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Experiences of Patient Family Members and Nurses on Family-Centered Care in Critical Care Unit at Coast General Hospital, Mombasa County: Phenomenological Study

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Abstract

Background: Family Centered Care utilizes the holistic approach of care by focusing on both the patient and their family members in caring for the critically ill patients. Despite family satisfaction with care being an aspect in evaluation of quality of care, FCC utilization remains low.

Study objective: The aim of the study was to explore the experiences of nurses and patient family members on FCC in Coast General Hospital.

Materials and Methods: Using the phenomenological method of qualitative research - deductive approach, interviews were conducted among six nurses and seven family members. Purposive sampling technique was used. Interview guides with open ended questions were used to collect data which was audio recorded and transcribed verbatim and data analysis done manually and data classified into themes and subthemes.

Results: Four themes were extracted from the interviews based on the conceptual framework: 1) Communication as a pillar of care 2) Involvement inpatient care decisions 3) Physical presence and proximity to the patient 4) Cultural sensitivity in care. The critical care nurses recognized family involvement and effective communication as a critical aspect in the critical care setting. However, constraints such as time limitations, staffing shortages, workload and prioritization of patient safety hindered the ability to fully engage with families. Conversely, family members expressed a strong desire for proximity to their loved ones admitted in the critical care unit, advocating for flexible or increased visitation times and transparent, consistent communication from health care providers even in cases of poor prognosis.

Conclusion and Recommendations: Bridging this gap necessitates the implementation of policies and interventions aimed at fostering a collaborative environment that aligns the needs and expectations of both family members and nurses in the critical care unit.

Keywords: Family Centered Care, Respect and dignity, Shared decision making, Family participation.

Introduction

Family-centered care (FCC) is an approach to healthcare based on partnership between patients, their families and the healthcare team in the planning, delivery and evaluation of healthcare. It is not only applicable to the pediatric population but also cuts across the age continuum in diverse health care setups. FCC views the family as an essential element of nursing care, focusing on the patient and their family instead of the patient as the focus of care and seeks to integrate the family in the patient care process. Family members are considered important aspects in evaluation of the quality of care they experience through determining family's level of satisfaction with care (Institution for Patient - and Family-centered care, 2017).

Growing demand for critical care services has generated an increased extension of critical care unit (CCU) capacity owing to the emergence and re-emergence of disease patterns. Moreover, the Corona virus disease-2019 (Covid-19) pandemic led to an increase of CCUs worldwide. As a result, an increase in CCU patients has proportionately increased the number of families affected by the admissions (Imanipour & Kiwanuka, 2020).

Conforming to the holistic approach of care, family members in the CCU are the responsibility of the CCU health care team. The aim of FCC is to create a partnership between families and healthcare providers to respond to family health care needs. Often, integration of family members in the healthcare team in CCUs is not achieved based on various factors within the healthcare system affecting delivery of FCC in adult CCUs (Bellou & Gerogianni, 2018). FCC is executed through family engagement in care planning, direct provision of health care and evaluation of care in interactive relationships that benefit both the healthcare providers and family. Additionally, psychosocial assistance, information sharing, family conferences and health beneficial discussions with families are also an essential aspect of FCC (Imanipour & Kiwanuka, 2020).

In South Africa Durban, nurses are trained to work with family members through seminars on FCC principles during orientation and ongoing trainings. The hospitals have procedures and policies in place to commence family support and to equip the family with information frequently during a crisis situation with specific personnel allocated to synchronize exchange of information with the family members. Family members' decisions with regard to patient care are respected by 90.9% of the nurses, giving timely information on patient condition and treatment while accommodating the diverse cultures of the families. The nurses in Durban were able to support family members in acquiring information through education materials (Almaze & Beer, 2017).

In a study conducted at Kenyatta National Hospital (KNH), family centered nursing was compromised as the expectations of family members of critically ill patients did not match with the family care given. The needs of family members in the KNH CCU were insufficiently met (32.7%). This was attributed to CCU nurses' shortages and time constraint making it difficult to support families and at the same time deliver critical care nursing services to the critically ill patients. This justified the restrictive visitation policy allowing a one-hour visiting period twice a day with a limit of two visitors and inability of CCU nurses to answer family members' questions in depth. The findings of the study also indicated that there were inadequate seating spaces in the family's waiting area. Additionally, the study revealed the need for comfort being the least met with family members citing lack of a toilet for the family members near the waiting space. Families received minimal information regarding their relatives' prognosis, diagnosis and treatment causing anxiety build up. The family members of the critically ill preferred receiving information pertaining to their relative from the primary care nurses rather than the nurse managers as the primary care nurses spent more time with the patients at the bedside. Nurses did not involve families in the care of critically ill patients citing lack of established policies to guide participation of families in CCU in KNH (Maina et al., 2018; Ngui, 2006). The objectives of the study were: To find out the experiences of families and nurses on information sharing between families and nurses; To explore the experiences of family members and nurses on collaboration and shared decision making; To assess the extent of family participation in caring for critical care patients and to explore how family members and nurses perceive respect and dignity in caring for patients in the critical care unit at Coast General Hospital.

METHODS

The study adopted a qualitative deductive approach using phenomenology to explore the experiences on FCC among patient families and nurses in caring for patients in the critical care unit at CGH. The study was conducted at the Coast General Hospital, Mombasa

County- Kenya. The study population for this study was the 33 nurses working in the CCU who were involved in direct patient care at the time of data collection and family members of patients admitted in the CCU. Purposive sampling technique was used to identify study participants where the sample was selected based on the characteristics of the population and study objectives. A sample of six nurses and seven family members participated in this study The ICU nurses and family members were interviewed until saturation when there was no new emerging information from the participants.

Nurses working in the CCU for at least 6 months performing direct patient care in the CCU and family members related to the critically ill patient were included in the study. Nurses on leave during the study period; family members of pediatric patients in the CCU and those who were below 18 years were excluded from the study. Data was collected using interview guides. Trustworthiness was ensured by engaging with an expert to review and critique findings after the data analysis. Use of direct quotes by participants was used to ensure credibility. To ensure transferability, the detailed descriptions of the study methods was used. Dependability was maintained by employing systematic and well documented data collection and data analysis steps.

The interviews were face to face and in-depth. The interview guide was developed by the researcher in line with the core concepts of the Patient and Family Centred Care model and the guidelines for PFCC in CCU by the Society of Critical Care Medicine. Open ended questions with probes were used to elicit in depth responses. The interview guide included the following topics: current family involvement in delivery of care and shared decision making, perception of respect and dignity and information sharing among patient family members and nurses in the CGH CCU. After building rapport and obtaining consent, the participants were invited to share their experiences regarding FCC in care provision for the critically ill patients. Each interview was audio recorded and transcribed verbatim to ensure accuracy. During transcription, personal identifiable information went through de-identification to preserve privacy of the research participants. Additionally, expanded interview notes were written to capture the fundamental points of the interview. Interviews were recorded with two different digital recorders to prevent data loss. The audio recordings were transcribed verbatim within 24 hours of the interviews being conducted and the expanded interview notes added to the transcripts. Data analysis was done manually where meaningful statements and were extracted word for word. The researcher developed general meaning for the extracted meaningful statements. Content analysis was be used to classify the data into identified themes with common meanings. Words that appeared commonly under each question were coded, and codes assembled into themes and subthemes. Data analysis occurred concurrently with data collection and continued until all interviews were complete.

Confidentiality and anonymity of the participants was assured. Coded data underwent de-identification and was stored securely in locked file cabinets only accessible to the researcher. Participation in the study was on a voluntary basis after a written informed consent was sought from the participants prior to data collection. Ethical clearance was obtained from Kenyatta University Ethics and Research Committee approval number PKU/23671/11504, National Council for Science and Technology approval number NACOSTI/P/21/13938 and CGH Ethics and Research Committee.

RESULTS

Socio-demographic characteristics

In this study, six nurses were interviewed. Among them, five were female, and two were male. Their ages ranged from 29 years to above 50 years, and their work experience in the CCU ranged from 1 year to 14 years. Five of them had education level at diploma level while only one had degree.

Table 1:Sociodemographic characteristics of CCU nurses

Variables	Category	N (%)
Age	29-39 years	2 (33%)
	40-50 years	3 (50%)
	Above 50 years	1(17%)
Gender	Male	1 (17%)
	Female	5 (83%)
Education level	Diploma	5 (83%)
	Degree	1 (17%)
CCU experience	1-5 years	2 (33%)
	5-10 years	3 (50%)
	Above 10 years	1 (17%)
CCU specialization	Yes	2 (33%)
	No	4 (67%)
FCC training	Yes	1 (17%)
	No	5 (83%)

Among them only two had a critical care specialization with only one having had FCC training which was received when she was working as a community health nurse.

Table 2:Sociodemographic characteristics of family members

Variable	Category	N (%)
Age	18-28 years	1 (14%)
	29-39 years	2 (29%)
	40-50 years	2 (29%)
	Above 50 years	2 (29%)
Religion	Christian	4 (57%)
	Muslim	3 (43%)
Level of education	Primary	1(14%)
	Secondary	1 (14%)
	College/University	5(72%)
Relationship with patient	Spouse	1(14%)
	Parent	1(14%)
	Sibling	1(14%)
	Son/Daughter	3 (44%)
	Other	1(14%)
Patient's CCU admission period	Less than 5 days	2 (29%)
	Above 5 days	5(71%)

Theme 1: Communication as a pillar of care

Sub Theme I. The need to know

This subtheme incorporates the participants' account of information sharing between the ICU nurses and family members. The ICU nurses recognized the family members' strong desire to be informed about their loved one's diagnosis, treatment plan and prognosis of their family members. *"… They don't get tired of asking. Even when they come now you will see. After you finish with the son, the daughter, and then the neighbour."* (N5)

"… in fact, they come twice or even thrice in a day asking, different people asking the same…. Who is the nurse here? How is my patient? You can even explain to them up to ten times in a day. As the primary nurse I always try to update the next of kin but sometimes it becomes overwhelming. I just tell them we've communicated to the next of kin" (N6)

Information sharing to the family is primarily the role of the bedside nurses according to the ICU nurses interviewed, with all of the nurses saying they shared the patient information with the next of kin. A number of the nurses mentioned to refer the family to doctors or the team leaders when the family inquired about results of diagnostic tests or when the prognosis of the patient was poor.

"On admission we normally communicate in terms of what is required for the patient which is not available in the hospital. Now for instance in the nursing care… we normally need small towels for bed bath, soap, water…. mineral water in case we feed we rinse…we need cup and spoon. "We normally have the contact for the next of kin and if we need anything outside of the visiting hours, we call them" (N4)

The nurses explained that they individualized communication to the families based on their understanding and diagnosis and prognosis of the patient. A number of the nurses mentioned that in situations such as brain death, they took time to explain to the family members the prognosis and reasons for minimal support and discontinuation of aggressive treatment

However, the nurses expressed challenges in providing comprehensive information especially when there was staff shortage in the unit thus limiting the amount of information or sometimes not even giving the family any update. The ICU nurses in the study expressed being overwhelmed by the heavy workload from shortage of nurses in the unit.

"Sometimes the workload…at times you have three patient, this one wants this the other one wants that so we only give skeleton information because at 12.30 is when you sit down to do the documentation and the relative wants to talk to you…..You might end up telling them to wait for the next shift while you could have given that information as you have been with that patient…… so workload here is a lot." (N2)

Sub Theme II. Breakdown in collaborative communication

The family members desire to receive information regarding their patient was overwhelming with majority of them expressing discontent in how they received updates of the progress of their family. Lack of awareness of the treatment plan was recurrent among the family members.

Family members mentioned nurses providing most of the information they wanted about their critically ill patient which was a source of reassurance for them.

However, the families said they had to approach the bedside nurse asking for updates and comprehensive updates depended on how busy the nurses were.

Most of the participant said they never met the doctors attending to the patients with some families saying that they had rely on indirect updates which sometimes they felt did not provide adequate and comprehensive information.

Some family members felt the ICU staff lacked understanding of the importance of regular updates and how having to wait in the visitors bay because the ICU were busy was tough for the family members

Sub Theme III. Having honest conversations

Most of the nurses expressed hesitance in sharing honest information with families particularly where they perceived it would interfere with the family's hope for positive outcome despite acknowledging the need to share honest information to the family.

"There are relatives who come with high expectations! When they are coming from casualty…they are told that the critical care will change everything. These relatives have high expectations which we find it difficult. When you try giving information especially negative it's like it bounces back. It is difficult to reverse the information they were given in casualty. We ensure that they understand what needs to be undertaken regarding the development and wellbeing of their patients. Such relatives are difficult to deal with. In case of negative outcome, they become so bitter and difficult to engage and it becomes very difficult to talk to that person." (N1)

It was also noted that there were inconsistencies sharing information among family members particularly the conversations that were perceived as difficult. Some of the nurses said they comfortable communicating to family members about a poor prognosis such as brain death while others mentioned they preferred involving the doctor or team leader to have the difficult conversations with family members.

"In case a patient has brain death, we normally explain to them that the patient is brain dead so that in case death occurs they are already aware that the patient was not to make it" (N4)

"When the prognosis is poor, I prefer having the doctor communicate with the relatives to let them know the situation is not getting any better" (N2)

Theme 2: Involvement In Patient Care Decisions

Sub theme I. Hastened decision making

The family members acknowledged that their patients in ICU were critically sick and that their conditions changed rapidly requiring immediate decisions. When such situations arose some family members felt that the health care providers rushed them into giving consents for surgery with scanty information on the procedure.

"I got a phone call from the hospital on the after admission that I was needed urgently to sign theatre papers for my sister because they were planning to take her to theatre that day but nobody had told me about any plan surgery the day before. They asked me to decide and sign the papers quickly because she would die. I signed but I did not understand clearly what I was signing for" (R 5)

"The only thing they have told us is that they want to discharge her home so that we take care of her at home…. But when we look at our patient, she has not recovered…. she has not been able to talk, there is no movement apart from the eyes." (R2)

Sub Theme II. Autonomy

The nurses in the study shared strong thoughts about care of the critically ill being their main focus and hence they felt the need to be in control of the interactions with the patient. Additionally, they expressed their professional responsibility as the patient's advocate. Some of the decisions that nurses in the unit mentioned involving the families included consent signing for surgical procedures and investigations and transfer of the patients to different health care facilities such as private hospitals. Most of the nurses expressed lack of reliance on the family members' decisions regarding the care that was provided to the patient citing the critical care decision that needed to be made.

"There are people who do not like intubation and we tell them the only way is intubating. Sometimes the relatives can even refuse but we do it according to the emergency. But you see we make the decision. " (N6)

In most cases, we make the decisions as some decisions require to be made quickly…... if we wait for families the patient's condition could deteriorate from long waiting times to intervene. (N3)

Several nurses mentioned difficulty in shared decision making with the family attributing it to family health literacy and family dynamics.

"In some critical situations the families do not want to make decisions. They will ask for your opinion or some will take long before they consult each other within the family and it could be an emergency. (N5)

The family members stated non-involvement in decision making of their loved ones.

"I have never been told to make any decisions… I don't know what options are available. We find things have already been done. The only thing they have told me is to buy medication, and find someone to donate blood for her" (R 1)

Some of the family members in the study expressed their preference for the healthcare team to have complete decision-making citing lack of necessary skills and capabilities to be included in the decisions believing that the healthcare providers know best. One family mentioned anxiety and emotional strain hindering their decision-making process.

"…. we listen to them [medical team] and leave them to decide what they want. It is their job and they know better than us……we cannot teach them their job. As long as our patient is getting the care they need." (R 2)

"…as a family we are going through a difficult moment with a lot of stress since they were admitted…...we are going to follow the doctor's decisions as they know better and we are psychologically stressed to make decisions at the moment. (R7)

On the contrary, some family members felt their input was dismissed by the nurses based on disparities in knowledge and professional levels.

"………when we told them (nurses) about how our mother would like to be taken care of…. they said we should not teach them their job!" (R 2)

Similarly, one family expressed willingness to participate in the decision-making process of their loved.

"I would want to be involved in making decisions as long as I am capable…any…as long as I can save the life of my father" (R4)

"I would want to be involved in making decisions where a procedure would potentially have harmful effects. I would like to know the options beforehand and to know the outcomes to be expected after the procedures" (R 5)

Theme 3: Physical Presence and Proximity to the Patient

Sub Theme I. Being present

Family members expressed their desire to be able to visit their relatives frequently citing it would help allay their worries and anxiety. Most of them mentioned the visiting hours (6.30am-7.30am and 5.30pm-6.30pm) as restrictive and insufficient to spend time with their loved one.

"I would like to be able to visit them as many times...to have time to talk and stay with her" (R 5)

"Even though I come to the hospital early I the morning, I stay for hours outside before I can come back I the evening. I spend the whole day outside the gate; they don't let you in and this stresses me the whole time I'm waiting" (R6)

"The visiting hours are not enough because you need to talk to the patient, spend time with the patient just to know how they are progressing and find out information from the nurses…. that is not enough time! (R 4)

"We have family and friends who have been told to go back home without seeing the sick person. It is very unfair because they set aside time, spent on fare and the determination to visit her…. Some even went back home crying. The hospital should let families to visit even if it is just for two minutes per person. I know Corona is there but they should let us in!" (R 1)

One family member expressed the wish to participate in the practical caring tasks while maintaining the personal values and preferences of the patient.

"I understand the ICU is a sensitive place but I would like us a family to be allowed to feed him because we know him better than the nurses. We have been with him for a long time and we are used to feeding him slowly because of the pain." (R 4)

On the contrary, one family member, expressed contentment with nurses performing caring tasks as professionals as opposed to families.

"I don't want to do all of the tasks because there are nurses who are professionally trained to do them. I am scared of touching something I am not supposed to touch. I would just like to hold her hands…sometimes to even feel temperature if she has a fever. (R1)

One day they were washing my patient and I happened to be there, they drew the curtains. At least they show respect to them even if they are not awake. They would not want everyone to see them when they are naked". (R6)

They did express discontent in how the nurse's provided self-care to the patient. The participants recommended a review of the visitation policy to allow a family member at the bedside throughout the CCU admission.

*"They (nurses) keep saying they bathe her [mother] everyday but we think she's never cleaned at all…you can tell from looking the eyes. She's very dirty! Before she came here, we used to clean her at home and change her diaper. But here they leave her dirty…if possible, they can leave one of the daughters to go in and wash her." (*R6)

*"The nurses and doctors have told us that our mother cannot talk or move…but how can she talk when she's alone in there? We would want them to put a chair at her bed so that one of us sits there to observe if she will have any movement and talk to her. It will give her the strength to talk. For example, in the European countries, you will find the relatives reading a story for their patient in ICU. But now here the patient is all alone most of the time. How will they start talking if no one is talking to them? Then the person at the bedside can be giving us updates". (*R2)

"The other day we came in and found her lips were cracked and dry. We asked the nurses if they could let us apply some coconut oil on her lips, but they declined. When we asked the reason, they said we are not allowed to touch her…. we even asked for gloves" (R7)

The nurses perceived the unit's visitation hours as adequate and expressed that only in exceptional situations such as when a patient is deteriorating, they allowed family members into the unit outside the visiting times.

"Mostly in ICU we allow one relative per patient. We tell the gate man to control the flow of relatives because of infection prevention and also because of privacy……and you know in ICU sometimes we are having emergencies. So, we control the flow of visitors." (N6)

On the other hand, ICU nurses expressed satisfaction in being able to perform all patient caring tasks with minimal involvement of the family members.

"A relative does not do anything, we do everything for the patient in terms of care" (N2)

"There is no time you will see a relative working for his or her patient. Everything we do for them. If it is bed baths, dressing and any procedures we do it. I better call a colleague but not a relative……no……That is the culture we found." (N4)

Sub Theme II. Challenges in balancing Family-Centered Care with Clinical responsibilities

The ICU nurses understood and appreciated the importance of family in the patients; most of the nurses mentioned that family were especially important during the discharge process where they aided in continuity of care. However, the nurses said that care of the critically ill patients was their main focus in the critical care setting hence, making it difficult to meet the needs of the family.

Some of the nurses expressed lack of knowhow on integrating families while providing care to the critically ill patients with most of them nurses stating that the clinical instability of the patients made it challenging to engage the family.

The nurses expressed empathy for the family acknowledging most of them being stressed from the ICU admission and uncertainty.

"It is so difficult in the ICU because you want to be there and help the family members because of what they are going through. But it is also difficult for you as the bedside nurse especially if the patient is not doing well and you have to first take care of the patient" (N3)

"…many times, you are caught up in between patient and the care I have to give and their families' wishes and most of the time they can be so demanding and unsafe for the patient" (N5)

The families in the study highlighted the need to be part of care and to be at the bedside for longer hours or throughout the hospitalization of their loved ones. However, the ICU nurses were sceptical in allowing the relatives to provide physical care of the patients admitted in ICU. The nurses cited family presence at the bedside as interruption to their tasks from the constant questioning and requests for updates which delayed care and documentation.

"They will make the care be delayed because they will keep asking……… "Why are you doing this?" (R2)

The nurses were concerned about involving family in care due to fear of disconnection of the patients from the ICU machines and tubing.

"I don't approve allowing family providing care because some of our patients have so many machines and these people are not trained. They may even worsen. So…let the relatives stay aside." (N2)

Some of the nurses mentioned that allowing families at the bedside throughout would heighten the families' anxiety when emergency situations arose or when the patients' conditions deteriorated.

"Maybe another patient has changed condition and they start panicking …………we don't want them at the bedside. Let them come during visiting time and go home." (N3)

"Having them at the bedside throughout will expose them to traumatic events which I don't think some can handle. Imagine having family members fainting or screaming when in the middle of CPR. Do you attend to the patient or the family members? (N4)

Sub Theme III. Role ambiguity

The family members in the study expressed that inconsistency in information and participation in care from the different members of the nursing team creating confusion among the family members on their role. One family member had engaged in feeding the patient when the nurses were busy which she described as giving her a sense of purpose and involvement.

"It is only once that we have been allowed to give her a wash. And it is because there was an emergency with one of the patients who was about to die. At least I can say I got to help her. But since then, we have not been allowed to do anything else for her." (R2)

The family members of the patients who had been admitted through the general wards where they were allowed to provide washes and feed their relatives felt discontent in the ICU policy of non- involvement in care which led to further confusion and a sense of exclusion.

Several nurses interviewed recognized the role of family in continuity of care especially during the discharge process hence allowed families to participate in some of the caregiving activities.

"I feel very important to involve family members in care…because there are some procedures when a patient is discharged, they have to continue care at their homes. For instance, an example, a patient who has a PEG…yeah, gastrostomy tube. We involve them in terms of how we are feeding so that they continue when they are at home. It is important for patient who are to be discharged from here to home." (N4)

"We need family for preparation of discharge especially the home-based care. We need the family to come so that we prepare them in ICU. We start discharge preparation here in ICU. We need to show them how to wash, turn, pressure areas and the drugs…sometimes we stay with patients here for long such that they are discharged home. We need to teach them what to do." (N 1)

"In HDU, we want the family to remain to just be with so that in case of any need they are available and they are able to assist and especially if the patient is walking. They are able to go with the patient to the toilet." (N5)

Theme 4: Cultural Sensitivity in Care

Sub Theme 1: Cultural and religious inclusion

The nurses said that they did encounter diverse cultures among the families and acknowledged different communities deal with the ICU admission in different ways culturally and religiously.

"They can touch the patient…because it's still their person. If they want to pray while holding their hands, that's fine as long as they don't touch the tube. We do not interrupt them. We also restrict photos just to maintain the dignity of the patient" (N1)

"Mostly when they say they want to pray, I allow them. Like for Christians…the Catholics they have the anointing of the sick, which they believe will heal the sick" (N3)

"Those that are Muslims come with small radios and put them on the bed…... we don't prevent. We just tell them to put a small volume. They believe through the prayers the patient will get well." (N4)

The critical care nurses expressed displaying cultural and religious sensitivity by setting aside their own cultural and religious values to understand the cultural values, beliefs, and practices of patients and their families.

"We normally have a lot of Muslims here and I am a Christian but I always accommodate them." (N3)

The critical care nurses also pointed out that allowing the cultural practices and religious practices involved striking a balance between being culturally sensitive and protecting the patient from harmful practices and rituals. The nurses said restriction of such practices deemed harmful to the patients created tension between the families and the nurses. One CCN was particularly against allowing cultural and religious practices in the unit saying that it will be difficult to accommodate and manage all the cultural expectations of the families.

"There are some cultures we do not allow. Even some religions where people are shouting and jumping, we cannot allow. For example, we allow prayers but then we cannot have them bring a whole church in here. We respect them but we have limits on what they can do especially to an ICU patient." (N 5)

"But not the practices of letting them use herbal medications…. no. It can be detrimental and goes against the care we are providing. Prayers and those practices are allowed as long as the patient safety is maintained" (N4)

The family members appreciated that the nurses accommodated their cultural rituals and beliefs by allowing them to have prayers at the bedside.

"We have been allowed to pray with my sister. It gives her hope because she keeps asking… "I'm I going to wake up after the operation?" (R 5)

"…we have been allowed to leave a small Bluetooth at the bed that plays the verses from Al-Quran" (R 2)

Family members in the CCU identified spiritual beliefs as an aid in coping with stressful situations and bringing consolation and hope into their lives. During visitation hours, the participants expressed praying for spiritual intervention on behalf of the patients as expressed by the following participants,

"When I go in, I take some time to pray quietly for him, without disturbing the nurses and other patients. I am always praying for God's intervention in this situation. I have never been interrupted. That way I feel respected" (R5)

…. I have left God to take control. This morning I was praying and I told God if she is feeling pain from the inside…..there is no need of her suffering. (nodding head sideways). She is really young…just 31 years. (R 1)

"We pray that Allah will continue using the doctors and nurses to take care of our patient, hoping that He (Allah) will heal our patient. Whatever happens to them, we will accept the will of Allah" (R6)

"One of us was allowed to come and read dua to her…and she actually showed response by eye movement" (R 2)

Sub Theme II. Physical Resources

From the narratives of the nurses and the families, there was a lack in the physical facilities to support family members during visitation periods in the ICU. Family updates were done at the bedside or at the nurses' desk. The nurses mentioned using the unit manager's office when death occurred where the family members would sit.

"We do not have meetings as such but at times when we need privacy especially when we are breaking news when a death has occurred, we usually use the office of the in charge. We let them sit and relax and then from there the doctor can break the news. But for the other information we can do it at our station, they just sit aside and tell the person about their patient." (N1)

Family members in this study expressed lack of physical facilities such as a comfortable waiting space. They described their experience as unpleasant as they spent long hours at the hospital with some sleeping on the hospital floors and benches. Majority of them had been referred from the periphery health facilities which are far away from the study site hence difficulties commuting on a daily basis.

…when they chase us from the ICU, I have nowhere to go …...So what I do is go outside and sleep on the benches or floor in casualty because I cannot afford to pay fare every day to the hospital" (R 2)

The waiting space outside the ICU is nice and private. But the other on the outside is really bad. I'm even sympathizing with my uncle who had to sleep on the benches in the cold. And the mosquitoes don't make it any easier" (R 4)

The family members recommended physical amenities to provide comfort for families vising the sick in CCU

"The county government should think about a resting area where they can sleep especially at night. They should also have clean toilets ad a bathroom area. Like now I have my toothbrush here, I'm wondering where to brush my teeth from because the toilets are disgusting." (R1)

Although the ICU nurses acknowledged the importance of having a comfortable waiting area, they cited limited resources to implement it.

Subtheme III: Impact of the Critical Care Environment on Family-Centred Care: Psychological support

Family members identified the ICU environment – the machines, screens, alarms and the sudden admission of their loved one into ICU, the uncertainty of the diagnosis and prognosis of their loved and financial difficulty as the major contributors of emotional stress.

"This is the first time we are having someone in the ICU in our family. Everything in the ICU is just shocking…. the patient with tubes and all the machines! (R4).

Some relatives interviewed expressed distress from the constantly beeping alarms of the ICU equipment and financial worries.

"All the sounds from the machines in the ICU are scary…it gives me the feeling of hopelessness and death" (R3)

"When I go home all I hear are the beeping from the machines, and especially at night I cannot sleep well as I have this feeling that they are dying" (R7)

"She does not have NHIF, I don't know if we are paying for the bed or just the medication. It is stressful because whatever the outcome the bill needs to be paid eventually." (R 1)

Some of the participants expected the CCNs to provide explanations or words to give them hope.

"Just an explanation that they are trying all that they can do will reduce my stress by knowing that my patient is getting the best care" (R 5)

"This is the first time having someone in ICU. It would be better if the nurses just spared some time to listen to us and give us hope" (R 3)

Family members mentioned making drastic changes in their personal life to adjust to the hospitalization of their loved one. Additionally, some of the families expressed family disintegration from the ICU admission of their loved due to separation from the rest of the family, "Our brother was the next of the kin and he was the only they give information about our mother to come and tell us. Because he is the only son and lives with our mother, he has been so affected that he doesn't sleep at all…he has been talking to himself a lot lately. When he gets inside [the CCU] he does not tell us what the nurses and doctors have said…Because he is always in the hospital, he lost his job." (R 2)

"If it were not for her, I would be at home continuing with my business. But now I have to shut it to be here…I had to leave my kids to be here!" (R 5)

From the participants interviewed, family cohesion, support and a sense of togetherness amongst the family members was evident.

"Yesterday, my uncle spent the night in the hospital. Then during the day come in to relieve him" (R4)

"This is my brother's daughter (the patient). As a family we have decided to have someone accompany the mother to hospital because she does not ask questions or give us updates at all…probably it is the stress. This evening my other sister will come and take over. My brother, the father is too weak to be travelling here so we let him stay home then we give him updates" (R 1)

They should have a small area where the families can sit and have conversations and console each other. But outside there, one person is crying, another one is sleeping. The other there was a woman wailing because her daughter had died. I had to step in and talk to her, I have never done counselling before. I had to tell the security officer to let her in so that she talks to the doctor. I have lost two children and I know the pain. We need counsellors as relatives because it is not easy! (R7)

The ICU nurses recognized that families in CCU were often stressed by high paced with multiple complex issues occur rapidly requiring immediate decision to be made. They were empathetic and expressed the need for provision of counselling services to families in ICU for psychological support. Some of the nurses mentioned referring families to counsellor who came up to the unit to provide counselling services to the unit.

"The family members they are stressed and psychologically affected. They tend to be anxious …so there's a lot in the family. They need psychotherapy." (N6)

"We have the psychological counsellors in the hospital who have made the communication easier because the technique they use is different from ours. For issues that are straining and sensitive like we had a case of a mother who had severe burns and it was a road accident. In the incident, the husband and the child died but the mother survived. This one, we could not communicate to the patient and also to the relatives knew everything but they said not to tell the patient until she recovers and we could not come into a consensus and so the counsellor came in between." (N1)

DISCUSSION

Sociodemographic characteristics of participants

Majority of the participants in the study had tertiary education. This has the implication on the families understanding of the patients' diagnosis and medical interventions. The education level of family members in the ICU is related to their knowledge and comprehension of the issues pertaining to the CCU hospitalization (Kalolo, et al., 2023). The study sample had more female participants as compared to the male counterparts. This could be attributed to the women being considered as the primary care givers in the African context. According to (Ekaete & Akpan-Idiok, 2020), the caregiving role is an expectation placed on families and has particularly been feminized and endorsed by a culture where women have taken up nurturing roles.

Communication as a pillar of care

The study findings showed that CCU nurses play an integral role in provision of clinical care as well as communication as they are easily accessible for families to communicate with and are in constant interaction with the patients. Communication is an essential but also challenging aspect in the critical care environment (Yoo, et al., 2020). Nurses are an important source of information about the CCU environment, treatment modalities and patients' condition ((Kalolo, et al., 2023). Family members in this study expressed accessing information of their loved one in the CCU as an important need with the need to know being related to the care that the patient was receiving, the diagnosis and the prognosis. Consistent with these findings is a study by Kalolo (2023), that reported patients' families requiring more information about the diagnosis and diagnosis, and type of care given.

Families reported both meaningful and negative interactions. Meaningful interactions included respectful treatment while negative interactions entailed dissatisfaction with the care delivery in relation to uncertainty in the treatment plan, delayed updates, impersonal communication, and intimidation of families by healthcare workers. These findings are corroborated by a similar study by Edward et. Al (2020) where the family members rated satisfaction with intensive care admission by the quality of communication rather than the level of care rendered. The study recommended utilization of the shared decision-making model in the CCU to guide how communication with family members is done to ensure consistency.

Balancing the heavy patient workload and communicating with family members in the CCU was a struggle the CCU nurses experienced. According to the unit's in charge and observation during the study duration, on an average the CCU nurse cares for two or three patients. The CCU nurses placed their focus on direct patient care tasks hence deprioritizing communication with family members. A study conducted in Korea among patients and their families in the intensive care unit reported communication challenges experienced by CCNs due to time limitations and high mental stress from the workload with nurse-to-patient ratios of 1:4 making it a stressful work environment which is consistent with the findings in the study (Yoo, et al., 2020). The same study corroborated the study findings by reporting that multiple competing demands in the CCU environment, high acuity, and staff shortages contributed to staff burnout which had a negative outcome on the emotional health of both the health care providers and family members. The overall effect was difficulty in communication and collaboration which negatively affects families. Interventions such as pre-recorded videos, pamphlets, booklets with information pertaining to the CCU have been found to be effective in educating family members, at their own pace without impacting on the staff workload (Pandhal & Wardt, 2021).

Clarity and transparency during information sharing was essential to the families even when it was perceived to interfere with their hope for positive outcome. Relatives expressed the desire to know exactly the condition of their patient to help them cope better and prepare psychologically. Family members in an Australian study by McLennan & Aggar (2020), found that family members perceived themselves able to handle honest information about their patient from the healthcare providers as this would enable them make sound decisions relating to treatment and end-of-life.

The study results showed family members initiating conversations about prognostic information of their patient in CCU which they expressed getting vague responses inconsistent to the patients' condition. On the other hand, the CCU nurses in the study expressed experiencing difficulty in maintaining transparency more so in situations perceived as difficult such as poor prognosis despite acknowledging the need for honesty when communicating with relatives. A similar study conducted in the UK showed different results to this study where conversations pertaining to prognostic uncertainty were done collaboratively with families with the health care providers being honest about the uncertainty and death without explicitly referring to it (Anderson, et al., 2020). The difference in the perspectives between the two contexts could be explained by the communitarian nature of the African societies, fear of death and grief, the African cultural belief system which does not encourage the contemplation or discussion of death. A study by Kalolo, Chimwemwe, & Gundo (2023) indicated that challenges related to conversations about negative health outcomes in the CCU were related to cultural taboos against talking about death.

Additionally, this could be attributed to the lack of training on family centred care during basic training among the CCU nurses interviewed. Nurses are in an ideal position to assist families in the CCU attain their needs as nurses are in constant close interactions with patients. However, nurses training places its focal focus on nursing needs of patients, hence family members' needs are often neglected (Kalolo, et al., 2023). The scope and practice for entry level nurses and midwives in Kenya by the Nursing Council of Kenya (2020), implements a systematic education system for nurses whose main focus is on therapeutic aspects such as ventilator management and hemodynamic monitoring with minimal focus on maintenance of therapeutic communication with patients and their families.

These findings highlight the importance of health care professionals addressing the information needs of family members in the CCU, as they often serve as patient advocates who in the CCU are unable to make decisions about their due to their critical condition.

Involvement in patient care decisions

There was minimal involvement of family members in the CCU in shared decision making with the CCNs citing family dynamics, rapid progression of life-threatening illness, and family stress from the CCU admission. A similar study by Cullen (2020) indicated that health care providers in CCU experienced challenges engaging family members in decision making due to physical, psychological and cognitive issues of having a loved one admitted in CCU, internal family conflicts and previous experience with healthcare systems. Health care providers' (HCP) perception of their role determines the shared decision-making process – HCPs who perceive themselves as educators and collaborators are more likely to involve families and patients in shared decision making as compared to those that perceive themselves as decision makers for their patients and families (Wadell, et al., 2021).

Despite family members assuming surrogate decision-maker roles on the treatment choices of their loved one in CCU, family members expressed dissatisfaction on the timing of inclusion and lack of inclusion during decision making. Contentment of the family members with the decision-making process in the ICU was dependent on the satisfaction with the care given to their loved one, comprehensiveness of the information provided to the substitute decision maker and the magnitude to which the family perceived support during decision making regardless of the outcome of their patient. Additionally, families cited lack of support and poor communication contributing to dissatisfaction with family involvement in decision making (Klas & Baliki, 2024).

Uptake of collaborative practices depends on the family's level of health literacy, health beliefs, education, prior healthcare experiences, organizational policies, norms and culture and societal norms (Cussen, et al., 2020). Family willingness to be involved during decision making was found to vary between desire to actively participate in the decision-making process to just receiving the information of the health care providers decisions. Denial of the diagnosis and prognosis, anxiety, and uncertainty of the families can affect decision making by the families. This is congruent to a study where some participants were unwilling to participate in shared decision making from family burn out resulting from shared decision making.

Difficulties in assimilation of information delivered by the CCU staff in addition to the emotional turmoil that the families underwent contributed to the families' lack of empowerment to participate in decisions. Additionally, the rapid progression of life-threatening illness and emergent nature of critical illness made it difficult for the CCU nurses to hold conversations to build trust with families to equip them with information for decision making. According to Cussen et. al (2020), the type of decisions that family members make are strongly influenced by how the information is relayed to them. The study further states that shared decision making involves the health care provider personalizing the information delivery process according to the background, wishes and experience of the families in a simple, understandable way while allowing them to understand each choice and the consequences of the choices.

Physical Presence and Proximity to the Patient

In terms of family participation in patient care activities, this study captured the family members' desire to participate in patient care – a desire stemming from the kinship ties among family members. The family members further explained being involved in the care of their relative would ensure that the dignity of the patient was upheld by ensuring they were clean and covered throughout.

The families strongly expressed the need to be in close proximity to their critically ill patient in the CCU as a means of showing psychological support, citing that it made them feel they had contributed to emotional care by being close. Visitation restrictions imposed by the CCU's visitation policy was interpreted by the families in the study as denial of access to their loved one and was viewed as an impediment to maintenance of family cohesion which is expressed through regular family visits especially during a family crisis. A study conducted in the Nordic countries reported having open or almost open access for family members. Despite having a liberal visiting policy, families still spent a considerable amount of time waiting outside the patients' room to allow for examinations and treatments. The study found that liberal visiting policies increased family satisfaction, and reduced family anxiety and stress (Frivold, et al., 2021). A similar study by Kalolo, Chimwemwe, & Gundo (2023) found that open visitation policy in the CCU helps allay relatives' anxiety as they get to spend longer duration with the patients.

Different families expressed varied reasons to be at the bedside such as to hold the patient's hands, to pray with them, to monitor the progress of the patients, for reassurance that their family was getting quality care. Family members expressed the desire to have at least one family member to stay in the CCU throughout to able to monitor progress and ensure their loved one was getting the care. This is congruent to a study by Boukje et al (2023) that demonstrated that family presence at the bedside was part of the family members' fulfillment of the participatory role in the care process. The same study further stated that family participation in care of patients in the

ICU setting enabled the relatives to cope with the situation and ICU environment, regain control over the situation and develop resilience. A similar study on family-based delirium management in intensive care unit reported better outcomes with family involvement during anxiety provoking situations such as extubation or mobilization due to presence of a familiar face. The study also emphasized the critical role of family members during the hospitalization process in the psychological recovery of the CCU patient to help them understand clinical throughout CCU admission (Pandhal & Wardt, 2021).

The nurses in the study stated that presence and participation of family in the CCU would affect the quality of patient care and would further increase their workload when meeting the needs of patients' relatives. In terms of family involvement in care, the nurses were strongly opposed as they perceived it as risky due to the patients' critical condition, infection transmission and fear of accidental disconnection from the CCU equipment and machines. Critical care nurses were hesitant to involve relatives in the care of critically ill patients raising concerns on patient safety and quality care preferring to involve them in non-direct caring activities such as religious support. A study by Leong et. al (2023) reported participation of family members in the CCU in activities such as massage, body washes, eye and oral care, and patient positioning. However, this necessitated overseeing by the health care providers due to concerns about accidental extubation and non-compliance to infection control measures which increased their workload and delayed other nursing care activities. The study further recommends development of policies within CCUs to guide assessment of families and patients, involvement level in care and supervision when the families are involved in care.

Cultural sensitivity in Care

Cultural and religious practices were a source of comfort for the family members and gave them a sense of hope as articulated by participants in the study. The family members from the different cultural and religious groups in the study expressed finding solace in religious beliefs, spiritual values, and practices which gave them hope that their admitted relative would recover quickly. This is consistent with the findings of Kalolo, Chimwemwe, & Gundo (2023) who found that religious and spirituality among the Malawi community as important aspects in coping with stressful situations.

The CCU nurses in the study expressed being culturally sensitive and cultural aware of the different cultures and religious groups by setting aside their own cultural and religious values to understand the cultural values, beliefs, and practices of patients and their families when providing care to the patients in the multi-cultural Coastal region. This is consistent to a finding by Badanta et. al (2021) where nurses facilitated Muslim religious practices despite language barriers while utilizing professional translators and understanding Muslim's perspective of death. The study also reported differences in incorporation of spirituality in clinical practice in various countries – Muslim and Asian countries tend to be open to incorporation of religious practices compared to countries in Europe that tend to be restrictive. Additionally, the Brisbane Declaration written by the World Federation of Critical Care Nurses stresses on the need for CCNs to possess knowledge, skills, and qualities to provide culturally sensitive care as it can significantly contribute to efficiency of the health care system globally. It highlighted the right to culturally based care for critically ill patients from different cultural backgrounds (WFCCNa, 2016).

The families of patients in the CCU recounted experiencing psychological distress during their family members' stay in CCU with both participants concurring on the need for psychological support structures in the hospital for the family members in ICU. The psychological distress was attributed to the unfamiliar CCU environment and the equipment, visiting restriction, uncertainty of prognosis, poor communication, insufficient decision making as expressed by the family members. These findings were similar to a study conducted among families of critically ill patients showed a relationship between family satisfaction with intensive care and psychological distress where family members who were more satisfied with quality of care experienced lower levels of depression, anxiety and posttraumatic stress. The study also depicted higher satisfaction levels among families whose needs were met especially in terms of communication and decision making (Naef, et al., 2021).

Family members reported in the study reported adjusting and neglecting their personal and daily routines during the hospitalization period which also contributed to their psychological distress. According to Shorofi et. al, the caregiving role, though considered a normative role is taken up by most people without prior preparation or readiness even when it causes disruption of their family, work or social life. The additional responsibilities can become overburdening, and potentially causing negative outcomes on the caregivers' health.

A study in an Australian ICU utilized a family support pathway and integrated an advanced practice family nurse into the ICU who provided psycho-educational interventions to families in ICU while delivering therapeutic conversations with families in collaboration with the ICU nurses and physicians. The family support intervention was found out to have increased family satisfaction with care with families reporting to feeling acknowledged, cared for and well informed (Naef, et al., 2022). These studies collectively corroborate that investing in family support and quality of communication has an effect on satisfaction in ICU care which subsequently has potential to minimize negative effects on families' mental health.

Family members expressed the need for a non-clinical space outside the CCU where families can stay after the visiting hours as well as clean sanitary amenities such as bathroom and toilets. This need being driven by the families' desire to be in close proximity with their loved ones during the CCU admission. Similarly, a study conducted in Malawi by Kalolo (2023) reported special shelter, food and financial needs as some of the physical needs among families in the CCU.

CONCLUSION

Critical care nurses recognized the importance of actively communicating and interacting with family members and informational support. The family members desire to receive information regarding their patient was overwhelming with majority of them expressing discontent in terms of transparency, lack of awareness of treatment plan, infrequent or lack of communication from the CCN.

The CCNs in the study expressed the struggle balancing provision of critical care to the patients and meeting family members' needs. This was related to nurse shortages in the unit, inability and discomfort interacting during interaction with family members who had unrealistic expectations about the care and prognosis and, heightened emotional displays by families.

There was minimal involvement of family members in the CCU in shared decision making with the CCNs citing family dynamics, rapid progression of life-threatening illness, and family stress from the

CCU admission. Despite family members assuming surrogate decision-maker roles on the treatment choices of their loved one in CCU, family members expressed dissatisfaction on the timing of inclusion and lack of inclusion during decision making.

Environmental factors related to the ICU environment were mentioned as causing distress to the families such as lack of private rooms for updates, constant noise from the CCU machines, and lack of physical resources such as a resting area for the relatives that was comfortable.

RECOMMENDATIONS

The study recommends that routine interprofessional family meetings scheduled on admission and regularly where the health care professionals introduce themselves and their role in the team.

Development and implementation of policies and frameworks to promote FCC in the CCU which will guide in provision of structured and standardized care among families consistently.

Interventions such as pre-recorded videos, pamphlets, booklets with information pertaining to the CCU in providing information to family members, at their own pace without impacting on the staff workload

Personalizing the information delivery process according to the background, wishes and experience of the families in a simple, understandable way while allowing them to understand each choice and the consequences of the choices to enhance willingness to participate in shared decision making while also assessing the reasons for unwillingness for the same.

Development of manuals on dealing with difficult situations based on actual clinical scenarios and incorporation of family-centered communication training to provide support for family members as an element of the critical care curriculum to improve family satisfaction and subsequently quality of communication in CCU.

Assigning family coordinators/care coordinators to CCU families throughout CCU hospitalization period whose role is to improve family satisfaction by acting as a link between the CCU families and the CCU health care team.

Area for further research

This study recommends further study on the benefits and risks of family presence and family participation in the CCU for patients, their families and the CCU staff. It also recommends further study on quantifying the importance of family partnership and the effect on patient outcome focusing on aspects such as satisfaction of care, quality of communication and quality of decision making.

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