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Cancer patients' Perceptions and their Carers' Opinions of their Disease in Lubumbashi

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Abstract

Background: Cancer poses significant challenges beyond its physical manifestations, impacting the psychosocial dimensions of patients and their caregivers. Understanding these complexities is crucial for delivering effective care. This study aims to explore the perceptions of cancer patients and their caregivers in Lubumbashi, Democratic Republic of Congo (DRC).

Methods: A descriptive cross-sectional study was conducted from November 2016 to July 2017, involving female cancer patients and their caregivers from major hospitals in Lubumbashi. Data were collected using standardized questionnaires and analyzed quantitatively.

Results: The majority of cancer patients were aged ≥45

years (88.9%), married (63.0%), and illiterate (44.4%). Cervical cancer (48.1%) was most prevalent, with late-stage diagnoses predominating. Only 22.2% of patients were informed of their diagnosis by a doctor. Palliative care was common (63.0%), reflecting advanced disease presentation. Caregivers reported significant financial challenges (92.6%) and anxiety (96.3%), suggesting unmet support needs.

Conclusion: This study underscores the urgent need for improved cancer awareness, early detection, and psychosocial support services in Lubumbashi. Addressing the cultural, educational, and economic barriers to cancer care is essential for enhancing patient outcomes and caregiver well-being in the DRC.

Keywords: Cancer, Perceptions, Patients, Carers

Introduction

Cancer, a complex disease with far-reaching implications, extends beyond its physiological manifestations to profoundly impact the psychosocial dimensions of both patients and their support systems (Stein *et al.*, 2008) ^[25]. The journey of cancer encompasses not only medical treatments and physical symptoms but also emotional, social, and existential challenges for both the individual diagnosed and those close to them (Jacobs M.L *et al.*, 2017) ^[11]. Understanding the multifaceted nature of cancer and its effects on the human experience is essential for providing comprehensive care and support to those affected by the disease.

In recent years, there has been a growing recognition of the importance of addressing the psychosocial aspects of cancer care (Grassi *et al.*, 2017) ^[9]. Research has highlighted the profound impact of cancer on mental health, relationships, and overall quality of life (Więckiewicz *et al.*, 2024) ^[29]. Moreover, studies have shown that psychosocial support can significantly improve patient outcomes, including treatment adherence, coping abilities, and emotional well-being (Smith *et al.*, 2021) ^[23]. Despite these advancements, there remains a need for further exploration into the intricate interplay between cancer and the psychosocial dimensions of individuals' lives. This includes understanding how perceptions of cancer vary among patients and their support networks, such as family members, friends, and healthcare providers. By gaining insights into these perceptions, healthcare professionals can better tailor support interventions and communication strategies to meet the diverse needs of those affected by cancer.

In Lubumbashi, a city facing its own unique challenges in cancer care, there exists a paucity of research focusing on the perceptions of cancer patients and their caregivers. However, their insights are invaluable for informing culturally sensitive support interventions and optimizing patient outcomes in this context. By exploring the perceptions of both patients and caregivers, we can gain deeper insights into the psychosocial dynamics surrounding cancer in Lubumbashi and identify specific areas for targeted intervention.

In this context, this study aims to determine the epidemiological profile of gynecological and breast cancers in the various health facilities in our study and to describe how cancer is perceived by patients and their careers.

Materials and Methods Study Design and Period

This was a multicenter descriptive cross-sectional study conducted in Lubumbashi from November 2016 to July 2017.

Target Population

The study population consisted of female patients with histologically confirmed cancer diagnoses and their caregivers attending the four major hospitals in Lubumbashi: Sendwe Hospital, University Clinics, GCM/SUD Hospital, and the SNCC Medical Complex in Lubumbashi.

Inclusion Criteria

Patients hospitalized with a confirmed cancer diagnosis during the study period who provided informed consent to participate were included in the study.

Exclusion Criteria

Patients hospitalized without a confirmed cancer diagnosis during the study period and those who refused to participate were excluded from the study.

Sample Size

The sample size was 27 cancer patients. According to Fortin, small sample sizes are sufficient for descriptive studies aimed at developing knowledge in a field, and the rarity of the pathology may also explain the use of a small sample size.

Sampling Method

The selection of study sites for defining the source population was done through purposive sampling, considering the existence of intensive care or palliative care services within the hospital capable of managing cancer patients at the end of life. The following hospitals were selected: Janson Sendwe Provincial Hospital, University Clinics of Lubumbashi, GCM Sud Hospital, and the SNCC/Lubumbashi Medical Complex.

Data Collection

Data collection was conducted using a specifically designed, tested, and standardized questionnaire. The first questionnaire was administered to cancer patients.

Data Analysis

The data collected were analyzed both qualitatively and quantitatively. All data were entered into Epi Info and analyzed using IBM SPSS Statistics version 23. Various frequencies were compared using the chi-square test. A p-value <0.05 was considered statistically significant. In univariate analysis, the chi-square test was used to assess the

relationship between independent variables and the dependent variable.

Ethical Considerations

Patients meeting the inclusion criteria were informed about the study objectives and participation conditions. Their oral informed consent was obtained before completing the questionnaires. Participation in the study was voluntary. Information was provided in a language understood by the participants, in a standardized and adapted manner. The protocol for this study was approved by the ethics committee of the University of Lubumbashi.

Results

Table 1: Distribution of cancer patients according to age, marital status, level of education, parity and gestation

Parameters studied	Number (n=27)	Percentage
Age in years		
<45	3	11.1
≥45	24	88.9
Marital status		
Bachelor	1	3.7
Bride	17	63.0
Widowed or divorced	9	33.3
Level of study		
Primary	3	11.1
Without	12	44.4
Secondary	12	44.4
Parity		
large multiparous	19	70.4
Multiparous	5	18.5
Pauciparous	3	11.1
Gesture		
Great multi-gesture	21	77.8
Multigesture	5	18.5
Paucigest	1	3.7

It appears from this table that 88.9% of cancer patients were aged greater than or equal to 45 years, 63% were married, 33.3% were widowed or divorced. It also appears in a balanced manner that 44.4% of the subjects were illiterate and 44.4% had secondary education. Large multiparous and large multigravid women represented 70.4% and 77.8% of cases respectively.

Table 2: Distribution of cancer patients according to reason for hospitalization, history, diagnosis and cancer examination

Parameters studied	Number (n=27)	Percentage
Reason for hospitalisation		
Pain	7	25.9
Dyspnea	2	7.4
Surgical intervention	5	18.5
Metrorrhagia	13	48.1
History of cancer		
Others	24	88.9
Brother or sister	1	3.7
Father or mother	2	7.4
Diagnostic		
Ovarian cancer	2	7.4
Cervical cancer	13	48.1
Breast cancer	7	25.9
Endometrial cancer	5	18.5
Certainty review		
Biopsy	27	100.0
Cytology	0	0.0

Table 2 shows that 48.1% of cancer patients were hospitalized for metrorrhagia, 25.9% for pain and 18.5% for surgical intervention. Nearly half of the cancer patients (48.1%) had cervical cancer, 25.9% breast cancer, 18.5% endometrial cancer and 7.4% ovarian cancer. Biopsy was the definitive test performed in 100% of cases.

Table 3: Distribution of cancer patients according to stage of cancer, treatment received, duration of treatment and progression of cancer

Parameters studied	Number (n=27)	Percentage
Stadium		
I	2	7.4
II	7	25.9
III	11	40.7
IV	7	25.9
Treatment		
Chemotherapy	1	3.7
Surgery	9	33.3
Palliative	17	63.0
Duration of treatment		
1 to 10 days	3	11.1
6 to 12 months	4	14.8
Undetermined	18	66.7
> 12 months	2	7.4
Evolution		
Deceased	5	18.5
Ongoing care	3	11.1
Exit alive	19	70.4

It appears that stages III represent 92.5% of cases with a peak (40.7%) at stage III and that stages II and IV have the same frequency of 7 cases (25.9%). In addition, 96.3% of cancer patients had benefited from palliative treatment (63.0%) or surgery (33.3%). In 66.7% of cases the duration of treatment was indeterminate. In terms of disease progression, 70.4% of cancer patients were left alive from the hospital and 18.5% died.

Table 4: Distribution of cancer patients according to knowledge of the diagnosis, the person who announced the pathology and participation in their own care

Knowledge of the diagnosis and the person who announced it	Number (n=27)	Percentage	
person who announced it	Number (n=27)		
Knowledge of diagnosis			
No	21	77.8	
Yes	6	22.2	
Person who announced the			
pathology			
Person	21	77.8	
Doctor	6	22.2	
Participation in one's own care			
Bill and medication payment	1	3.7	
Payment of bill and medication and	2	7.4	
taking prescribed medications	2	7.4	
Taking prescribed medications	13	48.1	
Take prescribed medication and report	1	3.7	
any abnormality observed	1	3.7	
Taking prescribed medications and	1	3.7	
providing requested tests	1	3.7	
Without answer	5	18.5	
Report the anomaly observed	4	14.8	
Perception of illness			
Accept the illness	1	3.7	
Non-acceptance of illness	26	96.3	

More than three quarters of cancer patients did not know their diagnosis (77.8%) and among those who did, it was announced by the doctor (22.2%). For participation in their own care, the highest rates related to taking prescribed medications (48.1%) and reporting abnormalities observed (14.8%). Note that only 3.7% of patients had a positive perception of their pathology.

Table 5: Distribution of cancer patients according to the attitude of family members, the difficulties encountered and suggestions for improving care

Parameters studied	Number (n=27)	Percentage	
Attitude of family members			
Accepting illness and financial help	1	3.7	
Financial and material assistance	19	70.4	
Indifference and neglect	6	22.2	
No answer	1	3.7	
Difficulties encountered in			
treatment			
Difficulties finding medications	4	14.8	
Financial difficulties, finding			
medications, and receiving care from a	5	18.5	
specialist			
Financial difficulties	18	66.7	
Suggestion for improving support			
Benefit from care from a cancer	1	3.7	
specialist	1	3.7	
Have a cancer specialist and receive	2	7.4	
medication from the hospital	2	7.4	
Early diagnosis of the disease	2	7.4	
Receiving medication from the	19	70.4	
hospital	19	70.4	
Receive medication from the hospital	3	11.1	
and have a specialized cancer service	3	11.1	

This table shows that 19 patients, or 70.4%, recognized that family members helped them materially and financially and that in 22.2% of cases there had been indifference and neglect. The greatest difficulty encountered in care is economic, financial difficulty (66.7%). As a suggestion for improving care, 19 patients out of 27 (70.4%) wanted the hospital to help them by making medications available to them.

Table 6: Distribution of those accompanying cancer patients according to knowledge of the diagnosis, the person who announced the pathology and the way of participating in the care of their loved one

Knowledge of the diagnosis and the person who announced it	Number (n=27)	Percentage	
Knowledge of diagnosis			
No	21	77.8	
Yes	6	22.2	
Person who announced the diagnosis	3		
Male nurse	1	3.7	
Doctor	5	18.5	
Person	21	77.8	
How to participate in the care of			
their loved one			
Encourage the patient	4	14.8	
Personal presence at the bedside	3	11.1	
Financial and material support	20	74.1	

A large majority of those accompanying cancer patients (77.8%) did not know what their loved ones were suffering

from. Among the six who knew it, 5 had found out from a doctor (18.5%) and one from a nurse (3.7%). In terms of participation in the care of their loved ones, 74.1% thought they would support them financially and materially.

Table 7: Distribution of those accompanying cancer patients according to their attitude, difficulties encountered and suggestions for improving the care of their loved ones

Attitude of accompanying persons	Number (n=27)	Percentage	
Anguish	26	96.3	
Regression	1	3.7	
Encountered difficulties			
Financial	25	92.6	
Financial and unavailability of	2.	7.4	
medications	Z	7.4	
Suggestion for improving the care of			
their loved one			
Early diagnosis of the disease	6	22.2	
Discover the disease in time and	1	3.7	
receive medicines from the hospital	1	3.7	
Receiving medication from the	20	74.1	
hospital	20	/4.1	

The majority of those accompanying cancer patients were anxious (96.3%) and had experienced financial difficulties (92.6%). Like the patients, 74.1% of them suggested that they receive medication from the hospital and in 22.2% of cases, they suggested an early diagnosis of the disease.

 Table 8: Average age of cancer patients depending on the type of

 cancer

Type of cancer	Effective	Average age in years	p
Cervical cancer	13	58.9±9.5	
Other types of cancer (endometrial, breast, ovarian, etc.)	14	50.8±9.7	0.037

This table shows that patients with cervical cancer had a mean age of 58.9 ± 9.5 years compared to 50.8 ± 9.7 years for other types of cancer. And this difference is statistically significant (p=0.037).

Discussion

Our study showed that the majority of cancer patients were married (63%), widowed or divorced (33.3%), large multiparous (70.4%) and multi-gestational (77.8%) women with at least 45 years old (88.9%), illiterate or with primary education. She also indicated that the majority of patients presented for consultation at a very advanced clinical stage of the disease (stage II, 25.9%, III, 40.7% and IV, 25.9%) and that the most diagnosed cancers were those of the cervix (48.1%), breast (25.9%) and endometrial (18.5%).

For cervical and breast cancers, African literature indicates that the ranks of these two cancers vary depending on the region. Sometimes it is one that occupies the first place and sometimes it is the other. Dem (Dem A, Dieng MM, Ka S & Diouf D, 2013) [7] in Senegal noted that cervical cancer (47.7%) ranks 1st and breast cancer (42%) ranks 2nd. Tonato Bagnan (Tonato Bagnan JA, Denakpo JL *et al.*, 2013) [26] in Benin had reported a rate of 44.3% of cases for breast cancer and 26.7% of cases for cervical cancer. Koffi (Koffi KE, Aman NA, Doukouré B *et al.*, 2013) [12] in Côte d'Ivoire had reported a rate of 45.69% of cases for breast cancer and 33.25% of cases for cervical cancer. Amegbor (Amégbor K, Alfa AK, Darré T, Napo-koura GA, 2011) [2]

in Togo had reported a rate of 49.88% of cases for breast cancer and 24.03% of cases for cervical cancer, Pongi(76)in Kinshasa had noted that cervical cancer was the most common Gynecological cancer (86.2%) followed by breast cancer (7.2%) and Kyabu (121) in Lubumbashi also noted a predominance of cervical (40.1%) and breast (38.9%) cancers.

The high frequency of cervical cancers observed in our study, as elsewhere in Africa, could be attributed to the different etiological factors generally accepted in developing countries. These factors are very varied, they are:

- Age: Our results corroborate those reported in several African studies, notably those of Ugwe and Amegbor(Amégbor K, Alfa AK, Darré T, Napo-koura GA, 2011; Ugwu EO, Iferikigwe ES, Okeke TC, Ugwu AO, Okezie OA, 2011) [2,27], showing an average age of diagnosis over 40 years. The age of onset of frequently encountered gynecological cancers, particularly those of the breast, cervix, and endometrium, as well as the lack of a screening program for gynecological cancers, would justify the advanced age of diagnosis in most African countries.
- Parity and gestation: The high rates of large multiparous (70.4%) and multi-pregnant (77.8%) are, here too, in agreement with the data in the literature according to which multiparity is classically known as a factor by excellence predisposing to cervical cancer(Dah et al., 2014) [5] (MBALA, NGUMA.M., NEMBUNZU., MBANZULU., NSIATA., EKBONDU., 2005) [15] (Sando et al., 2014) [21]. The number of multiple pregnancies and multiparity are accompanied by a significantly high risk in our regions. The numerous pregnancies, through the repeated trauma they cause, lead to changes in the architecture of the uterine cervix which evolve towards a dysplastic state in the presence of HPV infection. Most authors are unanimous, but in some developed countries such as Sweden, multiparity is considered a protective factor for gynecological cancers, including cervical cancer. In these countries, pregnant women are more subject to the screening program than others (Ahmadou Dem, B. Traoré, MM. Dieng, PS. Diop, T. Ouajdi, MT. Lalami, M. Diop, JM. Dangou, 2008) [1].
- **Sex life:** Cervical cancer is common among women who started their sex life very early (Vaccarella S, Franceschi S, 2006) ^[28]. However, in the literature we found that the risk of cervical cancer is doubled if the first intercourse took place between 15 and 17 years of age. (Mboumba Bouassa RS, Prazuck T, Lethu & Meye, 2017) ^[16]. Cervical cancer must be considered today as a sexually transmitted infection, meaning women who have had sexual intercourse are at risk; because virgin women are never affected (Elit *et al.*, 2011) ^[8].

The fact that our study indicated that married, widowed and divorced women were the most affected (96.3%) proves that this category of women who are, for the most part, multiparous and, as a result, exercise more sexual activity than single people. In addition, being considered a sexually transmitted infection, HPV can reach a married woman either through her husband, or following early marriage which can promote early infestation due to frequent early sexual intercourse. Note that the transmission of HIV by sex

workers has been known since the start of the epidemic in sub-Saharan Africa. Sex workers are 13.5 times more likely to live with HIV than other women and the risk of developing invasive cervical cancer linked to Human papillomavirus (HPV) is increased 5.8 times by the presence of HIV (Pierre Aubry, 2017) [19].

The late detection of the disease, highlighted in this work, agrees with the similar observation from a study carried out in Kinshasa in 2016 (Pongi Jackson M, Nguma Alois M, 2016) [20]. Comparatively, stages II, III and IV accounted for 85.6% of subjects in this study, with a peak of 35.4% in stage IV. In our case, the said stages corresponded to 92.6% and the highest rate was that of stage III (40.7%). The late delay in screening thus deplored may be justified in particular by one of the following reasons: The ignorance of the population regarding the condition, the financial inaccessibility of care, the absence of an insurance system health, the lack of adequate infrastructure in a context of poverty of our population. In our environment where medical care is provided by the patients themselves or by their families who, in most cases, are deprived of financial means, the treatment of cervical cancer constitutes a real ordeal both for the nursing staff, due to lack of adequate infrastructure such as a radiotherapy center, antimitotics unobtainable or very expensive, as well as for the patients themselves. To save many human lives, early detection of the disease is essential. There is no alternative.

It appears from our results that the rate of cancer patients who had been informed by a doctor of the diagnosis of their pathology was low, 22.2% and that that of those who had benefited from palliative treatment was high at 63%. However, elsewhere, the diagnosis is practically communicated to all cancer patients as well as their relatives (Huijer & Dimassi, 2007; Mackillop et al., 1988) [10, 14]. We attributed this large gap in communication of cancer diagnosis to cultural considerations. Indeed, it is not easy to break bad news to a patient given that it can potentially have a psychological impact on the patient and their family. Faced with such gravity, most of our doctors are confronted with several types of affects: Embarrassment, unease, worry, guilt, sadness, anxiety, feeling of failure and/or helplessness. For health professionals interviewed by Bettevy, (Bettevy et al., 2007) [3], improving the quality of the announcement requires improving "formal" consultations and interest "in the process of entry into the disease". The quality of the information transmitted throughout this phase will often determine the conditions of the ad consultation. Furthermore, contacting the treating physician makes it possible to take into account the personal dimensions of the patient which can influence therapeutic choices.

This is why it is up to the doctor to learn to identify his own reactions in order to better control them for the benefit of his patient. If the doctor does not manage to overcome these different attitudes, he will certainly have difficulty announcing the diagnosis of cancer. Hence the need for ad hoc training.

In terms of SP, as highlighted by Serigne Modou Kane Gueye (Serigne Modou Kane Gueye, Mamour Gueye, Sophie Aminata Coulibary, Alassane Diouf, 2016) [22], in a context where cancers are mostly discovered at late stages, palliative care is extremely important. They include all local care for infected, non-operable cancers, care for complications of surgery, radiotherapy or chemotherapy, changes in general condition and complications specific to

progressive disease. At these stages where the usual means are "outdated" with little chance of recovery, supporting the patient with local care, metabolic rebalancing, resuscitation, nutrition, psychotherapy are all crucial and useful methods in the improving the quality of life of patients. In our context, we must promote palliative care centers which would concentrate most of these multidisciplinary methods to respond to an increasingly growing demand for care and witness to the considerable pitfalls in the management of cancers. It is absolutely necessary to go beyond the 63% support in SP that we recorded.

The situation generated by cancer involves a series of consecutive crises that continually test the adaptive capacities of the sick person and also those of their family. These are crises associated with the first symptoms, diagnosis, treatment, return home, terminal phase and death. First of all, it should be noted that the diagnosis of cancer throws the family into an acute emotional crisis (Northouse, 1984, 1988) [17, 18]. This crisis is mainly triggered by the threat of losing a loved one and the questioning of the patient's and his family's fantasies of immortality. (COHEN MS & COHEN EK, 1981) [4].

Concerning the companions of the cancer patients concerned by the present study, it was noted that they were confronted with multiple problems such as anxiety (96.3%) resulting mainly from difficulties in financial and material order (70.4%), but to a certain extent also due to ignoring the real nature of the pathology (77.8%). Faced with this state of affairs, their main suggestion (70.4%) was to receive, free of charge and from the hospital, medications as part of improving the care of their patients.

By consulting some aspects of work similar to ours, we realized that the concerns of the relatives of our cancer patients were generally identical to those reported by other researchers. For example, according to Delvaux, the families of cancer patients are faced with anguish and sadness, alternating moments of hope and despair. (Delvaux, 2006) [6]. For Northouse *et al.* (Northouse, 1984) [17], generally the family mainly seeks emotional support and instrumental help, particularly for transport to the hospital, domestic tasks and looking after young children. The needs expressed by people with cancer and their loved ones are present throughout the continuum of care and services, particularly at the time of diagnosis and at the end of life. People with cancer are concerned about the disease, but also about the impact it has on their loved ones and their young children. The organization of care should take into account the crucial role of children and relatives in the disease process and support them at all levels. The humanization and quality of care and services cannot escape this obligation. (Sophie Beugnot, 2009) [24].

Conclusion

At the end of this study on "Cancer patients' perceptions and their carers' opinions of their disease in Lubumbashi", the majority of cancer patients (88.9%) were aged 45 or over, with an average age of 54.7±10.3 years; 96.3% of the subjects were either married (63.0%), widowed or divorced (33.3%); 88.8% of the women in our study were illiterate (44.4%) or had secondary education (44.4%).

In terms of parity and gestational age, the highest frequencies were found among large multiparous women (19 cases, i.e. 70.4%) and large multigestational women (21 cases, i.e. 77.8%). 48.1% of cancer patients were

hospitalized for metrorrhagia, and 25.9% for pain. Nearly half of cancer patients (48.1%) had cervical cancer, 25.9% breast cancer, and biopsy was the definitive examination in 100% of cases. Stages II, III and IV accounted for 92.5% of cases, with a peak (40.7%) in stage III, and stages II and IV had an equal frequency of 7 cases (25.9%). In addition, 96.3% of cancer patients had received palliative treatment (63.0%) or surgery (33.3%).

More than three quarters of cancer patients were unaware of their diagnosis (77.8%), and 70.4% had acknowledged that family members had helped them materially and financially, and that in 22.2% of cases there had been indifference and neglect. The greatest difficulty encountered was financial (66.7%). A large majority of cancer patients' carers (77.8%) did not know what their loved ones were suffering from, were distressed in 96.3% of cases, and had experienced financial difficulties (92.6%).

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