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Original Research Article

What do we know about palliative support for women with chronic diseases in Benin? For an African model of palliative and end-of-life care

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ABSTRACT

Background: In Benin, medical pluralism is omnipresent. This study analysed the therapeutic process of women with cancers, admitted to palliative or end-of-life care in Benin.
Methods: In-depth interviews were conducted with three caregivers from the CNHU-HKM palliative care unit; the study was part of a retrospective project examining the records of 299 patients admitted to the PCU between 2015 and 2021 and a participant observation. SPPS® was used for a descriptive analysis of file data. Those from the interviews and observation were subjected to thematic and content analysis.
Results: Upon admission to the PCU, 43.81% wanted healing and 13.38% wanted to seek complementary care (prayer therapy, herbal medicine). According to caregivers, patients do not fully adhere to the care provided to them. This could be due to the unaffordable cost of care and hospitalization, the shortage of care inputs and materials, perceptions about cancer and especially the failure to take into account the spiritual and cultural specificities of patients and families.
Conclusions: This study provided a basis for improving palliative support in the context of medical pluralism and precariousness. Palliative care in the community or at home is imposed on the traditional health care system with the integration of a combination of biomedicine care, so-called non-conventional medicine and the knowledge and expertise of community members.

Keywords: Benin, Cancers, End of life, Palliative care

INTRODUCTION

Faced with the impacts of chronic diseases, African health systems are being put to the test in a context of medical pluralism and financial precariousness. Medical pluralism exists in low-income countries and is well described for patients with chronic diseases in various international contexts.[1,2] As such, patients and their families may prefer “informal” health services because of their increased accessibility in low-resource areas.[3,4]

“Informal” health care is a factor in non-compliance with drug treatments.[5] But its “informal” care practitioners could be important allies for public health initiatives. Indeed, some chronic disease management programs have attempted to collaborate with informal care providers including training for them so that they can be resource persons capable of referring patients and their families to health centres.[6] However, in most cases, the effectiveness of the program has been limited by the fact that patients have flexibility to refuse to go to institutional palliative care. This is because when informal and formal health services are available in a community, patients do not engage equally in both options.

Current debates seem to suggest the importance of volunteering in the development of public health, especially in regions where qualified human resources are low.[7] Studies have shown that community members play a variety of roles in helping people with chronic conditions adhere to treatment regimens, relieve pain, avoid unnecessary hospital admissions, reduce dependence on healthcare professionals, stay at home longer, and maintain a good quality of life.[8]

Biomedicine, "informal" care services, and community knowledge and skills offer distinct forms of palliative support for patients and families. This study analysed the therapeutic process of women with chronic diseases, admitted to the palliative care unit (PCU) in Benin to define a holistic theoretical model of palliative and end-of-life support.

METHODS

Study design

This research was conducted at the Centre National Hospitalier et Universitaire-Hubert Koutoukou Maga (CNHU-HKM). It was the first hospital to implement palliative care for chronic diseases through its PCU since 2014. It was a cross-sectional and retrospective qualitative survey using a process in three complementary steps. In this article, details of data sampling, collection and analysis are presented according to the three stages of the study.

Step 1: Review of the literature to inform the research, data collect tool, data extraction and analysis

This step consisted of a relevant literature review, chart review, and analysis of patient medical records to provide an in-depth description of patient characteristics and expectations. The analysis of the literature review was published. In addition, based on the work of Hospice Africa Uganda (HAU) and the indicators contained in the records, a database was created using SPSS® software. For example, the following information had to be entered: socio-demographic characteristics, life history (as told by the patient or his/her companion), diagnosis, reason for referral to the PCU, history of the disease, type of treatment, patient expectations. A tool for extracting quantitative data from the PCU records was designed in Excel and exported to SPSS to facilitate data analysis. A total of 436 records of patients admitted to the PCU between 2015 and 2021 were mined. Records were included in the study based on whether the patients were female, receiving palliative care on the unit between 2015 and 2021. Exclusion criteria were that patients were not female or that the record was not properly completed or illegible. A total of 299 records were retained. From this database, descriptive statistics were produced. In this article, only these statistics are used for reporting purposes.

Step 2: individual semi-structured interviews, data collect tool, exclusion, and inclusion criteria

Three rounds of in-depth interviews using semi-structured interview guides were conducted to explore caregivers' perceptions of the nature of the chronic illnesses encountered in the PCU, the elements obstructing or facilitating the supply of and demand for palliative care, including contextual elements, the care environment, and barriers to achieving desired outcomes. Based on a purposive sample, three caregivers: a palliative care nurse, a psychologist, and a general practitioner, involved in the care of patients in the PCU were interviewed. Included in this sample were providers directly caring for patients in the PCU who had given their consent to participate in the study. Exclusion criteria were that the provider was not a palliative care specialist, did not consent to participate in the study, or was not in direct contact with patients. The results of these in-depth interviews were used to support the descriptive data in step 1, with the goal of gaining a greater appreciation of the palliative care delivery setting. This allowed for the tracing of the patient's journey through the medical system. This framework considers the typical pathway of patients and their families.

Step 3: Participant observation and empirical data analysis

A series of participant observations was conducted in the PACU and in the community, particularly in the homes of patients who were alive and receiving home support. This work made it possible to observe the users' use of the PHU, the caregivers' behaviors within the PCU and in the community. To carry out this work, we opted for a one-month professional internship in the PCU. This task allowed us to draw up an ethnography of the PCU and to describe the organization of cancer care, palliative care, and end-of-life care. The results of the observation were provided in narrative form. They were used to confirm or reject, expand, and deepen the explanation of the results in step 2. This analysis leads to a proposed model of palliative or end-of-life care support in a context of precariousness and medical pluralism (Figure 1).

Ethical provisions

The local Ethics Committee for Biomedical Research of the University of Parakou (CLERB-UP) examined the research project, with a favorable ethical opinion: 0364/CLERB-UP/P/SP/R/SA. Ethical provisions have also been to protect patients' personal information. Access to patient records had been under the gaze of a PCU health worker. The counts were carried out on the premises of the PCU, without any tool that could allow to photograph or copy this information. The database created for this purpose has been made available to the PCU team.

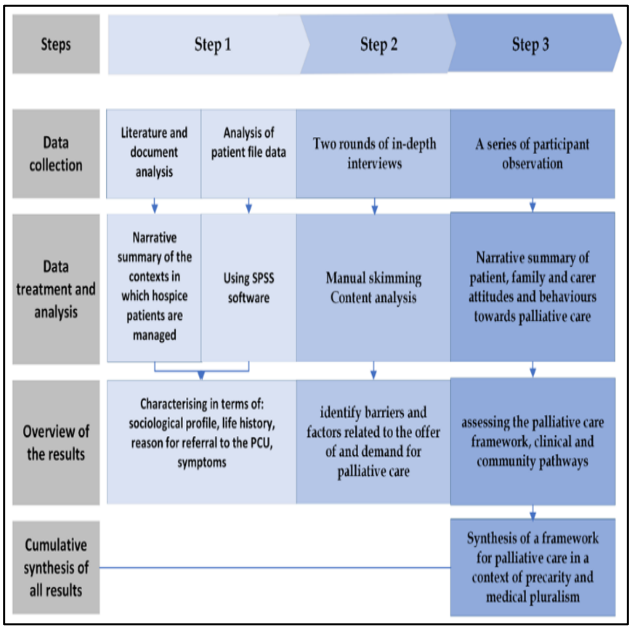

Figure 1: Research design summary.

RESULTS

Characteristics of patients who had access to the PCU

Of the sample of 299 patient records admitted to the PCU between 2015 and 2021, only one record was legible and two complete. The average age of the women whose records were accessed was 51.5 years. 28% were between the ages of 43 and 53 and 38.8% were married. As shown in Table 1, most patients have a history of HTA (16.72%) and diabetes (8.36%). In terms of symptoms, the pain score was high (between 3/5 and 5/5) in 55.18% of these women.

PCU palliative care framework

The major principle of palliative care administered by the PCU under study was based on the value of providing quality patient- and family-centred care, best supporting the patient and family, and minimizing costs. Decision-making and collaborative frameworks have been developed to facilitate the delivery of palliative care based on the needs of patients and their loved ones. This is reflected in the establishment of a National Palliative Care Program that reinforces the actions of the PCU. Based on in situ observations and interviews, the current model of integration of patients in palliative and end-of-life care is based on the consideration of the human factor (psychological, social), but less addresses the spiritual dimension of care.

Table 1: Baseline data of patients admitted to the PCU between 2015 and 2021.

Characteristics	Terms	n	%
Ages (years)	Average age=51.5		
State matrimonial	Bachelor	19	6.35
	Bride	116	38.8
	Divorcee	22	7.36
	Widow	57	19.1
	Not mentioned	85	28.4
Background before SP	Diabetes	25	8.36
	HTA	50	16.72
	Tuberculosis	3	1
	Surgery	69	23.07
	Other	18	6.02
	Not mentioned	134	44.81
Symptoms MS pain (score)	1/5	6	2.01
	2/5	9	3,01
	3/5	29	9.70
	4/5	33	11.04
	5/5	103	34.4
	Not mentioned	119	39.80
Level of education	Not alphabetize	51	17.1
	Alphabetize	3	1
	Primary	43	14.4
	College	75	25.1
	1st graduate cycle	36	12
	2nd graduate	3	1
	3rd cycle	1	0.33
	Not mentioned	87	29.1
Insurance health/illness	Yes	72	24.1
	Not	162	54.2
	Not mentioned	65	21.7

Source: Patient File Review, PCU /CNHU-HKM, July 2021.

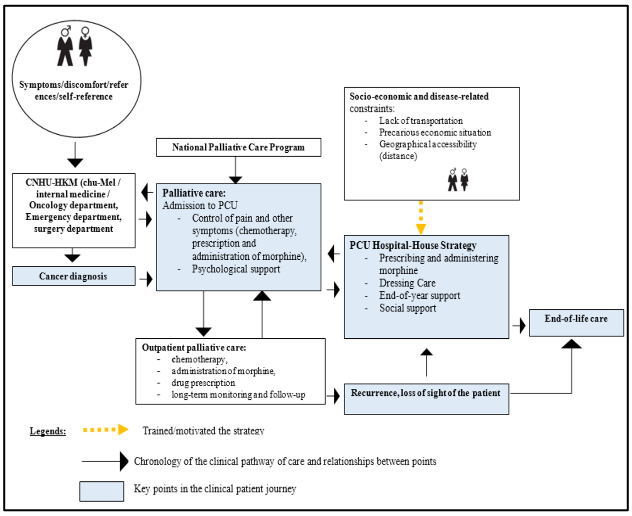

Figure 2: Palliative and end-of-life care framework and clinical pathway at the CHNU-HKM PCU.

Figure 2 presents the palliative care framework showing the typical pathway of patients and families. This framework includes the application areas of care in line with international recommendations on palliative and end-of-life support- pain management, chemotherapy, psychological support, long-term monitoring and follow-up- and country-specific conceptualized interventions-home hospital strategies that consists, apart from medical care, in socially supporting families and patients through: the relocation of the patient, financial, moral, food and bereavement visits.

Barriers to the provision of palliative and end-of-life care services

Several barriers to the provision of care have been identified. These are the troublesome appointment of disease, shortages of inputs and materials, and the unaffordable costs of care. In this article, a special focus is placed on unaffordable costs with a focus on chemotherapy.

The hospital has taken a big step in the development of palliative care by obtaining agreements at the regional and national level to equip its pharmaceutical laboratory with inputs and production materials for the oral morphine solution since 2018. The doctor's words: *"... with the technical support of the pharmaceutical company Denk pharma we were able to start the production of oral morphine syrup*" (interview 1, doctor, May 2021) illustrate this observation.

Table 2: Distribution of patients by care provided or treatment administered (n=299).

Care offered/treatment administered	n	%
Other	18	6.02
Chemotherapy	133	44.48
Not mentioned	4	1.34
Radiotherapy	26	8.70
End-of-life care	109	36.45
Psychological support	9	3.01

Source: field data, July 2021.

But, if this effort facilitates access to care related to pain management, this is not necessarily the case for chemotherapy, which alone represents 44.48% of the care offered (Table 2), for 78.59% of women classified as poor. The direct costs (products and materials) and indirect costs (transport for example) related to chemotherapy represent a barrier to access to care in the words of the nurse: "*I cannot say whether it is related to the country's pharmaceutical policy. But what I do know is that these are very expensive products that are not even found in all pharmacies*" (interview 2, palliative care nurse, May, 2021). The doctor, for his part, evokes the first consequence that results from this financial inaccessibility to the products of chemotherapy:

"*This is a real problem [...] I can tell you that there are some who come, and this very often, after the biopsy they do not come back because they should follow the chemo. We lose sight of them outright and they come back months later in a frankly disastrous state of health [...] because, at the time of diagnosis, there was no money and they tried other things that finally did not work [...]*" (interview 1, doctor, May 2021).

An important and implied element that should be noted in the words of the doctor is the phenomenon of therapeutic withdrawal. This withdrawal has, according to the comments collected, three forms of expression namely: (a) outings against medical advice of the patient very often supported by her relatives; (b) escape of patients in hospital and (c) exeat. According to the nurse, the cost of chemotherapy products alone cannot be considered as a factor underlying these three forms of expression of withdrawal. Also: "*[...] the cost of hospitalization, oxygen make the patients decide to go home to follow the care [...] in the unit we do not have a hospice, it may be badly perceived by the users [...] we hospitalize patients often in the room of internal medicine [...] it costs about 6000 to 16000 f per day. How many do you think can cope with this burden?*" (interview 2, palliative care nurse, May 2021). Indeed, by crossing this discourse with the socio-economic level of patients who had access to the PCU between 2015 and 2021, we become more aware of the concern of the nursing staff.

Determinants of demand for palliative and end-of-life care

One of the determinants documented in this article is "hope for a cure". According to Table 3, 43.81% of women sought healing; 12.04% hoped for an extension of life on earth. This desire can be explained by the "cultural resilience" of patients and their loved ones. Indeed, in an African social context, "*the prognosis of a patient is only really committed when he is no longer breathing!*" (interview 2, palliative care nurse, March 2021). In other words, he could heal at any stage of his disease regardless of its severity. This resilience refers to what the anthropological literature calls the "taboo of death"; that is, evoking a possibility of death to an individual seeking care is extremely troublesome and likely to lead to an interruption of medical care in the hospital in favor of a quest for holistic care.

Table 3: Distribution of patients by care requests/expectations in PCU (n=299).

Requests for care/patient expectations	n	%
Other	40	13.38
Cure the disease,	131	43.81
Not mentioned	2	0.67
Lengthening of life on earth	48	16.05
Moral support	41	13.71
Psychological support	37	12.37

Source: field data, July 2021.

In an African context, the use of multiple therapeutic responses at one time or another of a pathological episode is facilitated by factors related to the history of the disease and the history of treatment of patients. Three main elements influenced the journeys of these women. First, to give themselves a better chance of recovery, some patients combine chemotherapy and traditional pharmacopoeia. Then, other patients had opted for an answer that for the moment is not yet proposed by the PCU although being part of the elements around which the first consultation takes place: a spiritual accompaniment. It should be noted that spiritual beliefs were decisive in the choice of prayer camps to which his wives went, in the hope of a cure. Finally, a misdiagnosis made by a caregiver (not specialized in palliative care) which is one of the most important reasons explaining the use of the PCU as a last resort.

The patient had to think of a spell and found herself piling up several answers (medicine, prayer and herbal medicine) to cope with her cancer. The typical case of Latifath leads to another research hypothesis that the failure of prevention programs in sexual and reproductive health could lead to an increase in cases of women's cancer in Benin.

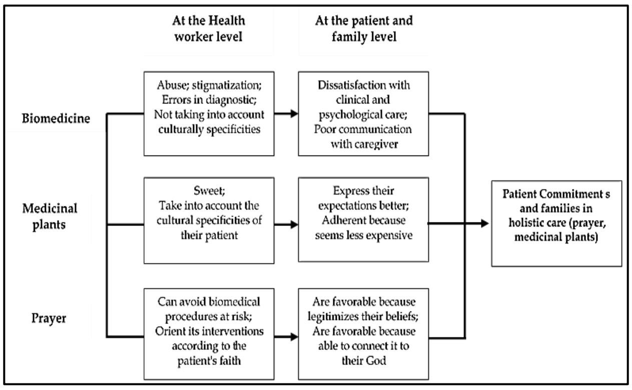

Figure 3: Conceptual model showing the key factors to different influencing patient and family behaviour for the use of "informal" or holistic care.

Based on these different empirical results, a conceptual model (Figure 3) is proposed showing the key factors at different levels (health care providers, patients and families) influencing the behaviour of patients and families in terms of the engagement or use of holistic care in palliative care in the context of medical pluralism and financial insecurity.

DISCUSSION

Palliative and end-of-life support: an attempt at a conception of a Beninese model in a context of precariousness and medical pluralism

In addition to cancer, Beninese women who had access to the PCU between 2015 and 2021 faced several challenges related to their financial situation and not taking into account their cultural specificity. In addition, problems such as loss of social support, culture shock and inappropriate housing arrangements, the influence of religious beliefs, the availability of other responses in a social context, echo the results of other Beninese studies.[9,10] These women have a strong tendency to turn to prayer therapy and herbal medicine. These results suggest that the care system, better the palliative care framework, must also be aware of cultural differences in communication and care styles and adopt culturally specific coping strategies.[11]

Shahid et al, revealed that a change in the healthcare system is needed to improve coordination between primary and tertiary cancer diagnosis and treatment services, to ensure that patients and families receive appropriate social support.[12] More recently, Taylor et al concluded that with a culturally appropriate and person-centered approach, involving the patient, family members, community caregivers, it is possible for patients who are strongly rooted in their beliefs to have positive experiences of cancer care in tertiary health services.[13] Other studies have shown that when the ethical, cultural and spiritual knowledge of patients and their families is lacking among palliative care caregivers, they can provide unmet palliative care and therefore lead to the search for holistic care elsewhere.[14]

In addition, the patients strongly expressed the need to heal from their affection and to be able to extend their lives on earth. The hope of a cure could stem from a lack of information about their diagnosis and treatment. They felt compelled to accept treatment without fully understanding what was at stake. Similar trends have been identified in other studies looking at cancer and other chronic diseases.[15,16] The reflection of this work on the integration of cultural specificities is in line with the conclusions of other studies on neglected chronic and tropical diseases such as HIV/AIDS, Buruli ulcer (UB) in Africa and Benin.[17,18] The model of care to accompany HIV/AIDS patients and UB was a community-based approach under community guideline.[19] In current palliative care interventions in sub-Saharan Africa, the community-based approach is used to better support patients and families.[20]

Indeed, health systems have been challenged to establish collaborative strategies between two systems of care (formal and informal). In Botswana, for example, a study found the importance of traditional healers in the palliative care model.[20] In Benin, the experience of the National Programme of Pharmacopoeia and Traditional Medicine (PNPMT) can be used through a contribution to the training and involvement of traditional therapists (naturopaths) and healers in palliative care support.[21] Already, studies have shown that healers are available to work with biomedical care providers to improve patient outcomes.[22]

In Kenya, for example, the development of low-cost, highly sustainable home care for people deemed “poor” was based on an approach that involved working with older women in local villages or neighbourhoods. These women participated in a series of intensive workshops designed to equip them with the knowledge and skills to provide terminal home care to all members of their community, regardless of the patient's status.[23] Other studies have shown that families of patients at the end of life would have liked to have been introduced to palliative care earlier in order to better contribute to the support of their sick loved one, because of the challenges they face.[24,25]

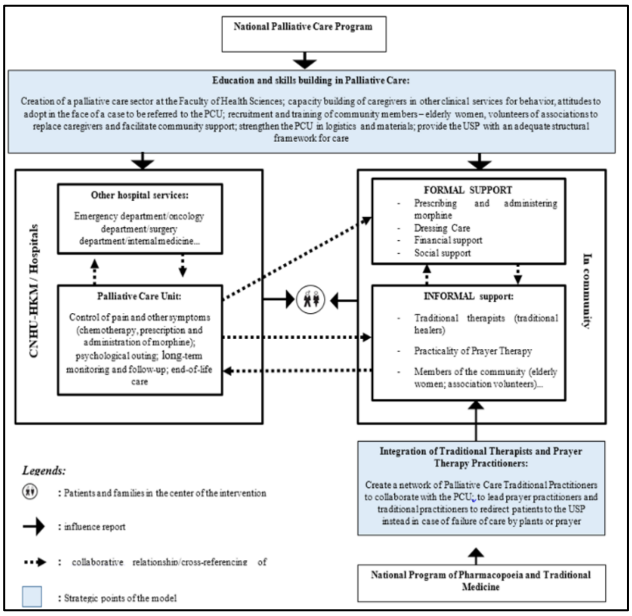

Figure 4: Design trial of a Beninese palliative 1and end-of-life care support model in Benin.

The results of this survey provide insight into the palliative and end-of-life care pathways of patients and families and can inform palliative care interventions to improve patients’ quality of life. Hence the proposal of a conceptual model (Figure 4). This conceptual model could allow caregivers to better adapt to the clinical, emotional, social and spiritual condition of the end-of-life patient and their loved ones.

The data suggest that palliative care users have a strong tendency to rely on traditional healers, pastors and/or religious men. But these users can also be better reassured if these actors were trained specifically for palliative care support. Therefore, the medical pluralism of communities should be seen as a lever for palliative care professionals and decision-makers. The main recommendation of this research is to involve traditional healers, prayer therapists, and community members in the design and implementation of community-based palliative care initiatives, as these are well-placed allies for health care programs.

However, there are some limitations to this study. The basic characteristics of the participants are extracted from their medical records, a bias of registrations could exist. This would not be the case if the patients had been taken in direct interview. These limitations open up new lines of inquiry for future research in public health and the humanities on chronic diseases, palliative care and end-of-life care.

CONCLUSION

Patients who had access to the CNHU-HKM PCU between 2015 and 2021 and their families mostly expressed the need to recover from their illness and extend their lives on earth, despite the severity of their health condition. This is clearly due to the lack of information about their diagnosis and treatment, the influence of religious beliefs, the availability of other responses in a social context, but above all the virtual absence of the cultural specificities of patients in palliative care in hospital.

These findings could inspire community-based or home-based palliative care interventions in medically pluralistic settings and underscore the importance of supporting meaningful collaboration with community members, traditional healers and prayer practitioners around patients and their families.

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