

#### CHARACTERISTICS, ROLES AND FACTORS ASSOCIATED WITH FAMILY INVOLVEMENT IN CARE OF HOSPITALIZED PATIENTS IN A LOWER-MIDDLE INCOME COUNTRY'S UNIVERSITY HOSPITAL: AN OBSERVATIONAL STUDY

Zohra Bahmane\*<sup>1</sup>, Jihane Belayachi<sup>1</sup>, Nawal Meknassi<sup>1</sup>, Cortney Hughes Rinker<sup>2</sup>, Redouane Abouqal<sup>1,3</sup>, Naoufel Madani<sup>1</sup>

1. Acute Assessment Unit, Ibn Sina University Hospital, Mohammed V University, Rabat, Morocco.

**2**. Department of Sociology and Anthropology George Mason University Fairfax, USA. **3**. Laboratory of Biostatistics, Clinical and Epidemiological Research, Faculty of Medicine and Pharmacy, Mohammed V University, Rabat, Morocco.

**Corresponding address: Zohra Bahmane, Affiliation:** Acute Assessment Unit, Ibn Sina University Hospital, Mohammed V University, Rabat, Morocco. E- mail: <u>bahmanezohra@gmail.com</u>.

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#### Abstract

Background: The concept of patient- and family-centered care emphasizes the importance of including family members in the care of their hospitalized loved ones. Limited data are available on family involvement in care in non-Western countries. Objective: This study aimed to provide a comprehensive description of the roles of family members in care participation and identify patient-related factors associated with the presence of family members. Methods: A monocentric prospective cohort study was conducted in the Acute Assessment Unit of the Ibn Sina University Hospital in Rabat, Morocco, involving 370 consecutive patients and their 793 family members. Patients' characteristics, information regarding their family members, and details about the care they provided to their relatives were collected. Univariate and multivariate analyses were performed to explore the association between patient variables and the continuous presence of family members, defined as being with their loved ones during the day and then spending the night. **Results:** 30% of patients were over 65 years of age, and 57.3% were male. Nearly all patients (97.6%) were accompanied by at least one family member, with 52.4% being continuously present. The primary category of care provided by families was related to dependency. Patient variables independently associated with a higher frequency of continuous presence were female gender (OR = 1.81; 95% CI 1.04–3.14), a larger number of children (OR = 1.11; 95% CI 1.01–1.23), frailty (OR = 1.45; 95% CI 1.08–1.95), loss of autonomy (OR = 4.36; 95% CI 2.47–7.70), and severity (OR = 1.05; 95% CI 1.01– 1.09). After adjusting for confounding factors, continuous presence of family members was not associated with unfavorable patient outcomes compared to non-continuous presence. Conclusion: In this Acute Assessment Unit, nearly all admitted patients had a family member accompanying them. Female patients, patients with multiple children, frail individuals, patients who had experienced a loss autonomy, and those with severe illness were more likely to have a continuous presence of family members throughout their hospitalization. The continuous presence of family members was not independently associated with unfavorable patient outcomes.

Keywords: Acute medicine; Africa; Family involvement in care; Patient- and family-centered care, Morocco.

#### Introduction

The presence of family members in acute care hospital settings and their involvement in caring for inpatients is a practice that has been adopted from the patient- and family-centered care (PFCC) approach, which is a model of care characterized by partnership and collaboration between healthcare workers and the family in all aspects of care. Its principles are information sharing, respect, honoring differences, partnership, collaboration, and negotiation [1,2]. Family involvement in the care of hospitalized patients aims to ensure that their loved ones' needs are met. Family members stay with an inpatient partly or entirely through the hospitalization period to provide physical, psychosocial, or spiritual care [3,4]. The benefits of PFCC are multiple and no longer need to be demonstrated: improved health outcomes, effective allocation of resources, and increased patient, family, and healthcare worker satisfaction [4]. Over the past two decades, PFCC has gained increasing

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attention in Western countries, leading to fewer restrictions on visitation even in intensive care units [5,6]. Data has shown that restricting family member access causes patient discomfort and contributes to anxiety, delirium, and post-traumatic stress disorder [7]. Surveys reveal that 77% of interviewed patients after hospitalization, express support for involving their families in their care [8]. Restricted access can also lead to anxiety and depression among family members for patients in intensive care, acute medicine, and other care units [8–11]. Furthermore, more liberal visitation policies do not compromise the overall quality of care, including healthcare-associated infection [8.12]. cluster-crossover prevalence In a randomized clinical trial. Intensive Care Unit (ICU)-acquired infections did not differ between units with flexible and restricted visitation (3.7% vs. 4.5%; adjusted difference -0.8% [95% CI, -2.1% to 1.0%]; p = 0.38) [13]. However, units with flexible visitation policies must consider patient condition and preferences, establish an appropriate structure, and address the needs of both the family and healthcare staff [14,15].

Traditionally, families of hospitalized patients have been passive observers, tolerated by the care team but without an active role in the care process. This mindset is changing, and families are now regarded as partners in care rather than spectators or guests. Involving families in care is recognized as one way of improving the quality of healthcare services [16]. This approach is supported by professional medical societies, even in units where patients with organ failure receive highly technical care from welltrained staff [17]. The tasks delegated to families should be supervised and involve basic care, such as providing food, maintaining hygiene, offering massages, ensuring comfort, assisting with eye care, and providing overall support. For more technical procedures (e.g., tracheal aspiration, positioning, equipment manipulation), it is recommended that family members undergo therapeutic education programs to ensure patient safety and minimize the risk of tension or conflict with the healthcare team [18].

While numerous studies have explored family involvement in acute care settings, most of them have focused on surveys assessing perceptions and opinions. Few studies have delved into describing active family involvement in care. Moreover, data from non-Western and low- and middle-income countries are scarce [3,19-21]. In most Western countries, various models for implementing different aspects of PFCC have been proposed [22– 24]. In contrast, family involvement in care is usually spontaneous and inadequately regulated in non-Western countries, where specific family dynamics and roles in the care process exist [19,25– 27]. In Morocco, a lower-middle income country in North Africa, no data are available about family participation in the care of hospitalized patients. This study aims to describe the extent of family involvement and identify patient-related factors associated with the presence of family members in an Acute Assessment Unit (AAU) of a Moroccan university hospital.

# Material and Methods

# Study design and setting

The study was a monocentric prospective cohort study and was conducted for eight months, between November 2018 and June 2019, in the AAU of the Ibn Sina University Hospital in Rabat, Morocco. This unit provides care for adult patients with acute medical conditions often transferred from the Emergency Department. It has a total capacity of 30 beds, six of which are equipped with both invasive and non-invasive monitoring, although invasive mechanical ventilation is not available within the unit's organizational capabilities. Patients who experience deterioration in their condition are transferred to the hospital's Intensive Care Unit, while those who show improvement are either discharged to their homes or transferred to other hospital departments based on their diagnosis. During the study, the nurse to patient and support staff to patient ratios were 1:10 each, with a ratio of 1:7 during the day and 1:15 during the night. The official visiting hours for family members in the hospital are from 4:00 p.m. to 7:00 p.m. The AAU follows an open-door policy, allowing one family member at a time to stay with their loved one for an extended duration and as long as they wish. Patients were considered to be accompanied when at least one family member remained outside the visiting hours, either during the day or at night.

# Participants

The study population included all patients admitted to the AAU during the study period and their family members. Adult patients admitted to the AAU and their family members were enrolled consecutively. Inclusion criteria were all patients admitted to the AAU and their most present family members who expressed willingness to enroll in the study. Exclusion criteria were patients and/or family members who refused to participate, patients with missing data, or patients with a hospital stay of less than 48 hours. A hospital stay of more than 48 hours was deemed necessary to be able to assess the family's participation in care and conduct the survey with them.

#### **Data collection**

Data regarding patients, their family members, and the care provided by the family throughout their participation in the study were collected.

The questionnaire used was drawn up by two members of the research team and consisted of two parts. The first part was designed to collect the patient's characteristics, and the second part was designed to collect information on family members and their involvement in care.

The care provided by family members to their hospitalized loved ones was identified and categorized by a research team member using medical terminology. Based on the results of previous studies [28,29], the care provided was adjusted to our specific context and classified into three distinct categories: dependent, intimate, and technical care.

Information about family members and their level of involvement in the care of their hospitalized loved ones was gathered through face-to-face interviews starting from the third day of hospitalization, conducted by the same nurse from the research team.

#### **Patient characteristics**

The data collected from hospitalized patients included 1) Sociodemographic characteristics, 2) Clinical characteristics: loss of autonomy, which was evaluated using the Activities of Daily Living (ADL) score [30]; level of co-morbidity assessed by the Comorbidities and Charlson Index (CCI) score [31]; and frailty prior to the acute episode leading to the hospitalization, assessed by the Clinical Frailty Scale (CFS) [32]. These characteristics were collected as they are directly associated with the dependency level of hospitalized patients and, consequently, the requirement for family support during their hospital stay. Other clinical characteristics considered were the diagnosis upon admission and the Simplified Acute Physiology Score II (SAPS II) [33]. This score estimates the probability of mortality for ICU patients, and 3) Clinical outcomes: Length Of Stay (LOS), changes in ADL and CFS scores, mortality.

#### **Characteristics of family members**

The presence of family members with their hospitalized loved one (the patient) was considered necessary if the patient's ADL score upon admission to the AAU was less than five. The ADL score is used to determine the patient's degree of dependence; the total score varies between 0 and 6. A score of 6 denoting the maximum level of autonomy, and the lower the score, the more dependent the patient. The data collected regarding the family members of hospitalized patients included the following informations: 1) Presence of at least one accompanying person: This indicated whether there was at least one family member present with the patient during their hospitalization beyond hospital official visiting hours, 2) Number of accompanying persons taking turns per patient, 3) Daily presence: It was noted whether the family member(s) were present with the patient on a daily basis, and 4) Continuous presence: Cases in which a family member was constantly present with the patient and spent the night with them were documented.

### **Characteristics of family care**

The assessment encompassed a total of 14 different types of care, including four types related to dependency care and five types each for intimate and technical care (Table 1). The types of care provided by the family were recorded by the interviewer face-to-face with the most present family member of each patient. The family member was asked to indicate which of the 14 types of care he or she had performed. In the case of dependency and intimate care, family involvement occurred spontaneously and without a predetermined structure. Families offered these types of care either independently or in collaboration with professional caregivers. Technical care, on the other hand, was supervised by healthcare professionals. In instances where families expressed a desire to participate in this type of care, healthcare professionals provided instructions on procedures such as handling oxygen through a nasal cannula or high-concentration oxygen mask. Hospital staff then ensured that these techniques were being implemented correctly.

Table 1: Categories and the 14 types of care assessed.			
Categories	Types of Care		
<b>Dependency Care</b>	Help with eating or changing clothes		
	Support while walking or in a wheelchair		
	Help change positions or to sit on a chair		
	Accompaniment to the sink		
Intimate Care	Styling hair, shaving, or massage		
	Accompaniment to the toilet		
	Assistance while using the toilet		
	Assistance in the shower		
	Empty urine bag or collect urine to check for diuresis or for other testing		
Technical Care	Give medicines orally		
	Perform oral care		
	Put on or take off nasal cannula for oxygen or the high oxygen concentration mask		
	Take temperature		
	Perform capillary blood glucose test		

#### Statistical analysis

Data are presented as mean with standard deviation for variables with a normal distribution, and as median and interquartile range for variables with skewed distributions. The normality of the distribution was tested by the Kolmogorov–Smirnov test with Lilliefors correction.

A multiple logistic regression was performed to explore the association between patient characteristics and the continuous presence of a family member, controlling for the potential confounders (gender, number of children, marital status, education level, inability to eat, and CFS, CCI, SAPS II, and ADL scores). Results are presented as the odds ratio and 95% confidence interval (95% CI). Univariate and multivariate comparisons were performed to evaluate the association of the continuous presence of a family member with patient outcomes (AAU and hospital lengths of stay, ADL and CFS scores six months after discharge, and mortality). Symmetrically distributed continuous data were compared using the Student's t-test. Skewed continuous data were compared using the Mann-Whitney U test and adjusted differences were obtained from quantile regression. Categorical variables were compared using the chi-squared test for independence. In multivariate analysis, The association of the continuous presence of a family member with outcomes symmetrically distributed continuous variables were explored using linear regression. Binomial logistic regression was used to describe the association between the continuous presence of a family member and mortality. A p value < 0.05 was considered statistically significant. Analyses

were performed using Stata 14 (StataCorp) and Jamovi Version 2.2 (The jamovi project, 2021).

#### **Ethical considerations**

The study was approved by the Biomedical Research Ethics Committee of Mohammed V University in Rabat (Reference number 41/15). Patients who had been admitted to the AAU and their family members were invited to participate by a nurse member of our research team. The nurse provided oral and written information about the study objectives and procedures to each participant. Patients and their family members were informed that their participation was voluntary and that refusing to participate would not affect their treatment and care. It was also explained that they can withdraw at any time they want to. Participants were reassured that anonymity and confidentiality of data were guaranteed. All participants gave informed consent before taking part in the study. Given the observational nature of the study, only oral consent was obtained.

### Results

### **Characteristics of the study sample**

During the study period, 459 patients were admitted to the AAU, and 89 were excluded from the analysis because of discharge within 48 hours (n = 42), missing data (n = 38), or refusal to participate (n = 9). Therefore, the final analysis included a total of 370 patients. During the hospitalization of these patients, the total number of family members taking turns to accompany their hospitalized loved one was 793 (**Figure 1**).



Figure 1. Inclusion of Patients and Their Families members.

#### **Characteristics of patients**

Of the 370 patients included, 57.3% were male. The median age was 60 years, and 30% were over 65 years old (n = 111). No level or a primary level of education was found in 77.6% of patients (n = 287) and only 25 (6.8%) had a university level. The median number of children per patient was 3. In 93% of cases, the patients lived with their families. The patients admitted to the AAU were primarily transferred from the Emergency Department, accounting for 97.5% of cases (n = 354). Among these transfers, 45.2% were completed within 24 hours. At least

one chronic disease was present in 56.5% of patients, with diabetes (30.3%) and arterial hypertension (29.7%) being the most commonly observed chronic pathologies. The median CCI score was two. The CFS score prior to the acute episode leading to the hospitalization was at  $3.2 \pm 1.1$ . Half of the patients (50.5%; n = 187) had a history of previous hospitalization. Upon admission to the AAU, 63.2% of patients (n = 234) had an ADL score of less than 5. The most frequent admission diagnoses were cardiac emergencies (49.7%) and sepsis (20.8%) (**Table 2**).

	2. *).
Characteristics	n (%)
Age, median [IQR*], years	60 [45-60]
Male gender	212 (57.3)
Female gender	158 (42.7)
Marital Status	
Married	241(65.1)
Widowed	61 (16.5)
Single	58 (15.7)
Divorced	10 (2.7)
Number of Children, median [IQR*]	3 [1-5]
Living Situation	
Lives with family	344 (93)
Lives with spouse only	14 (3.7)
Lives alone	11 (3)
Homeless	1 (0.3)
Distance between hospital and place of residence	
Within the city of Rabat (0 à 20 km)	207 (55.9)
Between 20 and 100 km	104 (28.1)
More than 100 km	59 (15.9)
Level of education	112 (30.3)
Heart failure	55 (14.8)
Chronic kidney disease	38 (10.3)
Other	55 (14.8)
None or primary	287 (77.6)
Secondary	58 (15.7)
University	25 (6.8)

 Table 2. Characteristics of Patients (N = 370).

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Chronic disease	110 (29.7)
High blood pressure	112 (30.3)
Diabetes mellitus	55 (14.8)
Heart failure	38 (10.3)
Chronic kidney disease	55 (14.8)
Other	209 (56.5)
High blood pressure	110 (29.7)
Diabetes mellitus	112 (30.3)
Heart failure	55 (14.8)
Chronic kidney disease	38 (10.3)
Other	55 (14.8)
Previous hospitalization	187 (50.5)
Charlson score, median [IQR*]	2 [1-4]
Frailty Scale, mean ± standard deviation	$3.2 \pm 1.1$
SAPS II*, mean ± standard deviation	$21.5 \pm 9.4$
Unable to eat at admission	90 (24.5)
ADL* score < 5 at admission	234 (63.2)
Diagnosis	
Cardiac emergencies	184 (49.7)
Sepsis	74 (20.8)
Endocrine or metabolic emergencies	42 (11.4)
Hematological emergencies and systemic diseases	25 (6.8)
Neuro-psychiatric emergencies	1
Other	2

\*IQR: Interquartiles range. SAPS II: Simplified Acute Physiology Score. ADL: Activities of Daily Living.

#### **Characteristics of family members**

At least one family member was present outside visiting hours for 361/370 patients (97.6%). This presence was considered necessary if the patient lost his autonomy, with an ADL score less than 5. All but two patients in whom the presence of a family member was necessary benefited from this presence.

The mean number of family members who took turns staying with their loved one was  $2 \pm 0.8$ per patient. Female family members were almost twice as likely to remain with the patient compared to male members (524 vs. 269). The spouse was the most common family member present, accounting for 36.6% of cases, followed by daughters at 32.1%. A regular daily presence of a family member was observed in 94.7% of patients. In 52.4% of cases (n = 189), family members were continuously present day and night. They spent the night next to their loved ones, either sitting on a chair or lying on a bed if it was not occupied by another patient. The frequency of continuous presence of family members living in or near the city of Rabat was not statistically different from that of families residing more than 20 kilometers away from Rabat (54% vs. 46%; p= 0.17) (**Table 3**). Several patient-related variables were independently associated with the continuous presence of a family member; these included being a female patient, having a larger number of children, significant frailty before the current acute episode, the need to be accompanied due to ADL score less than 5, and a high SAPS II (Table 4).

Characteristics	N (%)
Total number of family members	793 (100)
Female	524 (66.1)
Male	269 (33.9)
Number of family members who take turns per patient, mean $\pm$ standard deviation	$2\pm0.8$
Relationship of family member most often present	
Spouse	132 (36.6)
Daughter	116 (32.1)
Other	83 (23)
Son	24 (6.6)
Unrelated Daily presence of a family member in the 361 accompanied patients Continuous presence of a family member in the 361 accompanied patients	6 (1.6) 342 (94.7) 189 (52.4)

|--|

 Table 4. Patient-related variables independently associated with a continuous presence of a family member.

Variables	Odds ratio	95% CI *	P value
Female gender	1.81	1.04 - 3.14	0.036
Number of children	1.11	1.01 - 1.23	0.044
Married patient †	0.65	0.34 - 1.23	0.180
Low education level ††	1.34	0.70 - 2.54	0.380
Frailty Scale before hospitalization	1.45	1.08 - 1.95	0.014
Inability to eat	1.78	0.96 - 3.32	0.069
Charlson Score	0.94	0.78 - 1.13	0.490
Simplified Acute Physiology Score II¶	1.05	1.01 - 1.09	0.027
Need to be accompanied (Activities of Daily Living score <5)	4.36	2.47 - 7.70	< 0.001

\* 95% CI: 95% Confidence Interval.

† Reference category is represented by widowed, divorced or single patients.

<sup>††</sup> Low education level: never attended school or educated only through primary years. Reference category is represented by secondary or university level of education.

 $\P$  Simplified Acute Physiology Score II: An age > 65 years was associated in univariate analysis with a more frequent continuous presence but was not introduced into the logistic regression model because the Charlson score and the Simplified Acute Physiology Score II include age as an item.

# Characteristics of care provided by family members

Of the 361 patients accompanied by their family members, data on the care provided were available in 346. The remaining 15 families whose data were not available mentioned a lack of time to answer the questions. Of the 346 patients evaluated, at least one type of care was provided by their families in all but two cases (n = 344; 99.4%) as they were autonomous upon admission to the AAU (ADL score = 6).

The most common category of care provided by families was care related to dependency, with an average of  $82.7 \pm 21.9\%$  of types of care performed. This was followed by intimate care, with  $48 \pm 19.6\%$  of types of care performed, and technical care with  $33.7 \pm 17.8\%$  of types of care performed. The specific types of care within each category that patients received from their families are detailed in **Table 5**.

Table 5. Care activities carried out by family members ( $N = 346*$ ).			
Category and Type of Care	N (%)		
At least one dependency care activity performed by families	343 (99.4)		
Assistance with eating or changing clothes	343 (99.4)		
Assistance walking or with wheelchair	287 (82.9)		
Help with sitting in a chair or changing position	277 (80.1)		
Accompaniment to the sink	237 (68.5)		
At least one intimate care activity performed by families	335 (96.8)		
Styling hair, shaving, or massage	312 (90.2)		
Accompaniment to the toilet	256 (74)		
Assistance while using toilets	121 (35)		
Assistance in the shower	75 (21.7)		
Empty urine bag or collect urine to check for diuresis or other testing	66 (19.1)		
At least one technical care activity performed by families	324 (93.6)		
Give medicines orally	323 (93.4)		
Perform oral care	121 (35)		
Put on or take off nasal cannula for oxygen or the high concentration	68 (19.7)		
Take temperature	40 (11.6)		
Perform capillary blood glucose test	31 (9)		

\* Of the 370 patients included, 361 were accompanied par their family members. Of the 361 patients accompanied by their family members, data on care provided were available in 346.

#### **Clinical outcomes**

The median length of stay in the AAU and hospital were 8 days (range: 5–13) and 9 days (range: 6–15), respectively. The mortality rates in the AAU and in-hospital were 11.1% (n = 41) and 13.2% (n = 49), respectively. Six months after hospital discharge, follow-up was conducted for 346 patients, with 24 patients lost to follow-up. The six-month mortality rate was 23.7% (82/346).

In univariate analysis, the continuous presence of a family member was found to be linked to an unfavorable prognosis for patients compared to non-continuous presence. Patients with continuous family presence experienced extended length of stay in the AAU (median difference of 2.0 days; 95% CI: 0.75 to 3.25; p=0.002), had a lower ADL score six months after being discharged (mean difference of -0.43; 95% CI: -0.65 to -0.20; p< 0.001), exhibited higher levels of frailty six months after discharge (mean difference in CFS score of 0.49; 95% CI: 0.23 to 0.75; p< 0.001), and had increased mortality rates. However, upon adjusting for confounding factors, the continuous presence of a family member was not independently associated with a poor prognosis (**Table 6**).

Table 6. Patient's outcome variables associated with continuous presence of a family member (N=361*).				
Univariable and Multivariable Analysis.				

Variables	Continuous Presence (n = 189)	Non- continuous Presence (n = 172)	Unadjusted median difference (95% CI†)	P value	Adjusted median difference (95% CI)	P value
LOS¶, days						
In AAU	9 [6-14]	7 [5-12]	2.0 (0.75 to 3.25)	0.002	0.99 (-0.56 to 2.54)	0.21
In Hospital	10 [6-18]	8 [5-13]	2.0 (-0.19 to 4.19)	0.073	0.99 (-0.65 to 2.64)	0.24
			Unadjusted mean difference (95% CI)	P value	Adjusted mean difference (95% CI)	P value
ADL <sup>‡</sup> score at six months	5.4 ± 1.2	5.9 ± 0.6	-0.43 (-0.65 to - 0.20)	<0.001	-0.08 (-0.27 to 0.12)	0.44
FS** at six months	3.8 ± 1.3	3.3 ± 0.9	0.49 (0.23 to 0.75)	<0.001	0.07 (-0.15 to 0.28)	0.54
			Unadjusted OR (95% CI) Mortality††, n (%)	P value	Adjusted OR (95% CI)	P value
In AAU	32 (16.9)	9 (5.2)	3.69 (1.71 to 7.98)	<0.001	0.89 (0.73 to 1.09)	0.26
In Hospital	37 (19.6)	11 (6.4)	3.56 (1.75 to 7.24)	<0.001	0.87(0.72 to 1.05)	0.15
At six months	57 (31.8)	24 (15.1)	2.63 (1.54 to 4.49)	<0.001	0.88 (0.75 to 1.04)	0.12

\* Of the 370 patients included, 361 were accompanied by their family members.

† 95% CI: 95% confidence Interval.

¶ LOS: Length of Stay, expressed as median [interquartile range]. LOS was adjusted for age, SAPS II, ADL score at admission, and Frailty Scale.

‡ ADL: Activities of Daily Living Score, expressed as mean ± standard deviation. ADL score at six month postdischarge was adjusted for ADL score prior to the acute episode leading to the hospitalization, Charlson score without age, and SAPS II score.

\*\* FS: Frailty Scale, expressed as mean ± standard deviation. FS at six months post-discharge was adjusted for FS prior to the acute episode leading to the hospitalization, Charlson score without age, and SAPS II score. ¶¶ OR: Odds ratio.

<sup>††</sup> Mortality was adjusted for sex, Charlson score without age, SAPS II score, and ADL score at admission.

# Discussion

In this prospective study evaluating the participation of families in the care of their adult loved ones hospitalized in an open-door AAU of a Moroccan university hospital, nearly all patients were accompanied by at least one family member who actively participated in their care. The most commonly performed category of care by families was dependency-related care. Continuous family presence was more prevalent in the most frail and seriously ill patients but was not independently associated with a poor prognosis.

This study is the first of its kind conducted in an AAU in a North African country and one of the few to provide data on PFCC in a resource-limited setting [19,21,25,34]. The open-door policy adopted in this unit cannot alone fully explain the extensive and voluntary participation of families in care. The shortage of professional caregivers and the unique characteristics of family bonds in certain African and Middle Eastern societies contribute to a sense of duty to participate in the care of hospitalized loved ones [1,19,25,35]. These family ties also explain why even patients who had not lost their autonomy were supported by their family members. Spouses and daughters were the most common family members present, which aligns with findings reported in most published data, including Western countries [36-38]. Dependency-related care provided by families is a common feature in both Western and non-Western countries [34–38], whereas Western families are typically more reluctant to perform intimate care [39].

One noteworthy aspect of family involvement in this study is that it is not an attempt to implement one of the components of the PFCC approach, but rather an observation of how things unfold in an open-door unit in an African country, with technical care provided by the family being supervised. The participation of families in care, as observed in many African or Middle Eastern countries with limited resources, is both spontaneous and authorized, and is encouraged by the care team. This helps meet patients' essential care needs, which is crucial for ensuring optimal safety, particularly for frail and elderly patients, as well as promoting optimal recovery and positive healthcare experiences [40,41].

Patients with continuous family presence exhibited higher frailty, lower autonomy, and higher severity scores compared to patients who were not continuously accompanied. The association between continuous family presence and a poor prognosis, observed in univariate analysis, is clearly attributable to the more severe condition of patients, as demonstrated by adjusting for confounding factors (Table 6). It appears quite evident that the families of the most severely ill patients feel the necessity to stay with their hospitalized loved ones at all times.

It is important to note that the severity score used in this study is validated in ICUs [33]. Nevertheless, a portion of our AAU receives severe patients, and the mean SAPS II of our patients is similar to that of patients in ICUs in our country [42].

## Limitations of the Study

There are several limitations in this study that need to be acknowledged, particularly its monocentric nature. Despite the large sample size compared to similar studies, the findings cannot be generalized to other acute care units in Moroccan hospitals. Additionally, there is a lack of data on the frequency of implementing the open-door policy in acute care units across Morocco, although it is likely to be very low. This policy allows unrestricted visitation: A family member can come at any time during the day or night and stay as long as they wish with their hospitalized loved one. Future research should address these limitations by clarifying this information in Morocco and conducting multicenter studies about involvement of families in care. Another limitation of this study is the lack of evaluation regarding the satisfaction and opinions of caregivers, patients, and their hospitalized loved ones. While this evaluation was not part of the study's objectives, it will be addressed in a future publication. Lastly, the data collected is from 2019, and the practice regarding the study topic may have been affected by the Covid-19 pandemic. Indeed, during the pandemic, the presence of a family member was restricted to specific cases. However, unit practices have resumed since the end of the pandemic, and the data remain valid.

### Recommendations

This study represents an initial step in identifying priority actions to support family participation in care. It is crucial to establish an educational approach that focuses on supervising families and integrating them into care within the framework of PFCC principles. As families are true partners and are necessary in the care process due to the lack of adequate healthcare resources, they should also benefit from appropriate conditions and minimal comfort, especially for those who continuously accompany their loved ones. Zohra Bahmane et al. Characteristics, Roles and Factors Associated with Family Involvement in Care of Hospitalized Patients in a Lower-Middle Income Country's University Hospital: An Observational Study.

## Conclusion

This study found that in this open-door Acute Assessment Unit of a Moroccan university hospital, families actively and spontaneously participate in the care process on a regular basis, most often performing dependency-related care. presence with family Continuous their hospitalized loved ones is more common among the frailest, most dependent, and severely ill patients but is not independently associated with an unfavorable prognosis. Family involvement in care should be structured and organized within the framework of the patient- and family-centered care model, tailored to the context of this African country.

#### Author contribution statement

ZB: Conceptualization, Investigation, Writing -Original Draft. JB and N Me: Data collection. C HR: Writing - Original Draft. RA: Validation, Software, Formal Analysis, Review & Editing. N Ma: Conceptualization, Methodology, Software, Formal Analysis, Project administration, Supervision, Review & Editing.

All authors read and approved the final manuscript.

#### **Competing interest statement**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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**Data availability statement:** The data for this study are available and can be made available if necessary.

**Ethics approval and consent to participate:** Approval was granted by the Biomedical Research Ethics Committee of Mohammed V University in Rabat (Reference number 41/15). Oral informed consent was obtained from participants.

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## References

- Park M, Giap TT, Lee M, Jeong H, Jeong M, Go Y. Patient- and family-centered care interventions for improving the quality of health care: A review of systematic reviews. Int J Nurs Stud. 2018; 87:69-83. DOI:10.1016/j.ijnurstu.2018.07.006.
- Kokorelias KM, Gignac MAM, Naglie G and Cameron JI. Towards a universal model of family centered care: a scoping review. BMC Health Serv Res. 2019; 19:564. DOI: 10.1186/s12913-019-4394-5.
- Gwaza E, Msiska G. Family Involvement in Caring for Inpatients in Acute Care Hospital Settings: A Systematic Review of Literature. SAGE Open Nurs 2022; 8: 23779608221089541. DOI: 10.1177/23779608221089541.
- Gwaza E, Maluwa V, Kapito E, Sakala B, Mwale R, Haruzivishe C, Chirwa E. Patient guardian: concept analysis. Intermational Journal of Innovative Research & Development 2017, 6(8), 333–337.

doi:10.24940/ijird/2017/v6/i8/AUG17042.

- Boehm LM, Jones AC, Selim AA, Virdun C, Garrard CF, Walden RL, Wesley Ely E, Hosie A. Delirium-related distress in the ICU: A qualitative meta-synthesis of patient and family perspectives and experiences. Int J Nurs Stud. 2021; 122:104030. DOI:10.1016/j.ijnurstu.2021.104030
- 6. Dijkstra BM , Rood PJT, Teerenstra S, Rutten AMF, Leerentveld C, **Burgers-Bonthuis** DC, Festen-Spanjer B, Klarenbeek T, Van Den Boogaard M, E Ewalds, L Schoonhoven, Van Der Hoeven JG, Vloet LCM; from the EFfect of FAMily PARTicipation in essential care (EFFAMPART) Study Group. Effect of a Standardized Family Participation Program in the ICU: A Multicenter Stepped-Wedge Cluster Randomized Controlled Trial. Crit Care Med 2023. Online ahead of print. DOI: 10.1097/CCM.000000000006093.
- Hugelius K, Harada N, Marutani M. Consequences of visiting restrictions during the COVID-19 pandemic: An integrative review. Int J Nurs Stud. 2021; 121:104000. DOI: 10.1016/j.ijnurstu.2021.104000.
- Garrouste-Orgeas M, Philippart F, Timsit JF, Diaw F, Willems V, Tabah A, Breteviile G, Verdavainne A, Misset B, Carlet J. Perceptions of a 24-hour visiting policy in the intensive care unit. Crit Care Med. 2008; 36:30–5. DOI: 10.1097/01.CCM.0000295310.29099.F8.
- Pochard F, Darmon M, Fassier T, Bollaert PE, Cheval C, Coloigner M, Merouani A,Moulront S, Pigne E, Pingat J, Zahar JR, Schlemmer B, Azoulay E; French FAMIREA study group. Symptoms of anxiety and depression in family members of intensive care unit patients before discharge or death. A prospective multicenter study. J Crit Care 2005; 20:90–6. DOI: 10.1016/j.jcrc.2004.11.004.
- 10. Belayachi J, Himmich S, Madani N, Abidi K, Dendane T, Zeggwagh AA, Abouqal R.

Psychological burden in inpatient relatives: the forgotten side of medical management. Q J

Med. 2014; 107:115–122. DOI: <u>10.1093/qjmed/hct210</u>

- Hochendoner SJ, Villa G, Sokol E, Levy MM, Aliotta JM, Timothy H Amass SJ. Correlation Between Restraint Use and Engaging Family Members in the Care of ICU Patients. Crit Care Explor. 2020; 2(11):e0255. DOI: 10.1097/CCE.00000000000255
- Fumagalli S, Boncinelli, L, Lo Nostro A, Valoti P, Baldereschi G, Di Bari M, Ungar A Baldasseroni S, Geppetti P, Masotti G, Pini R, Marchionni N. Reduced cardiocirculatory complications with unrestrictive visiting policy in an intensive care unit. Results From a Pilot, Randomized Trial. Circulation 2006; 113: 946-52. DOI: 10.1161/CIRCULATIONAHA.105.572537.
- Rosa RG, Falavigna M, da Silva DB, Sganzerla D, Santos MMS, Kochhann R, de Moura RM, Eugênio CS, Haack TDSR, Barbosa MG, Robinson CC, Schneider D, de Oliveira DM, Jeffman RW, Cavalcanti AB, Machado FR, Azevedo LCP, Salluh JIF, Pellegrini JAS, Moraes RB, Foernges RB et al. Effect of Flexible Family Visitation on Delirium Among Patients in the Intensive Care Unit: The ICU Visits Randomized Clinical Trial. JAMA. 2019;322(3):216-228. DOI: 10.1001/jama.2019.8766.
- Pariseault CA, Copel LC, McKay MA. Original Research: Nurses' Experiences of Caring for Patients and Families During the COVID-19 Pandemic: Communication Challenges. Am J Nurs. 2022 ;122(1):22-30. DOI: 10.1097/01.NAJ.0000805644.85184.d2.
- Ibrahim Ali Abu Maloh H, Jarrah S, Al-Yateem N, Refaat Ahmed F and Eid AbuRuz M. Open visitation policy in intensive care units in Jordan: cross-sectional study of nurses' perceptions. BMC Nurs. 2022; 21:336. DOI: 10.1186/s12912-022-01116-5.
- Xyrichis A, Fletcher S, Philippou J, Brearley S, Terblanche M, Rafferty AM. Interventions to promote family member involvement in adult critical care settings: a systematic review. BMJ Open 2021; 11(4):e042556. DOI: 10.1136/bmjopen-2020-042556.
- Davidson J. E., Powers K., Hedayat K. M., Tieszen M., Kon A. A., Shepard E., Spuhler V., Todres I. D., Levy M., Barr J., Ghandi R., Hirsch G., Armstrong D. American College of Critical Care Medicine Task Force 2004-2005, Society of Critical Care Medicine (2007). Clinical practice guidelines for support of the family in the patientcentered intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. Critical care medicine, 35(2), 605–622. DOI: 10.1097/01.CCM.0000254067.14607.EB.
- McAdam J L, Arai S, Puntillo KA. Unrecognized contributions of families in the Intensive care unit. Intensive Care Med. 2008; 34:1097–101. DOI: 10.1007/s00134-008-1066-z.
- 19. Nayeri ND, Gholizadeh L, Mohammadi E, Yazdi K. Family Involvement in the Care of

Hospitalized Elderly Patients. J Appl Gerontol 2015; 34(6):779-96.

DOI:10.1177/0733464813483211.

- Park JY, Pardosi JF, Islam MS, Respati T, Chowdhury K and Seale H. What does family involvement in care provision look like across hospital settings in Bangladesh, Indonesia, and South Korea? BMC Health Serv Res. 2022; 22:922. DOI: 10.1186/s12913-022-08278-7.
- Mankhamba Kalolo A, Mula C and Gundo R. Family members' perception of their needs in critical care units at a tertiary hospital in Malawi: A qualitative study. BMC Nurs. 2023; 22:274. DOI: 10.1186/s12912-023-01433-3.
- 22. Bohart S, Møller AM, Andreasen AS, Waldau T, Lamprecht C, Thomsen T. Effect of Patient and Family Centred Care interventions for adult intensive care unit patients and their families: A systematic review and meta-analysis. Intensive Crit Care Nurs. 2022; 69:103156. DOI: 10.1016/j.iccn.2021.103156.
- Ciufo D, Hader R, Holly C. A comprehensive systematic review of visitation models in adult critical care units within the context of patient- and family-centred care. Int J Evid Based Healthc. 2011; 9:362-87. DOI: 10.1111/j.1744-1609.2011.00229.x.
- Hastings SE, Suter E, Bloom J, Sharma K. Introduction of a team-based care model in a general medical unit. BMC Health Serv Res. 2016; 16:245. DOI:10.1186/s12913-016-1507-2.
- Yakubu K, Malan Z, Colon-Gonzalez MC, Mash B. Perceptions about family-centred care among adult patients with chronic diseases at a general outpatient clinic in Nigeria. Afr J Prim Health Care Fam Med. 2018; 10(1):e1-e11. DOI:10.4102/phcfm.v10i1.1739
- 26. Tseng YS, Verklan MT. Fathers in situational crisis: a comparison of Asian and Western cultures. Nursing And Health Sciences 2008; 10(3):229–240. DOI: 10.1111/j.1442-2018.2008.00392.x.
- 27. Newman MC, Lawless JJ, Gelo F. Familyoriented patient care. Am Fam Physician 2007; 75(9):13061-310.
- Dijkstra B, Uit Het Broek L, van der Hoeven J, Schoonhoven L, Bosch F, Van der Steen M, Rood P, Vloet L. Feasibility of a standardized family participation programme in the intensive care unit: A pilot survey study. L.Nurs Open. 2023; 10(6):3596-3602. DOI: 10.1002/nop2.1603.
- 29. Yakubu YH, Esmaeili M, Navab E. Family members' beliefs and attitudes towards visiting policy in the intensive care units of Ghana. Nurs. Open 2019; 6 (2):526-534. DOI: 10.1002/nop2.234.
- Katz S, Downs TD, Cash HR, Grotz RC. Progress in development of the index of ADL. Gerontologist 1970; 10:20-30. DOI: 10.1093/geront/10.1\_part\_1.20
- Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longtitudinal studies: development

and validation. Journal of Chronic Diseases 1987; 40:373–83. DOI: 10.1016/0021-9681(87)90171-8.

- Rockwood K, Song X, MacKnight C, Bergman H, Hogan DB, Mc Dowell I, Mitnitski A. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005; 173:489-95. DOI: 10.1503/cmaj.050051.
- Le Gall JR, Lemeshow S, Saulnier F. A new Simplified Acute Physiology Score (SAPS II) based on a European/North American multicenter study. JAMA 1993; 270(24):2957-63. DOI: 10.1001/jama.270.24.2957.
- Wyskiel RM, Weeks K, Marsteller JA. Inviting families to participate in care: a family involvement menu. Jt Comm J Qual Patient Saf. 2015; 41(1):43-6. DOI: 10.1016/s1553-7250(15)41006-2.
- 35. Yakubu K, Malan Z, Colon-Gonzalez MC, Mash B. Perceptions about family-centred care among adult patients with chronic diseases at a general outpatient clinic in Nigeria. Afr J Prim Health Care Fam Med 2018; 10(1):e1-e11. DOI: 10.4102/phcfm.v10i1.1739.
- Ewart L, Moore J, Gibbs C, Crozier K. Patient- and family-centred care on an acute adult cardiac ward. British Journal of Nursing 2014; 23(4):213–218. DOI: 10.12968/bjon.2014.23.4.213.
- Azoulay E, Pochard F, Chevret S, Arich C, Brivet F, Brun F, Charles PE, Desmettre T, Dubois D, Galliot R, Garrouste-Orgeas M, Goldgran-Toledano D, Herbecq P, Joly LM, Jourdain M, Kaidomar M, Lepape A, Letellier N, Marie O, Page B et al. Family participation in care to the critically ill: opinions of families and staff. Intens Care Med. 2003; 29(9):1498-1504. DOI: 10.1007/s00134-003-1904-y.
- Alshahrani S, Magarey J, Kitson A. Relatives' involvement in the care of patients in acute medical wards in two different countries—an ethnographic study. J Clin Nurs. 2018; 27(11– 12):2333–2345. DOI: 10.1111/jocn.14337.
- Garrouste-Orgeas M, Willems V, Timsit JF, Diaw F, Brochon S, Vesin A, Philippart F, Tabah A, Coquet I, Bruel C, Moulard ML, Carlet J, Misset B. Opinions of families, staff, and patients about family participation in care in intensive care units. J Crit Care 2010; 25(4):634-40. DOI:10.1016/j.jcrc.2010.03.001.
- 40. Hoffman M, Mofolo I, Salima C, Hoffman I, Zadrozny S, Martinson F, Horst CVD. Utilization of family members to provide hospital care in Malawi: the role of hospital guardians. Malawi Med J. 2012; 24 (4):74–78.
- Feo R, Kitson A. Promoting patient-centred fundamental care in acute healthcare systems. Int J Nurs Stud 2016; 57:1-11. DOI: 10.1016/j.ijnurstu.2016.01.006.
- 42. Abidi K, Dendane T, Madani N, Belayachi J, Abouqal R, Zeggwagh AA. The clinical picture of severe leptospirosis in critically ill patients. Intensive Care Med 2017, 43:1740–1741. DOI: 10.1007/s00134-017-4870-5.