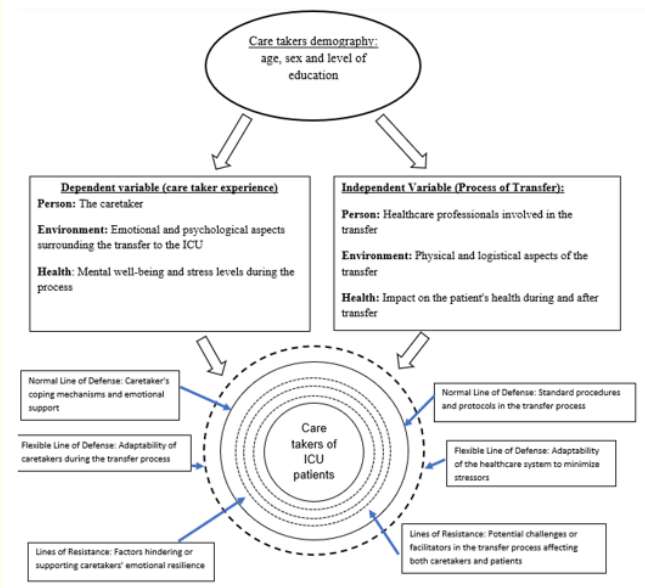

Figure 1: Diagram of stressors and coping strategies in the context of experience of care takers during transfer of their patients to the ICU. Adapted from Betty Neuman's Model (4,2011).

Literature Review

Introduction

This section will provide an overview of the topic and explain why it's important to study the experiences of caretakers of ICU patients. It will also describe the purpose of the literature review and how it will inform the study.

A study conducted by Kitko., *et al*. (2020) [30], titled " Family care giving for individuals with heart failure" used observational method of inquiry found physical and psychological effects being the most experience in this group. The same author further found out that care givers spend extended hours in the hospital

setting, they grapple with the challenge of finding time for rest, jeopardizing their own well-being. Another author who used central phenomenology Burns., *et al*. (2023) [8], found that the care giving role often exacts a toll on caretakers' physical health, evident in symptoms like muscle pain and headache. Notably, research has indicated an elevated risk of health issues such as high blood pressure and heart disease among those attending to ICU patients, underlining the critical need for comprehensive studies on the physical challenges they endure Lester., *et al*. (2020) [32].

In addition to the physical strain, caretakers find themselves grappling with the intricacies of maintaining a healthy lifestyle Tonkus *et al* (2020) [48]. The demands of caregiving can disrupt their ability to adhere to a balanced diet and regular exercise routine Ghorbanzadeh., *et al*. (2021) [17]. This further compound the physical toll, creating a cycle of challenges for caretakers striving to support their loved ones in the ICU Karlsson, (2021) [28]. Interventions tailored to promote physical health and well-being, encompassing aspects like exercise regimens and relaxation techniques, emerge as potential avenues for easing the burden on caretakers Jiyayi., *et al*. (2023) [23].

Another study found that, despite the well-documented physical challenges, the mental health implications for caretakers in the ICU remain an understudied area Lester., *et al*. (2020) [32].

The intricate interplay between physical and mental well-being demands attention, as caregivers navigate the stress and emotional strain of their roles Tonkus., *et al*. (2020) [48]. Research gaps persist in understanding the holistic impact on caretakers, emphasizing the need for comprehensive studies exploring both physical and mental dimensions Imanipour., *et al*. (2019) [22]. As caretakers play a pivotal role in patient outcomes, addressing their mental health becomes integral for fostering resilience in the face of the formidable responsibilities they shoulder Lester., *et al*. (2020) [32].

Moreover, the call for more extensive research echoes throughout the caregiving landscape Moss., *et al*. (2022) [34]. The effectiveness of interventions aimed at supporting caretakers in managing physical and mental strains requires closer scrutiny Bonnici., *et al*. (2020) [7]. The current body of knowledge underscores the imperative for in-depth investigations into strategies that can alleviate the physical and mental toll on ICU caretakers. Recognizing the interconnected nature of these challenges is pivotal in developing targeted interventions that can truly enhance the well-being of those who selflessly provide care to loved ones in critical conditions Tager and Hinojosa, (2023) [47].

In another study, caretakers narrated that caring for a loved one in the ICU is emotionally draining, causing them to grapple with grief, anxiety, and depression Moss., *et al*. (2022) [34]. Feelings of guilt and helplessness may arise, intensifying the emotional toll Karlsson, (2021) [28]. The lack of social support exacerbates the situation, leaving caretakers feeling isolated from friends and family. Maintaining relationships outside the hospital becomes challenging due to time constraints and exhaustion Imanipour., *et al*. (2019) [22]. Social support emerges as a crucial factor, with research indicating that caretakers with a strong support network experience lower stress and anxiety levels.

Different studies identified interventions targeting increased social support prove beneficial for caretakers of ICU patients. Support groups, online communities, and respite care services are identified as effective measures Burns., *et al*. (2023) [8]. Bonnici., *et al*. (2020) [7]. Despite these findings, more research is necessary to assess the interventions' overall impact on caretakers' mental health. The complexity of caretakers' emotional experiences underscores the need for a nuanced approach, recognizing the profound impact on both physical and mental well-being Senekal., *et al*. (2021) [43]. Acknowledging cultural and religious backgrounds is crucial, as these factors influence how caretakers navigate the stress of caregiving Kitko., *et al*. (2020) [30].

In conclusion, the emotional journey of ICU caretakers involves navigating grief, anxiety, and guilt, intensified by a lack of social support Karlsson, (2021) [28]. Interventions aiming to boost support networks prove promising, yet further research is required to gauge their effectiveness. The multifaceted nature of caretakers' emotional experiences underscores the necessity for tailored approaches, considering cultural and religious nuances.

Caretakers of ICU patients navigate a complex social experience that encompasses both challenges and rewards. Many find themselves isolated from their social circles, dedicating limited time and energy to relationships outside the hospital Ghorbanzadeh., *et al*. (2021) [17]. The pressure to be a "super caregiver" adds to the emotional strain as caretakers prioritize their loved one's needs over their own Karlsson, (2021) [28].

Despite these challenges, caretakers often derive a sense of purpose and satisfaction from their role, feeling they make a meaningful impact on their loved one's life. The social dynamics within the family unit and the existing relationship between caretaker and patient significantly influence this experience Kitko., *et al*. (2020) [30]. A strong and supportive relationship can alleviate stress, while strained dynamics may intensify the emotional toll Karlsson, (2021) [28].

The social support available in the community plays a pivotal role in shaping caretakers' experiences Karlsson, (2021) [28]. Some have access to services like respite care or caregiver support groups, providing valuable resource. In contrast, others may lack such support, affecting their overall social experience Schwartz., *et al*. (2022) [41].

In essence, the intricacies of caretakers' social experiences in the ICU are multifaceted, hinging on factors like available support, the nature of the caretaker-patient relationship, and community resources Burns., *et al*. (2023) [8]. This complexity highlights the need for a holistic understanding of caretakers' circumstances to effectively address the social challenges they face during the transfer of their patients to the ICU.

Literature summary

Caretakers of ICU patients undergo varied emotional experiences, including stress, anxiety, and depression Jiayi., *et al*. (2023) [23]. The demanding ICU environment can lead to feelings of isolation, making it challenging for caretakers to sustain relationships outside the hospital Bergman and Carlström, (2020) [5]. Despite these difficulties, many caretakers derive satisfaction and purpose from their roles Alhussaini, (2021) [3]. Support services like respite care and caregiver support groups significantly influence their overall experience, emphasizing the need for further research on unique challenges faced by diverse caretaker populations.

The literature underscores the crucial role played by ICU patient caretakers, emphasizing their limited research focus Senekal., *et al*. (2021) [43]. The available studies indicate a spectrum of emotions, including stress and anxiety, heightened by the intense ICU setting Burns., *et al*. (2023) [8]. Caretakers often feel isolated, struggling to maintain relationships beyond the hospital environment. While many find purpose in their roles, the significance of support services is evident, urging additional research on diverse caretaker experiences and effective interventions.

Most literature was about transfer of patients from ICU to general ward. Information about the experience of caretakers on transfer from ward to ICU is still lacking. It's vital to have this information to guide on how to support the caretakers psychologically during the transition process.

Little is known about the experience of caretakers in MRRH towards transfer of their Patients to ICU. Such information is necessary to provide psychological support for them. Therefore, this study will explore the experience of caretakers at MRRH towards transfer of their Patients to ICU.

Methodology

Introduction

This section describes the methods which were used in the study. It explains the location of the study, research design, target population, sampling methods, sample size, data collection methods, data analysis plan, ethical considerations and plan for dissemination of findings.

Study design

This study used phenomenological study design. 'Phenomenology is uniquely positioned to help health professions education (HPE) scholars learn from the experiences of others' Neubauer., *et al*. (2019) [35]. In this case, the phenomenon explored subjective experiences and views of caretakers at MRRH regarding transfer of their Patients to ICU. This design allowed the researcher to gain a deep understanding of the experience's caretakers go through during transfer of their Patients to ICU

Study site

The study was conducted at Mbarara Regional Referral Hospital which is a tertiary care hospital located in Mbarara, Uganda. It serves a population of over 3 million people from the Western region of Uganda. The hospital was founded in the 1940.The hospital's ICU unit has eight beds, and it is staffed by a team of highly trained doctors, nurses, and technicians. The unit is equipped with state-of-the-art technology (most advanced and current level of technological development), and it specializes in the treatment of critically ill patients.

Study population

The study population consisted of caretakers whose patients have been transferred to the ICU unit of Mbarara Regional Referral Hospital during the study period. The population included caretakers above 18years, genders, and ethnicities. It also included caretakers of patients with a wide range of medical conditions, including respiratory, cardiac, and other illnesses. The population did not include caretakers of patients who are discharged or transferred from the ICU.

Sample size

In choosing the sample size for this study, the principle of data saturation was used. Data saturation occurs when no new information or themes emerge from the data collection process, indicating that additional participants are unlikely to provide no new insights (redundancy) Guest., *et al*. (2020) [19], and Hennink., *et al*. (2019) [21]. The sampling plan was evaluated in terms of adequacy and appropriateness. An adequate sample is one that provides data without any "thin" spots (quality and sufficient data).

Sampling

Participants in this study were recruited from amongst the caretakers whose patients have been transferred to ICU at MRRH purposely with maximum variation. The sample was diverse in terms of age, gender. A purposive sampling technique is one where the researcher deliberately selects individuals or groups of people who are considered to be the most suitable/relevant for a study based on certain characteristics, traits or criteria Palinkas., *et al*. (2015) [38].

Participant selection criteria

Inclusion criteria

- Caretaker whose Patient are transferred to the ICU unit of Mbarara Regional Referral Hospital during the study period.
- Caretakers must be willing and able to participate in the study.

Exclusion criteria

- Caretakers who are unable or unwilling to participate in the study.

Data collection method

Data was collected using one-on-one in-depth interviews with participants. An interview guide was used by the moderator to facilitate the discussion. The interview guide had a section of socio-demographics for the Caretakers being interviewed, and questions on the experiences of the caretakers towards transfer of their Patients to ICU. The questions on this guide were mostly open ended questions, so that the participant would give maximum information to the interviewer (Bhanadari, 2020) [6]. The views of participants during these interviews were audio-recorded and transcribed verbatim.

Rigors of the study

The goal of rigor in qualitative research can be described as ensuring that the research design, method, and conclusions are explicit, public, replicable, open to critique, and free of bias. Rigor in the research process and results are achieved when each element of study methodology is systematic and transparent through complete, methodical, and accurate reporting" This was guided by the four-dimension criteria by Lincoln and Guba that include; credibility, dependability, confirmability, and transferability Stahl, (2020) [45].

Credibility

This is the confidence that can be placed in the research findings. It establishes whether the research findings represent plausible information drawn from the participants' original data and is a correct interpretation of the participants' original views. This was achieved through pretesting the interview guide, as well as engaging participants for a longer period of time. Korstjens and Moser. (2018) [31].

Transferability

This refers to the degree to which the results of qualitative research can be transferred to other contexts or settings with other respondents. The researcher facilitated transferability through a thorough detailed explanation of the characteristics of the study participants, setting, and method of data collection. This facilitated the evaluation of whether similar study findings can be generated in other settings. A purposive sampling technique was also ensured Korstjens and Moser., (2018) [31].

Confirmability

This is the degree to which the findings of the research study could be confirmed by other researchers. Confirmability is concerned with establishing that data and interpretations of the

findings are not figments of the inquirer's imagination, but clearly derived from the data collected from the participants. This was achieved through recording participants during data collection and assigning specific codes to ensure data identification Stahl. (2020) [45].

Dependability

This is the stability of findings over time so that other researchers are able to find the same information as the researcher. This was achieved through the use of in-depth interviews using mostly open-ended questions. This was to enable generation of in-depth information related to the purpose for this research Stahl. (2020) [45].

Data analysis

An inductive thematic analysis was used to analyze the data. The researcher familiarized herself with the data collected by listening to the audios, transcribing them, reading, re-reading the transcripts to identify and create codes that capture key concepts and ideas expressed by the participants. Once the coding was complete, the researcher then grouped related codes into broader categories that captured the overall patterns and trends in the data. The themes were reviewed and refined, and compared and contrasted to develop a comprehensive understanding of the participants' experiences Bhandari, (2020) [6].

Ethical considerations

The research proposal was approved by the nursing department, and then by the Faculty Research Committee. An informed consent was obtained from all participants before collecting data from them, their privacy and confidentiality was maintained throughout the study by keeping all information gathered under lock and key and concealing their identity. Participants was informed that they are consenting to both participation and audio recording and that the findings of this research would not be traced back to them. Participants were informed that they are free to withdraw from the study anytime without giving reasons.

Dissemination

The results of this study were shared with relevant stakeholders (clinical care team and site Administration/Management) in the form of a dissertation book. A copy of the report was sent to Nursing department and Faculty Research Committee. They were also prepared for publishing in peer-reviewed journals and presented in academic and health conferences in the form of brief summarized PowerPoint presentations.

Results

Introduction

This chapter presents findings obtained from the study conducted to explore the experience of caregivers during the transfer of their patients to the Intensive Care Unit (ICU) at Mbarara Regional Referral Hospital. A total of 10 participants took part in the study. The results are discussed in details as below.

Distribution of socio-demographic characteristics of participants

Participants were drawn from different demographic and social back grounds to give and in-depth understanding of experience of caretakers during transfer of their patients to ICU. Females were o6 and males were 04. Age range of 20-40 hast many 09 and the rest 1 was aged 40-60years. Formal employment had the majority 6 and 3 were self-employed, only 1was unemployed.

LIved experience of care takers during transfer their patients in ICU

Since the study focused on experience of care takers during transfer of their patient to ICU, four major themes emerged automatically from the findings, that is: emotional distress and anxiety, financial and resource concerns, communication and information, and accessibility and hospital policies. Each theme is further divided into several sub-themes, providing a detailed understanding of the caregivers' experiences.

Theme 1. Emotional distress and anxiety

Emotional distress was a common immediate effect of breaking the news of ICU transfer among all the care givers characterized by the persons words, actions and consistency of behaviors. All Caregivers expressed to have experienced intense emotional distress and anxiety when their loved ones were transferred to the ICU. This distress often manifested in several ways categorized as sub themes: under this theme five sub-themes emerged which included emotional roll coaster, emotional turmoil, post-traumatic stress, fear and lack of emotional support.

Emotional rollercoaster

Caregivers go through intense emotional highs and lows, oscillating between hope and despair. The involvement in the patient's care can sometimes provide moments of hope, but the overall experience is marked by significant emotional fluctuation.

Caregivers' perceptions of the quality of care provided in the ICU played a significant role in their overall experience. Positive interactions with medical staff and the visible efforts to care for their loved ones bolstered caregivers' hope and satisfaction.

"I was scared that my kaboy is going to pass on," reflecting the pervasive fear of losing a loved one. Later he had hope that he will survive as he participated in the transportation of the patient to ICU; "I helped them to ride the wheel chair when he was getting transferred to this place of ICU.....". "I am the one who helped doctors to wheel the chair". Said ZU.

"Our expectations have been fulfilled somehow... we cried, we over cried we were so anxious". said ZW.

Emotional turmoil

Many caregivers felt overwhelmed and distressed, often experiencing symptoms such as confusion, agitation, and physical manifestations like trembling, sweating, and hyperventilation. This state of turmoil can lead to forgetfulness and a sense of being mentally overwhelmed.

"I feel like the whole of my body is not feeling well. Am not ok at all [...] I feel the whole of my body is scared. Am not ok at all even they have given me aka food to eat but I don't feel like". ZS.

"I feel like the whole of my body is not feeling well. Am not ok at all [...] I feel the whole of my body is scared. Am not ok at all even they have given me aka food to eat but I don't feel like". ZS.

Post-traumatic stress

Past experiences with ICU admissions can exacerbate current stress levels. Caregivers who have previously lost a loved one in the ICU may experience heightened anxiety and fear when faced with another ICU admission.

"I was scared because I had a brother who was admitted in ICU and he passed on, even in this very room where my father has been admitted". ZX.

Fear

The ICU environment, the unfamiliarity with medical personnel and medical procedures instilled fear in caregivers. Concerns about communication barriers and the perceived complexity of the ICU setting contributed to this fear.

"I thought about many things, I thought about how the place looks like...I thought they will look at… they want… they only speak English and how will I communicate to them? But they organized us as the other ones that I'm with, some of them I'm still fearing them but many I'm used with them". ZQ.

Emotional support

Emotional Support and Understanding from medical staff: Caregivers valued empathy, calmness, and understanding from medical personnel. The way healthcare providers communicate and offer support can significantly influence the caregiver's emotional well-being, making them feel more supported and less isolated in their distress. Or can worsen their distress making them feel depressed.

"People who work in ICU need to be informed about people already traumatized... medical personnel need to be always a bit calm and understanding in the way they talk to people". ZX.

Theme 2. Financial and resource concerns

The cost of healthcare emerged as a significant burden for caregivers, influencing their experiences and stress levels. Financial and resource concerns are significant stressors for caregivers, particularly in resource-limited settings.

Affordability of healthcare

The high cost of ICU care, including medications and other medical supplies, placed a heavy financial burden on families. This added to the toll of their stress.

"You come from home and come here in the hospital, for the care it is there you get enough care, but you buy everything like medicine and other things if u can afford but in case you don't have money, your patient might die..." (ZZ).

"Now I failed to buy for her medicine and the medicine is too expensive they are asking me". "Aahhh I'm waiting for the last hour,

uuummm. Do you think she will survive? We may shell the land for buying medicine and then she dies which will be double loss". ZR.

Financial burden and resource management

Caregivers often need to purchase medications and supplies externally, sometimes at inflated prices. This financial strain is compounded by the need for immediate and unexpected expenditures, which many families are not prepared for.

"As we were told that he has got an accident, of course financially we are not always prepared". ZY.

"Normally what I have seen is that nearby drug sellers take advantage of you having a patient and sell the drugs at a high price". ZP

Theme 3. Communication and information

Effective communication and access to information are crucial for caregivers navigating the ICU environment.

Negative experience in communication

Caregivers frequently experience frustration due to poor communication from healthcare providers. Disagreements among doctors, lack of clear instructions, and exclusion from the care planning process contributed to their anxiety and distress levels."I think on the other side eee, people who work in ICU, they need to be informed about uuh, people are already traumatized eeh, about the conditions in ICU so by the time you "But for him to come here, I don't know how even he came here, when I was told that he was in the ICU and I was brought to find him here……" ZY.

"Are there I feel-a laa the medical personnel some of them need to be always a bit calm and understanding in the way they talk to people". ZX.

Positive experience in communication

Some caregivers appreciate clear and timely communication from healthcare providers, which helps them feel more informed and involved in the care process.

"As uhh immediately they finished the operation and called us and told us the situation, that he is not well and needed to be in ICU". ZX.

"The ICU doctor came in… came there, and she told us what is going on and what are we going to do there, then there I said aaahh, even though she told us what is going on……." ZR.

Lack of involvement in care plan

Caregivers often feel excluded from the decision-making process regarding their loved one's care, leading to confusion and a sense of helplessness.

"I was not involved in the making decision for the transfer, it was made only by doctors, uuuuhm". ZV.

"I happen I was here sitted, aahh not everyone knows this shows this, this shows this, me I stayed just sitted next to the patient, only from nowhere did this thing annoyed me, somebody from somewhere comes shouting don't you see that these numbers are not well nga you have not informed, that is some think that is so bad with medicine eee, medical personnel". ZX.

Orientation and education

Care givers expressed concerns about lack of clear orientation and education regarding ICU procedures and equipment. Caregivers who had prior experience of being shouted at for not communicating changes in physiological parameters expressed fear and anxiety of again going to pass through the same experience.

"There should always be orientation on how to interpret machines and when to call for help".

"Uuuhuuh the question that I'm having is that I don't know how to use these machines but the feeding machine I have already known and this one how to pull the bed, how to wash my patient, because I'm seeing there are tubes and I feel that if touch on her they will go away. I wish also to know what the numbers are for".

Theme 4. Accessibility and ICU policies

Under this theme three sub themes emerged and the details will be expressed in table: 5.

Frustration with ICU policies

Access and ICU policies Ranging from entry restrictions, eating restrictions, and lack of places of convenience negatively impacted caregivers' experiences and topped up their stress levels.

"We have never been in ICU, not sure about the access to the patient. Relatives and friends travelled from far to see patient but access was denied but went back complaining however much explanation was given about restriction". ZY.

"They only allow one person, it is as if he or she is not sure whether you are telling him the truth because he has not seen the patient". ZQ.

Access by relatives and friends

Restrictions on visitation can cause additional stress, as caregivers rely on the support of relatives and friends for financial and emotional help. Limited access can lead to feelings of isolation and frustration.

"We have never been in ICU, not sure about the access to the patient. Relatives and friends travelled from far to see patient but access was denied but went back complaining however much explanation was given about restriction". ZW.

"The room is locked, and it was hard to get back in". ZT.

"……. in most cases in that situation of touching here and there looking for money, some individuals sometimes they want to come see the patient, witness, so that they can pull out something and give you to take care of him". ZY lamented.

Access by Caregivers: Difficulty accessing the ICU due to hospital policies, such as limited visiting hours and locked doors, can exacerbate the stress and anxiety of caregivers. The logistical challenges of being locked out or unable to rest and eat properly contribute to their overall distress.

"There is no area for caretakers to go for a short call". ZQ.

"I even cried at the door when I was locked out for like an hour and could not access my patient and no one to open for me". ZW.

"You may find that they have sent away the people who are supposed to relieve you to go and eat, or rest are locked out, and you remain here, sometimes you spent like the whole day without eating". ZT.

Discussion of Study Findings, Conclusion and Recommendations

Introduction

This chapter highlights the discussion of findings, description of the phenomenon and the focused literature review on concepts related to thematic structures of lived experiences of caretakers during transfer of their patients to the Intensive Care Unit (ICU) at Mbarara Regional Referral Hospital. Using Interpretive Phenomenological Analysis (IPA), the findings illuminate the multifaceted emotional, financial, communicative, and policy-related challenges faced by caregivers. The analysis reveals four major themes: emotional distress and anxiety, financial and resource concerns, communication and information, and accessibility and hospital policies.

Discussion of study findings

Emotional distress and anxiety

The emotional distress and anxiety experienced by caregivers during the ICU transfer are profound and multifaceted. All caregivers reported significant emotional distress, characterized by intense emotional fluctuations, fear, and symptoms akin to post-traumatic stress. This aligns with findings from recent studies which underscore the psychological toll on caregivers in ICU settings. For instance, Kanmani TR., (2019) [26]. found that caregivers of ICU patients often experience high levels of stress and anxiety, exacerbated by the critical condition of their loved ones and the high-stakes environment of the ICU. Additionally, Davidson., *et al*. (2017) [14], reported that caregivers frequently face emotional turmoil, including symptoms such as confusion, agitation, and physical manifestations of stress like trembling and hyperventilation, echoing the experiences described by the participants in this study.

Financial and resource concerns

The financial burden associated with ICU care is a significant stressor for caregivers. Many participants highlighted the high costs of medications and supplies, which they often had to purchase externally. This financial strain is well-documented in the literature. A study by Cha JK., *et al*. (2019) [9], noted that the financial impact of ICU admissions can be devastating for families, especially in resource-limited settings where out-of-pocket expenses are substantial. Similarly, Tucker-Seeley., *et al*. (2015)

[49], observed that the need for immediate and often unexpected expenditures for medical care can lead to considerable financial distress among caregivers.

Communication and information

Effective communication and access to information are crucial for caregivers navigating the ICU environment. Participants in this study reported both positive and negative experiences with communication from healthcare providers. Poor communication often led to frustration and confusion, while clear and timely information helped caregivers feel more informed and involved. This is consistent with findings from Smith., *et al*. (2018) [46], who found that effective communication between healthcare providers and caregivers is essential for reducing caregiver anxiety and improving their overall experience. Additionally, Xyrichis., *et al*. (2019) [57], emphasized the importance of involving caregivers in care planning and providing them with adequate orientation and education regarding ICU procedures and equipment.

Accessibility and ICU policies

Hospital policies regarding access to the ICU can significantly impact caregiver experiences. Participants in this study reported frustration with restrictions on visitation and difficulties accessing the ICU, which compounded their stress and feelings of isolation. This finding is supported by a study by Dos and Nassar (2022), which found that restrictive ICU policies often leave caregivers feeling excluded and unsupported, highlighting the need for more flexible and inclusive visitation policies. Furthermore, KA Milner., *et al*. (2021) [56], discussed how logistical challenges, such as limited visiting hours and lack of facilities for caregivers, can exacerbate their distress.

Conclusion

The findings suggested that the transfer of patients to the ICU is a highly distressing experience for caregivers, encompassing Emotional distress, financial burdens, communication barriers, and restrictive hospital policies. To address these challenges, healthcare providers need to prioritize communication and collaboration with caregivers, ensuring they are informed and involved in decision-making processes. Additionally, healthcare systems should implement policies that support caregivers' access to their loved ones in the ICU while maintaining safety protocols. Addressing the emotional and financial needs of caregivers is essential for promoting their well-being and enabling them to provide optimal support to patients during critical illness. Further research is needed to explore interventions aimed at mitigating caregiver distress and enhancing their experience during the ICU transfer process.

Recommendations

Based on the results, several recommendations emerged to address the challenges faced by caregivers during the transfer of their loved ones to the Intensive Care Unit (ICU):

- **Improved Communication and Information Sharing**: Healthcare providers should prioritize open and transparent communication with caregivers. This includes keeping them informed about the patient's condition, treatment plan, and any changes in their status. Providing educational materials and resources and psychosocial support about ICU procedures and policies can also help alleviate confusion and anxiety.
- **Inclusion in Decision-Making Processes:** Caregivers should be actively involved in discussions and decision-making processes regarding the patient's care, including ICU admission and treatment options. This can help empower caregivers and ensure that their concerns and preferences are considered.
- **Financial Assistance and Support**: Healthcare institutions should explore options for providing financial assistance and support to caregivers, particularly those facing limited resources and financial strain. This could include assistance with navigating insurance coverage, accessing financial aid programs, and connecting caregivers with community resources and support networks.
- **Accessibility and Visitation Policies**: ICU policies should balance the need for patient safety with the importance of allowing caregivers access to their loved ones. Flexible visitation policies and innovative solutions, such as virtual visitation options, can help facilitate communication and emotional support while respecting infection control measures.
- **Research and Quality Improvement Initiatives**: Continued research and quality improvement initiatives are needed to better understand and address the unique

needs of caregivers during the ICU transfer process. This includes evaluating the effectiveness of interventions aimed at supporting caregivers and improving their overall experience.

Implication to nursing practice

- Nurses play a crucial role in facilitating communication between healthcare teams and caregivers. By honing their communication skills, nurses can ensure that caregivers are kept informed about the patient's condition, treatment plan, and progress in the ICU. Clear and compassionate communication can help alleviate anxiety and empower caregivers to actively participate in the patient's care.
- Nurses can promote self-care and resilience among caregivers by encouraging healthy coping strategies, providing emotional support, and validating their experiences. By acknowledging the challenges caregivers face and empowering them to.

Implication to nursing education

- Incorporate modules on emotional intelligence, stress management, and psychological support for both patients and caregivers into nursing curricula.
- Use simulation training to prepare nursing students for high-stress situations and teach them how to provide emotional support to caregivers.
- Emphasize the importance of clear, compassionate communication in nursing programs. Teach nursing students strategies for effectively communicating with caregivers and managing their expectations.
- Include training on cultural competence to ensure nurses can effectively communicate with and support caregivers from diverse backgrounds.

Implication to policy

- Develop and enforce protocols that ensure clear, consistent, and compassionate communication between healthcare providers and caregivers.
- Establish programs within hospitals to offer emotional support to caregivers, ensuring they have been oriented and have access to mental health professionals and peer support.
- Ensure the availability of necessary medications and supplies within the hospital to reduce the financial burden on caregivers who may need to purchase them externally.
- Review and potentially revise visitation policies to allow more flexible access for caregivers and family members, balancing infection control with the emotional needs of caregivers.
- Provide facilities such as resting areas, food services, and washrooms for caregivers who spend extended periods in the hospital.

Areas of further research

- Longitudinal Study on Emotional Impact: Investigate the long-term emotional and psychological effects on caregivers' post-ICU transfer
- Conduct comparative studies between different hospitals or regions to identify best practices in managing caregiver experiences.

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APPENDICES

APPENDIX I: INTERVIEW GUIDE:

Introduction:

Introduce yourself and thank the participants for accepting to take part in the interview and explain the purpose of the discussion briefly introduce the topic on patient transfer and explain the importance exploring the experience of care takers on transfer of their patient to ICU.

SECTION A: Demographic Characteristics (Tick as applicable)

1. Age: ..... in Years as at last birthday
2. Sex: Female Male
3. Employment status

1. Formal
2. Self

SECTION B: Main discussions:

What were your thoughts when you were told that your patient needs intensive care?

Can you express how you felt when the news of the transfer was announced?

Probe more

How did the physical demands of assisting with the patient's transfer affect your well-being during the process?

Can you describe in detail the range of emotions you experienced from the moment you were informed about the transfer to the time of reaching the ICU?

What was the social interaction with the patient in ICU like?

Conclusion:

- Thank participants for their time and contributions to the discussion.
- Summarize the key points that were discussed and highlight any area where further research or action may be needed

Invite participants to share any final thoughts or comments they have. (Is there anything that has not been asked but you think you had loved to share?)

APPENDIX II: PARTICIPANT'S CONSENT FORM.

Tittle of the study:

Investigator(s)

Bako Lilian

BNC 3 MUST

0774778520

bakolilian34@gmail.com

Introduction: you are being invited to participate in a discussion about your experience during transfer of your patient to ICU as a care taker of the patients who needs this care and the discussion will last for 30minutes to one hour.

Procedure; during the interview discussion, you will be asked to share your experience and opinions regarding the transfer of your patient to ICU. The discussion will be led by a trained facilitator and will be conducted one-on-one for each chosen participant.

Benefits: by participating in this interview, you will have the opportunity to share your thoughts and experiences on patient transfer to ICU and your feedback will help to inform future research and training initiatives.

Risks: There are no foreseeable risks associated with participation in this study.

Confidentiality: Your participation in this study is voluntary, and all information collected will be kept strictly confidential and anonymous. Kindly do not write any identifying information on this form. Your identity will not be disclosed in any research reports or publications. For purpose of this research study your comments from the interview will be put out there. The researcher will ensure your confidentiality by keeping the interview notes, audios, transcriptions and any identifying participants information secure.

Audio Recording: As the interview goes on, you will be audio recorded for research purposes and the findings of this recordings will not be traced back to any participant.

Consent: By signing below, you are indicating that you have read and understood the information above and that you voluntarily agreed to participate in this study.

Participant's signature……

Date……..

Investigator's……

Date……..

APPENDIX III: BUDGET.

ITEMS	ESTIMATED EXPENDITURE (UGX)
Stationery	20,000
Photocopying, printing and binding	225,200
Transport	10,000
Air time and data	100,000

Compensation for participant time	300,000
Meals and Refreshments	21,000
Miscellaneous	50,000
GRAND TOTAL 626,200	

APPENDIX IV: WORK PLAN.

Activities	Oct 2023	Nov 2023	Dec 2023	Jan 2024	Feb 2024	Mar 2024	Apr 2024	May 2024	Responsibility
Proposal writing and approval									Researcher and supervisor
Collecting introductory letter from department of Nursing									Researcher
Field visiting, orientation and seeking permission for research study									Researcher
Data collection									Researcher
Data analysis and report writing									Researcher
Report approval submission									Supervisor

Appendix V: Acceptance letter.