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The Role of Caregivers in the Management Process of Palliative Care Patients at a Leading University Hospital in Benin

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Abstract

Introduction: Palliative care requires an interdisciplinary approach and the involvement of the patient and their Caregiver in the care process. Objective: To assess the role of Caregiver in the care process of patients followed at the Palliative Care Unit of the CNHU-HKM in Cotonou. **Method:** A mixed descriptive design was adopted. Data were collected from Caregiver using a semi-structured self-questionnaire digitized with KoBoCollect version v2024.2.4 and inspired by the elements of the Malaboeuf model and from the Healthcare Staff using a semi-structured interview guide, all selected by non-probability

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random sampling. Quantitative data were analyzed using descriptive statistics while qualitative data were analyzed by thematic content analysis using the Braun & Clarke approach. **Results:** Sixty (60) Caregiver and nine (09) Healthcare Staff were included in the study. The main tasks performed by the Caregiver on their own initiative or on the instructions of the Healthcare Staff were hygiene and comfort care and assistance with the clinical and therapeutic monitoring of Palliative Patients. On the other hand, the prevention of pressure ulcers, a crucial care in a palliative context, seems to be little practiced by the Caregiver. They deplore the fact that the Healthcare Staff does not bother to know their identity, a factor in a good relational dynamic (weak functional relationship) and the lack of periodic interviews with them on the clinical evolution of the disease of their Palliative Patients (weak therapeutic support relationship). Furthermore, the level of education of the Caregiver and the obligation to respect professional confidentiality were the major obstacles limiting their involvement by the Healthcare Staff in the process of taking care of Palliative Patients. **Discussion and Conclusion:** The Caregiver play the role of substitutes for nurses and nursing assistants with palliative patients and are privileged interlocutors of the Healthcare Staff.

Keywords

Caregivers, Palliative Patients, Palliative Care, CNHU-HKM, Benin

1. Introduction

Palliative Care is one of the main areas of treatment for chronic diseases with the aim of improving the quality of life of patients. It consists of caring for people suffering from incurable, life-threatening diseases by relieving pain, discomfort symptoms and their suffering and supporting them and their loved ones in difficult times, all within a holistic approach to care (physical, psychological, social, spiritual, etc.) [1]. The growing need for palliative care today is a major public health issue. Already in 2004, it was estimated that 100 million people worldwide could benefit from basic palliative care [2]. In 2020, the World Health Organization (WHO) [3] estimates that each year, 56.8 million people, including 25.7 million in their last year of life, need palliative care, most of them living in low- and middle-income countries; among children, 98% of those requiring palliative care also live in low- and middle-income countries, almost half of which are in Africa. Unfortunately, globally, only about 14% of people in need of palliative care currently receive it [3] even though access to palliative care is recognized as a fundamental human right [4]; better still, palliative care must be provided in accordance with the principles of universal health coverage [3].

In Benin, more than 62,000 people are estimated to need palliative care each year [5]. Provided in parallel and within other care programs, palliative care concerns life as much as death and aims to help people suffering from: cancer, HIV, progressive neurological diseases, severe kidney failure or severe heart failure, terminal lung diseases and other life-limiting conditions; different models of palliative care provision exist including: Palliative Care in the context of home care, Palliative Care Clinics, Day Care Support, the Hospital Palliative Care Team and the Hospital Service [1].

The care of patients in palliative care is interdisciplinary and involves health professionals, social workers, spiritual guides and volunteers according to the individual and specific needs of patients [6]. The involvement of caregivers is crucial, as they play a central role in the palliative care process, considered as caregivers, especially when care is provided at home [7]. This involvement is a central element of the palliative care process on which health professionals can rely. Caregivers are therefore an integral part of the care process in Palliative Care Units where their role varies from participation in the planning and monitoring of care to support in meeting the needs of patients [7] [8]. This makes their presence with the patient essential in hospitalization or at home to improve their quality of life, which is the main objective of palliative care.

In Benin, the five-year palliative care plan 2022-2026 [6] has provided for the establishment of a support framework for both patients and their caregivers to better manage end-of-life and bereavement. It has been noted that the participation of caregivers in the palliative care process is often undervalued and poorly integrated, which limits the overall effectiveness of care, whereas by improving the understanding and integration of caregivers in palliative care, it is possible to provide more comprehensive and appropriate support, thus reducing the suffering of patients and their families [6]. It is therefore necessary and essential to explore in depth the role of caregivers in the specific context of palliative care in Benin, hence the interest of this study whose objective is to evaluate the place of caregivers in the process of care of patients followed at the Palliative Care Unit of the University Clinic of Internal Medicine-Palliative Care (CUMI-SP) of the Hubert Koutoukou Maga National University Hospital Center (CNHU-HKM) in Cotonou, Benin.

2. Materials and Methods

2.1. Research Design, Target Populations and Sampling Method

A mixed descriptive design with an exploratory aim was adopted. Two target populations were considered for the study: 1) caregivers of patients under care at the Palliative Care Unit of the University Clinic of Internal Medicine-Palliative Care (CUMI-SP) at CNHU-HKM in Cotonou, who had been regularly present with their palliative patients for at least 72 hours prior to the data collection date (self-administered questionnaire), and 2) healthcare personnel who had at least two weeks of experience working at the Palliative Care Unit before the start of data collection. Non-probability random sampling was used. Also known as convenience or blind sampling, this type of sampling requires the accessibility (or availability) of subjects at a specific location and time. For this study, caregivers were recruited during their relatives' hospitalization at the Palliative Care Unit of the CUMI-SP at the CNHU-HKM in Cotonou. Healthcare staff were recruited as they were on duty during the data collection period. Sample sizes were determined based on the principle of empirical data saturation. Data saturation occurs when new interviews become redundant and do not provide additional data or knowledge.

2.2. Conceptual Framework of Reference for the Study

To evaluate the quality of the caregiver-caregiver relationship for palliative patients, the conceptual framework adapted for the study was the Malaboeuf model [9]. According to the author [9], there are four levels of caregiver-patient relationship, established in ascending order:

- **Civility Relationship**: this generally occurs outside of the care process and corresponds to the social ritual of acknowledging the other person, which is part of the rules of civility and socio-cultural codes, such as knocking before entering, saying hello, introducing oneself, shaking hands, etc. The absence of these actions can have serious consequences and can signal impoliteness, a lack of respect, contempt, etc.;
- **Functional Relationship**: this generally corresponds to an investigative function through the collection of information on the patient in order to better understand them and to guide their care;
- **The Relationship of Understanding** (or support or reassurance): it intervenes with an empathetic aim to support the patient and;
- **Therapeutic Support Relationship**: it is established gradually by establishing a climate of trust while respecting at least two prerequisites: the minimum time to be devoted to the patient and for oneself and, a minimum of psychological "availability". Indeed, the support relationship is the ability that a caregiver can have to bring all people in difficulty to mobilize their resources to better experience a situation: it is a relational care.

The elements of adaptation of the Malaboeuf model [9] for the study of the quality of the caregiver-caregiver relationship for palliative patients are detailed in Table 1.

Table 1. Elements of adaptation of the Malaboeuf model [9] under the study.

Constituent elements of the Malaboeuf model [9]	Elements of adaptation of the model under study (Evaluation questions constituting the self-questionnaire for the benefit of caregivers of palliative patients)
	In general:
1st level of relationship: the relationship of civility	
Be polite	Does the healthcare staff **exhibit politeness** towards you when communicating?
Be courteous	Does the healthcare staff **show courtesy** towards you or communicate with you courteously?

Continued

Greet	Does the healthcare staff greet you spontaneously at the beginning of discussions?
Introduce yourself	Does the healthcare staff spontaneously introduce themselves to you at the beginning of discussions, including their name, first name(s), title, and role?
	2nd level of relationship: the functional relationship
Clinical and paraclinical signs of the pathology communication methods	Does the healthcare staff regularly inquire with you about the clinical signs of the illness affecting your hospitalized relative?
	Does the healthcare staff regularly inform you of the results of para-clinical examinations performed on your hospitalized relative? (While, of course, respecting professional confidentiality and discretion)
	Does the healthcare staff regularly update you on the clinical progression of your hospitalized relative's illness?
Communication resources	Does the healthcare staff address you by your name and first name(s)?
	Does the healthcare staff address you using your hospitalized relative's name and first name(s)?
	Does the healthcare staff inform you about the service's operational procedures at the beginning of your relative's hospitalization?
Quality of communication lifestyle habits	Does the service have a reception, information, and listening area dedicated to caregivers of hospitalized patients?
	Does the service provide you with a welcome booklet outlining its structure, operational procedures, and the rights and duties of caregivers at the start of your relative's hospitalization?
	Does the service provide you with a URL link giving access to its structural presentation, operational procedures, and the rights and duties of caregivers?
Family data clinical and paraclinical signs of the pathology communication methods	Does the healthcare staff correctly explain the contents of the medical prescriptions they give you for your hospitalized relative?
	Does the healthcare staff correctly explain the contents of the para-clinical examination reports they give you for your hospitalized relative?
	Does the healthcare staff provide you with the **necessary guidance** when handing you treatment prescriptions and para-clinical examination reports for your hospitalized relative?
	Does the healthcare staff explain **your rights** as a caregiver of a hospitalized patient in the service?
	Does the healthcare staff explain **your duties** as a caregiver of a hospitalized patient in the service?
Communication resources	Does the healthcare staff make you feel like you are also an active participant in the care process for your hospitalized patient?
	Does the healthcare staff regularly inquire about your living conditions (nutrition, hygiene care, accommodation, others) in the service?
	Does the healthcare staff regularly inquire about the situation of the family left behind by your relative due to their hospitalization?
Quality of communication	Does the healthcare staff regularly inquire about the ongoing function of the position (or role) left by your relative due to their hospitalization? **(if applicable)**

Continued

3rd level of relationship: the relationship of understanding (or support or reassurance)	
Active listening	Does the healthcare staff value your presence during discussions with them?
	Is the healthcare staff attentive during your conversations with them?
	Does the healthcare staff show interest in your proposals or suggestions during discussions?
Active listening	Does the healthcare staff express feelings of moral support towards you because of your relative's hospitalization?
	Does the healthcare staff help you feel confident about your relative's recovery during your discussions?
4th level of relationship: the therapeutic support relationship	
Active listening empathetic attitude	Does the healthcare staff organize periodic meetings with you regarding the clinical progression of your relative's illness?
	Does the healthcare staff explain the benefits of the treatment your relative is receiving?
	Does the healthcare staff explain the contents of the treatment your hospitalized relative is undergoing?
Authenticity/ congruence	Is the healthcare staff available to you when you have concerns about your hospitalized patient or need clarification on a treatment prescription or a para-clinical examination report?
	Does the healthcare staff show empathy towards you because your relative is hospitalized?
	Does the healthcare staff provide you with enough convincing information about para-clinical examination reports to motivate you to pay the associated fees?
	Does the healthcare staff provide you with enough convincing information about treatment prescriptions to motivate you to pay the associated fees?
Active listening	Does the healthcare staff offer clarifications on treatment prescriptions and para-clinical examination reports when you request them?

2.3. Data Collection Tools and Main Variables or Phenomena under the Study

A semi-structured self-questionnaire inspired by the elements of the conceptual framework of reference [9] (**Table 1**) and digitized with the KoBoCollect application version v2024.2.4, made it possible to assess among caregivers the quality of their relationship with the nursing staff (specific objective 1 of the study), to explore the tasks they perform in the process of palliative patient care (specific objective 2 of the study) and to identify possible obstacles to their involvement in the chain of palliative patient care (specific objective 3 of the study). In addition, a semi-structured interview guide also made it possible to explore among the nursing staff of the Palliative Care Unit the tasks performed by caregivers (specific objective 2 of the study), as well as the obstacles encountered in relation to their involvement in the process of palliative patient care (specific objective 3 of the study). The main variables or phenomena under study in relation to each specific objective are listed in Table 2.

Table 2. Presentation of the main variables or phenomena under study according to each specific objective.

N°	Specific objectives	Variables or phenomena under study and their modalities
01	Describe the quality of the caregiver-caregiver relationship of patients monitored at the Palliative Care Unit of CNHU-HKM in Cotonou.	○ **Civility** (being polite, courteous, greeting, introducing oneself) ○ **Functional relation** (information on clinical and paraclinical signs of the pathology, lifestyle habits, family data, socio-professional data) ○ **Supportive or understanding** (active listening, de-dramatization) ○ **Therapeutic support** (active listening, psychological availability)
02	Explore the roles of caregivers in the care process of patients monitored at the Palliative Care Unit of CNHU-HKM in Cotonou.	○ **Hygiene and comfort care** (complete toileting; natural cavity care; bedmaking; hair care; pressure sore prevention; foot baths; hand and nail care; beard shaving) ○ **Assistance with medication adherence** (purchasing medications, ensuring medications are taken on time) ○ **Assistance with eating** (ensuring meals are available and taken) ○ **Assistance with mobility** (regular position changes; assistance with walking; wheelchair use) ○ **Assistance with clinical and therapeutic monitoring** (attending check-ups, alerting caregivers in case of problems) ○ **Assistance with practicing religious values and beliefs** (helping with prayer, etc.) ○ **Assistance with bowel and urinary elimination** (giving a bedpan when needed, emptying the urine bag) ○ **Management of medical documents** (keeping prescriptions, test slips, and results) ○ **Assistance with emotional management** (active listening, speaking, and encouraging patients in pain)
03	Identify possible obstacles to the involvement of family caregivers in the care process of patients monitored at the Palliative Care Unit of CNHU-HKM in Cotonou.	○ **Level of availability of caregivers** ○ **Level of consideration of caregivers by healthcare staff** ○ **Type of care received by the patient** ○ **Existence of tensions, frustrations, misunderstandings** ○ **Marital status** ○ **Professional secrecy** ○ **Lack of information** ○ **Language spoken** ○ **Educational level** ○ **Degree of kinship**

As with any classic scientific research, data were collected in relation to the following sociodemographic and professional attribute variables: age; sex; professional profile; length of professional practice; marital status; language of communication; level of education; degree of kinship with the palliative patient; level of remuneration; experience as a caregiver.

2.4. Methods of Analysis of the Collected Data

The quantitative data, mainly from the study of sociodemographic and professional variables, were analyzed using descriptive statistics by calculating absolute and relative frequencies. As for the qualitative data from the main variables or phenomena under study, they were subject to a thematic content analysis according to the approach described by Braun & Clarke [10] in six distinct phases which are: 1- familiarization with the data; 2- generation of codes; 3- generation of themes; 4- examination of themes; 5- definition and choice of names of themes and; 6- writing or production of the report. Indeed, thematic analysis is the most commonly used in the context of qualitative data analysis [11] and it is particularly suitable for analyzing classifications and presenting themes related to the data [12]. This method of analysis is therefore well suited to the study. For Guest *et al.* [11], this is a set of rigorous but inductive procedures designed to identify and examine themes in textual data. It therefore involves analyzing thematic patterns in the data.

Verbatim transcripts were extracted from the respondents' speeches to clearly illustrate their comments on the various themes studied.

3. Results

The socio-demographic and professional characteristics of the caregivers of palliative patients surveyed and of the nursing staff are recorded in **Table 3**.

Table 3. Distribution of caregivers of palliative patients and nursing staff according to their socio-demographic and professional characteristics.

N°	Variables		Frequency	Percentage (%)
Socio-demographic and professional characteristics of caregivers (n = 60)				
01	**Gender**	Female	**56**	93, 33
		Male	4	6, 67
02	**Age**	[16 - 19]	3	4, 10
		[20 - 29]	**15**	20, 30
		[30 - 39]	**15**	20, 30
		[40 - 49]	**14**	18, 90
		[50 - 59]	7	9, 50
		[60 - 69]	5	6, 80
		[70 - 79]	1	1, 40
03	**Education level**	University	19	31, 67
		Secondary/Technical	**27**	45, 00
		Primary	13	21, 67
		Not in school	1	1, 67
04	**Marital status**	Widowed	3	5, 00
		Single	16	26, 67
		Married/Living together	**41**	68, 33

Continued

05	**language spoken**	Mahi	1	1, 67
		Tori	1	1, 67
		Kotafon	1	1, 67
		Yoruba	2	3, 33
		Goun	5	8, 33
		Fon	8	13, 33
		Nago	**22**	36, 67
		Dindi	5	8, 33
		Mina	3	5, 00
06	**Current occupation**	Active civil servant	12	20, 00
		Retired civil servant	16	26, 67
		Artisans/Traders	3	5, 00
		Pupils/Students	**31**	51, 67
		Mahi	10	16, 67
07	**Degree of relationship between the caregiver and the palliative patient**	Friend/Colleague	4	6.67
		Child	**25**	**41.67**
		Cousin/Cousin	6	10.00
		Nephew/Niece	2	3.33
		Uncle/Aunt	5	8.33
		Father/Mother	5	8.33
		Husband/Wife	6	10, 00
		Sister/Brother	7	11, 67
08	**Remuneration of the caregiver**	No	**58**	96.67
		Yes	2	3.33
09	**Experience as a caregiver of a palliative patient**	Yes	6	10
		No	**54**	90
Socio-demographic and professional characteristics of healthcare staff (n = 09)				
10	**Gender**	Female	01	11, 11
		Male	08	88, 89
11	**Professional status**	Physician	03	33, 33
		Palliative care nurse	03	33, 33
		State registered nurse	02	22, 23
		Psychologist	01	11, 11
12	**Language spoken**	French	09	100
		Fon	03	33; 33
		Nago	01	11, 11

Sixty caregivers of palliative patients (n = 60) were included in the study, with 90% of them experiencing this role for the first time. The average age was 38.42

years, with a predominance of females (93.33%). The majority were aged between 20 and 49 years (59.5%), and 27 (45%) had a secondary level of education. "Fon" was the most commonly spoken language (36.7%), and over half of the respondents (51.67%) were artisans or traders. A total of 41 (68.33%) reported living in a marital or cohabiting relationship, and many (96.67%) stated that they receive no remuneration for the daily support they provide to their palliative relatives. Additionally, from the perspective of the nuclear family, children were the most represented as caregivers (41.67%).

As for the healthcare personnel, nine were included in the study, of which eight were female. The majority were equally divided between doctors and nurses. They all communicated in French, and only three spoke the "Fon" mother tongue.

3.1. Quality of the Caregiver-Relative Relationship of Palliative Patients

3.1.1. Quality of the Civil Relationship

The elements for evaluating the quality of the civil relationship between healthcare staff and the relatives of the palliative patients surveyed are presented in Table 4.

Table 4. Assessment of the quality of the civil relationship between healthcare staff and family caregivers of palliative patients (n = 60).

Elements of the civil relationship	Assessment questions	Responses from caregivers	
		Yes	No
Be polite	Does the healthcare staff **exhibit politeness** towards you when communicating?	59	01
Be courteous	Does the healthcare staff s**how courtesy** towards you or communicate with you courteously?	59	01
Greet	Does the healthcare staff greet you spontaneously at the beginning of discussions?	60	00
Introduce yourself	Does the healthcare staff introduce themselves to you spontaneously at the beginning of discussions, including their name, first name(s), title, and role?	**23**	37

The data from Table 4 indicate that politeness, courtesy, and greetings are widely recognized by caregivers as indicators of a good civility relationship displayed towards them by the healthcare staff: "they are kind and respectful" (Caregiver 01, F, Friend, 50 years old); "they treat us well" (Caregiver 26, F, Sister, 27 years old). However, over 3/5 of the healthcare staff (37/60, or 61.66%) did not reveal their identity in terms of name, first name, and role to the respondents: "they do not introduce themselves" (Caregiver 39, F, Sister, 54 years old).

3.1.2. Quality of the Functional Relationship

The elements used to assess the quality of the functional relationship between healthcare staff and the caregivers of the palliative patients surveyed are recorded in Table 5.

Table 5. Assessment of the quality of the functional relationship between healthcare staff and family caregivers of palliative patients (n = 60).

Elements of the functional relationship	**Assessment questions**	**Responses from caregivers**	
		Yes	**No**
Clinical and paraclinical signs of the condition	Does the healthcare staff regularly inquire with you about the clinical signs of the condition affecting your relative?	55	05
	Does the healthcare staff regularly inform you of the results of your relative's para-clinical examinations? (While certainly respecting professional confidentiality and discretion)	44	16
	Does the healthcare staff regularly update you on the clinical progression of your relative's illness?	42	18
Communication methods	Does the healthcare staff address you by your name and first name(s)?	**1**	59
	Does the healthcare staff address you using your relative's name and first name(s)?	40	20
	Does the healthcare staff inform you about the service's operational procedures?	36	24
Communication resources	Does the service have a reception, information, and listening area dedicated to caregivers of patients?	**23**	37
	Does the service provide you with a welcome booklet outlining its structure, operational procedures, and the rights and duties of caregivers?	**00**	60
Communication resources	Does the service provide you with a URL link giving access to its structural presentation, operational procedures, and the rights and duties of caregivers?	**00**	60
Quality of communication	Does the healthcare staff correctly explain the contents of the medical prescriptions they give you for your relative?	38	22
	Does the healthcare staff correctly explain the contents of the para-clinical examination reports they give you for your relative?	36	24
	Does the healthcare staff provide you with the necessary guidance when handing you treatment prescriptions and para-clinical examination reports for your relative?	40	20
	Does the healthcare staff explain **your rights** as a caregiver of a patient in the service?	**05**	55
	Does the healthcare staff explain **your duties** as a caregiver of a patient in the service?	**19**	41
	Does the healthcare staff give you the impression that you are also an active participant in the care process for your patient?	39	21
Lifestyle habits	Does the healthcare staff regularly inquire about your living conditions (nutrition, hygiene care, accommodation, others) in the service?	**20**	40

Continued

Family data	Does the healthcare staff regularly inquire about the situation of the family left behind by your relative due to their hospitalization?	30	30
Socio-professional data	Does the healthcare staff regularly inquire about the ongoing function of the position (or role) left by your relative due to their hospitalization? (if applicable)	**24**	36

The data analysis from Table 5 shows several indicators of an acceptable functional relationship between the caregivers of palliative patients and the healthcare staff: "They always ask about his health condition at each session before the care" (Caregiver 24, F, Sister, 55 years old); "They ask us to always inform them when the situation changes. That's how they inquire about symptoms because we have to explain our observations" (Caregiver 34, F, Cousin, 55 years old). However, several points for improvement have been noted in the communication between stakeholders in general. Indeed, almost all of the healthcare staff (98.33%) do not take the time to learn the identities of the caregivers to establish a good relational dynamic: "they don't necessarily know our names, so not really" (Caregiver 21, F, Friend, 35 years old), nor do they explain their rights (55/60 or 91.67%) and duties (41/60 or 68.33%): "I haven't noticed anything like that" (Caregiver 01, F, Friend, 50 years old). Additionally, the Palliative Care Unit does not have a welcome booklet outlining its structure and mode of operation: "the caregivers didn't say anything about the service rules" (Caregiver 34, F, Cousin, 55 years old). Finally, the living conditions and well-being of the caregivers of palliative patients are of little concern to the healthcare staff (20/60 or 33.33%): "They don't ask these questions […]" (Caregiver 21, F, Friend, 35 years old).

3.1.3. Quality of the Relationship of Understanding (Or Support or Reassurance)

The elements for evaluating the quality of the relationship of understanding between the healthcare staff and the close caregivers of the palliative patients sur-veyed are presented in Table 6.

Table 6. Assessment of the quality of the understanding relationship between healthcare staff and family caregivers of palliative patients (n = 60).

Elements of the understanding (or support or reassurance) **relationship**	**Assessment questions**	**Responses from caregivers**	
		Oui	**Non**
Active listening	Does the healthcare staff value your presence during discussions with them?	52	08
	Is the healthcare staff **attentive** during your conversations with them?	57	03
	Does the healthcare staff show interest in your proposals or suggestions during discussions?	51	09

Continued

De-dramatization	Does the healthcare staff express feelings of moral support towards you because of your relative's hospitalization?	55	05
	Does the healthcare staff help you feel assured about your relative's quality of life during your discussions?	55	05

The analysis of Table 6 shows that in the majority of cases, caregivers were attentive to caregivers during interviews, expressed feelings of moral support through "comforting words" (Caregiver 35, F, Niece, 44 years old) and led caregivers to have reassurance about the quality of life of their patient: "They are respectful and take into consideration everything we say" (Caregiver 35, F, Niece, 44 years old); "They are really available when we need them" (Caregiver 49, F, Child, 25 years old).

3.1.4. Quality of the Therapeutic Support Relationship

The elements for evaluating the quality of the therapeutic support relationship between healthcare staff and the surveyed caregivers are recorded in Table 7.

Table 7. Assessment of the quality of the therapeutic support relationship between healthcare staff and family caregivers (n = 60).

Elements of the therapeutic support relationship	Assessment questions	Responses from caregivers	
		Yes	No
Active listening	Does the healthcare staff organize periodic meetings with you regarding the clinical progression of your relative's illness?	**20**	40
	Does the healthcare staff explain the purpose of the treatment your relative is undergoing?	44	16
	Does the healthcare staff explain the details of the treatment your relative is receiving?	43	17
Empathetic attitude	Is the healthcare staff available to you when you need clarification about a concern regarding your patient, a treatment prescription, or a para-clinical examination report?	59	01
	Does the healthcare staff show empathy towards you because your relative is hospitalized?	57	03
Authenticity/ congruence	Does the healthcare staff provide you with enough convincing information about **para-clinical examination reports** to motivate you to pay the associated fees?	34	**26**
	Does the healthcare staff provide you with enough convincing information about **treatment prescriptions** to motivate you to pay the associated fees?	37	**23**
Reformulation	Does the healthcare staff give you clarifications on treatment prescriptions and para-clinical examination reports when you express the desire for them?	43	17

For the majority of respondents (66.66%), the caregivers do not spontaneously organize periodic interviews with them on the clinical evolution of the illness of their palliative parents. The same applies to the convincing information to be given to caregivers on examination reports (43.33%) and treatment orders (38.33%) in order to motivate them to pay for their execution for the benefit of their parents. On the other hand, almost all caregivers (n = 59) recognized that caregivers give them clarifications regarding treatment orders and paraclinical examination reports when they express the wish.

3.2. Tasks Performed by Caregivers in the Process of Caring for Palliative Patients

3.2.1. Tasks Performed by Caregivers, on Their Own Initiative, in the Process of Caring for Their Palliative Patients

The frequency of tasks performed by caregivers, on their own initiative, in the process of caring for their palliative patients, is presented in Table 8.

Table 8. Frequency of tasks performed by caregivers, on their own initiative, in the process of caring for palliative patients.

Task categories	Occurrences	Frequency (%)
Hygiene and comfort care		
Complete cleansing	**37**	61, 67
Natural cavity care	44	73, 33
Bed making	56	93, 33
Hair care	47	78, 33
Bedsor prevention	**35**	58, 33
Beard shaving	37	61, 67
Helps with intestinal and urinary elimination		
Give a bedpan if needed	55	91, 67
Empty the urine bag	**28**	46, 67
Help with therapeutic compliance		
Go buy the medication	60	100, 00
Make sure you take your medication on time	59	98, 33
Assistance with clinical and therapeutic monitoring		
Attend check-ups	58	96, 67
Alert the caregiver if there is a problem	60	100, 00
Feeding assistance		
Buy food	55	91, 67
Help eating	52	86, 67
Mobility assistance		
Help with changing positions	40	66, 67
Help with walking	55	91, 67

Continued

Move in a wheelchair or other way	46	76, 67
Medical document management		
Keep prescriptions	60	100, 00
Keep test slips and results	58	96, 67
Help with emotion management		
Active listening, speaking, encouraging	58	96, 67
Help in exercising religious values and beliefs		
Help to pray	56	93, 33

The analysis of Table 8 shows us that the tasks performed by caregivers, on their own initiative, were as diverse as they were varied. However, complete washing, prevention of bedsores and regular emptying of the urine bag, which are essential care in a palliative context, seem to be little practiced by 38.33%, 41.66% and 53.33% of respondents respectively

3.2.2. Tasks Performed by Caregivers, on the Instructions of Nursing Staff, in the Process of Caring for Palliative Patients

The analysis of the speeches of the caregivers surveyed reveals that the most frequent tasks they perform, on **the instructions of the nursing staff**, include: assistance with clinical and therapeutic monitoring: "Explain how to take care of patients at home for continuity of care" (Caregiver 26, F, Child, 44 years old). Another essential aspect mentioned is the patient's diet "I have to give him medication on time, food and help him in case of difficulty" (Caregiver 23, F, Friend, 35 years old).

3.2.3. Tasks Performed Voluntarily by Caregivers according to Healthcare Staff

According to the statements of the Healthcare Staff (HS), the caregivers, on a voluntary basis, take care of the purchase of medications: "buying the medications" (Healthcare Staff 2, M, Doctor) or "honoring the medical prescription" (Healthcare Staff 9, M, Doctor). They also provide financial and emotional support: "financial aid, daily support, physical presence" (Healthcare Staff 6, M, RN/SP).

3.2.4. Tasks Performed by Caregivers, on the Instructions of the Caregiver, according to the Caregiver

Analysis of the responses from healthcare staff shows that family caregivers, on their instructions, ensure hygiene and comfort care: "bathing, making the bed, washing linens, personal hygiene, purchasing or preparing meals" (Healthcare Staff 4, M, IDE) and help with clinical and therapeutic monitoring: "administration of oral medications, in patient monitoring" (Healthcare Staff 5, M, Doctor).

3.3. Obstacles to the Involvement of Family Caregivers in the Palliative Patient Care Process according to Healthcare Staff

The obstacles to the involvement of family caregivers in the process of caring for palliative patients according to the healthcare staff are recorded in Table 9.

Table 9. Frequency of obstacles to the involvement of family caregivers in the process of caring for palliative patients according to healthcare staff (n = 9).

Obstacles	Frequency
Marital status of caregivers	4
Language spoken by caregiver	4
Educational level of caregiver	**6**
Degree of kinship with the patient	4
Lack of information	**7**
Obligation to respect professional confidentiality	**5**

Analysis of the data in Table 9 shows that lack of information, education level, and the obligation to maintain professional confidentiality are the major obstacles limiting the involvement of caregivers in the care process of their palliative relatives.

Furthermore, the irregular availability of some caregivers and language barriers are also factors limiting their involvement in the care chain for palliative patients. Also, when caregivers' expectations are not aligned with good care practices, healthcare staff sometimes refrain from involving them too much in the decision-making process concerning their patients: "I usually don't hide anything from caregivers when the patient is in a palliative situation. I always manage to convince the patient to share the key elements of their care with their caregivers" (healthcare staff 9, F, RN).

3.4. Difficulties of Caregivers of Palliative Patients in Their Relationship with Healthcare Staff

The difficulties of caregivers of palliative patients in their relationship with the nursing staff are recorded in Table 10.

Table 10. Difficulties encountered by caregivers in their relationship with healthcare staff.

Difficulties	Frequency
Gaps in communication and information	**14**
Poor reception and impatient attitude of healthcare staff	04
Caregiver burnout	02
Caregiver unavailability	06

When analyzing the information contained in Table 10, the lack of information concerning treatment, diagnosis, progression of the disease and the results of paraclinical examinations was the most cited by caregivers: "Lack of information on treatment, diagnosis and results of examinations" (Caregiver 5, F, Sister, 64 years old); "Unavailability of healthcare staff, lack of communication and information with the caregiver, follow-up" (Caregiver 30, F, Woman, 67 years old).

3.5. Suggestions from Caregivers and Healthcare Staff for Better Relational Dynamics between Stakeholders in the Palliative Patient Care Process

Suggestions from caregivers and healthcare staff for better relational dynamics between stakeholders in the process of caring for palliative patients are presented in Table 11.

Table 11. Frequency of suggestions from caregivers and healthcare staff for better relational dynamics between stakeholders in the palliative patient care process.

Suggestions	Frequency
Suggestions made by caregivers	
Better organization of care	**09**
Improve patient and family reception	02
Clearer and more direct communication	**10**
Install communication devices	02
Suggestions made by nursing staff	
Regular meetings between the healthcare team and caregivers	03
Training sessions for caregivers on their roles and palliative care	**06**
Strengthening psychological support for caregivers	03
Empowering healthcare staff to support caregivers before and after palliative care	02

The most frequently cited suggestions made by caregivers for better collaboration with healthcare staff in the palliative care process were: better organization of care and a more responsive presence of caregivers during calls; and clearer and more direct communication about the palliative patient's health status without constantly having to ask questions. "Take time for care, review the reception, learn how to pass on information, give importance to caregivers" (Caregiver 5, F, Sister, 64 years old); "Review the nurses' working methods" (Caregiver 12, F, Sister, 24 years old).

As for Caregivers, organizing training sessions for caregivers on their roles and palliative care would be beneficial to improve collaboration with them: "Organize refresher sessions for caregivers; help them understand their roles and limitations" (Healthcare Staff 03, M, Nurse/SP); "Make palliative care better known to family caregivers so as not to continue to appear as workers of death, strengthen psychological support for family caregivers" (Healthcare Staff 09, F, IDE).

4. Discussion

The role of caregiver of palliative patients is dominated, in our study, by women (93.33%), which corroborates the results of the study by Dubé *et al.* [13] who also reported a predominance of the female sex among their respondents (80.4%). These findings, especially in our context of palliative care, have both historical and socio-anthropological significance. Indeed, the preparation of girls for family tasks and mothering promotes the internalization of the basic attitude of care: concern for others which involves the protection of the body and mutual aid for oneself and for loved ones. This socialization inscribes "**Caring**" as an ingredient of feminine identity and therefore, seems to determine, for many women, self-responsibility for care [14]. Moreover, palliative care, by its specificities, is essentially based on the science of "Caring". Mayeroff [15] defines Caring as: "the activity of helping another person to grow and actualize themselves, a process, a way of relating to the other that promotes their development." As for Watson [16], it is a set of so-called "Carative" factors that form the basis of a caring approach that promotes either the development or maintenance of health, or a peaceful death. These "Carative" factors, ten in number, are formulated as follows: 1) the development of a humanist-altruistic value system; 2) taking into account and supporting the belief system and hope; 3) cultivating sensitivity to oneself and others; 4) developing a relationship of help and trust; 5) promoting and accepting the expression of positive and negative feelings; 6) the systematic use of the scientific method of problem solving in the decision-making process; 7) the promotion of interpersonal teaching-learning; 8) the creation of a mental, physical, sociocultural and spiritual environment of support, protection and/or correction; 9) assistance in the satisfaction of human needs and; 10) the consideration of existential-phenomenological factors. History also tells us that women were at the forefront in gathering activities, contributing to feeding, but also to caring [17]. For Sallaint [14], the care provided by women communicates a different language than the traditional medical language in relation to health and illness. This language is one that rejects the sanitized, measured, distant body-object, whose soul and affect are, ultimately, only sources of error for a diagnosis to be established. The language of the body carried by care is a language that carries the realities of life in motion: intimacy, fear of suffering, uncertainty, fragility, lack of control, transgression of norms, etc. This vision of Saillant [14] on the care provided by women, aligns with the ten so-called "Carative" factors which form the basis of Watson's "Caring" approach [16] which is a caring approach which promotes either the restoration (or maintenance) of health, or a peaceful death, unlike curative factors whose aim is to treat a patient's pathology. Care thus takes on its full importance through its function (protection of the body, mutual aid, accompaniment), its values (recognition of the other, non-exclusive values of independence and interdependence) by being more on the side of the liberation of the body than on the side of its control, which is also part of the principles of palliative care.

In our study, the role of caregiver was mostly played by members of the nuclear family (93.33%) of palliative patients (child; cousin; nephew/niece; uncle/aunt; father/mother; husband/wife; sister/brother), in particular children (41.67%). This observation seems to reveal the concept of "privileged caregiver" evoked by

Pueugueu [7] referring to the nuclear family (father, mother, brothers and sisters) of the African patient who only finds balance in the relationship with others, his family, his community. This corroborates the results of the study by Mimche & Feudjio [18] who reported that in the African sociocultural context, health problems are first experienced in a relational and family context. Pueugueu [7] also believes that in a hospital situation, the break with the family could be a factor in slowing down the speed of recovery, the reinforcement and/or the genesis of a mental disorder. For Sow [19], the African man residing in Africa is a relational being. The nurses are then culturally accepted as capital in the care system, often taking the role of substitutes for nurses and nursing assistants in the daily care of patients and residing in the care space itself for the duration of the hospitalization [7].

The analysis of the different levels of the relationship between caregivers and close caregivers of patients at the Palliative Care Unit of the CNHU-HKM in Cotonou in light of the Malaboeuf model [9], showed generally positive indicators. However, gaps were observed in the functional and communication dimensions, thus affecting the overall quality of the expected relational dynamics. In terms of civility (1st level of relationship in the study's reference framework), it was noted by more than half of the respondents (37/60 or 61.67%) that it is not yet ingrained in the habit of caregivers to introduce themselves to patients and their close caregivers by their name, first name(s), title and function in a systematic manner. The absence of this formal presentation could constitute an obstacle to the establishment of a climate of trust between stakeholders, essential for effective support in palliative care. According to Malaboeuf [9], the absence of elements of civility can have serious consequences and can notably indicate rudeness, a lack of respect and contempt towards caregivers. Fonseca [20] also believes that proximity and transparency are crucial factors in reassuring families. For the author [20], cooperation between the patient's own network and caregivers has a positive impact on their quality of life.

In terms of the functional relationship (2nd level of relationship of the study's reference framework), our study revealed as a priority, the absence of certain communication resources between the healthcare staff and the caregivers, in particular the lack of a welcome booklet from the Palliative Care Unit of the CNHU-HKM of Cotonou presenting the structure, its mode of operation, the rights and duties of the caregivers upon the hospitalization of the patients, which was reported by all the respondents (100%). Indeed, the welcome booklet in a health care service is an essential tool to inform, guide and reassure the patient, while meeting legal requirements and promoting a better relationship between the establishment and the person being cared for [21]. It is also part of the quality approach tools to be implemented in any health structure. There is therefore a need to structure communication to better inform and support the families of palliative patients because, according to Grant and Graven [22], family caregivers are central players in palliative care.

As for the relationship of understanding or support or reassurance (3rd level of relationship of the study's reference framework), it was appreciated by 57 respondents (95%) who perceived attentive listening on the part of the nursing staff and displays of moral support, which demonstrates a desire on their part to create an environment of comfort for caregivers because, according to Fonseca [20], the role of the caregiver in palliative care is part of the continuity of the support relationship and the help of relatives to identify their own suffering, even if this positive dimension does not totally compensate for the inadequacies noted in the functional aspects.

Finally, the most significant gaps were noted in the therapeutic support relationship (4th level of relationship in the study's reference framework). 2/3 of the caregivers surveyed (66.67%) reported a lack of periodic interviews with them by the healthcare staff on the clinical progress of their parents' illness, which could create a feeling of frustration and isolation at their level. The information concerning paraclinical examinations and prescriptions was even deemed unconvincing by 43.33% and 38.33% of respondents respectively, which could lead to a certain reluctance on the part of caregivers to commit financially to expensive treatments. Malaboeuf [9] had also estimated that the success of the therapeutic support relationship, which is relational care, necessarily requires at least two prerequisites: the minimum time to be devoted to the patient and to oneself and a minimum of psychological availability.

The caregivers surveyed play roles as diverse as they are varied, on their own initiative or on the instructions of the nursing staff, in the process of caring for their palliative relatives. These roles or tasks relate to hygiene and comfort care, assistance with intestinal and urinary elimination, therapeutic compliance, clinical and therapeutic monitoring, nutrition, mobility, emotional management, the exercise of religious values and beliefs and the management of medical documents. The caregivers then take care of the "taking care" of palliative patients which, according to Hesbeen [23], consists of paying particular attention to a person who is experiencing a situation that is particular to them (as is the case for patients in palliative care) and this, with the perspective of helping them, contributing to their well-being and health. These roles revealed by our study are similar to the empirical roles of nurses described by Pueugueu [7] who concludes that they serve as mediators between the nursing staff and the patients: they manage prescriptions, report on certain patient difficulties, and sometimes ease certain tensions between caregivers and patients. For the author [7], caregivers are generally the first responders for patients in terms of the helping relationship, that is to say, they are generally the source of comfort and security for them. Pepin and Hébert [24], as well as Beaudet and Allard [25], reported in their studies, similar tasks performed by caregivers of palliative patients included in our study. Pueugueu [7] returns and asserts that the presence of nurses within the hospital itself helps alleviate the separation anxiety from the daily living environment generated by the hospitalization situation and reconnects the patient with their social group, community, and family: the nurse is then the one who eases the tensions generated by the hospitalization situation and constitutes a kind of shield against excitement and support.

Despite the variety of tasks performed by caregivers, our study reported that 90% of them are in their first experience in this role. Also, they themselves expressed certain difficulties they experience in their collaboration with the nursing staff, particularly gaps in communication and information. All of this could justify the training sessions recommended by the nursing staff for their benefit and the empowerment of nursing staff who will be responsible for supporting caregivers before and after the palliative patient is taken care of.

Several obstacles limiting the involvement of caregivers in the palliative care process were raised by the healthcare staff, including the level of education of caregivers and the obligation for caregivers to respect professional confidentiality. In our study, 68.33% of respondents had an education level below university level, which is similar to the results of the Pueugueu study [7] which reported that 70% of caregivers had low levels of education. This low level of education of caregivers could explain the gaps in communication and information that they themselves mentioned, among other things, as a difficulty they encounter in their relational dynamics with the healthcare staff. This could affect their level of health literacy and put them in a certain informational vulnerability in the specific context of palliative care while limited health knowledge is therefore a threat to health care outcomes, to the improvement of populatio n health and to health equity [26]. Indeed, health literacy is defined as the knowledge, skills, motivation and ability to identify, understand, evaluate and use health information when making decisions in contexts of care, disease prevention and health promotion to maintain or improve quality of life [27]. It is also recognized as a determining element of public health, a factor in effective management of the health of populations, individually and collectively, by empowering patients and strengthening their sense of self-efficacy [28]-[30].

Healthcare staff reserve the right to involve caregivers more in certain decision-making processes because of the professional confidentiality to be preserved, which falls under ethical and professional standards. Several studies [31] [32] have reported the same findings where the notion of confidentiality to be preserved was the systematically identified constraint since caregivers considered the reconciliation between patient confidentiality and the support needs of caregivers to be very delicate and consider them insufficiently equipped to receive the strong emotions expressed by families. Although it is accepted that in hospital institutions, the only people responsible for care are officially the doctors, nurses and trained nursing assistants, it is empirically observed that the involvement of nurses is common in sub-Saharan Africa and seems to be one of the major supports of the treatment [7]. Faced with this dilemma, Pueugueu [7] proposes to rethink the place of nurses (caregivers) in the care team to achieve the objective of health and well-being by recommending the development of "ethno nursing care" as a new approach which recognizes nurses as a specific clinical modality for sub-Saharan

African countries including Benin. Indeed, the "ethno-nursing care" approach refers to ethno-nursing [33] [34] and ethnography [35] in nursing. It (ethno-nursing care) consists of taking into account the beliefs, expressions, and rituals related to health and care within a cultural group. The aim is to provide care that is more adapted and respectful of each individual's beliefs, values, and practices in order to foster better communication and a relationship of trust. For Debout [36], the practice of nursing increasingly involves encounters between a caregiver and a patient from very different cultures. It is therefore becoming necessary to develop cultural competence among caregivers, and this is what Pueugueu [7] proposes for better collaboration between nursing staff and the caregivers of palliative patients."

Finally, the study revealed a disparity in the communication languages of the stakeholders. While all the caregiver pockets surveyed speak their mother tongues with a predominance of the "Fon" language (36.67%), which also reflects the sociolinguistic reality of Benin, only three out of the nine caregivers surveyed use it. This language barrier could constitute an obstacle to the regularity of communication between the stakeholders, which corroborates the results of the study by Dray *et al.* [37] which showed that language barriers constitute a major obstacle to access to care and understanding of health messages among immigrant or French-speaking populations. For these authors [37], health literacy is seriously compromised when information materials are not adapted to the language or cultural context of the patients. All of this calls for linguistic adaptation strategies, particularly for audiences speaking national languages, in order to guarantee equal access to information in a multilingual context. The National Institute of Public Health of Quebec (INSPQ) [38] also recommends that culture, values, beliefs and mother tongue be taken into consideration to ensure that the messages and formats of written health material reach the target audience.

5. Conclusions

This study highlighted the crucial importance of caregivers in the management of palliative care patients at CNHU-HKM in Cotonou. This role, often voluntary, unpaid, and primarily performed by members of the patient's nuclear family, is essential for their daily support, whether in physical, emotional, psychological, or spiritual care. However, despite their unwavering commitment, caregivers face numerous challenges, including stress management, lack of formal preparation, and psychological support. Communication with healthcare personnel, a key factor in improving the effectiveness and efficiency of care, sometimes remains insufficient due to conflicts that arise when caregiver needs clash with the need to maintain patient confidentiality and respect personal wishes.

The study also revealed that better recognition of caregivers' roles, coupled with suitable training, could improve their well-being and ability to support patients. It is therefore essential to implement support mechanisms, both psychological and practical, to assist them and to enhance the understanding and appreciation of palliative care within society and the healthcare system. Promoting an integrated and collaborative approach between the healthcare team and caregivers, as well as increased awareness of palliative care issues, are crucial elements for improving the quality of care for patients and their families.

Scientifically, the study's results provide a knowledge base on palliative care by offering specific data related to the Beninese context. Practically, the study offers recommendations to improve the integration of caregivers into the palliative care process, which could lead to more effective and patient-centered practices. Socially, the study contributes to strengthening community and family support, thus helping to better manage end-of-life and bereavement, one of the primary objectives of palliative care. Furthermore, it must be acknowledged that the sample size of healthcare staff is small (n = 9), which could limit the generalizability of the results, but this does not, in our humble opinion, affect the scientific quality of the study since Palliative Care Units are special care environments where specialized staff often work in small numbers due to the multidisciplinary nature of palliative care.

In short, the role of family caregivers of palliative patients, in the African context in general and in Benin in particular, is complementary to that of healthcare staff, but unfortunately, it operates within an informal and unregulated framework. These caregivers provide considerable support of various kinds for the care of patients in a palliative setting in order to improve their quality of life: basic nursing care (hygiene and comfort care; pressure ulcer prevention; assistance with eating and toileting; etc.); and supportive care (assistance with mobility; attentive listening; emotional, psychological, and spiritual support; assistance with treatment adherence; etc.).

To improve the involvement of caregivers in the palliative care process, several avenues can be explored, including: 1) formalizing their role by designing a Reference Guide for caregiver care activities; 2) designing a welcome booklet for Palliative Care Units; 3) creating listening and information areas for caregivers in Palliative Care Units; and 4) training them on the role and limits of caregivers in the palliative care team, including the ethical and professional aspects of palliative care.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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