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Effective communication and missed opportunities during family conferences of patients in ICU in Western Uganda

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Abstract

Background Effective communication in the intensive care unit (ICU), such as conferences between clinicians and family members as surrogate decision–makers, is key since patients frequently lack decision-making capacity because of the severity of their illness. However, there is little evidence about family conferencing, processes and missed opportunities during family conferences from the perspective of family members. This study explored the process, structure and missed opportunities during family conferencing among the family members of patients in the intensive care unit (ICU) of one Regional Referral Hospital in western Uganda.

Methods A qualitative study was conducted in the general ICU. Close family members who participated in patient care provided information about the family conferencing procedure. The data were collected via individual interviews, transcribed verbatim and analysed using content analysis as described by Krippendorff.

Findings The participants were middle-aged and ranged from 25 to 60 years, with good level of education, and most of them were employed. The generated categories were dichotomized into two sections. The first section explored the factors related to the process linked to readiness and the structure of family conferences. The observations included accidental meetings, which were conducted in unfamiliar places, were attended by an unintegrated disciplinary team, and mostly discussed patients' values, care and treatment management. Uncertain experiences revealed perceived satisfactory communication to some family members, whereas others reported sadness with missed opportunities in the process of family conferences.

Conclusion Family conferences lack adequate preparedness, and family members' emotions are missed in care. This study recommends that family conferencing protocols be followed to enhance effective communication skills that align with family members' emotions.

Text box 1. Contributions to the literature

- There is little evidence on family conferencing processes and missed opportunities during family conferences of life-sustaining treatment to Patients in ICU from the perspective of family members especially in low-income countries.

- Missed opportunities, uncertain experience, and unmet expectations of family members trigger stress and anxiety of family members subsequently affect patients' care in the ICU.
- Family conferencing protocols on the family conference, processes, content are urgently needed to improve effective communication skills that align with family members' emotions.

Keywords Clinicians, Close family members, Conferences, Family meeting kit, Missed opportunities

1 Background

Effective communication in the intensive care unit (ICU), such as conferences between clinicians and family members as surrogate decision–makers, is key since patients frequently lack decision-making capacity due to their severity of illness [1]. Known family conferences are based on decision-making to continue life-sustaining management and often end-of-life care in the ICU [2]. However, little is known about the process, structure and missed opportunities of family conferences from the perspective of family members. Therefore, the aim of this study explored the process, structure and missed opportunities during family conferences from the perspective of family members of patients in the ICU in one of the Regional Referral Hospitals (RRHs) of western Uganda.

Family conferencing is a conversation that happens between healthcare teams and family members who are close relatives of critically ill patients [1, 2]. These conferences are essential for sharing information about patients' values and treatment preferences, delivering difficult news, setting goals and making informed decisions [3, 4]. Effective communication in this case needs a shared approach that is built on trust.

However, family conferences can be challenging due to many barriers associated with the nature of demanding dynamics in the ICU [5]. Haste procedures require critical and quick decision-making by nurses and physicians, the involvement of multiple specialists in care, inadequate training of physicians in communication skills, and differences in culture coupled with language barriers. Emotional stresses for clinicians and a lack of dedicated space for family meetings [6, 7]. Family members often report feeling anxious and uncertain about their loved one's condition when family meetings fail to happen in a timely, effective and reliable way [7–9]. Research shows that family members are frequently dissatisfied with the information provided by physicians, and approximately 50% misunderstood or were frustrated regarding the discussion of treatment plans due to stress of caring for critically ill patients [5, 9]. The critical care team provides support to family members to enable them to understand the information discussed in family conferences [10].

Missing opportunities during conferences between clinicians and family members in the ICU remain a significant concern [11, 12]. A missed opportunity refers to a moment or instance during a planned conference between clinicians and family members of a patient in the ICU when important information is not shared or is misunderstood to eliminate emotions [6, 13]. Effective communication during family conferences facilitates cooperation between clinicians with the aim of providing optimal care to achieve the desired outcomes [14, 15].

A previous study recommends use of communication bundle standards if patient and clinician communication has to be successful and appreciated [16]. The standards of

care and communication bundle suggest that an interdisciplinary family meeting be held on the 5th day of the ICU stay [17]. Fewer than 20% of patients in a multi-institutional study had interdisciplinary family meetings recorded by day five of intensive care unit (ICU) treatment [18], which implies that there is a need to examine family conferences in many critical care units [19]. Furthermore [19], asserts that a developed family meeting toolkit can help critical care teams to meet the important communication needs of ICU families. There are three specific tools that were developed to promote more successful implementation of family meetings in the ICU which are family meeting planner, a meeting guide for families and a family meeting documentation template. In the family meeting planner, there is a list of what should be done in preparation for the meeting. The family meeting guide clearly states what happens during the meeting and acts as a guide to physicians and nurses when talking to family members. All the information, actions and plans that result from the family conference should be documented in the family meeting documentation template for reference [18]. Another research-based model for family conferences states three elements that must be considered in a conference organization. A setting that includes a good room size, number of chairs in relation to space and participants considering participants' comfort/discomfort. The participants in these conferences must include a multidisciplinary professional team, all providers relevant to the conference topic and everyone there [20]. The structure of the family conference must be organized as follows: preparations, introductions, agenda setting, patient history, diagnosis/prognosis, patient explanatory models, care plans/discharge plans, closing/summarizing content and follow-up [21].

The study site presents unique challenges of limited resources, and family members are allowed to participate (shared role) in basic care as supervised by nurses. Little is known from family members' perspective regarding the role of family conferences in the process, structure and missed opportunities to meet expectations of ICU care.

2 Methods

2.1 Aim

The aim of this study was to explore this process, identify missed opportunities and describe family conferences from the family members' perspective of patients in the ICU of one RRH in western Uganda.

2.2 Design

A descriptive qualitative design was employed to study the family conferencing process among the family members of patients in the ICU to understand missed opportunities. The descriptive study design was used to obtain straightforward descriptions of experiences and observations in family conferences since little is known about the topic in our setting [22]. This study design was preferred with an intention to gather the required information from those experiencing the phenomenon under the study [23].

2.3 Participants

Purposeful sampling of information-rich participants was employed [24], and the inclusion criterion involved all family members whose patients had a Glasgow Coma Scale score less than 8 and consented to the study. These participants were with the patients for more than 24 h in the unit, with the patients providing basic care under the

supervision of nurses. Basic care refers to activities of daily living, such as hygiene and nutrition. The participants were adults who were more than 18 years of age and were recruited by the principal investigator (AAM) from the ICU. All family members who reported being visitors to the unit were excluded.

3 Ethical consideration -see declaration

3.1 Data collection

Data were collected between February and August 2024. Each interview commenced with standardized questions about the sociodemographic data of the participants. Then, a semi-structured interview guide was used, followed by open-ended questions on family members' experiences with family conferences in the ICU. The interview guide was developed on the basis of previous investigations at family conferences [6–8, 11, 19, 20]. It was peer reviewed by ICU clinicians, and a pilot test was conducted on four family members (not included in the study) with minimum corrections. The interviews were carried out using Runyankole, the local direct by a bilingual nurse (AMM) in a secluded room which was provided by the ward in charge. Sessions lasted 60–90 min and were tape-recorded and then transcribed verbatim in English.

3.2 Data analysis

This step followed the steps of content analysis as explained by Krippendorf [25]. The collection and analysis of data proceeded simultaneously until no new information was forthcoming from new sampled units, thus leading to a redundancy point. All the transcripts were read several times to obtain a general sense of all the information. Inductively, the process starts with the search for meaning units that respond to the research questions. The analyses were based on openness to variation in data and a search for similarities and contradictions by constantly comparing different statements of participants. By reviewing each line of the text, meaning units were identified and coded. Phrases with similar meanings were condensed into one common subcategory. Content categories that linked the text to answer the research questions were merged. Analytical analysis focused on the process, structure and missed opportunities of family conferences.

Table 1 Characteristics of the studied population

Variables	N (15)
Gender, n	
Females	7
Male	8
Age (Years)[1]	43(25–60)
Level of education	
Primary	0
Secondary	2
College	2
University	9
Religion	
Catholics	8
Protestants	6
Moslems	1

[1]Median (range)

3.3 Trustworthiness

Credibility was established by the first author conducting, transcribing and analysing the data [25]. The coauthor, AF, a nurse with vast experience in qualitative research, double-checked the content of the generated categories to confirm their relevance. The confirmability of the study was further ensured by the findings, which were supported by illuminative quotations from participants. Dependability was enhanced by a thick description of the research process [24;22] Table 1.

3.4 Findings

An example showing some data of content analysis as explained by Krippendorff (2004) [26]

Question 1. How were you prepared for the conference?			
Quotations from participants	code	subcategory	Analytical category
"The health worker called me and my children. He told us that our patient got a problem of the head and has a clot in the brain, she repeats blood clot again. They operated him and after operating him that's when they brought him to ICU and started treating him even at this time they are still treating. But I haven't understood the condition I see he's not seeing, and I have not understood if he will see again. They said we give this time because the head takes time to recover. After spending two three days that's when the clinician told us about the patient's condition." F1	Verbal call…, Informed about patient's condition after 2–3 days…, ongoing treatment….	**Call for unplanned meeting**	Accidental process
"There was no preparation for the meeting because it was an urgent meeting which did not need any preparation because they invited us urgently, and we discussed the issues concerning the patient." M7	Urgent Meeting…, No Preparation	Abrupt verbal call	
Question 2: **What content/topic was discussed?**			
"The topics discussed were feeding patient on time, cleanness, urine monitoring, giving the oral medication on time, cleaning the environment to prevent infections, not bringing visitors that are likely to bring more diseases like COVID to the patient, not to charge phones from the room, not eating from the room." F1	Patient care routines, …. Infection prevention, …. Visitor restrictions	**Assisted Activities of daily living**	**Patients' values, care, & management**
"The doctor told us what was happening to our patient…They told us she has a lot of blood in the brain that's why she can't move her leg nor arm and even if she was to go for surgery the chances that she would survive are few. Her kidneys have stopped working that's why they put a tube for her in the nose to remove the things we have been feeding her. The patient will not be given more medication apart from the one we had already bought…. The patient is weak and cannot be operated and her pressure is very low."(F4)	patient condition, medical options,	Case management	
Question 3: Where did the family meeting take place?			
"The meeting took place in ICU, we were standing outside the patient room in the corridor." F1	ICU corridor, standing.	**corridor**	**Unfamiliar place**
"in the centre of ICU, I was given a chair, the person leading the conference also sat and there was a nurse leaning against the station" M4	ICU centre …	In the ICU	
"it happened at the entrance of ICU. We were standing." F6	Entrance of ICU,	Entrance of ICU	
Question 4: **Who initiated the conversation?**			
The doctor initiated the conversation	Doctor	Clinician	**ICU clinician**
"We may not be able to tell you the ranks they have but while in the conference there was a doctor and a surgeon who witnessed the talk."(M3)	Doctor, Surgeon…	Clinician	

Question 5: Who was present during these family conferences?			
"There were two doctors and two student nurses, five family members." F3	…Doctors, Student nurses, Family members.	family members and clinicians	**Uninte-grated disciplinary team**
"There were 4 of us in this conference, the doctor, the nurse that was helping him, my mum and me." M2	.Doctor, Nurse, Family members…	Clinicians & Family members	
Question 6: Are there any questions you would have wanted the clinicians to answer but they were not answered? (Missed opportunities)			
"There are many questions I would have wanted to ask the clinicians on the way forward and if there are other places to take our patient to recover from." F1	Unanswered questions, … Alternative health facility	Information deficit, yearning for alternative care	**Unmet needs/ Missed opportunity**
"Because some speak English, and I am unable to ask them questions but if the clinicians speak Runyankole then I can communicate with them well." F4	Language barrier, Communication preference	Desire to ask questions but has communication barrier	
Question 7: What would you wish the clinicians to do better during family conferences in ICU?			
"The clinicians told me most of the things but because of the too much stress I had, I tend not to capture most of the things so as a health worker I would like him to handle me well because we as caretakers we have a lot of stress so they should not shout at us when we forget what they tell us." F1	Perceived stressful environment	**Perceived stress**	**Lack of assurance, comfort and support**
The conference should be done on the bedside, they should not fear to talk about death, they talk while hesitating. They should try to simplify the words as much as possible since not all people are health workers so that it helps with the acceptance for the ICU care. M2	Being suspicious with the environment	Uncertain situation	
. They did well and explained everything to me. F2	Explained everything	Satisfied	**Satisfactory clinician-family communication**
Nothing, we were satisfied with everything they told us because we know how our patient has been(F3)	Satisfied with everything	Satisfied	

The generated categories were dichotomized into two sections. The first section explored the factors related to the process linked to the readiness, structure, and alignment of family conferences. The process and structure formed the following categories:

Category 1: Accidental meetings emerged from abrupt verbal calls from the clinician for the meeting, as evidenced by some selected quotations from the participants.

. …"There was no preparation for the meeting because it was an urgent meeting, and we discussed the issues concerning the patient…" M7.
"Today, morning the doctor called me and sent me to get the family members who are closely attached to the patient…" F3.

Category 2: unfamiliar places. This was part of the process as a means of meeting venues for the conferences; however, diverse locations within the ICU were reported, such as in the corridor, patient rooms, and reception/nurses' stations, including at the entrance of the unit. Examples are as follows:

…"The meeting took place in the ICU; we were standing outside the patient room in the corridor." F1……." We sat in the patient room next to our patient." F3…. …. "The conference took place at the reception." M2…."….it happened at the entrance of ICU. We were standing." F6….

Category 3: The third category was the reflection of the structure of the procedure where the content of family conferences explored patients' values, care and treatment preferences, which were key issues for discussion: These points focused on **assisted** activities of daily living (AADLs) which were developed from specific guidance of basic care to promote hygiene, nutrition, and medication to maintain the dignity of the patient:

"The topics discussed were feeding patient on time, cleaning, urine monitoring, giving the oral medication on time, cleaning the environment to prevent infections, not bringing visitors that are likely to bring more diseases like COVID to the patient, not to charge phones from the room, not eating from the room." F3.... the doctor told us how our patient was taken to theatre, what they did. They removed the uterus because it was cancerous and did not want the cancer to spread to other parts of the bodyM2." "... talked about her disease, how to take care of her and how to feed her. Cooperation between family members to be able to take care of older patients who are above 80 years of age. They taught us how to feed the patient.... cause of our patient's condition was because of having diabetes and pressure for a long time that were not treated well." F5.

Category 4: Unintegrated interdisciplinary teams form the conference team structure

This was a challenge for the family members identifying the role and the clinician on the conference team. However, these were able to be recognized:

..."the Senior House Officer (doctor) was chairing the conference" M4....."A nurse called us and started the conversation "F1.....". We may not be able to tell you the ranks they have, but while in the conference, there was a doctor and a surgeon who witnessed the talk..." M3.

Category 5: satisfactory communication

The content of the conferences from the family members' perspective was as follows:

.... "Doctors answer all the questions." M2..... "We didn't have questions to ask the health workers because everything was well explained, and we were satisfied." F3... asked all the questions and understood and agreed to the issues we had in that meeting." M1 "Doctors answer all the questions." M2"no, I actually had no questions, they explained to me things that I understood, and they were clear" M4...." Everything went well." F7.

3.5 The second part explored the missed opportunities

Under this category, there were other unmet needs, such as a lack of assurance and comfort for family members, perceived insufficient communication, and other uncertain experiences.

Some participants showed signs of stress, yearning for comfort and assurance. They emphasized the need for effective communication strategies, especially when families are under stress related to anxiety and fear for their loved one's unknown outcomes.

"The clinicians told me most of the things but because of the too much stress I had; I tend not to capture most of the things so as a health worker I would like him to

handle me well because we as caretakers we have a lot of stress.... are many questions I would have wanted to ask the clinicians on the way forward and if there are other places to take our patient to recover from F1'.

3.6 Insufficient communication

Participants reported having insufficient information about patients' prognoses; some family members were not sure who was conducting the family conference, and they needed more clarity about certain issues that were discussed.

.... "They should not fear talking about death; they talk while hesitating... M2"There were no questions, but instead, we needed more explanations to be able to understand some things." F5.

Subcategory 3: **Unanswered questions**

Some participants noted having unanswered questions during family conferences. This highlights potential gaps in communication or understanding that could affect the family's ability to grasp crucial information about the patient's condition and care plan.

"There are many questions I would have wanted to ask the clinicians on the way forward and if there are other places to take our patient to recover from..." F1.

3.7 Uncertain experiences

Most participants were not sure about what was happening during the family conferences. Some noted that they got to know it was a family conference when they were signing family conference records after the conference.

Hmmm, I don't know how it goes with other people" ...M4 "Since it was the first time for me to come to the ICU, I don't know much of what happens" F6... I have noted that responsiveness can be variable. Sometimes, I receive prompt assistance, but other times, there's a delay....F1". Well, it's good to always disclose information the previous day so that they can call someone who is far to be able to make it since some people are important in making critical decisions about the patient... M3.

4 Discussion

This study reports unique findings from an area of low-income countries that focus on the process, structure and missed opportunities of family conferences from the perspective of family members of patients in ICU in one of the RRH of western Uganda. Little has been documented on this topic, so comparisons of our findings might be difficult with respect to the characteristics of the participants. The dominance of males in the study might be attributed to the fact that females could not manage the task of caring for acutely ill patients in the ICU. This study affirms the caring strain, stress and anxiety they have on family members, as some of these females cried during interviews. The data collection procedures involved counselling sessions with the affected participants between the conferences. A previous study in Uganda reported that decision-making for administering life-sustaining treatment in the ICU is determined by many factors, such as the financial capacity of the patient's family, the resource capacity of the hospital, the status of the clinical presentation of the patient, and the fear of litigation [26]. These observations might have increased the burden on these participants. However, the

patients in the ICU had family members who had a fairly good level of education; hence, their ability to remain in the unit was determined by the family members' stable income.

4.1 The process in this case considered preparation, content, and structure as key elements of the family conferences

Notably, family conferences followed abruptly without proper planning. This act is contrary to the family meeting planner because family conferences require identification and notification of the appropriate participants to ensure that all the members of the respective interdisciplinary team are present [5, 6, 19]. Furthermore, preparation for a family meeting requires preliminary conversations and data collection about family members' expectations and understanding of patients' individual values and preferences [27]. It is recommended that the ICU team identify the wishes of the patient prior to family conferences [7].

Owing to uncoordinated processes, the ICU lacked a designated area for holding family conferences or seats for the participants to make them comfortable, yet dedicated private areas that are suitable for holding such critical conversations are recommended [7, 20, 31]. Even though this could seem to be a small matter, the effect on families and the difficulty of setting up such spaces are both significant in facilitating effective communication [5]. The absence of an appropriate space for family meetings has been associated with increased levels of anxiety and depression among ICU families [28]. Furthermore, families have occasionally expressed concern that patients who seem unconscious can overhear inappropriate conversations at the bedside while being unable to meaningfully engage or show awareness [29]. This study explored undesired practices related to inadequate preparations at family conferences to generate many unmet expectations of family members.

4.1.1 Missing opportunities during family conferences

This study defines missed opportunities as potential benefits that could have been achieved but were missed or not pursued during family conferences. These are things that were supposed to be done but were not done, and this caused the family members and patients to miss out on emotional, spiritual and physical care. Unintegrated interdisciplinary teams and the unmet needs of patients' family members in the intensive care unit are the two main points pertaining to missed opportunities that were identified.

According to family meeting guidelines, family meetings need to be conducted in the presence of other allied professionals, such as a psychologist, a social worker, or a priest [6, 19]; in this study, the conferences lacked the input of the social worker, pastoral team, psychologist and others during the conferences to provide family-centred care. The benefit of family-centred care is the ability to establish and promote patients' welfare [13]. Although family members received counselling, most participants wished for more support, comfort, access to information, and assurance from clinicians. It is argued that in this study, family members' expectations were not fully met because of the lack of an interdisciplinary team to address physical, psychological, sociological and spiritual needs.

Studies have shown that physicians often miss the opportunity to provide support to family members because they lack good communication skills and struggle to handle their emotions at the same time as family members do [2, 30]. Extended bereavement

and other forms of psychological suffering are more common among family members of patients who die in the ICU when there is insufficient team assistance [31]. For this reason, they need physical, emotional and spiritual support from a multidisciplinary team. Families expect honest, intelligible, and timely information [32]; appreciate empathy, comfort, proximity, and reassurance; and feel that clinicians share in their hopes [33].

4.1.2 Insufficient communication

This study explored the uncertain experiences of family members during conferences.

Some members expressed perceived satisfactory communication, whereas others did not. Insufficient communication was discovered to address patients' values and treatment preferences to inform medical decisions. It was reported in this study that family members had unanswered questions during family conferences. There is always inadequate time spent listening and debating across clinicians; therefore, meetings are held only when physicians believe it is necessary [2].

Because of poor communication in the ICU, only half of family members understand the information delivered [34]. In this study, some participants also reported that they were unable to grasp much from the meetings because of the stress related to the burden of caring for critically ill patients [7], coupled with the language barrier. The main communication needs are clarity, jargon-free information about the patient, and patient prognosis, irrespective of who provides this information [5]. Since families may have diverse emotional reactions to these conversations, it may be challenging for clinicians to communicate with them. The **VALUE** metric [11] has been shown to be effective and includes **valuing** what families communicate (V), **acknowledging** their emotions with empathy (A), **listening** carefully (L), **understanding** who the patient is as a person by asking open-ended questions (U), and **eliciting** questions (E). It has been reported that during the ICU stay, families experience considerable stress, including symptoms of anxiety and depression, and these symptoms are worsened by poor communication [35].

4.1.3 Study limitations

There are limitations to our study since it is a baseline descriptive study on communication processes in the ICU and the first of its kind in Uganda. The interview guide was formulated using international guidelines on effective communication, and most of the studies addressed end-of-life communication in the ICU. However, effective communication is key in the ICU during family conferences. This study explored the process, structure and missed opportunities of which data were collected from the primary source of participants. Therefore, it is argued that the study sample is representative of the primary source of information. The findings of this study can be transferable to other settings since a thick description of the characteristics of the participants can be audited. Furthermore, the intention of this study was to generate primary information from family members' perspective, which is a strength.

5 Conclusion

Family conferences lacked adequate preparedness, and family members' emotions were missed in the care. However, some cases of perceived satisfaction in communication were ported.

5.1 Recommendations

- This study recommends that family conferencing protocols be initiated and followed to enhance effective communication skills that align with family members' emotions.
- The structure of family conferences should consider interdisciplinary collaboration so that the welfare of both patients and family members can be addressed.

Abbreviations

ICU Intensive care unit
RRH Regional referral hospital

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1007/s44250-025-00328-1.

Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

Acknowledgements
Acknowledgement goes to the study participants and Mbarara Regional Referral Hospital Administration for granting permission for this study.

Author contributions
Bothe authors were involved in the study design, data analysis and manuscript preparation.AAM was responsible for data collection, FA provided the overall supervision, technical guidance with research ethics, both were involved in report writing and approved the final manuscript and BT provided ethical guidence.

Funding
This work was supported by the grant from the Massachusetts General Hospital Centre for Global Health's project entitled 'First Mile: Powering the Academic Medical Centre to Delivery Healthcare in the Community in Uganda' the Wyss Medical Foundation.

Data availability
Responses from Participants are in safe custody for verification if needed.

Declarations

Ethics approval
was obtained from the Institutional Research Ethical Committee (IREC) of the university in the region (MUST- REC), and the approval number was MUST-2023–1109. The research procedures were conducted in accordance with the Helsinki Declaration [25], and all the participants received verbal and written information ensuring that they understood the study goals and the role of the investigators. The participants were informed about their voluntary participation and their right to end their contribution without any implications if there was a need to do so.

Competing interests
The authors declare no competing interests.

Received: 18 December 2024 / Accepted: 24 November 2025
Published online: 21 January 2026

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