Psychosocial Burden of Cervical Cancer Treatment at the Joliot Curie Institute of Dakar, Senegal

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Abstract

Cervical cancer is a high incidence disease in Senegal. Its management is problematic.
The objective of this article is to analyze the psychosocial burden of cervical cancer patients. Patients were recruited from the Joliot Curie Institute of Dakar. Semi-structured interviews were used to address patient/caregiver communication, the relationship between caregivers and patients, and the experience of the disease within the family and the community.
The results show that some patients have difficulty coping with their illness in the family and community, and others have conflicting relationships with their caregivers and hosts. This is a huge psychosocial burden for patients.

Keywords : *Cervical cancer, treatment, Institut Joliot Curie, psychosocial burden, Dakar*

Introduction

The incidence of cancer in the world amounted to 19,292, 789 cases in 2020, according to estimates by the International Agency for Research on Cancer (IARC). These data, show that 22.80% of cancer cases are concentrated in the European continent; 49.26% in Asia; 13.25% in North America; 7.62% in Latin America; 5.75% in Africa and 1.32% in Oceania (IARC, 2020).

Cancers are the second leading cause of death with nearly one of six deaths worldwide due to cancer and 9,958, 133 deaths in 2020. This mortality is quite high in Africa and Asia, certainly because of limited access to care and delayed consultation (IARC, 2020). Among these cancers, cervical cancer occupies a prominent place. It is a female genital cancer that results from infection with the human papillomavirus, usually serotypes 16 and 18 (Bosch at al, 2002). In 2020, the incidence of cervical cancer worldwide was estimated at 604,127 cases, of which 117,316 were diagnosed in Africa.

In Senegal, the number of people diagnosed with cervical cancer was 1,937 in 2020, with 1,312 deaths. This situation implies a systemic management of this pathology.

This is all the more important since the management of chronic diseases, such as cancer, requires not only financial resources but above all psychosocial support.

In this article, we aim to address the psychosocial burden associated with the management of cervical cancer patients followed at the Joliot Curie Institute of the Aristide Hospital in Dakar. More specifically, we will :

- To analyze the communication mechanisms between patients and reception staff at the Joliot Curie Institute of Dakar ;
- Describe the patient/caregiver relationships in the care process ;
- To analyze the experience of the disease within the family and the community.

1. Methods

The research began with an exploratory phase that consisted of observation visits during consultations with the treating physicians, during chemotherapy sessions, and during the patients' appointments. This phase, which was carried out with the approval of the patients and the treating physicians, allowed us to better contextualize the study and to understand the field.

This exploratory phase was also used to interview oncology resource persons and other health professionals working at the Institut Joliot Curie. These interviews with professionals were carried out with a minimum of one interview per specialty. Each specialist responding with his or her own vision, the aim was to have the widest possible range of professionals, not aiming for saturation but for maximum complementarity of the interviews.

1.1. Study Population

The study targeted patients diagnosed with cervical cancer at the Joliot Curie Institute of the Aristide Le Dantec Hospital in Dakar. Thus, specific inclusion criteria were defined according to the following Table 1.

Table 1: Criteria required for participation in the study
Table 1

Inclusion criteria	*Exclusion Criteria*
Have been diagnosed with cervical cancer between January and December 2018 at the Joliot Curie Institute of the Aristide Le Dantec Hospital of Dakar ; Have a follow-up medical record with a telephone number at the Joliot Curie Institute; Reside in Senegal during the study period ; Agree to participate in the study ; To be in good physical and mental health to participate in the study.	Patients with cancer other than cervical cancer; Patients diagnosed with cervical cancer during the study period (January and December 2018) at the Joliot Curie Institute of the Aristide Le Dantec Hospital of Dakar but whose relatives consider that their physical and mental health conditions do not allow them to participate in the study; Cervical cancer patients who are outside of Senegal during the study period ; Cervical cancer patients who died before the start of the study ; Cervical cancer patients who are physically and mentally able to participate in the study but are not interested in taking part despite the consent of their relatives.

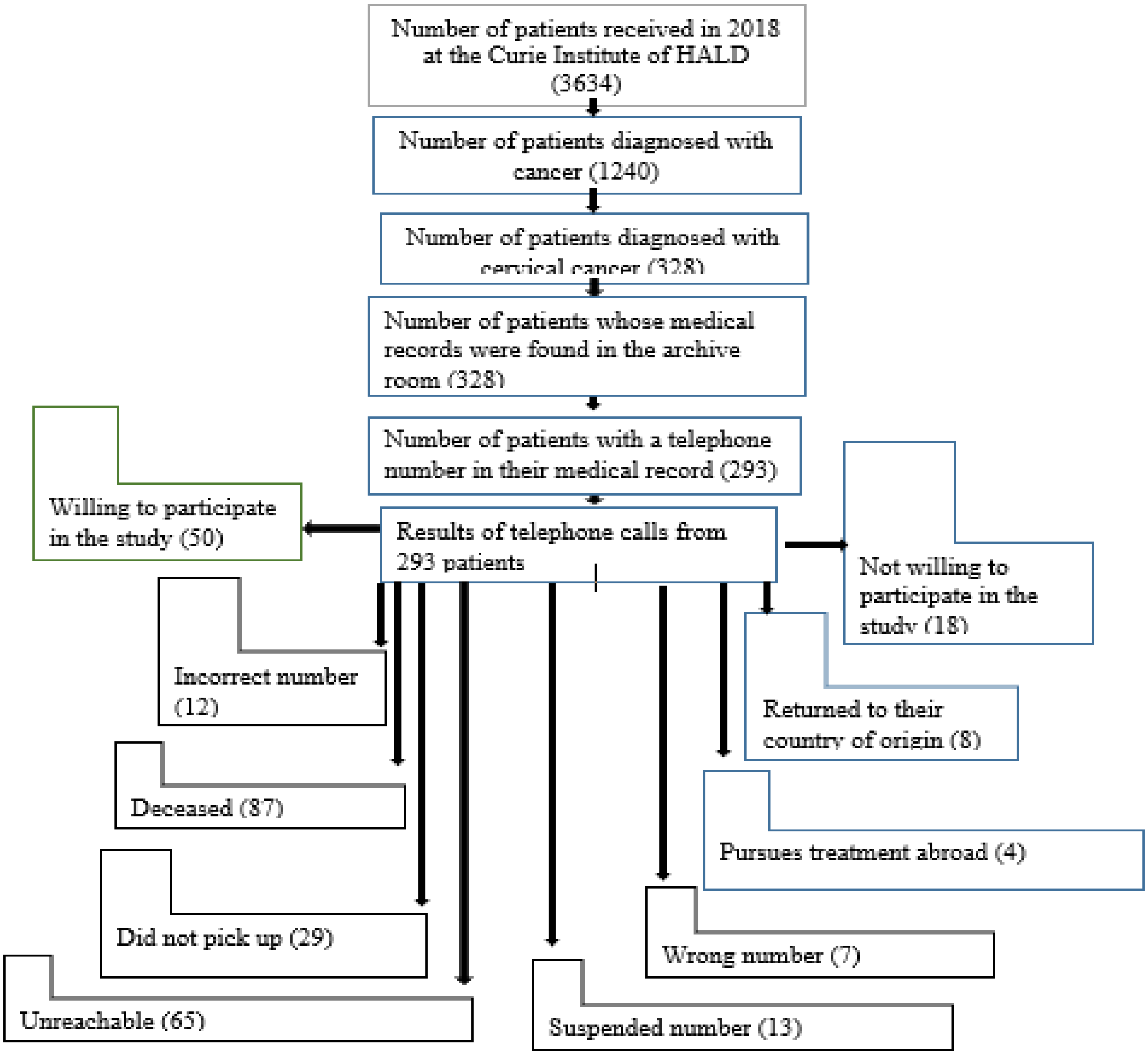
Taking these criteria into account, 50 patients were selected for the study on the basis of a systematic review of all patients' medical records. Prior approval was obtained from the director of the Institut Joliot Curie.
The accompanying persons were selected after the interview with the patients, who then indicated their main accompanying person, if any.

1.2. Sampling technique

Purposive sampling was used for patient selection. Based on the results of the telephone calls, modalities were defined to synthesize the results of the patients' telephone calls. Thus, the following Figure 1 show the sampling approach.

Figure 1: Sampling process

Figure 1



A total of 17% of patients with a telephone number in their medical record were included in the study.

1.3 .Data collection

A variety of data collection techniques were used. Semi-structured interviews, informal interviews and participant observation.

The semi-structured interviews were conducted with patients and their caregivers. The interviews aimed to describe the family and social context of these patients, the experience of their illness and the patient/caregiver relationship. The interviews were conducted out of sight of the patients' respective families. This was done in order to put the patient at ease and allow her to talk about any aspect of her illness.

However, exceptionally, some patients were interviewed at the Joliot Curie Institute of the Aristide Le Dantec Hospital in Dakar at their request. To this end, arrangements were made for the conduct of the interviews in compliance with the confidentiality criteria of the study. The interviews took place between December 9, 2019 and August 29, 2020.

They were recorded with a dictaphone after the participants' consent.

Direct observation of the patients' homes and places of care allowed us to understand, among other things, the relationships between family and patient, between patients and health personnel, and attitudes and behaviors in the hospital environment.

1.4. Processing and analysis

The recorded interviews were transcribed. After that, the data were reviewed and analyzed. This made it possible to highlight the main themes raised by the patients and their carers during the interviews. In particular, aspects relating to the experience of the disease within the family and the community, communication between patients and staff, and the patient/caregiver relationship. For ethical reasons, initials were used in the presentation of the results of the analysis to respect the anonymity of the interviewees.

2. Results

2.1. Socio-demographic characteristics of the patients

2.1.1. Age and marital status

The age of the patients ranged from 34 to 81 years with an average of 56 years. The most representative age groups were patients between 34 and 59 years of age, representing 64%. Patients aged 60 years and over constitute 36% of the sample.

Analysis of marital status reveals that 54% of the patients are married; 38% are widowed and 8% are divorced. The following table 2 presents the distribution of patients according to their age group and marital status.

Table 2: Distribution of patients by age group and marital status

Table 2

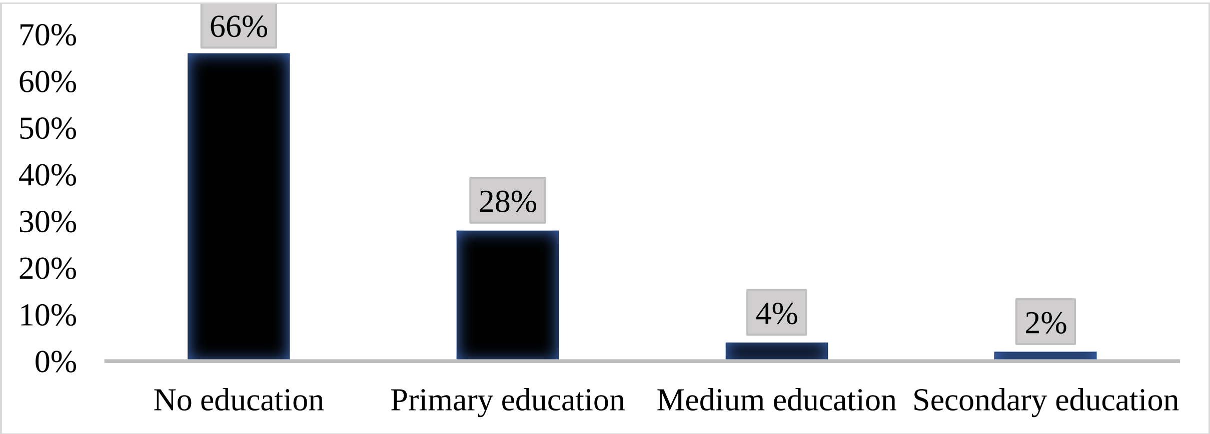
	Age		**Marital status**		
	(34 -59 years old)	60 years and older	Brides	Divorced women	Widowers
Frequency	32	18	27	4	19
Percentage	64 %	36 %	54%	8%	38%

Source : DIALLO.M, based on survey data

2.1.2. Level of education

Patients with no education made up 66% of the sample. Those with primary education make up 28%. Those with a middle or high school level of education represent 4% and 2% respectively. We note that none of the patients in the sample has a higher education level. Figure 2 below summarizes the distribution of patients according to educational level.

Figure 2: Distribution of patients by education level



Source : DIALLO.M, from survey data

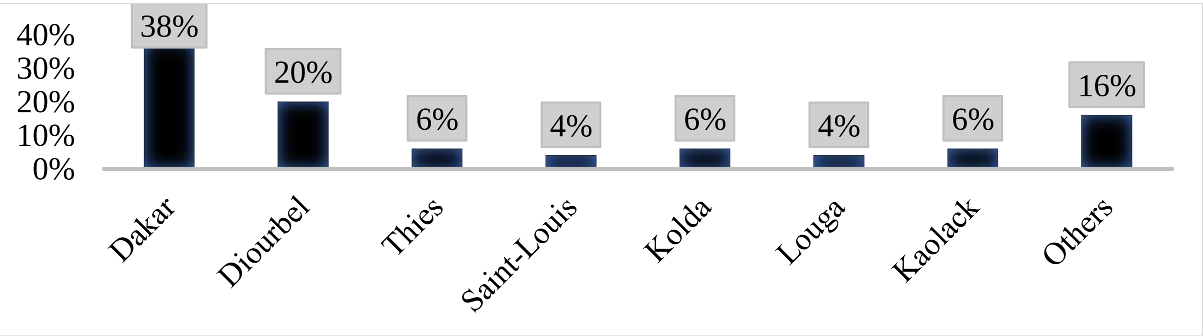
2.1.3. Profession

A significant proportion of the patients were housewives (34%). The other most represented professions were shopkeepers (30%) and restaurant owners (20%). Finally, other professions are also represented up to 6%. These include braiders, farmers, etc…

2.1.4. Place of residence

Most of the patients interviewed resided in the Dakar region. They represented 38% of the sample. For patients from the interior of the country, those from the Diourbel region represented 20% of the sample. The regions of Tambacounda, Ziguinchor and Sedhiou represented 16% of the respondents. The regions of Thies, Kolda and Kaolack each provided 6% of patients. Finally, the least represented regions were Saint-Louis and Louga, which each provided only 4% of the sample. In sum, Figure 3 below illustrates the distribution of patients by region of residence.

Figure 3: Distribution of patients by place of residence



Source : DIALLO.M, from survey data

2.2. Psychosocial burden of cervical cancer patients at the Institut Joliot Curie

Cervical cancer treatment requires a lot of financial resources. However, beyond the financial aspects, patients and their caregivers are confronted with various difficulties. For example, they largely mentioned communication with the reception staff at the Joliot Curie Institut, the experience of the disease within the family and the community, and the patient/caregiver relationship in the care process as the main difficulties.

2.2.1. Communication between patients and reception staff

Communication from the reception staff to patients and their companions was appreciated in different ways by the patients and their relatives. While some patients and their families thought that the reception was of good quality in the radiotherapy department, others mentioned difficulties with other departments of the Institute. The main problems raised at this level concern the inadequate sharing of information and the lack of empathy and concern on the part of certain staff.

The fact that cancer support structures exist and that some patients are not aware of them was strongly denounced. According to some patients, information about the existence of such facilities should be given to anyone diagnosed with cancer as soon as possible. The explanation for such a requirement is that, according to the perception of patients and those accompanying them, facilities such as the Joliot Curie Institut welcome more disadvantaged people ; those who are better off are generally cared for abroad or in clinics. In addition, these structures only assist patients according to their means. This is one more reason for each patient to be aware of their existence. For example, one patient interviewed explains :

« One day, after I finished my chemotherapy sessions, the doctor told me that I also had to undergo radiotherapy. I started to cry because I had no money left. I met a woman who works at the hospital who promised to help me. A few days later, she called me to ask me to bring her the documents because she was going to apply for assistance from the Senegalese League for the Fight Against Cancer to cover the radiotherapy. If I knew about the existence of this structure, I would have gone to make the request myself ».

Patients and accompanying persons were also offended by the fact that the reception staff often did not clearly explain the tests to be performed before their appointment. On this subject, a patient who was questioned said :

« One day, after a long wait, the person in charge of the chemotherapy room asked me in a violent tone : Where are your test results? I had to do some tests? I answered.

So, you will not be able to be treated, the person in charge of the chemotherapy room told me. That day, I wanted to cry in the room in front of everyone ».

The perception of the quality of the reception at the Joliot Curie Institut is assessed in different ways by patients and those accompanying them. Nearly half of them (46%) consider the quality of the reception to be good to very good, compared to 16% who think that the quality of the reception is moderate.However, 28% of patients felt that the quality of reception was not good and 10% felt that the quality of reception depended on the person on duty.Cases of verbal violence by junior staff at the Joliot Curie Institut were mentioned by some patients and their companions.This violence is materialized by curt, discourteous answers and even shouting.On this point, a companion explains :

« One day I came to the front desk to ask for information only.The guy didn't even give me a chance to talk to him, he just asked me to move away from the counter because he is currently very busy ».

In this vein, a patient interviewed recounts witnessing verbal abuse, which could even be considered a score-settling.Waiting patiently for her turn for chemotherapy, the assistant called the patient sitting next to her who was writhing in pain.The latter was slow to get up, and the assistant, furious, approached her and said :
« Come, I don't have time to waste, you stay at home until your vaginas rot and you come here to tire us out ».

2.2.2. Patient/caregiver relationship in the care pathway, from lack of information to wandering

A closeness between some patients and caregivers was noted.This is due to the fact that the treatment is long term.The caregiver is a key player in the medical care of cancer.The fact that they see the patient every time, means that the nursing staff and their patients very often form strong social relationships.This closeness manifests itself in the exchange of joking expressions (teasing, jokes by the caregivers towards the patients).

However, the meetings between caregivers and patients are at times stressful and frustrating, and this leads to attitudes of rejection and revolt on the part of patients.Some patients often feel dependent on their treating physician, powerless, and confronted with an authority that they do not dare to question in order to obtain clarification about their illness.These hesitations and fears are mainly motivated by precedents marked by frightening answers about their illness. The fear then interferes with the information given.Conversely, some patients have high anxiety when they cannot get the information they need.

The patient then feels alone with her fears and worries when the caregiver is too busy or reduces the scope of the consultation to technical discussions about medical treatment.

Sometimes the patient has high expectations of the caregiver, and may be disappointed or angry, and the anger and frustration of the illness may be displaced onto the caregivers. In fact, many patients complain about the way some treating physicians talk to them. According to some, the treating physicians do not tell them the whole truth about their status as patients, and this is an essential element in building their confidence.The following excerpt illustrates the lack of clarity that patients complain about in the information they receive from their physicians.

« At the beginning, at our first appointment, the doctor told me that the disease was not at an advanced stage and that I could simply continue my activities, telling me : It will not change anything in your life". Afterwards, after several appointments, the same doctor informed me that I was going to be operated on, you can imagine! He should have told me the truth from the beginning so I could have prepared myself accordingly ».
In addition, the lack of accessibility of some treating physicians was highlighted as a source of frustration and stress for patients. They feel left to their own devices, disoriented.This situation of patient wandering led R.G., 47 years old, to state that :

« When you see a doctor today, they give you an appointment for another day. And when you come back, they tell you that they didn't come or that they are out of town. Very often, you have no one to tell you when the doctor in question will return ».

2.2.3. Experience of the disease in the family and community

The family and the community play a very important role in the acceptance and management of the disease.It is a network of material or financial help, assistance and emotional support for the ill person.The family environment is affected by the illness of a loved one. In fact, the family circle is involved in the patient's medical journey; as a result, it is obliged to adjust socially, economically and emotionally to better accompany the patient.

However, some of the patients interviewed said that they experience stigma within the family and/or community.This is especially true during the chemotherapy phase, when the side effects of treatment are very evident. This stigmatization is very often the work of co-wives, sisters-in-law, mothers-in-law and even the neighborhood.The testimony of this patient illustrates this situation :

« During my chemotherapy, if I touch a container, my co-wives will not touch it again until my daughter washes it with bleach. Also, I often hear them whisper to their children to stay far away from me, otherwise I might contaminate them. Better still, they have even told some of their neighbors that I have AIDS ».

A significant proportion of the patients interviewed also said they were victims of abandonment. It is the relatives who are very often incriminated. First, it is the spouse who abandons his wife diagnosed with cancer.Then, it is the other family members who, in turn, abandon the patient after a few months of treatment. Finally, there are the friends who cut of all relations with the patient.Of these, 20% of patients who reported that the disease had a social impact on their lives said that they had been abandoned.

In the same vein, a patient tells us :
« My sisters-in-law have all abandoned me since I was diagnosed with this disease ».
In the same logic, another patient confides :
« The treatment affected my relationship with my husband a lot. After the radiation therapy my intimate part (vagina) had closed up.It was impossible for me to have intimate relations with my husband. But since that day, he doesn't pay attention to me anymore ».

The feeling of being an extra financial burden for one's loved ones in the course of treatment was widely raised by patients. In this regard, one patient interviewed said :

« I used to sell vegetables at the market. It was with my small savings that I started the treatment. It is my husband's brother who supports me a lot to finance the treatment. I also ask for assistance here and there to other family members and close relatives. In addition, yesterday the doctor asked me to do 6 more sessions of chemotherapy. How can I ask the same people I ruined to help me buy prescriptions again? I know that I am a great financial burden for these people ».

Another patient explains :
« The day I was diagnosed with cancer, my son's business was doing well. That's why he immediately took out a loan at the bank to cover his expenses, thinking that it was just for one or two months of treatment. Today, I have ruined him to the point that he no longer has enough money to buy goods ».

On the other hand, patients with very young children are also very busy with a constant fear of death.This fear is not related to their own person but most often to their children. At this level, one patient testifies:

« When I was told the results of the cancer diagnosis, I spent the whole night crying. I had suddenly thought about death because I was told that the treatment is extremely expensive and that sometimes even if the disease has reached a certain level, no one can treat it. But I am not afraid of death for myself. I am more afraid of dying at this time because my children are still very young ».
Still on the same register, another patient agrees with these words :
« I'm really afraid that this disease will take me right now because all my children are still very young »

3. Discussion

3.1. Socio-professional profile of patients

The average age of the patients in the sample was 56 years.This result is comparable with those of foreign series such as (Bouchbika at al, 2011) in Morocco who found an average age of 56 years in their study. On the other hand, (Lavoue at al, 2010) had found a mean age of 49 years in France. In Senegal (Mboup, 2017) had found an average age of 53 years.The most affected age group in this sample is 34-59 years followed by 60 years and older. This result is different from Mboup (2017) who had found the most affected age range 48-57 followed by 58-67. Similarly, (Lavoue at al, 2010) had obtained the 40-59 age group as the most affected.

In Brittany, (Lavoue at al, 2011) had obtained, in a second series concerning the cytological history of 191 patients with invasive cervical cancer, a peak of frequency in the age range of 36 to 45 years, almost identical to that found in America in the series of (Whitney at al, 1999).

The address of residence of patients indicated that 38% resided in the Dakar region versus 62% who came from the interior of the country. These results confirm those of (Mboup, 2017) who found that 35% of patients resided in the Dakar region compared to 65% who came from other regions. This data could be a limiting factor in patients' access to care. Indeed, the only referral cancer diagnosis and treatment center in Senegal is located at Aristide Le Dantec Hospital. Outside the regions of Dakar, Thies, and Saint-Louis, there are no other anatomopathologists in the country, which limits access to cervico-vaginal smears.

Married patients predominated in the sample with a frequency of 54%.These results are lower than those of (Mboup, 2017) who found 72.5% married. These results are also different with (N'guessan, 2009) and (Mariko, 2008) who found 63.2% and 64% of married patients respectively.This difference could be related to the fact that the patients in this sample are younger than those in (Mboup, 2017); (Nguessan, 2009) and (Mariko, 2008).

More than half of the patients in the sample (66%) had no education. They are followed by those with primary education (28%).The middle and high school levels were represented by only 4% and 2% respectively. These results are very different from those of (Rama Djouedjon at al, 2018) who had obtained 61.28% of the patients who have secondary level of study; 18.52% of higher level of study; 14.64% of primary level of study and only 3.37% of not educated.This difference could be related to the fact that the sample of Rama Djouedjon at al, was made up only of women residing in urban areas.

Similarly, these results are also different from those of (Haleemat at al, 2020) who had found 50.2% of the patients who have a higher education level.

On the other hand, these results are in phase with those of (Kofi at al, 2020) who had obtained 42.5% of the patients who had no formal education; 18.3% elementary education; 15.9% secondary education; 13.3% middle education and 10% higher education. Also, these results are also similar to those of (Ampofo at al, 2019) who had obtained a majority of illiterates (29.5%).

Most patients were housewives (34%). Traders and restaurant workers accounted for 30% and 20% respectively. On the other hand, (Ampofo at al, 2019) ; (Ebenezer at al, 2016) had obtained a majority of female traders of 45.5% and 79.1% respectively. In addition, (Ngwayu at al, 2019) had for their part had a majority of female farmers (46.7%) in their sample. However, the results of (Bernard at al, 2014); (Mohamed at al, 2012) had obtained a majority of housewives respectively of 41.3% and 95% are in phase with those of this study.

Moreover, with regard to the level of education and profession, it should also be noted that the Institut Curie is a public structure with relatively long waiting periods for treatment, so it is possible that the other categories (women working in the formal sector, with higher education) are not well represented.They may have more means to be followed up abroad where there is a better technical platform.

3.2. Patient/Caregiver Relationship in the Care Pathway

The relationship between patients and caregivers at the Joliot Curie Institute of the Aristide Le Dantec Hospital in Dakar shows that caregivers and patients do not always speak the same language and that the issues at stake in this type of face-to-face meeting raise a series of questions about the place that each of the actors occupies in the interaction. Some of the patients and caregivers interviewed emphasized the importance of good collaboration between caregivers in their treatment. This has been confirmed by other previous studies.

First, in the work of (Corbin at al, 1988); (Lorig at al, 2003), patient/caregiver collaboration is presented as essential to achieving psychological, medical and disease role self-management.
Second, in a study of Thai patients experiencing fatigue associated with radiation treatment (Lundberg at al, 2007), patients reported feeling positive about their collaboration with radiation oncologists and nurses.
Similarly, according to (Voelter at al, 2005), the patient wants to be treated as a subject in his own right, to be respected and informed. He expects his doctor to communicate the news in clear, understandable terms and in association with a management proposal.

Also, (Ristevski at al, 2011) had emphasized that for communication that involves difficult topics, it is important that a trusting relationship is established between the patient and the caregiver.
Similarly, according to (Jieyu at al, 2020), patients and/or caregivers emphasized the need for honesty, compassion, patience, respect in communication and the need for balanced communication between truth and hope.
In addition, (JM at al, 2018) had found that cancer patients needed clear and accurate information from healthcare professionals about their fertility whether the results were good or bad.

3.3. Communication between patients and reception staff

Communication between patients and reception staff, while generally well appreciated by patients, can be conflictual and/or unpleasant at times.Thus, this study is in line with the study conducted by France's Haut Conseil de la Santé Publique in 2009 on the reception of patients, which revealed that 32.5% of patients surveyed stated that they were afraid to go to a health facility because of the quality of the reception; 23.8% stated that they had been subjected to an act of favoritism on the part of the staff; and 34% of the respondents stated that they had had an argument with the reception staff because of the latter's bad behavior (High Council of Public Health, 2009).

Consistency and accuracy of information provided to patients was demanded by the respondents.This is in line with the work of the following authors who emphasized that, the provision of information should be clear and meaningful (Van at al, 2011) ; (Botti at al, 2006 cited by Delvaux, 2006) appropriate, accurate, detailed and thorough on topics tailored to the patients' needs and situation. Better yet, for (Langewitz at al, 2010 cited by Delvaux, 2006); (Van at al, 2011), information must nevertheless take into account the reduced ability to assimilate news and not overload patients.
According to the World Health Organization, the poor quality of care in health facilities, combined with high costs, is at the origin of the late recourse to hospital, which often occurs only in the case of "acute manifestations or long-term complications associated with cancers" and which accentuates the morbidity due to these diseases (Who,2010).

3.4. Experience of the disease in the family and community

Within the family and community, some patients experience stigma and abandonment. However, others receive a great deal of emotional support.This demonstrates that a cancer diagnosis disrupts family relationships. Furthermore, authors such as (Northouse at al, 1988) ; (Giacquinta at al, 1979 ; Snyder at al ,1986 ; Northouse at al, 1987 cited by Delvaux, 2006) have shown that the diagnosis of a chronic illness precipitates the family into an acute emotional crisis.
(Delvaux, 2006) state that this crisis is mainly triggered by the threat of losing a loved one and the challenge to the patient's and family's fantasies of immortality. Although the results show that most families are able to cope with the cancer diagnosis despite the suffering it causes, various studies show that there is no evidence that the family is able to cope with the diagnosis. However, various studies show significant psychological distress and psychosocial dysfunction in one-third of adult cancer patients, their spouses and children (Omne at al, 1993 ; Northouse at al, 1987 cited by Delvaux, 2006).

Regarding abandonment, the results of this study confirm those of (Bouhnik at al, 2014) who had found that 8.5% of the respondents who reported having been subject to attitudes of rejection or discrimination directly related to their disease (family members, close friends and work colleagues).

Similarly, (Schweicher, 1987 cited by Delvaux, 2006) points out that it can sometimes happen that the patient is isolated, ignored or marginalized within the nuclear family. Moreover, for (Keller at al, 1996 cited by Delvaux, 2006), this rejection can even occur within the couple.

The onset of cancer can in fact reveal latent conflicts and give rise to total breakdowns or at least breakdowns in communication, all the more so because the previous relational balance was precarious.
Furthermore, the work of (Lieber at al, 1976 cited by Delvaux, 2006) shows that in certain circumstances the announcement of a cancer diagnosis strengthens the bonds between family members and reinforces its cohesion.

Conclusion

Classified as a high-cost disease, cervical cancer is a public health problem. It generally affects sexually active women of all socio-professional categories, although our sample for this study was composed more of uneducated housewives.
People affected by this disease are very often confronted with financial problems for their treatment.This is all the more true since the diagnosis is often made at an advanced stage of the disease, hence the complexity of the treatment. Furthermore, it should be noted that regardless of the stage of the disease, the treatment generates side effects that are sometimes difficult to bear for patients and their families.Thus, covering the costs of managing the disease and the resulting side effects are very heavy for the patient and her family.This socio-economic burden has a negative impact on patients' compliance with treatment.Some patients who feel overwhelmed by the burden associated with their disease abandon their treatment for reasons of confidentiality.These cases can be explained by the stigmatization and sometimes psychosocial violence that patients suffer within their community, their family, or even their spouse. In addition to this, they face difficulties at the institutional level.

Communication, reception and scheduling of appointments remain among the aspects that make the treatment process more cumbersome for patients.They complain about this and ask for a better organization of the protocol and an update of their treatment plan.

Indeed, the health, financial and psychosocial burden that cancer patients face on a daily basis makes it more necessary than ever to reinforce their support in these areas.

At the Joliot Curie Institute of the Aristide Le Dantec Hospital of Dakar, it is noted that caregivers generally emphasize medical treatment to the detriment of psychosocial care. In this regard, a paradigm shift is needed for a more or less systemic management of cancer patients. For this, it is necessary, among other things, to :

- Involve social actors in the care of cancer patients and their relatives ;
- Humanize the treatment by paying special attention to the sick person in order to help him/her in the respect of his/her rights and human dignity.

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