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Comparison of Intensive Care Unit Nurses' and Family Members' Priorities of Patient and Family-centered Care in Ghana

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Purpose : Life-threatening illnesses represent a crisis for individual patients and their families. Little has been made to understand the priorities or perspectives in developing a care plan. This results in poor outcomes, and patients and families return home without being satisfied with the care provided. This study aimed to address nurses' and families' care priorities on patient and family-centered care principles and compare those priorities. **Methods :** A quantitative comparative descriptive research was conducted. The data were part of a study that was carried out to elicit and compare nurses' and families' perceptions of complying with patient and family-centered care (PFCC) principles in intensive care units (ICU) in Ghana. The respondents were ICU nurses (n=123) and family members of hospitalized patients in the ICU (n=111). The tool for the study was a "modernized version of a hospital self-assessment inventory on PFCC," and data analyses were performed using SPSS version 20.0. **Results :** Nurses and families differed significantly in their priorities of care based on the principles of PFCC. The means and *p*-values were significantly different for the definition, pattern of care and access to information/education, and the overall total scores of the patient and family-centered care principles (PFCCP) **Conclusion :** To render care that aligns with the care priority of families and patients in the ICU, nurses must plan care in consultation with their families.

Key words : Intensive care unit, Nurse, Family, Care priority, Patient-centered care

I. Introduction

Life-threatening illness represents a crisis for individual patients and a burden for their family members [1,2]. The family members become an integral part of decision-making in the care of the patient. The reality is that patients and families are often not included in important discussions and are left without any information on care management, treatment options, and diagnostics [3]. Nurses and other healthcare personnel misunderstand patient and family engagement to be a unilateral communication where patients and families fulfill their requests [4]. Little efforts are made to understand the priorities or perspectives of patients and families in developing a plan of care [5]. To im-

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prove patient outcomes and experience, critical care providers must prioritize care that aligns with patient and family healthcare goals and preferences [6]. There is also a need to leverage team function to include patient family members or loved ones [7].

Patient and family-centered care accepts and coordinates a patient's values, inclinations, and objectives into clinical decision-making and outcome assessments [8]. It seeks to move away from the thought that patients and their families are passive receivers of care to make them an active part of the care process [9]. Healthcare professionals' view families as active participants in planning care and the ensuring well-being of patients [10]. As a result, the patients and their families are empowered to take responsibility for their care decisions [11]. According to the Institute for Patient and Family-Centered Care, patient and family-entered care operates on four fundamental concepts: dignity and respect, information-sharing, participation, and collaboration [12]. These core concepts stipulate that there is a better health care outcome when the perspectives and beliefs of patients and their families are recognized, appropriate information rendered, and there is an encouragement for them to collaborate and participate in decision making [13].

Understanding patients' and families' priorities of care can be achieved through establishing patient and family-centered care (PFCC) and other evidence-based care programs by healthcare providers to measure and improve the patient experience. Paying greater attention to families' needs and preferences have been found to decrease adverse events during hospitalization [14,15]. For example, errors in administration of patient medications and or a delay in diagnosis and treatment [16]. There is also evidence that patient and family-entered care contributed to patients' and family members' reduction in stress, anxiety, depression, and improved care satisfaction and relationship with health care professionals [17]. In a secondary analysis of the rating by NHS (National Health Service), UK (United Kingdom), patients' experience, being treated with dignity and respect, and involving patients in their care receive the highest rating from patients [18].

Rendering care based on patient and families' priorities could improve satisfaction and reduce healthcare costs. Patients' annual health care expenditure with less client-centered care is about 50% higher than those where their values, beliefs, and objectives are accepted and incorporated into clinical decision-making [19]. Patients and family membmers with the right information and education will prioritize care decisions and may not opt for certain procedures [20,21]. Yet, little is known about what health care professionals perceive about clients' choices. For example, in a study at Emory hospital in the United States (2010), it was reported that patients, families, and healthcare providers differed in their views of health care priorities and the importance of patient and family-centered care [22]. Understanding the priorities of care on the principles of patient and family-centered care in a country like Ghana, which enjoys a strong extended family system, is generally lacking. Hence, healthcare professionals' ability to give care based on Ghanaian values remains a big question. This could be understood by evaluating what the nurse and families perceive to be patient priorities of patient and family-centered care principles. Hence, this study aimed to describe and compare nurses' care priorities and families' priorities in terms of patient and family-centered care principles (PFCCP).

Ⅱ. Methods

1. Study Design, Setting, and Participants

This descriptive cross-sectional study used a quantitative comparative descriptive approach. Using a survey, data were collected from study participants in a study which were conducted in the intensive unites of Cape Coast Teaching Hospital, Komfo Anokye Teaching Hospital, Tamale Teaching Hospital, and Bolgatanga Regional Hospital in Ghana.

Inclusion criteria for study participants were as follows. In the nurse group, study participants had to be registered general nurses and critical care nurses working in the intensive care units (ICU) for at least six (6) months. This was to ensure that a participating nurse has some experience in the care of ICU patient. That is, registered nurses either with a nursing diploma or bachelor's degree in general nursing or with an advanced diploma in critical care nursing with more than six months of working experience in the ICU were included in the study. In the family member group, study participants need to be family members of ICU patients who have stayed with the patient for 48 hours or more. In addition, they had to be a person identified to make decision on behalf of the patient according to ward protocols.

2. Sample size determination

A statistical priori power analysis was to calculate the sample size. G*power (version 3.1.9.7) software guided the sample calculation. Considering two groups for two-way ANOVA, a significance level of 0.05, power of 80% by applying a medium effect size of 0.3 based on previous studies, the samples size was 139 for each group. And considering an assumed 10% non-response 10%, a sample size of 150 was required for each group.

3. Measures

The instrument used for data collection was the modified version of the Hospital Self- Assessment Inventory Questionnaire (HSAIQ) by Woodruff Health Sciences Center, Emory, USA (United States of America) [22]. The HSAIQ was originally developed by the Institute for Family-Centered Care (https://www.aha.org/system/files/2018-02/assessment.pdf) [23]. In addition, we used six questions on information/education from the original HSAIQ. Thus, a total of 32 items was used to measure three sections of PFCCP. The first section of PFCCP is related to the definitions while the second section include patterns of care. Lastly, the third section of PFCCP consists of participants' access to information and education. Respondents were asked to rate the importance (in terms of priority) of the principles of PFCCP on a Likert scale. The cumulative sum of the responses used to interpret ICU nurses and families' priorities of PFCCP. That will be categorized as; 32-73 low, 74-115 is moderate and 〉115 as high. A demographic information form consisted of 7 questions nurses and 7 questions for patient families.

The face validity and consistency of PFCCP were previously assessed by five nursing faculty members and reported as a validated and widely used tool [22]. For this study, five ICU nurses in Ghana completed PFCCP and ascertained that the tool was applicable in the Ghanaian cultural context. In addition, the reliability was confirmed with a sample of ten ICU nurses and ten family members of hospitalized ICU patients in Ghana. Internal consistency reliability of PFCCP for nurses was .93 while the subscales were found to be from

.83 to .93 using the Cronbach's Alpha. That for families were .94 for internal consistency reliability with the subscales ranging from .77 to .94. In this study, the Cronbach's alphas of PFCCP and the subscales ranged from .70 to .90.

4. Data Collection Procedure

Upon the approval of institutional review board, the period of data collection was between July 2017 and November 2017. Study participants were recruited from the intensive unites of four hospitals in Ghana. The intensive care units admitted children and adults with medical, trauma, and surgical conditions. In addition, critical cases associated complications of pregnancy are admitted to the maternal ICU. A critical care nurse was identified in each of the participating hospitals to assist in data collection. The purpose of the study and the content of the questionnaire was explained to these nurses. The names of respondents and hospitals were excluded from the tool to ensure confidentiality. The questionnaires were distributed to nurses at various shifts of the day, and they were given time to answer and return them to the various identified nurses. The families were contacted the convenient time and the purpose of the study explained to them. After they concerted to participate, the questionnaire was administered, and they were also given time to answer. Participants In the group of ICU nurses, out of 144 potential participants, 123 nurses returned their questionnaires, indicating a response rate of 85.0%. Regarding family members, 111 out of 150 family mem-

Table1.Demographic Characteristics

Variables	Nurse (n=123) frequency (%)	Family members (n=111) frequency (%)
Age (mean±SD)	29.0±3.4	31.1±6.2
Gender		
Female	74 (60.2)	50 (40.7)
Male	49 (39.8)	61 (49.6)
Marital status		
Married	60 (48.8)	57 (46.3)
Single	63 (51.2)	54 (43.9)
Education		
Diploma	55(44.7)	-
Post diploma in critical care	29 (23.6)	-
BSc nursing	39 (31.7)	-
Primary/JHS	-	6 (4.9)
SHS/technical	-	56 (50.5)
Tertiary	-	49 (44.1)
Years of working experience (mean±SD)	4.5±2.6	-
Relationship		
Parent	-	15 (13.5)
Siblings	-	53 (47.7)
Spouse	-	23 (20.7)
Others	-	20 (18.0)

BSc=Bachelor of science; JHS=Junior high school; SHS=Senior high school; SD=Standard deviation

Table 2. PFCC Items Ranking for Nurses and Families

PFCC items	Nurses (n=123)		Families (n=111)		*p* value
	Mean±SD	Rank	Mean±SD	Rank	
Convey respect and preserve the dignity of each patient and family?	4.72±0.45	1	4.00±0.73	1	<.001
Acknowledge the individuality, culture, capacity, and abilities of each patient and family?	4.60±0.49	2	3.36±0.82	6	<.001
Show the importance of families to the care and comfort of patients?	4.58±0.65	3	3.59±0.85	3	<.001
Patients and families have help with transitions in care?	4.30±0.61	4	3.99±0.76	2	0.003
Staff acknowledge the individuality, culture, capacity, and abilities of each patient and family?	4.22±0.67	5	3.29±0.67	7	<.001
Partner with patients and families at all levels of care?	3.98±0.89	6	3.20±0.88	9	<.001
Patients and families are asked about their observations, goals, and priorities in the ICU ward.	3.64±0.75	7	3.47±3.02	5	0.250
Support a broad definition of family?	3.62±0.57	8	3.09±0.85	13	<.001
Patients and families are encouraged to participate in discharge planning.	3.59±0.76	9	3.49±1.04	4	0.199
Opportunities to learn and practice caregiving are provided to patients and families prior to discharge.	3.54±0.83	10	3.10±0.65	12	<.001
Policies and practices encourage patient and family involvement in decision-making regarding their health care.	3.37±0.68	12	3.23±0.72	8	0.064
There is continual, open, and honest communication among patients, families, and staff.	3.36±0.78	13	3.04±0.78	14	<.001
Each patient has a single, identified coordinator of care.	2.89±0.78	14	2.59±0.91	19	0.005
Family members are not viewed as visitors but are always welcome to be with the patient, in accordance with patient preference.	2.74±0.74	15	2.46±0.70	22	0.006
Staff collaborates with the patient and family to manage pain.	2.72±0.84	16	2.52±0.83	21	0.035
During doctor's visits, if the patient wishes, families can participate in doctor's discussions.	2.70±0.80	17	2.96±0.82	15	0.995
Families' and patient choices about whether families may remain with the patient are respected and supported by staff during examinations.	2.65±0.79	18	2.57±0.80	20	0.221
Patients and families are viewed as members of the health care team.	2.62±0.89	19	2.13±0.89	28	<.001
A range of informational and educational programs and materials are available to patients and families.	2.55±0.77	20	2.92±0.76	16	0.999
Patients and families have the opportunity to participate in interdisciplinary meetings to plan care.	2.5±0.78	21	2.12±1.06	27	0.003
Patients and families have telephone/email access to clinicians.	2.43±0.85	22	2.82±1.19	17	0.998
You feel that there is encouragement for communication among patients, families and staff.	2.33±0.76	23	3.19±0.80	10	1.000
Families' and patient choices about whether or not families may remain with the patient are respected and supported by staff during therapy/treatment.	2.24±0.91	24	2.23±0.84	25	0.183
During doctor's visits, if the patient wishes, families can remain with the patient.	2.24±0.66	25	2.40±0.72	23	0.939

There is open disclosure with the patient and family regarding all errors (whether or not there is a bad outcome) in written policy.	2.06±0.73	26	1.77±0.66	30	<.001
Families can remain with the patient during nurse change of shift, in accordance with patient preference.	2.00±0.78	27	2.21±0.62	26	0.988
Trained interpreters are available.	1.98±0.96	28	2.76±0.94	18	1.000
There is open disclosure with the patient and family regarding all errors (whether or not there is a bad outcome) in actual practice.	1.69±0.70	29	2.02±0.90	29	0.995
Written information is provided in the primary languages of patients and families.	1.50±0.62	30	2.23±1.38	24	1.000
Families' and patient choices about whether or not families may remain with the patient are respected and supported by staff during Painful/invasive procedures.	1.45±0.68	31	1.53±0.66	31	0.819
Families' and patient choices about whether or not families may remain with the patient are respected and supported by staff during resuscitations.	1.43±0.75	32	1.37±0.62	32	0.254

ICU=Intensive care unit; PFCC=Patient and family-centered care; SD=Standard deviation

bers participated in the study, indicating a response rate of 74.0%.

5. Data Analysis

The data were analyzed using Statistical Package for the Social Sciences (SPSS) Version 20. Descriptive statistics, including frequency, mean and standard deviation, were used to describe the characteristics of study participants as well as the items of PFCCP. The comparison between nurse and family member groups were done by t-test.

Ⅲ. Results

The demographic characteristics of nurses and patient families were presented in Table 1. In the group of ICU nurses, the mean±SD (standard deviation) of age was 29.0±3.4. Most of the respondents were females (60.2%) while 51.2% were unmarried. For education, nurses either has diploma in nursing (44.7%) or post-diploma in critical care (23.6%). The mean±SD of working experience in the ICU was 4.5±2.6 years.

Among the family members, more than half of respondents were males (49.6%) while 46.3% were married. Family members had mean±SD aged of 25-29, 31.1±6.2. Approximately, a half of family members were senior high school graduates (50.5%). Regarding participants' relationship to the patient, 47.7% were siblings.

1. Rank Order of Care Priorities

Care priorities by both ICU nurses and family members were revealed in the ranked orders of the items of PFCCP. The highest priority was "convey respect and preserve the dignity of each patient and family?" in both nurse (mean= 4.72, SD=0.45) and family member (mean=4.00, SD=0.73) respondents. Furthermore, "showing the importance of families to the care and comfort of patients" was ranked among the third highest care priorities in both nurse (mean= 4.58, SD=0.65) and family member (mean=3.59, SD=0.85) groups, indicating both nurses and family member respondents considered it as important. Interestingly, the second highest ranked priority differed between the two groups. It was "acknowledge the individuality, culture, capacity, and abilities of each patient and fam-

ily?" for the nurse group (mean=4.60, SD=0.49) while "patients and families have help with transitions in care?" for the family member group (mean=3.99, SD=0.76). Additional differences in care priorities between nurses and family members were detailed in in Table 2.

2. Comparisons of Nurses' and Families' PFCCP

Table 3 shows the comparisons of the scores of PFCCP between the two groups. There were significant differences in the total mean score (p<.001) as well as the subscales' mean scores. In particular, the nurse group had significantly a higher mean score in the subscales of definition (p<.001) and pattern of care (p<.01) than family members. However, in the subscale of access to information and education, the family member group was significantly higher than the nurse group (p<.001).

Ⅳ. Discussion

The findings of this study showed that nurses and families had different priorities to their needs, indicating that nurses may provide care for the ICU patients without prioritizing patient families. Thus, it may result in family members not being satisfied with the nursing care in the critical care unit. Nurses play a major role in ensuring that patients and family members have better outcomes and positive experiences during their stay in the ICU [22]. It is vital for nurses to plan care which aligns with patient and family healthcare goals and preferences [6].

Regarding patient and family-centered care, this study revealed the importance of conveying respect and preserving the dignity of each pa-

Table 3. PFCC's Subscales and Total Scores in the Two Groups

PFCC	Nurse (n=123)	Family members (n=111)	t	*p*-value
Total score (mean±SD)	93.70 (7.50)	88.70 (12.60)	7.59	< .001
32–73 (low)	0	9 (7.3)		
74–115 (moderate)	123 (100.0)	98 (79.7)		
> 115 (high)	0	6(13.0)		
Subscale scores (mean±SD)				
Definition	21.5±1.6	17.2±2.8	14.59	< .001
5–14 (low)	–	23 (18.7)		
15–19 (moderate)	12 (9.8)	66 (53.7)		
20–25 (high)	111 (90.2)	34 (27.6)		
Pattern of care	57.0±5.6	54.5±7.2	3.04	< .01
21–51 (low)	22 (17.9)	46 (37.4)		
52–81 (moderate)	101 (82.1)	65 (52.8)		
> 81 (high)	–	12 (9.6)		
Information/education	15.2±2.4	17.2±2.8	−5.88	< .001
6–14 (low)	43 (35.0)	42 (34.1)		
15–23 (moderate)	80 (65.0)	61 (49.6)		
> 23 (high)	–	20 (16.3)		

PFCC=Patient and family-centered care; SD=Standard deviation

tient and family. It was one of the definition items of PFCCP while being the highest-ranked priority for the nurses and family member groups in this study. It emphasizes the significance of showing respect to patients' human dignity during care, which entails kindness, empathy and compassion [24]. The importance of preserving the respect and dignity of patients and families has been stressed in other studies [25-27]. Respect and dignity are exhibited by recognizing equal human rights, considering the individuality of each patient, while considering patients' internal values [28]. The other highest-ranked priorities on the subscale of definition in PFCCP were acknowledging the individuality, culture, capacity, and abilities of each patient and family and showing the importance of families to the care and comfort of patients. The two items ranked either second or fourth in both groups.

In addition, nurses placed the importance in helping patients and family members in transitions of care and acknowledging the individuality, culture, capacity, and abilities of each patient and family members which were found to be ranked as the fourth and fifth priorities. Both items belonged to the patterns of care of PFCCP. Noticeably, Family members also placed a high priority in helping patients and families in transitions of care first under patterns of care, being encouraged to participate in discharge planning and being asked about their observations, goals, and priorities in the ICU as the second, fourth and fifth ranked order. This result shows that nurses and families have different priorities on the patterns of care in terms of ranking. Evidence shows that family members prioritize the patterns of care more than nurses [22].

Both nurses and families ranked policies and practices that encourage patient and family involvement in decision making regarding their health care, continual, open, and honest communication among patients, families, and staff, and a range of informational and educational programs and materials available to patients and families in order of priority. However, families ranked the items higher than nurses. This outcome may imply that families attached much importance to information and education to PFCCP principles in the ICU. That is, they want timely, clear, and understandable information and education about their patient's condition [29,30].

In comparison, the top most priority for both nurses and families were respect and dignity. This feature shows the importance of respect and dignity to health care, particularly in the ICU, where there is increased attention to improving patient and family members' experiences of care [31]. On the second most ranked priority, nurses and families differ in their perceptions. While acknowledging each patient and family's individuality, culture, capacity, and abilities was the second most important to nurses, families want help with transitions in care (e.g., unit to unit, hospital to other facilities, hospital to home, and between outpatient and inpatient). The nurse must understand that care transition across hospitals, other institutional settings, and homes are the vulnerable exchange of information that can contribute to adverse events, unmet needs, and low satisfaction with care in the ICU [32]. Both groups rate the importance of families to the care and comfort of patients in the third position. This rank implies nurses and families prioritized families in the care of the ICU patient. Therefore, the nurse should maintain continuous contact with the families as they play an important role in reducing stress in the ICU patient [33]. Also, when focusing on goals for patient recovery, the families have a significant

role in planning an appropriate care plan for the patient [34]. Nurses and families differ on the tenth most ranked priority on the principles of PFCC. For nurses, allowing families to learn and practice care given to patients before discharge was a priority. The ICU nurse is thus concerned with discharge planning, which begins at the time of admission. The families were more concerned about the current condition of the patient. That is, they prioritized encouragement for communication among patients, family member and staff. This outcome supported a report by Brain Boyle in his study [34]. A family member stated that the importance of communication was to help prepare for what was around the corner and build a foundation of trust and friendship in an unfamiliar environment [34].

Furthermore, care priorities between nurses and families differed based on the findings in which the means and p values are significantly different for definition, the pattern of care and access to information/education, and the overall total scores of PFCCP. This was similar to the finding of study conducted at Emory Hospital in 2010 in the USA [22]. It is important to note that family members always want to be abreast of patient treatment such as what is done, the type of treatment and reason for the treatment [35]. Thus, it was not surprising families prioritized access to information and education more than nurses. To render care that aligns with the priorities of families and patients in the ICU, it is critical for nurses to plan care in consultation with the families. Further research is needed on the development and evaluation of interventions to meet families' priorities and needs.

Limitations

The generalization of the findings in this study may be limited due to convenience sampling and recruitment. In addition, Individual ICU nurses and family members in Ghana have different sociodemographic and cultural characteristics along with their experience of care in the ICU. This aspect may have impacted how care is prioritized by either the nurses or the patient family.

V. Conclusion

Family members are an integral part of decision-making in the care of patients. This study revealed that nurses and families differ significantly on their priorities of care. It is critical for nurses to plan care in consultation with family members to render care that aligns with the care priorities of families and patients in the ICU. Families need to be provided with information and advice on evidence-based interventions and treatment options with possible outcomes [36].

To promote PFCCP in the ICU, it is necessary to review policies and provision of nursing care services that prioritized family needs of critically ill patients. Further research on PFCCP need to be conducted in different settings and countries with different demographics to have a broader perspective.

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